Accessing Medical Assistance in Death (MAiD)

An interpretative phenomenological analysis of experiences with MAiD by family members and providers in Manitoba

by

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Abstract

This research explored first-hand experiences with medical assistance in death (MAiD) in Manitoba. It aimed to uncover what experiences revealed about the process behind this new end-of-life option in Canada. Specifically, the research aimed to reveal positive and negative aspects of the MAiD process in Manitoba, from which recommendations can be extracted. To accomplish this, semi-structured, open-ended interviews were conducted with eleven family members (who assisted with the MAiD process) as well as six members of the MAiD team (physicians, nurses, and a social worker). Interviews inquired into participant experiences with the MAiD process and legislation. Interviews were subsequently transcribed (anonymously) and manually analyzed for common themes among participants.

Two major themes with subthemes were identified from participant responses. The first theme concentrates on the lack of MAiD awareness and understanding of MAiD requirements among the public and medical professionals. This lack of awareness stems from the absence of standardized education for medical professionals which in turn impedes access to MAiD for patients. The second theme discusses how moral objections (by loved ones, healthcare workers, or abstaining institutions) have also impacted the process. Notably, faith-based facilities (which prohibit MAiD), require patients to transfer elsewhere in order to access MAiD, which at times delays access or in some cases prevents it altogether. Transfers from abstaining facilities were described by participants as a drain on resources, morally distressing, and onerous for patients, sometimes ending unfavourably for them or preventing access to MAiD altogether.

These findings call for better information dissemination about MAiD and most importantly, standardized education or professional development for healthcare providers. Greater public awareness of MAiD and its' regulations is needed to ensure equitable access to this service, especially in rural areas. Finally, abstaining policies must be re-examined in order to alleviate transfer burdens for patients as well as healthcare providers and families. Further research is required to assess the depth and breadth of MAiD awareness across Canada, as well as track its progression over the years.

Contents

Introduction

> *After she died I had to really debate with myself whether or not to tell people, that she used the MAiD program. Again, the intellectual part of you says 'yeah, do' so people know about it, so people learn about it. It's like mental health, don't hide it and look ashamed. Be bold about it and talk about it, bring it to the surface. Then another part of you says, you know, 'are they gonna judge her' and I didn't want her to be judged. I just didn't want them to say 'oh my god assisted suicide'? There's still that word. The funeral home used it. I said she died with the assistance of the MAID program. 'what is that, assisted suicide?'. I said, 'no that's not a term they're using anymore'." (7P7)*

This experience was shared by a family member who supported her sister's medical assistance in dying (MAiD) journey and despite fear of judgement from others, she ultimately described it as a positive MAiD experience leading to a peaceful death. However, this particular quote displays the internal battle many family members undergo after their loved one's passing which is layered on top of their personal bereavement process. The internal dialogue regarding whether to tell others about participation in MAiD was repeated by multiple family members as well as some MAiD providers. It was most frequently highlighted by religious participants or those with religious/conservative social circles. Although multiple factors contributed to the decision of keeping the process private/secret, it was aggravated by the lack of public awareness and consequently lack of understanding of MAiD services. This is evident in the narrative above, through the funeral home employee's lack of MAiD knowledge which led to a misinformed comment and subsequently an uncomfortable experience internalized by the participant.

The reflection quoted here, speaks to a broader death experience that is changing under a legalized MAiD system. It also highlights a possible barrier to MAiD accessibility due to stigma from family/friends as well as a lack of public awareness regarding MAiD services. My goal with this research, however, was not to contrast differences in death experiences but to inquire into lived experiences with MAiD in order to reveal stories such as this one, that speak to the way enacted legislation and policies have been impacted by those with *direct* involvement in the service. I felt the voices of those who *actually* participated in or experienced the MAiD processes directly were not being given as much attention while more ethical and theoretical debates were gaining popularity. For example, the issue of mature minors, which was brought up constantly in federal debates about Bill C-14 and referred to by many legal scholars writing on MAiD in Canada. However, when I finally asked the MAiD team about requests from mature minors, they stated that there was only one inquiry from a mature minor which was not comparable to the daily inquiries they receive about advanced directives for MAiD.

In designing and conducting this research, I did not seek to prove/disprove a certain hypothesis or replicate findings from other scholarly works per-se. During my research I found numerous analyses of Canadian MAiD legislation from legal, medical, and sociological perspectives however, most of these were theoretical in nature and did not directly engage in research with relevant populations. I wanted to contribute to this gap and the empirical side of this literature by engaging in an open discussion with participants to learn from their experiences. I was interested in whether areas of contention debated in media and literature (such as mature minors, advanced directives, consent requirements, abstaining institutions, among others) were similarly important to those engaging the day-to-day of MAiD.

Although I assumed that not all of these issues would matter to participants, I was curious to see what type of concerns were brought up by participants (if any) and sought to set aside my personal opinions on these subjects, which I developed during my research. By utilizing a phenomenological methodology I was able to conduct qualitative research with an open ended interview format in order to allow participants reflect on their own experiences holistically, according to their own experiences and beliefs without confining answers to pre-determined outcomes. Hence, the questions guiding this research were as follows:

How do members of the MAiD team reflect on their experiences providing MAiD in Manitoba?
How do family members describe their experiences with the MAiD process?

I conducted open-ended interviews with key participants including seven members of the local MAiD team and eleven family members who participated in or assisted loved ones with the MAiD process. I sought to provide an inside perspective on MAiD as told by those who engaged with the process either through their work or personal life. This research specifically captured experiences with MAiD in Manitoba, which employs a unique single-entry system, overseen by a centralized team of physicians, nurses, social workers, among other specialists. There has been no published experiential research from this jurisdiction and very few similar studies from other provinces, which operate under different MAiD regulations/policies and therefore may have distinct findings (comparisons drawn in chapter 4).

I wanted to fill this gap by exploring how this new legislation and its mobilization in Manitoba has been experienced by family members and the MAiD team, to draw attention to possible areas for improvement whilst also highlighting the advantages of the system or things that done were done well. I was interested in examining what (if anything) these experiences revealed about the MAiD process, beyond the controversial areas that have been the focus of MAiD discussions and political debates. Therefore, I set out to highlight aspects of the MAiD process which may require additional attention (from legislators, governments, and medical communities), in order to improve experiences and overall accessibility of this legal health service. Due to the increasing demand for MAiD across Canada and the federal government's upcoming legislative revisions under Bill C-7, it is important to continuously evaluate experiences with MAiD in different jurisdictions to ensure quality care and equal access.

All interviews were recorded and subsequently transcribed. A few themes and subthemes were identified from participant responses. The first theme highlights barriers to accessibility caused by the lack of knowledge and understanding on MAiD. This was seen both among the public as well as healthcare professionals in the community. Gaps in knowledge were apparent from various participant accounts discussing not knowing MAiD was legal, being told inaccurate information, or misunderstanding MAiD eligibility/process requirements. This calls for better public/professional education as well as knowledge dissemination in the province on MAiD. The availability of accessible resources and proper information is crucial for equitable access to MAiD in the future, especially for rural and remote communities.

The second theme displays how moral objections (by individual health care providers and by faith-based hospitals) has led to delays, posed additional obstacles, and even excluded eligible individuals from having MAiD. Family members encountered moral objections from their physicians, friends, or family, at times resulting in the decision to keep the process private due to fear of judgement. The MAiD team experienced conscientious objection in their work through lack of cooperation from certain private practices or physicians as well as the prohibition of MAiD in faith-based healthcare institutions.

These ‘abstaining’ institutions require critically ill and often dying patients to be transferred to a different healthcare facility in order to pursue a peaceful death. Patient transfers were described by participants as a waste of valuable resources, placing institutional mandates above patient autonomy, inviting grave risks for patients, and emotionally distressing for all parties involved (including the MAiD team, staff at receiving/abstaining institutions, families, and patients). It is unclear whether public healthcare institutions are legally entitled to refuse certain medical services due to their faith-centered position however, these policies have not yet been formally challenged. Therefore, they continue to place institutional mandates above the well-being and autonomy of patients.

This research allowed a glimpse into MAiD experiences from Manitoba, contributing to a new area in Canadian literature with little published research. These findings also add to the growing discourses on MAiD internationally as well as introduce the application of interpretative phenomenological analysis to a social science field outside of psychology (where it is traditionally used). A few recommendations were made in light of the themes discussed above, including improved public and professional education on MAiD as well as re-negotiation with board of abstaining facilities. I hope these recommendations, especially those regarding public and professional education on MAiD services, will assist legislators and policy makers as they contemplate upcoming revisions and seek to provide equitable access to this new end-of-life option in Canada.

Chapter 1: Background & MAiD legislation

"My wife was going through dementia, and she…she went earlier, than she needed to go. My mother went through a couple days of reduced medication, in pain, because she had to be cognizant when they asked her if she wanted to go through with it." 3P4

Introduction

This chapter is dedicated to providing a brief explanation of medical assistance in dying (MAiD) in Canada. I begin by examining the history of MAiD in Canada (prior to legalization) in the infancy of assisted death debates among politicians and the public. I draw attention to the most prominent court cases on MAiD and related literature leading up to the *Carter* case, in which the court struck down the blanket prohibition against assisted dying. I then turn to a summary of current Canadian literature on MAiD (with a few comparative perspectives) highlighting various controversies that have dominated the literature including; the issue of whether mature minors should be eligible for MAiD, whether MAiD requests can be made in advanced (in case of loss of capacity), the obligations of healthcare providers when it comes to MAiD, as well as whether healthcare institutions should be permitted to decline MAiD on their premises due to religious affiliations. Some of these issues have already made their way through the courts and these cases will be discussed. In the following chapter I explore some of the early published research available on MAiD in Canada.

Background

Medical assistance in dying (MAiD), physician assisted death/suicide (PAD/S), or 'euthanasia', are often used interchangeably in literature to refer to a situation in which a medical professional aids an ill person in death by administering or prescribing a legal substance. Some will differentiate between 'active' and 'passive' euthanasia where former requires a positive action to cause death (injection of a lethal substance) whereas 'passive' euthanasia bring about death through omission of an action (stopping of eating and drinking). Those who differentiate between these often do so on moral grounds as allowing the natural dying process to take over is seek as markedly different than actively stopping the life of another. Theological scholars tend to favour the separation of these two forms due to the difference in intent. Where the intent behind 'passive' euthanasia is not to directly kill the patient but either allow the natural death process to take place. If the patient is in discomfort or pain, it is seen as acceptable to alleviate suffering through the use of medications (such as morphine) that *can* accelerate death, however, the intent was to relieve suffering (not hasten death). This is an important distinction for many conscientiously objecting healthcare providers and faith-based facilities (Iltis, 2006). However, some ethicists argue that there is little moral significance between the two, since taking a patient off life sustaining treatment is no different than never starting it in the first place (Gurt and Culver, 1986).

Despite this seemingly arbitrary distinction, for a long time only 'passive' euthanasia was allowed in Canada which includes voluntary stopping of eating and drinking (VSED) by patients, or withdrawing of life sustaining treatment/machines. However, hastening the death of suffering patients was only allowed in the confined of palliative care, when it was done with the intention of relieving suffering. The shaky moral distinction between these was also questioned in the Carter case that eventually struck down the prohibition on medical assistance in death. Today, there are two main types of MAiD practiced in Canada which are self-administered (patient ingests lethal substance prescribed by physician) or physician-administered (physician administers legal substance through IV). Although both are legal in Canada, self administered MAiD is not practiced in many provinces (including Manitoba) due to the unavailability of oral medicals and other concerns with prescribing such medications (Wiebe, 2019).

Legislative context

The Supreme Court of Canada's (SCC) decision in *Carter* is no doubt pivotal to the legalization of MAiD in Canada, however, this issue began to gain prominence much earlier than this case, sometime after the offence of suicide was taken out of the *Criminal Code* in 1972 (Lester, 1993; S.C. 1972, c 13, s. 16). The crime of (attempted) suicide, which carried over from English common law, considered suicide to be a type of homicide, offensive to both God and the monarchy due to their vested interests in life and citizens (Penney, 2014). This change reflected a change in societal understanding of suicide shifting from a criminal issue to one concerning public health and social policy (*Rodriguez v. British Columbia*, 1993, p. 558). However, aiding or abetting another person to commit suicide remains illegal under the *Criminal Code* even today, with exceptions for MAiD.

Crumley, Sheppard, Bowden, and Nelson (2018) analyzed Canadian newspapers' portrayals of medical assistance in dying from 1972 until 2016 and found that support for MAiD among Canadian has grown considerably during those years. Whereas a poll in the late 60's showed only 45% receptiveness to MAiD, "acceptance had grown to 77% by 1990" (p. 4). During this time period (late 70's, early 80's) Canadian courts were also exploring issues of patient autonomy, 'informed consent' requirements, and the right of patients to refuse medical interventions even when this would result in death (*Hopp v. Lepp*, 1980; *Reibl v. Hughes*, 1980). These debates were encompassed under the principle of self-determination, encompassing the right to make decisions about one's own life/body without government intervention, which was soon formally recognized by the courts ("The fight", 2009). This principle was central to the elimination of suicide as a crime but also to the continued regulation of suicide, since any external influences on an ‘informed decision’ were argued to effectively disturb a person’s right to self-determination (Penney, 2014).

Although various attempts were made by senate committees and members of Parliament to propose bills favouring the decriminalization of PAS not many made it to the voting stage in Parliament and reports on the subject seemed to favour reduced criminal sanctions instead (Schafer, 2013). Opponents of the legalization of PAS tended at that time to focus on slippery slope arguments, that is, they argues that if it were to legalized, the results would be a radical diminution of protection available to vulnerable Canadians, despite any safeguards. These arguments were advanced frequently despite lack of empirical support. It was also argued by opponents of PAS that legalization would produce ethical quandaries for healthcare providers (Stingl, 1998). Nevertheless, a lenient sentencing trend can be observed, with assisted death cases (mostly involving healthcare providers) in Canadian courts, which rarely involved prison sentences (Ogden, 1994). These decisions recognized a progressive public opinion regarding assisted death among Canadians with opponents arguing a permissive regime of careful regulation, monitoring, and reporting would yield a society that is “more respectful of patient autonomy” (Schafer, 2013, p. 530).

Decriminalization of MAiD

“If I cannot give consent to my own death, whose body is this? Who owns my life?”

– Sue Rodriguez

The first major case court case explicitly addressing the issue of euthanasia in Canada was the *Rodriguez* decision, resulting in a divided SCC decision in 1993. The *Rodriguez* case was brought before the British Columbia Supreme Court in 1992 by a 42-year-old woman named Sue Rodriguez who was suffering from amyotrophic lateral sclerosis (ALS) with a life expectancy between two and fourteen months. Sue Rodriguez asked the courts for the recognition of her right to determine the manner and time of her passing as she did not want to slowly lose all functioning of her body and be left to choke, suffocate, or starve to death. She thus applied to the Court that section 241(b) of the *Criminal Code* prohibiting assisted suicide be declared invalid. Section 241 then read:

> 241. Every one who
>
> (a) counsels a person to commit suicide, or
>
> (b) aids or abets a person to commit suicide,
>
> whether suicide ensues or not, is guilty of an indictable offence and liable to imprisonment for a term not exceeding fourteen years. (*Criminal Code*, 1985, s. 241)

Rodriguez argued that this prohibition violated her s. 7 of the *Canadian Charter of Rights and Freedoms* right to liberty and security of person as she was unable to make fundamental medical decisions relating to personal autonomy and the ability to choose the manner of her death. Rodriguez argued that she would be forced to take her life prematurely while she was still able (as suicide itself was not illegal). Additionally, Rodriguez claimed infringements on s. 12 as the prohibition subjected her to cruel and unusual punishment in the form of prolonged suffering. Finally, Sue Rodriguez stated that since it was legal in Canada to commit suicide, refuse life-saving treatments, insist upon the withdrawal of life support systems, and request palliative care (in the form of medication which may as a side effect accelerate death) death. Therefore, it was inconsistent under s.15 equality rights to deny physician assisted suicide, as suicide itself was not illegal and only those who are disabled would not be afforded this choice (*Rodriguez v. British Columbia*, 1993).

Unfortunately, Sue Rodriguez was not successful in her application and was ruled against at the British Columbia Supreme Court as well as the Court of Appeal and finally in a split decision at the Supreme Court of Canada (SCC). The SCC, in a 5-4 decision, upheld the blanket prohibition against assisted death finding that there were no other reasonable means of protecting vulnerable patients from being persuaded to obtain MAiD at a time of weakness. The court also held that allowing MAiD would undermine the sanctity of life (under s.7 right to life). Further, at the time, a blanket prohibition was the norm among other Western democracies with only a few having legalized/decriminalized the practice (*Rodriguez v. British Columbia*, 1993, paras. 605-614).

Despite this decision, Sue Rodriguez continued to advocate for MAiD, going as far as arranging her own physician assisted death in secret. In a short video interview with CBC Sue Rodriguez admits to having picked out a date for her death but refused to name the doctor who agreed to assist (Thompson, 1994). On February 12, 1994, Rodriguez drank a toxin provided to her through a straw and passed away. Although the incident was investigated by police, no charges were laid and the anonymous doctor's identity was never found (Farnsworth, 1994). This became the landmark case for MAiD in Canada for many years until *Carter*.

The *Carter* case also originated out of British Columbia and contested the same blanket prohibition under s. 241 of the *Criminal Code* as well as s. 14, prohibiting a person from providing consent to their own death. The main plaintiff, in this case, was Gloria Taylor, who (like Rodriguez) had ALS and wanted assistance in dying when she deemed her suffering no longer tolerable alongside Dr. Shoichet, a physician willing to provide MAiD. However, Gloria Taylor passed away naturally in 2012 leaving named plaintiffs Lee Carter and Hollis Johnson, to carry out the case. Carter and Johnson assisted a family member to pursue MAiD in Switzerland and therefore argued that this should be an option in Canada as they could be held criminally liable in aiding their family member. Despite Gloria Taylor's death, the decision of the court concentrated on the circumstances of her illness with more marginal comments made about the rights of other plaintiffs. The plaintiffs claimed that the blanket prohibition deprived Gloria Taylor of her life, liberty and security of person (under s. 7) as well as perpetuated disadvantage for disabled patients and thus, was discriminatory (infringing s. 15) (*Carter v. Canada*, 2015).

While Smith J. at the British Columbia Supreme Court sided with the plaintiffs, finding infringements on ss. 15 and 7, the Court of Appeal stated that this matter was already decided in *Rodriguez,* a decision which only the SCC could overturn. In 2015, *Carter* had reached the Supreme Court of Canada which unanimously struck down the blanket prohibition under ss. 241 and 14. The SCC agreed with Smith J.'s decision, stating that she was not bound by *Rodriguez* as there have been significant legal and societal developments since that decision (20 years prior), which fundamentally shifted MAiD debates (para. 48). However, the SCC did not endorse her finding of a s.15 violation (right to quality and freedom from discrimination), only finding infringements on life, liberty, and security of person (s.7).

The prohibition forced some individuals to take their lives prematurely while they were still physically able to do so (para. 58), creating a "duty to live", rather than a "right to life", calling into question the legality of any consent to the "withdrawal or refusal of lifesaving or life-sustaining treatment" (para. 63). The right to security of the person was violated as the prohibition forced people to remain in a state of intolerable suffering, while the right to liberty was infringed due to interference with "ability to make decisions concerning their bodily integrity and medical care" (para. 66). The SCC found the prohibition to be severe and noted that the goal was not to "preserve life whatever the circumstances" (para. 78), finally providing the government with a year to implement new laws [in a manner that is] consistent with the *Charter* (*Carter v. Canada*, 2015, para. 147).

Transition

Shortly following the *Carter* decision, the government responded by appointing various committees to research and provide recommendations on what some called physician assisted dying and others MAiD. First, the Ministers of Justice and Health established the 'External Panel on Options for a Legislative Response to *Carter v. Canada*' (2015) which was to hold discussions with Canadians as well as interveners in the *Carter* case to provide recommendations on possible legislative responses. This panel traveled abroad to study MAiD regulations in the Netherlands, Belgium, Switzerland, and the U.S., however, ran out of time and instead submitted a summary of key findings. The panel explored issues of eligibility, terminology, proper procedures, and oversight, also conducting a public survey that reported stronger MAiD support for those with life-threatening illnesses (Department of Justice, 2015).

Shortly after, a Provincial-Territorial Expert Advisory Group on Physician-Assisted Dying was formed to consult with experts on health, law, and ethics across Canada and provide recommendations on the implementation of physician-assisted dying. In their final report, released November of 2015, the advisory group outlined 43 recommendations encouraging public and professional education, ongoing research, improved palliative care, proper assessment procedures and documentation, oversight, provisions for conscientious objectors, among other safeguards (Ontario Ministry of Health, 2015). Most importantly, a patient centered approach was recommended and later endorsed by the Special Parliamentary Committee that presented findings directly to the House of Commons.

The ‘Special Joint Committee on Physician-Assisted Dying’ was tasked with researching and providing recommendations on what would become Bill C-14 outlining provisions for medical assistance in dying. The committee heard various perspectives including reports from the Advisory Group and External Panel (above), also considering the work of Quebec’s Select Committee on Dying with Dignity which has been debating MAiD regulations since 2009. The committee presented their final findings to the House of Commons in February of 2016 with 21 recommendations regarding eligibility criteria for applicants as well as safeguards against abuse of process. Many of these recommendations were similar to those of the provincial-territorial advisory group and would later be incorporated under Bill C-14 however, some others were left out entirely such as allowing access for those with psychiatric conditions (who met all other eligibility criteria) mature minors, and ensuring all publicly funded healthcare institutions provide MAiD. The conservative members of the committee (including the Vice-Chair) filed a dissenting reporting, believing that the recommendations reached were too permissive and did not sufficiently protect vulnerable individuals (House of Commons, 2016).

Due to the disruptions of the federal elections within that year, the newly elected Liberal government applied to the courts for a six-month extension but was given a four-month extension instead (to make up for the election disruptions). Finding it no longer reasonable to ask Canadians to wait for a legislative response, the court opened up the possibility for competent adults with grievous and irremediable illnesses to apply for an exception through the court and access physician assisted death (*Carter v. Canada*, 2016, paras. 13-14). All cases during this period had publication bans to protect the identities of applicants and physicians, with many cases not being published publicly at all. Of the publicly available cases, all were granted permission to access MAiD with the most common conditions being cancer and ALS, consistent with current federally published statistics (Government of Canada, 2019).

Two cases stood out during this four-month exclusion period. At the time, drafts of Bill C – 14 have been circulating and physicians were worried about the provision requiring a 'reasonably foreseeable natural death'. The first case of note, *I.J. v Canada* (2016), involved a 90-year-old patient with a multitude of grievous and irremediable conditions that caused him to suffer grievously however, none of which was terminal and would nevertheless allow him to live for years. The second case, *Canada (Attorney General) v E.F.* (2016), was the subject of an appeal by the government as a 58-year-old patient was granted permission to access MAiD despite the illness being psychiatric in nature (manifesting physical symptoms) and non-terminal. Both applications were granted despite the non-terminal nature of the applicants' illnesses, as that was not a requirement highlighted by SCC in *Carter*, to which courts adhered , at the time. In June of 2016, a few weeks past the deadline, the Government of Canada had finally decriminalized medical assistance in dying after the royal assent of Bill C-14 (Bill C-14, 2016), which is now set to be amended in July of 2020.

Legislating MAiD

Bill C – 14, named "an Act to amend the Criminal Code and to make related amendments to other Acts (medical assistance in dying)" laid out the federal regulations and eligibility criteria for MAiD in Canada, while recognizing that healthcare is under provincial jurisdiction which allows for various implementations of this legislation. While aiding and abetting a person to suicide remains illegal under s. 241(1) of the *Criminal Code*, there are now exceptions to this for healthcare professionals who follow certain guidelines. These exceptions applied to physicians, nurse practitioners, pharmacists, and any other person acting for the purpose of aiding a medical practitioner with MAiD in accordance with regulations. Section 241.1 of the *Criminal Code* defines medical assistance in dying and qualified this included circumstances of both self administered and physician administered lethal medications. Section 241.2 (1) lays out the eligibility criteria for MAiD:

> 241.2 (1) A person may receive medical assistance in dying only if they meet all of the following criteria:
>
> > (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.
>
> (2) A person has a grievous and irremediable medical condition only if they meet all of the following criteria:
>
> > (a) they have a serious and incurable illness, disease or disability;
> >
> > (b) they are in an advanced state of irreversible decline in capability;

> (c) that illness, disease or disability or that state of decline causes them enduring physical or psychological suffering that is intolerable to them and that cannot be relieved under conditions that they consider acceptable; and
>
> (d) their natural death has become reasonably foreseeable, taking into account all of their medical circumstances, without a prognosis necessarily having been made as to the specific length of time that they have remaining. (*Criminal Code*, 1985 s. 241.2(1) and (2))

In the remaining subsections, the *Criminal Code* outlines safeguards to be undertaken by medical professionals, including ensuring applicants meet all eligibility criteria as assessed by two separate physicians, are competent and able to make their own medical decisions, have two independent witnesses, be subject to a waiting period of 10 days (which can be waived in cases where imminent death or capacity loss is a concern), provide opportunities to withdraw consent prior to the procedure, among other administrative requirements.

These federal regulations were careful not to overstep their jurisdiction over criminal matters and left some aspects of the practice to be governed by provincial health authorities. Provincial governments and health authorities then implemented their own regulations/policies in response to the legalization of MAiD to ensure accessibility for all eligible Canadians as well as adequate protection for conscientious objectors (Bill 34, 2017). Manitoba had a unique (among the provinces) response to the MAiD legislation, which encompassed forming a single entry system into MAiD, with a multidisciplinary team of professionals to oversees all MAiD inquiries and requests across the province (Winnipeg Regional Health Authority, 2016).

Disputes over legislation

Time constraints were a major area of contention during legislative debates, highlighting that Quebec has been debating and writing MAiD legislation for six years (since 2009), taking time to research international MAiD schemes and listen to the testimonies of professionals in Canada (Deltell, 2016). These political debates alongside academic literature published during that period gave rise to a few major areas of concern with regard to current MAiD legislation, including: allowing access for mature minors, the possibility of making an advanced requests for MAiD, protecting conscientious objectors, and abstaining facilities while still ensuring equitable access to MAiD, and finally eliminating or clarifying the reasonably foreseeable natural death (RFND) requirement. These concerns prompted the government of Canada to sponsor a trilogy of reports from the Council of Canadian Academies exploring expert opinions on the issues of mature minors, advanced requests, and cases where mental illness is the sole underlying condition (discussed here briefly under the RFND section). All of these concerns contain multiple sub-issues within them, each of which can be (and have been) subjects of separate, in-depth literature reviews but will be more broadly outlined below.

Mature Minors

Federal law does not currently allow Canadians under the age of 18 to apply for MAiD which was consistent with the court's ruling in the *Carter* decision requiring the consent of 'competent adults'. Some scholars criticize this requirement for creating an arbitrary cut off that does not scientifically reflect achieving an age of competent decision-making skills (Raus, 2016; Cuman and Gastmans, 2017). In line with these criticisms the Expert Advisory Group as well as the Special Joint Committee recommended that the government implement allowances for mature minors within three years of decriminalization (House of Commons, 2016). Despite these recommendations, the legislation merely makes a commitment in its preamble to support and explore the possibility of MAiD for mature minors (Bill C-14, 2016).

A part of the difficulty in creating definitive allowances for mature minors is deciding where to draw the line (or whether there should be a line) as well as how a mature minor is defined. Currently, there is no consensus on a definition by either medical or professional communities and it is not explicitly defined by any Canadian legislation. Mature minors are commonly recognized as a population of individuals under the age of majority that have the capacity to make informed healthcare decisions. While there is no strict cut-off, the important difference to note between a minor and a mature minor, is that the latter has been deemed to have the capacity to make informed healthcare decisions (Council of Canadian Academies, 2018, p. 36). To date (2020), there have not been any court cases involving a minor's request for MAiD.

Minors have been previously allowed to make their own healthcare decisions including refusing life-prolonging treatments and withdrawing artificial support measures but mostly in cases where treatment was burdensome and would likely fail. Belgium and the Netherlands both allow ill minors to request and access MAiD (if eligible) however, that has not always been the case and these countries have allowed MAiD for much longer than Canada, eventually evolving into a more permissive regime.

The Council of Canadian Academies report highlights the importance of capacity not overshadowing voluntariness in youth choosing MAiD, since having capacity does not necessarily mean the decision was made autonomously. The Supreme Court of Canada formally recognized this as well, stating that while minors may possess the technical ability to make their own decisions, this does not mean that they have "the necessary maturity and independence of judgement to make truly autonomous choices" (*A.C. v. Manitoba*, 2009, para. 71) that are devoid of the influence of others (such as parents or other care-givers).

Bovens (2015) breaks down the five most common arguments for denying MAiD for minors the first of which is that minors are not permitted to do a range of things (such as vote or buy cigarettes/alcohol), why should life and death matters be any different. Minors are also said to be incapable of discernment, susceptible to pressure, or (alternatively) highly sensitive to the desires and expectations of others (absent overt pressure), and finally, it is sometimes claimed that suffering can always be alleviated via palliative care. In response, Bovens points out that minors have been previously involved in making decisions regarding artificial life support and onerous procedures which are much more comparable to MAiD than having the right to vote or buy alcohol. Some scholars argue that minors base their decisions on social norms which are handed down by their parents, which they are not able to critically scrutinize. Bovens points out that the critical scrutiny of identity formation and norms is not a requirement of authoritative decision making (definitely not for adults). Further, minors who deny MAiD are never questioned about a conservative upbringing.

Similar to this, scholars often argue that minors are especially susceptible and sensitive to pressure however, Bovens argues that this pressure is no greater than that an adult would feel under the same circumstances. Parents tend to hold on to their children's life much more than the converse, often reasoning they have lived so little, which may actually lead to a minor choosing to prolong their life. Additionally, in a socialized healthcare system (like Canada's), children are not a financial burden and parents do not stand to profit (an inheritance) in the case of their child's death. While the opposite is true in the case of an elderly parent pursuing MAiD who would face these pressures to a much greater degree from their family members, who would feel less of an obligation than a parent does to their child (Bovens, 2015).

Cuman and Gastmans (2017) classified the denial of autonomy for minors as a form of age discrimination. Supporters of MAiD for minors do not advocate for unrestricted access to MAiD for all but instead, argue that this should be decided on an individual basis. Whereas opponents of MAiD for minors, advocate for a better quality of palliative-care, using slippery slope arguments (absent empirical evidence) leading to abuse of process and an overly permissive regime in which vulnerable populations (such as minors) are left unprotected, thus, normalizing MAiD (Georges et al., 2008; Voorhees et al., 2013).

The Canadian Paediatric Society (CPS) surveyed some of their members, finding that MAiD discussions with minors are very rare with only 17 explicit requests reported (out of 1,050 respondents), yet are generating increasing interest. Perhaps the lack of discussion has to do with lack of awareness or knowledge of ineligibility as opposed to disinterest. Davies (2018) argues there is a growing interest in MAiD for minors but even if this criterion were to evolve, the surveys suggest only 19% of clinicians would be willing to provide MAiD to minors if it were legal. DeMichelis, Shael, and Rapoport (2018) explored the possibility of MAiD in the pediatric setting at their Toronto hospital, concluding that MAiD should be classified as any other end-of-life procedure in a pediatric setting.

Advanced Requests

Similar to debates about allowances for mature minors, allowances for advanced consent to MAiD also involve questions of competence. Patients with dementia are the most prominent group (though by no means the only one) connected with the issue of advanced requests as they stand to lose capacity to consent altogether. Dementia is a general term that describes a progressive disorder affecting the brain, causing memory loss, difficulty thinking, speaking, and problem-solving with more severe cases restricting everyday activities (such as eating). Patients under palliative sedation (often due to unmanageable pain) are also affected as they must have their medication reduced to the point of clarity, in order to undergo assessments as well as provide final consent and consequently often die in pain. Hertogh, Boer, Dröes, and Eefsting (2007) call dementia the “inevitable loss of selfhood and personality” (p. 48) in their exploratory study on the ‘dementia debate’ that occurred for years in the Netherlands. The most commonly known types of dementia are Alzheimer’s, Parkinson’s, and Huntington’s, among many others. MAiD scholars often concentrate their research on Alzheimer’s patients or use the term ‘dementia’ generally to cover all possible types (“What is dementia”, 2018).

Advanced requests are not currently legal in Canada as the legislation requires informed consent be given immediately prior to the procedure. This precludes patients with various forms of early stage/mild or moderate dementia (or at risk of capacity loss) from accessing MAiD or forces them to pursue it at a date earlier than they would like. The Audrey Parker case is the most well-known Canadian illustration of this dilemma. Audrey Parker was a Halifax woman who was approved for MAiD but at risk of losing capacity to consent (due to metastasized brain cancer) and publicly exclaimed that she was choosing to die earlier than she would have liked, due to the “poorly thought-out law” requiring a final consent (Patil, 2019). There is very little research published on the issue of advanced consent for patients who lose capacity, yet it remains one of the most polarizing MAiD debates.

Hertogh et al. (2007) indicate that caregivers can enhance the quality of life for dementia patients by involving them in autonomy decisions. The growing difficulty with this population is that they often adapt to circumstances which they previously condemned. It then falls on physicians as well as proxies to balance the previous preferences of a competent patient and the now forgotten directive, with the patient's new reality. DeGrazia (1999) calls this 'the someone else problem' referring to changing values and priorities of patients with dementia as they undergo psychological changes, which may in turn create an entirely different person. Hertogh et al. write that assessments for MAiD become complicated as a patient with advanced dementia cannot communicate their desires or comment on whether they believe their illness is 'grievous and irremediable'. Even if communication was not an issue, often the patient's subjective experience lacks the realization of dementia, making it difficult to appreciate their situation in full (Hertogh et al., 2007).

For these reasons, most permissive jurisdictions do not allow MAiD for dementia patients who lost capacity (even if they consented before losing capacity). Places that do allow this, such as the Netherlands, naturally evolved into this more permissive framework and is still used very rarely, with many finding it seldom ethically acceptable unless additional complications arise from unrelated illnesses (Rankin, 2019). Kouwenhoven et al. (2015) surveyed medical specialists and the general public (in the Netherlands) on their opinions about MAiD for a patient with advanced dementia based on advanced consent having been given while the patient was still competent. They found that physicians doubted due care criteria would be met, often wanting confirmation from the patient which is generally impossible, however, many still believed this should be allowed as an option. Members of the general public thought that MAiD requests as advanced directives should be respected as they recalled the suffering and humiliation of their friends/relatives with dementia. However, both groups predicted difficulties with this allowance such as patients changing their preferences and subpar quality of care in nursing homes. These results come in contrast to previous studies that generally find majority support among the public and minority support among medical professionals since they consider communication with the patient essential (Kouwenhoven et al., 2015; de Boer et al., 2011). Hertogh et al. (2017) advocate for improved symptom management with palliative care as studies show a significant underdiagnosis and undertreatment of pain in patients with dementia.

Important to note, these studies discuss advanced consent in the form of healthcare directives, which are different from advance requests following assessment and approval for MAiD. Advance directives or ‘health care directives’ are present in Canada (but not for MAiD) and constitute a more detailed form of the commonly known ‘living will’, where one declares a substitute medical decision-maker (proxy) in cases of incapacitation. Unlike a living will, a health care directive generally provides details (for the proxy) on a person’s values and beliefs, or circumstances they would want to be kept on life support, which will guide the proxy in medical decisions, especially those concerning artificial life support. A health care directive typically outlines the types of medical treatments that a person would/not want, including voluntarily stopping eating and drinking. Health care directives must be filled out and signed by a competent adult as well as renewed every five years (in Manitoba). However, there is no legal mandate to enforce a directive and it is solely the proxy’s responsibility to ensure it is followed by medical staff. Currently, a health care directive with a request for MAiD is not legally binding, yet, problematically allows requests for voluntary stopping of eating and drinking (“Advance Directive”, n.d.; Health Care Directive Act, 1993).

Menzel and Steinbock (2013) predict that the demand for MAiD via advanced directives will become more pressing with time as the world’s population is aging and studies show nearly half of people over 85 have some form of dementia. They argue that advanced directives for patients with dementia should be permitted and followed despite the lack of contemporaneous consent.

However, they qualify that this should be decided on a case by case basis and no patient should be held to their advanced directive if they change their mind or resist. There is currently no standardized guidelines to assess patient capacity in psychiatry with physicians using a variety of tools to assist with this decision. Despite a plethora of tools existing in the field, only a small number of these instruments have been demonstrated to encompass both validity and reliability. Further, specialists qualify that any capacity assessment is not global, but should be considered task-specific at a particular moment in time (Canadian Psychological Association, 2018; Lamont, Jeon, and Chiarella, 2013). Due to the various stages and types of dementia, it is impossible to know whether one will be happily demented or more anxious, confused, and angry. Therefore, when filling out an advanced directive, people should educate themselves about the many faces of dementia, state what exactly they would find unbearable to live through, and update their directives regularly so that clinicians can be confident in the desires of their patients (Menzel and Steinbock, 2013).

Conscientious objection

Conscientious objection with regard to MAiD is another multi-faceted issue that has generated legal action from various organizations due to the lack of protections under federal legislation. The *Carter* decision (at the Supreme Court of Canada – SCC) explicitly stated that nothing "would compel physicians to provide assistance in dying" (para. 132) however, concerns surfaced regarding the rights of conscientious objectors as federal legislation provided no explicit protections for healthcare providers that object to MAiD on religious or moral grounds. The Minister of Justice rationalized this as a matter of provincial (not federal) regulation considering their jurisdiction over healthcare matters but offered reassurance that objecting medical professionals would not be forced to provide MAiD (Wilson-Raybould, 2016). Most provinces had no issues incorporating conscientious objection into MAiD policies, mirroring existing protocols for objectors which only asked of physicians to provide timely access to a resource that would hold accurate information about MAiD (College of Physicians and Surgeons of Manitoba, 2016, s. I.C.).

The College of Physicians and Surgeons of Ontario (CPSO) responded to this by implementing policies that required physicians with a conscientious objection to make an 'effective referral' to another health-care provider who is non-objecting and accessible, in a timely manner. Further, in case of an emergency or risk of imminent harm to a patient, they qualified that a physician *must* provide care, regardless of their beliefs (College of Physicians and Surgeons of Ontario, 2018, s. 11). The Christian Medical and Dental Society of Canada challenged this policy claiming it infringed their s. 2(a) freedom of religion and conscience as well as s. 15 equality rights. They explained that some physicians view effective referrals as active participation in MAiD, which was against their religion and/or conscience. It was additionally claimed that this policy discriminated against physicians on the grounds of religion as it imposes an additional burden on objecting physicians (*Christian Medical and Dental Society of Canada v. College of Physicians and Surgeons of Ontario*, 2018).

The CPSO disagreed with these claims, pointing out that they held the authority to govern physicians in Ontario, further, non-compliance with this policy did not have any associated penalties and physicians had other avenues by which to provide 'effective referrals' (transfer of care). The Supreme Court of Ontario agreed that while the religious freedoms of objecting physicians as outlined in the Charter of Rights and Freedoms were infringed, the infringements were justified in a free and democratic society (s. 1). That is, the restriction on physician's religious freedom was reasonable under s.1 of the Charter. The court explained that the objectives of this policy were sufficiently important to override religious freedoms as any alternatives would be burdensome and create barriers for patients seeking MAiD (*Christian Medical and Dental Society of Canada v. College of Physicians and Surgeons of Ontario*, 2018). The decision was soon appealed but upheld by the Ontario Court of Appeal which agreed that physicians acted as 'gatekeepers' for specialized healthcare services and without proper referral would create unreasonable barriers for vulnerable patients (*Christian Medical and Dental Society of Canada v. College of Physicians and Surgeons of Ontario*, 2019).

Although these cases only speak to regulations in Ontario, it is necessary to remember that medical professionals across Canada are *not* required to condone or participate in the MAiD process. While these decisions caused an outcry and resistance in some religious communities, it has not caused nearly as much concern as the refusal of faith-based healthcare institutions to allow MAiD on their premises (including assessments). Across the country some hospitals, nursing homes, and long-term care facilities have been refusing to allow MAiD in their facilities (or sometimes even an assessment for MAiD) and require patients to transfer elsewhere for either the assessment or the provision of MAiD (or both) to take place. This issue has come up in various cities across Canada (Fraser, 2017) including Winnipeg, with St. Boniface, Misericordia, and Concordia hospitals along with nearly half of all nursing homes requiring the transfer of critically ill patients to access MAiD, a legal medical procedure (Swan, 2017).

Manitoba allows this exception for faith-based healthcare facilities under *The Regional Health Authorities Act* (*RHAA*) which states under s. 29.3 that health corporations owned and operated by religious organizations may "provide care and services in a manner that is consistent with the fundamental principles of the religion or faith to which it adheres". Additionally, the Winnipeg Regional Health Authority policy on MAiD states that abstaining facilities may refuse to provide

MAiD as long as they have identified as faith-based (previous to legalization) and published a policy expressing their position that is available to the public (s. 3.2). In response, various hospitals and nursing homes published policies prohibiting MAiD at their facilities, with some even requiring transfers for MAiD assessments. St. Boniface Hospital was one of the first to release a policy, with subsequent policies closely reflecting this format, which states:

> 3.1 As a faith-based facility and community of service within the Catholic Health Care Corporation of Manitoba (CHCM), St. Boniface Hospital shall not participate in an act that intentionally causes death, and therefore shall not deliver medical assistance in dying (MAiD).
>
> …
>
> 3.5 Individuals shall also be advised they will not be able to access MAiD should it be determined by the MAiD team in collaboration with SBH care team they are too ill or frail to be transferred or decline to be transferred to another WRHA Facility that permits MAiD. (St. Boniface Hospital, 2017)

This policy (and many others like it) not only requires that patients are transferred for the procedure but in the case a patient is too ill to be transferred, deprives that patient of the MAiD option altogether. Kelvin Goertzen (Manitoba's Health Minister) has publicly supported St. Boniface's position and said he believes this strikes the right balance between offering access but also respecting decisions of religious hospitals (Pursaga, 2017).

These policies were quickly criticized with various stories in the media displaying the burden this placed on patients. One story portrayed a patient in Alberta who was electronically lifted into a wheelchair only to be taken across the street for a MAiD assessment, conducted on the sidewalk, in the rain, with cars and people passing by (Prudy, 2018). Other stories portrayed intentional processing delays that prolonged requests for eligibility assessment, transfer of files, and finally the transfer of patients (Caruk & Hoye, 2017). This was a significant concern as applications for MAiD can be time-sensitive with preliminary data in Manitoba showing (in the first year since legalization) that 73 patients have died before approval due to initiating the process too late. Patients often do not realize that there is a process and waiting period behind MAiD applications and consequently apply too late believing they need to be in their final days, this was attributed to the lack of information dissemination on MAiD ("Number", 2017).

The deteriorating condition of patients must also be accounted for when considering a transfer. Patients applying for MAiD are often in a vulnerable state (physiologically and psychologically) where a mandatory transfer is likely to cause undue burden, discomfort/pain, even worsening their ailment. Multiple empirical studies have found that transfers of critically ill patients (constituting the majority of MAiD patients) face high rates of complications including the possibility of death and should be reserved for cases where potential benefits are in the patient's best interest (Droogh et al., 2015; Markakis et al., 2006; Beckmann et al., 2004). There has been at least one publicized case from British Columbia in which a man "faced excruciating transfer after [a] Catholic hospital refused assisted-death", with the man's family describing his screams of agony on his last living day (Blackwell, 2016). Patients are thus faced with an impossible choice between enduring an excruciating transfer that is likely to cause complications or discomfort at the least, or else continue living in a state that is intolerable to them until their natural death.

In Winnipeg, this issue is further complicated by the regional health authority's healthcare consolidation which is now in its final stages. Essentially, the Winnipeg Regional Health

Authority, under the advisement of the conservative government initiated a plan to consolidate services by merging specialized services at specific locations claiming this ensures concentrated expertise, reduce wait times, and provides better curated care (“More services”, 2018; “Editorial”, 2018). As a result, various healthcare facilities were restructured, with some emergency departments converted to urgent care centres and ambulance protocols changed to instruct paramedics of the best (instead of nearest) location to transport patients in an emergency (depending on their condition) (“Changes to ambulance protocol”, 2017). St. Boniface continues to specialize in cardiac care and holds one of only two palliative care departments in the city (Pursaga, 2017; St. Boniface Hospital, 2017). Therefore, patients will be transferred to abstaining facilities without a choice in the matter and unaware of their policies on MAiD, leaving them with little to no choice regarding end-of-life options.

This issue, caused many academics, practitioners, and members of the public to question whether religious hospitals, which receive public funding, have the right to assert institutional religious freedoms and refuse to permit legal procedures, or whether they have a duty to serve our secular and multicultural society, beginning discussions of a possible court challenge in Ontario (Fraser, 2017). Barry Bussey (2018) argues that hospitals do have institutional religious rights separate from the individual rights of their members. Bussey points out that community is integral to religious life and participating/being members of religious communities (academic, recreational, medical, etc.) is important to religious individuals. He argues that group rights have been recognized by the law throughout history, especially those of religious institutions and communities, while individual rights are a modern concept attributed to neoliberalism and the Constitution. Bussey asserts that hospitals did not exist prior to their introduction by Christianity and considering their extensive contribution to the public good through charity work, hospitals just as individuals should be able to reject certain practices.

While many of Bussey's arguments are valid, they ignore the governmental movement away from religion into a secular society that reflects the multiculturalism of Canadians. Kislowicz (2016) argues that public institutions have a duty to public neutrality which is what sets apart allowances for religious private schools from public hospitals. The state's role is to maintain public neutrality toward all denominations as not to favour one over another. Therefore, public institutions such as hospitals (including those with religious affiliations) must encompass this neutrality and strive to be inclusive of differences. Also, unlike private religious schools, hospitals do not have uniform membership (whether through employees or clients) that adhere to the same faith. Daphne Gilbert has argued that hospitals would not be able to assert institutional religious freedoms as they are public institutions ran by doctors, not priests, and were primarily constituted for medical as opposed to religious purposes (Gilbert, 2017). This draws attention to the clash between public rights especially when it comes to accessing healthcare, and those of semi-private institutions as well as what their responsibility is in following new public rights.

Gilbert (2017) stated that *all* hospitals (including secular ones) recognize the importance of spiritual care (at least in Canada) and all hospitals provide religious services upon request as well as a separate space for prayer. Rhodes and Danzinger (2018) critiqued religious hospitals for their choice of procedures, arguing that an ill person attending to a hospital "has a reason to expect medical care that is consistent with medical standards regardless of hospital ownership" (p. 52). Hospitals that do not intend to fulfill this social responsibility to those most vulnerable in our society, should choose a path that is more compatible with their conscience (outside of medicine). Just as Jehovah's Witnesses' could not operate a hospital that refuses blood transfusions, Catholic owners should not operate hospitals that neglect some of their duties (Rhodes and Danziger, 2018). Bussey, however, warns that some religious institutions (such as child and family service centres or schools), that have been forced to comply with secular demands contrary to religious positions, have chosen to shut their doors rather than operate in a manner inconsistent with their belief system.

While there is significant debate about allowing institutional religious freedoms for hospitals in the United States, this has been mostly overlooked in Canadian literature. Muniz-Fraticelli suggests that is due to the privatized nature of the American healthcare system which gives religious hospitals more power in such debates thus promulgating this dispute (Muniz-Fraticelli, 2017, para. 52). Catholic hospitals in the U.S. have historically refused to participate in medical practices contrary to their beliefs including performing abortions, providing contraception, or assisting with euthanasia, despite having made various changes to accommodate a variety of cultures (Iltis, 2006). On the other hand, Catholic hospitals in Belgium have begun offering euthanasia to their patients, in regular as well as psychiatric hospitals (Iltis, 2006). This is not without backlash from elements within the Catholic community as the Pope since demanded these hospitals cease the practice, threatening ex-communication (McGarry, 2017). Nevertheless, they continue to disobey Vatican orders and offer euthanasia for all patients despite the looming threat (Rocca, 2017). It remains to be seen how this debate unfolds in Canada.

Reasonably foreseeable natural death (RFND)

One of the most controversial eligibility criteria for applicants seeking assistance in death requires that a patient’s natural death be reasonably foreseeable without necessarily having a prognosis speaking to the specific length of time remaining (*Criminal Code*, 1985, s.241.2(2)(d)). The government indicated that this clause was put in place in order to protect vulnerable populations from abuse or exploitation. It is claimed that by requiring that death be reasonably foreseeable the practice of MAiD will be prevented from falling down a by preventing the practice from falling a ‘slippery slope’. The “reasonably foreseeable death requirement would restrict maid access to patients who are critically ill (Reel, 2018). However, this provision stirred quite a bit of controversy with many interpreting this criterion to mean that in order to be eligible for MAiD a patient had to be terminally ill and at their end-of-life. This was in line with the mandate provided to MAiD physicians (by lawyers) who advised limiting eligibility to those who will likely die within a year, eventually, MAiD providers relaxed this strict interpretation and now approve patients with various prognoses multiple years in length (Beuthin, 2018).

The Canadian Minister of Justice at the time explained on multiple occasions, that the RFND criterion does not require patients to have a terminal illness but leaves the discretion up to individual physicians (Wilson-Raybould, 2016). Multiple scholars and associations have since suggested various guidelines for interpreting this criterion and called the government to clarify the parameters encapsulating it or taking them out altogether. Downie and Chandler (2018) proposed some interpretations for the more ambiguous requirements under the federal legislation including the RFND. They point out that the requirement leaves unclear whether it refers to the timing of natural death, the cause of death (natural/unnatural), the probability of its occurrence, or any combination thereof. Given this ambiguity, they proposed it be interpreted as having been met if either the death is predictable within a period of time that is not too remote, or due to a predictable cause of natural death, but not necessarily both (Downie & Chandler, 2018). The Canadian Association of MAiD Assessors and Providers (CAMAP) released a similar mandate urging clinicians not to employ strict or rigid timeframes. CAMAP proposed the RFND be understood as ‘reasonably predictable’ considering the patient’s entire medical circumstances (including age and frailty) as well as potential sequelae (“The Clinical Interpretation”, 2017).

Shortly after the introduction of the RFND provision, multiple sub-issues emerged involving disabled patients as well as patients with psychiatric illnesses as the sole underlying condition, as both groups in one way or another do not meet the RFND. Scholars maintained that this provision disqualified a wide array of applicants who would qualify under *Carter*. For example, those who are disabled and completely care dependant yet not terminally ill (quadriplegics), as well as those with illnesses psychiatric in nature would not be eligible, even if their suffering were intolerable and irremediable, unless their deaths were reasonably foreseeable. The Special Joint Committee (under recommendations 2-3) suggested that MAiD be available for competent patients with non-terminal medical conditions which involve intolerable suffering, including patients with psychiatric illnesses (House of Commons, 2016).

Maneesha Deckha (2016) published a legal article through the lens of disability discourse shortly after the *Carter* decision, criticizing the SCC for remaining silent on the s. 15 (equality) issue and on disability rights generally at such opportune times. Deckha claims disability rights activists often point out that disabled populations are automatically rendered vulnerable (by the public and politicians) and unable to make informed decisions which only disadvantages and dehumanize disabled communities further. Excluding those with debilitating yet non-terminal disabilities from the MAiD legislation effectively discriminates against those disabled populations by denying their right to autonomy in the same way it is afforded to others who are disabled. At the same time, some disability communities expressed concern about the messaging *Carter* sends to disabled populations around ‘ableism’ which is the belief that the quality of life for a disabled person's is always so poor that they would be better off ending their life (Council of Canadian Academies, 2018).

This concern evolved into a secondary emergent issue regarding whether a mental illness (such as depression) should disqualify an otherwise eligible applicant as they may be temporarily vulnerable and their mental illness could vitiate their competence to give valis (i.e. informed and voluntary) consent (Wittwer, 2013). As mentioned earlier, there is no single approach to assess mental capacity and it is up to individual clinicians to assess capacity at a given time for a given task. Hewitt (2010) and Wong et al. (2000) conducted studies on the competence of mentally ill patients finding that for some groups' capacity was diminished, yet there existed several members in each group who could make informed decisions. This points to a need for assessments on a case by case basis so as not to arbitrarily exclude otherwise competent patients. But what does this mean for patients who apply for MAiD solely based on their untreatable depression or other mental disorder?

Various scholars considered the psychiatric illness element of these debates using international examples of how euthanasia laws have evolved in countries such as the Netherlands, Sweden, and Switzerland to allow patients who have psychiatric illnesses to access MAiD (Berghmans, Widdershoven, and Widdershoven, 2013). Ponsford (2018) presented arguments in favour of removing such stigma associated with mental illness by equating it to somatic illnesses/pain and expanding access to mental health services. Authors also point out that psychiatric patients will suffer longer as their illness is not terminal and use statistics from Belgium to show that only a very small number of psychiatric patients end up following through with MAiD (Schuklenk and Vathorst, 2015). Arguments against were also offered, such as difficulty diagnosing psychiatric illnesses, looming unpredictability of recovery, non-terminal nature of the illness, susceptibility to coercion, and the fear of normalizing suicide (Blikshavn, Husum, and Magelssen, 2017; Cohen, Dierickx, Deliens, and Chambaere, 2017; Ponsford, 2018).

The Canadian Psychological Association (2018) surveyed its members on this matter and found while 95.3% of respondents believed that mental illness can be grievous, only half believed these disorders are irremediable with 29.4% supporting a legislative expansion to include MAiD on basis of mental disorder alone. Although it is yet unclear whether Canada will follow in the footsteps of other jurisdictions and allow patients with mental disorders (as the sole condition) to access MAID, the RFND requirement was challenged on the grounds of disability and will be removed in the upcoming legislative changes, which would appear to open the door to access for patients suffering intolerably from an illness which is classified as mental. However, current drafts of Bill C-7 rule out this possibility until further research can be done.

Lamb, Truchon & Gladu, Bill C-7

From early legislative debates, the RFND requirement has been widely viewed as problematic and soon after its implementation, two separate court challenges were filed in separate provinces to strike this provision down. The first constitutional challenge, *Lamb*, was initiated by the British Columbia Civil Liberties Association (the same organization that litigated *Carter*) and involved a 25-year-old woman with spinal muscular atrophy. Spinal muscular atrophy while not terminal can lead to various fatal complications or discomforts later in life despite having a normal life expectancy.

Julia Lamb claimed the reasonably foreseeable death requirement disqualified her from MAiD eligibility as her illness was not terminal and therefore would not qualify under the 'reasonably foreseeable natural death' criterion, despite being grievous and irremediable. Other provisions challenged in this case include the requirement of an incurable disease and for an irreversible decline in health (Chu and Cook, 2018). However, since the case was first filed, a few years have passed and medical societies alongside the Canadian Association of MAiD Assessors and Providers (CAMAP) have acknowledged an their interpretation and understanding of the reasonably foreseeable death natural death (RFND) requirement indicating that Julia Lamb was no longer affected by this provision, as she would now qualify. Sworn testimony by a MAiD physician revealed that if Lamb "were requesting MAiD now I believe she would be found eligible under the current eligibility criteria" (p. 2), this led to the adjournment of the case (Li, 2019).

A second case was filed in Quebec (*Truchon and Gladu v. Canada (Attorney General) and Quebec (Attorney General)*, 2019), with plaintiffs Truchon and Gladu, both handicapped by grievous and irremediable degenerative illnesses, however, not terminal in the foreseeable future and therefore assessed as ineligible for MAiD. Jean Truchon, a 51 years old man who suffered mainly from spastic cerebral palsy leaving him paralyzed with limited movement in his left arm. In 2012, Truchon experienced further complications due to his condition that left him fully paralyzed and suffering from intense burning sensations and painful spasms, with no hope of improvement (paras 17-50). Nicole Gladu is 73 years old suffering mainly from degenerative muscular post-polio syndrome (which she has as a child and re-emerged at the age of 47), causing a variety of other sequelae leaving Gladu in a constant state of discomfort, pain, and malaise (paras 51-72). Both plaintiffs have considered other pathways for MAiD via travel to a permissive country, various forms of suicide, or through the voluntary stopping of eating/drinking.

On September 11, 2019, Christine Baudouin J. of the Quebec Superior Court, released a judgement siding with the plaintiffs and striking down the reasonably foreseeable death requirement in the federal legislation and a similar provision under the Quebec legislation. Baudouin J. found that the RFND requirement violated the plaintiff's rights to life, liberty and security of the person in a manner inconsistent with the principles of fundamental justice for similar reasons as the ones presented in *Carter*. As in *Carter*, Baudouin J. stated that the limitation was not arbitrary since it fulfilled the legislative mandate of protecting vulnerable populations from being induced to end their lived prematurely, however, found the RFND requirement to be overbroad in that it applied to non-vulnerable populations and disproportionate to the objective as the consequences for the applicants were serious.

The decision went a few steps further, also finding infringements under s. 15 which encompasses the right to equality without discrimination (i.e. based on mental/physical disability). The case argued that the RFND requirement created a distinction based on physical ability and "perpetuates prejudice and disadvantage for the applicants and the physically disabled precisely because of this personal characteristic" (para. 674). When discussing the legislative objectives, the court found that any benefits to society were minimal when compared to the deleterious effects on the plaintiffs. Therefore, the RFND requirement could not be justified 'in a free and democratic society' (s. 1) for both s. 7 and s. 15 infringements. The court allowed the provincial and federal governments six months to adjust legislation and granted the plaintiffs an exemption in the meantime allowing them to access MAiD if they wished (*Truchon and Gladu v. Canada (Attorney General) and Quebec (Attorney General)*, 2019). Although rumors of appeals emerged following this decision, neither the federal government nor Quebec's government appealed the decision in the allotted period (Downie and Gilbert, 2019; Gyapong, 2019; Curtis, 2019).

In response to the *Truchon* decision, the government of Canada launched a public consultation process between the months of January – February 2020 ("What We Heard", 2020). The consultation process consisted of a public opinion survey that was accessible by all Canadians online, as well as a more formal roundtable consultation process with experts and stakeholders in the field across Canada's major cities. The survey had an overwhelming response rate (300,140 respondents) and asked participants about the importance of potential safeguards in cases where a patient's death was not reasonably foreseeable. The survey additionally asked participants (using scenarios) whether they agreed with the use of advanced requests or advanced consent, which the majority of respondents supported (approx. 79%). Despite the limited space provided for comments and feedback (as well as the narrow scope of the survey), a large range of themes were identified. The themes identified in the comment sections touched on: waiting period, advanced requests, the right to die, eligibility expansion (for and against), MAiD opposition, personal experiences, the role of loved ones, and more specific concerns (funding, support, etc.).

The roundtable discussions held with "over 125 experts and stakeholders" ("What We Heard", 2020, s. 3.0) were hosted by the Minister of Justice, Minister of Health, as well as the Minister of Employment, Workforce Development and Disability inclusion. These discussions inquired about expert opinions on the themes of eligibility criteria (access and scope), safeguards (existing and potential), advanced requests/consent, as well as miscellaneous comments about additional supports and oversight. During the time of these discussions, the federal government proposed Bill C-7, 'An Act to Amend the Criminal Code (medical assistance in dying)', with its first reading on February 24, 2020, just a couple of weeks before the March 11 deadline the court set. However, due to legislative time constraints, the federal government was granted its application for a four-month extension, pushing the deadline to July 7. Shortly after, the government was completely re-tasked to address the ongoing Covid-19 pandemic and it seems likely that a second extension will be requested as the bill has been tabled since.

Despite the uncertain future of Bill C-7, the first reading provides a rough idea of what the government has planned in response to the *Truchon* decision. These changes include creating a separate pathway (with additional safeguards) for applicants whose death is *not* reasonably foreseeable, however, clarifying that patients whose sole underlying medical condition is psychiatric in nature remain ineligible. Applicants who meet the RFND criteria have had a reduction in safeguards, including removing the (10-day) waiting period and downsizing to only one witness (instead of the original two), who can now be a healthcare provider (but not the MAiD provider). Applicants who do *not* meet the RFND criterion will have an extended waiting period of 90 days, despite still enduring “suffering that is intolerable to them” (*Criminal Code*, s.242.2(2)(c)), beginning after their first assessment. Both pathways require that MAiD providers consult with the relevant specialist if they have no expertise in the area, communicate all alternative options to the patient (treatment/comfort care), and take all necessary measures to ensure the patient understands the information provided to them.

The other significant change proposed in this bill is the possibility of prior or advanced consent for MAiD, which should *not* be confused with an advanced directive (remaining illegal). This revision was implemented in response to the highly publicized Audrey Parker case discussed earlier and the public criticism/outcry it caused regarding the final consent requirement. This change allows MAiD to be provided on the basis of prior consent when a patient is assessed as eligible and is awaiting the date of the provision but lose capacity in the interim, except when signs of resistance or refusal are present. It requires the patient to waive their final consent requirement by entering into a written agreement with the MAiD provider. This agreement confirms the patient’s eligibility, states a specified date of provision, and acknowledges the patient's consent to follow through with the provision on (or before) the date specified if they were to lose capacity. The section qualifies that the agreement is nullified if the patient shows signs of refusal “by words, sounds or gestures” (Bill C-7, 2020, s. 241.2(3.2)(c)) but for greater certainty “involuntary words, sounds or gestures made in response to contact do not constitute a demonstration of refusal or resistance” (s. 241.2(3.3)).

The last revision of note includes allowing a physician to administer a substance in cases where self-administered MAiD does not fully take or the person loses capacity in the process. Self-administered MAiD is not practiced in Manitoba due to the unavailability of oral medications. Finally, the bill reiterated that parliament will begin a review of the legislative provisions relating to medical assistance in dying and the state of palliative care in Canada in June 2020, which may include issues of advance requests and requests where mental illness is the sole underlying medical condition. However, it is unclear how these dates have been affected by the ongoing Covid-19 pandemic response.

Chapter 2: Literature Review

"what nurses call a good death, peaceful death, gentle death, no struggling and that's what he had." 6P3

Medical assistance in dying is still new to Canada and therefore published research and literature on the subject is still in its beginning stages. Much of the literature and expertise that guided the implementation of MAiD in Canada came from international experiences (from other permissive regimes such as Netherlands and Belgium) as well as previously proposed policies and legislative bills written by Canadian politicians and scholars. One such proposal for a permissive regime was undertaken early on by Russel Ogden (1994) who constructed a legalized MAiD regime in Canada. Although not perfect, the policy was trailblazing at it's time as it came decades before legalization however, since then other proposals were proposed such as that of Jocelyn Downie, who still writes on the subject today (Downie, 2004). Ogden's policy proposal did not seek to restrict access to MAiD to only adults or the terminally ill (as the current legislation does) but chose to encompass the eligibility of these groups with greater regulatory oversight. Ogden's proposal for legalization centered on principles of autonomy and self-determination suggesting MAiD to be a natural extension of existing practices such as rights to withdraw/withhold futile treatments.

In contrast to current MAiD legislation, Ogden suggested a more comprehensive oversight system with a national board that reviews/keeps track of cases and is available to examine appeals based on denied applications. At the same time, he proposed that successful applicants be granted a 'license' to die (similar to a marriage license) that would expire three months from the date of issue and allow the applicant to access MAiD at any point (or not at all) in this time period. Ogden's policy outlines additional measures for central control while leaving practice-related details vague. In contrast, the current legislation allows considerable provincial discretion in how MAiD services are provided, which has led to inter-provincial variability of physician responsibilities in dealing with MAiD requests as well as the responsibilities of applicants.

Manitoba Process

Whether applicants come to know about MAiD as an option through a friend, healthcare provider, or due to seeing MAiD in the news, all requests and inquiries are connected to a centralized hotline overseen by the provincial MAiD team. This team consists of administrative support staff, physicians, nurses, social workers, a speech pathologist, and (when needed) will outsource the advice of specialists such as psychiatrists, oncologists, etc. During this initial contact (usually via phone or email), a team member will explain the process and eligibility requirements, as well as discern whether the patient seems to meet criteria preliminarily. The team member will also establish whether the inquiry is for informative purposes or to initiate a formal request and if so, whether it is urgent (as many tend to be).

Once it is clear that the patient seems to meet criteria and would like to initiate a formal request, one of the client care coordinators (nurses) on the team will triage the patient and request permission to access medical records from their physicians among other relevant healthcare providers/specialists. Upon reviewing medical records, the team will establish prima facie eligibility and arrange for a formal interview with the patient and the team, as well as any family members or loved ones that wish to attend, at the discretion of the patient.

The initial interview (or independent physician review) is conducted by a physician, nurse, and social worker (and speech pathologist where needed) on the team, who travel to the patient or in some circumstances can be done via Telehealth, for those living in rural/remote locations. During the initial interview, the team will confirm the voluntary request of the patient, inquire into the reasons behind the request (to rule out external pressures), ensure the patient fully understands all options available to them (including treatment, palliative, or comfort care), and confirm the patient's capacity to consent. At this point, if the team has any concerns about the patient's eligibility due to capacity or any number of factors, they may request that the patient see an additional specialist (such as a psychiatrist), undergo treatment, or take any other steps they deem appropriate for approval. However, if the team does not have any concerns, a second independent physician review will be arranged. In some circumstances both assessments can be conducted at the same time.

At these meetings, the team also provides the patient (or family) with the formal application form (written request) to be completed by the patient in front of two independent witnesses. If the patient is unable to write, they must designate a proxy to fill and sign the written request for them, who must be 18 years of age, understand the nature of MAiD, and will not benefit from the death of the patient. Witnesses (to the written request) are restricted even further than proxies, as they additionally cannot be the patient's healthcare providers or family members. Important to note, that the official application form can be completed at any point before or after contact with the MAiD team and it is upon the completion of this written request form that the 10-day waiting/reflection period begins (assuming approval). This reflection period can be waived under two circumstances; where the patient is at risk of imminent death, or at risk for losing capacity and would therefore be unable to confirm consent immediately prior to the procedure.

The second interview is essentially a repetition of the first, with a new combination of a physician, nurse, and social worker, the completion of which will conclude in a formal approval (unless some concerns are raised). It is at this second interview that most written requests are given to the MAiD team, which would formally begin the 10-day reflection period (now gone under Bill C-7). Under some circumstances, especially where time constraints or travel time are an issue, both interviews (with two physicians) may be conducted at once. Once the waiting period lapsed and the patient is formally approved, they may contact the team at any time to set a date for the MAiD procedure (often called the ‘provision’).

The patient may choose to set the date of provision immediately, however, many never contact the team again and die naturally. The team indicated (in interviews) that patients are often grateful for having the option of MAiD, allowing them to live out final days/months knowing they did not have to live with the suffering if it became too much. Where applicable, transfer arrangement will be made for those staying in abstaining faith-based facilities (of which there is a limited number in Manitoba). On the date of provision, the team will call the patient prior to traveling to confirm capacity and voluntariness. The patients can have as many or as few family members and loved ones present for the provision.

Once the team arrives, the nurse will start the IV and the physician will prepare the medications while the social worker talks to any family/friends present about the process, address any concerns and may provide resources for additional supports. The patient will be informed that they free to change their mind at any point and the physician will again re-confirm consent prior to administering medications. If a patient for some reason is not able to consent immediately prior to the provision, whether due to loss of capacity or any other reason, the provision will be canceled (as per June 2020 regulations, prior to Bill C-7 enactment) and may be rescheduled if the patient regains capacity. Once the medications are administered, the team will monitor the patient, confirm death, and issue a death certificate. A social worker on the team will often follow up with family members at set intervals following the provision to offer additional supports or participation in a MAiD bereavement group (“How to Access MAiD”, 2020; Participant 1, personal interview, 2020; Participant 4, personal interview, 2020).

Other provinces

While the MAiD process relies heavily on federal regulations, the single entry, centralized multidisciplinary team dynamic is unique to Manitoba. Most other provinces have implemented coordination hotlines (some divided by health regions) which provide resources for healthcare professionals and patients such as placing applicants in contact with willing assessors, providers, and healthcare facilities. This shifts the onus onto the patient to make contact and coordinate appointments.

Smaller (Atlantic) provinces as well as the territories have either provided an info line, a list of coordinators, or a generic health authority number to contact for further information. Surprisingly, *all* provinces recommend that those interested in MAiD should contact their healthcare provider (usually a family doctor/general practitioner), in Quebec, a request must be submitted through a physician.

Saskatchewan and Alberta, both of whom have MAiD teams of their own in addition to coordination hotlines have the most similar structures to that of Manitoba yet still not identical. Their teams are not centralized (there are multiple teams), do not form a single entry system. Additionally, these teams do not use a multidisciplinary approach, although some discussions of its' incorporation was taking place ("How to Access MAiD", 2020; "Navigating a request", 2020).

As the Canadian government prepares to evaluate and integrate legal changes to the current MAiD legislation (in 2020), local research on patient and provider experiences should play a significant role in determining the direction of these revisions. Some data is being collected by the Government of Canada on applicants (including unsuccessful applicants), however, this data is mostly quantitative in nature, concentrating on demographics and statistical representation (number of requests, rejections, transfers etc.) thus, lacking qualitative breadth and depth (Government of Canada, 2019). The few Canadian research studies published to date also concentrate on recording statistics but some provide interesting qualitative insights and are discussed next.

Canadian Research

There have been a few Canadian studies examining the opinions of physicians and nurses who provided or participated in MAiD (Beuthin et al., 2018; Bruce and Beuthin, 2019; McMechan et al., 2019; Shaw et al., 2018; Wiebe, Green, & Schiff, 2018) as well as medical student attitudes toward MAiD which seem to largely favour this option (Bator et al., 2017). Much Canadian research concentrates on describing statistics collected on MAiD cases as well as experiences of healthcare providers in practicing and establishing the first provincial MAiD schemes (Beuthin, 2018). Common lessons drawn from the experiences of providers engaging in MAiD for the first time across Canada include the need for collaboration, peer support, and standardized education for providers (which is already taking place in some provinces) (Khoshnood et al., 2018; McMechan et al., 2019; Shaw et al., 2018). This research suggests that MAiD providers are largely supportive of eligibility expansions (Bravo et al., 2018), also apparent from liberal interpretations of legislation endorsed by CAMAP and many are a reality due to the Truchon and Gladu case (“The Clinical Interpretation”, 2017). Canadian research on MAiD has been largely conducted in British Columbia and Ontario, highlighting a need to explore perspectives from other provinces, especially those with unique MAiD structures, as is the case in Manitoba.

Notably, Trachtenberg and Manns (2017) conducted a cost analysis of MAiD and predicted potential cost savings between $34.7 million and $138.8 million for the Canadian healthcare system annually. These cost savings were calculated by using published data from the

Netherlands and Belgium where MAiD has been legal for years, combined with Canadian mortality data and end of life cost data. Considering MAiD accounts for up to 4% of deaths annually (on average in other permissive regimes) with patient lives shortened between one week and one month on average, the cost savings were predicted to exceed any direct costs with implementing MAiD, or in the case of over-estimation, to be at least cost neutral. Studies such as this one are often criticized by ethics scholars who view cost savings as part of the slippery slope argument, which will see pressure from healthcare institutions and governments to use MAiD due to its economic savings (Burgess, 1993; Schaefer, 2013).

There has been little research published about variabilities in access to end-of-life care in Canada (pre-and post- MAiD) (Wilson et al., 2008; Wright and Shaw, 2018) or on the lack of education in the public sphere about end-of-life care and options (Froggatt, 2007). This is especially concerning for rural populations who experience healthcare disparities as compared to urban populations, often having less access to specialized medical services, limited space in healthcare facilities, and a need for professional development opportunities (Barnabe and Kirk, 2002; Lavergne and Kephart, 2012; Pampalon et al., 2006; Pong et al., 2009; Ramsey and Beesley, 2007; Ryan and Racher, 2004; Wilson et al., 2006). These findings are not specific to MAiD but discuss disparities in healthcare services generally, sometimes touching on disparities in other public services such as education.

Although most Canadian MAiD research still concentrates on reporting quantitative findings (Robertson et al., 2017; Rosso et al., 2017; Selby et al., 2019), experiential and qualitative MAiD research is becoming more popular. Some case studies examined the experiences of a particular healthcare provider or social worker engaging in the MAiD process for the first time (Antifaeff, 2019; Beuthin, 2018), while comparing the operationalization of MAiD in different provinces.

Dion, Wiebe, and Kelly (2019) evaluated the use of telemedicine from the perspective of healthcare providers, as telemedicine is becoming an increasingly popular option across the country, especially for those living in rural or northern or otherwise remote and medically underserved locations. They concluded that telemedicine is most appropriate for MAiD requests in rural/remote locations since they increased access to those populations despite this, they concluded that quality of care may be impacted. MAiD providers additionally expressed confidentiality concerns when using telemedicine among other limitations such as losing contextual factors impeding communication and difficulty empathizing. The loss of privacy and personal touch of face to face assessments calls into question whether assessors and providers can effectively detect the interplay of coercion. However, patients did not mirror concerns about privacy and the researchers noted that telemedicine has showed to increase access to other services such as abortion and palliative care (Dion et al., 2019, e728).

The experiences of family members and others supporting the request of a loved one for MAiD are also appearing rapidly in Canadian literature (Hales et al., 2019; Holmes et al., 2018) however, none of these have been conducted in Manitoba yet. Hales et al. (2018) research concentrated on finding ways to improve the quality of the MAiD process by concentrating on the perspectives of family/caregivers. They discovered some lack of clarity about the process, frustrations with the required waiting period, challenges scheduling and coordinating MAiD appointments, judgement from healthcare providers, and a need for bereavement support. These results should be taken with a grain of salt before they are applied to the experience of patients elsewhere, considering the structure of MAiD in Ontario which, unlike Manitoba, places much of the onus on patients and families. A study on experiences of volunteer witnesses found another possible barrier to the quality of MAiD as even the volunteers themselves believed the requirement for two witnesses on a written request was onerous and intrusive for patients, serving as an unnecessary barrier to MAiD access (Praslickova et al., 2020).

One group of researchers studied perceptions of MAiD as compared to perceptions of suicide among participants from a marginalized population and participants who have previously been involved with MAiD (as a provider or ineligible patient), discovering participants responded more favourably toward MAiD and did not view it as a form of suicide (Shaw et al., 2019; Wiebe et al., 2019). However, this same research also highlighted the fact that none of the marginalized participants were aware of MAiD or any other end-of-life options which suggests that these populations do not access MAiD as often (contrary to slippery slope arguments).

A lack of knowledge on MAiD can be seen among other sectors and populations as well. Recent reviews of Canadian research on MAiD have found a need for clearer regulations and protocols especially when it comes to professional roles and obligations. Additionally, little has been published on experiences of health care providers in supportive MAiD roles (such as psychiatrists, social workers, speech pathologists, and pharmacists) as well as experiences from provinces with team-based approached similar to that of Manitoba (namely Alberta and Saskatchewan. Although neither have a model that encompasses all elements of the Manitoba system (single entry, centralized, multidisciplinary) (Brooks, 2019; Fujioka et al., 2018). Several researchers ventured into the reasons behind choosing MAiD which largely concentrate on disease-related symptoms, loss of autonomy and control over decisions (Brooks, 2019; Nuhn et al., 2018; Wiebe et al., 2018; Khoshnood et al., 2018).

This research connects with a large field of literature exploring death and dying from various philosophical, social, and medical perspectives. One Canadian publication explored differences in death experiences pre-and post-legalization finding a transformed vocabulary among nurses who began describing the death process as peaceful and beautiful post-legalization (Bruce and Beuthin, 2019). Although this research did not set out to examine experiences with dying per-se (but an examination of experiences with local MAiD policies/protocols), death and dying perspectives (also known as thanatology or mortality literature) have much insight to offer into the dying experience overall. This literature provides an adjacent and relevant insight into experiences of death and end-of-life from different vantages such as the dying and those supporting the dying (family, healthcare providers), bereavement, social responses to death and much more.

Death and dying

Death is a subject often avoided in our everyday discussions, even with our loved ones. When we do finally talk about death whether briefly or in depth, it is often an uncomfortable conversation about someone else's death or the possibility thereof. However, death is inevitable fact and always present around us, especially when considering the expanding coverage of death in the media. Yet our own death is still something we struggle to understand and discuss with our close ones, despite the benefits this could bring. Scholars have been studying the reasons behind this fear of death among other death anxieties for quite some time, propelling death studies into a distinct research area. Some scholars attribute the inceptions of this – thanatology field (study of death) to Herman Feifel and his book *The meaning of Death* which came out in 1959 (Strack, 2003, p. 810). Since then, the field has expanded drastically into many areas of inquiry from philosophical to social, psychological and even clinical or medical examinations of death and its perceptions.

Although the death itself is not central in my research, as I was not inquiring into the experience of death itself but more-so into experiences with the MAiD legislation in practice. Obviously, death is still central to this topic as the legalization of MAiD has been and will continue to change the landscape of death in Canada from a concept which is often imposed on us to one we can freely choose ourselves. For this reason I will briefly some notable developments in death and dying literature that have been transforming death experiences before the legalization of MAiD. This brief overview of death literature will concentrate on aspects of mortality that discuss dignity at end-of-life, bereavement, hospice care, and death stigma as well as how these related to assisted death.

Dignity

Mortality literature, when it comes to research on MAiD, largely concentrates on the moral and philosophical debates behind MAiD (Ardelt, 2003; Walker, 2003; Yi Wood Mak and Elwyn, 2005). Specifically, how principles of dignity and autonomy at end-of-life are central when discussing death broadly and specifically the use of MAiD at end of life (Baillie, 2009; Barclay, 2016; Chochinov et al., 2002; Hall et al., 2009; Hoy et al., 2016; Kagan, 2015). Dignity and autonomy are multi-faceted ethical principles that have been drawn by both proponents and opponents of MAiD. Of course, the way in which they envision these principles to be upheld is very different and at times dependant on context. While dignity at death can be very personal and look differently for every patient, it is often additionally context dependant. The presence of dignity during the dying process can be influenced by the setting (death at a hospital, hospice, or at home) as well as created and co-created by those involved such as patients, healthcare professionals, and loved ones.

Chochinov and others (2002) researched how dying patients understand and define dignity. Their target population was cancer patients, who also notably comprise the majority of the MAiD requests and provisions in Canada. Using their findings, they presented a conceptual model for what dignity looks like and depends on at end-of-life. This model is trifold, consisting of: illness related issues, dignity conserving repertoire, and social dignity inventory. Illness related issues are further explained as related to symptom distress (being in pain or discomfort) as well as loss of independence patients endure at end of life, especially for those who are critically ill and dependant on care. By dignity conserving repertoire, Chochinov and others refer to the internal perspectives and feelings patients have about death and their self-talk repertoire which conserves their dignity. Finally, the social dignity inventory refers to patient sense of privacy, availability of social supports (family, friends, professionals), as well as feelings of being a burden to others. The authors argue that all of these factors combined, contribute to patient sense of dignity at end of life.

Barclay (2016) provided a philosophical analysis of dignity which ultimately supported other findings that the dignity of dying patients is enhanced in a healthcare setting when practitioners respect and do not transgress from patient standards and values. This re-affirms that in order to preserve patient dignity at end of life, the wishes of patients should be respected, whatever they may be. Until recently, patients wishes with regard to MAiD could not be honoured however, with legalization healthcare providers are now able to present their patients with additional options.

Baillie (2007) discussed the impact of interactions with healthcare providers on patient dignity in acute hospitals which can both bolster and discourage dignity. Baillie argued that loss of dignity in this setting is experienced due to impaired health and abilities however, patient supports, staff interactions, and privacy allowed patients to feel in control and therefore regain some of this dignity. Sao Jose (2016) examined how the elderly preserve dignity when receiving social care in the community, finding that many experience a loss of dignity in this setting and discussing techniques for dignity preservations (similar to others discussed here). This loss of dignity experienced by patients is often related to embodiment issues and has led some scholars to call the concept of dignity at death a modern romanticization of death. Street and Kissane (2001) paid special attention to this, emphasizing that dignity can be intertwined with embodiment, since our bodies is how we interact with the world around us and relates to our self-conceptualization. When our bodies change, lose function, and begin to deteriorate this limits experiences as well as how patients communicate with the world which thereby contributes to a loss of dignity and sense of identity.

Similarly, Hall et al. (2009) reviewed how dignity is experienced in nursing homes, finding that changing abilities of elderly (a reduction in normal activities) caused loss of dignity, however, also suggested that dignity therapy may bolster this. Dignity therapy is a therapeutic intervention which is intended to increase dignity in dying patients by allowing them to reflect on major accomplishments and events in their lives (Dignity in Care, 2016). Dignity therapy is often offered in palliative and cancer care departments, even in the city. The MAiD team in Manitoba use to offer this service, however, due to budgetary restrictions had to stop.

Hoy et al. (2016) additionally detailed that receiving care in a hospice or nursing-home facilities can increase dignity as patients are not constantly worried about their diminished ability to care for themselves (when living independently) due to the additional support. Therefore they are able to concentrate on upkeeping relationships and even some (modified) activities. At the same time, poor care (by themselves or by others), lack of care, as well as little choice in care/treatments can diminish dignity for these patients (Kagan, 2015).

These findings of increased dignity at end-of-life in nursing homes are not surprising considering they formed some of the basis behind the hospice approach to death (also known as palliative care), which is popular today all over the world. The hospice movement was primarily conceived of as a concept of care, providing humane and supportive end-of-life care for critically ill/dying patients in a manner that was conducive to the individual (as opposed to the healthcare setting/provider). For many patients, this meant receiving care (and ultimately dying) at home, which is a familiar and comfortable environment as opposed to the clinical hospital setting, where most critically ill patients die in (Leming, 2003). Unfortunately, the majority of Canadians who die each year due to deteriorating health/illness or old age, do not have access to such programs because of limited resources, strict eligibility requirements, and the uneven distribution of hospices across the country (Wilson et al., 2008). These strict eligibility requirements for hospice care are especially significant, considering some patients who are not eligible for palliative care or a hospice bed, may still be eligible to receive MAiD. Situations like this could lead to ethical dilemmas about whether patients are choosing MAiD sincerely of their own volition or only due to the fact they do not qualify for palliative care.

Hospice or palliative care is often provided by a multidisciplinary team with a patient-centered focus. This approach is supposed to address ongoing needs in the patient's life including those that are physiological (symptoms/pain management), psychological (death anxiety), spiritual, and financial, while also supporting familial relationships and aiding in bereavement (Leming, 2003). Interestingly, a version of this interdisciplinary approach is seen in the model of MAiD implemented by Manitoba, as it likewise seeks to address various needs of those who are considering an application for MAiD while providing a convenient patient-centered process.

Many scholars have argued there is little ethical distinction between the two practices (palliative care and MAiD). Morrison (2017) states that MAiD is highly compatible with the missions and values of palliative care due to practices such as palliative sedation and the withholding of life-sustaining treatment. Palliative sedation in particular entails heavily dosing the patient with medications to the point of sedation which is sometimes necessary to control symptoms. At the same time, heavy doses of medications (such as morphine) are also known to hasten death. For these reasons, some scholars are that there is little to no distinction between the two however, religious opponents would disagree and state there is a difference in intention. Whereas with palliative practices the intention to alleviate suffering, with MAiD it is to bring on death, which is seen as an infliction of harm (Iltis, 2006). Of course, at the end of the day patients should have both options available to them so that they may choose the option that represents their desires as opposed to the only option they have.

Central to hospice/palliative care movement as well as to MAiD is the idea of a 'good death' which circles back to dignity conserving practices such as respecting and fulfilling patient wishes (Froggatt, 2007; Read & MacBride-Stewart, 2018; Zhou and Shelton, 2020). Steinhauser et al. (2000) argue that what constitutes a 'good death' differs among individuals (just as preserving dignity) but generally concentrates on six areas: pain/symptom management, decision-making or control, preparedness for dying/death (the process, event, and follow up arrangements), feelings of life completion (life review, resolving conflict, time with loved ones), contribution to others or being remembered beyond death, and affirmation of the person (not reduced to a disease/patient). While this list seems exhaustive and largely encapsulates the entire death experience, Read and MacBride-Stewart (2018) argued that this list does not take into consideration those who lack capacity to make their own medical decisions and suggested extra consideration for the interplay of substitute decision makers or proxies.

Meier et al. (2016) conducted a meta-analysis of research on what constitutes a 'good death' from the perspectives of patients, families, and healthcare providers. They found that among all groups the top three indicators of a good death were abiding by preferences in the dying process (94%), having no pain (81%), and positive emotional well-being (64%). Some other notable markers of a good death were feelings of life completion, quality of life, dignity, familial relationships, and spirituality, similarities can be seen with Steinhauser et al.'s observations. These are considerations of a 'good' and 'dignified' death were similarly highlighted in the court cases and legislative debates about MAiD. Both opponents and proponents of MAiD come armed with their own personal conceptualizations of a dignity at end of life which is twisted in whatever way fits the narrative they want to portray. However, when you take a step back, it seems that the parties have more in common rather than less since at the end of the day, we all just want to have a peaceful death. However we conceptualize that dignity will be individualistic but this choice should always be left to the person, who can choose the path that makes the most sense for them. It is often when that choice is taken away from individuals that increases anxieties associated with end of life.

Death Anxiety

Lehto and Stein (2009), in their concept analysis of 'death anxiety', suggested that in reaching quality end-of-life care, palliative goals should strive to manage death anxiety. Death anxiety, which was defined as a "dread of complete annihilation" (p. 9) is said to be different from 'fear of death' as the latter is concerned only with the loss of physical existence while 'death anxiety' more broadly encompasses awareness of mental/spiritual loss of existence.

Lehto and Stein (2009) identified six common attributes of death anxiety including; *emotion* – feelings associated with death, *cognitive* – anticipating an altered state where the self does not exist causes anxiety, *experiential* – the repression of death in thoughts, *developmental* – varies across stages of human development, sociocultural shaping – vary by culture, and *source of* *motivation* – death is fundamental to the human condition thus a motivator in life. Gonen et al. (2012) examined death anxiety in cancer patients, discovering that those with death anxiety also had higher rates of psychiatric diagnosis, perceived their life expectancy as shortened, and had higher pain scores. They also found a statistically significant association with afterlife beliefs (but not religiosity), where those with higher death anxiety reported ‘nothing will happen’ after death more often. Suggesting that death anxiety is a consequence of unresolved psychological and physical distress. Although some research has suggested that religiosity improves death anxiety due to the certainty (faith) about the after life (Lehto and Stein, 2009), however, other researchers have showed that spirituality rather than religious affiliation predicted less death anxiety (Chen et al., 2000) or more specifically, uncertainty about what happens after death predicted higher death anxiety.

Death anxiety has been important in mortality literature considering the status of death in society which has become privatized, medicalized, and rarely discussed openly even in medical settings (Arnup, 2009; Fonesca and Testoni, 2012; Omori et al., 2020). Some researchers point out that chronically and terminally ill patients often do not discuss their end of life care preferences with their physicians (Curtis et al., 2000; Heyland et al., 2013; You et al., 2015). Heyland and others (2013) found that patient and family engagement in end of life care planning has markedly improved over the past twenty years yet also stated that only 30% of patients reported discussing end of life care preferences with a family physician and 17% with a specialist physician. They suggest barriers to engaging in these conversations are mostly personal in nature such as the perception that healthcare providers do not have the time or fears of upsetting the patient. Curtis et al. (2000) similarly found personal barriers alongside more common ones such as need for education/professional development and counselling for patients/families. Notably, clinicians not only identified more barriers than patients but also listed the only two barriers associated with the conception of end of life conversations, stating that some patients were not ready for the conversation or were not ill enough to warrant such discussions yet.

Many of these reasons can be attributed the taboo status of death in our society (similar to pornography), a subject we do not openly discuss in social gatherings or out everyday lives therefore missing out on opportunities to reflect and let others know our end of life preferences. While some argue this death stigma has been nearly eliminated in recent years due to expansive research and literature on the subject (Lee, 2008), others suggest that how death is perceived by individuals (depending on age and experiences with death) will dictate how they live their lives (Hayslip and Hansson, 2003). This is consistent with existential perspectives on death that view death as an aide for individuals to find value in life as the recognition and acceptance of death can help individuals develop goals, values, and priorities (San Filippo, 2006). However, many philosophical perspectives on death (Socrates, Plato, Aristotle, Epicurus) stipulate that one should never worry about death (regardless of afterlife beliefs) because it is not inherently bad for us as we are not there to witness it and we have previously felt non-existence (before our birth) (Bradley et al., 2013). Despite advancements in the academic world and some societal changes, discomfort with or denial of death persists among the public in many forms, including repressed conversations with family members and even healthcare providers (Tradii & Robert, 2019).

Hospice/palliative care, like the MAiD system in Manitoba, seeks to support these types of conversations and about death among families which strengthens relationships during these emotionally difficult times. The team additionally follows up with families for bereavement support and in order to provide other resources, if needed. Maass et al. (2020) conducted a meta-analysis of research on the efficacy of bereavement groups for symptoms of grief and depression in adults. Although their findings point to weak statistical significance when compared to control groups, some differences between the groups were found and tertiary interventions (for severe and prolonged grief disorders) have demonstrated to be most effective. Some Canadian research has suggested that healthcare providers are largely ill equipped to discuss death and bereavement with patients/families and further education is needed to increase comfort and thereby decrease stigma associated with death (Barnabe and Kirk, 2002; Hales et al., 2019; Health Canada, 2018;). Remarkably, Holmes et al. (2018) referenced a study finding bereavement as a result of MAiD resulted in less grief and posttraumatic stress than bereavement from a natural death of a relative.

One of the most notable contributions to bereavement literature has been Kübler-Ross's (1969) five stages of bereavement of the dying patient consisting of denial and isolation, anger, bargaining (to find meaning), depression (helplessness), and finally acceptance (with the follow up of hope). However, since this work was published, research findings and other literature have criticized this model as imperfect, instead describing bereavement by the critically ill (and even by families) as more of a continuum where various stages can be experienced at once (or not at all) and may recur over time. Some scholars have suggested variations for the bereavement model, such as addressing physical/psychological/social/spiritual needs or counteract circumstances by rebuilding and solidifying identities beyond death (Corr, 2019; Sandstrom, 2003).

Conclusion

Although discussions of and public support for MAiD have been prevalent in Canada for decades prior to legalization, Canadian research on MAiD remains in its infancy. We have come a long way since legalization learning from practice and mistakes made along the way (e.g. RFND, waiting period etc.). Lessons learned from other permissive jurisdictions were vital in the construction of the system we have today as well as predictions of future challenges, however, now is the time to expand our own literature base while continuously improving and learning from experiences across Canada.

MAiD remains a multi-faceted area of inquiry raising questions in a variety of fields such as medicine, law, sociology, and mortality that remain to be further unpacked, researched, and debated. The perspectives of those directly involved in the practice, across all (Canadian) jurisdiction should be accounted for when discussing the future of MAiD in Canada. Despite a constantly evolving literature base, the perspectives of patients seem to be largely missing from qualitative inquiries yet, as the target population, should be central in political (and academic) discussions about the future of MAiD services in Canada. Emerging research, of which there is still few publications, primarily concentrates on experiences of healthcare providers and few of family members.

These perspectives are important to research as federal and provincial regulators reassess and expand the availability of MAiD services, in order to ensure a smooth experience for any applicants. Research with direct experiences will help discern how the current legislation impacts the target population of this legislation (patients) as well as adjacent entities (families and MAiD providers). Literature indicates strong arguments for both expansion and restriction of eligibility however more research is needed to implement these in the best way possible. The literature also displays some areas where improvement is already required such as training/education for healthcare providers on end-of-life conversations and bereavement support. Concerns about access in rural locations exists across Canada and despite the little available research, some have already pointed out barriers to equitable access. These barriers should be taken seriously so not to exacerbate already divided resource allocation for rural and marginalized populations.

The purpose of my research was to examine *current* experiences with this legislation and its mobilization in Manitoba in order to reveal any obstacles or highlights of the service. I was interested in examining what (if anything) these experiences revealed about the accessibility of MAiD, beyond the controversial areas that have been the focus of MAiD discussions and political debates. Due to the increasing demand for MAiD across Canada (seen through increased provisions and assessments in Canada) and the federal government's intent to expand eligibility criteria (in response to the Truchon and Gladu case), it is important to continuously evaluate experiences with MAiD.

Manitoba has not been the subject of any published research on MAiD and provides for an interesting analysis as it uniquely utilizes a single entry system into MAiD overseen by a centralized multi-disciplinary team of professionals. I hoped that this research sheds light on possible areas for improvement in the legislation or through the process while pointing out best practices associated with this interdisciplinary approach. The next chapter discusses how I attempted to achieve/promote these goals through the chosen research design.

Chapter 3: Research Design

"But we've found that there's actually a therapeutic benefit to approving people. You can actually see people ***relax****, and we had one patient say… 'I want to get the business of dying out of the way, so I can carry on living.' 1P12*

Introduction

This chapter details the research design for this project and is broken down into two major sections. The first section describes some broader methodological and theoretical underpinnings of this research while the second discusses the specific methods and strategies utilized in data collection and analysis. I begin this chapter by reviewing the foundation of this research which is based on a qualitative research design informed by a phenomenological paradigm or more specifically, interpretative phenomenological analysis (IPA). I chose phenomenology as the methodological paradigm as it allows for an open-ended research design that does not seek to restrict data to pre-determined results. At the same time, interpretative phenomenological analysis allows for some structure and guidance in conducting qualitative research, providing a structured framework with concrete methods to assist with data collection and analysis.

The second half of this chapter outlines these methods in detail including: the sampling strategy, data collection, transcription process, ethics approval, and finally the data analysis approach. I further discuss some reasons behind the specific methods chosen for this qualitative research and why I found them most appropriate, not only due to its phenomenological underpinnings but also specifically to this subject area. Since I sought to research experiences with a specific phenomenon (MAiD), I consequently chose a purposive sampling strategy – in order to ensure that participants had sufficient experiences with this phenomenon. I recruited these participants via a third party (the MAiD team) who works with this population and therefore has contact with them on a daily basis. Using this recruitment strategy, ensured that recruitment materials reached the intended (target) population while still allowing for willing participants to come forward on their own (without overt pressure). I utilized an open-ended data collection approach by conducting semi-structured interviews with participants, which allowed them to reflect holistically on their experiences with the phenomena (MAiD). The data was then transcribed and analyzed guided by strategies common to IPA research and content analysis more broadly.

I have chosen to include some personal reflections throughout this chapter which provide some insight into my thinking process, reasoning behind decisions made during the research process, and as a way to reflect on the experience as a first time researcher. This is especially highlighted in the ethics section, as that is where I encountered the most obstacles and push back in conducting this research. Reflexivity is recognized by interpretative phenomenology as an essential part of research, since researchers actively co-create and assign meanings in research to experiences participants provide. These reflexive accounts are also intended to increase sincerity and credibility of findings by being a transparent researcher.

Methodology

The literature review describes the most publicized debates on MAID in Canada, however, these do not necessarily reflect the struggles and experiences of those who have been involved with the MAiD process. For this reason, the goal of this research was to examine the experiences of MAiD providers and family members with the MAiD process in Manitoba. I wanted to gain an in-depth perspective of the how the MAiD process effected was being experienced by effected parties. Therefore, I chose to use a phenomenological methodology, to directly inquire into experiences with MAiD, concentrating on revelations in participant stories. A phenomenological approach is said to be well suited when researching a new topic area with little pre-existing research, as is the case with MAiD in Canada. Medical assistance in dying is still a new practice in Canada, and while research in this area is growing, there are still many unknowns and gaps in literature.

Phenomenological research takes on a qualitative approach, focusing on a small sample size in order to capture the full range (in-depth) of human experience with a certain phenomenon. This was ideal for MAiD research, as the target population is exclusive (extremely limited in size) and difficult to reach, yielding a small sample size. Additionally, phenomenology prioritizes participant experiences and does not attempt to confirm or contradict any pre-determined hypotheses or theories (often gathered from existing literature). Instead, phenomenology collects and analyzes personal perceptions and interpretations of phenomena without claiming to extract an objective experience that can be generalized to the entire population. Participants are therefore free to reflect on their experience from their own perspectives, without conforming or disconfirming responses to pre-determined categories in order to confirm/deny hypotheses or theories. At the same time, I hope to find common themes among participants that while cannot be said to be generalizable for every MAiD experience, can point to some trends that require attention.

Converse (2012) wrote that phenomenology began as an inquiry into what takes place 'in the mind' rather than the traditional positivistic stream of objective realities to be examined. Smith (2011) provides a broad definition of phenomenology calling it "the philosophical movement concerned with lived experience" (p. 9) and pointed out that while there are various streams of phenomenology, there are many internal disagreements between them. However, one thing all the streams do agree on is the need to conduct a detailed examination of 'experience'. Groenewald (2004) contends that phenomenology is the "science of pure 'phenomena'" (p. 43) while Reeves, Albert, Kuper, and Hodges (2008) write that phenomenological studies often aim to elicit the meanings that individuals attach to their interactions (through personal reflection). This meaning is then analyzed inductively by the researcher, in other words, meaning arises out of specific events or circumstances discoverable through a personal account or reflection on these experiences.

Mitchell and Cody (1992) discuss and affirm the claim that all knowledge and thereby methods are theory-laden, which challenges the common notion that research should be objective or that qualitative research must begin in the absence of theory. Theories that guide research often arise from some philosophical assumptions or worldviews which may be recognized explicitly or present themselves implicitly through the choice of methods. These worldviews (or epistemologies) are commonly dichotomized in terms of quantitative and qualitative, or positivist and constructivist, presumably then, this qualitative research falls under a constructivist worldview. A constructivist worldview recognizes the subjectivity of data gathered during qualitative research, which is incompatible with positivist paradigms that assume there is one truth or common experience to be discovered.

Phenomenology, considers the experiences of participants within a certain definable entity or phenomenon (in this case, MAiD) that exists outside of them. In other words, the experiences of individuals (which are subjective to those individuals) with an outside phenomenon (objective, pre-exiting) are analyzed, enmeshing the two worldviews together. Consequently, phenomenological research falls somewhere between the two epistemologies and subscribes to a realist worldview, since “phenomenology is a mode of philosophical as well as scientific inquiry” (Mitchell and Cody, 1992, p. 174). Larkin, Watts, and Clifton (2006) reiterate this position using a phenomenological framework in their study, suggesting that human activity is a part of reality which exists whether people engage with it or not (i.e. some aspects of reality are independent of human experience). Yet all phenomenological research is immersed in an inhabited world where various phenomena have already been given a particular meaning. Humans can then only be understood as functions of their involvement and position in this pre-existing world.

This is the epistemological assumptions of my research, as MAiD providers and applicants are a part of this new reality where assisted dying is conditionally permitted and supported by legislation, regulations, and policies. However, how people perceive and give meaning to this reality is constructed by them, through their experiences and interactions with this reality. The participant's position is not objective, as everyone will experience the MAiD process in their own way with unique reflections to share. At the same time, many experiences will share similarities and it is in those convergences that I will look for themes and trends, which will form the basis for the recommendations. This is particularly true when considering the inter-group differences between the experiences of family members and MAiD providers, who interact with this phenomenon. However, participants come from different positionalities and therefore may come out with different perceptions. At the same time, there is a commonality and overlapping reality to their lived experiences, especially within these two sub-populations.

The origins of phenomenology are often traced back to philosophical roots, beginning with Husserl and Heidegger but some argue that they can be traced even further back to the work of Kant, Hegel, and Vandenberg (Conroy, 2003; Converse, 2012; Groenewald, 2004; Mitchell and Cody, 1992; Reeves et al., 2008; Wojnar and Swanson, 2007). Since these early beginnings, phenomenology has broken off into multiple sub-fields to reflect growth of different views and account for disagreements in the application of phenomenology to research. The two most prominent phenomenological approaches seen in research today are descriptive phenomenology and hermeneutic (interpretive) phenomenology, which stemmed from the views of Husserl and Heidegger, respectively (Wojnar and Swanson, 2007).

Edmund Husserl is frequently regarded as "the fountainhead of phenomenology in the twentieth century" (Groenewald, 2004, p. 43). Husserl used phenomenology to explain how individuals give meaning to social phenomena in their lives, believing that humans were responsible for influencing their own environments. Husserl's goal was to explore phenomena from the first-person point of view – the subject – and he argued that it was possible for the researcher to strip away any preconceptions or bias they brought into the study in order to observe phenomena objectively or neutrally through the 'consciousness' of the participants (Converse, 2012; Mitchell and Cody, 1992). This phenomenology appealed to objective and rational researchers and he eventually developed a procedure known as 'bracketing' which is meant to separate the phenomenon being studied, from the researcher and his/her assumptions, in order to understand phenomena objectively (or through the subjective eyes of participants)(Wojnar and Swanson, 2007; Converse, 2012).

On the other hand, Martin Heidegger, Husserl's successor and student, held a different phenomenological position which came to be known as hermeneutic or interpretive phenomenology (Converse, 2012). Heidegger sought to study the 'being' of phenomenon instead of the pure essence (like Husserl), arguing that people could not be studied separately from their culture, social context, or historical period (Wojnar and Swanson, 2007). Heidegger argued that interpreting the world is a part of human nature that could not be removed from research – *being is interpreting* (Converse, 2012; Groenewald, 2004). At the same time, we exist in an already constructed world, therefore, we also take on meaning from this pre-existing world. As opposed to setting aside researcher bias through bracketing, Heidegger's phenomenology encourages researchers to be reflexive by explicitly identifying their own bias as well as other contextual factors throughout the research process and addressing this as something which guides interpretations and results (Converse, 2012; Conroy, 2003). This is why Heidegger's phenomenology is called interpretive, as humans interpret phenomena around them in relation to their experiences (within a certain context) and so do researchers. Accordingly, researchers co-create meaning by drawing interpretations from subjects (Wojnar and Swanson, 2007).

My research more closely aligns with Heidegger's interpretive phenomenology as I seek to understand the experiences of family members and MAiD providers with MAiD (the phenomena) in specific context. This context includes various factors such as geographical location, political climate, legislative scheme, and social norms (among other things). The context shapes the experiences of these participants in a way that may not be immediately obvious but must be recognized and addressed. Experiences with MAiD may differ across the various Canadian provinces and territories due to different regulatory systems as well as the distinct cultural differences that affect perception. Another contextual factor important to consider is the current political atmosphere in Canada with relation to MAiD. MAiD is still a new service in Canada with its legalization being controversial for many and regulated differently according to each provincial health authority. The MAiD legislation has also been the subject of various litigations (pre-and post-legalization) and is currently being amended due to one of these cases (Bill C-7).

I do not claim to study the experiences of participants outside of this context, location, time, and circumstance. Instead, I acknowledge the influence of these contextual factors on participant responses and embrace the fact that this research is context dependant, which is what makes it unique and novel in this uncharted time during Canadian history. Further, I am not entering the study claiming that I, as a researcher, will have no influence on the data which I collect, transcribe, analyze, and report. I recognize the role of the literature review and prior academic findings (such as deficiencies in legislation) which have contributed to my understanding of MAiD and therefore my interpretation of participant experiences with MAiD. I realize the significance of reflexivity in my research process, as interpretive phenomenology would suggest, and have thus chosen to insert some personal reflections throughout this chapter as well as the last one. Many of the qualitative research methods discussed in this chapter were drawn from Smith's interpretative phenomenological analysis (IPA) who translated this methodology into concrete methods to be used by future researchers.

Qualitative study design

A qualitative study design was chosen largely for pragmatic reasons, such as the small potential sample size, due to the limited population (with MAiD experiences). Although a quantitative study is not impossible per se, I did not have the required length of time it would take to accumulate a sample large enough for the use of a larger-scale quantitative research. Additionally, the lack of existing Canadian research (at the time) led me into the direction of an open ended inquiry that could point to some areas of concentration for future research.

Quantitative studies are inherently limited in the amount of in-depth information they are able to gather, concentrating instead on pre-determined categories and data that can be easily quantifiable and calculated. However, I intended to allow participants to discuss their experiences in a way that was natural to them as well as allowed for the emergence of diverse themes, perhaps some that have not been previously thought of or written about. While quantitative designs are better suited for studying larger segments of the population and garner the ability to generalize results to this wider population, this type of research was not possible with the MAiD population in Manitoba, as it is highly limited in size. At the same time, wider generalizability could not be claimed regardless of the sample size, since provinces have deployed MAiD services and regulations in their own way, with Manitoba having a unique approach as compared to many. Some provinces will be able to draw more connections than others with experiences from Manitoba, such as Alberta and Saskatchewan. These two provinces have similar MAiD programs to Manitoba's, consisting of 'team' like structures that coordinate MAiD requests in specific areas - as opposed to 'hotlines' which provide information and contact referrals, as is the popular approach in the rest of the provinces/territories (see discussion in the previous chapters).

Quantitative designs also do not leave room for new or unanticipated themes to emerge or be explored in-depth, which stifles participants' rich and diverse experience reflections. This was especially valuable for MAiD research considering how new MAiD is to Canada and the small number of existing publications/research. A qualitative design is then the most suitable for this research as it allows for an in-depth analysis of lived experiences with MAiD in Manitoba. This allows a greater level of detail to emerge and for new issues to arise, uncovering both larger systemic experiences as well as individualized examples. A literature review can only uncover the most publicized, debated, and publish-worthy materials, which a quantitative study may confirm or reject while a qualitative study will delve more deeply into. A qualitative design allows inquiry into this wider array of experiences, that may be of greater significance (than issues identified in literature) to individuals directly involved in the phenomena and allows for the detailed exploration of these perspectives, albeit in smaller groups/numbers.

Further, interacting with participants in a natural setting using interviews with open-ended questions puts participants at ease and allows for the free flow of information, removing the often clinical and controlled environment research takes place in. This conversational method of inquiry also allows tacit information to emerge through body language, social cues, and the intimacy of face-to-face interactions. All these benefits contribute to a holistic account of events and experiences by participants which are often unavailable with quantitative designs and contribute to the reasoning behind why a qualitative approach was most appropriate for this subject area (Creswell and Creswell, 2018).

The role of the researcher is also important to note since qualitative studies acknowledge researcher involvement as a part of the knowledge-gathering process. This allows for an emergent research design that recognizes the researcher as an important aspect of the conversation and central to data interpretation. I sought to directly engage with participants and allow room for follow up on any narratives that could lead to interesting themes. A qualitative design allows for ongoing inductive and deductive analysis of data, in other words, inductively discovering patterns and making connections, and subsequently deductively returning to data to look for further evidence to support preliminary conclusions. However, just as all research designs are not perfect, neither is this research design, which allows researchers greater discretion in theme selection and some would say, even manipulation. This is minimized by the fact that I have no personal stake (financial or other) in the outcomes of the research. Additionally, I put effort into having a transparent research design, that points out any biases or worldviews that I carry into this research, in order to increase trustworthiness in the research process as well as the reliability of outcomes. One such bias, which I return to throughout the thesis, is the bias I hold in favour of MAiD. As someone who personally supports the availability of MAiD services in Canada, this could be said to influence the research design as a whole, especially theme selection, which is why it is important to point out.

A qualitative design, just such as a phenomenological inquiry, recognizes researcher involvement in the interpretation and analysis of data, encouraging explicit reflection on this position through ongoing reflexivity. Reflexivity enhances honesty and transparency in qualitative research by openly recognizing how past experiences, knowledge, values, or bias may shape research through interpretations and assumptions (Creswell and Creswell, 2018). This is also discussed by Smith in his adaptation of interpretative phenomenological analysis (IPA), a qualitative research methodology that informed many of my research method choices regarding sampling, data collection, and data analysis (discussed in detail next).

Interpretative Phenomenological Analysis

The origins of IPA as a definable methodology is often attributed to Jonathan Smith (Brocki and Wearden, 2006; Larkin et al., 2006) but phenomenological research designs similar to Smith's IPA have been utilized for much longer (Groenewald, 2004). Smith's (2019) IPA approach is reminiscent of Heideggerian roots, concerned with meaning-making for both the participants and researchers. Smith explains that IPA adopts a 'realist' middle-ground approach that falls between one extreme belief of uncovering a factual record, and another where participants are assumed to be 'acting' in order to appear a certain way to researchers. This middle-ground approach contends that "what respondents say … represents a manifestation of their psychological world" yet, can also be seen as a "'reality' for them beyond the bounds of this particular occasion" (p. 2). In other words, participants in a phenomenological inquiry both describe the factual record of their experiences and simultaneously iterate their personal understanding/interpretation of the event/experience.

The phenomenological roots of IPA stem from Heidegger's 'hermeneutical circle' or as Smith (2011) calls it 'the double hermeneutic' where researchers are interpreting how participants make sense of their experiences and other phenomena. Smith writes that “experience cannot be plucked straightforwardly from the heads of participants; it requires a process of engagement and interpretation on the part of the researcher” (p. 10). Inherent to this position is the fact that participants are “sense-making” agents, constantly interpreting their engagement with the world. Researchers are then making sense of how the participants understand their world, but this interpretation is second-order as researchers do not have access to the direct experiences of patients (Smith, 2011).

Phenomenological research can be conducted differently depending on the level of understanding a researcher seeks to uncover. Smith (2019) writes that there are five typologies (or levels) of meaning to be drawn from participants, the first level is a literal interpretation, involving the linguistic definition of something. The second, is pragmatic and relates to the specific meaning instilled in something by the participant (what does *she* mean by that?). The third level is experiential and the “centre of gravity for IPA” (Smith, 2019, p. 168), it is concerned with what something means to a certain person (what does this event mean to me). The fourth level is existential with regard to the significance something has to the identity of a person. Finally, the fifth level is also existential and deals with broader questions of life meaning broadly (Smith, 2019, pp. 167-168). IPA is said to function at the third level of understanding, as it addresses *what* certain phenomena mean to people but at the same time, IPA may fluctuate between levels (Smith, 2019).

Most IPA research to date has been in the field of psychology, specifically, health psychology. Some of these studies use an additional theory to narrow down their scope, however, Smith suggests we should concentrate on emerging themes and connections rather than attempting to fit findings into pre-existing theoretical perspectives (Brocki and Wearden, 2006; Smith, 2011).

Eatough and Smith (2017) write that IPA has three characteristic features, which are idiographic, inductive, and interrogative. IPA is *idiographic* as it begins with the detailed examination of one case/interview before moving on to the detailed examination of another case and only when all cases have been analyzed, cross-case connections can begin. IPA is also *inductive* since it is flexible enough to allow for anticipated topics/themes to emerge as well as those which are unexpected. Similar to qualitative research broadly, IPA is not meant to prove/disprove hypotheses. Finally, IPA is *interrogative* because it aims to make contributions to different academic fields by "interrogating or illuminating existing research" (Smith, 2004, p. 43).

This makes IPA the most suitable qualitative method for experiential MAiD research due to the flexibility in allowing new themes to emerge, as opposed to subjecting responses into pre-determined categories with the aim of proving or disproving a hypothesis. While research on MAiD is expanding rapidly in Canada, it is far from saturation, with many aspects of the practice not yet explored. IPA allows for the examination of diverse responses from participants who draw answers from their personal and directly related experiences. Further, as stated above, IPA is interrogative of existing research, seeking to grow contributions without necessarily replicating findings of another research, as they may not exist.

Eatough and Smith (2017) wrote that IPA is "neither a rule-bound rigidity nor a methodological free-for-all" (p. 206), meaning that researchers are not bound to a strict regimen of coding and theory-creating as is the case with grounded theory. Nevertheless, IPA provides guidance without stranding the researcher on how to carry out interpretative phenomenological research. Brocki and Wearden (2006) further point out that unlike grounded theory, IPA does not seek to reach saturation or select an arbitrary number of cases but instead strives to achieve understanding, coherence, and preserve nuances among gathered data. Nevertheless, sample size has been historically important in research and for this reason I allowed for the maximum data collection period I could have, in order to increase the number of participants. Despite the smaller sample size (of 17 participants), the results of this research still reveal patterns, that when contextualized with other research findings across Canada, are beneficial in pointing out trends and assisting policy makers during revisions.

IPA illuminates a particular research question by exploring the personal experiences, thoughts, and beliefs of people on a given topic. Brocki and Wearden specifically point out the usefulness of IPA in examining difficult healthcare decisions, acknowledging service-users, and patient-centered research (Brocki and Wearden, 2006, p. 100), as is the case with this research on experiences with MAiD. IPA often uses small sample sizes and semi-structured interviews in its research designs. This further affirms its compatibility with this research on local MAiD experiences as the potential population is very limited in number, making a qualitative inquiry in the form of semi-structured interviews the logical choice. These specific methods choices which are informed by IPA will be explained further below, and more specifically, how I employed them in this research on local experiences with MAiD.

Methods

The following section describes the methods utilized in this research, including the sampling strategy, target population, data collection methods, ethics, and finally data analysis. I chose a purposive sampling strategy as the goal of the research in order to study experiences with a specific phenomenon (MAiD), therefore, participants had to be able to reflect on this process in some depth and detail. In order to reach this exclusive population, an active recruitment strategy via a third party was chosen. Recruitment of participants was conducted through the MAiD team (some of whom were also participants), as they had direct access to this population.

As is common with qualitative research, the sample size was small (17 participants in total), which is larger than many IPA studies but normal for qualitative research generally. Inclusion and exclusion criteria for participants were kept to a minimum, in order to maximize participants to make up for the short data collection period (January-March). If the data collection period were longer, I would have liked to concentrate on one group of participants (family members *or* MAiD providers). Data was collected using semi-structured interviews with open-ended questions inquiring into participants' experiences with the MAiD process. Interviews were audio-recorded and subsequently transcribed for analysis. Transcripts were anonymized, removing participants' identifying information such as names, locations, among other identifiers. This research received ethics approval by both the university ethics board as well as the regional health authority ethics committee. Data was analyzed according to inductive/deductive strategies common to IPA, yet still keeping in mind original research goals of providing recommendations for the improvement of this practice.

Sampling strategy

Groenewald (2004) argues that in IPA research, the phenomenon dictates the participants, since they *must* experiences directly related to the phenomenon, preferably intimate and extensive ones. This ensures that participants can reflect on the phenomenon with sufficient detail for qualitative analysis. Therefore, IPA research utilizes a purposive sampling strategy, which means that participants are screened in due to certain characteristics or experiences they have had. This can be accomplished by directly targeting recruitment materials at participants with the relevant experiences or by identifying a few key participants who will recruit others matching the eligibility criteria (often for hidden or hard to reach populations).

The goal of this research was to examine experiences with MAiD in Manitoba, this information is held by an exclusive (and small) population which has participated in the MAiD process in Manitoba. The sample of potential participants is therefore narrowed down to patients who applied for MAiD, their family members who were involved in the process, as well as members of the local MAiD team who oversee all requests and inquiries across the province. I did not specifically exclude any participants whose applications were rejected, but no participants with rejected application came forward to participate either. With a purposive sampling strategy, I was able to ensure that all participants could reflect on the MAiD process from personal experience to yield rich qualitative data. This strategy had some elements of a snowball sampling method, as at least one participant heard about the research from another participant (both family members).

A common critique of purposive sampling is the homogeneity of the sample since it can be difficult to include diverse opinions and backgrounds within a purposive sample of participants who share similar experiences (Chapman and Smith, 2002). However, phenomenology recognizes this and as such places no broad claims on the generalization of results, especially considering the small sample size. Instead, phenomenology seeks to find common themes and make connections between similar experiences in order to offer some trends that when combined with other research, can aid in generalizability. I recognize that participants in my research sample had some homogeneity, especially among family members all of whom generally had a positive experience with MAiD and whose loved ones were all approved for and received MAiD (all but one – who died naturally). While this may indicate that Manitobans have a generally positive experience with the MAiD process, it could also indicate some sampling bias. At the same time, the experiences of family members were still distinct and unique in many ways, capturing different backgrounds (although predominantly white) and levels of personal/moral comfort with MAiD. The sample also encompassed diverse opinions among MAiD providers with varying levels of experiences, areas of expertise, and outlook on MAiD generally.

Sample size

Eatough, Smith, and Shaw (2008) write that IPA provides a flexible and non-prescriptive guideline for sampling strategies and sizes, with sizes usually fluctuating from one to thirty participants, mostly in the smaller range. Although Smith (2011) does not preclude the use of larger samples, he notes that in order to ensure a rigorous study, each theme should contain three or four extracts from different participants. This can be missed in larger studies as some participants will be left out or the excerpts will lack in detail, at the same time smaller studies may lack sufficient variance in experiences. Qualitative studies are commonly known to have smaller sample sizes however, IPA research is often limited to an even smaller participant pool. Eatough and Smith (2017) write that smaller sample sizes are a matter of practical consideration since IPA research seeks to uncover data that is detailed and rich in description. Concentrating on the differences and similarities between cases instead of seeking to generalize all findings allows less common (yet still significant) experiences to come through. Accordingly, smaller samples are not only the norm but the preferable route, as not to lose sight of original goals in exploring experiences holistically.

Guest, Bunce, and Johnson (2006) state that choosing a larger sample size or converging to the universally agreed upon '30-participants' in qualitative research is quite arbitrary and is not a marker for saturation. They contend that saturation is often reached with a small number of cases in qualitative research, in their study, this was reached with twelve interviews. Brocki and Wearden (2006) maintain that data saturation is not a primary goal of IPA when it comes to sample size but instead, should concentrate on rich detail. This is significant, as the target population for my research is quite exclusive and in order to estimate potential participants, I relied on government reported numbers of MAiD requests in the province.

At the time this research was designed, the Manitoba MAiD team had been reported to consist of nine members (Gowriluk, 2019) with a few more members who work on a part-time or casual basis (although since then the team has expanded). Additionally, the government of Canada reported that 198 people requested MAiD in Manitoba during a 10-month period in 2018, and while MAiD requests have been steadily rising since legalization in 2016, the report also stated that 57 of these members died before their assessments were complete and an additional 25 were declined or withdrew their requests (Government of Canada, 2019). Thus, the remaining 116 patient requests in a 10-month period averaged out to be approximately 11 requests a month. Therefore, there was potentially 11 participants (whether patients or family members) in every month of data collection.

Understandably, it was unlikely to have a 100% response rate during the short recruitment and data collection period (January – April) so I hypothesized this research would have between 10-20 participants. This ended up being an accurate estimation as I recruited and interviewed 18 participants altogether, however, one participant (the only patient) was excluded from the research. Of the 17 participants included, 6 were classified as MAiD providers and 11 were family members. Of the 6 MAiD providers, one was a psychosocial specialist (social worker) by profession, two were physicians, and 3 nurses – also known as 'client care coordinators'. Family members who participated in the research were all considered part of the patient's 'immediate family' including spouses (3), siblings (3), and children (5). A more detailed breakdown of participants is provided in the analysis chapter.

Population

Considering the goals of this research, which was to uncover the lived experiences of those on the front lines accessing and delivering MAiD in Manitoba, I chose three groups of participants who I believed would have the most direct and relevant experiences with MAiD. These three groups consisted of members of the MAiD team, patients who are applying for MAiD, and their family members who often assist the patients in the application process and are subsequently left behind when it is over. All willing participants were accommodated to the best of my abilities, for some participants this meant conducting interviews over the phone or a video call, which was the case in five interviews. This accommodation was necessary considering the research period overlapped with the Covid-19 pandemic (with gathering restrictions in place) as well as some participants' travel arrangements.

No participants were turned away from being interviewed for this research however, one participant was excluded from the research as it was the only participant in the patient sub-population. The patient was still interviewed but I later determined that his experience was too early in the process (after the first assessment) to provide sufficient details, combined with the fact that no other patients participated in the research, led to the exclusion of this participant. This was a disappointing realization as I strongly fought to include the perspective of patients, prolonging the ethical approval of the research (by the university ethics board) in order to accommodate this population. After realizing that I could not include the patient perspective in a meaningful way with only one participant, I chose to concentrate on the experiences of MAiD providers and family members, paying close attention to differences and similarities in the narratives of these groups. MAiD providers often discussed broader themes seen among their clientele from across the province, while family members provided more specific examples relating their personal (often singular) experience with MAiD.

Manitoba, unlike other provinces, has a single-entry system into MAiD comprising of a centralized multidisciplinary team operating out of a Winnipeg office, which oversees all MAiD applications and procedures across the province. While this spatially bounded the research to Manitoba, it also allowed for a unique sample of MAiD providers with extensive experiences with the process in the entire province (including rural and remote communities). This would not be possible in other provinces without a centralized team where MAiD providers work somewhat independently from each other and could not speak to communities outside of the areas they serve. The Manitoba MAiD team utilizes an interdisciplinary approach to MAiD (similar to that of hospice care) employing medically trained staff (physicians, nurses, pharmacists, psychiatrists) as well as professional and support staff (social workers, a speech pathologist, administrative support).

All members of the MAiD team, including full time, part-time, and casual workers, were asked to participate in the research due to the small size of the team and diverse perspectives the interdisciplinary team would yield. The team was contacted through a publicly available email, which included the recruitment letter (Appendix A) and was circulated among all team members by the administrative staff, who oversees this public email. Team members willing to participate were asked to self-identify for the study by contacting the researcher (myself) for an interview – whether by email or phone. This allowed for willing individuals to come forward while not placing any pressure to participate, as the email could be simply ignored. This resulted in a fairly representative sample of the MAiD team including one social worker, three nurses, and two physicians (one of whom was the medical director of the team). Of course, there is always the possibility of sample bias where those team members (and family members) who did not reach out to participate, may have been reluctant for a common yet unknown reason.

Participants in the family member sub-population provided more personal and singular experiences/reflections on the MAiD process, at times reflecting on the experience of the patients (as they perceived them) as well. Although I did not intend to ask family members about the patient experiences, some did reflect on how comments patients made or thoughts they verbalized during their MAiD journey. When considering experiences of patients as told by their family member, it is important to remember that this throws in an additional dimension of subjectivity, the interpretation of patient experiences by family members. These additional reflections on behalf of patients should be taken with a grain of salt, despite still likely being an accurate, since they may not encompass the full range of experiences and thoughts the patient was having.

All Family members interviewed supported the patients in their wishes to pursue MAiD, often logistically assisting them by reaching out to the team, filling out applications/forms, and fulfilling other requirements (finding witnesses, explaining the process etc.). Family members also reflected on their own private struggles throughout the process (such as a personal objections to MAiD) as well as those that arose after the process was over (bereavement, deciding to tell others about MAiD, feeling judged). Family members, in a sense, expanded the research period as some of them had experiences from outside the data collection period.

In order to avoid repetition, there was a limit of one family member for each family or experience. This exclusion criterion was implemented to ensure a diversity of perspectives and prevented allocating too much weight to one experience. However, this was not something I encountered, as multiple members of the same family did not come forward to share their experiences. Additionally, family members were excluded if they were under 18 years of age (due to ethics-related restrictions), and if they did not have direct experience participating in (or assisting with) the MAiD process. Again, I did not come across these circumstance either so no family members met these exclusion criteria and therefore none were turned away or excluded from the research. All participants in this category (11 in total) were in the immediate family of the patient, the most common being the child of the patient (5/11), and less common were siblings (3/11) and spouses (3/11). Family members self-identified for the research and contacted the researcher directly via phone or email, which was included in a recruitment letter provided to them through the MAiD team or Dying with Dignity volunteers, further detailed below on recruitment strategies are discussed next.

Recruitment

All recruitment for the research was conducted through the use of a recruitment letter distributed via email (to the MAiD team) or via a third party (the team and dying with dignity) to family members. The recruitment letter (Appendix A) detailed the study, what participation would entail, as well as reassured participants that their identity will be kept confidential and names will be anonymized in any research reports or publications. Most importantly, the letter explicitly stated that participation in this study was entirely voluntary and in no way connected to the MAiD process or team. This recruitment letter was intended for all participants, however, after some consultation with the MAiD team, it was shortened and made more accessible to the general public's reading level (grade 6). A list of interview questions (Appendix B) was also included on the back of recruitment letters for patients and families. While there are no patients included in this research, the original research design was intended for the recruitment and accommodation of patients and therefore, some mention of patients will be seen throughout this chapter as it had some significance on the process (but not the results – due to exclusion).

Originally, patients and family members were to be recruited with the help of a local chapter of a national organization, called Dying with Dignity (DwD), that advocates for MAiD and organizes volunteers to act as witnesses on the written requests, for patients who have trouble finding witnesses (Dying with Dignity, n.d.). I came into contact with the local coordinators of the Winnipeg DwD chapter through a workshop they held on advanced directives and subsequently met with one of the coordinators to discuss MAiD and my research. At this point, I asked whether their volunteers would be willing to provide patients and families recruitment letters for my research. DwD was very receptive to the research and agreed to help, additionally receiving approval (and a support letter) from the DwD head office (in Toronto) as well as with the Manitoba MAiD team, to ensure that there were no concerns. After some discussion with all parties, it was decided that recruiting through DwD alone may skew the sample, since their volunteers do not come into contact with *all* patients and family members, while recruiting via the MAiD team would allow for a larger potential sample without skewing the potential participant pool.

I contacted the MAiD team through a publicly available email and phone number and was subsequently connected with the medical director of the team, who had some prior knowledge of my research from discussions with DwD representatives. The team agreed to help with recruitment as well and were central to this research. I met both with the medical director individually as well as with the rest of the team to discuss any concerns they had and take their suggestions. The team qualified that research materials had to be clearly differentiated from other MAiD related paperwork – since they provide patients and family members various other documents during the initial assessment. Therefore, I placed recruitment letters inside an envelope and ensured the university letterhead was seen in both the letter and envelope (to differentiate from the rest of the documents).

The MAiD team was then given 200 recruitment letters (100 for patients and 100 for family members), which team members distributed to their clients during initial or subsequent assessments, for the duration of the data collection period (January – April). These recruitment letters were additionally emailed to the team in PDF format so they could send them electronically to any patients/families in rural and remote communities, or those they met with over tele-health. DwD was also provided with recruitment letters, however, these were for family members only (as per ethics agreement). It is unclear if any participants were recruited through DwD as most family members discussed receiving the letter from the team and notably one person, heard about the research from another participant.

Patients and family members then self-identified for the study by contacting me via email or phone number provided in the recruitment letter. MAiD providers were recruited via the original recruitment letter circulated between members through the team admin. MAiD providers also self-identified for the study by contacting me by email or phone and arranging for an interview. This recruitment path ensured direct engagement with the intended population who would receive recruitment materials without engaging confidentiality concerns. This option also ensured voluntariness as willing participants could decide whether to contact the researcher or not, without exerting additional pressure, since the letter could simply be ignored or thrown away. When participants contacted me with potential interest in partaking in research, I ensured they knew it may take about an hour of their time and that it would be recorded. I often provided them with my availability and allowed them to make the choice regarding date/time as well as location for the interview to ensure they were in a comfortable environment.

Data collection

Data was collected using semi-structured interviews which contained open-ended questions about the participant's experiences with the MAiD process. Semi-structured interviews are the typical choice of data collection with IPA research, as they allow for a flexible yet structured format which guided the interview. However, there was no a strict script of questions with pre-determined categories or closed-ended responses, which I believe would have stifled the richness of data and prevented themes from emerging on their own (Eatough and Smith, 2017). Smith (2004) writes that the "advantage of semi-structured interviewing for IPA is that the researcher is, in real-time, in a position to follow up interesting and important issues that come up during the interview" (p. 50). The interview style is conversational and 'non-interventionist' in nature with the only structure coming from the interview protocol itself (see Appendix B) which consisted of open-ended questions asking about experiences with MAiD as a whole as well as some pointers to stir the conversation in the right direction and ensure relevant topics were covered (Smith, 2004).

In most interviews, I used gentle probes to clarify a statement or expand on an idea (Creswell and Creswell, 2018). These probes were meant to clarify ideas – could you explain, what do you mean by, provide an example – as well as keep the conversation on track (going back to..) however, not in a way that shut down the open-ended nature of the interview and conversation. I also active listening skills, often nodding and responding to participants and at times sharing personal details. The interviews felt mostly like a natural conversation and were not done in a rigid question/answer format.

The interview locations were not fixed, and I traveled as far as 40 minutes away to a nearby town for an interview with a participant (family member) who had mobility issues. When scheduling the interviews, I allowed patients to choose the location that was most convenient for them, as the conversation would be recorded and I wanted the participant to feel comfortable sharing personal details. For some participants, it was their home, for others their office (mainly the MAiD team), and only two participants choose to have the interview at the university. A few interviews had to be done over video or phone calls because of pandemic (Covid-19) restrictions as well as travel arrangements that intersected with the research period. These participants still provided a signed consent form via email and confirmed consent verbally during the interview. Interviews lasted anywhere between 20-70 minutes but approximately 30 minutes on average. Interviews with MAiD providers were often on the longer end of the spectrum (40-70 minutes).

All interviews were recorded using a password protected hand-held recorder and subsequently uploaded to my laptop for transcribing. Groenewald (2004) points out that "the human mind tends to forget quickly, [therefore] field notes by the researcher are crucial" (p. 48) and for this reason, I started out by taking as many field notes as I could during interviews. However, I did not personally find the field notes useful – even during the transcription process, perhaps this is because I transcribed interviews soon after and could still recall many details. I found that I could recollect a lot of tacit information from the interview such as body language, gestures, facial expression, emotion, intonations, as well as the thoughts I was having at the time. At the same time, one of the recordings had technical issues, and the field notes were very helpful (even crucial) for the data collected in this interview.

Although I set out to use the worksheet technique – taking research notes and reflexive thoughts at the same time (Mauthner and Doucet, 2003, p. 419), I was not consistent with this and decided to instead keep a separate reflexive journal where I checked in at various stages in the research process. This was done due to the fact I found myself scrambling to take notes during the interviews and when subsequently reviewing the notes, found that they were not useful in the transcription process. I utilized the reflexive journal to capture my thinking process at various stages, reflect on anything that was unclear or new to me as a first-time researcher, as well as check in with how I was feeling or being effected by the interviews and research process.

Mauthner and Doucet (2003) encourage paying special attention to "characteristics such as gender, race, class, and sexuality [which] influence the nature and structure of research relationships" (p. 417). All of the participants were older than me (most were much older) and I personally never felt that the research relationship ventured into inappropriate or uncomfortable territory. All of the participants were very friendly and happy to share their experiences with me. Some, particularly the older participants, definitely saw me from a more parental role, one participant sent me home with a bag of freshly made cookies. Although I did not record race/ethnicity among participants, all of the participants appeared Caucasian and so am I, therefore I do not believe there was any overt race interplay in the research relationship. This is particularly interesting as it may suggest that minorities and marginalized populations may not be accessing MAiD as much as the white participants in this sample. This would contradict various arguments by MAiD opponents (especially present in legislative debates) that minorities and marginalized populations would be disproportionately pressured into pursuing MAiD (a dimension of the slippery slope argument).

Guillemin and Gillam (2004) discuss another use for reflexivity in research which is for the purpose of 'ethics in practice'. Working on a sensitive issue such as MAiD and interviewing family members who lost a loved one, required some additional consideration regarding "how far to probe a participant" (p. 265). A few participants became emotional during the interview, denoted by a break in the voice, short pause, or crying, however, most composed themselves quickly. In one instance, I let the person talk it out and recuperate before stirring the conversation back on track. As a researcher, I continually questioned whether I handled these situations correctly or if there is something I could have done better or differently, I still think about this today. I did not initially think that these instances affected me personally, as I did not get emotional during the interviews when participants did. This could be for a variety of reasons such as lack of familiarity with participants or insufficient time to process the information provided at that moment. However, I felt more of an emotional toll when transcribing these interviews as I listened to (and had more time to internalize) these stories repeatedly for hours.

I did not record demographic information and ensured to redact all personal details (i.e. name, age, locations, personal stories) disclosed in the course of the interview to protect participant identities. Some demographic identifiers can be derived from quotes and may be necessary for context, such as gender, or occupation (for MAiD providers). Participants were informed of this in advance on their consent forms and given the opportunity to request for details to be left out of the transcript, which they could indicate at any point during or after the interview. Further, due to the nature of the MAiD team, absolute anonymity cannot be ensured, especially for any readers who know the participant personally or are aware of their occupations, which was also explicitly stated in the consent form. Participants were assured that all recordings, transcripts, and field notes will be (and have been) kept on a password-protected computer or in a locked private cabinet, inaccessible to the public.

Interview recordings have not been and will not be shared with anyone (unless required by law, in the case of a subpoena, which is highly unlikely) however, anonymized transcripts may be shared with the supervisory/research team. Participants were asked before and after the interview, if they wanted to review or retain a copy of any research materials (consent form, transcript, or research publications) however, most participants were dismissive of this, except for the MAiD team who was interested in seeing the final thesis. I also reminded participants that they can ask for anything to be redacted from their transcripts at any point throughout the interview (and some did), however, no interviewee requested to review their final transcript or withdraw participation. All participants initialed the box on the consent form agreeing to the use of direct quotes from the interview.

Transcription

Cindy Bird (2005) argues that transcription – just as a conversation – is a social act and therefore an interpretive act, consequently, the decisions a researcher makes regarding what is transcribed (as well as how) will "constrain their [data's] subsequent uses" (Lapadat and Lindsay, 1999, p. 73). Data analysis begins with decisions made during transcription and Smith (1995) advises that IPA researchers transcribe the interview in its entirety. However, it is up to researchers to leave out any information they deem irrelevant. As the sole researcher in this project, I was able to make these decisions for myself and did leave out sections of interviews which got off track or related to participant personal lives outside of the research topic.

Since I interviewed all the participants and subsequently transcribed all the interviews myself, I was able be fully in control of all data which prevented issues of confidentiality. Further, as the sole transcriber, I was able to ensure the consistency and reliability between transcripts. I made all transcription decisions, ruling out issues of inter-coder reliability due to different transcription styles and use of discretion, therefore increasing consistency and therefore reliability of results. Additionally, having conducted all the interviews, I was in the best position to recall tacit details (gestures, emotions, context) from interviews to produce a wholesome transcript. These strategies enhanced the reliability of the transcript content and therefore the quality of research content overall. I transcribed most interviews shortly after conducting them, usually within a couple of days, in order to have the most accurate recollection of events and enhance the credibility of transcripts.

I found that the transcription process, more than interviews or interactions with participants, elicited emotional responses from me. I had no trouble remaining composed during interviews, even when participants became emotional (only a couple did – often due to unrelated tangents) however, while transcribing I found I became upset as well and sometimes had to take transcription breaks. Perhaps this is because I was not an experienced transcriptionist and had to listen to the same interview for hours (up to 10 times the interview length) or due to the extra time spent internalizing these personal reflections that I may have glazed over during the interview. This was especially true for the only patient that I interviewed, as this was my second interview (and transcript) ever, and the realization that this patient would not live long enough to see the completed thesis felt unsettling to me. However, this improved with time and experience, as I became better and faster at transcribing (and possibly even desensitized to some of the content).

The transcription of the first interview was very time consuming, taking about ten hours to transcribe an hour-long interview. This improved over time but was easily the most time consuming and frustrating part of the research process. I tested out multiple free transcription software and found VLC (a free online media player) to work best for me. Once I adjusted the hot-keys and got used to the stop-rewind pattern, the transcription process improved greatly. Initially, I set out to transcribe interviews in their entirety, including all non-verbal responses (nods, gestures) as well as any filler words (um, uh, hmm), interruptions, short/long pauses, expressions, demeanor, etc. However, this increased the time of transcription, the length of the transcript, and yielded confusing or messy quotes.

Following the first few interviews I decided that it was unnecessary to transcribe all these filler words, as not every ‘uh, um, oh, so, like’ was crucial to the transcript content, especially since the objective was to conduct content analysis, not speech pattern analysis. I then returned to the first few transcripts and edited them to exclude these filler words, which I felt were hindering the content more than ensuring accuracy. Nevertheless, I transcribed most verbal cues and intonations including laughter, emotional responses (displayed in square brackets), drawn-out or emphasized words (italicized), long pauses (denoted by ‘..’), and gestures that were related to the conversation (usually when a participant would point to something or nod in lieu of a verbal response).

I decided not to transcribe parts of the interview that got off track, which often happened toward the end of interviews. This excluded information consisted of any interruptions, tangents, highly personal stories that did not relate to MAiD, anything the participants requested be left out, and often the small talk that occurred immediately before and after the interview. All interviews were anonymized during the transcription process by redacting personal information in order to protect the confidentiality of participants as well as prioritize time for transcription of materials relevant to the research. Personal identifiers such as names, locations, and dates were removed and often replaced with a generic title such as the relationship of the person [husband], occupation [doctor], or other any designation [abstaining hospital], [month], [nursing home], etc.

I numbered the transcripts in the order the interviews were conducted, this way there would be no need to use the names of participants and the assigned number would serve as the denotation or reference point for referral when extracting quotes. Following the transcription process, I printed each transcript with sufficient space on the margins to make notes for the next step of the research process, that is, data analysis.

Research Ethics

This study was reviewed and received ethics clearance by the University of Winnipeg Research Ethics Board and the Winnipeg Regional Health Authority (WRHA) Ethics Committee. I obtained support letters from the MAiD team as well as Dying with Dignity for ethics approval, since all recruitment activities were to be done through these third parties. The WRHA ethics board did not request any additional materials, clarification, or modification of research activities. This may be due to the social science orientation of the research (as opposed to medical research), as well as the fact I did not require the collection of personal medical data, access to medical databases, or any other WRHA resources.

On the other hand, the university ethics board had extensive feedback and requests for adjustments at every step of review. Going into this research project I was highly aware of the nature of this research, which engaged with a population that may be bereaving and sharing personal or sensitive information (with the possibility of eliciting emotional responses). I expected to discuss various aspects of the research with the ethics board (recruitment, interview protocol, etc.) and in preparation ensured that I covered all my bases in terms of resources, background research, and supports from relevant parties/organizations. However, I was not prepared for the outright rejection of my application by an independent reviewer in a manner I viewed as belittling and inconsistent with other research existing research on MAiD. The ethics approval process required extensive back and forth which ultimately shortened the recruitment and data collection periods.

First, the ethics application was sent for approval to the department committee, from which I received comments, made some revisions, and resubmitted. Following department approval, the application underwent review by the ethics committee chair, who also submitted minor comments, and when these were revised the application moved onto the next step of the review. During the next step, the application was reviewed by two independent members of the ethics board (typical for minimal risk research) and was supposed to be the final round of review. The first reviewer had approved the application upon some revisions (as have all the others), while the second reviewer outright rejected the application, adding that unless the research was entirely modified including the population, recruitment, timing, and interview protocol, it would not be approved.

The rejecting reviewer elaborated that it was never acceptable to interview dying patients, and family members could only be interviewed "well after" their experience have passed. The reviewer made comments external to the purview of the ethics board, including criticizing the literature review (which was under a strict character limit), requesting sources (although the application explicitly instructed not to include these), and generally made inappropriate comments toward the research design (calling it a "grab bag approach" and advising the researcher narrow down the focus in a "less ethically-contentious and partisan fashion"). The reviewer assumed I had ill intentions toward the target population, would be exploiting them for the purposes of my research, and "imposing upon the last moments of their lives". However, it was never my intention to interviewing anyone who was on their deathbed, and in order to avoid such conflict, I utilized the expertise of the MAiD team with whom I collaborated on various details of the research (especially recruitment). As a first-time researcher, having never dealt with ethics board rejection previously, I was distressed believing that I had to change my entire research under an already tight timeline.

Upon further discussions with my supervisor, I re-submitted the application with revisions as well as comments to the rejecting reviewer expressing why I thought this evaluation was unjust. In my comments, I explained my thinking behind certain recruitment decisions, reasoning that third party recruitment was most appropriate for this limited and hidden population, whilst preventing overt pressure to participants by allowing willing parties to reach out independently. I provided the requested sources and referred the reviewer to my thesis proposal which had a detailed and elaborate literature review on the subject. I provided references to other published Canadian research on the subject which was conducted with similar populations – but went further to collect personal identifying information as well as inquired into more sensitive subjects.

Further, I pointed out the reviewer's assumption of patient vulnerability in effect undermined the patient's ability to make their own choices, their self-determination, and silenced an important perspective of an already powerless group. Especially considering these patients would have already been cleared by the team to be competent decision-makers (in the context of MAiD). This was also something I had discussed with the MAiD team in advance, who agreed that patients should have the option of voicing their opinions in research, as group exclusion from medical research due to perceived 'vulnerability' was a known gap in medical research historically. The reviewer still ultimately rejected the application stating that it did not pose minimal risk and requested the research to undergo full review. This was very confusing to me, as the research adhered verbatim to the Tri-Councils' definition of 'minimal risk' and did not view it as equivalent to medical research (among other higher risk research).

Under full review, the university ethics board discussed the application collectively and submitted a request for further revisions alongside a third support letter from the medical director of the MAiD team. This additional support letter was intended to confirm that all recruitment of patients would occur through the team, at the discretion of the medical director. I drafted this letter which the medical director agreed with and signed following a team meeting where I was invited to discuss my research with other members. Following this meeting, I made revisions to the recruitment letters by simplifying the language, increasing the font size, including research questions on the flip side, and highlighting the contact information for visibility. I received ethics approval from the university in January of 2020, about five months after approval from WRHA, which limited my data collection period by a few months. However, at the time, it was important to me not to exclude the perspective of patients from this research as I believe their experiences should be central to MAiD discussions, despite the fact that there are no patients included in my analysis/findings.

From the inception of this research, I was fully aware of its' sensitive nature and compensated for it with thorough consent/recruitment forms, opportunities to withdraw participation, and having a comprehensive list of resources available if anyone experienced any distress due to the interviews. This was in addition to resources and supports already provided by the MAiD team to both family members and patients alike. I did not find that any participants had a negative or distressing experience during or following the interview and certainly no participants have reached out to me with any complaints. Most of the participants were more than happy to discuss their experiences with me, some even felt it was their duty to help and were surprised to find out that more people did not reach out. One participant, in particular, discussed how this was his first opportunity to reflect on the process and wished there were more opportunities for him to be a proponent of MAiD. Interestingly, the ethics board was not concerned with the psychological well being of a young graduate student conducting qualitative research on a sensitive topic for the first time. Fortunately, I had a supportive supervisory team who reassured and helped me navigate this process.

Data analysis

Chapman and Smith (2002) write that IPA research involves "a detailed case-by-case analysis of individual transcripts" (p. 127). The approach to data analysis with IPA is flexible, Smith (1995) notes, generally a researcher will begin by looking "in detail at one transcript" starting with specific themes and "working up to generalizations" (p. 9). The detailed analysis of one transcript may require multiple readings, while looking for new/different insights each time and making comments on the margins. Smith suggests writing down things that strike the researcher as interesting on one side of the margin and during a subsequent reading, documenting theme titles on the other margin. This way, at the end of the first transcript analysis, the researcher is able to come up with a master list containing all discovered themes. The researcher can then choose to either analyze a different transcript in the same manner or use the themes already created to evaluate subsequent transcripts, while simultaneously keeping an open mind to new themes (Smith, 1995).

I followed Smith's suggestions and guidelines during data analysis as I initially felt a bit overwhelmed at the amount of data I could extract from transcripts. Although I planned to analyze each interview immediately after transcription, the majority of interviews came in a single burst (conducted in the same week) and I decided to wait until after they were all transcribed to begin analysis. Having conducted and transcribed all the interviews myself, I already had a good idea of the prominent themes prior to beginning the formal analysis. I chose not to use qualitative content analysis software (such as NVivo) as the sample size was too small to benefit from the use of the software and upon consultation with a supervisor, I felt the time I would invest in learning how to use it would not pay off in time savings down the line. Instead, I analyzed the transcripts manually which allowed for a more detail-oriented and flexible coding style.

I analyzed transcripts individually first, by reading through each transcript and sectioning off the various discussion points. I labeled each topic on the margin with a generic description such as: witnesses, waiting period, prior knowledge, moral objections, compliments/complaints, advice, etc. This signified to me the topics each interview covered and those that were most impressionable for each participant. This also served as markers or reference points which I returned to later when I wanted to find a quote/experience speaking to a specific subject. At this point, I also highlighted quotes that stood out to me because I thought they were powerful, captured a unique experience/story, or eloquently summarized an issue that was repeated by multiple participants.

While most of the participants touched on similar themes, there was still divergence among experiences. Some participants had in-depth personal experiences with various parts of the process that many participants did not encounter at all (such as abstaining facilities or conscientious objection). Through individual transcript analysis, I intended to enhance the credibility of findings by ensuring that each transcript allowed its own themes to emerge without attempting to corroborate findings from other transcripts or confirm any pre-existing ideas. In using this technique, divergent experiences became immediately apparent and often stood out in transcripts (and my memory).

Following the transcription process, Smith (1995) suggests comparing themes by joining them all on one master list, refining each category, and beginning to make connections between themes. At this point, I compiled all the categories/themes into one list, allowing space below each theme for new entries representing the opinions/experiences of different participants. Each entry had a summary of the participant's response (if any) relating to that theme and sometimes was accompanied by a direct quote, if I found it captured the point very well. This compilation of themes allowed me to take a step back from the data and examine it in its entirety, thereby recognizing where data was concentrated and how the categories fit together. Only after seeing all the themes in one place and discussing this list with my supervising committee, I was able to choose the themes that were most prominent in participant accounts and those that spoke to the accessibility of MAiD overall, which was one of the primary goals of this research.

Creswell and Creswell (2018) suggest concentrating on a smaller number of themes to allow for a rich description of data. This tends to have a more significant impact as opposed to a diluted data set with a large number of themes that may lack the same level of depth. For this reason, I decided to concentrate on two themes (with subthemes) that highlighted barriers to accessibility to MAiD in Manitoba, including information-based and process-based obstacles encountered by participants. In breaking down and explaining each theme, I made every effort to let participant experiences speak for themselves via direct quotes. Each quote (seen in the next chapter) was accompanied by the corresponding transcript code (transcript/participant 1, page 4 = 1P4) which served as a reference point while also promoting confidentiality. I chose not to assign pseudonyms (in addition to transcript numbers) as I did not believe it would be necessary and could lead to additional confusion (for myself especially).

Once the major themes were established, I returned to the transcripts and looked for divergences among experiences that could contradict these themes. I integrated these discrepancies (or differing opinions) to display individuality among experiences while also establishing rigour and transparency in research. I was not attempting to affirm the themes I chose by solely displaying data that validated my ideas but to show experiences holistically by including those that differed from the majority as well. I believe this increased the trustworthiness of myself as a researcher and the findings of this research due to the open and honest display of data. Other criteria I utilized to ensure quality of research included reliability, credibility, rigour, trustworthiness, and transparency.

These quality markers can be seen through the second comparison of themes which ensured themes logically connected with each other, were not too repetitive or similar and highlighted an area of MAiD that may not have been a part of mainstream discussions on the subject. The use of reflexive/auto-ethnographic notes during research (which can be seen throughout this chapter and chapter 4) as well as a feedback loop with the supervisory team ensures a transparent research process and therefore trustworthy/reliable results. Triangulation of data through the use of multiple perspectives (i.e. family members and MAiD team members, having various backgrounds, socioeconomic statuses, and occupations) contributed to the credibility and reliability of research findings. Although generalizability or transferability was not a goal of this research (or most qualitative research), the similarities in accounts and extensive experience of some MAiD team members lead to the conclusion that the findings reflect an accurate representation of the average MAiD experiences in urban Manitoba. The next chapter will explore these experiences and the themes discovered in detail.

Chapter 4: Results

"One last thing he said is 'isn't this better than me full of IV's and people trying to keep me alive, and there's nothing left of me'. So he was very very grateful." 10P5

Introduction

In this chapter I present and discuss the themes extracted from interviews with participants who reflected on their experiences with MAiD in Manitoba. Participants are separated into two categories: family members and members of the MAiD team. I begin this chapter with a brief description of these participant groups and the data I collected from them. Findings are discussed separately for each participant group, considering their different positionality to the phenomenon (MAiD) and nature of the experiences (personal vs. professional). Similarities were more easily discerned when considering intra-group data, however, many themes were common to both groups. These two perspectives on the MAiD process are merged and contrasted with existing literature on MAiD in Canada in the subsequent discussion section.

During data analysis, I aimed to highlight not only those themes which emerged most frequently but additionally play close attention any themes that may impact the accessibility of MAiD overall. A major goal of this research was to provide a first-hand perspective into MAiD that would allow for the extraction of recommendations (based on positive and negative observations) from participant experiences and MAiD team expertise. I wanted to emphasize the aspects of the local MAiD delivery system which were commendable and could be implemented elsewhere while also pointing to areas that require improvement. The information I gathered from participants directly led to these recommendations, which are provided at the end of the next chapter. I hope these recommendations will assist in informing future revisions of this legislation or any other regulatory MAiD initiatives. This goal, of analyzing participant experiences in order to extract recommendations, is intimately connected with the themes chosen. The first theme discusses how lack of knowledge about MAiD hinders access to the service while the second theme, speaks to difficulties incurred during the process itself, which have shown to delay or prevent access to MAiD for patients.

The first theme, related to MAiD education, discusses how participants came to know about MAiD, highlighting some struggles to find information, receiving misinformation, having trouble being referred to legitimate sources, or misunderstanding the provided information. This theme discusses the lack of public and professional education on MAiD in Manitoba which ultimately affects how accessible (and to whom) this newly legalized medical service is. The second theme discusses potential barriers in accessing or proceeding with the process of MAiD itself, largely due to various forms of moral objection. Moral objections were encountered by both participant groups, largely from conscientiously objecting healthcare providers, abstaining facilities, and personal objections of family/friends. Moral objections from close social circles were described as especially upsetting by family members as it stigmatized the use of MAiD and led to the choice of some families to keep the process private/secret, thereby missing an opportunity to advocate for MAiD. The MAiD team discussed encountering objecting healthcare providers more often than family members which caused some delays in the process. Both participants groups discussed challenges posed by objections of faith-based facilities, which require patients be transferred to another facility for the provision (and sometimes assessments as well). Participants provided examples of the negative effects that transfers have on all parties involved in transfers (healthcare workers, family, patients), which have led to delays, complications, and at times even prevented access to MAiD altogether.

After elaborating on these two major themes with the use of direct quotes from interviews, I conclude this chapter with a discussion section that presents these themes in light of similar

Canadian research and trends from other provinces. The findings are discussed in light of the upcoming legislative changes (under Bill C-7), among other relevant literature that re-affirms the need for better education on MAiD not only in Manitoba, but across Canada.

Description of data and participants

In the interest of the participants' confidentiality, I have chosen to refer to them according to their transcript numbers (not by name), and group membership (family members vs MAiD team members). Therefore, I describe the sample characteristics and data provided in two parts. First, concentrating on themes and trends seen among family members and second, discussing experiences from the MAiD team as well as comparing and contrasting themes from the two groups. This section provides a broad overview of what participants chose to share from their experiences in interviews, followed by the two major themes I extracted from their narratives. The last section under this chapter, the discussion, places these themes in the greater Canadian context, accounting for current literature and discussions on the subject. A breakdown of all participant can be seen in the table below.

Family members		
Transcript #	*Gender*	*Relation*
3	Male	Wife and mother had MAiD*
6	Female	Brother had MAiD
7	Female	Sister had MAiD
8	Female	Husband had MAiD
9	Male	Father had MAiD
10	Female	Husband had MAiD
11	Male	Mother had MAiD
12	Male	Mother had MAiD
13	Female	Mother approved for MAiD

15	Female	Sister had MAiD
16	Male	Mother and Father had MAiD*

* These participants had multiple experiences with MAiD but were counted as one.

MAiD team		
Transcript #	*Gender*	*Title*
1	Female	Psychosocial specialist (social worker)
4	Female	Medical Director (physician)
5	Female	Client Care Coordinator (Nurse)
14	Female	Client Care Coordinator (Nurse)
17	Female	Physician
18	Female	Client Care Coordinator (Nurse)

* Participant #2 was the only patient and thus excluded from this research.

Family members

I interviewed eleven family members altogether, most of whom were recruited through the MAiD team, with one family member who indicated hearing about the research from another participant. All of these participants were unrelated to each-other and discussed separate experiences, as outlined under inclusion/exclusion criteria previously. A few participants experienced two provisions (for two different family members, at different times) and reflected on both experiences.

Most interviews were conducted in person, at a location that was most convenient for the participant including: the university, participant’s home, office, and in one instance the participant wanted to meet at a local restaurant. Three interviews had to be conducted over the phone or skype due to travel arrangements and covid-19 gathering restrictions, these participants still provided written as well as verbal consent during the interview. The majority of participants had recently experienced the MAiD process (within the past few months), however, a few family members were reflecting on their experience from a couple years before. I did not find significant differences between these participants' experiences, except for one participant. This participant's spouse went through the process in early 2016 and discussed some frustrations (mostly delays) associated with the infancy of legislation at a time when interpretations of MAiD regulations by physicians were more conservative. The participant recognized these issues were associated with the infancy of legislation and stated that during his second MAiD experience, the delays were not an issue.

Although I did not collect demographic data specifically, all of the participants were older than me (24 years old, at the time) with most being closer to (or past) retirement age. There was nearly an even split between female and male family members, with one more female. All of the family members were in the immediate family of the patient who pursued made, comprising of – spouses, siblings, or children. The degrees of involvement among family members with the process varied. Some had substantial involvement in every step of the MAiD process, often being the primary caregivers of that patient. Others had less direct participation, often attending only one of the meetings as well as the provision, yet were still fully informed during all aspects of the process.

Most family members had some prior knowledge of MAiD. Commonly these participants were long-time supporters of MAiD or were just aware of its legalization from the news. Notably, a few participants mentioned knowing someone who pursued MAiD and therefore had more detailed insight into the process. A smaller number of family members stated they had no idea MAiD was legal and were even surprised when they found out this was an option, often from a healthcare worker or friend. All family members were supportive of their loved one's wishes, although some held personal reservations at first. These participants came from religious backgrounds which led to their questioning of spiritual consequences for the use of MAiD, but ultimately supported the patients' right to choose. Some family members who were not religious themselves, discussed the decision to keep the use of MAiD private/secret, worrying about adverse judgement from less accepting family and social circles. However, a few family members stated that they discussed it openly with others and did not care who knew.

Family members discussed numerous parts of the process which they or their loved one found burdensome including witness requirements, waiting periods, having two interviews, and enduring a transfer (or the possibility thereof). Some of these concerns are addressed under the new Bill C-7 (see chapter 1) however, this research took place before these amendments were proposed. There was no consensus among family members on a single overarching issue as all of these burdens effected participants to varying degrees; however, most stated that the team alleviated many of these concerns.

Almost half of the family members described being worried that the patient would lose capacity and become unable to provide final consent. A couple of other participants discussed anxieties associated with the possibility of a transfer, although they did not endure one in the end. One participant actually experienced a transfer from an abstaining facility and stated that some dignity was lost in the process due to this. In one instance, the possibility of a transfer became a concern for a family member while they awaited a palliative bed to free up, hoping it would not be in an abstaining facility. In another instance, the patient was already being treated at the abstaining facility when they found out about the possibility of transfer.

Conscientious objection by healthcare providers, friends and family alike was described as an inconvenience more than a concern or barrier. Some family members discussed instances of friends refusing to act as witnesses, unsupportive family/friends, being worried about telling hospital staff about pursuing MAiD, and having healthcare providers identify as objectors (yet still fulfill obligations).

All family members reflected positively on the MAiD provision, commonly describing the provision and death as ‘beautiful’, ‘peaceful’, or ‘amazing’ despite it still being an emotionally difficult time. Family members largely described the process itself as convenient, they cited various reasons including the availability of Telehealth, the fact that the team traveled to patients, availability of volunteer witnesses, and the team’s coordination of transfers/provision room. A minority of family members had described provisions with a small number of attendees, however, the majority had large family gatherings on the day of the provision. Some provisions had multiple generations of a family present, even if they chose not to be in the room at the time of death. Family members valued the quality of time they got to spend with the patient and other family during this time, describing it as an emotionally difficult but gratifying day, allowing for a proper goodbye.

The majority of *positive* feedback, however, was directed at the MAiD team, which family members praised as ‘compassionate’, ‘empathetic’, ‘accommodating’, (among many other compliments), often stating that the team was the highlight of the whole experience. Family members had little to no criticisms for the team, with most difficulties described being associated with process-related inconveniences due to legal requirements. All family members stated they understood the reason for these legal safeguards, and did not think they should be eased. Some has issues with specific contentious eligibility requirements such as having to repeat consent prior to the procedure as well as the waiting periods. All family members stated that the process was simple, clear, and explained well, confirming they understood everything. At the same time, I noticed some of these participants made incorrect statements about eligibility or procedural requirements. This may be related to memory attrition, or having been less involved in the process, yet, may also indicate a lack of understanding about the process/requirements among family members despite their opposite belief.

When I asked participants whether they would change anything about the process, many of the family members took this time to describe disagreements with legislation and advocated for advanced consent allowances for patients at risk of losing capacity. One family member explicitly stated that this would have benefited both his mother and wife who had MAiD earlier than they would have liked due to the fear of losing capacity. A few others objected to the policies of abstaining facilities however, one family member stated that people should respect faith-based institutions. Most participants said that they would not change anything about the process because it was very well done. When asked what advice family members would give others considering pursuing MAiD, most family members recommended speaking to the team and finding out more about the process. Some highlighted the importance of end-of-life conversations with family, so that the patient's end-of-life wishes are known and most importantly supported, even if there is personal disagreement. One participant said that family members should be prepared for the grieving process and ask for help if needed.

MAID providers

I interviewed six members of the MAiD team including: one psychosocial specialist (social worker) with three year's experience on the team, three client care coordinators (nurses by profession), all of whom had been with the team for over a year, and two physicians, one of whom was the medical director of the team and took part in the original advisory committee that established the MAiD team in Manitoba. All of the team members interviewed were female, as is the majority of the team, which leads me to believe this to be a representative sample of the team. The interviews were largely conducted at the MAiD office, two were done over the phone, and another at the participant's home.

I found interviews were longer with members that had more experience, the longest of these interviews was an hour a half (with the medical director). MAiD providers discussed their day-to-day work, their thoughts on possible legislative expansions, and provided some insights into the evolution of eligibility criteria interpretation. The only consensus among team members about which criteria *should* be modified in the legislation (at the time, prior to C-7), was the final consent requirement, with most providers agreeing that allowances should be made for prior consent, especially in case of loss of capacity. This was mostly agreed upon in the shorter term, for patients who have been approved and scheduled for MAiD, while at risk of losing capacity. Longer term advanced consent (months or years ahead) or consents written into an advanced health directive, was seen as a more complicated issue. A few team members were worried about whether the patient's ability to change their mind (about MAiD) would be compromised with advanced consent. This brings up issues of identity and whether doctors would be following the wishes of the fully coherent patient who provided consent or the demented patient who may be resistant.

There was division among team member about whether the legislation should be expanded to include mature minors, patients whose sole underlying condition is psychiatric, or allowing prior consent as part of an advanced directive. MAiD team members differed in their comfort levels as some disagreed with all expansions or certain expansions, with little consensus. All team members stated that there were few to no inquiries coming from mature minors (only aware of a couple over the years). However, they receive significantly more inquiries about including

MAiD requests in an advanced directive, being disappointed to find out that the legislation does not currently allow for this (including Bill C-7 amendments). Nonetheless, all providers described being comfortable with current legislative regulations, many elaborating that with experience they become more comfortable interpreting criteria and have seen how these interpretations have evolved among MAiD providers across Canada.

The evolved interpretation of ‘reasonably foreseeable natural death’ (RFND) requirement being the most significant, which use to be interpreted quite conservatively (patient death prognosis under a year) by providers. However, as providers across Canada became more comfortable with assessments and provisions, they began to interpret ‘reasonably foreseeable’ more liberally. This evolution in interpretation could be seen in the *Lamb* case (see chapter 1) which challenged the RFND requirement was but ultimately led to the adjournment of the case, since the plaintiff (Julia Lamb) would meet criteria under these more liberal interpretations. Currently (as of 2020), the team described this criterion to be understood as ‘will die in the next few years’, taking a broader and more discretionary interpretation as compared to the one-year window first suggested.

The RFND requirement was not the only part of the legislation which expanded, as the MAiD team discussed the cases in which the reflection period was waived, also evolved in interpretation over time. According to legislation, it is under the discretion of MAiD providers whether the waiting period is to be waived, limited to circumstances where the patient is at risk of imminent death or loss of capacity. The physicians on the MAiD team stated that with more experience they became comfortable using their discretion in waiving the waiting period for patients. This may also be related to the fact that in early post-legalization (and still to a certain extent today), patients waited until their last days of life to reach out to the MAiD team, with many dying or losing capacity before reaching the provision or being assessed. What had expanded is the use of discretion by providers as well as their interpretation of ‘loss of capacity’. Whereas early on, the waiting period was waived for patients who were at risk of dying or losing capacity within the 10 day waiting period, at the time of research, MAiD providers were additionally waiving this period for patients under palliative sedation. Notably, this requirement is lifted under Bill C-7 with no waiting period for those whose death is reasonably foreseeable yet extended to three months (from ten days) for those patients whose death is *not* reasonably foreseeable.

While the family members had largely positive experiences with the MAiD process and praised the team on their efforts, some MAiD providers were able to offer critiques of this system including a limited capacity to handle a large number of requests, especially from rural/remote locations. Due to this, providers mentioned anxieties associated with the upcoming legislative changes, anticipating being overwhelmed by an influx of inquiries (due to a lack of resources), if the legislation were to broaden eligibility substantially. Members stated that it was becoming harder for the team to keep up with increasing requests and traveling to patients, considering the team has already expanded operations and resources, and suggested that future involvement from healthcare providers in the community may be required.

In order for the team to request the help of healthcare professionals in the community, they would have to become familiar with MAiD services, eligibility, how to conduct assessments among other aspects. This is complicated by the fact that there is no standardized professional development or education on MAiD for healthcare providers in Manitoba. The Colleges of Physicians and Nurses released policies explaining MAiD requirements, a couple years after legalization. The nurses guide was created in collaboration with the MAiD team with all inquires directed at the MAiD team (“Medical Assistance in Dying: Guidelines for Manitoba Nurses”, 2018; “Standard of Practice Medicine”, 2019).

MAiD team members stated that misinformation among public and professionals seems to be regarding eligibility requirements and how the process works, rather than general knowledge of MAiD legality. Although knowledge of MAiD among the public is lacking as well, as seen by the team through an influx of calls/inquiries every time MAiD appears in the news, despite there being a comprehensive website and resources available online. For this reason, MAiD team members consistently recommended that anyone considering MAiD should educate themselves about all end-of-life options as well as inquiring with the team early on. This way the team can dispel any misconceptions early on by providing the most up to date information and allowing patients to access MAiD when they truly want it/need it, instead of waiting until they are crisis to begin the application process.

When asked about working with patients at abstaining facilities, MAiD team members described this as a major burden on resources, the MAiD team, patients, and families who have to experience it or worry about it, as well as the healthcare staff at sending/abstaining institutions. The team did mention that abstaining facilities do not prevent or stop MAiD from happening in most circumstances as they have work around the policies and transfer patients when needed. At the same time, team members described transfers as distressing, onerous, and cruel to put dying patients through (as well as their distressed family members). The team stated that abstaining facilities often delay or even prevent access to the service, sometimes by not providing the required information and at other times due to the coordination and scheduling of transfers.

The MAiD team described instances where patients lost capacity (or faced other complications) during the transfer which rendered them unable to receive MAiD when arriving at the receiving facility. For patients who could not be accommodated at any other facility or transferred safely (due to specialized needs or equipment), the abstaining facility essentially takes away MAiD as an option altogether. The MAiD team was disappointed that they could not help these patients and discussed how staff at abstaining facilities often did not support the institution's policies and found transfers upsetting as well. These discussions of transfers and abstaining institutions were seen among a few family members as well and thereby comprise a major part of the second theme.

Theme 1 – access to information

Access to information is perhaps the most important factor in determining access to MAiD overall. It is also a vital component of informed consent when it comes to making healthcare decisions. When patients are unaware of MAiD as an option they would not think to ask their healthcare provider about it, thereby, limiting or preventing access to MAiD. Additionally, when healthcare providers lack the knowledge or comfort level to discuss MAiD as an option (alongside other end-of-life options), then patients cannot make a truly informed decision about their end-of-life care.

In fact, awareness of *all* available options at end-of-life is so important that it was written into the *Criminal Code* under MAiD eligibility requirements. This provision (s.241.2(1)(e)) states that an eligible patient must "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" (*emphasis added*). This section essentially states that every patient who chooses MAiD should be informed of other options available to them, however, the same does not apply when discussing other end of life services/programs. While the team has to ensure every patient is informed of their options outside of MAiD, it seems the same curtesy is not extended to MAiD services as well.

Dissemination of end-of-life options (including MAiD resources) begins with healthcare providers, who are on the front lines directly engaging with potentially eligible patients and often looked upon as gatekeepers of all medical services. While online educational initiatives may reach a larger portion of the population, they may miss the target population for MAiD entirely, which is often older and less comfortable in accessing online resources. Ensuring that healthcare providers in the community understand MAiD and are comfortable discussing this option with their patients will provide a stable and long term resource for those patients in the community who were not previously aware.

Some research suggest that physicians wait to discuss these options with terminally ill patients late into their illness when other viable treatments have been exhausted and often during acute hospital visits (Keating et al., 2010; Mack et al., 2012). Ladin et al. (2018) found that only 13% of dialysis patients discussed end-of-life preferences with their physicians, with 25% of patients never even considering their preferences. These conversations should be taking place much earlier (and more frequently) for patients, to fully appreciate the totality of their circumstances and options available to them. In order to increase acceptance and appreciation of end-of-life care while normalizing the naturalness of death and dying, especially among critically ill and senior populations, increased public and professional awareness is required (Ross et al., 2002).

Interviews with eleven family members revealed that while most had some antecedent knowledge of MAiD, whether by knowing someone who accessed it or following its progression in the news, there were a few participants who had no idea MAiD was legal in Canada. These participants were eventually informed of this option, often times at the last minute when the patient was in dire straits. Participants without prior knowledge of MAiD services accessed information primarily in two spaces including through healthcare providers (family doctors, nurses, specialists) or social circles (friends or family) who were aware of their condition and told them about MAiD. It remains unknown (and concerning) how many individuals went on without ever finding out about MAiD as an option, even if it was something they would have considered/chosen.

Interviews with six members of the Manitoba MAiD team revealed that while knowledge among professional communities is improving, there are still examples of false and inaccurate information being passed down to patients about MAiD. Even more concerning is the complete absence of information among some healthcare providers (especially in rural communities), which needlessly restricts end of life options for patients. Over four years have passed since the first legal cases of MAiD in Canada and while the word is spreading, the team is still seeing increased call volumes after MAiD appears in the news from people who never knew it was legal.

Nevertheless, prior knowledge of the existence of MAiD does not necessarily point to a full understanding of the MAiD process or its eligibility requirements. MAiD providers discussed various examples of misunderstandings (especially of eligibility requirements), among both the general public and medical professionals, which led to impaired access for patients. Family members also showed some signs of inadequate understanding in terms of the MAiD process and its requirements, despite insisting that everything was clear and simple. This can be attributed in part to memory attrition over time, emotional distress during the process, or even lack of involvement. On the other hand, literature would suggest that this fragmented understanding has more to do with health literacy. A 2008 expert panel report on health literacy commissioned by the Canadian Public Health Association suggests that a large proportion of Canadians have lower than required levels of literacy which impede their ability to respond to health information demands in different contexts.

This calls for better public education and knowledge dissemination for end-of-life options in the province. Alarmingly, there have been no initiatives by the government to publicly disseminate information on MAiD in any standardized way, although federal (*Criminal Code*) and provincial laws were amended in order to regulate this service. While guidance and policies were released, the provincial government or regional health authorities have not required any standardized educational upgrading or undertaken any other initiatives for healthcare providers, considering the Criminal Code was altered which directly effects a large proportion of healthcare workers in the community as well as those specifically working in geriatrics or with critically ill populations.

The MAiD team, especially the client care coordinators (nurses), described numerous shortfalls related to information dissemination with examples of missing information/ resources as well as wrong information given to patients by healthcare providers. These instances of misinformation or lack of information are still seen with providers who work within Winnipeg, which suggests an even more dire need for information in northern and rural communities. The MAiD team holds information sessions whenever they are asked by outside groups in the form of presentations to nursing programs, medical residencies, hospitals, care homes, among other forums and upon request. However, the team's priority remains assessing patients and providing MAiD as well as answering inquiries from the public.

Although larger urban healthcare facilities are reportedly improving their staff education on MAiD, healthcare providers in the community are left to self educate and it is unclear what kind of information on MAiD is permeating in rural and remote communities from which the team never receives any inquiries. As the number of people requesting MAiD increases, seen through growing numbers of inquiries and provisions, the MAiD team may need to outsource some responsibilities to healthcare providers in the community (such as one – or both – assessments). The availability of proper educational materials and training will be crucial for the continued accessibility of MAiD to patients across *all* of Manitoba.

Finding out about MAiD

Walter et al., (1995) write that death is ever more present in our lives today, reported daily by the news, seen on social media, and have become central to all forms of entertainment (movies, shows etc.). Despite this, death remains an uncomfortable subject to bring up in conversations, for some, even with family, friends and healthcare professionals. Although portrayals of death in entertainment are often sensationalized as opposed to rooted in the reality of dying, most family members I interviewed had some prior knowledge of MAiD (7 out of 11 family participants) *due to* its coverage in the news/media.

> "my mom had been talking about MAiD for, I don't know, about two and a half years, but she had known about it before that." 13P1

Many of those family members who had previously known of MAiD, were already supporters of it prior to legalization and some had even discussed it with others.

> "it was something we discussed as a family" 12P1

> "we knew about it [MAiD] as an option, we have a friend that, his wife used medical assistance in dying" 10P1

Some families were surprised to find out not only that MAiD was an option for them, but that it was legal in Canada at all. These participants were often informed by a healthcare provider, a friend, or another family member of this option. Notably, in these instances patients were informed of the option at the last minute, instead of through the proper channels at an appropriate time.

> "We didn't even know about the MAiD program" 7P1

In one instance, the family member I interviewed was aware of MAiD due to previous healthcare experience but did not want to suggest it to the patient (a sibling) without some indication of desire first. Eventually, the patient indicated a desire to die to another family member (not knowing this was a legal option) which prompted the participant to initiate a conversation and subsequently an application for MAiD. This participant later regretted not having this conversation earlier and stated:

> "I just wish I would have approached her about it earlier. It was a scramble to get it done in time sort of, you know." 15P2

Another family member who had prior knowledge about MAiD, chose to keep the information to himself while the rest of the family (including the patient) were left unaware of this option. The patient then began VSED (voluntary stopping of eating and drinking) in order to hasten death at which point he was informed by a healthcare specialist at the hospital of a third option, MAiD. The rest of the family was shocked when told of MAiD.

> "My brother and sister had not heard of this ever." 9P3

> “And my sister who was there didn’t have a [clue], she’s 10 years younger than I am and had been sort of his care giver. She didn’t know about this either, and she just went ‘whoa’ [shock]” 9P2

Given this lack of prior knowledge, the MAiD process had to be rushed in this case (the waiting period was waived) as the patient was already nearing death and at risk for losing capacity due to the VSED. The rushed process in this instance led to some tension in the family as many felt they had little time to prepare for or process the decision to pursue MAiD, prior to the provision. Due to this shortened timeline, some family was now able to attend in time however, the room was still packed with multiple generations on the date of provision.

> “I had one more sister that wasn’t there, she was on a cruise halfway around the word and couldn’t make it back. She was *not* in the same place that the rest of us were, she called this a medically assisted suicide” 9P6

This rushed process was not an unusual experience, statistics provided by the MAiD team show that in 2019, 49 of the 177 MAiD provisions conducted in Manitoba had to be acted on within the waiting period due to the risk of death or loss of capacity. This represents about 28% of provisions (not applications or approvals) which is similar to findings by Robertson et al. (2017) who found the waiting period was waived in 25% of cases on Vancouver Island. The higher proportion of shortened waiting period was reported by Selby et al. (2020) in Ontario, during a two month period where 39% of provisions had to have shortened waiting periods. Of course, at the time participants were not aware of Bill C-7 and that it would eliminate the requirement for a waiting period for patients like them, who met the reasonably foreseeable natural death criterion.

Although most family members had some prior knowledge of MAiD, even if it was cursory (aware of its existence or legality but not that there is an application process), they still insisted that there was lack of knowledge about MAiD. Participants stated that they had many friends/family who had no idea MAiD was legal and in general did not believe the greater public had knowledge of MAiD legality either.

> “I think the MAID process could be made to be a little more well known maybe by the public.” 11P5

> “I wish everybody could be educated so they could tell others about it. That it’s available and how fortunate we are to have that option, that choice, even if you choose not to, it’s there.” 7P10

MAiD team members corroborated this portrayal of the average MAiD recipient, agreeing that within the past few years or so, there have been more individuals inquiring with some prior knowledge of MAiD, and even a minority of people who actually knew someone who used MAiD.

> “Certainly, within the last 6 months for sure, 8 months maybe even… People know a whole lot more information, they’ve gone online and they have looked up what the process involved. We also have way more people know somebody who had MAiD” 18P1-2

However, the team is still seeing an influx of inquiries after any news or media coverage on MAID, revealing that the availability of MAiD as an end of life option in Canada is not a matter of common knowledge yet, even after four years of controversies, court cases, and other publications. Additionally, many of the inquiries the team receives after some media coverage ask about advanced directive for MAID, not realizing the law currently prevents this. This further points out that while some information is being disseminated on MAiD, it is not always the most accurate and can be often misinterpreted by the general population.

> "We do see every time there's like a local story in the paper we get a flood of calls, there's still a lot of the public that don't know that it's legal, and don't know that it's available in Manitoba." 4P4

> "every time MAiD's in the news we get a lot more inquiries. So with the changes with the government, that's been in the news several times. So every time there's a story, we get calls." 18P1

> "we get probably 1-3 calls a week, of patients wanting it [MAiD] in their advanced directive, and wondering how to go about doing that." 4P6

The team painted an even less informed picture of public knowledge on MAiD, believing that there is a large portion of the public simply unaware of MAiD as an option. This lack of freely available knowledge among the population ultimately has the effect of delaying or preventing access for those who do not know to ask about it.

> "I think there's patients that would like to have MAID but don't know it exists and aren't told about it in a timeframe that works." 4P12

> "it's still baffling to me that we hear all the time that patients didn't even know that this existed in Canada. That health care providers didn't even know that this was allowed." 14P3

This lack of information, coupled with sources of misinformation, is especially concerning in rural communities, some of which have submitted no inquiries or requests to the team. One of the physicians on the team noted that *mis*information and lack of information are still prevalent in the city (Winnipeg) and likely even worse in rural communities which ultimately impedes access for rural patients.

> "We've never had a request from an on reserve… Is it because no one wants MAID on the reserve? Or its because they don't know how to access it?" 1P10

> "it's harder to permeate in those smaller communities unless there are actual active engagement from the practitioners…the onus needs to be on the physicians and nurse practitioners who are living rurally to make sure they are aware of all of the options that are available to their patients." 5P7

> "I think there's still a lot of misinformation and probably no information at all. It still comes, even in Winnipeg, comes across to us through these assessments that you know, a lot of physicians don't know, don't understand, or don't *want* to provide that. So if that's the case *here*, I can just imagine northern Manitoba or anywhere outside the city probably has much more difficulty with accessing this service." 17P3

The lack of provisions from some rural Manitoba communities may be related to religious roots and historically conservative political affiliations which would explain the total lack of engagement about MAiD from those communities. However, a complete lack of inquiries in concerning since it remains unknown what kind of information on MAiD is available in these communities and whether this is a subject local healthcare providers feel comfortable discussing with their patients at all.

Urban and rural healthcare disparities have been well documented in Canadian medical literature. Rural citizens often have less access to specialized services and a lower proportion of family physicians (Wilson et al., 2020). This split also extends to other areas such as education, often due to differences in available resources due to provincial policy decisions that lack consideration for rural communities (Giesbrecht et al., 2016; Soles et al., 2017; Wilson et al., 2020). One of the nurses on the team described an interaction with a patient from a remote community, who not only lacked knowledge about *any* end-of-life options but also did not understand that he could make autonomous choices regarding treatment (or refusal thereof).

> "I've had a conversation with a patient who lives up north… He didn't even understand that he could decide that he didn't wanna have to fly to Winnipeg anymore… and this isn't somebody that chose MAID, but it was a conversation where you can have palliative care, you can be made comfortable at home, you can have help to die, it's legal and he knew *none* of that." 18P6

The MAiD team described regular encounters with patients who experienced delays in receiving information or a referral with some being turned away or given false/inaccurate information by healthcare providers.

> "There was just a gentleman recently had asked 8 different healthcare providers, and nobody connected him with us, until palliative care consulted." 4P5

> "we had a patient that I met last week, and in reading his chart, there was a note from oncology, saying that he asked about MAiD but prognosis is likely longer than 6 months so not eligible." 4P5

> "I think there still is very much misinformation that is out there, we've heard of patients saying they didn't call us ahead of time because they were told that the service cost $10,000, or that it takes a full year to go through" 5P6

These are examples of instances from urban areas, which leaves one to wonder what information (if any) is being disseminated in rural communities from which the team has not had any inquiries. One of these examples originated from an oncology (cancer) unit which mixed up the eligibility requirements of MAiD with those of palliative care. While a common mistake, it is alarming when it comes to oncology, since they comes into contact with many potentially eligible patients, considering cancer patients make up the vast majority of MAiD provisions in Canada.

While the team attempts to contact and correct all known sources of misinformation they come across, this is can be the tip of the ice-berg with much deeper lack of knowledge in individual communities. At the same time, many healthcare providers are simply uncomfortable bringing up MAiD as an option. This occurs because providers are not trained in end-of-life care options, do not want to be misconstrued as suggesting a patient pursue MAiD (due to uncertainty about legal responsibilities), or they have a conscientious objection. All MAiD team members I interviewed believed that MAiD should be a part of regular end-of-life conversations between patients and healthcare providers.

> "MAID should be incorporated into all end-of-life conversations…letting somebody know assisted dying is available is not the same as recommending that they do it" 4P11

This was (and still is) a real concern among healthcare providers as 'counseling a person to commit suicide' remains illegal under the *Criminal Code*. Further, guidelines released by governing medical and nursing colleges proscribe providers from bringing up MAiD as an option without explicit indication from the patient about wanting to die ("Medical Assistance in Dying: Guidelines for Manitoba Nurses", 2018). Incorporating MAiD into all end of life conversation would allow patients to weigh all their options and make a truly informed decision in light of *all* available information. However, not all barriers to accessibility relate back to the lack of information but often can be connected wrong or inaccurate information that is being disseminated (as seen in a few examples above). These instances of misinformation can stem from an honest misunderstanding of MAiD requirements and processes, and are discussed in the next section.

> “Not to mention barriers to accessibility by providers not understanding what’s available and how it works, and the public not understating.” 4P16

Understanding MAiD

Information dissemination about MAiD may begin from a legitimate and accurate source however, can often be mis-interpreted, mis- remembered, or confused with other end-of-life options (like palliative care). Healthcare providers who do not fully understand or misinterpret information will in turn communicate this to their patients causing a snowball effect of misinformed Canadians. Often, the patients themselves misunderstand information they read or confuse it with other materials provided to them.

Even for those healthcare providers who have all the appropriate information on MAiD eligibility and its process, there can be confusion surrounding the referral process. MAiD services do not require a referral from a physician as is the case for many specialized healthcare services in Canada (e.g. dermatology, psychiatry etc.) including palliative care and end-of-life services. This causes confusion between patients and healthcare providers, since providers often assume that patients will self-refer to MAiD at their own discretion, while patients assume that physicians will provide a referral when/if they qualify. This assumption that doctors will provide the referral stems back to a societal belief that the physician acts as the gateway for any and all healthcare services. Recall in the first chapter, the Ontario court of appeal officially recognized "physicians as "gatekeepers" in the public health care system" (para. 43) using this as a justification for upholding the 'effective referral' requirement for MAiD (*CMDSC v. CPSO*, 2019). However, the effective referral requirement is not present in Manitoba and physicians are merely required to provide access to an accurate resource (such as a pamphlet).

> "Certainly in generations past, the doctor was like on this pedestal. Everything was filtered through the doctor because 'they know everything'. So some older adults wouldn't think to phone anyone *but* their doctor." 1P11

> "doctors are assuming that patients are going to call themselves, but patients assume that a doctor is going to send a referral because that's what doctors do." 5P9

Commonly, these misinterpretations of the MAiD process lead to delayed access to MAiD or in some instances, prevent patients from having MAiD as an option altogether. This is because of a variety of misunderstandings about eligibility, or the length of the time applications take, which prevents patients from contacting the team sooner in order to initiate the process early.

> "We do end up meeting some patients that say well I didn't think I qualified because I don't have pain, because the pain medicines work pretty well, my pain's controlled. It's the fact that I can't get out of bed and someone has to wipe my bum for me, and I have no life anymore because I can't do anything. So the public doesn't understand that *that is* suffering, and that you don't need to have physical suffering and similarly a lot of

> healthcare providers, and the public, think that it's just for terminal cancer. They think it doesn't apply to heart failure or COPD and things like that." 4P8

This example, provided by the medical director of the team, highlighted public interpretations of legal criteria which are not exactly false, but more conservative than the interpretation taken on by many MAiD providers at the time. If patients simply reached out to the team themselves, they could be properly assessed for eligibility and may even have been approved. These interpretations of eligibility criteria have evolved over time, beginning with a more conservative and literal interpretation (especially of the RFND criterion) of eligibility and slowly transitioning to a more liberal interpretation with practice.

However, most recently, a lot of the confusion has stemmed from the misunderstanding of the 10-day reflection period, including when it starts and who qualifies for a waiver.

> "there's a lot of confusion about the 10-day waiting period." 14P7

> "I'd say the majority of the unknown is surrounding the 10-day waiting period, and how that starts and where that starts and where that fits in with the two physician assessments." 18P2

Some patients/families who know about MAiD as an option for them, often do not realize that there is an intricate process behind a MAiD request which takes time, including this waiting period. As a result of this misunderstanding, many patients call at the last minute, frequently in urgency or during a medical crisis, believing they can have it on the same day and become frustrated when told about all the steps they have to undergo. Fortunately, Bill C-7 combats this by removing the waiting period for patients who meet the RFND criterion.

> "I think one of the big things is that a lot of people, patients and people who just work at

> the hospital don’t understand is that it doesn’t happen right away. You can’t just call us and say that you want it, it’s a process and for the time being.. It’s something that there’s that 10 day waiting period after the consent is signed, like people don’t understand its not.. quick. I think often people wait until the last minute and then it becomes stressful and difficult and sometimes can’t happen, for a variety of reasons.” 17P1
>
> “we explain this written request puts into motion this 10-days. They, yeah some people kind of go [shock] ‘what! no, no, can we fast track that’. That’s still something, they just don’t quite understand.” 18P2

Although the team does their best to prioritize inquiries and requests in order to accommodate more urgent/last-minute applications, this cannot always be done in a timeline that works for the patient. This was especially common during the first year post-legalization as reported by CBC (“Number”, 2017) when patients were waiting until their final weeks of life to contact the team and frequently died (or lost capacity) before the provision or before the team could conduct any assessments. Selby et al. (2020) reported MAiD statistics from Ontario during a two month period in 2019, showing that this still occurs today. In their report, 12 patients lost capacity prior to date of provision, six others were determined not to have capacity during assessments, and one person died before the provision. Statistics provided by the Manitoba MAiD team also show this to be common in 2019, where 14 patients died before their provision date and another 77 died before or during the assessment process. These numbers do not account for the additional 57 patients who were assessed, approved, and did not book their provision, eventually dying naturally. Many of these instances could have been simply avoided if the team was contacted for clarification and the process was initiated early.

This delayed connection with the team sometimes prompts patients to draw their own interpretations about eligibility criteria which at times do not concur with those of MAiD providers at the time, leading to rejected applications and frustrated patients. The medical director of the team describes these rejections as the most difficult part of the job:

> “The hardest part of the work right now is the declines, is telling people they don’t meet criteria… like yes the fact you don’t meet criteria doesn’t mean that you’re not suffering… you’re not declining them *as a person*, you’re declining their request for MAID because their current condition doesn’t meet the criteria. We usually try to leave the door open a little bit and say *currently* your condition doesn’t meet criteria but if things change you can call us back and we’ll reassess.” 4P8

Misconceptions about MAiD eligibility/process, therefore, occur due to various reasons including misinterpretation of information, miscommunication, or even just confusion with other end of life information provided. Oftentimes, these misunderstandings go unnoticed by families/patients, as they are guided through the process by the team, but became apparent during my interviews with family members. Despite the fact that most (if not all) family members insisted that the process was clear, simple, and well explained, they made multiple inaccurate statements about the process or its eligibility. One participant, whose husband’s provision was a year prior, believed that her husband became eligible only when he was accepted into palliative care.

> “that’s what I thought, once you were in palliative care it was an option…You definitely had to be terminal and just under comfort care” 10P4

This is a common misconception, if you recall in the previous section was also held by an oncology physician, where eligibility for palliative care and that of MAiD are assumed to be the same. Another misconception seen in this statement, is that the patient has to be terminal, which is not true for a many suffering patients that qualify, despite having years left to live.

In multiple interviews, family members indicated confusion behind the reason that waiting periods were waived. One family member in particular, believed it was due to his mother's imploring requests for MAiD.

> "I realize there's supposed to be a 2 week waiting period but for some reason they were able to waive it for her…I guess she just was able to make a very impassionate plea for it." 12P2-3

This participant later admitted that his mother's health was deteriorating quickly and there may have been concerns about capacity, not realizing these were the reasons for allowing a shortened waiting period. Similarly, another family member did not understand why the process was rushed, despite acknowledging that his father would likely not make it through the waiting period, as he began VSED. This participant was also concerned about why palliative care was not offered as an option, yet admitted that the patient was not in any pain (negating the need for comfort care).

> "I said 'is there palliative care available'. Does this have to go this way, can we.. can he be brought to *that place* in a natural way and so that he doesn't feel that he's suffering, even though he wasn't in pain per-say. But that didn't go anywhere. They said that they were going to investigate palliative, but I'm not sure that they did, so that's a big question mark for me. And I kind of feel like it was sudden, especially for my siblings who went from zero to.. watching my dad die, in five days." 9P5

At the end of the day, the MAiD team is there to fulfill the wishes of the patient, not the families.

This was difficult for some family members to understand and led to these instances of confusion or frustration because the patient wanted an accelerated process, despite the wishes or expectations of the family. However, this confusion was not exclusive to family members as some described instances of confusion among the patients themselves. One family member described his mother's lack of understanding when it came to certain aspects of the process, specifically, the waiting periods and delays. In this particular case, the team referred the patient to a geriatric psychiatrist to undergo a round of anti-depressants due to concern about underlying mental health issues, prior to approval for MAiD.

> "She didn't totally understand *why* she was all of a sudden dealing with a psychiatrist, because he was delaying her request within MAiD, all she saw him as was a nuisance." 11P2
>
> "All of those waiting period, were frustrating to my mom because she couldn't understand why." 11P3

Some of these misunderstandings can be associated with memory attrition over time. At the same time it is understandable to that misunderstandings among family occur, given the death of a loved one can be a highly emotional time. If these misconceptions are present among family members who supported their loved ones through the process, often assisting with completing the various procedural requirements along the way, then it is safe to assume there exists an even higher prevalence of fallacy among the public. At the same time, it is not out of the ordinary for families or patients to misunderstand medical information provided to them, especially considering the exact interpretation of MAiD legislation is still being debated today.

Research on Canadians' health literacy has pointed out that while Canadians have a higher understanding when compared to Americans, 60% of Canadians still do not have the skills necessary for adequate management of healthcare needs ("Health Literacy", 2008). Canadians of lower socioeconomic status often have lower levels of health literacy and have been found to be generally in poorer health. The family members who participated in this research were not members of these low socio-economic groups, yet they still experienced confusion about the MAiD system that they took part in. These findings call for better education and knowledge dissemination about MAiD services, not only for the public but for all practicing and future healthcare providers. Although other provinces are ahead of Manitoba in terms of educating their healthcare professionals, many still lack public education initiatives or standardized professional development.

Education on MAiD

> "They've gotten many pieces of MAID right in the province. Including funding the team, and there's no cost involved, they fund us for traveling to remote areas. But they haven't done anything with public awareness. And that's a gap" 4P5

The lack of education on MAiD in the public sphere was touched on by family members who commented on the need for more awareness. Multiple family members discussed a lack of knowledge among their own family/friend circles about MAiD, wishing it was better known overall. When asked if there was any advice family members would give others considering using MAiD, many suggested speaking to the team to learn more about MAiD.

> "I think the MAID process could be made to be a little more well-known maybe by the public. I don't know how many people really know." 11P5

> "It should be [shouted] from the rooftops, it should be advertised. I don't know what to say, more people need to know about it." 7P4

> “Go and sit down with the team and find out how it goes, what it’s about, what your options are, educate yourself about it, about the MAID program. I wish everybody could be educated so they could tell others about it.” 7P10

> “it's important now that I've gone through this that there be opportunities for people to have conversations about it and that there be some public awareness done about it” 12P7

This narrative was much more common in interviews with the MAiD team. Multiple team members discussed the lack of knowledge as well as formal educational initiatives on MAiD in the province for both the public and professional entities.

> “we hear all the time that patients didn’t even know this existed in Canada. That health care providers didn't even know that this was allowed. So I think there needs to be a lot more education both for patients, the public and health care providers.” 14P3

MAiD providers described public and professional education as crucial in combatting misinformation on MAiD which is often passed down by healthcare providers in the community to their patients. The team created a streamlined website to improve access to information with both public and professionals resources including: guidelines, forms, frequently asked questions, and contact information. The team also collaborated with nursing colleges on releasing guidelines for nurses in dealing with MAiD (“Standard of Practice Medicine", 2019). The team gives educational sessions and workshops whenever they are asked and time permits (mostly to medical/nursing programs, residencies, nursing homes, etc.). At the same time, it is becoming increasingly difficult to keep up with both educational initiatives as well as rising inquiries and requests.

> "I give educational sessions whenever I'm asked, so I certainly have presented to the med school, I presented to several residency programs, but it's not a standard part of curriculum anywhere, where it should be." 4P16

> "I do talks. I think I've done about 50 in the two and a bit years I've been there" 1P2

> "we are doing talks with nursing programs and physician programs and going to care homes and hospitals and doing education days, we're trying to get education out there as much as we can, to make sure the appropriate information is out there." 5P6

> "we go and do talks as much as we're asked to do talks but I think the government has dropped the ball on that sort of providing education." 14P3

The medical director of the team discussed some plans early on to develop a teaching module for the medical school, but the development of a centralized single entry service negated this need (at the time). Since then, the team became too busy responding to inquiries and requests, to take on new educational initiatives. This may be something that can be partially adopted from other provinces and then adapted to include Manitoba-specific regulations. However, the province has not mandated any professional development for healthcare providers across the province, including those who work in adjacent areas such as palliative care. Although many of these healthcare facilities with units from these adjacent fields (palliative care, oncology, etc.) have since provided workshops and educational materials on MAiD for their employees.

> "I say to my palliative care colleagues all the time, what would you guys be doing if there wasn't a team, because 80% of the patients, are your patients, you would have to figure out how to provide MAID." 4P15

This lack of standardized training on MAiD is similar to other end-of-life services such as palliative care which the Canadian Medical Association (CMA) recognized “varies greatly” (p. 41) across the country in terms of undergraduate training (Canadian Medical Association, 2015). The medical director of the team pointed out that other provinces are further ahead in terms of educating their healthcare professionals on MAiD.

> “Other provinces are way ahead of us in that, in putting it into the curriculum, so that every nurse and every med student is getting educated about MAID as part of their standard curriculum.” 4P16

This may be due to the different landscape of MAiD services across Canada, as most provinces do not have a centralized team overseeing all requests but instead provide patients with a list of willing assessors/providers of MAiD in their area to coordinate the process themselves. This is not a new concern, Koshnood et al. (2018) researched the experiences of MAiD physicians in Canada highlighting the fact that there is no standardized education or training on MAiD and there is a need to better integrate this into medical curricula.

Standardized education is also missing from nursing student communities who receive mixed messages throughout their schooling about their roles and responsibilities when it comes to MAiD. McMechan, Bruce, and Beuthin (2019) explored experiences of Canadian nursing students with MAiD in the course of their education finding that nursing students commonly held misconceptions about their role in the MAiD process. Many students were left with the impression that they were not allowed to discuss MAiD with patients and if the subject was brought up improperly, they could face legal ramifications such as losing their license. This stems from the lack of clarity in legislation as the *Criminal Code* still prohibits counselling a person to suicide.

The lack of clarity surrounding what constitutes counselling someone to suicide as opposed to bringing up MAiD as an option for patients was discussed by the medical director of the team as hindering end-of-life conversations, especially among nurses. Many nurses have opted not to mention MAiD at all until a patient led them in that direction.

> “It is still a crime in Canada to counsel somebody to end their life. So that was interpreted, taken to say ‘well you can’t talk about MAID unless they brought it up because otherwise you could be accused of counseling them to end their life’. That has shifted over the last year with a pretty clear understanding that letting somebody know assisted dying is available is not the same as recommending that they do it, and so you are legally protected to inform patients of their options. But that’s a recent shift in thinking, particularly amongst the nursing community. That really had hindered I think, a lot of conversations with patients. We still hear, that ‘well you know they keep saying that they want to die, but they didn’t mention MAID so I couldn’t talk to them about it’.”
> 4P11

Although governing bodies have since clarified that discussing MAiD as an option is not the same as counselling someone to suicide, some nurses remain vigilant as there has been no formal protection instituted into legislation. The Canadian Association of MAiD Assessors and Providers (CAMAP) was one of these bodies that issued a guide for healthcare professionals to assist them in bringing up MAiD with their patients. This guide also discussed the obligations of conscientious objectors when it comes to conversations about MAiD, recommending that national guidelines be implemented to ensure due-care (“Bringing up”, 2020).

At the same time, some healthcare providers are uncomfortable bringing up MAiD or engaging in any end-of-life discussions with patients. This hesitation to discuss MAiD may be due to employment with an abstaining facility, being unsure of responsibilities, being worried about coming off as suggestive, or due to their own conscientious objections.

> “some people are uncomfortable just bringing it up to people if they don't already bring it up because they don't want to be seen as suggesting that you know maybe they should have an assisted death or something. But there's a big difference between suggesting something and making sure someone is aware of all their treatment options.” 14P4

The team’s perspective regarding end-of-life conversations is that they should encompass all options available to patients, which includes MAiD. All team members that I interviewed believed that MAiD should be conceptualized as a natural extension of any end-of-life conversations. This is the approach that the team takes when engaging with patients requesting MAiD by ensuring the patient is aware of *all* other options available to them, considering their circumstances.

> “at MAID we provide the patients with all of the options. So we don’t say ‘MAID, pick MAID, MAID is best’. We give them all five options, or four options, or three options, or whatever they are. I don’t think other disciplines do that as well as we do it.” 18P8

> “If you are talking palliative care, you are talking about MAID, because how can you make an informed decision about your end-of-life options without talking about both of us, right.” 5P6

This was something that surprised me during interviews with the MAiD team, since exploring medical options available to patients seems like common practice in the medical community and is integral to informed consent in medical decision making. Therefore, when discussing end of life options with critically ill patients, MAiD should never be excluded from the list of options for any reason. Whether due to personal objections or lack of knowledge/understanding, healthcare providers hold a certain responsibility to their patients which does not include withholding information about healthcare services. However, education of professionals on MAiD currently remains the sole responsibility of individual healthcare providers (or the facilities employing them), who may choose the depth and breadth of knowledge they provide on MAiD. Without regulation from provincial health authorities, or governing medical associations, healthcare providers are left to determine for themselves how to handle patient inquiries and requests. Other provinces (such as Ontario) have some generalized requirements, compelling physicians to provide 'effective referrals' to those requesting MAiD (discussed in chapter 1). However, Manitoba did not implement similar guidelines and when compounded with the lack of formalized education on MAiD, leaves a myriad of potential ways healthcare providers can choose to handle requests/inquiries for MAiD.

This is particularly troubling for people living in rural communities, who rely on local healthcare providers to be a one-stop-shop for all medical concerns.

> "I don't really know how to permeate that more, aside from continuing education and the onus needs to be on the physicians and nurse practitioners who are living rurally to make sure they are *aware* of all of the options that are available to their patients." 5P7

The rural to urban divide is well documented in Canadian literature, displaying healthcare disparities between these two residency groups (Ramsey and Beesley, 2007; Ryan and Racher, 2004). Although there is much debate surrounding the exact definition of rural (geographical, cultural, etc.), Canadian research shows that rural populations generally have poorer health outcomes on various fronts including mortality, suicide, accidents, infectious diseases, and being overweight (Pampalon et al., 2006; Pong et al., 2009). Access to healthcare services is among these concerns, as one quarter to one third of rural residents reportedly face access inequalities due to difficulties retaining healthcare providers and the limited capacity of healthcare institutions (hospitals, clinics, etc.) (Pampalon et al., 2006). While this may be less of a concern in Manitoba, as the MAiD team travels province-wide, accessibility becomes obstructed prior to this, at the referral/inquiry stage.

Since there is no regulation for professional development, it remains unknown how informed healthcare providers in these rural areas are on MAiD requirements as well as how they are treating inquiries/requests from their patients, especially in historically religious/conservative communities. Some members of the team discussed how the lack of information among healthcare professionals in the community (rural and urban) may be due to the implementation of a centralized system. Without a centralized system, there would be more onus placed on physicians and nurses in the community to educate themselves on the requirements behind MAiD, as they would often have to take part in the process or provide a referral to someone who will. However, due to the centralized single-entry system in Manitoba, healthcare providers can simply choose to remain uninformed about MAiD, funneling inquiries directly to the team or assuming patients will do so themselves.

> "What other provinces have done, I worry in Manitoba, that we in some ways have shot ourselves in our own foot by developing the team and making it too easy for other physicians to stick their head in the sand about it." 4P15

This is not sustainable in the long term due to annual increases in requests and inquiries for a small MAiD despite considerable expansions since legalization in 2016. This may require further cooperation with community physicians in the future, as the team is already asking (willing) providers to conduct one or both assessments, especially in rural areas.

> “if we were getting *tons* of referrals, our system might collapse.” 1P4

> “I worry that our model is going to hit the wall at some point in time, and then accessibility will be greatly diminished for patients, because we’re not gonna have enough people to manage all the requests and see people in a timely fashion. We occasionally now ask a family doctor to do one of the two assessments, if it’s an urgent case and we know we’re not gonna be able to.” 4P15

Healthcare providers would have to not only familiarize themselves with MAiD eligibility and the process but also on how to interpret these eligibility criteria and take part in the process. The team’s expertise would then be left for more complicated or specialized cases as well as educational initiatives/training. One of the physicians on the team reflected on the learning process behind interpreting the legislative criteria stating that just as interpretations slowly evolved across the country, she felt this progression in her own sense of comfort with assessments.

> “I think as time goes on this is something that, the criteria seems a bit more clear, just from experience, and the longer you do it.” 17P3

This was specifically associated with understanding of the reasonably foreseeable natural death (RFND) criterion that is now comfortably interpreted and applied by the physicians on the team, and would have to be learned anew by physicians in the community. However, the RFND requirement was struck down by the Quebec Superior Court in the case of *Gladu and Truchon* and the new legislation (under Bill C-7) is currently being debated at the House of Commons (scheduled to receive royal assent in early 2021). The new legislation (assuming no further modifications) provides the possibility of MAiD for patients whose death is not reasonably foreseeable however, the waiting period for these patients is extended to 90 days. For those patients who do meet the RFND requirement (majority of applicants) will not have to serve the 10-day waiting period at all any longer. How these new eligibility requirements will be interpreted and applied will remain to be seen. However, it is clear that once this new legislation (Bill C-7) receives royal assent, public and professional education on MAiD is going to be even more *essential* in order to avoid confusion and the spread of misinformation about who qualifies and what the process looks like for them (which is dependant on their condition).

Theme 2 – access to the MAiD process

The availability of educational resources on MAiD is a crucial first step to ensuring equitable access to this service, however, participants discussed other concerns that have come up during the process itself such as moral objections of friends/family/healthcare providers, as well as hurdles associated with healthcare institutions that abstain from MAiD. Moral objections of family and friends or social community permeated conversations with both family members and MAiD providers, the most concerning of which was the objections of healthcare institutions.

For family members, experiences with moral objectors were most often encountered from other family or friends who disagreed with MAiD on moral or religious grounds. They discussed these encounters in terms of the stigma and judgement they (or the patient) felt about participating or assisting with MAiD. Encounters (by family members) with objecting physicians were less common and did not seem to pose additional obstacles for access, at least from the perspective of participants I interviewed, who were obviously successful in connecting with the MAiD team.

However, objections from close social circles created some difficulties in finding willing witnesses for the written request and led to lower feeling of support among family members. At times, this put them in the difficult position of deciding whether to tell other family or friends about the utilization of MAiD, or whether to keep this information and process private. This concern extended to the patient in some circumstances, where family members wondered if their loved ones would be judged for this decision, especially by more conservative and religious social circles, often choosing to keep the process a secret in those cases.

On the other hand, narratives by the MAiD team concentrated on other forms of moral objection including those of abstaining healthcare facilities as well as the conscientious objection of healthcare providers. These forms of conscientious objection included initial reluctance from psychiatrists to assist with capacity assessments (to make medical decisions), requesting medical records from objecting healthcare providers or private practices, and telling friends/family about their work with MAiD. At times, these objections, especially those of abstaining facilities complicated (delayed or prevented) the delivery of MAiD services.

The team also discussed the stigma associated with providing or accessing MAiD and the initial hesitation to tell others about their occupation. However, it is unclear if this is a stigma that they perceived as being there or if they had negative experiences when telling others. At the same time, various team-members described seeing a shift among their clients within the past year (2019-2020) with patients and families being less concerned about keeping the process private (or secret). The team stated more and more patients do not cate about who knows they used MAiD, perhaps indicative of a shift in public opinion or acceptance of MAiD. This may be due to any number of reasons such as increased knowledge of MAiD or greater comfort and acceptability of MAiD as an end-of-life option.

The most difficult part of the process to overcome as described by the MAiD team and several family members was associated with abstaining facilities. As discussed in the first chapter, this is a controversial form of moral objection as many scholars and professionals have argued that abstaining facilities cannot claim to have ‘morality’ or a ‘conscience’ outside of its membership (clients/employees/stakeholders). Since the law clearly states that no *individual* has to participate in MAiD if they object to it, abstaining healthcare facilities are simply preventing MAiD from taking place inside of their facilities (as the process is undertaken by external staff). These faith-based facilities shift the burden onto critically ill patients to endure uncomfortable transfers to a different facility for the procedure and at times, for the assessments as well.

MAiD team members stated that these transfers from abstaining facilities were a drain on healthcare resources as a single transfer requires extensive coordination between various facilities and personnel, sometimes delaying or preventing access to MAID altogether. Transfers did not only produce strain in terms of resource allocation but MAiD team members additionally described transfers as morally alarming, horrible, and very onerous for patients (who are often fragile). These transfers can, and have previously, ended terribly for patients, who are at a heightened risk of encountering complications along the way. Transfers have also led to a loss of capacity in some patients once arrive at the receiving facility, rending these patients no longer eligible to provide consent. In some instances, patients were prevented from having the option of MAiD altogether as transfers posed too many risks, or the patient simply could not be accommodated at another facility due to the nature of their condition and treatment.

For these reasons, some patients have actively refused palliative beds at faith-based facilities, opting to wait longer in hopes of a bed coming up at a non-abstaining facility. This concern was similarly discussed by family members, some of whom were worried about their loved ones ending up at an abstaining facility and having to endure an uncomfortable, painful, and exhausting transfer in order to access MAiD. For rural and remote communities with more limited access to healthcare facilities, the choice may be taken away altogether, if the only facility nearby is faith-based. Transfers were difficult not only for family members who witnessed their loved one's unnecessary turmoil but also hard on healthcare staff at these abstaining facilities who had to pack up and send off their patients to die. This is not a great scenario for any parties involved but especially for patients, who ultimately wished to have a dignified and peaceful dying process.

Moral objections

Objections to MAiD, whether on moral or religious grounds, were discussed by all participants in one form or another. Family members largely discussed objections of other family members and friends where in some cases it led to the decision of keeping the use of MAiD private. The MAiD team however largely discussed conscientious objection from other healthcare providers and religious institutions. Some objections were seen as a nuisance while others posed hurdles for patients wanting to access MAiD. This section discusses how the two participant groups experienced these moral objections and what kind of effect it had on them. The second part of this theme specifically highlights experiences with abstaining facilities which proved to be distressing and frustrating for all parties involved.

Family members had diverse encounters with moral objectors, some of which had no impact on the process other than an awkward conversation (such as that with an objecting physician), while other objections caused a bit of a hurdle when looking for two witnesses (a legal requirement). Family members discussed facing the additional burden of deciding whether they should tell friends, family, and others about the utilization of MAiD or keep this fact private, some chose not to tell their family and friends. Of course, in many instances, the patient was also involved in this decision but sometimes, the family members were left alone with the decision after the death of the patient. Those who ultimately chose to keep the process private or seriously struggled with this decision, often mentioned fearing stigma and judgement associated with choosing/supporting MAiD, especially among more conservative and religious circles.

This fear of adverse judgement is not unfounded since opposition among religious and conservative groups is well-documented in literature and clearly still contentious for most religious communities (e.g. faith-based hospitals). Conservative disapproval of MAiD is especially apparent in legislative debates concerning Bill C-14 where Conservative party members heavily criticized the formulation of this bill by the Liberal party (*Hansard*, 2016). Conservative members of parliament even presented a dissenting report with their own recommendations in contrast to the ones provided by 'The Special Joint Committee on Physician-Assisted Dying' (discussed in the first chapter). Unsurprisingly, the vast majority of the conservative party voted against the MAiD bill (81-14) in the third reading (House of Commons, 2016). Research on attitudes toward MAiD/euthanasia among professionals and the public has also shown that strong religious beliefs/affiliations determine a person's support of- or willingness to- participate in MAiD, more so than other factors. This does not mean that all religious people object to MAiD, but of those who do object, religious affiliations were the most common reason cited (Bator, Philpott, & Costa, 2017; Elie et al., 2017; Warner et al., 2001; Wilson et al., 2013).

Interestingly, the most recent survey of public opinion on MAiD in Canada pointed to a vast majority support of this practice. Ipsos Reid, a company hired by Dying with Dignity, conducted a public opinion survey on MAiD, finding that 84% of Canadians surveyed believed a physician should be able to provide MAiD for terminally ill and suffering patients (Ipsos Reid, 2014). While a similar survey from Alberta, which is known to be a long time conservative province, found 72.6% of respondents supported MAiD for terminally dying patients (Wilson et al., 2013).

These may be even higher today, as gradual increase in support for MAiD among the Canadian public has been additionally noted by Crumley et al. (2019) who analyzed Canadian newspapers' coverage of MAiD topics from 1972-2016. Despite this seemingly majority approval, fear of judgement and even personal uncertainty about MAiD were present in conversations with participants.

A few family members had explicitly discussed their religious upbringing, beliefs, or being involved in a religious community. At the same time, all family members interviewed were supportive of their loved one's choice to use MAiD. A few family members mentioned having mixed feelings or hesitations initially and at times still holding reservations about it but at the end of the day, they still assisted and supported the patient through the process. One family member who had mixed feelings about MAiD due to her religious upbringing discussed worrying about what the utilization of MAiD could mean for her sister's (the patient) spirituality after death.

> "That was really rough for me, one thing I couldn't help myself from doing was asking her over and over again 'are you sure'… The other part that bothered me was that religious part…is she going to go to heaven, because she's actually, you know, taking her life." 7P1-2

Another participant whose family was heavily involved in a religious community discussed the reservations of family who held opposing views to MAiD. These initial reservations were attributed to the hastened process and lack of previous awareness about MAiD, as the waiting period was waived in this case, which led to that relative being unable to attend the provision. This family member later experienced a shift in thinking, presumably as there was time to reflect on and process this decision.

> "she called this a medically assisted suicide and I wrote back '*it is* not'. She was quite upset, she's very conservative in her religious views…She's in a much different place now than she was then." 9P7

This quote also displays the aversion of some participants at the use of 'suicide' when referring to MAiD, even if it was simply a misunderstanding. The term 'suicide', clearly still holds negative connotations and was said to misrepresent the purpose MAiD, which is to respect patient autonomy and end suffering. Some participants were even offended when someone used the word 'suicide', believing that the term did not capture the nature of the process correctly and made sure to correct the source.

> "I just didn't want them to say 'oh my god assisted suicide?' There's still that word. The funeral home used it. I said she died with the assistance of the MAiD program, [they said] 'what is that assisted suicide?', I said no that's not a term they're using anymore." 7P7

This was not an opinion exclusive to family members but also held by some members of the MAiD team. The medical director stated that currently (not considering upcoming amendments), the work does not feel like assisting in 'suicide' but truly assisting suffering patients in dying peacefully. She elaborated that in her experience, these patients are not suicidal, they often wish that circumstances were different so that they were healthy and able to live fully. However, in embracing their conditions, MAiD allowed them to regain some control and pursue a dignified and peaceful death since they were already on that trajectory.

> "certainly now, it does not feel like suicide. Most patients that we talk to, we ask everybody 'is there anything that would change your mind', and the vast majority say, well they say 'no', and then they say 'short of a miracle and a cure' and many go on to

> say ‘I don’t want to die but I’m dying regardless of what anybody does and given that I’m gonna die I want some control over how and when that happens, but I would much rather *not* be talking to you, and I much rather be healthy and live’. To me that’s not suicide, those people aren’t suicidal.” 4P12

The use of the term ‘suicide’ caused hesitations among family members when discussing MAiD with others in their social circles due to the negative underlying assumptions and connotations this word carries. One participant, a family member who came from a religious background and family, described some concerns in telling others about the use of MAiD, due to their involvement and standing in this community.

> “my dad was one of the patriarchs of the Mennonite community, certainly in the city, province, but even across the country. I mean he was very very highly looked up to and for *him* to choose something like this was ‘woahh’ quite shattering… that was one of the issues for my two siblings like, well for all of us, like ‘*what* are they going to say’.” 9P3

This was a recurring thought for many participants, some of whom were not religious themselves, yet still worried about telling friends, family, and neighbours about using MAiD and whether they would react negatively. Some participants described not being able to speak about their MAiD experiences openly due to the perceived stigma. While others were concerned about their loved one being judged for this choice and therefore chose to keep the decisions/process a secret.

> “I had to really debate with myself whether or not to tell people, that she used the MAID program…are they gonna judge her, and I didn’t want her to be judged.” 7P7

> “I think people are worried about what other people will think of the decision…So we were very careful in any discussions about her passing…and that’s really *sad* because it’s an opportunity for us, as a family, to be a proponent for it” 12P7

As this last quote displays, some family members who chose not to tell others about the utilization of MAiD saw this as a missed opportunity to open a discussion and advocate or raise awareness for MAiD. In one instance, the family chose to conceal the use of MAiD even from the hospital staff (other than the attending physician). Although the hospital was not an abstaining institution, the family feared possible delays or judgement from staff.

Additionally, this choice to keep the MAiD process or request private, at times (especially early on), increased difficulty in fulfilling witness requirements on the written request form. One of the team’s physicians stated that often families had a hard time finding witnesses for the patient since they did not want others in their social circles to know about the use of MAiD.

> “So asking for those witnesses, initially, was a lot harder, because people didn’t want to tell friends what they were doing, or a neighbour what they were doing. It’s still difficult, I think though, for getting those two witnesses.” 18P3

In other instances, moral objections among friends were unexpected and caused a bit of a delay in finding willing witnesses for their written request forms. One participant described being turned away from an objecting friend when asked to be a witness. Although the family member respected this friend’s decision, it came as a surprise but minimally delayed the application without significantly affecting the process. The same MAiD physician as above further elaborated that the reluctance of others to act as witnesses was due to a misunderstanding of the witness’ role. People assumed that in order to be a witness, they had to agree with MAiD however, their role was simply there for legal reasons, to confirm the identity and voluntary request of the patient.

> "I think sometimes, patients think that the witnesses have to *agree* with them having MAID, whereas the witnesses are just basically witnessing that you are who you say you are and you understand these questions on this form." 18P3

However, most family members I spoke with did not have trouble finding witnesses due to the availability of witness volunteers from Dying with Dignity (DwD). The use of DwD volunteers became popular (and necessary) shortly after legalization due to these exact difficulties patients and families were experiencing in finding witnesses. Additionally, considering the restrictions on who could be a witness as no family, beneficiaries, or direct healthcare providers were allowed. At the same time, all of my participants lived in (or near) urban areas, where DwD volunteers were available which would not necessarily be the case for patients living rurally. Fortunately, the new Bill C-7 addresses this issue, by reducing the witness requirements to just one and allowing this witness to be a healthcare provider (who does not stand to benefit from the patient's death).

The perception of stigma, or concern about judgement was similarly noted by Kelsey Antifaeff (2019), in her case study examining the role of social work in MAiD practice. Antifaeff suggested that integrating social workers into MAiD services could help manage the perceived stigma regarding the choice of MAiD and possibly even increase feelings of solidarity within families. However, social workers are already part of- and integral to- the Manitoba MAiD team and as such, involved in all steps of the process. Unfortunately, there is currently no published research on MAiD stigma in Canada.

Fear of stigmatization among family members was very much present in narratives and repeated in interviews, despite public opinion surveys suggesting majority support for MAiD among Canadians. Yet, not all family members were concerned about whether they would be stigmatized for supporting or pursuing MAiD and were thus surprised when encountering objecting physicians in their search for information/referrals. Despite this, family members who encountered objecting healthcare providers qualified that they did not cause delays or any other kind of obstruction to accessing or pursuing MAiD. The objecting physicians simply stated that they will not be participating in the process and provided contact information for the MAiD team with whom they also coordinated medical records. This was only experienced by a couple of family members I interviewed and is not necessarily representative of all experiences with objecting physicians, and how those physicians may be dealing with these inquiries.

The MAiD team was highly sensitive to concerns of judgement among patients and families however, they described a shift in thinking among their clients in recent months. Whereas early on patients were more often deciding to keep the process private, more recently, there seems to be a growing population of patients/families who do not care that others know. The team attributed this shift in thinking to more awareness and public receptiveness, since MAiD services have already been offered for a number of years.

> “Now MAID is way more acceptable and talked about then it was… even a year ago when I first started with MAID. There was a lot more, not gonna say secrecy, but it was very very private. We just finished talking to a gentleman …and he’s like ‘I don’t care who knows’. We’re starting to see a bit more of that mentality where it doesn’t have to be secretive. You know, people, it’s not that they advertise or broadcast it, but it’s now seen more acceptable by I guess, the greater whole of people than it use to be.” 18P3

> "it's not as big of a deal anymore, whereas you know in the beginning patients were wanting to keep it very private and now they don't care who knows and everybody knows." 14P2
>
> "very little stigma, there's very little negative reaction, from the majority of the public, not all of it." 4P4

Team members also observed this trend in their personal lives after joining the MAiD team, where initially they were inclined to keep the details private and only tell a few close family/friends but over time becoming more open about it.

> "I was hesitant to tell my family, I was hesitant to tell my coworkers, I was hesitant to tell friends kind of what I was doing, 'cause you just didn't know how people were going to react…it's been far less controversial that we thought it would be. But there was a lot of secrecy at the beginning, which made it harder in some ways." 4P2

Although the public seems to be more accepting of MAiD today, or at least that is the way the team perceives it, this has not always been the case. The medical director of the team described some difficulties in establishing the practice early on, due to objections among other healthcare providers especially when reaching out to psychiatrists. The specialization of psychiatrists was required in order to help with capacity and mental health assessments for certain cases. Federal legislation requires this consultation, where the capacity to consent or voluntariness (due to underlying mental health issues) is a concern. Initially, the medical director stated that all the psychiatrists refused to help with these assessments because they were for the purpose of MAiD, despite clarification that psychiatrists would not be actively conducting assessments (or approving) patients for MAiD.

> "I said well it's not for MAiD, I'm not asking you to approve them for MAiD, I'm just asking you to decide if they have capacity to make decisions and they said 'well you can't separate it out from the decision that's being made'." 4P14

The psychiatric association responded by clarifying how capacity assessments are conducted, since they are *task* and *time* dependant. Therefore, the task (consent to MAiD) cannot be separated from the capacity assessment, as psychiatrists would be directly evaluating whether patients have the capacity to consent to MAiD, but not necessarily having the capacity for other tasks, at a given point in time.

> "as psychiatrists they consider capacity task and time specific. So you can have capacity for one task but not another and you can have capacity at one time but not another. As long as you have capacity for the specific task at hand, at the specific time at hand, that suffices. Even if you don't have capacity for other tasks, or you don't have capacity for even that task at another time." 4P13

In the end, consultations with psychiatry were *required* by legislation which led to a small group of psychiatrists agreeing to participate on a casual basis, when necessary. Thankfully, this issue was resolved early on, at least for urban residents with privileged access to healthcare resources as compared to rural/remote residents.

Recently, the team encountered a new barrier under the umbrella of conscientious objection. The medical director of the team discussed how the team ran into difficulties retrieving medical records in order to assess requesting patients. In a couple of instances, private practices refused to provide these records altogether, citing personal objections as the reason.

> "we still have issues getting medical records. You know, if there's some physicians who don't support MAID, they can refuse to supply medical records. If they're in a private

> practice. If they work within a regional health authority, then they are obligated to provide records, and that still comes up every once in a while." 4P5

The team is still unsure of the legality surrounding this refusal but these instances have been too few and far between to warrant legal action. Thankfully, in these instances, other medical records proved sufficient to determine patient eligibility for MAiD.

> "I don't know if it's legal, and I don't know what the process is to obtain them if people refuse. We've only had one person that I've been involved with that has refused records and in the end it turns out that we didn't really need that physician's records to sort of make a decision, and it was based on that physicians discomfort of MAID" 5P2

However, it remains unknown what impact this type of objection would have on MAiD accessibility in the future as thus far, there have only been isolated cases for which workarounds existed. If these instances rose in number, this could cause further delays in process and warrant legal action. Communication between the various sectors of the healthcare system including private practices and abstaining facilities will be instrumental in ensuring proper and timely access to MAiD going forward. Research on systems operations and responses to policy changes shows that communication between various sectors as well as meaningful feedback mechanisms are essential for the successful implementation of system changes. Further, the systems approach holds that change requires time, as people need to live through and experience change, rather than be told about it (Organization for Economic Co-operation and Development, 2017).

In some respects, the addition of MAiD services into the healthcare system paved the way for strengthened communication between various medical sectors including palliative care, cancer care, hospice, etc. These relationships will likely continue to improve and adapt while new connections with other sectors (psychiatry, pediatric oncology/hospice etc.) will be made, due to expanding eligibility.

Of even greater concern when considering the anticipated influx of eligible patients (due to growing numbers and opening up of RFND), is the increase in requests coming from patients in abstaining facilities as well. This is the most common form of conscientious objection discussed by participants as it not only affected every single MAiD provider but was also a concern among family members. For this reason, the next section is dedicated to participant narratives and experiences with abstaining institutions. As seen in chapter one, this form of conscientious objection is highly controversial as some scholars are unsure whether facilities can even claim to have a conscience outside of their members, which was also argued by many participants during interviews.

Abstaining facilities

There are various forms of abstaining facilities across Canada including hospitals, nursing homes, and other long-term care centres. These facilities make up about half of all nursing homes in Winnipeg and one of the two largest hospitals in the province (among other smaller community hospitals). In Manitoba, the list of abstaining facilities is limited to healthcare facilities that previously identified as faith-based, and have maintained this position prior to the enactment of MAiD legislation (Winnipeg Regional Health Authority, 2017). However, this is not consistent across Canada, as some provinces allow any healthcare facility wishing to abstain from MAiD to do so by publishing a policy with this position, with some others not required to make this position known at all, leaving patients uninformed and confused (Fraser, 2017).

As discussed in the first chapter, the ability of faith-based facilities to abstain from a legal practice such as MAiD has been criticized by scholars and professionals, given these institutions accept public funding and serve a diverse Canadian population (Fraser, 2017; Gilbert, 2017). Further, they do not abstain from providing MAiD per-se but from allowing it to take place on their premises, since no law or policy compels objecting healthcare providers to participate in MAiD. This means that employees of abstaining facilities (or any other facility for that matter) would never be required to participate in the process, especially in Manitoba, where the MAiD team oversees all provisions and requests. Interestingly, St. Boniface hospital's (SBH) board first voted to allow MAiD on their premises in extreme circumstances, where transfers were not possible. However, following this decision the Catholic corporation that owns SBH appointed ten new board members who overturned this decision causing the resignation of the director of the board at the time, as he did not support the new policy ("Catholic Health Corp.", 2017; Swan, 2017).

Further, results from a staff survey at SBH presented by Marcus Blouw, president of the hospital at the time, showed that only 8% of employees agree with the prohibition of MAiD in the facility ("Catholic Health Corp.", 2017). This was also highlighted by multiple MAiD team members, all of whom had direct experiences with abstaining institutions and saw first-hand the negative impact of patient transfers on staff at these facilities. This is in addition to the emotional and physical burdens placed on patients, their families, and the team. Some members of the team did not understand why these healthcare centres could even choose to abstain despite having staff that is supportive of MAiD. One member in particular brought up the ethical conundrum of whether buildings can claim a conscientious objection.

> "I don't understand how brick and mortar building can abstain from a medical treatment." 1P19

This is an argument often cited by critics of abstaining facilities and furthered by legal commentary on the subject, as seen in chapter one. There are only two arguments advanced by proponents of abstaining policies, which is the healthcare facility's historically consistent position with regard to MAiD as well as the legal agreements these institutions enter into – which detail the services they are to provide. Neither of these arguments, however, considers the impact they have on patient/family/staff and do not encompass any ethical or moral arguments that defends their position. Abstaining policies were further criticized by the team as being disconnected from the population they impact, since those implementing policies are never on the front lines to see the consequences for patients and families, or respond to the aftermath.

> "they're never on the front lines to see what the impact of these policies are on the patients." 1P19

> "if you just *listened* and you just *understood*, maybe you would change your mind and allow this [MAiD] to happen." 18P6

Admittedly, there are some workarounds for some patients in abstaining facilities, who are not too frail, by way of transfers to non-abstaining facilities. These are mostly used for the final procedure but in some instances for the assessments as well (depending on the institutional policy). MAiD providers largely did not agree with transfers, as they did not believe transfers were in the best interest of the patients or that they should be occurring at all.

> "So it's easy to… look away from the cruelty of transfers and say 'well, they do it, like we do work around it, and we have other places we can admit to', like that's true but at the end of the day, we should not be doing it." 1P18

> “When people are *dying*, it’s cruel to make them get in that stretcher service, on our crappy bumpy roads.” 1P18

Several of the team members were quite distressed over transfer requirements as they coordinated and witnessed their impact(s). This is a personal struggle that was repeated in other Canadian literature exploring MAiD provider experiences. Rosanne Beuthin, a MAiD coordinator in Canada, described feelings of helplessness when unable to assist patients who had to transfer to another site for the provision or when informing patients there was no willing physician available in their area (Beuthin, 2018, p. 1687). The MAiD team did not discuss feelings of helplessness per-se but these were evident in their descriptions of transfers as horrible and cruel. In particular, one of the nurses stated it was the first time she felt moral distress due to her job. Transfers are not only difficult for everyone involved but they additionally delay access or even prevent access for patients altogether.

> “That is the first time in this work that I've actually ever felt you know.. moral distress or whatever you call it because I 100% do not agree with it and I think it's awful for patients” 14P5
>
> “having to spend the last hours of your life being schlepped across the city is very disturbing to me.” 14P5
>
> “abstaining facilities either prevent it or delay it, or don’t provide info.” 17P2

MAiD providers described numerous instances in which abstaining facilities hindered access or complicated it for patients. These instances were also heavily covered by the media during the first few years post-legalization (Adach, 2017; Blackwell, 2016; Caruk and Hoyle, 2017; Castillo, 2018; Russell, 2018; Russell, 2018; Prudy, 2018). The obstructions began with delays in letting patients know MAiD is an option for them, providing proper resources/referrals for MAiD, all the way to the implementation of prohibitive policies that require transfers to non-abstaining facilities for the provision and in certain cases, even for the assessment(s). One physician on the team discussed how some patients would not know to ask about MAiD if they are unaware of its legality, and would certainly hesitate to ask staff at a faith-based facility.

> "I also think there's some abstaining facilities that, again, like the patients up north, the patients are unaware and they would never bring up that conversation that 'did you know, that you could have help to die'. So, I think those patients are missing out on what's available to them." 18P7

The transfer requirement alone compounds the possibility of delays as it restricts timeframes due to the extensive coordination required between facilities, staff (transport, MAiD team, employees at sending and receiving institutions), and patients. Transport staff (whether ambulance or stretcher service) can also have busy schedules and at times have shown up to pick up patients late, delaying the entire process. Transfers can (and do) strain numerous areas of the healthcare system including staff at both sending and receiving institutions, the MAiD team, ambulance/stretcher services, among other resources at these institutions. As a result, the team saw transfers as a drain of valuable healthcare resources and time that could be better deployed elsewhere.

> "It takes a lot of coordinating and it delays, often the timing of it because it takes time to coordinate transfer." 4P6
>
> "It's a big dedication of time to coordinate that… It's a huge use of resources, when these people could be caring for people that are sick." 18P7

The team mentioned that policies require a nurse from the sending (abstaining) institution to accompany the patient to the receiving institution. Again, removing a valuable resource (worker) from the sending institution, who could be instead caring for others. Moreover, transfers can be tough for the staff at sending institutions who often care for these critically ill patients for prolonged periods of time and build connections with patients during their continuous care. This is especially upsetting considering staff at these facilities for the most part do not personally subscribe to these policies.

> "I know it's very hard on the staff at these facilities because I've talked to them about it and a lot of them don't feel right about it either, having to send people out." 14P6

> "It's a huge burden on patients and families. And on the staff, that work at both facilities. Many staff that work at abstaining facilities are supportive of MAiD, and it's hard for them to pack up their patient and send them off." 4P6

This was experienced first-hand by one of the family members I interviewed, whose father had to be transferred from an abstaining facility for the provision. This family member indicated that the staff at the abstaining institution were upset and bothered about the transfer, despite trying not to convey this on the day of the provision. One of the nurses who had been caring for his father up to that point chose to come in on her day off and ride along during the transfer to see her patient off.

> "the front-line people there, were so angry…Anyway, one of the rules is a nurse from the sending institution has to ride along. She came in on her day off and volunteered to do it. Which was really, really beautiful on their part, they were fantastic." 9P7

This nurse ride-along is required by policy in order to deal with any complications that may arise during the transfer, which is not uncommon for a critically ill population. These complications were discussed in detail by the MAiD team, who described them as onerous and burdensome for patients, who are critically ill and often already dying. Yet, they are faced with the added possibility of numerous potential complications arising during the transfer that could ultimately prevent them from accessing the dignified and peaceful death they had originally sought after.

> "We've had transfers go terribly wrong." 14P5

> "placing upon them an additional burden with having to transfer in an ambulance or a stretcher service across the city, and potentially risk any number of things happening to them along the way, increased discomfort, aspiration, like name it." 5P2

MAiD providers offered a few examples of instances where complications came up during transfers that led to a loss of capacity, leaving the patient unable to provide final consent for MAiD. Thankfully, Bill C-7 addresses this with the availability of entering an 'advanced agreement' with a MAiD provider who could proceed with the provision as scheduled based on prior consent. Occasionally, these patients will regain capacity later on and reschedule the procedure, however, sometimes they never regain capacity and in the end, cannot access MAiD. There have also been instances of patients dying shortly after arriving at the receiving facility and while that was the original intention, it was obviously not the dignified and pain-free death the patient or their family hoped for.

> "There have been occasions where the patient arrives at the other end confused and not being to consent." 1P18

> "I mean we just had a patient that… didn't handle the transfer well, and died before we could come to provide MAID." 4P16

In some instances, patients simply cannot be transferred and are prevented from accessing MAiD altogether because the risk of complications is too great without a safe or reliable way to keep the patient secure during the transfer. Furthermore, certain patients cannot be accommodated at any other healthcare facility due to the nature of their illness and reliance on specialized treatment/care. In Winnipeg, specialized healthcare services concentrate at specific locations and facilities due to healthcare consolidation. For example, St. Boniface Hospital specializes in palliative care, gastrointestinal disease, and cardiac sciences, among others (St. Boniface Hospital, 2018). Patients requiring intensive care falling under these specializations, can only be accommodated at this location and depending on the type/intensity of care required, may not be able to transfer elsewhere.

> "So when they are so acutely unwell that they are requiring treatments that can only be done at the St. Boniface hospital, we can't transfer them, it's unsafe." 5P2

> "we don't want to have to risk somebody who is really wanting a dignified death potentially dying or becoming unconscious in transfer, that's not safe or appropriate and it's unfortunately putting patients in this difficult and unnecessary position." 5P3

> "In some occasions, it means that MAiD is not an option for patients cause there's some patients that just aren't transferable." 4P6

> "we've had a few who could not have MAiD because they were too unwell to transfer so their choice was taken away from them because of an abstaining building." 14P5

One physician on the team even discussed instances where the transfer is so unsafe they have to talk patients out of going through with it, due to high chances of complications arising.

> “I think we actually have tried to talk people out of being transferred because we know that the transfer won’t go well, we know it’s not in their best interest, we know they’re at risk of losing capacity and not having it at the other end. I’ve been part of that conversation where we’ve had to just say ‘you know what, we’ve exhausted every option on how we could transfer you, and get you there pain free and still alert and still breathing and there’s no way we can do it’, and so we just can’t provide MAID.” 18P7

While transfers were a concern discussed by *all* members of the MAiD team, only one out of the eleven family members I interviewed actually experienced a transfer from an abstaining facility for his father’s provision. However, this possibility was still brought up by other family members due to concerns over potential transfers or anticipations of one. The sole family member whose father experienced a transfer was also an active member of a religious community, as was his family, and pointed out the irony in having to be transferred out of this facility.

> “Even though we were Mennonite, we got kicked out by a Mennonite hospital [chuckles], to die somewhere else.” 9P2

While this family member made light of the situation during the interview, this was not how he (or the rest of his family) initially felt about the transfer. This participant described the transfer as upsetting and felt that some dignity was lost in the process. The patient, in this case, was transferred in the middle of winter, after a few days of VSED (voluntary stopping of eating and drinking), and was therefore at elevated risk of losing capacity and dying.

> “We were upset, it was cold, you know, he’s starving and stuff. All the way to the hospital, bouncing around in the back of a truck basically. So yeah, that was not fun. Some dignity got lost, I think.” 9P4

Transfers can strongly affect family members, especially those who elect to ride alongside the patient, as they have to witness the suffering of their loved one and at times, even vicariously feeling the pain through them. A social worker on the team, who normally meets with the family prior to and following the provision, discussed how much transfers affect family members emotionally:

> “We had one person who… the person accompanying them, a family member, ended up in tears because like *every* single bump their loved one was feeling it.” 1P18

Due to the heightened risk of complications arising during transfer, one family member usually elects to ride along with the patient. This was discussed by another family member, whose sister (patient) voluntarily chose to be transferred by stretcher service to another facility, as she did not want to receive MAiD at home. The threat of transfer related complications did not escape the family and for this reason, the patient’s son joined the ride.

> “I know that some people have died on the way, but that just means they were that close to dying. So we put [son] with [patient] in the stretcher service because that entered my mind, just in case she died. I didn’t want him to feel like he wasn’t with her, when she passed away.” 7P10

For some patients and families, the possibility of undergoing a transfer is so distressing that they try and avoid abstaining facilities at all costs. MAiD providers specified that patients will reject palliative beds at abstaining facilities and endure further suffering or discomfort because they know they would ultimately need to be transferred.

> “We have palliative patients who refuse to go to St. Boniface if they have to be admitted, they’ll refuse a bed there because they know they’ll have to move.” 14P5
>
> “we have met people who…need to be admitted somewhere, who will stay at home, in pain or struggling to manage, to avoid going to St. B… because they know if they go there, they can’t have MAiD.” 1P18

However, this is not a possibility in many circumstances, particularly for patients who require specialized care, exceeding that which their families can provide or assist with. This was discussed by another family member, since the family was no longer able to provide proper care for the patient due to the progression of illness, leading them to request a palliative-care bed. This family member stated that the circumstances would not allow them to turn down any location that was offered first, but they were afraid it would come at an abstaining facility.

> “We knew we had to take the first palliative bed that came up but we were terrified it would come at St. Boniface and just complicate matters.” 15P1

In this case, the MAiD team assisted with arranging accommodations at a non-abstaining facility. However, this cannot be done for every patient and at the end of the day should not pose an added burden for patients at the end stages of their life. In particular, many patients/families are not aware of restrictions present in abstaining facilities (especially for those admitted during an emergency), it can be frustrating and upsetting to learn that they would have to endure a transfer to fulfill their wishes. One of the family members I interviewed expressed concerns about her mother (the patient) having to endure a transfer in a frail condition after being informed of abstaining policies. This patient ended up dying naturally, without accessing MAiD.

> “I think the only issues that, knowing that the transfer to another facility could take a lot out of her. You know, when she doesn’t have two months, when she’s so fatigued” 13P4

It is important to keep in mind that patients do not get a choice as to which healthcare facility they go to. This depends on a variety of factors including where their needs can be best accommodated, the nature of the illness, or at times it just comes down to which facility has space. This is further complicated by the provincial government’s restructuring (or consolidation) of healthcare services, where specialized services were rearranged to concentrate at specific locations (elaborated in chapter one).

> “people don’t choose where they go, with restructuring” 4P16

Therefore, patients do not always have the luxury of waiting for an opening at a different facility, especially if they require services only offered at an abstaining facility. Access becomes even more restricted in rural areas, where there is very few healthcare facilities available and if they happen to be abstaining, then the choices for patients in those communities are grim. This further highlights the rural/urban healthcare divide discussed in previous themes. Unfortunately, transfers from abstaining institutions are becoming more common given the increasing numbers of requests for MAiD and the fact that one of two palliative care units in the city are housed in an abstaining facility.

> “they’re certainly more common when you have abstaining facilitates that are three of your major health institutions in the city.” 5P2

Interestingly, published Canadian research on the subject, including articles that specifically enumerated quantitative data on MAiD in their province, do not detail the figures behind transfers or even discuss them at all (McMechan et al., 2019; Robertson et al., 2017; Rosso et al., 2017; Wiebe et al., 2018). This is unfortunate as this can be a central part of the MAiD process, influencing timelines, experiences, and ultimately can sway the decision whether to pursue MAiD in the end. The lack of published academic research on transfers from abstaining facilities also makes it difficult to draw comparisons between experiences enumerated here and those in other provinces. The MAiD team provided data showing that out of 484 provisions performed since 2016 (up to May 31, 2020), 59 required transfers from abstaining facilities. This makes up 12% of all MAiD provisions during this period and does not account for those who were prevented from accessing MAiD due to any transfer complications such as loss of capacity or just the inability to transfer.

There is one positive aspect that the team highlights regarding this issue which is Manitoba's restrictions on which institutions can abstain in the province. Whereas other provinces allow any healthcare institution to become abstaining (faith-based or not), Manitoba has limited these facilities to a finite list of healthcare institutions that have previously identified as faith-based.

> "the other piece they got *right* is around abstaining facilities. In Manitoba, there's a list of faith-based facilities, that identify as faith-based, including hospitals and nursing homes, and the government of Manitoba has restricting abstaining from MAiD to that fairly short list of facilities. Whereas other provinces allow any facility to abstain even if they're not faith-based, for instance in BC most of the hospices won't allow MAiD, even though they're not faith-based." 4P6

At the end of the day, despite the workarounds (transfers) and limitations on facilities, abstaining institutions delay or prevent access to a medically legal service. The conscientious objection of faith-based institutions (whether we agree that they hold this right or not) wastes valuable resources in the healthcare system, places institutional mandates above patient autonomy, poses grave risks for patients, and is emotionally distressing for all parties involved (including the team, staff at receiving/abstaining institutions, families, and patients).

These policies act as remnants of the past, prior to the *Charter* and even the Bill of Rights, when religion was central to these institutions and other aspects of public life (government, education, etc.). Since then, Canada has welcomed a multitude of religions and cultures contributing to the pluralistic nation we have today. The courts have (over the years) eliminated religious hold on public institutions such as schools. This pushed religion into the private sphere, yet, religious healthcare institutions have maintained their identity and refuse to evolve alongside societal and legal developments which their religious owners deem immoral (Muniz-Fraticelli & David, 2015; Muniz- Fraticelli). Although there has been some discussion in the media of a possible court challenge alongside criticism over the rights of faith-based healthcare facilities, these have yet to come to fruition (Fraser, 2017; Gilbert, 2017; Paetkau, 2018).

Discussion

First, I would like to recognize the interpretative methodological underpinnings of this research, meaning that participants derive meanings from their experiences within a certain context. As phenomenology does broadly, I recognize that this research is influenced by contextual factors such as location, time period, political climate, and cultural norms. These factors comprise the system and institutions under which participants discuss their experiences as well as how I, as a researcher, interpret and analyze their experiences. Therefore, it should be noted that this research occurs in a western democratic country four years after the initial legalization of MAiD – despite some of the participants reflecting on experiences from a few years back. For further context, public opinion surveys have shown Canadians to be supportive of MAiD as an option for eligible patients, even years prior to the legalization of MAiD. At the same time, Canada is still adjusting MAiD laws as various issues are brought before the courts prompting governments to revise policies and legislation (Ipsos Reid, 2014; Wilson et al., 2013).

Although similarities exist between the various legislative schemes across Canada's provinces and territories, Manitoba has a unique take on the delivery of this service (similar to that of Alberta or Saskatchewan). In Manitoba, all MAiD requests are overseen by a centralized multi-disciplinary team of professionals consisting of physicians, nurses (client care coordinators), and social workers (psychosocial specialists), as well as other specialized professionals who assist on a casual (as needed) basis (such as a speech pathologist, psychiatrists, etc.). Therefore, this research only captures experiences within this specified time, place, and political/social context.

Additionally, it is worth mentioning that MAiD team members had diverse experiences delivering MAiD province-wide which also spanned over a long period of time, for some since the first days of legalization. However, family members had more limited and singular experiences, although a few were present for multiple provisions. Family members as well as the MAiD team were largely from Winnipeg with some family members coming from surrounding rural municipalities (up to 40 minutes out of the city), which may not reflect the experiences of those in more remote communities.

This is important to mention as the urban vs. rural healthcare divide is well known in Canadian and international literature, with rural communities having less access to specialized and general health services (Giesbrecht et al., 2016; Soles et al., 2017; Wilson et al., 2020). Access to MAiD is no exception. Although the team travels province-wide for provisions and it may seem as though rural dwellers are not affected, the added travel time restricts timelines for patients and limits their accessibility to MAiD. It remains a mystery as to what kind of information is permeating these communities, as some have not inquired about or submitted any requests for MAiD. This is even more of a concern among the traditionally conservative/religious communities where it is unclear how much or how accurate the information healthcare providers have on MAiD is, as well as how forthcoming they are with these resources. This comes on top of already constricted timelines due to the added travel as well as coordination with rural healthcare providers/facilities. For these reasons, family members participating in this research may not necessarily represent the experiences of those in remote Manitoba. Although it seems that there are not many of those experiences to share.

Overall, family members who participated in this research were highly satisfied with the service and care their loved ones received from the MAiD team as *every single* participant praised the team on their compassion, professionalism, and attention to detail. Initially, I attributed this to a skewed sample (due to the self-identifying recruitment strategy) however, the MAiD team stated that they consistently receive similar feedback from patients and families. These similarities are important to point out especially when they cross participant groups, as they indicate a common experience for MAiD participants in Manitoba and provide further context for the themes identified earlier.

Holmes et al. (2018) found comparable experiences of a peaceful death among family members interviewed after their loved one's provisions who reported the advantage of MAiD as compared to natural death. This vocabulary was also used by *all* family members I spoke with, a few of whom happened to be retired nurses, and commonly used the terms 'beautiful death', 'peaceful', ‘amazing’, ‘remarkable’, ‘sacred’, and ‘gentle’. Of course, family members were not entirely satisfied with every aspect of the process, though the negative experiences were mostly attributed to procedural/legal requirements (such as waiting periods, transfers, etc.) as opposed to team conduct.

Similarly, MAiD team members described their work as rewarding, feeling that they were truly helping patients fulfill their wishes despite some concerns about the implications of expanding legislation. Notably, the medical director of the team who was involved in structuring the Manitoba MAiD system from the beginning, stated that this role allowed for “some of the most gratifying and fulfilling work I’ve done in my 30 years of medicine” (4P2). This was likewise found across multiple Canadian studies inquiring into the experiences of MAiD providers, finding that participants described the work as very rewarding despite any logistical challenges they faced along the way (Khoshnood et al., 2018; Shaw et al., 2018; Voorhees et al., 2013).

Voorhees and others (2013) examined the experiences of physicians working in jurisdictions with legalized MAiD (Netherlands & Oregon) as compared to jurisdictions where MAiD was illegal (USA). They found that while all physicians were asked about MAiD by patients, those from countries where MAiD was legal, were better equipped to navigate end-of-life conversations, and described these conversations as rewarding yet emotionally taxing, with some reporting an enriched doctor-patient relationship. In contrast, where MAiD was illegal, physicians’ personal beliefs dictated the content and extent of other end-of-life conversations, often keeping these vague and dealing with requests in isolation.

While MAiD has been legal in Canada for a few years now, the lack of standardized education on MAiD in Manitoba has prolonged similar trends as those observed (by Voorhees and others) in places where MAiD is illegal. Narratives from the MAiD team as well as some family members show that healthcare providers in the community need better legal guidance and regulation when it comes to their responsibilities in approaching end-of-life discussions. This would ensure that the information they provide is not only accurate but also standardized, so that patients can make informed decisions on all the facts, as opposed to the options their physician chose to tell them about.

Moreover, Bruce and Beuthin (2019) specifically studied how experiences of nurses have transformed since the implementation of MAiD in Canada assessing narratives pre- and post-legalization. They found that pre-legalization nurses (who worked with dying patients) described feeling taken for granted, however, following legalization of MAiD, they used a transformed vocabulary replacing words of suffering with positive experiences of a 'beautiful death' alongside some residual discomfort. One family member I interviewed, who was a retired nurse, having worked with many palliative patients, attested to that when reflecting on her brother's MAiD process, she stated:

> "one of the things that was always important to me when I was working is that someone would have… what nurses call a good death, peaceful death, gentle death, no struggling and.. that's what he had." (6P3)

This sentiment was repeated in all the interviews including those with MAiD providers who experienced numerous provisions and saw first-hand the relief it brought to many patients, sometimes even just knowing that MAiD is an option. The team, however, seemed to be the highlight for most family members despite some complaints about procedural requirements (such as paperwork, waiting period, witnesses). Even participants who were more in the moral middle ground, unsure of whether they personally agree with MAiD for themselves or what it means for their belief systems, supported others in pursuing it nonetheless, and all agreed that the process was done impeccably well, even advocating for more widespread awareness.

Having said that, the main goal of this research was not only to explore positive experiences with MAiD but to additionally shed light on aspects of the process that posed barriers for accessing MAiD in the province. As is apparent from the themes in the previous two sections, I discovered some of these barriers, which I believe largely stem from a lack of proper information dissemination, not only about the availability of MAiD but also regarding the regulations and restrictions surrounding procedural and eligibility requirements. Without standardized information dissemination, certain communities and populations are left with unequal access to MAiD (alongside many other public services) due to being unaware of this option or misunderstanding legislation. This lack of education on MAiD either prevents or delays access to MAiD for affected populations, and thereby access to equality and justice.

Information

Information dissemination about legislative changes is often done through public awareness/education campaigns (seen via advertisements) as well as professional development or additional training for specialized sectors. For example, when the Trudeau government legalized the recreational use of cannabis, it was followed by extensive education campaigns which ensured Canadians were aware of the new laws, including: where cannabis can be purchased, who can purchase it, where it can be used among other restrictions and guidelines. In Manitoba, posters and commercials about the restrictions and dangers associated with Cannabis could be seen in various public and private spaces prior to and following legalization (Liquor, Gaming and Cannabis, 2018). However, this was not done following the legalization of MAiD as neither the federal nor provincial governments initiated any public awareness campaigns to ensure that citizens were informed of this major legislative change and new end-of-life option.

It is unclear why certain legislative changes (such as cannabis legalization or distracted driving restrictions) warrant public awareness campaigns while others do not. It may be largely at the discretion of elected governments to choose which issues are most important to allocate funding for depending on how many citizens it will affect and whether it posed any risks to the public. Although arguably, a new end-of-life option is relevant to all citizens (at some point). However, MAiD largely applies to senior citizens and critically ill populations, assuming they meet criteria. Therefore, there may be the assumption that healthcare authorities will disseminate relevant materials to their professional bodies who would in turn be able to point patients in the right direction. However, the lack of regulation when it comes to information dissemination and professional development on MAiD in Manitoba has led to some confusion and misinformation among professionals and the public alike, leaving the team to pick up the pieces from education-sessions to correcting misinformed sources. This is a significant theme identified in interviews as it ultimately hinders ill and suffering patients who may be interested in pursuing MAiD but are unaware of it or do not have access to the appropriate information/resources.

Obviously, all participants in my research were aware of MAiD being legal at the time I interviewed them, and most of the family members even knew about MAiD prior to coming in contact with the team/process, due to its coverage in the news. At the same time, some of these family members first found out that MAiD was legal through a friend, family member, or often times from a physician during the late stages of an illness or final weeks/days of life. This was a real concern immediately post-legalization as patients were contacting the team too late and would die or lose capacity to consent before being able to complete the process (“Number of”, 2017). Although the team indicated that this has improved over the years, the client care coordinators (nurses who triage all the patients and answer inquiries) stated they still encounter many people who had no idea MAiD was legal in Canada or misinterpreted the legislative requirements in some way. This lack of knowledge among the public was also evident to the team due to the influx of inquiries every time MAiD appeared in the news/media. There has been no published research measuring public awareness of MAiD (or other end-of-life services) in Canada which makes it difficult to gauge how widespread this lack of awareness is or how much of an obstacle this poses for access, especially in rural or remote communities.

Rural populations, although largely under-researched, have shown poorer health outcomes across Canada on various fronts including mortality, suicide, accidents, infectious diseases, and obesity (Lavergne and Kephart, 2012; Pampalon et al., 2006; Pong et al., 2009; Ramsey and Beesley, 2007; Ryan and Racher, 2004). Access to healthcare services is among these concerns, as rural residents face unequal access to services due to difficulties retaining healthcare providers and small capacity of healthcare institutions (Pampalon et al., 2006). However, some point out that there is great cultural diversity and demographic heterogeneity among Canada's rural communities having variable incomes, education, and employment rates which leads to equally variable health outcomes (Lavergne and Kephart, 2012). Some members of the MAiD team reinforced this, pointing out the lack of requests from certain rural areas yet an abundance from others.

Wilson and others (2006) stated that research on rural end-of-life care is uncommon and while it is clear that it is not as extensive as in urban areas, it is important to recognize the unique challenges and differences in these communities, such as a greater desire to die at home. Barnabe and Kirk (2002) conducted an educational needs assessment on physicians in rural Manitoba finding a lack of training and physician confidence in some aspects of end-of-life care such as bereavement. These researchers (among many others) recommended better and continuing education for rural physicians on end-of-life care. Considering this, education on MAiD is arguably of even greater importance today, as the already lacking knowledge on end of life options, have now undergone drastic changes and continue to be challenged in court. Health Canada released a report on palliative care in 2018, putting forth these same recommendation put forth decades prior by Barnabe and Kirk, including enhancing education/training, research, and "measures to facilitate equitable access to palliative care across Canada" (p. 3). Additionally, recognizing inequalities present among 'underserviced populations' from rural and remote communities (Health Canada, 2018).

If the government is still recommending improved education for palliative services, which have been around considerably longer than MAiD, it is grim to consider how long before MAiD is finally comfortably integrated as a standard option in the spectrum of end-of-life care in rural as well as urban areas. In early 2019, the government of Canada conducted a public opinion survey on MAiD eligibility requirements, to gauge public receptiveness for certain legislative expansions. This survey was distributed online (with a mail-in option) and had the highest response rate of any government public opinion survey ever. However, the survey asked very narrow questions that were related to the revisions that are now a part of Bill C-7 such as: waiting periods, capacity assessments, and advanced requests for MAiD. Most of the participants in my research stated they filled out this survey and were not impressed with the confusing language and limited space for comments, Manitoba represented 3.5% of these responses (or 10,563 respondents) ("What we heard", 2020).

Further indications of the lack of MAiD awareness among the public was corroborated by multiple family members during interviews and seen in some recent Canadian studies on MAiD. Wiebe, Shaw, Wright, and Kelly (2019) researched perceptions of MAiD and compared these to perceptions of suicide by interviewing 52 Canadians, 13 of whom were directly involved with MAiD, while 39 were "members of marginalized populations" (p.1) in Vancouver and Calgary. They found that "with few exceptions, most of these marginalized people did not know about MAiD or about other end-of-life choices such as palliative care and hospice" (p. 4). Although participants were living in large urban areas, yet still unaware of MAiD. Shaw and others (2019) had similar observations in their research on MAiD perceptions "among illicit substance users and people living in poverty", finding a severe "lack of awareness about end-of-life care supports" leading to barriers in "accessing treatment and palliative care" (Shaw et al., 2019, p. 9). I similarly observed this lack of awareness among family member experiences and narratives as did the MAiD team who discussed various encounters with people who were shocked to find out it is legal or found out too late. Again, we are left to wonder about those who never found out, misunderstood the regulations, or were maybe even discouraged from inquiring. Nonetheless, it is clear that this experience is not uncommon or unique to Manitoba but is mirrored in other parts of Canada as well.

This absence of adequate public education on MAiD has led to instances of patients contacting the MAiD team too late and dying or losing capacity before being assessed or during the waiting period. MAiD providers largely attributed this to a few reasons, including patients being informed of this option too late or misunderstanding requirements and waiting until their final weeks/days of life to contact the team. Both of these reasons were cited in the experiences of family members I interviewed as well. Shortened waiting periods were granted to a few of the cases discussed by family members, due to the process being initiated too late or being informed of the option when their loved one was in their final days of life. MAiD providers discussed how last minute inquiries still occur and cause extra stress on the team, sometimes taking the option of MAiD away from the patient altogether, since the team cannot respond to all requests on short notice. Likewise, this caused some emotional distress for family members who felt rushed and had little time to process the idea of MAiD before it was already in motion and over. These instances were additionally observed in other published Canadian research on MAiD displaying a national trends of approximately 30% of all applicants requiring shortened waiting periods.

Selby, and others (2019) found in their analysis of MAiD cases in Ontario that initially 39% of their cases had to have shortened reflection periods, which has climbed over time and now amounts to approximately 50% of eligible patients. Rosso, Huyer, & Walker's (2017) case analysis showed this proportion to be closer to 20% (also in Ontario) while Robertson and others (2017) found that the reflection period had to be shortened in 25% of cases on Vancouver Island. This is similar to statistics provided by the MAiD team in Manitoba, showing that 49 out of 177 MAiD provisions conducted in 2019 had to be acted on within the waiting period, amounting to about 28% of all cases.

Although I did not explicitly inquire with family members whether there was a shortened waiting period, three participants indicated having shortened waiting periods for their relatives. Notably, the new legislative expansions under Bill C-7 eliminate this waiting period for patients whose deaths are reasonably foreseeable (meet the RFND requirement), which research findings would suggest is a step in the right direction. At the same time, the new changes require an even lengthier waiting period (90 days) for applications who do *not* meet RFND (yet are still eligible under other criteria).

Besides patients impeded by the waiting period, it is unclear how many patients fell through the cracks in other ways by dying before being assessed or while waiting for the provision. Numbers provided by the MAiD team show that there have been 465 applicants with completed requests who died unassisted, the most common reasons being: dying (or losing capacity) before or immediately after assessments, dying (or losing capacity) prior to the provision, deferring the provision and subsequently dying, or never scheduling a provision.

The team noted that some patients simply appreciate the option of MAiD, often not necessarily planning on utilizing it, having the option lifts a burden of never ending pain allowing them to feel in control and live out their final days naturally. Pihlström (2015) argues that the need to control one's circumstances especially at the end-of-life, is a western norm (that death challenges), as we are ultimately helpless to it. Pihlström's suggestion is to find a balance between control and surrender and I believe the effect of being approved for MAiD serves the need for control, allowing patients to maximize the time they have left knowing they do not have to suffer indeterminately.

Even among family members with pre-existing knowledge of its legality and availability, there often exist misconceptions or misunderstanding related to the eligibility criteria or other regulations, causing patients to be misdirected or assume they do not qualify and never reach out. The team provided examples of this in their experiences dealing with confused inquirers who held false beliefs due to misunderstanding something they read/heard or being told inaccurate information by their healthcare providers. Some common misconceptions among healthcare providers (across the province) included mixing up MAiD eligibility with that of palliative care, associated costs, long waiting periods, among other examples mentioned by their patients. Hales and others (2019) researched family/caregiver perspectives on the MAiD process in Ontario and found that families reported “a lack of clarity regarding the MAID process [which] led to unnecessary complexity and anxiety” (p. 591) for patients and families.

This displays that a lack of knowledge is not unique or limited to Manitoba, however, I did not find similar anxieties regarding process ‘complexity’ among family members I interviewed. On the contrary, family members stated that the team took care of all concerns and explained everything very well, simplifying the process, clarifying regulations, and leaving no questions unanswered. Participants seemed to appreciate this openness and honesty yet, comments they made during interviews displayed (to me) some common misunderstandings about these very same aspects (eligibility and procedural requirements), including: being able to access MAiD immediately upon contact, or only becoming qualified once palliative.

This may be attributed to memory attrition for participants with older experiences however, the team indicated that misunderstanding like these (and many others) are common and reinforced by other Canadian studies. Finding by Hales et al. (2019) about coordination anxieties among clients perhaps speak more to the structure of MAiD in Ontario than the broader MAiD experience. Ontario requires patients (or their caregivers) to contact a ‘coordination service’ hotline that will direct them to willing assessors and providers of MAiD (often separate entities due to varying moral boundaries) in their area (“Medical assistance”, 2019). The Ontario MAiD system consequently requires more coordination on behalf of the patient or their caregivers including arranging appointments, transfers and so on, which is not the case in Manitoba.

Of greater concern, is the misinformation prevalent among healthcare providers instead of the public, as physicians in the community are often seen as the gatekeepers of all options and specialized healthcare services. Thus, one misinformed physician may potentially misdirect many patients and thereby impede accessibility to a whole community, even if unintentionally.

The ‘effective referral’ requirement, which was implemented in a few provinces (not including Manitoba) was supposed to combat this. Manitoba merely requires that healthcare workers provide an inquiring patient with an accurate resource such as pamphlet or contact information. The ‘effective referral’ requirement on the other hand requires that the objecting physician provide a direct resource and refer to another *willing* provider. Notably, this led to a court challenge by a Christian association in Ontario claiming this infringed rights to conscientious objection of individual physicians. The claim was rejected by the court (initially, and on appeal), explaining that physicians hold great power in society, as the ‘gatekeepers’ for medical services and had a greater responsibility to ensure patients have still have access to services they do not provide. This notion of medical responsibility was repeated by a few members of the MAiD team, who agreed with the effective referral requirements, believing they should be introduced everywhere, also citing the great responsibility that physicians take on with their careers. For this very reason, the court ruled that objecting physicians *had* to provide an effective referral for MAiD in order to ensure accessibility is not fickle or hindered due to individual objection (*Christian Medical and Dental Society of Canada v. College of Physicians and Surgeons of Ontario*, 2018).

The Manitoba college of physicians states that objecting physicians who receive a request for MAiD can refuse to not only provide it but also refuse to “personally offer specific information about it” or even to “refer the patient to another physician who will provide it” ("Standard of Practice Medicine", 2019, p. 99). The fact that there is no effective referral requirement in Manitoba inserts additional concern about whether potentially eligible patients are provided with proper resources as patients may not look beyond the advice of their physicians (which could be wrong or misleading). Additionally, this is a missed opportunity for all healthcare providers to get more comfortable having end-of-life discussions with their patients.

Research has shown that there is often a norm in healthcare, with providers waiting to initiate end-of-life discussions when the patient is critically ill with only days remaining to live. This delay is largely attributed to physician discomfort at having end-of-life conversations or a lack of proper education on how to approach the topic (Mori et al., 2015; Nouvet et al., 2016). However, end-of-life discussions are important not only for patient autonomy, in order to make fully informed decisions (after knowing all the options), but also for their ongoing patient care as it can be determinant of future treatment options and preferences. Physician discomfort or difficulty talking about death and dying have shown across multiple studies to be a strong barrier for end-of-life decisions (Curtis et al., 2000; Nouvet et al., 2016). To avoid the subjection of patients to unwanted treatments or life-sustaining measures, these conversations have to occur regularly and early, with MAiD integrated into all end of life conversations, as a standard option (Nouvet et al., 2016; Zhou and Shelton, 2020).

Selby et al. (2019) attributed the increasing number of patients granted a shortened reflection period, in their analysis of Ontario cases, to a general lack of comfort with end-of-life discussions among healthcare providers. They reported that many patients asked healthcare providers about MAiD but were not referred for weeks or months, often finally being referred upon admission into acute care or doing so independently. This was also a theme among MAiD team members I interviewed. They reported that many healthcare providers were not comfortable having end-of-life discussions, while others do not want to bring up MAiD specifically, since it could be seen as suggestive.

This fear of appearing ‘suggestive’ can be partially attributed to a lack of clarity, as discussed by the team, about the distinction between counselling someone to commit suicide, (which remains an offense under the *Criminal Code*) and informing a patient about MAiD as an end-of-life option. The distinction between informing about and recommending MAiD was a major concern in nursing communities, who were originally directed not to bring up MAiD unless explicitly requested to do so by the patient (Downie, 2018; “Medical Assistance in Dying: Guidelines for Manitoba Nurses”, 2018; “Standard of Practice Medicine”, 2019). This becomes difficult when patients do not know this is an option to ask about, and meanwhile, nurses are worried about the repercussions of bringing up MAiD.

Regardless of the reason, the lack of information and comfort level of healthcare providers in discussing *all* end-of-life options acts as an obstacle for patients to make fully informed end-of-life decisions. MAiD team members I interviewed believed that MAiD should be included in *all* end-of-life conversations as a natural extension in the continuum of care for patients. Wiebe, Green, and Schiff (2018) agree with this notion in their article about MAiD education for medical residents stating that “all family doctors must be prepared to answer questions from patients about MAID and give accurate information regardless of their personal feelings and values” (p. 315). MAiD providers highlighted how this discomfort (specifically with MAiD) may be a weakness of the centralized system in Manitoba, as it allows healthcare providers in the community (mostly general practitioners) to ‘bury their heads in the sand’ and remain uninformed about MAiD, since they do not have to participate or even formally refer patients.

The lack of public and professional education about MAiD is not equal across all Canadian provinces, as many provinces have had more news/media coverage of MAiD (Ontario and B.C.), a history of activism (B.C.), and even general political receptiveness (Quebec) with many provinces far ahead of Manitoba in terms of standardized educational initiatives. Robertson et al. (2017) attributed the high number of MAiD cases on Vancouver Island in the first year post-legalization to this “greater awareness resulting from a history of assisted dying advocates in BC” (p. 305) which is where both the Rodriguez and Carter cases began. Further, other provinces (and governing medical associations/colleges) across Canada have been more advanced in educating their healthcare professionals on MAiD as well as establishing effective referral procedures for objecting healthcare providers. Several Canadian publications have highlighted the lack of standardized education on MAiD for healthcare professionals, recommending that training be included in medical education (Bator, Philpott, & Costa, 2017; Khoshnood, Hopwood, Lokuge, Kurahashi, Tobin, Isenberg, & Husain, 2018; McMechan, Bruce, & Beuthin, 2019; Shaw, Wiebe, Nuhn, Holmes, Kelly, & Just, 2018).

While physicians and nurses are required (as per college regulations) to continuously upgrade their education in the form of professional development workshops or conferences, healthcare providers are free to choose conferences most relevant to their field and seemingly, MAiD training is not compulsory (The College of Physicians and Surgeons of Manitoba, 2020). The medical director of the MAiD team discussed the various educational initiatives the team has taken on which at times, had to take a backseat in order to catch up with requests and provisions. This includes developing a standardized curriculum for the medical school, which time has not permitted.

Shaw et al. (2018) studied the experiences of MAiD providers one year post-legalization in British Columbia and found participants faced emotional and structural challenges due to the responsibility of having to educate others on MAiD protocols and procedures which they were learning and developing themselves. Since then, Shaw et al. state that regional health authorities have offered training sessions across Canada, however, the Manitoba government, regional health authorities, and governing medical colleges have not required or taken proactive steps toward standardized training or professional development on MAiD for healthcare providers or medical/nursing students, beyond releasing policies guidelines.

Many members of the MAiD team have conducted numerous educational sessions/workshops on MAiD to the general public and with specific healthcare communities, two of which I had the privilege of sitting in on. Though they also indicated difficulties keeping up with these initiatives, as requests are doubling year after year making it hard even for the growing team to keep up with. Further, the team tries to follow up with any known sources of misinformation (typically among physicians and specialists) whenever they come across them through patients or medical records. However, the team highlighted that the province has made no advancements in standardized education for professionals or any public education on the matter, which is further exacerbated by healthcare cutbacks occurring across in Manitoba.

Healthcare cutbacks as well as general misalignment of MAiD with Conservative priorities have not allowed for much expansion of the team despite constantly increasing requests. However, even prior to these cutbacks the team was beginning to have a difficult time responding to requests in a timely fashion (including last-minute urgent applicants) and were discussing the possibility of a waitlist. Other provinces experienced similar rises in requests, but many were not having as much trouble keeping up because in those provinces, much of the coordination fell on families and patients instead of on MAiD providers or a dedicated team. Hales et al. (2019), researched MAiD experiences in Ontario, stating that “[f]amily members were distressed by challenges in the scheduling of MAID” (p. 592). They explain that family members were required to coordinate with hospital occupancy and availability of clinicians, often causing delays or rescheduling of the provision.

This was not the case among family members I spoke with as the MAiD team subsumed all coordination responsibilities for patients and families including scheduling appointments, retrieving health information, conducting assessments, and coordinating transfers when required. One participant I interviewed expressed concerns about their loved one ending up at an abstaining facility, which the team followed up by arranging a bed at a non-abstaining facility. Another participant, who was caring for a patient that did not want to die at home, found that the team was able to set up a room at a healthcare facility for the provision on short notice and required no additional action on the caregivers or patient's part. Again, this observation by Hales and others (2019) may be primarily attributed to differences between the Ontario and Manitoba MAiD systems. Whereas in Manitoba, the team will coordinate and arrange for all assessments/provisions, in Ontario (and other provinces) this responsibility falls onto patients/families.

Abstaining facilities

Concerns about ending up in an abstaining institution (nursing homes or palliative wards) are common as patients do not get to decide where they go, often having to take the first available spot/bed. Sometimes patients at abstaining institutions are unaware of these abstaining policies, although they are a matter of public record. At the same time, some patients need the additional care and cannot refuse a bed in order to wait for another in a non-abstaining facility. This had been complicated by the restructuring (or consolidation) of healthcare services by the government of Manitoba, which has both cut back on services and concentrated them at few locations ("Changes to ambulance protocol", 2017; "Editorial", 2018; "More services", 2018; St.

Boniface Hospital, 2017). Of course, it is not possible for the team to arrange special accommodations for every patient who may want MAiD, especially considering that one of only two palliative-care wards in Winnipeg is at an abstaining facility, displaying what a serious hinderance abstaining policies can be on already strained palliative capacity.

Shaw et al. (2018) similarly identified challenges in providing MAiD stemming from coordination with abstaining facilities such as retrieving information and conducting assessments which can lead to rejected applications of eligible patients. These challenges were identified by the MAiD team members I spoke with, many of whom expressed frustration due to difficulties caused by abstaining facilities or more specifically the required transfers to a non-abstaining facility. Most MAiD providers described transfers as frustrating, horrible, and onerous for the patients and families. One provider stated that it is the only time she felt morally distressed in her job. The client care coordinators on the team (nurses) who arrange these transfers, highlighted the extensive resources and coordination required for a transfer from an abstaining facility which is often dependant on many other factors (transport teams, sending and receiving institutions, space allowance, appropriate accommodation) which may cause delays or adverse complications for patients as well as disqualify eligibility.

These experiences are not unique to Manitoba and have been reported across Canada in media and research publications (Beuthin, 2018; Blackwell, 2016; Holmes et al., 2018). Religious board and organizations that own these hospitals often cite their religious freedoms as a defense for these policies, stating that they have always operated in accordance with their beliefs, going back to the origins of hospital-care, which are rooted in Christian hospitality (Muniz-Fraticelli, 2017). Bussey (2018) argues that faith-based healthcare institutions have had the right to conscientious objection historically as part of religious communal practices and forcing them to conform may lead to closures and shortages instead. However, hospitals employ and serve a diverse Canadian public which does not necessarily subscribe to the ‘institutional faith’ and the communal argument. Rhodes and Danziger (2018) argued that patients have “reason to expect medical care that is consistent with medical standards regardless of hospital ownership” (p. 52). They elaborated that hospitals which do not intend to keep this social responsibility should not operate, just as Jehovah’s Witnesses’ could not operate a hospital that refused blood transfusions.

Seemingly, the only reasons that faith-based facilities have to support their assertions over the kind of services they provide is the origins of hospitals (beginning with Christianity) and religious freedoms under the *Charter*. However, it has been pointed out to me by multiple participants in interviews that staff at abstaining facilities often did not support the policies they were bound by, and experienced their own emotional challenges associated with having to transfer the care of their patients. Abstaining facilities were a source of stress for family members as well, who worried about their loved one’s ending up at an abstaining palliative care unit or the burden a transfer would place on them. One family member who experienced a transfer from an abstaining facility stated that some dignity was lost in the process which was mirrored in MAiD provider narratives. The distress associated with abstaining facilities is seemingly felt by all parties who engage in this process, including patients, families, MAiD providers, staff at abstaining facilities, as well as staff at receiving facilities. This raises the question of who these policies actually benefit.

The issue of abstaining facilities has been covered in academic and legal papers extensively from both sides of the debate, however, has not been the subject of much empirical or experiential research in Canada. Additionally, no Canadian research has discussed outcomes and consequences of transfers for MAiD patients, despite some alarming cases of delays and other horrible transfer experiences covered by the media (Blackwell, 2016; Caruk & Hoyle, 2017). Medical research on transfers generally as well as research specifically for critically ill populations, has consistently displayed elevated risks for life-threatening complications and death (Beckmann et al., 2004; Droogh et al., 2015). The MAiD team observed this first-hand through instances of transfers going wrong for the patient and arriving on the other end unable to access MAiD due to loss of capacity or medical complications. In some circumstances, the medical demands of the patient's condition render them untransferable and therefore take away the choice of MAiD altogether due to the abstaining policies. MAiD providers wondered why this has not been the subject of a court challenge but understand that patients or their families are often in no state to start a lengthy legal battle.

The issue of transfers is actually worse in some other Canadian provinces as they allow *any* healthcare facility (faith-based or not) to implement abstaining policies, whereas in some provinces (like Manitoba) only facilities previously identifying as faith-based can abstain from allowing MAiD. Manitoba in particular, only allows a set list of faith-based facilities to abstain and this was identified as a positive undertaking (as compared to other provinces) by MAiD team members. Of course, the team stated that ideally transfers would not occur and abstaining facilities would not force their patients into transfers.

Recently, in a ground-breaking move, B.C. health authorities announced they will be removing funding from a Vancouver hospice given their refusal to allow MAiD despite being on public land (Larsen, 2020; Little, 2020). B.C. has been the only province in Canada to do this however, some organizations have discussed legally challenging the policies of abstaining facilities. Other countries where MAiD is allowed, have moved toward allowing MAiD at faith-based facilities, including psychiatric ones (Rocca, 2017).

It is important to remember that no conscientiously objecting healthcare provider in Canada is required to participate in any aspect of the MAiD process, which includes all staff working at abstaining facilities. Therefore, it is truly the facility that 'abstains' from MAiD, not the people within it, raising the question of how a facility/organization can claim rights that are independent of its members. In saying this, even participants who encountered conscientiously objecting healthcare providers, stated that the objecting providers still fulfilled all of their obligations and never stood in their way or posed barriers in the process. Moral objections were also experienced by family members when searching for witnesses to sign the written requests as friends and others in their social circles declined, equating witnessing duties with moral obligations. This aspect of the process (independent witnesses) was framed as a barrier by some family members however for most, the availability of witness volunteers alleviated this hurdle. Praslickova and others (2020) found in their research of volunteer MAiD witness experiences, that witnesses too felt this requirement was intrusive and posed an unnecessary barrier to MAiD access.

Hales et al. (2019) had different findings among family members they interviewed, reporting that many family members felt "a sense of judgment and/or objection from care providers with respect to their loved ones' decision to pursue MAID" (p. 592). Although, it was unclear whether that impeded the process or just constituted unprofessional conduct. While I did not have similar findings from discussions with family members or MAiD providers, there were concerns among family members about being judged by others, who therefore decided to keep the use of MAiD private or secret. This was largely a concern among family members with religious social circles, who were worried about intolerance. However, another explanation may be related to stigma associated with death generally as well as the norms instilled in societies over years of assisted death criminalization which has the effect of inhibiting discussions leading to patient isolation (Haberman, 2015; King, 2018; Li et al., 2018).

This is the only theme that is common to narratives presented by family members in this research and those from Hales et al., who also described personal struggles with telling others about the use of MAiD. These concerns were felt by the MAiD team too, who were unsure about telling others details regarding their line of work at the beginning. Shaw et al. (2018) found through discussions with MAiD providers that many faced challenges arising out of “disagreement with colleagues who did not support MAiD” (p.e398), and described peer support as essential in working through these challenges. I did not have similar findings with my discussions with MAiD providers, although it was clear that the team dynamic allowed for this peer support and collaboration. Team members felt their input was important in the process, even if it was not legally required for every position, and often referred to discussions they had with other members of the team about the moral and emotional challenges they faced in their work. Additionally, many of the team members described a recent shift in public acceptability of MAiD, which they observed in patients and families who now increasingly do not care who knows about their use of MAiD.

Shaw et al. (2018) explained this by saying that “as MAID becomes more socially acceptable and more readily available, both the number of physicians who are willing to offer MAID and the number of patients who request it will increase” (p. e398). Although the number of requests is indeed increasing and MAiD providers discussed seeing more social acceptability of MAiD, it seems that expanded eligibility requirements may drive away providers who are comfortable with the current MAiD framework. This was seen in interviews with a few providers who expressed moral concerns about the possibility of providing MAiD to minors or patients where psychiatric illness is the sole underlying condition. Some members of the MAiD team were highly supportive of all expansions for eligibility (for minors, those with psychiatric illnesses as sole underlying conditions, and those whose deaths were not reasonably foreseeable) while others struggled with them morally, going as far as stating that it would be difficult to continue providing MAiD if some (or all) these expansions were permitted. However, at the end of the day, team members found their work personally rewarding and believed that they made a difference in people's lives, providing peace of mind, control, and comfort – similar to findings among other Canadian studies (Bruce and Beuthin, 2019; Khoshnood et al., 2018; Shaw et al., 2018).

We have come a long way since the days of Rodriguez or early proposals for legalization and regulation of MAiD (such as that of Russel Ogden or Jocelyn Downie), however, there is still a long way to go before equitable access (for rural and marginalized populations as well urban ones) to MAiD is achieved, which should be a priority for governments. In order to achieve equitable access, we have to start with standardized public and professional education on MAiD. From the themes and experiences described above, it is clear that not only are many Canadians uninformed about MAiD services, what they entail, who qualifies, and where they can be accessed, but healthcare providers can be equally mistaken in their interpretations which continues this cycle of misinformation. The cycle of misinformation is not the only thing that stands in the way of patients seeking to access MAiD, they additionally must consider the possibility of being transferred from the faith-based hospital or long term care home they are staying in, so that they can pursue their wishes to have a peaceful death. Clearly, improvements can be made and therefore the next chapter draws recommendations in light of these themes.

Chapter 5: Contributions & Conclusion

"this is the way I thought of my dad, he put his arms around us and gathered us together, and took us to that place and then he waved goodbye and went through the door and we got to see it. what a gift." 9P8

Introduction

This thesis concludes by presenting research strengths and limitations, contributions, policy recommendations, and suggestions for future research. This qualitative phenomenological inquiry into MAiD experiences revealed some interesting insights into the local MAiD process. Findings contribute to local and national MAiD discourses, as they are relevant not only to our communities, but when combined with research from other provinces suggests wider systemic issues such as a lack of knowledge about MAiD. The recommendations I provide are relevant not only to our province but can benefit some other provinces as well, who have reported similar issues.

The most significant of these recommendations is the need for standardized education on MAiD for healthcare professionals and the public. There needs to be increased public awareness of MAiD in order to ensure lack of knowledge does not a hinder equitable access to this service. At the same time, current barriers, such policies of as abstaining facilities which require patients to transfer for MAiD, need to be re-examined. Patient access to MAiD is being violated in cases where transfers go wrong or are simply not possible, in the name of conscientious objection for a building. A better balance needs to be reached between the right of these facilities to provide services according to their mandated and patient right, but *not* at the expense of patient autonomy and dignity.

Further research on MAiD in Canada should consider bringing in the voices of the patients, whose experiences can provide a new as well as *crucial* perspective to MAiD discussions. The experiences of those on the front lines should always be prioritized when considering future research and providing policy recommendations. This is one such area that I attempted to contribute to with my research, the strengths and limitations of which are explored next.

Strengths and limitations

As with any research design, the one utilized here was not perfect and not without its limitations. While the use of phenomenology in this qualitative research was beneficial considering how new MAiD is to Canada, it was also accompanied by some limitations, similar to those of qualitative research generally. Due to the scarce research available on MAiD at the time, and still no published research from Manitoba, phenomenology allowed for a broad and rich exploration of experiences, without limiting participants to any area specifically. Using Interpretative Phenomenological Analysis (IPA) allowed some guidance for conducting phenomenological research such as using an open ended interview style and recognizing the importance of examining experiences holistically without leading participants in directions pre-determined by previous research. Despite these advantages phenomenology holds some limitations, the most significant of which is the small sample size which normally means an inability to generalize findings to the wider population.

Although I cannot claim with this research to represent the Canadian experience as a whole, many similarities were seen with published research from other provinces, and limited generalizations can be made. Additionally, due to the nature of the centralized Manitoba MAiD team, I was able to recruit participants from all over the province (although largely from urban areas). This also allowed the MAiD team to reflect on experiences from rural and remote communities, which could not have been possible in other provinces, where MAiD providers only serve their immediate communities.

In the spirit of interpretative phenomenology, which recognizes the subjective nature of experiences and the researcher's role in interpreting/analyzing these perspectives, I recognize that as the sole researcher, I brought my own worldview, experience, biases, and prior knowledge of MAiD. This influenced the way in which I engaged with this research including choices I made regarding methods, especially data collection and analysis. My personal biases included those in favour of MAiD and in opposition to policies undertaken by abstaining facilities. The themes explored in the discussion were further subject to my discretion which were inevitably shaped by my personal interests and goals associated with this research, specifically in exploring experiences with MAiD locally.

At the same time, there were undeniably similarities in participant accounts which is how I developed my themes, through concerns expressed by participants. I presented these themes in a way that let the experiences of participants, illustrate the point and impact it had on them. These similarities point to areas that need addressing or require further inquiry. While not conclusive, they are suggestive of a local concern and when combined with research across the country, indicates some wider trends (such as a need for better education on MAiD). Generalizations are drawn with caution, limited to provinces with similar delivery systems (such as Saskatchewan and Alberta), at this point in time (2020) prior to enactment of Bill C-7, and largely speaking to urban experiences. At the same time, the sample included diverse experiences and presented a glimpse into the average MAiD provision experience in Manitoba, as participants did not markedly differ from statistics provided by the team.

Additionally, this research is limited to urban/suburban populations. While not all participants experienced the process in Winnipeg, as some were from neighbouring cities/towns, no participants were from northern, remote, or indigenous communities. It is a well known fact that rural and remote communities experience healthcare disparities thus the experiences of those populations could be vastly different from those living in more accessible urban/suburban areas. At the same time, the centralized nature of the MAiD team allowed them to reflect on experiences across the whole province and provide a wider picture of MAiD experiences, which only emphasized the lack of engagement from these communities. This is also a significant finding as it suggests that marginalized and isolated populations are under-accessing MAiD instead of not being disproportionately pressured to use MAiD, as argued by some opponents of MAiD.

Due to the unique nature of Manitoba's MAiD system and team, their experiences cannot be directly compared with provinces that differ in MAiD delivery systems (such as B.C. and Ontario) however, similarities can be drawn with those in Saskatchewan or Alberta. Differences among provincial regulations also explain research findings from Ontario that show patients and families feel coordination burdens during the process, findings not replicated here. Thus, this local inquiry with limited generalization abilities, can still helps other provinces reveal some shortfalls in their systems. Including both the MAiD team and family members in this research added reliability and credibility to conclusions as themes could be triangulated, cross referenced and compared from both perspectives.

At the same time, the methods used in this research not only limited the sample size but the recruitment strategy specifically, opened the door for a biased participant pool. Recruitment was largely reliant on the MAiD team with only one participant being recruited through dying with dignity. This was the best strategy to ensure equal distribution of recruitment materials for all participants as well as a low pressure way to recruit for the research. However, it cannot be discounted that those who decided to participate in the research perhaps had some commonalities which made them more likely to self-identify. Using interviews as the chosen data collection method may have deterred more introverted/private participants from coming forward or those with busier schedules. Using a survey may have yielded more responses however, they would not be as rich in detail and description.

This skewed sample could have also occurred if the MAiD team was not distributing recruitment materials equally to all potential participants or perhaps if the self-identification strategy prevented certain groups of individuals from coming forward. All the family members in this research reflected positively on the MAiD team, even commended them on their work. While the team indicated that this is consistent with the majority of the feedback they receive from family members, the research could have discouraged participants with more negative or complicated experienced from self-identifying. At the same time, I believe the sample captured diverse experiences with the process from family members and even from the MAiD team. Participants held different beliefs and moral boundaries with some having more unique experiences with the process than others (such as a transfer).

Future research could benefit from a longer data collection period, which would allow for a larger sample size and access to populations that need more time to come forward (like patients). Using a survey would also allow for more flexibility as participants can fill it out on their own time, can be anonymous, but should be reserved for more specific inquiries. I hope this research encourages broader inquiries into MAiD across Canada especially in more rural communities, to better gauge any disparities in access. Canadian research on MAiD is scarce but the combination of multiple inquiries can significantly contribute to and improve our understanding of the ‘bigger picture’ and essence of MAiD in Canada.

Contributions

This research makes academic contributions, discursively to the area of MAiD literature, and methodologically with the use of interpretative phenomenological analysis (IPA). This research makes contributions to literature on Interpretative Phenomenological Analysis (IPA) expanding its use outside of traditional psychological fields. IPA stemmed from psychological/medical research origins whereas this research uses IPA in a more socio-legal and multidisciplinary direction. The use of IPA in this research will hopefully encourages others to use this open ended qualitative methodology in future research, and provides an example of its transferability to other academic disciplines.

Second, this research stands to contribute globally to academic and public discourses on MAiD by highlighting a local Canadian experience as well as its successes and shortfalls. Some countries across the world have allowed MAiD for decades, yet each legalization or decriminalization experience is different and they cumulatively contribute to global MAiD discourses. Canada was in a special position during the construction of Bill C-14, to learn from international experiences with MAiD and more recent ones from Oregon and Washington, USA. Now it is Canada's turn to expand this literature and this research aims to do just that by contributing to ongoing MAiD discussions globally.

The third contribution is a continuation of the first, providing direct insight into national Canadian discourse on MAiD and guide new legislative initiatives. The federal government is currently redrafting MAiD legislation, with Bill C-7 scheduled to receive royal assent any day, and another review of legislation awaiting later in 2021. Considering these upcoming changes, any research on the subject provides valuable insights into the experiences of those who actually engage in the process, whether as service providers, service recipients, or family members thereof. Whereas a great deal of academic literature on MAiD focuses on political debates, legal issues, and academic perspectives, this research provides direct insight into the impact of federal and provincial legislation on those accessing and providing MAiD in Manitoba. These first hand experiences provide a more intimate picture of MAiD than government collected statistics or public opinion surveys are able to and for this reason, research such as this should be instrumental in future revisions of MAiD legislation.

Additionally, Canadian research is heavily emerging out of Ontario and British Columbia, which have different MAiD systems than Manitoba's. This research seeks to fill that gap by providing experiences of MAiD providers and families of patients from a different jurisdiction with a unique application of MAiD regulations. These experiences reveal some lessons that can be adopted by other provinces which are struggling streamlining the process for patients/families who are experiencing burdens associated with the onerous process. At the same time, other provinces also stand to learn from the gaps found in this research, such as lack of public and professional education on the subject.

The fourth and last contribution relates to policy contributions on the local scale, as this research has implications directly translatable to local policies for our province and regional health authorities. Canadian legislators and policy makers should account for lessons learned from MAiD participants to help inform any changes or policy-related decisions. An intimate examination of experiences with MAiD could be used by policy makers provincially and federally to narrow down policies that are working well as well as those which require further improvement. Additionally the experiences of those on the front lines should always be at the centre of inquiry.

MAiD legislation is set to undergo a federal assessment in 2021 (five years post-legalization) in order to determine possible areas for expansion and findings from this research can help inform the recommendations of the reviewing committee. Findings discussed in the analysis chapter point to some disparities in the quality of care as well as accessibility across Canada. These disparities should be noted by policy makers and legislators who can actively improve experiences of MAiD providers, patients, and their families through better support, resource allocation, and education.

Recommendations

This research draws recommendations from both negative and positive aspects of the Manitoba MAiD service delivery system, as was one of the original research goals. The highlight of the process for all family members was the MAiD team which was commended on their knowledge, compassion, and professionalism. During a period of grief, family members had nothing but excellent feedback for the team with more contentious comments reserved for frustrations with legislative restrictions or abstaining policies. I highlight two positive aspects of the Manitoba MAiD system which were not only regarded as advantages by participants but their positive impact became even more apparent when compared to struggles reported in other provinces. Additionally, I provide three recommendations based on findings regarding the lack of public and professional education as well as barriers caused by abstaining institutions.

The single entry, multidisciplinary nature of the Manitoba MAiD team has many advantages, some of these could aspects be helpful for other provinces to adopt, especially those that employ a coordination hotline. As seen in the discussion of the previous chapter, literature/research emerging out of Ontario portrays a different and more onerous experiences with the MAiD process, which isolates MAiD assessors/providers (often separate entities) while placing much of the burden with regard to coordination and scheduling on patients or their families. These jurisdictions should consider the benefits of having a centralized multidisciplinary team that ensures patients and families are fully informed during every step, explores unmet needs with patients/families, and undertakes all coordination of appointments for transfers or assessments. For reason, as part of my recommendations, I highlight two aspects of the MAiD system in Manitoba which were identified as advantageous by participants and can be adoption in some fashion by other provinces seeking to make improvements to their process.

These two elements include the use of a single entry system into MAiD as well as taking on a multidisciplinary approach to MAiD which allows a combination of expertise, mimicking a hospice care approach. First, all provinces should consider the implementation of a single entry system into MAiD, as it minimizes confusion among inquirers and ensures that they receive the most accurate, relevant, and up to date information/resources. This further prevents patients and families from bouncing between different healthcare providers who may tell conflicting or partially accurate information. Additionally, the single entry system removes the burden of coordinating appointments, assessments, and procedures from patients or families and realigns this with healthcare provider responsibilities (as it should). As Hales et al. (2019) found in their analysis of experiences in Ontario, placing the burden on patients/families causes distress during an already difficult time and can leave patients scrambling to find available assessors/providers in close proximity within a timeline that works. Allowing for this single entry system would take away this burden from patients and ensure not only a dignified death, but also a dignified and peaceful process.

Second, the multidisciplinary nature of the team (mirroring a hospice approach) which encompasses the expertise of physicians, nurses, psychosocial specialists, a speech pathologist (and outsources expertise of other specialists such as psychiatrists) is highly beneficial for patients and their families. This multidisciplinary approach has the unique ability to address a wide variety of unmet needs and concerns (psychosocial and medical) of patients and their families during appointments, increasing confidence and accountability in assessments. Many family members who participated in my research praised the team on their compassion and attention to detail during the process which encompassed the consideration of family members, their concerns, and following up with supports/services.

Additionally, MAiD providers pointed out various instances where requests for MAiD stemmed from unmet needs or contacts during crisis/complications. However, once the team (with the help of psychosocial specialists, psychiatrists and other specialists) were able to address these unmet needs, the patients ultimately delayed or deciding not to go through with their request. This is an important consideration and can serve as a safeguard, ensuring voluntariness and ruling out decisions due to distress in MAiD applications. While healthcare providers are great at what they do, it is the combination of expertise and introduction of psychosocial specialists that allowed for this rich exploration of unmet meets. For these reasons, I recommend that other provinces consider a more multidisciplinary approach through consultations with social workers.

Despite the many strengths of the team, provincial initiatives fell short in terms of educating the public and healthcare professionals on MAiD. The absence of standardized education for healthcare providers hinders accessibility for citizens, acting as a double barrier. Leaving professional development and education on MAiD to be self-directed, allows for healthcare providers to bury their heads in the sand about the subject while at the same time opens the door for misinterpretation. This double barrier to access, is something that can be easily avoided through standardized educational initiatives, beyond a published policy. Lack of knowledge and understanding among healthcare providers is unacceptable, as it hinders access for patients who may not already know about MAiD legality or do not understand that it could be an option for them (misunderstanding eligibility), and thereby do not know to ask someone about MAiD. Simultaneously, healthcare professionals who are not properly educated on MAiD can spread wrong information and mislead patients due to mistakes in interpretation, confusion regarding the physicians role (to refer or self-referral, eligibility), or discomfort with end of life discussions.

This was seen by the MAiD team in instances where they encountered sources of misinformation through client stories and followed up with those healthcare professionals to correct their misunderstandings of MAiD. Some healthcare professionals were unsure of their obligations in light of the fact that ‘counselling a person to suicide’ remained an offence under the criminal code and they did not want to be perceived as suggestive. This largely stems from a guide released by the Manitoba nursing college, which states: "Nurses must not initiate a discussion on medical assistance in dying with clients because this could be interpreted as counseling a person to die, or the client may feel undue pressure." (Medical Assistance in Dying: Guidelines for Manitoba Nurses", 2018, p.11). Governing medical associations have since clarified that letting a patient know about MAiD is not the same as counselling them to suicide, however, healthcare providers remain hesitant with this subject in general.

Some provinces are ahead of Manitoba in terms of educating medical communities on MAiD legislation and procedures, this can be (in part) attributed to the different actualization of MAiD services across Canada. Since most provinces do not have a centralized team to process all MAiD requests, individual providers need to be more intimately familiar with the process to provide accurate information. Additionally, provinces with coordination hotlines such as

Ontario, require physicians to provide an ‘effective referral’ for MAiD if they object to participate in MAiD themselves. However, these provinces still fall short on educating the *public* about the existence of MAiD as well as the eligibility criteria for this new legal medical service. For this reason, recommendations three and four are the two most important recommendations I make, regarding public and professional education on MAiD.

The third recommendation is the undertaking of a public education campaign on the availability of MAiD in Canada (highlighting changes under the *Criminal Code*) as well as on the eligibility criteria and procedural requirements of this service. This will be especially crucial going forward with the integration of Bill C-7, as new populations will qualify for MAiD, under a modified process that needs to be made explicit for people in the community. These new legislative changes will create further confusion among the public which already have a limited understanding of MAiD. Public education on the availability of MAiD should be at the forefront of information dissemination on the subject however, provinces should not make the mistake of implementing a narrow education campaign that simply outlines the availability of this service. Instead, public education on MAiD should also outline *who* can apply for MAiD (eligibility) as well as the major steps along the way – emphasizing the fact that it is a *process*, requiring takes time to review and should be explored as early as reasonable, rather than at the deathbed (or in crisis).

The fourth recommendation is that the provincial government (having jurisdiction over education and healthcare) in collaboration with regional health authorities and medical associations, standardize professional development on MAiD as well as education for students in medical fields. Education for healthcare professionals should take place in medical schools, residency programs, practicums, and in the case of already-practicing healthcare providers, via professional development workshops/days. The education of professionals should not be limited to listing the *Criminal Code* provisions, eligibility requirements, or a description of the process itself (differing provincially). They should additionally cover the legal boundaries surrounding and obligations of physicians/specialists when receiving requests from patients or communicating this as an option. Healthcare providers should not be caught in a legal grey area, wondering if they can bring up MAiD as an option to their patients or whether this could be construed as counselling to suicide (which remains illegal under the *Criminal Code*). This will require an exploration of responsibilities for providers who are conscientious objectors and how far their obligations extend when it comes to providing information/referrals. These professional development initiative should additionally be repeated and re-written every time the practice undergoes major amendments (as is the case with Bill C-7).

These educational initiatives are essential for improving access to MAiD for eligible populations (both urban and rural) as well as ensuring Canadians are making fully informed decisions when it comes to their end of life, which encompasses weighing *all* options available to them. For Manitoba in particular, improving education on MAiD among medical communities will benefit the future of MAiD services, as the team would be able to outsource some assessments (to community physicians) in order to keep up with rising demand. As discussed in the previous chapter, requests for MAiD are doubling year to year and the small team (which has grown since its inception in 2016) is now struggling to keep up with requests and inquiries in a timely fashion. Implementing widespread professional education will ensure that healthcare providers are up to date on the latest MAiD guidelines as well as potentially assist the team by disseminating information or conducting an assessment. Taking some of the pressure off the team will allow for faster case processing and leave team expertise for more complicated cases.

Although this was not the original intention behind the creation of a centralized multidisciplinary team, without greater resource allocation to the team it seems involvement of external providers may be required to ensure equitable and timely access to the service.

The fifth and final recommendation pays an ode to the issue of abstaining facilities under the second theme. While Bill C-7 alleviated a few concerns such as eliminating the waiting period for RFND patients, allowing prior consent to MAiD, and alleviating witness requirements – it did not address the issue of abstaining institutions. Current abstaining policies place patients at risk, cause delays in process, and rob some citizens of their choices (and thereby autonomy) altogether due to their frail state. There needs to be greater collaboration and discussions between the MAiD team and the boards of these abstaining institutions in order to reach a compromise that does not undermine patient rights (especially during such a sensitive time) as the current ones do. Transfer policies at abstaining facilities have real life impacts on all parties involved including the patients, their families, the MAiD team, as well as staff at sending institutions. I suspect in weighing these impacts, the brunt of the burden would fall on individual Canadians, not on the facility and render it unjustifiable. The government should seek the advice of courts in determining where the boundaries of patient rights and institutional mandates lie.

All members of the MAiD team I interviewed as well as any family members who experienced or worried about a transfer, disagreed with these policies and pointed out the burdens this caused, especially for patients who are often already in a frail state. It is nothing short of cruel to force critically ill patients to endure a transfer and risk numerous complications along the way, in order to access the peaceful and dignified death they desired. While the government believes that the proper balance has been reached between religious freedoms and patient rights, I would question whether the impacts of *allowing* MAiD at these facilities would have a similar effect on the abstaining institution considering the staff at these facilities do not necessarily subscribe to the same views. Current regulations place an institutional mandate (citing reasons of historical standing) above the rights and welfare of patients, and should be renegotiated to reach a better balance, while taking into consideration the effects that it has on all parties involved.

Although no one MAiD delivery service is perfect, I believe these recommendations highlight the advantages of the MAiD system in Manitoba while also learning from some of the areas in need of improvement discussed by participants. Of course, further research on MAiD in Canada is needed in order to continue providing relevant and up to date recommendations in light of evolving legislation and policies. It is important to concentrate on grounded and qualitative research as quantitative statistics are already being collected and reported by the federal government as well as individual provinces.

Research on experiences with MAiD is lacking and the voices of patients seem to be missing from discussions altogether. Although I recognize this is a vulnerable and sometimes inaccessible population, their experiences and opinions are central to the future of MAiD policies in Canada and may be better captured with a longer data collection period. Experiences with MAiD should be examined from different perspectives (patients, family members, healthcare providers), across different provinces, and at different points in time. Smaller studies will allow for research to be directly translatable into actionable changes or recommendations for these communities while still contributing to great mosaic of MAiD in Canada. It is difficult to recommend research for such as new area (as further inquiry is needed from every vantage) however, experiential research is important in that it provides examples of the real-life impacts of legislation for those on the front lines.

Conclusion

The purpose of this research was two-fold, first, to explore and describe experiences with MAiD in Manitoba as told from the perspectives of the MAiD team and family members in order to better understand the legislative impact in practice. The second goal was to consider what these experiences revealed about the accessibility of MAiD service and provide recommendations based on these findings.

To accomplish this, I drew from interpretative phenomenological analysis to explore and analyze participant experiences with the phenomena (MAiD). This open-ended approach allowed me to interview participants with directly related experiences, including members of the Manitoba MAiD team and family members who assisted a loved one with a MAiD application. I conducted semi-structured interviews with 17 participants (11 family members and 6 MAiD team members). Semi-structured interviews allowed the free flow of information between the researcher and participants as well as the ability to follow up on interesting themes in real time. Interviews were transcribed and analyzed manually, looking for common and interesting themes in participant narratives.

A couple themes and subthemes were identified from participant responses. The first theme discussed how the lack of knowledge among both healthcare professionals and the wider public creates barriers to access for patients. This was seen in various accounts of participants not knowing MAiD was an option until circumstances were dire, being told false information, or misunderstanding eligibility/process requirements for MAiD. These findings call for better public and professional education on MAiD in the province, especially in rural communities. Improving awareness of MAiD among the public as well as requiring standardized professional development for impacted professions will ensure that access to MAiD is equitable, for anyone who qualifies and desires it.

The second theme discussed how moral objections, largely on the part of healthcare providers and abstaining healthcare institutions (but also those of family and friends), have led to delays, emotional distress, and impeded access to MAiD. Family members discussed objections from friends/family when looking for witnesses or bringing up the use of MAiD, which led some participants to keep the process private due to judgement they felt. Encounters with conscientious objectors were less common among family member and did not pose significant barriers. The MAiD team discussed how conscientious objection complicated their practice due to objecting physicians refusing to cooperate, however, transfers from abstaining facilities were seen as the most difficult form of conscientious objection to overcome.

The team described transfers (due to abstaining facilities) as a drain on resources, morally distressing (to patients, families, and healthcare personnel), and onerous for patients/families, sometimes ending unfavourably for the patients. Family members were additionally worried for their loved ones at the possibility of having to endure a transfer from an abstaining facility. Transfers have been known to end unfavorably for critically ill and frail patients who are at a heightened risk of experiencing complications during the transfer including loss of capacity or death. Due to these risks, patients in abstaining facilities are sometimes robbed of their right to choose MAiD, as they are too frail to be transferred, or simply cannot be accommodated anywhere else.

This research allowed a glimpse into experiences with MAiD in Manitoba and not only contributed to an under-researched area in Canadian literature but also revealed potential areas for improvement. Other provinces can stand to learn from Manitoba's single entry multidisciplinary approach to MAiD services but at the same time, the province can make some improvements of its own. The most significant of the recommendations provided has to do with expanding information dissemination on MAiD to the wider public, as well as standardizing education and professional development on MAiD across the province. This would ensure that patients are not falling through the cracks due to lack of knowledge or receiving false information about MAiD. Another area for improvement, is the allowance of faith-based institutions to abstain from MAiD on 'moral' grounds. A better balance needs to be reached between patient rights and policies of abstaining institutions, that do not undermine patient autonomy and shift some of the burdens back to the abstaining institution.

These findings add to the growing discourses on MAiD in Canada and internationally as well as introduce the application of interpretative phenomenological analysis to a social science field outside of psychology (where it is traditionally used). Interpretative phenomenological analysis allowed a broad inquiry into a phenomenon (MAiD) that had little existing Canadian research, while letting participant experiences reveal the themes. I hope the recommendations provided, especially those regarding educational initiatives, assist policy makers and regulatory bodies of healthcare institutions/providers as they incorporate any future changes into current policies and practices.

Elected members of parliament should strive to provide equitable access to this new end-of-life option in Canada which begins by informing citizens about what MAiD is and who can access it (in user-friendly language). Equitable access encompasses a burden free process which places patient needs at the center of the process, as opposed to institutional mandates. I would implore that a new compromise be reached with abstaining institutions that better balances the impacts of these policies. After all, we are all going to die one day, and I hope that when the time comes we can all do so in the way that we wish.

Appendix A

Hello,

My name is Aleksandra Manzhura and I am a graduate student in the Criminal Justice department at the University of Winnipeg. I am currently working under the supervision of Dr. Kelly Gorkoff conducting research on medical assistance in dying (MAID) in Manitoba for my Master's thesis.

I am interested in studying experiences with medical assistance in dying (MAID) in Manitoba, specifically experiences with assisted dying applications through interviews with medical staff, patients, and their families who have been involved in the process. This research has no influence or connection to applications for medical assistance in dying or any other aspect of that process, it is an external study. I hope this research will help contribute to Canadian literature on medical assistance in dying and help inform future policy decisions to improve the experience for all parties involved.

I invite you to participate in this study, regardless of the extent/nature of your involvement with the application, I would appreciate the opportunity to speak with you as your experiences are unique and will help me gain a better understanding of what MAID applicants face in Manitoba. Your participation in this study is completely voluntary and should you choose to participate, I will find a time that is most convenient for you to conduct an interview. The interview may take anywhere from thirty minutes to two hours, this time frame can be broken up into shorter periods if you require and you may end the interview at any time.

Interviews will be audio recorded for transcription purposes, but I can assure you that your identity will be kept confidential and once recordings are transcribed, they will be erased, with your identity anonymized on paper. You may further request to review interview transcripts and delete or modify any quoted material. Your identity will not be shared with anyone at any point in time and any excerpts or quotes used in research publications will not include identifying information along with any other details you would like to stay private.

I would love to hear your story and assure you that your personal information will be kept under lock and key. This study has been reviewed and received ethics clearance by the University of Winnipeg Research Ethics Board and Winnipeg Regional Health Authority Ethics Committee. If you are interested in participating, you can contact me at **204-899-9395** or **cj.research@uwinnipeg.ca** or alternatively ask someone to contact me on your behalf.

Thank you for your consideration,
Aleksandra Manzhura

Appendix B

Interview protocol

Begin by going over consent form and begin recording.

For the Medical Assistance in Dying (MAID) team

Describe your role with the MAID team
Length of time working
General and specialized responsibilities
What has been your experiences following policies/regulations surrounding MAID?
Describe the application process for patients (what are they required to do)
From initial contact to setting a procedure date
How are patients in various locations accommodated?
What do patients find most difficult/inconvenient about the process?
What is your opinion regarding the eligibility assessments/requirements?
Do they pose any difficulties/issues? (use of discretion)
Do you think the current framework reaches the intended population?
Are vulnerable patients screened out with sufficient precision?
Is there any advice you would give to patients considering pursuing MAID?
Do you see assisted dying expanding in the future? In what ways?
If not mentioned, specifically ask about: advanced directives, underage patients, eligibility criteria, and psychiatric patients.
Do you believe these expansions should be permitted? Are they prone to abuse?

For families

What has been the nature of your involvement with medical assistance in dying?
Are you satisfied with the care your loved one received?
Were there any obstacles you/your loved one faced in accessing MAID?
What would you change or wish was done differently?
What do you wish you had known earlier?
How were you accommodated/helped throughout the process?
Is there any advice you would give to patients considering pursuing MAID?

Works Cited

A.C. v. Manitoba (Director of Child and Family Services), 2009 SCC 30.

"Advance Directives". (n.d.). Health Law Institute, Dalhousie University. Retrieved from: http://eol.law.dal.ca/?page_id=231

Allard, J., & Fortin, M.C. (2017). Organ donation after medical assistance in dying or cessation of life-sustaining treatment requested by conscious patients: the Canadian context. *Journal of Medical ethics*, *43*(9), 601-605.

Antifaeff, K. (2019). Social Work Practice with Medical Assistance in Dying: A Case Study. *Health and Social Work*, *44*(3), 185-192.

Ardelt, M. (2003). Physician-assisted death. In C. D. Bryant & D. L. Peck *Handbook of death & dying* (pp. 424-436). Thousand Oaks, CA: SAGE Publications, Inc.

Arnup, K. (2009). Lessons in Death and Dying. *Journal of Palliative Care*, *25*(2), 109-111.

Baillie, L. (2007). The impact of staff behaviour on patient dignity in acute hospitals. *Nursing Times*, *103*(34), 30-31.

Balboni, M. (2015). Everyday religion in hospitals. *Society, 52*(5), 413-417.

Barclay, L. (2016). In sickness and in dignity: a philosophical account of the meaning of dignity in health care. *International Journal of Nursing Studies*, *61*, 136–141.

Barnabé, C., & Kirk, P. (2002). A needs assessment for southern Manitoba physicians for palliative care education. *Journal of Palliative Care*, *18*(3), 175–84.

Bator, E., Philpott, B., & Costa, A. (2017). This moral coil: a cross-sectional survey of Canadian medical student attitudes toward medical assistance in dying. *BMC Medical Ethics*, *18*(1), 58-65.

Beckmann, U., Gillies, D., Berenholtz, S., Wu, A., and Pronovost, P. (2004). Incidents relating to the intra-hospital transfer of critically ill patients. *Intensive Care Medicine*, *30*(8), 1579-1585.

Berghmans, R., Widdershoven, G., & Widdershoven-Heerding, I. (2013). Physician-assisted suicide in psychiatry and loss of hope. *International Journal of Law and Psychiatry, 36*(5-6), 436-43.

Beuthin, R. (2018). Cultivating Compassion: The Practice Experience of a Medical Assistance in Dying Coordinator in Canada. *Qualitative Health Research*, *28*(11), 1679-1691.

Beuthin, R., Bruce, A., and Scaia, M. (2018). Medical assistance in dying (MAiD): Canadian nurses' experiences. *Nursing Forum*, *53*(4), 511-520.

Bill 34: The Medical Assistance in Dying (Protection for Health Professionals and Others) Act, 2nd Session, 41st Legislature, 2017. Retrieved from: https://web2.gov.mb.ca/bills/41-2/b034e.php

Bill C-7: An Act to amend the Criminal Code (medical assistance in dying), 1st Session, 43rd Parliament, 2020. Retrieved from: https://www.parl.ca/DocumentViewer/en/43-1/bill/C-7/first-reading

Bill C-14: An Act to amend the Criminal Code and to make related amendments to other Acts (medical assistance in dying), 1st Session, 42nd Parliament, 2016. Retrieved from: http://www.parl.ca/DocumentViewer/en/42-1/bill/C-14/royal-assent

Bird, C. (2005). How I Stopped Dreading and Learned to Love Transcription. *Qualitative Inquiry*, *11*(2), 226-248.

Blackwell, T. (2016, September 26). B.C. man faced excruciating transfer after Catholic hospital refused assisted-death request. *National Post*. Retrieved from: https://nationalpost.com/news/canada/b-c-man-faced-excruciating-transfer-after-catholic-hospital-refused-assisted-death-request

Blikshavn, T., Husum, T. L., & Magelssen, M. (2017). Four reasons why assisted dying should not be offered for depression. *Journal of Bioethical Inquiry, 14*(1), 151-157.

Bovens, L. (2015). Child Euthanasia: should we just not talk about it? *Journal of Medical Ethics*, *41*(8), 630-634.

Bradley, B., Feldman, F., and Johansson, J. (2013). *The oxford handbook of philosophy of death*. Oxford University Press.

Brocki, J., and Wearden, A. (2006). Critical Evaluation of IPA in Health Psychology. *Psychology and Health*, *21*(1), 87-108.

Brooks, L. (2019). Health Care Provider Experiences of and Perspectives on Medical Assistance in Dying: A Scoping Review of Qualitative Studies. *Canadian Journal on Aging*, *38*(3), 384-396. Retrieved from: https://pubmed.ncbi.nlm.nih.gov/30626453/

"Bringing up Medical Assistance In Dying (MAiD) as a clinical care option". (2020). Canadian Association of MAiD Assessors and Providers. Retrieved from: https://camapcanada.ca/wp-content/uploads/2020/02/Bringing-up-MAiD.pdf

Bruce, A., and Beuthin, R. (2019). Medically Assisted Dying in Canada: "Beautiful Death" is Transforming Nurses' Experiences of Suffering. *Canadian Journal of Nursing Research*, *0*(0), 1-10.

Burgess, J.A. (1993). The great slippery-slope argument. *Journal of Medical Ethics*, *19*(3), 169-174.

Bussey, B. (2018, May 23). The Right of Religious Hospitals to Refuse Physician-Assisted Suicide. *Supreme Court Law Review*, 85(2d). Retrieved from: https://papers.ssrn.com/sol3/papers.cfm?abstract_id=3183767

Canada (Attorney General) v E.F., 2016 ABCA 155.

Canadian Council on Learning. (2008). Health Literacy in Canada: A Healthy Understanding. Ottawa. Retrieved from: https://escholarship.org/uc/item/890661nm

Canadian Medical Association. (2015). Palliative Care. Retrieved from: https://www.cma.ca/sites/default/files/2018-11/palliative-care-report-online-e.pdf

Canadian Psychological Association. (2018). Medical Assistance in Dying and End-of-Life Care. Retrieved from: https://cpa.ca/docs/File/Task_Forces/Medical%20Assistance%20in%20Dying%20and%20End%20of%20Life%20Care_FINAL.pdf

Canadian Public Health Association. (2008). A Vision for a Health Literate Canada: Report of the Expert Panel on Health Literacy. Retrieved from: https://www.cpha.ca/sites/default/files/uploads/resources/healthlit/report_e.pdf

Carter v. Canada (Attorney General), 2016 SCC 4.

Carter v. Canada (Attorney General), 2015 SCC 5.

Caruk, H. & Hoyle, B. (October 26, 2017). Waiting to die: Winnipeg man says faith-based hospital delayed access to assisted death. *CBC News*. Retrieved from: http://www.cbc.ca/news/canada/manitoba/misericordia-assisted-dying-maid-1.4371796

"Catholic Health Corp. stacks St. Boniface Hospital board to stop assisted dying". (17 June 2017). Retrieved from: *CBC News* <https://www.cbc.ca/news/canada/manitoba/catholic-health-st-boniface-hospital-assisted-dying-1.4165890>

"Changes to ambulance protocol in Winnipeg come in to effect Tuesday". (2017, October 2). Global News. Retrieved from: https://globalnews.ca/news/3781503/changes-to-ambulance-protocol-in-winnipeg-come-in-to-effect-tuesday/

Chapman, E., and Smith, J. (2002). Interpretative Phenomenological Analysis and the New Genetics. *Journal of Health Psychology*, *7*(2), 125-310.

Chen, S. C., Wu, L. Y., & Tseng, H. T. (2000). Students' attitudes towards death in a senior high school of nursing. *Journal of Health Science*, *2*(3), 226–249.

Chochinov, H.M., Hack, T., McClement, S., Kristjanson, L.J, & Harlos, M. (2002). Dignity in the terminally ill: A developing empirical model. *Social Science & Medicine*, *54*(3), 433-443.

Christian Medical and Dental Society of Canada v. College of Physicians and Surgeons of Ontario, 2018 ONSC 579.

Christian Medical and Dental Society of Canada v. College of Physicians and Surgeons of Ontario, 2019 ONCA 393.

Chu, H. & Cook, G. (2018, June 1). Seeking Expeditious Justice on Behalf of Suffering Canadians. *British Columbia Civil Liberties Association*. Retrieved from: https://bccla.org/2018/06/seeking-expeditious-justice-on-behalf-of-suffering-canadians/

Cohen, J., Dierickx, S., Deliens, L., & Chambaere, K. (2017). Euthanasia for people with psychiatric disorders or dementia in Belgium: Analysis of officially reported cases. *BMC Psychiatry, 17*(1), 1-9.

College of Physicians and Surgeons of Manitoba. (2016). *Medical assistance in dying*. Schedule M to By-Law No. 11. Retrieved from: https://cpsm.mb.ca/cjj39alckF30a/wp-content/uploads/PAD/Status%20update%20MAiD%2020160714.pdf

College of Physicians and Surgeons of Ontario. (2018). *Medical Assistance in Dying*. Retrieved from: https://www.cpso.on.ca/Physicians/Policies-Guidance/Policies/Medical-Assistance-in-Dying

Conroy, S. (2003). A Pathway for Interpretive Phenomenology. *International Journal of Qualitative Methods*, *2*(3), 36-62.

Converse, M. (2012). Philosophy of phenomenology: how understanding aids research. *Nurse Researcher*, *20*(1), 28-32.

Corr, C. A. (2019). The ‘five stages’ in coping with dying and bereavement: strengths, weaknesses and some alternatives. *Mortality*, *24*(4), 405–417.

Council of Canadian Academies. (2018). *The State of Knowledge on Medical Assistance in Dying for Mature Minors*. Ottawa (ON): The Expert Panel Working Group on MAiD for Mature Minors, Council of Canadian Academies.

Council of Canadian Academies. (2018). *The State of Knowledge on Advanced Requests for Medical Assistance in Dying*. Ottawa (ON): The Expert Panel Working Group on Advanced Requests for MAiD, Council of Canadian Academies.

Council of Canadian Academies. (2018). *The State of Knowledge on Medical Assistance in Dying Where a Mental Disorder Is the Sole Underlying Medical Condition*. Ottawa (ON):

The Expert Panel Working Group on MAiD Where a Mental Disorder Is the Sole Underlying Medical Condition, Council of Canadian Academies.

Creswell, J., & Creswell, D. (2018). *Research Design: Qualitative, Quantitative, and Mixed Methods Approaches*, 5th edition. Los Angeles: Sage.

Criminal Code, R.S.C. 1985, c.46.

Criminal Law Amendment Act, 1972, S.C. 1972, c. 13, s. 16.

Crumley, E., Sheppard, C., Bowden, C., & Nelson, G. (2018). Canadian French and English newspapers' portrayals of physicians' role and medical assistance in dying (MAiD) from 1972-2016: a qualitative textual analysis. *BMJ Open*, *9*(4), 1-20.

Cuman, G., and Gastmans, C. (2017). Minors and euthanasia: a systematic review of argument-based ethics literature. *European Journal of Pediatrics*, *176*(7), 837-847.

Curtis C. (2019, October 3). Quebec court invalidates some requirements for assisted death. *Montreal Gazette*. Retrieved from: https://montrealgazette.com/news/quebec/quebec-court-invalidates-some-requirements-for-assisted-death

Curtis, J., Patrick, D., Caldwell, E., Collier, A. (2000). Why don't patients and physicians talk about end-of-life care? Barriers to communication for patients with acquired immunodeficiency syndrome and their primary care clinicians. *Archives of Internal Medicine*, *160*(11), 1690-1696.

Davies, D. (2018). Medical assistance in dying: A paediatric perspective. *Paediatrics and Child Health*, *23*(2), 125-130.

De Boer, M., Dröes, R., Jonker, C., Eefsting, J., and Hertogh, C. (2011). Advance Directives for Euthanasia in Dementia: How Do They Affect Resident Care in Dutch Nursing Homes? Experiences of Physicians and Relatives. *Journal of the American Geriatrics Society*, *59*(6), 989-996.

Deckha, Maneesha. (2016). A Missed Opportunity: Affirming the Section 15 Equality Argument Against Physician-Assisted Death. *McGill Journal of Law and Health*, *10*(1), 61-121.

DeGrazia, D. (1999). Advance directives, dementia, and 'the someone else problem'. *Bioethics*, *13*(5), 373-391.

Deltell, G. (2016, May 2). "Criminal Code". Canada. Parliament. House of Commons. *Edited Hansard 148*(46). 42nd Parliament, 1st session. Retrieved from: https://www.ourcommons.ca/DocumentViewer/en/42-1/house/sitting-46/hansard

DeMichelis, C., Shaul, R., and Rapoport, A. (2019). Medical Assistance in Dying at a paediatric hospital. *Journal of Medical Ethics*, *45*(1), 60-67.

Department of Justice. (2015, December 15). Consultations on Physician-Assisted Dying: Summary of Results and Key Findings. Retrieved from: https://www.justice.gc.ca/eng/rp-pr/other-autre/pad-amm/pad.pdf

Derish, M., and Heuvel, K. (2000). Mature Minors Should Have the Right to Refuse Life-Sustaining Medical Treatment. Journal of Law, *Medicine and Ethics*, *28*(2), 109-124.

“Dignity therapy”. (2016). Retrieved from: https://dignityincare.ca/en/

Dion, S., Wiebe, E., & Kelly, M. (2019). Quality of care with telemedicine for medical assistance in dying eligibility assessments: a qualitative study. *Canadian Medical Association Journal Open*, *7*(4), E721-729.

Downie, J. (2004). *Dying Justice: A Case for Decriminalizing Euthanasia and Assisted Suicide in Canada*. University of Toronto Press.

Downie, J. (2018, July 3). Can Nurse Practitioners Mention MAiD to Patients? *Impact Ethics*. Retrieved from: https://impactethics.ca/2018/07/03/can-nurse-practitioners-mention-maid-to-patients/

Downie, J., & Chandler, J. (2018). Interpreting Canada’s Medical Assistance in Dying Legislation. Institute for Research on public policy. Retrieved from: https://irpp.org/research-studies/interpreting-canadas-medical-assistance-in-dying-maid-legislation/

Downie, J. and Gilbert, D. (2019, September 16). Parliament should not wait to act on assisted dying ruling. *Policy Options*. Retrieved from: https://policyoptions.irpp.org/magazines/september-2019/parliament-should-not-wait-to-act-on-assisted-dying-ruling/

Droogh, J., Smit, M., Absalom, A., Ligtenberg, J., & Zijlstra, J. (2015). Transferring the critically ill patient: are we there yet? *Critical Care* 19(1). Retrieved from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4335540/pdf/13054_2015_Article_749.pdf

Dying with Dignity Canada - Winnipeg Chapter. (n.d.). Retrieved from: http://www.dwdwinnipeg.ca/about.html

Eatough, V. & Smith, J. (2017). Interpretative phenomenological analysis. In Willig, C., & Rogers, W. *The SAGE Handbook of qualitative research in psychology* (pp. 193-209). London: SAGE Publications Ltd.

Eatough, V., Smith, J., and Shaw, R. (2008). Women, Anger, and Aggression: An Interpretative Phenomenological Analysis. *Journal of Interpersonal Violence*, *23*(12), 1767-1799.

"Editorial: Hospital consolidation plan is the right move". (2018, December 19). *Winnipeg Sun*. Retrieved from: https://winnipegsun.com/opinion/editorials/editorial-hospital-consolidation-plan-is-the-right-move

Elie, D., Marino, A., Torres-Platas, S., Noohi, S., Semeniuk, T., Segal, M., Looper, K., & Rej, R. (2017). End-of-Life Care Preferences in Patients with Severe and Persistent Mental Illness and Chronic Medical Conditions: A comparative Cross-Sectional Study. *The American Journal of Geriatric Psychiatry*, *26*(1), 89-97.

"Euthanasia". (2019). *Encyclopaedia Britannica*. Retrieved from: https://www.britannica.com/topic/euthanasia

Farnsworth, C. H. (1994) Woman Who Lost a Right-to-Die Case in Canada Commits Suicide. *The New York Times*. Retrieved from: www.nytimes.com/1994/02/15/world/woman-who-lost-a-right-to-die-case-in-canada-commits-suicide.html

Fraser, L. (2017, August 14). Dying with Dignity may challenge Ontario law exempting religious hospitals from offering assisted death. *CBC News*. Retrieved from: https://www.cbc.ca/news/canada/toronto/assisted-dying-religion-ethics-accessibility-1.4244328

Fonseca, L. M., & Testoni, I. (2011). The emergence of thanatology and current practice in death education. *Omega*, *64*(2), 157–69.

Froggatt, K. (2007). The 'regulated death': A documentary analysis of the regulation and inspection of dying and death in English care homes for older people. *Ageing and Society*, *27*(2), 233-247.

Fujioka, J. K., Mirza, R. M., McDonald, P. L., & Klinger, C. A. (2018). Implementation of Medical Assistance in Dying: A Scoping Review of Health Care Providers' Perspectives. *Journal of pain and symptom management*, *55*(6), 1564–1576. Retrieved from: https://pubmed.ncbi.nlm.nih.gov/29477968/

Georges, J., The, A., Onwuteaka-Philipsen, D., & van der Wal, G. (2008). Dealing with requests for euthanasia: a qualitative study investigating the experience of general practitioners. *Journal of Medical Ethics*, *34*(3), 150–155.

Gerring, J. (2004). What is a Case Study and What Is It Good for? *American Political Science Review*, *98*(2), 341-354.

Gert, B., & Culver, C. M. (1986). Distinguishing between active and passive euthanasia. *Clinics in geriatric medicine*, *2*(1), 29–36.

Giesbrecht, M., Crooks, V. A., Castleden, H., Schuurman, N., Skinner, M. W., & Williams, A. M. (2016). Revisiting the use of 'place' as an analytic tool for elucidating geographic issues central to Canadian rural palliative care. *Health and place*, *41*, 19–23.

Gilbert, D. (2017, April 3). Catholic Hospitals have no right to refuse assisted dying. *The Globe and Mail*. Retrieved from: https://www.theglobeandmail.com/opinion/why-hospitals-have-no-right-to-refuse-assisted-dying/article32278732/

Gonen, G., Kaymak, S. U., Cankurtaran, E. S., Karslioglu, E. H., Ozalp, E., & Soygur, H. (2012). The factors contributing to death anxiety in cancer patients. *Journal of Psychosocial Oncology*, *30*(3), 347–58.

Government of Canada. (2019, April). 3rd Interim Report on Medical Assistance in Dying in Canada. Retrieved from: https://www.canada.ca/en/health-canada/services/publications/health-system-services/medical-assistance-dying-interim-report-june-2018.html

Government of Canada. (2018, June 21). 4th Interim Report on Medical Assistance in Dying in Canada. Retrieved from: https://www.canada.ca/en/health-canada/services/publications/health-system-services/medical-assistance-dying-interim-report-april-2019.html

Gowriluk, C. (2019, March 29). Deciding to die. *Winnipeg Free Press.* Retrieved from: https://www.winnipegfreepress.com/local/deciding-to-die-appointment-with-death-507839922.html

Groenewald, T. (2004). A Phenomenological Research Design Illustrated. *International Journal of Qualitative Methods*, *3*(1), 42-55.

Guest, G., Bunce, A., and Johnson, L. (2006). How Many Interviews Are Enough? An Experiment with Data Saturation and Variability. *Field Methods*, *18*(1), 59-82.

Guillemin, M., and Gillam, L. (2004). Reflexivity and 'Ethically Important Moments' in Research. *Qualitative Inquiry*, *10*(2), 261-280.

Gyapong, D. (2019, September 19). Quebec court strikes down safeguard of 'reasonably foreseeable' death. *Catholic Register*. Retrieved from: https://www.catholicregister.org/item/30275-quebec-court-strikes-down-safeguard-of-reasonably-foreseeable-death

Haberman, C. (2015). Stigma Around Physician-Assisted Dying Lingers. *The New York Times*. Retrieved from: https://www.nytimes.com/2015/03/23/us/stigma-around-physician-assisted-dying-lingers.html

Hales, B., Bean, S., Isenberg-Grzeda, E., Ford, B., & Selby, D. (2019). Improving the Medical Assistance in Dying (MAID) process: A qualitative study of family caregiver perspectives. *Palliative and Supportive Care*, *17*(5), 590–595.

Hall, S., Longhurst, S., & Higginson, I. (2009). Living and dying with dignity: a qualitative study of the views of older people in nursing homes. *Age and Ageing*, *38*(4), 411–416.

Hayslip, B. & Hansson, R. (2003). Death awareness and adjustment across the life span. In C. D. Bryant & D. L. Peck *Handbook of death & dying* (pp. 437-447). Thousand Oaks, CA: SAGE Publications, Inc.

Health Canada. (2018). Framework on Palliative Care in Canada. Retrieved from: https://www.canada.ca/content/dam/hc-sc/documents/services/health-care-system/reports-publications/palliative-care/framework-palliative-care-canada/framework-palliative-care-canada.pdf

Hertogh, C., de Boer, M., Dröes, R., and Eefsting, J. (2007). Would We Rather Lose Our Life Than Lose Our Self? Lessons From the Dutch Debate on Euthanasia for Patients With Dementia. *The American Journal of Bioethics*, *7*(4), 48-56.

Hewitt, J. (2010). Schizophrenia, mental capacity, and rational suicide. *Theoretical Medicine and Bioethics: Philosophy of Medical Research and Practice, 31*(1), 63-77.

Heyland, D.K., Barwich, D., Pichora, D., Dodek, P., Lamontagne, F., You, J.J., Tayler, C., Porterfield, P., Sinuff, T., and Simon, J. (2013). Failure to Engage Hospitalized Elderly Patients and Their Families in Advance Care Planning. *JAMA Internal Medicine*, *173*(9), 778-787.

Holmes, S., Wiebe, E., Shaw, J., Nuhn, A., Just, A., and Kelly, M. (2018). Exploring the experience of supporting a loved one through a medically assisted death in Canada. *Canadian Family Physician*, *64*(9), e387-393.

Hood, R. (2016). Combining phenomenological and critical methodologies in qualitative research. *Qualitative Social Work*, *15*(2), 160-174.

Hopp v. Lepp, [1980], 2 S.C.R. 192.

House of Commons. (2016). Medical Assistance in Dying: A Patient-Centred Approach. Report of the Special Joint Committee on Physician-Assisted Dying. Retrieved from: https://www.parl.ca/Content/Committee/421/PDAM/Reports/RP8120006/pdamrp01/pdamrp01-e.pdf

House of Commons. (2 May, 2016). Parliament. Edited Hansard 148(46). 42nd parliament, 1st session. Retrieved from: the Parliament of Canada website: https://www.parl.ca/LegisInfo/BillDetails.aspx?Language=E&billId=8177165&View=1

"How to Access MAiD". (2020). *Shared Health*. Retrieved from: https://sharedhealthmb.ca/services/maid/access/

Høy, B., Lillestø, B., Slettebø Åshild, Sæteren, B., Heggestad, A. K. T., Caspari, S., Aasgaard, T., Lohne V., Rehnsfeldt, A., Råholm, M., Lindwall, L. & Nåden D. (2016). Maintaining dignity in vulnerability: a qualitative study of the residents' perspective on dignity in nursing homes. *International Journal of Nursing Studies*, *60*, 91–98.

Hutchison, C. (2017, August 1). Why are women with disabilities being given help to die, instead of help to live? *Coalition for HealthCARE and Conscience*. Retrieved from: https://www.canadiansforconscience.ca/why_are_women_with_disabilities_being_given_help_to_die_instead_of_help_to_live

"'I can still clearly hear his screams': Medically assisted dying access questioned". (2017). *CBC News*. Retrieved from: https://www.cbc.ca/news/canada/calgary/medically-assisted-dying-calls-1.4166707

I.J. v Canada, 2016 ONSC 3380.

Iltis, A. (2006). On the Impermissibility of Euthanasia in Catholic Healthcare Organizations. *Christian Bioethics*, *12*(3), 281-290.

Ipsos Reid. (2014). Most (84%) Canadians Believe a Doctor Should be Able to Assist Someone Who is Terminally Ill and Suffering Unbearably to End their Life. Retrieved from: Ipsos https://www.ipsos.com/en-ca/most-84-canadians-believe-doctor-should-be-able-assist-someone-who-terminally-ill-and-suffering

Kagan, S. H. (2015). Dignity, evidence, and empathy. *Geriatric Nursing*, *36*(5), 394–6.

Keating, N.L., Landrum, M.B., Rogers, S.O., Jr, Baum, S.K., Virnig, B.A., Huskamp, H.A., Earle, C.C. and Kahn, K.L. (2010). Physician factors associated with discussions about end-of-life care. *Cancer*, *116*(4), 998–1006.

King, M. (2018). Stigma, controversy persists around medically-assisted dying. *Bradford Today*. Retrieved from: https://www.bradfordtoday.ca/local-news/stigma-controversy-persists-around-medically-assisted-dying-928715

Kislowicz, H. (2016). Developments in Religious Freedom: What Saguenay and Loyola Tell Us – and Don't – About the Trinity Western University Law School Cases. *Supreme Court Law Review*, *72*(2d), 75-95.

Khoshnood, N., Hopwood, M., Lokuge, B., Kurahashi, A., Tobin, A., Isenberg, S., Husain, A. (2018). Exploring Canadian Physicians' Experiences Providing Medical Assistance in Dying: A Qualitative Study. *Journal of Pain and Symptom Management*, *56*(2), 222-229.

Kouwenhoven, P., Raijmakers, N., van Delden, J., Rietjens, J., van Tol, D., van de Vathorst, S., de Graeff, N., Weyers, H., van der Geide, A., and van Thiel, G. (2015). Opinions about euthanasia and advanced dementia: a qualitative study among Dutch physicians and members of the general public. *BMC Medical Ethics*, *16*(7).

Kübler-Ross, E. (1969). *On death and dying*. New York: The Macmillan Company

Ladin, K., Buttafarro, K., Hahn, E., Koch-Weser, S., & Weiner, D. (2018). "End-of-Life Care? I'm not Going to Worry About That Yet": Health Literacy Gaps and End-of-Life Planning Among Elderly Dialysis Patients. *The Gerontologist*, *58*(2), 290–299.

Lamont, S., Jeon, Y.H., & Chiarella, M. (2013). Assessing patient capacity to consent to treatment: an integrative review of instruments and tools. *Journal of clinical nursing*, *22*(17-18), 2387-2403.

Lapadat, J., and Lindsay, A. (1999). Transcription in Research and Practice: From Standardization of Technique to Interpretive Positionings. *Qualitative Inquiry*, *5*(1), 64-86.

Larkin, M., Watts, S., and Clifton, E. (2006). Giving voice and making sense in interpretative phenomenological analysis. *Qualitative Research in Psychology*, *3*(2), 102-120.

Larsen, K. (2020, February 25). B.C. pulls $1.5M in funding from Metro Vancouver hospice for refusing to allow assisted dying. *CBC News*. Retrieved from: https://www.cbc.ca/news/canada/british-columbia/funding-maid-delta-1.5475780

Lavergne, M., and Kephart, G. (2012). Examining variations in health within rural Canada. *Rural and Remote Health*, *12*(1), 34-46.

Law Society of British Columbia v. Trinity Western University, 2018 SCC 32.

Lee, R.L.M. (2008). Modernity, mortality and re-enchantment: the death taboo revisited. *Sociology*, *42*(4), 745–759.

Le Grange, L. (2005). Reflexivity and new modes of knowledge production: The case of the human and social sciences. *South African Journal of Higher Education*. 19, 1444-1455.

Lehto, R. H., & Stein, K. F. (2009). Death anxiety: an analysis of an evolving concept. *Research and Theory for Nursing Practice*, *23*(1), 23–41.

Leming, M. (2003). The history of the hospice approach. In C. D. Bryant & D. L. Peck *Handbook of death & dying* (pp. 485-494). Thousand Oaks, CA: SAGE Publications, Inc.

Lester, D. (1993). The Stigma against Dying and Suicidal Patients: A Replication of Richard Kalish's Study Twenty-Five Years Later. *OMEGA – Journal of Death and Dying*, *26*(1), 71-75.

Li, M. (2019, September 6). Lamb adjournment testimony (published letter). Retrieved from: https://bccla.org/wp-content/uploads/2019/09/2019-09-06B-LT-Court_adjournment-of-triaL.pdf

Li, M., Watt, S., Escaf, M., Gardam, M., Heesters, A., O'Leary, G., Rodin, G. (2017). Medical Assistance in Dying – Implementing a Hospital-Based Program in Canada. *The New England Journal of Medicine*, *375*(21), 2082-2088.

Liquor, Gaming and Cannabis Authority of Manitoba. (2018). Cannabis Regulator launches Know My Cannabis Limits Campaign. Retrieved from: https://lgcamb.ca/cannabis-regulator-launches-know-my-cannabis-limits-campaign/

Little, S. (2020, May 30). Delta Hospice head says B.C. policy could force people 'into euthanizing themselves'. *Global News*. Retrieved from: https://globalnews.ca/news/7007377/b-c-delta-hospice-euthanizing/

Maass, U., Hofmann, L., Perlinger, J., & Wagner, B. (2020). Effects of bereavement groups-a systematic review and meta-analysis. *Death Studies*, 1–11.

Mack, J., Cronin, A., Taback, N., Huskamp, H., Keating, N., Malin, J., Earle, C., & Weeks, J. (2012). End-of-Life Care Discussions Among Patients With Advanced Cancer: A Cohort Study. *Annals of Internal Medicine*, *156*(3), 204-210.

Markakis, C., Dalezios, M., Chatzicostas, C., Chalkiadaki, A., Politi, K., and Agouridakis, P. (2006). Evaluation of a risk score for interhospital transport of critically ill patients. *Emergency Medical Journal*, *23*(4), 313-317.

Mauthner, N., and Doucet, A. (2003). Reflexive Accounts and Accounts of Reflexivity in Qualitative Data Analysis. *Sociology*, *37*(3), 413-431.

Medical Assistance in Dying. (2018). Winnipeg Regional Health Authority. Retrieved from: http://www.wrha.mb.ca/maid/patients_and_families.html

"Medical assistance in dying and end-of-life decisions". (2019). Ontario. Retrieved from: https://www.ontario.ca/page/medical-assistance-dying-and-end-life-decisions#section-0

"Medical Assistance in Dying: Guidelines for Manitoba Nurses". (2018). College of licensed Practical Nurses of Manitoba, College of Registered nurses of Manitoba, The College of Registered Psychiatric Nurses of Manitoba, in collaboration with the Provincial Medical Assistance in Dying Team. Retrieved from: https://www.crnm.mb.ca/uploads/ck/files/MAID%20guideline%20FINAL.pdf

Meier, E. A., Gallegos, J. V., Thomas, L. P. M., Depp, C. A., Irwin, S. A., & Jeste, D. V. (2016). Defining a good death (successful dying): literature review and a call for research and public dialogue. *The American Journal of Geriatric Psychiatry*, *24*(4), 261–271.

Menzel, P., and Steinbock, B. (2013). Advance directives, dementia, and physician-assisted death. *Journal of Law and Medical Ethics*, *41*(2), 484-500.

McGarry, P. (2017, August 11). Pope orders half to euthanasia at Catholic hospitals in Belgium. *Irish Times*. Retrieved from: https://www.irishtimes.com/news/social-affairs/religion-and-beliefs/pope-orders-halt-to-euthanasia-at-catholic-hospitals-in-belgium-1.3183804

McMechan, C., Bruce, A. & Beuthin, R. (2019). Canadian Nursing Students' Experiences with Medical Assistance in Dying. *Quality Advancement in Nursing Education*, *5*(1), Article 2.

Mitchell, G., and Cody, W. (1992). The Role of Theory in Qualitative Research. *Nursing Science Quarterly*, *6*(4), 170-178.

"More services, staff on the move as part of Winnipeg's health-care overhaul". (2018, September 11). *CBC News*. Retrieved from: https://www.cbc.ca/news/canada/manitoba/wrha-consolidation-phaseii-health-system-hospitals-1.4818742

Mori, M., Shimizu, C., Ogawa, A., Okusaka, T., Yoshida, S. and Morita, T. (2015). A National Survey to Systematically Identify Factors Associated With Oncologists' Attitudes Toward End-of-Life Discussions: What Determines Timing of End-of-Life Discussions? *The Oncologist*, *20*(11), 1304-1311.

Morrison K. (2017). Finding a home (somewhere) for medical aid in dying. *Journal of Pain Management, 10*(1), 9–13.

Muniz-Fraticelli, V. (2017). The Social Ontology of Religious Freedom. *Supreme Court Law Review, 79*(2d), 115-141.

Muñiz-Fraticelli, V.M., & Lawrence, D. (2016). Religious institutionalism in a Canadian context. *Osgoode Hall Law Journal*, *52*(3), 1049-1113.

"Navigating A Request For Medical Assistance In Dying". (2020). Dying with Dignity. Retrieved from: https://www.dyingwithdignity.ca/navigating_a_request

Nouvet, E., Strachan, P., Kryworuchko, J., Downar, J., & You, J. (2016). Waiting for the body to fail: limits to end-of-life communication in Canadian hospitals. *Mortality*, *21*(4), 1-17.

Nuhn, A., Holmes, S., Kelly, M., Just, A., Shaw, J., and Wiebe, E. (2018). Experiences and perspectives of people who pursued medical assistance in dying. *Canadian Family Physician*, *64*(9), 380-386.

"Number of medically assisted deaths on the rise in Manitoba". (2017, October 20). *CBC News*. Retrieved from: https://www.cbc.ca/news/canada/manitoba/assisted-deaths-on-the-rise-manitoba-1.4364594

O'Kelly, C., Urch, C., & Brown, E. (2011). The impact of culture and religion on truth telling at the end-of-life. *Nephrology, Dialysis, Transplantation: Official Publication of the European*

Dialysis and Transplant Association - European Renal Association, *26*(12), 3838-42. doi:10.1093/ndt/gfr630

Ogden, R. (1994). The right to die: a policy proposal for euthanasia and aid in dying. *Canadian Public Policy*, *20*(1), 1–25.

Omori, M., Jayasuriya, J., Scherer, S., Dow, B., Vaughan, M., & Savvas, S. (2020). The language of dying: communication about end-of-life in residential aged care. *Death Studies*, 1–11.

Ontario Ministry of Health. (2015, November 30). Provincial-Territorial Expert Advisory Group on Physician-Assisted Dying. Retrieved from: http://www.health.gov.on.ca/en/news/bulletin/2015/docs/eagreport_20151214_en.pdf

Organization for Economic Co-operation and Development. (2017). Working with Change: Systems approaches to public sector challenges. OECD Observatory of Public Sector Innovation. An initiative of the OECD's Public Governance and Territorial Development Directorate. Retrieved from: https://www.oecd.org/media/oecdorg/satellitesites/opsi/contents/files/SystemsApproachesDraft.pdf

Paetkau, J. (2018). B.C. doctor predicts ban on assisted death in faith-based institutions will go to court. *CBC News*. Retrieved from: https://www.cbc.ca/news/canada/british-columbia/jonathan-reggler-goo-bye-medical-assistance-dying-assisted-death-providence-health-fred-salmon-1.4483910

Pampalon, R., Martinez, J., & Hamel, D. (2006). Does living in rural areas make a difference for health in Québec? *Health and place*, *12*(4), 421–435.

Patil, A. (2019). Halifax woman posthumously calls for fix to Canada’s assisted dying rules. *CBC News*, Retrieved from: https://www.cbc.ca/news/canada/nova-scotia/audrey-parker-canada-assisted-dying-fix-halifax-1.5006445

Penney, L. (2014). Self-Determination and Counselling to Commit Suicide: Beyond Rodriguez. *CanLII Connects*. Retrieved from: https://canliiconnects.org/en/commentaries/30674

Pesut, B., Fowler, M., Taylor, E., Reimer-Kirkham, S., & Sawatzky, R. (2008). Conceptualising spirituality and religion for healthcare. *Journal of Clinical Nursing, 17*(21), 2803-10.

Pihlström, P. (2015). Controlling death: philosophical thanatology meets pragmatism. *Mortality*, *20*(1), 48-66.

Pong, R. W., DesMeules, M., & Lagacé, C. (2009). Rural–urban disparities in health: How does Canada fare and how does Canada compare with Australia? *Australian Journal of Rural Health*, *17*(1), 58–64.

Ponsford, M. (2018). Chronic, irremediable depression constituting mental disability: Expanding legal rights to euthanasia in Canada. *Supreme Court Law Review*, 82(2d). Retrieved from: doi:10.2139/ssrn.2818898

Praslickova, Z., Kelly, M., & Wiebe, E. (2020). The experience of volunteer witnesses for Medical Assistance in Dying (MAiD) requests. *Death Studies*.

Prudy, C. (2018, October 23). Patient wheeled outside Alberta Catholic hospital to have assisted death assessment. *Global News*. Retrieved from: https://globalnews.ca/news/4587014/edmonton-woman-assisted-death-assessment-catholic-hospital-covenant-health/

Pursaga, J. (2017, June 20). Health minister defends hospital's right not to allow medically assisted deaths. *Winnipeg Sun.* Retrieved from: https://winnipegsun.com/2017/06/20/health-minister-defends-hospitals-right-not-to-allow-medically-assisted-deaths/wcm/1060e995-8e06-45a6-adae-6ed9de4c02be

Ramsey, D., & Beesley, K. B. (2007). 'Perimeteritis' and rural health in Manitoba, Canada: perspectives from rural healthcare managers. *Rural and Remote Health*, *7*(4), 850–850.

Rankin, J. (2019, August 26). Netherlands euthanasia case: doctor 'acted with best intentions'. *The Guardian*. Retrieved from: https://www.theguardian.com/world/2019/aug/26/doctor-on-trial-landmark-euthanasia-case-netherlands-dementia

Raus, K. (2016). The Extension of Belgium's Euthanasia Law to Include Competent Minors. *Bioethical Inquiry*, *13*(2), 305-315.

Read, S., & MacBride-Stewart, S. (2018). The 'good death' and reduced capacity: a literature review. *Mortality*, *23*(4), 381-395.

Reel, K. (2018). Denying Assisted Dying Where Death is *Not* 'Reasonably Foreseeable': Intolerable Overgeneralization in Canadian End-of-Life Law. *Canadian Journal of Bioethics*, *1*(3), 71-81.

Reeves, S., Albert, M., Kuper, A., and Hodges, B. (2008). Why Use Theories in Qualitative Research? *British Medical Journal*, *337*(7670), 631-634.

Reibl v. Hughes, [1980], 2SCR 880.

Rhodes, R. & Danzinger, M. (2018). Being a Doctor and Being a Hospital. *The American Journal of Bioethics*, *18*(7), 51-72. https://doi.org/10.1080/15265161.2018.1478021

Robertson, W., Pewarchuk, J., Reggler, J., Green, S., Daws, T., and Trouton, K. (2017). Case Review of Medically Assisted Deaths on Vancouver Island. *BC Medical Journal*, *59*(6), 305-309.

Rocca, F.X. (2017, October 27). Catholic Hospital Group Grants Euthanasia to Mentally Ill, Defying Vatican. *The Wall Street Journal*. Retrieved from: https://www.wsj.com/articles/catholic-hospital-group-grants-euthanasia-to-mentally-ill-defying-vatican-1509096600

Ross, M. M., MacLean, M. J., & Fisher, R. (2002). End-of-life care for seniors: public and professional awareness. *Educational Gerontology*, *28*(5), 353–366.

Rosso, A., Huyer, D., & Walker, A. (2017). Analysis of the Medical Assistance In Dying Cases In Ontario: Understanding the Patient Demographics of Case Uptake In Ontario Since the Royal Assent and Amendments of Bill C-14 in Canada. *Academic Forensic Pathology*, *7*(2), 263-287.

Ryan-Nicholls, K.D., and Racher, F. (2004). Investigating the health of rural communities: toward framework development. *Rural and Remote Health*, *4*(1), 244.

Samson, S. (2019). Fighting system created by health-care changes 'totally burned you out,' says retired Winnipeg nurse. *CBC News*. Retrieved from: https://www.cbc.ca/news/canada/manitoba/fighting-system-created-by-health-care-changes-totally-burned-you-out-says-retired-winnipeg-nurse-1.5176045

Sandstrom, K. (2003). On coming to terms with death and dying: neglected dimensions of identity work. In C. D. Bryant & D. L. Peck *Handbook of death & dying* (pp. 468-474). Thousand Oaks, CA: SAGE Publications, Inc.

San Filippo, D. (2006). Philosophical, Psychological & Spiritual Perspectives on Death & Dying. *Faculty Publications*. *31*. Retrieved from: https://digitalcommons.nl.edu/faculty_publications/31

São José JM. (2016). Preserving dignity in later life. *Canadian Journal on Aging*, *35*(3), 332–47.

Schafer, A. (2013). Physician Assisted Suicide: The Great Canadian Euthanasia Debate. *International Journal of Law and Psychiatry*, *36*(5-6), 522–531.

Schuklenk, U., & Vathorst, S. v. d. (2015). Treatment-resistant major depressive disorder and assisted dying. *Journal of Medical Ethics, 41*(8), 577-583.

Selby, D., Bean, S., Isenberg-Grzeda, E., Henry, B., & Nolen, A. (2019). Medical Assistance in Dying (MAiD): A Descriptive Study From a Canadian Tertiary Care Hospital. *American Journal of Hospice and Palliative Medicine*, *37*(1), 58-64.

Shaw, J., Harper, L., Preston, E., Wright, A., Kelly, M., & Wiebe, E. (2019). Perceptions and Experiences of Medical Assistance in Dying Among Illicit Substance Users and People Living in Poverty. *OMEGA - Journal of Death and Dying*, *0*(0), 1-22.

Shaw, J., Wiebe, E., Nuhn, A., Holmes, S., Kelly, M., & Just, A. (2018). Providing Medical

Assistance in Dying: Practice Perspectives. *Canadian Family Physician*, *64*(9), e394-9.

Smith, J. (2019). Participants and researchers searching for meaning: Conceptual developments for interpretative phenomenological analysis. *Qualitative Research in Psychology*, *16*(2), 166-181.

Smith, J. (2018). "Yes It Is Phenomenological": A Reply to Max Van Manen's Critique of Interpretative Phenomenological Analysis. *Qualitative Health Research*, *28*(12), 1955-1958.

Smith, J. (2011). Evaluating the contribution of interpretative phenomenological analysis. *Health Psychology Review*, *5*(1), 9-27.

Smith, J. (2004). Reflecting on the development of interpretative phenomenological analysis and its contribution to qualitative research in psychology. *Qualitative Research in Psychology*, *1*(1), 39-54.

Smith, J. (1995). Semi-structured interviewing and qualitative analysis. In J. A. Smith, R. Harré & L.V. Langenhove, *Rethinking methods in psychology* (pp. 10-26). London: SAGE Publications Ltd.

Soles, T. L., Ruth Wilson, C., & Oandasan, I. F. (2017). Family medicine education in rural communities as a health service intervention supporting recruitment and retention of physicians: Advancing Rural Family Medicine: The Canadian Collaborative Taskforce. *Canadian family physician*, *63*(1), 32–38.

"Standard of Practice Medicine". (2019). The College of Physicians & surgeons of Manitoba. retrieved from: https://cpsm.mb.ca/assets/Standards%20of%20Practice/Standards%20of%20Practice%20of%20Medicine.pdf

St. Boniface Hospital. (2017, June 12). Responding to Inquiries and Requests for Medical Assistance in Dying. (VI-1010). Retrieved from: http://www.sbgh.mb.ca/files/maid.pdf

St. Boniface Hospital. (2018). Brief Historical Facts and Summary of Activity Levels (2017-2018). Retrieved from: https://stbonifacehospital.ca/about-us/facts-and-figures/

Steinhauser, K., Clipp, E., McNeilly, M., Christakis, N., McIntyre, L., Tulsky, J. (2000). In Search of a Good Death: Observations of Patients, Families, and Providers. *Annals of Internal Medicine*, *132*(10), 825-832.

Stingl, M. (1998). Euthanasia and Health Reform in Canada. *Cambridge Quarterly of Healthcare Ethics*, *7*(4), 348–370.

Strack, S. (2003). Herman Feifel (1915-2003). *American Psychologist*, *58*(10), 810–810.

Street, A. F., & Kissane, D. W. (2001). Constructions of Dignity in End-of-Life Care. *Journal of Palliative Care*, *17*(2), 93–101.

Stulberg, D. B., Lawrence, R. E., Shattuck, J., & Curlin, F. A. (2010). Religious hospitals and primary care physicians: conflicts over policies for patient care. *Journal of general internal medicine*, *25*(7), 725-30.

Swan, M. (2017, September 22). Winnipeg Catholic hospital draws euthanasia battle lines. *The B.C. Catholic*. Retrieved from: https://bccatholic.ca/content/winnipeg-catholic-hospital-draws-euthanasia-battle-lines

“The Clinical Interpretation of ‘Reasonably Foreseeable’”. (2017). Canadian Association of MAiD Assessors and Providers. Retrieved from: https://camapcanada.ca/wp-content/uploads/2019/01/cpg1-1.pdf

The College of Physicians and Surgeons of Manitoba. (2020). Continuing Professional Development. Retrieved from: https://cpsm.mb.ca/standards/continuing-professional-development

"The fight for the right to die" (2009). *CBC News*. Retrieved from: https://www.cbc.ca/news/canada/the-fight-for-the-right-to-die-1.809224

The Health Care Directive Act, C.C.S.M. 1993, c. H27. Retrieved from: http://web2.gov.mb.ca/laws/statutes/ccsm/_pdf.php?cap=h27

The Regional Health Authorities Act, C.C.S.M. 1996, c. R34, Retrieved from: https://web2.gov.mb.ca/laws/statutes/ccsm/r034e.php

Thompson, J. (1994, February 21). Rodriguez chooses suicide. *CBC News*. Retrieved from: www.cbc.ca/archives/entry/rodriguez-chooses-suicide

Trachtenberg, A., & Manns, B. (2017). Cost analysis of medical assistance in dying in Canada. *Canadian Medical Association Journal*, *189*(3), e101-105.

Tradii, L., & Robert, M. (2019). Do we deny death? ii. critiques of the death-denial thesis. *Mortality*, *24*(4), 377–388.

Truchon and Galdu v. Canada (Attorney General) and Quebec (Attorney General), 2019 QCCS 3792.

Volandes, A., Paasche-Orlow, M., Gillick, M., Cook, E., Shaykevich, S., Abbo, E., & Lehmann, L. (2008). Health Literacy not Race Predicts End-of-Life Care Preferences. *Journal of Palliative Medicine*, *11*(5), 754-762.

Voorhees, J., Rietjens, J., van der Heide, A., & Drickamer, M. (2013). Discussing Physician-

Assisted Dying: Physicians' Experiences in the United States and the Netherlands. *The Gerontologist*, *54*(5), 808-817.

Walker, G. (2003). Medical euthanasia. In C. D. Bryant & D. L. Peck *Handbook of death & dying* (pp. 405-423). Thousand Oaks, CA: SAGE Publications, Inc.

Walter, T., Littlewood, J., & Pickering, M. (1995). Death in the News: The Public Invigilation of Private Emotion. *Sociology*, *29*(4), 579–596.

Warner, T. D., Roberts, L. W., Smithpeter, M., Rogers, M., Roberts, B., McCarty, T., Franchini, G., Geppert, C., & Obenshain, S. S. (2001). Uncertainty and opposition of medical students toward assisted death practices. *Journal of Pain and Symptom Management*, *22*(2), 657–667.

"What is dementia". (2018). *Alzheimer Society Canada*. Retrieved from: https://alzheimer.ca/en/Home/About-dementia/What-is-dementia

"What We Heard Report: A Public Consultation on Medical Assistance in Dying". (March, 2020). Department of Justice, Government of Canada. Retrieved from: https://www.justice.gc.ca/eng/cj-jp/ad-am/wwh-cqnae/index.html

Wiebe, E., Green, S., & Schiff, B. (2018) Teaching residents about medical assistance in dying. *Canadian Family Physician*, *64*(4), 315-6.

Wiebe, E., Shaw, J., Green, S., Trouton, K., and Kelly, M. (2018). Reasons for requesting medical assistance in dying. *Canadian Family Physician*, *64*(9), 674-679.

Wiebe, E., Shaw, J., Wright, A., & Kelly, M. (2019). Suicide vs Medical Assistance in Dying (MAiD): a secondary qualitative analysis. *Death Studies*. DOI:10.1080/07481187.2019.1614110.

Wiebe, K. [Dr. Kim Wiebe]. (2018). Physician perspective [Video file]. Retrieved from: https://drive.google.com/file/d/0B0Pz2YLMOG83ZTVEakVKaFVLVXc/view

Wilson, D. M., Birch, S., MacLeod, R., Dhanji, N., Osei-Waree, J., & Cohen, J. (2013). The public's viewpoint on the right to hastened death in Alberta, Canada: findings from a population survey study. *Health & Social Care in the Community*, *21*(2), 200–208.

Wilson, D. M., Birch, S., Sheps, S., Thomas, R., Justice, C., & MacLeod, R. (2008). Researching a best-practice end-of-life care model for Canada. *Canadian Journal on Aging*, *27*(4), 319–330.

Wilson, D., Justice, C., Sheps, S., Thomas, R., Reid, P., and Leibovici, K. (2006). Planning and Providing End-of-life Care in Rural Areas. *The Journal of Rural Health*, *22*(2), 174-181.

Wilson-Raybould, J. (2016, April 22). "Criminal Code". Canada. Parliament. House of

Commons. *Edited Hansard*, *148*(45). 42nd Parliament, 1st session. Retrieved from: https://www.ourcommons.ca/DocumentViewer/en/42-1/house/sitting-45/hansard

Wilson, C.R., Rourke J., Oandasan I.F., & Bosco C. (2020). Progress made on access to rural healthcare in Canada. *Canadian Journal of Rural Medicine*, *25*(1), 14-19.

Winnipeg Regional Health Authority. (2017). *Medical Assistance in Dying*. Policy Number 110.000.400. Retrieved from: https://wrha.mb.ca/files/wrha-policy-110-000-400.pdf

Wittwer, H. (2013). The problem of the possible rationality of suicide and the ethics of physician-assisted suicide. *International Journal of Law and Psychiatry, 36*(5-6), 419-26.

Wojnar, D., and Swanson, K. (2007). Phenomenology: An Exploration. *Journal of Holistic Nursing*, *25*(3), 172-180.

Wong, J. G., Clare, C. H., Holland, A. J., Watson, P. C., & Gunn, M. (2000). The capacity of people with a 'mental disability' to make a health care decision. *Psychological Medicine, 30*(2), 295-306.

Wright, A., & Shaw, J. (2018). The spectrum of end-of-life care: an argument for access to medical assistance in dying for vulnerable populations. *Medicine, Health Care and Philosophy*, *22*(2), 211-219.

Yi Wood Mak, Y. & Elwyn, G. (2005). Voices of the terminally ill: uncovering the meaning of desire for euthanasia. *Palliative medicine*, *19*(4), 343-350.

You, J.J., Downar, J., Fowler, R.A., Lamontagne, F., Ma, I.W., Jayaraman, D., Kryworuchko, J., Strachan, P.H., Ilan, R., Nijjar, A.P., Neary, J., Shik, J., Brazil, K., Patel, A., Wiebe, K., Albert, M., Palepu, A., Nouvet, E., des Ordons, A.R., Sharma, N., Abdul-Razzak, A., Jiang, X., Day, A., Heyland, D.K. (2015). Barriers to goals of care discussions with seriously ill hospitalized patients and their families: a multicenter survey of clinicians. *JAMA Internal Medicine*, *175*(4), 549-56.

Zhou, Y., Shelton, W. (2020). Physicians' End-of-life Discussions with Patients: Is There an Ethical Obligation to Discuss Aid in Dying? *HEC Forum*, *32*(3), 227–238.