Supporting Palliative Care in a Post-*Carter* World

by

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Author’s Declaration

I hereby declare that I am the sole author of this thesis. This is a true copy of the thesis, including any required final revisions, as accepted by my examiners.

I understand that my thesis may be made electronically available to the public.

Abstract

Traditionally, most Palliative Care physicians have adhered to the World Health Organization's definition of Palliative Care, according to which it "intends neither to hasten nor postpone death." The 2016 legalization of Medical Assistance in Dying (MAiD) in Canada, however, has thrown this understanding into question, and has forced Palliative Care physicians to reconceive their role in caring for patients who experience intolerable suffering.

The role of Palliative Care in MAiD, in particular, has provoked intense debate amongst Canadian Palliative Care physicians and their representative organizations. In November of 2019, three national organizations—the Canadian Society of Palliative Care Physicians (CSPCP) in conjunction with the Canadian Hospice and Palliative Care Association (CHPCA), and the Canadian Association of MAiD Assessors and Providers (CAMAP)—each issued conflicting policy statements that addressed the role of Palliative Care in MAiD. The CSPCP and the CHPCA distanced the practice of Palliative Care from MAiD, arguing that MAiD differs substantially from Palliative Care in "philosophy, intention, and approach," and should not be considered part of Palliative medicine. Alternatively, CAMAP strongly advocated for the integration of MAiD and Palliative Care to support the needs of patients.

This national divide caused distress amongst the Palliative Care community, as many physicians are still deciding how they will continue to respond to MAiD, and are turning to their professional organizations for guidance. Given this sharp division, my dissertation aims to understand two things: first, the challenges that Palliative Care and its physicians face in the era of MAiD, and second, the best way of conceiving of the relationship between Palliative Care and MAiD. In order to advance this conceptual understanding, I conducted interviews with 51 Palliative Care physicians. This dissertation is grounded in the voices of those physicians who have a particular, nuanced understanding of Palliative Care practice, and what supports it needs going forward. It is from these interviews that I offer systems and policy recommendations that are designed to support Palliative Care overall, and those whom it serves.

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I am grateful to the Department of Philosophy at the University of Waterloo. The Department has supported me in my learning and my (unusual) research. For this, I am thankful to everyone in the Department, for supporting and believing in me, and helping me complete this work. Thank you to Angela and Tawnessa for your continued administrative support.

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To my research team, the MAiD and Palliative Care Research Group (MAP), I extend my heartfelt thanks and gratitude. Thank you for your continual support -- from the first study that led to this dissertation, and throughout my Ph.D.

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Finally, to my parents, Mike and Anne, who deserve all of the thanks that I can give. I would not be where I am today or have been able to do this without your unyielding love and support. You are my inspirations in life, both personally and professionally. Thank you for always believing in me and trusting my path, especially when I did not.

Dedication

This dissertation is for all Palliative Care physicians. Thank you for your devotion to the practice of Palliative Care, and to the care of your patients. Each of you inspired me and was the motivation for this project. It has been a privilege and honour to hear your stories and experiences. Thank you for trusting me and allowing me to share them.

I want to dedicate this dissertation to two Palliative Care physicians in particular. First, to my dear friend and mentor, Dr. Brian Kerley. Dr. Kerley, it is because you believed in me that I began this work and my first research study in 2016. This initial study led me to pursue doctoral studies in supporting Palliative Care and its physicians. Throughout my Ph.D., you were one of the physicians who was a reminder of why I am doing this work. I am grateful for your mentorship, friendship, and unwavering support. Thank you for your continued dedication to Palliative Care, the compassion and support that you offer to your patients, and everyone you interact with.

Second, to my mother, Anne. You have been my inspiration since you went to medical when I was three years old. As I have grown up, I have witnessed the unparalleled compassion and care that you give to your patients and to everyone in the medical field. You do so much that is often unnoticed and underappreciated. You have sacrificed a lot to be a Palliative Care physician, and the world of Palliative Care is better because of you. It is a privilege to be your daughter, and to have the experiences and life in Palliative Care because of you. This Ph.D. is for you. Thank you.

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Chapter 1: Introduction

In 2015, the Supreme Court of Canada struck down the legal prohibition on Medical Assistance in Dying (MAiD). Subsequently, the government legalized MAiD with the passage of Bill C-14 in June 2016. This legislative change altered the landscape in Canada, culturally, legally, and medically, both for its citizens and its physicians. This change has become particularly acute for Palliative Care physicians as they care for the patient population to which the MAiD legislation may apply: those who have a life-limiting illness, and who are suffering intolerably.[1] Consequently, the introduction of MAiD has created new challenges for Palliative Care physicians. In addition to navigating a complex medical system, they are now faced with having to quickly adapt to the host of ethical, legal, and practical issues that have accompanied the practice of MAiD. Palliative Care physicians are now engaging in increasingly difficult cases (and conversations) in end-of-life care as they are managing conflicting views and values of their patients, colleagues, and institutions. These changes and the pace in which they are occurring (and have occurred) contribute to a context in which physicians are at risk of feeling distressed, disenfranchised, or experiencing burnout.

The obligation to understand the experiences of Palliative Care physicians, the challenges that they face, and what support needs they have (particularly since the introduction of MAiD) has become critical for institutions, organizations, policymakers, and governmental bodies. These parties have an interest in understanding these issues because Palliative Care physicians (as well as other healthcare professionals who work in Palliative Care)[2] have a sophisticated, nuanced

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[1] Having a life-limiting illness and intolerable suffering are the two criteria that a patient must meet to be eligible for MAiD. Having a life-limiting illness alone is insufficient.

[2] I recognize that there are many groups and people who make up the "backbone" of Palliative Care – from nurses, social workers, other allied health, and administrators. However, as this research focused on Palliative Care

understanding of what Palliative Care is like in 2020 and what the discipline needs going forward. The distinct insights that Palliative Care physicians have around what supports they need to continue to provide high-quality Palliative Care is vital not only to physicians but also to the patients that they care for, and the healthcare system as a whole. In supporting the physicians who practice Palliative Care, we will support the development of Palliative Care as a discipline, as well as the care of patients, and access to Palliative Care, a service that 62-89% of our population, and nearly all of those who do not die unexpectedly, will benefit from or experience.[3] As such, there is a responsibility of those who can effect change in the medical systems, to make legislative or policy changes that will support Palliative Care and its physicians. If the current policies and systems do not evolve to better support physicians, they will not be able to care for their patients as well as they could, which would be detrimental to the current state of health care.

To understand what changes needed to be made to support Palliative Care in Canada better, I interviewed Canadian Palliative Care physicians who belong to the Canadian Society of Palliative Care Physicians, or are part of the Palliative Care section of the Ontario Medical Association. Through qualitative interviews with 51 Palliative Care physicians from across Canada, I came to understand what Palliative Care means to them, the specific patient populations they care for, and their perceptions of them, how MAiD as affected them and their practice of Palliative Care, what role they see as Palliative Care having in the ongoing development of MAiD in the future, and what systems and policy changes need to be implemented to support them and the patients or whom they care. Hearing these physicians' voices and experiences is vital to understanding how

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physicians specifically, the attention is on how to support them. Physicians are part of the backbone of Palliative Care.

[3] Canadian Institute for Health Information. *Access to Palliative Care in Canada*, 2018.

to improve Palliative Care as a discipline and the unique support needs of patients receiving Palliative Care in this changing medico-legal landscape.

While gaining insight into Palliative Care physicians' perspectives on what Palliative Care needs in 2020 is objectively important, my engagement in this research is grounded in my personal experiences and work in Palliative Care and with Palliative Care physicians.

I grew up in the world of Palliative Care. My mother is a Palliative Care physician who went to medical school when I was three years old. As a result, it was not uncommon for my mother to take me with her to the hospital, or for a home visit if my father was away. While she tended to her patients, her colleagues looked after me. Consequently, I came to know those who practiced Palliative Care quite well and now call many of them my close friends or even family. Growing up around Palliative Care physicians, I gained a particular insight and perspective into who these physicians are, [4] the practice of Palliative Care, and the patients whom they look after. I came to know that these physicians care for patients with complex illnesses, are in pain, scared, and at times actively dying or suffering tremendously. I witnessed these physicians going on house calls in the middle of the night (because my mother and her colleagues did so) to manage the pain or symptoms of a patient, be there as their patient died, or simply support a scared or grieving family. Over the years, I saw the commitment and care these physicians, and their team members had for their work and the personal sacrifices to care for their patients. Because of these experiences, I have a strong appreciation and admiration for Palliative Care physicians and the practice of Palliative Care. Their work is not always easy; at times, it is incredibly difficult.

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[4] I also came to know the nurses, social workers, chaplains, and residents well as my mother's team and colleagues are multi-disciplinary. However, because this dissertation focuses on physicians' views, I have limited it to physicians.

However, this is outweighed by the care and support they give to patients and their families, and the joy they experience from these interactions.

In 2014, I became colleagues with some of these Palliative Care physicians when I assumed the role of an in-house ethicist at a local hospice. I worked with Palliative Care physicians and their teams and saw the care they provided to patients and their families. I also witnessed them navigate the myriad of issues that arise when caring for patients (and, their families) who are in hospice: understanding and supporting the needs and values of each patient as they neared the end of life, the complexity of family dynamics and differing values, communication, withdrawing or withholding interventions, and pain and symptom management, to name a few. The way these Palliative Care physicians (and their teams) approached these complex issues with the utmost skill, grace, care, and compassion was impressive. Amongst the issues that they were confronted with were requests for hastened death. While these requests were not common, they were also not uncommon. At the time we heard these requests, assisted death (now MAiD) was illegal. As such, a request for MAiD was one on which physicians could not act. However, Palliative Care physicians understood these requests as a plea to end suffering or that their patients could not live any longer in their current state. Physicians continued to provide them with excellent Palliative Care to help these patients and improve their quality of life, to alleviate their pain and suffering as much as possible.

In 2015, the nature of the interactions and conversations with patients around MAiD changed, as MAiD became a legal option for some patients. This change distressed many Palliative Care physicians because they care for the patient population that the *Carter* ruling and later Bill C-14 would most directly affect (those who had a life-limiting illness and were suffering intolerably). I saw Palliative Care physicians whom I had come to know and love, wrestle with what this ruling would mean for them, and the practice of Palliative Care. Initially, many physicians spoke of how the practice of MAiD stood in contrast to everything they believed in and had been practicing. Physicians believed that while they had been trained to help patients live as well as possible until the moment of their death, and to die well, ending a patient's life intentionally had not been part of their training, or part of the philosophy of Palliative Care. Given the uncertainty of the medical landscape at the time, some Palliative Care physicians wondered if and how they could continue to practice in this field of medicine, or medicine at all. Many Palliative Care physicians were heartbroken because MAiD called into question the purpose and intention of Palliative Care, a specialty that they viewed as their vocation in life. There were pervasive concerns and uncertainty around the relationship between MAiD and Palliative Care, including whether Palliative Care physicians would be asked to provide MAiD as part of their practice of Palliative Care.

Some physicians, however, were in favour of the ruling and thought they would participate in providing MAiD to their patients. Initially, these views divided the Palliative Care community into two camps: those against the ruling, and those who were in favour of it. This division exacerbated the distress felt by all physicians because they felt that they could no longer turn to their colleagues for support. Physicians in both camps were worried about what their colleagues would think of them and how this might affect their collegial relationships. The inability to turn to their colleagues for support during this time left many physicians feeling worried and alone.

As I witnessed the mounting distress amongst this community of physicians, it was evident that research was needed to understand Palliative Care physicians' views around MAiD and how to support them as MAiD was developed in Canada. I reasoned that if the physicians I worked with felt this way, other physicians likely had similar worries. I approached a well-known researcher in the area and asked her thoughts on my idea to study the impact of the *Carter* ruling on Palliative Care physicians. She told me that, "Europe has already figured this out," that my idea was "stupid" and that no one would care about the findings. My instincts, however, told me that she was wrong. A few weeks later, I spoke with the Palliative Care physician with whom I was working at the hospice about my intuition to start this study. He said, "Cait, that researcher is wrong. She is not a physician, and she is not practicing medicine during this time. We need this work. I need this research to be done. Get going." I heeded the advice of this trusted physician. In March of 2016, I assembled a research team comprised of a Palliative Care physician, a Palliative Care nurse, and a psychologist (who focuses on Palliative Care),[5] and started a study to understand the impact of the *Carter* ruling on Palliative Care physicians, and what supports they needed going forward. With the support of this team, I interviewed 44 Palliative Care physicians who practiced within Local Health Integrated Network (LHIN) 4 and within the McMaster University catchment area, about the impact of the *Carter* ruling on Palliative Care physicians, and their perceptions of the decriminalization of physician-assisted death. We completed all interviews before June 2016 when Bill C-14 was passed to capture physicians' views and concerns during the time of uncertainty as to how MAiD would be enacted in Canada. At the time, the 44 interviews conducted represented a 94% response rate from the Palliative Care physicians practicing in the LHIN. This response rate indicated that the decriminalization of MAiD, and the concerns around it, were of great importance to Palliative Care physicians. They wanted to share their thoughts and experiences and have their voices heard.

The study found that Palliative Care physicians believed that the landscape in which Palliative Care is practiced had changed. As a result, many of them were reconceiving what

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[5] Later, our team grew to include two additional Palliative Care physicians, as well as a researcher.

Palliative Care meant and how it would continue in parallel with, or intersect with MAiD. The physicians had layered, multilevel ways of thinking and feeling about the ruling, and their views were diverse. Interestingly, some physicians had mixed feelings within themselves; while some viewed the ruling as a "great thing for society," they had concerns for Palliative Care, stating that "taking human life just changes us fundamentally who we are as human beings."[6] The internal struggles within many physicians were visible, and several of them wrestled with delineating their views as a physician from their views as a person. Many physicians went into Palliative Care because it aligned with a belief or value set that they sincerely held as individuals. Therefore, when asked what their reaction to the ruling was as a human versus as a physician, many said, "It is the same thing." As such, many physicians spoke about how the *Carter* ruling has made them "re-evaluate what [is] meant by the whole do now harm, and the *Hippocratic Oath*, and everything we have been working towards" and that assisted death forced them to reflect on what it means to be a person and a physician because "physician-assisted death is harm and it contradicts everything we have been trained to embody."[7]

When asked what they would do (which many physicians interpreted as "will you participate?"), the responses were varied with very few definitive "yes" or "no" answers. Interestingly, some physicians who were in favour of the ruling also said they would not be able to provide MAiD. While they believed that allowing MAiD might be the right option for some of their patients, they knew within their hearts that they could not end the life of another person, intentionally. Alternatively, some of the physicians who were (and are) fundamentally against MAiD, said that they might consider it if it is what a patient wanted. The majority of physicians were thinking through where they stood on the issue at the time of the interviews and did not view

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[6] Woods et al., 2017. Interview 44.

[7] Woods et al., 2017. Interview 30.

their decision to participate in MAiD as binary. Many believed that their decision might be situationally dependent or might consider it on a case-by-case basis. Irrespective of their position, all physicians wanted to learn as much as possible about MAiD to educate patients, their families, and other colleagues, and could participate in the process to the extent of their comfort level.

After completing this initial study, it was evident that, with the subsequent passing of legislation, new court cases, and patient cases, there was still work to be done as policy around MAiD was enacted and developed in Canada. I knew that my team's study, from 2016, had just begun to scratch the surface in terms of the research needed to support Palliative Care in Canada and the physicians who practice it. Knowing this, I wanted to further my research and understanding through doctoral studies. This is why I chose to do my Ph.D. in the Applied Philosophy Program at the University of Waterloo. As many of the debates and questions surrounding MAiD and Palliative Care are philosophical, I knew that my work would be best supported by a Philosophy Department with academics who specialize in applying philosophical thought and concepts to real-world applications. Having a firm understanding of the philosophical issues that underpin MAiD and Palliative Care would situate me well to engage and reflect upon my research from multiple perspectives. To contribute to the academic work and literature on the intersection and relationship between MAiD and Palliative Care in a meaningful way, I knew that I first had to understand the various perspectives, and why they are held. Philosophy challenges current ideologies and asks us to think in a new way and understand others' thinking; it asks us to critically evaluate assumptions and arguments. Through my doctoral studies, with the mentorship of applied philosophical scholars, I gained the skills to look at contentious issues from multiple perspectives, and understand these perspectives with compassion.

As I worked through my Ph.D. studies, it became apparent that Palliative Care physicians were still struggling. While MAiD was a pervasive issue amongst all Palliative Care physicians, it became clear that it was not the only challenge that they faced. The overarching concerns, including MAiD, were systems and policy issues that posed challenges and impeded their ability to practice Palliative Care and provide high-quality care to their patients. As a result of these challenges, physicians struggled and, in some cases, were burning out or leaving the practice of medicine. Physicians told me that when they voiced their frustrations around their troubles to those who could effect change, they were given responses that revolved around micro-level solutions of individual health and wellness. However, what physicians needed were macro-level supports, support in changing systems, and Palliative Care policies. Physicians were frustrated by systems and institutions not listening to their concerns, and the subsequent lack of change and support. These frustrations and struggles were the impetus for the Ph.D. study research: to understand how to support Palliative Care at the systems and policy level, what systems and policy changes need to be implemented to support Palliative Care, the physicians who practice it, and their patients. The overall goal of the study and this Ph.D. was to make recommendations to medical organizations and governmental bodies about how to support Palliative Care going forward. This work had not been done before, and as such, a gap needed to be filled.

Less than three months before I began the interviews for my Ph.D. research in March 2019, the Federal Government published the national Framework on Palliative Care in Canada, highlighting the need for Palliative Care research.[8] The Framework called for research and data collection on Palliative Care and what measures are needed to support Palliative Care providers. The Framework pointed to the need for the research to be done as there is a current gap in

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[8] The Framework was released on December 11, 2018.

knowledge about to support Palliative Care and its physicians. The publication and content of this Framework indicated that my research would fill a gap in this area and contribute to the body of knowledge on how to support Palliative Care and its physicians and ensure better access to patients who need it.

Organization of dissertation chapters

The organization of this dissertation is designed to promote an understanding of Palliative Care, and how to support it by grounding it in the current medico-legal landscape of Medical Assistance in Dying. The subsequent chapters have been written to facilitate this. Beginning with a brief introduction to Palliative Care, and the decriminalization of MAiD, the dissertation moves through and examination of Palliative Care from the perspective of the physicians who practice it, the issues that they face, and their views on how Palliative Care should intersect with MAiD. After an examination of the views of physicians, highlighting the national debate, I adjudicate the role of Palliative Care in MAiD by introducing a new way of thinking about the relationship between the two practices. Finally, I offer recommendations as to how Palliative Care can and should be supported in the future. A brief description of each chapter follows below.

Chapter 2 introduces Palliative Care at a fundamental level: how it has *traditionally* been understood, what Palliative Care physicians do, the origins of the practice and how it came to Canada, and why it is at the forefront of the minds of Canadians. The Chapter begins with a discussion of the World Health Organization's (WHO) definition of Palliative Care. The WHO defines Palliative Care as,

> …an approach that improves the quality of life of persons and their families facing the problem associated with **a life-limiting illness**, through the prevention and relief of suffering by means of early identification and impeccable **assessment and treatment of pain and other problems, physical, psychosocial and spiritual.**[9]

Furthermore, Palliative Care intends neither to hasten nor postpone death.[10] This definition has been traditionally accepted and adhered to by many Palliative Care Physicians, particularly by those physicians who have been practicing for many decades, and before the introduction of MAiD. With a basic understanding of what Palliative Care is, the Chapter will move to a brief examination of the origins of Palliative Care, focusing on the work and story of Dame Cicely Saunders, and how Dr. Balfour Mount (a Canadian Palliative Care physician) was introduced to the practice, and, subsequently, how the practice of Palliative Care came to Canada. This Chapter acts as a foundation for the subsequent chapters. It is only with this understanding that we can move to discussions around Medical Assistance in Dying (MAiD), and why the decriminalization of it has posed problems for Palliative Care as a discipline and for the physicians who practice it, understanding Palliative Care physicians at a nuanced level, and the challenges that they face as a discipline and as individual physicians, and why the intersection of MAiD and Palliative Care is complex.

Chapter 3 will introduce Medical Assistance in Dying (MAiD). The Chapter begins with a history of MAiD in Canada and examines the legal cases that led to the practice's decriminalization. Starting with an examination of *Rodriguez v. British Columbia* (1993), the Chapter details the reasons why Rodriguez applied for her physician to assist her in her death, and the Court's reasoning to dismiss her case and the final ruling. With an understanding of *Rodriguez*,

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[9] "Palliative Care." *WHO International*, 28 Jan. 2012, www.who.int/health-topics/palliative-care. Accessed 10 Feb. 2018.
[10] Ibid.

the Chapter moves to a discussion and examination of the *Carter* rulings (both from 2012 and 2015), focusing on the 2015 decision from the Supreme Court to overturn the formerly held prohibition on physician-assisted death. After a discussion of the legal rulings that led to the decriminalization of MAiD in Canada, I discuss Bill C-14, the Bill that amended the Criminal Code in Canada, and created legislation and eligibility criteria for MAiD in Canada. After an examination of the legislation, I will provide a brief scan of the policies and procedures that individual provinces have crafted around the implementation of MAiD. I will highlight the inter-provincial similarities and differences, focusing on the impact of these differences on a patient's ability to access MAiD services.

After establishing the background for MAiD in Canada, Chapter 4 engages in a linked discussion of the philosophical and bioethical debates around the practice. This Chapter summarizes some of the most influential moral and philosophical arguments for and against the legalization of MAiD. While the moral permissibility of MAiD was a hotly contested issue in Canada well before the *Carter* ruling in Canada (and, even after the *Carter* ruling), and remains the subject of active debate in other jurisdictions where MAiD has not yet been decriminalized or legalized, this debate will not be taken up in this dissertation. Instead, since the dissertation focuses on and was written in and for a "post-*Carter"* world, this Chapter will focus on issues that have *resulted* from the legalization of MAiD in Canada. Some of the issues that will be examined in this Chapter are the continued debates over the moral significance between "killing" and "letting die"; conscientious objection to, and conscientious provision of, MAiD from the perspective of both physicians and institutions; and the impacts of both decisions. The Chapter will also discuss the current eligibility criteria and the issues surrounding the broadening of the criteria with particular attention to mature minors, those with a mental illness, and those with progressive, (neuro) degenerative illnesses such as Amyotrophic Lateral Sclerosis or dementia who make advanced requests for MAiD.

With the two foundational Chapters on Palliative Care and MAiD complete, the dissertation moves to a discussion of the research that was conducted with Canadian Palliative Care physicians.

Chapter 5 outlines the qualitative study done for this dissertation, which involved interviews with 51 Palliative Care physicians from across Canada. The Chapter sets out the aims and methods of the study and then briefly outlines the findings, which are taken up in more detail in the subsequent chapters. It was found that five themes emerged from the interviews with physicians.

1. MAiD is a prevalent issue amongst all Palliative Care clinicians (for those who provide it as well as those who conscientiously object to the practice);
2. Access to high-quality Palliative Care is not readily available to all Canadians;
3. Community and Homecare support are under-resourced and under-funded;
4. Professional teams and family members are sources of support for physicians; and,
5. Education in and around Palliative Care is lacking for the public, policy makers, medical learners (students and residents), and other healthcare professionals.

Following a brief discussion of each theme, the Chapter concludes with a brief analysis of the findings.

Chapters 6 and 7 examine the study's findings, focusing on the challenges Palliative Care and Palliative Care physicians face and how Palliative Care should relate to or intersect with MAiD in the future.

Chapter 6 explores the Palliative Care physicians who practice in Canada, focusing on the demographics of the physicians who participated in the study, what Palliative Care means to them, and how and why they came to practice it. With an understanding of *who* the Palliative Care physicians are in Canada, the Chapter highlights themes from the responses of physicians to questions around the challenges facing Palliative Care and what they find to be most challenging as individual Palliative Care physicians. The Chapter then shifts to understanding the systems and policy changes that physicians identified as needing to be implemented in order to support them as Palliative Care physicians better, and what changes would better support Palliative Care patients.

The interviews revealed that the relationship between Palliative Care and MAiD is a critical and passionately debated issue within the Palliative Care community. Chapter 7 explores this relationship through the lens of a disagreement between two organizing bodies for Palliative Care physicians. In November 2019, the Canadian Society of Palliative Care Physicians (CSPCP) and the Canadian Association of MAiD Assessors and Providers (CAMAP), published competing statements about their views and vision of the relationship between Palliative Care and MAiD, highlighting differing models as to how this relationship should be approached. The CSPCP opposes the practice of MAiD and wants it to remain a separate practice from Palliative Care. It argues for what I will call, a Separation-Opposition Model. Alternatively, CAMAP advocates for the two practices to be integrated, thus proposing an Integrated Model. Chapter 7 examines the policies and models from these organizations as well as the views of physicians about what they believe their role should be in the ongoing development of MAiD in Canada. After examining these models and values, in Chapter 8, I propose a third model, the Collaborative Model, that can reconcile the two practices, their respective organizations, and the physicians' views.

Chapter 9 is divided into two sections. The first will discuss what systems and policy changes Palliative Care physicians cited would better support them, and their patients. The latter part of the Chapter will propose recommendations that are designed to support Palliative Care in general. These recommendations were devised for medical organizations and government bodies, or those who can effect change.

Chapter 2: An Introduction to Palliative Care

Introduction

The Supreme Court of Canada's decision in *Carter*, and the subsequent passage of Bill C-14 that legalized MAiD, has brought conversations around end-of-life to the forefront of our society. These conversations have shone the spotlight on Palliative Care, explicitly highlighting the role of Palliative Care in caring for patients who have intolerable suffering, and in the development and practice of MAiD. Despite these increased discussions, there is still a general misunderstanding of what Palliative Care is, what it is not, what Palliative Care teams do, and who can benefit from a palliative approach to care.[11,12,13] The unfortunate reality is that Palliative Care is often viewed as being synonymous with death and dying. There are prevalent misconceptions that Palliative Care providers are "Dr. Death,"[14] that "Palliative Care is MAiD" or that Palliative Care means "you give morphine and they die."[15] The other assumption is that Palliative Care happens only, "when other specialties have given up hope."[16] These misunderstandings are rooted in the general lack of understanding of Palliative Care. While the public may be aware of Palliative Care, now primarily due to the spotlight from discussions around MAiD, they do not have an adequate or accurate understanding of it. This lack of understanding is not isolated to the general public; it extends to some (healthcare) policymakers and even some healthcare providers. The problem with this widespread lack of understanding is that it impedes access to Palliative Care. If the general public does not understand Palliative Care, they will not ask for it. If policymakers do

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[11] McIlfatrick, Sonja, et al. "How well do the general public understand Palliative Care? A Mixed Methods Study." *BMJ Supportive & Palliative Care*, British Medical Journal Publishing Group, 1 March. 2014, p 1.

[12] Lane, Trevor, et al. "Public Awareness and Perceptions of Palliative and Comfort Care." *The American Journal of Medicine*, vol. 132, no. 2, 2019, pp. 129–131.

[13] Patel, Priya, and Laura Lyons. "Examining the Knowledge, Awareness, and Perceptions of Palliative Care in the General Public Over Time: A Scoping Literature Review." *American Journal of Hospice and Palliative Medicine*, vol. 37, no. 6 May, 2019, pp. 481–487.

[14] Interviews 33, 45.

[15] Interviews 11, 40.

[16] Interview 25.

not understand Palliative Care or its value, they will not enact legislation or policy, or allocate funding to support it. When other healthcare providers do not understand Palliative Care, it can result in them not consulting Palliative Care, or consulting them too late when there is little that can be done. However, if these groups had a more nuanced understanding of what Palliative Care is, the aims and goals of this approach to care, and how it can support patients (and their families), not only would misconceptions be less prevalent, it would mitigate the perpetuation of stereotypes that Palliative Care physicians face, and the barriers to patients accessing care.

This chapter will provide a brief introduction to Palliative Care: what it is, the origins of the profession and how it came to Canada, and why issues related to Palliative Care are now at the forefront of the minds of many Canadians. It is with this initial understanding that we can move to understand the impact and importance of the legalization of MAiD in Canada, the challenges that face Palliative Care and the physicians who practice it, how Palliative Care can intersect with MAiD, and what systems and policy changes will benefit the discipline of Palliative Care, its physicians, and the patients to whom they provide care.

Palliative Care: A basic understanding

One of the most widely cited definitions of Palliative Care is from the World Health Organization (WHO).[17] The WHO describes Palliative Care as:

> …an approach that improves the quality of life of persons and their families facing the problem associated with **a life-limiting illness**, through the prevention and relief of suffering by means of early identification and impeccable **assessment and treatment of pain and other problems, physical, psychosocial and spiritual.** Palliative care:

- Provides relief from pain and other distressing symptoms;
- Affirms life and regards dying as a normal process;

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[17] The WHO definition is widely used when defining Palliative Care. The Framework on Palliative Care in Canada, a document created by the Government of Canada, uses the WHO definition to define Palliative Care.

- **Intends neither to hasten or postpone death**;[18]
- Integrates the psychological and spiritual aspects of care;
- Offers a support system to help persons live as actively as possible until death;
- Offers a support system to help the family cope during the person's illness and in their own bereavement;
- Uses a team approach to address the needs of persons and their families, including bereavement counseling, if indicated;
- Will enhance the quality of life, and may also positively influence the course of illness;
- Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to understand better and manage distressing clinical complications.[19]

From this definition, we see that Palliative Care is distinguished from many other specialties of medicine because its aim is not to cure the patient's life-limiting illness or to prolong or postpone death. Rather, the goal of Palliative Care is to support patients who are living with a life-limiting illness by helping to improve their quality of life, to mitigate or alleviate pain and suffering, support their goals of care in the context of their illness, and help them to die well. Unfortunately, due to these aims, and their patient population, Palliative Care has been misunderstood as distinct from active medicine and viewed as a practice that is only implemented "…after life-prolonging treatment has been ineffectual, and death is imminent."[20] This understanding of care for patients who have life-limiting illnesses is mistaken for at least two reasons. First, it mistakenly implies that the treatment of pain and suffering is not central to the practice of medicine. Second, it overlooks the ways in which Palliative Care often works in conjunction with other therapies that prolong life, such as chemotherapy or radiation.[21] In these instances, Palliative Care may actually help to prolong life. For example, a patient who has cancer and is undergoing chemotherapy may

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[18] I added the bold to emphasize part of the WHO's definition that Palliative Care physicians have adhered to in the past, particularly those who object to MAiD.

[19] "Palliative Care." *WHO International*, 28 Jan. 2012, www.who.int/health-topics/palliative-care. Accessed 10 Feb. 2018.

[20] CAPC Palliative. "Dr. Diane E. Meier, Defining Palliative Care." *YouTube*, 5 Feb. 2015, www.youtube.com/watch?v=kCbNeAlRitY. Accessed 23 May 2020.

[21] "Palliative Care." *WHO International*, 28 Jan. 2012, www.who.int/health-topics/palliative-care. Accessed 10 Feb. 2018.

have such severe symptoms such as nausea, vomiting, and constipation, that they feel that they are physically unable to continue with their chemotherapy treatment. However, if Palliative Care is able to treat these symptoms then the patient may be able to return to chemotherapy, which is a life-prolonging treatment. It is instances like this one that we see that Palliative Care works in conjunction with other disciplines to not only improve the quality of life of patients living with a life-limiting illness but to prolong life.

While addressing and treating physical symptoms is an important aspect of the work of Palliative Care, it is not the only way in which Palliative Care cares for their patients. Palliative Care also tends to the non-physical, psycho-social, or spiritual elements of a patient's suffering. As one physician stated, Palliative Care is "…the perfect blend of science and art."[22] It uses medicine to first tend to the medical needs of the patient by addressing the physical symptoms and suffering. Once those physiological needs have been tended to, Palliative Care is able address the psychological, social, emotional, and spiritual needs of the patient and support the caregivers.[23] In this way, Palliative Care is holistic because it focuses on "treating the disease but also on the human being who is living with that disease."[24]

The ability to treat the whole person is accomplished through the interdisciplinary team approach to care. Palliative Care often works in multidisciplinary teams with members from medicine, nursing, psychology, social work, chaplaincy or spiritual care, physiotherapy,

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[22] Woods A, O'Donnell C, et al., "Uncommon Bedfellows: New Insights into the Complex Relationship between Palliative Care and Medical Assistance in Dying." Canadian Bioethics Society Conference. Montreal, QC, 25 May 2017.

[23] Health Canada. "Framework on Palliative Care in Canada." Government of Canada, 4 Dec. 2018, www.canada.ca/en/health-canada/services/health-care-system/reports-publications/palliative-care/framework-palliative-care-canada.html. Accessed 4 Dec. 2018.

[24] CAPC Palliative. "Dr. Diane E. Meier, Defining Palliative Care." *YouTube*, 5 Feb. 2015, www.youtube.com/watch?v=kCbNeAlRitY. Accessed 23 May 2020.

occupational therapy, and even music therapy.[25] The team aims to treat the whole person and support them in a treatment plan that best aligns with the patient's goals, given the context of their illness. While Palliative Care cannot provide a panacea to their patients, they will try to support them to be cared for in a way that they want and to live in a way that accords with their values, given the context of their illness. Palliative Care works with patients and discusses the goals of care, treatment, and care options that are possible given the context and stage of the illness as well as what the patient (and their loved ones) wants or needs as their illness progresses.

Origins of Palliative Care (in Canada)

The story of Palliative Care as a distinct medical specialty began in 1939 in London, England, with a young woman named Cicely Saunders. When World War II broke out, Saunders, then a social worker, became a nurse and started working at St. Thomas Hospital in London, England.[26] During this time, she met David Tasma, a 40-year-old Polish Jew who was dying of cancer, alone, away from his home.[27,28] Nearing the end of his life, David expressed significant physical and moral distress; he was in pain but also felt as if his life was meaningless and unfulfilled.[29] Noticing this distress, Saunders visited David regularly and began to care for him. During their visits, the two would talk about "everything of the mind: research, learning, and scientific rigour."[30] During their two months together, the two became close friends, which Cicely described as "The friendship of the heart [and] the vulnerability of one person before another."

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[25] While other specialties may also employ a multi-disciplinary team approach, Palliative Care is known for this approach because of their goal to provide whole person care to patients. This is not to say that other specialties do not care for the whole person, but it is more likely for a Palliative Care physician to work with a chaplain than an orthopedic surgeon or nephrologist, for example.

[26] Lamau, Marie-Louise. "Origin and inspiration. Cicely Saunders at the birth of palliative care," *Review of ethics and moral theology*, vol. 282, no. 5, 2014, pp. 55-81.

[27] Ibid.

[28] Saunders, C. "The Evolution of Palliative Care," 8.

[29] Ibid.

[30] Ibid.

When David died, he left Saunders 500 British Pounds to "open a window in [her] future establishment."[31]

As Saunders continued her work at St. Thomas Hospital, she noticed that her physician colleagues did not take into account the individual needs of each patient, and were "reluctant to see the patients as a 'whole.'"[32] At the time, hospitals were hesitant to admit patients whom they deemed to be incurable because medical treatment for these patients was "against the will of the Gods."[33,34] Principally, the hospital (and its physicians) focused on the ability to cure physiological ailments, and if this could not be done, treatment was deemed futile. However, Saunders did not agree with this idea that patients who had life-limiting illnesses should not be cared for simply because they could not be cured. For patients with terminal or life-limiting illnesses, Saunders believed that the new goal of physicians should be to "*care* rather than *cure.*"[35,36] Saunders expressed her frustrations with the status quo of the approach to care for the dying to a surgeon with whom she was working. He said that it was physicians who often deserted the dying and that Cicely should "go and read medicine" because there was so much more to learn about pain and that she would continue to be frustrated unless she did it properly, herself.[37] Thus, at the age of 33, Saunders went to medical school to change the approach to care for patients who could not be cured of their illnesses. Nineteen years later, in 1967, Saunders, granted David Tasma's wish by building *St. Christopher's Hospice*.[38] The hospice was a place where patients who faced life-limiting illnesses could be cared for while dying.

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[31] Ibid.
[32] Ibid.
[33] Ibid.
[34] This highlights the traditional view of medicine, which was to *cure.*
[35] Ibid.
[36] Saunders, 1976a.
[37] Saunders, "Evolution of Palliative Care," 9.
[38] Lamau, 63.

The idea of, and approach to, caring for those patients who could not be cured of their illnesses and who were dying (now Palliative Care), was introduced to Canada when Dr. Balfour Mount, a former urologist working at Montreal's Royal Victoria Hospital (RVH), heard about Dr. Saunders after reading Elizabeth Kubler-Ross's book *On Death and Dying.*[39] In 1973, Mount contacted Saunders and asked to visit *St. Christopher's* to understand the work that was being done on caring for patients who were dying. Saunders would not allow Mount to just "visit" but demanded that he *"*roll up his sleeves and be prepared to work*"* with her to care for patients.[40] After working with Saunders and her team at St. Christopher's, Mount knew that there was a better way to care for patients who were at the end of life.[41] Knowing that it would be financially implausible to give every patient who needed it the hospice experience, Mount started a pilot project at RVH, from 1975-76.[42] The project was comprehensive; it included caring for inpatients on the ward, a consultation service for other specialties, a homecare team that cared for 100 patients in the community, grief, and bereavement support for patients and their families, as well research and teaching.[43]

With the pilot project underway, this new approach to care still needed a name. While the term hospice already existed, Mount stated that his francophone colleagues advised against using that term "hospice" because it had a negative connotation, and that is "…suggested a dumping ground for mediocre care, signifying the worst of nursing homes."[44] As such, an alternative name for this practice of medicine needed to be created. Thus, this approach to care for patients who were at the end of life or who had life-limiting illnesses was given the name "Palliative Care" by

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[39] "Balfour Mount." *Palliative Care McGill*, 3 May 2016, www.mcgill.ca/palliativecare/portraits-0/balfour-mount. Accessed 3 Apr. 2019.

[40] Ibid.

[41] Ibid.

[42] Ibid.

[43] Ibid.

[44] Ibid.

Balfour Mount.[45,46,47] The term "palliative" is rooted in the Latin term "*palliare*," which means to "cloak" or "protect."[48] However, to Mount, it meant to "improve the quality of." As such, it was the perfect etymology for what Dr. Mount was trying to convey, a type of medicine that would improve the quality of life of patients with life-limiting illnesses.[49] Since Mount first coined the term of Palliative Care in the 1970s, the definition, scope, and practice of this particular field of medicine have expanded.

Conclusion

Since its inception as a distinct specialty in London in the mid-1900s, and its introduction to Canada later in the century, Palliative Care has evolved and has changed the understanding and goals of medicine. From an unknown approach to care started by a former nurse in the United Kingdom, further developed by a Francophone Urologist, Palliative Care has become a specialty of medicine that focuses on the care of patients who have terminal or life-limiting illnesses or who are actively dying and whose illness cannot be cured. Palliative Care seeks to care for the whole person at the end of life by helping to alleviate or mitigate suffering of any kind and help patients live and die well.

Many physicians who practice Palliative Care have understood it as an approach to care that supports patients by improving their quality of life and helping them live and die well; it does not aim to hasten or postpone death. Consequently, the enactment of MAiD in Canada has forced Palliative Care to reflect upon their role in addressing and alleviating suffering in patients who may request a hastened death. Since this enactment, Palliative Care has had to contemplate the

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[45] Ibid.

[46] Allegedly, the name "Palliative Care" was thought of one day while Mount was in the shower.

[47] Saunders, "Evolution of Palliative Care," 10.

[48] Wiener et al., 2.

[49] Ibid.

aims, intentions, and the boundaries of their specialty, specifically, whether Palliative Care should participate in MAiD or if the practice, belongs under the umbrella of their discipline. These questions have caused significant distress and tension within the Palliative Care community and have contributed to the challenges and distress felt by the physicians who practice it. The remainder of this dissertation is devoted to exploring in detail, Palliative Care in Canada, the physicians who practice it, the challenges they face, and what changes need to be made at the systems and policy level to support them now that Palliative Care is practicing in the era of MAiD.

Chapter 3: Medical Assistance in Dying (MAiD)

Introduction

On February 6, 2015, in the case of *Carter v. Canada*, the Supreme Court of Canada (SCC) ruled to overturn our country's prohibition on physician-assisted dying (now Medical Assistance in Dying (MAiD)).[50,51] In its unanimous ruling,[52] the Court declared sections 241(b) and 14 of the Canadian Criminal Code to be invalid.[53] Once the Court had ruled, it was "…in the hands of physicians' colleges, Parliament, and Provincial legislatures" to craft relevant legislation as to how MAiD should be enacted in Canada.[54] Sixteen months after the *Carter* ruling, on June 6, 2016, Parliament passed Bill C-14, *an Act to amend the Criminal Code and to make related amendments to other acts*. With this Bill, MAiD officially became part of the Canadian medical landscape.

The introduction of MAiD in Canada has been a significant change for many physicians and has brought with it a host of practical, moral, and ethical implications. While some physicians welcomed the introduction of MAiD into Canada, many physicians thought that MAiD contradicted what they had been taught throughout their medical career, and what they believed.[55] Before MAiD, Palliative Care physicians were taught how to care for patients with life-limiting illnesses, and to support them to live and die well; however, they were not taught how to end a patient's life intentionally and safely. As such, the introduction of MAiD has led to some physicians reconceiving what they do, and the goals of medicine.[56] Many wondered if they would

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[50] Physician-assisted dying was re-named to Medical Assistance in Dying (MAiD) after Bill C-14 was passed in 2016. Bill C-14 allowed for medical practitioners, other than physicians, to provide MAiD to eligible patients. Therefore, the name was changed from "physician-assisted dying" to "medical assistance in dying."

[51] From here on, I will use the terms MAiD and assisted death interchangeably. It was only after Bill C-14 that assisted death was called MAiD.

[52] A unanimous ruling is significant as it indicates a marked shift in how the Justices believed our country should move forward with MAiD in Canada.

[53] *Carter v. Canada*, Reasons for Judgment.

[54] *Carter v. Canada,* at 132.

[55] Woods et al., 2017.

[56] Woods et al., 2017.

be forced to participate. What would happen if they had a patient who had requested MAiD, but they (the physician) were not comfortable to assist that patient in their request? Alternatively, physicians who have welcomed the introduction of MAiD, or who have come to participate in the practice, have struggled with the stigma around MAiD, feeling isolated or alienated by colleagues, the institutions in which they work, or by their professional associations. These physicians wondered if they would be cast out by their colleagues for supporting their patients in MAiD, or, how could they support their patients if their institutions did not permit MAiD. Further, they worried about working with colleagues who had distinctly different views on the issue.[57] Both camps of physicians struggled with questions of working with other health care professionals, and in institutions, that do not share the same values around MAiD.[58] These were just some of the questions that Palliative Care physicians worried about when MAiD was first introduced to Canada.

This chapter will provide the legal history of MAiD in Canada and will summarize the current state of MAiD policies across Canada. The chapter will begin with a discussion of the predominant legal cases that lead to MAiD being part of the medico-legal landscape in Canada: *Rodriguez v. British Columbia* (1993), the first case that Canada heard about decriminalizing MAiD, and *Carter v. Canada* (2015), the case that decriminalized MAiD in Canada. Following this, I will discuss briefly Bill C-14, the Bill that created Federal legislation around MAiD in Canada. This background will provide the foundation for the subsequent discussion of the practical challenges that coincided with the introduction of MAiD and the current state of MAiD in Canada. Through a brief provincial scan of the provincial policies around MAiD in Canada, I will highlight

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[57] Ibid.
[58] Ibid.

the similarities and differences amongst policies while introducing issues that will be taken up in subsequent chapters.

A Brief History of MAiD in Canada
Rodriguez v. British Columbia (Attorney General) 1993 3 S.C.R. 519

In 1991, Sue Rodriguez was diagnosed with Amyotrophic Lateral Sclerosis (ALS), most commonly known as "Lou Gehrig's Disease."[59] Her condition was deteriorating so rapidly that within a few months, Rodriguez knew that she would lose the ability to speak, swallow, walk, or even move her body without assistance.[60] Eventually, she would be unable to breathe without a respirator, eat without a gastronomy tube, and would be bedridden.[61] While Rodriguez valued her life and wanted to live as long as possible, she was aware of the trajectory of the disease and did not want to endure the end stages of her illness. Rodriguez knew that when her condition deteriorated to the point that she was no longer able to enjoy life on her terms she would not have the physical ability to end her own life. Thus, she petitioned the Court to allow her physician the legal right to assist her in ending her life when she was no longer physically able to do so herself.

Rodriguez applied to the Supreme Court of British Columbia for an order that declared s. 241(b) of the Criminal Code invalid. [62,63] She argued that prohibition on physician-assisted dying infringed upon her Charter rights, specifically her right to life, liberty and security of person (section 7), her right to not be subjected to cruel and unusual treatment or punishment (section 12),

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[59] *Rodriguez,* Reasons for Judgment.

[60] *Rodriguez,* Reasons for Judgment.

[61] *Rodriguez,* Reasons for Judgment.

[62] Section214(b) of the Criminal Code states that,

> Everyone is guilty of an indictable offence and liable to imprisonment for a term of not more than 14 years who, whether suicide ensues or not, aids a person to die by suicide.

[63] Criminal Code, RSC 1985, c C-46, s241(b).

and the right to equal treatment before and under the law, and the right to protection and equal benefit of the law without discrimination (section15). Considering Rodriguez's application, Justice Melvin J, stated that,

> [Rodriguez's] fundamental decisions concerning her life are not restricted by the state. Her illness may restrict her ability to implement her decisions but, in my opinion, that does not amount to an infringement of a right to life, liberty or security of the person by the state. The interests she seeks to protect pursuant to section 7 are not those which determine the means by which she may be brought before or within the justice system.[64]

The judge argued that it was Rodriguez's illness that impeded her ability to end her own life, and not the actions of the State.[65] Furthermore, in petitioning the Court, Rodriguez was effectively asking the Court to "…go beyond the judicial domain and into the realm of public policy," which Courts have been cautioned from doing.[66] As such, the Court dismissed the application. Ms. Rodriguez appealed the decision; however, the Court of Appeal affirmed the decision of the lower Court and dismissed her appeal.

After the lower Court dismissed her initial application, Rodriguez appealed her case to the Supreme Court of Canada. In reviewing the case, the Court considered each of the Charter rights that Rodriguez claimed were violated by s.241(b) of the Criminal Code. First, the Court turned to section 7. Rodriguez argued that as she was physically unable to end her own life, and that the prohibition on assisted death deprived her of her right to life, liberty, and security of person. In examining this claim, the Court sought first to understand what was meant by "security of person" as described in the Charter, and whether this right had been violated. The Court stated that,

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[64] *Rodriguez,* at 533.

[65] Ibid.

[66] Ibid.

> ... personal autonomy, at least with respect to the right to make choices concerning one's own body, control over one's physical and psychological integrity, and basic human dignity ... at least to the extent of freedom from criminal prohibitions which interfere with these.[67]

Based on the interpretation, that section 7 rights include an element of personal autonomy, which, "…protects the dignity and privacy of individuals with respect to decisions concerning their body,"[68] the Court found that s.241(b) did deprive Rodriguez of her right to security of person. With this understanding, the Court then considered Ms. Rodriguez's fear that she would slowly deteriorate until her physical functioning was dependent upon machines, and would eventually die from choking, suffocation, aspiration or pneumonia.[69] It was noted that up until the moment of her death, Rodriguez would maintain full cognitive abilities thus being completely aware of her physical deterioration.[70] While Palliative Care was presented as an option, Rodriguez worried that it would not alleviate the psychological or existential distress of her suffering; it would not help to give Rodriguez back her feelings of dignity, which would be lost from her dependence upon others.[71] Considering these potential ramifications, the Court affirmed that s. 241(b) deprived Rodriguez of autonomy over her person which might result in physical pain and/or psychological stress, to the extent that it would jeopardize her security of person.[72]

Once the Court had confirmed that s. 241(b) of the Criminal Code did infringe upon Rodriguez's section 7 rights – the right to life, liberty, and security of person - it was necessary to

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[67] *Rodriguez,* Reasons for Judgment, 10.
[68] Ibid.
[69] *Rodriguez* at 588
[70] Ibid.
[71] Ibid.
[72] *Rodriguez* at 589.

understand if this violation was demonstrably justified by the fundamental principles of justice.[73,74] While the principle of autonomy is a recognized value of Canadian society,[75,76,77] the Court was aware of the need to balance the rights of the individual with those of the state. The Court found that the state had a fundamental interest in protecting human life, and this interest was encapsulated in s. 241(b) of the Criminal Code since its inception in 1985, which was designed to protect vulnerable people who, in moments of weakness, may be persuaded to commit suicide.[78] The concern of coercion was the reason for the Court's reluctance to actively condone assistance in death, even if the person is terminally ill. Furthermore, the Court unanimously agreed that a blanket prohibition was needed in order to protect the lives of the vulnerable.[79] Thus, the Court found that the prohibition of assisted death served its intended purpose to protect the lives of the vulnerable,

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[73] Rodriguez at 589.

[74] Charter rights may be violated if the Court can show that the violation is justified as a limitation under Section 1 of the *Charter* by passing the *Oakes Test* from the case of *R v. Oakes* [1986]. The onus is on the Crown to show that the Oakes Test is passed. There are two steps to determining if the government can justify a law that infringes upon and individual's *Charter* rights. The first step is to determine the goal of the law is both pressing and substantial. The second step, the proportionality test, has 3 components: rational connection (the law must be rationally connected to the goals), minimal impairment (the law must impair the rights of the individual as little as possible), and proportionate effects (the Court must determine if the effects of the law are proportionate to the goal) (*R v. Oakes,* [1986] 1 SCR103).

[75] Autonomy is widely held societal value; we value autonomy in all respects of the good life, and it plays a foundational role in philosophy, medicine, law, and ethics.

[76] In medicine and medical ethics, the principle of autonomy is often considered to be foundational. In a seminal Bioethics text, *Principles of Biomedical Ethics*, Beauchamp and Childress address the concepts of autonomy, autonomous choice, and respect for autonomy. Beauchamp and Childress state that there are many understandings of the principle of autonomy. However, at their core, they all share the same conditions of liberty (free of controlling of coercive influences) and agency (capacity for intentional action (Beauchamp and Childress, 102). The idea of agency is important to Beauchamp and Childress as it highlights the difference between autonomy and autonomous choice. This distinction is particularly relevant in the context of decisions in healthcare. Beauchamp and Childress argue autonomous persons have the capacity to self-govern but do not always make autonomous choices (Beauchamp and Childress, 101). To make this distinction clearer, the authors set out their three criteria for autonomous choice (decision-making): intentionality, understanding, and non-control. An intentional choice is one in which the outcome corresponds to the actor's intention – the final outcome may not be what the actor had intended, but there is intent; it was not accidental (Beauchamp and Childress, 104). For a choice to be autonomous, the actor must have an adequate understanding of the potential outcomes, consequences etc. of their choice (Ibid.). Beauchamp and Childress contend that someone who does not have the cognitive ability to understand a decision cannot be said to make an autonomous choice. Finally, for a choice to be autonomous, it must be free from coercive influences (Ibid.).

[77] I recognize that there are multiple understandings of autonomy. For this dissertation, I have used Beauchamp and Childress' conception of it.

[78] *Rodriguez* at 590.

[79] Ibid.

and was in accordance with the principle of the sanctity of life.[80] Therefore section 241(b) could not be said to violate the principles of fundamental justice.[81]

The Court quickly dealt with the challenges to sections 12 and 15 of the Charter. In addressing section 12, the Court argued that for a Section 12 right to be violated, the appellant would have had to prove that she was subjected to "cruel and unusual treatment or punishment."[82] The Court found that the prohibition on assisted death was not viewed as a "treatment" within the meaning of section 12 because the State did not have the requisite control over Rodriguez.[83] Consequently, the prohibition could not be said to violate Rodriguez's rights as prescribed under section 12.

Moving to Rodriguez's claim that section 241(b) violated her rights under section 15 as it discriminated against persons with disabilities who were unable to commit suicide. The Court argued that the intention of s.241(b) was to protect the lives of the vulnerable.[84] Thus, to allow an exemption to this rule would lead to a slippery slope, as the current safeguards were insufficient to prevent abuse of permitting assisted death.[85] Thus, it could not be guaranteed that assisted death would only be provided to those who truly consented to die. As such, any violations under section 15 were saved under section.

The Court dismissed Rodriguez's appeal, upholding the ban on assisted dying. While the Court agreed that the ban on assisted death did violate Rodriguez's s. 7 rights, this violation was justified under section 1, as the ban would protect the interests of the vulnerable.[86]

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[80] Ibid.
[81] Ibid.
[82] *Rodriguez* at 609-610.
[83] *Rodriguez* at 611-12.
[84] *Rodriguez* at 600-606.
[85] *Rodriguez* at 608.
[86] *Rodriguez* at 625-627.

For twenty-two years, the ban on assisted death in Canada remained. However, in 2015, the Supreme Court of Canada was tasked with revisiting the issue in the case of *Carter v. Canada*.

Carter v. Canada (Attorney General) Background[87]

In 2009 Gloria Taylor was diagnosed with ALS. Like Sue Rodriguez, Taylor did not want to slowly deteriorate, dying "piece by piece" or "wracked with pain."[88] By 2010, Taylor's condition had deteriorated to the point that she required the use of a wheelchair to go further than short distances, was in significant pain due to the deterioration of her muscles, and became dependent on others to be able to continue to live at home.[89] Taylor viewed her dependence on others as "…an assault to her privacy, dignity, and self-esteem."[90] At the time, due to the prohibition on assisted death, Taylor knew that she was faced with the "cruel choice" between prematurely ending her life while she was physically able to do so or to die from her disease slowly, relinquishing control over how and when her life ends.[91] In an attempt to prevent this from happening, Taylor (like Rodriguez) challenged the constitutionality of section 241(b) of the Criminal Code of Canada that prohibited assisted death.

In 2012, Taylor's case was brought before Justice Smith of the Supreme Court of British Columbia. Justice Smith found that the prohibition on physician-assisted death violated Taylor's rights as prescribed under section 7 of the *Charter.* As such, she invalidated the ban on assisted dying for one year and granted Taylor a constitutional exemption.

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[87] The case name is '*Carter'* because the family of Kay Carter, a woman who traveled to Switzerland, January 2010, to receive assisted death as it was illegal in Canada at the time. Knowing the difficulty of accessing the service, and fear or prosecution, the family of Carter joined Taylor's suit to decriminalize assisted death in Canada.

[88] *Carter* at 11.

[89] Ibid.

[90] *Carter* at 12.

[91] Ibid.

However, Canada appealed this ruling and brought the case before the Court of Appeal. The appellate court found that the trial judge (Justice Smith) did not follow legal precedence and was bound by the Supreme Court's ruling from Rodriguez; a lower court cannot overturn the ruling of a higher court. As such, the Court of Appeal reversed Justice Smith's ruling.

Taylor appealed this decision and brought her case before the Supreme Court of Canada. More than two decades after their ruling in Rodriguez, the Court would revisit the question of legally permitting physician-assisted death in Canada.

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

In their opening remarks, the Court noted that since their ruling in *Rodriguez*, debates around assisted death have continued; between 1991 and 2010, at least six private member bills seeking to decriminalize MAiD were heard.[92] However, none were passed.[93] In addition to these bills, in 2011, the Royal Society of Canada published a report on decision making at the end of life.[94] One of the Report's recommendations was that the Criminal Code should be modified to permit physician-assisted death in particular situations.[95] This report, combined with the various attempted Bills indicated to the Court that, despite their ruling in 1993, Canadians were still (interested in) engaging in debates of whether or not to allow MAiD in Canada.

In revisiting the case, the Court considered why Canada had previously upheld the ban on assisted dying. It was noted that at the time of *Rodriguez,* no other Western, democratic jurisdictions permitted physician-assisted dying. However, by 2010, eight jurisdictions (the Netherlands, Belgium, Luxembourg, Switzerland, Oregon, Washington, Montana, and Colombia)

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[92] *Carter v. Canada,* at 6.

[93] Ibid.

[94] Royal Society of Canada Expert Panel. *End-of-Life Decision Making*. November 2011.

[95] Ibid.

permitted some form of assisted death.[96] To the Court, this indicated a shift in the views of the international community on assisted dying. However, it was noted that despite this shift, many Western countries still viewed MAiD as a criminal offence.[97] Therefore, any consideration of lifting the ban on assisted dying in Canada should be taken seriously.

The crucial issue before the Court was if the prohibition on assisted death was still saved by section 1.[98] Recall from *Rodriguez,* it had already been established that the prohibition did violate an individual's rights under section 7. However, in 1993, the Court found that this violation was not arbitrary nor contrary to the principles of fundamental justice.[99] Thus, the Court had to determine if, two decades later, this was still true.

To better understand if the law prohibiting MAiD was saved under s. 1, the Court considered the right to life separately from the right to liberty and security of person. Addressing the right to life, the Court questioned if this right should extend beyond the traditional understanding of the preservation of life, to include the quality of one's life, personal autonomy, self-determination, and, thus, a right to die with dignity.[100] In doing this, the Court looked at how the lower courts had interpreted the right to life. It was noted that Justice Smith of the Supreme Court of British Columbia rejected the qualitative approach to the right to life and stated that that the right to life was only engaged when there was a threat of death.[101] Mainly, the right to life was a "right not to die."[102] However, the Court in *Carter* did not agree that the "right to life" required an absolute prohibition on assisted death, or that individuals could not relinquish their right not to

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[96] *Carter v. Canada* at 8.
[97] Ibid.
[98] Recalling *Rodriguez,* the Court found that the even though the prohibition did violate Rodriguez's rights that this violation was justified and saved by section1, because at the time the Court believed that the need to protect the vulnerable outweighed an individual's right to assisted death.
[99] Rodriguez, *Reasons for Judgment.*
[100] Ibid.
[101] *Carter v Canada* at 61.
[102] *Carter v. British Columbia* at 1322 from *Carter v. Canada* at 61.

die. If this were the case, then the right to life would create a duty to live, and this stood in contrast to an individual's right to refuse or withdraw life-sustaining treatment, actions that might result in their death.[103] The Court stated that,

> The sanctity of life is one of our most fundamental societal values. Section 7 is rooted in a profound respect for the value of human life. But, s. 7 also encompasses life, liberty and security of the person during the passage to death. It is for this reason that the sanctity of life "is no longer seen to require that all human life be preserved at all costs."[104]

By interpreting the right to life as transcending the preservation of life, the Court argued that this right should include an individual's right to choose how and when one's life ends.[105] With that, the Court then turned its attention to understanding what was meant by a right to "liberty," and "security of person."

Citing *Blencoe v. British Columbia*, 2000, the Court defined liberty as, "the right to make fundamental personal choices from state interference."[106] From *R v. Morgentaler*, the Court defined security of person as the "notion of personal autonomy involving …control over one's bodily integrity free from state interference,"[107] arguing that "security of person" becomes a matter of importance when the state interferes with the physical or psychological integrity of the individual.[108,109]

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[103] *Carter v. Canada* at 63.

[104] *Rodriguez* at 595 from *Carter v. Canada* at 63.

[105] *Carter v. Canada* at 63.

[106] *Blencoe v. British Columbia* at 54.

[107] *Morgentaler* at 30.

[108] *New Brunswick* (*Minister of Health and Community Services*) v. *G (J.)* at 46 and *Carter v. Canada* at 64

[109] It is important to note that personal autonomy underscores section 7 Charter rights. Recall in *Rodriguez*, the right to security of person defined by personal autonomy which is the right to make choices concerning one's body, and the control over one's physical and psychological integrity (*Rodriguez* at Reasons for Judgment, 10). In *Carter,* the Court argued that both the right to life and the right to liberty involved personal autonomy, namely and individual's right to choose how and when one's life ends as well as control over one's body without state interference.

Considering these two definitions, the Court stated that the ability to make decisions about how individuals respond to a grievous and irremediable illness is a matter that is fundamental to their liberty and security of person; denying a person such would cause some individuals to suffer intolerably, and others to take their lives prematurely. As such, it was found that the prohibition on assisted death violated section 7 of the Charter, and that denying a person of it would amount to a violation of section 7 rights.

Once the Court had reaffirmed that the prohibition on assisted dying violated an individual's rights under section 7 it was necessary to determine if this violation was in accordance with the fundamental principles of justice. To determine if this was still relevant, the Court had to determine if the prohibition on assisted dying was arbitrary or overbroad. The Court established that the prohibition was not arbitrary because it helped to achieve the legislative objective of protecting vulnerable persons from being coerced into death during moments of weakness.[110] However, it was found that the prohibition was overbroad because it caught people outside the class of protected persons and violated the rights of those individuals.[111] It was noted that the original intention of the blanket prohibition was to protect vulnerable persons from being persuaded to commit suicide at times of weakness and that a total ban on physician-assisted death achieved this goal.[112] However, while the general prohibition protected the vulnerable, it also caught people who were outside of the class of protected persons.[113] As such, while the prohibition was rationally connected to its objection (protecting the vulnerable), the Court found that the law was extended beyond its intended scope. The concept of a law being overbroad is relatively new

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[110] *Carter v. Canada* at 83-84.

[111] *Carter v. Canada* at 86.

[112] *Carter v. Canada* at 84,99.

[113] Ibid.

in its application as it first appeared in the case of *Heywood* [1994],[114] which was one year after *Rodriguez.* However, in discussing the principle of overbreadth, the Court referenced the more recent case of *Canada (Attorney General) v. Bedford* (2013). The Court stated that the,

> … overbreadth inquiry asks whether a law takes away rights in a way that generally supports the object of the law, goes too far by denying the rights of some individuals in a way that bears no relation to the object… The question is not whether Parliament has chosen the least restrictive means, but whether the chosen means infringe life, liberty or security of the person in a way that has no connection with the mischief contemplated by the legislature. The focus is not on broad social impacts, but on the impact of the measure on the individuals whose life, liberty or security of the person is trammeled.[115]

Applying the logic from *Bedford*, the Court found that the ban on the prohibition on assisted death was overbroad. While the law was designed to protect the vulnerable population, it was noted that not every person who has a desire to commit suicide is vulnerable, and that there may be other people who have a "considered, rational, and persistent wish to end their own lives."[116] Thus, the Court determined that the limitation of rights of those who were not considered to be vulnerable was not justified. It was found that proper safeguards and guidelines would protect this class of people from being abused. Thus, the Court overturned the ban on physician-assisted dying in Canada. As it was not the Court's mandate to prescribe law, they stayed their ruling for one year (later extended by four months) to allow Parliament to craft legislation for assisted dying in Canada. Sixteen months later, Bill C-14 came into effect.

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[114] In *Heywood,* the Court determined that overbreadth meant that the means were "…too sweeping in relation to the objective", and that, "…in some applications the law is arbitrary or disproportionate" (*Heywood*, *Reasons for Judgment).* The purpose of determining overbreadth is to ensure a balance between the interest of the state and those of the individual, and that the measures taken by the state do not go beyond what is required in order to accomplish the objective (Ibid.).

[115] *Carter v. Canada* at 85; *Bedford* at 101.

[116] *Carter v. Canada* at 86 citing *Carter (2012)* at 1136.

Bill C-14: An Act to amend the Criminal Code and to make related amendments to other Acts (medical assistance in dying)

Once the Court had struck down the prohibition on assisted dying, the Canadian Government was tasked with crafting relevant legislation around how Medical Assistance in Dying should be implemented in Canada. In June of 2016, Bill C-14, also known as the Act to amend the Criminal Code and to make related amendments to other Acts (medical assistance in dying) was passed, albeit after extensive debates. This Act amended sections 241(b) and 14 of the Criminal Code of Canada to permit assisted dying (now MAiD) in Canada. In addition to amending the Criminal Code to formally decriminalize[117] MAiD in Canada, the Bill set out the eligibility criteria for MAiD, mandated the safeguards to protect (vulnerable) patients, required education and training around the practice for healthcare professionals, and specified the punishments for offences related to failing to comply with the regulations and safeguards around MAiD.

Bill C-14 specifies that a person may receive MAiD only if they meet the following criteria. The person must be at least 18 years of age, have a grievous and irremediable medical condition, make a voluntary request for medical assistance in dying, and give free and informed consent to MAiD after understanding the alternative means that are available to relieve their suffering

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[117] Bill C-14 decriminalized MAiD as it changed section 241(b) of the Criminal Code that once said that it was a criminal act to assist another person to die by providing exemptions. The exemptions are as follows: Exemption for medical assistance in dying
(2) No medical practitioner or nurse practitioner commits an offence under paragraph (1)(b) if they provide a person with medical assistance in dying in accordance with section 241.2.
Exemption for person aiding practitioner
(3) No person is a party to an offence under paragraph (1)(b) if they do anything for the purpose of aiding a medical practitioner or nurse practitioner to provide a person with medical assistance in dying in accordance with section 241.2.
Exemption for pharmacist
(4) No pharmacist who dispenses a substance to a person other than a medical practitioner or nurse practitioner commits an offence under paragraph (1)(b) if the pharmacist dispenses the substance further to a prescription that is written by such a practitioner in providing medical assistance in dying in accordance with section 241.2.
Exemption for person aiding patient
(5) No person commits an offence under paragraph (1)(b) if they do anything, at another person's explicit request, for the purpose of aiding that other person to self-administer a substance that has been prescribed for that other person as part of the provision of medical assistance in dying in accordance with section 241.2.

(including Palliative Care).[118] The phrase "grievous and irremediable medical condition" refers to a person who has a serious and incurable illness, disease or disability, is in an advanced state of irreversible decline, has an illness, disease or disability causes them enduring physical or psychological suffering that they deem to be intolerable and that is not alleviated under conditions that they consider to be acceptable and that their natural death is "reasonably foreseeable."[119]

The Bill also establishes safeguards and protocols for MAiD. Section 3, which stipulates the safeguards, ensures that: two independent medical (or nurse) practitioners believe that the person requesting MAiD meets all of the eligibility requirements, that the individual's request was made in writing to two independent witnesses, and that there were 10 clear days between when the request was first made and the date when it is provided, and that the patient is aware that they are able to withdraw their request at any time. Section 3 also ensures that if the patient has difficulty communicating, the medical (or nurse) practitioners must provide means to ensure understanding and communication by the patient. The rest of the Bill sets out the protocol for MAiD that includes, but is not limited to, communication with the pharmacy and what information must be provided on the death certificate. Ultimately, these safeguards stand to ensure that the eligibility criteria are met.

While the Bill establishes the proper protocol for those who are willing providers, it does not engage in future issues such as for those who do not meet the eligibility requirements (advance directives, mature minors, or issues of mental health) nor does it set out specific provisions for what is to be done for physicians or institutions who conscientiously object. While the Bill mentions that,

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[118] Legislative Services Branch. "Consolidated Federal Laws of Canada, Criminal Code." *Justice Laws Website.* 17 June 2016, laws-lois.justice.gc.ca/eng/acts/c-46/page53.html#:~:text=Suicide&text=241%20(1)%20Everyone%20is%20guilty. Accessed 20 Apr. 2019.

[119] Ibid.

> Whereas everyone has freedom of conscience and religion under section 2 of the *Canadian Charter of Rights and Freedoms*; Whereas nothing in this Act affects the guarantee of freedom of conscience and religion…[120]

it does not give specific recommendations as to how those individuals or organizations who conscientiously object to providing MAiD should proceed. As such, these issues are to be addressed in the future by regulating bodies and organizations.

The Current State of MAiD in Canada - Demographics

Since the enactment of Bill C-14 in 2016, approximately 13,946 patients have died by MAiD.[121] In 2019, MAiD accounted for 2.0% of all deaths in Canada.[122] However, these 2.0% of deaths were not distributed evenly amongst Canadian provinces, with MAiD accounting for higher percentages of deaths in some provinces than others. For example, in Newfoundland, only 0.3% deaths resulted from MAiD, whereas 3.3% of patients in British Columbia died via MAiD. The number of men and women who receive MAiD is (fairly) equally divided, with 50.9% of patients being men and 49.1% being women. The average age of patients who received MAiD was 75 years old. 80% of all MAiD patients are older than 65, and few patients younger than 65 or older than 90 receive MAiD.[123] The majority (67.2%) of patients who received MAiD had a cancer-related illness. The other underlying illnesses of the patients who received MAiD were respiratory (10.8%), neurological (10.4%), and cardiovascular conditions (10.1%) respectively.[124]

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[120] *Canadian Charter of Rights and Freedoms,* s 2, Part 1of the *Constitution Act,* 1982, being Schedule B to the *Canada Act 1982,* UK, 1982, c 11.

[121] Health Canada. *First Annual Report on Medical Assistance in Dying in Canada,* 2019, 5.

[122] Ibid.

[123] Ibid, 22.

[124] Ibid, 21.

The majority of patients (82%) who received MAiD had received some Palliative Care services before requesting MAiD. Of that 82%, more than 54% had received Palliative Care for more than one month, almost 20% received Palliative Care for 2-4 weeks, and 19.3% had received Palliative Care services for two weeks or less. These statistics strongly suggest that a lack of *access* to Palliative Care is not driving people to request MAiD. The *quality* of the Palliative Care services available to them, however, is unknown.[125] So despite widespread access, it is possible that some patients choose MAiD because they do not have access to adequate high-quality Palliative Care. Patients who pursued MAiD reported one of the overarching reasons was inadequate control of pain and symptoms.[126]

The majority of MAiD procedures occurred in a hospital setting (36.3%) or a private residence (35.2%). 20.6% of procedures took place in a Palliative Care facility, with the remaining procedures occurring in residential care facilities (6.9%) or “other” (1%).[127]

Regarding providers, in 2019, there were 1,271 "unique" MAiD providers, with physicians being the dominant MAiD providers as they comprised 94.1% (1,196) of MAiD providers, with nurse practitioners accounting for less than 6% (75) of providers.[128] This number *may* be due to two factors. First, not all nurses are nurse practitioners. Of the 300,669 nurses in Canada, only 6,159 (less than 2%) are registered nurse practitioners.[129] Second, not all provinces allow for nurse practitioners to provide MAiD. For example, Quebec and Manitoba only allow physicians to administer MAiD. Of the physicians who provide MAiD, 65% are family physicians, 9.1% are

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[125] Ibid, 24.
[126] Ibid.
[127] Ibid, 29.
[128] Ibid, 28.
[129] Canadian Institute for Health Information. *Nursing in Canada,* 2019.

Palliative Care specialists[130], 5% are Anesthesiologists, 4.7% are Internal Medicine physicians, 1.7% are Critical Care and Emergency medicine physicians, or Oncologists respectively, and 1.2% specialize in psychiatry.[131] 4.5% of providers identified themselves as a "MAiD provider," which is not a recognized medical specialty in Canada.[132]

Provincial MAiD Policies

While all provinces adhere to the eligibility criteria and safeguards set out in Bill C-14 for MAiD, each province has its own policies around MAiD, specifically around the expectations of providers. Essentially, who can access or be considered for MAiD does not differ across Canada, as the eligibility requirements are standard and federally mandated. However, each province has crafted particular practices and policies that are specific to the delivery of MAiD, and the requirements of providers in that province. While each policy is different, generally, the provincial policies around the provision of MAiD differ in three main areas: who can administer MAiD (physician only or physician and nurse practitioner), whether MAiD may be self-administered by the patient, or if a practitioner can only administer it, and whether practitioners who object to MAiD are required to provide an effective referral.

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[130] It is interesting to note that most MAiD providers are family physicians and that Palliative Care accounts for only 9% of all providers. This fact will become relevant in a later discussion about the fears of the CSPCP that any involvement in MAiD would lead to Palliative Care physicians pioneering the practice.

[131] Health Canada. *First Annual Report on Medical Assistance in Dying in Canada, 2019*, 29.

[132] Ibid, 29.

Who can administer MAiD?

Except for Manitoba and Quebec, all provinces and territories allow MAiD to be assessed for and administered by a physician *or* a nurse practitioner. However, Manitoba and Quebec only allow for physicians to provide MAiD.[133]

Self-administered or practitioner administrated?

The country is fairly evenly divided between regions that allow MAiD to be self-administered by the patient versus those that only allow MAiD to be provided by a physician or nurse practitioner. Only a medical professional can perform MAiD in PEI, Nova Scotia, Quebec, and Manitoba, while patients can self-administer MAiD in Newfoundland, New Brunswick, Ontario, Saskatchewan, Alberta, British Columbia, the Northwest Territories, and the Yukon.[134] Of the regions that allow a patient to self-administer, British Columbia, Saskatchewan, and the Northwest Territories require a physician or nurse practitioner to be present during the administration. Newfoundland requires a practitioner to be present when if a patient self-administers MAiD *only* if the patient decides to administer it to themselves in a place other than a clinical or hospital setting or a care home.[135] Alberta and Ontario advise, but do not require, that a physician or nurse practitioner be present during the administration of MAiD.[136] Even in the provinces that allow self-administration, an overwhelming majority of MAiD procedures are still provided by a physician or nurse practitioner. In 2019, only seven cases of MAiD were self-

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[133] The College of Physicians and Surgeons of Manitoba. *Standards of Practice of Medicine*, 2018; Act respecting end-of-life care, RSQ c S-32.0001, http://canlii.ca/t/52t5r. Accessed on 15 October 2020.

[134] The Department of Health for Nunavut has yet to provide information on MAiD that is available to the public.

[135] The College of Physicians and Surgeons of Newfoundland and Labrador. *Standards of Practice: Medical Assistance in Dying,* 2017.

[136] The College of Physicians and Surgeons of Ontario, *Medical Assistance in Dying*, 2018; Alberta Health Services. *Medical Assistance in Dying,* 2018.

administered.[137]This low number of self-administered MAiD cases may be due to concerns (from the patients and physicians) about the patient's ability to properly self-administer MAiD and any complications that may result.[138] As such, many provinces are still reflecting upon safety guidelines, policies, and protocols for self-administered MAiD.

Conscientious Objection and Effective Referral

The policies around the requirements of physicians who conscientiously object to participating in MAiD vary across the country. Of the ten provinces, only Ontario and Nova Scotia require an objecting physician (or, nurse practitioner) to provide an effective referral to another willing and available practitioner. The Yukon also requires that any physician who objects to providing a patient with a service, connect that patient with timely access to another willing provider. Under the guidance of the College of Physicians and Surgeons of Ontario, physicians in Ontario must ensure that they take positive action to connect a patient with another non-objecting physician, healthcare provider, or agency accessible to the patient.[139] Furthermore, this referral must be done promptly. In Nova Scotia, physicians or nurse practitioners who object to MAiD must complete an "effective transfer of care," which requires the objecting physician to transfer the care of the patient to another practitioner who is accessible to the patient and willing to provide MAiD should the patient meet the eligibility requirements.[140] In the Yukon, the Medical Council mandates that when moral or religious beliefs affect a physician's willingness to provide a patient

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[137] Health Canada. *First Annual Report on Medical Assistance in Dying in Canada,* 2019.

[138] Ibid.

[139] The College of Physicians and Surgeons of Ontario, *Medical Assistance in Dying*, 2018.

[140] The College of Physicians and Surgeons of Nova Scotia, *Professional standard Regarding Medical Assistance in Dying*, 2018.

with a service or information about that service, the objecting physician must connect the patient with another willing provider or resource.[141]

Of the three regions that require action on the part of an objecting physician or practitioner, Ontario and the Yukon are similar in the sense that an objecting physician must provide the patient with a timely referral to another willing provider or resource. Nova Scotia is somewhat more demanding of objecting practitioners by requiring them to complete an "effective transfer of care," which goes beyond an effective referral by ensuring that the patient's care has been transferred to a willing provider.

The remaining provinces do not require an objecting physician or practitioner to provide an effective referral to a patient. Each province differs in its expectations of practitioners. Generally, the professional standards mandate that objecting practitioners communicate to their patients that they object to MAiD and suggest providing patients with information to enable them to make an informed decision. While some provinces *recommend* that practitioners facilitate timely access to another willing practitioner, it is not required. For example, in Prince Edward Island, objecting practitioners are only required to provide the patient, or another practitioner, with the patient's chart.[142] In Saskatchewan, the objecting practitioner's obligations extend only so far as to provide the patient with information and resources about access MAiD. In Alberta or Quebec, objecting physicians are only required to inform their manager or director of their institution that they object to providing MAiD.[143,144] The burden then falls to the manager or director to connect the patient with a willing provider.[145] Generally, both regions state that the manager or director

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[141] The Yukon Medical Council, *Standard of Practice*, 2018.
[142] The College of Physicians and Surgeons of Prince Edward Island. *Policy on Medical Assistance in Dying, 2*018.
[143] Alberta Health Services. *Medical Assistance in Dying, 2*018.
[144] Act respecting end-of-life care, RSQ c S-32.0001, http://canlii.ca/t/52t5r. Accessed on 15 October 2020.
[145] Ibid.

must then ensure that a willing and able healthcare provider assumes the patient's care.[146,147] Some could argue that the manager or director provides an "effective referral" to the patient in these provinces. However, as I will argue in later chapters, having the physician report to the manager or director who then must connect the patient with a willing provider seems to be an unnecessary and timely middle step. As has been discussed, in cases of MAiD, *timely* access to MAiD resources and services is often vital.

The Northwest Territories do not have an effective referral policy as they have a central care coordination service that patients may self-refer for MAiD. However, if a physician or nurse practitioner objects to providing MAiD, they must provide the patient with a contact card for the coordination centre.[148,149] While having a central coordination centre is not equivalent to a patient being provided with an effective referral, as the burden is placed on the patient to contact the central coordination centre, this burden is not overly taxing for most patients.

Discussion

The statistics around who receives MAiD and where it occurs is relatively similar across Canada. However, as discussed, the policies around the delivery of MAiD vary greatly between provinces, lending to patients in some provinces having more support and easier access to MAiD than others. The lack of interprovincial consistency around standards and guidelines is problematic for patients and physicians. While healthcare is provincially mandated, and individual provinces can design their practices and policies around MAiD, delivery, and conscientious objection, standards should be standardized across Canada. As all provinces and territories adhere to the

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[146] Ibid.

[147] Alberta Health Services. *Medical Assistance in Dying, 2*018.

[148] Government of Northwest Territories. *Medical Assistance in Dying: Interim Guidance for Northwest Territories*, 2018.

[149] Nunavut has not published information available to the public on the question of conscientious objection.

eligibility requirements and safeguards set out in Bill C-14, the same should be true of policies around MAiD and its delivery.

The differing policies around MAiD in Canada, specifically those around whether a nurse practitioner may administer MAiD and what is to be done in the case of conscientious objection, have the potential to create barriers for patients to access MAiD. While nurse practitioners only account for a small percentage of providers, allowing nurse practitioners across Canada to provide MAiD would increase the number of providers for patients, even if only marginally. The provinces (British Columbia, Manitoba, Saskatchewan, PEI, and Newfoundland[150,151])[152,153,154,155] that do not require physicians or nurse practitioners to provide an effective referral should they conscientiously object to providing MAiD, and do not have a Care Coordination service that patients may self-refer to, have created inequitable barriers to patients accessing MAiD. This approach to MAiD does not align with the Collaborative Model, as will be discussed in Chapter 8. The Collaborative Model is designed to support physicians who object to providing MAiD or cannot ensure that patients receive expert Palliative Care and MAiD services. The discussion of creating care coordination services for MAiD self-referral and national standards for conscientious objection will be taken up in Chapters 8 and 9.

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[150] British Columbia requires that objecting physicians provide an "effective transfer of care," which entails the objecting physician to advise their patient that other providers are available to them and that the patient's records are transferred.

[151] The College of Physicians and Surgeons of British Columbia. *Practice Standard: Medical Assistance in Dying*, 2020.

[152] The College of Physicians and Surgeons of Saskatchewan. *Medical Assistance in Dying*, 2018.

[153] The College of Physicians and Surgeons of Manitoba. *Standards of Practice of Medicine*, 2018.

[154] The College of Physicians and Surgeons of Prince Edward Island. *Policy on Medical Assistance in Dying, 2*018.

[155] The College of Physicians and Surgeons of Newfoundland and Labrador. *Standards of Practice: Medical Assistance in Dying,* 2017.

Conclusion

This chapter has outlined the legal history that led to the decriminalization of MAiD and its subsequent legalization that resulted from the passing of Bill C-14, 2016. From the case of *Rodriguez* in 1993 to the *Carter* cases in 2012-2015, I have discussed the Courts' rationale as to why MAiD was prohibited until 2015. In 2016, MAiD became legalized when Bill C-14 received Royal Assent. After the passing of Bill C-14, as stated by the Court in *Carter*, it was the provincial legislatures and colleges' responsibility to craft and enact relevant policies around how MAiD would be implemented.[156] The second half of this chapter included a survey of the current state of MAiD in Canada, canvassing both the demographics of MAiD providers and the patients who receive it, as well as the variation of policies between jurisdictions. Demographically, it was noted that Palliative Care physicians account for only 9% of MAiD providers. Therefore, despite initial concerns around Palliative Care pioneering MAiD, or MAiD becoming part of Palliative Care, we see that Palliative Care physicians are not overly involved in the active provision of MAiD, and that initial fears have not come to fruition.

Policy wise, while all provincial policies were premised upon Bill C-14, thus having standard eligibility criteria and safeguards, healthcare remains an area of provincial responsibility. Therefore, each province has crafted its own specific MAiD policies which has resulted in variation across the country. This variation has arguably led to inadequacies, inconsistencies, and inequalities in a patient's ability to access MAiD. As such, changes to provincial policies to ensure that all eligible patients are able to access MAiD services are required. I will return to this issue in later chapters.

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[156] *Carter*, Preamble at 126.

Chapter 4: Ethical issues around MAiD

Introduction

The practice of MAiD (formerly physician-assisted death) has garnered significant debate amongst philosophers, ethicists, physicians, and legal scholars for decades.[157] The permissibility of MAiD was a hotly contested question well before the *Carter* ruling in Canada (and, even after the *Carter* ruling), and remains the subject of active debate in other jurisdictions where MAiD has not yet been decriminalized or legalized. This debate will not be taken up in this dissertation. Instead, since the dissertation focuses on and was written in and for a "post-*Carter*" world, it concentrates on issues that have *resulted* from the legalization of MAiD in Canada. The remainder of this chapter will discuss some of these issues. The purpose of this discussion is to raise and explore *some*[158] of the ethical issues that are present now due to MAiD in order to highlight potential sources of disagreement among physicians and bioethicists. The goal is not to solve these issues, offer concrete solutions, or to endorse or condemn particular viewpoints; rather the goal is to flag issues that are still being debated and need further attention.

The following section will discuss issues such as conscientious objection to MAiD by physicians and institutions, physicians who participate in MAiD feeling alienated and unsupported by colleagues and professional societies or affiliations, access to Palliative Care, and MAiD, and the expansion of the eligibility criteria for MAiD. I will also engage in the debate of the moral significance between "killing" and "letting die." While this debate existed 40 years before *Carter*,[159] the differing views on whether or not there is a moral significance between MAiD (killing), and withholding or withdrawing life-sustaining treatment (letting die) of a person with a

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[157] *Rodriguez v. British Columbia*, 1993; Rachels, 1975.

[158] The ethical issues that have arisen due to MAiD are wide-ranging. However, for the scope of this chapter, only a few will be discussed. It is recognized that the relevant ethical issues extend beyond those that are discussed in this dissertation.

[159] Rachels, 1975.

life-limiting illness, is at the heart of the ongoing debate amongst Palliative Care physicians, precisely how, or if, Palliative Care should intersect with MAiD.[160] This distinction, and how individual physicians understand it, is often one of the reasons why they choose to participate or object to practicing MAiD. As this discussion existed pre-*Carter*, it will be examined before moving onto the ethical issues that arose as a result of the *Carter* ruling.

Pre and Post-Carter: "Killing" v. "Letting Die" – a moral difference?

A debate that has circulated the ethical and philosophical world well before MAiD was decriminalized in Canada was whether there is a morally significant difference between killing and letting die. In his influential 1975 article, "Active and Passive Euthanasia," James Rachels argues that the conventional doctrine holds that passive euthanasia, which he considers to be the withholding or withdrawal of life-sustaining treatment and "letting" the patient die,[161] is morally permissible, whereas "active euthanasia," (which we now refer to as MAiD) is never morally permissible because doctors should never "kill" their patients.[162] Rachels highlights the flaws in this traditional understanding of the distinction, and argues that there is not always a morally significant difference between "killing" and "letting die." His argument relies on the example of a patient who is dying of cancer of the throat and is in terrible pain. In this example, the patient will die within days, even with the current treatment; however, his pain is so intolerable that he does

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[160] A detailed discussion of issue of how Palliative Care should intersect with MAiD will be taken up in Chapter 6, paying close attention to the views of Canadian Palliative Care physicians.

[161] Some authors such as Garrard and Wilkinson, and Cartwright, argue that passive euthanasia involves withholding or withdrawing treatment in order *to* end the patient's life. However, when treatment is withheld or withdrawn in the healthcare context, the intention is not to end the patient's life but to respect the patient's wishes or not cause the patient with harm or burden. While I recognize that there are other conceptions of "passive euthanasia," I will not be employing them in this dissertation. I will be adhering to Rachel's understanding of "passive euthanasia."

[162] Rachels, 1975.

not want to endure these last few days. Not wanting to continue to suffer, the patient asks his physician to end his life. Rachels says that according to the conventional doctrine, the physician may be permitted to withdraw the current treatment (or withhold new treatments) because prolonging the patient's life would cause him to "suffer needlessly."[163] However, Rachels argues that by withholding or withdrawing treatment may cause the patient to take longer to die, and to suffer longer than if the physician had granted the patient's request and ended his life via lethal injection.[164] In this case, Rachels argues that “active euthanasia” would be morally preferable as it is the quicker and more humane option; as such, if withdrawing treatment with the aim of allowing death to occur is morally permissible, then so too should actively bringing about that death. If this is accepted, then "killing" in this case should not be considered inherently wrong. Rachels therefore concludes that killing is not always worse than letting die, and so that active euthanasia can be morally preferable to passive euthanasia.

Making arguments specific to physicians who care for patients who have life-limiting illnesses, Rachels argues that there is no “bare difference” between a physician letting a patient with a life-limiting illness die, and the physician intentionally ending the life of that patient. [165]

Rachels recognizes the main objection to his argument is that in the case of a patient with a terminal illness, passive euthanasia would mean that the doctor would withdraw or withhold the treatment that is prolonging life. The illness itself would be the cause of death. In active euthanasia, however, the physician is actively causing the patient's death. This main point here is one that is significant in debating the physician's views about MAiD. Those who oppose MAiD treat this distinction as important, since they see that cause of death as morally significant. These

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[163] Rachels, 1975.
[164] Ibid.
[165] Rachels argues that both would be morally impermissible if the patient had a curable illness.

individuals see withholding or withdrawing life-prolonging treatments at the patient's request as potentially morally permissible, since in those cases it is the illness, rather than the physician's actions, which is the cause of death. By contrast, those physicians who participate in MAiD tend to treat the cause of death as less significant, and adhere to Rachel's original point that there are instances in which active euthanasia is the more humane option, and thus, morally permissible.

Rachels argues that those who believe that "letting" the patient die is morally permissible because it does not involve an intentional act that leads to the death of the patient are incorrect because even withholding or withdrawing treatment consists of an action or decision. Thus, Rachels argues that if a physician lets a patient die, the act cannot truly be viewed as "passive" in the sense that the physician is not doing anything to cause the death of the patient.[166] As such, Rachels argues that both "passive" and "active" euthanasia involve a physician's decision, resulting in the patient's death. As such, they are morally indistinguishable.

Other philosophers such as Guichon et al., and Wayne Sumner have agreed with Rachels and argued that there is no moral distinction between a "refusal of treatment" and euthanasia. Guichon et al., and other scholars who are in favour of allowing MAiD have argued that there is no ethical distinction between passive and active means of ending life.[167] Accordingly, Sumner argues that there is no moral distinction between passive and active euthanasia. He affirms that if we allow the former, then we must also permit the latter. He argues that if death is the outcome of refusal of treatment, withdrawal of treatment, and MAiD, there is no moral distinction between them. He states, "There is no bright line between the first and last measure: if treatment refusal is

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[166] Rachels, 1975.

[167] Guichon et al., 799.

permissible, so is euthanasia."[168] This argument distinguishing between passive and active euthanasia has been used by those who favour the permissibility of MAiD.

The question of the moral distinction between providing MAiD (active euthanasia) to a patient who has a life-limiting illness, and withdrawing or withholding life-sustaining treatment, which may result in the hastened death of a patient, is a crucial distinction in Palliative Care. Palliative Care physicians who oppose MAiD take up the objection to Rachel's that there is a moral difference between actively ending someone's life by lethal injection versus withholding or withdrawing treatment that would sustain or prolong life. For this population of physicians, Rachels' argument that withholding or withdrawing treatment is an "action" detracts from the real moral argument around ending the life of another human. This is one the reasons why the CSPCP, for example, has argued that MAiD is fundamentally at odds with Palliative Care. For the CSPCP, what Rachels calls active euthanasia is morally and professionally impermissible, whereas "passive euthanasia" is accepted.

Alternatively, those physicians who support MAiD, including CAMAP, would endorse Rachel's argument for why MAiD is the more humane option because it puts an end to the patient's suffering earlier, rather than to wait for the illness or disease to be the cause of death. Dr. Buchman stated that when he provided MAiD to his patient, he felt that he had "done the right thing" and "This (MAiD) can't be inconsistent with who I am as a doctor."[169]

The disagreement between the moral distinction of MAiD and what is called passive euthanasia is at the heart of the divide within the Palliative Care community and the disagreement around the intersection of MAiD and Palliative Care. This discussion will be taken up later in the dissertation, specifically in Chapters 7, 8, and 9.

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[168] Sumner, 92.
[169] Ibid.

Conscientious Objection

Individual (physician) objection

A physician's decision to participate in MAiD is "…a matter of conscience, and sometimes, of religious belief."[170] Recognizing this, in invalidating the prohibition on MAID, the Court had to consider the physicians who might object to providing MAiD on moral or religious grounds. Accordingly, the Court stated that nothing in their Declaration of invalidity would compel physicians to provide MAID. Essentially, the Court allowed physicians to conscientiously object to participating in the practice of MAiD.[171]

To better understand conscientious objection in this context, it is important to first understand what is meant by the term 'conscience' and why individual conscience is worthy of protection. Udo Schuklenk argues that there are several understandings of what is meant by conscience, and philosophers have yet to reach a consensus on a universal definition.[172] However, many philosophers and bioethicists have offered their respective views. John Stuart Mill refers to conscience as the "internal sanction" that prevents us from doing wrong.[173] Daniel Sulmasy asserts that conscience has two interrelated parts. First is a commitment to morality and one's choice to act morally to the best of one's ability.[174] Second is the judgment about a past act, or an act that we are contemplating that may violate or contradict that commitment to morality.[175] For Sulmasy, conscience is our conviction that we should act in a manner that accords with our individual understanding of what is moral or right.[176] Both Hannah Arendt and James Childress agree that conscience is a reflection of what one would deem as wrong or bad, and is accompanied by feelings

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[170] *Carter v. Canada* at 132 citing *Morgentaler* at 95-96.
[171] Ibid.
[172] Schuklenk, 49.
[173] Mill, John Stuart, 1975.
[174] Sulmasy, 2008, 135.
[175] Ibid.
[176] Ibid.

of shame or guilt.[177] As Arendt states, “A good conscience does not exist except as the absence of a bad one.”[178] Often we do not think of our conscience when we feel at peace with ourselves, but only when we have feelings of shame or guilt and feel the need to ‘clear our conscience.’

Childress agrees with the retrospective nature of conscience, and also suggests that it is a subjective and prospective way of thinking about one's own acts concerning his own judgment standards.[179] Conscience is retrospective because it is often invoked when considering past acts. Often, our sense of guilt comes from doing or not doing something in the past. However, conscience may also be prospective in that we judge the moral permissibility of actions that we anticipate we might be faced with in the future.[180] It is subjective because it applies only to that individual; while we may judge the actions of others based on our conscience; often, we do not feel remorse or have a guilty conscience from another's actions.

Freedom of conscience, is often referred to when thinking about the individual nature of conscience, and how we protect it. Freedom of conscience “…extends to an individual’s right to limit cooperation with others or the degree of involvement in a practice to which he or she objects on the grounds of conscience…”[181] This is typically invoked when participation in an act would conflict with an individual’s legitimately held moral and ethical beliefs. Accordingly, freedom of conscience is proclaimed to be something that allows one to act following their closely held set of morals, values, and beliefs; what they believe to be "morally good and right."[182] As a society, we have recognized individual conscience as valuable and worthy of protection. This is seen in the Canadian Charter of Rights and Freedoms. Section 2(a) of the Charter states that *everyone* has the

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[177] Ibid.

[178] Arendt, Hannah. “Thinking and Moral Considerations: A Lecture.” *Social Research,* 38 (Autumn 1971): 418.

[179] Childress, 1979, pp.317-318.

[180] Sulmasy, 135.

[181] The College of Family Physicians of Canada. *A Guide for Reflection on Ethical Issues Concerning Assisted Suicide and Voluntary Euthanasia.* Sept, 2015, 4.

[182] Schuklenk and Smailing, 2.

fundamental freedom of conscience and religion.[183,184] While freedom of conscience is embedded in our Charter, it is not the only reason it is considered worthy of protection. We protect an individual's right to conscience because it distinguishes individuals as moral agents in themselves whose moral choices and integrity should be respected,[185] and it "encourages morally responsible agency."[186] This responsible moral agency is what allows individuals to act in agreement with their beliefs but also keeps them morally accountable to themselves and society. Schuklenk and Smailing argue that we respect conscience because asking someone to act in a way that would contradict these moral beliefs would undoubtedly cause psychological harm. Mark Wicclair suggests that by respecting conscience, we also acknowledge the importance of moral diversity and toleration in a multicultural society, while also acknowledging other valid perspectives and judgments.[187]

Moral agency and one's ability to act in a manner that accords with their conscience, but also in a way that keeps them accountable to society, is ever-present in medicine. Medicine is not just a science but an art because it is a very human practice that includes professionally and socially accepted moral standards and ethical norms. As such, the practice of medicine requires physicians to make moral decisions on a regular basis, decisions which the physicians will make based on their conscience or perception of right and wrong, even if done so unconsciously. Allowing physicians to act in a way that accords with not only their (moral or religious) beliefs also allows physicians to make decisions that they believe to be in the best interests of their patients. This

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[183] Canadian Charter of Rights and Freedoms.
[184] Schuklenk argues that this right is not an absolute right to "follow the tenets of their convictions or religion" regardless of the consequences to others (Schuklenk, 50).
[185] Wicclair, Mark R. "Managing Conscientious Objection in Health Care Institutions." *HEC Forum*, vol. 26, no. 3, 30 June 2014, pp. 267–283.
[186] McLeod, Carolyn, "Taking a Feminist Relational Perspective on Conscience." *Philosophy Publications,* 2011, p.14.
[187] Wicclair, M. "Conscientious Objection in Health Care: An Ethical Analysis." Cambridge, Cambridge University Press, 2011, 150.

ability to make professional judgments about their patient's care is integral to a physician's professional autonomy.[188]

This professional autonomy also allows physicians to *object* to participating in a service or procedure based on clinical judgment or ability, or on the basis of conscience. The latter objections are known as a conscientious objection or refusal. Conscientious objection occurs when an individual declines an action on the basis that it would contradict or conflict with their strongly held moral or religious beliefs. In medicine, this applies to a physician or medical practitioner who objects to providing a service or partaking in a medical act on the basis that it would conflict with their moral or religious beliefs.[189] Common examples of conscientious objection in medicine have been seen in the refusal to prescribe birth control, perform abortions, and now, MAiD. Physicians who object to participating in MAiD have argued that MAiD is equivalent to the intentional taking of human life, and stands in contrast to the Hippocratic Oath, or what medicine has taught them, to avoid doing harm. For these physicians, participating in MAiD would contradict their strongly held personal and professional morally held beliefs.

Many bioethicists have taken issue with a physician’s right to conscientiously object to practices such as MAiD. While respecting a physician’s conscience is important, and allowing conscientious objection in some form has been accepted by most bioethicists, not all bioethicists endorse a physician’s unqualified right to conscientiously object to medical practices such as MAiD, and question whether we should accommodate appeals to conscience.[190] For example, Julian Savulescu opposes granting physicians the right to conscientiously object to medical practices. Savulescu, in several articles, has argued that physicians should not be permitted to

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[188] It is worth noting that protecting conscience is important because of the its connection to autonomy. The value of autonomy is precisely the value that entitles eligible patients to access MAiD.

[190] Wester, 427.

conscientiously object and that a doctor's conscience has no place in modern medicine. Further, the individual values and conscience of a physician should not interfere with the (type of) care of a patient, or cause them to deny a patient legal treatment which they may be entitled to.[191]

Alternatively, bioethicists such as Giles Birchley and Christopher Cowley have argued in favour of permitting conscientious objection in medicine, particularly in a publicly-funded healthcare system. Birchley argues that conscience is intrinsically valuable, and essential to good medical practice. Cowley argues respecting a physician’s conscience is a matter of protecting their moral integrity, and this moral integrity is attached to the physician’s ‘calling’ to a particular practice in medicine.[192]

Wicclair takes more of a middle ground and argues that refusals based on conscience may be permitted so long as the refusal will not impede a patient’s timely access to care, nor will it place an undue burden on other colleagues or the institution in which the patient is being cared for.[193]

Conscientious objection to MAiD has raised serious questions and concerns about professional obligation, justice, and timely access to care. Ideally, while physicians should be allowed to practice in a way that aligns with their conscience, they have professional obligations as physicians, one of which is to ensure patients can access particular services. Immediately we see the potential for tension between the physician's right to conscience, their professional obligations, and the patient's right to access a legal service in a timely manner. These issues were highlighted and taken into serious consideration by the Supreme Court in *Carter,* when the Court stated that the rights of physicians to conscientiously object to the practice of MAiD needed to be

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[191] Savulescu, 2006; Savulescu and Schuklenk, 2016.
[192] Cowley, 2015.
[193] Wicclair, 2014.

“reconciled” with the rights of eligible patients to access the service.[194] However, it was not the job of the Court to determine how this should be done. As healthcare is a provincial jurisdiction, each of the provincial medical bodies was tasked with crafting policy around physicians' professional requirements and obligations who object to providing MAiD. As such, the policies differ across Canada. In Ontario, the College of Physicians and Surgeons of Ontario (CPSO) mandates what is to be done in physicians who conscientiously object to providing MAiD.

The CPSO has addressed conscientious objection to MAID in several of their documents,[195,196] with the most relevant being the Policy on *Medical Assistance in Dying.* In this policy the CPSO sets out very clear expectations for how physicians are to act if they conscientiously object to MAID. There are five definitive expectations. The College states that,

> … physicians who decline to provide MAiD due to a conscientious objection:
>
> a. **must** do so in a manner that respects patient dignity and **must not** impede access to MAID.
> b. **must** communicate their objection to the patient directly and with sensitivity, informing the patient that the objection is due to personal and not clinical reasons.
> c. **must not** express personal moral judgments about the beliefs, lifestyle, identity or characteristics of the patient.
> d. **must** provide the patient with information about all options for care that may be available or appropriate to meet their clinical needs, concerns, and/or wishes and **must not** withhold information about the existence of any procedure or treatment because it conflicts with their conscience or religious beliefs.
> e. **must not** abandon the patient and **must** provide the patient with an effective referral.
>   i. Physicians **must** make the effective referral in a timely manner and **must not** expose patients to adverse clinical outcomes due to a delay in making the effective referral.[197]

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[194] *Carter,* 2015, at 132.

[195] This document is consistent with the College’s other policies on Conscientious Objection. The CPSO’s policy on MAiD is grounded in their overarching document entitled, *Professional Obligations and Human Rights*, which details the actions that physicians must take should they object to any treatment or practice on the basis of conscience.

[196] The College of Physicians and Surgeons of Ontario *Professional Obligations and Human Rights*, 2015.

[197] College of Physicians and Surgeons of Ontario. *Medical Assistance in Dying*, at 11.

Further, this referral must be made in "good faith, to a non-objecting, available, and accessible physician, nurse practitioner or agency," and must be made promptly to ensure the patient's access to MAID.[198] The College does not view providing an effective referral as equivalent to participating in MAID.[199]

The requirement of an effective referral became a point of contention for many physicians who object to MAiD based on conscience and religion. When the CPSO published its policy, it was found that the requirement of providing an effective referral for MAiD was one of the most contested issues amongst Canadian physicians.[200,201] A prominent worry held by objecting physicians is that even in referring a patient to a willing physician, they are still complicit in the act. One physician's submission aptly articulated this concern.

> When a doctor makes a referral, she puts her name behind the request and, in effect, indicates that she believes a patient would benefit overall from the service being sought … making a referral is a deliberate action undertaken by a doctor that has intended consequences for the patient. Although the referring doctor does not directly provide the requested service to the patient, in making a referral, her actions are closely linked to and play a causal role in what ultimately happens … the principle that one shares responsibility for an action performed by another person if one facilitates or arranges that action is ingrained in our society's norms and legal code. Carrying out an activity oneself or arranging for someone else to do it is morally equivalent. Therefore, requiring doctors to refer for services to which they morally object coerces them to become active participants in acts that they believe to be wrong and, hence, to violate their consciences grossly.[202]

This worry, specifically that providing an effective referral was morally equivalent to providing MAiD, was held by many physicians who conscientiously objected to providing MAiD and a referral for MAiD.[203]

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[198] Ibid.
[199] Ibid.
[200] Canadian Medical Association. *Summary Report: Online Dialogue*, 2016.
[201] In consultation with its over 80,000 members, the CMA's *Summary Report: Online Dialogue* from 2016, the report encompasses practicing Canadian physicians' views. An online forum from 8 June – 20 July 2016, heard from a variety of physicians on their opinions on MAID (CMA Summary Report, 2). This online dialogue asked physicians questions about six particular themes: 1) principles-based approach to assisted dying; 2) responding to a request for assisted dying; 3) oversight and data sharing; 4) conscientious objection and equitable access; clinical specifications or requirements; and 6) supporting resources for physicians (Ibid.).
[202] Canadian Medical Association. *Summary Report: Online Dialogue*, 9.
[203] It must be noted that not all provinces require an effective referral.

When the CPSO issued its MAiD policy to guide physicians, it was disputed by groups of physicians who argued that an effective referral was equivalent to the physician being complicit in or endorsing the act. The Christian Dental Group, along with other allied organizations, and individual physicians, challenged the CPSO's requirement that physicians provide an effective referral to patients who are seeking MAiD. The applicants argued that the effective referral provision of the CPSO's MAiD provision infringed upon their Charter rights, namely their right to freedom of conscience and religion, and their right to be treated equally under and before the law (Sections 2 and 15). The groups brought the case before the Divisional Court of the Ontario Superior Court of Justice in 2017-18. The Court dismissed the application stating that the CPSO policy represented reasonable limits on religious freedom and that any Charter violations were saved under section 1.

The groups appealed this ruling to the Court of Appeal for Ontario. The appeal was dismissed. The Court of Appeal argued that while physicians may have the right to freedom of conscience and religion that they chose to practice medicine, and that,

> As members of a regulated and publicly-funded profession, they are subject to requirements that focus on the public interest rather than their interests. In fact, the fiduciary nature of the physician-patient relationship requires physicians to act at all times in their patients' best interests, and to avoid conflicts between their own interests and their patients' interests.[204]

The Court stated that while the requirement of making an effective referral presented real issues for some physicians that the CPSO had offered a number of reasonable choices as to how to satisfy

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

the requirements.[205,206] The Court also noted that the situation was not ideal for patients either; when patients are most vulnerable and asking for assisted dying, they will lose their trusted physician when they need their physician's support the most. Moreover, the Court of Appeal for Ontario aptly noted that a physician conscientiously objecting to providing MAiD, and referring on to another physician, creates problems for dying patients when they are their most vulnerable. In an affidavit to the Court, Dr. Kevin Imrie stated that,

> Patients who find themselves in the position of seeking MAiD are often in the most vulnerable of positions, are very sick, and facing all of the physical, mental and emotional burdens and trauma associated with facing the end of their lives. During such a time, they are enormously dependent upon their doctors and the health care system for what quality of life they do have.[207]

Realistically, patients in Ontario—and elsewhere—rely upon their physicians to connect them with resources, particularly at the end of life.[208] This is even more acute in communities where patients do not have the luxury of accessing "multiple specialists for second and third opinions; they rely on their physicians."[209,210] Essentially, the notion of providing an effective referral becomes an issue

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[205] The CPSO Fact Sheet entitled: Ensuring Access to Care – Effective Referral offers five means that a physician who objects to providing MAiD may satisfy the requirement of an effective referral. They are as follows:

- The physician or designate contacts a non-objecting physician/healthcare professional and arranges for the patient to see that physician/professional.
- The physician or designate transfers the care of the patient to a non-objecting physician/professional.
- The physician or designate contacts an agency that is charged with facilitating referrals and arranges for the agency to see that patient.
- If working at a hospital system, through a triage system, the patient will be seen by a non-objecting physician or professional.
- A practice group may designate a point person who will facilitate all referrals.
- The objecting physician will connect the patient to that point person.

[206] The College of Physicians and Surgeons of Ontario. *Fact Sheet: Ensuring Access to Care – Effective Referral*, 2018.
[207] *Christian Medical and Dental Society of Canada v. College of Physicians and Surgeons of Ontario* at 54.
[208] *Christian Medical and Dental Society of Canada v. College of Physicians and Surgeons of Ontario* at 45.
[209] Ibid.
[210] Schuklenk argues against conscientious objection for the reason that physicians are gatekeepers because they have a monopoly on access to certain healthcare services. As such, their patients are reliant upon them for access (Schuklenk, 52).

of timely access to MAiD. As Schuklenk and Smailing affirm, a physician's objection to provide a service such as MAiD or provide an effective referral is more than an inconvenience to the patient, but could be an "insurmountable barrier to access care."[211] For example, patients who live in rural or remote areas may not have the option of accessing another physician for MAiD services. This rationale is one of the reasons why the Court of Appeal for Ontario concluded that when a conflict arises between the rights of patients and the rights of physicians that the former must prevail.[212] Thus, in Ontario,[213] while physicians may be permitted to conscientiously object to providing MAiD, this objection cannot impede or impair a patient's access to MAiD services.

Institutional Objection

Traditionally, conscience has been understood as characteristically human.[214] While both *Carter* and Bill C-14 state that *individual* physicians can refuse to participate in MAiD for reasons of conscience,[215] what is less clear is whether conscientious objection extends to healthcare *institutions*. Specifically, can faith-based healthcare institutions object to providing MAiD for reasons of conscience and religion? This is an important question as many hospitals in Ontario and across Canada are faith-based. Some philosophers and ethicists such as Daniel Sulmasy have argued that healthcare institutions are moral agents because they have an overriding purpose and identity.[216] Following, if a healthcare institution is a moral agent, it can be argued that this moral agency lends itself to the institution having a conscience.[217] Sulmasy affirms that institutions have

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[211] Schuklenk and Smailing, 5.

[212] This is an interesting statement as it is different from what the Supreme Court of Canada stated in *Carter*. In their ruling, the Court stated that patients and physicians' rights had to be *reconciled* (*Carter* at 132).

[213] The rules for conscientious objection and effective referral differ across provinces.

[214] As stated above, conscience is what gives way to moral agency and allows individuals to act in accordance with their deeply held values and beliefs.

[215] Some provinces such as Ontario may require an effective referral upon objection.

[216] Sulmasy, 143.

[217] Ibid.

a conscience if they possess a set of "fundamental moral commitments" and therefore, must act in accordance with them.[218] This conscience is employed when the institution makes the moral judgment that a (potential) decision would violate their fundamental moral commitments. Sulmasy concludes that conscience involves,

> A commitment to uphold fundamental moral precepts and moral identity and, based upon these fundamental moral commitments, to make use of reason, emotion, and will to arrive at proper moral judgments and to act on these judgments. By these criteria, health care institutions have consciences.[219]

From this understanding, institutions have consciences which may permit them the possibility of conscientious refusal.

Other philosophers such as Durland have disagreed with this and argued that institutions cannot have a conscience and, thus, cannot make conscientious objections.[220] Durland argues that a hospital or healthcare institution is not a person; rather, it is a physical structure in which medical providers care for patients.[221] Due to the fact that a healthcare institution does not function in the same way as a human being (it does not take lunch breaks or vacations), and lack the fundamentally human characteristic of conscience, Durland argues that institutions cannot have a conscience, and therefore cannot conscientiously object to providing services.[222,223]

Faith-based institutions, and in particular Catholic hospitals and hospices, have adhered to Sulmasy's understanding and argued that they will not permit the provision of MAiD within their walls because it goes against the Catholic Church's teachings. One reason for this is that Catholic

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[218] Ibid.
[219] Sulmasy, 2008, 144.
[220] Durland, 1659.
[221] Durland, 1659.
[222] Ibid.
[223] Durland, 1678.

hospitals have a long-standing religious and moral tradition of tending to the sick, vulnerable, suffering, and marginalized populations that adhere to the tenets of the Catholic faith. Operating as a Catholic institution is at the core of their identity. As such, to ask a Catholic institution to provide MAiD would force them to provide care in a manner that contravenes their deeply rooted beliefs, and would go against the teachings of the Catholic Church.

For Catholic institutions, not providing MAiD is in keeping with their denominational values and ethics as MAiD contradicts the tenets of the Catholic faith. The Catholic teachings hold that the intentional taking of human life violates the fundamental principles that human life is sacred.[224] Neither the provision of nor participation in assisted death is consistent with the beliefs and values of Catholic Health Care and, as such, are not to occur within the walls of a Catholic healthcare institution.

Most Catholic Hospitals are influenced by their commitment to the ethical and religious directives (ERDs). ERDs are guidelines that are drawn from the moral and theological teachings of the Catholic Church. The ERDs are directed primarily at institutionally based Catholic Healthcare Services. Their purpose is to reaffirm the Catholic Church's teachings and provide authoritative guidance for the ethical and moral dilemmas that Catholic Healthcare institutions may face. For example, when considering MAiD, the Ethical Directives of the Catholic Bishops (Fifth Edition) state that, “Suicide and euthanasia are never morally acceptable options.”[225] Explicitly, the Catholic Bishops Declaration on Euthanasia states that,

> Euthanasia is an action or omission that of itself or by intention causes death to alleviate suffering. Catholic health care institutions may never condone or participate in euthanasia or assisted suicide in any way. Dying patients who request euthanasia should receive loving care, psychological and

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[224] Catholic Health Alliance of Canada. *Medical Assistance in Dying – Alliance Briefing*. September 2015.

[225] *Ethical and Religious Directives for Catholic Health Care Services Fifth Edition*. 2009. p 29.

> spiritual support, and appropriate remedies for pain and other symptoms to live with dignity until the time of natural death.[226]

This Declaration is one of the statements that may influence a Catholic Hospitals' response to MAiD. By not providing MAiD, the institution is in keeping with the traditions, beliefs, and value system of the Catholic Church.

Adhering to the ERDs is one example of how a hospital can have an identity, as a distinctly Catholic institution. This particular identity also serves as a moral identity, which signifies an overall goal and purpose.[227] As the Catholic hospitals were first created to help the sick, poor, and marginalized populations, this guiding purpose still exists as one of most Catholic healthcare institutions' overall values. Adhering to these values is an ongoing commitment of most Catholic hospitals. This commitment to a particular set of values/morals could indicate a conscience of a religious institution; bricks and mortar are not concerned with values or morals, but Catholic hospitals are.

If we are to adopt Sulmasy's thinking and agree that Catholic hospitals or healthcare institutions are moral agents that have a conscience, and thus are permitted to conscientiously object to providing services that contradict their moral beliefs, we are still left with how to reconcile this objection with the rights of patients to access MAiD. We see that when a healthcare institution objects to providing MAiD, some ethical and practical issues arise. Some examples of such issues are: ensuring access to care and transferring patients to alternative sites. Each of these has a subset of moral issues within them.

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[226] Ibid, 32.

[227] Sulmasy, 2008, 143.

Access to Care

The issue of patients being able to access care was addressed in the discussion on physicians who conscientiously object to providing MAiD. If an institution does not provide MAiD, the issue of access to care arises once again. If an institution does not provide MAiD, how will patients (who are eligible, and have requested MAiD) access the service if the hospital where they are being treated does not provide it? This access includes access to assessments as well as the provision. Most Catholic healthcare institutions have partnered with, or work well with other providing institutions, and have a referral system in place to help resolve this dilemma.

Issues of access to MAiD (both assessment and provision) have arisen across the country. Two cases that highlight this issue were seen in the patients Doreen Nowicki, and Bob Hergott who both were forced to go outside of their hospital, in weak and frail conditions, to receive assessments or sign request forms on the streets outside of their institution. Doreen Nowicki was dying from ALS at a Catholic-based hospital in Edmonton.[228] The hospital would not allow MAiD to be performed on the premises but was legally obliged to arrange for the service elsewhere. In her weak and frail state, Doreen was granted an exemption from having to go off-site for her assessment for MAiD.[229] However, just before the assessor was to arrive, she was told that the exemption was canceled. In a scramble to ensure her assessment, Doreen's family used a mechanical lift to get her out of bed and wheeled her across the street to meet her assessor. Her assessment for MAiD occurred on a sidewalk, in public.

A similar situation occurred with Bob Hergott. Mr. Hergott nearly paralyzed from ALS, was forced to sign his request form for MAiD in a bus shelter because Covenant Health would not

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[228] Russell, Jennie. "Paralyzed, Terminally Ill Man Had to Sign Assisted-Dying Papers in Bus Shelter."*CBC*, 18 Nov. 2018, www.cbc.ca/news/canada/edmonton/convenant-health-assisted-dying-edmonton-1.4888114. Accessed 18 Nov. 2018.

[229] Ibid.

allow any MAID assessments or requests to take place at St. Joseph's Auxiliary Hospital, where Hergott had been a patient.[230]

These two cases call attention to the dilemmas that arise when institutions do not allow the assessment for eligibility or provision for MAiD. Both stories included patients who had to leave the institution in which they were being cared for, and had to have their assessments in a public space. These cases highlight the potential worries around physically burdening patients who are already facing a terminal illness, and jeopardizing their dignity and privacy. Causing harms like these all stand in contrast to the goals of the Catholic Church, and the hospitals created under their auspices that had the intention to care for the sick and vulnerable.

The issue of access to MAiD becomes particularly acute when the objecting institution is the only accessible institution for the patient. For example, in large cities such as Vancouver, Toronto, or Ottawa, there are likely to be providing institutions that the patient could go to, or be transferred to, which would not cause much undue harm to the patient. In large city centres, patients would have the ability to access MAiD relatively easily. However, in rural or remote areas, access to care becomes problematic, and issues of justice arise. In the healthcare context, Lyckholm et al. argue that the principles of justice demand that healthcare resources be equitably distributed based on need (those who are eligible for, and need MAiD), rather than the patient's ability to access or obtain it.[231] Some examples of these justice issues are found in Pembroke, Mattawa, or Elliott Lake, where patients who request MAiD will have difficulties accessing the service because each of their local hospitals are faith-based. For those who reside in Pembroke or Mattawa, the closest city that would have a hospital that would provide MAiD is Ottawa, which is

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[230] Purdy, Chris. "Patient Had Assisted-Death Assessment on Sidewalk Outside Catholic Hospital in Edmonton." *The Globe and Mail*, 3 Oct. 2018, www.theglobeandmail.com/canada/article-patient-had-assisted-death-assessment-on-sidewalk-outside-catholic/. Accessed 3 Oct. 2018.

[231] Lyckholm et al., 134.

approximately 150km away. For those living in Elliott Lake, they would have to travel to Sudbury or Sault Ste. Marie to access MAiD, causing the patient to travel 170-200km to receive care. Traveling such distances is problematic for patients who are suffering, or actively dying; thus, to deny them access to the service may be considered harmful. Situations like these put the onus on patients, and create unjust access to care. Thus, in rural or remote areas where the local hospital is faith-based, how can the patients access the service in a timely fashion that would not cause them harm? Thus, the issue of how to reconcile the patient's right to access care with an institution's right to conscientiously object to the provision of MAiD, remains.

Not Medically Fit for Transport

Even in cases where there are available institutions nearby, how should Catholic institutions care for patients who are not medically fit to be transported? Two examples are patients who are suffering intolerably, or are so near death, that transporting them to a different hospital would only add to their suffering, or those patients whose cognitive ability is in decline that transferring them may render them ineligible for MAiD. Since the eligibility conditions include cognitive awareness at the time MAiD is being delivered, this is a real concern and must be taken seriously.

One of the goals of Catholic health care is to tend to the suffering of patients. However, if in their attempt to adhere to the tenets of the Catholic faith (not providing MAiD), the hospital causes the patient to suffer more, are they not violating one of their fundamental values? In such situations, Catholic hospitals will struggle to live by their values and morals. When faced with such situations, the institution will have to decide which value will prevail. For example, Catholic hospitals abide by the teachings of a Catholic Church and will try to live by their guidelines. However, these hospitals were first created to tend to the suffering of the sick and vulnerable populations. So, in a situation where a patient is actively dying and has requested MAiD, the hospital finds themselves conflicted between adhering to the Catholic tradition (not providing MAiD) and not causing undue suffering (an original goal of the institution). It seems doubtful that adherence to ERDs is sufficient justification for a Catholic Hospital to transfer a patient out of their institution for the purposes of MAiD, if this transfer contributes to or exacerbates the suffering of a dying patient. Given the ruling from the Ontario Court of Appeal with the CPSO, it might be the case that if there was a conflict between the rights of patients and the rights of institutions to conscientiously object, that the rights of the former would prevail.

Conscientious ***Provision***

While the focus, until now, has been on physicians and institutions who conscientiously *object* to providing MAiD, physicians who have chosen to participate in the practice have also struggled with significant worries and concerns. When MAiD was first legalized, the focus was on protecting the conscience of those healthcare providers who objected to the practice. However, what about those physicians who agree with Rachels and believe within their hearts that the morally right thing to do is to assist their patients in dying when they are suffering intolerably? When MAiD was first decriminalized, physicians who chose to provide MAiD to their patients were among the minority of their colleagues. Consequently, many MAiD providers worried about being judged, and not being trusted by their colleagues; furthermore, they worried they will not be supported by their professional organizations if they provide MAiD to their patients. Those physicians who have chosen to provide MAiD to their patients are aware of many of their colleagues' and professional associations' views around MAiD. In a 2017 *Maclean's* article, Dr. Sandy Buchman, a prominent Palliative Care physician and current president of the Canadian

Medical Association, spoke out about his involvement in MAiD and the fears and worries that came with the decision to become a provider.

> I have a lot of colleagues I highly, highly respect in palliative care—I even worry about it now—and I just know how strongly opposed they are to medical assistance in dying being legal … I have total respect for their beliefs and values, and I think they're good people. Still somewhere in me is the fear that they'll think I'm not a good palliative care physician.[232]

While many Palliative Care physicians did not believe that MAiD was consistent with Palliative Care, or medicine in general, those who have chosen to provide it feel very differently. Those who provide MAiD believe that they are doing the right thing for their patient and that the service of MAiD is "…so peaceful and loving that it can't be inconsistent with [who they are] as doctor[s]."[233]

Physicians who have chosen to provide MAiD have turned to their colleagues and their professional organizations for support. Outside of the Canadian Association of MAiD Assessors and Providers, the national organization of physicians and clinicians who participate in MAiD, many physicians still want to belong to their discipline-specific national bodies, yet are finding it difficult to do so. For Palliative Care physicians, that is the Canadian Society of Palliative Care Physicians (CSPCP). In a recent document, the CSPCP stated that MAiD is not a part of Palliative Care and that Palliative Care physicians should not be involved in the practice.[234] This has left members of the Palliative Care community feeling isolated, alienated, and alone; when physicians go through periods of change such as MAiD, their national organizations are where they seek support and professional guidance. However, the current stance of professional organizations like the CSPCP have Palliative Care physicians who provide MAiD feeling unsafe and unsupported.

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[232] Proudfoot, Shannon. "The Doctor who took on death." *MacLean's*. 15 August 2017.

[233] Ibid.

[234] Canadian Society of Palliative Care Physicians, *Key Messages: Palliative Care and MAiD*, 2019.

This raises the question of protection of conscience. If we truly respect conscience, then we must respect all consciences. Therefore, if we are to respect and protect the conscience of those healthcare providers who object to the provision of MAiD, then the same protection and respect must be extended to those who have conscientiously decided to provide MAiD to their patients.

Physicians who chose to provide MAiD, particularly in the early days when MAiD was first being implemented, have also faced issues around being able to provide their patients with assessments or the provision of MAiD. Physicians who work in institutions that do not provide MAiD have struggled with how to best support their patients, in assessments, and the provision. When MAiD was first being enacted, it was not uncommon to hear of physicians meeting with patients outside of their institutions (park benches, on the street) to provide initial assessments, similar to what was experience by Doreen Nowicki and Bob Hergott.[235] Again we see the issue of institutional access creating a barrier to care, where the patient has requested MAiD, and their physician is willing to support them, yet the institution in which they are being cared for does not permit it. Situations such as these present difficulties for the patient, but also the attending physician. Physicians need to be able to care for their patients, but also in a way and place that is safe both for patients, and physicians. These issues around balancing competing rights of patients, physicians, and institutions with respect to the provision of MAiD is a very serious question that has not yet been fully resolved by the Courts, policymakers, and institutions.

Eligibility criteria for MAiD

A concern in *Rodriguez, Carter,* and the crafting of Bill C-14 was ensuring that the created legislation would allow for eligible patients to receive MAiD while also protecting vulnerable

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[235] See comments about patients in the section about *institutional autonomy.*

populations. The worry was that permitting MAiD, even in limited cases, might open the door to others who were not the intended population to access it, receive it, or be abused by it. This 'slippery slope' argument was a consideration in both cases of MAiD in Canada. In *Rodriguez,* the Court did not feel that, at the time, sufficient safeguards were in place to ensure that vulnerable populations would not be abused by the practice, or coerced into taking their own lives during times of weakness.[236] However, by the time the Court revisited the issue in *Carter*, it was felt that the necessary precautions were in place to ensure that only those who met the eligibility requirements would receive it.

One of the concerns with broadening the eligibility criteria for MAiD was similar to that of the opening of floodgates; once one group was allowed access to MAiD, more would apply for the same access. The worry is not merely that the unintended or vulnerable populations will have MAiD forced upon them against their will. Rather, the worry is that other groups who do not meet the initial eligibility requirements will apply to expand the criteria, before our society and medical system has had time to ensure that any groups whom receiving MAiD are doing so safely, and also that the MAiD criteria are in line with the values of society.

This is currently the case with advocates or advocacy groups for mature minors, those with mental illness, and those with progressive, degenerative, but non-terminal illnesses like Alzheimer's disease or ALS, who want to be able to make advance requests for MAID. The next section will briefly discuss some of the arguments for permitting these groups' access and the concerns around widening the eligibility criteria.

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[236] *Rodriguez v. British Columbia* (Attorney General), [1993] 3 S.C.R. 519.

Mature Minors

Currently, the legislation stipulates that *only* an *adult* (18+ years) who suffers intolerably from a grievous and irremediable medical condition may request MAiD. However, the question has been asked if mature minors, who experience the same conditions, might be considered to be eligible for MAiD?[237] In the 70-page report, *Medical Assistance in Dying: A Patient-Centred Approach*, the Canadian Council of Academies calls policymakers to reconsider mature minors' access to MAiD within three years of the passing of Bill C-14. The Report recommends that the Government allow individuals 18 years or older to access MAiD immediately, and that policy that allows for competent, mature minors to access MAiD be enacted within three years of Bill C-14 being passed.[238]

When considering if mature minors should have access to MAiD, questions around **autonomy** (specifically, self-determination, and capacity), **equality,** justice, beneficence, and non-maleficence arise.[239,240] Generally, the principle of autonomy allows for competent, adult individuals who have capacity to make decisions for themselves. In the context of healthcare, competent adults have the legal right to make decisions about consenting to or refusing particular healthcare treatments that they believe to be in their best interests. This determination is due to capacity which is the, "the patient's ability to understand information relevant to a treatment decision and to appreciate the reasonably foreseeable consequences of a decision or lack of decision."[241] However, in the case of young children, we do not assume the same level of capacity, either because it is lacking or difficult to determine. As such, parents or legal guardians are often

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[237] Canadian Council of Academies. *State of Knowledge on Medical Assistance in Dying for Mature Minors, Advance Requests, and Where a Mental Disorder Is the Sole Underlying Medical Condition*, 2018, 5.
[238] Canadian Council of Academics, 21.
[239] Cuman and Gastmans, 840-845; Giglio and Spagnolo, 147; Guichon et al., 799.
[240] Each of these principles has been used both by proponents and opponents of allowing mature minors to access MAiD.
[241] Etchells et al., 658.

substitute decision-makers for young children.[242] While we do not allow young children to make autonomous decisions about their health, questions about mature minors having developed sufficient, meaningful autonomy and self-determination and, thus, capable of making end-of-life care decisions, have arisen. In the context of MAiD, it is wondered if mature minors possess a level of self-determination that is required to make complex decisions about actions that will result in their death. The Supreme Court of Canada recognizes the common law mature minor doctrine, a doctrine of consent that shifts the focus from chronological age to an individuals lived experience and understanding of their illness.[243] The doctrine stipulates that some minors may have the capacity to make decisions about their healthcare, namely in consenting to or refusing treatment.[244] However, the mature minor doctrine becomes more complex if the minor refuses or withdraws life-sustaining treatment, which would result in their death, or in the case of MAiD, opts for a treatment that would end their life. In the case of *A.C. v. Manitoba,* the Court reflected on the ability of a minor to make a decision that results in their death, but only after significant consideration.[245]

> In those most serious of cases, where a refusal of treatment carries a significant risk of death or permanent physical or mental impairment, a careful and comprehensive evaluation of the maturity of the adolescent will necessarily have to be undertaken to determine whether his or her decision is a genuinely independent one, reflecting a real understanding and appreciation of the decision and its potential consequences.[246]

However, in the case of *B. (S.J.) v. British Columbia (Director of Child, Family and Community Service),* 2005 BCSC 573, the Court argued that the legislature has the power to protect a child

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[242] Coughlin, 138.
[243] Government of Canada, Department of Justice. "Department of Justice - Article 12 of the Convention on the Rights of the Child and Children's Participatory Rights in Canada." *Department of Justice*, 18 Mar. 2016, www.justice.gc.ca/eng/rp-pr/other-autre/article12/p3a.html. Accessed 7 Mar. 2019.
[244] Ibid.
[245] Guichon et al., 792.
[246] *A.C. v. Manitoba*, at 95.

whose refusal to accept necessary medical treatment may result in their life being endangered.[247] In both cases, *A.C. v Manitoba* and *B (S.J.)* the Court concluded that the minor should not be permitted to make life-ending decisions.[248] The reason for this is because the state has an obligation to protect vulnerable populations, which includes children.[249] For example, in *AC v. Manitoba,* the Court ruled that forcing a 14-year-old girl to receive potentially life-saving blood transfusions was constitutionally sound as it balanced the rights of a child to make autonomous medical decisions against the overarching obligation of the state to protect the vulnerable (children).[250]This obligation is one that the Court wrestled with in *Carter.* The Court asserted that a total ban caught individuals outside of the protected class. Currently, mature minors (anyone under the age of majority)[251] is considered to belong within that protected class. While we may allow for some mature minors[252] to refuse life-saving or sustaining treatment, they are not legally permitted to access MAiD. If we were to allow mature minors to access MAiD, then they may have more options for end of life care.[253] Alternatively, if we do not permit mature minors to access MAiD, there will be cases involving Charter challenges; challenges that will be justified because denying them access to MAiD violates their rights.[254]

Those who are in favour of mature minors being permitted to access MAiD have applied the 'no moral distinction' argument, stating that as there is no moral distinction between passive euthanasia (withdrawing or withholding life-saving treatment) and active euthanasia (MAiD), that mature minors should be able to access MAiD.[255] If we allow minors to withhold or withdraw

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[247] *B. (S.J.) v. British Columbia (Director of Child, Family and Community Service),* 2005 BCSC 573 at 662.
[248] Guichon et al., 793.
[249] Cuman and Gastmans, 844.
[250] A.*C. v. Manitoba* (Director of Child and Family Services), 2009 SCC 30, [2009] 2 S.C.R. 181.
[251] The age of a mature minor varies between provinces.
[252] Those over the age of 16 (A.C. v. Manitoba).
[253] Canadian Council of Academies, 13.
[254] Ibid.
[255] Guichon et al., 799.

treatment that they know might result in their death, why should we not allow them to consent to MAiD? For example, a 16-year old would arguably be allowed to decide to cease chemotherapy or radiation treatments which are temporarily sustaining their life, even if they knew that stopping these treatments would mean that they die sooner.[256] Proponents for allowing mature minors to access MAiD have taken up the arguments of Rachels, Sumner, and Guichon et al. that if we allow a mature minor to decide to withhold or withdraw life-sustaining treatments, they should be permitted to make decisions about MAiD.

Proponents of MAiD have also employed principles of beneficence, equality, and justice to support their arguments. The argument of beneficence has been used for the purposes of promoting the best interests of the patient while protecting their dignity and relieving suffering.[257] The principles of equality and justice have been used to argue that if we value adults' dignity and respect their suffering, the same should be true of children. However, all three of these arguments are susceptible to the arguments about self-determination and protecting vulnerable patients. Draulans and Van der Giessen argue that mature minors' best interests can be difficult to discern as there are questions of if minors can decide if ending their life is in their best interest.[258] While children's suffering and dignity are worth serious consideration, the issue becomes one of protecting vulnerable populations.

Many have argued that allowing mature minors to access MAiD would be "pushing the boundaries" too far and going beyond the scope of the Court's intention.[259] Canadian Bioethicist and Professor of Law, Trudo Lemmens, argued that the Court did not equate MAiD with any other

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[256] This differs from the cases of AC v Manitoba, *B. (S.J.) v. British Columbia,* because chemotherapy would not be viewed as life-saving treatment in the same way that a blood transfusion would.

[257] Cuman and Gastmans, 842.

[258] Draulans and Van de Giessen, 492.

[259] Kirkley, Sharon. "Toronto's Sick Kids hospital preparing policy for euthanasia for youth over 18 that could one day apply to minors." *The National Post.* 9 Oct 2018.

medical treatment.[260] Pushing back on those who have argued that if we allow children to withhold or withdraw treatment that results in their death that we should allow mature minors to access MAiD, Lemmens argues that the two are not equivalent and that mature minors should not have access to MAiD.[261]

As MAiD, in general, is new to the medico-legal landscape in Canada, the issue of allowing mature minors and MAiD is still in its infancy. Further, as discussed, the question of allowing mature minors to make a healthcare decision that is intended to end their life is riddled with complex, moral, and legal questions. While a few countries have allowed mature minors to access MAiD, the reality is that there not enough empirical data or lived experiences to make informed decisions about allowing minors to access MAiD in Canada.[262]

Advance Requests for Progressive Illnesses

Another issue to be considered is allowing those who have progressive illnesses the right to make an advance request for MAiD. Currently, the legislation mandates that the patient must have cognitive capacity immediately prior to the provision of MAiD. If an individual loses the capacity to give consent at the time of provision, then the request becomes invalid.[263] Because of this criteria, individuals who have illnesses such as advanced dementia, in combination with another life-limiting illness, that may render them cognitively incapacitated at the time they would want MAiD, are advocating to be able to an advanced request to have MAiD at the point when they are no longer able to consent.

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[260] Ibid.
[261] Ibid.
[262] Cuman and Gastmans, 846.
[263] Canadian Council of Academies, 16.

Typically, consent can only be given for a treatment (or to withhold or withdraw it) if the patient has cognitive capacity at the time of consent. Because it is known that there may be situations in which a patient cannot express their wishes at the time, we have created advanced directives to allow for wishes to be known ahead of time. There are two types of advanced directives: Instructional directive and proxy directive.[264] An instructional directive sets out the instructions for the type of care that you wish to receive when you are no longer able to give instructions.[265] Instructional directives can include Do Not Resuscitate, not wanting extraordinary measures being taken, wishing to die at home, or who/what you would like to be surrounded by. These instructions serve as guidelines to your caregivers to understand what you would want when you cannot give express consent. Alternatively, a proxy directive allows for a chosen substitute decision maker to make decisions on your behalf. This is also known as "durable powers of attorney for healthcare."[266]

The Canadian healthcare system allows for individuals to use advance directives for other treatment decisions at the end of life. Therefore, should we also allow individuals to make an advance request for MAiD when they are no longer able to provide consent?

One of the reasons to consider advance requests for MAiD stems from the Court's ruling in *Carter* for permitting MAiD in Canada: how an individual responds to a grievous and irremediable illness is integral to their autonomy and dignity.[267] It has been argued that access to MAiD via advance directives would promote these values. A second reason the Court offered is that the prohibition on MAiD violated the right to life and security of the person, by leading people

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[264] "Advance Directives." *End-of-Life Law and Policy in Canada*, Health Law Institute, Dalhousie University, eol.law.dal.ca/?page_id=231. Accessed 5 Apr. 2019.
[265] Ibid.
[266] Ibid.
[267] *Carter,* Reasons for Judgment.

to take their own lives prematurely because they did not want to endure their illness when they were physically unable to take their own life. Access to MAiD would extend the lives of such patients. A predominant reason for allowing MAiD was that we recognize the desire for control at the end of life, how and when they wish to die. For individuals diagnosed with progressive illnesses such as advanced dementia, where the trajectory of the illness is well-known, there is fear around the point of their disease where they would lose decisional capacity and thus not request MAiD.[268] David Campbell argues this point in favour of allowing advance for requests for MAiD. He argues that because dementia or other neurological disorders advance at unpredictable speeds, that patients who suffer from these illnesses may feel anxiety or pressure to die while they still have some quality of life, out of fear that they will lose the opportunity due to decisional capacity.[269] This is the same thinking that the Court in *Carter* used to advanced permitting MAiD. Therefore, it could be argued that it may be used to permit advance directives as well.

There are benefits and disadvantages to considering advance requests for MAiD. The benefit would be that the allowance aligns with our country's value of respecting autonomy and self-determination.[270] It may provide a sense of comfort to those who are diagnosed with an illness where the loss of decisional capacity is known, to be able to make an advance request for MAiD. However, the problem lies in the alignment of the wishes when making the advance request for MAiD, and at the time, it would be provided. It is well known within the literature of Palliative Care that the desire to die fluctuates with patients who are receiving Palliative Care.[271] Often, a patient's Edmonton Symptom Assessment (ESAS) score for physical symptoms (pain, nausea,

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[268] Canadian Council of Academies, 17.

[269] Campbell, 2018.

[270] Canadian Council of Academies, 22.

[271] Chochinov, Harvey Max, et al. "Will to Live in the Terminally Ill." *The Lancet*, vol. 354, no. 9181, Sept. 1999, pp. 816–819.

etc.) directly correlates with their desire to die. When the physical symptoms are reduced, often so does the desire to die.[272] Thus, it is difficult to determine if a patient who has made an advance request for MAiD would really want this request carried out when they are no longer able to express consent or dissent. Thus, the worry is if it is known that the desire for death may fluctuate, advance requests for MAiD may result in patients receiving MAiD who cannot dissent. If we do allow advance requests for MAiD for patients who have lost capacity, can we be certain enough that their decision to die has not changed since they gave their directive? Jennifer Gibson, as part of the Canadian Council of Academies panel, asserted that when considering advance requests for MAiD that there will always be an element of uncertainty. She stated that, "We can try for greater assurance, greater burden of proof, but the risk will never be zero."[273] As a country, it is to be decided if this is a risk that we should or are willing to take.

Issues where Mental Disorder is the Sole Underlying Medical Condition

Another group that is advocating for access to MAiD is those who suffer from mental illness or disorders, where the illness is the "sole underlying medical condition" (MD-SUMC) and reason for requesting MAiD.[274,275] While individuals who have mental disorders are not directly excluded from accessing MAiD, per se simply because of their mental illness, it is unlikely that said individuals would meet the eligibility requirements as set out under Bill C-14, particularly those who did not have a life-limiting illness and whose death was not reasonably foreseeable.[276]

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[272] Ibid.

[273] Gibson, Jennifer. "Should Canada Introduce Advance Requests for MAID?" *Healthy Debate*, 7 Feb. 2019, healthydebate.ca/2019/02/topic/advance-requests-for-maid. Accessed 1 July 2020.

[274] Canadian Council of Academies, 26.

[275] While there have been questions about access to MAiD for patients who have a mental illness but also have comorbidities that would make them eligible for MAiD, I will not be focusing on this group here. While many of the same questions around capacity and consent will overlap, I will be focusing on patients who are requesting MAiD, who do not have a foreseeable death, and whose mental illness is the reason for requesting MAiD.

[276] Canadian Council of Academies, 26.

There are several issues around eligibility criteria for allowing MAiD for MD-SUMC. Arguments have been made on both sides, those against allowing those with MD-SUMC to access MAiD, as well as those arguments which urge us to reconsider the true suffering of those who have mental illnesses. While there are extensive arguments on both sides, their details go beyond the bounds of this dissertation as they are not the sole focus. However, some of the arguments both against and for allowing MAiD for MD-SUMC and their reasoning are worth discussing. This section will briefly highlight some of the key arguments proposed.

Those who argue against expanding the eligibility criteria to allow for MD-SUMC typically invoke three common arguments. The first concerns capacity and decision-making. While many individuals with mental disorders can make decisions regarding healthcare and treatment options, some disorders do impair an individuals' ability to make decisions and can impair their capacity.[277] Furthermore, while individuals might have the cognitive ability to make treatment decisions, some have argued that these individuals, due to the "pathological values that arise from their illness, might not be able to appreciate the consequences of their decisions."[278] Charland et al. offer the example of patients who suffer from anorexia. They state that while a person who suffers from anorexia might have the *cognitive* ability to make treatment decisions, this judgment is impaired by the thinking that comes along with the illness. When considering a decision for a patient with a mental illness to have MAiD, we must be sure that the patient's decision is unclouded by their illness. The precaution here it that the decision to have MAiD is unlike giving consent to any other treatment option for MAiD is an "irreversible, life-ending

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[277] Canadian Council of Academies, 27.

[278] Charland et al., 7.

practice."[279,280] While this reasoning certainly justifies limiting and strictly regulating MAiD access for MD-SUMC, it cannot justify the complete prohibition of the practice.

A second common worry highlighted is that suicidal ideation, or the desire to die may be a symptom of the mental disorder. From the work of Dr. Harvey Chochinov, the desire to die is not a natural symptom of dying, and a persistent desire to die is indicative of a mental disorder.[281] This implies that the patient may not really want to die, but rather their mental illness is impairing their judgment or that their illness is so intolerable that they want to die. With the latter, mental health experts have argued that perhaps this desire to die might be mitigated if the illness is treated. One question raised around MAID for MD-SUMC is how we can separate whether a request for MAID arises from a person's mental state versus sound reasoning grounded in a desire to cease prolonged suffering?[282] Schuklenk and van de Vathorst have argued that assisted death may be morally acceptable in cases of treatment-resistant depression (TRD) because not all cases of TRD render the patient incompetent of making a decision for MAiD. While physicians have urged the authors that it is better to err on the side of caution, Schuklenk and van de Vathorst argue that even if the patient accepts MAiD due to the somatic conditions of their depression, that the compassionate stance leads us to see that the patient is still suffering intolerably, and thus MAiD might be permissible.[283] However, Blikshavn et al., worry about MAiD for mental disorders, specifically treatment-resistant depression, and push back on Schuklenk and van de Vathorst. The authors are concerned that allowing MAiD in these circumstances will normalize the practice of MAiD to the point where it becomes part of routine practice in treatment for mental health, and that it will act

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[279] Charland et al., 4.

[280] However, this worry about ascertaining certainty may be mitigated by the physician's ability to assess capacity and competence as they would with any other patient who requested MAiD.

[281] Wilson, Keith G, et al. "Mental Disorders and the Desire for Death in Patients Receiving Palliative Care for Cancer." *BMJ Supportive & Palliative Care*, vol. 6, no. 2, 4 Mar. 2014, pp. 170–177.

[282] Tanner, 170; Canadian Council of Academies, 28.

[283] Schuklenk and van de Vathorst, 590-91.

as “an escape” from unwanted mental states.[284] The normalization of MAiD becoming and accepted treatment for TRD is a legitimate concern.

Third, is the requirement of a “reasonably foreseeable death” (Bill C-14). For most patients who have mental disorders, their death is not reasonably foreseeable in the same way as a patient who is suffering from a terminal illness. One of the reasons why MAiD has the condition of a reasonably foreseeable death is it would not take away a long life for those who might have the opportunity to live, and for whose illness might be cured or improved. Trudo Lemmens argues that MAiD is restricted to end-of-life cases to reduce the chances of premature death for someone who may still have a long life ahead of them.[285] He also states that by not allowing MAiD for individuals whose death is not reasonably foreseeable we, "…create the opportunity for those afflicted by a debilitating illness to overcome what may only be temporarily perceived as being unbearable suffering associated with it. It creates space and opportunity for the individual to change their mind."[286] This concern is born out of our societal value for life; that life is inherently “good” and that taking it away prematurely, for someone who does not have a life-limiting illness is inherently bad. Furthermore, we do not want to take away the life of someone who might change their mind. This point has been pushed back on by proponents for MAiD for MD-SUMC, who argue that those who have a severe mental illness, their quality of life is diminished and that the "wait and see" approach does not work.[287] Tanner argues that this approach also assumes that the individual’s psychological suffering is intolerable and irremediable. A person suffering to this extent may want their life to end, regardless of whether or not their death is foreseeable.[288] Patients in this state, “do

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[284] Blikshavn et al., 155-6.
[285] Tanner, 156.
[286] Ibid.
[287] Tanner, 156-7.
[288] Tanner, 157.

not want to hurt themselves, but they do not want to hurt anymore."[289] If we are to consider this last point seriously, the questions then become about respecting autonomy, and what suffering we view to be so intolerable that as a society, we would allow a person to end their life in order to end their suffering.

For all of the above-listed issues of expanding the eligibility criteria for MAiD, the problem is with balancing the respect for the autonomy of individuals requesting MAID, on the one hand, with protecting those who are considered vulnerable, on the other. With each population, mature minors, progressive illnesses, and mental disorders, there are compelling arguments to allow for MAiD; however, there are also real concerns for abuse and over-inclusion. It has already been stated that Canada's policy on MAiD is more liberal than of those countries that adopted the practice years ago. The worry is that if Canada expands the policy to include more populations too quickly, we risk over-inclusion or MAiD becoming the norm for those who no longer wish to live, regardless of their condition. The reality is that as MAiD is still in its infancy in Canada, we do not have sufficient data or lived experience to widen the eligibility criteria for MAiD yet. While there are valid reasons for why each of these groups should have access to MAiD, we should proceed with caution, as the decision to have MAiD is an irreversible end-of-life decision.[290]

Equitable Access to Palliative Care

A prominent concern that was heard amongst physicians when MAiD was decriminalized was that our country had spent so much time, money, and resources enacting MAiD when many Canadians still do not have equitable access to high-quality Palliative Care. Physicians who participated in the interviews, particularly those in 2016, wondered if we should be offering patients a way to end their life when it became intolerable before first ensuring that they had access

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[289] Tanner, 167.

[290] Charland et al.; Cuman and Gastmans.

to Palliative Care, a specialty of medicine that is focused on living and dying well, as well as pain and symptom management? The Hospice and Palliative Care Fact Sheet states that only 16-30% of Canadians have access to Palliative Care services in Canada, with less than 15% having early access in the community.[291] As the law requires access to Palliative Care be part of the implementation of MAiD, how can we justify MAiD if less than one-third of Canadians have access to high-quality Palliative Care? According to the government document, *Monitoring Medical Assistance in Dying Regulations,*[292] Schedule 4 s. 2 (e) states that,

> The patient gave informed consent to receive medical assistance in dying after being informed of the means available to relieve their suffering, including palliative care.[293]

Moreover, section 3 states that Palliative Care should have been made available to the patient. As Pesut et al. argue, Palliative Care is viewed as an essential service and, at times, a human right.[294] Accordingly, if Palliative Care is viewed as a right, then all Canadians should have access to it. However, how do we ensure access to Canadians who live in lower socio-economic areas, are vulnerably housed, or who live in rural or remote areas?[295] The lack of access to consistent, high-quality Palliative Care raises issues of social and distributive justice.

In the recent report published by Health Quality Ontario, entitled *Palliative Care at the End of Life,* it was found that those who live in high-income neighbourhoods are 12% more likely to receive home care and palliative specific home care to meet their needs.[296] Unsurprisingly, it

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[291] Canadian Institute for Health Information, *Access to Palliative Care,* 2018.

[292] Government of Canada, Public Works and Government Services Canada. "Canada Gazette – Monitoring of Medical Assistance in Dying Regulations." *Government of Canada*, 16 Dec. 2017, www.gazette.gc.ca/rp-pr/p1/2017/2017-12-16/html/reg6-eng.html. Accessed 7 May 2019.

[293] Ibid.

[294] Pesut et al., 46.

[295] Ibid.

[296] Health Quality Ontario. *Palliative Care at the End of Life,* 2016, 7.

was found that individuals who resided in low-income areas had poorer access to palliative specific care.[297]

Another issue around access to Palliative Care concerns those who are vulnerably housed or homeless. How do we ensure that those who do not live in stable or safe living conditions receive high-quality palliative Care? When dying, most Canadians say that they want to die at home, but what do you do when you are homeless? Dr. Naheed Dosani, a Palliative Care physician who cares for the homeless population, said, "Being sick is hard enough, but being sick and dying on the street is harder."[298] Helping those who are homeless and dying and needing to receive Palliative Care is a real challenge.

> We find that the vast majority end up dying in the ER, and in some cases, they are dying suddenly in transitional spaces, which is really just a fancy word for the park bench or a sidewalk … it's hard to strategize providing care and pain medications for this population because if anyone knows that [they] have them on them, they become victims of abuse or assault.[299]

The social factors play a significant role in the access to and quality of Palliative Care for those who are at the end of life and homeless. "We know that these social factors play a role in how we live, but should they influence how we die?"[300] This is one question of access to Palliative Care that we have not answered yet.

Similarly, those who live in rural areas face issues with access to Palliative Care resources, namely the equitable distribution of healthcare resources. Lyckholm et al. and Hadler and Rosa,

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[297] Ibid.

[298] "CBC News: The National. "Journey Home: Inside a Hospice for the Homeless." *YouTube*, 2 July 2018, www.youtube.com/watch?v=J-hP1EhjZRI. Accessed 8 May 2019.

[299] Ibid.

[300] Ibid.

both address the issues of equity and distributive justice for rural Palliative Care.[301] Lyckholm et al. argue that the equitable distribution of healthcare resources means that resources should be distributed based on need instead of the ability to access it.[302] However, the geographic location of patients who live in rural or remote areas challenges this principle.[303] It is well known that those who live in urban centres in Canada are much more likely to have access to resources such as hospitals, Palliative Care specialists, and the requisite medications. The challenge of providing Palliative Care in rural areas comes down to a lack of resources: namely, institutions such as hospitals or hospices, specialist palliative care physicians, and medications. A Palliative Care nurse who works in a rural area of Northern Ontario said,

> …Being so rural, we don't have the availability of a lot of services or the frequency of services that they do in urban centres. My nurses are only able to visit end-of-life, actively dying patients in-home once a day, to set up medications and to provide teaching … same with PSWs – they could maybe go in three times a day to check-in if we're lucky, but there is no one available overnight or for longer than absolutely necessary.[304]

The uneven distribution of healthcare resources for end-of-life care for those who do not live in a metropolis or urban areas presents questions about how those living in rural or remote areas can receive adequate care at the end of life, and what their options are. A worry that has been raised is that if all patients do not have access to high-quality palliative care, will they opt for MAiD by default if it is the only way they can alleviate their suffering? Alternatively, did our country have a moral obligation to try to ensure access to Palliative Care before legalizing MAiD? These

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[301] Lyckholm et al., 134; Hadler and Rosa, 1239.
[302] Lyckholm et al.,134.
[303] Ibid.
[304] Ibid.

questions around social and distributive justice, and equitable access to care, are some of the questions that have arisen from the introduction of MAiD in Canada.

Conclusion

This chapter discussed some of the ethical issues around MAiD and those that have arisen since its introduction in Canada. The debate over the ‘killing/letting die’ distinction long predates the legalization of MAiD, and played a central role in the debates over whether or not MAiD is morally permissible. But it is also relevant in a post-Carter world, since it bears on the distinction between MAiD and Palliative Care. The rest of the ethical issues discussed in this chapter are more obviously a result of the introduction of MAiD in Canada. The purpose of highlighting these issues was to raise some of the ethical dilemmas and not solve them as each of these issues could have an entire thesis devoted to it and subsequently goes beyond this dissertation's bounds. However, many of the ethical issues raised, specifically those around killing and letting die, and access to care, have become particularly acute for Palliative Care physicians as MAiD was aimed at the population of patients they care for. As a result, the relationship of Palliative Care and MAiD has come to the fore of many societal discussions; there is a very serious question of how Palliative Care should be related to MAiD, if at all. Because many Palliative Care physicians struggled with how MAiD and Palliative care should interact, a study was conducted on how to best support Palliative Care physicians in the future, given the advent of MAiD in Canada. The next chapter will discuss the study in detail.

Chapter 5: The Study

Introduction

From the previous chapters, it is evident that the introduction of MAiD in Canada has shone the spotlight on Palliative Care by calling attention to discussions around end-of-life care. In addition, this introduction has created specific challenges for the discipline of Palliative Care and for the physicians who practice it, because they care for the patient population which is most likely to be eligible for MAiD. Consequently, in the post-*Carter* world, understanding the challenges that Palliative Care faces, the best ways to support it (and, its physicians), and the roles it should play in the ongoing development of MAiD in Canada have become chief concerns for physicians, administrators, medical organizations, and government bodies.

To understand some of the answers to these questions, I conducted a qualitative research study in which I interviewed 51 Palliative Care physicians from across Canada. Palliative Care physicians were chosen as participants because they have a particular, sophisticated, and nuanced understanding of the current practice of Palliative Care, and of the changes that are needed to support it going forward. During the semi-structured interviews, I asked participants about the challenges faced by Palliative Care and its physicians, and about how they have been impacted by MAiD. I also asked physicians about how MAiD and Palliative Care should converge in the future, what systems or policy changes would address challenges faced by Palliative Care physicians, and what these physicians hoped for the future of Palliative Care in Canada. The study sought to answer the following questions[305] (including, but not limited to):

- What are the challenges facing Palliative Care and Palliative Care physicians?
- What are the ***ethical*** challenges that are unique to Palliative Care and Palliative Care physicians?

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[305] These questions were some of the questions that I asked physicians in the interviews.

- What has been the impact of Medical Assistance in Dying (MAiD) on Palliative Care and Palliative Care physicians?
- What is the role of Palliative Care in MAiD?
- Going forward, how do we support Palliative Care physicians?
- What system or policy changes would support better care of:
    - Palliative Care patients?
    - Palliative Care physicians
- What are the opportunities for Palliative Care in the future?

The purpose of these questions was to identify the specific challenges facing Palliative Care from the perspective of Palliative Care physicians to identify potential policy and systems-level changes that would best address those challenges. In this chapter I describe the study and outline some main results. In the following chapters I will discuss the proposed recommendations on how Palliative Care and MAiD should intersect, as well as policy and systems changes that would better support Palliative Care in Canada, and the physicians who practice it.

Procedures

The study was reviewed and received ethics clearance through a University of Waterloo Research Ethics Committee (ORE#40469). Upon receiving ethics confirmation, letters of invitation were sent to the Canadian Society of Palliative Care Physicians (CSPCP) and the Palliative Care Medicine Section of the Ontario Medical Association. Both organizations emailed all current members the letter of invitation to participate in the study. Willing physicians contacted me directly to set up an interview.

Interviews began at the beginning of March, 2019 and ended on July 31, 2019. In total, fifty-one physicians were interviewed. Interviews were done in person or via a secure teleconference line. The majority of the in-person interviews were conducted at the annual Hospice and Palliative Care Conference of Ontario at the end of April 2019, and at the annual CSPCP Conference in Calgary in June 2019. Physicians who reside outside of Southern Ontario were given preference to being interviewed at these events as it would be unlikely to interview them in-person, otherwise. Outside of the conferences, I agreed to meet with physicians in person if they were located within a 3-hour drive from Hamilton. For interviews that were conducted in-person, physicians were met at a location of their choosing, wherever they felt most comfortable. Locations ranged from professional offices, hotel lobbies, cafes, restaurants, or the homes of physicians. If I was unable to meet with a physician in person, a telephone interview was arranged. All interviews were conducted at a date and time that was most convenient for the physician. The interviews lasted from one to three hours.

All interviews were audio-recorded to facilitate the collection of information and later transcribed for analysis. All information that was obtained as a part of this study was confidential and was de-identified to protect the privacy of physicians. Any identifying information was removed during transcription. When participants are quoted below, names or identifying information have been removed.

Methods

Design

I conducted qualitative interviews with Canadian Palliative Care physicians in a variety of settings. Any physician who is a current member of the Canadian Society of Palliative Care Physicians, or the Palliative Care Section of the Ontario Medical Association, received an email to participate in the study. Any currently practicing Palliative Care physician was invited to participate. No physicians from these email lists were excluded.

I collected demographic information from physicians, including the year they graduated from medical school, years practicing medicine, years practicing Palliative Care, training in Palliative Care, gender, and age.

The study focused on understanding the challenges faced by Palliative Care and its physicians and the supports and systems or policy changes they needed to be supported in their field and to continue to do their work. Physicians answered broadly (what was needed for Palliative Care in Canada, for all physicians) and individually.

Each physician was asked the same interview questions and in the same order.[306] I asked how physicians came to practice Palliative Care, where they practiced, the population for whom they cared for, their understanding of and perceptions of MAiD, the challenges they faced as Palliative Care physicians, the challenges they saw facing Palliative Care, and what supports and systems or policy changes they needed going forward. Physicians were also asked about what enabled them to continue to care for patients and practice Palliative Care.

While not a primary focus of the interviews, the study sought to understand physician's views around MAiD, their degree of involvement in the practice, and how they thought Palliative Care and MAiD should intersect or interact in the future.

Analysis

Interviews were recorded digitally, transcribed verbatim (except for what physicians asked to be kept off the record), and de-identified. Qualitative data were analyzed using thematic analysis to generate themes and trends that emerged from the interviews. Thematic analysis extracted themes from the transcripts, focusing specifically on the physician's Palliative Care practice,

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[306] Some physicians would speak to some questions more than others which naturally lead to follow up questions or side conversations. Despite this, each physician was asked all of the interview questions in the same order as their colleagues.

perceptions of MAiD, challenges facing Palliative Care, and support needs. Through the use of qualitative content analysis, codes were taken from transcripts directly and were not preconceived.

As the sole investigator, I coded all transcripts. Twenty transcripts were coded initially to develop a set of preliminary codes. Codes were categorized into themes for responses to questions. I reviewed codes and themes regularly with my supervisor, Dr. Mathieu Doucet, particularly as specific sections of the dissertation were written.

Data Limitations

By design, this study focused exclusively on the experience and perceptions of *Palliative Care physicians*. That means that it does not include insights from any other healthcare professionals involved in Palliative Care or MAiD, including other physicians who practice MAiD such as Family Medicine, Internal Medicine, or Anesthesia, and other professionals such as nurses, social workers, or chaplains. Therefore, the results will necessarily represent a distinct professional *perspective* and leave out other important and potentially competing perspectives on MAiD.

Despite these limitations, the study's intentional focus on a single specialty has several benefits. First, I had access to the professional organizations for Palliative Care, so I was able to interview 51 Palliative Care physicians from across Canada. This means that the study results are much more likely to represent *Palliative Care* specialists' views than a study of 51 physicians from a range of specialties, which would be of the views of physicians more generally. What the study loses in breadth, it gains in-depth. Second, the design is suited to the project's central research question. The study's primary aim—and indeed the dissertation project as a whole—is to understand how the introduction of MAiD has affected *Palliative Care* in particular and how Palliative Care physicians believe Palliative Care should intersect with MAiD in the future. The advent of MAiD had a unique effect on Palliative Care as it stood in opposition to the traditional understanding and goals of Palliative Care. Therefore, MAiD forced Palliative Care to reconceive its goals and intentions, as well as its role in the care of patients who have a life-limiting illness and who are suffering intolerably. Other specialties did not experience these existential or practical concerns in the same way. Moreover, MAiD did not present itself as a threat to other specialties. In contrast, many Palliative Care practitioners initially viewed MAiD as an approach to care that stood in opposition to Palliative Care and potentially endangered or called into question the care of patients at the end of life. Consequently, Palliative Care has been uniquely affected by MAiD, and understanding how the two practices relate is important.

The study focused on the perceptions of Palliative Care *physicians* intentionally. While Palliative Care physicians are only one part of the Palliative Care team, this study aimed to understand physicians' views as a specific group. This was done for three reasons. First, physicians were chosen, specifically, because, at the time of the *Carter* ruling, MAiD was then referred to as "physician-assisted dying." Consequently, before Bill C-14, only physicians were allowed to provide MAiD. Therefore, *physicians* were the first professional group who were asked to deal with requests for MAiD. Second, even after Bill C-14 was passed and allowed for nurse practitioners to provide MAiD, we have seen that nurse practitioners are the minority group of nurses and that not all provinces allow nurse practitioners to provide MAiD. As of 2019, physicians accounted for over 94.1% of all MAiD providers, while nurse practitioners only accounted for 6%.[307] Other members of the Palliative Care team are not permitted to provide MAiD. Finally, questions around MAiD, or other major medical decisions, must involve a physician. As such,

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[307] However, it should be noted that while physicians may account for the majority of MAiD providers, nurses are may often be involved in the administration of MAiD, such as placing intravenous lines.

responsibility and accountability fall to physicians, more so than professionals from other fields. For example, while nurses and social workers may be intimately involved in patient care and assist in decision-making, the ultimate decision and responsibility and accountability of that decision falls to the physician. Therefore, physicians will have different experiences than other professions involved in Palliative Care. Accordingly, to understand physicians' perceptions and needs and their understanding of how MAiD has impacted Palliative Care, it was essential to interview physicians as an isolated group—having a group of one profession allowed for an analysis of trends and differences across the country. By limiting my study to Palliative Care *physicians*, I was able to focus my research and analysis, which led to richer data and a more in-depth understanding and expertise about the perceived needs and challenges of that group.

While this research captures the perceptions of Palliative Care physicians, it has not included the views or opinions of other professions involved in Palliative Care, such as nursing or social work. These groups will have different experiences of Palliative Care and MAiD as their relationship with patients and the healthcare system is different. Studies that focus on these other groups and their experiences, challenges, and needs are required. Having a specific study devoted to each group is important as the findings will expand the understanding of Palliative Care and how to support it as a discipline going forward. Consequently, future research should include the perspectives of other members of the Palliative Care team and other disciplines of medicine who care for patients who have a life-limiting illness and request MAiD, as these perceptions may differ from those of Palliative Care physicians and may result in new findings. As such, a comparative analysis of the findings of these studies would be worthwhile.

Other limitations included not having representation from all provinces and territories. Physicians from Nova Scotia, Prince Edward Island, Nunavut, the Northwest Territories, and the Yukon did not respond to invitations to be interviewed. As a result, data from the experiences of physicians in these areas are missing. Also, only two physicians from the Atlantic provinces were interviewed. Having more physicians from the Atlantic provinces, including physicians from each province, would lend to more inclusive data.

While physicians interviewed were not currently living in the Northwest Territories, many had practiced there in the past, did locums, or had temporary contracts throughout the year. While they could discuss their experiences of practicing Palliative Care in the Northwest Territories, these physicians were not permanent residents. As a result, these physicians did not have the same nuanced understanding as physicians who resided and practiced solely in the Northwest territories.

Formal member checking was not included before the write up of this dissertation. Time limitations precluded this. However, the next stage of this project involves member checking, which will occur before the results are published in peer-reviewed journals. Members who participated in the research will be sent copies of the results and asked for feedback before publication.

Participant Characteristics

Of the 51 participants interviewed, 33 were women, and 18 were men. They hailed from across Canada, representing every province, except for Nova Scotia.[308] Respondents varied in age,

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[308] Physicians from Nova Scotia and Prince Edward Island did not respond to the invitations to participate.

culture, professional background, years working in health care, and years working as a (specialist) Palliative Care physician.[309]

The majority of physicians (49/51) were between the ages of 30-69, with the median age being 50 years old. Only two physicians were outside of this age range, with one being younger than 30 and the other being older than 69. Participants varied in their years of working in health care and their years working in Palliative Care, specifically. Of the 51 physicians interviewed, 27 had worked in healthcare for over 20 years, 6 for 16-20 years, 8 had been in healthcare 11-15 years, 5 had been working for 5-10 years, and 6 were within their first 5 years of practice. When asked about their years working in Palliative Care specifically, 11 were in the first 5 years of practice, 9 had been practicing for 6-10 years, 9 had been practicing for 11 to 15 years, 10 had been practicing Palliative Care between 16 and 20 years, and 13 had been in the field for over 20 years.

The physicians' geographic location varied, with most physicians (66%) residing in Ontario. Below is a percentile breakdown of where the physicians practiced.

British Columbia (4/51) = 7.84%
Alberta (7/51) =13.73%
Manitoba and Saskatchewan (3/51) = 5.88%
Ontario (34/51) = 66.66%
Quebec (4/51) = 7.84%
Atlantic Canada (2/51) = 3.92%

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[309] Any physicians who trained and practiced prior to 2017 when the Royal College of Physicians and Surgeons accredited Palliative Care as a *specialty* program with formal training, are not considered to be “specialists.” However, these physicians specialize in Palliative Care, and it is their sole practice area. The physicians I interviewed are Palliative Care physicians, and not physicians in other areas who practice Palliative Care.

Results

The general themes that emerged from the interviews were:

1. MAiD is a prevalent issue amongst all Palliative Care clinicians (for those who provide it as well as those who conscientiously object to the practice);
2. Access to high-quality Palliative Care is not readily available to all Canadians;
3. Community and Homecare support are under-resourced and under-funded;
4. Professional teams and family members are sources of support for physicians; and,
5. Education in and around Palliative Care is lacking for the public, policy makers, medical learners (students and residents), and other healthcare professionals.

Each of these will be discussed in greater detail below. Specific results came from the challenges identified by Palliative Care physicians that they see as facing their discipline, that they face as individual Palliative Care physicians and the issues that they find to be most ethically challenging. As such, some of these themes will be taken up in subsequent chapters in greater detail.

MAiD is a prevalent issue amongst all Palliative Care clinicians

Three years after medical assistance in dying in Canada received royal assent, Palliative Care physicians continued to struggle with MAiD. Physicians who were morally or practically against MAiD struggled with it being an accepted practice, and with ongoing requests for MAiD. Two of the physicians who interviewed indicated that they have (temporarily) left the practice of Palliative Care because of their discomfort with assisted death. Alternatively, those physicians who practiced MAiD felt alienated by the Palliative Care community. They felt unsupported by their national governing association, the CSPCP, which published formal statements against the practice of MAiD and its place in Palliative Care. On the other hand, the national association for MAiD providers, the Canadian Association of MAiD Assessors and Providers, has stated that

Palliative Care should be involved in MAiD. The question of how the two practices should intersect is a question that is unanswered due to the divisive views on the issue. The pervasiveness and complexity of this issue, as well as the divide amongst the Palliative Care community, was emblematic of the need for further discussion. The sixth chapter of this dissertation will take up this particular issue and analyze it in greater detail.

Access to High-Quality Palliative Care is not readily available to all Canadians

Physicians argued that all Canadians do not have access to high-quality Palliative Care. It was suggested that this is primarily due to the location of the patient and where resources are available. Canadians who live in major city centres such as Toronto or Vancouver are more likely to access high-quality Palliative Care than those who live in rural areas. Physicians articulated that those who live in rural or remote areas are less likely to access the care they need due to the lack of Palliative Care physicians who practice or reside in these areas, coupled with the lack of community healthcare support, and few healthcare institutions.

The inability of every Canadian to access quality Palliative Care is problematic for many reasons, with a chief concern being that patients are not receiving a Palliative Care approach to their end of life care, which may result in poorer quality of life. Now, with MAiD, physicians worried that a patient's inability to access Palliative Care, and potentially poor quality of life; as a result, more patients may receive MAiD because they are not able to access Palliative Care. Because MAiD can be administered by a variety of healthcare practitioners and does not need a specialist Palliative Care approach, it is more readily available in some areas where Palliative Care is not. Thus, the absence of quality Palliative Care in all areas of Canada is problematic not only because Canadians are not able to have the care they deserve at the end of life, but also because they may choose MAiD as a means to end their suffering because they lacked access to high-quality Palliative Care. Physicians wondered if some of the individuals who chose MAiD would have done so if they had access to Palliative Care, or if they would have had MAiD at a later time if their symptoms were managed.

Community and Homecare support are under-resourced and under-funded

Physicians stated that community or home care support for patients receiving Palliative Care in their homes is lacking, and needs to be better funded. Participants discussed the need for more experienced nurses in the home and more hours for nursing and Personal Support Worker (PSW) support. Several physicians spoke about the discrepancy in pay and benefits for nurses who work in hospitals compared to those who work in the community. The institutional jobs are coveted and thus attract the more senior, skilled nurses. As a result, physicians stated that many of the nurses (not all) who work in the community are newer, younger nurses who typically have less training in Palliative Care. Some physicians believed that the lack of training and experience resulted in newer nursing graduates feeling less confident about providing adequate care for patients with complex palliative care needs. This insecurity, combined with the complexity and emotional toll of Palliative Care, was why physicians believed that there was a high turnover rate. Physicians indicated that this high-turnover rate leads to a lack of reliability, which they depend upon when caring for patients in the community. As physicians are not always able to be in the homes with patients, they rely on the assessments of the nurses. Several physicians discussed the poor quality of the assessments from nurses, which was the result of a failure of the coordinators to hire qualified nursing and home care staff. While physicians were frustrated in their inability to trust the community nurses' assessments, they were cognizant of the fact that the nurses were not to blame for their lack of skill. Instead, it was the fault of the coordinators or organizations for putting unskilled nurses in these scenarios or nurses who did not want to work in the community.

Physicians also stated that the lack of funding for nursing and PSW hours is problematic because very few patients can afford 24/7 care. Consequently, physicians noted that patients are only allotted a few hours a day of home care (2-4 hours), which leaves them on their own, or the burden of care falls to family members or friends. This often leads to caregiver burnout and the need for respite care. Physicians were aware that their patients who do not have family members to care for them outside of the time that the nurse or PSW is there, often end up in the hospital because they are unable to care for themselves.

Professional teams and family members are sources of support for physicians

When asked what enabled them or allowed them to continue to practice Palliative Care, the majority of physicians indicated that it was because they work in supportive professional teams, and, or, they had a supportive spouse or partner in their lives.

Palliative Care teams often include other physicians, nurses, social workers, spiritual care, or other allied health professionals.[310] Physicians stated that by working with these team members, they could take time away from clinical work (for personal or professional reasons) but knew that their patients were still looked after. These professional teams provided much more to physicians than clinical coverage. It was noted that these teams were also a source of collegial support; colleagues with whom the physicians knew shared in and understood their experiences and

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[310] Allied healthcare professionals include (but are not limited to): dieticians, physiotherapists, audiologist, speech and language pathologists, occupational therapists, or medical device engineers.

challenges. Furthermore, physicians relied upon their team members to discuss or debrief patients or cases, which was a source of support and a way to maintain resiliency. Working in a team means that often the physician did not feel alone or siloed.

Additionally, many physicians attributed their ability to continue to practice medicine due to having a supportive partner or spouse at home. It was noted that partners often took on the burdens that came with homelife (childcare, meals, home maintenance), which allowed the physicians to work the hours needed to care for their patients. Partners were also a source of 'home' and comfort to the physician; a person they knew they could always turn to for support.

Education in and around Palliative Care is lacking for the public, policy makers, medical learners (students and residents), and other healthcare professionals

General knowledge around Palliative Care lacks both among the public and (some) other healthcare providers; this lack of knowledge leads to myths and misperceptions that make the job of a Palliative Care physician more difficult. Consequently, Palliative Care physicians discussed the desire and need for increased education and understanding about Palliative Care within society, at the learner level (undergraduate as well as residency), and interprofessionally.

Physicians discussed problems of the public not understanding Palliative Care, and equating it with death, dying, or MAiD. Consequently, many physicians stated that due to these misperceptions, patients and their families are hesitant to have conversations about the end of life or to have Palliative Care consulted at all. Physicians found that once they engage in conversations with their patients about what Palliative Care is and could offer them, there was less resistance and more willingness to have Palliative Care be involved in their care. Therefore, Palliative Care physicians wanted a public campaign to educate members in society about what Palliative Care is and how it can benefit patients.

Many participants argued that education in Palliative Care lacked at all levels in healthcare. This problem was particularly evident in the lack of Palliative Care in the medical curriculum for all medical learners. Physicians strongly believed that Palliative Care should be a federally mandated rotation in medical school for all undergraduate learners, as well as a mandatory rotation for all residents. This training should also extend to include all learners in healthcare, specifically nursing and social work. Palliative Care physicians noted that it would be beneficial for all learners to have mandatory education in Palliative Care so that they can care for their patients better, and work with the Palliative Care teams in a more collegial manner. If learners are aware of what Palliative Care is and does, they are more likely to understand when their patients will benefit from a Palliative Care approach, and thus consult Palliative Care as soon as possible. The lack of education in Palliative Care will be discussed in greater detail in subsequent chapters as it was identified as a challenge facing Palliative Care, and improved education in Palliative Care is one of the proposed recommendations.

Interprofessionally, two themes emerged: that other disciplines are unclear of what Palliative Care does and that this lack of an understanding results in colleagues from other professions not consulting Palliative Care for their patients. Physicians noted that these colleagues are not aware that Palliative Care should be consulted early on as Palliative Care can help to manage a patient's symptoms early on. Participants complained that all too often, Palliative Care is only consulted in the last hours or days of a person's illness, at the point of which it is often too late for Palliative Care to make any significant difference in the patient's quality of life. Palliative Care physicians expressed the need for their colleagues in other specialties to understand what they do so that they would be consulted earlier; not only to offer Palliative Care to the patient earlier but to be able to care for the patient alongside the other specialties and create more of a seamless transition when the patient did reach the end of life.

Conclusion

The purpose of this study was to understand the perspectives of Canadian Palliative Care physicians on the challenges that Palliative Care faces, and particularly those challenges resulting from changes in the medico-legal landscape brought about by the *Carter* ruling. Through interviews with 51 physicians, the study collected data that was used to make recommendations about changes in systems and policies that would support the improvement of Palliative Care in Canada. The reader will see that many of the themes addressed in this chapter are taken up in subsequent chapters where I discuss the challenges facing Palliative Care and its physicians, the intersection of MAiD and Palliative Care, and what changes need to be made going forward to support Palliative Care and the physicians who practice it.

Chapter 6: Understanding Palliative Care in Canada and the Physicians who practice it

Introduction

To understand how to support Palliative Care in Canada, it is important to understand who the physicians are who practice it, as individuals within their own context. This chapter will introduce some of the Palliative Care physicians who practice in Canada. Understanding who these physicians are, both as individual people, and as Palliative Care physicians, is essential because it contextualizes their perspectives on the current state of Palliative Care, the issues it is facing, and what changes need to be made to support the discipline as a whole.

In their interviews, physicians spoke about how they came to practice Palliative Care, what Palliative Care means to them, the challenges they see facing the practice of Palliative Care, and the challenges they face as individual physicians. Participants also highlighted the philosophical and ethical issues that they encountered within their practice of Palliative Care, focusing on those they considered to be most troublesome.

Having an understanding of the physician's nuanced perspective on these issues is critical to understanding the changes that need to be made, and proposing recommendations that will support Palliative Care in Canada, as these physicians see the day-to-day effects of changes or inadequacies in the current system. The voices of these physicians were taken seriously. They were integral in the recommendations made in chapters 6 and 7 on how Palliative Care and MAiD should intersect and what systems and policy changes need to be made to improve Palliative Care in Canada.

How did they come to practice Palliative Care?

Many of the physicians interviewed did not start their medical practice in Palliative Care. As such, in their interviews, physicians spoke about how they were introduced to the field. The stories about how physicians came to practice Palliative Care were unique, personal, and reflective; every physician had a story about something that changed them and their career trajectory, either in general or in medicine. Of the 51 physicians interviewed, just under half found, or went into, Palliative Care after training in family medicine. The other physicians came from varying backgrounds, ranging from teaching high school, obtaining a Master's degree in Public Health, Anthropology, or Divinity, Hospital Administration, working with Human Immunodeficiency Virus /Acquired Immune Deficiency Syndrome (HIV AIDS) patients, having battled cancer themselves, volunteering at the Royal Victoria Hospice, Nursing, Physiotherapy, completing an MD/Ph.D. program in Neuroscience, working in Internal Medicine, Oncology, Hematology-Oncology, Pediatrics, Obstetrics, Gynecology, Geriatrics, Ophthalmology, Psychology, and Emergency Medicine. How each one of these physicians discovered or learned about Palliative Care and came to practice the specialty is personal.

Many of the early Palliative Care physicians started practicing in this area because of an experience with a particular patient whose illness perplexed them, yet to whom they had committed to caring. Consequently, the physicians mustered the courage and sought help and the requisite resources to learn about how to best care for their patients. Recall that Palliative Care was only introduced to Canada in the 1970s when Balfour Mount brought his learnings to Canada after training with Cicely Saunders in England, so it is a relatively new specialty. For that reason, any physicians who were contemporaries of Mount were learning about how to care for dying patients as they practiced. A common phrase that was used amongst physicians who started practicing before 2000 was that they learned Palliative Care "on the job" because “always, it’s your patients who teach you.”[311] These physicians looked after patients who were dying from various illnesses and taught themselves how to provide appropriate care. Importantly, they sought help from other colleagues along the way. One physician, while practicing in the early 80s treated, a young man who with presented with symptoms of Kaposi's sarcoma or *Pneumocystis carnii pneumonia* (PCP) (now known as HIV/AIDs). Not having an understanding of how to treat this illness, he told his patient that he could refer him to another clinic that was known for treating patients who had PCP. However, the young patient trusted his physician and asked him if he believed that the clinic would care for him better than he could. The physician said 'no,' and said that he would care for him if that is what he wanted. The patient stayed under his care, and the physician sought help from another colleague who was also starting to practice Palliative Care. The two Palliative Care colleagues collaborated to care for this young man at the end of life.[312] Together, they learned about PCP and how to care for patients with similar illnesses, and who were dying.

Another physician shared an analogous story. In her early days of practice, this physician was faced with a patient's illness that she did not know how to treat.

> So, in about 1983, I had an encounter where I was looking after a patient with progressive metastatic melanoma. She was one of my family practice patients. And I had no clue how to look after her. ***So, typically everything starts around a patient.*** And so, I did look after her, establishing connections with other teams … like, a pharmacist in the community, for instance, working with someone who could start an IV in the home. We had no home care back-up. So, I had to get permission from one of our hospitals to borrow equipment and supplies and take … because you couldn't order it anywhere – those kinds of things. And through that working, we had to establish a hospice team for this patient…. I worked just basically learning by osmosis because there wasn't any fellowship at that time unless you went to England and worked for Cecily Saunders.[313]

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[311] Interview 16.
[312] Interviews 3, 16.
[313] Interview 34.

This physician went on to explain that once she had learned more about Palliative Care that she contacted colleagues and offered to assist them with their patients. She said, "Look, I've done this work. If you would like help with any of your patients, please contact me." Once she had done this, two fellow physicians (an oncologist and a general practitioner) contacted her to help them care for the patients with terminal illnesses in the community.[314]

Other physicians told similar stories about a patient who was dying or had a life-limiting illness in which they were unfamiliar;[315] however, despite not knowing how to treat their patient, the physician had committed to caring for them. In order to do this well, they sought education or training about how to best care for the patient and how to mitigate their suffering. They did not turn away from something that they did not know how to manage; instead, they sought out the resources needed to care for their patients at the end of life. Once these physicians learned how to care for patients with unusual or uncommon illnesses, they trained other physicians. Palliative Care was, and still is, a collaborative practice where physicians teach each other how to care for patients who have life-limiting illnesses.

The younger generation of physicians spoke about how they worked with a senior Palliative Care physician (during a rotation or elective during medical school or residency) who showed them what Palliative Care was and how patients and their families benefited from it.

> I went through medical school and medical training; that we didn't really talk about death and dying. When I was in residency, I always thought I would do family medicine. My first weekend in residency, I was working with (senior physician), and I went and saw a patient who had ALS and died that weekend. It was my first experience with providing palliative care in the community. And I was just struck by how I was welcomed into that home, and how it was so personal and how even though we saw this patient twice, I had such a big impact on the family. And so, those are the kind of experiences over time that build up, and that's why I decided I wanted to go into palliative care.[316]

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[314] Interview 34.

[315] Interviews 27, 50.

[316] Interview 47.

From this story, it is apparent that a prominent reason why physicians came to practice Palliative Care was because of a patient. While the older physicians entered the field because they had a patient whose illness perplexed them, the younger generation became Palliative Care physicians because they saw the impact that the practice of Palliative Care had on patients and their families. For both generations of physicians, it is the experience with patients that made them want to be Palliative Care doctors.

What does Palliative Care mean to the physicians who practice it?

For Palliative Care physicians, their specialty is not just about death and dying; rather, it is about living well and improving quality of life. To them, it means supporting patients in living their best life (as the patient sees it), focusing on caring for the patient as a whole, and not just the disease or organ. It means helping the patients to live fully even with the recognition that their death is "…in the present tense."[317]

When asked what Palliative Care means to them, almost all physicians (49 of 51) provided an individualized definition – ones that departed from or expanded on the commonly accepted definition from the World Health Organization (WHO). One physician offered the following definition of what Palliative Care meant to them.

> I think of somebody falling, and you can't stop them from falling, but you can hold them as they fall. That's what I think of when I think of palliative care. All you can do is hold them and not drop them. It doesn't mean that they're not falling. It doesn't mean that it's not scary or, you know, there aren't really difficult things along the way, but you're there. You're accompanying them, and whatever you can do to make it easier, you make it easier. To me, that doesn't include dropping them. And, you know, it doesn't include pushing them … For me,

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[317] Interview 46.

> you cannot make it go faster, but you can do everything in your power to make it easier. And you can be with them. I think that's a primary thing; it is not abandoning. You're with them.[318]

This image conveys the intention of Palliative Care; that it cannot stop death, prevent it from happening, or even slow it down, but it can be there with the patient through their journey. It can do whatever it can to make dying easier, less painful, and a little easier. Palliative Care walks alongside the patient throughout their journey and never abandons them.

Physicians are well aware that while Palliative Care is non-curative, it can change the trajectory of an illness by helping patients to live better or even longer. Of the 51 interviewees, 36 spoke to this idea.

> At its most fundamental level is care that is directed to the patient irrespective of its impact on the patient's duration of life and so the most simplistic explanation I use when teaching is that if you have a 2-year-old with an ear infection, and you prescribe antibiotics that's a curative approach when you prescribe Tylenol that's a positive approach because it doesn't change the ear infection, but it does make the quality of their life better during the ear infection.[319]
>
> I think the bottom line for Palliative Care is making the journey, not necessarily the end of the journey, but making the journey more comfortable …It's about a smooth ride, basically.[320]

Another theme that emerged from the definitions that Palliative Care seeks to care for the entire person and "their circle."[321]

> It means addressing suffering to me. So, in all its domains as Dame Cicely Saunders kind of wrote. So, pain and all physical symptoms, of course. The psychosocial and spiritual aspects of suffering as well. It means having conversations about it… you know, about what's happening and what's going to happen. It means not only addressing the patient's needs but addressing the needs of his or her circle of care – family, friends, supports. It's all the people involved in the care, it's dealing with their aspects to a … not only a system and caring for the … for the patient, but assisting them with everything that they're going through during this phase. So, it's really that focus on all aspects.[322]

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[318] Interview 32.
[319] Interview 9.
[320] Interview 39.
[321] Interview 16.
[322] Interview 16.

21 of 51 of the physicians said that Palliative Care includes caring for the patient's family (or their chosen family) or whomever they have decided to have in their circle of care. Addressing the needs of those who are involved intimately with the care of the patient is part of what Palliative Care does. This interpretation lends itself to the commonly accepted understanding that Palliative Care is *whole-person* care; it means caring for the patient in their entirety and not just their illness, which includes their loved ones and those most important to them. While Palliative Care may not provide medical care to "the circle," it recognizes the patient's illness in the context of their circle and works to provide unique and innovative ways to meet the patient's care needs.

These definitions provided are particularly interesting because they represent a shift in mentality of physicians from 2016 to present day. Palliative Care physicians who were interviewed in the study on the "Impact of the MAiD Ruling on Palliative Care Physicians," in 2016 predominantly listed the WHO definition of Palliative Care.[323] However, in 2019, only two physicians referred to it. Thus, we see an evolution in the responses given by physicians, particularly those who participated in both the 2016 and 2019 studies. The same physicians who, in 2016, offered definitions that resembled that of the WHO, gave very different, and much more personal definitions in 2019. A plausible hypothesis for this change is that the introduction of MAiD has led Palliative Care physicians to rethink what Palliative Care means to them. This is indicative of the fact is that the practice of Palliative Care is not a static or impersonal; rather, it evolves over time and with the experiences of the physicians who practice it.

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[323] Woods and O'Donnell et al. "Uncommon Bedfellows: New Insights into the Complex Relationship between Palliative Care and Medical Assistance in Dying." Canadian Bioethics Society Conference. Montreal, May 25, 2017.

What are the challenges facing Palliative Care?

Each physician described their understanding of the challenges that Palliative Care, as a discipline, faced. Physicians raised (approximately) seventeen challenges, which are highlighted in the table below.

Challenge to Palliative Care	**# Physicians who cited this challenge**
Lack of (funding for) homecare/community resources	26
General misperception and misunderstanding of what Palliative Care is/does	13
Not enough trained Palliative Care physicians to do the work	11
Medical Assistance in Dying (MAiD) (varying issues)	10
Fragmentation/ lack of Palliative Care services across Canada	10
The need for Palliative Care to be integrated with other specialties/ the need for other specialties to have basic competencies in Palliative Care	9
We live in a death-denying society/ there is a stigma around death and dying	8
Lack of funding for Palliative Care in general	8
Insufficient training in Palliative Care for learners (including a lack of residency spots) and other healthcare providers	6
Palliative Care (as a discipline) missing opportunities to advance	4
Not having seamless care or transitions between specialties or institutions	4
Patients sent to hospice or Palliative Care units who are not actively dying, or near-death	3
Caring for marginalized and vulnerable populations	3
Other specialties not respecting Palliative Care (regarding it as "soft" medicine)	3
Patients being deemed "palliative" or "non-palliative"	3
Specialist Palliative Care versus Palliative Care that is provided by Primary Care physicians (lack of a standard)	2
Dying at home is not always feasible	2

The five most commonly discussed issues facing Palliative Care were:

1) the lack of funding for home care or community resources;
2) the widespread misperception or misunderstanding of Palliative Care by the public and even other colleagues;
3) the lack of Palliative Care specialists to do the work;
4) Medical Assistance in Dying, as well as (4b) the fragmentation of Palliative Care services across Canada; and,
5) the need for Palliative Care to be integrated into other specialties.

Each of these will be discussed below.

Lack of funding for home care and community resources

The lack of funding and resources for home care and community care was the most reported challenge that Palliative Care, as a discipline, faces. Physicians recognized that while many people die in institutions in urban areas, most are cared for throughout much of their illness at their home, with only episodic admission to hospital. Moreover, when asked where they want to be cared for, most patients state that they want to be cared for in their homes. Therefore, Palliative Care relies on caregivers (family and friends), nursing staff, and personal support workers (PSWs) to look after patients who remain in the community. However, due to the complexity of patients who have life-limiting illnesses or who may be at the end of life, physicians noted the need for experienced nurses and PSWs in the community. Several participants noted nurses and PSWs who work in institutions like hospitals and hospices are paid more than their counterparts who work in the community.[324,325] Therefore, it is unsurprising that those who have more experience and seniority often gravitate towards the more lucrative positions, leaving the community positions to be accepted by new graduates or those who have less experience. It is the perception of physicians that some the nurses and PSWs who are in the community are less experienced and have less of an understanding of how to adequately care for patients who are dying or have life-limiting illnesses than their senior or more experienced colleagues. To have inexperienced caregivers working in the community with patients who require Palliative Care is worrisome because these caregivers are less comfortable, and at times scared, with caring for individuals with complex

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[324] Interviews: 10, 30, 44, 45.

[325] Some physicians cited this difference in pay was as much as 40%.

healthcare needs on their own. Unfortunately, the result is a high turnover rate, and patients who have complex illnesses continue to be treated by new, less confident nurses and PSWs.

> …in terms of resource allocation, in terms of effort and energy and financial support and all those things, we are not meeting the needs of people at home, to be at home. We are asking them (PSWs and caregivers) to do the things that are sometimes somewhere between a real stretch and downright dangerous in terms of their capacity to administer medications and to really make personal decisions … we have really, really undervalued the role of PSWs health care system. We pay them poorly. They are by and large people who deal with new arrivals in some way, shape, or form … They do as much or more of the work that allows people to be at home as any clinical person.[326]

Therefore, in order to retain experienced caregivers in the community, they must be paid competitive wages to what they might earn in an institutional setting. In addition to paying community nurses and PSWs, higher wages, the health care system must train and hire more as the demand for community care is high. Currently, most patients are allotted one to three hours (maximum) of nursing or PSW support each day.[327] However, as patients still require care for the remaining hours of the day, the responsibility falls to family or friends, or in some situations, just the patient. One physician described a common problem that patients face when they choose to remain at home.

> Okay, if you got really, really sick, where would you want to be at the end of your life? So, most people said home … But now you can't make that happen because you can't get a Palliative Care nurse to pick up that patient, never mind a doctor. You can't get a nurse. And PSWs, forget about it. There's not enough PSWs in the system. They're all looking after the bridge to long-term care … So, when they're going home or if they go to a retirement home, sometimes the retirement homes alert the family and say, "Well, we can take them home, but we need 24-hour PSW." So, that sucks a tremendous amount of resources out of the system. So, that's a problem, delivery. And if you're in a rural area like (identifying name). I've got one guy who's incontinent, but we can't even get him one PSW visit a day. So, he lays in bed until the PSW comes. Sometimes she comes about 12:30. He cannot get up on his own. Once he gets up, he can walk with his walker and … And he's lying in his own excrement. But he wants to be at home. So, in rural areas, it's even tougher to get the resources that you need to make it possible.[328]

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[326] Interview 30.
[327] Interview 32.
[328] Interview 34.

Caring for patients with complex needs (like the one mentioned above) requires skilled, confident practitioners. The physicians recognized that there are experienced nurses and support workers who stay in the community they do so because they are dedicated to working with patients who require Palliative Care. However, these workers are doing so at a financial cost as it is known that they could have a more lucrative career if they worked in an institution. The irony is that it is the nurses and PSWs in the community, the ones who are paid less, are the ones who are saving our healthcare system money.[329] While there is a population of Palliative Care patients who require hospitalization because of the need for expertise, technology, and 24-hr care, many patients can be cared for in the community. A skilled workforce that is paid adequately would support the care of patients in the community. As such, our healthcare system would be better served if more resources were given to support patients in the community, in order to keep them out of hospital (as long as possible). It can be presumed that if community caregivers are paid more, the retention of skilled workers will increase, and turnover will decrease. Later, it will be suggested that an investment in home and community care will benefit patients, but will also benefit the healthcare budget and system overall.

General Misunderstanding of Palliative Care

Palliative Care is widely misunderstood by those who do not practice it. Physicians interviewed discussed the widespread misunderstanding of Palliative Care by the general public and physician colleagues who practice other specialties. The lack of understanding by both groups presents a challenge to Palliative Care.

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[329] Interviews 35, 38.

Physicians told stories of patients or patient's families being afraid of Palliative Care, and believing that Palliative Care was only for when there was no more hope, or that they were in the last few days of life. The patients or families used phrases that simultaneously represent their fear and misunderstanding. For example, "grim reaper" or "bringer of doom and gloom" were often cited by physicians regarding how their patients and families viewed them. These physicians want the public, and their patients, to understand that Palliative Care does not mean that patients will die tomorrow, and it is not (always) equivalent to end-of-life care. Physicians interviewed want everyone to understand that when Palliative Care becomes involved with them or their loved ones, it does not mean that other specialties have given up or that patients will just be given high doses of opioids.[330] Physicians articulated these misperceptions:

> People are so scared of us because they think it means you are going to die tomorrow, and it's like, "No."[331]
>
> The image of Palliative Care being end of life care, that's a big challenge. You know, when all hope is lost, when nothing more can be done, when … I had a patient say to me just a couple of days ago, "Doc, the cancer clinic has given up on me, so all I have left is Palliative Care."[332]

One physician retold an experience with a member of the public when discussing MAiD and Palliative Care and how the two are viewed as equivalent.

> "Well, that's the same thing. You just give people morphine, and they die." So that's the public understanding of Palliative Care: you give people morphine, and they die.[333]

These common misunderstandings have triggered physicians to advocate for a public campaign to educate about Palliative Care; about what it is, what it is not, how it can support patients and

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[330] Interviews 7, 8, 11, 15, 22, 25, 31, 37, 38, 40.

[331] Interview 38.

[332] Interview 25.

[333] Interview 40.

families, and how it can help patients to have a better quality of life. Physicians want the public to understand that Palliative Care means, "really good care" and "excellent, whole-person focused care."[334] Physicians want their patients and families to know that Palliative Care is about,

> …living well, helping with symptoms, helping families, letting people hopefully do better and hopefully live longer, and that it's not about stopping things and taking everything away and giving morphine.[335]

Many physicians have attempted to address this misunderstanding when caring for their patients. One physician disclosed their personal strategy for educating their patients about what Palliative Care is and can do for them.

> I usually tell my patients, "Listen, I'm a palliative care doctor, and I have two jobs, one of my jobs is pain, and symptom management and I will improve your quality of life, and you'll be able to live better with this disease, and the other part of my job is end-of-life care. Now we can talk about this one, and we can talk about the other one when you're ready," and to me, that works because at least I'm honest about what we are providing.[336]

The challenge of the widespread misunderstanding of Palliative Care is a barrier to patients wanting and accepting it from Palliative Care clinicians. If the public is afraid of Palliative Care because they misunderstand it, it creates an impediment to patients and families seeking Palliative Care earlier in the trajectory of their illness and really missing out on the opportunity for excellent care.

The same is true of colleagues in other specialties. Of the 13 interviewees who spoke about the misperception of Palliative Care, 8 addressed the collegial misunderstanding and misperception of their specialty; that physicians and healthcare workers in other specialties

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[334] Interviews 7, 31.

[335] Interview 40.

[336] Interview 11.

misunderstood Palliative Care. Some of the responses heard were that physicians in other specialties viewed Palliative Care as paramount to "being nice and just talking to people,"[337] or withdrawing treatment and "giving up."[338] Physicians discussed their frustration with collegial misunderstanding of their specialty when colleagues would deem patients as "palliative" and would stop all treatments such as transfusions, IVs, or BiPAP (Bilevel Positive Airway Pressure machine) because they were non-curative and considered to be futile for a patient who was "palliative." One participant spoke of their hospital being the only one that would provide blood transfusions to patients who were being seen by Palliative Care because the transfusions would allow the patients to feel better and improve their quality of life. However, it was noted that if this same patient was seen by other specialties, the transfusions and other treatments that improved his quality of life were halted because he was "palliative" and that they would not "cure" him.[339] Several participants expressed frustration at the use of the terms "palliative" and "non-palliative" to describe patients, as they imply that there is a scale or metric to determine when a patient has officially become "palliative" which often means, by other specialties, that the patient is actively dying, or they feel that there is nothing else they can do. Physicians articulated their exasperation with this identification of patients.

> …this notion that someone is palliative or not palliative runs rampant … no one really appreciates The WHO definition a palliative care, which is an approach, not a timing and disease or trajectory.[340]
>
> … People still refer to our patients as "palliative patients"… it distinguishes this fine line between where a patient was and where they are now.[341]

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[337] Interview 25
[338] Interview 5.
[339] Interview 2.
[340] Interview 2.
[341] Interview 31.

What is problematic with the stark classification of someone being "palliative" usually means that treatments are stopped, and other specialties consult or refer to Palliative Care too late, and only when the patient is actively dying. If this means of identification was less pervasive, and other specialists understood what Palliative Care is, and that it can help any patient with a life-limiting illness to live and die better, then Palliative Care would likely be consulted earlier on. By helping colleagues to better understand Palliative Care (discussed below) then patients would receive care that improves their quality of life, and that Palliative Care physicians would be consulted earlier in the patient's illness, and not only in the last hours or days. This change would improve not only the collegial understanding of the specialty but also the quality of care and life of patients who have life-limiting illnesses. Many Palliative Care physicians interviewed believed that, "… if society truly understood what it [Palliative Care] was and what it was intending to offer, they would be mobilizing more to demand it."[342]

Not enough Palliative Care physicians to meet the demand

The third most cited challenge that Palliative Care faces is the lack of trained physicians who specialize in Palliative Care. Physicians are acutely aware of the need for more physicians to be trained in Palliative care in order to care for the looming "tidal wave," "avalanche" or "boomer bulge" of patients that is coming.[343] With the "baby boomers" approaching later stages of life, physicians anticipate that there will be an increase in the number of patients with terminal illnesses or who will be needing end-of-life care. Participants noted that there is an inadequate number of physicians needed to serve even the current demand, and that we will certainly not have enough

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[342] Interview 31.
[343] Interviews 5, 34, 40.

physicians to care for the increased patient population that will come in the coming years. What is needed is more physicians who want to do the work, and want to do it well, and to become Palliative Care specialists, soon. The message from physicians was clear: Palliative Care is in desperate need of people who want to do the work, and who want to do it well. One physician articulated this clearly: “We need more docs that are willing to do Palliative Care and do a good job of it with us.”[344] Palliative Care needs more physicians who have the passion and wherewithal to enter the field.

One problem lies with attracting physicians to want to train in Palliative Care. Physicians recognized that it is difficult to recruit new physicians to the field. The phrases, “Not enough people willing to do it” or “How do we recruit into Palliative Care?” or “There is not enough funding to make it attractive” were commonly heard. However, the speculated reason for why new trainees are not entering the field, and the difficulty in making the field more attractive, is very similar to the problem facing the shortage of skilled homecare and community staff: adequate allocated funding from decision-makers. The unfortunate reality is that while many physicians enter this field because it is a calling, they do so at a financial cost. One physician stated that in choosing Palliative Care, many physicians are "taking a $200,000 a year hit to become a Palliative Care doctor," and that while many are willing to take a "20, 30 or even $40,000 hit" that a financial cut of $200,000 is too much for many physicians to fathom.[345]

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[344] Interview 45.

[345] Interview 50.

Medical Assistance in Dying (MAiD)

Several Palliative Care physicians cited MAiD as a challenge for their discipline. Interestingly, of the physicians who listed MAiD as a challenge, only two discussed it from the standpoint of conscientious objection and viewed the practice as morally problematic.[346] The majority of physicians worried that patients would opt for MAiD due to their inability to access adequate Palliative Care, or that patients would misconstrue Palliative Care for MAiD and that the lines between the two specialties would be blurred. This misunderstanding highlights the worry that physicians had around how MAiD and Palliative Care would and should coexist.

A prominent concern expressed was that MAiD would become a default option for patients who did not have access to (high-quality) Palliative Care, e.g., rural areas.

> …if we can't provide high-quality care in the locations that people want to be, that allows them to feel like they've achieved a quality end of life…to achieve a quality end of life experience, that is going to drive: "Well, what are my alternatives?" "Well, you can die earlier if you want."[347]

The concern of patients choosing MAiD due to a lack of (high-quality) Palliative Care was a worry amongst physicians, no matter where they fell on the spectrum from conscientious objector to conscientious provider. Those who provided MAID wanted to ensure that it was a true choice, that their patients had access to Palliative Care, and that MAiD was not a default due to lack of access. For patients that did have access to Palliative Care, physicians worried that the general

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[346] This is a shift from the responses in 2016, when many physicians interviewed had moral concerns or reservations about MAiD. A potential hypothesis for this shift may be due to the timing of the interviews, that in 2016 physicians were interviewed before Bill C-14 received Royal Assent, whereas, by 2019, MAiD had been legal in Canada for almost the years. The time between the two sets of interviews has allowed for legislation around MAiD to become clearer, and perhaps for physicians to become more comfortable with the practice knowing that they would not be legally or professional forced to actively participate in MAiD, or that other concerns around the practice overshadowed their moral concerns.

[347] Interview 46.

misunderstanding around MAiD and Palliative Care might cause some patients to think that MAiD would be forced upon them rather than something that must be initiated by the patient.[348]

The worry around the misunderstanding between MAiD and Palliative Care lends itself to the question of how the two practices should intersect. What should the relationship be between MAiD and Palliative Care? One physician articulated this concern.

> And I guess the other challenge is how are we going to incorporate MAID or have MAID sort of existing parallel to Palliative Care in sort of a mutually respective environment? … Yeah, particularly because we all want the best thing for our patients. That's why we're doing this work. And I love my Palliative Care work. I think that the two can coexist. And obviously, I am a MAID provider because I want the best thing for my patients, which is what everybody wants at the end of the day. So, there has to be a way that we can coexist respectfully.[349]

The question of how MAiD and Palliative Care should intersect is one that has divided the Palliative Care community. Some physicians, and organizations, believe that the two are entirely separate and should be kept that way; that MAiD should not be affiliated with Palliative Care in any way. Other physicians and organizations believe that the two should work together and that they can and should coexist. This relationship between MAiD and Palliative Care will be discussed in detail in Chapter 6 which is dedicated to the question of how Palliative Care should be involved in the development of MAiD in Canada, and the role of Palliative Care physicians.

Inconsistency and fragmentation of Palliative Care services

The inconsistency and fragmentation of Palliative Care services was the fourth most cited challenge that is facing Palliative Care. As healthcare is a provincial jurisdiction, care can vary

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[348] Interview 4.

[349] Interview 48

between provinces. It can also vary *within* provinces, and even within regional health authorities. Thus, the challenge of inconsistency and fragmentation of Palliative Care services is one that exists at both the macro (federal across Canada) and micro (within provinces and even streets) level.

The most obvious challenge is the discrepancy between the care that is available in urban centres versus rural or remote locations. It is not a surprise that patients who live in rural areas have difficulties in accessing care at all, nonetheless consistent care. This an issue that is not unique to Palliative Care; however, as has already been discussed, much of Palliative Care occurs within the home and the community, so patients who require Palliative Care and live in rural areas are disadvantaged. Physicians spoke of patients who live in remote areas being unable to access twenty-four-hour care or accessing care "after 5 pm in rural (province name)" when the homecare coordination centres are closed.[350] In these situations, physicians described the only option for patients, which is an ambulance to the emergency room, and possibly having to be transported to a major centre where the services are available.[351]

Even within major city centres, because of the way that the regional health authorities are organized, and various services are coordinated, the quality and access to services can vary within the same neighbourhood, or even as one physician stated, “what side of the street you lived on” (sometimes) determined the access to home care services.[352] This physician summarized the issues to access at a macro and micro level.

> …like all of health care, it's a provincial jurisdiction, so there's a lot of variability placed to place in the country. So, that can create inconsistency. So, some places in some provinces have much more established and robust systems than others. Within provinces, there is huge variability in urban/rural probably being the most striking. But also, just region to region. In (name) we've been really, really lucky. The (regional health authority) helped provide funding to our regional palliative care program that helped work on systems development and integration, helped work on training, advance care plan volunteer-based programs, a huge amount of things at a systems planning level, plus we've had the academic division here, plus we have a fairly robust group of

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[350] Interviews 33, 46.

[351] Interview 37.

[352] Interview 36.

> community palliative care providers for those who don't have family doctors who provide end of life care. But you hit edges of the city, and the options start to reduce. You hit outside of (name) … the regional programs haven't had the infrastructural support that we've had here. …So, that inconsistency can really make a big difference where you live. I know in (name of major city) they talked about sometimes **it was a difference of one side of the street to the other because the different areas have different home care services, and the home care services have different rules even though they're all provincially funded**. They would set different bars and different standards around what you could access and when. So, on one side of the street, you might be able to access service … certain services, and on the other side, maybe not.[353]

This quote highlights the difficulty that so many Palliative Care physicians face when trying to care for their patients and ensuring that their patients have care. Participants expressed concern that unless a patient resides within an urban city centre, and is receiving full-time care at a tertiary hospital or hospice, then they are likely going to face access issues to care. The problem is that not every patient can or wants to be cared for around the clock in the hospital; this is not feasible from a healthcare point of view, nor is it the preferred environment for many patients. The issue of fragmentation and inconsistency of care (outside of the major tertiary medical centres in major cities) presents similar problems to the lack of homecare resources: the inability for patients to receive the care that they need and deserve.

Lack of training in Palliative Care for other Healthcare Professionals

Palliative Care physicians struggled with the lack of training in Palliative Care provided to, or received by, their medical colleagues and other supporting specialties such as nursing, social work, and PSWs. Because Palliative Care can assist a wide range of patients and is needed by so many patients who are under the care of other specialists, physicians were perplexed that Palliative Care is not considered to be a core competency for all medical learners,[354] nurses, and other new staff.

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[353] Interview 36.

[354] In Canada, students in medical school are considered Undergraduate Medical Learners whereas Residents are considered Postgraduates.

Consequently, physicians called for Palliative Care to become part of the core curriculum for medical learners and that everyone who works in the healthcare system needs to have a basic understanding of and skills in practicing Palliative Care.

> We need to do a way better job in educating learners in all professions because we are an inter-disciplinary profession, and the fact that many disciplines still have little or no education is shocking … and needs to be corrected.[355]
>
> I applaud the work that's being done, but we have to do a better job of figuring out how to integrate our teaching and undergraduate and post-graduate training for physicians, but also in nursing and for personal support workers and all of these pieces, right? Like, how do we… how do we help people at least have some basic awareness, skill set, competence to go into those situations, and then again, how do we support them in those situations when they are feeling scared?[356]

Several participants noted that medical learners and residents only receive training in Palliative Care if they choose to do an elective rotation, which is 2-4 weeks at most.[357] However, if the students do not choose to electively train in Palliative Care, then they miss out on any formal training. While the core curriculum for medical undergraduates includes mandatory training in obstetrics and gynecology, the same cannot be said for Palliative Care. However, it can be argued that physicians, regardless of specialty, are more likely to treat patients who require or would benefit from Palliative Care than a patient who requires the services of an OBGYN specialist. Due to the lack of required training for healthcare clinicians, the result is varying degrees of clinical exposure to Palliative medicine, which results in physicians, nurses, social workers lacking the basic competencies in Palliative Care.

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[355] Interview 40.
[356] Interview 30.
[357] Interviews 11,25.

Challenges that individual Palliative Care physicians face

After physicians discussed their perspectives on the challenges that face Palliative Care in general, they spoke about the specific challenges that they face as individual Palliative Care physicians. Similar to when asked about the general challenges, the physicians responded with a wide variety of issues. However, five common challenges affect most physicians. They were: (1) not enough time to do everything that their work and life demanded of them (18/51); (2) the work-life balance (14/51); (3) the emotional toll of the work (12/51), (4) being underfunded or under resourced (11/51); and (5) MAiD (10/51).

Time constraints on work and life

The most common stress heard from physicians was that they felt that they did not have enough time, or hours in the day to accomplish everything that their profession and life demanded of them - that other projects, commitments, or publications were "falling off of the side of their desk."[358] As a result, many physicians felt that they were consistently behind or trying to play 'catch up' or not performing at their highest level. Clinically, having to be available 24/7 for call because there is no one else to cover their patients, not being able to tend to non-clinical duties, constantly feeling worried about things not getting done, and not having enough time to care for patients the way that they want, feeling pressured if they take too long on a consult, or worrying about end of life conversations because they cannot fit into time blocks, was a stress for physicians. Some of the following quotes embody these feelings.

> Time... **Just never enough time**.[359]

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[358] Interview 30.

[359] Interview 10.

> I'd say not enough hours in the day. **Not enough time to be a human being** and address all these concerns that you see as urgently needing addressing … **Sometimes feeling like you just end up doing a bad job of everything {chuckles} because there just aren't enough hours. So, you're not a good educator, and you're not a good wife, you're not a good anything {laughs} anymore.** Like, it does feel like that sometimes. But that's just 'cause we're too thin on the ground … I do think it would be interesting to have some Chairs in palliative medicine so that there can be some … like a senate. Like, that chamber of a sober second thought. **Like, people who actually have time to think. But we're all so busy doing that it's hard to think.** And I think there's value in the doing because you know intimately what the urgent issues are, but there's no bandwidth to enact some of the good ideas just **because there are literally not enough hours in the day**.[360]

> **Stretched in too many simultaneous directions without enough time in the working day**. And I think though that's something you're going to just hear from everybody … "**Oh my God, I haven't done my research publication and I… you know, I've got to get to another meeting, and I haven't been to the washroom, and I haven't had any lunch, and I've got to do seven million things. And when I get home, I've got to get the kids to bed, and then I've got to work again for another three to four hours.**" That would be my personal biggest worry, is that you know, there are always more tasks than there are hours in the day.[361]

Most physicians discussed being too busy to have time to think that other projects, research, and publications that would advance Palliative Care do not get done.[362,363]

Other physicians discussed how the lack of time impacted their clinical work, and how many felt they did not have adequate time to give all of their patients the time they needed. Either because it was not feasible, or that there was not enough time in general. The physicians recognized that this was not unique to their discipline or profession; it was noted that other physicians or professionals likely face these challenges. However, there are some particularities or reasons why the lack of time affects Palliative Care.

> I guess time. I mean, I know that sounds trite. That's probably what everybody says, but like it seems like there's never enough hours in the day, and this particular discipline of medicine is very time-intensive because a lot of it is about having conversations; really fundamentally important conversations that you can't rush. If your clinic is booked, like, back to back, and you are rushing through these conversations, you know, you just feel like you're doing a disservice to your patients. So, time is probably the biggest one.[364]

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[360] Interview 40.
[361] Interview 46.
[362] Interview 44.
[363] This is spoken to specifically in Chapter 7 on Recommendations.
[364] Interview 48.

> We call it the "doorknob questions," when you're on the way out of the room and your patient and says, "Oh, doctor, one more question," and that becomes the most important question. In palliative care, you can be sitting there having a really encompassing conversation about what is going on, yeah, it's when you stand up to finish the visit that they always say oh by the way, and that's when they bring up MAiD. (laughs) Then you have to sit down again (laughs), so that becomes a longer conversation. For me, I think it becomes a longer conversation because I don't want anyone ever to think that I'm just dismissing their request, and you if you rush out, I don't want anyone ever to think that I wouldn't be there to support them.[365]

In the context of Palliative Care, lack of time is an issue when caring for patients; conversations about goals of care, advance care planning, or other conversations that occur at the end of life cannot be had in the allotted time that there is to see each patient. One physician discussed feeling rushed or pressured because they were taking too long assessing a patient because one patient needs more time while other patients are waiting to be seen.[366] Another physician echoed this sense of feeling the pressure of not having the time to attend to all of the needs of every patient every day.

> I don't always have the time or the resources to kind of attend to suffering as much as I would like to, in a patient … my patients. So, when I look at my list right now, I have like 25 patients that I'm trying to look after. And so, I don't have time to get into the really key conversations for every single patient every single day. So, that's a bit of a struggle for me.[367]

The sense of having so many patients to care for, whom all have essential needs to be attended to, but not having the time or resources to be able to give the time that is needed to each patient is a real stress for many Palliative Care physicians. Several mentioned feeling overwhelmed about completing all of their work, or not to an adequate personal standard. Over time, that feeling of not having enough time, not being able to do enough, or just not being enough could potentially take a toll on the wellbeing of the physician.

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[365] Interview 51.
[366] Interview 42.
[367] Interview 47.

Work-Life Balance

Similar to the feeling of not having enough time, another commonly discussed challenge by Palliative Care physicians was having to balance their work-life with their personal life. While this dilemma is not necessarily unique to Palliative Care, what many physicians found to be particularly strenuous was balancing their personal life with the demands of medicine and the heaviness or the emotional toll of their work. The responsibility of having to care for patients who may be at the end of their lives, or have died while still caring for others in the personal lives. Two physicians spoke to this specifically:

> I think a challenge is also just balancing the heaviness of the work with the other facets of my life like being a mom, being a wife, being a friend, just trying to live, even though you're experiencing so much sadness in your job oh, so that's a good challenge that I'm always struggling with.[368]
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> I have two very young children at home, and it is tiring to see people dying constantly, especially when you're not sleeping, and you're fatigued. That's also a challenge I face personally.[369]

Similarly, the other stress voiced by physicians was having to leave work, or say no, and go home at the end of the day. Physicians are conscious of the fact that when they go home at night, their patients are still sick and still dying, yet, realistically, the physicians cannot be there all of the time. However, physicians articulated feeling guilty about leaving their patients to go home, or guilty about not being with their family when caring for patients.

> There's always more work to be done. Like, there's always more to be done. And I think in Palliative Care it is hard to turn away … it's really hard to say, you know, "I can't do this. I'm out," You know, "I gotta go home." That is always a challenge. Going home. "I need to be with my spouse." Or, "I need to be with my kids." I have to be at their … at their soccer game. And those things are really important. And we know they're really

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[368] Interview 5.

[369] Interview 14.

> important because we're palliative care physicians, and we see people, and they say to us every day, "This is what's really important."[370]

The tension of feeling torn between staying to care for patients, and having a personal life is one that every physician knows all too well. This stress is compounded by the awareness of the gift of life and making the most of the time one has with loved ones because Palliative Care physicians know all too well what it looks like when loved ones are spending their last few moments together, or what it looks like for someone to be dying alone. These are the moments that make Palliative Care physicians want to have that life outside of their place of work, but they are also the moments that make them want to stay because they know that there is always a little bit more that can be done to make that patient's or that family's life just a little bit better. The constant conflict between the two worlds is one that many physicians felt.

However, physicians articulated their inability to stop work even when they were able to leave patients and go home. One physician noted that even when at "home," they did not feel that they were truly away from work because they still needed to be accessible to patients who need them.

> The biggest challenge is, for me who is doing a little bit of everything is just time management and balance. You know, life/work balance and all of that stuff. So … So, not specifically related to palliative care, but only specifically related cause I've chosen to take on a field that, you know, I mean, my phone is never off …That doesn't particularly bother me, but it often does bother people around me. {laughs} You know, again, for me, it's easier to solve a problem in 30 seconds than to have a patient suffering and calling six different people to try and get an answer that I can give them in 30 seconds. Or something that I can fix right away. Whereas, I don't … I don't have coverage when I'm away, so I answer my phone.[371]

Cited earlier in the challenges that face Palliative Care, in general, is that there are not enough people doing the work. Many physicians know that when they leave, in many instances, there is

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[370] Interview 30.
371 Interview 39.

no one else to cover their patients. Therefore, the lack of resources results in being *de facto* on-call all of the time. Therefore, while they are not formally on call, for many it is simply easier to keep their pager or cellphone on outside of work hours because they can answer a question, or solve a problem over the phone, a problem that once solved will help alleviate patient's suffering, mitigate a family's worry or concerns, or assist a new or younger physician or nurse who might not be as comfortable with that patient. All of these are reasons for physicians to, in some ways, always be available.

The individual challenges of not having enough time, and the work-life balance are both directly related resources: not having enough physicians to care for the patient demand. Thus, we see that a systems challenge (lack of Palliative Care physicians) trickles down and becomes a challenge to individual physicians of not having enough time because they are always on-call and always playing 'catch up' to care for their patients. The demands of their work compounded with the type of work that they do, results in consequent feelings of guilt and inadequacy.

The Emotional Toll of the Work

"Oh God, I swear this work takes years off your life."[372] This sentiment was felt by many of the physicians interviewed. While Palliative Care physicians find joy in their work and went into this field because it was their calling or vocation, fourteen of the physicians interviewed cited the emotional toll that the work takes on them. Physicians were conscious of the:

> …moral and emotional distress that comes from the sort of recurrent losses of working with patients who the vast majority die in our care or shortly thereafter.[373]

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[372] Interview 15.

[373] Interview 36.

When physicians bear witness to so much suffering and are consistently caring for people who are facing the end of life, the question becomes how they navigate this and stay practicing medicine while maintaining their mental and emotional wellbeing. This is a daily challenge, and as a result, physicians require strategies for their practice. When every patient is facing a life-limiting illness, might be suffering, and may even be actively dying, caring for those patients throughout the day is noticeable. One physician discussed finding ways to be 'fresh' after each patient, and the need to navigate the emotional toll of the work throughout the day.

> Boy, you're done by the fourth one, I can tell you, right. And every person you go into, when we do our rounds, you have to be as fresh as if that's the first person you were seeing that day. You can't carry the burden of everything you've done in the clinic or other patients from the day, right. So, Palliative Care can be emotionally very draining unless you take care of yourself.[374]

This toll becomes particularly acute when a patient, whom the physician has cared for over time, and become close with, dies. As many physicians have patients whom they care for, for months or even years, the death of that patient is loss of a real relationship that has been built up over time.

> I think we deal with really emotional journeys and we get very attached to our patients because we're working one-on-one with them, and as of late I have become part of families. They invite me to family events and things like that which is great but also when you're part of a family, and then someone in that family passes away then you're no longer part of that and not in contact with that family anymore. And that's hard. There is an emotional journey that you go through with that.[375]

Losing one patient whom you have been close with is difficult, but when that loss becomes recurrent, the grief becomes cumulative.

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[374] Interview 21.

[375] Interview 7.

Several physicians discussed coping with the loss of patients that they became close with, or the cumulative grief, and the concern of potential psychological distress that results from both. Physicians acknowledged the need to find ways to be able to deal with the persistent loss throughout their careers. As one physician stated, "The question becomes, 'How long can you stay in the game?'"[376] An early-career physician spoke about the difficulty of dealing with persistent loss within their first year of practice and wondered how they would cope throughout the rest of their career.

> I'm kind of finding it hard to deal with loss on a daily basis (tells the story of a patient). It was a big loss for me, and I was surprised at how much I reacted to that loss because … I think what was happening was that I'd been kind of pushing the emotion and the loss down. And when he died, it kind of came out. And I was really, really upset and sad. I think one of the reasons why he touched me so much was because he was young. He was my age. But I was surprised that I reacted in that way. And I think it's just the cumulative effect of all of that ... that loss and that grief that can have an impact on you emotionally. And I don't really know what the best way forward to deal with that is … But I don't know how you keep moving forward with that. I don't know how I'm going to keep moving forward with all of that cumulative grief for the rest of my career because I'm in my first year of practice, and I hopefully have many, many more years. So, how I deal with that is a bit of a struggle, and it's an ongoing struggle.[377]

As physicians recognized the emotional toll of their work, many were taking the initiative to look after their wellbeing in order to continue practicing medicine. Physicians cited strategies as simple as turning off their pagers, taking breaks and holidays, meeting with colleagues regularly to share stories, the need to work in teams (not be siloed) to debrief, seeking counseling or support from a mental health specialist, to radical measures of moving to a city centre so that they would not be as isolated in their practice. Although many physicians felt the toll of their work, they are pre-emptive in their wellness strategies so that they continue to practice Palliative Care. These

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[376] Interview 15.

[377] Interview 47.

physicians are resilient because they are aware of the difficulty of their work, and are resourceful in their means of staying well.

Lack of funding and resources

A prevailing challenge discussed by physicians is the lack of resources and funding that impedes their ability to care for their patients in the ways that they think their patients deserve: the inability to spend time tending to the needs of patients, the inability to guarantee regular or good homecare, or the inability to secure needed resources for those who cannot afford them. Physicians felt impotent due to the financial restraints and questioned the reality of universal healthcare in Canada. One physician highlighted this:

> I think it's resources in general. Yeah, resources. The frustration of having this idea of universal health care which doesn't exist…So, my frustration is that we, as physicians, cannot deliver universal healthcare to everyone.[378]

The lack of resources is at the heart of many of the challenges that physicians felt they faced both as individuals and as a discipline. With the exception of the emotional toll of the work, the issues that physicians faced individually (lack of time, work-life balance, and MAiD) are all directly correlated to a lack of resources. The lack of time and work life balance are linked to the lack of trained Palliative Care physicians to meet the patient demands; the concerns of patients receiving MAiD because patients are not able to access adequate Palliative Care; the lack of homecare services that result in patients being admitted to institutions are issues of lack of resources. Looking back to the challenges that Palliative Care physicians face in general, six of the issues are the result

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[378] Interview 47.

of a lack of resources: (1) lack of funding for community and home care resources; (2) lack of trained specialists to do the work; (3) Insufficient funding for training learners and creating residency spots; (4) lack of funding for Palliative Care, in general; (5) caring for marginalized and vulnerable populations; and (6) lack of coverage and fragmentation of Palliative services across Canada. Looking at these lists together, we see that the issues faced by Palliative Care physicians as individuals are the same issues that Palliative Care faces as a discipline in general: the need for more trained Palliative Care physicians, and improved access to (home) care across Canada. If resources for Palliative Care can be improved, many of the issues that are plaguing Palliative Care and the physicians who practice it will be resolved. This proposed idea will be discussed in greater detail in Chapter 6.

Medical Assistance in Dying (MAiD)

The few physicians who did raised MAiD as an *individual challenge*[379] rather than a challenge for the discipline, cited four reasons for doing so: working in Palliative Care after the introduction of MAiD in Canada,[380] keeping Palliative Care and MAiD separate so that patients know that MAiD is something they have to initiate and not something that is “done to them,”[381] conscientious objections to MAiD,[382] the slippery slope of expanding the eligibility criteria,[383] and patients getting MAiD because they are unable to get the care they would like due to a lack of resources.

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[379] MAiD was many times cited as a challenge to Palliative Care as a discipline, and as an ethical issue. However, it was not noted as frequently when in the context of challenges that *individual* Palliative Care physicians face.
[380] Interviews 3, 15, 16, 33.
[381] Interview 8.
[382] Interview 32.
[383] Interview 23.

> …I have a patient who would rather get MAiD on Monday because we can't hire a PSW for him … there is a shortage of PSWs. So, he is choosing death over life because of this.[384]

While MAiD was referred to as a challenge for some physicians, it did not seem to be as great of a concern as when physicians spoke about having ethical concerns around MAiD (discussed below in the ethical challenges), or how MAiD presents challenges to the discipline of Palliative Care. How MAiD was referenced as an individual issue suggests that MAiD is not an insurmountable challenge for individual physicians as it does not impede their individual abilities to continue to care for patients.[385]

What are the challenging ethical issues that Palliative Care physicians face?

One of the goals of the study was to understand which issues Palliative Care physicians found to be most challenging within their practices. As one physician stated:

> …every day there's something that taxes you fully. And I love that about our job ...To me, that's not a challenge, that's the privilege of our job, is that it is life and death. And it matters.[386]

When asked which ethical issues they found most challenging, four general themes emerged. In order of prevalence, they were:

1) MAiD (21/51),
2) Family dynamics (17/51),
3) Lack of adequate resources or inability access Palliative Care services (11/51),
4) Providing culturally appropriate care (10/51).

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[384] Interview 15.

[385] This is not to imply that some physicians have very real and very serious conscientious reservations about MAiD, or of that some physicians have not left the practice of medicine because of it. However, these concerns were not highlighted when physicians spoke about the challenges they face as individual physicians.

[386] Interview 46.

MAiD

Of the 51 physicians interviewed, 21 participants (41%) identified MAiD as the predominant ethical issue that they wrestle with in their practice of Palliative Care. When asked about the ethical issues that they grappled with, many physicians did not hesitate before giving answers like:

> "MAiD. Period. That is the biggest challenge for me."
>
> "For sure, MAiD stuff, right?!"
>
> "Well, MAiD...MAiD for sure."
>
> "Well, the MAiD issue is a major one"
>
> "Well, so, obviously, like MAiD is a big issue, right?!"[387]

Much like the challenges facing Palliative Care and the challenges they face as individual Palliative Care physicians, the reasons why physicians struggled with MAiD were diverse. It was not surprising that some Palliative Care physicians felt that the practice of MAiD was ethically problematic. What was surprising was that the response was not isolated to physicians who conscientiously object to the practice; conscientious participators had similar concerns. The reasons why both groups struggled with MAiD was because they were concerned about their patient's best interests, the profession, and society in general. Physicians who conscientiously objected to providing MAiD, despite their beliefs about the practice, tried to ensure that they were having objective, non-biased conversations with their patients and that their patients who requested

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[387] Interviews 3, 12, 26, 34, 38.

MAiD received timely access to it.[388] Alternatively, MAiD providers worried about patients not having access to Palliative Care, and worried about the widening the eligibility criteria.[389,390]

Generally, the majority of concerns around MAiD were issues of priority access over Palliative Care, and the "right" to MAiD trumping other methods of care - that Canada legalized MAiD before ensuring that Canadians have better access to high-quality Palliative Care, and that MAiD has received more widespread attention than Palliative Care. The public knows they have a right to ask for MAiD without being aware that they have the right to ask for Palliative Care as well.

> MAiD. That's the biggest ethical challenge for me; should we be doing this, or shouldn't we ... Because the societal, ethical challenge is how do we provide good end-of-life care for patients across Canada? How do you provide care to patients in remote locations? Should everyone have access to palliative care before we even think about MAiD?[391]
>
> …But it's part of our healthcare system, so how do you manage the fact that it's there and we can deal with that and people have a legal right to access? In other countries and all other countries, it was pitched as an option of last resort. So, for people who are really suffering, you can use this as an option of last resort, and Canada is the only country that I know of that didn't position this at the last-resort option, well Quebec did but the Supreme Court positions this as a right of patients. So, this put us at odds with the rest of the world because you're seen as a bad person because you're depriving someone of their " right," but people don't have a right to a caesarean section, there are still medical things that have to be lined up around that, so do patients have a right to demand whatever they want? Or are there limits on that? So that's kind of the terrain we're in.[392]

Physicians struggled with MAiD becoming a first option or choice for patients instead of a way to alleviate truly intractable and intolerable suffering for patients who have a life-limiting illness which is what was intended by the Supreme Court's ruling and subsequent legislation (Bill C-14).

Another concern around MAiD was eligibility criteria;[393] making sure that everyone who received MAiD met the criteria, and realizing that some patients who request it are ineligible.

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[388] Interviews 12, 40.

[389] Interviews 16, 23.

[390] Recall in the earlier chapter on MAiD, three groups (who are deemed ineligible under the current criteria) are advocating for access: mature minors, advance requests, and mental illness as the sole underlying medical condition.

[391] Interviews 3.

[392] Interview 8.

[393] Four physicians (Interviews 5, 11, 29, 39) spoke to this issue specifically.

> I'd say that MAiD is still an ethical dilemma. Oh, some patients who either meet the criteria or don't meet the criteria. So, sort of making sure you do due diligence on those cases, especially if the disease is non-malignant or there's a question of underlying mental health which has come up before versus what is a true, treatable depression versus a real request.[394]
>
> One of the biggest challenges as a MAID provider is telling somebody they don't meet the criteria. That's really hard. That's… that's really, really, really hard. And again, I didn't really anticipate that until I started doing it because I just assumed everybody would meet the criteria. And they don't all meet the criteria. And that's a challenge.[395]

The care and due diligence that these physicians put into their MAiD assessments highlight the fact that MAiD providers are making sure that everyone who receives MAiD meets the eligibility criteria.[396]

An additional concern around MAiD was that patients were receiving it because they had not been provided with adequate care; that their basic needs were not being met, or if there was any sense of coercion. Put simply, physicians worried about patients who were requesting or receiving MAiD other than asking for it voluntarily, after everything else has been done.

> MAiD for sure. I think initially there felt to be a responsibility that, you know, if a person chose MAiD, it was because I didn't do something well enough, right?[397]
>
> …So for me, it's the patients that you see that are very vulnerable, and you feel like their basic needs haven't been met, or they are being coerced, or they don't quite understand what they are asking for…it's a lot around people choosing MAiD whom I don't think actually want to die, and that's very distressing.[398]

Family Dynamics

Palliative Care cares for patients *and* their families. The second most-cited ethical problem for physicians was family dynamics, dilemmas that came from the families of the patients for whom

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[394] Interview 5.
[395] Interview 39.
[396] Eligibility criteria is set out by Bill C-14. See Appendix.
[397] Interview 33.
[398] Interview 44.

they provide care. One participant stated immediately, "Oh, the biggest [ethical issues] are the families. Bar none. It's the families."[399] Navigating family issues when caring for patients with a life-limiting illness is complicated.[400] Out of the multitude of issues that arise from dealing with family members and loved ones, four general trends tended to create dilemmas for physicians: disagreement between patients and their family, disagreement amongst family members, family members or substitute decision-makers making decisions that the physician believes are not in the best interest of the patient, and providing culturally appropriate care.

Maintaining the focus on the patient as the primary relationship and the number one priority was mentioned by several physicians. They spoke about feeling pulled in multiple directions, particularly between what the patient wanted or needed (or, what the physician believed what the patient wanted or needed) and what the family was directing the physician to do. Physicians spoke about reminding themselves and their colleagues that their primary concern was the patient, and this needed to remain their focus when there was disagreement amongst family members and with the physician, and even more so when the patient is no longer able to express their wishes.

> Where there is disagreement about how things ought to be managed and as a direct result, some practitioners, including me from time to time do nothing, so as to not stir the pot or to avoid the whole situation. As a result, we aren't giving this patient what he or she needs or deserves. I think that would be it if there is one tough thing in my day; it's reminding myself and my colleagues that our responsibility is the patient. And as long as we have clear direction from him or her, then we need to stand ground with them when there are opposing forces. And, I think we should extend it even more when the other person, him or herself, can't tell us what they want, or what the disease trajectory is, we need to use our knowledge and skill to stand up for the treatment of a patient who isn't able to voice their concerns when maybe the opinion of the SDM or POA is contrary to the best interest of the patient.[401]

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[399] Interview 50.
[400] Interview 31.
[401] Interview 2

Another physician echoed this sentiment, discussing his concern about "How much do I listen to the patient versus how much to I listen to the family? But I remind myself that my primary relationship is with the patient. My secondary relationship is with the family."[402]

The other issue physicians struggled with was family members actively disagreeing with one another about treatment decisions for patients. Many physicians cited having to call security because tensions escalated between family members. One physician discussed the difficulty in navigating disagreement between the husband (and, SDM) of a dying woman and the woman's mother, where tensions became so high that security was called regularly.

> We have a patient right now who is (young), and she is married with (number) children, her husband is her substitute decision-maker by law, and I have no doubt that he's making decisions that are in her best interest, but the patient's mother is really struggling at this loss of control over the fate of her daughter, and there's an insane amount of tension to the point that security is involved every single day. So, they literally blow up at each other, and the mother refused to leave the room to give the husband any alone time with a patient. But, now the patient is in her final hour that she's really unwell and we're trying to allow both the chance to be with her while she's dying because they both really love her… it's just so hard in every way because it feels awful to have to kick and I mean I'm not the one doing it but when you have to call security and kick the mother out and deny her the chance to be around her daughter as she is dying, feels absolutely disgusting as it just makes me want to throw up, but at the same time I have a legal responsibility to respect what the SDM wants and says. And, I don't question that he's acting her best interest I just think that there's so much tension has built up that it's become really hard to decipher what's best for who at this point. So, I'd say family tensions where you have to make a decision, we have to listen to one person, but there are other people who love the patient but have very different views is really challenging for me to navigate.[403]

Another physician spoke of a similar situation with caring for man who was dying yet had lost capacity and had not named a decision maker. The common law-partner of the man stepped in and made decisions that the family disagreed with. What added to the complexity of the case was that the common-law partner was a fairly new partner, which called into question the status of her as a decision maker, and it was believed that she had mental health issues. The team caring for the man

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[402] Interview 18.
[403] Interview 5.

struggled with navigating the family dynamics while still trying to ensure that their patient received the best care possible. This situation is what the physician referred to as, "The full Monty of ethical types of dilemmas."[404]

The third issue that physicians struggled with in regards to family dynamics was family members or Substitute Decision Makers (SDMs) who were not making decisions that the physician believed to be in the best interest of the patient. Physicians recalled instances where decisions were well-intended, as well as those where there was malicious intent. What is to be done when the family or decision-makers are making decisions that are futile or actually causing potential harm or suffering for the patient?

> …a common thing that we struggle with is family members insisting on certain treatments when they are identified spokesperson for a loved one, when they can't speak any longer, that you know are not going to give the patient any more comfort that may actually be causing them some discomfort or even potential harm. Trying to educate and explain that to families. But knowing they, in their hearts, feel that they're doing the right thing.[405]
>
> I guess the things that I have seen and the things that have bothered me sort of from an ethical standpoint are around where a substitute decision-maker, I don't think, is making choices that are in the best interest of the patient, and are prolonging suffering.[406]

In both cases, the family or decision-makers are not making decisions that are what the physician believes to be in the patient's best interest. Physicians wrestled with how to navigate such situations, or how to tell family members who have known the patients for years that they are not making the right decision. However, if the physician believes that the SDM is not making decisions that they believe to be in the best interest of the patient, or are inconsistent with the patient's

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[404] Interview 46.
[405] Interview 25.
[406] Interview 43.

wishes, the physician may seek to override the SDM by applying to the Consent and Capacity Board.[407,408]

The other issue discussed for family dynamics was working with families who are of a different culture and do not want the physician to inform their loved one of their illness, what physicians referred to as the “Do not tell mom/dad” problem. This issue was cited so much that it is the fourth most identified ethical issue, and will be discussed in further detail below.

Lack of adequate resources or inability to access Palliative Care services

The third most cited issue that physicians found to be ethically troublesome was inadequate or lack of resources and access to Palliative Care services. Eleven physicians cited this as a dominant issue that they struggled with. As one physician stated, "Resource inadequacy. That is probably what burdens me the most."[409] The issues that physicians spoke to specifically were around community and homecare, caring for patients in rural communities, lack of resources for vulnerable or under resourced populations, and resource allocation.

Community and Homecare

How do you provide care for people in their homes, if that care is not possible? While many patients want to die in their homes and communities, the reality is that often this is infeasible. One physician referred to home care as “the *notion* of in-home Palliative Care."[410]

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[407] *Cuthbertson v. Rasouli* at 79-88.

[408] As per section 21 of the Health Care Consent Act, SDM’s “shall act in the incapable person’s best interest.” If this is not being done, the physician may apply to the Board to revoke or override the authority of the SDM (*Rasouli* at 79-88).

[409] Interview 37.

[410] Interview 9.

> An example is the notion of in-home palliative care and sending someone home in a scenario where families are either choosing adequate care but the wrong environment, which is the hospital or inadequate care in the right environment, which is the home. Because they're going home because they want to go home, but you know that they are not going to have access to the care that they need. They also don't have access to the expertise they need in the home which is a double-edged sword because there is a patient packed and ready to go and then there's all the ethical impact of what you were doing to the nurse who may not be comfortable with the skill set, and asking her to go into a home all by herself, nobody to bounce ideas off of.[411]
>
> Yeah, not being able to get the care for people that really need it. Like, they say, "Okay, you can get shift care at the end of life." What's called wrap-around care in the last days or weeks of life. And then sometimes they just can't get it because not enough bodies are out there. That's distressing… it's hard to say, "You have access 24/7 assistant palliative care" when they don't… but that's a big ethical dilemma…patients not being able to access the care they need.[412]

Physicians struggled with providing patients who live in rural areas with the resources they need to stay alive.

> You know, patients who are determined to return home to their own community where they can't have oxygen. And so, you know, they're on tentative oxygen. And they're saying, "But I want to go home." But in the community, it can take three weeks to put home oxygen in place. They don't have three weeks, or they don't want to wait three weeks. And so, you're sending them home with, you know, either way too much or way too little opioid. You don't really know what their symptoms are going to be like when their big oxygen tank that they'll fly there with runs out.[413]

The issue becomes having a patient in the hospital, when the patient does not want to be in the hospital, or sending the patient home without the resources they need.

Caring for patients in rural communities

The problem of providing adequate coverage to patients across Canada, particularly those who live outside major city centres in rural or remote areas, is another issue that physicians find to be ethically problematic and a hurdle in their patients receiving the care they need.

> I worked kind of up north (a rural, fly-in area). I did little short stints here and there, so I understand the resource issue around Canada, which is obviously not just palliative care, but everywhere. Like… for palliative

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[411] Interview 9.
[412] Interview 35.
[413] Interview 28.

> care to say, "We need the same degree of palliative care for every Canadian everywhere is just not going to happen. You can't get that same degree of care… So, it's a little kind of unrealistic to say that, but… but there are gaps in care. If someone was far away, I'm like, "Oh geez, I have to drive an hour to see this patient, {chuckles} and… and I'll do it… so… so that's unfortunate as well; that… that we're kind of looking after people a little farther away who probably have fewer resources, just because of that.[414]

While some physicians can drive to see patients, there are areas of the country where it is not feasible to see the patients physically either due to location or time constraints on the physician. One physician spoke of the difficulty of caring for patients via telehealth because: "So much of Palliative Care is that presence, being there" and, how can patients access other services needed at the end of life, such as chaplains, via telehealth?[415] The reality is that every Canadian in Canada does not have access to the same degree of care. Physicians felt powerless in their inability to care for patients whom they know need and deserve care, but where physical location prevents that.

Lack of resources for vulnerable or under-resourced populations

Even patients who live within urban centres face issues of access to resources if they are vulnerable. Two physicians spoke to the inequity of Palliative Care resources for patients who are socioeconomically disadvantaged and vulnerably housed. These patients often fall through the cracks and depend upon ambulances to the emergency room as their predominant form of care.[416] The patients who are socioeconomically vulnerable are the ones who need access to Palliative Care services because they are suffering so much in other areas of their life. One physician who provides care to patients who are homeless or vulnerably housed stated,

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[414] Interview 41.
[415] Interview 23.
[416] Interview 36.

> I think some of the issues of working with vulnerable populations is access issues, and issues of social justice…And those people who can't access palliative care and who need it so desperately and are suffering so desperately, that is a huge, again, ethical and social justice issue… Again, it's sort of equity. And I sort of see challenges and this almost together. The fact that people with resources like most things get so much better care because they have resources versus those that don't have any resources. We see that every day. I think that's problematic.[417]

Like every other resource issue, physicians struggled with ensuring that vulnerable populations received the care they so very needed and deserved when they do not have access to the same resources as other members of society. How can physicians provide care to patients who do not have a home or a home that is not safe? How do you ensure regular access to medications or care? As one physician stated, "Dying is hard, dying on the streets is harder." [418]

Resource Allocation

Physicians struggled with providing care even to those patients who lived in major city centres and were receiving care at a tertiary centre, due to inadequate resources for the number of patients who require them. Physicians spoke of the stress in having to decide which patients received physical resources such as beds or ventilators. Two examples are:

> We have so few resources. This person's going to die in a week or two and if we follow what the patient's family wants, they might die in three or four weeks, having gone through potentially more pain and suffering, but also blocked a bed for somebody who could really use it in a hospital that's in 115% capacity all the time. So, I mean, I feel ethically challenged to put resources where they're most required. I feel ethically challenged to make the best use of our hospital beds and our hospice beds.[419]
>
> I worry a little bit about social justice in that if there are only so many resources around, how do you make those hard decisions? Because if you only have six ventilators, what do you do when you have seven patients? Right? And that will become an issue, I would say, within the next five years, is resource allocation, just because of the boomer bulge.[420]

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[417] Interview 16.

[418] CBC News: The National. "Journey Home: Inside a Hospice for the Homeless." *YouTube*, 2 July 2018, www.youtube.com/watch?v=J-hP1EhjZRI. Accessed 8 May 2019.

[419] Interview *25.*

[420] Interview 40.

In addition to providing Palliative Care, which is emotionally draining work, these physicians are also tasked with trying to determine which patients at the end of life have access to a bed or have access to assisted breathing. How can a physician decide between two patients with similar needs, which one will be more comfortable being able to breathe in a bed, versus someone who will be discharged without a ventilator? Being the person who decides which resources patients will have access to at the end of life is morally and ethically difficult.

Lack of resources, or their patients' inability to access resources, has been a recurring theme among physicians. It was cited as an issue that Palliative Care as a discipline faces, a challenge that individual Palliative Care physicians face, and as an ethical issue that physicians wrestled with. Many of the physicians connected the lack of resources or access to resources as an issue of justice and living up to the values of our society. As a society, we have stated that we believe and value equity in healthcare, however, our healthcare resources and how they are accessed and allocated does not reflect those values. Thus, as will be discussed in the final Chapter on policy considerations, a policy change in resources in Palliative Care will help to mitigate the challenges to Palliative Care in general, the challenges that Palliative Care physicians face individually, and the ethical distress that these physicians feel from being unable to provide their patients with the resources that they need.

Cultural issues and providing culturally appropriate care

Many physicians struggled with requests made by family members to not disclose details to the patient about their illness. Physicians struggled with treating patients who had life-limiting illnesses, aggressive diseases, or were offered risky procedures, when these patients did not know, were not told, or did not want to know the details of what they were up against.

> I think it's the… It's those age-old ethical issues of the, "Don't tell Mum." "Don't tell Dad." "Do they know?" "Do they understand?" "Is that being addressed adequately?"[421]

> We work in a population that is less than 50% Caucasian, so a large number of immigrants mostly South Asian and I think many ways in which we interpret medical ethics like nonmaleficence and so on, particularly the sending of very sick patients and how we view consent in capacity are quite different in different cultures… For example, we know that non-disclosure is very common in almost all cultures of the world except for North America, but yet our consent and capacity framework is based on truth-telling, not paternalism. The patient has autonomy, and the patient decides, but yet the patient that I see day in and day out it's absolutely not like that. Many times, patients, very clearly, they don't want to know, and so how does that work? …we see many patients whose family members choose for them to receive aggressive life-prolonging measures, and while we might consider a futile, for them, I've always thought that's what you do and that anything less than that would be giving up. So, I think those are some of the most challenging scenarios, right?[422]

What seemed to trouble physicians most was that their patients were making decisions about health care treatments that needed informed consent, or were having substitute decision-makers decide for them without truly understanding the consequences of their decisions.

Physicians also felt that they wanted to ensure that they were providing culturally appropriate care.[423] While navigating the cultural nuances for different cultures and not having informed consent was an issue, physicians recognized that there are ways that patients are cared for in other countries. They wanted to make sure that they were providing culturally appropriate care to their patients when possible. While navigating issues of non-disclosure were difficult, most physicians were willing to work with patients and families to compromise on a care regimen that was culturally appropriate for the patient and their family, but also with which the physician felt comfortable.

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[421] Interview 40.

[422] Interview 10.

[423] Interview 40.

Conclusion

This chapter has discussed in detail who the Palliative Care physicians are in Canada, how they came to practice their discipline, and what it means to them. Many were pioneers in the field, and for many of them it was a calling. Their passion and commitment to the field of Palliative Care has allowed Palliative Care to evolve and grow in Canada. While Dr. Mount was the first person to formally introduce Palliative Care to Canada, it was the physicians who cared for patients and learned as they practiced who made it a professional discipline; it is the physicians who are practicing today who have helped to shape and advance the discipline.

However, there are challenges facing Palliative Care. These challenges impede Palliative Care physicians' ability to provide the care they want to their patients while maintaining wellness and resiliency. This Chapter has highlighted the challenges facing Palliative Care as a whole, the challenges faced by individual physicians, and the ethical issues that they confront. Having an understanding of these challenges, as well as understanding who the Palliative Care physicians are as physicians, will inform the systems and policy changes needed to support and improve Palliative Care, the care provided to patients, and healthcare in Canada as a whole. Many of the challenges mentioned in this Chapter have been taken into consideration and are addressed in Chapter 7, where system and policy changes are proposed.

Chapter 7: The Intersection of MAiD and Palliative Care

Introduction

When the Supreme Court overturned the prohibition of MAiD in Canada, Palliative Care was placed in the spotlight because the Court's ruling was aimed at patients who have a life-limiting illness *and* intolerable suffering. Since such patients also commonly receive Palliative Care, some Palliative Care physicians worried that they would become primarily responsible for the development and provision of MAiD. As one physician stated,

> I just felt like this came out and then so much buzz around Palliative Care started coming up, and I thought okay like it seems now like people are going to expect that because we deal with individuals who have advancing non-curable situations that we are going to be the ones who are the pioneers of this and that that… almost that assumption that I felt like was being made was very uncomfortable.[424]

Many Palliative Care physicians had similar worries. They wondered if MAiD would legally become part of the practice of Palliative Care, and if they would be looked at to pioneer MAiD because of their patient population. Consequently, the introduction of MAiD has likely raised more questions for Palliative Care than for any other practice area. Should Palliative Care physicians be involved in the development of MAiD policy and provision? How should the two practices interact, and to what degree?

These questions surrounding the role of Palliative Care in MAiD have been debated since the *Carter* ruling. A vivid illustration of the controversy surrounding this role is highlighted in competing sets of policies published at the end of 2019 by two national organizations, the Canadian Society of Palliative Care Physicians (CSPCP) and the Canadian Association of MAiD Assessors

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[424] Woods et al., 2017.

and Providers (CAMAP). The CSPCP, the national representative body for Canadian Palliative Care physicians, argued that MAiD and Palliative Care should remain distinctly separate practices (that MAiD is not part of Palliative Care, nor should the two practices overlap), as MAiD is fundamentally different from Palliative Care. Further, they asserted that Palliative Care physicians should not be involved in the practice of MAiD in any capacity. Alternatively, CAMAP, the MAiD association that many Palliative Care physicians belong to, called for the integration of MAiD and Palliative Care. The organization argued that all patients who request MAiD should be consulted by a Palliative Care physician, and therefore the two specialties should be linked. The difference between the two policies has highlighted the stark contrast between two perspectives on the relationship between Palliative Care and MAiD, and what it should be in the future.

This chapter explores how Palliative Care and MAiD should intersect, and what role (if any) Palliative Care physicians should play in the ongoing development of MAiD in Canada. The chapter will be organized into three sections to facilitate an understanding of the nuanced views around the intersection between MAiD and Palliative Care now, and what the relationship between the two should look like in the future. The first part of the chapter contrasts the competing policies published by the CSPCP and CAMAP, and analyzes their respective views about the relationship between MAiD and Palliative Care. The CSPCP, which stands in opposition to the practice of MAiD, wants to separate MAiD from Palliative Care entirely, thus promoting what I will refer to as the 'Separation-Opposition' model. By contrast, CAMAP, views MAiD and Palliative Care as intrinsically linked and advocates for the integration of the two practices, which I will refer to as the Integrated model.[425]

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[425] It should be noted that the models do not represent the organizations, and that the organizations would not agree with all aspects of each model. However, I have based the models on the policies that each organization has published. The models are meant to be representative of the general views espoused by the CSPCP and CAMAP, respectively, but are not designed to represent the views of all members of each organization.

The second part of the chapter will report on Palliative Care physicians' views towards their involvement in the ongoing development of MAiD in Canada, highlighting common themes. With this understanding, I will move to the third and final section of the chapter. In this final section, I will advance the substantive normative argument that for patients who pursue MAiD, that Palliative Care and MAiD need to collaborate, in order to offer their patients expertise in both Palliative Care and MAiD. The Collaborative Model recognizes Palliative Care as distinct from MAiD, but highlights how the two practices can benefit from overlapping and working together when required. It will be shown how the Collaborative Model can support the needs and goals of the CSPCP, CAMAP, Canadian Palliative Care physicians, and their patients.

Why, and Who?

Before engaging in a discussion of the policies put forth the CSPCP and CAMAP around the intersection of MAiD and Palliative Care, it is essential to understand why these two organizations were chosen as examples, who they are as organizations, how they came to be, and their general mandates.

These two organizations were chosen for two reasons: first, each is the national representative organization for their field; the CSPCP represents Canadian Palliative Care physicians[426], and CAMAP is the national organizing body for MAiD Assessors and Providers in Canada. As such, both are the expert organizations in their field and represent Palliative Care physicians across Canada. The second reason is that the majority of physicians interviewed (if not all)[427] belong to the CSPCP, and many interviewed were also members of CAMAP. These are the

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[426] It must be noted that not all Canadian Palliative Care physicians belong to the CSPCP.

[427] As invitations were sent out on my behalf by the CSPCP and the OMA to their members, I cannot discern to which organization participating physicians belonged. The OMA sent out their invitation after the CSPCP, however, and the

two professional organizations that many of the physicians interviewed belong to and look to for collegial support and guidance within their fields.

Founded in 1993 by Canadian Palliative Care physicians, the Canadian Society of Palliative Care Physicians is a federal organization, comprised of 550+ *physician* members who specialize in Palliative Care, or physicians with a particular interest in Palliative Care.[428,429,430] The mission of the CSPCP is to promote Palliative Care and to improve access to Palliative Care for all Canadians.[431]

The Canadian Association of MAiD Assessors and Providers was established in 2017 to support and advocate for all health professionals involved in MAiD. While it began as an interdisciplinary group of physicians (family physicians, hospitalists, internists, and anesthetists), the membership has grown to include other healthcare professionals such as pharmacists, administrators, and bioethicists.[432] The goals of CAMAP are to support MAiD assessors and providers, to educate the healthcare community and public about MAiD, and to be a leader in the development of standards and guidelines around MAiD in Canada.

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significant majority of responses arrived prior to the OMA's invitation, which suggests that the majority of participating physicians belonged to the CSPCP.

[428] Canadian Society of Palliative Care Physicians. "History of Palliative Care by Physicians in Canada since 1993." *CSPCP*, www.cspcp.ca/about/history/. Accessed 4 May 2020.

[389] Canadian Society of Palliative Care Physicians. "Who we are." *CSPCP,*www.cspcp.ca/about/who-we-are/. Accessed 4 May 2020

[430] It should be noted that membership to the CSPCP is limited to physicians only. Other healthcare specialists are not allowed to be members.

[431] Canadian Society of Palliative Care Physicians. "Vision, Mission and Goals for Palliative Care in Canada." *CSPCP,* www.cspcp.ca/about/vision-mission-goals/. Accessed 4 May 2020.

[432] Canadian Association of MAiD Assessors and Providers. "CAMAP Corporate." *CAMAP,* camapcanada.ca/camap-team/. Accessed 4 May 2020.

The Canadian Society of Palliative Care Physicians: The "Separation-Opposition" view towards MAiD and Palliative Care

Since the *Carter* ruling in February 2015, the CSPCP has consistently voiced their staunch opposition to the practice of MAiD and has strongly advocated for the complete separation of MAiD from Palliative Care. On February 12, 2015, less than a week after the *Carter* ruling, the CSPCP released its position statement on MAiD. The Society stated that many of their members believed that Palliative Care physicians should not provide MAiD, but they would respect the "rights of the minority [of patients] who seek this mode of death."[433] In a parallel statement released in the same month (February 2015), the CSPCP published a survey of their membership, of which 74% of their members participated. Of those who responded, 73% were opposed to the decriminalization of assisted suicide (now MAiD), and 74% did not believe that Palliative Care services or clinicians should provide MAiD.[434]

In May 2019, the CSPCP once again addressed the question of the role of Palliative Care in MAiD Canada. This may have been a reaction to discussions abroad in countries such as Australia[435,436] and New Zealand[437,438] that were considering legalizing MAiD, or due to the national discussions within Canada about the expansion of the eligibility criteria for MAiD. Whatever the reason, days before their annual national conference in May 2019, the CSPCP published *Key Messages: Palliative Care and Medical Assistance in Dying (MAiD).* It emphasizes that MAiD is a distinct practice from Palliative Care, because Palliative Care seeks to help people live well until

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[433] Canadian Society of Palliative Care Physicians. *Position Statement Following Supreme Court Judgment Re: Carter,* February 2015.

[434] Canadian Society of Palliative Care Physicians. *February 2015*, February 2015.

[435] Victoria, Australia passed the Voluntary Assisted Dying Act 2017 in November of 2017. However, the Bill did not come into effect until June of 2019.

[436] Bill 61, Voluntary Assisted Dying Act 2017, http://www.legislation.vic.gov.au/. Retrieved January 9, 2019.

[437] The End of Life Choice Bill for New Zealand was first introduced in June of 2017 but did not receive Royal Assent until November 16, 2019.

[438] End of Life Choice Bill, 2017 No 269-1.

their *"natural death."*[439] Furthermore, Palliative Care aims to "reduce suffering, not to end life intentionally."[440] These two points (natural death, and not ending life intentionally) are intended to signal that Palliative Care and MAiD are incompatible in their aims and intentions, thus drawing a sharp contrast between the two practices. The society maintained it should be the responsibility of the healthcare system to implement a process in which patients can self-refer for MAiD services, and that MAiD should not fall to the shoulders of individual healthcare professionals or institutions.[441] Further, it was stated that Palliative Care physicians should only be required to discuss MAiD as an option if the patient made an inquiry or request. Finally, all physicians who do not wish to participate in MAiD should be protected.

Directly addressing the role of Palliative Care in MAiD, the CSPCP stated what they believe are the four aims of their specialty:

1) To explore the nature of a patient's suffering and to address it through effective symptom management and psychological, social, and spiritual support.
2) To provide education and support to colleagues regarding the role of Palliative Care to help patients live as fully as possible until their natural death.
3) To advocate for a high quality, accessible palliative approach to care with access to specialist Palliative Care services when needed for more complex cases.
4) To prioritize and advocate for harm reduction, including:
    a. Potential harm to patients who choose MAiD because of inadequate support, including Palliative Care;
    b. Potential harm to any other person who may be negatively impacted, including those physicians that object to participating directly or indirectly in actions involving MAiD based on medical, moral or religious principles;
    c. Potential harm to the specialty of Palliative Care.

These views are consistent with what the CSPCP has espoused since the decriminalization of MAiD in 2015. The organization maintains that Palliative Care seeks to mitigate the suffering of

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[439] Canadian Association of MAiD Assessors and Providers. *Key Messages: End of Life Care and Medical Assistance in Dying (MAiD) November 2019*, 2019.
[440] Ibid.
[441] Ibid.

patients through pain and symptom management, and helps patients to live and die well (naturally). Moreover, MAiD is a distinct practice from Palliative Care, and should not fall under the umbrella of Palliative Care. As the CSPCP is opposed to the practice of MAiD, the organization calls for a complete separation of MAiD from the practice of Palliative Care.

The CSPCP reiterated their views on November 27, 2019, when it published a joint statement with the Canadian Hospice and Palliative Care Association (CHPCA) on the relationship between Palliative Care and MAiD. In their statement, *A Joint Call to Action,* the two organizations sought to "clarify the relationship" between the two practices.[442] In this clarification, it was stated, in no uncertain terms, that MAiD is a "fundamentally different practice" from Palliative Care and that it should not be considered to be any part of the practice of Palliative Care.[443] The statement maintained that MAiD is not an "'extension' of Palliative Care, nor should it be considered to be one of the tools 'in the Palliative Care basket.'"[444] Further, it was argued that MAiD and Palliative Care, "…substantially differ in…philosophy, intention, and approach" because Palliative Care seeks to help improve the quality of life through pain and symptom management, and views dying as a "normal part of life and helps people to live and die well."[445] However, it does not seek to hasten death or intentionally end life.[446] The CSPCP asserted that MAiD stands in stark contrast to Palliative Care because it addresses suffering through the intentional ending of life by the administration of a "lethal dose of drugs."[447] The Statement

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[442] Canadian Society of Palliative Care Physicians and the Canadian Hospice Palliative Care Association. *Joint Call to Action*, 27 November, 2019.

[443] Ibid.

[444] Ibid.

[445] Ibid.

[446] Ibid.

[447] Ibid.

purports that national and international organizations, as well as Dr. Balfour Mount,[448] support them in their views that MAiD is not part of Hospice Palliative Care.[449]

The CSPCP's statement called for action from the provincial and federal governments to focus more attention on Palliative Care than on MAiD. It argues that while MAiD is a protected right for Canadians under the Canada Health Act, it accounts for less than 1.5% of deaths across Canada.[450] Alternatively, 90% of Canadians would benefit from a Palliative approach to care at the end of life, yet only 30% of Canadians have access to high-quality Palliative Care.[451] The Statement ends with the phrase, "Canadians must have a right to assistance in living with Hospice Palliative Care, and not just a right to the termination of life."[452]

The Canadian Association of MAiD Assessors and Providers: The "Integrated" view towards MAiD and Palliative Care

Days after the CSPCP and CHPCA released their joint statement on Palliative Care and MAiD, the Canadian Association of MAiD Assessors and Providers (CAMAP) published "Key Messages: End of Life Care and MAiD." [453,454] The statement published by CAMAP differs in the tone and overall message from that of the CSPCP and CHPCA. In their key message, CAMAP suggests eight recommendations, three of which endorse the overlap of MAiD and Palliative Care.

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[448] Recall from Chapter 1 on the Origins of Palliative Care, that Dr. Balfour Mount brought Palliative Care to Canada after working with Dr. Cicely Saunders. Because of this, he is referred to as the "Father of Palliative Care" in Canada and is revered by those who practice it.

[449] Ibid.

[450] Canadian Society of Palliative Care Physicians and the Canadian Hospice Palliative Care Association. *Joint Call to Action*, 27 November, 2019.

[451] Ibid.

[452] Ibid.

[453] Canadian Association of MAiD Assessors and Providers. *Key Messages: End of Life Care and Medical Assistance in Dying (MAiD) November 2019*, 2019.

[454] This statement was later updated in February 2020.

The final recommendation is, "CAMAP strongly supports the integrated work of Palliative Care and MAiD clinicians." The eight recommendations are (emphasis added):

1. **All end of life care should be ideally grounded in the provision of high-quality Palliative Care.** If requested, MAiD should be integrated seamlessly into the end of life care the patient is receiving.
2. **All MAiD clinicians should be familiar with Palliative Care.**
3. MAiD should be included as an option in all end of life goals of care conversations with potentially eligible patients.
4. For patients wishing to pursue MAiD, CAMAP strongly supports full access to MAiD services, regardless of geography, facility, or institution.
5. All healthcare providers who wish to participate in MAiD should have access to training and be respected, permitted, and supported in their work of assisted dying.
6. All health care providers who do not wish to participate in MAiD should be respected and supported in their decision.
7. Conscience based objection should not impair patient care. CAMAP strongly supports the professional requirement of an effective referral.
8. **Recognizing the primacy of patient care and outcomes, CAMAP strongly supports the integrated work of Palliative Care and MAiD clinicians**.[455,456]

In their key messages, CAMAP highlighted three areas that draw a close link between MAiD and Palliative Care: (1) MAiD should be grounded in the provision of high-quality Palliative Care, (2) All MAiD providers should be familiar with Palliative Care, and (8) MAiD and Palliative Care should be integrated.

CAMAP also stated that physicians who conscientiously choose to participate or object to MAiD should be supported and respected. While Bill C-14 stipulates that, legally, MAiD assessors and providers must counsel all patients who request MAiD on all of their options, including Palliative Care,[457] the statement released by CAMAP reads more like an olive branch and desire to

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[455] Ibid.

[456] This version of the Key Messages is no longer available online as it has been replaced by the updated version. The full document is included in the appendix.

[457] Section 241.2(e) of the Bill mandates that, “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.” An Act to amend the Criminal Code and to make related amendments to other Acts (medical assistance in dying), Bill C-14, As passed June 17, 2016 (Canada, 42d Parl., 1st sess).

collaborate with Palliative Care in order to provide, what they believe to be, the best care to their patients. From this statement, CAMAP openly recognizes the benefit of Palliative Care and the need to have Palliative Care involved with patients who request MAiD.

In February 2020, CAMAP updated its policy, "Key Messages: End of Life Care and Medical Assistance in Dying." The swiftness in the evolution of this policy is indicative of the dynamic nature of the question of how MAiD and Palliative Care should intersect, and how quickly views around this relationship are evolving. While the CSPCP has yet to change their position on the intersection of MAiD and Palliative Care, CAMAP's change shows that the relationship between MAiD and Palliative Care, and how the two should intersect, has not yet been firmly established by all parties.

Since November, CAMAP's position on the intersection of MAiD and Palliative Care has further highlighted their support for Palliative Care and their desire for the two practices to be integrated. In November, CAMAP highlighted eight key messages. In February, these messages were updated to include a 9th message, the first three points being changed, and the last two amended.

In their initial publication of the "Key Messages: End of Life Care and Medical Assistance in Dying," the first three points read as:

> 1. **All end of life care should be ideally grounded in the provision of high-quality Palliative Care.** If requested, MAiD should be integrated seamlessly into the end of life care the patient is receiving.
> 2. All MAiD clinicians should be familiar with Palliative Care.
> 3. MAiD should be included as an option in all end of life goals of care conversations with potentially eligible patients.[458]

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[458] This third point has been moved to the fourth bullet in the February 2020 statement and remains unchanged.

By February, CAMAP had changed the first three messages to:

1. High-quality palliative care should be available to all patients who desire it at the end of life. CAMAP strongly supports the development, extension, and proper funding of excellent palliative care services in all communities across Canada. This includes ensuring support for all clinicians who provide these services for their patients.
2. All clinicians participating in MAiD work should be knowledgeable about palliative care options and other potential supports available to the patient. All clinicians who provide end of life care, including palliative care clinicians, should be knowledgeable about MAiD and the resources available in their locality for patients seeking information about and/or referral for MAID.
3. Respect for patient autonomy should be the foundation of all end of life care; there should be a clear understanding of and respect for the patient's goals of care. Should a patient choose to pursue MAiD, they should be supported in their decision. All medical care, including palliative care, if involved, should be continued.

Examining these changes individually, we see that CAMAP has moved from asserting that MAiD should be grounded in high-quality Palliative Care to a focused statement that promotes the development of Palliative Care in Canada, and supports the need to access it. CAMAP goes beyond its original statement by extending its support for the development and funding of Palliative Care services in all communities across Canada and support for Palliative Care clinicians. This new statement highlights a notable level of support for Palliative Care from the Canadian MAiD organization, while removing any specific reference to MAiD.

In their second point, CAMAP shifts from their original statement that all MAiD providers should be familiar with Palliative Care to including an important addition, that *all Palliative Care providers should also be knowledgeable about MAiD*. This addition indicates that CAMAP sees such a close connection between the two practices and the likelihood of a shared patient population that they insist that practitioners of both MAiD and Palliative Care be knowledgeable of the other. If anything, this further emphasizes CAMAP's view of the integrated nature and more significant connection between MAiD and Palliative Care.

The third bullet, the addition, highlights CAMAP's integrated view of MAiD and Palliative Care, indicated their view of the interconnected nature of the two practices. In stating that they believe that all patients who request MAiD should be supported in their decision *and* that all medical care, specifically Palliative Care, be continued shows how CAMAP sees the close connection between the two practices, and the *need* for Palliative Care to be part of the care of a patient who receives MAiD.

The seventh and eighth bullets from the November policy, now the eighth and ninth bullets, were expanded to emphasize the previous policies. In November, the policy read:

> 7. Conscience based objection should not impair patient care. CAMAP strongly supports the professional requirement of an effective referral.
> 8. Recognizing the primacy of patient care and outcomes, CAMAP strongly supports the integrated work of Palliative Care and MAiD clinicians.[459]

In February 2020, these points were updated to read as:

> 8. Conscience-based objection should not impair patient care. If a clinician objects to MAiD on the basis of conscience and is unwilling to carry out a MAiD assessment, CAMAP strongly supports the professional requirement of an effective referral to a clinician known to provide MAiD or to a local or provincial MAiD coordination service.
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> 9. Recognizing the primacy of patient-centred care and outcomes, CAMAP acknowledges and appreciates the value of inter-professional teams and especially encourages the integration of palliative care and MAiD.

Comparing the above point on conscience-based objection, we see that CAMAP has included the same wording from 2019, with the addition of two points. First, CAMAP specifies assessments in the latter policy and argues that even physicians who object to providing an assessment must make an effective referral. The second change, the last part of the eighth bullet, is now specific to what is required of an objecting physician. Here, CAMAP goes beyond what

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[459] Ibid.

the CPSO requires of physicians and states that an objecting physician must refer the patient to a known MAiD provider or a MAiD coordination service.

Finally, considering the last point in both policies, we see that CAMAP makes a subtle but significant change. Formerly, CAMAP stated their support for the "integrated work of Palliative Care and MAiD clinicians." The final bullet of the updated policy goes beyond this to assert their support and appreciation of interdisciplinary teams and their encouragement of "the integration of Palliative Care and MAiD." Here we see that CAMAP is voicing their recognition that those patients who request MAiD will likely be cared for by an interdisciplinary team (recall from the chapter on Palliative Care that Palliative Care is known for working in interdisciplinary teams) and that they want the specialties of MAiD and Palliative Care, not just the providers, to be integrated.

Brief Analysis of the Separation-Opposition and Integrated Views

The models espoused by each organization highlight the difference in views as to how MAiD and Palliative Care should intersect. Most important to note is that the CSPCP wants a complete separation of MAiD from Palliative Care while CAMAP proposes the integration of the two specialties. While both organizations have the overarching goal of alleviating suffering, *how* this is achieved is the dominant point of contention. The CSPCP has highlighted continually that Palliative Care seeks to support a patient in a ‘natural’ death, and that MAiD is incompatible with this aim. The CSPCP has made it clear that they do not believe that Palliative Care should participate in MAiD because it starkly contrasts with their values about how a patient should die. As such, their Separation-Opposition Model is based on their values as an organization (that patients should die “naturally”) and do not want Palliative Care to be conflated with MAiD. The

CSPCP views the aims of MAiD and Palliative Care as incompatible, and thus insist on a sharp distinction between the two. One of the driving reasons for this sharp distinction is their desire for the public to have a proper understanding of (what they believe to be) the aims of Palliative Care, and how it differs from MAiD.

CAMAP, on the other hand, highlighted how Palliative Care can support MAiD, the physicians who provide it, and the care of the patients who request and receive it. CAMAP's Integrated Model focuses more on the overall outcome and how best to support patients and physicians instead of the distinction between the two practices. The aim of their model is to ensure that their patients receive the best care possible, their physicians are practicing safely, and that they have the requisite skill set to care for patients who have requested MAiD.

With the views of each representative organization as to how Palliative Care should intersect with MAiD understood, it is now time to move to the views of the physicians who belong to each organization.

Views of Physicians: What is the role of Palliative Care in the ongoing development of MAiD?

Understanding the national organizations' views is helpful as they ground the current debate around the role of Palliative Care in MAiD, and contextualize the views and feelings of Canadian Palliative Care physicians. During the interviews, physicians were asked several questions about MAiD. These questions explored the impact of MAiD on them as individual physicians, on their practice of Palliative Care, on their relationship with their patients, and on their relationships with their Palliative Care colleagues and the Palliative Care community. Concluding these questions, physicians shared their thoughts on what they believe to be the role of Palliative Care in the ongoing development of MAiD in Canada.

An overwhelming majority of the physicians interviewed believed that Palliative Care should be involved in the ongoing development of MAiD in some capacity. Of the 51 physicians, only three physicians spoke about the need to distance Palliative Care from MAiD. Interestingly, one of those three physicians stated that while they believe that MAiD should be separate from Palliative Care, they also believe that Palliative Care should be involved in the care of patients who request MAID throughout the process by providing excellent Palliative Care until the moment of MAiD, and assisting the family or loved ones after the provision. While this physician wanted the two practices to be separate, in practice having Palliative Care involved throughout the process highlights the interconnectedness of the two practices, and the difficulty of separating them completely.

While few physicians spoke to the need to strongly separate MAiD from Palliative Care, this does not mean that participants strongly endorsed erasing the distinction between the two**.** In fact, very few physicians spoke about the need for Palliative Care physicians to be actively involved in MAiD as providers. Three physicians spoke directly about the benefit of having Palliative Care physicians provide MAiD.[460,461] Another three indicated their support for Palliative Care physicians being MAiD providers but did not name it as a specific role. These latter three physicians (all MAiD providers) support Palliative Care physicians in providing MAiD. However, they do not believe that the provision of the service is an obligation of Palliative Care physicians, or that MAiD is a part of Palliative Care.[462]

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[460] Interviews 1, 16, 27.

[461] These physicians did not say that it was the role of Palliative Care physicians to provide MAiD. Instead, one indicated that they were happy that Palliative Care physicians willing to provide MAiD because of their competencies. Another said that Palliative Care physicians should be the most competent in MAiD, but not necessarily the provision. The third mentioned the necessity of having rural Palliative Care physicians provide MAiD when other providers were unavailable.

[462] Interviews 37, 43, 50.

So, if most participants rejected both a strong separation between the two practices and the idea that MAiD is simply part of Palliative Care, how did they think the two practices should interact? The majority of physicians (45/51) spoke about the need for the involvement of Palliative Care in the development of MAiD in Canada in some way. While few Palliative Care physicians believe they should be involved in MAiD as providers, the majority believe that Palliative Care should be involved in education, caring for patients who have requested MAiD, and developing policy. After analyzing the responses, six general themes emerged around the role of Palliative Care physicians in MAiD.

1) Palliative Care physicians have expertise in assessing and addressing suffering, particularly suffering that comes from having a terminal illness or at the end of life (12/51);
2) Palliative Care physicians are uniquely qualified to assess the suffering of patients who request MAiD, and are in the best position to be MAiD assessors (for their patients) (8/51);
3) Palliative Care physicians can support the patient and their family throughout the process by providing high-quality Palliative Care up until the point of MAiD, and supporting the family after the provision of MAiD (10/51);
4) Palliative Care physicians are the best suited to educate their patients and colleagues about what Palliative Care is, and its benefits (9/51);
5) Palliative Care needs to be 'at the table' and part of the ongoing discussion of MAiD so that their voices and experiences are heard (6/51), and;
6) Palliative Care needs to advocate for Palliative Care to remain a priority (4/51).

Note that other than the role of being an assessor, five of the six themes do not have Palliative Care participating in the actual practice of MAiD (assessments and/or provisions). Instead, physicians believe that the role of Palliative Care in the ongoing development of MAiD is to ensure that all patients with life-limiting illnesses (regardless of their choices at the end of life) receive the best possible care, to be educators and advocates for Palliative Care, and to continue to be an integral presence in discussions around the development of MAiD in Canada. Each of the following themes is discussed below in further detail.

Role 1: To assess and address suffering

Most commonly heard throughout the interviews was that Palliative Care physicians have an unparalleled level of expertise and a depth of knowledge and wisdom about treating the suffering of patients with life-limiting illnesses. Physicians spoke about the need for Palliative Care physicians to be intimately involved in the care of patients who have requested MAiD because eligible patients must have a life-limiting illness and be suffering intolerably, which is the patient population whom Palliative Care cares for regularly. As one physician stated, when caring for patients who request MAiD, Palliative Care physicians are "sine qua non"[463] because they have many of the skills needed to address the needs and requests of patients who have such intolerable suffering that they request hastened death. Because of the nature of their work and the patient population that they care for, "Palliative Care physicians are the most competent in dealing with that wish [to die]."[464] Another physician echoed the sentiment that Palliative Care physicians are the most well-positioned of any specialty to be involved in the care of patients who request MAiD.

> I think that we are very well positioned and have a lot of experience in looking after patients with immense suffering, physical and otherwise…I mean, you know, again, who better to assess? And who better to help ensure that this isn't a vulnerable person who doesn't have access to good Palliative Care? You know, by having their assessment done by a Palliative Care provider. I actually think that we have an obligation to be involved in MAID, not necessarily provision, but certainly in legislation and developing safe and ethical practices around MAID.[465]

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[463] Interview 14.
[464] Interview 16.
[465] Interview 43.

This physician noted the need for the involvement of Palliative Care with MAiD requests because of the intense vulnerability of the patients. Patients who request MAiD are some of the most vulnerable because they are either dying or facing a life-limiting illness; are suffering physically or emotionally; are faced with their finiteness; and may be dealing with other issues such as vulnerable housing, addictions, or traumas.[466] It is in this state that patients are asking for assistance to die, and thus the request is not (and should not) to be taken lightly. When a patient requests MAiD, having a physician who is skilled in recognizing, identifying, and addressing this suffering and vulnerability is essential. Fortunately, Palliative Care physicians happen to be experts in both. Because of this experience and knowledge, many physicians felt that Palliative Care physicians had a lot to offer to the development of MAiD in Canada. One physician stated,

> … Palliative Care is seen and acknowledged and invited in as having this incredible depth of wisdom…I feel that we have, within health care… the most breadth around living and dying and around natural death, around trajectories of illness. We see it from diagnosis right through to death and into bereavement. So, it would be nice to think, as MAID goes forward, that there's, like, a more wholesome embracing of this incredible wisdom; that we would be seen as leaders in death and dying… going forward, a wholesome embracing of this to say, "who has the wisdom we need to inform us on this?" That MAID would turn to Palliative Care.[467]

Aware of their specific expertise in assessing and addressing suffering, physicians suggested that they should be explicitly involved in the patients who request MAiD. As one physician said, "[There is] no one better than us to have the courage to look at the real human plea here [MAiD request]."[468]

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[466] Interviews 12, 16, 30.

[467] Interview 15.

[468] Interview 15.

Role 2: To assess for MAiD because of their ability to assess suffering

Aware of their expertise in caring for patients with life-limiting illnesses and who are suffering, physicians believed if a patient were to request and be eligible MAiD,[469] they must be assessed by a Palliative Care physician (or, someone who has a nuanced understanding of Palliative Care). Several physicians noted that because of their specific skill set in recognizing and addressing suffering, Palliative Care physicians are the best equipped to have discussions around MAiD and be assessors for it.

> I think we have to continue to be involved that's for sure. But not as far as providing Medical Aid in dying, but maybe doing assessments or being the assessor on patients we already know.[470]
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> …whether or not somebody chooses actually to be involved in the provision of MAID, I still think Palliative Care is well situated for things like assessments and conversations and all those sorts of things.[471]
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> I do think [patients who request MAiD] need to have an opportunity to have their suffering addressed…I would trust a Palliative Care physician to assess somebody's suffering and be the expert at addressing their suffering. And so, that would be more where I would see the role of Palliative Care, is that… There are so many people for whom a request for MAID is… is the only way they can express their suffering. I would hate for that piece to be missed.[472]

What these physicians expressed is what so many others indicated. When a patient requests MAiD, it is an indication of suffering, and the physician present needs to recognize that the

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[469] Bill C-14 states that in order for a patient to be eligible to receive MAiD, two independent physicians must find the patient to satisfy the following eligibility criteria:

1) Be at least 18 years old;
2) Be eligible for government-funded health insurance in Canada;
3) Have a grievous and irremediable condition as described under section 241.2 (paragraph 2) of the *Criminal Code*;
4) Made a voluntary, uncoerced request for MAiD;
5) Give informed consent to receive MAiD after having been informed of all of their options to alleviate their suffering, including Palliative Care (Bill C-14).

[470] Interview 4.

[471] Interview 13.

[472] Interview 49.

patient is saying, "Doctor, my life is intolerable. I need help. Help me, help me, help me."[473] Palliative Care physicians recognize that when a patient asks for MAiD, it is as an expression of unbearable suffering, and view it as an opportunity to assess and address the patient's suffering. When a Palliative Care physician hears a request to die, they will first wonder if something was missed when treating the patient? Is there pain or symptoms that have not been managed well yet? Is there suffering that has not yet been identified or addressed? Because of this approach, some Palliative Care physicians believe that they are the best suited to assess patients for MAiD in order to ensure that the patient's suffering is truly intractable, and what the patient wants before initiating a MAiD assessment. As one physician stated,

> I think that we are very well positioned and have a lot of experience in looking after patients with immense suffering, physical and otherwise. It *should* be Palliative Care physicians who are taking a leading role… I mean, you know, again, who better to assess? And who better to help ensure that this isn't a vulnerable person who doesn't have access to good Palliative Care? You know, by having their assessment done by a Palliative Care provider. So… I think that we have an obligation to be involved in MAID, not necessarily provision, but certainly in legislation and developing safe and ethical practices around MAID. [474]

What this physician captures in their statement about the role of Palliative Care in MAiD is that Palliative Care physicians are well situated to be making some of the big decisions around MAiD; from the assessments of patients and eligibility to the ethics and practices around the service to legislation. Palliative Care physicians are apt for these roles because they are actively involved in the care of patients who have such intolerable suffering that they wish for their life to be ended. Because they care for patients who, at the end of life, suffer intolerably, Palliative Care had heard and addressed requests to die long before MAiD was brought before the Courts or legislators. It

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[473] Interview 16.

[474] Interview 43.

was noted that before MAiD was legal, Palliative Care was tasked with addressing this suffering and alleviating it to the best of their ability (without the legal capacity to end someone's life). Certainly, there were patients whose suffering could not be alleviated entirely, such as existential suffering, or other intractable symptoms. In these situations, many physicians may turn to terminal sedation (aka "palliative sedation"); however, terminal sedation is usually only used when the patient's suffering cannot be mitigated by other means. Furthermore, the medical practice guidelines do not recommend the use of terminal sedation for patients whose prognosis exceeds two weeks.[475] Therefore, if a patient had an extended prognosis, the physician had to find alternative methods to alleviate their suffering. Before MAiD was available, and due to the restrictions around sedation, Palliative Care physicians became experts in human suffering and finding ways to address it and alleviate it (when possible). Thus, when considering who is most competent to assess for MAiD, it is no wonder that Palliative Care physicians believe that they are best suited for the role; because assessing and addressing suffering is what they have been doing all along.

Role 3: To provide high-quality Palliative Care to patients who request or receive MAiD

When asked about the role of Palliative Care physicians in the development of MAiD, several physicians noted that their role is to do their job, to provide high-quality Palliative Care to their patients, and those who are suffering so intolerably that they request MAiD. As one physician phrased it, the role of Palliative Care physicians is to continue "doing their job"[476] and that a request for MAiD should not change this. Physicians believed that all patients,

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[475] Collège des médecins du Québec. *Palliative Sedation at the End of Life Practice Guidelines*, 2016, 9, 13, 34.

[476] Interview 40.

irrespective of their choices at the end of life about how they would die, had the right to have their suffering addressed first through excellent pain and symptom management.[477] Physicians believed that this is particularly true of patients who have requested MAiD to ensure that these patients have had the opportunity to have their pain and symptoms addressed.

> **We have to see MAiD as an extension of Palliative Care and not as a failure of its delivery**… MAiD and Palliative Care go hand-in-hand… if we believe that people have a right to excellent pain and symptom management and that they should be provided with that pain and symptom management, and should be able to access that as a prerequisite before MAiD is even considered, then how can Palliative Care not be involved? Should there be a mandatory Palliative Care consult for any requests for MAiD? Should the patient be given the opportunity to have excellent pain and symptom management? … So, should a Palliative Care consult be mandatory before someone considers MAiD? Should we be given the opportunity to help people first? To relieve stress, I don't want to say symptoms but any stress, but shouldn't we at least be given a chance? So, if I say that I don't want any part of this, am I denying patients the opportunity…? Do you know what I am saying? … We should be involved to the extent that we make sure that people have the opportunity for the best symptom management and psychosocial support that is possible to have before they even access MAiD.[478]

> It is our role to provide good symptom management, psychosocial support, and spiritual support as well. I think we actually play a big role in patients who request MAiD… you can't really say that someone has refractory suffering or refractory existential suffering or distress unless you've had a comprehensive Palliative Care team or Palliative Care approach before that.[479]

These quotes reflect the role of Palliative Care to be involved in the development of MAiD because of their expertise, their ability to assess suffering, and their ability to provide high-quality Palliative Care. Every physician felt that Palliative Care should be intimately involved with patients who request MAiD because it ensures that patients have had the opportunity to have their suffering alleviated, suffering that might be the cause of a request for MAiD. These physicians spoke of Palliative Care as a right and a failsafe to ensure that the suffering of

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[477] There are some patients who, due to geographic location, may not have access to a Palliative Care physician in person. However, the advent of Telemedicine allows for physicians to engage with the patient and consult about Palliative Care before the patient receives MAiD.

[478] Interview 2.

[479] Interview 47.

patients who have requested MAiD is truly intractable. One physician spoke of the necessity of having Palliative Care consult patients who had requested MAiD because, time and time again, this physician had seen patients who were brought into the ER in agony and requesting MAiD. However, after Palliative Care had seen them and addressed their suffering, the patients would then say, "Ah! I don't have pain anymore! I want to live!"[480] Examples like this reinforce the importance of ensuring patients have access to the best pain and symptom management and to have their needs addressed before MAiD was considered. This way, patients who receive MAiD will have done so because their symptoms are genuinely refractory and their suffering intolerable, and not that anything was left unmanaged. In such cases, a request for MAiD should not be seen as a failure of Palliative Care but rather as an indication of the limits of what Palliative Care can offer the patient, or simply what the patient wants at the end of life. As one physician stated,

> …if this is what a person wants MAiD; it's not a reflection that you failed as a Palliative Care physician. You can't interpret that as, like, a personal failure or a failure of our profession. It is because of their personal fundamental personality characteristics and values. And we need to respect that. And we need to not view it as, you know, Palliative Care just wasn't good enough, because we know from the evidence that that is not why people are requesting MAID.[481]

Accordingly, every physician believed that those patients who choose to have MAiD should have the best Palliative Care possible, "all the way through to death;"[482] patients should not be forced to choose between Palliative Care or MAiD, that it is not an "either-or."[483] Even the physicians who are opposed to the practice of MAiD, and will not be assessors or providers, stated that despite their views around MAiD, they will support their patients all the way through. As one physician

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[480] Interview 14.
[481] Interview 48.
[482] Interview 44.
[483] Ibid.

said, "I may be 100% against MAiD, but I'm 100% for my patients" and noted that he is aware of his own "bias in the situations and says to [himself], 'OK, how can I still be involved?'"[484] Other physicians shared this attitude. Irrespective of their views towards MAiD, what was common among all physicians was their desire to ensure that all patients received the best care possible until their death[485] so that patients would choose MAiD because they did not have access to Palliative Care or the care that would support their quality of life.[486]

In line with the continuum of care (caring for patients until the moment MAiD is provided), many physicians spoke to their role as Palliative Care providers to provide high-quality Palliative Care, and to work with the members of the care team who were going to provide MAiD. Physicians who are morally or philosophically opposed to MAiD still viewed their commitment to their patients as paramount and would advocate for their patient's right to receive the best possible care (even MAiD if that is what the patient wanted).

> That whatever we – people who are Palliative Care physicians – can do is to ensure that we are meeting the needs of patients, that's what we have to do. So, however, we work with MAID providers, it has to be with the focus always on the patient, not on an "us or them." So …what do we need to do? **We need to do what Palliative Care tells us to do, which is to provide good whole-person care. And then we'll be** OK. And literally, help people live as well as they can for whatever time they have… **So, basically, what we have to do is do our job.**[487]
>
> I think Palliative Care absolutely should be supporting patients all the way through to death, no matter what their end of life choice is, whether they have a natural death, or they have an assisted death. I think our duty and my professional role to provide the very best care I can for the patients regardless of their choice. And to collaborate with the whole care team.[488]

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[484] Interview 10.
[485] Interviews 2, 31, 32, 34.
[486] Interview 31.
[487] Interview 40.
[488] Interview 44.

These quotes highlight the overarching desire of all physicians to ensure that they continue to do their job; to provide high-quality Palliative Care to all patients with life-limiting illnesses, irrespective of how they choose to die.

Role 4: To educate patients and colleagues about Palliative Care

Many physicians articulated the Palliative Care physicians' role in the ongoing development of MAiD is to educate their patients and colleagues about Palliative Care. As discussed in the previous chapter on the challenges faced by Palliative Care physicians, physicians struggle with the widespread misunderstanding of Palliative Care throughout society and with their colleagues from other disciplines. As such, physicians felt that they have a role to play in educating their patients to ensure that they are informed about Palliative Care so that they are aware of all of their options at the end of life, and that their colleagues in other disciplines needed to know about Palliative Care and when and how to consult Palliative Care services. As the reasons why both groups would benefit from education in Palliative Care have been discussed in Chapter 4, they will only be discussed briefly.

Educating Patients

Physicians articulated their concern for patients who request MAiD without being fully aware of Palliative Care, thereby making a decision that is not fully informed. The worry was that if patients are uninformed about how Palliative Care might benefit them or about how to ask for it, then they might choose MAiD by default.[489,490] Physicians want their patients and families to know

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[489] If patients and their families do not have an adequate understanding of what Palliative Care *is* and what it can offer them, they are not making a fully informed choice about MAiD. Informed consent is a legal requirement for medical decision making, and knowing about the option of Palliative Care was stated explicitly in the *Carter* ruling for any patient who is requesting MAiD.

about Palliative Care so that they are aware of all of their options, and that MAiD is not their only option at the end of life. Physicians understand that there is a population of patients who will receive excellent Palliative Care but will still request MAiD. These are not the patients who invoked worry or distress amongst physicians. The patients who troubled physicians were those who requested MAiD, but withdrew their request once Palliative Care had seen them and managed their pain and symptoms. These cases distressed physicians, because they suggest that there is a population of patients who choose MAiD because they have not had the opportunity to receive Palliative Care. This is why physicians want to ensure that patients who request MAiD are fully informed about *all* of their options.

> So that people have… don't see MAiD as their only option. I've explained the available options, and they say, "oh, that's what I want," and what they're saying is I want Palliative Care. They don't know the term.[491]
>
> I think our role really is to help educate and to really try to ensure that people are aware of all their options.[492]
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> I have spoken to a few MAID assessors, and part of their training is on things like making sure people have had exposure to all the other options… And so, that was a big wake up moment for me, where I was like, "Why are we not at the table and having these conversations with our patients so that they understand all the options and the whole spectrum?" I especially also don't think it's an either-or. I think there's a whole spectrum of things that people at the end of life are interested in exploring and discussing and knowing about.[493]

Physicians want to ensure that their patients are aware of all options and know what they are asking for and how to ask for it. If patients understand Palliative Care, they will be aware of it as an option, understand how it differs from MAiD, and know that they have a right to ask for it, just as they have a right to request MAiD.

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[490] In *Carter v. Canada*, the Court referenced the trial judge from who stated that in order for a person to be considered eligible for assisted death that it must be, "… ensure[d] a patient is properly informed of her diagnosis and prognosis," and the treatment options described included all reasonable palliative care interventions." from para 831 at 27 in *Carter*.

[491] Interview 22.

[492] Interview 33.

[493] Interview 42.

Educating other physicians and healthcare providers

Palliative Care physicians can also educate physicians (or other healthcare providers) in other disciplines. Returning to the collegial misunderstanding of Palliative Care, physicians want their colleagues to understand Palliative Care for two reasons: 1) For those colleagues who assess and provide MAiD need to be adequately trained in Palliative Care, and 2) clinicians in other specialties must be informed about Palliative Care so that they know when how to access Palliative Care specialists if needed.

> I also think, directing physicians who aren't as familiar with Palliative Care and when they should be referring their patients for Palliative Care or how they can access Palliative Care.[494]

Palliative Care physicians saw that they have a role to play in the development of MAiD by educating their colleagues about Palliative Care, ensuring that those involved with the practice have an adequate understanding, not just of what Palliative Care is but about death and dying in general. One physician expressed their concern that their colleagues' lack of understanding might lead to a misrepresentation of Palliative Care to their patients.

> And I worry a little bit that those providing and doing the discussion and assessment around Medical Assistance in Dying may not always actually have a good understanding of what Palliative Care is and what a natural death looks like. Those are the things that I think one of our big roles is making sure that the people who are discussing Palliative Care as an option actually can do that in a meaningful way, whether it's Palliative Care providers who are doing the assessment, but most importantly when it isn't Palliative Care providers who are doing the assessments and provision because that can be pitched very, very differently depending on that… the person's perception and understanding of it…it is important for us to make sure that for any training programs around Medical assessment… MAiD assessment and MAiD provision, that people actually have adequate exposure and understanding of Palliative Care to really be able to give an informed… to make… again, present that as an option in an informed, realistic way…[495]

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[494] Interview 7.

[495] Interview 36.

One physician saw this lack of understanding from other specialties about Palliative Care as an opportunity to educate his colleagues and build relationships between Palliative Care specialists and those actively involved with MAiD.

> …family physicians, you know, ICU docs, whoever, that are taking on the MAID piece and anybody that I've talked to that hasn't been Palliative Care trained and has taken up MAID is… has always said, "Boy, I wish I knew more about Palliative Care." Well, that's an opportunity for us. These people are already doing… providing an end of life service. Let's give them some education. Let's bring them on board on the palliative side, and then we have got more manpower. I think we can help each other… I think MAID is open to Palliative Care. I don't think Palliative Care is open to MAID.[496]

Educating other physicians is an opportunity for Palliative Care to provide education to other specialties about the Palliative Care competencies. As discussed earlier in this chapter, Palliative Care physicians are experts in the type of suffering, pain, and symptoms that occur at the end of life, which may be the reason a patient asks for MAiD. Palliative Care physicians are the best suited to consult a patient who has made such a request. However, if Palliative Care physicians are not the ones who are caring for patients who request MAiD, or are not doing the assessments or provision themselves, then they can educate their colleagues on the necessary Palliative Care skills.[497] This education extends to also ensuring that their colleagues have an adequate understanding of what Palliative Care is so that there may be a collaboration, and increased earlier referrals. MAiD assessors and providers need to know about Palliative Care so that they can work with Palliative Care physicians for patients who have requested MAiD. If other specialties have a

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[496] Interview 39.

[497] Additionally, everyone who assesses or provides MAiD must have an adequate understanding of Palliative Care as it is required on the assessment form that the patient is informed of all other treatment options including, Palliative Care (Section 3, Ontario Assessment form). Considering this, Palliative Care physicians want other colleagues who are providing these services to understand Palliative Care to be able to inform their patients fully and to be legally compliant with the MAiD assessment.

better understanding of Palliative Care, they are more likely to refer their patients to Palliative Care and to have discussions with their patients about what Palliative Care can offer them.

Role 5: To be "at the table" and part of discussions around MAiD

Every physician, regardless of their views towards MAiD, believes that Palliative Care needs to be "at the table" or "part of the discussion" in the development of MAiD in Canada.[498] Some physicians asserted that while Palliative Care should be part of the discussion of the development of MAiD in Canada, they should not take a leadership role in said discussions. The worry was that if Palliative Care becomes a leader in the development of MAiD, or pioneers it, that society might conflate Palliative Care with MAiD. As one physician aptly stated, "We need to be part of the conversation, but we do not need to be designing the conversation."[499] Another physician captured the concern felt by several Palliative Care physicians.

> I think the worry that I have is if Palliative Care physicians are the ones to lead on this, then I think what it leads to is the natural assumption that MAiD is Palliative Care. I think we should be involved, and I think you could contribute, but I don't know if we should be the ones leading on it for that reason…But I do feel strongly that Palliative Care and Medical Aid in dying need to remain separate. I think they're worried that I have is that the bigger the leadership role we take, the more synonymous that they become with each other.[500]

While many physicians indicated the need for MAiD and Palliative Care to be kept as distinct practices, they still viewed Palliative Care as essential to the ongoing development of MAiD in Canada, and know that their voices and experiences must be heard.[501]

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[498] Interviews 23, 30, 35, 39, 42.

[499] Interview 12.

[500] Interview 11.

[501] Interviews 11, 12, 23, 35.

> By being at the table and giving influence, you don't own it, are you condoning it? I don't think so. Because if you are not at the table either collectively, at a government level, at a provincial level, at a local level, if you think your voice is not going to be heard, and people are going to make decisions without you … we need to be engaged and don't think it's under the umbrella of Palliative Care. Like any other procedure, it's not owned by Palliative Care. Do we need to be involved? Yes. But, the balance between the two is where it becomes tricky.[502]

While some physicians were still trying to navigate or understand their role in MAiD, what was consistent amongst every physician was that Palliative Care needs to be involved in local, provincial, and federal discussions around MAiD. The role of Palliative Care in the ongoing development of MAiD is to be part of all future discussions and to ensure that their voices and experiences are heard.

Role 6: To advocate for Palliative Care

Due to the media attention that surrounded the *Carter* ruling and Bill C-14, MAiD has received more public attention than Palliative Care. As such, some physicians believed that the specific role for Palliative Care is to advocate for Palliative Care, and in particular for better access to and better resourced Palliative Care for Canadians. Since its introduction, MAiD has received ample attention in the form of increased funding, attention to policy work and eligibility criteria, training for MAiD providers, and promotion of access. However, this attention and promotion of MAiD came at a time when less than 30% of Canadians have access to high-quality, specialized Palliative Care.[503] Some physicians wondered why our country decided to decriminalize MAiD before attempting to improve Palliative Care.[504] This was a question, concern, and criticism of our country heard by

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[502] Interview 23.

[503] Hawley, Pippa. *How to Improve Palliative Care in Canada*, 2016, 8.

[504] While the concern and questions from physicians are valid, it should be noted that the *Carter* ruling was the Supreme Court's response to a Charter challenge; it was not a political policy decision.

physicians in this set of interviews, as well as those conducted in 2016.[505] As was highlighted in the role of education, physicians know that there are patients who withdraw their MAiD requests once they have received Palliative Care. Physicians are, and were, concerned that the Canadian government legalized MAiD before it took steps to ensure better access to Palliative Care for all patients. Instead of supporting and promoting Palliative Care, the services that can help patients who are suffering, some physicians believed Canada was premature in their decision to legalize MAiD. The concern is that the government placed more value on helping patients to die instead of finding ways to help them live and die well. Consequently, some physicians feel as though their role in the development of MAiD is to advocate for Palliative Care, for patients to have better access to it, and to ensure that Palliative Care remains a priority and is not overshadowed by MAiD. Palliative Care should be at the fore of the public and government's attention so that it remains the standard of care for those with life-limiting illnesses and that MAiD does not become a default option.

> So, I think that loud advocacy for the fact that these requests are coming from intolerable suffering and the majority of Canadians do not have access to adequate Palliative Care, to address that suffering and all too often that suffering is in the psychosocial, emotional, spiritual realm versus necessarily just physical. So, I think Palliative Care needs to be developed in parallel with anywhere where this [MAiD] is being developed to say that we need to ensure that we are meeting these needs.[506]
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> …the most important thing is that Palliative Care still remains a priority. And that we continue to focus on the need to improve access to Palliative Care and improve the quality of Palliative Care all across Canada and be in every kind of institution.[507]
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> The main role of Palliative Care at large is to protect access to Palliative Care. To make sure that access to good Palliative Care is the priority. And that medical aid in dying is um, you know, remains as rare as it can remain.[508]

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[505] Woods et al., 2017.
[506] Interview 9.
[507] Interview 25.
[508] Interview 26.

While many physicians interviewed support MAiD as an option, every physician indicated the need for Palliative Care to have improved access, be better resourced, and held as the standard of care for patients with life-limiting illnesses. Many physicians suggested that Palliative Care should be a prerequisite for MAiD and that MAiD should only be considered if Palliative Care is unable to alleviate the patient's suffering or if the patient has voluntarily declined Palliative Care. These suggestions indicate physician’s belief and trust in the ability of Palliative Care to alleviate or mitigate suffering, and desire to ensure that patients have had the opportunity to have their suffering tended to and have explored every avenue before pursuing MAiD. Recall the story of the physician who saw a patient in the ER who was calling out to die. However, once Palliative Care saw the patient, and treated his pain and symptoms, the patient no longer wanted to die. Cases like this one is the reason why Palliative Care wants to be involved with all patients who have requested MAiD to ensure that the request is one born out of truly intractable suffering. However, in order for all patients to have access to Palliative Care as precursor to MAiD, physicians argued that Palliative Care needs to be developed in parallel with MAiD. Physicians stated that the attention needs to be shifted to Palliative Care and that Palliative Care should receive the same recognition, resources, and funding that have been given to MAiD.

Conclusion

This chapter has examined the role of Palliative Care in MAiD, and the views as to how the two should intersect from the CSPCP, CAMAP, and physicians. The differing views towards this role, as espoused by the CSPCP and CAMAP, highlight the ongoing debates around the relationship between the two practices. Since the Carter decision, the CSPCP has been consistent in its advocacy for a complete separation of MAiD from Palliative Care. Alternatively, CAMAP has called for the integration of MAiD and Palliative Care, recognizing the need for Palliative Care expertise with patients who request MAiD. The physicians who practice Palliative Care in Canada saw their involvement in the ongoing development of MAiD as necessary for the benefit of patients, providers, Palliative Care physicians, and the discipline of Palliative Care as a whole. As Palliative Care cares for patients who may request and receive MAID, and because Palliative Care should consult all patients who have requested MAiD, the need to reconcile the two practices is apparent. While some Palliative Care physicians provide and MAiD, not all do.

Similarly, while some MAiD assessors and providers are trained in Palliative Care, not all are. The need for expertise in both is the reason for the Collaborative Model; it allows for the two practices to collaborate in order to ensure that their patients receive expert care in both areas. However, this model does not achieve all goals of every party, namely it does not oppose the practice of MAiD nor does it appease the CSPCP's desire to separate MAiD from the practice of Palliative Care completely. The very nature of collaborating with MAiD is a limitation to my model because we know that those who *oppose* MAiD and believe that it should be separated from Palliative Care on this basis, will not agree with the idea of collaborating with MAiD providers.

While the values of all parties must be respected and understood, what is essential is that we shift our focus from exacerbating the dichotomy between the two and seeing how Palliative Care and MAiD can work together to provide their patients with the highest level of care and expertise. As one physician stated, "…too much energy has been spent differentiating and not enough energy has been spent, collaborating."[509] Thus, let us shift our energy to the Collaborative Model that will result in better care for patients at the end of life.

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[509] Interview 30.

Chapter 8: How Should Palliative Care and MAiD intersect? A Collaborative Model

Introduction

We have now been presented with the views of two national organizations, the CSPCP and CAMAP, as to how Palliative Care should intersect with MAiD, as well as the perspectives of the Palliative Care physicians who are members of the organizations. The CSPCP has advocated for MAiD to be kept completely separate from Palliative Care in every domain. I have referred to this view as the Separation-Opposition Model. Alternatively, CAMAP suggests the integration of the two practices for the sake of patients, which I have named the Integrated Model. From the physicians, we heard that there are several roles they want to play in the development and provision of MAiD in Canada. Interestingly, the majority of physicians interviewed did not call for a complete separation from MAiD, nor did they believe that MAiD and Palliative Care should be integrated. Thus, neither of the models proposed by the organizations fit with what the physicians called for. Therefore, a new model is needed. Given the tension around how MAiD and Palliative Care should intersect, if at all, is rooted in conflicting, deeply held values and beliefs, it is unlikely that there will ever be a unanimous consensus as to how these two practices should relate to one another. However, a working model that allows us to move beyond the conflict in order to care for patients is needed. To do this, I propose the Collaborative Model; a middle ground between the separation-opposition and the Integrated Models.

The Collaborative Model will support the overarching goals of both organizations as well as the physicians who practice Palliative Care and MAiD. This model presents a new way of thinking about the interaction and relationship between Palliative Care and MAiD, and will support both practices to work together to care for their patients. This model recognizes each practice as distinct,[510] while highlighting how collaboration can benefit both Palliative Care and MAiD, their representative organizations, their physicians, and the patients they look after. Due to the limitations and scope of each practice, the reason for adopting the Collaborative Model is to support practitioners of each practice and the patients whom they care for by bringing together expertise in both Palliative Care and MAiD, and showing how the two practices can be mutually supportive.

The Collaborative Model

The Collaborative Model maintains the clear distinction between MAiD and Palliative Care, focusing primarily on Palliative Care, and having Palliative Care intersect or collaborate with MAiD services when MAiD is what the patient has requested, or when the limitations of Palliative Care have been reached. This model views each practice as separate, yet highlights the instances in which the two may benefit from collaboration, working jointly to support patients at the end of life. The Collaborative Model differs from the Integrated Model in the frequency and closeness of the two services' interaction. While Palliative Care should *always* be involved in the practice of MAiD because every patient who requests or receives MAiD will benefit from, or needs to be consulted by a Palliative Care practitioner (or, someone with a nuanced understanding of the practice), MAiD should not always be involved in the practice of Palliative Care because not every patient who is being cared for by Palliative Care will need or want MAiD. Since MAiD accounts for only 1.5% of Canada's deaths, the minority of patients receiving Palliative Care will request or receive MAiD.[511] (Consequently, most Palliative Care patients will not want or benefit from a

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[510] While some view MAiD as inherently part of Palliative Care, this model recognizes that Palliative Care is separate from MAiD. However, there may be instances when a Palliative Care physician who provides MAiD to their patient is acting as a Palliative Care physician and is considered to be providing Palliative Care.

[511] Health Canada. "Fourth Interim Report on Medical Assistance in Dying in Canada." *Health Canada*, 2019, www.canada.ca/en/health-canada/services/publications/health-system-services/medical-assistance-dying-interim-report-april-2019.html. Accessed 5 May 2020.

MAiD practitioner's expertise. Thus, Palliative Care as a discipline will not benefit from integrating the specialties in the same way that MAiD will.) However, a specific patient population receiving Palliative Care will request MAiD either because of personal values or because their suffering transcends modern medicine's current abilities. With this minority of patients, MAiD and Palliative Care can *collaborate* to support their patients at the end of life to ensure that their patients receive expertise in both areas. In this context, while there is close collaboration, the two practices are working together but remain separate.

How does the Collaborative Model differ from the Integrated Model?

The careful reader may be wondering how the Integrated Model differs from the Collaborative Model, and why the latter was proposed. This is a valid question, as both models posit similar recommendations as to how MAiD and Palliative Care should intersect. However, the distinctions that separate the two models are each practice's goals and the frequency in which they interact. These distinctions become clearer upon an examination and analysis of the terminology of their names.

The Integrated model, or the integrated relationship, as promoted by CAMAP, "encourages the integration of Palliative Care and MAiD."[512] When CAMAP suggests "integration" of the two practices, they are suggesting that Palliative Care and MAiD work together regularly, and become professionally intertwined. This suggestion is unsurprising because MAiD needs and benefits from the close involvement of Palliative Care. As previously discussed in this chapter, Palliative Care should be a prerequisite for MAiD to ensure that any patient who requests MAiD has had their

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[512] Canadian Association of MAiD Assessors and Providers. *Key Messages: End of Life Care and Medical Assistance in Dying (MAiD) February 2020*, 2020.

suffering thoroughly assessed, addressed, and alleviated to the best ability of the physician and modern medicine.

More specifically, MAiD needs an eligibility assessment, which includes an assessment of suffering, and such assessments require expertise that is most specific to Palliative Care. Accordingly, MAiD should not happen without first calling on the expertise of Palliative Care.

Furthermore, for consent to MAiD to be valid, it requires that the patient is fully informed of all of their options, including Palliative Care.[513] While any professional may inform the patient of the option of Palliative Care, for consent to be fully informed, the patient must be educated in what Palliative Care is, its aims, and how it can benefit the patient (and their family). As discussed previously, Palliative Care physicians (practitioners) are the most situated to inform and educate patients about Palliative Care.

For these reasons, we see that the expertise of Palliative Care is a necessary element of every potentially valid MAiD request. In this view, and from the perspective of CAMAP, MAiD and Palliative Care need to be integrated from the beginning, as MAiD benefits from being intertwined with Palliative Care because of their expertise and skillset, and what Palliative Care can offer to patients who request MAiD. The Integrated Model emphasizes a more consistent, enmeshed integration of the two practices, primarily advocating for MAiD to *become part of the practice of Palliative Care*. One interpretation of this integration is that all MAiD providers should, at the very least, be trained Palliative Care specialists, (even if they do not practice other aspects of Palliative Care). Further, MAiD training should be a standard part of Palliative Care education. Under this model, it would be expected that the Palliative Care physician would perform MAiD assessments, and may even provide MAiD, with the exception of conscientious objections.

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[513] *Carter v. Canada, 2015.*

Consequently, the two practices would exist under a single governing college and abide by common standards.

The suggestion from the Integrated Model that MAiD becomes part of Palliative Care is very different from the intention of the Collaborative Model that posits that Palliative Care and MAiD are separate practices that will overlap *on occasion* when a patient under the care of a Palliative Care physician requests or needs MAiD. When this happens, Palliative Care and MAiD will collaborate to provide expert care to their patient. However, the careful reader may be wondering what happens to the two models when the Palliative Care physician is a MAiD provider. Evident from the interviews, there are excellent Palliative Care physicians like Dr. Sandy Buchman, who are also MAiD providers. In cases where the Palliative Care physician is also a MAiD provider, the interaction between MAiD and Palliative Care would look less like collaboration and more like integration. This is a murky situation that deserves brief attention.

Until this point, the two models have focused on the general interaction between Palliative Care and MAiD and have not focused as much on the actual provision and provider. It should be noticed that the models proposed by all parties assume that the MAiD practitioner and Palliative Care practitioner are separate individuals. However, when the Palliative Care physician provides MAiD to their patients, the distinction between the two models becomes less clear, and the Collaborative Model becomes complicated. In their interviews, Palliative Care physicians who are also MAiD providers told me that, in theory, they did not view MAiD as part of Palliative Care and that MAiD was distinct from it, which supports the idea of the collaboration model, rather than the Integrated Model. However, they also noted that when providing MAiD to their patients, they did not view themselves as transitioning from being a Palliative Care physician to a MAiD provider, but viewed MAiD as a way to alleviate the suffering of their patient who had a terminal illness. On this view, it might seem like the physicians are supporting the Integrated Model. In these instances, physicians did not take off their Palliative Care 'hat' and become a MAiD provider but viewed MAiD as a continuum of care provided to their patients. In such instances, the physician did not collaborate with another specialty or physician to provide MAiD to their patient. Instead, they integrated Palliative Care and MAiD in order to care for their patient. In practice, where the MAiD provider is also a Palliative Care physician, the model looks less like a Collaborative Model and more like the Integrated Model where the physician provides a continuum of care. However, because the Palliative Care physician is providing MAiD does not mean that MAiD and Palliative Care are synonymous. To make this clearer, take, for example, a family physician who has been trained in obstetrics and gynecology. This physician might be able to deliver a baby. In doing this, they are providing a continuum of care to their patient. In this instance, the physician is employing the skills of an obstetrician and gynecologist (OB/GYN), but we would not say that family medicine and OB/GYN are the same. Despite the overlap between the two specialties, they remain separate because not all patients will need an OBGYN expertise. All women who require the expertise of an OB/GYN will benefit from the care of a family medicine physician. Admittedly, this is a murky distinction and, the lines between the Integrated Model and the Collaborative Model are less apparent when the Palliative Care physician is also the MAiD provider.

However, we can put this issue aside because the models for interaction between MAiD and Palliative Care were not designed for these instances where the physician is comfortable and skilled with providing Palliative Care and MAiD, and has expertise in both. Instead, the models were designed to support physicians and organizations that have reached their limits, either in professional skill or personal comfort. Specifically, the models were designed for MAiD providers who are not specialized Palliative Care practitioners, and Palliative Care physicians who are not trained in MAiD or are uncomfortable with or opposed to the practice.

To better understand the differences between the models it may be helpful to address real-life ethical questions from the perspectives of each model. By approaching some specific questions about the role of Palliative Care in MAiD and the intersection between the two practices, we will be able to parse out areas of similarity and difference between the three models, with specific attention to the collaborative and Integrated Models. In the majority of responses, we will see that the Separation-Opposition Model stands alone while the integrated and Collaborative Models posit similar conclusions. However, while the two models may reach similar conclusions, their reasons and intentions for getting there are different.

Does a Palliative Care physician have a professional and ethical obligation to raise the question of MAiD when discussing options at the end of life with their patients?

The CSPCP has adopted the Separation-Opposition Model because they are opposed to the practice of MAiD and want it completely separated from the practice of Palliative Care. The CSPCP goes beyond separating Palliative Care from MAiD in the sense that they disagree with the practice of MAiD, and that is why they want to be distanced from it. Thus, from the stance of the CSPCP, when considering if physicians have a professional and ethical obligation to raise the question of MAiD when discussing options at the end of life with patients, the society would say that physicians must ***not raise*** the issue because they believe that the practice of MAiD is wrong. In their Key Messages: Palliative Care and Medical Assistance in Dying (MAiD) published in May of 2019, the CSPCP stated that Palliative Care physicians should only be required to discuss MAiD as an option if the conversation is initiated by the patient. Otherwise, the CSPCP would argue that by initiating conversations about MAiD, the physician suggests or condones the practice, which the CSPCP remains staunchly opposed.

In not initiating conversations about MAiD, the CSPCP is trying to protect the practice of Palliative Care from any intersection with MAiD. As they consider MAiD to be fundamentally different from Palliative Care, they do not want their physicians practicing or engaging in conversations about it because they do not believe that it is the right option for patients under the care of Palliative Care. Another likely reason for this view is that the CSPCP is trying to protect conscientious objectors from engaging with MAiD on any level, even conversations.

To the extent that the Separation-Opposition Model denies that there is any obligation, it has several problems. First, it is unethical because it assumes that the patient knows that MAiD is a legal option and that they have the courage to raise the topic with their healthcare provider. This is troublesome for patients who are not aware that MAiD is a legal option and rely on their physician to inform them. Schuklenk argues this point when he states that physicians are the gatekeepers to healthcare, and services such as MAiD.[514] This also applies to knowledge about particular services and treatments. It would be unfair to assume that all patients have the same depth of knowledge about their rights and eligibility for MAiD as physicians. Assuming that all patients have sufficient understanding and knowledge about MAiD to initiate conversations about the practice with their physicians, places an undue burden and unreasonable expectation on patients.

Second, the stigma around MAiD combined with the imbalance in authority between physicians and patients creates a barrier to patients raising the question about MAiD or asking their physician for it. Patients may be worried that if their physician has not brought up the

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[514] Schuklenk, 52.

conversation of MAiD that they should not, and that they may be judged or offend their physicians if they broach the subject.

Third, while the CSPCP opposes MAiD and wants to keep it separate from Palliative Care practice and wants to protect their physicians who conscientiously object to the practice, neither is a reason to deny the patient access to information. Even if the CSPCP does not want any of their physicians to engage in conversations, they have a duty to support the patient in gaining access to information. Sections 11(d) of the CPSO's document on MAiD states that,

> …physicians who decline to provide MAID due to a conscientious objection **must** provide the patient with information about all options for care that may be available or appropriate to meet their clinical needs, concerns, and/or wishes and **must not** withhold information about the existence of any procedure or treatment because it conflicts with their conscience or religious beliefs.[515]

Finally, recall from the Ontario Court of Appeal case that concluded that where the physician's beliefs conflict with the patients' wishes to receive MAiD, patients' rights prevail. In this context, physicians would have a duty to call upon another physician's services to discuss MAiD with their patients.

As articulated by CAMAP, the Integrated Model would argue that physicians must discuss MAiD as part of the discussions around options at the end of life because MAiD is a part of the standard range of Palliative Care options. For the Integrated Model, the physician has the professional obligation to raise the option of MAiD because physicians are required to inform patients of their options for care. The fourth recommendation from CAMAP in their "Key Messages: End of Life Care and MAiD" is that MAiD is included in the goals of care discussion

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[515] College of Physicians and Surgeons of Ontario. "CPSO - Medical Assistance in Dying." *CPSO*, Dec. 2018, www.cpso.on.ca/Physicians/Policies-Guidance/Policies/Medical-Assistance-in-Dying. Accessed 8 July 2020.

for all potentially eligible patients. This suggestion highlights the need for MAiD to be integrated with Palliative Care. As such, proponents of the Integrated Model would argue that a Palliative Care physician has an obligation to initiate MAiD discussions with their patients to ensure that their patients are aware that MAiD is an option.

The Collaborative Model would also argue that Palliative Care physicians have a professional and ethical obligation to initiate discussions around MAiD. However, their justification for arriving at this conclusion is different from that of the Integrated Model. The Collaborative Model focuses on ensuring that patients receive expert care and information in all, specifically from Palliative Care and MAiD. The Collaborative Model recognizes the limitations of what Palliative Care may offer to their patient in alleviating their suffering. This is why this model would advocate for physicians to initiate discussions around MAiD because they are acutely aware of how Palliative Care can support patients, the limitations of care, and when those limitations have been reached. A potentially significant difference between the two approaches is the timing of addressing the MAiD conversation.

The Integrated Model would argue that discussions about MAiD and Palliative Care should coincide because, as previously discussed, the Integrated Model views MAiD as part of Palliative Care. However, it might be argued that the Collaborative Model would initiate discussions about MAiD if it were felt that Palliative Care was unable to alleviate the patient's suffering, or if it might be what the patient wanted. Whether the Collaborative Model discussed MAiD at the beginning of a goals of care discussion, or later on in the care of the patient is not as important as the fact that the model would say that the physician must initiate discussions in order to ensure that the patient has access to information and expertise in all areas.

For both the integrated and Collaborative Model, engaging in conversations about MAiD would not be viewed as *active* participation in MAiD, nor would engaging in conversations be viewed as condoning the practice. The purpose of the physician initiating the discussion is to ensure that the patient is aware of their options and how to access the care they want or need. For a physician to initiate a discussion about MAiD, it may be as simple as telling the patient that MAiD is an option and discussing eligibility criteria and the procedure. At the very least, the physician may ask another willing physician to speak with the patient about MAiD. Neither would be viewed as active participation because the physician does not provide the assessment or the procedure itself. It is also not to be viewed as complicit in the act because discussing MAiD as an option should be viewed as equivalent to discussions of any other treatment option available. However, it is recognized from the perspective of objectors that MAiD is not viewed as any other treatment option. Conceding this point, if the patient's physician conscientiously objected to the practice of MAiD, at best, their conscientious refusal would pertain to the referral. Even then, as the CPSO and Courts have stated clearly, the physician must support the patient to access another, willing physician's services.

Conscientious objection to a practice should not include discussions of it with a patient. There is an apparent difference between initiating a conversation about MAiD and referring a patient for the service. The former ensures the patient has the information they need to decide, whereas the latter is assisting the patient to access the service.

If a patient requests MAiD, do all Palliative Care physicians – including conscientious objectors – have a professional and ethical duty to continue to provide high-quality Palliative Care until death?

All three models would agree that all patients, regardless of their choices at the end of life, should have high-quality Palliative Care until death. Despite its views against MAiD, the Separation-Opposition Model advocates for Palliative Care and would want the patient to receive Palliative Care as long as possible. This is where the Separation-Opposition Model converges with the integrated and Collaborative Models. While the Separation-Opposition Model wants MAiD to be completely separate from Palliative Care and disagrees with the practice on a fundamental level, the model is based upon the belief that all patients have a *right* to Palliative Care. While the Separation-Opposition Model disagrees with MAiD, it would be inconsistent with their approach and belief system to deny a patient Palliative Care because they opted for MAiD. Similarly, the Collaborative Model would ensure that the patients receiving MAiD have Palliative Care until death because this guarantees that they are receiving expert palliatives care in combination with MAiD services.

The Integrated Model would also agree that Palliative Care would be provided up until the moment of death. The third point of their updated messages states that all patients who request MAiD should have Palliative Care up until the end. However, this model would ensure that this happened because Palliative Care would be integrated with the provision of MAiD. If it were not a Palliative Care physician who was providing MAiD, this model would advocate for a Palliative Care working alongside the MAiD provider until the moment of the patient's death.

Should Palliative Care physicians be required or expected to conduct MAiD assessments as part of their regular practice?

As assessments may be viewed as active participation in MAiD, the Separation-Opposition Model would insist that the Palliative Care physician object to being an assessor for MAiD. This model would go beyond supporting a physician to conscientiously object to being an assessor and state that the physician *should* object to assessing patients for MAiD, and insist that the physician provide the patient with an effective referral to a practitioner in a specialty other than Palliative Care. This position is rooted in the Separation-Opposition Model being opposed to the practice of MAiD.

The Collaborative Model would support the physicians to choose to participate as an assessor, but would not expect that a Palliative Care physician provide MAiD assessments as part of their practice. As the Collaborative Model recognizes Palliative Care and MAiD as distinct, it would not assume that a Palliative Care physician would provide or expect them to assess patients for MAiD. Instead, the Collaborative Model would presume that a Palliative Care physician would collaborate with a MAiD assessor to provide their patient with an assessment. As the foundation of this is to recognize limitations and to collaborate or call on another physician or specialty to assist when those limitations have been met. Thus, while the Collaborative Model would not expect or impose a professional duty to provide a MAiD assessment, it would expect the physician to collaborate with a voluntary MAiD assessor or provide an effective referral. As the Collaborative Model's goal is to respect and support physicians' limitations within each practice while ensuring that patients receive expert care, the Collaborative Model would not expect Palliative Care physicians to provide MAiD assessments. However, it would expect them to ensure that the patient received an assessment from a voluntary assessor.

The Integrated Model, wanting the two practices of Palliative Care and MAiD to be intertwined, would expect a Palliative Care physician to provide a MAiD assessment because if the two specialties were truly integrated then the Palliative Care physician would be trained to provide assessments, and there would not be a need to call in another party to do so. While the Integrated Model would expect the that the majority of Palliative Care physicians would provide at least the initial assessment for MAiD, it would respect physicians who conscientiously object to providing assessments. In their *Key Messages* (2019 and 2020), CAMAP stated that "All healthcare providers who do not wish to participate in MAiD should be respected and supported in their decision."[516] However, should a Palliative Care physician object to assessing their patient for MAiD, the Integrated Model would argue that the physician's objection must not impede the patient's access to care and that the physician must provide the patient with an effective referral. The eighth message in the 2020 policy speaks to this specifically. The policy states that should a physician object "to MAiD based on conscience and is unwilling to carry out a MAiD *assessment*, CAMAP strongly supports the professional requirement of an effective referral to a clinician known to provide MAiD or to a local MAiD coordination service."[517]

These ethical situations have highlighted the similarities and differences between the three models. We have seen that except for patients having access to high-quality Palliative Care until death, the Separation-Opposition Model stands alone in the majority of their responses. As this model wants Palliative Care and MAiD to be kept separate because they stand in opposition to the practice of MAiD, it does not agree with nor converge with the integrated or Collaborative Models in other areas.

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[516] Canadian Association of MAiD Assessors and Providers. *Key Messages: End of Life Care and Medical Assistance in Dying (MAiD) November 2019*, 2019.

[517] Canadian Association of MAiD Assessors and Providers. *Key Messages: End of Life Care and Medical Assistance in Dying (MAiD) February 2020*, 2020.

The integrated and Collaborative Models, while arriving at similar conclusions, diverge on the frequency and overall understanding of the relationship between the interaction of MAiD and Palliative Care. The Integrated Model sees MAiD and Palliative Care as inherently linked and need to work together regularly. This view seems to be borne out of MAiD's need for Palliative Care expertise when caring for patients who request or pursue MAiD. Conversely, the Collaborative Model holds the two practices of MAiD and Palliative Care as distinct, collaborating only when a Palliative Care patient requests MAiD or when a MAiD provider needs Palliative Care expertise. The Collaborative Model sees this intersection as infrequent but mutually supportive.

Why the Collaborative Model works

When the Supreme Court decriminalized MAiD in 2015, it is understandable why the CSPCP and many other Palliative Care physicians distanced themselves from the practice of MAiD. While the question of decriminalizing MAiD had been in the Courts for several years before the Supreme Court's final decision in February 2015, the decision to permit MAiD devastated many Palliative Care physicians.[518] In a single decision, the medical landscape for patients who are suffering with life-limiting illnesses, and for the physicians who care for them, was drastically changed.[519] This ruling worried many Palliative Care physicians because they were concerned that Palliative Care would be looked at to pioneer or be leaders in MAiD. After all, the Court's ruling affected Palliative Care's patient population. At the time, this worry was not unfounded because legislation had not been enacted around how MAiD would be implemented in

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[518] Woods et al., 2017.

[519] Ibid.

Canada. It was almost a year and a half after the *Carter* ruling that Bill C-14 received Royal Assent, and the guidelines and eligibility criteria for MAiD were set. During this time of uncertainty, it is understandable why Palliative Care physicians worried that MAiD would become part of Palliative Care, or that they would be asked to provide it. However, five years after the Supreme Court's decision, we see that MAiD has not become a (formal) part of Palliative Care, nor have the physicians who practice it been forced to provide MAiD to their patients.

In 2020, we know that any physician who does not wish to participate in MAiD cannot be forced legally to *actively*[520] participate. This was pointed to in *Carter* as well as in Bill C-14.[521,522] We also know that MAiD has not fallen under the umbrella of Palliative Care because MAiD providers hail from a wide variety of medical specialties. While some providers are Palliative Care physicians, many others come from specialties such as Family Medicine, Emergency Medicine, Internal Medicine, or Anesthesia. Therefore, the wide range of specialists qualified to provide MAiD and have chosen to participate indicates that Palliative Care has not been forced to take ownership or pioneer the practice, nor does MAiD belong to any one specialty. While Palliative Care physicians should have leading voices in the development of MAiD, they do not need to be leaders in the practice in terms of provision. In reality, the provision can practice that may be provided by any qualified physician who is caring for an eligible patient who requests it. Therefore, while the initial worry was that Palliative Care would be asked to take a leadership role with MAiD

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[520] *Active* participation includes assessing for or providing MAiD. The College of Physicians and Surgeons of Ontario and the Supreme Court of Ontario both require that any physician who conscientiously objects to providing MAiD must provide the patient with an effective referral, a referral to a willing MAiD practitioner. Providing an effective referral is not, legally, viewed as constituting active participation in MAiD.

[521] Citing *Morgentaler*, The Court in *Carter* highlighted that "…a physician's decision to participate in assisted dying is a matter of conscience and, in some cases, religious belief." While the Court did not want to "pre-empt legislative and regulatory responses to [their] judgment" they did state that in accordance with the *Charter* that the rights of patients and physicians will need to be reconciled (*Carter* at 132).

[522] In the preamble, Bill C-14 states that the Government is committed to respect the personal convictions of healthcare providers (Bill C-14, preamble).

(because Palliative Care cares for the patient population that is eligible for MAiD), we see that this has not happened. The reality is that MAiD is an option that may be considered or received by some patients who are treated by Palliative Care physicians. However, it has not become a mandatory part of the practice of Palliative Care, just as it has not become part of any other specialty in particular. MAiD is not a particular specialty of medicine but remains a practice that may be provided by Palliative Care physicians to their patients.

While MAiD has not become a (formal) part of the practice of Palliative Care, it is an option that some patients with life-limiting illnesses, and who are suffering, may request. As we know, Palliative Care helps to alleviate pain and suffering, improve quality of life, and help patients live as well as they can until they die. However, the unfortunate reality is that Palliative Care is not a panacea for all forms of suffering for all patients; there are some types of suffering, or patient experiences, for which Palliative Care is not enough. For example, non-physical suffering, such as existential suffering, is one type of suffering that Palliative Care (as well as every other specialty of medicine) struggles to alleviate. This area of suffering perplexes physicians because there is no single cure or treatment for it. Several physicians spoke to the limitations of Palliative Care to alleviate non-physical suffering.[523] As one physician stated,

> …that is something that I'm struggling with on a daily basis; is how to manage existential suffering in my patients…. It's a sort of an ethical challenge because we don't have a really good way to measure existential suffering. We don't have a good way to intervene in existential suffering.[524]

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[523] Interviews 11, 47.

[524] Interview 47.

Existential suffering may be a limitation for Palliative Care (and modern medicine in general). In some cases of existential distress, sedation may be used. However, the patient may not be eligible for sedation or it may not be what they want. Some patients may not want to be sedated; some patients just want to die. Considering the patient's wishes at the end of life is equally important. We know that some patients receive excellent Palliative Care and yet still request MAiD. Recall, from earlier in the chapter, when a physician stated that a patient might request MAiD, "…because of their personal, fundamental personality characteristics and values. And we need to respect that."[525] These types of requests should not be viewed as a failure of Palliative Care, but rather as the patient declaring that MAiD aligns more with their wishes and values at the end of life, or is how they want to die. This is where MAiD and Palliative Care can intersect. In instances where Palliative Care is unable to alleviate a patient's suffering entirely, or if Palliative Care is no longer what the patient wants, MAiD and Palliative Care can collaborate to provide the patient with the care and death that they want. In such instances, MAiD can support Palliative Care by offering another approach to care when the limitations of Palliative Care, or the practicing physician, have been reached.

Comparably, the safe development and practice of MAiD rely on the expertise and involvement of Palliative Care. As has already been discussed at length in this dissertation, Palliative Care physicians are experts in recognizing, identifying, and addressing suffering; they have an unparalleled depth of wisdom and knowledge about the types of suffering that might cause a patient to request MAiD. This extensive knowledge is what physicians who assess or provide MAiD need. They need to have the knowledge and understanding to be able to explore the patient's suffering adequately. When the physician hears a request for MAiD, instead of initiating a referral

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[525] Interview 48.

immediately, they need to explore *why* the patient is requesting MAiD. Those who assess for and provide MAiD need to have the wherewithal to look past the initial request to understand what is at the heart of the request for MAiD – that the patient is suffering so intolerably that they want to die. As Palliative Care is not yet part of the core curriculum, it cannot be assumed that all MAiD providers have the skills or competencies in Palliative Care, the skills and competencies that should be present in the provision of MAiD. It is this knowledge and skillset, and comfort in end of life care, that MAiD needs. This is where Palliative Care can assist MAiD – in exploring, understanding, and addressing the suffering of a patient who asks to die, and educating assessors and providers in these skills. There are three specific instances that highlight how Palliative Care can assist MAiD. First, MAiD needs Palliative Care because, as stated, Palliative Care physicians are best placed to assess for MAiD because of their expertise with the patient population that may request MAiD. Second, as highlighted earlier in the chapter, MAiD needs Palliative Care because a true request for MAiD must be made with full knowledge of Palliative Care and how Palliative Care can alleviate the patient's suffering. Palliative Care physicians are uniquely qualified to educate and inform the patient about Palliative Care and how it might be able to help them. Third, for many patients, MAiD comes after having had Palliative Care, and is viewed as part of the continuum of their care. For these patients, MAiD needs Palliative Care in order to ensure the seamless care for patients who have requested and are eligible to receive MAiD.

Having outlined, briefly, how the two practices can support each other, we can see how collaboration between the two practices can be mutually beneficial and may be able to reconcile the overarching needs of both the CSPCP and CAMAP and the physicians who belong to each organization.

In Further Defense of the Collaboration Model

The benefit of adopting the Collaborative Model is that it supports patients' needs, and the majority of Palliative Care physicians, and all MAiD providers. While it would not be supported by those who hold steadfast to the Separation-Opposition Model, we know that from the interviews, many of the Palliative Care physicians in Canada do not belong in this camp. We heard from physicians that most want Palliative Care to be involved with MAiD in some capacity. The Collaborative Model would support this.

The Collaborative Model supports those who want Palliative Care and MAiD to remain separate (but are not opposed to the practice) and support those physicians who favor the practice. In each instance, the Collaborative Model seeks to respect and support the personal and professional limitations of Palliative Care and MAiD providers, while also ensuring that patients have access to expert care in both areas.

While Palliative Care and MAiD are distinct practices that differ in their approach to care, the reality is that Palliative Care cares for patients who may request MAiD, and all patients who request MAiD who are not currently under the care of Palliative Care, should be consulted by a Palliative Care specialist. As such, we see the natural need for collaboration between the two practices because of their shared patient population. The Collaborative Model highlights how the two practices can benefit one another by working together. MAiD may assist Palliative Care in caring for patients whose suffering is intractable or beyond the limits and scope of Palliative Care, thus providing another option for patients whose suffering cannot be alleviated by traditional means. Comparably, Palliative Care is integral to the practice of MAiD to ensure that all patients who request MAiD have had their symptoms and suffering addressed to ensure that they are intractable and cannot be alleviated. Most importantly, the Collaborative Model ensures the seamless care of patients at the end of life, particularly those who are receiving Palliative Care and choose to pursue MAiD.

The Collaborative Model does not change what each practice does but reconceives of how the two can interact with one another, and how the relationship between the two practices can be viewed. This will not be easy for some Palliative Care physicians who, in their heart, believe that MAiD stands in contrast to what they believe. However, the Collaborative Model does not ask physicians to change what they believe their specialty to be. All it asks is that when a Palliative Care physician has reached the limits to what they can do or provide to their patients within their own heart, that they seek the support of another specialty to provide the care their patients need. Palliative Care will still care for patients as they always have, and MAiD has not changed that. While the legalization of MAiD changed the medical landscape, and the options for patients who have a life-limiting illness and are suffering, it did not change how Palliative Care physicians care for their patients. What was heard by every physician was MAiD had not changed the way that they care for patients and that they will continue to provide high-quality Palliative Care to all patients until the moment of their death, regardless if that death is natural or the result of MAiD. How the patient dies does not change the quality of care they will receive. We know that all patients can benefit from Palliative Care, and for many, it will be what they need and want to have a good life and a good death. However, there is a particular population of patients who will request MAiD to address their suffering, despite having had excellent Palliative Care. For these patients, Palliative Care may have been excellent and met their needs for a certain time, but their illness progressed to a point where Palliative Care could no longer provide them with what they need.[526] In these cases, MAiD will assist in giving patients the death that Palliative Care cannot offer.

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[526] Interview 16.

The Collaborative Model focuses on this, the needs of the patient, and asks us to change our thinking towards the relationship between Palliative Care and MAiD. The Collaborative Model does not purport that MAiD is part of Palliative Care in any way, or that it should be viewed as an extension. What it does promote is the collaboration of two distinct practices in certain circumstances to ensure seamless care for patients at the end of life and to ensure that MAiD is developed and practiced with the input of experts in suffering: Palliative Care. The Collaborative Model will help each organization and physicians to achieve their goals. For the CSPCP, it recognizes the separateness of Palliative Care from MAiD and promotes the need for Palliative Care in the care of patients who have a life-limiting illness and who are suffering. For CAMAP, it allows for the integration of Palliative Care in MAiD with patients who request MAiD, and supports the need for MAiD to be grounded in the expertise of Palliative Care. For physicians, it allows for their involvement at all levels from education in, and advocacy for, Palliative Care, to doing assessments or providing it. The Collaborative Model does not take away or detract from either discipline or ask them to change how they practice. What it does ask is to recognize instances where the two can overlap and work together for the benefit of patients and physicians.

The Collaborative Model and the Status Quo of MAiD Policies in Canada

So far, I have been arguing that the Collaborative Model is superior to both the Separation-Opposition Model and the Integrated Model. But which of those models most accurately describes *the status quo* of MAiD policy in Canada? Answering that question will help determine whether the Collaborative Model generates any proposals for policy changes, and if so, what those changes might be.

A look at the evidence surveyed throughout this dissertation suggests that the *status quo* of MAiD policies, specifically the inconsistencies between policies, across Canada does not reflect the Collaborative Model's goals or intentions. At the heart of the Collaborative Model is supporting patients to receive the care they want and need at the end of life while also respecting and protecting practitioners' boundaries and consciences.

Currently, most MAiD policies across Canada protect practitioners' limitations but do not support patients to access MAiD services *easily*, should their practitioner object. Ontario, Nova Scotia, and the Yukon, all require that objecting physicians or practitioners provide some form of effective referral by ensuring that the patient is connected with, or has their care transferred to, a willing and able provider in a timely manner. The North West Territories has a central coordination centre for MAiD, which, while allowing the patient to have access to resources, places the burden on patients to contact the coordination centre. Both Alberta and Quebec have a system that requires objecting practitioners to notify their managers or directors of their objection, which then places the onus on said manager or director to connect the patient with a willing and able provider. While this system may seem similar to an effective referral, the difference is the middle party or parties involved, resulting in a less timely referral to MAiD services. As discussed previously, the remaining provinces have not implemented policies or measures to support patients whose primary physician or practitioner objects to MAiD to be connected with MAiD services. This forces patients to navigate a complex medical system on their own.

The inconsistencies between MAiD policies, particularly those regions that have not enforced an effective referral policy has led to barriers to patients accessing MAiD and signals the need for provinces to adopt the Collaborative Model's approach in their policies. The reason for adopting the Collaborative Model is to ensure that patients who wish to pursue MAiD have expert care if their Palliative Care physician does not provide MAiD. It ensures that Palliative Care physicians who do not provide MAiD are not pushed past their boundaries. Thus, to ensure that all patients who want and are eligible for MAiD can access MAiD services, all regions should adopt a policy that centres around the idea of an effective referral. This will be discussed in more detail as a recommendation in the following chapter.

Conclusion

This chapter has discussed the Collaborative Model, an approach that seeks to bridge the current divide between the Palliative Care and MAiD organizations while supporting physicians and ensuring that patients can access expert care at the end of life. While the CSPCP wants to separate the practice of MAiD from Palliative Care completely, this is not prudent because every patient who pursues MAiD needs to be consulted by Palliative Care. Alternatively, the approach suggested by CAMAP that involves integrating the practices of Palliative Care and MAiD frequently does not work because Palliative Care does not always need the services of MAiD providers. However, for the patients who are under the care of a Palliative Care physician and who wish to pursue MAiD, the Collaborative Model works to support them to receiving expert care in Palliative Care and MAiD while protecting the boundaries or limitations of their physicians. Furthermore, we know from the interviews with physicians that they do not want to be separated entirely from MAiD nor do they wish to have Palliative Care integrated with MAiD. The Collaborative Model can support physicians to be involved with MAiD to the extent of their comfort.

While the Collaborative Model was proposed as a recommendation for organizations and physicians to reconceive the interaction between MAiD and Palliative, we also see that it is an approach that should be adopted by provincial policymakers for the delivery of MAiD. From the brief policy scan in Chapter 3, it is evident that each province has different policies for their expectations and requirements around the delivery of MAiD. While the provinces have adhered to the eligibility criteria and safeguards set out in Bill C-14, there are inconsistencies between provinces about who could deliver MAiD and the expectations of physicians for nurse practitioners who conscientiously objected to MAiD. Some provinces established an effective referral policy, while others had more lenient policies around supporting patients to access MAiD. These provinces have not taken measures to ensure that patients can access MAiD stand in contrast to the Collaborative Model's spirit and ideology. While respecting physicians' boundaries, the Collaborative Model ensures that patients are still able to access the care they need and want. It will be recommended in the following chapter that each province should craft a policy around requiring physicians or nurse practitioners who object to MAiD and provide their patients with an effective referral.

Chapter 9: Recommendations

Introduction

One of the overarching goals of this dissertation was to make relevant systems and policy recommendations that would support Palliative Care in Canada, and the physicians who practice it. To make relevant recommendations for Palliative Care, it was necessary first to better understand the physicians who practice it, their perceptions of the challenges they face, and how MAiD has impacted Palliative Care in this post-*Carter* world. The preceding chapters sought to provide the foundation on which these recommendations can be made.

During the interviews, participants were asked direct questions about what systems and policy changes would improve Palliative Care for physicians and patients. The first half of this chapter is devoted to the physicians' responses to these two questions, highlighting several themes that emerged. The second half of the chapter will use the findings of the study to propose specific systems and policy changes that will support Palliative Care. These recommendations are based on the cumulative findings of the study. They will present systems and policy changes needed to support Palliative Care in Canada better – the discipline as a whole, the physicians who practice it, and the patients who benefit from its approach to care.

What are the systems and policy changes that would better support Canadian Palliative Care physicians?

When asked what systems or policy changes would better support Palliative Care physicians across Canada, physicians offered a variety of responses. However, amongst the responses, 5 themes emerged. They were:

1) Better remuneration and payment models for Palliative Care physicians (20/51)
2) The need for (and, importance of) collegial support and opportunities for PC physicians to connect (10/51)
3) Increased funding and financial resources allocated for Palliative Care (including training more Palliative Care physicians) (9/51)
4) National standards or mandated core competencies for Palliative Care physicians (6/51)
5) Protected time for non-clinical work (5/51)

Each of these will be discussed in greater detail. It is important to note that the first section of the chapter is devoted to reporting on what physicians stated they needed to be supported in the future. As this section is based on the analysis of the interviews from physicians in the sense that themes emerged, the aim is not to analyze the validity or express agreement with the aforementioned support needs. Instead, the objective is to briefly highlight the support needs stated by physicians and their reasoning for citing them. Analysis and recommendations based on the responses from physicians will be in the subsequent part of the chapter.

Better remuneration/payment plans for Palliative Care physicians

Almost 40% of the physicians interviewed discussed the need for increased remuneration for Palliative Care physicians. They called for a payment model, such as an alternate payment plan (APP) or alternate funding plan (AFP), or salary, that would better reflect the value and quality of their work and not just for the number of patients that they see.[527] Presently, physicians feel disadvantaged because the current billing model reflects the number of patients seen and not the complexity or time spent with a patient. Unlike some specialties that can see multiple patients per hour and bill for each one, Palliative Care cannot. For example, discussing goals of care

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[527] Most physicians are paid through a combination of payment models, particularly due to their various roles. Clinically, some physicians may receive remunerations through Fee for Service, alone. However, other physicians have some form of salary or APP/AFP that also requires them to keep track of their billing.

discussions, or discussion about MAiD, can take several hours yet the physician is only allowed to bill one code for each patient visit.[528] Physicians also spoke to the complexity of the care that they provide, and the time that it takes to provide this care; time that is essential to the care and well-being of the patient. However, this time spent with each patient results in Palliative Care physicians seeing fewer patients than their counterparts in other specialties. As such, physicians feel disadvantaged by the status quo in billing and advocated for a salaried model that reflects their work (instead of fee for service)[529]. Two physicians spoke to this request:

> Up until 2 years ago our palliative care physicians earned less [money] in an hourly basis. I remember when the resources were very skinny. But they earned less in an hourly basis than they would if they went and taught first year medical students how to examine patients…So, **what would support palliative care physicians perhaps is a fee schedule that recognizes worth. I also think palliative care is not a fee for service medicine item. When I look at palliative care physicians, the ones that do it well are not trying to do it on fee for service, 'cause again it just leads to that: How many do I have to see in an hour to pay my overhead; to…?** You know. …There are so few physicians that go and do house calls because they have to take their office time, go and do house call, lose their income from their office, and still pay their overhead. **So, on a policy wide basis I think it's not just about money; I think that it is about recognizing the intensity of the work and the quality of the work.** And building in checks and balances so there isn't someone who's greedy and just, you know, taking the money and not doing any work for it, but I've never met a Palliative Care doc that I felt was really in that category anyway.[530]
>
> We need proper remuneration, especially for the types of visits that we do. You have to compare apples to apples when you're looking at how physicians are remunerated. **And you cannot compare, you know, a dermatologist who sees patients every 10 minutes to a palliative care physician who needs an hour and a half to do a consult. And you have to value that in a different way… and just an overall better recognition of how important this is for people, because, you know, not all of us are going to get heart disease. And not all of us are going to get a nasty cancer, but all of us are going to die**.[531]

What these physicians articulated was that they want their pay to reflect the "intensity and quality of the work" but also the fact that, unlike other specialties, they are not able to see multiple patients per hour. Some Palliative Care physicians might have a patient with a complex illness who takes

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[528] Interview 44.

[529] Fee for service payment model pays physicians per patient visit. As such, it favours physicians who have a high volume of patients. Alternatively, a salaried model pays the physician a set fee for the year regardless of the number of patients seen. This model favours physicians who do not see as many patients but spend more time with them, or have other professional duties to tend to that are non-clinical.

[530] Interview 37.

[531] Interview 43.

several hours to be seen, and therefore, the payment model should reflect and value that. While other specialties, such as surgical or obstetrics and gynecology, may also argue that they are unable to see multiple patients per hour and that some patients require several hours, their payment models and salary are much higher than that of Palliative Care physicians and often are based on understanding that providing adequate care to their patients requires more time.

Physicians also spoke to the after-hours, indirect aspects of their jobs that require time, but for which they are not financially compensated. It is common for most Palliative Care physicians to be on-call and take after hours phone calls, drive outside of workhours to fill out death certificates, and have teaching roles because all are part of being a Palliative Care physician. However, these duties are usually accomplished outside of clinical hours and, cut into the personal time of the physician.[532] As physicians already indicated that they have so little time, and need more hours in the day, any extra time they spend on professional tasks should be remunerated.[533,534] While this is not unique to Palliative Care, and is likely to be true of many other specialties, it was noted by Palliative Care physicians as an issue that exacerbates the problem of other under-pay issues. As such, physicians stated that increased remuneration is a change that would mitigate these issues.

Several participants concluded that the current billing model that recognizes the number of patients seen, might be equal across specialties but is not equitable. In order to be *equitable,* the salary of Palliative Care physicians needs to reflect the work that they do and not their patient volume. Therefore, physicians suggested that an equitable payment model such an Alternative

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[532] This is true of other specialties as well.

[533] It is accepted that this is not unique to Palliative Care.

[534] It needs to be kept in mind that this first section is highlighting what physicians said they needed. While having non-clinical duties that may not be paid for is not unique to Palliative Care, when asked what systems and policy changes Palliative Care physicians needed to support them, they stated payment plans that considered their non-clinical duties.

Funding Plan (AFP) might mitigate some of their financial concerns. In Ontario, an AFP is a contract between academic physicians, teaching hospitals, universities and the Ontario Medical Association that pays physicians a salary for a comprehensive set of duties that align with being a (Palliative Care) physician.[535,536]

> {chuckles} I would wish that we were essentially salaried. You know. And you can massage that in whatever way you need to, to try and make sure we're, that lazy people aren't going to palliative care… As a physician. Do I need to be doing more teaching? Do I need to be doing more palliative care? Do I need to be, you know…? And what are my interests in trying to match those things up? I think that's my skills. {chuckles} Right? So, I really feel that… Like, if I was honest about all of the things that I would change, I think that's one thing I would definitely change as a palliative care physician. I want an AFP.[537]

Physicians noted that a funding model like an AFP would allow for more flexibility to tend to non-clinical work, which ties into the fifth most cited system and policy change: protected time for non-clinical work. While the AFP or Alternate Payment Plan (other provinces) is not unique to Palliative Care, as it is available to other specialties as well, this change in payment is what was highlighted by Palliative Care physicians as something that would support them going forward.

The need for (and importance of) collegial support and opportunities to connect

As mentioned in Chapter 4, Palliative Care takes an emotional toll on physicians, and can be isolating. Particularly during times of distress (such as the introduction of MAiD), it was found

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[535] An Alternative Funding Plan (AFP) is a contract between academic physicians, teaching hospitals, universities, the Ontario Medical Association (OMA) and the Ministry of Health and Long-Term Care (MOHLTC) that sets out non-fee-for-service funding for a range of services and which aligns the interests of the parties by merging multiple funding sources for the remuneration of involved medical staff for clinical service, education, research and associated administration. In exchange for the merger of funding sources, the parties of an AFP agree to meet a comprehensive set of deliverables in clinical service, education, research and associated administration.

[536] Ontario Ministry of Health and Long-Term Care. "MOHLTC - Resource Manual for Physicians."*Ontario,*www.health.gov.on.ca/english/providers/pub/ohip/physmanual/pm_intro_toc/toc_iii.html#sec_6. Accessed 10 May 2020.

[537] Interview 30.

that Palliative Care physicians look to their Palliative Care colleagues for support.[538] In the interviews (as well as in those conducted in 2016 for a separate study), physicians identified their collegial relationships as vital to their wellbeing and their ability to continue to practice Palliative Care. Almost 20% of the physicians interviewed (10/51) articulated the specific *need* to connect with their colleagues at the provincial and national levels through conferences, but also at the local level within their own organizations and institutions.

> …we are very isolated. I think the Society of Palliative Care physicians has a big role, but I think it almost has to come from the outside, like outside of our immediate institutions. Oh, and I do see the Canadian Society of Palliative Care physicians as having a tremendous role. I have been calling for support groups for palliative care physicians since the maid law came in, and nothing has happened. I've asked at the University level and nothing has happened.[539]
>
> Yeah oh, I love the conference's that kind of get everyone together to talk and learn from each other because I think those are great… Those are certainly helpful.[540]

What these physicians highlighted was the value of being able to connect with colleagues and the real need to maintain these connections for purposes of resilience and general well-being. This need is particularly acute for those physicians who do not work in teams and practice alone; they rely on other opportunities, to connect with their colleagues, in order to stay in touch with what their colleagues are doing, but also for their own well-being.

However, participants noted that there are barriers for some physicians connecting with colleagues at in-person events such as conferences, because not everyone has the means to be able to leave their homes, their clinical practice, or to travel. For example, conferences that require travel may not be feasible for physicians who have families to tend to or busy practices where there is not coverage if they are away.

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[538] Woods et al., 2017.

[539] Interview 4.

[540] Interview 5.

> …but it's hard with a young family to make them when they're outside of Toronto.[541]

> I think, you know, when I speak about teams being very healthy; maybe it's just more opportunity to be with other palliative care physicians. So, perhaps a way of getting us together at more conferences, cause clearly you can't all go to the conference, right. So, some people go, and some people stay back. But it's difficult to find the time and the finances to go to conferences, but maybe exploring ways of doing… doing more of that.[542]

> Perhaps, on a system level Canada-wide, it would be nice if I knew our colleagues… my colleagues better. And I have to travel to do that. I mean, I do sign in to some of the webinars that CHPCA puts on…How to recognize that, you know, for me to go and take time away, I'm actually paying it out of my own pocket to go to the conferences. That some of that could perhaps be built into the work as sustainability and nourishment for the docs that are doing the work. Maybe Ontario has that worked out. I don't know. I think the larger the centre, the more the people… We try to do small little lunch and learns and, you know, try and introduce new things, new ideas, new ways of doing things, but um… It's hard to figure out how to stay connected.[543]

While physicians look forward to, and would like to attend, the large-scale conferences such Advanced Learning in Palliative Medicine Conference hosted by the CSPCP, for many, taking time away from work, family, and traveling across the country is a barrier to attending. As such, physicians called for smaller scale, more local events that would allow them to connect with their colleagues without the financial or time costs. Suggestions as to how this might be done will be discussed in the latter section of the chapter

Increased funding and financial resources allocated for Palliative Care (including training more Palliative Care physicians)

Palliative Care physicians cited the need for an increase in funding and financial resources devoted to (the improvement of) Palliative Care. Physicians spoke about the need for Palliative Care to be better funded in general, as well as increasing financial resources to be able to train new physicians, specifically. Interviewees suggested that Palliative Care would likely receive more

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[541] Interview 5.
[542] Interview 34.
[543] Interview 37.

funding if its national status was improved. For example, it was indicated that if Palliative Care was recognized as important as Cancer Care (for example) then funding would be more readily available.

> … if palliative care was considered as important as Cancer Care, then it would have a provincial mandate oh, there would be a provincial program, it would mean there'd be provincial funding… So, I think if Palliative Care has the same status as, for example Cancer Care, the cancer has probably the best one because everyone jumps on the cancer care bandwagon oh, you can't trip over someone who's not wearing a ribbon, and they're at all sorts meetings, and they've always got the ear of the governments because cancer is so important, if we had that kind of status that would be a really good thing for palliative care, in general. And what works for palliative care works for palliative care physicians.[544]
>
> …so, there's no push at all from within the ministry of health to support Palliative Care physicians.[545]

These physicians spoke to the need for Palliative Care to be recognized at the governmental level in order to gain more funding and resources. If the government understood that Palliative Care is valuable because the majority of people who die (not unexpectedly) could benefit from Palliative Care,[546,547] then more funding and resources would be allocated. With increased funding more training spots and positions could be created in order to increase the "manpower" in Palliative Care. An immediate effect of this would be increased access for patients and a decrease in the workload of the current physicians.

> So, the argument is that we can't train enough specialist to do the job.[548]
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> I'm sure some people would argue from a system planning and development level making sure that we have enough specialists to build up the capacity of areas that are in deficit of palliative care resources would be

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[544] Interview 1.

[545] Interview 4.

[546] Canadian Institute for Health Information. *Access to Palliative Care in Canada*, 2018, 9.

[547] The document, *Access to Palliative Care in Canada*, published by the Canadian Institute for Health Information reports that between 62-89% of all non-unexpected deaths could benefit from a Palliative approach to care (p.9).

[548] Interview 11.

> another one***. So, you know, with that obviously comes funding and human resources***, but I think that that would be ideal.[549]
>
> I think from a [system's perspective] …So, more physicians trained in palliative care, really.[550]
>
> I would say we need more training spots… For physicians, even if we had some short-term funding for extra positions so that we can increase our manpower to do some of this much needed work is really important.[551]

What physicians called for was the need for more funding to be dedicated to Palliative Care, specifically so that funding may be allocated to training more physicians. However, physicians indicated that this will only happen if the Ministry of Health recognizes the value of Palliative Care, and considers it to be equally important as Cancer Care.

National standards or mandated core competencies for Palliative Care physicians

Physicians recognized that while training more Palliative Care physicians would improve the state of Palliative Care, training more specialists, alone, is insufficient. What Palliative Care physicians suggested is a system change that requires national standards for Palliative Care and core competencies to be met for all trainees. Until recently, there has not been a mandated set of standards or core competencies[552] for Palliative Care physicians. Two possible reasons for this is that Palliative Care is a relatively new specialty that only received accreditation by the Royal College of Physicians and Surgeons in 2017, and, as a result, is not part of the core curriculum in medical schools.

Before Palliative Care became a recognized specialty by the Royal College, there was not a set of standards or competencies that every physician training in Palliative Care had to meet. Recall, Palliative Care was only introduced to Canada in the 1970s by Balfour Mount. Therefore,

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[549] Interview 31.

[550] Interview 39.

[551] Interview 40.

[552] Core Competencies are skills that are deemed to be essential for having for that particular discipline of medicine.

any of the physicians who began their practice of Palliative Care in the 1970s and 1980s, when Palliative Care was still in its infancy, learned about Palliative Care "on the job," and through informal means because formal education in Palliative Care did not exist at the time, and core competencies had not been yet established. However, competencies in Palliative Care are beginning to be recognized; competencies that every physician working in Palliative Care should have. As such, physicians are calling for the standardization of training.

> I think having a framework that establishes expectations for care and having a competency framework that establishes expectations within disciplines is important. Because once you have the competencies, hopefully people will work towards those.[553]

There are many examples of core competencies that have been established in Canada. These include but are not limited to those from the Educating Future Physicians in Palliative and End-of-Life Care (EFPPEC) group,[554] the Ontario Palliative Care Network,[555] or the British Columbia Centre for Palliative Care.[556] All of these organizations have devised some form of competency framework for their physicians and healthcare trainees. Thus, participants are calling for the development of a national framework for Palliative Care to ensure that all Canadian Palliative Care physicians have the same basic skills and competencies. If there are required competencies then it can be trusted that everyone trained in Palliative Care has the same skillset and will provide safe care to patients.

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[553] Interview 40.

[554] Educating Future Physicians in Palliative and End-of-Life Care. *Palliative Care Competencies for Undergraduate Medical Students in Canada*, 27 June 2018.

[555] Cancer Care Ontario, and Local Health Integrated Network. *The Ontario Palliative Care Competency Framework A Reference Guide for Health Professionals and Volunteers*, 2019.

[556] British Columbia Centre for Palliative Care. *Inter-Professional Palliative Competency Framework FINALIZED*, 21 May 2019.

Protected time for non-clinical work

The fifth most cited suggestion for systems change was the need for protected (professional) time to tend to non-clinical duties. Palliative Care physicians are responsible for more than caring for patients; they have non-clinical roles that include teaching, chairing committees, being board members, writing policy, and research. However, very few physicians have protected time that allows them to tend to these duties. Therefore, the result is that physicians end up having to fulfill these obligations on their own time, and often without pay.[557,558]

> **We have a huge role in education and research and not just clinical work. And so, we need to actually have protected time to do all those non-clinical activities, which are going to improve patient care and allow us to build capacity for those primary care providers.** And so, there's a lot of ARPs like the one I moved from in Alberta. It's 100% clinical. So, I had to keep reducing my FTE over the last 5 years. I was down to 70%. So, I was getting paid for 70% job and doing all my other stuff for free. So, to have roles and salaries that reflect the… all of that work, like, at least I mean, I think… At least people should have 30% protected time to do non-clinical work, which is essential for palliative care.[559]
>
> This is now me talking to you from my division head perspective. I haven't got a way to increase the number of palliative care physicians who have protected time to do the other pieces. I think we've got great clinicians. Personally, in our particular part of the country we've got a fantastic model. We're well resourced. We've got clinical care covered. We're able to spend the time we want with each person and family, where, you know, we're not so stressed that we're unable to function. We've got resilience. We have very low staff turnover, high retention. Like, we're good. **But where do we need to go next to support our specialties is that none of those people have protected time. So, every time we educate. Every time we write a policy. Every time we attend a policy meeting. Every time we research to… or do quality improvement to change how we do… We do all of that un… un… not just unremunerated, but also under or on top of what we're already doing**.[560]

What these physicians indicate is that by not having protected time to tend to their non-clinical duties, they are doing so on their own time on top of a full clinical load, and without pay. Recall,

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[557] This recaptures the need to change the current funding model to allow for Palliative Care physicians to have AFP's or to be salaried.

[558] Other physicians likely have the same problem. However, it is important to remember that protected professional time is what physicians stated they needed to support them going forward. Whether this is unique to Palliative Care is beside the point. Palliative Care physicians struggle with a lack of time and stated that protected time would support them.

[559] Interview 44.

[560] Interview 46.

in Chapter 4, physicians cited the lack of time as one of their greatest challenges to individual Palliative Care physicians. Therefore, physicians indicated they needed a change in the work model for Palliative Care physicians; a model that allows for non-clinical duties to be met as well as a salary that pays for the work that physicians have to do as part of their job, but is non-clinical. These non-clinical duties are essential for Palliative Care because they involve teaching learners (which tends to the need of training more Palliative Care specialists) and for research and innovation which not only advances Palliative Care, and improves patient care, but also allows physicians time to work on projects that they are passionate about.

What are the systems and policy changes that would better support Canadian Palliative Care patients?

When asked about systems or policy changes that would better support Canadian Palliative Care patients, physicians offered a variety of suggestions and needs. Interestingly, many of the themes that emerged from these responses were very similar to the responses that physicians gave when asked about the challenges that face Palliative Care in general, indicating that changes that would support Palliative Care would support patients, or vice versa. The policy and systems changes that physicians stated would better support the care of Palliative Care patients, are:

1) Increased funding to improve homecare and community care (26);
2) Improved access to Palliative Care (8);
3) Mandatory education in Palliative Care for all healthcare specialists (7);
4) Increased funding dedicated towards hospices and hospice beds (7); and,
5) Integrating Palliative Care with other specialties (5);

The first three policy suggestions (the need for improved homecare and community care, improved access to Palliative Care, and the need for other healthcare specialist to have basic competencies) have already been discussed in great detail in chapter 5. As such, this section will highlight that physicians identified these changes to support Palliative Care patients, but the reasons for why these changes are necessary will not be reiterated. The need for more funding towards hospices, as well as the need for the integration of Palliative Care into other specialties, are two of the top five identified changes needed to support patients have yet to be discussed. Accordingly, they will be discussed in greater detail below.

Increased funding to improve homecare and community care; 2) Improved access to Palliative Care; and 3) Mandatory education in Palliative Care

The need for improved homecare and community care, or more funding allocated to them, improved access to Palliative Care, and mandatory education in Palliative Care are not new challenges or needs identified by Palliative Care physicians. Each one of these has been discussed at length either in Chapter 4 or earlier in this chapter. The reasons for the need to improve homecare/community care, access to Palliative Care, and training in Palliative Care for other specialties did not change throughout the interviews. However, when asked about the systems and policy changes needed to support Palliative Care patients, physicians once again identified these three issues as changes to systems and policies that would benefit and support Palliative Care patients.

Increased funding dedicated towards Hospices and Hospice beds

Seven physicians spoke to the need to increase funding for residential hospices in the community. Their concerns around funding for hospices revolved around two basic ideas: hospices do not have enough government funding for maintenance and day-to-day expenses, and there needs to be increased funding to provide more hospice beds to meet the demand, and for low income or socio-economically disadvantaged areas to have access to hospice care.

Currently, residential hospices receive 20- 50% of their funding from the Ministry of Heath, and rely upon donations and community fundraisers to account for the remainder of their budget.[561,562] Usually, hospices are able to acquire funding or grants for the building to be erected as many donors want to invest in the building of the hospice. However, the struggle is in finding the funding to maintain the building, keep it running, and to provide essential services.

> …only 50% of their budget is maintained by the Ministry of Health so they have to come up with the operating budget. It's relatively easy to get money for a building or an elevator or an atrium, but no benefactor is going to give a donation to pay for nursing or Home Care or spiritual care.[563]
>
> … it's ridiculous that the hospice system isn't under the Healthcare System, yes patient care is covered by OHIP, and they're covering some of them, like 20 to 40% of the actual hospice cost but the majority is by the community.[564]

As one physician pointed out, the problem lies in having the community fund paying for the caregivers in the hospice, bills, or other costs that are not viewed as "exciting" to the larger donors. Therefore, the physicians want the operating budget of hospices to be provided by the Ministry of Health so that they are not reliant upon community fundraising to keep their doors open.

Physicians also requested that every area has a hospice, and that hospice beds need to be increased in order to meet the current demand. Moreover, it was noted that hospices are unevenly distributed in the country and that hospices tended to be located only in socio-economically advantaged areas.

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[561] Interviews 2, 12.
[562] Canadian Hospice Palliative Care. *Fact Sheet: Hospice Palliative Care in Canada*, 2014.
[563] Interview 2.
[564] Interview 12.

> But certainly, like, if every place had a hospice…[565]
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> I think that, you know, more… more hospice beds available… We just need more beds as well. You're supposed to have, I think, 10 hospice beds per 100,000. And we're nowhere near that.[566]
>
> There are no hospices at Jane and Finch or places like that. There are no hospices in Scarborough, straight up, like look where poverty is, and you won't find a hospice there, and actually that was a huge problem.[567]

What these physicians are calling for are more hospices (and beds) to be available, and for every area to have access to hospice care. Currently, hospices are built in well-populated, socio-economically advantaged areas, and are typically clustered together. Furthermore, physicians do not believe that we have enough hospice beds to meet the current demand of 7-10 hospice beds per 100,000 people.[568] Therefore, physicians requested that hospices receive more funding so that more hospice beds can be made available to all patients, irrespective of where they live. Similar to the reasons for improving homecare and paying homecare staff more, by funding more hospices and hospice beds, we allow for patients to remain in the community for their care at the end of life, and keep them out of the hospitals. Physicians stated that both patients and the healthcare system as a whole would benefit from residential hospices receiving increased funding.

Other specialties collaborating with Palliative Care

The collaboration of Palliative Care across other specialties will support the care of patients. Patients who require or would benefit from Palliative Care often have complex medical needs, and

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[565] Interview 38.
[566] Interview 43.
[567] Interview 12.
[568] Residential Hospice Working Group. *Environmental Scan for Strengthening Residential Hospice Care in Ontario*, 2015.

are usually being seen by other specialties. However, Palliative Care physicians noticed is that Palliative Care is not always, or typically, consulted for patients who might need it. This is to the detriment of both the patients and the members of their care team. It was argued that when Palliative Care specialists are not part of the discussions of care, seamless care is not provided.

> We're really a part of every specialty, if you think about it. Like, whatever you're dying from, whether it's cancer or heart failure, PD, whatever it is, we're always… Like, we're always there. So, it has… And we're in hospital. Wherever you go, someone is gonna need palliative care at some point. So, it should be a part of all the pathways of care. And, I find some people often forget that. … And then they have meetings, daily huddles together every morning… But then I had to kind of force my way in and say, like, "Don't forget about palliative care because a lot of your patients are gonna eventually need that. And we don't want them to be in a separate bucket of care, and then you to totally forget about us.[569]
>
> I think I would just like to see more palliative care input in patient rounds. You know, if there's gonna be a team meeting about patients and what to do in the moment of crisis, that Palliative Care maybe should be a voice in those conversations as opposed to leaving it to the internist and the intensivist and the folks who are just by way of their training devoted to trying to fix or mitigate the underlying medical contributors, rather than seeing the forest for the trees and acknowledging that there might be another way to do this that enables this family to recognize the dying for what it is, call the people in who need to be called in, and not to miss an opportunity when there are no do-overs basically.[570]

These physicians called attention to the need for other specialties to collaborate with Palliative Care for those patients with life-limiting illnesses. Some participants felt that Palliative Care is "forgotten about" which results in patients who have complex care needs being tended to physicians who may not have the same skillset and knowledge base as Palliative Care. What these physicians want is to be included in the care of patients by other specialties, so that their patients get the care they need the first time around.

Physicians also spoke to the discord that occurs when Palliative Care is not involved with other specialties, and the havoc it plays in trying to provide seamless care to patients. When other specialties do not collaborate with Palliative Care specialists to care for patients who would benefit

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[569] Interview 41.

[570] Interview 48.

from it, the result is multiple care plans being set up, or the patient having to see multiple specialists at varying times; neither of which improve patient care. What Palliative Care physicians want is to be involved in the plan of care for the patient, so that every patient has one plan instead of several.

> …integrated care systems where, in fact, people can set up a care plan for a patient versus every discipline having their own. And sometimes they actually fight with each other. {laughs} both physiologically and in terms of whose opinion is most important um politically. Truly having better integration would be important.[571]
>
> I think there should be a way to care for them that is much more integrated, so that they're not seeing six specialists in isolation who don't talk to each other, who don't inform the family, that don't… See, the problem is, with somebody who's got advanced illness, everybody is circling around saying, "It's somebody else's job to do the illness education." … So, I feel like integrating those folks together so that they empower each other, they actually do it as a team… 'Cause I don't do it alone either. I have to speak to the specialist and find out what the options are, what they're thinking, and I can do it. So, that's what I think we need for people with serious illness.[572]

Here physicians highlight the need for teams to collaborate because patients with life-limiting illness or pain needs are often complex and require the attention of multiple specialties. Collaborating with Palliative Care ensures not only that all needs of the patients are met, but that the care plans are coordinated between specialties. This is both efficient, and better for patient care.

Overall, physicians called for the other specialties to collaborate with Palliative Care to ensure that their patients receive the care that they need (the first time around), complex illnesses are not left to be tended to by physicians who are not skilled in Palliative Care, and that the care plans will be coordinated. Each one of these would improve patient care.

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[571] Interview 36.

[572] Interview 49.

Systems and Policy Recommendations

The previous section highlighted the physician's views towards the systems and policy changes that they believe would better support them as Palliative Care physicians, as well as those that would support Palliative Care patients. Grounded in the research findings and from what physicians spoke about in the interviews, the next section will propose systems changes for Palliative Care in general. These recommendations are meant to indicate or point towards systems or policy changes that will support Palliative Care improvement in Canada, Palliative Care physicians, as well as their patients. However, the level of research needed to support detailed recommendations for each change goes well beyond the scope of this thesis. Each recommendation could easily be the subject of its own study or dissertation. As such, the following recommendations are meant to highlight changes that deserve further attention or consideration. The eight proposed recommendations are:

1. Improve homecare by providing more hours to patients and stable positions for workers
2. Increase the salaries and benefits of Personal Support Workers (PSWs)
3. Remunerating family members who provide care;
4. Increase access to residential hospice care;
5. Increase education about Palliative Care at all levels;
6. Create more opportunities for physicians to connect and create a community of practice; and,
7. Palliative Care and MAiD organizations and physicians must respect one another and collaborate for their patients.
8. All provinces must implement policies that ensure patients can access MAiD

It should be noted that increasing the salary of Palliative Care physicians has not been included in the recommendations, despite it being the predominant systems change called for by physicians. While the salary of Palliative Care physicians compared to that of their colleagues in other specialties, is an issue that is worthy of attention and concern, particularly as it may pertain to recruiting new physicians, it is believed that increasing the pay of an already well-paid physician group[573,574] is not the best use of financial resources to support Palliative Care. The eight proposed recommendations are written to support *all* of Palliative Care as each of these recommendations will increase capacity for Palliative Care in some way. It is with the hope that medical bodies and government organizations will consider these recommendations and why they should be implemented.

Improve homecare by providing more hours to patients and stable positions for workers

From physician experiences and surveys, we know that at least 75% of Canadians want to die at home or in their community.[575,576] However, the reality is that only (approximately) 15% of patients get to do so.[577] The need to improve homecare was a common theme throughout the interviews; the inadequacy of our current homecare system was identified as a challenge to Palliative Care in general, and its improvement would support both Palliative Care physicians and their patients. Two issues that impede a patient's ability to remain in their home at the end of life are the lack of hours provided by homecare and the inconsistency in care due to high-turnover rates of homecare staff. If homecare is improved this will improve patients' quality of life by

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[573] A recent job posting for a Palliative Care physician at the University Health Network cited the successful candidate would be remunerated between $220,000-300,000 CAD. https://www.cspcp.ca/wp-content/uploads/2020/05/2020.05.19.PM-Physician-Posting.FINAL_.pdf

[574] According to physicians interviewed, the amount, and way, that Palliative Care physicians are paid compared to other specialties disincentivizes new physicians from joining the field. For example, in general, the average salary of ophthalmologists is $714,000 CAD per year, cardiologists $578,000, or internal medicine is $398,000 compared to Palliative Care physicians which average approximately $275,000 (Canadian Institute for Health Information. Physicians in Canada, 2016: Summary Report. Ottawa, ON: CIHI; 2017).

[575] Canadian Institute for Health Information. *Access to Palliative Care in Canada*, 2018.

[576] Interview 34.

[577] Ibid.

allowing them to remain at home for as long as possible, and will also allow for more effective use of healthcare resources.

Currently, the Community Care Access Centre (CCAC) gives each patient a maximum of 120 hours of homecare per month (formerly 80 hours), which is approximately 4 hours (formerly 2.5) per day.[578] Patients who have complex care needs therefore do not always have access to sufficient care to meet all of their needs, and the extra burden often falls to family members. However, family members are not always able to care for their loved ones. With shifting demographics and geography, smaller family sizes, and the geographical proximity between family members, families are not always able to provide the necessary care that patients need.[579] Furthermore, even if the family members are physically present, they have implications for having them provide the majority of care. For example, it is known that family caregivers are vulnerable to emotional, physical, and financial pressures, which may lead to caregiver burnout.[580] Additionally, this assumes that a patient has family members and that those family members are physically able to provide care. Imagine if a patient is a 92-year-old man whose only family is his 90-year-old wife. It is not difficult to see that this patient's wife would be unable to provide the care her husband needs. Therefore, patients who do not have family members who can care for them or do not have the requisite homecare support are often forced to go to the hospital out of sheer necessity.

Inconsistent or unreliable care is another reason why patients may end up in the hospital. Recall from Chapter 4 that there is a high turnover rate of nurses, PSWs, and homecare aids in the

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[578] Ministry of Health and Long-Term Care. *2014 Annual Report of the Office of the Auditor General of Ontario*, 2014.
[579] Framework on Palliative Care, 5.
[580] Ibid.

home and community settings. There are two reasons for this: 1) they earn less than their counterparts who work in institutions, and 2) their contracts unstable.

From the interviews, physicians reported that because institutions offer higher paying positions with benefits, they are often coveted and obtained by more senior caregivers with more experience.[581] As a result, the homecare positions are often left to new graduates or less experienced staff who do not want to work in the community, nor do they have the experience to care for patients with complex care needs.[582] Consequently, these care providers will take a job in an institution at the first opportunity. As such, the turnover rate for home care nurses is high, leading to inconsistent and less reliable care.

Another reason for high turnover rates is because most homecare workers are contracted through organizations. Previously, the Local Health Integrated Networks[583] had contracts with various service providers to homecare workers for patients who are in their homes or the community. However, if the organization changed or was no longer in charge of staffing home care workers to a community or organization, then the contracts are changed, which often resulted in the loss of jobs for trained homecare staff, consequently disrupting the consistency and reliability of care. Having new workers in the homes of patients regularly is difficult for the patient as they cannot develop a trusting relationship, but also for the physicians. The physicians indicated that they rely on having consistent, skilled workers in the home they can speak to about the patient's condition and care.[584] If the workers are always new, it is difficult for the physician to trust their assessment of the patient as the worker will not know the patient as well, and the physician cannot trust their assessment.

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[581] Interviews 3, 40, 44.

[582] Ibid.

[583] These have now been switched to Ontario Health Teams, and there are multiple service providers involved.

[584] Interview 3.

It is known that if patients are provided with Palliative Care in the home and community, they are 2.5 times more likely to remain in that setting, and are less likely to be admitted to the emergency room or intensive care unit or to need care in an acute care setting.[585] However, if patients do not receive the homecare that they need, from insufficient hours to unreliable care, often they are forced to go to the hospital out of necessity, despite not needing to be cared for in a hospital setting. Having patients admitted to hospital who do not need to be there is problematic for at least two reasons. First, because if patients would prefer to die at home, this means that they are not receiving the care they want. Second, because hospital beds are limited, and, therefore should be used by patients who need to be cared for in the hospital, and because the cost of a patient stay in hospital is exponentially more expensive than providing homecare. For example, in Ontario, the cost of homecare per person per day is approximately $42, whereas the average cost of a hospital bed is $842.00.[586,587] Financially we can see that if the patient does not require care in the hospital, then it is a more effective use of our healthcare resources and dollars to support patients to be cared for in their homes or community, which is where they want to be.[588]

Therefore, home care needs to be improved in order to support patients to remain there. Thus, it is recommended that the Government increase the budget of homecare in order to provide patients with more hours and to ensure that the staff who work in the homecare setting earn commensurate wages and benefits to those who work in an institution. Homecare hours be should be increased so that patients have more hours if they require them. As mentioned above, the average cost of home care is $42 per day in Ontario. Even if that number is quadrupled to provide

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[585] Canadian Institute for Health Information. *Access to Palliative Care in Canada*, 2018, 6.

[586] Home Care Ontario. "Facts & Figures | Home Care Ontario." *Home Care Ontario*, 2017, www.homecareontario.ca/home-care-services/facts-figures/publiclyfundedhomecare. Accessed 20 May 2020.

[587] This cost might be slightly higher in rural areas; however, it would still be less expensive than the cost of care in a hospital.

[588] Framework on Palliative Care, 24.

patients with four times the homecare hours, the cost is only $168 per day, which is less than one-fifth the cost of a hospital bed ($842). While the initial investment in increasing homecare hours might seem daunting from a financial perspective, overall, it is a cost-saving measure that will support patients to remain in their homes and will save valuable healthcare resources.

While adding homecare hours is a step in the right direction, patients and their physicians depend upon consistent, reliable, quality homecare staff. Patients need to be able to rely upon these staff to turn up, and physicians must be able to trust the information given to them by community caregivers. One way to ensure a higher rate of consistency and reliability is to have stable funding to the agencies to pay their workers better, and so that contracts are not always changing. By having consistent caregivers in the community, physicians will trust the information that they are told, and patients will trust the caregivers they have come to know. This will support patients to remain in their homes, will reduce hospital admissions and lengths of stays, which, in turn, will save valuable healthcare resources and dollars.

However, while increased funding is necessary, it is insufficient. There may need to be regulatory changes to make sure that the better funded care is integrated into the larger healthcare system in an effective way.

Increase salaries and benefits of Personal Support Workers

Currently, PSWs and homecare aids are not remunerated adequately for the work that they do in the homes of patients and care centres where they reside. Compared to their counterparts in institutions, they are paid less, and often do not have benefits, hazard pay, or the ability to take sick leave.[589,590] These workers are often female immigrants who are working multiple jobs just to make a decent living.[591] Nevertheless, these healthcare providers are doing vital work by caring for patients in their homes and community settings; this care reduces admissions to the emergency room, long-term care homes, or expensive hospital care. Despite the complexity and value of these workers' work, they do not receive the same benefits as those who work in institutions. However, it could be argued that those who work in the homecare setting should be paid just as much and have benefits because they often work alone, in challenging settings, and without the support of other staff. They are the one of the main reasons why patients stay out of the hospital. Therefore, it is important to ensure that skilled, confident caregivers stay in the community to care for patients. Because of these workers, our loved ones are cared for when their family cannot care for them, or when they cannot be in the hospital. Therefore, to ensure that we keep good, caring staff in the home and community setting, we need to support them to do their jobs well by paying them a decent wage that is commensurate to their counterparts in tertiary institutions, offering them the same benefits as sick leave and hazard pay. [592,593] By doing this, not only will we ensure that good staff remain in these roles, but we will recognize the value of their work and care that they provide to patients.

One way to support home care workers is to move away from the private agency model and become employees of the provincial Government, which would support them in having a better

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[589] Gee, Marcus. “Opinion: Let’s Value Our Personal Support Workers.” *The Globe and Mail*, 24 Apr. 2020, www.theglobeandmail.com/opinion/article-lets-value-our-personal-support-workers/. Accessed 26 Apr. 2020.

[590] Interview 10.

[591] Gee, Marcus. “Opinion: Let’s Value Our Personal Support Workers.” *The Globe and Mail*, 24 Apr. 2020, www.theglobeandmail.com/opinion/article-lets-value-our-personal-support-workers/. Accessed 26 Apr. 2020.

[592] Currently, home care workers in Ontario make approximately $16.50.

[593] Harmsen, Natalie, and Megan Sibley. “Home Alone? As Demand Outpaces Resources, Ontario Moves to Reshape the Future of Home Care.” *Catalyst*, cusjc.ca/catalyst/project/time-is-money-how-increased-government-funding-would-shape-public-home-care-in-ontario/. Accessed 10 May 2020.

salary and benefits. In Ontario, this has been put in motion by the Personal Support Services Ontario (PSSO), an agency designed to support home care workers.[594] Under the PSSO model, homecare workers would have proper training, better wages, and benefits if they are government employees. This will support workers, recognize their work, and improve retention. However, this change will come at a financial cost that needs to covered by the Canadian Government, specifically from the Ministry of Health and Long-Term Care. An investment in homecare will support the workers who care for patients in their homes and will save the government health dollars overall if patients are kept in their homes, and out of the hospital.

Remunerating family members who provide care

What has not yet been discussed in this dissertation is the idea of providing funding to family members who stay at home to care for their loved ones. Currently, family members or loved ones can apply for Compassionate Care benefits from the Canadian Government to be able to take time away from work to care for a loved one who is terminally ill. However, Compassionate Care benefits are only given for up to 26 weeks (6 months).[595] Many patients who require home-based Palliative Care, however, need care beyond six months; such patients may be facing a life-limiting illness for a year or more. Therefore, there is not funding allocated for patients who need care beyond six months.

In addition to the limitation of time that the benefits are given, the benefits do not account for the total amount of income lost from staying home to care for a loved one. Furthermore,

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[594] Ibid.

[595] Government of Canada. Employment and Social Development. *Caregiving Benefits and Leave: Eligibility*. 24 Aug. 2018, www.canada.ca/en/services/benefits/ei/caregiving/eligibility.html. Accessed 10 May 2020.

compassionate care benefits are not extended to those who are not working but are staying in the home to care for loved ones. For example, a stay-at-home parent, while they would not be taking a leave from a paid job, is taking on the roles of someone paid to care for patients in the home, such as a PSW or homecare aid.

Therefore, the recommendation is that benefits for family or friends and family be extended to be available for the entire time that the patient is alive and to be increased so that the caregiver does not acquire debt while caring for their loved one. Additionally, any person who is providing around care (for a significant amount of time) be included in the compassionate (leave) benefits from our Government. Hospital costs exceed any of those that are needed to care for patients in the home or the community. Keeping patients in their home, by supporting their caregivers, is a decision that is both financially responsible and compassionate.

Increase access to Residential Hospice Care

Improving access to residential hospice care by funding more hospice beds is a systems change that would support the care of patients in the community. This is a clear distinction from hospices. As one physician pointed out, there should be 7-10 hospice beds for every 100,000 people.[596,597] In Ontario, we are not meeting this target.[598] Currently, there are 271 hospice beds which is less than the estimated need of 755-1080 hospice beds needed for our population.[599] As such, more hospice beds need to be made available. However, this does not require building new hospices. Hospice

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[596] Residential Hospice Working Group. *Environmental Scan for Strengthening Residential Hospice Care in Ontario*. 2015.
[597] Interview 43.
[598] Residential Hospice Working Group. *Environmental Scan for Strengthening Residential Hospice Care in Ontario*, 2015.
[599] Ministry of Health and Long-Term Care. *2014 Annual Report of the Office of the Auditor General of Ontario,* 2014.

beds can be made available in existing structures or institutions. By using already available space would not only ensure improved access to hospice beds but would also allow for hospice beds to be set up in areas where hospices do not currently exist, such as existing structures or in patient's homes. As some physicians pointed out, hospices are not built in socio-economically disadvantaged areas. By focusing on creating more hospice beds available to care for patients, and by using existing spaces, or providing patients with a bed in their homes, we become more efficient with the use of our valuable, and limited healthcare resources, including saving healthcare dollars for other uses and would allow for patients in all areas to have access to hospice care. While the argument for homecare is that it is exponentially cheaper than being treated in the hospital, the reason for re-purposing existing spaces for hospices is because some patients require more than what can be provided in the home (particularly if there is a need for specific beds or bathing units) but do not need to be cared for in hospital. Moreover, the reason why many patients want to die in the hospice setting is that they are able to receive wrap-around care while being in a less clinical, more home-like environment. Therefore, by re-purposing existing spaces for hospice care we will save healthcare dollars from building new infrastructures while providing patients with an environment in which they can receive the care they need in an environment that feels more like home.

Similar to the investment need to improve homecare, the initial investment needed to create more hospice beds in existing spaces may seem daunting. However, it would save on building a structure that already exists, finding somewhere to build it, and saving on the cost of building hospitals and hospices.

Increase education in Palliative Care at all levels

Participants worried that a lack of education in, and understanding of, Palliative Care is common amongst patients, the public, policymakers, and even other healthcare professionals. This widespread misunderstanding is detrimental to all groups, including Palliative Physicians, because patients who do not know about Palliative Care (or, are afraid of it) do not request it, policymakers do not allocate funding because they do not understand the value of it, and specialist in other fields to not collaborate with Palliative Care or consult them too late. All of these negatively impact the practice of Palliative Care, its physicians, and the patients who might benefit from it. However, by educating all groups, Palliative Care, the physicians who practice it, and the patients they care for will benefit. It is clear from these concerns that it is important that the public, patients, and other healthcare professionals all have an adequate understanding of Palliative Care.

The Public

In order to support public education, Palliative Care needs to be given the same widespread attention as MAiD. The *Carter* ruling, the subsequent legislation, the creation of coalition organizations either for or against the practice, combined with the novelty of MAiD, gave medical assistance in dying much attention. While discussions around end-of-life care were brought into the spotlight, Palliative Care did not receive the same consideration as MAiD. MAiD was being developed at a surprising speed while Palliative Care was not. As physicians discussed, Palliative Care needs to be developed in parallel to MAiD. Therefore, in order for the public and policymakers to understand Palliative Care, there needs to be a concerted effort to raise the public profile of Palliative Care. Some mechanisms for achieving this are public campaigns such as the

Speak Up! Campaign that highlights and educates about advanced care discussions.[600] There is a national Advance Care Planning Day dedicated to educating the public about having discussions with their loved ones about what they want at the end of life. The Speak Up! Campaign uses social media, has created videos about advanced care planning, and has free conversation kits and packages designed to help the public understand advance care planning. If the Government of Canada created a similar platform and mechanism for Palliative Care, it would be a start in the right direction to educate the public about what Palliative Care is, how it is beneficial, who may benefit from it, and how to access it.

From the patient's perspective, understanding what Palliative Care is, how it can benefit them, and when it is implemented will equip patients and their family members with the knowledge to make more informed choices when faced with a life-limiting illness or when they are at the end of life. By educating the public about Palliative Care patients will be armed with the knowledge that Palliative Care can improve quality of life, and that Palliative Care focuses on helping patients to *live* well, and is not just about death and dying. Public education is critically important because the consumer (patient) needs to be aware of the treatment they can receive, and what to ask for. If the public is aware of the quality of care that Palliative Care can provide, they will "mobilize to demand it."[601]

When the public recognizes the value of Palliative Care, then they will demand it, and this demand will drive supply. From a policy-making perspective, if patients understand that access to Palliative Care is just as valuable as access to MAiD, then they will be calling on policymakers and legislators to enact Palliative Care as a right under the Canada Health Act. If Palliative Care

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[600] "Speak Up: Parlons En." *Speak Up* | *Parlons En*, www.advancecareplanning.ca/.
[601] Interview 31.

is recognized as a right, it will fuel more attention in the form of education campaigns and resources allocated for Palliative Care as a right for patients.

Other Healthcare Professionals

Educating other healthcare providers about Palliative Care is important because of the lack of Palliative Care education, amongst other medical specialties and allied health has created a multitude of problems for Palliative Care. It perpetuates the global misunderstanding of Palliative Care (named by several participants as a challenge), the discomfort and fear of clinicians caring for patients with life-limiting illnesses or who are at the end of life, lack of collaboration with Palliative Care from other specialties and involving Palliative Care earlier in the trajectory of a patients illness, and lack of physicians providing Palliative Care.

Consequently, it is imperative that Palliative Care training is improved and increased for all learners and staff with the expectation that all healthcare professionals have basic competencies in Palliative Care.[602] By educating other specialties about Palliative Care, there will be an enhanced understanding of Palliative Care, how it can benefit patients and when it should be implemented, it will, in turn, lend to improved collaboration and integration amongst other specialties (which was suggested by physicians), and other specialties knowing how to care for patients and when to call in a specialist. However, this needs to be implemented. Recognition from the Government that Palliative Care should be considered as mandatory training for all medical learners is insufficient; this recognition needs to be put into action and implemented as part of the Curriculum for all undergraduate medical learners across Canada.

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[602] Framework, 5.

What is recommended is that Palliative Care become a federally mandated part of the core curriculum of all Canadian medical schools. At the moment, Palliative Care does not have a designated curriculum, nor is it a mandatory rotation for medical students or residents. This lack of core training perpetuates the fragmentation of training in Palliative Care. For example, McMaster medical school has a 63-week clinical program that includes mandatory rotations in medicine, general surgery, orthopedic surgery, family medicine, anesthesia, psychiatry, pediatrics, obstetrics and gynecology, and emergency medicine.[603,604] The suggestion is that Palliative Care be part of the rotation. While it is argued that there is not enough time to create time for another medical rotation, but taking one day away from the other rotations to devote to Palliative Care would allow for almost two weeks (8 business days) of teaching time. While this is not a significant amount of time, it would be enough for medical students to be introduced to Palliative Care and gain clinical exposure to the discipline.

This suggestion is not a new idea as organizations such as the CSPCP have been calling for this for years. Furthermore, in 2018, the need for mandatory training in Palliative Care gained national traction when The National Framework on Palliative Care listed the need to,

> …develop national core competencies for palliative care specialists, and all other health care providers, including unregulated providers, such as personal support workers, etc., to equip future health care providers with the competencies and skill base to provide palliative care services appropriate to the needs of the population being served, [and] to support the development of mandatory palliative care courses as part of undergraduate health provider curricula.[605]

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[603] McMaster University. "Our Curriculum." *McMaster University*, 2015, mdprogram.mcmaster.ca/md-program/our-curriculum. Accessed 10 May 2020.

[604] Generally, each rotation is given 2-weeks for training. However, some rotations are allotted 6 weeks.

[605] Framework on Palliative Care, 18.

as priorities in Canada. Thus, the need for Palliative Care to be integrated into undergraduate medical schools has been recognized as important, yet it has not been done. This change needs to be mandated from the federal level that Palliative Care must become part of the core curriculum for all Canadian medical schools.

This mandatory training should extend into residency. All residents, regardless of specialty, should have a mandatory rotation (4 weeks) in Palliative Care.[606] Even if residents are not going to specialize in Palliative Care, most specialists will have to work with Palliative Care or collaborate care of their patients with Palliative Care. This rotation would allow them to understand what Palliative Care is, how they can provide basic palliative Care approaches with their patients, and when to consult Palliative Care physicians.

Create more opportunities for physicians to connect and create a community of practice

The emotional toll of Palliative Care, the hours, the everchanging landscape of medicine, combined with silo-ing, has many physicians feeling stressed, isolated, out of touch with their Palliative Care colleagues, and on the edge of burnout. In 2016 it was found that the professional relationships Palliative Care physicians have with their colleagues are a prominent source of resiliency.[607] As such, many physicians expressed a need and desire to be better connected with Palliative Care colleagues across the country and have more opportunities for interaction with them. While many physicians enjoy and look forward to the national conferences such as the Advanced Learning in Palliative Medicine conference hosted by the CSPCP, the International Congress on Palliative Care (hosted every two years in Montreal), and CAMAPs Annual

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[606] University of Toronto. "PGY-1 Entry Programs." *Department of Medicine*, 8 Oct. 2015, www.deptmedicine.utoronto.ca/pgy-1-entry-programs. Accessed 10 May 2020.
[607] Woods et al., 2017.

Conference on Medical Assistance in Dying, these not as frequent as physicians would like, and often difficult to attend due to work or family commitments. Therefore, in addition to the largescale conferences, Palliative Care organizations and institutions should collaborate to create local, smaller-scale opportunities for physicians to come together. Some examples of these may webinars, online teaching sessions, or web-based rounds that allow physicians to connect on a more regular basis, learn from one another, and engage in conversations from the comfort of their practices or institutions and without having a significant time commitment. While face-to-face interactions are preferred, there are creative ways Palliative Care clinicians can create a community of practice. Physicians called for this in the interviews when asked what supports they need going forward. The mere fact that the desire to have more opportunities to connect with colleagues across the country suggests that what is currently offered is insufficient. However, due to COVID19, we have witnessed institutions and organizations become more innovative in finding virtual means to connect people, and to learn from one another. For example, grand rounds that were once held in person are now done virtually and allow for individuals across the country to connect in, and engage via online questions.

Another example is CAMAP's annual conference that was held on April 30, 2020. Originally, the conference was supposed to be held in Toronto. However, the organization found a way for their research forum to be held online. Presenters gave their talks virtually, and registrants were able to ask questions via text or through their computer’s cameras after the presentation. While the virtual forum may not be equivalent to an in-person meeting, it did allow for a community of healthcare providers to come together, learn from another, and engage with each other. This is just one way that shows that it is possible to create means for physicians to connect, engage and learn in a meaningful way without having to travel or leave their practice or families.

The creation of more opportunities for Palliative Care physicians to connect, will facilitate education amongst Palliative Care physicians, foster innovation, and new ideas for the development and advancement of Palliative Care in Canada while giving physicians the human professional connection that they need. As Palliative Care can be emotionally taxing, it is imperative that physicians who are not part of teams, or who work in rural areas can connect with colleagues and know that they are not alone. While Palliative Care physicians are resilient and take pre-emptive measures to look after their wellness, they also realize that this is due to their connection with colleagues. By creating more avenues and platforms for a community of Care, the well-being of Palliative Care physicians and their ability to provide high-quality Palliative Care to patients will be supported.

Palliative Care and MAiD organizations must respect one another and collaborate for their patients.

The introduction of MAiD into Canada has caused significant divisions within the Palliative Care community, particularly as to how the two practices should intersect. Chapter 7 highlighted the diverse views on how Palliative Care and MAiD should converge, if at all. It explored the views of individual physicians who practice Palliative Care, along with a focus on the views of the national representative bodies for both Palliative Care and MAiD (CSPCP and CAMAP). While CAMAP and the physicians see the benefit of having Palliative Care be involved in the development of MAiD, even at the academic or legislative level, the CSPCP maintains that Palliative Care should remain completely separate from MAiD and that Palliative Care physicians should not be involved in the practice. While it is understood why the CSPCP has such strong views towards MAiD, maintaining the exaggerated separation between the two practices is no longer helpful, and may even be harmful. The reality is that MAiD is a legal practice in Canada.

Some patients receiving Palliative Care will choose MAiD, and some Palliative Care physicians assess for or provide MAiD. The overlap between the two practices is quite visible in the patient population and the physicians who practice Palliative Care. By perpetuating the divide between MAiD and Palliative Care we risk denying *some* patients the highest level of care and expertise, leaving them feeling unable to inquire about MAiD. We also risk physicians feeling alienated, and for Palliative Care to be dismissed from future discussions and decisions around MAiD in Canada. In order to ensure this does not happen in the future, the recommendation is that all physicians who practice Palliative Care and/or MAiD, and their relevant organizations must respect the expertise of the other and *collaborate* when necessary to provide patients with the highest level of care from each practice. Physicians who conscientiously object to the practice are not legally or professionally obligated to participate in the practice actively, and their beliefs are respected. However, it is for the benefits of patients, physicians, and the development of both specialties we reduce the dichotomy between Palliative Care and MAiD and collaborate. Whenever MAiD is considered, Palliative Care should be “at the table,” or in the room.

Effects on Patients

When the national representative organization for Palliative Care denounces MAiD publicly and states that their physicians should not be involved in the practice, the worry is that this silences patients from speaking up about their suffering or inquiring about MAiD with their (Palliative Care) physicians. If a patient receiving Palliative Care believes that MAiD is something that Palliative Care does not believe in, is "bad," or that their physician cannot assist them or speak to them, they may not ask their physician about it out of fear of repercussions or being judged. Patients with illnesses or suffering that would cause them to ask for MAiD are already vulnerable, and it takes a tremendous amount of courage and trust for them to ask their physician to help them die. Many physicians in the interviews, when asked how they respond to MAiD requests, viewed it as a "privilege" that their patients trusted them to engage in such an intimate conversation about their suffering and how they wanted to die, that they wanted the patients suffering.[608] Physicians also spoke about hearing MAiD requests as indications of suffering and an opportunity to address something that might have been missed or not yet alleviated. Either way, physicians viewed requests or inquiries about MAiD as opportunities to have deeper conversations with their patients, educate them, or address their suffering in another way. Thus, if we continue to keep MAiD completely separate from Palliative Care, we risk losing a part of this trusting relationship with patients. If patients do not feel comfortable discussing MAiD with their physicians out of fear or shame, we risk closing the door to potential conversations and opportunities to alleviate suffering.

Effects on Physicians

The CSPCP's stance towards MAiD, as well as the general view that MAiD and Palliative Care should not overlap, isolates and alienates good, caring Palliative Care physicians who have chosen to participate in MAiD, or who might consider it. Palliative Care physicians rely upon their collegial relationships, which includes professional associations like the CSPCP, for strength and resiliency. This became particularly acute when MAiD was decriminalized, and physicians were wading through MAiD and their thoughts and values around the practice. It was heard from all Palliative Care physicians, conscientious objectors, and conscientious providers alike, that they worried about being judged by their colleagues for their views around MAiD, and were most worried about losing their collegial relationships as a result.

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[608] Interview 16.

A recent article published in *Maclean's* spoke to Dr. Sandy Buchman (a prominent Palliative Care physician and now President of the Canadian Medical Association) about his decision to become a MAiD provider. Buchman spoke about his decision was not made lightly; it took him two years to reflect upon his values, faith, and practice of medicine to decide to become involved in the practice of MAiD and to provide it to his patients. [609] Despite knowing that providing MAiD aligned with his values and was consistent with who he was as a doctor, he still feared that his colleagues would not respect him or trust him because he decided to participate in MAiD.[610]

> I have a lot of colleagues I highly, highly respect in palliative care—I even worry about it now—and I just know how strongly opposed they are to medical assistance in dying being legal. I have total respect for their beliefs and values, and I think they are good people. Still somewhere in me is the fear that they will think I'm not a good palliative care physician.[611]

Dr. Buchman is not alone in these fears. It was found in the study in 2016, as well as in the study for this dissertation, is that for many physicians who thought they might decide to participate in MAiD were most worried that they would not be trusted by their colleagues, and would no longer be viewed as a good Palliative Care physician.[612,613] Like Buchman, how physicians decided their involvement with MAiD in any capacity was, and is, not black and white; it is dependent upon the changing medical landscape, their values, the context, and the wishes of their patients. Physicians

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[609] Proudfoot, Shannon. "The Doctor Who Took on Death." *MacLean's.* 15 August 2017.
[610] Ibid.
[611] Ibid.
[612] Woods et al., 2017
[613] O'Donnell, Caitlin et al., Who Am I and How Am I Doing? Professional Relationships as a Source of Identity and Resilience for Palliative Care Physicians. 22nd International Congress on Palliative Care. Montreal, QC. 5 October 2018.

spoke about how the decision to provide MAiD to a patient might "break their heart," but they would do so to support their patients if that is what their patient needed.

Therefore, when the CSPCP publishes statements, like their *Joint Call to Action* in 2019, that state that MAiD is in no part of Palliative Care, and that Palliative Care should not be involved, effectively, they are telling their members who might be MAiD providers or who are considering it that what they are doing is wrong or stands against the values of their representative organization. Telling physicians like Dr. Buchman or those physicians who would risk their own heart to support a patient, that what they are doing goes against their practice of medicine lacks compassion and does not represent the views of Palliative Care physicians across Canada. Physicians interviewed felt that the statements released by the CSPCP do not represent the majority of the views of their members, or Canadian Palliative Care physicians.[614] As a result, many physicians have felt angry, unsupported, and isolated by the CSPCP and, consequently, have left the organization. As one physician stated,

> I have not found the CSPCP very supportive, quite frankly about MAID. And that does upset me, and I know that there's… there are many other colleagues that have already left the CSPCP because of that.[615]

Here we see that the CSPCP's static and unyielding stance on MAiD has resulted in their members leaving the organization. By distancing themselves from MAID, and denouncing the practice, the CSPCP has alienated physicians who have chosen to participate or who are thinking about participation and who need the support of their colleagues and professional association.[616] As many

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[614] Interviews 27, 39.

[615] Interview 39.

[616] Several participants who provide MAiD said that they have felt alienated and villainized by the CSPCP for participating in MAiD and that they no longer have a professional organization. Many physicians discontinued their

physicians stated during their interviews, the current view of the CSPCP towards MAiD only represents a small percentage of physicians. It is not representative of Palliative Care physicians as a whole. Unfortunately, the CSPCP has taken away a support system for Palliative Care physicians who have chosen to participate in MAiD.

Effects on involvement in discussions and decisions around MAiD

By distancing themselves and saying that MAiD is not Palliative Care and that Palliative Care will not participate in MAiD, the CSPCP will close doors to invitations and opportunities for discussions about the ongoing development of MAiD in Canada; discussions that *need* the voice of Palliative Care physicians. As the physicians stated, Palliative Care does not have to be a leader in MAiD or design the discussions, but they do have to be part of the discussions, and in doing so, are not owning or condoning MAiD. What Palliative Care will be doing by being involved in ensuring that patients receive the best possible care, that those who are providing MAiD or caring for patients who will be receiving MAiD have the requisite skills, competencies, and knowledge, and will be providing knowledge and guidance to those who are designing policy and legislation around the practice. MAiD is only going to continue to develop in Canada as we already see legal challenges for the eligibility requirements. As one physician said, "…we are spending too much energy on fighting it when we should be collaborating."[617] Another (a conscientious objector) who said, "MAiD is here, like, get with it!"[618]

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memberships with the CSPCP after their statement against MAiD, and are left without a professional Palliative Care organization.

[617] Interview 30.

[618] Woods et al., 2017.

The benefit of including Palliative Care in the ongoing development of MAiD is that it can help shape the discussions around MAiD and the perception of Palliative Care. If the CSPCP is worried about the ongoing misperception of Palliative Care, they should take an active leadership role in educating others about what Palliative Care is. There is no one better suited to educate society and professional colleagues about Palliative Care than Palliative Care physicians themselves. Instead of distancing themselves, Palliative Care needs to be involved in the ongoing development of MAiD so that MAiD is developed with the knowledge of those who tend to this suffering day in and day out. Canada needs Palliative Care to continue to be involved in the ongoing development of MAiD for patients, physicians, and policymakers. As suggested in Chapter 7, the divide between the two specialties can be bridged through the adoption of the Collaborative Model: understanding how and when Palliative Care and MAiD can support each other, and not view the other as a threat or detraction from their practice. The Collaborative Model will allow for expertise in both Palliative Care and MAiD to be brought to the patient interaction. This would not force Palliative Care to be involved with MAiD per se but would ensure that the patient received Palliative Care and had the expertise of a Palliative Care physician while at the same time having a qualified MAiD provider. The Collaborative Model would allow the two fields to come together, which would support the care of patients, the physicians who care for them, and the development of the field.

In order for the Collaborative Model to work, both Palliative Care and MAiD physicians and organizations need to be open to collaboration. From CAMAP's statement about MAiD and end-of-life care, and from the Palliative Care physicians who are MAiD providers and members of CAMAP, we see that MAiD is open to Palliative Care. What is left is for Palliative Care, more specifically the CSPCP, to be open to MAiD. The CSPCP needs to recognize publicly that MAiD is a reality that some of their patients, despite having had excellent Palliative Care, will choose MAiD, and that some of their members are MAiD providers. Therefore, while it is understood that the CSPCP has deeply held beliefs about what they believe to be Palliative Care, they need to expand their views to be more inclusive for the sake of their patients and their physicians. As an organization that represents Palliative Care in Canada, they are obligated to ensure that their views and published statements represent the needs of their patients as well as their physician members' views. Therefore, the CSPCP should modify its stance on MAiD in recognizing that MAiD is a legal practice that patients may choose and may be provided by their physicians. The CSPCP must publish a statement that recognizes this publicly. In doing so, the CSPCP will support patients in their ability to speak about MAiD, support physicians who participate (thereby also maintaining their membership) and will invite discussions around MAiD. This will open the door to communications with the MAiD community and will begin facilitation between the two practices. By acting on this recommendation, the CSPCP will help to align the current relationship between Palliative Care and MAiD with the Collaboration Model.

All Provinces must implement policies that ensure patients can access MAiD

In Chapter 3, I reviewed the provincial policies on how MAiD is delivered, highlighting the differences, particularly in whether it can be self-administered, who can provide it, and the requirements of physicians (or nurse practitioners) who object to providing MAiD to their patients. This last difference regarding the requirements of (conscientious) objectors is important as it is pertinent to a patient's ability to access the care they need at the end of life, and consequently, the application of the Collaborative Model at the provincial and healthcare policy level.

As highlighted previously, there are inconsistencies between provinces regarding the expectations of physicians or nurse practitioners who object to providing MAiD to their patients. Ontario and Nova Scotia have created policies that require objecting physicians to provide their patients with an effective referral to ensure that patients are not faced with barriers to MAiD. By providing an effective referral, the physician (or nurse practitioner) recognizes a limitation to the type of care they are willing to provide, but supports the patient to access that care from another willing provider. While not explicitly collaborating with MAiD providers, in the instance of an effective referral, the physician is not condoning MAiD, but is ensuring that the patient is connected with an expert who can provide the care that they cannot. However, not all provinces have adopted this approach in their policies around MAiD.

Provinces such as Newfoundland, PEI, Manitoba, Saskatchewan, British Columbia[619,620621,622,623,624] that do not require objecting physicians or nurse practitioners to provide an effective referral create a potential barrier for patients to access MAiD. By not providing the patient with an effective referral, the physician or nurse practitioner places the burden on the patient to find a willing provider while having to navigate a complex healthcare system. For example, provinces such as Prince Edward Island or Saskatchewan only require objecting physicians to provide patients with their medical charts or information about MAiD. In small provinces such as Prince Edward Island, or in under-resourced rural areas in larger provinces,

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[619] British Columbia requires that objecting physicians provide an "effective transfer of care," which entails the objecting physician to advise their patient that other providers are available to them and that the patient's records are transferred.

[620]The College of Physicians and Surgeons of British Columbia. *Practice Standard: Medical Assistance in Dying*, 2020.

[621] The College of Physicians and Surgeons of Saskatchewan. *Medical Assistance in Dying*, 2018.

[622] The College of Physicians and Surgeons of Manitoba. *Standards of Practice of Medicine*, 2018.

[623] The College of Physicians and Surgeons of Prince Edward Island. *Policy on Medical Assistance in Dying,* 2018.

[624] The College of Physicians and Surgeons of Newfoundland and Labrador. *Standards of Practice: Medical Assistance in Dying,* 2017.

asking a patient to navigate the healthcare system for MAiD services is inequitable and jeopardizes their ability to access good care, as most patients are not capable of navigating a complex healthcare system to find or access the services that they need.

Furthermore, policies that do not require objecting physicians to make an effective referral assumes that the patient has the resources and the ability to seek out MAiD services. Consider, for example, a patient with a life limiting illness who lives in a small or rural region, such as PEI or northern Saskatchewan, and who is vulnerably housed or experiencing homelessness. The patient does not have access to resources such as the internet or a phone, and their physician is one that they see at a walk-in clinic. Or, a less extreme example is of an elderly patient who lives in the same area. This patient lives alone, does not have family, is not used to technology, and does not have a computer or smart phone. If either of these patients were to request MAiD, and their (clinic) physician conscientiously objects to MAiD and does not provide them with an effective referral, how will they access the service? According to the policies of provinces like PEI or Saskatchewan, the objecting physician is only required to give the patient their chart or information about MAiD. In this instance, how is either patient expected to navigate a complex healthcare system with little to no resources? Consequently, these patients need an effective referral because they rely upon their physician to help them to receive the care they need. As stated in the affidavits to the Court in the case of *Christian Medical and Dental Society of Canada v. College of Physicians and Surgeons of Ontario*, patients- by the very nature of their relationship to the physician- are at a disadvantage; they do not know how to navigate the healthcare system or access services in the same way physicians do. Moreover, patients who request MAiD are even more vulnerable because they are dying and—if eligible—are experiencing intolerable suffering. As Dr. Imrie puts it,

> Patients who find themselves in the position of seeking MAiD are often in the most vulnerable of positions, are very sick, and facing all of the physical, mental and emotional burdens and trauma associated with facing

> the end of their lives. During such a time, they are enormously dependent upon their doctors and the health care system for what quality of life they do have.[625]

Thus, it is unacceptable for provinces to burden patients to find a willing and accessible MAiD provider. Physicians or nurse practitioners who decline to provide MAiD should be required to provide patients with an effective referral. As a referral (as understood by the CPSO) does not imply being complicit in the act. Instead, a referral ensures that the patient can receive high-quality care for MAiD. Thus, to ensure that all patients who want and are eligible for MAiD can access MAiD services, all regions should implement an effective referral policy should practitioners object to providing their patient with MAiD services.[626]

While healthcare is provincially mandated, all provincial policies should have some version of an effective referral policy that requires objecting physicians or nurse practitioners to ensure that their patient is connected with a willing and available MAiD provider. Should a province be opposed to implementing an effective referral policy, an alternative is to emulate the North West Territories and create a central care coordination centre that the patient may contact if they wish to pursue MAiD. While a central care coordination system is not as ideal as having physicians provide patients with an effective referral (as it places the onus on the patient to contact the care coordination centre)it is preferable to forcing patients to navigate the healthcare system to access MAiD services, with only their records in hand. Whichever option provinces adopt, they are assuring that all patients who have a life-limiting illness and who are suffering so intolerably that they are requesting a hastened death are not left to navigate a complex healthcare system on

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[625] *Christian Medical and Dental Society of Canada v. College of Physicians and Surgeons of Ontario* at 54.

[626] While Quebec and Alberta have policies that require objecting practitioners to notify their manager or director or their objection, thus essentially requiring the manager or director to provide the patient with an effective referral, their policies are inefficient because they lend themselves to the creation of middle parties which inevitably increases the time it may take for a patient to be connected with a willing and able provider.

their own. By acting on the recommendation of creating a provincial policy that requires all objecting healthcare practitioners to provide patients with an effective referral or creating a central coordination system for MAiD requests, provinces will help to align the status quo of MAiD in Canada with the Collaboration Model.

Conclusion

This chapter has examined the systems and policy changes that Canadian Palliative Care physicians identified that they believe will support them and their patients. The changes that would support Palliative Care physicians included increased remuneration, the importance, and need for opportunities to connect with colleagues, increased financial resources for Palliative Care, mandated national standards for Palliative Care learners, and protected time to accomplish non-clinical work. For patients, recall that many of the changes that would support patients had already been identified in chapter 5 as challenges that Palliative Care physicians face. Therefore, we can conclude that increasing funding to improve home care and community care, improving access to Palliative Care, and mandating education in Palliative Care for all medical learners would support Palliative Care physicians and improve the care of their patients. In addition to these three changes, physicians identified increasing access to residential hospice beds and the integration of Palliative Care with other specialties as two changes that would also support the care of Palliative Care patients.

The latter half of the chapter recommended systems and policy changes that would better support or improve Palliative Care in Canada, including the physicians who practice it and the patients under their care. I recommended that access and reliability of homecare be improved, along with providing adequate remuneration and benefits to personal support workers and expanding the eligibility criteria and length of compassionate care leave and funding. Additionally, it is recommended that access to residential hospice care be improved by the Ministry of Health funding hospices and create more hospice beds to meet patients' needs in all areas. Each of these would better support the care of patients in the community, allowing patients to have an improved chance of remaining in the community and keeping them out of the hospital, where they do not want to be and would exhaust valuable healthcare resources. The last four recommendations were to improve education in Palliative Care for all healthcare workers with a focus on mandating it as part of the core curriculum in medical school and residency, creating more opportunities for Palliative Care physicians to connect with colleagues, for MAiD and Palliative Care organizations (namely the CSPCP) to collaborate for the primacy of patient care, and for provincial legislatures or colleges to create policies that ensure all eligible patients can access MAiD.

While the majority of the recommendations are not directly related to MAiD, they are indirectly related because by improving healthcare and the ability for patients to live well and receive the care they need, we provide an alternative way to patients to live and die well, and with dignity. By improving Palliative Care overall, not only we will support patients but will also alleviate some of the worries that physicians had around patients receiving MAiD due to their inability to access high-quality Palliative Care, which in turn may reduce some of the tensions between Palliative Care and MAiD.

These eight recommendations were written to improve patient care, support Palliative Care physicians, and contribute to the overall betterment of Palliative Care in Canada. It is with the hope that medical organizations and governmental bodies consider these recommendations seriously and implement them to improve Palliative Care and our health system.

Chapter 10: Conclusion

When the Supreme Court of Canada decriminalized MAiD in the landmark *Carter* ruling, Canada's landscape was changed legally, medically, and culturally, both for its citizens and physicians. While this legislative change had effects on many disciplines in medicine, it had particular effects on Palliative Care, because Palliative Care physicians care for the patient population at which the *Carter* ruling and subsequent legislation was aimed. In order to understand these challenges, I interviewed Palliative Care physicians from across Canada. I chose to interview Palliative Care physicians because of their distinct insights into the current practice of Palliative Care, the challenges it faces, and the systems and policy changes that are needed to support it. This dissertation examined the reasons for conducting this study, the interviews' findings, and the proposed recommendations to support Palliative Care in Canada.

In Chapter 1, I introduced the reasons for needing to understand Palliative Care physicians' perspectives on the issues and challenges that are currently facing Palliative Care and what changes are needed to improve and better support it in the future. I also discussed my reasons for engaging in this particular topic and study: my mother is a Palliative Care physician. Consequently, I grew up in the world of Palliative Care. For this reason, I approached this study and dissertation in a particular way, because supporting Palliative Care and its physicians are of personal and particular interest. Because of this close, personal connection, I was in a strong position to conduct this research and articulate the voices, experiences, and needs of Palliative Care physicians. The physicians, nurses, social workers, and other allied health professionals who practice Palliative Care, whom I consider my closest friends and family, were my motivation for this research and throughout the writing of this dissertation.

Chapter 2 introduced Palliative Care to educate readers about what Palliative Care is, what it is not, the myths surrounding Palliative Care, and how it became a medical specialty. Understanding the roots of Palliative Care and why it was created and the traditional understanding of aims and practice of Palliative Care, is essential to understanding why the advent of MAiD has had such an impact on the practice of Palliative Care and its physicians.

Chapter 3 examined the legal history of MAiD in Canada, going back to the original case of *Rodriguez* and then moving through both *Carter* rulings. Understanding the rationales of the Courts over the years, particularly as to why MAiD was prohibited, and subsequently, why the Court overturned the ban on it in 2015, is vital to understanding some of the ethical and medical issues that have arisen as a result.

Chapter 4 highlighted some of the ethical issues that have arisen from the introduction of MAiD, focusing on the moral significance between killing and letting die, conscientious objection, conscientious provision, access to care, as well as the concerns around widening of the current eligibility criteria for MAiD.

Chapter 5 provided a brief overview of the qualitative study that was conducted for this dissertation. It focused on the methods and the preliminary themes that emerged from the interviews. Chapters 6 through 8 go into more detail about the specific content and findings of the interviews.

Chapter 6 focused on the Palliative Care physicians, namely who they are, how they came to practice Palliative Care, what the practice means to them, and the challenges they face and their perspectives on the challenges facing Palliative Care.

Chapter 7 examined the intersection of MAiD and Palliative Care, highlighting the conflicting views from the national professional organizations, the CSPCP, and CAMAP, and the models (the Separation-Opposition Model and Integrated Model, respectively) that each espouses.

Chapter 8 builds on the perspectives of physicians uncovered during the interviews in order to propose a distinct model for the relationship between Palliative Care and MAiD, which I call the Collaborative Model. In this model, the two practices remain distinct, but also intersect in several crucial ways. I argue that there are several areas where the two must actively collaborate in order to ensure the primacy of patient care; this model avoids the pitfalls of both the separation/opposition model, which treats the two practices as entirely distinct and the Integrated Model, which does not sufficiently distinguish them.

Chapter 9 considered the physician's perspectives about what systems and policy changes are needed to support Palliative Care, specifically, its physicians and patients. In this chapter, I proposed recommendations that are designed to support all of Palliative Care. The careful reader will note that I did not include all of Palliative Care physicians' suggestions, specifically those needed to support physicians in the final recommendations. While these suggestions had merit and are undoubtedly important and worthy of further consideration, I did not feel that some of these recommendations would benefit all of Palliative Care.

I conclude this dissertation with the hope that medical organizations and government bodies will seriously consider the data collected from this research and the proposed recommendations. At the very least, I hope that these parties will understand why and how Palliative Care needs improvement and the areas in which this can be done.

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Appendix

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*No longer available on CAMAP's website.

Appendix

Eligibility Criteria for Medical Assistance in Dying

Bill C-14 would enact a new section 241.2 of the *Code*, which in essence sets out the criminal rules surrounding the provision of medical assistance in dying. New subsections 241.2(1) and 241.2(2) would set out the eligibility criteria for such assistance in Canada. Under the proposed legislation, medical assistance in dying would be available to a person who meets all of the following criteria (subsection 241.2(1)):

- being an adult (at least 18 years old) who is mentally competent ("capable") to make health care decisions for themselves;
- having a grievous and irremediable medical condition (as defined under subsection 241.2(2));
- making a voluntary request for medical assistance in dying which does not result from external pressure;
- giving informed consent to receive medical assistance in dying; and,
- being eligible for health services funded by a government.

A grievous and irremediable medical condition would be expressly defined under the Bill as (subsection 241.2(2)):

- having a serious and incurable illness, disease or disability; and,
- being in an advanced state of irreversible decline in capability; and,
- experiencing enduring physical or psychological suffering, due to the illness, disease, disability or state of decline, that is intolerable to the person and cannot be relieved in a manner that they consider acceptable; and,
- where the person's natural death has become reasonably foreseeable taking into account all of their medical circumstances, without requiring a specific prognosis as to the length of time the person has left to live.[627]

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Assessors and Providers

Association canadienne des évaluateurs
et prestataires de l'AMM

Key Messages: End of Life Care and Medical Assistance in Dying (MAiD) (November 2019)

Background

In June 2016, the Parliament of Canada passed federal legislation that allows eligible Canadian adults to request and receive an assisted death, adopting the term medical assistance in dying.

The Canadian Association of MAID Assessors and Providers (CAMAP) was established in 2017 to offer peer support, research and advocacy for all professionals involved in medical assistance in dying. Our mission is to:

- Support MAiD assessors and providers in their work
- Educate the health care community (and the public) about MAiD
- Provide leadership on determining standards and guidelines in MAiD provision

The goal of this document is to help elucidate CAMAP's position on end of life care, including the option of MAiD.

Key Messages

1. All end of life care should ideally be grounded in the provision of high-quality palliative care. If requested, MAiD should be integrated seamlessly into the end of life care the patient is receiving.
2. All MAiD clinicians should be familiar with palliative care.
3. MAiD should be included as an option in all end of life goals of care conversations with potentially eligible patients.
4. For patients wishing to pursue MAiD, CAMAP strongly supports full access to MAiD services, regardless of geography, facility or institution.
5. All health care providers who wish to participate in MAiD should have access to training and be respected, permitted and supported in the work of assisted dying.
6. All health care providers who do not wish to participate in MAiD should be respected and supported in their decision.
7. Conscience-based objection should not impair patient care. CAMAP strongly supports the professional requirement of an effective referral.
8. Recognizing the primacy of patient care and outcomes, CAMAP strongly supports the integrated work of palliative care and MAiD clinicians.