

“If Not Me, Then Who?”

**The Narratives of Medical Aid in Dying (MAiD) Providers and Supporters Around
Their Professional Identity and Role in MAiD**

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“I do not want to, but I am going to die; that is a fact. I can accept death because I recognize it as a part of life. What I fear is a death that negates, as opposed to concludes, my life.”

- Gloria Taylor

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Abstract

Medical Assistance in Dying (MAiD) became legally accessible to Canadians in 2016, bringing with it significant changes to the Canadian health care landscape. With legalization of MAiD, physicians, nurses and allied health care workers had to consider their own systems of values, beliefs and their professional identity and decide whether or not they would be able to contribute to this practice or participate actively in this new medical procedure.

I argue that health care professionals who participate in this practice create a professional identity that is intrinsically bound to the ethics and practice of MAiD, thus making it permissible for them to support and participate in the procedure actively. Moreover, I argue that this system of morals and beliefs has been accrued by these health care professionals across experiences and time that contribute to their capacity to participate in MAiD.

Hamilton Health Sciences (HHS) was the locus for this research. HHS encompasses a network of five hospitals in the Hamilton, Ontario area. Each hospital region in Ontario has a unique staff and values, and HHS is no exception. HHS houses the Assisted Dying Resource and Assessment Service (ADRAS) group, a team of uniquely skilled MAiD providers, assessors and health professionals who service the HHS patient community. It is this group that is at the center of this research. Through interviews with members of ADRAS, I determined that values of altruism, belief in self-determination and deep respect for patients and families are central to the individual and collective identities of this group. In light of this ethical stance, members of ADRAS have crafted complex professional identities both individually and as a collective that enable them to participate in MAiD in a complete and meaningful way.

Table of Contents

Acknowledgements.....	iv
Abstract.....	v
Table of Contents.....	vi
Chapter 1: Introduction.....	1
Chapter 2: Literature Review.....	18
Chapter 3: “We’ve Always Done This”, Allied Health Professionals and MAiD.....	33
Chapter 4: “Walking Alongside Patients”, Nursing and MAiD.....	48
Chapter 5: “If Not Me, Then Who?”, Physicians Who Provide MAiD.....	65
Chapter 6: Discussion.....	77
Chapter 7: Conclusions.....	89
Appendix I: General Interview Questions.....	93
Appendix II: ADRAS Interview Questions.....	95
Works Cited.....	96

Introduction

Initially, my research interests were focused largely on palliative care. Growing up in a region with limited health resources, I became interested in the ways in which people accessed acceptable palliative care that met their needs. I felt that the best way to pursue my interests in health, end of life (EoL) care and palliation was to pursue placement within the hospital system that handled sensitive topics of this kind. I applied and was a successful candidate for an internship in clinical and organizational ethics at Hamilton Health Sciences (HHS). The coincidence of my research and major changes to Canadian healthcare was fortuitous to say the least. 2016 would mark the year that Medical Assistance in Dying (MAiD) became legal in Canada. As a result of the 2015 Carter Case, the Supreme Court of Canada (SCC) determined that criminalization of MAiD was a violation of Charter Rights. Afterwards the Federal Government was given a year in which to introduce legislation permitting MAiD, which expired in February 2016. Starting in that month patients could apply to the SCC for permission to access MAiD, until June 2016, when Bill C14 legalizing MAiD was passed by the Federal Government. Through the kindness of my internship supervisor, Dr. Andrea Frolic, Director of Clinical Ethics, HHS I was offered the opportunity to explore the situation of healthcare providers who participated in MAiD in this changing medical and social context.

In the earliest days of decriminalization, I began attending meetings and briefings regarding how MAiD would be carried out in Hamilton. Starting in February 2016, assisted dying became accessible to Canadian patients on a case-by-case basis with permission from

the SCC. Patients needed to pay legal fees in order to have a lawyer bring their case to the SCC and advocate on their behalf. At this point, no cases at HHS had been brought forward. Within HHS, the creation of protocols and procedures for MAiD was developing quickly, in an effort to be prepared in the event that a case was to arise. Preliminary criteria for access to MAiD were outlined, and served as the basis for the development of a protocol for the procedure. The Director of Clinical Ethics determined that a team of qualified and capable health care providers was required in order to best resource and provide MAiD. Ultimately, an Assisted Dying Resource and Assessment Service (ADRAS) was conceived and constructed.

With the passing of Bill C14 by the Federal Parliament in June 2016, those seeking MAiD no longer needed to appeal to the SCC. The procedure became available to all patients who qualify under the Carter Criteria established by the SCC ruling. The Carter Criteria will be described below in the section on the history of MAiD in Canada. In June 2016, a symposium was held for health care providers within HHS as well as those in the community to discuss and develop competency with MAiD. A physician, researcher and provider of MAiD from the Netherlands, where MAiD has been legal since 1984, was instrumental in providing information on the procedure to health care professionals at the symposium. After the MAiD symposium, a training session was held for the ADRAS team in which the Dutch physician coached the team through scenario-based training for the purposes of developing individual capacity and skills to successfully undertake the many facets of the MAiD procedure.

In Hamilton, MAiD has been accessed both within the hospital and within the community and homes of the patients seeking this service. Perhaps the largest question to arise from the introduction of MAiD centers on the way that death is viewed by health care providers. How are the particular health care professionals who provide MAiD different in their understandings of their role and identity from those that abstain from or object to participation in MAiD? What factors have constructed and influenced the moral position taken with respect to MAiD by health care providers who are involved in this practice?

Research Objective and Thesis Statement

I argue in this thesis that it is the professional identities of health care providers that inform their capacity to participate in MAiD, rather than their personal, religious, or social identities. Accordingly, the objective of this research is to assess how professional identities are constructed among health care providers (HCPs) who either participate in or actively support MAiD in the Hamilton Health Sciences hospital network. In order to accomplish this goal, I set out to:

- 1) determine the impact of personal and lived experiences on the construction of professional identity,
- 2) explore how this construction of professional identity impacts the HCP's capacity to support and participate in MAiD, and
- 3) explore how HCPs construct and enact their values in their overall practice and specifically through the provision of MAiD.

MAiD in Canada

This section focuses largely on the involvement of physicians and other HCPs in the history of MAiD in Canada. Assisted dying in Canada has an extensive history, spanning twenty eventful years and culminating in legalization of this practice in all Canadian provinces. With an abundance of life-sustaining measures and technologies, the question of a patient's right to die in the face of a long protracted illness was raised in the early 1990's. The issue of access to medical assistance in dying was first brought in to the public and legal eye in Canada in 1992 with the case of Sue Rodriguez. Rodriguez was diagnosed with Amyotrophic Lateral Sclerosis (ALS), an irremediable and degenerative condition (Bereza, 1994). According to Rodriguez's case file, she was "rapidly deteriorating and she will soon lose the ability to swallow, speak, walk and move her body without assistance" (British Columbia Supreme Court [BCSC], 1993). Rodriguez, with the assistance of various advocacy groups based in B.C, brought her case for medical assistance in dying forward to the Supreme Court of Canada arguing that the current state of Canadian law prevented her access to "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 which is free from state interference, and basic human dignity" (BCSC, 1993). Rodriguez' case was ultimately overruled, in a decision that was very narrowly divided with five judges voting against and four in favor of her claim (Butler, Tiedemann, Nicol, & Valiquet, 2013). Rodriguez passed away with the assistance of an unknown doctor on February 12, 1994 (Ogden, 1994; Sumner, 2013).

Several years later, Dr. Nancy Morrison of Halifax, a Canadian respirologist, was accused of murder when she provided a potentially lethal dose of potassium chloride to a patient with esophageal cancer (Robb, 1997). The charges were ultimately dropped as it was deemed medically feasible that this patient had actually died from a cardiac arrest as a result of the significant volume of pain management drugs administered to manage their distress (Robb, 1997). Nancy Morrison maintained her innocence throughout the case, with her lawyer going so far as to state that "What this was is nothing more than a doctor making a judgement call that this person should be dying in comfort" (Robb, 1997).

While cases of assisted dying had been brought forward to various Canadian courts, in 1998 Dr. Maurice Genereux was the first physician legally prosecuted and found guilty of assisting in suicide following *Rodriguez v. Canada* (Butler, Tiedemann, Nicol, & Valiquet, 2013). Genereux had "prescribed barbituates for two HIV-positive patients who used them for suicide attempts, [he] was sentenced to two years imprisonment" (Sumner, 2013). Though there are cases of physicians hastening death and aiding dying prior to Genereux, he was the first to experience formal legal repercussions and his case set a precedent for physicians who endorsed assisted dying. In North America, Genereux's incarceration was followed by that of Dr. Jack Kevorkian in Pontiac, Michigan, for assisting in the death of patients (Time Magazine, 2011). Perhaps the most famous physician to participate in MAiD is Dr. Kevorkian, who provided devices that assisted in the suicide of approximately 130 terminally ill patients (Time Magazine, 2011). According to Kevorkian, "Obstructive taboos born of social morés, philosophical dogma, and ill-advised laws were responsible for earlier unnecessary martyrdom in the suppression of medical practices now considered

acceptable, such as abortion and birth control. The current situation with respect to planned death is just as agonizing, and again unnecessary” (Kevorkian, 1988). Due to his very public presence and his openness regarding euthanasia, Dr. Kevorkian was ultimately tried and found guilty and sentenced to prison (Time Magazine, 2011). Dr. Kevorkian was released from prison in 2007, and died in 2011 at the age of 83 due to a pulmonary thrombosis (Scheinder, 2011).

In 2014, Quebec passed the “dying with dignity” bill, or Bill 52, which permitted medically competent adults to access assisted dying if they were to experience intolerable suffering. This law extended this option to those who did not have a foreseeable death, and thus aligns itself much more closely than the 2016 federal legislation to the euthanasia laws that exist in Europe (CBC News, 2015).

The final case in Canada which influenced the criteria for MAiD created by federal legislation in 2016 was that of Gloria Taylor, joined by the family of Kay Carter and the British Columbia Civil Liberties Association (Chan, Sommerville, 2016). Kay Carter had left Canada to seek MAiD in Switzerland through Dignitas, an assisted dying organization in Europe (Chan, Sommerville, 2016). Her supporters argued that the necessity of travelling abroad to obtain physician assistance in dying was evidence of shortcomings in Canadian health care. Gloria Taylor, much like Sue Rodriguez, had ALS and was seeking assistance in ending her life should she lose the capacity to do so herself (Death with Dignity, 2016). Ultimately, the SCC ruled that, in light of changes to culture and law, the Rodriguez case did not set an adequate precedent and that preventing individuals from determining the timing and means of their death was unconstitutional (Chan, Sommerville, 2016).

In order to highlight the specifically Canadian aspects of MAiD, we must first explore the ways that MAiD is conducted in other parts of the world. Canadian MAiD guidelines were produced using the Dutch model of euthanasia, which emphasises certain criteria that must be met in order for a patient to be found eligible. The Dutch criteria as described by Rietjens et al, (2009) are as follows:

1. The patient's request is voluntary and well-considered;
2. The patient's suffering is unbearable and hopeless;
3. The patient is informed about his situation and prospects;
4. There are no reasonable alternatives. Further,
5. Another independent physician should be consulted; and
6. The termination of life should be performed with due medical care and attention.

Perhaps then, the core difference between the Netherlands and Canada is how MAiD began. In the Netherlands, MAiD was occurring years prior to legalization, and the first case that triggered the debate for legalization of MAiD was the case of Dr. Postma who, in conjunction with his wife (also a physician), assisted his terminally ill mother-in-law to die in 1971 (Sheldon, 2007). Sheldon states that "As the first euthanasia test case, it broke social taboos in a country with strong Christian traditions. It also reflected a new wave of concern among many young medical professionals about the limits of medical care and patients' self-determination" (Sheldon, 2007:320). Ultimately, a symbolic charge was laid and neither Postma nor his wife were convicted of murder. This case marked the true

beginnings of euthanasia in the Netherlands and the legal distinction between assisting in death and homicide.

The Complex History of Bill C14

Kay Carter, who had spinal stenosis (a painful yet non-terminal illness) was 89 at the time of her death, which she accessed in Switzerland in 2010 due to the criminalization of physician assisted dying in Canada at that time (BCCLA, 2015). According to the British Columbia Civil Liberties Association (BCCLA), which represented Carter with the involvement of her daughter Lee and her partner Hollis Johnson, “Kay was fiercely independent and determined to leave life on her own terms. Because she had to keep her plans to receive assistance in dying a secret, Kay could not even risk saying good-bye to many of her loved ones” (BCCLA, 2015). Gloria Taylor joined Carter’s petition to the Supreme Court, but before the case was decided, Taylor unfortunately died due to infection as a complication of her ALS in 2012 (Ruf, 2015). The Carter Case led to the decision by the Supreme Court, decriminalizing physician assisted dying in Canada. Subsequent legislation by the federal government in 2016, Bill C14, made physician assisted dying accessible for patients meeting the “Carter Criteria,” based on the Supreme Court’s decision. These criteria are also known as the eligibility criteria established by Bill C14 and include the following principles:

241.2 (1) A person may receive medical assistance in dying only if they meet all of the following criteria:

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

(Bill C14, 2016)

A grievous and irremediable medical condition is legally defined in Bill C14 as follows:

Grievous and irremediable medical condition

- (2) A person has a grievous and irremediable medical condition only if they meet all of the following criteria:
 - (a) they have a serious and incurable illness, disease or disability;
 - (b) they are in an advanced state of irreversible decline in capability;
 - (c) that illness, disease or disability or that state of decline causes them enduring physical or psychological suffering that is intolerable to them and that cannot be relieved under conditions that they consider acceptable; and

(d) their natural death has become reasonably foreseeable, taking into account all of their medical circumstances, without a prognosis necessarily having been made as to the specific length of time that they have remaining.

(Bill C14, 2016)

This bill is problematic in the sense that the definition of grievous and irremediable illness would have prohibited Kay Carter, for whom the criteria are named, from accessing assisted dying. Her spinal stenosis was incurable and was causing suffering that she considered intolerable, but her natural death was not reasonably foreseeable at the time when she requested assistance in dying. The requirement that death be “reasonably foreseeable” is one of the many features of Bill C14 that have been questioned by advocates of assisted dying since the passage of the Bill in 2016. Publicly, debate has also centered on the requirement for patients to be mentally competent to give informed consent to the procedure at the time when it is to be performed, which effectively prevents people with dementia from accessing MAiD, since advance directives are not permitted under the legislation. In addition, critics of Bill C14 have argued that the same criterion prevents patients with severe mental health disorders from accessing MAiD. Other critics point to the fact that the criterion specifying that only those over the age of 18 can request MAiD precludes mature minors from the possibility of obtaining legal assistance in dying. It is likely that changes to Bill C14 will be made over time, when legal cases are brought to the Supreme Court that set precedents for revisions of the law.

Terminology – Usage in this Thesis

Term	Definition
MAiD (in the context of HHS)	Medical Assistance in Dying, an act wherein an HCP provides sufficient medications intravenously to end a patient’s life if they meet the prescribed criteria
PAD	Physician Assisted Dying, a term that is no longer in use at HHS but was interchangeable with MAiD
AD	Assisted Dying, see MAiD*
Active Euthanasia	The act of an HCP directly ending the life of a patient through the manual injection of medications intravenously
Euthanasia	In this thesis, euthanasia refers to active euthanasia, and is used interchangeably with MAiD
Passive Euthanasia	defined as withholding or withdrawing a treatment that could potentially sustain life

Study Design

Narrative theory is the primary theoretical framework guiding the interpretation of the findings of this study. According to social theorists Ivor F. Goodson and Scherto R. Gill, “narrative is an inherently human way of constructing and communicating meaning and expressing human horizons of experience and aspiration. Narrative can be seen as discourse that articulates events, actions and agency within broad social, cultural and historical contexts” (Goodson and Gill 2011: 93). The experiences of HCPs that have led them to actively endorse and participate in a controversial practice like MAiD are communicated through their personal narratives, which in turn influence the enactment of their professional identities within medical culture. Discourse expressed through oral narrative formed the crux of this research. Medical assistance in dying challenges existing professional identities, which are often formed through personal and professional experiences of care, and through witnessing death and dying. Participation in MAiD leads

HCPs to construct new understandings of their role and identity as caregivers. It is evoking these experiences and conceptions of professional identity that constitutes the heart of this research.

Study Population

Hamilton Health Sciences is a large, tertiary care hospital network which encompasses five hospitals of varying specialties, and over 15,000 staff members. The population for this study consists of HCPs at Hamilton Health Sciences (HHS) who are members of ADRAS as well as other HCPs within the HHS system. ADRAS is a small clinical inter-professional team comprised of approximately 20 members. ADRAS is a unique team to HHS with its own protocols dedicated to the provision of MAiD. There are other teams devoted to MAiD in various health systems across the province, but the way they are operated and the dissemination of roles and responsibilities among team members varies on a system-by-system basis. In Ontario, there are approximately 200 physicians for every 100,000 people (CMA Canadian Medical Association, 2015), and approximately 700 nurses for every 100,000 people (RNAO Registered Nurses Association of Ontario, 2016). This leaves a ratio of approximately 2 physicians for every 7 nurses, or 1 physician to every 3.5 nurses. On ADRAS, there are, as of June 2017, 5 physicians and 4 nurses. In this study, there were 4 physician participants and 4 nurses, at a ratio of 1:1. This is not representative of the average Ontario physician to nursing population, but ADRAS is unique in terms of its inter-professional composition. There is limited data regarding the number of allied health professionals to physicians and nurses, as allied health is an umbrella term for multiple professional practices. For this study, fifteen interviews were conducted with 13

individual HCPs. Two of the interviews were re-interviews of nurses after they had participated in a provision of MAiD. Of the interviewees, four were physicians, four were nurses (one of whom supported but was not directly involved in MAiD), and six were allied health care professionals from a variety of backgrounds that either supported or had indirect participation in MAiD. Allied health care professionals included social workers, spiritual care providers, pharmacists, genetic technologists and psychologists.

Methods

Recruitment was conducted through snowball sampling, beginning with the ADRAS team and clinical ethicists in the Department of Clinical and Organizational Ethics. The interview questionnaire was designed by conducting a preliminary interview with a physician/clinical ethicist with the expressed goal of assessing professional identity. Questions that arose organically during this preliminary interview were assessed with the assistance of this physician/clinical ethicist for relevance and the questionnaire was assembled accordingly. This person was not interviewed formally for the purposes of their research, and their responses were not captured and used as data. This study was submitted to the Hamilton Integrated Research Ethics Board (HiREB) rather than the McMaster Research Ethics Board (MREB), as the only participants in this study would be health care professionals associated with Hamilton Health Sciences. This study was approved by HiREB in the summer of 2016. Participants were told that the data collected would be confidential, and when circumstances dictated, a pseudonym would be used in place of their name. No participants expressed wishes to be identified; however many expressed that they are not secretive about their involvement in this practice. There are certainly

challenges in maintaining the confidentiality of such a small population, and as such, gender neutral pronouns have been used throughout this thesis in order to maintain the confidentiality of their identities.

- a. Participant observation:** Participant observation involved attending meetings and training sessions and observing trends in conversation. In addition, participant observation involved attending the Assisted Dying symposium alongside various HCPs from the community and HHS. I also attended the ADRAS training session, where ADRAS members engaged in scenario-based learning to develop capacity related to MAiD provision with the guidance of a visiting MAiD provider from the Netherlands. The bulk of participant observation involved attending monthly ADRAS meetings and Assisted Dying Steering committee meetings.
- b. Interviews:** Fifteen interviews were conducted in total. Two of the fifteen interviews were re-interviews with two nurses from intensive care. Both nurses had been interviewed before assisting a physician in the provision of MAiD. I re-interviewed them subsequently to assess if there were differences in their moral position, degree of support for MAiD and professional identities before and after assisting in provision. Interviews were conducted with four nurses in total. Three of these nurses are active members of ADRAS and the other is a supporter of MAiD, a member of the clinical ethics committee, and an organ donation nurse who works with the Trillium Gift of Life organ procurement agency. Four physicians were interviewed, with varying backgrounds. Two of the four are semi-retired family physicians from the community who have been involved in varying capacities in

the HHS system throughout their careers and are now members of ADRAS. One of the other two physicians interviewed is an intensive care physician with a background in cardiology, and the last is an Emergency Room physician with training in palliative care. Both the intensivist and the emergency physician are currently employed full time with HHS. Five interviews occurred with allied health care professionals, four of whom belong to the ADRAS team. One interview occurred with a genetic technologist who is affiliated with the clinical ethics committee at HHS and who is based at the McMaster University Medical Center (MUMC). The allied health care professional members of ADRAS who participated in interviews include a pharmacist, a spiritual care provider and psychotherapist, a social worker who wears many hats as an allied health care professional at HHS, and a clinical psychologist. The role of ADRAS allied health care professionals is to support MAiD in many facets, including patient assessment, debriefing of clinical teams and provision of the medications vital to this procedure.

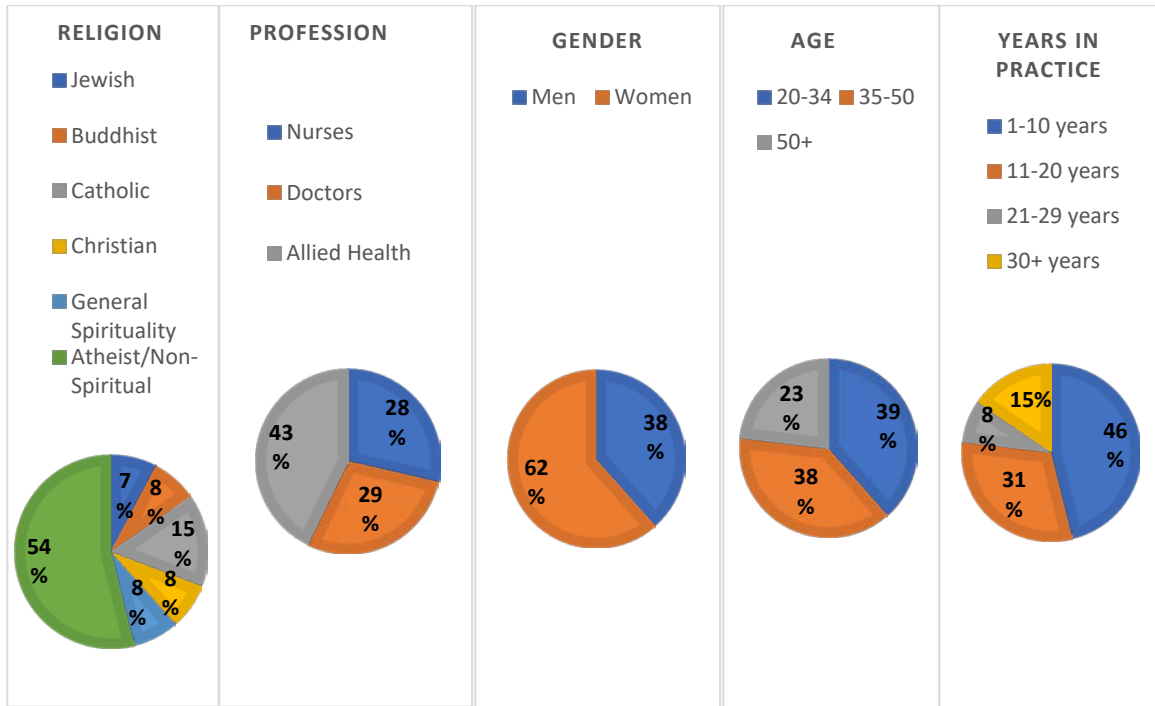


Figure 1.0 – Demographic Data of participants

Analysis

The data acquired from this study are qualitative in nature. As such, the data were analyzed using thematic coding. This method of coding is well suited to the objectives of this study, as it assists in the delineation of linguistic and social categories expressed in interviews and observed during participation at symposiums and meetings. This method of data coding is applicable to the study of narrative as it reveals commonalities in both personal history and experience as well as professional experience. These commonalities or themes can be used to demonstrate how these experiences relate to professional identities. Once codes were established, quotes corresponding to the codes were extracted from the transcripts of meetings and interviews. Grounded Theory was

the primary methodological framework of this study, and descriptive summaries were prepared based on the themes that emerged from the data.

Chapter 2: Literature Review

Goals of Medicine, Formation of Professional Identity and Values, and Death

When considering the formation of professional identity, perhaps a logical place to begin is in the discussion of the overarching goals of medicine as an institution, and in the training of medical professionals. Medical educator Tara Tucker observes that the acknowledgement of death as a certainty is avoided in the earliest days of medical education. She describes an experience as an attending physician:

During the witnessed patient encounter of one resident under my tutelage, the patient expressed a desire to speak about her dying. On three occasions in a 1-hour conversation, the resident eluded the question. When confronted with this later, she acknowledged her fear of speaking of dying with the dying. This resident was in training to be a palliative care physician. Because of the hegemonic positioning of the doctor over the patient, the doctor can often dictate the course of these conversations. Shifting from lay-language to medical jargon, a physician can devise a buffer zone to retreat behind inequality and language (Tucker, 2009:1105).

Capacity to have conversations in an accessible manner is a phenomenon that was studied by Schmit et al. (2016). In a study involving 176 medical residents, 81% reported receiving no end of life care training during their residency. The study concluded that those who had received additional support and guidance and practiced having effective end of life conversations ultimately felt more comfortable engaging in these conversations once they were an active member of their medical profession. It was concluded that those who received little education on this matter would experience long term discomfort and this could prevent effective referral to hospice care and timely conversations with patients affecting quality end of life care (Schmit et al., 2016).

Death is a topic of deep discomfort from the earliest days of medical education. Physician attitudes towards the death of their patients can affect the provision of care and result in the extension of life beyond the time desired by the patient. In a study conducted by Rodriguez and Young (2006) regarding patients' goals of care versus those of their physicians, this issue is explored. The most commonly recurring theme expressed by patients in this research was that they would rather have a shortened life with higher quality, whereas they felt their health care providers sought to prolong their life with importance placed on their biological functioning. This study concluded that there are four goals of medicine, which involve extending the length of life, improving the quality of life, maintaining or improving specific biological functions, and assisting the body for a specific length of time (Rodriguez and Young 2006).

The conception of futility in medical treatment presents an ethical quandary that calls into question the goals of health care. The term "futility" is linguistically significant, revealing how this type of care is perceived, and speaks to a larger understanding of professional identity amongst those providing the care in question. Treatment that does not reduce or eliminate the likelihood of death is often referred to as futile. However, this discourse implies that death is something that can be avoided, which in itself is futile. There are two main views of futility in health care, one of which centers on the patient and the other which centers on the physiological effect of treatment (Jecker, 1995). Jecker states that "Some have objected to a patient-centered definition of medical futility, claiming that a treatment should be called futile only when it fails to produce any physical effect on the patient's body" (1995:287). This concept of futility is deeply rooted in medical philosophy,

and the perception of futility is largely values-based and dependent upon the experiences of the physicians that have influenced the formation of their professional identities.

Since MAiD is a relatively new practice, there will inevitably be questions and discussion about its legitimacy. In the following example, Avery Kolers describes a situation that highlights some of the challenges to MAiD as an acceptable medical practice:

Suppose a pharmacist refuses to fill a prescription for contraceptives. Here the pharmacist objects to the content of the act in question – dispensing these particular pills for that particular reason in this particular case. But on consent, a moral objection to the content of the act becomes irrelevant (Kolers, 2013: 5).

This statement is relevant to the current context of professional identity in medicine. For health care professionals who are currently active, when they engaged upon their careers, MAiD was not an available option to patients. Thus, currently active HCPs did not wilfully choose to practice with the knowledge that MAiD would be part of the health care system. The notion that HCPs consent to the roles of their practice by wilfully engaging in it does not necessarily apply to new roles that develop over time. Consequently, at this point in time there may be an element of professional consent to MAiD that is absent, making for a larger opposition to MAiD at this time in Canada than there may be in the coming years. In the article “Opinions of health care professionals and the public after eight years of euthanasia legislation in the Netherlands: A mixed methods approach,” Kouwenhoven et al. suggest that after eight years, the vast majority of Dutch health care providers at all professional levels support MAiD to varying capacities depending on their stance on the limitations of the legislation (Kouwenhoven et al., 2012). It is feasible to assume that HCP

attitudes toward MAiD in Canada will trend in a similar direction as competencies and comfort with this practice increase.

The goals of medicine are ultimately complex, however the literature suggests that the majority of the goals espoused in medicine involve the curing of disease. Atul Gawande in his book *Being Mortal* describes this phenomenon as he describes the care provided to a dying cancer patient. He says that

the chances that he could return to anything like the life he had even a few weeks ago were zero. But admitting this and helping him cope with it seemed beyond us. We offered no acknowledgement of comfort or guidance. We just had another treatment he could undergo. Maybe something very good would result (Gawande, 2014: 6).

This goal of curing disease is evident in the values of health care providers as well as in the ways that professional identity and practice are developed with respect to handling death and end of life conversations.

Goals of MAiD

The right to bodily autonomy is perhaps the most critical component of the legalisation concerning MAiD in Canada. An example of this concept can be found in the Gloria Taylor's appeal to the SCC, which forms the basis for the Carter Criteria. In "A Review of Euthanasia in Canada," David Jerome, states that:

[The Carter v. Canada case] had multiple plaintiffs including a woman named Gloria Taylor, who also had ALS. Justice Lynn Smith ruled that, despite the precedent of the Rodriguez case, there had been sufficient change in the applicable legal principles since 1993 that she was not bound to the previous Supreme Court decision. She then concluded that since able-bodied individuals had no legal impediment to committing suicide, but physician-assistance would be required for

some disabled individuals wishing to commit suicide, section 241(b) created a distinction between the two groups and “the effect of this distinction was to create a disadvantage by perpetuating prejudice and stereotyping” (Jerome, 2015:3)).

Conceptions of autonomy and what it means to be truly self-determining have certainly evolved since the Rodriguez Case in 1994. Justice Smith’s ruling reflects societal norms that grant a far greater capacity to patients to determine and direct their end of life care given that they are capable and able to consent.

However, MAiD is deeply divisive, with arguments both for and against the procedure that hinge upon the same core concepts of self-determination and autonomy. In an article titled “When Self-Determination Runs Amok”, clinical ethicist and professor emeritus of the Hastings Center, Daniel Callahan, debates how far reaching self-determination should be. He states that he has “yet to hear a plausible argument why it should be permissible for us to put this kind of power in the hands of another, whether a doctor or anyone else. The idea that we can waive our right to life, and then give to another the power to take that life, requires a justification yet to be provided by anyone” (Callahan, 1992:52). This paper was published at a similar time to the Sue Rodriguez case, and reflects the opinions of health care professionals and physicians at this time. While current polls place the public opinion between 70% and 80% approval for this procedure, physician opinion remains fairly evenly split (Canadian Medical Association, 2011). According to Robert Lowes, in late December of 2016, “Fifty-seven percent of [Canadian] physicians believe physician-assisted death should be available to terminally ill patients, up from 54% in 2014 and 46% in 2010” (Lowes, 2016). This indicates that while there has been an

improvement in terms of physician comfort since Callahan's publication, this topic remains deeply divisive and is progressing slowly in the field of medicine.

Many argue that while it is true that a person's right to life must be assured, it is also necessary to assure the right to self-determination in regards to continuing one's life in the face of an incurable and degenerative illness that will ultimately lead to death. Medically speaking, there was very little difference between the Rodriguez, Taylor and Carter cases. However, the sociocultural atmospheres surrounding their appeals ultimately led to differences in outcome. According to Chan and Sommerville in regards to the Gloria Taylor and Carter case, "The trial judge found that she was not bound by the Supreme Court of Canada judgment in Rodriguez, the then precedent governing physician-assisted death in which the Supreme Court of Canada upheld the constitutional validity of the Criminal Code's prohibition of assisted suicide. Judge Smith reasoned that she could legitimately revisit Rodriguez primarily on the basis of social and legal developments since that judgment was handed down in 1993" (Chan and Sommerville, 2016: 147).

Social Science and MAiD

There are a handful of countries around the globe that have legalised access to MAiD broadly, or in isolated states and provinces within these countries. In many of these locales, social scientists have studied the meaning and social features that characterise these practices within their unique contexts. Unfortunately, as euthanasia practice is relatively recent in most geographical locations, there are some limitations in respect to the volume of works published.

While the following works did not directly involve research on MAiD, they do consider euthanasia and death through an anthropological lens. “...And a Time to Die: How American Hospitals Shape the End of Life” by Sharon R. Kaufman (2005) addresses passive euthanasia in the form of intubation tube removal and the provision of pain management medications with the known outcome being a hastened death. In “No Place for Dying”, Helen Stanton Chapple addresses the many modes of avoiding death and prolonging life and how physicians and other HCPs “carry out the mandates of society” (Chapple, 2010: 107) in respect to death avoidance and taboo. Both texts indirectly address MAiD, and the culture that currently surrounds death. James W. Green refers to MAiD legalization in Oregon as a “ballot box rebellion” and as a victory against the culture of death avoidance (Green, 2012:3).

In a study conducted in South India in 2017, social science researchers Vijayalakshmi et al. explored the gendered aspects of care involved in euthanasia in India. The authors claim that this is the first study of its kind to address gender roles as they pertain to euthanasia practice. While euthanasia remains a deeply divisive topic in India due to religious influences, gender norms and other social factors, 66% of patient requests for euthanasia were reported to be due to patients’ fears of becoming a burden on their families. This fear of burden is deeply socially rooted in how dependence would affect family structures, women and households. The authors state that “family members in India may subtly suggest euthanasia since death is inevitable and [the dying person is a] financial burden to the family members and those involved in caring for terminally ill” (Vijayalakshmi, Nagarajaiah, Reddy & Suresh, 2017:13). It is suggested that women in the

nursing profession and outside of it express greater support for euthanasia practice in India than men. However, this data is problematic as it primarily explored the opinions of professional nurses, who are predominantly female in India, and the data may be biased.

The Netherlands is often central in the conversation regarding euthanasia law and access. As a result, there is some Dutch social science research that has been translated to English regarding the anthropology and sociology of the practice of euthanasia and the legal context of euthanasia in the Netherlands. Sociologist Heleen Weyers explored the social factors affecting the way law was created around euthanasia in the Netherlands. She identifies several factors that impacted the legalization of euthanasia in that country, including: i) decreasing taboos about death and a culture of practicality and candour around death, ii) the development of medical technology and a need for medical ethics to ensure the appropriate use of medical techniques following World War II, and iii) a social milieu characterized by non-atomistic individualism similar to that of Scandinavian countries (Weyers, 2006). Anthropologist Francis Norwood explored euthanasia in the Netherlands in her work “Nothing More To Do: Euthanasia, General Practice, and End-of-Life Discourse in the Netherlands” (2007). Norwood recounts a story in which a patient repeated the words “Niks Meer Aan te Doen”, which means “nothing more to do”. This attitude is reflective of the practicality and candour mentioned in Weyer’s article. Norwood’s article, written approximately 20 years after the legalisation of euthanasia in the Netherlands, can be helpful in predicting and anticipating the future of MAiD in Canada. The author identifies that after 20 years, there are still some misconceptions

amongst the public regarding euthanasia, but overall the practice itself has become acceptable and normal, with most acts of euthanasia occurring in patient's homes.

Cheryl Mwaria, Professor of Medical Anthropology at Hofstra University, highlights the significance of medical anthropology in the conversation around MAiD in her article "Physician-Assisted Suicide: An Anthropological Perspective". She states that

In considering physician-assisted suicide, the real challenge lies in understanding the nature of culture itself. By definition, culture is learned behavior pertaining to norms for what is considered proper, moral, or even sane; as well as values, customs, beliefs and artifacts that comprise the knowledge and technology by which we adapt, or fail to adapt, to the physical environment. Focusing as it does on the individual, our current approach to death seems to presume culture is irrelevant. Nothing, however, could be further from the truth (Mwaria, 1996:859).

Dr. Mwaria's work pertains directly to this research, as it is the identities and cultural norms of the professionals who engage in this practice, and how those identities are shaped, that is at the center of this work.

Nurses and Euthanasia

A) Nurses' Professional Identity

Nurses take on many roles in health care, specifically in end of life care. In a meta-analysis of 44 papers, Adams et al. describe the roles a nurse can play at the end of life by categorizing nurses' responsibilities into five key roles. They discuss the nurse as the information broker, the giver of information to physicians, the giver of information to families, the mediator, and the advocate for the family (Adams et al., 2011). These roles taken on by nurses in end of life care can certainly be translated to the context of

MAiD. In a study conducted in Scandinavia, Olen et al. discuss how a nurse develops a professional identity through the incorporation of personal characteristics. This process is described as follows:

Self-knowledge, curiosity, generosity, tolerance of stress, professional knowledge, trust in one's own capacity, and feelings were discussed as personal characteristics of a nurse with a developed professional identity. However the most distinguished feature was the feeling of being a nurse as opposed to working as a nurse (Olen et al., 1998: 772).

This statement is significant, as it illustrates the ways a nurse's personal identity can become a part of and inform their professional identity.

Nurse Jean Watson in her article "Professional Identity Crisis, Is Nursing Finally Growing Up?" explores the professional identity of nurses through a feminist and historical perspective. She discusses the concept of "deep wounds left by severe belittlement" (Watson, 1981). This concept refers to the effects felt across generations of nursing, since nursing originated as a profession of women whereas men dominated the profession of physician. This gendered division of labour created a power imbalance in the early days of nursing practice that is just now beginning to change. Now, Watson states that nurses "can develop a sense of autonomy and interdependence with an ability for self-direction. This is supported by our developing body of knowledge, clinical research, establishment of nursing as a distinct discipline, and changes in nursing education and practice" (Watson, 1981: 1490). These changes have been especially significant over the last 30 years, as the scope of nursing practice has expanded and nurses have developed skills that make them increasingly autonomous in their practice.

B) Nurse's Historical Involvement in MAiD

Nurses have an interesting history pertaining to their involvement in MAiD. A study conducted by Dr. David Asch in Intensive Care Units (ICUs) in the United States revealed that a group of 135 nurses answered “yes” when asked about their participation in euthanasia, however some were excluded for various inconsistencies in their response. Of those remaining, 129 (16%) reported participating in euthanasia at least once. 65% of that group reported having done so three or less times (Asch, 1996). Asch also revealed that in a survey conducted in Australia involving 943 nurses, 218 claimed to have been asked to engage in euthanasia by a physician and 85 percent reported having gone through with it (Asch, 1996). These findings are interesting, as they suggest that a large number of nurses have been active in the provision of MAiD over many years. As such, they were technically engaging in illegal activity, but the legal status of euthanasia was apparently not a strong deterrent to participating in various forms of this practice for nurses.

A study conducted by researchers at the University of Leuven in Belgium revealed that nurses generally experienced fears associated with euthanasia, as their ethical practice places them very close to the family and patient (Berghs et al., 2005). This finding is relevant to the current context of MAiD, as nurses take up a supportive role for both the physician and the patient rather than acting as the provider of MAiD and advocate for the patient.

Doctors and Euthanasia

A) Physicians' Practice Relating to MAiD

Perhaps the physician's role in MAiD is the most clearly defined of all the professional practices that intersect with it. A biography of Dr. Henri Bataille, a Belgian physician who accessed MAiD himself, makes it clear that physicians hold a unique role in this practice. Dr. Bataille often expressed frustration at not being able to provide his patients with assistance at the end of their lives if they were experiencing pain, stating that "I will want it if ever I'm in that situation" (Hurley, 2015: 351). This sense of powerlessness and loss of control at the end of a patient's life, while not expressed solely by physicians, is perhaps most well documented for physicians who support MAiD. This frustration about powerlessness to help patients may be related to physicians' understanding of their role and professional identity as "doctors who are in control." (Hurley, 2015: 351).

A study of oncologists conducted in Michigan following the assisted suicides conducted by Dr. Jack Kevorkian found that one in seven oncologists would refuse to withdraw or withhold life supportive treatment even if it were requested by the patient. The article addressed the possibility that these positions were rooted in the fear of being perceived as a provider of euthanasia, or that it was morally wrong to either perform euthanasia or stop pursuing aggressive measures to save a life (Doukas, Waterhouse, Gorenflo, & Seid, 1995). The phenomenon of death avoidance has been studied at length among physicians diagnosing dying. According to Ellershaw and Ward, the diagnosis of imminent death:

is often a complex process. In a hospital setting, where the culture is often focused on “cure,” continuation of invasive procedures, investigations, and treatments may be pursued at the expense of the comfort of the patient. There is sometimes a reluctance to make the diagnosis of dying if any hope of improvement exists and even more so if no definitive diagnosis has been made (Ellershaw and Ward, 2003:30).

Given the reluctance of physicians to diagnose death as imminent, it is reasonable to imagine that conversations about MAiD would be challenging for many doctors. Therefore, the doctors who do participate directly in the provision of MAiD likely stand out as unusually willing to address end of life issues relative to their colleagues.

An article published in Canadian Medical Association Journal (CMAJ) regarding MAiD in Canada states that, in a poll conducted in 2015 of 350 participating members, 75% of respondents felt that, even if MAiD were to become legally accessible, it should not be provided by palliative care physicians or palliative care centers. The reasoning cited for this conclusion is that MAiD violates the tenets of palliative care, since the goal of palliation is not to hasten death but rather to make the symptoms of dying manageable (Eggertson, 2015). This perspective poses a challenge, since many physicians outside of palliative care avoid dealing with death, while those within palliative care who are familiar with end of life issues largely do not support MAiD in their practice.

Allied Healthcare Professionals and Euthanasia

A) The Practice and Professional Identity of Allied Healthcare Professionals in Relationship to MAiD

There is limited literature regarding the roles, values and ethical stance of allied healthcare professionals with respect to assisted dying. The majority of the literature pertaining to allied healthcare professionals focuses on pharmacists and their role in the MAiD process as the distributors of the medications used to end a patient's life. Elvey, Hassle and Hall conducted a study of 40 pharmacists to better understand their perceptions of their profession. The study results indicated that pharmacists see themselves in several ways: as scientists, as advisors about medications, as social carers (community pharmacists), as clinical practitioners, as producers of medicines, as suppliers, as business persons, as managers, and as “unremarkable characters” (Elvey et al. 2012). While this study does not pertain directly to MAiD, it does suggest some of the roles pharmacists may see themselves adopting as requests for the dispensing of MAiD drugs arrive at their workplaces.

A study conducted by Hackett and Francis concluded that 83% of pharmacists felt that a patient had the right to choose their own manner of death (Hackett and Francis, 2001). This study was conducted in England, with a total of 295 pharmacists. Interestingly, 67% of respondents reported having a religion, with 40% of this group reporting that their religion should not influence their patients' care (Hackett and Francis, 2001). This tendency to value supporting patient autonomy regardless of personal religion or belief system emerged as a common theme in my interviews with various allied healthcare professionals. Many of my respondents stated that the legalization of MAiD has not changed anything in their profession, as the skills required

for MAiD are skills they have always used, and they continue to uphold the codes of their profession.

Chapter 3

“We’ve Always Done This”: Allied Health Professionals and MAiD

I must admit, I was unsure what to think when a spiritual care worker agreed to participate in my research. I knew that this individual was a member of ADRAS, and I knew they supported the practice, but how would my interview be received? At this point in Hamilton, St. Joseph’s Hospital, the Catholic health care center, had issued an institution-wide objection to MAiD, leaving the work to the community and Hamilton Health Sciences. So, what made this spiritual care worker, who identified as being of Catholic upbringing, want to be tied to this research and work? After my interview, I concluded that all of my assumptions regarding spiritual care, chaplaincy and workers of a religious nature in the hospital were incorrect to say the least. This chaplain was extraordinary, and deeply insightful and altruistic. After a few more interviews with allied health professionals, I would come to learn that this is the default state of allied health professionals on ADRAS and beyond that support this practice.

For the purposes of this research, I have grouped professions into certain categories for analysis. Allied health professionals, in this context, refers to non-nurse and non-physician health care workers who operate as a wrap-around service to nurses, physicians and their patients. My interviewees included a chaplain (spiritual care worker), a social worker who works in varying roles within the contexts of ADRAS and HHS, a pharmacist, a genetic technologist, and a clinical neuropsychologist from the trauma and complex continuing care centers. While their professions and professional identities do vary, their

common unifier is active participation in ADRAS and MAiD, or vocal and outward support of the practice.

A Capacity for Change

My meeting with the chaplain was nothing short of comfortable and pleasant. The chaplain has a small office in a quiet space of the hospital, lit with soft table lamps and filled with items such as a basket of lollipops and tissue boxes on each table, that suggest that this is a safe and nurturing place. It was truly an embodiment of this participant. We began our interview discussing their professional journey, and how they came to be in their current occupation. They painted an extraordinary picture of travel, self-discovery and growth as they came to realise that what they truly did want out of life was to be present in the moments of people's greatest challenges and suffering. They had begun their professional pursuits as a young student who wished to be a lawyer, and after graduation and without direction, decided to work abroad with disadvantaged children. They witnessed Mother Theresa's hospices, and noted the ecumenical aspects of religion rather than the staunch Catholicism they had anticipated. I suspect that it is this early experience with the beneficial aspects of ecumenical spirituality at the end of life that helped them in the earliest days of their professional identity development. They identified this experience as the launching point for their career, stating that

“I saw, or visited, mother Theresa's hospices, which were set up right along the Ganges river by the burning docks, and you know it... it essentially is the holiest of holy places the Hindus and the Buddhists that live there, which I thought was

amazing because it was set up by mother Theresa who's like, a hard core Catholic right? So, I thought "this is kind of awesome" but I was sceptical so I thought "I'm going to go in and I'm going to find like, chapels, there's going to be big crucifixes, it's going to be so Catholic"... No. the whole thing is super Hindu and Buddhist, it was awesome. So, I kind of fell in love with that idea, and um, and caring for people, um, while they're dying and providing for their spirituality and whatever way that they needed spirituality."

A trend that emerged as I continued to speak to allied health professionals about their origins was that almost none seem to have ended up in the field that they had initially pursued. During the development of their professional pursuits, an event or experience almost always came about that sent them on a different course. Much like the chaplain prior to their experience abroad, the genetic technologist, neuropsychologist, and pharmacist had all began their education with aspirations of becoming something else.

The genetic technologist, who had been raised on a cattle farm, had aspirations of becoming a veterinarian. However, as they progressed through their degree at the university of Guelph (the locus of a large veterinary school), they realised that the work and time requirements were no longer aligned with their interests. However, they were in a biological science program at a turning point in technology, when the human genome was just beginning to be sequenced and was of rising interest in the scientific community. This examination of the human genome was not without its controversy. Their interest in the human genome was not passing, and became something of a hobby. This is clear in the statement that "I've always liked family history. I've always liked family history... I've actually traced my family back many generations, on both sides, and it's interesting to me". This trend of self-discovery during undergraduate degrees is not isolated, as the pharmacist I interviewed had a very similar experience. They stated that

“I was kind of a science nerd, I went to science camp up to grade 10 so... you know, I wanted to pursue academics. Really, kind of, wet lab research. I did a co-op degree, then had a few work placements throughout my first degree, and along the lines I came to the realization that my preceptor, or, my mentor... the principle investigator...often times was spending just, a lot of time hunting after grants and just not doing a lot of research”

The neuropsychologist was no exception. They, too had gone to a top-ranking school, with the intent of becoming a physician. However, their Life Sciences degree had failed to engage them the way that their arts psychology electives had. They had always been socially engaged, being the personal “therapist” to their friends as they grew up, and that was perhaps the component of themselves that was best mirrored by psychology as a practice rather than psychiatry as a medical profession. They stated that

“I did life sciences at [university] and was in my third year and was not very happy, really, in life sciences. So, I thought I wanted to be psychiatrist... that was where I initially started off. I didn’t actually know there was such thing as clinical psychologists or neuropsychologists, I didn’t really know that was a thing [sic] so then I learned it was and thought... well! That’s pretty good! And I took psych [sic] electives all through my undergrad and those were the classes where I was sort of on the edge of my seat.”

Last but certainly not least, the social worker I interviewed had also seen career changes, as they were currently no longer working in that capacity. Their parent had been a social worker, and they were “drawn to issues of injustice from a young age”. They had expressed interest in the human condition, and had worked with troubled and disabled youth in the pursuit of this profession. When they were in their young twenties, they began the first leg of their profession as a social worker with the Children’s Aid Society in Hamilton. They describe the experience as

“a crisis, for lack of a better description. For the first six months or so, although I had worked with kids who had been abused... this was my first immersion in to all of the family dynamics and having to navigate [these dynamics] really.... Experiences that I had never been exposed to, like, just abject poverty and just all sorts of pathology... you can imagine, all sorts of mental health issues, safety issues, drug and addiction issues... and all how that intersected with parenting and safety

for kids. And so, it was a whole lot of the dark side of the world, sort of on a plate in front of me, that I had to not only process and navigate from a professional perspective but also from a personal perspective. For the first six months, literally, I would come home and fall over in to bed and not even change and wake up the next day and have to get changed...”

This account of crisis and distress in the beginnings of a career seemed so at odds with the person who sat in front of me, sipping tea on their sofa, surrounded by soft blankets and mix-matched pillows. Perhaps, I thought, this transition from social work into their current role (which has been omitted as they are a rarity in the hospital and to disclose their role would disclose the person’s identity) is what provided them with the peace and tranquility I see now. They did derive some hard skills from this trying period, explaining that “it really honed my skills and sharpened my skills, and allowed me to sort of see the variety of dynamics. I developed the ability to sort of project... like, when you get *this* feature and *this* quality and *these* dynamics, it kind of ends up like *this*. Or, *this* is what it can look like, or *these* or what the consequences can be”.

So why are these career changes and paths to self-discovery relevant? MAiD, as a new practice, will be changing the way that medicine as an institution functions. The capacity to be flexible, recognize hard and soft skills and interests, and move with the ebbs and flows of practice changes will be critical to the reception and functioning of MAiD. In these five interviews with ADRAS team members and vocal supporters, it is clear that they do not fear change. Rather, they embrace it and steer in to it. These allied health professionals are unique in this, compared to the other health professionals I interviewed. They were able to set a course for themselves, and change it as they evolved as people.

They approach their careers and goals as plastic and fluid, rather than fixed. This makes them uniquely qualified to be a part of this practice.

“We Have Always Done This Work”

Perhaps one of the most significant themes to emerge as I interviewed allied health professionals was the sentiment that their work had not changed. Rather, the reasons why their services might be requested have changed, but their goals and patient care remain virtually the same.

The spiritual care provider identified that the final lethal injection in the MAiD practice, while intrinsic to the procedure, is really the culmination of events as opposed to the entirety of the process itself. It is through this lens that they see their role in this practice, and the value of non-physicians and nurses in MAiD. They stated that

“my job is to walk alongside that person through whatever choice they make. And so, it’s not even just to support patients who decide to go through it but to support the patient’s room-mate who might think it’s abhorrent or the patient’s doctor who is a conscientious objector or the patient’s nurse who is so for it that she’s almost over-enthusiastic. It’s to walk alongside all of those people and make sure that they are cared for in whatever way that they need to be cared for. Regardless of the outcome. The pushing of the drugs is so irrelevant to all of the things that happen around it.”

This statement reveals an interesting facet of the culture of MAiD provision. Public discussion of MAiD focuses largely on the providers of the injection rather than those that support the process through assessments, education, emotional support and the dispensing of materials necessary for the lethal injection to take place. When pressed a bit further about

how they discuss death and if that has changed, the spiritual care provided simply responded with “I’m a chaplain! We talk about death all the time!” Admittedly, I laughed. It had never occurred to me that this state of affairs might be normal, that talking about death before and after the legalization of MAiD might not be controversial or even remotely different in terms of how a health care professional navigates their day-to-day professional role. In this sense, I too had been too focused on the provision and not the process. The chaplain elaborated, stating that they had been receiving informal requests from patients for assistance in death since they first began in their profession. To discuss dying and suffering now is, simply, more of the same.

This sentiment was echoed time and time again, in varying detail. The genetic technologist explored the similarity between MAiD and abortion, and the role genetics may play in determining MAiD provision. They reflected upon the gravity of what genetic results may be used for. They stated that “we’ve always been cautious, and we’re extra paranoid because our prenatals do that sort of thing [lead to abortion decisions]”. This is the level of controversial work and decision-making that this health care professional was already very actively involved in, prior to the legalization of MAiD. Our conversation digressed to a few recent cases where the decision to abort or to continue the pregnancy was urgent, and it became apparent how similar these decisions could be to decisions about MAiD. Genetic confirmation for illnesses such as cancer is commonplace, and it is these certainties attained through genetic testing that will inform health care decision-making regarding MAiD.

Others took a more conservative approach in defining how they understand their role with patients. The pharmacist, being a scientific and technical expert, responded to my question of whether or not MAiD had changed his relationship with patients by stating “I haven’t actually had to talk to families or patients because, again, this is something that the physician takes to the patient’s bedside. So, no, I haven’t had... there has been no change but I’m now more prepared and in a better position to maybe have a discussion with a patient if the patient does bring it to my attention”. Pharmacy is a highly technical profession, straddling the boundary between chemistry and medicine. As a result, for pharmacists, the provision of medications for MAiD is a new technical skill as opposed to a practice that generates a change to pharmacy practice. Pharmacists have always dispensed drugs, some of which can be lethal if taken against medical advice. As such, dispensing lethal volumes of drugs for MAiD has only changed the intent, rather than the practice of pharmacists.

The psychologist and social worker grounded themselves in very similar goals concerning their practice. Both felt that it was the responsibility of those in their professions to respect choice, and honor patient autonomy. The social worker stated that

“one of the sort of...foundations, of our belief system is that... or our professional values... is that people have the right to self-determination. And our job is not to judge any of those things but to provide support to the degree that... you have an obligation and that you feel comfortable. Like, some people wouldn’t put themselves, as a social worker, in an abortion clinic because it doesn’t align with their principles and they would feel in constant conflict with themselves to provide support to somebody in that setting. But I think for the most part, social workers have a pretty wide realm of things that they would support patients through

regardless of whether it conflicted with their own principles or morals. Recognizing that patients are people and really have a right to self-determination.”

This statement was interesting, in part because it recognized that there could be a diversity of opinions on what the professional role of a social worker might be, while simultaneously recognizing that there is a certain type of person that tends to make their way into social work. Overall, it was felt by this particular social worker that the patient is always at the center of their care and efforts, regardless of outcome. This sentiment was expressed in a similar way by the psychologist, who received an extraordinary level of support from their psychology colleagues at HHS. They were openly congratulated on their involvement with ADRAS, an email announcing their role in MAiD was sent to the psychology professionals across the institution, and they received very vocal support and encouragement from their supervisors. They were certainly not invisible as a supporter of assisted death amongst their colleagues, and as they were speaking about this level of visibility, I realised they felt safe being as visible in their support as they were due to the way that the psychology profession sees its role with patients. They stated that

“it just comes back to some of the core principles of psychology and I think [we all have them]. I think that the patient has the right to choose and so I know that even when we do an assessment, do treatment... the patient has the right to refuse and we make that really clear to our patients. We have very strong ethics training so I think that, probably a combination from our training and our background and we're just nice people?”

The psychologist's concluding statement applies to all the allied health care professionals I interviewed. They were all nice people by every metric. Kind, altruistic, people who saw a role for their practices in assisted dying because it felt like such a natural shift for them. They had “always done this.”

The Significance of the Injection, and Professional Intention

All allied health professionals that were interviewed expressed some desire for change in legislation that would open up MAiD to populations of patients that currently do not have access to this service. As stated earlier, there are certain criteria that must be met in order for patients to access MAiD. The two most contested points amongst this group was that the patient must be mentally competent at the time of provision rather than expressing their wishes for MAiD in an advance directive, and that the patient must be the age of majority (18 or older) in order to make this request. All members of the allied health professional group uniformly expressed interest in some form of change to the legislation governing MAiD. In addition, they all described the types of suffering they have observed and deem intolerable, which largely influences their interest in legislative change.

	Minors being able to access MAiD	The use of advanced directives
N total: 5	2	4

Figure 2.0: Types of Legislative Changes Allied Health Professionals Advocated

Almost all participants expressed interest in legalization of some sort of advance directive, based on their experience of suffering. The social worker expressed general interest in access for minors, due to their experience as a social worker in pediatric oncology. They stated that

“certainly, when I was working in pediatric oncology, there were parents seeing their child dying and, you know... thinking *what was the purpose...asking what purpose is this? How much longer does this go on?* You know? And it...you can...sort of the silent question behind the question [sic]. So no, [I’ve never received] formal requests [for MAiD], but certainly I think [I have seen] probably people who may have considered pursuing that if given the option.”

The other participant who expressed interest in both access for minors and the use of advance directives was the spiritual care worker. They stated that

“I work in peds [pediatrics] so, I’m aware that there are children [from different cultures] who are in seriously intolerable suffering and culturally... you’re an adult. For a [Muslim] girl, I believe its 9 and for a boy it’s 14 so, all of a sudden you have to be 18 before you can make that decision but within your culture you’ve been making it for 9 years already?”

Overwhelmingly, interest in the use of advance directives was expressed by all but one allied health professional, who abstained from commenting for personal reasons that they requested I not disclose. Of the four who expressed interest in this type of legislative change, three spoke specifically about dementia as a condition in which advance directives would be useful. The pharmacist, psychologist and genetic technologist all referred to dementias or neurological disorders impacting cognitive capacity. The pharmacist, who was otherwise very technical in responses during our interview, described their perceptions of the suffering felt by not only patients with dementias but by their families as well. The pharmacist stated that

“just from friends and relatives who have died of those diseases it’s not...there are more awful ways to go, but with Alzheimer’s... when you’re not able to feed yourself anymore, you forget how... and you starve to death over a course of days or weeks, and that’s like... the only thing that will take your life at that point... I wish that these people could have that other option too before they get to that point.”

These sentiments were echoed by the genetic technologist, who referred to this concept through a personal lens. They stated that, if they were to develop dementia, “I’d love to be able to say that if I don’t recognize someone that is important to me... I’m done”. The psychologist straddled a boundary between personal and professional when discussing their perceptions of suffering as a result of dementia. They had conducted a large amount of their work in dementia care, and their experiences of suffering as a result were complex. When asked about their stance on the legislation and support for advance directives, they stated that:

“not that I don’t know where I stand on this piece, but rather on things like advance directives because I work with patients with dementia who wouldn’t be capable at that point. But I see their suffering.”

Their next statement perhaps expresses the root of their concerns both personal and professional, and in order to best explain this statement, I have added a graph to detail precisely the phenomenon that concerns the psychologist most:

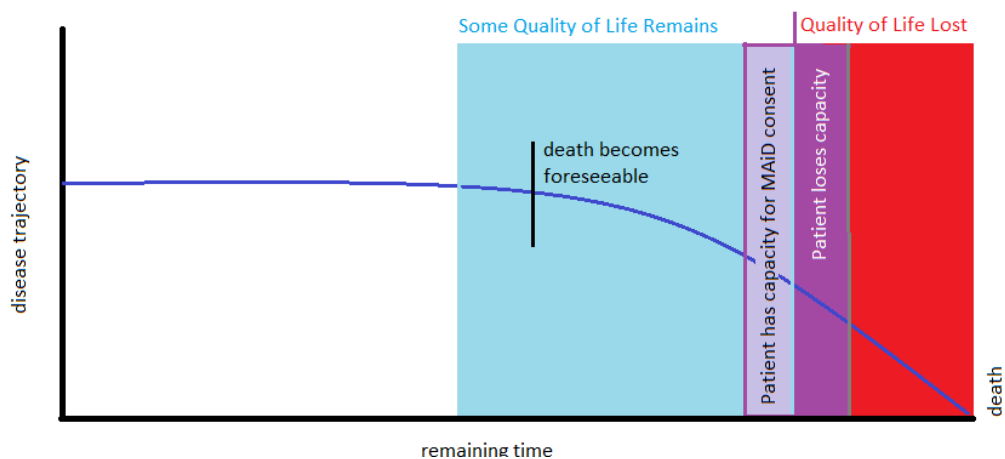


Figure 3.0: Based on the Graph presented by Timothy Christie of Horizon Health Network, 27th CBS Conference 2016

I came upon this graph during the summer of 2016, at the Canadian Bioethics Conference in Toronto. Timothy Christie of Horizon Health Network in New Brunswick was giving a presentation based on his experience as an epidemiologist who is now in the role of a clinical ethicist. This graph explores how, because of the legal requirement that patients requesting MAiD be mentally competent, some patients who wish to have physician assistance in dying may ultimately end their lives while some quality of life remains. While what constitutes quality of life is very personal, and it was discussed in the context of cognitive capacity. It should come as no surprise that neither Dr. Christie, nor my participants who were all highly educated, found lack of cognitive capacity to be the key factor in loss of quality of life. The psychologist referred directly to this graph as they discussed why they feel advance directives may have a place in MAiD:

“You have a graph... the idea behind it was to maximize quality of life in giving someone the choice about when they can have assisted dying but then if there are advance directives... if there isn't, if there is not advance directive, people may be cutting off some of that time because they are concerned about the future but then, what if later in the moment their feelings about it change and now it's a part of the disease process... yeah. It's going to be very complicated.”

At the heart of these statements is the desire to provide patients with as much choice and opportunity as possible. This position, while deeply influenced by their personal experiences, neglects the challenges that would be associated with the legislative changes needed to make provision for advance directives. As allied health professionals do not have to directly provide medications or interventions, they are not subject to the same questions of capacity to provide MAiD to a minor or to a cognitively impaired person who may not be able to give that final consent. These sentiments were not necessarily echoed by the

nurse and physician respondents in this study, with some nurse and physician respondents even suggesting that they would hesitate to provide MAiD in these circumstances, particularly in regards to providing to children and mature minors. This data suggests that there is significance in terms of professional identity and consideration around the actual act of provision itself, and how the professions that deliver MAiD compared to those that support it view the significance of that final step.

In a study that explored the intention-foresight model of care for palliative care, Douglas et. al (2011) explore the significance of intention when engaging in an activity such as terminal palliative sedation, and whether it has the potential to hasten death and the physician's knowledge of this event. This study identified that palliative care has the professional goal of alleviating suffering, and that it desires to be considered distinct from euthanasia. When a palliative care physician is to provide sedation that has the potential to hasten death, there is a window of feasible deniability that makes this practice easier to engage in, as it does not lead to social fall-out with colleagues or challenges to their professional goals and identity (Douglas, Kerrage, and Ankey 2011). They have set their intentions as professionals who alleviate suffering, and there is no real means of assessing how much a death might be hastened in a quantifiable way. This is certainly true of allied health professionals, who can maintain their professional identities and uphold their intentions in this practice by supporting MAiD and MAiD providers, but do not have to actively engage in physical provision and can thus speculate more widely on its potential as they are not beholden to providing it and the meanings associated with direct involvement in the termination of a patient's life. As mentioned above, the chaplain

suggested that the injection itself is a culmination of events rather than the most significant event. While not inaccurate, this statement does minimize the social significance and the impact on those who provide it to some degree. While allied health professionals certainly are specialists in the supportive aspects of MAiD, they do not have to engage in the physical act of it, and can thus recognize the potential for the involvement of more vulnerable groups. This reflects their professional intention as supporters of practice, but they can disassociate from the physical act itself as they will never have to be providers themselves.

Overall, the role of allied health professionals as supportive team members with unique skills and competencies around death should not be overlooked as insignificant in this process. However, there is a degree of detachment from the physical act of MAiD itself that does shape their perspectives and minimizes the social, physical and emotional significance that the physical act of MAiD provision has on physicians and nurses.

Chapter Four

“Walking Alongside Patients”: Nursing and MAiD

My experience with nursing prior to my internship had been limited purely to signatures that released patients into my care for transport when I worked as an ambulance attendant. What I had failed to notice at the time was that it was, in fact, nurses rather than physicians, who were consistently signing my forms, providing me with advice, and directing me on the needs of their patients. Nurses really do know the ins and outs of their patients and their needs. Nurses also know the families that frequent their units. This specialized knowledge about patients and their families was brought into focus as I interviewed nurses for this thesis.

I interviewed four nurses from diverse backgrounds. In all cases, their work was extremely complex and demanding.

	Trillium Gift of Life Organ Donation	MAiD	Intensive Care Unit	Emergency Room	Psychotherapy
Primary Practice			3	1	1
Additional Practice	2	3		1	

Figure 4: The roles of the nurses who participated in interviews (n=4)

As demonstrated in Table 1, their practices involved multiple roles with a complex array of skills and competencies. Of the nurses interviewed, three were members of ADRAS, and one of these was also a member of the Trillium Gift of Life Organ Donation team. All three ADRAS nurses worked in Intensive Care Units (ICU) as their primary nursing practice. The nurse whose primary practice was in the Emergency Room also worked for Trillium. One of these nurses identified as having two primary practices, both as an ICU nurse and as a psychotherapist in private practice as well as being a MAiD provider. All nurses interviewed had a minimum of one primary and one additional practice.

All of these people project an image of being ambitious, determined and strong. These characteristics make them uniquely skilled to address patients with complex needs at the end of life, and provide support for the families of those patients. The nurses demonstrated through their interviews and through their discussion of their professional identities that they have an extraordinary capacity for caring, and extending that care from patients to families in times of crisis. All emphasized that crisis is frequent in their areas of work. This chapter will address how these nurses accept death and dying as part of their social environment, their capacity to participate in MAiD, their perceptions of themselves as patient advocates, and the roles nurses play as part of their profession when death occurs in hospital.

Walking Alongside Death

It should come as no surprise that some units of the hospital see death more frequently than other units, and through different means. Oncology often deals with patients

who are dying after prolonged hospitalisations due to metastatic cancers or cancers that have progressed beyond treatment. Although there is some overlap between oncology and palliative care, patients in palliative care have often exhausted all possible treatments and have come to the unit to die, hopefully peacefully. In the ICU and the Emergency Room (ER), especially at Hamilton General, a regional trauma center, many of the deaths that occur are a result of sudden violence. There is a sense of chaos in both of these units that was identified repeatedly by my interviewees, one of whom works in both ICU and ER. In the ICU, patients are in critical condition and in need of serious medical intervention following events such as traumatic accidents or sudden crises in long-term illnesses. Truly, the ER and the ICU are deeply connected, as the ER often receives the critically ill patient, who is then moved to ICU for longer-term management. To quote the nurse/psychotherapist, “I like the drama”. These units are, indeed, dramatic and fraught with high intensity, life and death work, particularly, for nurses.

The role of nurses in health care is to directly support the patient. This role incorporates a broad range of skills from placing IV lines, to administering drugs, carrying out physician orders, hearing patient and family concerns, ensuring these concerns are being directed to the correct people, and ensuring that the patient is being cared for in a dignified way. As a result of the multiplicity of tasks performed by nurses and their close contact with patients, quite frequently, it is to a nurse that a patient or family member first speaks about the possibility of assistance in dying. These first tentative queries can come in many forms. Sometimes a patient may say to a nurse something to the effect of “I’m just done.” In other cases, a family member may say “they wouldn’t want to live like this”.

Each of the nurses I interviewed told a story about being asked to facilitate a peaceful death, either by family or by a patient. All of these stories occurred before legislation had passed legalizing MAiD, so MAiD as such, was not a viable option. The ER nurse spoke of a patient who had acquired a grievous brain injury as a result of an unintentional overdose. This patient met neurological criteria for brain death, and there was no foreseeable improvement. They had survived for a few weeks following their diagnosis of brain death, and the family expressed on many occasions that it would be a mercy for the patient to die rather than continue to live in a brain dead state. The ER nurse had been allocated to this family as a Trillium organ donation nurse, and had discussed the pending death of their loved one with the family on many occasions. I had always assumed such discussions would be met with hostility, but according to my interviewees, that was not the case. Both Trillium nurses stated that they have a family-centered approach in their conversations about death. The ER nurse stated that “I like the experience of being able to make [death] a better experience. That celebration of life rather than the mourning of death. And Trillium completely encompasses that. From their very core.” The ICU nurse stated that “with donation, it’s not horrible. It’s sad, but the family... they get the opportunity to make something good happen”. Both nurses had found a way of seeing death as not only meaningful, but as a positive experience that can help relieve some of the suffering experienced by the family. For these two Trillium nurses, death is not something to be avoided, especially since it can provide the occasion for organ donation. As a result, they have evolved competencies specific to death. They are skilled in opening up conversations

around death and providing support for families facing the death of a loved one that may not have been anticipated.

The ICU nurses shared these skills. As in the ER, patients frequently die in the ICU due to unpredictable circumstances. Often, care can be futile in preventing death in the ICU. In hospitals, ventilators can be used to keep a heart beating and maintain blood oxygenation, even though a patient may be neurologically dead and lack consciousness and cognition. Such technology can create ethical dilemmas for families and healthcare professionals. The ICU is the epicenter of many of these ethical quandaries. And it is often a nurse who turns off the ventilator, removes the intubation tube, or provides sedation and pain management so that a patient may die in peace. One nurse, who works both in the ER and with ADRAS, addressed a problem that had arisen regarding a patient's dying wish. The nurse had spoken to a young patient about dying, as they felt it was their responsibility to give a clear picture of the patient's most likely prognosis so that this person could make informed choices regarding end-of-life care. As this nurse explained, it is central to the way they practice their profession that they do not "give false hope if there is no hope there". After some considering this information with the family, the patient embraced the imminence of death and expressed a clear wish to "die sleeping". This request was all that the nurse needed to hear, and they were eager to provide the patient with this level of care and facilitate their dying wish. They had the skills and experience to provide palliative sedation through IV, a minimally invasive and painless process that involves providing an adequate and consistent dose of certain medications to keep the patient unconscious and comfortable as they die. However, the palliative care physician would not permit this

patient to receive palliative sedation, as they had not received previous palliative care. On the palliative care unit, protocols are clear about this requirement. The nurse had spoken to the patient at the end of the day, and palliative care would not be available over night. This patient was imminently dying, and their wishes would not be fulfilled. The nurse was angry, not because the patient would die, but rather because their death would not take place in the way they had requested. This nurse recalled multiple times when patients had requested they facilitate the patient's death prior to the legalization of MAiD. One patient had even gone so far as to request a gun. Death was not new for this nurse, nor was it an uncomfortable phenomenon. However, in their view, refusing to allow someone to die according to their own terms was unacceptable.

The psychotherapist/nurse whom I interviewed had been in practice in the ICU for much longer than the other nurses, almost 35 years. They had been exposed to death and dying for 35 years, and it has become a part of their life. Reflecting back on their professional life, and chuckling, they told me that they had always been known as the "death person." They recall receiving phone calls at home after they had left the hospital, from colleagues who wanted them to come and speak to imminently dying patients. Following the legalization of MAiD in 2016, they participated in an assisted death. After this experience they stated that "death can be healing. And so, we finally get to choose and in life we don't get to choose so much. We think we do, but very little do we choose, really". This woman had been a nurse first, and decided to train for their second profession as a psychotherapist when they realized that they had the capacity to care for a patient's emotional needs as well as physical needs, and allow for emotions and grief to be expressed

as a patient dies, which was an all too frequent experience in the nursing profession. Conversation and support flowed easily with them, and our interviews often lasted hours. It was clear that the patients and families that this nurse has encountered felt cared for in their moments of crisis, as this nurse feels it is their role to connect with patients and families on an emotional level. This nurse went so far as to state that their capacity to connect and support people through trauma is their reason for existing, and their way of earning their right to exist.

“Nurses are Patient Advocates”

I heard this statement from every nurse I interviewed. When asked about their professional identity, they consistently portrayed themselves as patient advocates. They stated that they will champion their patient, regardless of their own personal beliefs, because they feel that that being a good advocate for the patient is what makes a good nurse. They saw altruism and caring not as weaknesses, but as strengths tied deeply to their profession. The ER nurse stated that “there are times when your patient wants something that you absolutely do not agree with. But you know what? I’m not them. It’s not my body. Would I do CPR on an 85-year-old [grand]mother? No. But you [the family members of patients] will, because you know her and I will do that for you”. This statement reflects the nurse’s willingness to provide care that they may not deem appropriate, but that the patient and the family want. The other Trillium nurse told a story about praying with a patient at his bedside, despite not being religious themselves. However, the patient needed a trusted person to pray with him at a critical point in his illness, and the bedside nurse was the one he trusted most. The psychotherapist-nurse spoke about incorporating tools from

psychotherapy such as art so that patients can use their own language and means of communicating to express their wishes and be understood and validated on their own terms. The ICU nurse caring for the patient who was refused palliative sedation campaigned so tirelessly for that person even against palliative protocol, simply on the grounds that to die while asleep was what the patient wanted. This nurse recalled that they felt strongly that the situation was unjust to the family, who wanted to see their loved one's wishes respected at the end of life.

This role of advocacy is deeply rooted in the concept of autonomy, according to which a patient decides what is best for them. These wishes are often expressed to nurses at the bedside as they go through their daily routine with their patients (Segesten & Öhlén, 1998). Conversations about end of life care often arise informally in this context, either with the patient themselves or with family. MAiD and advocacy are closely connected, as both are intrinsically bound to patient autonomy. The nurses in my study who saw themselves as advocates could readily place their personal needs second to that of their patients' needs. All the nurses I interviewed expressed comfort with and support for MAiD. Three of the four nurses had participated in provision of MAiD through ADRAS. In addition, the ER nurse had received a request for MAiD from a patient and had transmitted this request when the patient left ER for further follow up and assessment, with the hope that the patient would be provided this service. The nurse did not find out about the outcome of this request; however they had expressed a very clear message that this patient wished to access MAiD. As this example suggests, a nurse who constructs their professional

identity around advocacy and their role as a patient advocate, appears likely to be a supporter of and/or participant in MAiD.

Death by Omission versus Commission: An Unclear Line for Nurses

Nurses in hospital carry out order sets. An order set is a written direction from a physician for a patient, and can involve administering a specific volume of medication, delivering medication through a specific method such as IV or sub-cutaneous (under the skin), or stopping a medical or life-sustaining treatment. Carrying out physicians' order sets is a large part of nursing as a practice. I will be discussing three medical practices in this section. The first is NPO (*nulla par os* or nothing by the mouth). This involves not providing a patient food or drink, which may hasten death. For the purposes of this chapter, NPO will be discussed as a decision at the end of life, rather than as a part of routine care such as going NPO before surgery. The second procedure is extubation, which involves the removal of an endotracheal tube from a patient reliant on a ventilator in order to breath. Extubation is likely to hasten death. The third practice involves administering drugs for pain management to critically unstable patients when the outcome of the drug dosage is likely to be death. Nurses take part in these practices directly as a part of their profession, and as such, contribute to dying in hospital. These practices were routine in the hospital context prior to the legalization of MAiD.

A patient can decide for themselves to opt for NPO. I recently witnessed my partner's grandfather die over a period of weeks after he had decided to refuse food and drink. He was provided with pain management through an IV until he passed away. While

this is not an easy death, he was ready and mentally competent and this was the route he chose. If a capable patient decides that they would like to hasten their own foreseeable death by opting for NPO, then their wishes are to be respected. This option was legally accessible for capable adult patients prior to the legalization of MAiD. Bedside nurses provide care during this time, and do not give fluids or other nutritional support by mouth. By definition, this practice is an omission of routine care that will lead to the predictable outcome of death. What makes this experience unique to nurses is that they provide daily support to an NPO patient up until the time of death. This support includes pain management, symptom relief, and other routine care. However, in order to respect a patient's wishes, sometimes a nurse must intervene with family. The psychotherapist nurse recalled an occasion when they had to actively stop a daughter from feeding her mother, who had chosen NPO as a means of hastening her death. The psychotherapist nurse had previously ensured that the daughter understood her mother's wishes and was willing to support her in her decisions. The nurse recounted that the daughter said, "She needs to eat or she's going to die!" The nurse's response was a simple "Yeah. That must be scary [for you]". While honouring a patient's wishes to be NPO involves the omission of an act of care, it is carried out daily by nurses who reinforce this decision and ensure that it is respected by all parties. It is committing an omission, for lack of a better description, since nurses are charged with ensuring a smooth end of life by NPO. They have direct, hands-on contact with the patient every day, ensuring that their wishes are being upheld by family and colleagues alike and sometimes actively intervening to make sure this is the case. Death is an intended outcome.

Perhaps a clearer commission by omission is the removal of endotracheal tubes with the intention of hastening death through hypoxia (lack of oxygen causing death). This is the standard of practice for organ donation, though the timing is regulated to ensure organ viability. Death has to be predictable for the purposes of organ donation, which is why neurologically dead patients on ventilators are desirable candidates. In fact, the ICU Trillium nurse even stated that “You cannot be an organ donor unless you are intubated”. As such, the nurse who turns off the ventilator and removes the tube is treading once more into the grey area of hastening death. This is a practice that both Trillium nurses participate in as a meaningful part of their career. Similarly, the ICU ADRAS nurse commented that ventilators are a futile means of treatment for certain patients, as there are some that are placed on ventilators when the known outcome is that they will never come off of them successfully.

Finally, the ICU ADRAS nurse discussed a clear example of a situation in which death is knowingly hastened, yet not acknowledged. In patients who are very fragile medically, yet require robust pain management, the medications for pain can cause the patient to go into respiratory failure. If a patient is at the end of their life, and has a Do Not Resuscitate (DNR) order in place, lifesaving efforts will not be performed when they stop breathing after pain medication is administered. This likely outcome, however, does not mitigate the need for pain management – in other words, healthcare professionals recognize that it is unethical to withhold pain medication, even if it may lead to respiratory failure. This effect can also occur with palliative sedation in patients who are fragile. The ICU ADRAS nurse stated that “palliative sedation, which I have done multiple times on people,

who aren't going to breath with the drug that I'm putting in... that's been done for a long time and not called anything". The practice predates the legalization of MAiD. This practice is commission in the sense that the outcome of death is predictable, and yet the medications must be administered based on symptoms. This nurse identified some differences between this practice and MAiD however. Palliative sedation and pain medications can lead to death, but the amount of time the patient will spend in respiratory distress or slowly dying is not predictable. With MAiD, the time it will take for a patient to die and their experience of dying are predictable and well managed. The ICU ADRAS nurse made it clear that based on their experience of futile care and administering palliative sedation, MAiD is a better way to proceed. This sentiment was shared by the other ADRAS nurses, who all expressed to some degree, that MAiD has been one of the more peaceful and intimate means of dying that they had witnessed in their careers.

Feminism, Policy Development and Nursing

I had been attending ADRAS meetings and working groups for some time, and in the earliest days of this team and this practice there was a phenomenon that had occasioned a rather significant and vocal outrage. The CNO (The College of Nurses of Ontario) had issued a less than desirable stance in regards to nurse participation in MAiD. The statement was ambiguous, and outlined that it was not the job of Registered Nurses (RNs) to have assessment conversations with patients, nor could they administer the drugs for MAiD provision. Nurse Practitioners (NPs) would be given the capacity to provide MAiD, but not RNs. The ICU/psychotherapist nurse was furious, as they had been in practice for over 35 years and couldn't comprehend how their skills were being cast away. They exclaimed

“how dare [they] tell me I can’t have a conversation! Are [they] saying I have to cut off the therapeutic relationship?”. The issue they took was not necessarily with drug administration, but with the practice of conversation that they perceived as intrinsic in their profession and an identifying aspect of what it means to be a “Good Nurse”. Nurses have always been the frontline for patients who have questions, concerns or just want company. Nurses have cultivated this “therapeutic relationship” in all other medical respects, and yet, assisted dying legislation requires that a physician be present to conduct the assessments. ADRAS has a model where two people (one of whom is a physician) attend the assessment, but this is not echoed in law. Rather, it is a structure that has been put in place by the chairs of ADRAS who saw a benefit in having various skills and capacities at the patient’s bedside during these conversations.

Nursing is still a field primarily staffed by women, and as such, there are some feminist issues to consider when exploring power, comprehension of professional skills, value of the nursing profession, and related issues. In their article “Nursing and the F Word”, nurse/researchers Kane and Thomas state that “nurses agree that salaries, status, autonomy, and power are negatively influenced as a result of gender discrimination” (Kane and Thomas, 2000:19). In almost all aspects of work in the hospital, the nurse carries out delegated acts. This means that an RN can carry out physician order sets to deliver any number of medications through the appropriate means to patients at all stages of their illness. Nurses are autonomous in the sense that they can deliver certain amounts of the total prescribed medication according to their best professional judgement and the needs of the patient. This is one of the senses in which they act autonomously. As previously

mentioned, they are also often the first point of contact for patient concerns and requests, and it is their responsibility to not only respond appropriately but to also ensure that those concerns and requests are heard in the correct and most effective way. In this sense, they are autonomous brokers that relay the information they deem significant and necessary, and to ensure appropriate follow up and action. In the guidance on MAiD provided by the CNO, the RN is only mentioned in the context of support to the NP or physician, and then in their responsibilities to their patients if they are to object to this practice. Otherwise, little guidance is given, but it is made clear that RNs are not to administer drugs or conduct assessments independently. Both of these principles seem to be at odds with nurses' daily practice, goals of their profession, and expertise. Through a feminist lens, we must critically consider the reasons why nurses have lost their professional autonomy for this particular practice.

In a study regarding the benefits of nursing autonomy in European ICUs, Papathanassoglou et al. state that “The ability to make discretionary and autonomous decisions based on comprehensive knowledge, clinical expertise, and evidence-based findings is a hallmark of professionalism. In general, ICU nurses make 1 care decision every 30 seconds and approximately 9 important patient-care decisions per hour, suggesting that exercising judgment is a core nursing activity and influences the quality of care provided” (Papathanassoglou et al., 2012: 42). In their study, they found that lower levels of nursing autonomy directly correlated with experience of moral distress, desire to resign from their positions, and a lower perception of collaboration between nurses and

physicians (Papathanassoglou et al., 2012). Another nurse researcher, Milisa Manojlovich, found that

Autonomy represents one kind of power nurses need, and has been defined as "the freedom to act on what one knows" (Kramer & Schmalenberg, 1993:62). Therefore a key element of empowerment is nurses' control over their practice (Page, 2004). The ability to act according to one's knowledge and judgment is known as control over the content of nursing practice (Laschinger et al., 1997), and is often synonymous with autonomy. High levels of autonomy increased nurses' identification with the profession in one study (Apker, Ford, & Fox, 2003), providing recent empirical support for this supposition (Manojlovich, 2007:4).

Autonomy as it relates to power is deeply rooted in the feminist narrative, which is intrinsic to the practice of nursing as a predominantly female profession, with 97.3% of nurses identifying as women in demographic data collected by the Canadian Institute for Health Information (CIHI) in 2011. The relationship between power and autonomy is also central to the dynamic of relationships between physicians and nurses, since the profession of physician has been and remains rooted in masculinity and paternalism. The linguistic usage around MAiD placed the physician in a key role in MAiD, with early reference to the practice at HHS referring to ADRAS as "PADRAS" (Physician Assisted Dying Resource and Assessment Service) until recognition of the contributions of other health professionals led to the "P" being dropped from the title. This perspective was consistent across Canada, with the physician often being deemed central to MAiD, and the nurse being perceived as secondary. The lack of recognition for nursing skill represents a problematic aspect of medicine, wherein a female dominated profession experiences challenges having its expertise recognized with the same immediacy as that of those in greater positions of professional and social power. In her sociological study on the embodiment of practice and

power of nurses and physicians, Dr. Karen Davies describes the professional identity of the physician in her statement that

the foundational underpinnings of a profession – where medicine’s status is of course firmly assured – are inextricably bound up with a certain masculinist ideal, what could be called, I would argue, ‘hegemonic masculinity’ in Connell’s (1995) terms. The qualities that are associated with this form of masculinity, which Connell shows are historically constructed, can be described in the following terms: rationality, hierarchical authority, objectivity, decisiveness, physical and mental strength, competitiveness and individualism” (Davies, 2003:725).

Davies describes hegemonic masculinity in the context of physicians as a position in which their power is assumed without question, and is a form of social privilege (Davies, 2003).

However, it is in her description of the social structure of nursing that a clear problem emerges:

Medical technical knowledge and related skills are central to the occupation, although the nurse’s working day also involves a large degree of communication and administrative/managerial work. At the same time an important attribute of nursing from its inception to the present day is caring – the ability to nurture, to give comfort, show concern, dedication and warmth, make emotional contact and even sacrifice (Davies, 2003: 723).

These nurturing characteristics are traditionally associated with women, and as a result nursing is not constructed along the same lines of masculinist power that structure the profession of the physician. Socially, this leads to a degree of undervaluing the work of nurses, despite their technical expertise. In the context of MAiD and MAiD protocol development, these gendered stereotypes directly affected the designation of RNs as being insufficiently technically skilled to engage in assessment conversations. Paradoxically, since these conversations pertain to sociological, existential, and psycho-emotional

suffering, RNs are thus likely equally capable if not more capable than doctors in their capacity to carry out effective eligibility assessments.

Chapter 5

“If Not Me, Then Who?”: Physicians Who Provide MAiD

During my research, I was told a story by Sam, a physician participant, which not only resonated with me, but connected to the narrative of another physician whom I interviewed. Sam had begun their professional life as a social worker, and had seen first-hand the social inequalities affecting women’s health. They decided that the way they could best help women was to become a physician themselves. This decision was the start of their path to working in family medicine. Their entry into family medicine occurred during a period of change and controversy in medical practice when abortion, while still illegal, was being performed in Toronto. This period saw the arrests of both Dr. Morgentaler and Dr. Scott, pioneers in providing abortion services. Sam joined an advocacy group on behalf of women and their rights to self-determination, and stood among other like-minded physicians at the various criminal trials that ensued. Sam was among those physicians who stated that they too would step forward to perform abortions if these abortion providing physicians were sentenced to prison, so that abortions would continue in Canada, regardless of the outcome of these trials. This was a turning point, both in Canadian medical history and in Sam’s career. They trained to provide safe abortions in a clinical setting, and began their practice by providing abortions. At first, Sam only provided abortions a few times a week, but eventually their work led them to become a full-time abortion provider and a champion of women’s health both at a personal and professional level. A few years ago, they were giving a talk to young medical students and residents, and Sam was asked by a

student in the crowd why they did this kind of work. Their response was “If not me, then who?”

Out in the crowd at Sam’s talk, a young medical student, Alex, heard this response, and it resonated deeply. Alex would go on to become an Emergency Room physician, and then a key member of ADRAS. They played a crucial role in the development of the MAiD program at Hamilton Health Sciences. I was fortunate enough to interview both Sam and Alex, separately and without their awareness of my having interviewed the other. As I sat in Alex’s office and asked them how they had decided to become involved in MAiD, such a new and controversial practice, they repeated Sam’s words to me...

“If not me, then who?” ...

Physicians and Nurse Practitioners (NPs) take on a very specific role in MAiD assessment and provision. Under Bill C 14, it is these healthcare professionals who are required to conduct the two assessments to see if the patient qualifies for MAiD, and prescribe and provide the medications that hasten a patient’s death. ADRAS as a team is unique, in that it was constructed with a very team-based model at its center. On the ADRAS team, physicians do not have to stand alone as the sole assessors and providers, and in many cases, this structure provides support for physicians that is not common in other units within the hospital

For this chapter, I interviewed four physicians, all members of ADRAS. The following chart describes the specialties and areas of interest of the four physicians:

	Intensive Care	Emergency Medicine	Family Practice	End of Life Care	Abortion
Primary Clinical Practice	1	1	2		1
Areas of competency and interest				4	2

Figure 5.0: Areas of Specialty and Areas of Competency/Interest for Physician Participants (n=4)

The primary practices of the physicians were in the Intensive Care Unit (ICU), in the Emergency Room (ER), and in family practice. One physician identified themselves as equally involved in family practice and abortion provision. All participants expressed interest in and medical competency for end of life care (unrelated to MAiD provision). Both family medicine physicians had begun their careers in other fields, with the abortion provider beginning as a social worker and the other family physician beginning with a PhD in molecular biology and working for the Canadian government in occupational health and safety. The ICU physician and the ER physician both noted that they were motivated to become physicians by their life-long love of medicine, by a desire to emulate family members already practicing medicine, and by their ambitions to become a physician which dated from their earliest memories. Both family doctors who had chosen to become

physicians in their second career observed that they had been motivated to make this career decision by changes in women's rights, experience with inequalities in women's healthcare and roles in the workplace, and by the experience of taking on active roles in their communities and through organizations on behalf of women.

In this chapter, I will discuss how the professional identities and beliefs of these four physicians have impacted their willingness to participate in MAiD. I will discuss how this practice departs from the model of the "lone doctor" in medicine, and how that departure has been beneficial both professionally and personally for these physicians. I will address their beliefs around autonomy and self-determination, and their experiences with death and dying before Bill C14 was passed.

ADRAS, an Effective Shift from the "Lone Doctor" Model of Care

In 2013, Zwarenstein, Rice, Gotlib-Conn, Kenaszchuk and Reeves conducted 150 hours of qualitative data collection regarding the inter-professional engagements of physicians in an Ontario urban teaching hospital. This study involved participant observation of physician behaviours in four Clinical Teaching Units (CTUs) in an urban tertiary healthcare setting. The hospital setting described by Zwarenstein et al. (2013), is very similar to the hospital and teaching structures present at Hamilton Health Sciences. This article explores the daily, qualitative interactions that occur between physicians (intra-professionals) and other health professionals on their units (inter-professionals). The sociologist and the anthropologist who conducted the fieldwork observed brief, and at times "terse" interactions between physicians and non-physician health professionals, consisting

mainly of “reports, requests for information, or patient-related orders” (Zwarenstein et al. 2013: 1). The authors stated that “Without inter-professional problem identification and discussion, physician decisions take place in isolation” (Zwarenstein et al. 2013:1). This study provides an example of physicians conducting their work largely in isolation, as there were seldom more than a handful of physicians staffing a unit at any given time. Recognition of this phenomenon of physician isolation led to research into patient safety, with many studies attempting to explore ways to improve inter-professional communication, with the aim of improving patient outcomes. A study conducted by Leap et al. and cited in the policy statement issued by the College of Physicians and Surgeons of Ontario (CPSO) on “Physician Behaviour in the Professional Environment,” states that

the fundamental cause of our slow progress is not lack of know-how or resources but a dysfunctional culture that resists change. Central to this culture is a physician ethos that favors individual privilege and autonomy. We propose that disrespectful behavior is the “root cause” of the dysfunctional culture that permeates health care and stymies progress in safety and that it is also a product of that culture (Leap et al., 2012: 845).

ADRAS is inter-professional, comprised of allied health professionals, nurses, physicians, and clinical ethicists. The physicians who collaborate in the work conducted by ADRAS identify this team structure as a strength rather than a burden. The family physician cited the team dynamic as the reason for his willingness to provide MAiD, stating that

“I wasn’t sure that I wanted to do provision, but I could definitely see myself doing assessments and all that... taking on that position. But then, I was on the team, and the development and the training and that kind of stuff.”

This physician went on to discuss the two-person model of MAiD provision that the ADRAS team engages in. While this two-person model can include two physicians, it often

consists of a physician and a nurse or other allied health professional. The ER doctor made clear the value of collaborating with other health professionals, stating that,

“it has certainly been an enriching experience, to see and learn from others. To hear other nurses, physicians, and [allied health] professionals describe why they do it... I’ve watched a lot and have been listening to where they come from.

I have not been a part of a team before that has been [so] vocally supportive. The values, the constructs around the pre-briefing and the de-briefing, and the team support... the individual support... you know? I have been on lots of committees and lots of teams, but they just don’t function at that level. With that recognition that... there is more in the room than just the people’s job descriptions.”

That final statement is critically important, as it reflects appreciation for the personal experiences and investments that these non-physician professionals bring to MAiD. ADRAS, which brings together people from various professional backgrounds and allows them to share equally in the experience of providing MAiD, has broadened and strengthened this physician’s understanding of other health professionals.

The ICU physician went so far as to state that they “felt safe”, as they discussed their potential participation in MAiD with the ADRAS leaders. They stated that the team structure makes them feel secure in this practice, as they might otherwise feel very isolated and unsure conducting MAiD alone. In their mind, having team members from diverse backgrounds functioned as a quality assurance measure, and ensured that they would be protected both socially and legally as they participated. The abortion provider echoed this sentiment, stating that MAiD “is not scary” like performing abortion was in the early days. While there were other healthcare professionals who participated in abortion, it was not generally conducted using multiple professionals assigned simultaneously to a single

patient. Times have certainly changed since the earliest days of abortion and the general public is largely accepting of MAiD. Nonetheless, the team dynamic of ADRAS does create a sense of shared values and safety. The abortion provider stated that:

“I think that one of the reasons that being involved in ADRAS and this Canadian group (the Canadian Association of MAiD Assessors and Providers), is that you can speak about your work with pride. You can ask questions without worrying about people judging you, because you know you are in a friendly environment.”

After a career spanning decades working independently in abortion provision, this physician expresses appreciation for the benefits experienced working in a supportive team with shared morals and values. This team dynamic of support and collegiality is viewed positively and has had a significant impact on the way these physicians engage in their profession. The same abortion provider stated that ADRAS...

“is way beyond my expectations, it has been a positive experience. The support is so good, [sic] that I think it will really support my feeling good as my professional identity is enhanced by being on ADRAS. I feel like I will be on top of things, I will know when things are changing, so I can really give people [good care at the end of life].”

Since MAiD is a new practice, navigating these unknown waters together has meant that the ADRAS team members are all in a similar state of vulnerability and equality with regards to the distribution of power and knowledge. While inequality in power and knowledge distribution has previously been explored as a cause for tension among physicians and other health care professions (Leap et al., 2012), in the case of ADRAS, the team structure and shared commitment to MAiD provision served to break down these social barriers. As a result, ADRAS provides an example of the type of professional

development and collaboration that has been so sought after, but rarely achieved, in medicine.

Respect for Autonomy versus Allowance for Self-Determination

In order to fully address the differences between these concepts, we must first consider the issue of paternalism in medical practice. In her article “Can Medical Paternalism be Justified?” Katherine Brown (1985) explores the complexities of this hotly debated concept. In sum, Brown contends that medical paternalism involves decision making by physicians on behalf of patients in regards to what medical treatments will serve them best (Brown, 1985). This type of approach could be justified on the grounds that physicians hold specialized knowledge about medical care and health outcomes, but such paternalism creates complex ethical issues with respect to patient self-determination. A patient’s autonomy can be respected in many senses, however this respect may be more superficial than deeply rooted. A physician’s capacity to truly respect and honor self-determination requires a unique reverence for the patient as a person and for their rights.

The ADRAS physicians orient themselves toward the latter approach. Their respect for their patients and for patients’ rights is demonstrated through these physicians’ selfless and altruistic work both on their units and in their professional practices, as well as in their practice as MAiD providers. An example of true respect for patient self-determination came from the ICU physician. They discussed a patient they had treated a few years ago, who had sustained a significant traumatic injury to his head and spine in a vehicle accident. This patient was sedated, intubated, and had no prognosis of being able to live independently of

the ventilator and other supportive technologies. The family expressed the view that the patient would not want to live this way, and they wanted to take him off of life support. The family was interested in organ donation. However, the doctor knew that the patient was being kept in a medically induced coma, but might be able to return to consciousness and determine their own course of treatment. The unknown factor was whether or not this patient had that capacity or if waking him from the medically induced coma would add to his suffering. Ultimately, this physician ruled in favor of attempting to allow this patient to fully determine his own care and dying, and decided to wake him to have a conversation about his prognosis and potential organ donation. Upon awakening, the patient could only nod yes or no, but after probing conversations, he was determined to be competent and capable. He agreed with his family's decision to remove life support and donate his organs. He effectively became the first first-person organ donation to occur in Ontario.

This deep respect for self-determination is felt by the abortion provider/family physician as well. While personally opposed to sex-selective abortion, they had performed it. I had never previously considered that a pro-choice stance could lead to performing sex-selective abortions, but as this physician described it, "We do not decide their circumstances". They expressed a complex understanding of the social conditions affecting women, and understood that, in order to end sex-selective abortion, efforts must first be made to correct the social inequities that led women to make such decisions. No specific case was described by this physician, but rather a general experience with this phenomenon across their career. This was a deeply reflective, altruistic conversation that clearly

described the depth to which they tried to empower self-determination in their practice.

They stated that they had a unique

“willingness to simply allow people to make decisions about their own life. Which is about autonomy, but [also], the characteristic in the physician to recognize that a person has a right to full autonomy and to be willing to provide a service that meets their end, not mine.”

Similar sentiments were shared by the other family physician, who had a friend who had obtained an abortion in the United States before the procedure was legally accessible in their home state. This openness and willingness to provide a patient with care that meets their needs and only their needs was expressed by both family physicians through their descriptions of providing women’s health care.

In addition, the ER physician expressed the desire to allow for patient self-determination at the end of life in the context of medical care and culpability. He also clearly detailed how he has been able to participate in MAiD, and described the role that medicine can play in prolonging suffering. He stated that:

“I feel modern medicine has an obligation to be with them [the patients] in that spot [dying] as well, and provide options. It is really that process around whether or not we, as physicians, contributed to the suffering of this patient that they are now experiencing... in my opinion, the answer is yes. Therefore, we have an obligation to be there to respond to that suffering as well. And because not all suffering can be alleviated through other means, [that] is why I have been able to square that circle in my mind.”

A History of Caring for Those who Wish to Die

Family medicine was once a very broad practice, incorporating many procedures from delivering babies to palliative care for patients who were imminently dying in their homes. Family doctors cultivate personal relationships with their patients, and one of the

family doctors I interviewed lamented the loss of some of these relationships after giving up their practice to semi-retire. End-of-life care and follow-up with actively dying patients is a familiar process for these family doctors who have known their patients intimately over many years, and are therefore able to have difficult and emotional conversations with patients about death and dying. This familiarity gives family doctors a particular advantage when it comes to engaging in the assessment process for MAiD, as these difficult emotions and close personal connections to patients are not necessarily common in a tertiary care hospital setting.

One of the family physicians I interviewed discussed following patients as they moved into long-term palliative care facilities at the end of their lives, and visiting them to ensure that their needs were being met. They expressed sadness when their patients died in those settings, and when they were informed of their passing by family members. Both family doctors spoke of attending patients' funerals. The abortion provider/family physician discussed an elderly couple, who told them of their very rational wish to die if their health were to worsen. This elderly couple, whom they described as "lovely, bright, funny people," had been coming to see them more frequently for prescription medications. Upon probing, they learned that they were stockpiling these medications and were part of the Hemlock Society, an organization that advocated the right to die. It was at this moment that they realised how rational the desire for a peaceful death was, and they stated that they "presented it to me in such a way that it just seemed to be totally reasonable".

The ER physician has competency in palliative care, which at first, seemed like an odd combination to me. Surely, the skills to manage end-of-life care would be at odds with

the ER goal of saving patients' lives. However, this physician described how the ER has become the place where palliative patients in the community come to die, in his experience.

They stated that

“When there is a crisis, many call 911 and come to hospital where the system kicks in around them...you see patients actively dying, so you see people within the last hours and days of their lives and on a regular basis. Because of [the way] our society [works], we are not comfortable with our loved ones dying at home with us. It's not something we are familiar with, even in the last 30 or 40 years there has been a dramatic change in the way people die.”

This sentiment that familiarity with death and palliative care is a regular part of practice was shared by the ICU physician. They stated that

“most of the time, in the context that I work, most people are asking to have life support taken away. Which is a form of asking for assistance in dying, but it's not like someone who is well, and giving them a medication. So I've had patients who have wanted to come off life support, and I've had family members who have wanted their loved one to come off life support, so I have intersected with this very grey line.”

Physicians in these positions are no strangers to death and to providing support for the dying and their families. This unique engagement in end-of-life care, even though it did not define their professional identity prior to MAiD, has provided them with the skills and capacity to provide a compassionate response in challenging situations. These physicians have brought these skills, among others, to ADRAS and MAiD provision.

Chapter 6:

A Discussion of MAiD Practice and ADRAS

There are many features that make MAiD in Canada uniquely Canadian, just as there are many factors that make the ADRAS team unique to Hamilton Health Sciences. This chapter will focus on the broad themes that were detected throughout this research, as well as on the specific cultures and norms that contributed to the development of MAiD in a Canadian context and in the context of ADRAS at Hamilton Health Sciences. The chapter will conclude with a review of the methodology used in this research, and the ways that it affected the data and participant recruitment.

Canada and the Culture of MAiD, and its Future

The distinction between homicide and MAiD and the language around Bill C14 are critical in the construction of this practice, as is evident by how deeply divisive MAiD remains in Canadian medicine. A CBC news report from Halifax in 2015 stated that a “significant minority” of physicians would be interested in performing MAiD with only 29% of respondents willing to provide it (CBC, 2015). Approximately a year after this report, I listened to another CBC radio broadcast from Halifax on assisted suicide, which featured a physician as an expert who spoke out against MAiD. The ICU physician I interviewed for my study had also heard this broadcast, and felt outraged that the featured expert was speaking for the medical profession in general. The ICU physician commented that their outrage about this broadcast had been a motivator for their own vocal public support of MAiD. However, the ICU physician also confirmed my own observation, which

was that the majority of the members of the public who participated in the “call-in” portion of the broadcast drew attention to the needs of patients over the needs of physicians who might be reluctant to participate in MAiD. The ICU physician referred to these callers as courageous, and paraphrased their sentiments in our discussion, claiming that the general public view is “I don’t care what you think, this is my body, and my life, and if this is what I want, I expect you to step up to the plate even if it’s a little uncomfortable”. The advocacy group Dying with Dignity found in 2016 that “Eight in 10 Canadians agree that individuals with a grievous and irremediable medical condition, including patients with dementia, should be permitted to consent to assisted death in advance” (Dying with Dignity, 2016). It should then come as no surprise that in Canada, advocacy for MAiD began with patients and families.

Zones of MAiD and the Importance of the Identity of Professionals and Clinical Units

Through this study, I have had the opportunity to shadow the ADRAS team and other clinical groups in HHS over the first year during which MAiD has been available in the system. As a result, I have had a unique opportunity to observe how this practiced has developed. The most common areas of MAiD provision in HHS are in oncology and palliative care, which is not surprising as these units are concerned with suffering and dying. However, the ADRAS team is composed of clinicians from the ICU, Family Medicine, Emergency, and the allied health professions, who are not bound to any single unit.

I have also observed some of the tensions that have arisen around MAiD at a professional level. For example, some palliative care physicians in a broad context across Ontario, and psychiatrists specifically in HHS, have taken a stance against this practice. This is not to say that all professionals in these fields across Canada share the same opinions, but in HHS, representatives of each field have expressed the following principles:

“we do not hasten death”

“we do not encourage suicide.”

Earlier this year, palliative care physician and vocal opponent of MAiD Dr. Mark D’Souza published a commentary on Bill C14 in the Toronto Sun, arguing that it

ignores the conscience rights of doctors like myself, who oppose euthanasia on ethical grounds and, in its current form, will decrease public access to palliative care. In 2015, the College of Physicians and Surgeons of Ontario changed its human rights policy to say doctors who oppose euthanasia must refer their patients who want to be considered for it to another doctor to carry out. Doctors like myself argue this provision — known as effective referral — involves us in the euthanasia process against our will (D’Souza, 2017).

There are several concepts worth noting and exploring in this stance, which is certainly not held by all palliative health care professionals, but which I have observed in the HHS network. The first concept to be explored is what constitutes palliative care and the goals of palliative care professionals. The College of Physicians and Surgeons (CPSO) describes effective end of life care in the following statement:

Providing quality end-of-life care involves addressing and managing the physical, psychological, social, and spiritual needs of patients, while being sensitive to their personal, cultural and religious values, and beliefs. Quality end-of-life care also

aims to reduce suffering, respect the wishes of patients, and lessen conflict and distress (CPSO, 2016).

Comparing the excerpt from Dr. D’Souza’s article with the excerpt from the CPSO document, it is notable that one stance is centered around the ethics and beliefs of the physician, and the other centers around the ethics and beliefs of the patient. The capacity to prioritize patients’ wishes in health care is closely related to the ways in which professionals identify themselves and attribute meaning to their work. How they identify the goal of their work will have a significant impact on the care they are able to deliver. The difference between a patient-centred approach and a physician-centred approach is not based on protocol, policy development, or practice guidelines but rather on how a physician or other health care provider interprets the goals of medicine and constructs their professional role around these interpretations.

The relationship between psychiatry professionals and MAiD is complicated by the fact that MAiD involves patients in actively seeking death and psychiatry has traditionally sought to prevent suicide. Psychiatric illnesses and their relationship to the Carter Criteria and impact on patient capacity have been hotly debated. Dr. Sonu Gaind, president of the Canadian Psychiatric Association, has stated that “the lack of established standards and guidelines, compounded by barriers to mental illness services and treatments, leaves people with mental illness vulnerable [to excessive personal and bodily risk] and must be addressed before making PAD available to them” (Canada Post, 2017). Fears about the abuse of MAiD are not unfounded in psychiatry. Patients who have depression or any other type of mental disorder as their sole medical condition could theoretically meet the Carter

Criteria of suffering from a grievous and irremediable illness. However, as they would not technically meet the criteria of having a reasonably foreseeable death (although that too, could be debated), it would seem that MAiD would not currently be available to them. There have been some expressed concerns by psychiatrists that, due to the limited number of individuals in this profession, those that involve themselves would quickly find themselves overworked and over-used in MAiD assessments. This certainly presents ethical challenges to psychiatrists who, under no conditions, would counsel mentally ill patients to commit suicide. However, this consideration should not exclude psychiatrists entirely from all MAiD practice, which all of the physicians who participated in my research identified as a potential problem. At times, cognitive capacity to give informed consent to a procedure can be hard to assess and psychiatry would seem to be uniquely skilled to clarify such cases. The relationship between psychiatry and MAiD has been additionally challenging in Hamilton, as inpatient adult psychiatry is currently housed at St. Joseph's Hospital, which is a Catholic health care institution. While the St. Joseph's CEO Kevin Smith clearly stated in an interview with the Hamilton Spectator that the hospital would provide effective referrals for patients and allow them to transfer to other institutions that do provide MAiD, he also stated that "We think it's pretty important to remain true to the mission, vision and values" (Frketich, 2016). This position provides another example of how institutional identity, as well as professional identity can impact MAiD provision and the willingness of health care practitioners to participate in the procedure.

The Effect of Personal Experience on Professional Identity and MAiD Participation

This thesis addressed the broad range of thoughts, professions, and motivations for participating in MAiD. The way that one identifies with their profession and how they determine what their professional goals and objectives should be is an iterative and complex process that is steeped in both personal and professional experience. The following matrix identifies the facets of values formation in the context of MAiD:

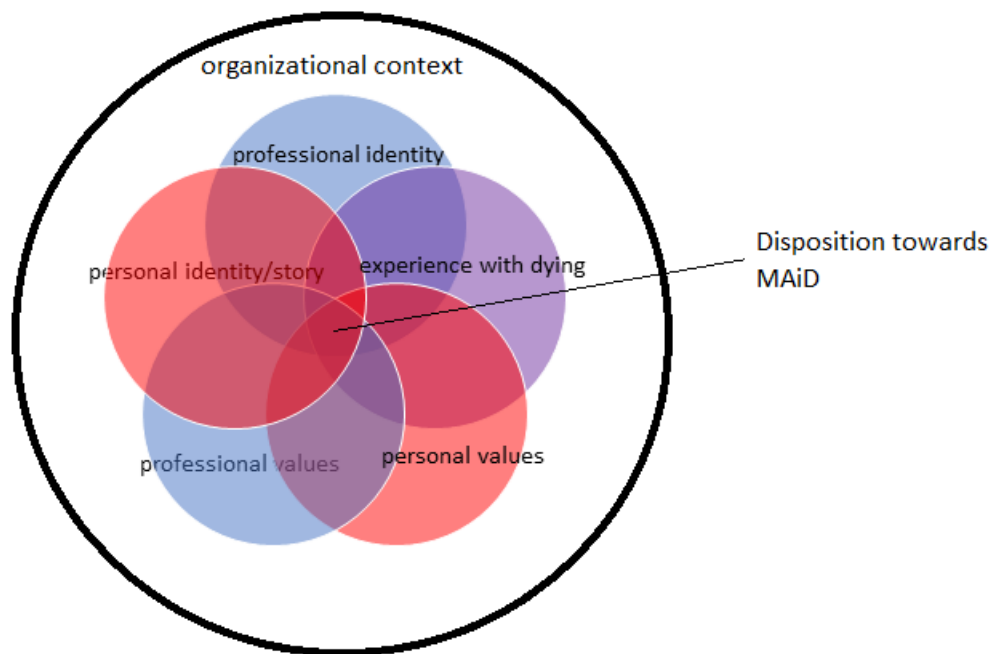


Figure 7.0: disposition of professionals towards MAiD participation, Venn diagram

MAiD is complex, and often individual experiences and influences directly contribute to how an HCP will operate within their profession, form their professional identity and define the goals of that profession. In this sense, it offers an explanation for why there is variability

in support and participation in MAiD, as not all HCPs will share identical experiences of their lives and careers. The above graphic explores how experience with death and dying, personal identity/story, personal values, professional identity and professional values affect disposition towards MAiD participation within overarching organizational contexts. How these circles are influenced by the context of one's lived experience changes the types of values and identities that HCPs use to construct and operate within their practice in a way that is morally correct to them. In the cases of the MAiD providers who participated in this research, their personal experiences with death and dying both in professional settings and personally deeply affected their capacity to participate in this practice. All instances of death were discussed in relation to their other lived experiences, and how they understood suffering was deeply related to these experiences. In this sense, one cannot separate the personal and the professional spheres of life. Instead, they feed one another.

The concept of self and the concept of group are often held as distinct in the anthropological literature. Anthropologist Martin Sokefeld states that

Anthropological characterizations of “the other” are often inversions of European self-images (Fardon 1990: 6). This certainly applies to understandings of others' selves. In the conceptualization of non-Western selves, the Western self was taken as the starting point and the non-Western self was accordingly characterized as its opposite: unbounded, not integrated, dependent, unable to set itself reflexively apart from others, unable to distinguish between the individual and a role or status that individual occupies, unable to pursue its own goals independently of the goals of a group or community (Sokefeld, 1999: 417)

He describes how concepts of “self” even vary cross culturally, and are no more fixed than any other form of identity. The identity of a person and the identity of a profession directly

influence one another, and are thereby intrinsically bound. I remember hearing a term in evolutionary biology many years ago, that resonates in regards to those that participate in MAiD. Preadaptation is a biological principle, whereby in nature organisms may have certain features that are adaptive in a new ecological niche or changing environment that result in excellent functioning in this new environment with very little structural adjustment required. These organisms are thus already in possession of a characteristic that is advantageous for their survival and reproductive fitness in their new environment (Russel, 2010). I argue that in the case of MAiD, some HCPs have been preadapted to become an effective part of this practice, through their previous personal and professional experience. For these individuals the right circumstances, professional goals, and predisposition were already in place to enable them to adapt quickly to MAiD, when it became a part of their environment. The particular professionals who participated in this study were metaphorically, like organisms living very close to the edge of change, and thus when the change came, they were able to adapt and succeed in this new environment.

The Role of the Applied Anthropologist in MAiD and ADRAS

The establishment of the ADRAS team was a long process, with significant advance research conducted in both the Netherlands and Quebec, jurisdictions where MAiD was already legal, by Dr. Andrea Frolic who is a clinically applied anthropologist and clinical ethicist at HHS. Readiness assessments and assessments of what services and resources would be required in order to enable HHS to offer MAiD with a high level of care, compassion and effectiveness were carried out by Dr. Frolic as well (Frolic and Miller,

early 2016). Finally, hiring and structuring of the ADRAS team was conducted by Dr. Frolic. This situation had significant influence on the language used in provision of this service, the way that MAiD is practiced at HHS, and the professionals involved in MAiD (Frolic and Miller, June 2017).

The language used in this service is very unusual in medicine. The language of the ADRAS team often involves terms such as “reflection” and other such language that is common to social sciences and humanities research, but not necessarily present in a medical setting. Almost all of the participants in my study recognized at one point in our interviews that the language used to present MAiD to the public and other health care professionals at HHS had evolved under the guidance of this anthropologist. In addition, the willingness of ADRAS team members to address the variation in patient language and worldview in order to provide an assessment of suffering on the patient’s own terms reflects the anthropological principle of listening to emic, experience-near or insider voices. ADRAS incorporates anthropological methods into the assessment process. For instance, ADRAS members use reflexivity to enhance their understandings of patient experiences and suffering, as well as changes to their own lives and values (Miller and Frolic, August 2016). This has made ADRAS capable of conducting appropriate patient assessments by thinking reflexively and recognizing a patient’s words and how their own life and story have attributed unique meanings to their choice of language and ascribed meaning to their illness.

Medical paternalism has been previously mentioned in this thesis. I have shown that the ADRAS team members I interviewed are opposed to such paternalism and this attitude

is connected to their willingness to participate in MAiD. As the team was developed largely by Dr. Frolic, the incompatibility of medical paternalism with MAiD practice was recognized early on in the process. It is reasonable to assume that the recruitment materials for the team, the interview structure and the HHS policy and protocol for MAiD assessment and provision as developed by an anthropologist worked to discourage health care providers who might have been paternalistic in their practice from participating in ADRAS.

Religious Diversity and ADRAS

ADRAS is extraordinarily religiously diverse, as indicated in the following chart:

ADRAS Team members	No Particular religion	Christianity	Roman Catholicism	Buddhism	Judaism	Atheism	General Spirituality
Primary Orientation	3	1	2	1	1	1	1
Indirect experience			1				

Figure 8.0: Religious Orientations of Interview Participants from ADRAS (N=11)

Three of the participants identified with no particular religion or spiritual beliefs. One identified as having a Christian background, two identified as Roman Catholics, one identified as a Buddhist, one identified as Jewish, one as an atheist and one who had general spiritual beliefs but not within the doctrine of a religious institution.

This is an interesting phenomenon, and could influence future research around the degree of religious involvement and MAiD provision. However, since I had no opportunity

to assess the degree of affiliation or importance of religion in their lives, I am hesitant to advance definitive conclusions about the degree of impact this factor might have on their participation in MAiD practice.

Limitations of this Research Methodology

The recruitment for this research was structured around snowball sampling, beginning with the ADRAS team. While this approach resulted in two non-ADRAS members being recruited to this study, ultimately it led to very consistent opinions about support for MAiD. I also sought to recruit members of other steering committees and teams at the hospital through the Director of Clinical and Organizational Ethics at HHS. While I attempted to recruit health care providers who were strongly opposed to this practice, and who had made their stance publicly known in HHS, I was ultimately unsuccessful in recruiting them to this study. There are a handful of factors that affected recruitment.

The first factor that likely had an impact on recruitment was time. Interviews for this study were between 45 minutes and an hour in length, making participation challenging for health care providers with busy careers and a large patient load. The second factor that may have affected recruitment involved the ways in which I constructed an interview guide. I constructed it by doing a mock interview with the clinical ethicist and a physician who is a supportive of MAiD practice. As a result, my questionnaire may have inadvertently conveyed a bias in support for this practice that acted as a deterrent for those who conscientiously object to it. In addition, through my method of snowball sampling, I

received contacts from health care professionals who are actively participating in this practice, and that may have meant that I was less likely to encounter conscientious objectors or those with moderate opinions about MAiD.

Despite these limitations, the use of a grounded theory method for data analysis led to an enhanced understanding of the professional identities of active participants in MAiD, and this constitutes a relevant and unique contribution to the literature on assisted dying in Canada.

Chapter 7:

Conclusions

This research has assessed the ways that health care professionals supporting and participating in MAiD construct their professional identities. The study has established that allied health care professionals who participate in MAiD on the ADRAS team have experienced few changes to their professional roles since the legalization of MAiD. Rather, these allied health care professionals have found that their professional experiences and expertise offer additional skills and supports to the physicians and nurses who are the assessors for and providers of MAiD. Nursing professionals who support and participate in MAiD identify themselves as patient advocates, whose primary professional goal is to support the physical, spiritual, and social needs of patients from a holistic medical standpoint. The physicians who participate in MAiD reject the paternalistic notions that are deeply engrained in their profession, and instead see themselves as providing meaningful care to patients at the end of life when there are no longer acceptable treatment options. Canada decriminalised MAiD as a result of patient and public advocacy, but there is still work to be done.

The future of MAiD in Canada will be in flux for a few years to come, as precedent-setting cases are brought forward challenging Bill C14 on issues such as the provision of MAiD for patients with mental health disorders, the use of advance directives to request MAiD, the accessibility of MAiD for mature minors, and for those whose death is not reasonably foreseeable but who determine their suffering to be intolerable and

irremediable. ADRAS, a team characterized by exceptional patient-centeredness, will continue to evolve and grow with the legislative changes and under the guidance of its physicians, allied health care professionals, and nurses. It has seen extraordinary growth in its first year, and will continue to provide MAiD to patients at Hamilton Health Sciences and beyond for years to come.

Contributions of this Thesis to Clinically Applied Anthropology

Currently, there is limited anthropological work on MAiD in a Canadian context. This thesis contributes to the understanding of professional identity in a medical context, as well as to the ways that MAiD is being integrated into the Canadian medical landscape.

This thesis also contributes to the literature concerning assisted dying, which has been largely physician-focused. The ADRAS team has experienced name changes over the first year of its existence, with MAiD originally being referred to as PAD (physician assisted dying) and ADRAS being referred to as PADRAS (Physician Assisted Dying Resource and Assessment Service). The changes to these terms occurred once the contributions of nurses, chaplains, social workers, pharmacists, and psychologists became recognized as necessary and valuable in the construction of this practice.

This thesis also addresses the role of anthropology in a tertiary care hospital setting, in which many social conditions and actors are present. Medicine extends far beyond the physiological and biological pathologies that constitute disease, and anthropology is vital in understanding and navigating the social and cultural subtexts of this system. The applicability of anthropology to real-world problems and issues is evident in the

contributions of the medical anthropologist who took on a central role in the structuring of ADRAS. Much of the knowledge communicated to this team relating to patient experiences, language and social needs is derived from anthropology.

Future Research

Topics for future research concerning the relationship between professional identities and MAiD, and the moral diversity that is intrinsic to this practice, have been identified as this research was being conducted.

Research regarding the significance of religious orientation, and how religious faith affects attitudes toward MAiD would be a significant contribution to the research on assisted suicide and anthropology. This thesis suggests that while religion does play a role in the construction of personal identity, it has little impact on professional identity in non-religious medical institutions. A comparative study between religious and non-religious medical institutions and professional identities in those different types of institutions would expand upon some of the themes identified in this research.

More research with palliative care health professionals and psychiatrists would provide insight into their specific stances on MAiD and how the development of their professional identity informs their moral position. As this thesis used a grounded theory approach and the sampling methodology led to data that only involved supporters and providers of MAiD, research pertaining to dissenting opinions would provide a complementary contribution to the anthropological literature.

Research on how MAiD will affect professionals in terms of their psychosocial wellbeing, resilience, and identity will need to be addressed in the years to come. This study was conducted on participants in the very first year of MAiD access, and as such they have not formed identities affected by long-term participation. I would recommend that a study similar to this occur after five years of MAiD practice.

Finally, research on the role of patients and families in MAiD, and the changing doctor-patient dynamic associated with this new practice would build upon current anthropological literature about the meanings of being a patient, the sick role and the changes MAiD has brought to patient self-determination.

Closing Remarks

I hope this thesis will help medical professionals identify their goals and moral positions with regards to MAiD. I also hope that my study can help in the recruitment of additional capable and engaged participants to the ADRAS team. Finally, I hope this thesis will help remove some of the taboos around MAiD as a practice, and encourage health care providers to discuss death and dying in ways that allow patients to have a clear picture of their outcomes and their end of life options. I hope that by doing so, patients can truly plan for and facilitate a death that honours their life, dignity and experience.

Appendix I

General Questions

Introductory Questions

- a. Tell me about your professional history
 - i. When did you become interested in it and why?
 - ii. How did you pursue your profession, what motivated you?
 - iii. How would you describe your profession when you first started?
How would you describe it now?
- b. Do you have a system of beliefs that help guide you in your practice?
 - i. Can you speak to the origins of these beliefs?
 - ii. How did they develop?
 - iii. Have they changed over time? If so, how and why?

Main Questions

- c. Have you ever received an informal request for assistance in dying before the legislation was produced?
 - i. What was your experience with that?
- d. Would you say you have observed intolerable suffering?
 - i. How would you diagnose this degree of suffering in a patient?
- e. What concerns you most about receiving a request for assistance in dying now?
 - i. What would be an effective means of addressing these fears or concerns?
- f. What good do you hope will come from access to assisted dying for patients?
- g. Can you identify your moral position on assisted dying?
 - i. How has your position developed? Has it always been as you stated?
 - ii. What experiences led you to develop this position?
- h. Has assisted dying changed the way you view your professional role?
 - i. Do you think it has changed your relationship with colleagues?
 - ii. Do you think that has changed your relationship with patients?
 - iii. What was your relationship with patients like prior to assisted dying?
- i. How do you think assisted dying will shape your profession in the future?
- j. How far would you feel comfortable following a patient who makes a request for assistance in dying?
 - i. What barriers would you expect to encounter?
- k. Is there anything you wish to add?

Additional Questions

- l. One of the criteria required to be eligible for assisted dying is that the patient must be experiencing intolerable suffering.
 - i. What is your understanding of intolerable suffering?
 - ii. How would you diagnose intolerable suffering?
 - iii. What are the limits of medicine, in terms of treating suffering?
- m. What would you say, is the biggest risk (be it legal, social, etc.) to you both personally and professionally when you are approached with a request for assistance in dying?
 - i. How will you minimize this perceived risk?
 - ii. Do you feel that the process of educating those entering your profession will be changed as a result of assisted dying?
 - iii. How do you think these changes will be addressed?
 - iv. How would you like to see it addressed?
- n. Is there anything else you wish to say?

Appendix II

ADRAS Questions

- A) What were your thoughts and motivations when you first applied to be a part of ADRAS?
- B) What were some of your hopes and worries when your application was accepted?
- C) Do you perceive any risks associated with being a part of ADRAS?
- D) How do you think being part of ADRAS might affect your professional identity?
 - a. Does it affect how your colleagues see you?

Works Cited

- Asch, D. (1996). The role of critical care nurses in Euthanasia and assisted suicide. *New England Journal Of Medicine*, 335(13), 971-974.
<http://dx.doi.org/10.1056/nejm199609263351312>
- Attaran, A. (2015). Unanimity on death with dignity — legalizing physician-assisted dying in Canada. *New England Journal Of Medicine*, 372(22), 2080-2082.
<http://dx.doi.org/10.1056/nejmp1502442>
- Bereza, E. (1994). The Private and Public Deaths of Sue Rodriguez. *The McGill Law Journal*, 39(2), 719-724. Retrieved from
http://lawjournal.mcgill.ca/userfiles/other/4579767-39.3_Bereza.pdf
- Berghs, M. (2005). The complexity of nurses' attitudes toward euthanasia: A review of the literature. *Journal Of Medical Ethics*, 31(8), 441-446.
<http://dx.doi.org/10.1136/jme.2004.009092>
- Blank, K., Gruman, C., Schwartz, H., & Curry, L. (2002). Could Adequate Palliative Care Obviate Assisted Suicide?. *Death Studies*, 26(9), 757-774.
<http://dx.doi.org/10.1080/07481180290106535>
- Brown, K. (1985). Can medical paternalism be justified?. *Canadian Medical Association Journal*, 133(7), 678-680.
- Butler, M., Tiedemann, M., Nicol, J., & Valiquet, D. (2013). Euthanasia and assisted suicide in Canada. *Library Of Parliament*. Retrieved from
<http://www.lop.parl.gc.ca/Content/LOP/ResearchPublications/2010-68-e.pdf>
- C-14 (42-1) - Royal Assent - An Act to amend the Criminal Code and to make related amendments to other Acts (medical assistance in dying) - Parliament of Canada.*

(2016). *Parl.ca*. Retrieved 11 August 2017, from <http://www.parl.ca/DocumentViewer/en/42-1/bill/C-14/royal-assent>

Callahan, D. (1992). When self-determination runs amok. *The Hastings Center Report*, 22(2), 52. <http://dx.doi.org/10.2307/3562566>

Canada, P. (2017). *Psychiatrists welcome cautious approach to mental illness and medical assistance in dying - Canadian Psychiatric Association - Association des psychiatres du Canada*. Canadian Psychiatric Association - Association des psychiatres du Canada. Retrieved 11 August 2017, from <http://www.cpa-apc.org/psychiatrists-welcome-cautious-approach-to-mental-illness-and-medical-assistance-in-dying/>

Canadian Medical Association. (2011). *Physician views on end-of-life issues vary widely: CMA survey*. Retrieved from <https://www.cma.ca/Assets/assets-library/document/en/advocacy/EOL/2011-CMA-End-of-Life-Survey-Press-Release-e.pdf>

Carter v. Canada - BC Civil Liberties Association. (2015). *BC Civil Liberties Association*. Retrieved 10 August 2017, from <https://bccla.org/our-work/blog/death-with-dignity-case/>

Cassell, E. (1991). Recognizing suffering. *The Hastings Center Report*, 21(3), 24. <http://dx.doi.org/10.2307/3563319>

Chan, B., & Somerville, M. (2016). Converting the 'Right to Life' to the 'Right to Physician-Assisted Suicide and Euthanasia': An Analysis of *Carter v. Canada* (Attorney General), Supreme Court of Canada. *Medical Law Review*, 24(2), 143-175. <http://dx.doi.org/10.1093/medlaw/fww005>

Chapple, H. (2010). *No Place For Dying*. Walnut Creek: Taylor and Francis.

- Chochinov, H. (2016). Physician-assisted death in Canada. *JAMA*, *315*(3), 253.
<http://dx.doi.org/10.1001/jama.2015.17435>
- Christie, T. (2016). *Assisted Dying presentation, Horizon Health Network*. Presentation, Toronto, Canadian Bioethics Conference.
- Clinch, J., Karam, A., Fainsinger, R., Kuhl, D., O'Shea, F., & De Luca, M. et al. (2007). Desire for euthanasia or physician-assisted suicide in palliative cancer care. *Health Psychology*, *26*(3), 314-323. <http://dx.doi.org/10.1037/0278-6133.26.3.314>
- Close, J., Zou, F., Dai, Y., Duff, J., Meyer, L., & Schmit, J. (2016). Perspectives on death and dying: A study of resident comfort with end-of-life care. *BMC Medical Education*, *16*(1). <http://dx.doi.org/10.1186/s12909-016-0819-6>
- Davies, K. (2003). The body and doing gender: the relations between doctors and nurses in hospital work. *Sociology Of Health And Illness*, *25*(7), 720-742.
<http://dx.doi.org/10.1046/j.1467-9566.2003.00367.x>
- De Beer, T. (2004). Involvement of nurses in euthanasia: A review of the literature. *Journal Of Medical Ethics*, *30*(5), 494-498.
<http://dx.doi.org/10.1136/jme.2003.004028>
- Docherty, S., Anderson, R., Bailey, D., & Adams, J. (2011). Nursing roles and strategies in end-of-life decision making in acute care: A systematic review of the literature. *Nursing Research And Practice*, *2011*, 1-15. <http://dx.doi.org/10.1155/2011/527834>
- Donato, A., Smilovitch, M., Liben, S., Hutchinson, T., Anthony, D., & Wald, H. (2015). Professional identity formation in medical education for humanistic, resilient physicians. *Academic Medicine*, *90*(6), 753-760.
<http://dx.doi.org/10.1097/acm.0000000000000725>

Douglas, C., Kerridge, I., & Ankey, R. (2011). Narratives of Terminal Sedation, and the Importance of the Intention-Foresight Distinction in Palliative Care Practice. *Bioethics*, 27(1), 1-11. <http://dx.doi.org/10.1111/j.1467-8519.2011.01895.x>

Duffy, O. (2015). The supreme court of Canada ruling on physician-assisted death: Implications for psychiatry in Canada. *The Canadian Journal Of Psychiatry*, 60(12), 591-596. <http://dx.doi.org/10.1177/070674371506001211>

Durkheim, E. (1897). *Suicide*. republished in 2013, Routledge Co. London: Www Snowballpublishing Co.

Dyer, J., & Keller-Cohen, D. (2000). The discursive construction of professional self through narratives of personal experience. *Discourse Studies*, 2(3), 283-304.

Eggertson, L. (2015). Most palliative physicians want no role in assisted death. *Canadian Medical Association Journal*, 187(6), E177-E177. <http://dx.doi.org/10.1503/cmaj.109-5003>

Ellershaw, J. (2003). Care of the dying patient: The last hours or days of life * commentary: A "good death" is possible in the NHS. *BMJ*, 326(7379), 30-34. <http://dx.doi.org/10.1136/bmj.326.7379.30>

Elvey, R., Hassell, K., & Hall, J. (2013). Who do you think you are? Pharmacists' perceptions of their professional identity. *International Journal Of Pharmacy Practice*, 21(5), 322-332.

Emanuel, E. (2000). Attitudes and practices of U.S. Oncologists regarding Euthanasia and physician-assisted suicide. *Annals Of Internal Medicine*, 133(7), 527. <http://dx.doi.org/10.7326/0003-4819-133-7-200010030-00011>

- Evans, R., & Stoddart, G. (1990). Producing health, consuming health care. *Social Science & Medicine*, 31(12), 1347-1363. [http://dx.doi.org/10.1016/0277-9536\(90\)90074-3](http://dx.doi.org/10.1016/0277-9536(90)90074-3)
- Francis, S., & Hackett, E. (2001). Pharmacists' characteristics and their views of physician-assisted death. *International Journal Of Pharmacy Practice*, 9(S1), 19-19. <http://dx.doi.org/10.1111/j.2042-7174.2001.tb01079.x>
- Frketich, J. (2017). *St. Joseph's Health System wants to opt out of doctor-assisted death* / *TheSpec.com*. *TheSpec.com*. Retrieved 11 August 2017, from <https://www.thespec.com/news-story/6499982-st-joseph-s-health-system-wants-to-opt-out-of-doctor-assisted-death/>
- Frolic, A., & Miller, P. (early, 2016). *Preparing for Assisted Dying: a values-based approach to a paradigm shift*. Presentation, Hamilton Health Sciences.
- Frolic, A., & Miller, P. (2017). *Creating an interprofessional, whole-person, values-based approach to Medical Assistance in Dying (MAiD) in acute care*. Presentation, Canadian Foundation for Healthcare Improvement, June 21st.
- Gawande, A. (2014). *Being mortal*. Doubleday Canada.
- Georgakopoulou, A. (2006). Thinking big with small stories in narrative and identity analysis. *Narrative – State Of The Art*, 16(1), 122-130.
- Green, J. (2012). *Beyond the good death*. Philadelphia, Pa.: University of Pennsylvania Press.
- Groundbreaking poll: 8 in 10 Canadians support the right to advance consent for assisted dying*. (2016). *Dying With Dignity Canada*. Retrieved 10 August 2017, from http://www.dyingwithdignity.ca/advance_consent_assisted_dying_poll

Guidance on Nurses' Roles in Medical Assistance in Dying. (2017). *CNO.org*. Retrieved 2 September 2017, from <https://www.cno.org/globalassets/docs/prac/41056-guidance-on-nurses-roles-in-maid.pdf>

Hewitt, J. (2013). Why are people with mental illness excluded from the rational suicide debate?. *International Journal Of Law And Psychiatry*, 36(5-6), 358-365.
<http://dx.doi.org/10.1016/j.ijlp.2013.06.006>

Hurley, R. (2015). A doctor who chose an assisted death. *BMJ*, h4385.
<http://dx.doi.org/10.1136/bmj.h4385>

Jecker, N. (1995). Medical futility and care of dying patients. *The Western Journal Of Medicine*, 163(3), 287+. Retrieved from
go.galegroup.com/ps/i.do?p=AONE&sw=w&u=ocul_mcmaster&v=2.1&id=GALE%7CA17568217&it=r&asid=2d341a30c34fde459165d425f04b2ed1

Jerome, D. (2015). *A Review of Euthanasia Policies in Canada. Historical Review of Medical Aid in Dying.* Retrieved 12 September 2017, from
http://www.physicianslegacy.ca/FileManager/Recipients/docs/awards_scholarships_11.pdf

Kane, D., & Thomas, B. (2000). Nursing and the "F" Word. *Nursing Forum*, 35(2), 17-24. <http://dx.doi.org/10.1111/j.1744-6198.2000.tb00994.x>

Kaufman, S. (2006). ... *And a time to die.* Chicago: University of Chicago Press.

Kevorkian, J. (1988). The Last Fearsome Taboo: Medical Aspects of Planned Death. *Medicine And Law*, 7(1), 1-14.

Kirkey, S. (2017). 'Agent of mercy' or doctor of death? *First physician jailed over assisted suicide has no regrets. National Post.* Retrieved 8 March 2017, from

<http://news.nationalpost.com/news/canada/agent-of-mercy-or-doctor-of-death-first-physician-jailed-over-assisted-suicide-has-no-regrets>

Kolers, A. (2013). Am I My Profession's Keeper?. *Bioethics*, 28(1), 1-7.

<http://dx.doi.org/10.1111/bioe.12056>

Latest nursing numbers from CIHI reveal Ontario has the worst RN-to-population ratio in Canada | Registered Nurses' Association of Ontario. (2017). *Rnao.ca*. Retrieved 27 August 2017, from <http://rnao.ca/news/media-releases/2016/06/01/latest-nursing-numbers-cihi-reveal-ontario-has-worst-rn-population-ra>

Leape, L., Shore, M., Dienstag, J., Mayer, R., Edgman-Levitan, S., Meyer, G., & Healy, G. (2012). Perspective: a culture of respect, part 1: the nature and causes of disrespectful behavior by physicians. *Academic Medicine*, 87(7), 845-852.

<http://dx.doi.org/10.1097/acm.0b013e318258338d>

Lowes, R. (2016). *Assisted Death: Physician Support Continues to Grow.* *Medscape*.

Retrieved 20 April 2017, from <http://www.medscape.com/viewarticle/873844>

Manojlovich, M. (2007). Power and Empowerment in Nursing: Looking Backward to Inform the Future. *The Online Journal Of Issues In Nursing*, 12(1), 1-15.

Mauron, A., & Hurst, S. (2006). The ethics of palliative care and euthanasia: Exploring common values. *Palliative Medicine*, 20(2), 107-112.

<http://dx.doi.org/10.1191/0269216306pm1109oa>

Medical Assistance in Dying (MAID) in the ED: Implications for EM Practice - CanadiEM. (2017). *CanadiEM*. Retrieved 26 September 2017, from

<https://canadiem.org/medical-assistance-dying-maid-ed-part-ii/>

Miller, F., & Brody, H. (1995). Professional integrity and physician-assisted death. *The Hastings Center Report*, 25(3), 8. <http://dx.doi.org/10.2307/3562107>

Miller, P., & Frolic, A. (August, 2016). “My patient is asking about assisted dying... what do I do?” *Practical tips for tough conversations*. Presentation, Hamilton Health Sciences.

Mwaria, C. (2017). Physician-Assisted Suicide: An Anthropological Perspective. *Fordham Urban Law Journal*, 24(4).

Norwood, F. (2007). Nothing More To Do: Euthanasia, General Practice, and End-of-Life Discourse in the Netherlands. *Medical Anthropology*, 26(2), 139-174. <http://dx.doi.org/10.1080/01459740701283165>

Oak, S., & Pols, H. (2013). Physician-assisted dying and psychiatry: Recent developments in the Netherlands. *International Journal Of Law And Psychiatry*, 36(5-6), 506-514. <http://dx.doi.org/10.1016/j.ijlp.2013.06.015>

Ogden, R. (1994). The right to die: A policy proposal for Euthanasia and aid in dying. *Canadian Public Policy / Analyse De Politiques*, 20(1), 1. <http://dx.doi.org/10.2307/3551832>

Ogden, R. (1994). The right to die: A policy proposal for Euthanasia and aid in dying. *Canadian Public Policy / Analyse De Politiques*, 20(1), 1. <http://dx.doi.org/10.2307/3551832>

Öhlén, J., & Segesten, K. (1998). The professional identity of the nurse: concept analysis and development. *Journal Of Advanced Nursing*, 28(4), 720-727. <http://dx.doi.org/10.1046/j.1365-2648.1998.00704.x>

- Onwuteaka-Philipsen, B., Willems, D., Rurup, M., & Pasman, H. (2009). Concept of unbearable suffering in context of ungranted requests for euthanasia: Qualitative interviews with patients and physicians. *BMJ*, 339(nov16 1), b4362-b4362. <http://dx.doi.org/10.1136/bmj.b4362>
- Papathanassoglou, E., Karanikola, M., Kalafati, M., Giannakopoulou, M., Lemonidou, C., & Albarran, J. (2012). Professional Autonomy, Collaboration With Physicians, and Moral Distress Among European Intensive Care Nurses. *American Journal Of Critical Care*, 21(2), e41-e52. <http://dx.doi.org/10.4037/ajcc2012205>
- Parker, M. (2013). Defending the indefensible? Psychiatry, assisted suicide and human freedom. *International Journal Of Law And Psychiatry*, 36(5-6), 485-497. <http://dx.doi.org/10.1016/j.ijlp.2013.06.007>
- Parliament of Canada*. (2016). Retrieved 9 November 2016, from <http://www.parl.gc.ca/HousePublications/Publication.aspx?Language=E&Mode=1&DocId=8384014>
- Physician Behaviour in the Professional Environment*. (2016). *cpso.on.ca*. Retrieved 8 August 2017, from <http://www.cpso.on.ca/CPSO/media/documents/Policies/Policy-Items/Physician-Behaviour-Professional-Environment.pdf?ext=.pdf>
- Physicians per 100,000 population by Province/Territory, 1986-2015*. (2017). *Canadian Medical Association*. Retrieved 27 August 2017, from https://www.cma.ca/Assets/assets-library/document/en/advocacy/12-Phys_per_pop.pdf
- Porter, S. (1992). Women in a women's job: the gendered experience of nurses. *Sociology Of Health And Illness*, 14(4), 510-527. <http://dx.doi.org/10.1111/1467-9566.ep10493131>

Quill, T. (1995). 'You promised me I wouldn't die like this!' A bad death as a medical emergency. *Archives Of Internal Medicine*, 155(12), 1250-1254.

<http://dx.doi.org/10.1001/archinte.155.12.1250>

Regulated Nurses: Canadian Trends, 2007 to 2011. (2017). *Canadian Institute for Health Information*. Retrieved 3 September 2017, from

https://secure.cihi.ca/free_products/Regulated_Nurses_EN.pdf

Rietjens, J., van der Maas, P., Onwuteaka-Philipsen, B., van Delden, J., & van der Heide, A. (2009). Two Decades of Research on Euthanasia from the Netherlands. What Have We Learnt and What Questions Remain?. *Journal Of Bioethical Inquiry*, 6(3), 271-283. <http://dx.doi.org/10.1007/s11673-009-9172-3>

Robb, N. (1997). Death in a Halifax hospital: a murder case highlights a profession's divisions. *CMAJ*, 157, 757-762.

Robb, N. (1998). The Morrison ruling: the case may be closed but the issues it raised are not. *Canadian Medical Association Journal*, 158, 1071-1072.

Rodriguez v. British Columbia (Attorney General) et. all (1993).

Ruf, C. (2015). *Gloria's story*. *Dying With Dignity Canada*. Retrieved 10 August 2017, from http://www.dyingwithdignity.ca/gloria_taylor

Russell, P. (2010). *Biology* (p. 455). Toronto: Nelson Education.

Ryynänen, K. (2001). *Constructing physician's professional identity – explorations of students' critical experiences in medical education*.

SCHNEIDER, K. (2017). Dr. Jack Kevorkian Dies at 83; A Doctor Who Helped End Lives. *The New York Times*. Retrieved from <http://www.nytimes.com/2011/06/04/us/04kevorkian.html>

Segesten, K., & Öhlén, J. (1998). The professional identity of the nurse: Concept analysis and development. *Journal Of Advanced Nursing*, 28(4), 720-727. <http://dx.doi.org/10.1046/j.1365-2648.1998.00704.x>

Seid, J., Gorenflo, D., Waterhouse, D., & Doukas, D. (1995). Attitudes and behaviors on physician-assisted death: A study of Michigan oncologists. *Journal Of Clinical Oncology*, 13(5), 1055-1061. <http://dx.doi.org/10.1200/jco.1995.13.5.1055>

Sheldon, T. (2007). Andries Postma. *BMJ*, 334(7588), 320-320. <http://dx.doi.org/10.1136/bmj.39111.520486.fa>

'Significant minority' of doctors support assisted death, CMA says. (2015). *CBC News*. Retrieved 10 August 2017, from <http://www.cbc.ca/news/canada/nova-scotia/canadian-medical-association-still-polarized-by-doctor-assisted-deaths-1.3203143>

Sökefeld, M. (1999). Debating Self, Identity, and Culture in Anthropology. *Current Anthropology*, 40(4), 417-448. <http://dx.doi.org/10.1086/200042>

Somerville, M., & Chan, B. (2016). Converting the 'Right to Life' to the Right to Physician Assisted Suicide and Euthanasia: An Analysis of Carter v. Canada (Attorney General) Supreme Court of Canada: Table 1. *Medical Law Review*, 24(2), 143-175. <http://dx.doi.org/10.1093/medlaw/fww005>

Stott, J., & Tomlinson, E. (2014). Assisted dying in dementia: A systematic review of the international literature on the attitudes of health professionals, patients, carers and

the public, and the factors associated with these. *International Journal Of Geriatric Psychiatry*, 30(1), 10-20. <http://dx.doi.org/10.1002/gps.4169>

Sumner, L. (2013). *Assisted death: A study in ethics and law*. Oxford: Oxford University Press.

Timeline: Assisted suicide in Canada. (2015). *CBC News*. Retrieved 2 September 2017, from <http://www.cbc.ca/news/health/timeline-assisted-suicide-in-canada-1.2946485>

Tucker, T. (2009). Culture of death denial: Relevant or rhetoric in medical education?. *Journal Of Palliative Medicine*, 12(12), 1105-1108. <http://dx.doi.org/10.1089/jpm.2009.0234>

van der Heide, A., van Tol, D., Weyers, H., Vezzone, C., van der Vegt, B., & van de Vathorst, S. et al. (2012). Opinions of health care professionals and the public after eight years of euthanasia legislation in the Netherlands: A mixed methods approach. *Palliative Medicine*, 27(3), 273-280. <http://dx.doi.org/10.1177/0269216312448507>

Vijayalakshmi, P., Nagarajaiah, Reddy, P., & Suresh, B. (2017). Indian Nurses' Attitudes Toward Euthanasia. *OMEGA - Journal Of Death And Dying*, 0(0), 003022281668857. <http://dx.doi.org/10.1177/0030222816688576>

Vollmann, J., & Gather, J. (2013). Physician-assisted suicide of patients with dementia. A medical ethical analysis with a special focus on patient autonomy. *International Journal Of Law And Psychiatry*, 36(5-6), 444-453. <http://dx.doi.org/10.1016/j.ijlp.2013.06.016>

Watson, J. (1981). Professional identity crisis-is nursing finally growing up?. *AJN, American Journal Of Nursing*, 81(8), 1488-1490. <http://dx.doi.org/10.1097/00000446-198108000-00027>

- Werth, J., Preston, T., & Blevins, D. (2005). Characteristics of persons approving of physician-assisted death. *Death Studies*, 29(7), 601-623.
<http://dx.doi.org/10.1080/07481180591004606>
- Weyers, H. (2006). Explaining the emergence of euthanasia law in the Netherlands: how the sociology of law can help the sociology of bioethics. *Sociology Of Health & Illness*, 28(6), 802-816. <http://dx.doi.org/10.1111/j.1467-9566.2006.00543.x>
- Widdershoven-Heerding, I., Widdershoven, G., & Berghmans, R. (2013). Physician-assisted suicide in psychiatry and loss of hope. *International Journal Of Law And Psychiatry*, 36(5-6), 436-443. <http://dx.doi.org/10.1016/j.ijlp.2013.06.020>
- Wittwer, H. (2013). The problem of the possible rationality of suicide and the ethics of physician-assisted suicide. *International Journal Of Law And Psychiatry*, 36(5-6), 419-426. <http://dx.doi.org/10.1016/j.ijlp.2013.06.009>
- Young, A., & Rodriguez, K. (2006). Patients' and healthcare providers' understandings of life-sustaining treatment: Are perceptions of goals shared or divergent?. *Social Science & Medicine*, 62(1), 125-133.
<http://dx.doi.org/10.1016/j.socscimed.2005.05.023>
- Zwarenstein, M., Rice, K., Gotlib-Conn, L., Kenaszchuk, C., & Reeves, S. (2013). Disengaged: a qualitative study of communication and collaboration between physicians and other professions on general internal medicine wards. *BMC Health Services Research*, 13(1). <http://dx.doi.org/10.1186/1472-6963-13-494>
- Zwarenstein, M., Rice, K., Gotlib-Conn, L., Kenaszchuk, C., & Reeves, S. (2013). Disengaged: a qualitative study of communication and collaboration between physicians and other professions on general internal medicine wards. *BMC Health Services Research*, 13(1). <http://dx.doi.org/10.1186/1472-6963-13-494>

