

Putting a Bow on Death and Dying

Health Care Professionals' Experiences with Medical Assistance in Dying (MAiD)

A Foucauldian Discourse Analysis with Agambian Insights

Practice Based Research Paper

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Abstract

This paper employs a Foucauldian Discourse Analysis perspective to enrich the understanding of the experiences that health care professionals in Ontario, Canada have with medical assistance in dying. Interview data is analyzed by situating the health care professional as an effect, as a producer, and as a challenger of power-knowledge systems. Philosophical theories of Giorgio Agamben are applied to the data to challenge Foucauldian principles, and to bolster the discussion of defining of the body that deserves to live, and the body that deserves to die.

Major findings that emerged include the dominant discourse of aligning right and good within confines of the law, and the absolution of quantification and generalizability in relation to definitions surrounding dying. In terms of next steps for social work practice, this paper concludes by asking social workers to interrogate why we feel the need to ‘put a bow on death and dying’, so that we may engage in critical conversations with our colleagues.

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Chapter 1: An Introduction

Introduction to the Research Topic, Me, the Participants, and the Ethics

My objective is not to make generalizations. When you put on your Foucauldian and Agambian lenses, coloured with your own unique tint, you may see the uncanny in the so-called common place and the remarkable in the mundane. I do hope to leave you questioning what we consider normal and common sense. As the data will reveal, and as social workers know, it is discourses of common sense and normal that serve to privilege some and marginalize many.

Medical assistance in dying (MAiD) became legal in Canada in June of 2016 (Browne and Russell, 2016). This recent legislation means that not enough time has passed, both historically and politically, to accumulate a large body of Canadian literature that takes up the experiences of health care professionals who work with people seeking support in accessing MAiD. Much of the literature that does exist disseminates opinions of MAiD, and examines how MAiD fits within or opposes palliative care models. Many scholars argue that social workers must be trailblazers in facilitating conversations about death and dying. However, social workers are also implicated in that they contribute to a powerful body of knowledge that reproduces discourses which give way to ideologies that describe bodies that have the right to die, and bodies that have the right to live (Good, Higgins, Sneesby and van der Riet (2009) & Lutfiyya and Schwartz (2013).

My own relationship with MAiD was inspired by the conversations I had with staff and clients at a hospice where I completed my BSW field placement. These conversations were further complicated by applying critical theoretical perspectives, like Foucauldian Discourse Analysis (FDA), which I gained a richer understanding of during my MSW. In the media, and in

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talking with friends and family, I found it fascinating that MAiD could not be discussed without tying in one's own opinion. I questioned where opinions come from, and if an opinion is the sole responsibility of the person who holds it. I thought it would be interesting to talk with people who work directly with those considering MAiD. I chose to complicate their experiences using FDA, in which does not seek to find the truth, but can provide a base for a deep analysis of relationships with power and knowledge (Foucault, 1982). Through this, I hoped to provide myself and social workers with a more critical understanding of dying and death, so that we may feel comfortable with starting conversations about dying and death with others.

The data and interview excerpts that inform the analysis of this research comes from seven nurses, social workers, and personal support workers. I interviewed these participants over the phone and via Skype, which seemed to work well, as it accommodated various schedules and further honoured confidentiality. The interviews ranged from twenty five minutes to over an hour. I maintained the specifics outlined in my proposal: I asked a few structured questions and then allowed the conversation to flow more organically; in any direction the participant wanted to go. As my confidence and inspiration grew after every interview, so did the breadth and depth of the interviews. I began to understand that discussions of MAiD were personal, deep, and complex, and needed to be undertaken with utmost care, consideration, and openness. Often times, when dialogue was permitted to roam freely, most of my structured questions were also answered. If people think their thoughts are important to others, and are given unlimited time in an appropriate setting, they are happy to talk.

ExpressScribe software churned out my own and my participant's voices at 40% of their usual speed, so that I could accurately type along. This method of transcribing allowed me to analyze between dialogues. Listening to my own and participant's cadence, pauses, and emotion

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proved an important asset to my data coding and analysis process. It gave me important insight into how I can improve as an interviewer. An added bonus, though unrelated to the specifics of my study, is that my typing average words per minute increased substantially.

I began my coding process by considering Foucault's "modes of objectification" (Foucault, 1984, p. 11). By considering these modes, which serve to "categorize, distribute, and manipulate" (Foucault, 1984, p. 12), I was able to group the data into ten broad themes. These themes were made up of language and behavior that spoke to power relations at large, and also focused on ideologies that function through law, ethics, and policy: the outputs, or practices of power. I included two standalone themes: language and behavior that reinforces dominant discourses, and language and behavior that mutually reinforces and disrupts dominant discourses. Here, the awareness of my own influence over my research washed over me, and I felt slightly nauseous. While Foucauldian and Agambian theory and methodology are the anchor of my research, I am the root of it, and by selecting and focusing on certain data versus others, I am subconsciously and consciously reproducing and disrupting dominant discourses.

Ten themes were too many. When I went back and read through my colour-coded themes, I saw a beautiful, yet overwhelming rainbow. I went back to my research question, back to my theory, back to my methodology. I read a few more articles. I took a nap, went to work, and purposefully didn't look at the data again for a few days.

I re-read my themes, and ended up focusing now on how each theme could fit very well within multiple themes. The most common overlapping themes were ethics and law, and each remaining themes seemed to collapse into these two themes. My issue now was the distinguishing characteristics of each theme. I realized that the only reason I was still separating

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“law” from “ethics” was linguistic, in that I had allotted a full theme to “law” because I had placed any reference to law and legislation immediately into this category. In my mind, the law seemed like this over-arching power, there as a constant but to never be challenged, yet always used as the end all, be all argument rebuttal: “Well, it’s the law.” But law itself is not a discourse, so there must be something that shapes and defines law. In the interview: “The Ethic for the Concern for the Self as a Practice of Freedom”, Foucault refers to freedom as “the ontological condition of ethics” (Foucault, 1984, p. 284). Ethics provide us a map where we can position ourselves along axis that define our sense of professional subjectivity. By locating a spot on this map that suits the requirements of our selves, it affords us the freedom of professionalism.

Foucault refers to ancient Greek and Roman constructions of caring for the self in discussing the origins of ethics. According to Foucault, this self-knowledge was very important, especially to the Greeks, because a thorough understanding of one’s self was a critical foundation for achieving mastery. Foucault argues that ethics allow people to turn an inward lens on themselves, thereby allowing them to see if they measure up to societal standards of care (Foucault, 1994, p. 285). If you are familiar with western and British social work literature, you may be familiar with contentions surrounding the importance of mastery. Foucault’s (1994) example of freedom through mastery affords us a poignant, yet dated reference to a human performance that is still very much practiced, albeit sometimes unconsciously and necessarily today. In her thesis, *Desire for Development: The Education of White Women as Development Workers*, Barbara Heron (1999) posits that white, female bourgeois identities that began in the late eighteen hundreds are still being acted out and reinforced in today’s development work done to the south by the north. Women were afforded little rights surrounding property ownership and personhood, and were left to seek power in places less occupied by men, including religious

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charitable missions, and therefore oversea missions. In reality, even though women occupied positions of power concerning defining and controlling the welfare of themselves and other people, women then and now rarely occupy the highest positions of power: the positions that have the most influence. Concerning development projects, Kagwanja (1997) and Heron (1999) contend that the fundamental right to develop Africa is not that of Africans. It is very dangerous when developments occur that are not self-driven or controlled. I argue that the term *development* should only be used when applied to the self, as any other meaning can only bring about harm. Heron's (1999) thesis supports the dire need for education surrounding anti-racism and the "deconstruction of whiteness" (Heron, 1999, p. 3) for white learners. While my research is not explicitly grounded in anti-racist or feminist theory, I believe that it is imperative to acknowledge and address the undeniable intersectionalities of gender and race (namely Whiteness) that emerge through the data. Foucault (1994) and Heron (1999) discuss how we come to define ourselves as subjects based on morality and goodness. To know what we are, we must also know what we are not, and in applying this to contemporary, Western social work, and to my own subject positionality in particular, I therefore must interrogate my white, female self and my role in the theoretical and methodological interpretation of the data. Heron (1999) discusses how the positioning of the white, female development worker came to be. I believe this can be applied to white social work acted out in Canada as well, because my experiences as a white social worker in Toronto have almost always, if I have allowed them to, magnetized me towards defining and then fixing a problem in someone. My history as a white, Canadian-born, cis-female raised in a Catholic, nuclear home compels me to find those problematic that are not me. At the same time, my academic and practical experience as a critical social worker means that because I am a white, Canadian-born female raised in a Catholic, nuclear home, I must

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always work intentionally to counter the magnetic pull of my privileges that make it all too easy for me to check out and become complacent.

The rather long-winded point of my bringing up Heron's work on white development efforts is that that development work and professional ethics are two in the same, and are created, defined, and reinforced via standards of Whiteness. Each findings chapter will discuss how professional ethics surrounding MAiD are taken up, reinforced, and challenged by health care professionals. The first chapter will focus on language and behaviour ascribing to Foucauldian notions of power and knowledge. The second chapter will take on an Agambian lens to unpack ideas that serve to reinforce and challenge definitions of a body deserving of death and a body deserving of life. When reading this, I challenge you to bear in mind that this is my perception of the data; which is serving to uncover hidden meaning and alternative discourses. Also, please remember as you are reading to challenge any thoughts you may have or that you see written here that attempt to create single stories (Badwall, 2016) of the living and the dying. This is one way to challenge dominant discourses, and create new narratives.

Situation Within a Scholarly Field

My review of the literature points to the necessity of conversations with social workers, nurses, doctors, and other health care professionals about their professional experiences with MAiD. By interviewing these professionals and analyzing these interviews through Foucauldian discourse analysis (FDA), I hope to identify discourses that discuss rights to life and rights to death.

As a white, female, Canadian born, diagnostically healthy, social worker and researcher, I do hold a certain amount of influential power. The limitations and ethical challenges of my

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proposed study will shape the entirety of my study. I too will be contributing to literature that produces discourses, and tells only one perception of truth: my own. My conclusions will morph and change, as my subject positionality shifts throughout different parts of this research study, whilst my identity as a researcher develops in tandem.

This research will strive to fill gaps identified in my literature review. Several themes emerged from existing literature. Many studies position MAiD legislation in relation to best practices in palliative care, but these studies are founded on professional opinions of broad populations. Only narrative studies offered up experiences that did not reach for generalization, or single-storying. Multiple definitions of medical assistance in dying emerged in the literature. This further suggests professional's removal from an individual's dying process. Another theme that emerged was the idea that conversations about death are difficult for all parties involved, and that the responsibility for fine-tuning these conversations rests on the shoulders of social workers. This paper will further expand on this theme, and what it means for future social work practice.

Methodological and Theoretical Framework

The orientation of social work has not changed much since its' conception. It masks as an egalitarian profession that vies to raise up marginalized peoples, when it in fact seeks to impress political figures. In doing so, social work forces people into white, Christian standards of normalcy (Chambon, Irving, & Epstein, 1999). Social work, as we know it was created by social workers. We continue to problematize and define illness, sanity, and essentially, the moral aptitude of the populations that we work with. This protects our professional livelihood – our agencies rake in the funding, and we appear indispensable. But we are lying to ourselves and to

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those we are supposed to be providing equitable service to if we deny this truth. This nagging, soul-crushing truth is my impetus for completing this research project as honestly as possible. To do this, I will have to understand and utilize a methodology that places a mirror in front of social workers and other helping professionals. I think it's time we interrogate how even our micro practices can create discourses that further divide, marginalize, and ostracize groups of people. Through my own experience, and through my review of the current literature, it is evident that health care professionals have many concerns about MAiD, but many of these concerns do not include the perspective of the people accessing MAiD themselves. This research will attempt to reveal how this is influencing our definition of bodies that are healthy and full of life, and bodies that are sick and near dying. Through Foucauldian understandings of power and knowledge, this research may also lessen the divide between patients and professionals.

Foucauldian discourse analysis informed my research, but cannot be appropriately defined as a theory or methodology (Foucault, 1982). According to Foucault (1982), FDA seeks to understand how history shapes people as subjects, and how people's objectification by different types of power shapes people as subjects. While FDA is neither a methodology nor theory, I will discuss the ways in which FDA informed how I collected and analyzed data, and how FDA coloured the lens through which I viewed my study.

I chose this particular mode of analysis because FDA seeks to examine how discourses created by the state regulate control over bodies through governmental structures and punishment (Foucault, 1975, 1978, Rose 2000, Buckland, 2016). According to Foucault (1972) and Buckland (2016), discourses change throughout history, and are massively influenced by political climate. Discourses produce ideologies that prescribe truth, knowledge, and language (Foucault, 1972).

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Foucauldian discourse analysis differs from other discourse analysis methodologies in that it does not seek to analyze talk and text, but rather seeks to “describe rules, divisions, and systems of a particular body of knowledge” (Arribas-Ayllon & Walkerdine, 2008, p. 99). FDA seeks to find out how certain things came to be. In terms of my research, it will be helpful in determining how and why certain practices surrounding death have become normalized, and what constitutes these normalities. FDA examines discipline through the specification of institutional knowledge, and through the practices by which these knowledges are formed (Arribas-Ayllon & Walkerdine, 2008).

Perhaps the most applicable characteristic of FDA to my research is that it examines practices that produce knowledges and truths (Arribas-Ayllon & Walkerdine, 2008). In terms of my study, I believe that listening to and analyzing health care professional’s experiences of MAiD will give way to a greater understanding of how discourses shape our society’s knowledge, and more specifically, our beliefs and values surrounding life and death. Furthermore, my study will perhaps reveal further insight into which bodies fit into categories that discern the right to die from the right to live.

Foucault situates power in the objectification of subjects in three realms: language production, the constitution of the productive subject, and how bodies become objectified by simply being alive (Foucault, 1982). Within these realms exist “dividing practices” (Foucault, 1982, p.777). These practices seek to objectify subjects both internally and externally. These practices divide “the sane from the insane, the criminals from the “good boys”, and the sick from the healthy” (Foucault, 1982, p.778).

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While critical social work practice most commonly aligns Foucault's divisions on a continuum rather than existing in a vacuum, I think it is important to ask why these divisions exist at all. In reference to Immanuel Kant's influence on philosophical discourses, Foucault (1982) challenges us to go beyond thinking that it is good enough to simply know that political justifications are capable of immense influence. We may think that we are not meant to know what else exists outside of our own political and historical existence. These notions are within us because of structural powers over us. These powers give way to dominant discourses, which Foucault argues that we must take up, question, and find the roots of in order to solve "original problems" (Foucault, 1982, p. 779).

In the first chapter of my findings, I will apply Foucault's concepts of power-knowledge systems to main themes revealed through the data. I will discuss the experiences of health care professionals through the results of being subjugated to specific power-knowledge systems. I will detail the dominant discourses that health care professionals are mutually the effects of, and produce. I will also identify points where participants challenge power-knowledge systems by resisting dominant discourses and attempting to create new discourses.

In the second chapter of my findings, I will be utilizing concepts from Giorgio Agamben's *Homo Sacer* (1995). Agamben argues that sovereign power is connected to bare life, which is life that solely exists in exclusion through violence and subjugation of sovereign power (Genel, 2006). Agamben challenges Foucault's posit that sovereign power is directly correlated to one's ability to have rights. Agamben's conceptualizations of the overcomatose body, bare life, and biopower will be applied to my discussion of data that speaks to definitions and characteristics of bodies that have the right to die, versus the right to live. The idea of bare life will help me discuss death and dying from a critical perspective, which will destabilize and

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interrogate what we often take for granted as normal or common sense when it comes to dying and death.

I want to be clear that I am a junior researcher borrowing FDA and Agambian interpretations from a small pool of scholars whose understandings and applications of FDA appeal to me, and are applicable to my study. I was first introduced to FDA while completing a class on mental health and madness during my undergraduate social work degree. Concurrently, I was taking a philosophy class for the first time. I became very aware of my mind expanding and my thinking becoming deeper and less exhaustive. I devoured the assigned literature, and searched for literature to read on my own time. I fell in love with critical modes of analysis and metaphysics. I enjoyed the challenge of thinking deeply, conversing with others on this new wavelength, and attempting to address questions I realized I always had, but was finally able to draw out of myself after being exposed to this new way of seeing the world.

Shortly after, I completed my fourth year, BSW practicum with a community-based hospice. I was asked to research how; if possible, MAiD could be integrated into hospice philosophy. My first reaction was to fear and doubt my capability to do any amount of justice to this research question, as hospice “neither hastens nor prolongs death” (Balfour et al., 2013, p.6). I spent a long while painstakingly trying to figure out how to mesh these two approaches. After spending more time listening to hospice stakeholders, I realized that their main concerns were not related so much to policy amalgamation and bigger picture items, but were more individual and team oriented concerns. To put it simply, they were concerned with how to work within a new historical and political environment. They did not know what to expect, and therefore could not anticipate how they would cope. They were trying to find courage within the unknown, as they were all of a sudden tasked with going first - being trailblazers. One of the clients I was

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working with was considering MAiD, and the ripple effect of their consideration was challenging and emotionally draining to navigate as a student, as a younger person, and as a social worker.

I learned from this experience that it's not possible to do justice. Not then, during my hospice practicum, and not now, while I begin my first research study. I am, by way of my subject positionality, objectifying those considering MAiD. I am bringing this up because FDA allows me to become as close to the object while being a subject. FDA will allow me to extract and analyze discourses that emerge through the interview questions. I hope to be able to use FDA to reflect these discourses back at myself, and back to health care professionals. I believe the data will reveal discourses surrounding life and death, and that social workers, and more broadly, health care professionals, are implicated in the production of these discourses, and therefore the categorization of sick and healthy, and the right to die and the right to live.

Badwall (2016) asks us to write against single stories so that we do not homogenize entire groups of people and/or conjure up groups of people that do not exist outside of "isms". In attempting to do this, I want to make it explicitly obvious that I will not assume the interviews are experiences in their entirety. I have learned that people have their own process of telling stories, and often already know what they want to say, and how much they want to disclose. I understand this is also dependant of my subject positionality in relation to those I will interview. Furthermore, each section of this research paper and the sum of its parts is my interpretation only. This is unsettling to me because I know that my act of research is reproducing power over and dominant discourses. Before I started this research study, I was not aware of my own power. I had read and listened to how social workers had impacted people via various systems levels, but I had never felt like I was committing acts of violence before the commencement of this research.

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Macias (2016) writes about the ethics of archiving data. The author asks researchers to consider how they are reproducing dominant discourses through acts of collecting, analyzing, and archiving data. Macias (2016) argues that placing someone else's story on a page is an act of violence in that it reconstructs an already reinterpreted account of someone else's story. In completing my study, I am using my own analysis to reconstruct and interpret other people's experiences. This violence continues throughout the data analysis and writing process, and is continued during archiving, which is when this story – a mere interpretation, is organized, stored, and passed on to readers. The part of this whole process that makes me the most scared of my own dangerous power is the idea that my work can become encapsulated in time. Archiving is an exercise of dominant power in that it produces only certain accounts of history. A major example of this is the deliberate omission of history from an Indigenous perspective in classrooms across Canada. In the case of my particular research study, it may stay perpetually confined to the MSW PRP library on the eighth floor of the Ross building. Nevertheless, anyone who reads this will be influenced not by the truth, but only by my interpretation of the stories others tell me.

Research Design

Health care professionals were selected via purposive and snowball sampling. I chose to facilitate one-on-one, semi-structured interviews with health care professionals because this method reveals how discourses are shaped and informed. While I previously defined the professions that fit within the confines of *health care professionals*, I was interested to see if any potential participants challenged this definition by interrogating the word *professional*, or inquired whether they are indeed health care professionals if they did not fit into my categories of *social worker, nurse, doctor, or volunteer*. I was aware that my defining the term *professional* was deliberate and with purpose. In my experience, the above-mentioned professions work the

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closest with people who are dying. Again, I want to restate that my experience, which has shaped my perspective, motivated me to select these specific professions for my study. This is only one perspective, it is not *the* truth. I had chosen to call my participants *professionals* for the sake of clarity in my study description and title. While doing this, I realized the problematic elements of professionalizing those other than people accessing MAiD themselves. I believe that people know themselves better than anyone else, and I think that this ideology disrupts dominant discourses surrounding truth, knowledge, and professionalism. By naming my participants as health care professionals, I am contributing to the dominant discourse of White, Western professionalism.

Purposive sampling allowed me to interview professionals I had already established relationships with, which was helpful due to the time constraints of this research study. Snowball sampling ensured that I interviewed both people I know and people I don't know, and allowed for the data to become more applicable to the experiences of other health care professionals in Canada. The confidentiality of interview participants was protected in several ways. A flyer outlining the study was posted throughout York University and several social services agencies, circulated on Facebook, passed on via email, and circulated by professional contacts I had already established. Participants sourced through snowball sample were able to contact me via email, and I sent them further information about my study.

I facilitated semi-structured interviews with health care professionals. Semi-structured interviews allowed respondents to have more control over the direction the interviews took, as they could speak more freely about experiences that were important to them (Barbour, 2014). Similarly, one-on-one interviews facilitated an environment where respondents felt more comfortable in sharing their experiences, without concern of being scrutinized by their peers.

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Additionally, one-on-one interviews minimized the risk that respondents' confidentiality could have been jeopardized. I believed that this method for gathering data meshed well with FDA in that it could create a space that facilitated openness and honesty.

Interview data was audio recorded and subsequently transcribed by myself. Barbour (2014) and Hammersley (2010) argue that interviewers establish how and what they transcribe on very powerful assumptions. In constantly bearing in mind my own assumptions that I brought to this study, I began my data coding by examining my research questions and field notes. I utilized a conventional, data-derived analysis, as described by Hsieh and Shannon (2005) and Barbour (2014). This analysis firstly identified themes and codes presented throughout the entirety of each transcript. Secondly, I interrogated these themes and codes to see if they were related and produced sub-categories (Barbour, 2014). Thirdly, I looked for themes and codes that emerged when making cross-comparisons of each participant's answer to each question. I then looked for patterns and repetitions that occurred across transcripts.

While themes and codes emerged during the data analysis phase of this research study, I utilized Foucault's (1978) discussion, "Right of Death and Power Over Life" as a lens that directed and focused my thought process on the data. Foucault (1978) asserts that power over life and death is maintained by two levels of force: the largest being "bio-political regulation" (Foucault, 1978, p.135), which regulates and defines which bodies are deserving of life and death, and disciplinary powers, such as schools, that "seek to optimize the use of the body's capacities" (Foucault, 1978, p.135). Foucault (1978) argues that while bio-power can be found in ideological forms, it is more evident discursively, in the ways some elements are and become homogenous and static, such as sexuality, healthy, and sick.

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Ethical Considerations

I complied with York University's standards for ethical research. I submitted my dissertation proposal, informed consent form, and recruitment flyer to the graduate program office for approval. I understood that my participants could have been at emotional risk due to the sensitive nature of my research study, and so I prepared counselling referrals, and had factored interview breaks into the timing of my interviews. I was explicitly clear, both verbally and in hard copy that participants could end their participation in the study at any time.

I had many personal ethical considerations in completing this study, which I have elaborated on in previous sections of this chapter. My biggest concern was that I would commit acts of violence in capturing and interpreting stories that were not mine. I continued this research study whilst being fully aware that while I attempted to write against (Badwall, 2016) dominant discourses, I also perpetuated them through my subject positionality. As I contemplated this, I cried because I weighed, after reading and learning what I know about the research process, if this was at all even worth doing. At that point in my learning journey, I was doubtful of the possibility of doing research without enacting harm. Furthermore, in terms of how our society values academic knowledge, I knew not many people would read or care about my study. I cared because I have integrity and respect for my work, and for all who are implicated because of it. Perhaps then, along with the lenses I have described that I used, the idea of respect and integrity could be incorporated into my attempts to be as ethically sound as possible. I remained acutely aware that I am both subject and object. While I attempted to reveal some sort of conclusion, it is only a conclusion from my perspective. Throughout my collection of data, coding, analysis, and

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writing, I remained critically and ethically sound in knowing that when research attempts to capture experiences that are not mine, that is unethical in itself.

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Chapter 2: Literature Review

Introduction to Literature Review

In order to further understand the experiences that health care professionals have with medical assistance in dying (MAiD), it is imperative to understand its history within Canada and the political climate that gave way to its fruition. MAiD is highly controversial legislation. The purpose of this literature review is to identify any gaps in research associated with the experiences that health care professionals have with MAiD. MAiD has only been a part of national Canadian legislation since June of 2016; therefore minimal literature from Canada exists. This literature review will be organized into categories that are intended to identify the history of and current legislation of MAiD in Canada, experiences of death and dying from the perspective of social work field and partnering fields, current professional views on MAiD, and existing studies that are similar to mine in their area of study and methodological and theoretical frameworks.

This literature review will compare and contrast key arguments from scholars who have professional affiliations to MAiD. I will conclude by discussing common themes that emerge from the literature, gaps in the literature concerning MAiD, as well as limitations to my literature review.

History of MAiD in Canada

Browne and Russell (2016) trace the history of MAiD to 1982, when the *Canadian Charter of Rights and Freedoms* became embedded in Canada's Constitution Act. Those who opposed the criminalization of MAiD were now able to argue via the court system that not being able to access MAiD was a violation of constitutional rights. Specific items within Canada's

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Constitution Act concerning the right to hold rights and freedoms within legal limits, the right to life within legal limits, and the right to equality were most applicable to bolstering the argument for MAiD legislation (Browne and Russell 2016). My findings sections will further unravel the subjectivity of rights and freedoms, and the paradoxicality of applying them to MAiD.

Browne and Russell (2016) utilize a politically historical lens to discuss relevant themes concerning MAiD: access, conscientious objection, and misuse prevention. Their article is grounded in historical occurrences that precipitate the legalization of MAiD. The authors argue that in order to implement national regulations pertaining to MAiD, the complexities of access, including safeguards and defining conscientious objection must first be developed (Browne & Russell, 2016). The authors use case study examples of some of the first physician-assisted death court cases to illustrate the ethical complications that can occur when legislation is in its infancy. This article is relevant to my study, as it connects the evolution of policy making to political climate. Browne and Russell's (2016) study supports my research as it can be helpful to ground post-structural discourse analysis within a timeline of history. Browne and Russell's (2016) article disrupts MAiD as a normative, linear legal process by delving into the complexities that arose from specific historical cases. Analyzing socio-political uptakes during specific eras and decades can serve as a purposeful jumping off point for analyzing how dominant discourses surrounding MAiD, death, dying, and life came to be.

Canada decriminalized MAiD in 2016, 74 years after Switzerland, the first country to legalize MAiD (Emanuel, Onwuteaka-Philipsen, Urwin & Cohen, 2016). Emanuel et al. (2016) review nation-specific policies and practices that shape the attitudes that health care professionals and the general public have concerning MAiD. Quebec was the first province in Canada to legalize MAiD in 2014 (Emanuel et al., 2016). Following this, the Supreme Court

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mandated that remaining provinces and territories outline their respective legislation specifics by February of 2016 (Emanuel et al., 2016). By June of 2016, MAiD was accessible to adults aged 18 and over in Canada (Emmanuel et al., 2016). To access MAiD, a period of 10 days must pass between a person's written request and their date of access (Emanuel et al., 2016).

Through the use of polling data, surveys and national databases, the authors were able to conclude that while public support for MAiD was relatively high in most nations, physician support was not. While Emanuel et al. (2016) provide an important comparative analysis of MAiD attitudes in different nations; their study could not delve deeper into the experiences of health care professionals, as their data was pulled from secondary sources, and not the professionals themselves. Emanuel et al. (2016) describe an accurate, yet oversimplified account of the access criteria for MAiD in Canada. The authors' decision to opt for breadth rather than depth is understandable, as their article was focused on international legislations.

The Government of Canada (2016) delves deeper into the particulars of accessing MAiD. Momentum behind the legislation began in 2015 when Gloria Taylor and three other plaintiffs challenged the criminalization of MAiD in Canada. The plaintiffs identified as either wanting to access MAiD for themselves or as relatives of persons that desired to access MAiD. Taylor and the other plaintiffs argued that the criminalization violated Charter rights. The plaintiffs won, and provinces were given until June of 2016 to open up access to MAiD (Government of Canada, 2016).

Requesting MAiD does not always mean it will be granted. According to the Government of Canada (2016), candidates must adhere to the following specifics:

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Request the service of their own free will, are able to make health care decisions for themselves (be mentally competent), have a grievous and irremediable medical condition, make a voluntary request for medical assistance in dying that is not the result of outside pressure or influence, give informed consent to receive medical assistance in dying.

(Government of Canada, Medical Assistance in Dying)

Most of the criteria for eligibility contains imbedded, detailed descriptions of the summary offered in point form on the *Medical Assistance in Dying* homepage. While thorough and specific to national legislation, government information is just that – legislation. The nuances and contexts that surface from the point of inquiry about MAiD to death can be laden with complex conversations and relations between patients and their loved ones. For example, it can be a lengthy and complex legal and familial process in concluding that one is mentally competent or not. Furthermore, if we interrogate mental competency criteria, we will find that it is subjective to the point of access (medical, legal, property, personal care), the subject positionality of the person attempting to access, and, in some circumstances, the person's documented history by social workers, nurses, and doctors.

Many points of contention can occur in a person's life from the time they find out they are terminally ill up until their time of death. The next section of my literature review will place meaning behind the overused and often thoughtlessly used phrase *a good death*, in relation to health care professionals immersed in death and dying.

How do Health Care Professionals Define a Good Death?

Cooper (2016) aligns *a good death* to the hospice philosophy. He argues that many of us will never understand this supposed *good death*, as most of us will not have access to round the clock

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medical attention, pristine pain management, and a support system in place to meet all of our needs in the best way for us. In essence, Cooper (2016) argues, we hold this idea of *a good death* on a pedestal that we believe we will someday be in reach of, but we likely never will be.

Inspired by the works of Atul Gawande (2014), Cooper (2016) and qualitative researcher, Denise Turner, use a narrative approach to tell us their experiences with familial deaths. Turner knew that when professionals came to her home to remove her son's body that everyone present was feeling horrible and struggling to cope with the magnitude of the situation: a dead infant, his twin alive and healthy, an older child reporting that one of her infant siblings did not respond to her greeting when she entered their room wish them good morning, parents shocked and horrified. The professionals who arrived at the scene were beyond themselves, but did their very best to support Turner and her family (Cooper, 2016).

Turner describes a starkly different atmosphere in her home later than evening. It was quiet, and no one came to visit (Cooper, 2016). Through Turner's story, Cooper (2016) explains the enormous pressure on health care professionals, who even in the times when they are most needed, cannot perform the honed humanitarian skills that allowed them to succeed in their profession to begin with: compassion and empathy. Neoliberalism has impacted the health care field in a detrimental way insofar that professionals can't always follow up appropriately and personally with families that perhaps for only a morning, have potentially impacted their professional and personal lives forever (Cooper, 2016).

Cooper (2016) profoundly asks us: how are health care professionals working with people who are dying supposed to find the courage to work with people *towards* the more anxiety-ridden, painful reality that is dying and death?

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As a social worker, the reality of this relationship is counter-intuitive to my professional learnings and to how I define a supportive relationship. Being in these types of situations breaks my heart. Cooper's (2016) narrative approach allows room for emotional work to be described and worked through. This approach is inspirational to my research, as my motivation to explore the topic of MAiD in relation to the experiences of health care professionals comes from my own lived experiences. Cooper's (2016) writings provide a well thought out roadmap for how to write from the heart while at the same time being guided with purpose, and with more than a cathartic motive. Cooper (2016) and Denise Turner were able to harness their personal experiences with death to accomplish acts of selflessness. My next section will discuss the relationships that social workers have with MAiD and other avenues of end-of-life care.

What Experiences do Social Workers have with MAiD and Other Avenues of End-of-Life-Care?

Hobart (2001) discusses the increased propensity of social workers needing to facilitate conversations about death and dying in their places of work. Today, almost 17 years later, Hobart's conclusion that future medical advancements will increase the frequency of these conversations is accurate.

In reference to a past ethnographic study completed with aging women, Hobart (2001) refers to how the taboo nature of death manifests itself in the spaces taken up by social work. Participants involved in Hobart's (2001) study were at a stage in their lives where they desired to know more about end-of-life matters such as power of attorney specifics, wills, and general end-of-life directives.

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Hobart (2001) elaborates on the responsibility of social workers to provide psychosocial support to people who want to discuss end-of-life matters. Many women involved in the ethnographic study stated that they would have appreciated the facilitation of a more comfortable discussion in the space of their choice, rather than in an institutional setting. When they inquired about end of life matters, they were more times than not met with the prompt retrieval and handover of forms, practiced instructions, and dismissive attitudes from professionals. Hobart (2001) concludes that many people don't know how to tell their families that they are dying, and could use the support of social workers. Hobart (2001) challenges social workers to use academic channels and to be leaders in opening up avenues for dialoging about death and dying. Social workers can familiarize others on death and dying, including providing opportunities for social work students to engage with the subject. Hobart (2001) argues that if we know something is wrong about how death and dying are being approached, then it is up to us to attempt to make it right. I argue this statement can be applied to every inequity that social work attempts to address.

While Hobart's article relates social work to end-of-life care in a broad sense, Bern-Klug, Forbes and Gessert (2001) go back in time to observe leading causes of death during the past century. Bern-Klug et al. (2001) argue that medical advancements, among other things, have made dying invisible. People are well, and indeed, appear physically well for much longer than in the past. End stage illness trajectories often leave family members shocked, confused and unable to manage a loved one's death without professional aid. Bern-Klug et al. (2001) conclude that social workers should take on more of an active role in ensuring people who are dying receive end-of-life care that suits their individual needs. This can be done by facilitating conversations between the dying person and their loved ones, being an advocate, and acting as a

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liaison between the dying person and other members of their circle of care. The social worker has opportunities to get to know the history and personality of the dying individual in a non-bio-centric way. They can offer a different perspective on the person's wellbeing than medical teams in order to ensure the individual is receiving care tailored to their desires. Bern-Klug et al. (2001) offer important insights into the amount of power social workers hold in determining whether or not people will receive their death of choice. However, their conversation is still very broad, and does not focus specifically on MAiD.

Ogden and Young (2003) examine the attitudes that social workers in Washington, D.C. have concerning MAiD. The majority of social workers felt that religion was not a determining factor in their motivations for being supportive or unsupportive of MAiD. Many felt that their professional role in being able to situate critical issues like MAiD within a broader context meant that they had a greater responsibility than other professions in ensuring equitable access to MAiD.

In a similar study completed in 1998, Ogden and Young examine the attitude of social workers from British Columbia, Canada. They found that social workers were less likely to consider MAiD for themselves, but strongly believed that MAiD should be accessible to all, and that social workers should be involved in policy level decisions regarding MAiD (Ogden & Young, 1998). This study insinuates that social workers may separate their personal feelings about MAiD from their professional feelings.

Miller & Norton (2012) discuss their qualitative study undergone with nine hospice social workers in Oregon. Three themes emerged from their discussions with the social workers: values, policy implications, and the role of social workers. The emergence of values is important

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in this discussion, as it cannot be generalized throughout all the literature. This could potentially point to the fact that hospice philosophy, traditionally, does not support MAiD.

I did manage to find several more articles that discussed social workers and end-of-life care, but most were quite dated, American, and concluded with similar recommendations: that social workers need to become more comfortable with the increase in people asking questions about MAiD, and social workers need to take a more active role in their circle of care teams and in policy development. However, some central themes did emerge from the above discussion. Social workers understand that allied professionals and the general public look up to them to take the lead on normalizing discussions of MAiD and dying. Another theme that emerged was the critical role social workers play in ensuring patients are heard. Ideally, social workers should act as a liaison between patients and medical teams to ensure that patient's self-determination is maintained as much as possible.

The next section of this paper will discuss perspectives on MAiD from social work's partner fields. I believe that our partners influence us, and that if we are to work in multidisciplinary collaboration, then we should understand where each other are coming from.

What are Perspectives on MAiD from Social Work's Partnered Professions?

Pholpirul and Rukumnauykit (2017) apply behavior economics, a psychological ideology, to decision making about one's death. The authors suggest that death can be managed most effectively when one can list the pros and cons of dying versus the pros and cons of undergoing medical procedures in order to live longer. They argue that a person should weigh "the benefits of life and the cost of death" (Pholpirul & Rukumnauykit, 2017, p. 625). The article is confusing as the authors apply behavior economics almost exclusively to cases where

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someone may be considering suicide, but also state that “a decision to accept death and forego life-extending medical procedures can be both rational and irrational” (Pholphirul & Rukumnauykit, 2017, p.625).

Academics consistently use the terms *suicide* and *medical assistance in death* interchangeably. This error may be unintentional and subconscious, however, it can have dangerous implications. In knowing those who have taken their own life, and those who have accessed MAiD, I also think it is quite lackadaisical and disrespectful. The experiences are different, and within those respective experiences there are millions of stories.

Brock’s (2012) article views MAiD from a social policy perspective. The usefulness of a partnership between non-profit, private, and public sectors is taken up. Brock’s (2012) research shows that people living in Canada are concerned that the cost of medical provisions during end-of-life care can motivate health care professionals to lean towards convincing their patients to opt for MAiD. During a period of deficit, it is feared that public values would collide with those of the state. Brock concludes by recommending that a governing body comprised of equal proportions of the three sectors be established in order to provide true legitimacy and thoroughness to what was, at the time, the potentiality of MAiD legislation (Brock, 2012). Each sector proved to be excelling in different arenas concerning MAiD, so the idea was to have each sector maintain control of their assigned divisions of expertise (Brock, 2012).

Vachon (2013) discusses MAiD from a palliative care perspective. The author argues that palliative care is still in the early stages in Quebec, and until it is more fully developed, the idea of MAiD can’t be discussed. Vachon (2013) argues that MAiD cannot replace proper palliative care, and I agree. While Vachon’s article is not current, the points made are timeless in that the

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author considers MAiD and palliative care to be separate and unique, yet congruent in that they both can meet a person's need to *die with dignity*. One interrogation I have with dying with dignity is how it came to define the dying experience. Also, who gets to define dignity in relation to dying? I am also left questioning how and if dying with dignity is defined, if at all, in non Euro-western countries.

Fishman, Karsoho, MacDonald and Wright (2016) situate MAiD within the meaning of what it is to suffer. The authors take up suffering related to MAiD access and the debate on MAiD legislation. Using a medical framework, the authors contest how those who support MAiD define suffering while considering the pros and cons of medication (Fishman et. al, 2016). While this argument does not, at first glance, seem to apply directly to the social work field, it magnifies the permeating medical discourse that is present within western helping professions. Generally, the first point of access someone has when confronted with an illness is the medical system. Those trained in medicine have learned how medications can impact an illness, and sustain life. Some doctors consider MAiD to be the antitheses of their profession. Fishman et al. (2016) address how medical professionals respond when their patient decides to abstain from medical procedures and opt for MAiD.

Lutfiyya and Schwartz (2013) utilize critical discourse analysis to examine media coverage between 2004 and 2006 of the case of Marielle Houle, who was accused of helping her disabled son commit suicide. Lutfiyya and Schwartz (2013) conclude that in the case of Marielle Houle and her son, Fariala, the media portrays "disability as a fate worse than death" (p. 36). Lutfiyya and Schwartz's (2013) article is highly applicable to my study, as the authors have used a similar methodology. Furthermore, the authors' findings have tremendous implications for disability communities and helping professions. Their article speaks to how we as social workers

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contend with striving towards equity through political action in a society where our value depends on how desirable our roles are. Wolfensberger (1983) speaks to this in describing the controversial analysis, *Social Role Valorization*. Wolfensberger argues that people with intellectual disabilities should be supported to take on roles that are praised in our society, such as *worker*, *volunteer*, and *supervisor* in order to be taken seriously and treated with respect (Wolfensberger, 1983). Social Role Valorization contributes to our society's condemning of disabilities in that it forces people to conform to social norms. It does not problematize social norms or hold systems accountable for the exclusion of people with disabilities. Lutfiyya and Schwartz (2013) use text analysis as their method, and pull out dominant discourses from the journalistic sector, which has a massive influence on the general public. Both authors have done extensive work related to disability studies, and their article is comprehensive and easy to understand. While my study aims to extract discourses from interview data, I intend on using Lutfiyya and Schwartz's (2013) work for inspiration and instruction. I am a junior researcher, and I find it helpful to gain insights from more seasoned colleagues.

Based on the literature described above, it appears that some allied professions and the public are removed from how MAiD impacts people at the individual level. There seems to be consensus that MAiD legislation is so preliminary, that palliative care and policy development need to be honed first before we can fully implement and perfect the MAiD process.

Conversations on what it means to suffer and the critical discourse analysis of media portrayals of dignity, death, and disability are particularly applicable to my research. These conversations speak to dominant value systems which inform who we believe has the right to life, and who we believe has the right to die.

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I will now explore peer-reviewed literature of current positions on MAiD. It is important that I know what academics are saying about MAiD so I can get a sense of how discourses of living and dying are taken up in our society, particularly by those in positions of power.

What are Current, Peer-Reviewed Positions on MAiD?

Trigg (2017) argues that doctors should not have to support a patient to access MAiD if they do not believe it is moral. The author further argues that doctors who are morally opposed to MAiD should not be forced to referral their patients to a physician willing to comply with their patient's wishes. Trigg (2017) argues that mandatory physician support for MAiD "goes against the principles of liberal democracy" (p.43). The author concludes by questioning the future of medicine. Trigg (2017) states that medicine can either be a positive influence on humanity or a highly accessible product lacking moral structure.

Balch (2017) positions their article similarly to Trigg (2017). Balch (2017) discusses new Belgian legislation that allows for physicians and a patient's loved ones to make the decision to access MAiD on the patient's behalf if they determine the patient has "no prospect of a meaningful recovery" (p. 42). Balch (2017) contends that similar trends are beginning to be seen in North America. Some physicians are refusing medical treatment to older patients if they believe that medicine will not extend the patient's life, despite the wishes of loved ones. Balch (2017) warns health care professionals that more and more older people may feel that they have a "duty" (p.45) to accept MAiD over palliative care, as our society views older people as cumbersome, financial burdens to the healthcare system.

Morrison (2017) offers a different perspective in identifying similarities between MAiD and palliative care. The author explains how MAiD and palliative care are often accessed in tandem

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by patients. The author discusses how many people opt for palliative care during the required waiting period to access MAiD, and many also plan for palliative care until death, and end up choosing MAiD. The author uses these cases to support the argument that allowing conscientious objection to MAiD in palliative care units counters well-established values of palliative care: “compassion towards patients, and [to uphold] the autonomy and longevity of patients” (Morrison, 2017, p. 13).

Dr. John Wootton, a physician located in Quebec, offers a unique perspective on the lack of rigor within research related to MAiD (Wootton, 2017). Wootton (2017) questions how we can know if a medical error has occurred during MAiD, when the procedure always ends in death. Wootton is critical of MAiD due to the lack of accountability and non-liability it affords physicians (Wootton, 2017). The author is worried that once physicians normalize MAiD, they may practice negligently. Wootton’s (2017) position of holding his own profession accountable adds credibility and legitimacy to his concerns.

The last component of this literature review will examine the results of a study that is similar to mine. I will then conclude my literature review by summarizing common themes in the literature, gaps in literature, and limitations to my literature review.

What Similar Studies Exist?

Good, Higgins, Sneesby and van der Riet (2009) use critical discourse analysis in order to reveal the dominant discourses that emerge when doctors and nurses feed and hydrate critically ill persons with brain injuries. An interesting discourse that emerged from their study was “the blurring of boundaries” (Good et al., 2009). Doctors and nurses had a hard time drawing the line between potentially extending a poor quality of life by providing nutrition, or ceasing nutrition to

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provide less suffering. Another critical theme that emerged was the use of metaphors like *vegetable* that serve to objectify people and reinforce the idea of specific bodies being a burden. I am interested to see how and if my conclusions are similar to those of Good et al. (2009) as this literature review has thus far revealed quite a balance of different perspectives, as well as some grey areas.

Common Themes Throughout the Literature

The literature speaks to MAiD as a grey area itself. Much of the literature positions MAiD in relation to palliative care. Many authors argue that the quality of palliative care in Canada needs to be higher, so that people won't think of MAiD as the only way to end their suffering. A common argument was for the incorporating of MAiD into palliative care itself. The words *suffering* and *dignity* were common throughout the literature. It seems these words are prescribed to death and dying so that people have concrete ways of measuring pain in relation to their quality of life. However, it is unclear how these terms came to define the dying experience, and who gets to define them: the dying person, health care professionals, the state?

Many authors expressed concern that MAiD may serve to further oppress people who are aging and people with disabilities. Studies imparted from multiple disciplines place responsibility on social workers to further discussions on death and dying.

There is very little literature from Canada concerning MAiD and the role of health care professionals. Many articles expanded richly on details from the United States, Great Britain, Europe, and Australia. Much of this literature was not applicable to MAiD in Canada, as it had been disseminated at the time MAiD became legal in other respective countries. At times, there were decades of difference between the literature. Most of the Canadian literature that exists is

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from a period of time when the legislation of MAiD was still a highly contested debate in Canada. This is why the history section of my review is quite bulky compared to other sections. For similar reasons, peer-reviewed articles were challenging to find, because many articles that covered MAiD were from newspapers. I did find a few articles that applied critical discourse analysis methodology to topics related to health care, but none that captured the nuances and uncertainties of end-of-life care like that of Good et al. (2009).

Critical discourse analysis was employed in some studies relatable to mine, but none employed Foucauldian discourse analysis. Many peer reviewed articles used the terms *medical assistance in dying*, *medically assisted suicide*, and *suicide* interchangeably. They are not one in the same. Using these terms interchangeable promotes misinformation and is disrespectful to the people that have died through these methods, their families, and all who love (d) them. I recommend that academics speak with people who have experience with these three pathways to death, and read up on narratives of people who have died or thought about dying by these methods.

Limitations to the Literature Review

My literature review has limitations. Some of the literature I reviewed is highly applicable to my own study, and highlights the complexities of power and human relationships, and is not from Canada. My study will focus solely on the experience of health care professionals within Canada.

This literature review explores relationships with MAiD through the lens of the Canadian health care system, where MAiD can be accessed through provincial health insurance coverage, such as OHIP, which is paid for by taxpayers. It focuses very much on Western belief systems

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surrounding pain and death, and does not focus on the experiences of health care professionals and MAiD outside of a Canadian context. It is important that I acknowledge that many Western and European relationships with pain and death exist because of privileged access to medication (van Deldin & Battin, 2005).

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Chapter 3: Findings Through a Foucauldian Discourse Analysis

The Health Care Professional as an Effect, as a Producer, and as a Challenger of Power-Knowledge Systems

Foucauldian ethics, as discussed in the previous chapter, is care done to the self in order to define oneself against power and knowledge (Foucault, 1984; Macias 2013). This chapter will discuss Foucauldian ethics by elaborating on how health care professionals speak and behave relative to power and knowledge concerning MAiD. I will organize this by positioning the professional subject as an effect of power-knowledge systems, followed by positioning the professional as a producer of power-knowledge systems, and finally, by positioning the professional as a challenger of power-knowledge systems (Foucault, 1984; Macias 2013).

The Professional Subject as an Effect of Power-Knowledge Systems

Foucault relates *the professional* to the need for commonality. Professional identity groups subjects according to like-minded goals or *knowledges* (Foucault, 1994). Social workers and nurses, for example, subscribe to the power-knowledge systems of their similar, yet distinctive colleges that provide the surveillance of and punishment of their members (Foucault, 1994). Collegiate memberships are required by health care professionals in most institutional settings, and serve to remove individuals “who in their estimation cause disturbance and disorder (Foucault, 1994, p. 31). The Foucauldian representation of the professional as one who has completed specifically defined actions in order to gain required skills so as to perform elite actions is at parallel opposition to that of the dying individual. The professionally trained individual is profitable, useful, and investable, by way of their relationship with their regulatory college (Foucault, 1994). The dying subject is made non-investable and without use or purpose

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by measurements set out by professionally trained individuals. I will elaborate further on the positioning of the dying subject in the next chapter.

The impact of the professional subject as an effect of power-knowledge systems was most pronounced when interview participants related their level of comfort with MAiD to legal limitations:

Uhh... and so if an individual chooses MAiD that's what they want and now it's within the law then it's comfortable for me. Like it's...okay...they made murder legal all of a sudden...I might you know...be uncomfortable with that I think hahaha but so far you know there is...all the laws that we have are I think upholding everybody's civil rights and human rights. (Participant 5, 2018)

In this example, we can see Foucault's ethical ideology emerging. Foucault (1980) and Macias (2013) discuss Foucauldian ethics in relation to the identity formation of the subject, in this case the professional, and how the professional uses their identity to interact with power and knowledge, and to compare themselves to others in order to determine their own level mastery. In the response given by the participant above, we can see they take ease when someone's wishes align with the law. The participant separates MAiD from murder. It is unknown whether the participant was comparing MAiD to assisted death that occurs outside of the law. There is also the assumption that the law upholds rights. This quotation speaks to the discourse of what is right being defined not by the individual subject, but by societal ethics, or law. The professional, as a subscriber of ethical codes, is an effect of this power-knowledge discourse which automatically aligns what is right and good within the confines of legal structures.

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I think University Health Network has done a really good job in trying to appropriate the legal aspects to the actual practical aspects of medical assistance in dying so...um now the process is starting to be a little bit more smooth and less complicated or complex. (Participant 7, 2018)

This participant identified less complexity with legalities. This statement similarly identified professionals as taking comfort, or aligning themselves with legal processes. When applying FDA, this is not surprising because Foucault sees the law as an extension of power. Turkel (1990) argues that the law, in partner with similar discourses, work together through the subject as the instrument for the creation of even more dominant discourses. Participants appreciate seeing legal processes in action, and we can see a dominant discourse of using the law as the backbone for unraveling or undoing complexities. There is the assumption that the law will be the answer and the finite solution, and the ultimate measuring stick. However, utilizing law as the final answer leaves little to no room to examine ethical nuances. The discourses revealed through the data serve to silence the individual and demote the power of the single subject. Throughout much of the data, participants showed how they are an effect of power-knowledge systems by holding the state accountable by considering government the most capable of managing situations that are fraught with ethicalities. The professional is an effect of power-knowledge systems because while they, in dialogue, separate “legal aspects” (Participant 7, 2018) from “practical aspects of medical assistance in dying” (Participant 7, 2018), they are speaking to the same ethical sounding board that is created by the state and reproduced by subjects who are effects of ethical codes that make distinctions between proper and improper practice. The two referenced excerpts were only two of many that revealed and repeated telling dominant discourses of confidence in law being the final, uncontested, deciding factor between

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appropriate and inappropriate courses of action, and the trust and belief in legal and institutional mastery. By using FDA, we can see how the law is doing exactly what it is intended to do.

Through subjects who must access law in order to perform their job, law is upheld and they are effects of its power because of their utmost confidence in it. In relation to MAiD, which is still in its infancy in Canada, professionals are left to look up to the law for guidance and assurance, similarly to how a young person looks up to elders for guidance and assurance.

I will end the insertion of these valuable interview excerpts here for the sake of the giving enough space and time for my next posits. It is imperative that I note that while articulated in many ways, every individual interviewed measured MAiD eligibility against legal qualifiers. I choose to elaborate on these two quotes because they articulate popular discourses that emerged from very rich data. These quotes demonstrate how professionals are the effects of a system that relies on ethics as truth. The data was full of examples where participants aligned law with what they believe to be the right course of action. We have established that law is ethics in action, but to appropriately analyze through FDA, we must understand what Foucault refers to as *biopower*.

Biopower represents a focal shift in the way the sovereignty (or state) exercise power over its' subjects (Deveaux, 1994). In the early 1800's, the state's gaze became less focused on authoritative prohibition, and more focused on the regulation of the subjects' bodies. Education and health care became paramount (Deveaux, 1994), and order through institutionalization became a key imperative of the state. This time period, perhaps most famously monikered as the industrial revolution also gave birth to first wave feminism, which happened as a response to the state's regulation over women. First wave feminism was inarguably an organic response to the state's repressive policies aimed at reducing women's autonomy. However, the origins of social

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work can be described as an offshoot of first wave social feminism, which continues to perpetuate White, Westernized notions of goodness and truth (Johnstone, 2016).

With biopower came the definition of intellectualist positions in society in opposition to positions taken up by manual labour. Intellectualism, and thereby professionalization, work to uphold institutional categorization, which Foucault argues is taken up as the ultimate power or truth (Foucault, 1994a). In the case of the interview participants being subjects as an effect of power-knowledge systems, the dominant discourse of law being the ultimate truth prevails, and this discourse is played out in how professionals identify MAiD eligibility by using legal criteria. Biopower also influences sovereign power, which results in subjects producing certain truths (Kristensen, 2013). My next section will discuss this further by applying Foucault's concept of how subjects produce power-knowledge systems.

The Professional Subject as a Producer of Power-Knowledge Systems

This section demonstrates the challenge of separating Foucauldian implications of power-knowledge systems, because professionals simultaneously are effects of and produce power-knowledge systems. Foucault (1994) connects truth “in a circular relation with systems of power which produce and sustain it, and to effects of power which it induces and which extends it. A “regime” of truth” (Foucault, 1994, p. 74). In speaking to the production of power-knowledge systems, interview participants spoke to discourses that were touched upon in the literature review:

Cause I think sometimes people might feel like...like if you had a terrible depression and like you also had stage four cancer...and what's really talking? What's really asking for

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the MAiD? Is it the person's just soul suffering? I'm not saying that's any less...that that's any less...umm...awful...than say cancer pain or whatever it is...or not being able swallow or whatever it is but I'd want some assurances that the mental health pieces were appropriately addressed before saying okay, this patient's eligible. (Participant 4, 2018)

In this excerpt, the participant is drawing a separation between mental health and physical health. As touched upon in the literature review, in order to access MAiD, professionals look for the disease to speak, not the person outside of their disease. The literature review also revealed the dominant discourse of the biomedical model of health (Government of Canada, 2016; Wade & Halligan, 2004), which assumes outward presentations of malady must be due to an inner disease. The biomedical model of health is very much focused on treating or curing deficits, versus other models of health that promote prevention and adaptation to different ways of living in a body that may change the way it functions throughout the course of a person's life. This is an interesting discourse because the biomedical model, which is more challenged than ever in North America, is still the prevailing method of treatment. So, we treat mental and physical ailments equally in terms of the prescription and administration of medicine, except when a person opts to end their life. There is an invisibility to depression as there is to many mental health challenges, and the data revealed the albeit, seemingly unconscious perpetuation of ableism in terms of whether or not someone should be eligible for MAiD based on their mental health status. I will speak further to the discourse of invisibility in my next chapter. Another emerging discourse from the data is the need to measure a person's self-determined pain to pre-determined eligibility standards. Multiple participants mentioned stage four cancer almost as if it is a baseline measurement for MAiD eligibility, and of intense pain and suffering. This is interesting, as cancer is a common disease and is very highly mentioned throughout social media and

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charitable campaigns. I wonder if diseases that people feel less personally connected to have a greater chance of being unqualified for MAiD. Finally, it is worthwhile to mention that the data showed that mental health potentially clouds a person's judgement, which is an issue of contention when it comes to MAiD eligibility. This speaks to larger discourses of fear of the unknown in terms of mental health, and that a non-dominant (or non-normative) way of perceiving the world is less true or valid. The next examples of professionals as producers of power-knowledge systems point to the value of specialization or mastery:

...so she referred him to umm...a physician that specializes in MAiD...because we only have one on staff that specializes right now. (Participant 3, 2018)

I think you need not just the assessing physician for MAiD, I don't think they alone should make that call, I think there should be some consultation with the person's primary psychiatrist. (Participant 4, 2018)

Professionals are producing power-knowledge systems in how they relate to other professionals and patients in order to continue forming their self-truths. We can see many dominant discourses at work here. The ranking of professional knowledge over the knowledge of patients and their families suggests the upholding of self-mastery. Fillion (1998) connects Foucault's process of self-mastery to pleasure, and thereby, freedom. The end goal of this self-mastery process, argues Fillion (1998), views the subject as the following: "The individual fulfilled himself as an ethical subject by shaping a precisely measured conduct that was plainly visible to all and deserving to be long remembered" (Foucault, 1985, p.91). We can see this end goal acted out through the way participants describe the role of physicians throughout the MAiD

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process. People as dying subjects are positioned as not possessing the intellectual power and knowledge to decide that they are ready to die – they do not have sovereignty of their bodies.

Health care professionals produce power-knowledge systems in maintaining and upholding the ranking of types of knowledge: in first place, the professional as the determiner of the ultimate truth (the psychiatrist), secondly, the professional as the measurer (the physician), thirdly, the professional helper (the nurse), fifthly, the professional listener (the social worker), and lastly, the lived experience (the patient and their loved ones). In producing power-knowledge systems, professionals also rely on systems of measurement to determine where a patient fits in terms of MAiD eligibility, and what level of professional they should be referred to.

These professionals are stuck between a rock and a hard place. They navigate through the spaces in which they occupy as products of power-knowledge systems, and therefore there is no way they will not reproduce these power-knowledge systems. Professionals produce power knowledge systems by subscribing to the value of specialization in caregiving. Drawing on Giddens's Structuration Theory and Foucault's conceptualization of power, Heron (2005) describes this contention of the self in relation to social location and subject positionality: "the self is, then, a co-constructor of a social reality and cannot escape playing a part in (re)producing the structures of society." (Heron, 2005, p. 345). In the case of the interview participants, much of their professional identity is perhaps rooted in their earliest relationships to caring and caregiving. This relationship can become fraught with complexities as the nursing and social work professional is made up of mainly women. Women are conditioned from birth to identify with societal expectations surrounding femininity, motherhood, and nurturing. I was praised as a small girl for playing nicely with my dolls and being 'such a good little mommy'. My parents rewarded me for being polite, clean, and playing nicely and quietly. My professional identity as a

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social worker exists because of my ability to care and be compassionate. I am a social worker because of the socially prescribed feminine characteristics that I embody. My professional and personal identity is one in the same. If my interview participants share this duplicity of identities crisis with me, I cannot fathom how they tread the line between being at times, the sole provider that has invested the time and energy into getting to know their patient, to the depth where they can act as a megaphone for them in their times of greatest need, and being ethically barred to interfere any more with a patient's care, because it is not in their within the scope of their role. My heart aches for these professionals. I understand how it feels to know how much more I could do for people if I was given permission to do so by superiors who sometimes seem so removed from frontline work. The final section of this chapter is more uplifting than this section. Aside from it meeting the need of answering my research question, it also highlights the limitless compassion, empathy, courage, and love that is within the hearts of my participants.

The Professional Subject as a Challenger of Power-Knowledge Systems

I came across this video at my MSW field placement. It was on a website pertaining to my placement that my supervisor recommended I check out. This particular day was stressful, as I was feeling overwhelmed with new challenges at placement, and I was also feeling stuck and didn't know how to move forward with the work I was doing on this project. Chimamanda Ngozi Adichie's (2009) story gave me that ah ha! moment, or to be more social work-centric, a critical breakthrough, a self-reflective crisis, a major fundamental and philosophical shift in my thinking.

Chimamanda Ngozi Adichie spoke of the danger of writing and speaking "single stories" (Ngozi Adichie, 2009) to a TedTalks audience. In sharing her story of growing up in Nigeria, Ngozi Adichie reminds us how single stories give us the illusion that someone's story is

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definitive, which robs them of their dignity. Ngozi Adichie (2009) asks us to question authenticity and warns us that if we are to show a single way of being over and over and over again, this single way will become the being that others seek to define. Ngozi Adichie's story highlighted White, Western perceptions of Black Africans.

At this point in my data analysis process, I was separating interview participant's 'breakthrough' thoughts from broader groupings. I chose to separate these thoughts because they were atypical of the responses that I was getting from participants, who mostly referred me back to being ethically and legally accountable to the legislation surrounding MAiD when applied to their specific professional designation. Sometimes though, when the conversational climate was just right, and when I felt confident in letting the interview take its own course as per the participant, how they really felt and what they really thought emerged. It was as if, momentarily, they broke through the confines of their subjection as controlled professionals, and spoke, rather remarkably, as revolutionaries who were completely aware of their subscription to and production of power-knowledge systems. As our conversations became more candid, I was able to hear emotion coming through in participant's voices. Their cadences became less measured, and the volume of their voices rose and fell because they felt able to express themselves from their hearts. At times, it seemed their thoughtful silence after speaking or listening represented and solicited from me respect for the dead and the dying, seething inner anger, and perhaps the quietude that one experiences when their physical body feels the effects of being a challenger and resister in the strongest way possible. It was in these expressions of their experiences that their respective 'ah-ha' moments' united with my own and we, as subjects became the challengers of our own doings.

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Professionals challenged power-knowledge systems by speaking of the importance of trying to give some amount of power back to the patients. Some spoke of this in relation to their one-on-one work with patients:

Sometimes there's a strange dynamic between the patient where they are trying to...gain control they do it through kind of weird ways and I think accepting that and...uh, yeah. Kind of letting them have control over what they can have control over. (Participant 1, 2018)

It's disgraceful! This poor man, it's disgraceful! And he was capable, and I think he has the right to self-determination. (Participant 4, 2018)

You know, like I'll just give an example...they all...I'll just give an example...you could have one...I'm not going to talk about vendors because that's a bias...and in my mind, I think, well why not give a list of 3 vendors, you know? Why not provide that list, because you know? And let the person decide...you're not telling them what to do, but your kind of at least giving them that information. Because for me...with vendors...that can be a lot of work. (Participant 3, 2018)

And I think it's like anything, you can find ways to work around it. Do you know what I mean? You know, it's like you can have rules, but you can think...I think that's the beauty of social work...we can make things happen that sometimes seem impossible. Does that make sense? Do you know what I mean? Hahaha. (Participant 3, 2018)

In speaking to Foucault's writing, Gaventa (2003) praises Foucault for painting power as productive and positive and not simply negative, as much of society tells us. In telling me about their day-to-day routines with patients, participants challenged the discourse of professional

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knowledge being the truth by expressing the importance of control over one's own actions and body. Professionals were using their power, within their professional roles as caretakers of other's bodies to creatively shift power back to the patient in order to give them some amount of control of their bodies.

Another discourse that emerged through the challenging of power-knowledge systems was the awareness of and challenge of the power held by professionals with more power than the participants. Participants did not always equate the holding of more professional power and distinction to being more ethical or trustworthy:

Umm, I think it is um, I think where I am going to be stretching and growing is really around the perceptions of other people, and the spin that they're putting on it. So for example, with that physician, that issue...and I need to...I feel like I need to connect with them at some point...umm...but I...there is a part of me...I did speak to someone else about it and uhh...and this individual said this physician has gotten into trouble because of his approach but there was a piece of me...there is a piece of me that's planning to talk to him about it. (Participant 3, 2018)

Participants often mentioned the ethical dilemmas they faced when they observed physicians attempting to sway the decisions of patients. Many participants expressed their belief that physicians were using their positions of authority to lord their personal beliefs about MAiD over their patients. Participants expressed their desire to report what they had witnessed to their respective ethicists, but were hesitant because they thought it could damage professional relationships with physicians, whom they work closely with. In the above example, we can see the professional challenging power-knowledge systems by speaking to a colleague about what they had seen. This "piece" described by Participant 3 (2018) suggests a deeper ethical dilemma

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in terms of meeting the needs of the patient versus working in a potential caustic environment.

This sentiment was echoed by many participants.

Many participants challenged power-knowledge discourses by critiquing MAiD eligibility criteria:

Um...well...I don't know. I think...I don't know...I think the option should always be there regardless of where they are and what, you know, whether they're in their own home or in a hospital at any age. (Participant 2, 2018)

Age of eligibility was interrogated a few times by participants. This challenged dominant discourses that determine who has credible knowledge, and place age as a major factor in determining a person's ability to be autonomous. On a much broader level, this speaks to ablest discourses which make our society the most accessible to those with the most esteemed power-knowledge. When applying an FDA lens to the relationship between age and ability, we can refer back to the point in history when the state shifted its concern to biopower and thereby, population control. Birthrate and ages of marriage were heavily surveilled and measured (Tremain, 2015), which suggests young adulthood being of the most valuable age group, and childhood and aging populations being less desirable due to their inability to contribute to state efforts.

While some outliers emerged from the data, I have chosen to insert the following outlier because of its particular interest and relevance to this study. This participant suggested that a patient create a life review, a practice I have also been taught in practicum and classroom settings, which can be a therapeutic activity for people who are nearing the end of their lives.

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The patient did want to complete the life review, as they “did not have a very good childhood” (Participant 3, 2018). This excerpt is the participant’s self-reflection of the event:

But isn’t that beautiful? It was beautiful too...it was a beautiful journey for me and...you know? Sure, it might have been sad but he was quite content with everything we were doing? You know...like it was...and that was enough...because I was all for wanting to put a bow on it and make it into something...I dunno...you know? What else was in there for me, where was I coming from? I dunno. (Participant 3, 2018)

There is this thought that at the end of our life, we take on a stance of forgiving peacefulness: we reminisce fondly about our childhood; times spent with siblings, parents, friends. On television, social media, and in literature, childhood is portrayed as a wistfully happy time. It’s interesting, and perhaps necessary that we separate the dying person from ourselves, and from reality. This professional is grappling with how her identity implicates her assumptions about death and childhood. What I find quite meaningful about this particular moment of reflection is how even though the patient did not want to participate in a life review, he was able to impart legacy through this professional, who shared their experience by participating in this study. The patient, even after his death, is challenging discourses surrounding the idea that certain life stages are more pleasant than others, and that a good death should contain prescribed rituals.

Participants challenged power-knowledge systems by telling me what they really thought about MAiD eligibility, even though their professional colleges hold them to a level of accountability that only permits them to follow what they are legally permitted to. These participants challenged dominant discourses around caregiving and what it means to be a woman

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in nursing and social work. They do not put all of their trust in their superiors, and they question the intentions and motives of physicians. They are not wallflowers, but the opposite. The very fact that they participated in this study challenges and resists dominant discourses that say that women should not speak up. These participants trusted me enough to protect their anonymity, and resisted the dominant discourse of allowing the law and their respective college's code of ethics to dictate what they believe about who should and who should not access MAiD, and who should be in control of accessing information about MAiD.

To conclude this chapter, I believe I have discussed the complex nuances of the data gifted to me by participants through FDA. The most telling discourses that emerged were discourses surrounding law as the ultimate truth, and the need for professionals to define their roles based on aspects of finite measurability. While their responses echoed the dominant discourses surrounding age, ability and mental health status touched upon in the literature review, participants are actively involved in challenging power-knowledge discourses. They are doing this by responding to patient's desire for more control, in confronting colleagues when they witness unethical practice, and in challenging current MAiD eligibility criteria. While the discourses that emerged from the data were divided into three sections, I argue that all the data mutually produces, reinforces, and challenges dominant discourses.

My next chapter will further unravel biopower, the invisibility of death and the dying subject, and the prominent intersection of critical disability theory within the realm of Agambian conceptuality.

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Chapter 4: Finding the Hidden Intersections Through an Agambian Perspective

Justification for Utilizing an Agambian Perspective

I anticipated that the data which emerged from the interviews could reveal to some degree perceptions of dying rights and living rights. I knew that my research topic was a controversial one, considering how new and unrefined MAiD legislation is in Canada. The ethical contentions that participants elaborated on stressed how challenging it is to define one's professional self in the face of MAiD, which in itself disrupts notions of what it means to have a timely and good death. The reason I have chosen to explore my topic through an Agambian lens is to firstly answer the suspicion I outlined in my proposal that the data may reveal dominant discourses that define the body that deserves of life versus the body that deserves of death. Secondly, Agamben challenges the Foucault's conception of biopower, by "grafting it onto another terrain" (Genel, 2006, p.43).

The Overcoma and the Ideal Dying Subject

In *Homo Sacer*, Agamben (1995) critiques Foucault's position that biopower and sovereign power exist on separate continuums. Instead, Agamben argues that biopower and sovereignty are one in the same (Ojakangas, 2005). Agamben illustrates his argument in what I think is quite a profound example in chapter six of *Homo Sacer*, which explores the body as being political. Agamben supports his argument through his exemplification of the comatose body.

An increase in focus on the dead and dying body occurred as the technology to complete organ transplants advanced, along with life-sustaining medicine and equipment. In 1959, a

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French study was published in the *Revue Neurologique* that described a new level of coma, called coma dépassé or “overcoma”. The authors of the study described the overcoma as an addition to the already existing three levels of coma that could be distinguished. The overcoma could only exist when a person was put on life support apparatuses. It could not be obtained without external support, as the body had ceased every single aspect of functionality. According to Agamben (1998) this newly defined level of comatose presented a “deliberately paradoxal formulation” (Agamben, p. 92, 1998), as it simultaneously redefined and defied the definition of “dead” at that time, which referred to the stopping of the heart and the cessation of breathing. The overcoma was considered an ideal state for the removal of organs to be transplanted, but without a declared hour of death, a physician could be charged with homicide. A comatose person, regardless of the level or degree of coma, is considered alive. So, a physician could commit homicide in order to give life to a patient whose organs were failing, or the patient with organ failure could die, and the patient in an overcoma could sustain organ function for years via external mechanical support. Agamben’s argument supports his claim that sovereignty and biopower are not mutually exclusive because the subject is never in a position where they have complete power over their bodies. We can see evidence of this in today’s MAiD legislation, and in past criminalization of suicide. If I want MAiD, it is not up to me in terms of when, where, and how I may receive it. According to participants, I may also even be denied my request for information about MAiD.

Agamben’s comatose patient can be compared to what interview participants consider to be the ideal dying subject. When asked who should be able to access MAiD, and when giving their own examples of patients who met eligibility criteria for MAiD, many participants replied when a patient is in a palliative state, and stage 4 cancers in particular:

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...he...he's palliative like in the sense that he...he has incurable cancer so I think stage 4 and he's elderly and so he had asked about...(Participant 3, 2018)

...the patient is stage 4 colon cancer, this patient actually asked about MAiD as an option further down the road, he wasn't ready yet but he was just asking for information. (Participant 4, 2018)

You hear these stories of people that they know they have terminal cancer or whatever so they will pick the time and the place and who they want around and then they take a pill and then they end their life...(Participant 2, 2018)

An interesting discourse presented itself through idea of using stages to determine someone's chances of survival, and the need for professionals to have something finite and concrete to measure. Another discourse that emerged through conversations with participants was how control (or masterhood) equates to people's sense of wellbeing. Participants expressed wanting to afford their patients some elements of control throughout their decline in order to uphold some aspects of their dignity. However, when autonomy slips away from a person as their body begins the process of dying, so does the likelihood of their being able to consent to the MAiD procedure. Much like Agamben's (1995) thoughts on the paradoxicality of the comatose patient, MAiD itself presents a paradox insofar as one can be too sick to access this form of assistance that is exclusively designed to bring death to the most critically ill people.

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The Creation and Perpetuation of Dying with Dignity

Along with the access issues to MAiD bolstered by the works of Agamben, the discourse of dying with dignity was prevalent throughout the data:

I think it's a human right to be able to decide...I think you have a right to decide as a capable, sentient person if this is what I'm facing and I want to be able to make a choice if the care that is offered to me is not what I want I don't want a painful death, I want to be able to have an option to die with dignity. (Participant 4, 2018)

You're in pain or you know you need um assistance with your personal hygiene and you're waiting for a nurse or PSW to come like you're losing that control uh with that goes your dignity and I think that is a huge...what's hard for people is that they aren't in control like they're at the mercy of someone else or a disease where it gets to decide or another person gets to decide when and how you kind of experience something. (Participant 1, 2018)

Um, just who gets to decide the suffering? I guess it should be the patient and if the whole thought of uh, that their life is coming to an end and they're going to lose control is enough then I guess that's umm, I guess that might be suffering enough knowing that you're being faced with...the end of your life and that you might lose some element of control. (Participant 1, 2018)

Dying with Dignity, while used as a popular catchphrase, is actually a Canadian, non-for-profit organization that supports people who are interested in MAiD (Dying With Dignity Canada, 2015). The discourse of dying with dignity begs us to question what dying without dignity is. The contention with how we think, speak of, and prepare others for a dignified death

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is that the opposite of this must be undignified. We perceive a dying and death that lacks motor function and muscle coordination, is noisy, and is carried out by oneself to be undignified. We are horrified by the release of bodily fluids, and the sounds of death, and so we attempt to make these invisible by sanitizing death. While I will say that I don't think I'd be comfortable lying in my own urine, blood, or otherwise, I do think we are set on autopilot to clean up fluids and silence noise. Health care professionals are effects of discourses and produce discourses surrounding the dignified death by nature of their positions. They are taught to make patients feel more at ease with whatever health concerns they are facing. Silence and cleanliness inform classist, ablest, and sanist discourses. The overtly subjective cleanliness, sounds and language that are socially appropriate are rendered covertly objective and become sanist practices through the "...charting and case notes in which the individual is constructed based on an "expert's" perception" (Meerai, Abdillahi & Poole, 2016, p. 22). We have made death socially appropriate through sanist practices.

The Unattainability of Bare Life

Agamben was widely known for his discussion of *bare life*: the valuing of life itself over how life is lived (Agamben, 1995). Participants expressed mainly contentious views surrounding this philosophy, mostly in reference to religious beliefs influencing physician's responses to patient inquiry regarding MAiD:

I think...it's something like where it's this dirty secret you know there's so many values that are like, people are...again, it's putting your personal value and your personal spin to then decide if somebody gets access to something and that is my biggest problem with this. Like I told you, that case with that physician, I was just like wow! I was like, this

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poor person just wants information and you just basically told him that his church wouldn't give him a burial. I was just like wow! I still think about that, I'm like who the heck do you think you are! You're not God! You know? (Participant 4, 2018)

Many participants expressed similar frustrations to that of Participant 4. Some also made a point in saying that that it is not their patients' and colleagues' religious beliefs that are concerning to them, but the transferring of these beliefs by colleagues with extreme amounts of power onto their patients in order to serve the needs of their beliefs rather than their patients'. This data spoke to larger discourses of the need for control. People like to hold enough control to maintain self-determination, and recognize this need in others, but take issue with other's use of power in order to control the course by which someone dies. In essence, participants seem to be saying that control is a good thing when it is exercised over one's own direction, but not others. A Foucauldian argument to this might be to question whether we hold any power over the control that we believe is ours. Agamben may argue that we do not, as we are in fact not in control or ownership of our being whatsoever.

Locating the Intersection of Biopower and Law

In speaking to Foucault's call for the extraction of sovereignty from its theoretical reign in order to examine power away from a legal standpoint, Agamben (1995) asks us if it is possible to arrive at the convergence of "individualization and totalizing procedures" (Agamben, 1995, p. 7). In other words, can we locate the intersection of biopower and law (Agamben, 1995)? Agamben says that we cannot, as this point is deeply concealed, and the two are of the same analyses. He argues that biopower is the first act of sovereignty (Agamben, 1995). As a novice researcher, I struggle to wade through Foucauldian and Agambian territories. To me, their

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thoughts are metaphysically sky high, and it takes me awhile to grasp their ideas and form an accurate interpretation of their philosophies. However, the importance of understanding how and why the two philosophers compliment and critique each other's lenses has been a valuable learning for me. While we may not be able to satisfy Agamben's urge for us to locate and identify this hidden intersection, his question compels me to closely examine how participant's disclosures of their experiences with bare life can implicate the individual outcome of a patient's life, and discourses surrounding who the ideal dying subject is, and isn't.

As discussed in the literature review, request for MAiD must be made without "outside pressure or influence" (Government of Canada, Medical Assistance in Dying, 2016). I question this stipulation to access, because it holds only the patient accountable to potential interrogation from health care professionals in determining eligibility. Health care professionals have noticed physician's gatekeeping, but fear reporting it as it could effect their professional relationships and perhaps even their livelihoods. While I do not know the outcome of the cases participants identified, their experiences highlight one aspect of who has the right to die – seemingly not the person who is shamed through religious and professional powers. Through the data, it is clear that whether or not a patient will be determined eligible for MAiD falls certainly within legal criteria, and within that legal criteria nests a far more individual scale of measurement whose points of positive or negative increments are determined by the outcome of the relationship between professionals and patients. However, if we apply my interpretation of Agamben's hidden intersection, and Foucault's posit that subjects are effects of power, produce power, and are challengers of power mutually and simultaneously (Macias, 2013, Foucault, 1994b), there is no way to separate the ethics that inform law from the ethics that inform the individual, as they

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mutually inform and sustain each other. The individual act is informed by institutional power, and institutional power is informed by many individual acts. Collective power informs law.

Participants also connected a dignified death with being socially connected to family, friends, and community, and at times, with *not* with opting for a medically assisted death:

I think in the case of that woman, she had family. She had family here, she had grandchildren...and in my mind I was like, wow how...how would you come to that place where you would want to ask for assistance? Like it didn't make as much sense for me as it did for him. (Participant 3, 2018)

A common theme was to identify an appropriate candidate for MAiD as someone being without direct contact with family members. I think is common to assume that people cannot feel isolated if others are around them, and on the other hand, that people who want to access MAiD feel isolated. It is interesting to me that many people who are professional or personal caregivers to someone who is dying cannot fathom how a person could want to leave their family presumptuously, prematurely by opting for MAiD, and yet it is caregivers that subscribe to and perpetuate notions and definitions of what it means to be undignified, including, but not limited to “when a person becomes helpless, incontinent, incoherent, dependent, drooling, a burden to others, and of poor general deportment” (Behuniak, p.22, 2011).

The importance of having social connections also emerged through participant's discussions of barriers to accessing MAiD. Much importance is placed on the legal requirements to have two witnesses sign a person's written request for MAiD, as well as the implication that someone's family member is the party responsible for supporting the patient in requesting information about MAiD:

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Somebody had placed a card on his bedside table that talked about this program but nobody would help him even make a phone call but he couldn't make the phone call because he was physically unable to...and it wasn't until months before a family member visiting actually helped him make the phone call...(Participant 4, 2018)

You need two witnesses to sign that the person has made the decision. They don't need to witness the actual...uhh...the MAiD, but they need to witness...be a witness on the paperwork and the two people can't be anybody in the social...the circle of care. So it can't be a social worker or a nurse or a doctor obviously. (Participant 1, 2018)

All of those people who wouldn't be her witness were there and saw her like that and obviously had heard her saying what she didn't want so it kind of makes you wonder if this...if this whole witness thing is really fair because it's um, it's not happening to the witnesses, right? It's happening to the patient and I don't really understand the whole needing a personal witness to sign off on that. (Participant 1, 2018)

Along with perpetuating paradoxal discourses surrounding being socially well connected enough to obtain witness, but too socially connected to want to die, these statements are representative of what it means to die with dignity. In discussing Pullman's (2002) article, *Human Dignity and the Ethics and Aesthetics of Pain and Suffering*, Behuniak (2011) attempts to unravel the complexities of *dignity*, as Pullman makes a distinction between individual dignity from "basic dignity" (Pullman, 2002, p.76). While individual dignity is determined by one's subject positionality, basic dignity is arguably a universal experience (Behuniak, 2011). I question the very meaning of basic dignity, however, Pullman's (2002) assertion that both forms of dignity stem from the need for people to feel morally good is interesting when applied to

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health care professional's experiences with MAiD. Pullman argues that when faced with the expression of pain, people feel morally obligated to mitigate it. On a personal level, when we experience pain, we want it eased so that we can go on living an aesthetically pleasing life. Our personal and interpersonal reactions to pain are what we use to distinguish a dignified life and death from an undignified life and death (Behuniak, 2011; Pullman, 2002).

In summary, I applied an Agambian lens to the data to challenge FDA by attempting to deepen my focus on the body deserving of life, versus the body deserving of death. Participants typically described the ideal dying body in terms of measurements, such as stage four cancer. Participants also expressed the importance of maintaining control, or mastery over one's life. They were able to push against dominant discourses that place all power in the hands of the professional by creatively finding ways to give patients more control over their lives. To understand what it means to die with dignity, we first needed to define what an undignified death was. Professionals contribute to discourses that portray a painful and loud death to be undignified. As professional caregivers, we are taught to silence noise, to mitigate pain, and to clean up bodily fluids and body odours. I argued that I would not want to lay dying in pain and in my own bodily fluids, and I used Behuniak (2011) and Pullman's (2002) arguments to bring awareness to our human recoil of pain, and of the sounds and smells of death.

If dignity is indeed attached to a moral duty to mitigate pain in order to feel good about ourselves, I wonder how much of what I do for the people I work with is truly for their benefit. Sometimes I think I may benefit just as much, if not more from the results of our interaction. I hate pain, and I take a pill at the first sign of a headache. Dying is marginalizing because we make it so. We measure it, sanitize it, and make it silent. And if voices dare become louder, we are watching you, and you are disturbing others, so we will quiet your pain the best way we

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know how. And if you start leaking red, yellow, brown fluids, we will see them right away against the white sheets you lay upon. Everything will be so clean and bright, you will become invisible.

As health care professionals, is there a way we can meet our current dying process in the middle? Can we commit to thinking about what we are doing as we are doing it and reflect on it to understand why we are doing it? What are our intentions? Who are we saving? The paragraph I wrote above is macabre, but why is it so? If we can make visible what we try so hard to unsee, then perhaps we can start to understand why and when we “put bows” (Participant 3, 2018) on dying. The more we can understand about ourselves and how we perpetuate the power-knowledge systems that influence our professions, the more we can challenge the status quo. If we can locate where we have put our bows on dying, perhaps we have located Agamben’s hidden intersection of biopower and law.

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Chapter 5: Conclusion

Findings Summary

Participants are an effect of power knowledge systems most markedly in their comfort of legal limitations and the ability to measure MAiD eligibility against legal qualifiers. The most dominant discourse that emerged from this data set was participants aligning what is right and good within the confines of the law. Participants produce power-knowledge systems by upholding the medical model of health, which separates and values mental health and physical health differently. Participants produced discourses of mastery by designating roles and responsibilities based on knowledge hierarchy. Most marked was participant's adherence to disease measurements in determining a patient's eligibility for MAiD. This produces and reinforces power-knowledge systems that seek quantifiable, generalizable answers rather than tailoring to the needs of the individual. Participants challenged power-knowledge systems by creatively using their professional roles to shift some control to their patients. They were also able to identify power structures at work, and challenged other professionals who they thought were being ethically unsound. Some challenged power-knowledge systems by critiquing MAiD eligibility criteria, especially when it came to age and ability to consent. They challenged dominant, ablest discourses of our society by pointing out what and whose knowledge is to be believed and sanctioned by law. A particular participant was able to learn about herself from an assumption she made about what a dying person wants, which challenges discourses that attempt to define a good death. Participating in this study challenges and resists dominant discourses that say women shouldn't speak up, and that death, dying, and MAiD should not be talked about.

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An Agambian lens further revealed potential reasons for using stages to determine someone's chances of survival: the need for professionals to have something finite to measure. Having control or masterhood equates to people's sense of wellbeing, whether it be the professional or the dying person. The ideal dying person that emerged from the data presented paradoxical arguments, in that one can be too sick to die by MAiD, and one's being socially well connected can hinder dying wishes. Dying with dignity was dominant throughout the data, and with it came the realization that we, as professionals, are effects of and produce and define what is an undignified death in order to know what is, or should be a dignified death. Indeed, it is we who construct the ideal dying person. I argue for finding a middle ground in our current dying process, paying attention to why we do the things we do with our clients or patients, and questioning when, where, why, and how we put a bow on dying.

What I Learned from Completing this Research

This study allowed me to learn more about myself than about MAiD. The passionate conversations I had with participants further cemented my loyalty to social work. Hearing social workers and partnered professionals speak with so much dedication to their profession and so much care for their patients made me weep at times, out of love for all they do, and out of seeing their passion in myself and the lengths I will go to support and protect the needs of the people I work for. It makes me feel confident and proud that I will graduate into a field where I will have extraordinary role models.

It is rare that I have experienced a prolonged amount of time listening to people think and speak through their heart. I got to experience this firsthand by listening to my participants. I learned that if the right type of space is provided, people will talk. I learned to have more

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confidence in my ability as a researcher. I am a novice, but my participants and I had enough in common to establish trust. When participants could hear how passionate I was about this topic, they were more likely to become engaged themselves. I needed to open up my heart to my participants in order for my participants to open their hearts to me. This research has taught me the critical importance of understanding who I am in relation to my participants and my research topic. I do not think data would have been so rich if I didn't have anything in common with my participants. When I began this study, I knew enough about MAiD to begin an informed literature review and discussion of the topic, but not enough to have exhausted my interest in the topic.

I believe choosing FDA and Agambian perspectives as my methodological and theoretical lenses worked well because they helped bring practicality and process to the abstract and metaphysical – which life, death, and MAiD are at their core. I found it extremely challenging to bring complex conclusions to life on paper. I would often apply data to a Foucauldian or Agambian thought, understand it, and speak about it, but when it came to write it down, I struggled to write something that made sense. Rewriting and editing took up the majority of the time that I spent on this paper. I think communicating my thoughts in writing was so challenging because Foucault and Agamben challenge us to think in a way that goes outside of thinking that we have been controlled into believing is productive. These philosophers ask us to abnormalize the normal, question common sense, and take the time to examine how people have come to be in Canadian society. Initially, when friends and family would ask how my research coming along, I would reply negatively that I took on a topic and methodology that was too big. I thought I was treading outside of my circle of knowledge. But, as I learned throughout my research process, that is exactly how I am supposed to think. As a student, I am the product of

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power-knowledge systems that make me feel inferior, junior, novice. I reproduce these power-knowledge systems by adhering to western academic standards so that I may end up with an advanced degree. A *Masters* degree. I have mastered nothing more than any other person doing any other thing, but this degree will disguise my knowledge as greater than that of others. I challenged power-knowledge systems by taking on an interview-based MSW thesis, even though I was told it was the hard way to go about it. I challenged power-knowledge systems by centering myself in my research, understanding how I influence and perceive data, the dangers of this, and how I will mitigate these dangers in my writing.

Areas for Further Study

Considering the nature and depth of this study, I believe it would have been greatly enriched with further participants and more time allotted for data analysis. I attempted to address what I thought was timely research topic, and the data that emerged from it was densely rich. I think that focusing on health care professionals' experiences with MAiD from a FDA and Agambian lens allowed for so much critical interpretation of the data, that it would perhaps make a better PhD thesis. Furthermore, while my research does not focus on the relevance of chance or geographical location when it comes to what factors can influence relationships with MAiD, considering the data, I think it would certainly make an interesting follow up study. I am also curious to know how many people who have accessed MAiD or have opted not to in Ontario had their final decision ultimately swayed by physicians. I think this would be a challenging, yet important study in further examining the effect of power-knowledge systems that exist, and potentially relevant to future MAiD policy amendments. Finally, I have written about how the sanitation of death and dying is grounded in sanism, which seeks to normalize some and abnormalize others. I think there is another layer to this idea, and I believe it would be relevant to

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engage in a historical analysis of how this process of dividing people came to be, and how it informs current discourses surrounding death and dying.

Limitations

The foremost limitation to this study is myself. As I have said multiple times throughout this paper, I am the only one listening to the interviews, and interpreting them through only one of many possible methodological and theoretical frameworks. However, at the highest level of my interpretation, and what all of my conclusions are rooted in is me. My subject positionality, all of my relationships with the world and how I take up space as a white, cisgender, female, Canada-born social worker and student inform how I have interpreted this data. This is a limitation because I am only one person, and my interpretation is just that. It is not a truth, and I am aware of the risk I am taking in potentially single-storying the experiences of health care professionals.

MAiD is not recognized internationally, and is therefore not an option, nor even thought of at all necessarily, by everyone on earth. My study is very much from a Western lens, and I do not for a minute assume it is generalizable whatsoever.

Relevance to Social Work

Professionals are trying to understand, apply, and cope with the aftermath of MAiD. It is new in Canada, and while it has been around in other countries for many years, it is not possible to generalize other experiences to that of an entirely different political time and state.

Professionals are trying to make sense of MAiD, which in itself cannot make sense. Two professionals I spoke with outside of the interviews made time to speak with me because they

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felt so strongly that there needs to be more policies in place for how professionals are to be supported by their workplace when working in an environment that supports access to MAiD. They also questioned how to support volunteers whose clients may opt for MAiD. MAiD changes the experience, and perhaps even the definitions of grief and bereavement, and unfortunately current models of support for professionals working with those who are dying are still playing catch up.

The findings of this study are relevant to social work because they offer a much needed glimpse into the perspectives of current professionals who support people considering MAiD. If we can gain a deeper understanding of the experiences of professionals in relation to MAiD and their patients who are considering MAiD, we can perhaps get a sense of where future MAiD legislation is headed. Both the literature review and participants spoke to it being the responsibility of social workers to be able to normalize talking about MAiD. I used to think of this responsibility as more applicable to worker and client relationships. Now I see the weight of this responsibility a little off balance in favour of making room for inviting, facilitating, and listening to colleagues talk about their experiences, worries, and expectations of working within a time where MAiD is just barely legal. New changes require a supportive team environment, and I see relevance to social work here: in supporting other social workers and partnered professions first and foremost. It's only when we are healthy and well looked after that we can even think of supporting our clients and patients throughout their MAiD journey. Perhaps the greatest lesson this study has to offer the social work profession is to always remain critical of the work we are doing, and interrogate the motivation behind our intentions in order to challenge dominant discourses. If we're trying to put a bow on someone else's death, we should at the very least ask ourselves, why?

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Appendices

Appendix 1: Recruitment Flyer

York University School of Social Work

Health Care Professionals' Experiences with Medical Assistance in Dying(MAiD)

Volunteers Wanted for a Research Study

Since MAiD is recent legislation in Canada (2016), very little Canadian literature exists that captures the experiences that health care professionals have with MAiD. This study will contribute to existing literature, and has the potential to offer new insights to an aspect of the caring field where little is known.

To be eligible for this study, you must be 18 + years of age, and identify as someone who has professional experience in working with people who have considered accessing MAiD, or people that have accessed MAiD.

By participating in this study, you will have the opportunity to talk about your experiences in a confidential space. You will also be contributing to new understandings and knowledge building pertaining to professionalism and MAiD.

For more information about this research study, please contact Alison Townsley at:
townsley@yorku.ca

This research is conducted under the direction of Alison Townsley, Masters of Social Work candidate at York University, Toronto, Ontario, Canada.

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Appendix 2: Informed Consent Document**Informed Consent****Study Name:**

Health Care Professionals' Experiences with Medical Assistance in Dying (MAiD)

Researchers:

Alison Townsley, MSW, School of Social Work, York University, atownsley@yorku.ca

Purpose of the Research:

The purpose of this research is to gain further insight and understanding of health care professionals' experiences in working with people accessing MAiD. As a participant in this study, you are being asked to participate in a one-on-one, audio-recorded interview with me. I will present the study findings to my supervisor, Teresa Macias and these findings will be reported in my Practice Research Paper, submitted for the degree of Masters of Social Work.

What you will be asked to do in the research:

You will be asked to participate once in a 45min-1hr long, audio recorded, one-on-one interview with me. The purpose of this interview is to discuss your opinion on MAiD and any professional experiences you may have with people who have accessed, or have considered accessing MAiD.

Risks and discomforts:

Psychological and emotional risks will be minimized by my encouragement of breaks during the interview at the participant's request. Informed consent will be continuously asked for throughout the study, as well as my consistent verbal emphasis of participant's ability to withdraw from the study at any time. I will encourage debriefing after the interview, and referrals to Toronto Distress Centre will be available in hard copy for participants who would like emotional support and immediate counseling. You may withdraw from this study at any time, and you may refuse to answer any questions during the interview. Your decision to withdraw will have no bearing in any future or ongoing professional relationship with me.

Benefits of the research and benefits to you:

It can be therapeutic and cathartic for participants to be able to speak of sometimes intense, professional experiences in a confidential environment. Participants may gain new knowledge about their personal and professional selves while thinking about the research questions.

Voluntary participation:

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You may stop participating in the study at any time, for any reason, if you so decide. Your decision to stop participating, or to refuse to answer particular questions, will not affect your relationship with the researchers, York University, or any other group associated with this project. In the event that you withdraw from the study, all associated data collected will be immediately destroyed wherever possible.

Confidentiality

You will be given the option to disclose your profession. No documentation obtained during the interview, or recorded information will contain identifying information. Data will be collected via audio recording equipment, and will be transcribed by the researcher. Data will be organized by pseudonym (colours, letters, and numbers). The researcher and faculty supervisor will have access to this data. Hard copy data will be stored until January 1, 2020 in a locked filing cabinet. On January 2, 2020, it will be destroyed via shredding. Audio files will be stored until January 1, 2020 in a password protected computer file. On January 2, 2020, these audio files will be deleted. Confidentiality will be provided to the fullest extent possible by law.

Questions about the research?

If you have any questions about the research, please contact the researcher at: townsley@yorku.ca, or their faculty supervisor, Teresa Macias, at: tmacias@yorku.ca. You may also contact the graduate program office at: gsthesis@yorku.ca.

This research has been reviewed and approved by the ethics review committee for master's research, School of Social Work, York University. If you have any questions about this process, or about your rights as a participant in the study, you may contact the Senior Manager and Policy Advisor for the Office of Research Ethics, 5th Floor, York Research Tower, York University, telephone 416-736-5914 or e-mail ore@yorku.ca

Legal Rights and Signatures

I _____, consent to participate in Health Care Professionals' Experiences with Medical Assistance in Dying (MAiD) conducted by Alison Townsley. I have understood the nature of this project and wish to participate. I am not waiving any of my legal rights by signing this form. My signature below indicates my consent.

Checking this box indicates my consent for my interview to be audio recorded

Signature _____ **Date** _____

Participant:

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Signature _____ **Date** _____

Principal Investigator:

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Appendix 3: Interview Questions

1. What is your profession?
2. What are your professional responsibilities to someone considering MAiD?
3. Who, in your professional opinion, should be able to access MAiD?
4. Who, in your professional opinion, should not be able to access MAiD?
5. How do you continue to support someone who wants to access MAiD, but cannot?
6. Are you bound by your regulatory college to support people that are considering MAiD?

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Appendix 4: PRP Approval Form



PRP Approval Form

Alison Townsley

Student Name

Teresa Macias

PRP Supervisor Name

Putting a Bow on Death and Dying: Health Care Professionals' Experiences with Medical Assistance in Dying. A Foucauldian Discourse Analysis with Agambian Insights.

Title of PRP

Recommendation:

Accepted
Accepted

Accepted Pending Revisions

Not

Date: _____.

Requested revisions have been completed

Date: _____.

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Comments:

Recommend for PRP Conference

Recommend for Gerry Erickson PRP Prize

Teresa Macias

PRP Supervisor Name

PRP Supervisor Signature

Date

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