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Expanding the concept of 'care': A narrative study exploring lessons from end-of-life patients to inform 'Medical Assistance in Dying' curriculum in Canada

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Abstract

This research primarily investigates what we can learn from patient experiences that can help inform the expected curricula that will be developed in response to the new Canadian legislation regarding Medical Assistance in Dying (MAiD). This is a compelling area of research because of the rapidly evolving attitudes in the general population — largely driven by terminally ill patients asserting their legal rights over their bodies and the decision to put an end to their lives as a consequence of the illness they face. The issue of medical assistance in dying has been patient initiated and patient driven. Through the lens of narrative critical research, the listeners are witness to participants exploring through different social media forums, their end-of-life stories.

The results of these participant narratives were significant in that primary themes were drawn despite being from different cities, countries, gender, and socio-economic backgrounds. Implications of this work can inform curriculum for health professionals, in particular physicians and nurse practitioners who must expand their concept of ‘care’ in light of the new legislation.

Keywords

Bill C-14; Committed Suicide; Completed Suicide; Death Denial; Dying with Dignity; Euthanasia; Medical Assistance in Dying; MAiD; Mental Illness; Suicide; Palliative

Care; Palliative sedation; Physician Assisted Death; Physician Assisted Dying; State of Suffering; Thanatology; Unbearable Suffering; Withdrawal of Care.

Acknowledgments

In 2007 I was sitting in the Brescia library studying for an exam while my three-year-old and one-year-old were being cared for at home. I had a chance telephone encounter with my friend's husband whom I was making arrangements for some items to be picked up. I left a message and within a day her friend's husband returned my call. He introduced himself as Rethy, and I am not certain how we got into a personal conversation so quickly, but I learned that he was a radiologist at University Hospital and had been all over the world examining ancient bones. "How exciting!" I thought compared to the life I was living of diapers and toilet training. He went on to tell me with only \$50 in his back pocket he left for medical school in Paris as he fled Cambodia. I asked him if he ever went back to Cambodia to see his family and he told me there was nobody there to see as everyone had been killed. I asked him how is it that he can move forward in his life after experiencing that kind of atrocity. He introduced me to the word "resilience" and I believe he is a fine example. My friend Vanessa came to mind who had an inoperable brain tumor but lived her life as if she was living with cancer and not dying from cancer. With a new sense of purpose, I heard a quote by Mahatma Gandhi who said, "You must be the change you wish to see in the world". I reflected on this and wondered, "How can I make a difference? Who am I to make a difference for I am only one small person?" After seeing that quote for the first time, I started to see it more often in my daily transactions, as if the energy of this quote was following me until I was consciously present. As mentioned, I was sitting at the Brescia library in 2007, a couple months after learning of these two examples of resiliency. I looked up from my desk and high on the library wall, five feet across and three feet high, were those words of Gandhi, "You must

be the change you wish to see in the world". It was official. I did not know how or when, but I believed that I would change the world in which I lived in to some capacity.

(Dombroski, 2015)

August 2017 – It was the above passage I had written in Dr. Hibbert’s class that she first mentioned how using my story telling to situate my work was a very Narrative Inquiry thing to do. I have always appreciated the stories told and the richness and change they can bring in our own lives.

It is my pride and joy to share how I have been the change in my world ten years later. It is not a path in life that I ever dreamed to be a passenger, so I chose to be the driver, and I have not looked back since.

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I am so grateful for our time spent together that was usually between assignments and bouncing ideas for the next paper over a cup of coffee or glass of wine.

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My sister – Whose support and encouragement helped me to realize my potential.

Especially for Dixie – I am grateful for the lessons learned from those slow walks. The constant companionship, and forever being my shadow.

“You have to know what sparks the light in you so that you, in your own way, can illuminate the world.” — **Oprah Winfrey**

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Prologue:

It was Easter weekend in 1999. I sat in the sunroom watching my ailing grandad sleep. It was certain this would be his last Easter. As I sat there, I wanted to tell him how much I had loved him and what an incredible grandfather he had been to me. I reminisced on how I loved driving out to the farm with him after a breakfast of toast and tea, and Granny's home-made jam, to help him feed and check the cows, maybe fix a fence, or check his traps along the river. I wish I had a camera so I could feel and see the picture in my hand, for it is only sketched in my memory. Grandad stirred, but he didn't wake. I thought of that day going down to the river and stopping at the Co-op to buy some hotdog buns, wieners, mustard, water, and a couple of Cuban chocolate bars. Once we got out of the canoe and onto the shore, Grandad brought paper and had taken a match from his pocket and managed to light the fire with the dead branches by the riverbank. He had propped himself up on his elbow while we ate our roasted hotdogs. We sat in silence witnessing the serene environment around us. I can't remember our conversation, but I remember looking at him a long while. Maybe that is why this moment is etched so clearly in my memory.

Grandad had finally woken from his cat-nap. He wondered how long I had been there. I just smiled, trying to hold back from crying, and told him I had just arrived, even though I had been staring at him for a half-hour. I wanted to tell him that I didn't want him to die, that I would miss him, and that he meant, and taught me, so much in my life. I just smiled. Then I thought how I would regret this moment for the rest of my life if I did not tell him how sad I was. But what if telling him this made him sad; I didn't want to make him feel worse. He was the one facing death, not me. Finally, I started to tell him, as I

choked through my tears and high-pitched voice, about how I didn't want him to die, that I would miss him, how much he meant and had taught me in my life, and that I was sorry for crying about this in front of him. He put his hand on my shoulder and told me that it was okay to cry as Jesus cried too knowing he would die soon. While his response was in the third-person, I felt better knowing that he knew how much I loved him and that I would miss him.

That Good Friday was the only time I acknowledged my Grandad's impending death. After that weekend, he went into hospice care. He died a few weeks later, but in the weeks prior, I sat with him a lot and stayed overnight at the hospital on a lazy-e-boy chair to help him in the night as he needed. He had always called me his 'right-hand-man', and I beamed with joy at the title. In those last weeks, I watched his breathing, his hallucinations, his coherent moments, and finally, his last breaths. It was serene. He didn't seem to suffer. It was peaceful. I couldn't have asked for a better death for him. In my opinion, it was a good death.

Chapter 1

1.1 Context

In 2016, the Canadian government introduced legislation Bill C-14, for Medical Assistance in Dying (MAiD). Prior to its passage - although a need for more attention to palliative medicine was established in 2011 - physician training has been largely focused on diagnosing or assessing, establishing a treatment plan (sometimes including therapeutic intervention), and seeking the continuous improvement, or pain and symptom management in a patient's health. However; Bill C-14 adds urgency to the need for physicians to play a new role. Bill C-14 requires physicians to provide MAiD if the requesting patient meets specific criteria. Assisting in death, rather than evading it, is a significant change in the health care professional's fundamental purpose, and it is not addressed in their current training. Whether they participate or refer, MAiD will change the role of the physician; therefore, the medical system will need new curriculum to address this development. Currently, there is no formalized curriculum to deal with the new legislation. Education around individuals' desire for a 'good death' is as unique as the person. Patients who are at their end-of-life may have much to teach us if we take the time to learn from their experiences. This work will significantly contribute to the development of responsive curricula, as medical schools and Continuing Medical Education groups re-conceptualize their program offerings to best prepare physicians for a new context.

1.2 Background

The health and welfare of others has always been my passion. For years, I practiced in the healthcare industry, nurturing others to a happier and more fulfilling lives as a Registered Massage Therapist and Doula. This foundation in the healthcare field allowed me to more easily care for my ailing grandparents with knowledge and compassion as they were dying. It is my own experience as a caregiver that led me to study *thanatology*: the scientific study of death and practices associated with caring for the needs of the terminally ill and their loved ones. My experiences with death and dying led me to wonder what the state of knowledge might be in the medical education curriculum that prepares many physicians. Given the recent changes in legislation with Bill C-14, I wondered how medical education curriculum will change in order to prepare physicians to expand their notions of care to include the new role of helping patients navigate their own end-of-life decisions.

The story of my grandfather's death was an experience that allowed me to think about viewing his death as a good death. It was with difficulty that I did express my sadness to him and in doing so he provided a spiritual metaphor about his death and my sadness. Beyond that, I am left with only assumptions about the quality of his death as I saw it. Perhaps if I had been more prepared, I might have overcome my reservations sooner, allowing me to better understand his experience of death from his perspective. The narrative of a dying patient is one that needs to be heard. Compared to historical times, in our contemporary society, we have distanced ourselves from our mortality:

Death ... has become something that we overwhelmingly learn about and consume through the media. But as such it is shorn of any pain, any real understanding ... pain is for the professionals, not something to detain the ordinary mortal (Jacques, 2004, p. 21).

A lack of attention to dealing with the issues associated with death and dying (fear, emotions, pain, and so on) has resulted in a situation where too often, neither the patients nor the caregivers are prepared to navigate the difficult conversations (Bhatnager, 2013; Penson, Partridge, Shah, Giansiracusa, Chabner, and Lynch, 2005; Lowry, 1997). In my view, it is a complex issue that is further complicated by the varying spiritual, religious, and cultural belief systems. What I learned from my own experiences with my grandfather's dying and his death, coupled with my studies in Thanatology and Feminist Research, is that one place we might begin is acknowledging our past experiences and the role that they play in our approach to this challenging topic. For the purposes of this research, I have elected to focus on what we might learn from those willing to share their experiences of dying.

1.3 Conceptual Framework

To address this issue, I am employing both feminist standpoint theory, feminist poststructuralism and thanatological lenses.

Feminist Standpoint Theory

Standpoint theory emerged over the past half a century to challenge "the relations between the production of knowledge and practices of power" (Harding, 2004, p. 1). The

concern of standpoint theorists is that science's "commitment to social neutrality" was often counter to the needs and desires of women or other vulnerable groups (p. 5). Howell (n.d.) wrote how Feminist Standpoint theorists such as Dorothy Smith and Sandra Harding argue that knowledge and power relations are socially situated and those marginalized groups that are socially situated are more aware of these processes and ask questions more so than the non-marginalized (p. 1). In the same realm with feminist poststructuralism, the perspectives to analyze and challenge the constructs of meaning and power relationships in our society have influence in the decision-making process (Arslanian-Engoren, 2001, p. 513). Both paradigms have a great deal of influence on our society in how we think and act upon those decisions, especially health care decisions that are challenging these traditional methods. Patient experience is created through the context in which the patient lives in - this is an example of the lens that feminist theories bring forth in healthcare. Dorothy Smith (1989) maintains how:

"institutionalized practices restricting the access, of the rules, the marginal, the excluded, to knowledge are deeply built into the ordinary working practices of academia, and are, for the most part, below the level of consciousness" (p. 51).

To understand a patient's experience, we must have knowledge of the patient's context in which they drew that experience. Understanding another's experience, can inform physician practices at end-of-life care. A focus on patient experience values their particular knowledge in the interaction between doctor and patient.

For example, let's consider the shift in care since the industrial revolution as large groups of people were brought together. We experienced a shift from necessarily being self-sufficient (baking our own bread, making and mending our own clothing, and

administering care to each other) to relying on others for the expertise, or specialization of the product or service we needed or wanted.

A similar example can be found in childbirth. Historically, a woman gave birth surrounded by other women supporting her. As childbirth moved from home to hospital, the knowledge and experience passed down from woman to woman was unavailable in the practical sense. While there is no denying that the shift led to a significant decrease in infant and maternal mortality under standardized medical care and conditions, (Canadian Public Health Association, 2017) the average women's knowledge and experiences of the birth process was reduced.

With the medicalization of labour, birthing, and delivery, decision-making was designated to medical professionals effectively transferring their rights (choices, and decision-making) in many cases to their doctor. Medicine had become professionalized and assigned within a patriarchal structure. The role of the physician had shifted to develop increasing medical expertise, and away from considering the experiences of the labouring woman. A male doctor, for example, may surmise that his knowledge about childbirth was superior to the lived experience of his pregnant patient. Knowledge was gained from reading a book, and performing deliveries, rather than from understanding the experiences of the women who experienced childbirth. Certainly, all doctors are taught to expect anomalies, but standard knowledge is a powerful and dominant discourse. More recently, "patients and physicians are beginning to find a healthier balance of power through a process of shared decision making" (Truog, 2012, p. 1). To focus and value the patient narrative is a return to the historic relationship of patient and caregiver. This shift is happening at a time when patients are advocating for more

decision-making authority in allowing them to die with dignity, on their own terms. We are at the very beginning of this shift, and have much to learn from patients themselves about just what that means to them.

Thanatology

Since the 1960s, a “death awareness movement” (Neimeyer, 2001) has emerged to challenge the medicalization of death. Two particular events piqued academic and research interest in death: “First, the modern hospice movement developed in England and rapidly spread to the United States and other nations... Second, the 1969 publication of Kubler-Ross’ *On Death and Dying* caught the public’s imagination” (Doka, Neimeyer, Wittkowski, Vallergera & Currelley, 2015, p. 343).

Thanatology is “the study of death, dying, grief and loss” (Chapple, Bouton, Chow, Gilbert, Kosminsky, Moore & Whiting, 2017, p. 118). Thanatology is the study of death (and care for the dying), particularly focused on the needs of the terminally ill, and their families. As a profession, some consider thanatologists to be gate-keepers of death, the dying, and grief given its perception as a new field of study (Fonseca & Testoni, 2011).

Thanatologists

see death as and dying as a central and rich human experience, ... [and they] promote recognition, respect, and reconciliation of death experiences.

Thanatologists may act as change agents who open the conversation around death, provide direction through research and best practice, and heal the pain of grief...

[They] notice that understandings of what constitute both life and death are socially constructed... [They] recognize the role that ritual often plays ...in

attempts by individuals, communities and societies to restore order in the wake of disruption... [and, they see advanced care planning as a] way to exert some control over dying ahead of time (Chapple et al., 2017, p. 121).

Across cultures, people have devised various ways of dealing with the physical, psychological, economic and spiritual aspects of death. Over time, like the example from childbirth, we see shifts in how people understand and deal with death (Imogie, 2000). As people left their small-knit communities and moved into cities away from their families and communities, certain cultural traditions were left behind (p. 56). One of these traditions was how people dealt with death and dying. What once was a rite of passage for family and friends to participate in became institutionalized and the dying were segregated (p. 56). From this segregation, children were raised with minimal – if any - exposure to death, and became confused when death occurred (p. 56). The implication is not only the separation from family, but the separation of dying from the home.

When the experience of dying was moved from the home to a hospital, the medicalization of death led to a mystification surrounding what was happening. It transformed what had been an integral part of ‘life’ to something we no longer witnessed in the same way, and therefore found hard to ‘believe’, leading some to live in denial of the one sure certainty in life – our death.

The Canadian Medical Association has a code of ethics for physicians, residents, and medical students to abide by that includes compassion, beneficence, non-maleficence, respect for persons, justice and accountability (CMA, 2015). If in fact this is the case for a health care professional who may have little or no experience with death and dying

prior to medical training, the disconnect to the experience with patients dealing with dying, may be challenging.

As I have progressed and trained in my studies of thanatology, I have come to view that MAiD is an important element of the health care offering. I recognize and acknowledge the tensions between the advocates and/or critics of a medically assisted death, but it is now law and we need to know how to better support physicians.

1.4 Inquiry as Narrative

In most cultures, we are cared for by our primary caregivers until we leave the home environment. Within those early years, we are socially constructed according to what our caregivers taught us with how to think, feel, and act. Some lessons were taught through storytelling, mirroring, and giving examples of what to expect as we grew up. One of those family lessons can be exchanges about death and dying, or alternatively, through a lack of conversation about death and dying. For example, a former classmate once shared with me that her father was diagnosed with pancreatic cancer and his life expectancy was cut incredibly short. They never explicitly spoke about his impending death or a life without him in it, but instead, she showed her love by making a scrapbook of their family to share with him. From this observation, I noted the gaps in end-of-life conversations with loved ones, much like the one I had not had with my own grandfather. I wondered about the hesitation surrounding the communication encompassing the end-of-life experience. This conversation is especially important between a physician and her/his terminally ill patients.

Using Narrative Critical Research in this study helped me understand and illustrate how an institutional “narrative of silence” appears to have emerged with respect to conversations in end-of-life situations. The institutionalization of medical and health care led to a separation of patients from the home and from their social support. We can see examples of this where the dying are sequestered in an isolated room, sometimes in an isolated wing, with limited visitation times for visitors. More recently, we have begun to see a shift in attitudes to this health care “norm” with advocacy groups focusing on considerations for a home death. A home death may be an option over dying in an institution depending on the health care and family support with open lines of communication and preparation (Stenekes & Streeter, 2015).

Hendry (2010), a narrative researcher, looks at the ways in which humans make meaning of their experiences, and how some of the boundaries and binaries that are constructed are there to serve others’ interests (p. 78). Exploring these boundaries and binaries critically is what drives this research.

Critical Narrative Research (CNR) was the most appropriate to study end-of-life conversations and practices, given the resistance it places on “the colonial underpinnings that have traditionally plagued ethnographic practices” (Iannacci, 2007, p. 55). CNR creates a deepened awareness of the participant’s stories that intersects and acknowledge: “the complexity and multiplicity of lived experience and the importance of fully disclosing the subjectivity of the research process” (p. 57). As researchers, in an effort to be present with your participant’s journey through their story telling, we must be present and aware of our own journeys. Iannacci (2007) suggests that we learn to identify three voices within narrative research that must be heard and reconciled in order to move

through the story: “Reconceptualization is realized through a process of construction, deconstruction and re-construction. This is a threefold mimesis (that) refers to three domains: a past, a present mediating act, and a future” (p. 57). What this means for the participant and researcher, is critical thinking that transpires from what was, what is, and what could be. In understanding where you have been, you can make changes to where you want to go from that point forward. Using this approach, this thesis provides an overview of what may have led us to our current practices, and provides insights into where we might go from here.

1.5 Key Words

I have laid out a few key words or terms along with a brief definition of how they are being used in this study. Additional key words are provided in Appendix A.

Bill C-14 – An Act to amend the Criminal Code and to make related amendments to other Acts (medical assistance in dying) (Statutes of Canada 2016).

Committed Suicide VS. Completed Suicide – Committed suicide is the term regularly used to describe someone who has died by suicide. The issues with this term are the negative feelings (e.g., dishonor, immoral) conjured when used and the stigma that comes with it (Silverman, 2006). The preferred language is *Completed Suicide* (Nielsen, Padmanathan, and Knipe, 2016).

Death Denial – Death denial originates from the Industrial Age (Imogie, 2000), where death was hidden from the former death rituals of family and friends (Tucker, 2009, p. 1105).

Dying with dignity – Dying with dignity should not be equated with euthanasia, as a dignified death is possible without euthanasia (CMA, 2014, p. 5).

Euthanasia – Euthanasia is drawn from two Greek words meaning ‘good death’ (Kuhse, 1993, p. 294). If you knowingly and intentionally perform an act, with or without consent, that is explicitly intended to end another person’s life (CMA, 2014, p. 5).

Medical Assistance in Dying – MAiD – Legally, a physician or nurse practitioner may actively administer for patient, or patient self-administers, substance that causes their death (CMA, 2014, p. 5).

Mental Illness – Mental illness varies from mild to severe conditions that are distinguished by variations in thought, mood, and behavior associated with significant distress and impaired functioning over an extended period of time (Health Canada, 2012).

Palliative Care - An approach that improves the quality of life of patients and their families facing the problems associated with a life-threatening illness. It involves the prevention and relief of suffering by means of early identification, assessment, and treatment of pain and other physical, psychosocial, and spiritual symptoms (CMA, 2014, p. 5).

Palliative sedation - The use of sedative medications for patients who are terminally ill, with the intent of alleviating suffering and managing symptoms. The intent is not to hasten death, although this may be a foreseeable but unintended consequence of such action (CMA, 2014, p. 5).

Physician-assisted death and euthanasia are distinguished by who performs the action: in the former case the patient performs the action with the physician providing the means, and in the latter the physician or another person performs the action (CMA, 2014, p. 5).

Physician-assisted dying – The process in which a physician knowingly and intentionally provides a person with the knowledge and/or means required to end his or her life, including counselling about lethal doses of drugs and prescribing such lethal doses or supplying the drugs (CMA, 2014, p. 5).

State-of-Suffering V (SOS-V) – A quantitative comprehensive and structured assessment used to prove unbearable suffering related to symptoms which may be physical, psychological, social, and existential (Ruijs, Van der Wal, Kerkhof, and Onwuteaka-Philipsen, 2014).

Suicide – Suicide is a cause of death and our language should reflect this; people die by suicide (Nielsen, Padmanathan, and Knipe, 2016).

Thanatology – Thanatology is the study of death and dying (Chapple et al., 2017, p. 118).

Unbearable suffering – Unbearable suffering is a state of mind one must be in for consideration when patients request MAiD (Dees, Vernooij-Dassen, Dekkers, & Van Weel, 2010, p. 339).

Withdrawal of care – Withdrawal of care is stopping interventions such as feeding tubes with dying patients (not euthanasia), which will lead to the person's eventual death (CMA, 2014, p. 5).

1.6 Organization of the Thesis

In chapter One, I have introduced the current legislative changes in Canada, through Bill C-14 that necessitate changes in the traditional role played by physicians and health care teams, along with the conceptual framework that I bring to the study. In Chapter Two, I offer a brief overview of the historical, legal, ethical, and medical education practices that provide insight as to why a medically assisted death is controversial. In Chapter Three, I introduce Critical Narrative Inquiry as the methodology best suited to explore the experiences of the terminally ill who have shared their thoughts through documentaries, blogs and other media. Woven throughout the chapters are analytic observations made through a feminist lens and theories from thanatology which I introduce in Chapter Two. In Chapter Four, I present the findings of this research, with salient examples drawn from the research texts. In Chapter 5, I offer conclusions, discuss limitations, and suggest implications for further research into this expanding area.

Chapter 2

2.1 Literature Review

The literature that addresses topics related to MAiD appears in a variety of contexts including legal, moral, patient needs, ethics, policy, and physician readiness. Reviewing the literature allowed me to locate how I am entering the scholarly conversations taking place on MAiD to date.

In the 16th century when the French first landed on what they thought was undiscovered land, later known as Canada, they brought their Christian values which has largely shaped Canada's history (Leacock, 1976, p. 16). More recently, the Government of Canada has created the National Truth and Reconciliation Commission that has started to acknowledge values, practices and teachings of the country's First Nations, Metis, and Inuit people (Elias, Mignone, Hall, Hong, Hart, & Sareen, 2012, p. 1568). As a result of these demographic, political and cultural evolutions in our history, we citizens are positioned in ways that ask us to consider multiple ideas, beliefs, and practices that will have some influence on the laws of our country. The scope of this thesis does not allow me to go into great detail on the historical or political debates for each of these significant topics. However, it is important to recognize the influences that have contributed to our historical past, consider where we are at this moment, and imagine where we may go in the future in terms of MAiD.

2.2 History of Completed Suicide

Human death occurs in a number of ways: murder, accident, illness, age, war, and death by suicide. While the first five items listed are often viewed as acceptable, if not an honourable end to the cycle of life, suicide is a complex topic, and one that has often been shrouded in shame, secrecy, and silence. The completion of suicide has been written about since the days of Greek scholars such as Socrates (Fedden, 1972), and his student Plato where suicide was viewed as an insult to society: to complete suicide, was to desert one's country (Holmes & Holmes, 2006). Moving to the Roman times, the attitudes toward suicide were society-driven and that depended on the death being considered negative or righteous (Fedden, 1972, Holmes & Holmes, 2006). To die by one's own sword was more dignified than a Roman soldier being captured and killed by his enemy (Fedden, 1972, Holmes & Holmes, 2006).

By the 5th century, St. Augustine proclaimed that life is a gift from God and that killing one's self was a rejection of God (Holmes & Holmes, 2006), therefore making suicide intertwined into the moral values and teachings of the Christian church. During the Middle Ages, death by suicide was considered a civil crime; land owner's property would go to the King, and they were buried at 'crossroads' to represent their shameful death (Fedden, 1972). Up until 1972, attempted suicide and assisted suicide were still criminally liable according to the Criminal Code of Canada, but by June of 1972, suicide was decriminalized and no longer charged as a criminal activity (Spiwak, Elias, Bolton, Martens, & Sareen, 2012). Only in 2016 was assisted suicide by a medical professional

considered unconstitutional and therefore no longer criminally charged (Emanuel, Onwuteaka-Philipsen, Urwin, & Cohen., 2016).

Finding information about Indigenous beliefs on death by suicide was not possible. In the Indigenous culture, many teachings are handed down through oral traditions and not always shared outside of their communities. While there is a lot of research suggesting why death by suicides are happening at higher rates in the Indigenous communities compared to their peer group in the rest of Canada (Chrisjohn, McKay, & Smith, 2017), there is little or no research available on a medically assisted death within the Indigenous communities besides what has been published through the mass media.

For example, in a 2016 Globe and Mail interview, an Indigenous liberal MP, Robert Falcon-Ouellette, spoke out against Bill C-14 and said: “Traditionally, in Indigenous cultures, suicide never existed” which resonated with former judge and Senate member Murray Sinclair:

From the Indigenous perspective, ending one’s own life was not encouraged, in fact it was discouraged and there are teachings in my community, Ojibwa teachings, around whether or not you will be able to travel to the spirit world in the proper way or a ceremony could be done for you if you make the decision to end your life without good reason (Bryden, 2016).

It is conceivable that concern has arisen from the growing youth suicide epidemic in many Indigenous communities. Senator Lillian Dyck feels that historical and cultural beliefs are a completely separate issue from the current crisis of suicide in Indigenous communities. Further, we recognize that one Indigenous leader cannot speak for all nations, which is considered Pan-Indianism (Chrisjohn, McKay, & Smith, 2017, p. 62).

Understanding the chronicled history of death by suicide as a social construct informs how Canadian society has understood and processed this event, and aids in our consideration of how individuals may view the new legislation that has led to MAiD. However, Canada was not the first country to pursue medically assisted death. Several other countries have developed protocols to provide “euthanasia” or physician-assisted suicide. To date, these countries can legally practice euthanasia or physician-assisted suicide: the Netherlands, Belgium, Luxembourg, and Colombia (Emanuel et al, 2016, p. 79). Only physician-assisted suicide, and not euthanasia, is legal in Switzerland (p. 79), and Germany (Staff, 2014), and only these five American states: Oregon, Washington, Montana, Vermont, and California (Emanuel et al, p. 1). A physician assisting a patient’s death in Japan does not have the same strict requirements as they do in other countries (Hall, 1996, p. 833). The patient must have a clear request to end their life, but no documentation is needed from other physicians or psychiatrists (p. 834).

One cannot compare mental illness and suicide with those seeking MAiD. Those who seek MAiD do not have a mental illness. Incidentally, one of the factors in obtaining a medically assisted death is that one must be capable of making decisions and without other psychosocial pressures to pursue MAiD (CEP, 2016). “We now live in a time when we seek to understand people who experience suicidal ideation, behaviours and attempts, and to treat them with compassion rather than condemn them” (Beaton, Forster, & Maple, 2013).

Table 2. States and Countries With Legalized Euthanasia and Physician-Assisted Suicide

State	Euthanasia Current Status	Physician-Assisted Suicide Current Status	Method of Legalization	Year of Landmark ^a	Age Requirement, y	Required Diagnosis	Waiting Period ^b	Psychiatric Consultation Required?	Patient Symptom State
Oregon ¹²	Illegal	Legal	Referendum	1997	18	Terminal <6 mo	15 d oral request, 48 h written request	No	"Capable" ¹²
Washington ¹³	Illegal	Legal	Referendum	2009	18	Terminal <6 mo	15 d oral request, 48 h written request	No	"Competent" ¹³
Montana ¹⁴	Illegal	Legal	Court ruling	2009	None specified	None specified	None specified	Not specified	None specified
Vermont ¹⁵	Illegal	Legal	Legislation	2013	18	Terminal <6 mo	15 d oral request, 48 h written request	No	"Capable" ¹⁵
California ¹⁶	Illegal	Legal	Legislation	2015	18	Terminal <6 mo	15 d oral request, 48 h written request	No	Has "capacity to make medical decisions" ¹⁶
Switzerland ^{17,18}	Illegal	Legal ^c	Penal code ^c	1942	None specified	None	None	No	None specified
Colombia ¹⁹	Legal	Legal	Court ruling Guidelines published ^d	1997 2015	18	Terminal phase	Within 15 d after committee approval	No, but psychiatrist on committee	In terminal phase ¹⁹
Belgium ^{10,20,21}	Legal	Legal ^e	Legislation	2002	None	None, adults Terminal, children	None, terminal 1 mo, nonterminal	Yes, children (<18 y) and adults (≥18 y) with psychiatric condition No, all others	Medically futile condition of constant and unbearable physical or mental suffering ²⁰
Netherlands ^{10,22,23}	Legal	Legal	First legal review procedure ^f Legislation	1994 2002	12	None	None	No	Patient's suffering is unbearable and there is no prospect of improvement ²²
Luxembourg ²⁴	Legal	Legal	Legislation	2009	18	None	None	No	Incurable medical situation with constant and unbearable physical or mental suffering without prospect of improvement ²⁴
Canada ²⁵⁻²⁷	Legal, national Legal, Quebec ^g	Legal, national Legal, Quebec ^g	Legislation, national Legislation, Quebec	2016	18	None	10-d written request	No	"Grievous and irremediable medical condition that causes enduring and intolerable suffering" ²⁷

^a "Landmark" indicates legislation, court rulings, and major events.

^b In US states, patients must make 2 oral requests separated by at least 15 days, followed by 1 written request. After the written request, patients must wait at least 48 hours before receiving a prescription.

^c Article 115 of the Swiss penal code only considers assisting suicide a crime if the motive is selfish. Does not require assistance to come from a physician. Switzerland allows noncitizens to utilize physician-assisted death ("suicide tourism").

^d Colombia's highest court ruled in 1997 that physicians cannot be prosecuted for euthanasia if the patient has a terminal condition and has consented but no official case of euthanasia took place until the Health Ministry published guidelines in 2015.

^e While the law does not address physician-assisted suicide directly, it is treated as a form of euthanasia by the Federal Control and Evaluation Committee for Euthanasia.

^f In the Netherlands the first legal notification procedure started (by the public prosecutor) in 1994; it was enacted as a law in 2002. The requirements mentioned in this table are similar in the 2 procedures, except for the age requirement that was explicitly mentioned first in the 2002 law.

^g The Quebec law does not mention euthanasia or assisted suicide but medical aid in dying (aide médicale à mourir), defined as the administration of medications or substances to a person at the end of life, at the person's request, to relieve their suffering by causing death. The law also stipulates that the physician must administer "such aid" personally and take care of and stay with the patient until death ensues. It is unclear whether physician-assisted suicide can be considered as a possibility under this description.

Table 1 States and Countries with legalized Euthanasia and Physician-Assisted Suicide (Emanuel et al, 2016).

2.3 A Death Denying Culture

Scholars have suggested that our current culture is one that reflects a denial of death. (Tucker, 2009, p. 1105). To understand the emergence of this culture, we look to the history of medicine and its origins in the Industrial Age (Imogie, 2000). Prior to the Industrial Age, death was a regular part of life that included family and friends in death rituals (Tucker, 2009). The expected age of death was earlier because life spans were shorter. A shorter life span could be traced to poor nutrition, sanitization, and available knowledge of medicine. Death was also an expected punishment for crimes that included

murder, adultery, or suspicion of witchcraft, as examples (Pinker, 2011). Given a largely rural lifestyle, the kind of death was unambiguous — there was an obvious and direct cause of death. There was a certainty to death. Death was centered in life itself. As people became urbanized, hospitals were built. Doctors who had customarily gone into a patient's home increasingly conducted their work in sterile hospitals where a growing mystique about their practices grew. Over time, the practice of medicine became professionalized and institutionalized, further distancing their activities from the public. The combined evolutionary changes constructed a social norm where death was seen to be something that happened outside of the purview of family and friends, thereby distancing them from what were common death rituals (Tucker, p. 1105).

Some of the problems of trying to overcome death, or neutralize death, emerged in the medicalization of death. Interrupting the natural death time line with either machines or pharmaceuticals can become problematic when these interventions occur. We see examples of this when people become gravely ill and make their last wishes known or unknown, leaving the families to struggle with decisions to use all measures possible, including life support, to keep them alive. French Philosopher Françoise Dastur (2004) contends that,

Death can never come to a human being at the right time, when he or she has fulfilled all his or her possibilities: there could always have been more to achieve...
Death is not... an accidental interruption of human life, but rather its foundational finitude (p. 96).

Dastur goes on to suggest that “at any price can be the expression of a real denial of [one’s] humanity” (p. 45), and defining mortal, immortal, and the idea that death is not an imperfection ... but we must see the joy in existing ... until we die (Dastur, p. 47). One example of the medicalization of death may be found in a patient who suffers a massive aneurism. Previously, this patient would have almost certainly died. However, with the help of modern medicine, machines may interrupt that death, technically keeping the heart beating and the lungs functioning. This result—diminished quality of life — is a perfect example of medicine, often at the urging of family members, trying to overcome death. A patient or their family members may not be ready to acknowledge that death is inevitable; they remain in denial that it is not possible to sustain a life in which they are a functioning part. Physicians too, through their training, may go to heroic lengths to prevent or avert death as the most appropriate response to an illness or injury.

More recently, there have been calls for discussions about one’s death with family, friends, and one’s health care team, preferably before the need arises. Dastur (2012) asked the question, “How are we to confront death?”, and one answer comes in the way we describe how we live our lives. One’s ability to acknowledge and manage their attachments to a loved one, and the loss of that loved one should also be considered. To accept death is: "being able to die, and thereby seeing death not as an imperfection of the human being, but on the contrary, a capacity...that anxiety in the face of death is in no way incompatible with the joy of existing” (p. 47). Joan Halifax's (2008) book, *Being with Dying*, refers to about confronting death: “I believe that studying the process of how to die well benefits even those of us who may have many years of life ahead” (p. x5). Confronting death, therefore, should happen prior to a terminal prognosis, or a sudden

death. Although such a conversation could be very difficult, “planting seeds of kindness, love, compassion, helps us ride the waves of change without drowning” (p. 44). In my opinion, by having these end-of-life conversations with those with whom you have an attachment, a plan can be made together to detach and know that your loved ones, although they will mourn for your death, will live on with their lives.

2.4 Legal Conversations

In June 2016, after years of legal and public debate the Government of Canada passed Bill C-14, allowing patients who meet specific criteria to access Medical Assistance in Dying. This comes after years of debating the principles within the legal system of the Canadian Charter of Rights and Freedoms. Bill C-14 is the document that outlines the amendment to the Criminal Code that frames the provisions in the new legislation. What this means for qualifying Canadians who want to pursue a medically assisted death is that they may have a chance to fulfil this act, and physicians will not be charged with homicide as a result of providing this form of care. However, finding physicians willing to provide the service has been challenging to date. To date, Ellen Wiebe is the only physician in her particular health authority in British Columbia “currently prepared and available to receive referrals and provide assistance” (Clark, 2016, p. 1151). The law requires an abundance of information about the patient’s medical history and symptoms to be gathered through the referral, patient assessment, and interviews with family to ensure the patient is competent, not being coerced, and firm in their choice.

... [Patients] are seen many time in person or by telemedicine to discuss and detail the procedure which consists of three medications to induce sleep, coma, and

cessation of breath. Given the new role physicians play in medical assistance in death, they will need the curriculum to inform their decision if this is something they want to be a part of, or refer it on to another physician (p. 1151).

According to Wiebe, “there is no right without access” (p. 1151), and Canadian Medical health teams (including pharmacists, nurses, nurse practitioners and physicians) need to be available and properly prepared. There are also issues surrounding the criteria laid out in MAiD that some argue are not consistent with the Supreme Court of Canada’s 2015 decision in *Carter v. Carter*. The Supreme Court argued that the illness, disease, or disability be ‘irremediable’ rather than ‘incurable’. The Bill, therefore, “compels patients to exhaust even treatment options that they find unacceptable in order to be eligible to access to assistance in dying” (Downie, 2016, p. 2). This change suggests that although the legal community has made provisions under Bill C-14 for MAiD to be legal, additional challenges and amendments are expected to be coming, leaving those responsible for providing the service ill-prepared to cope with a changing context.

2.5 Moral Conversations, Ethics, and Policy

There are many individual and distinctive factors to be considered when contemplating medical assistance in dying. What warrants moral accountability and keeping professional integrity when it comes to end-of-life decision making? According to Murray et al. (2004), *informed decision making* and being part of the conversations in treatment decisions constitute what the patient considers a ‘good death’ (p. 270). Coming to the decision of choosing medical assistance in death potentially includes a myriad of conversations when it comes to decisional conflict. Decisional conflict arises when the

decisions to be made involve risk, loss, regret, or challenges personal life values (p. 272).

Deciding when it is time to die occurs ideally only after numerous discussions with health-care providers, family, care-givers, and friends. Ontario patients have access to a structured form of questions, assessment, eligibility, and numerous resources for the patient and family to read to make the most informed decision through the Centre for Effective Practice to bring to their team of health-care providers. As for Ontario physicians, there are resource tools for capacity and consent that help further inform the physicians in their role with MAiD (National Initiative for the Care of the Elderly, 2017).

There are often tensions between ethics and policy, particularly when working within the context of fiscal restraints. From an economic point-of-view, Tanuseputro (2017)

estimates that the implementation of medically assisted deaths lessens the strain on the health-care system, could be saving anywhere from \$34 – \$138 million dollars annually (p. 99). These financial statistics produce further alarm for those that oppose this Bill by suggesting how expendable the dying really are. At the same time, they can be viewed as a call for better resources to improve palliative care (p. 99). Tanuseputro (2017)

optimistically thinks that introducing “appropriate policies, education and surveillance ...[will] ensure the availability of care throughout all levels of society” (p. 100).

However, others, like Rosoff (2013) hold great concern for patients who are from vulnerable populations, and therefore may not have these access to the same level or type of end-of-life care (p. 194), and may feel coerced into MAiD.

Medical futility is a slippery slope and offers an ethical dilemma for many who face the end of their life. Historically, health care has been paternalistic in nature with *physicians knowing best*, there are complex entanglements with patients having the right to refuse

treatments, or patients demanding treatments not initially offered to them (Moratti, 2009, p. 369). Treatments granted to patients to prolong their life at any cost, despite the odds sometimes being stacked against them, can be considered a waste of resources. For example, the practice of triage was first introduced to prioritize patients that were most likely to survive (p. 371).

In the ruling of *Carter v Canada* (2015) the precedential outcome of the 1993 British Columbia Supreme court judgement on *Rodriguez v British Columbia* weighed in on section 7: “the object of the prohibition was to protect vulnerable persons from being induced to commit suicide at a time of weakness” (*Carter v. Canada*, 2015, p. 37). It was decided in the *Carter v Canada* ruling that it did violate section 7 of the Charter of Rights and Freedoms whereby:

“...there is no clear societal consensus on physician-assisted dying, there is a strong consensus that it would only be ethical with respect to voluntary adults who are competent, informed, grievously and irremediably ill, and where the assistance is “clearly consistent with the patient’s wishes and best interests, and [provided] in order to relieve suffering” (para. 358). (*Carter v. Canada*, 2015, p. 22).

While the concern remains for some groups that Bill C-14 could take advantage of the most vulnerable of Canadians, the policies in place to safeguard these requirements, are very stringent. Informed consent is a procedure that must be met even to access health-care professionals.

According to the Government of Canada’s website under *Medical Assistance in Dying*, one can legally access this program if: you are over 18 years old and are mentally

competent, personally request to pursue MAiD, provide informed consent, have a serious illness, disease or disability, be in some type of irreversible state-of-health, are experiencing unbearable suffering, and a natural death is reasonably foreseeable. Some of the differences between what is a suitable reason to pursue MAiD include, *intolerable suffering* maybe a requirement in the Netherlands, but it is not in Oregon (Ganzini, 2017, p. 7). Another difference can be seen where lethal injections are illegal in the US, so all people are required to take those lethal doses, it must be oral medications (p. 8).

Competence and capacity are the requirement for pursuing a medically assisted death as some patients that start the process, may become incapacitated and not able to administer the lethal dose themselves. This raises the issue that they may feel they need to die sooner than they want.

2.6 Patient-centered Practice

The patient-centered model we see today only started in the 1990's, beginning with educating patients on their treatments and treatment goals. Until then, the needs of the patients were not considered, and nor were they accountable for their own health and lifestyle choices (Hoving, Visser, Mullen, & Van den Borne, 2010, p. 2). Since this time, the patient and health-care provider relationship has been evolving to keep up with change. The reasons for some of these factors include bio-medical advances, an ageing population, and cultural diversity (p. 4). The shift from one physician making all the decisions for the patient changed with the introduction of physician specialties in chronic illness and disease. Although patient-centered care is the focus, a team of professionals to assist with the patient also came to fruition in an effort to keep patients at home and not

in the hospital (Hoving et al, p. 3). Understanding the history of the patient and physician relationship is important to further understand the autonomy of a patient who is considering MAiD.

The introduction of MAiD means that patients have arrived at a place in the health care system where they legitimately have a say in their treatment plan: to choose treatment or have no treatment in their illnesses. Unbearable suffering is one portion that is evaluated and while a patient may say their suffering is unbearable, it is only considered unbearable if someone else sees it as that. What this means, according to Dees, Vernooij-Dassen, Dekkers, and Van Weel (2010), is that even though this is meant to give autonomy to the dying, it is what is perceived by the professionals that determines if they are allowed to die through medical assistance (p. 339). Yet Ganzini (2007) notes that in the case of an Oregon family, the reason for requested assistance in death was about being in control of their body, dignity, wanting to die at home, and the least important reasons were financial or depression (p. 154). Understanding the patient's point of view on why they would choose a medically assisted death helps the professionals in their decision-making. Murray, Miller, Fiset, and O'Connor (2004) also advocate that patients maintaining some perception of control is valued and promotes quality of end-of-life care (p. 270). Whatever the reasons may be, they are their own and need to be legitimized.

2.7 Physician Readiness

Even though minimal literature has been published about physicians' personal readiness to provide a medically assisted death, the news media has discussed this topic. Since the

passing of Bill C-14 in June 2016, the National Post released an article in February 2017 stating that some doctors who are willing to participate in a medically assisted death, want their names put on hold or taken off the list they are available to assist, completely. While it is noted that some feel they are coming from a place of compassion, others may not feel the same for their own moral reasons but also the legal concerns due to the ambiguous wording without the physician being prosecuted for murder (Kirkey, 2017). This article, as well as the other articles noted below, serve to report what physicians are really saying privately and offers a better idea about patient experience and a physician's own concerns can impact and inform curriculum (see Table 2).

DATE	SOURCE	NAME	THEME(S)
June 8, 2016	Maclean's interview with Dr. Jeff Blackmer – VP of medical professionalism at CMA (Proudfoot, S.)	A CMA doctor on the burdens and ethics of assisted death	-burden (of MAiD) placed on physicians -ambiguous language -poll: 70% physicians will not participate, 30% unsure/will participate -unknown psychological impact -personal for each physician
October 24, 2016	The Washington Post (Szabo, L.)	'Death with dignity' laws and the desire to control how one's life ends	-research shows that less about controlling pain and more about controlling end-of-life -physician says: "It's almost never about pain ... It's about dignity and control" (p.2) -patients concerned about loss of autonomy, burden to care-givers -control body, control life -patients are white, well insured, college educated -bait-and-switch; hasten patient's death because of existential suffering. -some people find meaning and purpose and adequate symptom control -some hold on to their legal prescription, because they can control the timing and method of death
February 2017	Critical Care Medicine Journal (Goligher, E., Ely, W., Sulmasy, D., Bakker, J., Raphael, J., Volandes, A., . . . Downar, J.)	Physician-Assisted Suicide and Euthanasia in the ICU: A Dialogue on Core Ethical Issues	-benefit or harm of death -relationship of physician-assisted suicide and withholding or withdrawing life support -morality of physician deliberately causing death -management of conscientious objection
February 26, 2017	National Post (Kirkey, S.)	'Take my name off the list I can't do any more': Some doctors backing out of assisted death	-physicians no longer willing to participate due to emotional fear or prosecution -too distressing for some doctors - far bigger issues are the paperwork and bureaucracy, medications, qualifications, faith-based hospitals refusing to forward requests -doctors need to be supported and assured
April 2, 2017	The Globe and Mail (Grant, K.)	Ontario lacks coordinating service for patients who want an assisted death	- No public coordinating service connecting patients to seek MAiD is putting pressure on physicians that do not want to participate -physician's patients attempting suicide due to not being referred -some physicians object due to moral grounds -some physicians want the provincial government to insert a "conscience protection clause" due to the distress it is causing some physicians -March 24, 2017 – 138 physicians on the list, 30/138 will only access and not inject

Table 2 *Concerns Physicians are reporting with MAiD (synopsis of articles)*

2.8 Summary of the Literature Review:

The review of the literature points to at least two narratives that are relevant to this study: the first traces the rise of the role of patients in making choices about their own lives and deaths; the second presents the often-competing roles that church and state have played in both the identity formation and realization of both patient and physician with respect to end-of-life decisions. It is here that I locate the contribution to the scholarly conversation that this work will make.

Chapter 3

3.1 Methodology

This study is about identifying what we as researchers, can learn from the articulated experiences of patients who have chronicled, through one form or another, their end-of-life journeys. It is a timely topic, given the political and legislative shifts that have happened over the past year in Canada. As a result of these shifts, numerous documentaries, media interviews, and blogs have been produced. While we can never truly know another's experience, access to representations of patients' thinking and actions can help us collectively and individually better understand the challenges that they faced, and offer us insight into what informed their decision-making.

Critical Narrative Inquiry (CNI) as a systematic study of experience allows us to make public the deeply personal and reflective experience of others in ways that allow us to reflect critically upon cultural and historical traditions, power relations, and identity formation.

Using CNI to make sense of death or dying aligns well with the meaning-making goals of a narrative methodology. The process of this reflexive methodological approach clarifies the issues or 'narratives' at play, offering insights into how physicians might improve professional practices with respect to end-of-life care.

As we engage with the experiences of others, we can juxtapose differences to consider 'two-way inquiry learning' (Hooley, 2009, p. 157). It is a recursive and reflexive approach that encourages fluidity and co-construction of meaning between researcher, texts, and reader. The themes or patterns that unfold while considering the collective experiences are instructive, and can form the

basis for new understanding. Counter narratives are sought and explored for insights that they offer.

3.2 Narrative Inquiry

Critical narrative inquiry holds a space for those that may be otherwise silenced (Clandinin & Murphy, 2009). It provides an opportunity for their experiences to be expressed on their own terms and in their own words. The researcher becomes very much part of the process by observing and hearing what the participant is saying and then querying the data (p. 600). The researcher also considers issues of power: Who is this working for? What are the assumptions? Where is power located in this exchange? Iannacci (2007) argues that the researcher must be in tune with their own journey while observing the journey of their participant. The past, present, and future idea for both participant and researcher causes a natural self-reflection to what was, what is, and what can be. There is no linear method expectation; however, Iannacci (2007) argues that to move through each act, you need to acknowledge each phase before you can successfully move on to the next.

As researchers assemble these stories, they are gathering “knowledge from the past and not necessarily knowledge about the past” (Bochner, 2007, p. 203). The information brought forward is not always about the events that were happening at the time. It is about how that person was experiencing those events. Language is the value in the research as there can be many values to one word and what that word means is understood and deciphered depending on the individual (Polkinghorne, 1988). Hendry (2010) observed: “Wandering, and perhaps getting lost, is key to the ongoing process of inquiry” (p. 78).

CNI allows both time and sometimes distance to reflect on the process and experience of the information shared. This allows for the information to be considered as Iannacci (2007) articulated regarding the process of construction, deconstruction, and re-construction in an effort to re-conceptualize the experience. The relationship the researcher has with the participant, by listening and being present with their experience, allows the researcher to focus on what they are saying or not saying, since what a participant is not saying is just as valuable as what they are saying. It is within these sorts of dialogues or silences that we are witness to the participants and our own powerful and persuasive experiences.

3.3 Strengths

Polkinghorne (1988, 1995) had astute perspectives on how narrative critical inquiry can provide a fruitful method of research. Besides the experiences providing different perspectives on previously researched subject matter, it is from the point of view of the participant that their experience need not be corrected, as their experience is perfectly correct. Polkinghorne (1995) states: “It is often only retrospectively that we come to understand and give meaning to events” (p. 11). It is in the act of reflection and distance from our research that we may see the experience differently.

3.4 Weaknesses

Like all methodologies, CNI has its weaknesses. One often voiced is that participants will manipulate stories to suit the researcher, or reflect their own bias. In any written text, as Connelly and Clandinin (1990) describe: “the judgement of whether or not one is ‘telling the truth’ has to do with criteria such as adequacy, possibility, depth, and sense of integrity. There is

no ‘quest for certainty’ in the writing of narrative inquiry” (p. 245). As a researcher, I acknowledge that I engage in the memories of others, and in representing them, I am implicated in the co-construction of what is produced. Narratives are always partial and constructed. It is in that engagement and process of constructing those memories in the telling of stories is in and of itself, an important part of our shared experience of meaning-making and because of that, is something that we should include in something so personal and sensitive as considering our death. However, as a researcher, I can work to mitigate the concerns by remaining faithful to the language of the participants, being forthcoming and transparent in my analysis and in my own knowledge and experience that undoubtedly influences my ‘reading’. I am also actively working to disrupt my own prior knowledge through the application of my conceptual framework.

3.5 Illness Identity and Narrative

A focus on narrative inevitably leads to a focus on identity. In this study, we are concerned with shifting identities of both patient and physician. However, our data will examine the patient perspective only.

When is the transition a person crosses over to becoming viewed as a patient rather than a person with an illness? What are the boundaries of patient identity? Is it when first diagnosed? Or does it only start once a treatment plan begins? Does the patient identity cease when treatment is complete? Is it only when in a hospital one is considered a patient? Is it in response by people treating you differently? Is it about reduced mobility, making choices for your treatment plan, or all the above?

Facing his own terminal diagnosis, Dr. Paul Kalanithi (2016), wrote a memoir *When Breath Becomes Air*. In it, he explored the conflicting experiences of identifying as a physician, but also as a patient, following the diagnosis of a terminal disease:

Like my own patients, I had to face my mortality and try to understand what made my life worth living ... Torn between being a doctor and being a patient, delving into medical science and turning back to literature for answers, I struggled, while facing my own death, to rebuild my old life - or perhaps find a new one (p. 139).

This is an example of the need to find balance when a new identity has been thrust upon someone. It is at this crossroad, where medical expert meets patient expert, and the tensions are revealed between the two: “Once again, I had traversed the line from doctor to patient, from actor to acted upon, from subject to direct object. My life up until my illness could be understood as the linear sum of my choices” (p. 180).

Unlike Dr. Kalanithi, most patients are not “dual citizens” in medicine. Most of the participants in this study were professionals in their 60s and 70s. Smart, articulate, with a deep sense of awareness, these are people seeing another side to themselves as their bodies began to break down on them.

Dr. Kalanithi faced his death with substantial support from his loved ones. One of the most interesting parts of the book was the discussion of life saving measures versus meaningful time. His wife Lucy writes, “Paul explored the alternative: in lieu of intubation, he could choose comfort care, though death would come more surely and swiftly. “Even if I make it through this,” he said, thinking of the cancer in his brain, “I’m not sure I see a future that includes a meaningful time” (p. 208). She added: “He doesn’t want a Hail Mary,” I said. “if he doesn’t have

a chance of meaningful time, he wants to take the mask off and hold Cady” ... “and said clearly, his voice soft but unwavering, “I’m ready.” Ready, he meant, to remove the breathing support, to start morphine, to die” (p. 210). While the mask Lucy is referring to is an oxygen mask, it could also be construed as the mask of mortality: the moment when the mind finally concedes.

Considering my thesis sought to learn from patient experience in ways that could inform medical education curriculum, Dr. Kalanithi’s dual roles as physician and patient offered both points of view: “I was physically debilitated, my imagined future and my personal identity collapsed, and I faced the same existential quandaries my patients faced” (p. 120). He chose a peaceful death for himself and to lessen the anguish for those around him. These same choices were shared with the participants in this study.

3.6 Method

In order to gather the stories of experience from those who were at the end of their lives, I turned to publically available data sources that have proliferated given the public dialogue on this important topic. I will review a combination of different data sources, (e.g., documentaries, blogs, media interviews) outlined in Table 3.

3.7 Data Collection

There were three distinct stages of data collection that I encountered. The first stage was finding the relevant documentaries from the National’s CBC – “Last Right: Assisted Suicide in Canada” documentary. It was important to choose participants whereby the participant’s voice was fully connected to their psychological, physical, and emotional being. The second part was looking at printed articles, blogs, and books to consider how a voice in print may seem different. The third

portion led me to more specific documentaries, and a podcast which helped with further insight into the plight of persons who wish to pursue medical assistance in dying as outlined in Table 3.

NAME	SOURCE	DATE	TIME
APTN Investigates – “Dying with Dignity”	TV Documentary	February 17, 2017	23:58
The National – CBC – “Last Right: Assisted Suicide in Canada”	TV Documentary	October 28, 2013	
Episode 1 - Bill Kennett’s Story Sub-story – Dr. Donald Low	TV Documentary	October 28, 2013	19:24
Episode 2 - Harriet Scott’s Story	TV Documentary	October 28, 2013	15:51
Episode 3 - Sandy Trunzer’s Story	TV Documentary	October 28, 2013	16:40
Brittnay Maynard	Video Blogs	Video 1 – Oct. 6, 2014 Video 2 – Oct. 29, 2014 Video 3 – March 31, 2015	6:30 5:58 6:33
Sandy Trunzer	Blog	June 3, 2009 – January 24, 2014	
Curt	Website – Canadian Medical Association Journal – Blog	Ongoing	
Nagui Morcos	Website – naguimorcos.com dyingwithdignity.ca Radio Interview	April 22, 2011	White Coat, Black Art – Will to Die Part One – 27:30 WCBA – Nagui’s Choice Special – 27:30
Audre Lorde	Book	1980	The Cancer Diaries
Dr. Paul Kalanithi	Book	2016	When Breath Becomes Air
Atul Gawande	Book Documentary	Book – 2014 Feb 10, 2015	Being Mortal 5:20
Jill Dombroski	Journal	March 2017	

Table 3 *Data Sources*

3.7.1 Analysis

To analyze the data, I first prepared a schema based upon my conceptual framework.

1. Review all texts to document the experiences reported.
2. Look for the dominant narratives that cross all data.
 - 2.1. Example - Exploring common themes.
3. Look for the counter-narratives or those that don't fit the pattern.
 - 3.1. Example – What is not being said, and are there any outliers?
4. Look for where power is located in their stories.
 - 4.1. Example – Who is not being represented, why, and where is the power?

A secondary analysis (Table 4) will use a schema based upon my conceptual framework and designed to point to curricular innovation for the field.

<i>Secondary Analysis</i>		
Feminist Lens	Preliminary Observations	Secondary Observations
Is there a place for patient voice in the decision?	-Most participants are professionals, so likely they will be heard by someone.	-There is a place if your physician does not object and how easy will it be for a referral to see another physician.
Standpoint theory and Critical Narrative Theory - how does this intersect between the ability to access MAiD, where power is operating, assumptions, autonomy	-Accessing MAiD seems to be from a higher socio-economic status.	The participants were higher educated and professionals which would have more access to medical professionals to be listened to.
Thanatological Lens	Preliminary Observations	Secondary Observations
Levels of pain management - State of suffering	-This wasn't as much about pain, as it was losing control of one's physical and mental state.	-participants understood where they were at in their physical health.
-Is death denial a factor.	-No. Everyone who shares their story are knowledgeable with their rights and what they want and what they do not want to endure physically.	-These participants have been dealing with the slow progression of their body failing them. They are not going to recover and are present and accepting in their wish to end their lives.

Table 4 *Secondary Analysis*

3.8 Theoretical Analysis - Participants

After considering many potential participants, I found myself engaged with the end-of-life stories these people choose to share publically. A little voice in my head kept asking of each person whose documentary I was watching, blog I was reading, or podcast I was listening to: “What did they want their audience to know?” Of all of the possible experiences that have been shared publicly, I have selected these for their ability to communicate what they felt their audience *needed* to know about their end-of-life choices.

In order to orient readers to the participants, I offer a brief overview of who these people were and their decisions to share their death with the world. It was important to share more of who they were outside of the data presented to have a fuller understanding of their journey as they reached the end of their lives. It was in those minute details, away from a medical facility when they were representing themselves, the person and not the patient, that physicians can learn from their experience during their end-of-life.

Esther Supernault

I first heard about Esther through my mom. My mom described her as spiritual, connected to the land, and a celebrated author with numerous books under her belt. My mom had informed me in the days before Esther died, that Esther was planning a medically assisted death. I was not aware at the time that Esther was being interviewed during those last days before her death. When listening and watching the interview everything I heard about Esther, Esther really was that woman and so much more.

During her interview, Esther described when she was first diagnosed. She dreamt of a black horse and they rode through all her obstacles with the cancer and the effects from the cancer. Since deciding to pursue a medically assisted death, she now dreams of a white horse waiting for her to take her home. Esther was a wife, mother, grandmother, working woman, and author. She had a close-knit family that got together often. She had her diagnoses for 17 years. She felt her training as a nurse and connection to her own spirituality helped her to deal with her cancer and she never believed in chemotherapy with all the research she had done. Without a doubt, she believed she was in better shape and pain-free due to not receiving chemotherapy. Esther was married to a dedicated husband Cliff for 48 years who supported her and understood that he must let her go. Esther firmly believed the choice of a medically assisted death was a personal choice that should be respected. The alternative of taking painkillers would have helped her, but it would only have prolonged the inevitable for a few months.

She would not assign the decision around MAiD for anyone but herself. Her body was shutting down which she believed was a sign it was time to go. She believed our spirits were eternal and she would go on to something else and she was looking forward to that. She saw her final legacy was to love life, to savour every moment, to love people and allow them to love you in return. As her final comment on going through with a medically assisted death: “I don’t want to go, but I can’t stay” (House, 2017).

Bill Kennett

At seventy-four years old, Bill Kennett was diagnosed with ALS. He worked as a senior public servant in Canada for his professional career and his wife, Valerie Kennett, to

whom he had been married for 50 years, and who had recalled him saying early on his diagnosis that he was not going to go to the end of the disease. She said he had Googled suicide, but he kept the details secret to protect his family from the law so they wouldn't be charged with homicide. Bill's body declined over the year, and, as Valerie shared, that year was like another honeymoon, or they agreed it was "*the radiance of the ordinary*". His death was peaceful, quick, surrounded by his family, and as he wished on his timing and in his home. Maybe he could have waited longer, but his worry was if he waited longer he would lose the ability to do it himself (McCue, 2013).

Dr. Donald Low

Dr. Low became well known during the Severe Acute Respiratory Syndrome (SARS) crisis as he saved a lot of lives, and now, he was asking for the right to end his own life. He understood there was a lot of clinician opposition: "I wish they could live in my body for 24 hours and they would change their opinion". For a man who controlled the many destinies of patient's lives, he could not control his own life legally: "I'm just frustrated not being able to have control of my own life, not being able to make the decision for myself when enough is enough we have come far enough time to bring it to an end". Dr. Low died when he was 68 years old and his death was not medically assisted (McCue, 2013).

Harriet Scott

Harriet Scott religiously worked out and lived a healthy lifestyle, but her body still failed her. She was diagnosed with liver cancer at age 69, and at 72, she had been told she had two weeks to two months to live. She was present with her diagnoses and with preparing

and organizing her affairs. While her wish was for a natural death without pain she would try and do *something about it* if she was in a lot of pain and it could not be relieved. She watched her mother suffer from bone cancer for six months and it was horrible for her to witness, and for this reason it bothers her that no one can assist her to end her life in Canada. She felt no one had the right to make those decisions for her except her. In anticipation of potential pain, she stockpiled medication knowing there was the assurance of assistance, but did not want to put her husband in that dilemma. She did not want to die when she was having a good day, but said it in a roundabout way that if she had to “do it” because of uncontrollable pain, that was what she would do as she was determined not to suffer. As she said: “I don’t have that type of courage”. As it turned out, she no longer had the option to control her death as she was rushed to the hospital and went into palliative care. The day her son arrived she said her journey was complete and died the next day. Days before she died, the journalist asked Harriet what she wanted people to know and she stated for there to be more choice than she was given at her end-of-life: “There are options and people should vote for choice, the right to die with dignity.” She pinpointed that it’s a generational thing like pro-choice where people can make free choice and have free will, even if you choose not to use it, just give me choice (McCue, D., 2013).

Sandy Trunzer

I first listened and watched Sandy tell her story on CBC’s The National documentary series *Last Right*. The few minutes she is speaking on camera—and the journalist is speaking about what they have talked about and her plight—we see a focused snapshot of who we are meant to see of Sandy. What I did not expect when Googling her name was

that she had been writing a blog since the beginning of her health decline. In the documentary, we learned that Sandy was dying from an incurable disease. Part of her health concerns was a pacemaker that was keeping her alive but soon needed changing and while it is her right to decide to turn the pacemaker off, hospice is not comfortable providing comfort care as she dies. What we know about her from the television documentary, is that she was recently divorced, her daughter had left school to come and care for her, she was mostly bedridden but she seemed present in her reality and acknowledged her looming death: “There will never be a time that I do not wake up in pain. I am still enjoying time with friends, volunteers, and my daughter ... but I can’t escape.”

What the listener learned on her blog was that she was recently divorced as her second husband left her for someone else as he could not manage her health decline. During the years she was blogging about her disease, she kept it relatively positive with an upbeat demeanor about living with the disease in the hopes of helping anyone else with the same disease. By June, six months before she died, the narrative changed by using metaphors of hanging onto ledges and going up a step or two on a staircase for a moment, only to step back down because she could not hang on and needed to let go. She said in her interview she had no more milestones to reach. Her body was in a great deal of physical distress and while she would not replace her pacemaker, she was still unsure about letting the battery run out without care in place. The journalist added that Sandy would go to a hospice where she would be able to turn off the pacemaker and die possibly before Christmas (McCue, 2013). As it turned out via her blog, she died in early January (Trunzer, 2014).

Brittany Maynard

As children we sometimes draw straws and the person who ends up with the shortest straw is the one who lost the bet. In this case it was a 29-year-old woman's life, and the short straw meant due to an aggressive cancer, she had less than six months to live, all the while newly married, wanting to start a family, and looking and hoping for miracles. She moved her family from California to Oregon where people can choose a death with dignity in that state by ingesting life-ending medication when they feel their time is right to die on their own terms. The medications would be administered by their own hands. Since becoming ill she continued to travel and create memories with her loved ones. She did not want to die the natural course of death with her disease, but every day that passed she risked that she could become incapacitated in which case she could no longer ingest the medication on her own. She still enjoyed the days with her family with some difficulty, but she got sicker with each passing week.

Brittany knew she could live in her body for a longer period of time but the pain and suffering that she would go through and her family would endure seeing her suffering, was not what she wanted for her end-of-life. She enjoyed each day surrounded by people she cared for and loved with each day as full as it could be. She strongly believed that having access to death with dignity, should be available to any other terminally ill American and stated emphatically, "I am not killing myself, cancer is killing me." Her public conversation on being allowed a death with dignity, was given a lot of attention throughout North America. She was young, beautiful, newly married, and had the world at her feet. The idea that she would not choose a natural death stirred debated

conversations as her story captured millions of people with the message of dying with dignity (Compassion Choices, 2015).

Curt

Although Curt's experience is based from the point of view of Curt's brother Chris who helped him die with dignity, I believe the accuracy holds true in what Curt wanted his family to carry out for him. Curt was a man who controlled every aspect of his life and wanted control of his death. Curt was 62 years old and diagnosed with incurable prostate cancer. Because of his diagnosis, he moved back from working overseas to die close to his family. They found a hospice facility where physician assisted death was legal as Curt's independence was a testament to how driven he was and how he lived his life on his own terms. His greatest fear was being bedridden and unable to perform basic tasks. He knew he would die and asked his brothers and their wives to support him in obtaining permission for a physician-assisted death. This allowed for some autonomy while still having some control not only over his life, but in his death and he followed through with the permission to seek a physician assisted death. The family was united in supporting Curt's final wishes. While the facility was not able to facilitate his death in the end, the hospice was supportive. Curt was removed from the hospice to one of his brother's homes and bought the prescription. The night before he was scheduled to consume the drugs and die, they enjoyed a last meal together. The next day, he did consume the drink, and although was expected to die within five hours, 23 hours later he finally stopped breathing. The family fully supported their brother's wishes to die with dignity, and it struck Chris with frustration how the process for Curt should have been simpler considering our modern medical age (Canadian Medical Association Journal, 2016).

Nagui Morcos

Huntington Disease is said to be the very worst disease anyone could have. Nagui called it a ‘cruel disease’. Nagui knew that he had the Huntington gene for 18 years with some symptoms over the last 8 years, but progressively worsened the last year of his life. What motivated him the most was being able to plan ahead, and because of that plan he felt content, which to him, was fundamental to dealing with the day to day struggles and giving him peace of mind. He owed this contentedness to Dying with Dignity for giving him clear options and speaking freely on how to hasten his death safely and humanely. Having that knowledge, Nagui felt provided him with an improved quality of life.

It was his wish to hasten his death before his symptoms and disease made him powerless to do so, but he did not want to die too early if he was still feeling happy and competent. He did not identify as being suicidal and very much loved the life he had created with his wife, but with a terminal disease, in his words, “you must let us go”. There is never a right time when Nagui chose to die, but he did not want to die in a horrific way or his family witness a horrible death for him. Nagui would have preferred a physician assist him in his death, but legally actively choosing death by suicide was the only option: “...we have to let each other go. Incurable progressive disease to hasten one’s death ... we will always find a way ... this issue will never go away ... I beg people, let us go” (Goldman, 2012).

Audre Lorde

Audre Lorde was an author and feminist activist. Her book, *The Cancer Journals*, was written in 1980, therefore Audre did not comment on a medically assisted death, but she

spoke on autonomy based on her own diagnosis with cancer and this book represented her experiences and powers encompassing this disease. The resounding message from her book was: "...my silences had not protected me. Your silence will not protect you" (p. 18-19). A lot has changed within the culture of medicine since 1980 that has made terminally ill people become collaborators with their health care teams. This has in turn influenced the way professionals proceed through their care decisions. But it is the conditioning of the culture of medicine and the "all-knowing" that has previously divided the doctor, health professionals and law makers; that silence remains. A silence that advocates plead for people to speak up and be heard. The process of understanding her disease started with fear, and grew into knowledge of what Audre was facing in death. Her message was not only mourning the physical loss, but coming to terms with one's mortality. By facing it and being aware of how silence and invisibility go together with powerlessness' she determined: "maybe this is the chance to live and speak those things I really do believe, that power comes from moving into whatever I fear most that cannot be avoided" (p. 79).

Dr. Atul Gawande

Dr. Gawande's (2014) book *Being Mortal*, had an overall message about a person's end-of-life plan and the need for specific communication between a patient and their physician became increasingly more important as he was witness to his own father's death journey and what really matters at the end-of-life. Dr. Gawande understood he had not dealt with a patient's bleak prognosis in the past by being positive and trying to cure, as he had worried he may have given false hope to his dying patients. On the other hand,

more conversations have been happening with patients about their end-of-life than ever before, but they are happening sometimes too late (Gawande, 2014, p. 154).

Patients that seek a medical assisted death need to have these challenging conversations with their families and doctors prior to the last days of their lives. Dr. Gawande derived five questions from his research that require thoughtful and concise responses so everyone understands ahead of time what the person wishes at end-of-life.

1. What is your understanding of where you are and of your illness?
2. Your fears or worries for the future
3. Your goals and priorities
4. What outcomes are unacceptable to you? What are you willing to sacrifice and not?
5. What would a good day look like? (pps. 207 - 212)

Jill Dombroski

March 30, 2017 – Journal Entry

As I was looking for further information on Physicians and a Medical Assistance in Dying, I looked up the website of Canada's Dying With Dignity. Nagui Morcos was featured and his views were explored on the 2012 CBC commentary of "White Coat, Black Art" with Dr. Goldman. It was difficult for Dr. Goldman to understand why Nagui would want to die when he could have further access to palliative care treatments. Further to listening to an interview after Nagui had died, Dr. Goldman had come to understand why Nagui wanted to choose his death and fully supported those that wish to pursue a medical assistance in death.

I am in awe of some of the language used, and the silences.

Similar, but different, I made choices for my dog once she had her second stroke within six months. I did everything I could to help her recover, but while her mind was sharp, her body was expiring. As we locked eyes and I kept talking to her, she lifted her head as the needle pricked her hind leg, and as quickly, the light left her eyes (Dombroski, 2016).

3.9 Demographics of Participants

Table 5: Participant Demographics:

Name	gender	age	ethnicity	country of origin	marital status	profession	when diagnosed	family support	change in diagnosis to nearing end-of-life	Medium of work	Time frame	Pain Discussed
Esther Supernault	f	66	First Nations	Canada	M	Writer, Nurse	17 years	Y	She chose how she would deal with her cancer	Documentary	17	N
Bill Kennett	m	75	Caucasian	Canada	M	Lawyer	1 year	Y	Clear he would die within the year	Documentary	1	N
Dr. Don Low	m	68	Caucasian	Canada	M	Doctor – infectious disease	February 2013	Y	Frustrated with the law	Documentary	7 mos.	N
Harriet Scott	f	72	Caucasian	Canada	M	House wife	3 years	Y	Wants choice	Documentary	3	Y
Sandy Trunzer	f	49	Caucasian	Canada	D	Photographer	5 years	Y	-Making the best out of it -Difficulty each day to function	Documentary and Blog	5	Y
Brittany Maynard	f	29	Caucasian	United States of America	M	Teacher – MA	10 months	Y	Hoping for a miracle but living life as full until she died	Blog	10 mos.	Seizures
Curt	m	62	Caucasian	Canada	S	Worked abroad	Less than a year	Y	Wanted comfort at end of life	Blog	unknown	Y
Nagui Morcos	m	Late 50's	Middle Eastern	Canadian citizen	M	Marketing professional	18 years	Y	Message for Canadians to support a death with dignity	Website – Dying with dignity, naguimarcos.com, CBC – radio -	8	N

Name	gender	age	ethnicity	country of origin	marital status	profession	when diagnosed	family support	change in diagnosis to nearing end-of-life	Medium of work	Time frame	Pain Discussed
										WCBA		
Audre Lorde	f	58	Black	American	S	Author, advocate	14 years	Y	unknown	The Cancer Journals	unknown	unknown
Atul Gawande	n/a											
Jill Dombroski	n/a											

Table 5 *Participant Demographics (continued)*

3.10 Trustworthiness

The sources of the data I will be using are publically available and/or already published. I am researching multiple sources: documentaries, news media, blogs, medical journals, religious texts, mental health articles, and newspaper articles. By choosing different conversations that are being taken up by various groups and texts, it is also trying to understand the experience than just what is being described. It is not only representing one view point while triangulating it with literature, but also my own experiences. What will show similarities and will there be conflicts or tensions? What can we learn when we listen to those experiences that can help us better understand and prepare health care professionals through the decisions of their patients?

As the researcher, I will benefit from the expert interpretation of what the patient says or what is motivating them towards a decision to end their life. Through my observations of these varied sources, key topics and themes may be noticeable.

Using these separate forms of data, its triangulation impacts how different modes of media produces different forms of knowledge. The time stamp in the interviews are shrunk from several hours of conversations. These are not quick glimpses but in-depth end products that I'm looking at.

Chapter 4

4.1 Findings

In order to triangulate (Keats, 2009) multiple data sources to generate a cross section of experiences and modes of representing those experiences, I am drawing on texts produced through television documentaries, patient blogs, and interviews conducted in the media, primarily focused in Canada. I recognize that representations are just that: they have been created, edited and produced for a purpose that I cannot be entirely certain of, but that surely include matters of advocacy, politics, seeking a voice when feeling marginalized, wishing to leave a legacy, and so on. Issues of representation of the ‘Other’ have long been taken up in Critical Narrative Inquiry (Iannacci, 2007, 56). However, in this work, I am drawing on representations either created by the patients themselves or televised documentaries created by others that will allow me to see and hear at least the final edited version of what they said. By allowing multiple ways of expressing stories, the researcher has a clearer understanding of the person’s narrative and how these influences construct their experiences (Keats, p. 182).

As a narrative researcher, I come to this study with my own beliefs, experiences, and understandings accumulated from living a life, in which I have, experienced the deaths of those who have been close to me. I bring a lens as a feminist researcher, interested in the improvement of society and the lives of all of us, regardless of gender, race or ethnicity as a platform for praxis (Arendt, 1958). This, combined with my training in Thanatology, shapes my interest in this work. While I practice researcher reflexivity to expand my capacity to learn from the documented experiences of others in this research, I

intentionally apply a feminist lens and thanatology perspectives as I make sense of what I study.

4.2 Research Questions

My research questions then become: What are the narratives of patients seeking MAiD? How are these similar or different? Which narratives are dominant and which ones are counter narratives? In what ways do these narratives reflect (or not) the conformity, conflict and tensions with power relations and dominant discourses on MAiD and on death in general? What can researchers learn from individual's end-of-life experiences that might inform medical education curriculum development to address Bill C-14 changes in the role of the physician?

4.3 Data Analysis

Reading the articles, watching the blogs, and listening to the podcasts about people who are contemplating a medical assisted death, it becomes my responsibility to be non-judgemental and loyal to the person sharing their experience. While I think of the laws surrounding a medically assisted death and how others play into the process of a medical assisted death, the awareness of a participant's story needs to be the focus. Esther Supernault shared what was her truth as to why she was choosing a medically assisted death and helping to prepare her family and friends for her death departure. I was struck by her openness and her ability to have spoken to her family and friends to prepare them for her death:

“my biggest job was to bring my family along and my friends to help them start to process them letting me go in a loving way and that was my goal and I think I was blessed to have this time to spend it with my friends to love them and hug them and say goodbye. It’s been hard but I’m glad I had that chance and it feels like closure probably for them and for me too and I’m ready and I’m at peace with that” (House, 2017).

In my thanatology studies, I have read how the survivors deal with the death of their loved one for a very long time, trying to cope with a life that no longer involves their loved one. While there is no “right way” to grieve, it is my opinion that if you can speak to your loved one about their impending death, the survivors integrate much more positively back into their life, figuring out what they do now, and perhaps continuing a legacy in a positive way. Esther’s niece Tina, who interviewed her, reflected:

“I will miss my aunt – death is the ultimate fear in all of us. She fought a long courageous battle against cancer and took tremendous courage to make that final decision and to see it through the end of this lifetime. As she said ... she would not allow cancer to decide when she went, but rather she would be the one to decide” (House, 2017).

4.4 Answering the Research Questions

What are the narratives of patients seeking MAiD?

The main recurring theme from not only the participants but also their families was choice. We live autonomously up until we have a serious illness, and then someone else

decides how we are to die. For many participants like Harriet Scott and Esther Supernault, it didn't make sense that someone else would control how they died. Harriet watched her mother suffer, and did not want that for her end: "...I don't want anyone making those decisions for me, I don't think anyone has the right to make those decisions for me" (McCue, 2013). For Esther, a natural death was not something she wanted: "...and for those that ask for a more traditional one with pain killers ... keep comfortable and but it will drag on for months and seen friends and I don't want that for me or my family and grateful this is available for me" (House, 2017). Some participants voiced not enduring horrific pain or their family seeing a rapid decline in them. For many, it was about controlling their end-of-life. Brittany Maynard echoed this in a legislation testimony: "...I am dying and I refuse to lose my dignity. I refuse to subject myself and my family to purposeless, prolonged pain and suffering at the hands of an incurable disease" (Compassion Choices, 2015).

How are these similar or different?

Their stories were all similar but the main difference was it was not legal for a medically assisted death before June 2016. People that sought a way to hasten their death prior to that date, had to be healthy enough to ingest the life ending drug so it would not implicate a family member or loved one resulting in a murder charge if someone else was to help them. This also meant that for the people that did hasten their death, had it been physician-assisted, chances are they may have had a choice to live longer. This was something that Bill Kennett's wife, Valerie, said he worried about: "... (Bill) was worried he would lose his ability to do it himself if he waited any longer as the law simply wasn't on his side" (McCue, 2013). Given Nagui Morcos was pursuing his death prior to the 2016

legislation, he too was concerned about waiting too long:

“...stay within the current laws and must do it by myself and a precarious balance of doing it too early and missing out on my rich life and doing it too late and not being able to do it. It will be sooner than later. There will never be a right time that works for everyone” (Goldman, 2012).

Sandy explained in her documentary how her pace-maker battery was running out and her choice was for it not to be changed. In which case that would hasten her death:

“...hospice were not comfortable with turning the pacemaker off and receiving comfort care at the hospice. Doing best to work within the confines of Canadian law. But it is my right to turn the pacemaker turned off, it is also my right to have palliative care and comfort care after that and trying to make the two fit together is proving to be quite the challenge” (McCue, 2013).

Which narratives are dominant and which ones are counter narratives?

The dominant narrative throughout all participants studied was unanimous choice to control their end-of-life. The counter narrative was not wanting to be in a place where their body was so debilitated that their loved ones had to care for them. Perhaps the strongest voices on this topic were Nagui Morcos, Brittney Maynard, and Esther Supernault. Although both women were in situations that the law allowed them to choose a medically assisted death, all three were very articulate about autonomy. Esther stated:

“...not all family members agree with what I do because of their own religious faith, but it's a personal choice and everyone should be respected and allowed to

make their own choices and not everyone doesn't need to agree with it" (House, 2017). Brittany stated: "The freedom of this patient right is choice" (Compassion Choices, 2015).

Even when it came to family members understanding of the choice their loved one has made, Esther's husband Cliff said: "...Where I am at with that is that I have to at least let her go, which I have. And understand she has to go" (House, 2017).

For these participants, pain and the idea of their family taking care of them as they were dying slowly were dominant factors in their choice to seek a medically assisted death. Counter to this, I did not have any participants that opposed MAiD, or were not able to qualify for the specific guidelines despite no physical pain but physically wasting away. This topic remains contentious due to its infancy of the law in Canada, and multiple points of view.

In what ways do these narratives reflect or do not reflect the conformity, conflict and tensions with power relations and dominant discourses on MAiD and on death in general?

When people are speaking to the media through different sources, telling their audience they want choice to hasten their death due to an incurable disease which will vastly shorten their life, we must listen. These participants recognized that the potential for incredible pain that may not be controlled with drugs, and if controlled with drugs the person is not coherent, and their quality of life is questionable? The idea that people in positions of power are making choices for their body, poses the question of 'Who owns our body'? Nagui's Morco's wife said during the interview: "...who's life does this

belong to?” (Goldman, 2012). Nagui pleaded when it came to people wanting to hasten their death: “Incurable progressive disease to hasten their death...we will always find a way ... this issue will never go away ... I beg people, let us go” (Goldman, 2012).

Similar to Nagui’s plight, Esther stated similar sentiments: “I can’t stay. I can’t stay. I don’t want to go, but I can’t stay” (House, 2017). These two examples from Nagui and Esther should not be confused as giving up. Both would have preferred to live longer with their loved ones, but not in their failing bodies. In my opinion, it becomes our job as the loved one to let them go and not compel them for our own reasons of wanting their physical presence, but a presence they no longer can manage as they once did.

It also must be noted that there are certain socio-economic considerations of the people who had the ability to access media in these forms and have a platform to speak. If someone has pursued MAiD, and was denied because they do not fit in the regulated parameters, we do not always know about those people who pursued their own death by suicide.

What can researchers learn from individual’s end-of-life experiences that might inform medical education curriculum development to address Bill C-14 changes in the role of the physician and nurse practitioner?

We need to listen to our experts: the patient. What may work for one patient may not be the same for another patient. It really is about the individual and creating a dialogue and a plan that works for patient, family, and physician.

Dr. Donald Low strongly advocated for the ability to die with dignity. As a physician he had helped save numerous lives during the SARS crisis in Toronto, and then found

himself on the other side of the diagnosis as the patient. Playing dual roles doctor and patient, he understood the opposition but said:

“... I wish they could live in my body for 24 hours and I think they would change that opinion. I’m just frustrated not being able to have control of my own life, not being able to make the decision for myself when enough is enough we have come far enough time to bring it to an end...” (McCue, 2013).

Esther’s sister-in-law Mary, who did not support Esther at first, eventually accepted Esther’s decision: “We don’t know another person’s pain. We can’t imagine what they are going through” (House, 2017).

4.5 Additional Themes

There were several themes that arose from my findings demographics included similar age, professions, marital status, socioeconomic status, ethnicity, and support. For instance, the majority were between the ages of fifty and seventy, married, working professionals with solid emotional support, and financial stability. One outlier in age was a twenty-nine-year-old American woman, but she fit the demographics of the other participants as she was married, had solid support, was a professional, with higher socioeconomic status, and access to social media.

Baby boomers

In the CBC documentary with journalist Duncan McCue and Dr. Lowe, McCue commented about the baby boom generation that some of my participants would have grown up in – “...defined by its activism during the 1960’s by its power to bring about

change, a generation now ready to fight for one last right” (McCue, 2013). It is without a doubt the Canadian population is aging and the baby boom generation is entering its end-of-life phase that are showing the Canadian government that they want changes made to have a right to access MAiD. Harriet was part of this generation, and when Duncan asks her: “what do you want people to know?” (McCue, 2013). She responds: “I’d like them to know there are options and I would like them to vote for choice ...the right to die with dignity ... a generational thing ... Like the pro-choice thing ... people can make free choice and free will” (McCue, 2013).

Second honeymoon for couples

There were two participants’ spouses in *The Last Right* that made the connection that once their husband/wife had been diagnosed, some things became trivial and the simple things in life mattered more. Both spouses considered it a “second honeymoon” of sorts, where they were surrounding themselves with people whom they loved and cherished, or spending time alone together to bask in that sunshine of love and friendship they shared for many years. At the end of your life, who do you want to be surrounded with? Bill Kennett’s wife Valerie, called it “the radiance of the ordinary” (McCue, 2013) which meant the last year of his life felt like another honeymoon and they basked in the glory of an ordinary day. Harriet Scott’s husband had similar sentiments with a closer connection and “a more peaceful life” with his wife knowing it is nearing the end of her life, “... savor these last weeks and days or ending her life while she can so she doesn’t put anyone in that position” (McCue, 2013).

Jill's Observations

I was amazed at some of the things that I had overlooked and what I had observed when compared to the first time I went through these documentaries. While my focus is on the participant who is seeking medical assistance in death, it is the voice of their loved ones that I have come to realize without their support, they may not have been in a position of speaking to the media. The support and ability to respect their loved ones' choice, no matter how painful, allowed the participant true freedom of choice.

Some of the things the participants said we must understand are that the present moment to a healthy person is a different present moment to someone who has a shorter life expectancy. After Bill Kennett had died, the family called the police. Everyone present at Bill's death was interrogated for 4 hours in separate rooms once the police understood what Bill had done; however no charges were laid. One police officer asked Valerie why she had not stopped him. She responded: "...you know anything about ALS? I think you need to learn what that is about. ... There has to be a better way that this kind of death can be handled. It was the ending of a good life in a peaceful way" (McCue, 2013).

One of my biggest surprises was learning more about Sandy through her blog. We knew from the documentary that she was divorced but did not know it was a second divorce and her husband left her for another person because he did not want to be a caregiver to her any longer. I think this can be an example of the silencing that can happen during an interview. One could assume that there may be many hours of footage to produce the five-minute interview. Perhaps the producers decided that one's personal life was not as important as their decision to seek a hastened death and edited accordingly. When it

comes to making decisions for their patient's interest to pursuing MAiD, knowing the bigger picture would be helpful for doctors as they learn about their patients who are seeking a medically assisted death.

One of the last participants that I wanted to include in my research was Dr. Paul Kalanithi. His memoir depicts the crossroad where expert meets patient. But in this case, the expert is over-qualified to be just a patient. Not that one person's experience means more than another person's, but this man's experience as informed patient is because of his profession and treating hundreds of patients just like him, asking the same questions and looking to being saved. Participant, Sandy Trunzer also had a similar awareness being treated differently:

I didn't want to be defined as a patient. I wanted to be a wife and mother to the two people who mattered most in my life. It was, and still is, me in here. A person who still wants to do what she can despite growing challenges, to love and be loved and continue to grow intellectually, spiritually and emotionally. And I suspect many others finding themselves in this position would offer the same sentiment (Trunzer, 2012)

For Paul Kalanithi, at the end of his days, he relinquished his professional doctor status and became only patient, husband, father, son, friend, and brother. What I see as the theme is choice. His need to be informed, his understanding as a professional doctor and healer, but now he had to rely on someone else's expertise to be the doer and healer. However, when it comes to his personal crossroad—mortality—how he wants to see, and

how he wants his family to see his end of times... he surrenders. The importance of choice.

Nagui Morcos was the participant that had the most impact on advocating for a medical assisted death. Like Brittany Maynard who advocated for a death with dignity in America, I finally had a Canadian speaking in more than one interview about the need for a legal medically assisted death. I came across his name when I was searching for information on dying with dignity in Canada. By this time, he had already died but I found an interview on CBC radio speaking about his disease and the need to legalize assisted death in Canada. In the time that the interviewer, Dr. Goldman was first introduced to Nagui, compared to his last interview with Nagui, Dr. Goldman had changed his mind to supporting a medically assisted death. Nagui gave witness to his disease and the compelling thought process of how he came to come to such a decision was understandable and above all, personal. He made it make sense, and this was what Dr. Goldman came to realize; the idea of having a choice of hastening your death. The idea of you and your family not witnessing the destruction of your body at the hands of a disease. A disease to your body, soul, and the person they knew you to be. As Nagui put it to Dr. Goldman when asked if he had the means to end his life, Nagui stated:

“...if you haven’t noticed, is that I am content. Because I have a plan. It is fundamental to my contentedness and I owe that to dying with dignity ... gave me clear options and talked no nonsense how I can hasten my death safely and humanely and improved my quality of life and dealing with my day to day struggles and gave me a peace of mind” (Goldman, 2012).

Feeling the control of one's life seems to motivate these participants when seeking a medically assisted death. Brittnay shared the sense of peace knowing the choice was hers: "Knowing that I can leave this life with dignity allows me to focus on living. It has provided me enormous peace of mind" (Compassion Choices, 2015).

Of all my Canadian participants, only one was given a medically assisted death due to the legislation that took place June 2016, Esther Supernault. Choice was the common denominator to the participants prior to June 2016, and it was choice that proved to be the anchor post legislation of Bill C-14.

Chapter 5

5.1 Discussion

One of the reasons to do this study is to learn from people going through the medically assisted death process in order to help better prepare physicians to deal with this situation. Since MAiD has been legalized, there has been little curriculum created and physicians need standards and a point of reference for training. While there have been standards and education training created, more is needed since this form of legal practice is so new.

Including curriculum on medical assistance in death is a medical culture change. What can help to integrate these new ways of knowledge into medical curriculum is to bring awareness to physicians about their own ideas, values, thoughts, feelings, and experiences about moral distress, dying, and death. This will help to ensure that the death and dying conversation is never avoided when speaking to their patient, students, or colleagues.

5.2 Linking back to the Literature

How does my research link to the literature review?

In trying to teach people to understand this topic of a medically assisted death, I felt it was important to show the history of this controversial subject. There are many reasons for the controversies and they are mostly due to societal norms. Taking one step back

further, we should understand what was the societal norm, for whom and what purpose did it serve and benefit.

Prior to the legalized form of medical assisted death, choosing a death by suicide had, and still has, shame attached to it for the person who died and their survivors. Mental health issues usually are linked to someone choosing a death by suicide. However, choosing a medically assisted death demands a non-mental health diagnoses that must be one of the cornerstones in an effort for access to be considered for medically assisted death. Many people have stated that they would prefer not to die, they want to live, but not live in their failing body.

We would not be where we are without the industrial age, and therefore our societal norms are based on whom and what purpose is it served and for whose benefit?

Understanding the culture of medicine is important for teaching curriculum and adding what physicians need to know about MAiD. Daily, MAiD is evolving with numerous moving parts. Even now, due to legal technicalities, assisting your patient to die is not without concerns for the involved physician. Another point of view is the idea that medically assisted deaths will save healthcare money in the future when all the baby boomers are at their end-of-life.

I will always come back to the idea that if in fact we follow a patient-centred model, the first question should always be to the patient, “what do you want?”

Does it point to the need to do research in other areas that I may not have touched on?

This topic has many rabbit holes of which cannot be explored in a Master’s thesis. It is important to note that my participants were all in favour of medical assistance in death.

Those that may have been candidates for a medically assisted death, but preferred a natural death, their stories were not explored. Another topic not discussed is the need of death and dying to be included in the curricula of medical undergrad and residency. In my opinion, this would prove to be a positive step toward changing the culture of medicine in exploring death denial and death awareness. Change the culture of death denial in medicine and this will change how medicine is practiced and have a possible positive difference for people at their end-of-life.

What does it say in terms of curriculum development?

It takes someone in medical education to review the historical importance and the negative impact death denial has had on our society, and help make that change by teaching about death and dying in medical undergrad programs.

Where is the opportunity to connect curriculum development for physicians?

For the physicians that are already working, perhaps teaching through grand rounds or podcasts where they can listen to this series on the drive to work or during downtime, as a mandatory part of their continuing education.

Where does this go next?

I would like to create a course specifically designed for undergrad medical students, residents, and working physicians that would be specific to the stage in their career. Some of the modules in the course could include the following topics: the history of death by suicide, the medicalization of health, how death denial has influenced and changed the culture of end-of-life practices, conversations with patients about their end-of-life choices and decisions, and self-care for the physician.

One primary research goal is to create a longitudinal study that would follow first year undergrad medical students into their residency, and a year after their professional practice. This would be achieved through short surveys, twice a year – at the beginning and end of their academic careers, to understand what their personal death awareness is and how and if that changes, and what factors influence their awareness, or lack there-of to establish and create medical curriculum to support our physicians and their eventual patients.

There is very little on this topic using Canadian content, which is why it is important for Canadians to be represented within the context of our health care practices.

5.3 Goals

The goal of this study was to explore what researchers can learn from patient's end-of-life experiences and to inform curriculum development in an era of medical assistance in death. In 2016, the Canadian government introduced legislation on Bill C-14, an Act to amend the Criminal Code and to make related amendments to other acts to allow for Medical Assistance in Dying (MAiD). This Bill marked a significant shift in the role of physicians. Prior to the passage of this Bill, physicians had assumed a professional role in which they were expected to diagnose, treat, and save lives. In cases of the terminally ill, they were to provide care in the form of reducing symptoms, and aiming to ensure patient comfort. Bill C-14 introduced a new professional role: physicians are now called upon to provide medical assistance in dying where requesting patients meet specific criteria.

Assisting in death, rather than evading it, is a significant change in the health care professional's fundamental purpose and identities, and it's not currently addressed in their medical training. Whether individual physicians choose to participate or to refer the

patient to another physician, the medical system lacks in developing thus far, a medical education curriculum to address this legislative change. While I am aware of the significant controversies surrounding Bill C-14, (e.g., non-terminally ill but suffering; protecting vulnerable people, and so on) this study focused on the affordances of the Bill in its current state.

5.4 So, what does this have to say about Curriculum?

What this must say about curriculum is that physicians not only need to look up from their textbooks but to listen and hear the teacher: their patient. As mentioned earlier, Dr. Gawande suggested five questions when speaking to patients. It is in these five questions he learned more precisely what he needed to know about how to proceed in his practice. His patients are his teachers.

Is bringing up the topic of death the most difficult task for physicians? While it is important to have a regulated group of questions to start off the conversation, that may be the perfect springboard for the conversation to go deeper between patient and physician. When a person is diagnosed with an incurable disease and their lifespan is considered shortened because of it, having a list for a patient such as the five questions Dr. Gawande uses in his practice could be useful. This would give time for the patient to take home and think about what is important to them and subsequently could open up further and deeper conversations with their family. With those questions, all invested parties can hear what their loved one wants for their end-of-life care. It also gives some time of reflection for the person's loved ones to understand what exactly they want for their end of life. If

seeking a medically assisted death, the survivors have no questions or doubts about what their loved one wants, and the physician has a clear picture of what their patient needs.

The best way to determine the content, form, and structure of a curriculum will be derived from the conversations from these public documents with people that have determined they choose medical assisted death. The dying have a lot to teach us and we must keep this in mind when developing curriculum. First and foremost, we must consider the patient and what they want.

5.5 Limitations

As mentioned previously with editing pieces on social media, what the audience is seeing in the photo does not always exemplify what may really be happening in the person's life. Often, people will avoid having end-of-life conversations with loved ones. When dealing with a dire prognosis, our reflex is to hope for the cure—the very best possible outcome—but realistically who of us is not trying to evade facing our death (Walter, 1993, p. 129). Others may not be comfortable to speak about it and view the person as morbid, or superstitious and that discussing dying will bring on death quicker.

The participants I sought out for this research were not chosen by age, socio-economic status, or ethnicity. Very simply, there is not a lot of information on a medically assisted death in Canada and I felt fortunate to find the participants I did who were at a stage of contemplating medical assistance in dying that were accessible, willing, and able to participate through a social media forum.

My age range was from the late-twenties to the seventies and many of the participants were over 50. Of the eight participants, almost all were professionals or working in some

capacity, almost all were married or in a relationship, there was a lot of support for each participant, and only two were not Caucasian.

It would be difficult to suggest why certain participants had access to tell their story, while others did not. Some likened it to someone who knew someone, but that does not dismiss the time to be reflective of one's end-of-life and resources to take these steps. Marginalized groups were not found in my research. Someone who is marginalized at the end of their life may not get the perspective of someone who is nearing end-of-life because of lack of supports in place for the non-marginalized. For instance, as an example of poverty in other poor countries, the medical development versus their economic development, and the people in extreme poverty die at home as they have no access to diagnosis or treatment (Gawande, p. 192). While Canada may not be considered a third world or developing country, a person's socio-economic status may play a vital role in who receives medical treatment. The opportunity for these participants to choose a medically assisted death had very strong support systems in place which meant they had access for their voices to be heard, they were middle-class, professionals, and had the support of a loved one.

This work does not attempt to generalize who the participants were, but the readers need to be aware of what kind of messages may be useful in curriculum or to expand the studies for further dialogue in the future. Pointing out that the demographic of a particular population is useful to help the readers understand who this speaks for and who it does not include.

I am interpreting what other people have already represented in their documentaries, news media, blogs, medical journals, religious texts, mental health articles, and

newspaper articles. The people involved in the documentaries or blogs, would have been a particular kind of patient with a specific communication personality and access to technology and journalists. Also, it is important to note that many people that were interviewed or wrote blogs, have more than likely died since publication.

The significance of this work is important due to the recent passing of legislation Bill C-14. While the law states the only people that can access this are individuals whose death is in the reasonable foreseeable future. This has critics that say Bill C-14 excludes some people that would choose MAiD due to their physical conditions, yet other critics such as disability and mental health advocates worry this would influence people given the economic pressure on the health care system by keeping people alive.

5.6 Conclusions

Shadows and light. “Can you feel what I feel? See what I see that is so important?” That is what would go through my mind if I was diagnosed with a terminal disease and someone told what I needed to do. I watched a television show called “Scandal” and one of the characters stated: “We can have a choice: we can hide in the shadows or we can stand in the light” (Rhimes, 2014). Death and dying is never far from my mind whether I am watching or listening to the news, or people are sending me articles on medical assistance in death, or I am watching a television show that is meant to be frivolous and diverting until I go back to my research. I found this quote so fascinating as it can mean so many things to so many people. In this context, I’m going to use it in the manner in which it spoke to me; the idea that a medical assisted death is something that if someone wants to pursue and qualifies, they should receive it.

The metaphor of *hiding in the shadows* may conjure up the idea of being uninformed and unable to pursue medically assisted death, or informed, but lacking the courage to speak up for oneself, or family members not in agreement with their loved one's decision.

When it is our own impending death, one would think we should be the person navigating our ship; our last days of living on the planet.

Standing in the light may indicate choice, but more than that. The *freedom* of choice. The freedom to choose what you feel is the way to die for you. This is an issue that has been in the shadows for too long and it is by the will of patients asserting sovereignty over their bodies – and in some measure with resistance from the medical profession, laws, and social attitudes, into the light. The freedom to access MAiD and knowing it is available to you by choice is crucial.

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Appendix A Key Words

Given the complex pieces involved in this topic, I have laid out further terms, along with a brief definition of how they are being used in this study.

Advance Care Planning - individuals indicate their treatment goals and preferences with respect to care at the end of life. This can result in a written directive or advance care plan, also known as a living will. It provides clarity about what the dying person wants (CMA, p. 5).

Coping Mechanisms - good or bad, positive or negative, are created to get us through what is usually a challenging time. Our bad and negative coping mechanisms can be a direct symptom of burnout that causes detachment from patients (Dyrbye & Shanafelt, 2016).

Death Anxiety - emotional distress attached to 'death' experienced because of either fear of known consequences or of little or no experience around death when dealing with end-of-life situations or thoughts (Nienaber and Goedereis, 2015, p. 483).

Formal Education – received instruction from a subject-matter expert in a classroom or clinical setting.

Hidden Curriculum – information that is assumed or misconstrued.

Medicalization –describes a process by which nonmedical problems become defined and treated as medical problems, usually in terms of illnesses or disorders (Conrad, 1992).

Curriculum Vitae

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2015 Association of Death Education and Counseling in San Antonio, TX

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2014 – 2015 BON – Bereavement of Ontario Network – Member at Large - Board of Directors

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2014 – 2015 SAGE Student Coordinator for Mature Students at Western University

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