

The Meaning of Suffering: Shaping Conceptualizations of Assisted-Death

Antoine Przybylak-Brouillard

Under the Supervision of Professor Ari Gandsman

Thesis submitted to the

Faculty of Graduate and Postdoctoral Studies

In partial fulfilment of the requirements

For the Master's of Arts in Anthropology

School of Sociological and Anthropological Studies

Faculty of Social Science

University of Ottawa

December 2016

Abstract

In recent years the right to die has emerged from the fringes as a global movement - locally tailored - advocating for patient access to medically assisted-death. Although proposed and actualized models of assisted-death vary in method and level of accessibility, a majority of right to die advocates are motivated by a belief that suffering can at times be “unnecessary”. Based on an overview of the anthropology of suffering and fieldwork in Quebec, Ontario, and Belgium, my research focuses on right to die advocates’ conceptualization of suffering in relation to assisted-death and on how their understanding suffering shapes their views on when assisted-death should be permitted. I argue that those supporting assisted-death are brought in a form of solidarity through the belief that at times suffering is meaningless and devoid of deeper significance.

Acknowledgements:

There are many people who have either supported me or contributed to the completion of this dissertation and who I would like to thank. To start with, I would like to show appreciation for my family: parents, grandparents and close family friend Ramona Randall who were not only supportive of my decision to continue studying anthropology, but also accepting of my early attempts to discuss assisted-death over dinners and family gatherings. Furthermore, I would like to thank my loving partner Lorna Mungur for her moral support, patience, and crucial editing skills.

I would also like to acknowledge the role of my fellow graduate students with whom I was lucky enough to embark on this two year journey and share both the good times and the less pleasant moments. In particular I would like to thank Bradley Dunseith who provided me with a bottomless well of morale and humour when I needed it. I would also like to recognize the role of Elijah Herrington as my co-investigator and friend in tackling similar research interests and existential questions. Know that both of you made my days brighter and more stimulating.

If this thesis has any merit it was only due to the instruction and guidance I received throughout the course of my studies. Over the years I have learned many things from both discussions in class and those taking place in the hallway. I owe an incredible debt of gratitude to both members of my committee: Professors Julie Laplante and Meg Stalcup. Julie has always provided me with encouragement to explore my curiosities and has acted as a role model wielding an unrelenting passion for anthropology. Meg, with her push towards academic inquiry and the search for knowledge, has been a shining source of inspiration. Furthermore, Meg's generosity with her time and patience has never made me feel completely alone throughout the course of this research.

Finally, I would like to acknowledge the tremendous influence that Ari Gandsman has been throughout the last few years. As a thesis supervisor Ari has been a mentor and an incredible guide through the tempestuous waters of this thesis. His supervision approach allowed me to carve out my own path, yet kept me out of the rabbit holes and the weeds; I would not have changed a thing. Ari is a rare breed of person who is at once a brilliant academic and a mensch.

Thank you all and please do continue spreading your influence to others.

Table of Contents

<u>Introduction</u>	1
Background.....	2
Dissertation Breakdown.....	6
Into the Field.....	7
Methodology.....	14
<u>Chapter One: Anthropology of Suffering</u>	16
Meaning of Suffering.....	19
Causes of Suffering.....	24
Experiences of Suffering.....	29
(In)Communicability of Suffering.....	34
Responses to Suffering.....	40
<u>Chapter Two: Assisted-Death & Suffering</u>	49
Old Values on Suffering:.....	51
(Un)Bearability.....	56
Medical Gaze.....	66
<u>Chapter Three: Advocates' Perspectives: What is Meaningless Suffering</u>	75
Observing Suffering.....	76
Subjectivity of Suffering.....	87
Validity of Suffering.....	91
Meaningful/less Suffering.....	103
<u>Conclusion</u>	110
<u>References</u>	118

INTRODUCTION:

“Euthanasia feels much like delivering a baby.” This quote took me by surprise when I encountered it in an article Dr. Jan Bernheim had co-published the year before our interview (Bernheim et al., 2014). Upon meeting the Emeritus Professor of medicine at the Free University of Brussels and long time advocate of access to assisted-death, He explained the parallels between the two. While the birth of a child is often considered a joyous occasion, similarly, helping someone die “in a dignified, emotionally, and intellectually satisfying fashion gives one satisfaction in doing something right which may have contributed to elimination of suffering and in a number of cases was looked forward to by the patient” (Bernheim, October 2015). Bernheim provides insight into a worldview shared by many right to die advocates that underlines the direct relationship between conceptualizations of suffering and attitudes towards assisted-death.

Dr. Bernheim, along with other right to die advocates I encountered, consider certain forms of suffering gratuitous to human experience. As a result, they believe that an individual should have the choice to end their life if that is the only means to eliminate their suffering. Although right to die advocates unite around the general understanding that certain forms of suffering are meaningless, they differ in their conceptualizations of what constitutes a valid form of suffering. The purpose of this dissertation is to explore how advocates conceptualize their vision of assisted-death practices in relation to notions of severe suffering acting as the underlying reason for hastening of death. Furthermore, suffering - a term that lacks strict parameters, yet is the core reason for the right to die movement - will be examined for its potential to separate the individual from their desire to live.

Background:

Currently there are only a handful of countries that have successfully implemented assisted dying laws in various forms. As of 2016 euthanasia is accessible in Belgium (2002), Luxembourg (2009), and Quebec (2015)¹ while physician assisted-death is legal in Switzerland (1942) as well as the United States in Oregon (1994), Washington (2008), Montana (2009), New Mexico (2015), California (2015) and Vermont (2014). A legal framework that officially allows for both euthanasia and physician-assisted suicide exists in the Netherlands (2002) and Canada (2016) (Gandsman, Herrington, & Przybylak-Brouillard, 2016).

Within the community of assisted-death supporters and opponents, the different terminology is important. The term medical aid in dying allows for the possibility of including both what has been traditionally termed euthanasia (lethal dose administered by a medical professional) and what is sometimes referred to as physician assisted-death (a term that implies medical supervision, but leaves the act of administering the dose to the patient (e.g. oral ingestion). The commonly used term 'assisted suicide' refers to aid in dying that may or may not be performed by a medical professional (CMA, 2014). However, the medical terms used and the reality of end of life procedures can often enter grey zones of interpretation; although Belgium only recognizes access to euthanasia, "assisted suicide can be regarded as being the same as

¹ Quebec falls under both Bill-52 - part of provincial healthcare legislation implemented in December 2015. However, as of June 2016, the province is also encompassed within the decriminalization of assisted death and Bill C-14.

euthanasia, providing that all the conditions for the implementation of euthanasia, as prescribed in the law, have been properly met” (Thienpont, 2015, p. 141). In Belgium, the difference between physician-assisted death and euthanasia is rarely distinguished, leaving it up to patient preference. Yet, certain advocates from all over the world will strongly argue for one over the other based on strong historical and political narratives.

Terminological narratives around assisted-death were important in my fieldwork since they are usually the first indicator in decoding how an advocate conceptualized the ideal form of dignified death in relation to suffering. Proponents of a self-administered death physician-assisted death (or assisted-suicide) often prioritized the ability for the patient to both determine and perform their own death. Those in favour of a physician-administered death (euthanasia) placed more importance on their own intellectual ability to decide while assuring a level of safety and greater medical intervention.

Aside from the individual advocate’s preference towards self-administered death versus physician-administered death, there exists a historic-political debate concerning assisted-death terminology itself. For example, the word euthanasia originates from the ancient Greek term *eu* (good or peaceful) and *thanatos* (death) that relate to the purposeful death of a person by another based on principles of compassion (Lossingol, October 2015). The use of the term can be traced back to Plato who first argued that individuals who are not in good health should be allowed to die for the common good of the city (Mystakidou et al., 2005). The global right to die movement emerging in the late 20th and early 21st century has been divided on the use of the term

euthanasia due to its conflation with Nazi orchestrated elimination of those considered 'undesirable' through the T4 program².

The negative historical connotations associated with the term 'euthanasia' have led certain advocates to push for a refashioned term with same meaning. One of my participants, Ghislain Leblond, a former civil servant with the Quebec government and co-founder of a small right to die organization called *Le collectif de mourir digne et libre*, argues for the term 'medical aid in dying' as opposed to 'euthanasia'. For him, it is critical to avoid ambiguity as the term, "is medical aid in dying and not medical aid in knitting or in writing one's doctoral thesis. Medical aid in dying is clear and does not hide that by its very definition it is an act of euthanasia," but does not use the term itself (Leblond, August 2015). Leblond, along with certain other advocates, are willing to move away from euthanasia - a word that for them has become tainted - so as to embrace a newer term without the same political baggage.

Efforts to use clear terminology, void of past associations, were important for Quebec (and Canadian) advocates facing strong political opposition in passing right to die laws. In their eyes, fighting over terminology was not worth it if it meant risking an assisted-death law altogether. Similar attempts have been made by numerous right to die advocates to distance themselves from the term assisted-suicide since it creates a misguided understanding of assisted-

² In the late 19th century, German philosopher, Friedrich Nietzsche, in his book *Twilight of the Idols*, states, "The sick man is a parasite of society. In a certain state it is indecent to live longer" (Nietzsche, 1998, p. 36). These views were later taken up by German academics such as Karl Binding, a legal scholar, and Alfred Hoche, a medical professor who performed psychologically based research on mental illness. Together they published *Allowing the Destruction of Life Unworthy of Life*, in which they provide a detailed account of who, within society, deserves to live and what category of people (notably the mentally and physically disabled) no longer merited life. Binding took great interest the potential legality of various forms of euthanasia and drafted hypothetical laws and methods of implementing these laws within German legal framework (Wright, 200, p. 30). The ideas provided by Binding and Hoche became influential in the 1930's for Nazi Eugenists. According to Wright, "their work helped create a climate in the German medical profession that permitted physicians to accept the idea of killing their patients", and after the war they justified their actions using Binding and Hoche's work (2000, p. 32). It was from Binding and Hoche's work that the ethical justification and proposal for legal implementation of the Nazi T4 program emerged.

death, however this is equally debated within the movement. Advocates I met with were usually rather careful to use terminology that corresponded closest to their own views on how assisted-death ought to be conceptualized. It became vital to my research project to distinguish between the more nuanced distinctions associated with each term used so as to gain a more complete understanding of how my participants conceptualized assisted-death as a response to suffering.

Terminological distinctions between various types of suffering among advocates (e.g. physical suffering, psychological, existential, etc) is significant because it is directly tied to the validity of assisted-death to that form of suffering. For example, advocates who are able to conceptualize the existence of existential suffering are far more likely to be in favour of a more open-ended eligibility for assistance in death that qualifies non-terminal suffering. However, other advocates consider assisted-death to be reserved to somatic forms of suffering and will rarely acknowledge the existence of or validity of non-terminal suffering.

Dissertation Breakdown:

In attempting to analyze how right to die advocates envision idealized assisted-death practices and their personal understanding of human suffering that shape their beliefs, this dissertation will first explore how past medical and social scientific inquiry has responded to the question of human suffering. By grounding this research in the literature on suffering, the goal is to provide the reader with an overview of intellectual responses to the question of suffering and to situate right to die attitudes in relation to past philosophical inquiries. The question of how humans respond to suffering with emphasis on assisted-death advocates will therefore be my main interest and will be discussed throughout the three main chapters of this thesis.

Chapter one, entitled *The anthropology of suffering*, provides the reader with a general background into anthropological inquiry into the question of suffering. Since suffering is by no means a new phenomenon there exists extensive literature on how humans have interacted and interpreted experiences of suffering within various contexts (e.g. cultural, religious, historical, etc). In drawing from researchers and literature that examine human understandings of suffering, the first chapter contextualizes a more expansive literature on the topic of suffering, providing parallels to the more precise question of suffering and assisted-death.

Chapter two, entitled *Assisted-death and suffering*, examines the recent literature that has emerged in the last few decades on the relationship between end-of-life procedures and the experience of human suffering, creating its own subcategory of literature. Serving as a bridge between the first and last chapter, chapter two pulls from literature on suffering while including the narratives of right to die advocates who have greatly contributed to this literature. In engaging in this relationship, the chapter will serve as an indicator of where my participants

stand within the already existing literature and, more importantly, reveal what holes exist within this interdisciplinary body of research.

The third and final main chapter, entitled *Right to die advocates' conceptualization of suffering*, focuses on the accounts of my participants and their arguments surrounding access to assisted death. In this chapter the distinction between various conceptualizations of suffering, and therefore assisted death, will be deconstructed to gain a deeper understanding of what motivates them to dedicate their lives to this cause. The reader having read the previous two chapters should be able to better understand where right to die advocates position themselves in relation to the anthropological body of literature and the current writing in other disciplines on suffering and assisted-death.

In my concluding remarks I provide a larger overview of the philosophical parallels between right to die advocates and existentialists. Moreover, this last part includes my own personal interpretations of how advocates or even those who support the choice of assisted-death are shaped by their own conceptualizations of suffering.

Into the Field:

Following my curiosity into what motivates right to die advocates, and more specifically how imagined understandings of assisted-death models are shaped by the advocates' view of suffering, I undertook research aimed at gaining a greater comprehension of the complex phenomenon. This research, as part of my master's degree, took place between 2014 to 2016 a time when assisted-death was of great political concern within Canada. To provide the reader with a brief contextualization, in the summer of 2014 the Quebec National Assembly approved a

Bill that would permit 'medical aid in dying' within the health system for those with terminal and intolerable suffering. On August 18, 2014 Gillian Bennet ended her life using barbiturates having posted her intention on her blog: "I will take my life today around noon. It is time. Dementia is taking its toll and I have nearly lost myself. I have nearly lost me" (Deadatnoon, 2014). Bennet's introductory line declares her willingness to end her life as a form of assisted-death in spite of laws prohibiting such action. In justifying her future self-administration of death, Bennet elaborates on how she is suffering and how dementia is stripping away a self-perception that she values as making her life meaningfully worth living.

Less than a year after Bennet's death, in February 2015, the Supreme Court of Canada ruled in favour of decriminalizing assisted-death in the case of Carter vs. Canada for those suffering intolerable conditions, to be implemented in June 2016. The Canadian Liberal Government passed Bill C-14 that, according to Dying in Dignity Canada, is considered "unconstitutional" since it restricts access to those "suffering intolerably from an excruciating, irremediable medical conditions, but who are not approaching end of life" (Dying with Dignity, June 17, 2016). This law will allow only those with a foreseeable death ahead of them and who are severely suffering to access the right to die. This brief overview the events that transpired during the period of my research should give the reader a basic understanding of the political climate in Canada at the time around the topic of assisted death.

My initial fieldwork began in the winter of 2015 during which time Elijah Herrington, my passionate and dedicated co-investigator, and I began attending events in the Ottawa area

organized by Dying with Dignity Canada³. Our preliminary fieldwork involved attending meetings concerning advanced directive planning, panel discussions and eventually interviews of the organization's members provided us with a glimpse of the worldview (perspective based on a group of people) that right to die advocates had prior to the implementation of assisted-death laws in Canada.

Following a few interviews and fieldwork excursions in the Ottawa area, I moved to looking at Quebec where a euthanasia (medical aid in dying) bill had been already been passed. The Quebec right to die advocates I encountered understood autonomy to be the underlying reason and justification for assisted-death laws. For them autonomy was based on the intellectual capacity to decide for oneself and for that wish to be respected by a physician⁴. It was therefore their main reasoning for euthanasia (l'Ésperence, August 2015). The proposed Quebec model, based on the Belgium model, highlighted a difference in how Quebec advocates understood the concept of personal autonomy in comparison to Ontario who highly valued advocates self-administration of one's death, therefore putting an emphasis on physician assisted-death over euthanasia. These differences in how various advocates conceptualize the delivery of death through differing representations of personal autonomy (in relation to the patient requesting euthanasia) initially made me interested in researching assisted-death advocates.

³ Dying with Dignity is the largest right to die organization in Canada that has local branches in most Provinces (with the exception of Quebec).

⁴ Dying with Dignity differentiates itself from Quebec's main right to die organization, l'Association Québécoise de mourir dans la dignité (AQDMD), in that they advocate at a federal level for the decriminalization of assisted death as opposed to through provincial healthcare (Dying with Dignity, 2015). Another notable distinction between these two organizations included the proposed method of delivery a dignified death.

Prior to going into the field, my preliminary research and analysis of available literature gave me the impression that the right to die movement rested upon the foundations of the emerging concept of patient autonomy. It was only while conducting fieldwork in Belgium that it became clear to me that although autonomy (or self-determination) constitutes a major argument for one's self-decision right, advocates are motivated by their belief in the existence of meaningless human suffering.

My initial misconceptions concerning the core reason supporting the right to die was further perpetuated following my reading of the New Yorker's article on Belgian right to die advocates. In June 2015, with my fieldwork trip to Quebec and Belgium quickly approaching, I was grateful when an article in the New Yorker was published detailing the accounts of numerous right to die advocates in Belgium. The publication of 'The Death Treatment: When should people with a non-terminal illness be helped to die?' by Rachel Aviv seemed to me at the time like a much needed stroke of luck. Little had been written on right to die advocates themselves and I was becoming increasingly worried about my ability to find research participants.

Aviv's article examines Belgium's right to die movement and laws resulting from it focusing in particular on euthanasia cases of non-terminal patients. The journalist starts by recounting the story of a woman in her sixties who received euthanasia for reasons of severe and long-term depression (2015). Her adult son, Tom Mortier, claimed to have learned of the

procedure only following her death and confronted the physician responsible, Wim Distelmans⁵. He has since spoke out against the Belgian euthanasia model and those involved, namely assisted-death advocates and practitioners. Aviv structures the article in a way that threads Mortier's narrative against advocates throughout the entire piece interspersing his story with the perspectives of various opponents and right to die advocates.

After reading the article, I was under the impression that the Belgian right to die scene was marred with political drama and controversy, yet at the time I was glad for any information on the people who I had set out to research. Therefore it seemed logical to use the article as a sort of list to contact potential participants, especially considering that many of my Quebec advocates had spoken about Aviv's work enthusiastically. This tactic of contacting those advocates mentioned in the New Yorker article yielded no traction. I arrived in Belgium with only a few confirmed interviews (referred to me by Quebec advocates) and a significant amount of stress about my research prospects.

It was only once I met with Dr. Jan Bernheim that I began to understand how many Belgian advocates had negatively interpreted the portrayal that Aviv had painted of them. Furthermore, it helped me understand why some of my participants were wary of me as a researcher and would become angry at the mention of the New Yorker. Dr. Bernheim, upon reading the article, sent the New Yorker a response that was never published by the American magazine, but was published by a Belgian newspaper under the title: "Hasty Euthanasia: don't

⁵ Wim Distelmans is perhaps the most prominent right to die advocate and euthanasia practitioner in Belgium. He has received numerous prestigious awards (Free Speech Ark Prize 2003, Laureate for Liberal Humanism 2015, and the Medal of the Flemish Community in 2016) for his commitment to Belgium's end of life laws.

believe everything that is in the New Yorker” (Bernheim, October 2015; De Morgen, June 26 2015). In Dr. Bernheim’s opinion, Aviv was, “a serious and intelligent journalist, but she had an agenda to focus on this Tom Mortier case” and he believed that Mortier suffered from pathological bereavement (Bernheim, October 2015). This condition is according to him, “when a person who has lost a loved one never gets over it and goes down and eventually dies of grief” (Bernheim, October 2015). Following this interview I began to suspect that having mentioned the New Yorker article in contacting so many of my potential participants had been a major fieldwork mistake.

Although having entered the field with Aviv’s portrayal of how advocates conceptualized assisted-death, this view became increasingly problematized once I met numerous advocates (a few of which had also been interviewed by Aviv). While the New Yorker article lent credibility to Tom Mortier, one of my participants referred to him as “completely nuts” and another participant openly told me that they had lost trust in those interested in the Belgian euthanasia debate and was adamant that I not publish anything prior to them having reviewed it. I began refraining from discussing the article as I found that it would anger or upset my participants and detract from the interviews. Ultimately, Aviv’s article created an atmosphere of distrust that made it harder to gain access to right to die advocates who had felt burnt by her journalism.

The article’s depiction of the controversy surrounding the death of Godelieva, Tom Mortier’s mother, positions itself in direct opposition to the fundamental precepts of right to die advocates (Aviv, 2015). In giving a voice to Mortier, who feels hurt by his exclusion from his mother’s choice to end her life (due to their poor relationship), Aviv provides a view that supports the belief in the sacredness of life over the individual’s choice of death. Belgian right to

die advocates who believe in the existence of meaningless suffering and thus the person's right to decide for themselves are undermined by this opposing view that echoes medical and family paternalism. Wim Distelmans and doctors who support the decision to perform a euthanasia procedure on Godelieva defend the individual's right to decide when their life no longer has meaning (assuming it is compatible with the medical assisted-death framework).

The existence of Aviv's article and the controversy surrounding Tom Mortier are of significance to my research for two reasons. First, the piece provided a cold and detached depiction of right to die advocates who solely justified their advocacy with concepts of personal autonomy - this complicated both my research question and my ability to approach participants. Second, much of the responses provided to me by my Belgian advocates were clearly fashioned in relation to implied criticism of the right to die movement in Aviv's writing. Third and finally it provided me with a proper understanding of the two distinct camps that exist in relation to suffering - those that perceive suffering as sometimes meaningless and support access to assisted-death and those who do not. My research focuses on the former and how different interpretations of what constitutes meaningless suffering can shape idealized conceptualizations of assisted-death practices.

Logistically the publication of the New Yorker article a few months prior to my entering the field created the necessity to alter my methodological approaches in response to advocates' distrust and defensive attitudes towards foreigners interested in assisted-death.

Methodology:

The majority of the interviews I managed to schedule resulted from what is commonly referred to as ‘the snowball effect’, which means being recommended by one advocate to another. I found this method one of the most agreeable since participants were often more keen to speak with me if I was referred by their friend or colleague. I was able to reach the rest of my interviewees through contacting right to die organizations directly and explaining my research to them. In contacting these organizations I found it to be important to use vocabulary around assisted-death that advocates themselves used and avoid language of the opponents. An example of this would be that very few advocates would ever refer to the ‘slippery slope’ the fear that euthanasia laws will inevitably degenerate into eliminating the vulnerable unless to criticize the notion. Therefore, my use of certain terms and absence of others in contacting my participants was, I believe, vital in being given access to interviews.

The interviews I conducted were based on semi-structured questions that attempted not to lead participants into a pre-determined response. The length and intensity of the interviews truly depended on the participants themselves and ranged from thirty minutes to almost four hours (often depending on other obligations). During the interviews I would use my phone to record what they were saying so as to later be able to transcribe their words and analyze them for the sake of this project. Moreover, the interviews were conducted both in English and French, but French quotations were translated so as to keep consistency within the dissertation.

The countries and regions of my research were based on places where right to die advocates were well mobilized or reached significant political gains Canada (Ontario and Quebec) as well as Belgium (Flanders, Wallonia, and Brussels). However, the exact localities

where I met my participants were often based on where a given participant lived. Since I was researching an attitude towards suffering that existed within a dispersed right to die community, my fieldwork took place in numerous cities, namely: Ottawa, Quebec City, Montreal, Brussels, Ghent, Namur, Antwerp and Leuven. Generally, the individuals I met with were only connected by their involvement in the right to die movement and their similarities in how they understood suffering to be: at times, meaningless. During the course of my fieldwork that took place on and off during the period of November 2014 to October 2015, I conducted sixteen interviews with right to die advocates.

It was through my interviews with those who advocate for choice of assisted-death, that I came to understand the complex interconnectedness between one's view of assisted-death (varying in terms of eligibility and procedure form) as being directly shaped by a conceptualization of another's suffering (validity of perceived experience). My hope is that, upon completion of this dissertation, the reader shall have gained an expanded insight into the worldview of assisted-death advocacy and the complexities involved with human suffering that could lead one to question whether their own life is still worth living. However, it is more important for the reader to become aware of the relationship between suffering, a subjective human experience, and assisted-death, a medicalized elimination of suffering at the cost of life.

CHAPTER 1: ANTHROPOLOGY OF SUFFERING

The notion of suffering is particular because it is simultaneously an individually subjective experience and based in shared collective social realities that in turn influence how individuals interpret suffering. In acknowledging the vastness of the term, anthropologists have taken up the research of suffering from a multitude of different angles, providing numerous understandings of what suffering is and how it became conceptualized. Nuanced discussion of how suffering is individually and collectively conceptualized have only emerged in more recent works within the social sciences (Kleinman & Kleinman, 1996; Das 1996; Wilkinson & Kleinman, 2016).

The anthropological literature, outlining the changes to conceptualizations surrounding suffering, provides the reader a greater understanding of the worldview of right to die advocates. The review of these works traces a lineage of social thought on how suffering has been interpreted by various human groups and to what extent. Furthermore the social sciences have taken interest not only in how suffering manifests itself in human lives, but more importantly in how human beings attempt to deal with the consequences of suffering (on various levels). Through an anthropological framework, right to die advocates see themselves as contributing to the reduction of suffering in the world – a belief based in their acknowledgement of the potential meaninglessness of suffering that can be traced through social theorists.

The discussion on suffering within social thought, according to anthropologist Clara Han, has deep roots and can be linked to early sociologist Max Weber's work on theodicy within 'primitive' societies (2013). Theodicy originated from German philosopher and mathematician Gottfried Wilhelm Leibniz in his 'Essais de théodicée, sur la bonté de Dieu, la liberté de

l'homme, et l'origine du mal' (1999/1710) as a concept that attempts to explain human suffering as being presided over by an supreme being or God (Morgan & Wilkinson 2001; Das 1997). Sociologists Morgan & Wilkinson argue that, "the Judaeo-Christian concept of God as all-loving, omnipotent and omniscient ensured that theodicies occupied a central place in Western theologies" (2001, p. 201). Belief in the divine therefore provided a reassuring promise of reward and logic for all earthly suffering.

The question of divinity becomes crucial to Weber's attempt to understand human response to suffering. For Weber, the problem of suffering or how to explain suffering is, "the driving force of all religious evolution" (Weber, 1958, p. 122-23). Religion becomes an attempt to explain the existence of suffering and give meaning to it. For Weber, an intersubjective (commonly understood) perception of suffering emerges following a shared experience of violence that alters the development of rationality and shapes a given worldview (Wilkinson, 2001). Thus for Weber, it can be speculated, right to die advocacy comes from a secularized disdain for suffering that is considered as both meaningless and arbitrary. Weber is credited with the development of a sociological understanding in how problems of group suffering contribute to the creation of cultural change on a mass scale (e.g. wars, natural disasters, etc). However, his analysis of suffering does not take into account the discrepancies in experience within the same collective group - the individual subjectivity of suffering in relation to a larger event.

Karl Marx, although pre-dating Weber, addresses the concept of suffering as experiences that can vary within the same societal group. He perceives suffering as means through which to create a docile working class that is used to produce capital at the expense of labour so as to survive; a system that maintains class violence and perpetuates further suffering (Das 1997;

Marx, 1961/1867). Marx believes the knowledge of suffering to be a vital force within the dialectics of social change. Furthermore, his understanding of religion is that of an “illusionary sun” that “shines to protect against real suffering” (Marx 1961/1867, p. 134). He foresees that, as a result of suffering caused by economic oppression, the proletariat will eventually dispense with the illusion of religion and act to abolish the material conditions responsible for their misery (Wilkinson 2005). Through framing suffering as the direct result of imposed violence, Marx provides a major contribution to the understanding of how suffering is unequally distributed.

The inequality in the distribution of suffering as determined by Marx is later elaborated through ‘social suffering,’ a major concept that emerges within the social sciences in the late 20th century to explain what factors cause this delivery of violence (Wilkinson & Kleinman, 2016). Social suffering can be traced as far back as the mid 18th century in the works of writers and thinkers (notably; Wordsworth, Frothingham, Blacklie, etc) where the term was used in reference to the need for social reform in response to conditions of poverty and human struggle (Wilkinson, NP). According to Wilkinson & Kleinman the possibility, of referring to social suffering allowed for a distinct form of moral experience that created a framework through which to understand the nuanced complexities of suffering (2016). Within the social sciences, the concept of social suffering only became used significantly in the later half of the twentieth century championed by anthropologist Arthur Kleinman and sociologist Pierre Bourdieu. Their approaches to social suffering vary in focus. In brief, for Kleinman social suffering refers to suffering resulting from social, economic, and political circumstances that in turn influence social disparity. For Bourdieu, it is a symptom and critique of a greater neoliberal capitalist programme imposed through government institutions. The uses of social suffering as a

conceptual tool in understanding the causes of violence will be further explored in this chapter through an overview of various anthropological texts.

This chapter will outline the current literature that shapes the anthropology of suffering. In the 'Meanings of suffering' I will discuss the current debates in anthropology over how suffering is conceptualized and what are the various types of suffering that have been identified. Second, the 'Causes of suffering' will explore the literature on how anthropologists have interpreted the reasons for which violence takes place and the suffering is distributed. This section will elaborate on concepts such as 'social suffering' and 'exclusion' that attempt to explain the various factors contributing to the existence of suffering. Third, a section entitled 'Experiences of suffering' will outline attempts made within anthropology to understand what shapes the experience of suffering. Sub-section four, the '(In)Communicability of suffering' will discuss the literature on how experiences of suffering are expressed and disseminated through such mediums as media or language. This part of chapter one explore anthropological critiques of the representations of suffering. The fifth and last sub-section will deal with the anthropological literature on the 'Responses to suffering' and the works that have resulted in human reaction to the existence of suffering in the world.

Meaning of Suffering:

What suffering means has garnered much discussion from within anthropology and other social sciences. Contemporary anthropologists are continually in the process of identifying and analyzing forms of suffering of their informants and attempting to explain why such lived experiences should be considered through the rubric of suffering.

Psychiatrist-anthropologist Arthur Kleinman has worked with conceptualizations of suffering since the 1980's and in recent years became a caregiver to his late wife diagnosed with Alzheimers. Speaking of his own experience, Kleinman writes that,

Experiencing loss is always framed by meanings and values, which themselves are affected by all sorts of things like one's age, health, financial and work conditions, and what is happening in one's life in the wider world. The collective and personal process we usually refer to as culture is one sort of framing: a kind of master framing (Kleinman, 2012, p.1).

Although Kleinman does not extensively explain what he means by culture, he illustrates a shared understanding of reality that frames a collective stream of consciousness - the intersubjectivity of experience. He claims that these shared conceptualizations of given experiences act within a interconnected network of meanings that in itself is inseparable from the individual experience of suffering. The meaning behind an experience (e.g. event causing suffering) is put into a greater narrative guided by a master framing. Therefore, the danger of considering one factor (e.g. culture) as being exclusively responsible for an individual's interpretation of suffering reduces lived experiences into overly simplistic prepackaged classifications and neglect a larger human complexity.

In his earlier book *The Illness Narrative*, Kleinman argues that the experiences of suffering are interpreted through an individually constructed framework of socially situated meanings (Kleinman, 1988). Therefore a person's interpretation of suffering is based on their interpretation of both an internal and external understanding of their lived experience. In coming to this conclusion, Kleinman develops the concept of the 'explanatory model' emphasizing greater attention to listening to how patients understand their own suffering.

The explanatory models of illness can be understood in imagining the Roman God Janus, a two faced guardian of gates who was simultaneously looking outwards and inwards. Looking outward to public symbols, while inward to personal ones form “the interpersonal processes of denial and dissimulation, retrospective narration and rationalization, dependence and domination, reality construction and manipulation, that are basic to communication” (Kleinman, 1988, p. 376). According to Kleinman, explanatory models of illness seek to avoid the routinization and objectification of patients in a clinical setting that undermine their experiences of suffering (2013). Explanatory models are useful in their ability to link suffering to the individual’s personal experiences and concerns that do not appear in medical exams. The complexity of suffering, as a feeling of personal experience yet equally belonging to a body of shared knowledge, creates an especially rich topic of anthropological inquiry that has yet to fully be explored in relation to ever-changing understandings of suffering (e.g. psychological and existential suffering).

The notion of suffering as an experience that is not only based on somatic pain, but can be experienced in a multitude of different and subjective ways is a rather new re-conceptualization of a timeless phenomenon. In his 2012 book *Humanitarian Reason: A Moral History of the Present* medical anthropologist Didier Fassin presents the concept of suffering as contemporary invention. By this Fassin means that,

It is not, obviously, that people have not always suffered, nor even that anyone could say they were less aware of it before: it is just that suffering remained an essentially private matter, or else something set within the framework of religious experience and the redemptive suffering of Christianity. Suffering is therefore a recent invention to the extent that it has entered the public sphere and become a political issue (2012, p. 41).

Fassin's analysis implies a shift in how suffering is understood as an issue that demands political attention due to its collective impacts. This observed change of how the notion of suffering is seen by political bodies implies a change in the basic understanding of what suffering means.

Fassin puts himself in dialogue with philosopher Charles Taylor who states that the West as a whole has become, "much more sensitive to suffering, which we may of course just translate into not wanting to hear about it rather than into any concrete remedial action. But the notion that we ought to reduce it to a minimum is an integral part of what respect means to us today" (1989, p. 13). Through this claim, Taylor is underlying that the core notion of human respect has evolved into avoidance of suffering and as a result has brought more attention to its eradication through political measures (a theory that can be applied to right to die advocacy).

Although Fassin overall appears to agree with Taylor's view that Western attitudes towards suffering have shifted, he challenges Taylor's use of suffering as synonymous with bodily pain. Fassin further argues that suffering has undergone a change in meaning that has added a "whole range of affects assumed to be present in individuals facing difficult social situations, and hence imputed to an immaterial agency. We are witnessing an extension of the domain of suffering" (2012, p. 41). Thus, suffering can no longer be simply discussed as a physiological or psychological fact, but as a social construction that has a cause and effect.

Medical anthropologist Allan Young, specializing in traumatic suffering and PTSD, understands the conceptualization of suffering through two distinct ways that neither limit nor exclude physical pain. In his article "Suffering and the Origins of Traumatic Memory," Young explains that historically until the nineteenth century, all suffering, whether psychological, existential or spiritual, was explained through overarching conceptualizations of religion or

philosophy (1996). Such justifications of suffering seldom left room for introspective understanding of one's own. Young identifies that suffering has two meanings,

First, the term identifies a disvalued state to which certain organisms are susceptible because of their biological makeup: suffering is associated with somatic pain and the moments of consciousness that accompany or anticipate this pain. To experience such suffering, an organism requires only a nervous system evolved to the point where we can say that it is conscious of its pain. The second kind of suffering includes states that are variously described as psychological, existential, or spiritual and that are identified by such words as "despairing" and "desolated." This second kind of suffering has a social moral dimension, in the sense that it is understood locally, by identifiable groups and communities, in the context of ideas about redemption, merit, responsibility, justice, innocence, expiation, etc (1996, p. 245).

Young considers these two forms of suffering as having the potential to coincide and overlap rather than necessarily exclude the other. The first form of suffering that Young describes is limited to the ability to consciously understand or anticipate physical pain while the second form is based on a state of mind linked to social circumstances.

The expansion of what suffering means has become increasingly represented within the ethnographic literature in attempts to contextualize various situations where more complex forms of suffering occur. Fassin, in providing an analysis of new forms of suffering in France, draws attention to psychic suffering that he identifies as an invisible form of misery reflecting the stress and anxiety associated with precarious conditions and expectations of contemporary society (2012). Anthropologist Talal Asad examines how torture and deprivation contribute to a more complicated form of suffering characterized through experiences of desperation and isolation that often have both psychological and physiological dimensions (1996). Another anthropologist E. Valentine Daniel has written ethnographic material on the particular forms of suffering experienced by Sri Lankan Tamil refugees who have landed in the UK and the realities of being

an asylum seeker (1996). The shift and expansion of what suffering means is intrinsically tied to a host of ever-changing factors that contribute the distribution of violence and therefore the continued advent of new forms of suffering. These new conceptualizations of what suffering can include make it difficult to reduce it to a single factor as often it is multi-dimensional and deeply subjective elements that add complexity to the lived experience.

Causes of Suffering:

Anthropology's concern for the existence of suffering has extended to attempts to link how conditions of human distress are rooted in socially determined circumstance and social organization (Davis, 1992). Through recent conceptualizations within anthropology of how to trace the origins of individual and collective human misery, the concept of social suffering has emerged as both a conceptual paradigm and an analytic tool used in ethnography. According to Wilkinson & Kleinman, "social suffering is a critical issue that brings moral debate to the human costs exacted by our social arrangements, economic organizations, cultural values, and modes of governance" (2016). The framework of social suffering therefore allows for a clearer conceptual connection between acts of violence and their social consequences.

The concept of social suffering elaborated by Kleinman and Bourdieu has become frequently used in ethnographic texts to explain the causes of suffering in a given group of people. The vagueness of what suffering actually entails can be confusing. In attempting to understand the concept, Wilkinson makes clear that, "social suffering is used to refer us to the lived experience of pain, damage, injury deprivation and loss. Particular social conditions and distinct forms of culture both constitute and moderate the ways in which suffering is experienced

and expressed” (NP, p. 1). Wilkinson & Kleinman elaborate by adding that such sudden destruction and loss that can be either the product of humans or a natural calamity that intersect with the diversity of structural and economic conditions creating various experiences of suffering (2016). However, social suffering does not provide a means of gauging the intensity of the lived experience, but rather indicates who is most likely to be effected.

According to Arthur Kleinman, the concept of social suffering is applicable to all levels of society, however it is especially apparent and prevalent within those who experience forms of oppression and have been routinely damaged through forms of violence and isolation (2013). These forms of oppression often result from social and economic disparity, and in turn further perpetuate it among specific groups of people (e.g. poor, racialized, etc) making it more likely for someone to be subject to structural violence (inflicted through established institutions and social norms) thus creating a system of unequal suffering.

Medical anthropologist Paul Farmer draws from the concept of social suffering to help explain structural violence that reproduces suffering in poverty stricken populations in the global South (Wilkinson NP; Farmer 1997). In his book *Pathologies of Power*, Farmer depicts the vicious circle of social suffering through the ethnographic example of a rural Haitian girl, Acéphie, from an impoverished farming community that was experiencing draughts due to the construction of a dam. In this community the military is the only salaried jobs and it often imposes arbitrary restrictions and fines on farmers (2003). One day a captain, known to have a family and reputed for sexual promiscuity, begins pursuing Acéphie and there is little option to refuse without actions being taken against her family. The affair ends shortly after and Acéphie eventually leaves to become a maid in the city, but is let go once it is discovered that she had

become pregnant. She returns to her hometown where she gives birth and is subsequently abandoned by her boyfriend. She is diagnosed with HIV/AIDS, but is unable to receive treatment in her village. She grows incredibly sick and struggles to take care of herself while tending to her child. She eventually dies in squalid conditions, her family helpless to provide her with any sort of aid.

Farmer sees Acéphie as victim of institutionalized forms of oppression that made her particularly susceptible to experiencing events that led to poverty, isolation, disease, as well as an untimely and undignified death. Using Acéphie's narrative as an example for factors that lead to increased chance of social suffering, Farmer elaborates that these sorts of violations are not haphazard, but "rather, symptoms of deeper pathologies of power and are linked intimately to the social conditions that so often determine who will suffer abuse and who will be shielded from harm" (2003, p. 7). For Farmer, social suffering serves as an analytical tool in determining the root cause of structural violence and furthermore what groups are most vulnerable to be subject to it.

Social suffering becomes intimately tied to institutions with power to delineate certain privileges to a prevailing group while leaving the rest to the consequences of violence (e.g. African-american populations left to fend for themselves following hurricane Katrina in Louisiana). For Wilkinson, social suffering can be understood to "mark the arrival of a cultural and polecat outlook that holds that there are many occasions where an inordinate amount of suffering takes place as a result of our social organization; and further, that the many problems that arise in connection with the moral meaning of human suffering warrant social inquiry above all else" (ND, p. 5). Wilkinson is making it clear that human suffering is the direct result of how

social institutions are structured and is clearly linked to acts of violence, that although arbitrary, still affect some groups more than others.

Anthropologist Nancy Scheper-Hughes in her fieldwork in South Africa attempts to use social suffering as an analytic tool to identify how acts of violence during the Apartheid era can be linked to political instability and conflict that in turn produces suffering based on a range of social, economic, and racial disparities (Wilkinson, ND; Scheper-Hughes 1992; 1998). Scheper-Hughes, through her interview based fieldwork, provides numerous accounts of how both black South Africans and white South Africans experienced suffering during this turbulent period. In her presentation of these narratives Scheper-Hughes implies that the suffering of black South Africans experience was the result of structural violence that severely limited their economic and social opportunities keeping them in positions of poverty. This oppression produced acts of frustration that were made publicly known through acts of violence towards white South African communities. These incidents produced an increased division within South Africa and continued to perpetuate the violence and suffering.

Scheper-Hughes' use of the concept of social suffering attempts to track how these systemic acts of violence are used to reproduce suffering within South African communities. Her article "Undoing: Social Suffering and the Politics of Remorse in the New South Africa" only briefly discusses factors that lead to the unequal distribution of suffering and mainly focuses on the narratives of South Africans discussing why they have chosen to forgive those who have committed violence towards them. Scheper-Hughes' uses social suffering as a means through which to describe the causes of this suffering and applaud national reconciliation. Her article does not advance the potential use of the concept, but rather simply pulls from social suffering,

“to promote humanitarian concerns; an early attempt to consolidate movements to oppose the deleterious effects of human suffering via programmes of social reform” (Wilkinson, ND).

Wilkinson provides a mild critique of directly applying social suffering as a means of advocacy since it breaks from the concept’s established purpose to further deepen knowledge on what factors contribute to the distribution of suffering.

Similarly to the concept of social suffering, ‘politics of exclusion’ has emerged as another method through which social scientists attempt to identify the causes of suffering. Following Fassin’s fieldwork with French police officers, in heavily immigrant populated suburban Paris, he observes that those who seem to be in lower social-economic situations are often both socially and geographically excluded from the dominant. He describes the cause of such exclusion as, “the combination of instability and insecurity generated both the suffering that translated into violence among young people and the mistrust that developed into fear among adults” (Fassin , 2012, p. 23). These politics of exclusion work on public perception of the other and lead to greater probability to be in conditions that are predisposed to cause suffering.

Clara Han, in describing the criticism of humanitarianism’s moral and political agenda in the representation of suffering and alienation, compares it to Fassin’s concept politics of exclusion. Similarly to certain humanitarian campaigns, “representations of exclusion and suffering mobilize moral sentiments of compassion, indignation, and care, and these moral sentiments have political value, which entails specific forms of intervention” (Han, 2013, p.23). In following the literature on the causes of suffering it becomes clear that through an anthropological perspective suffering is directly tied to disparity and the violence that accompanies maintains these inequalities.

Experiences of Suffering:

Iain Wilkinson, in his book *Suffering: A sociological Introduction*, notes that most sociological and anthropological texts focus on the causes and consequences, but only as of recently and few works discuss the phenomenology of lived experience of suffering (2005). In the past, attempts to explain experiences of suffering through digestible units of measure have been met with much criticism from anthropologists. Kleinman & Kleinman provide an example of Development Report published by the World Bank that attempts to create an objective metric of suffering to simplify meaning and experience as being uniform worldwide (1996). Such a comprehension of suffering assumes that all humans will react the same to various forms of experiences. Sociologists Morgan & Wilkinson support a similar argument claiming that reductionist approaches, “trivialize suffering by consistently failing to capture the intensity of personal awareness and its cultural complexity” (2001, p. 206). Furthermore, “the problem is not so much that suffering resists understanding, but rather that analytic categories seldom engage with the actual experience of affliction” (2001, p. 206). Critiques of this nature dismiss attempts to ‘cheapen’ the necessary complexities that shape experiences of suffering. Wilkinson believes that the difficulty with standardizing experiences of suffering is that it, “is largely understood as amounting to the absence of symbolic forms of culture for giving a sufficient meaning to the experience of acute pain” (Wilkinson 2001, p. 429). Therefore, he argues that experiences of suffering need to be filtered through an understanding of specific values and expectations.

Wilkinson's more nuanced approach to the interpretation of suffering follows a Geertzian⁶ view of anthropology that, "understands subjective life by analyzing the symbolic forms - words, images, institutions, behaviours - through which people actually represent themselves to themselves and to one another" (Biehl et al., 2007, p. 7). The Geertzian vein of anthropological inquiry is strongly based on viewing human interaction through the lens of 'culture'. The 'culture question' as a means of measuring suffering enters into a greater anthropological debate that has been raging since the 1980's on whether using culture, as an analytical tool, is still relevant in the discipline (Biehl et al., 2007). Anthropologists who oppose the use of 'culture' believe that its existence creates a dangerously over simplistic framework of anthropological inquiry.

Anthropologist Jason Throop moves past the notion that experiences of suffering are exclusively based on culturally pre-determined values. Through his research with the Yap in Micronesia, he questions how the experience of suffering can be interpreted as sacred. He argues that the experience of suffering has the potential to be generative in representing notions of sacredness. Drawing from Scarry, he describes how intense and indescribable pain can be understood as "world-destroying" in how its manifestation removes significance from the sufferer's world (Throop 2015; Scarry 1985). This "world-destroying" pain is otherwise indescribable in words and therefore cannot be accessed by others and creates a form of otherness and unknown experience (Throop 2015). The destabilizing and unknown form of

⁶ Clifford Geertz a cultural anthropologist who conceptualized culture as "an historically transmitted pattern of meanings embodied in symbols, a system of inherited conceptions expressed in symbolic forms by means of which men communicate, perpetuate, and develop their knowledge about and their attitudes toward life" (Geertz 1973, p. 89).

experience that presents itself in various forms of suffering has the potential to be transformed into a symbolic representation of sacredness. Desjarlais & Throop theorize that such transformations occur due to, “the otherness of our own and others’ embodied modes of being-in-the-world that suggests a beyond, a horizon, or an elsewhere that is also yet still immediately intertwined with this world” (2015 p. 74).

In conceptualizing another’s experience of suffering as sacred suffering becomes accepted as ungraspable and further adds a layer of mystery to an already obscure human experience.

Referring to his fieldwork, Throop observes that the perception of sacredness in the sufferer’s affliction can, “produce extreme forms of social isolation, fear, hurt, and loss,” for the sufferer, which adds a pain that is not only based on somatic agony, but also has social implications (2015, p.84). Paradoxically, the mysticism and lack of access to the experience of suffering equally produce the notion of sacredness as it socially isolates the individual. Drawing from the phenomenologist philosopher Edmund Husserl, Throop likens the emergence of suffering in our lives to a major shift in orientation that rattles the, “existential tethering to our ongoing self-experience, experience of others, and of the surrounding world is unsettled, is made anew, even if just for a second, as now something evidencing a beyond, an elsewhere, a horizon, a potential, or a limit” and further introduces new “forms of being that do not eclipse the given as such, but instead reveal possibilities for encountering differing aspects of it” (2015, p.85).

An encounter of this nature cannot be imagined before experiencing it, yet does not completely remove the sufferer from the collective lived experience since the basic notion of suffering can be intersubjectively understood.

Throop steeps his analysis of suffering among the Yap in a phenomenological perspective of experience where such, “distinctions between subjective and objective aspects of reality, between what is of the ‘mind’ and of the ‘world,’ are in part patterned by the very attitude, perspective, or mode of perceiving that a social actor takes up” (2015, p.76). Throop’s use of subjective and objective are attempts to simply distinguish between the internal modes of interpreting and an externally shared understanding of reality. Through his work, Throop moves away from any attempts to universalize the experience of suffering and equally acknowledges the importance of individual subjectivities working in relation to collective modes of understanding. Throop however does not go further to examine what makes up the concept of subjectivity and how more precisely it shapes personal experiences of suffering.

The question of subjectivity is taken up in a collaborative book *Subjectivity: Ethnographic Investigations*. In a chapter of this book entitled “The experimental basis of subjectivity: How individuals change in the context of societal transformation” Kleinman & Fitz-Henry provide a deeper anthropological analysis of what is understood to compromise human subjectivity. According to the authors,

Our subjectivities certainly have a biology, but they also, and perhaps more critically, have an equally influential history, cultural specificity, political location, and economic position. In short, we are as responsive to biological blueprints as we are to alterations in political economy and social positioning, both of which, in turn, refashion the very biology of those blue prints (2007, p.53).

Human subjectivity is therefore shaped in tandem by biological determinants and a product of experience, history, and memory that influence human decision-making.

Kleinman, through attempting to conceptualize lived experiences, creates the concept of local moral worlds; a stage for moral experiences that convey what is of the most significance for a local network of relationships within communities. These conceptualized networks of relationships in anthropology have surpassed traditional inquiry in outpost villages to “extend to networks where everyday life is enacted and transacted, where individuals’ inner subjective experience is in interaction with the practices and engagements of other people” (Kleinman, 2013, NP). Within these local moral worlds, lived experiences are produced and reproduced for the collective and the individual in diverse, yet parallel ways.

Kleinman, in presenting at *The Tanner Lectures on Human Values* at Stanford in 1998, elaborates his understanding of experience as,

“the felt flow of interpersonal communication and engagements. Those lived engagements take place in a local world. Experience is thoroughly intersubjective. It involves practices, negotiations, contestations among others with whom we are connected. It is a medium in which collective and subjective processes interfuse. We are born into the flow of palpable experience” (p. 358).

Human subjectivities in turn will act in relation to symbols and interactions that underline everyday intersubjectivity of a network of relationships within a community constantly, re-working and reinterpreting them. An experience, such as suffering, therefore is both based on a collectively understood intersubjective reality as it is with an individual’s subjectivity towards these shared realities.

Following the notion of individual human subjectivities being reworked and reconfigured in relation to local moral worlds, suffering (like all other experiences) is shaped by events within

these communities. According to Ware & Kleinman, an experience of suffering affects the structure of the local world, changing the character of social life for the sufferer and those with whom they interact (1992). The experience of suffering, such as an illness, “initiates a sequence of changes in the sufferer's environment, and his or her place in it, which originate in the experience of impairment” (1992, p. 548). These changes often influence the individual’s employment and can lead to stigmatization of the sufferer, however other forms of illness can lead to negotiating transformations in one’s environment. The experience of suffering eventually intersects with interpersonal events that affect the subjective understanding of illness, shaping the social course of the illness. In attempting to comprehend the lived experiences of suffering, it is impossible to exclude the simultaneous and ever continuing influence of both subjective and intersubjective human constructions that shape our interpretation of events.

(In)Communicability of Suffering:

Following the aftermath of the Holocaust which eradicated human life in unprecedented quantities and a war that left much of the world in ruin, Hannah Arendt emphasized the need for the social sciences to focus on the existence of evil in the world; where suffering is the consequence of evil in the world. In her book of essays *Men in Dark Times*, Arendt suggests that there is something sinister at work in our everyday language used to speak of extreme events of suffering, misery and despair, however, the core reality of human affliction is made “by no means visible at all” (Arendt 1968, p.8; Wilkinson, 2001). Arendt, in addressing the incommunicability of suffering, enters into a multi-century complaint against the human ability to transmit a universal, yet unique, experience.

Sociologist Max Weber had similarly observed that whenever writers attempt to comment upon the existence of suffering, they are often unable to find a language which adequately expresses and reflects such experiences (Weber, 1958; Wilkinson, 2001). In relation to Weber's observation, Wilkinson, comments that there seems to be something in the phenomenon of suffering which lacks any sort of existential meaning. Some have attempted to link suffering to a human overall "cultural experience" that rests as, "a matter for conceptual analysis and 'scientific' research are inclined to labour under the conviction that there is some-thing of vital importance here which always remains (painfully) obscure to our understanding" (Wilkinson, 2001, p. 423). The ability to accurately communicate one's suffering and for another person to fully understand that lived experience has yet to occur. Such a breakthrough would be significant in allowing one to recognize another human's suffering that goes beyond compassion.

Social theorist Elaine Scarry who has written on the conceptualization of suffering explains that even the most eager efforts to understand another's suffering can only illuminate a fraction of what that person is experiencing (1985). Therefore, she claims that one human's recollection of pain compared to another human would be a description of two separate and very different events (1985). Scarry's conceptualization of pain as a fundamentally individual experience that cannot be adequately expressed by the sufferer nor fully understood by the observer can be further built upon through the incorporation of social suffering that acknowledges an infinite plurality of suffering based on past experiences and lived conditions.

Similar to Scarry's inquiry on the communicability of somatic pain, anthropological interest in suffering has in recent decades concerned itself with human ability to transmit these experiences to others, moving away from the re-creation of representations of how suffering

manifests itself within ethnography. Anthropologist Tobias Kelly sharply questions, “at what point does an ethnography of suffering turn into a voyeuristic quasi-pornography? What is the point of yet another description of the capacity of humans to feel pain and suffer?” (2013 p. 214). Disagreeing with Kelly, Clara Han claims that the literature on suffering is neither limited to a human capacity to feel, nor to the ignorance of the suffering of others but, “rather, anthropologists have sought to elaborate problems such as how pain gains expression in language and the stakes in the acknowledgement of pain: what is at stake when that acknowledgment is withheld?” (2013, p.233). Han claims that in expressing suffering, there is importance in another’s understanding or recognition of the experience.

The inability to convey suffering appears to be a perennial issue, and according to Arthur Kleinman, drawing from Elaine Scarry, “a major preoccupation in the Western tradition has to do with the incommunicability of pain, its capacity to isolate sufferers and strip them of cultural resources, especially the resource of language”(Kleinman, Das, & Lock., 1997, p. xiii; Scarry 1985). The belief that the experience of suffering cannot be properly expressed and fully understood by others is accepted by the majority of anthropologists, yet there are still government institutions and media outlets that attempt to appropriate and communicate the suffering of others. Han’s and Scarry’s use of the term ‘pain’ in attempts to vaguely describe the characteristics of suffering corroborates, consciously or unconsciously, their point that the language around such experiences is severely underdeveloped.

The incommunicability of suffering, as described by Kleinman and Scarry, takes on legal and political dimensions when victims seek compensation based on validation of their suffering. Veena Das explores such scenarios through her research on the aftermath of Bhopal, India

(where corporate negligence led to an industrial disaster in 1984 causing extensive loss of life) and the Agent Orange affair (referring to chemicals being sprayed over US soldiers and Vietnamese civilians during the Vietnam war that reputedly caused severe sickness decades later). She argues that, in those cases, for suffering to be recognized within the judicial system, victims were obliged to reduce their experiences to basic definitions of injury and pain that did not properly address their actual experience of suffering (Das 1996, 1997; Morgan & Wilkinson, 2001).

The pragmatic use of language, which Das describes, is an attempt by the sufferers to make their experiences understood even if only partially. Das further elaborates that although the language used to describe suffering is lacking, the violence and thus the suffering inflicted are not unimaginable, the problem lies in the inadequacy in expressing these experiences (Das, 2007; Morgan & Wilkinson, 2001). Das' account of her fieldwork on relating experiences of suffering for judicial reasons brings practical dimensions to the quest for greater communicability of suffering.

Attempts to communicate suffering on an individual and mass scale have taken place through recent media technologies with the ability to record moments when humans are experiencing intense forms of pain. In a basic sense these can be understood as recreating instances of suffering that are then disseminated throughout the world. Kevin Carter's 1993 award winning photograph of a Sudanese child crouched in the fetal position with a vulture behind him can be seen as an example of the construction of suffering through media (Kleinman & Kleinman, 1996). This is a photo often used in attempts to make reference to the collective suffering of an entire continent which in turn shapes the perceptions and expressions associated

with the conglomerate of unnamed African countries. Kleinman & Kleinman argue that the dissemination of imagery on such a global scale shifts an individual experience into a decontextualized image of something that “carries with it a cultural representation of suffering, being remade, thinned out and distorted” and is impossible for the viewer to comprehend (1996, p. 2). Attempts to capture suffering through media essentializes another’s experience imposing upon it already established and often reductionist representations (e.g. poverty in Africa) while ignoring the individual and subjective nature of suffering.

Following the anthropological literature on how suffering is used within media and public discourse, Fassin boldly states that, “we [the West] have become used to the global spectacle of suffering and the global display of succor. The moral landscape thus outlined can be called humanitarianism” (2012, ix). Fassin is therefore claiming that the emergence of humanitarianism as a direct result of modern dissemination of representations of suffering. In Wilkinson and Kleinman’s book, *Passion for Society: How we think about suffering?*, they trace the ‘politics of pity’, referring to the history of discourse around the suffering of distant groups of humans. The authors dates back to humanitarian campaigns of the 18th and 19th century where news of catastrophic events of faraway would inspire moral sentiments and acts of generosity - a reason that still governs major humanitarian organizations.

With the emergence of sentiments justifying humanitarian action followed the potential for human suffering to be culturally appropriated in pursuit of commercial or ideological advantage (Wilkinson & Kleinman, 2016; Han, 2013). Wilkinson & Kleinman go as far as to claim that, “humanitarian organizations are set to be identified as cynical manipulators of public feeling, while those assailed by images of extreme suffering for their charity are bound to feel an

unprecedented sense of political and moral impotence” giving others the public authority to speak of their suffering (Wilkinson & Kleinman, 2016, p.105). Furthermore, depiction of suffering within the public realm works to “compromise cultural forces that are radically transforming the bounds of collective subjectivity” where collective subjectivity refers to the public conscious of particular issues formed by media representations (Wilkinson & Kleinman, 2016, p.106). Mediatized representations of an experience provide an understanding of what suffering is supposed to look like to best garner sympathy that can be transformed into a form of political currency and action.

Attempts to communicate representations of suffering through various channels whether through language or media technologies, inevitably fail to authentically nor adequately transmit the experience or the context. Das argues that blasting audiences with shocking suffering does not mobilize social action nor create solidarity, but rather transforms it into “commodities to be consumed” and “has refashioned the experience of suffering as if it were passing scenery for the viewer” (1997, p.570). At the same time, the viewer can never be expected to have the appropriate moral response in witnessing actions of extreme violence brought into their home through the marvels of technology (Wilkinson & Kleinman, 2016). The authenticity of these representations of suffering is put into question by both the receiver's ability to understand what they are taking in and the medium's ability to transmit the multilayered subjective and intersubjective aspects of a human experience.

Although anthropologists (Das 1996; Kleinman & Klienman 1996; and Wilkinson, ND) have criticized mediatized representations of suffering due to the viewers' inability to properly comprehend the suffering experienced, the viewer has the ability to sympathize with the

suffering on their screen. If this were not the case, humanitarian organizations would have ceased to exist. This recognition of suffering has pragmatic value in that it provides an element of concern and sympathy. However, such forms of sympathy are harder to garner for distress that cannot be made visible to viewers a potential issue for those experiencing forms of invisible suffering (e.g. psychological suffering). These forms of suffering are not given the same level of validity as measurable and visible anguish.

Similar to humanitarian organizations who also often aim to reduce human suffering, right to die advocates have used imagery and language that portray unbearable agony in attempts to inspire public support for their cause. This presents a paradoxical situation where advocates argue for the belief in individual subjectivity and right to chose when one's life is no longer worth living while using strategies that further distort lived experiences of suffering. However, unlike mediatized depictions of suffering that attempt to impose meaning to the imagery, right to die advocates use representations of suffering with the aim of deconstructing meaning. Arguably, right to die advocates' response to suffering as being potentially meaningless is then represented through imagery that itself imposes meaning.

Responses to Suffering:

With the existence of suffering comes the inevitable question of how to extract meaning from an experience that is present for all humans. For Veena Das, a concern to explain human suffering has led to the historical discussions surrounding theodicy a divine rational for human suffering and the later development of secular theodicies explanation for suffering provided in the future potential human achievements (Das 1997). These reactions to the existence of

suffering are significant in anthropology because they are produced by past individual and collective understandings of suffering and in turn produce a new framework through which suffering is to be interpreted.

As previously touched upon, sociologist Max Weber initially took up the ‘problem of theodicy’ the human need to provide an explanation for the existence of suffering. In analyzing the existence of theodicy Weber argues that attempts to rationalize the idea of God created a necessity to explain the unequal distribution of suffering (1963). Moreover, he posits that suffering seems necessary to a teleology of community life, “providing a religious significance to misery moves it away from an individual and isolating agony into a shared experience that is based on hope for a latter reward” (Das, 1997, p. 563). For Weber, these eschatological solutions to the problem of the distribution of suffering require a belief in a life following death where greater suffering in this world can lead to reward in the next. Weber’s contribution to future works of anthropology included an increased focus on how suffering is understood as a key element for proper ethnographic inquiry.

Following observations made by Weber, anthropologist Clifford Geertz in his book *The Interpretation of Cultures* claims that the notion of meaningless suffering has the potential to destroy current patterns of life centred around religions purpose to explain the otherwise unexplainable existence of unequal human suffering. Geertz explains that the problem of suffering is, “paradoxically, not how to avoid suffering but how to suffer, to make of physical pain, personal loss, worldly defeat, or the helpless contemplation of others’ agony something bearable, supportable” and ultimately sufferable (1973, p. 104). Therefore to a believer, religious symbols, “provide a cosmic guarantee not only for their ability to comprehend the world, but

also, comprehending it, to give a precision to their feeling, a definition to their emotions” that ultimately allow them to endure suffering (1973, p. 104). Geertz, in describing the constructed role of religious symbolism, furthers Weber’s notion that the explicability of suffering acts as the underlying reason for the existence of religion.

Following the same vein as Geertz, Talal Asad examined the practices of penance and repentance in medieval Christianity supporting his argument through explaining how a monk’s voluntary acceptance of imposed suffering in this life is motivated by the belief of avoiding greater suffering in what follows death (1993; Das 1997). Such ethnographic works move away from the debate of whether theodicy can be taken seriously as a concept, but instead indirectly acknowledge that anthropological concern is rather in how human understandings of suffering are shaped.

Although the trend to follow how theodicy shapes conceptions of suffering was initiated by Weber, he himself saw the decline of religion being used as a means to explain suffering in Western societies. Weber’s understanding of modernity involved an aggressive intellectualization of the unknown that would result in the elimination of speculation and the immeasurable (Wilkinson, ND). Morgan & Wilkinson consider the decline of belief in theodicies as the result of a growing perception of religion’s rational implausibility and furthermore its inability to explain the arbitrary nature of suffering (2001, p. 202). The observation that Morgan & Wilkinson describe outlines a decline in the belief that there is a divine purpose to severe suffering and thus the understanding of suffering to be redemptive for immoral acts perpetuated in life.

For Levinas, the destruction of 20th century, specifically, “the magnitude and savagery inflicted on the Jews, the Holocaust” was for him was, “above all other events and also as a sign of violence of this century, meant the end of traditional theories of theodicy” (Das 1997, p.567). In other words, the explanation of suffering through a divine plan that can only be speculated upon does not produce satisfying answers for the human capacity to perpetuate such acts of violence (and thus suffering) in such a routine and mechanized manner. It still leaves the question ‘but why?’

Nancy Scheper-Hughes claims that in a world “devoid of any theological mediation, we are destined, like Sisyphus, to collapse under the weight of our attempts to ‘make sense’ out of the senseless or, to cite Emmanuel Levinas (1986) - of useless suffering” (1998, p.118). Levinas further believes that humanity’s never-ending attempt to render suffering meaningful has been historically turned on the sufferer who becomes blamed as the bearer of their own agony attributed to poor moral behaviour (Levinas, 1986). Scheper-Hughes is therefore arguing that under systems of theodicy, humans are often unable to accept the possibility that suffering is free of divine purpose. The practice of accusing the sufferer of having committed a moral wrong is an attempt to link human suffering to celestial designs.

An alternative to theodicy was therefore imagined. Termed sociodicy or secular theodicy, it emerged from religions’ failure in adequately justifying the arbitrary suffering resulting from the world’s inevitable injustices such as war, crime, and natural disasters (Das, 1997). Secular theodicies attempt to bring a certain degree of analysis to how pain and suffering are caused and distributed, however they fail to address the reason why they occurred in the first place. Veena Das investigates the concept of sociodicy within her fieldwork on the aftermath of Bhopal and

Agent Orange, but argues that such explanations often lead to promises of future betterment. On her subject matter Das states that, “chemical hazards, the court have argued [pose] some risk to the population but have to be tolerated as a condition for future production of wealth” (1997, p. 570). Although such statements point to the direct causes of suffering in the case of Bhopal lack of concern for Indian workers leading to minimal safety standards they do not provide the explanation for why these conditions of disparity were present in the first place. Furthermore, such explanations of suffering exist within a framework where future potential gains (of an unclear nature) are used as justifications for the reason.

Anthropologist Margaret Lock, in her book *The Quest for Human Organs and the Violence of Zeal*, explores this notion of lesser sacrifice in the present for potential of greater good into the future. Lock provides the example of how experimental biomedical technologies are often tested on fragments of the population that are considered expendable and “who are defined as human waste” in aspiration of increasing the future wellbeing (Lock, 2000). Secular theodicies in attempting to explain suffering often simply end up following a similar formula as theodicies did the promise that through progress current suffering will one day bring societal purpose.

Similar conclusions to the dangers of secular theodicies were reached by Weber in response to the popular movement of Bolshevism in the 1920s. Here he warns that it is important to “think without illusions” and to not get caught up in the fervour of ethical idealism, as they are contingent on the irrational reality of the human world (Weber, 1963; Wilkinson & Kleinman 2016). Weber’s writing deconstructs how beliefs in ultimate ideals, whether secular or religious,

are ultimately misleading in that they are based on factors that cannot be proved. Morgan & Wilkinson expand this idea that whereas,

a coherent conception of order, sociodicies - inverted or otherwise - presuppose relatively stable systems of meaning, yet faced with the dislocation of past and present, reflexivity and risk, the prospects for sociodicy are now open to the same incredulity as theodicies from an earlier age (2001, p. 201).

This critique holds that although an effective compass of current social disparity, secular theodicies do not provide a proper framework in comprehending the meaning behind suffering. Furthermore secular theodicies, unlike theodicy, are liberated from the need to believe in divine explanations that surpass limits of rationale asking instead that faith be placed in human led projects.

In acknowledging the shortcomings of both theodicy and secular theodicies in adequately accounting for how suffering is meaningful, some have looked towards anthropology for answers on why suffering exists and how humans are to come to terms with it. In her article, "Undoing: Social Suffering and the Politics of Remorse in the New South Africa" Scheper-Hughes states that, "anthropology of suffering has emerged as a new kind of theodicy, a cultural inquiry into the ways that people attempt to explain the presence of pain, affliction, and evil in the world" when deriving meaning for suffering from a supreme form of divinity or promise of progress becomes dissatisfying (1998, p. 118). In asking herself whether anthropology is an appropriate means through which to seek understanding for why humans suffer, Scheper-Hughes comes to the conclusion that humans have difficulty not only to see human suffering as meaningless, but furthermore assign self-blame or blame others as the source of suffering.

In drawing from Levinas, Scheper-Hughes addresses the need to consider possible the “existential meaningless and the uselessness of the suffering of the other” through which a person’s suffering can only be seen as tragically evil and absurd (Scheper-Hughes, 1998, p. 124; Levinas, 1986). Through proposing an understanding of suffering that is devoid of deeper significance, Scheper-Hughes inevitably questions anthropology’s ability to provide an alternative form of explanation for injustice and violence. What she is proposing implies the use of anthropological methods to examine the root causes of suffering that take place as a result of violence. Here Scheper-Hughes is making a direct reference to the need to identify social factors that lead to uneven distribution of suffering. Social suffering can be considered the closest form of anthropological analysis that lends itself to an explanation of suffering.

Other anthropologists such as Veena Das have come to similarly conclusions, acknowledging the need for a social science based approach to studying suffering. Das emphasizes the often locally situated political ends that undermine individual suffering of victims. Therefore, she proposes that social sciences need to re-think secular theodicies to include a frame of analysis that addresses how suffering is caused and distributed in order to develop and improve its communicability (Das 1997; Wilkinson NP). These suggestions seek to position the discipline not only to study forms of suffering, but to devise ways through which to lessen its impact.

Anthropological inquiry into suffering has also studied how medical sciences approach the concept. Margaret Lock observes that medicalization attempts to reduce suffering by ‘repairing’ the body whereas, “the social origin of suffering and distress, including poverty and discrimination, even if fleetingly recognized, are set aside, while effort is expended in controlling

disease and averting death through biomedical manipulations” (1996, p. 210). Lock’s statement can be understood as a critique of a societal understanding of managing suffering as opposed to addressing root causes she ultimately points to social disparity as the main source of unnecessary suffering.

Didier Fassin more optimistically believes that through medical classifications a, “diagnostic framework; a normative polarity that makes it possible to distinguish positive from negative; the possibility of observing the phenomenon, making it visible and measurable” can be established and provide “the opportunity to resolve a social problem that finds no other solution” (2012, p. 29). Although Fassin does not dispute the social origins of suffering, he views its medicalization as the necessary first step in addressing those social causes. Kleinman on the other hand warns that the medicalization of suffering carries with it the risk of reformulating an individual’s complex experiences into dehumanizing medical terms (1988). Medically established understandings of suffering become the dominant narrative of what experiences are valid and consequently undermine the rest. Kleinman et al. observe that, “the state, its institutions, and groups that contest state control press medicalization for its advantages in regulating persons, their bodies, and networks” (1997, p. xii). The political struggle surrounding the degree of how certain experiences of suffering are legitimated by state institutions becomes about control of what the discourse of suffering is.

The political discourse around suffering is elaborated in anthropologist Adriana Petryna’s book *Life Exposed: Biological Citizens After Chernobyl* (2002) in which she provides ethnographic narratives of Ukrainians affected by the nuclear disaster in Chernobyl. Petryna explains that following the aftermath of Chernobyl, the sufferer became a legal classification that

provided numerous financial and healthcare benefits, otherwise unavailable to citizens. Such actions point to the larger phenomenon of “appropriation of suffering at all levels” which is one aspect of “how images of suffering are becoming increasingly objectified in their legal, economic, and political dimensions” for the gain of a specific group of people (Petryna, 2002, p. 251). This struggle to access the political category of ‘sufferer’ creates distinctions between those who are legitimated through category and those who are not or as Petryna puts it: biological citizenship, a form of sociality that creates a community of sufferers who share political interests based on their health designation. Similarly, right to die advocates are united by a sense of sociality based on a shared belief in meaningless suffering.

The issue of suffering within anthropological literature is the question of how humanity has engaged with the general existence of suffering. Through exploring the themes in this chapter meaning, causes, experiences, (In)communicability, and responses relating to the concept of suffering, the reader should have a general understanding of how this topic has been addressed. Furthermore, this chapter elaborated on the complexities that exist with the concept of suffering as it relates to humans since it’s interpretation and responses are tied to personal subjectivity and meaning that are not fully understandable to others.

It is through these complicated and paradoxical notions of suffering, established in the literature, that the following chapters shall be built on. They will attempt to give the reader a deeper understanding of the worldview that right to die advocates take on and how such conceptualizations become a response to the existence of suffering in itself. It is through the remaining chapters that I will contextualize how the modern right to die movement, based in a medicalized and regulated framework, came to conceptualize the existence of suffering as,

ultimately meaningless therefore advocating for the use of administered death as a means of elimination of suffering.

CHAPTER 2: ASSISTED-DEATH & SUFFERING

This chapter draws from anthropological literature on suffering examining how humans conceptualize both the purpose of suffering and its sources. It re-interprets much of these works to re-position itself in relation to the question of assisted-death. Moving past the question of ‘why does suffering exist’, and towards how responses to suffering have become conceptualized in the face of voluntarily death, this chapter applies the works of contemporary intellectuals, from a variety of sciences, to weigh in on the question of ‘when is life no longer worth living’ and what factors need to be considered in making such a decision. Furthermore, this section will discuss how various conceptualizations of suffering emerging from religious, historical, and ideological roots can be understood in relation to the question of assisted-death.

The question of when the understanding and practice of medically assisted-death originated is important in addressing the question of both the existence of human suffering and the discourse relating to maintaining life in relation to such suffering. The main question being is assisted-death a new phenomenon or does it have an older history? Anthropologist Sharon Kaufman claims that “the notion of technological progress in medicine has been seriously challenged in recent years by grass-roots movements in the United States and elsewhere that call for ‘death with dignity’ that is, patient control over the dying process” (2000, p. 74). Kaufman argues that medical technological advancements prolonging life have been challenged in recent years by new attempts to control the dying process through hastening death itself. Her understanding of

assisted-death as a response to life-extending technologies obscures the origins of assisted-death ethics in relation to suffering.

Sociologist Shai Lavi attempts to shed light on the origins of the modern medically assisted-death movement (as opposed to simply euthanasia) by tracing its origins to 19th century avant-garde British physicians (2005). Lavi argues that assisted-death advocacy is less a reaction to life-prolonging technologies nor “a response to emerging medical dominance over all spheres of life, the right to die is a manifestation of the same historical process” (Lavi, 2005, p. 2). Thus, Lavi claims that the ability to control one’s death, as with prolongation of life, falls in line with attempts to gain mastery over life. Such arguments position the right to die as part of the human project for control over biological limits and move away from Kaufman’s idea of assisted death as a reaction to recent technological changes.

As briefly outlined in the introduction, although the concept of euthanasia has a long genealogy going back as far as ancient greek philosophers, Lavi argues that medicalized assisted-death is a much more modern concept. Thus, the literature that discusses aspects of suffering (whose alleviation/elimination is often considered the role of medicine) in relation to assisted death have only significantly been medically implemented since the turn of the 21st century. Texts previous to this time discussed assisted death as an ethical dilemma, rarely taking into account the perspectives of the patients’ lived experiences and the extended possibilities of suffering that can be encompassed in right to die legislation. The emergence of assisted-death as a medicalized concept as elaborated by Lavi will be further explored in relation to both new social and scientific understandings, which I argue in turn shapes the conceptualization of medical access to death and its practice.

This chapter will seek to find the links between the perennial human question of suffering and medically assisted-death, a more recent response to suffering, so as to underline the shift in biomedical attitudes. First, ‘Old Values on Suffering’ presents past debates and religious values that led to the shaping of the current literature on suffering in the context of terminating life. The second section, ‘(Un)Bearability,’ looks at the legal and ethical implications of unbearable suffering that is usually the pre-condition to assisted death. The medical literature on ‘unbearable suffering’ exposes problems in the term’s lack of proper definition. Section three, ‘Medical Gaze’ discusses the various understandings of suffering from physicians’ view, as well as elaborates upon why the medical community has struggled with concepts of suffering and assisted death.

Drawing from the anthropological literature on suffering as outlined in the previous chapter, chapter two draws from both a response to human suffering through theodicy (greater divine meaning) and attempts to address suffering without considering the option of divine reason. In doing so, this chapter seeks to contribute to the argument that right to die advocates, in embracing a view of suffering which at times is considered meaningless, have developed a conceptualization of suffering that prioritizes individual agency over the notion of life as sacred.

Old Values on Suffering:

In *The Modern Art of Dying: A History of Euthanasia in the United States*, sociologist Shai Lavi provides a historical account of the development of attitudes towards assisted death in America. Lavi argues that Methodists⁷ in 19th century America understood dying as, “a moment

⁷ Lavi argues that Methodists made up a large portion of 19th century America and were greatly influential in shaping the attitude towards end of life suffering in America.

in life that captured its entirety” (2005, p. 39). Thus the suffering that accompanies the end of life takes on symbolic significance in reflecting the extinguishing life. According to Lavi, Methodists believed the proper dying process should not be painless, but rather an experience where pain is overcome as both redemptive and strengthening. Therefore, the notion of hastening death through assisted death would deprive them of such an end, and take away from this moment of religious significance.

Similarly, Gerald Larue, Professor of Religion and Gerontology, explores how various world religions understand the relationship between the right to die and suffering. In his book *Playing God: Fifty Religions' View on Your Right to Die*, he draws from sacred texts and statements made by religious leaders in attempts to express how religious values shape conceptualizations of suffering. Numerous Christian religions have opposed assisted death based on the argument that there is a redemptive value in suffering, especially a suffering that accompanies end of life (Larue, 1996; Lavi, 2005; Badham, 2009). Such attitudes influence by religion have been the voice of major opposition towards the right to die movement based on the notion of sacredness of life and utility in suffering.

Larue provides a concrete example of how notions of theodicy within the Russian Orthodox Church contribute to the belief that physical and mental suffering furthers one's spiritual growth in at least three ways. First, it is supposed to reveal the undeniable reality of our sins and human flaws. Second, once other forms of false hope fail the person has no choice but to put their faith in God. Third, through choosing between despair and God, suffering can foster a certain sense of self-discipline over human flesh and the sense of self (Larue, 1996; Badman, 2009). However, Larue points out that the Russian Orthodox Church no longer views all forms of

suffering as redemptive, admitting that certain forms of suffering are dehumanizing due to factors outside of the individual's control (Larue, 1996). Therefore, according to him, the Russian Orthodox Church has in recent decades changed tunes, claiming that some suffering is simply absurd and appears without reason, yet still maintains a victim blaming attitude stipulating that suffering occurs as a form of punishment for immoral acts.

A similar set of arguments is provided by the Roman Catholic Church, who has been the main opponent to the right to die movement. According to the late Pope John Paul II, "suffering seems to belong to man's transcendence: it is one of those points in which man is in a certain sense 'destined' to go beyond himself, and he is called to this in a mysterious way" (1984, 2). John Paul's comment on suffering at the end of life underlines a belief in a necessary and transformative process that has meaning in its mystery, yet presumed significance in a later life. A worldview of suffering similar to most monotheistic religions where values of bare human life outweigh an individual's agency over life. Religious assertion of suffering as meaningful, as previously outlined by Weber in chapter one, has been considered the main purpose of organized faith in a divine, yet has had limited conceptualizations of new and expanded forms of suffering - basing redemption, generally, on physical suffering (1963).

Many religious based arguments thus fundamentally disagree with the premise of the right to die movement: the elimination of unnecessary and meaningless suffering. Lavi traces the Christian outlook on pain as a means of explaining a chronology of thought on how America's attitudes towards assisted death has developed. He boldly claims that euthanasia can be understood as a modern art of dying, in that it provides hope in facing death, rather than denying death's imminent arrival (Lavi, 2005). Thus Lavi posits that by the 19th century, "the suffering of

dying was [considered] devastating and the medical profession was gradually seen as responsible for freeing the dying from such torture” (2005, p.62). This gradual realization simultaneously prompted both technological attempts to exceed limits of biological life and a method of “intervention that promises to end life with the least amount of suffering possible while giving people control over the process” (Gandsman, Herrington, & Przybylak-Brouillard., 2016, p. 3). It is clear that until recently the first attempt to master death, through medical extension of life, had been the dominant paradigm through which biomedicine reacted to suffering.

Lavi argues that the idea of a patient experiencing agony on their deathbed was not always believed in. He references British physician William Munk who in 1887 published *Euthanasia; or, Medical Treatment in Aid of an Easy Death* in which he asserted that the dying suffer no pain an understanding of suffering that was prevalent among physicians at the time (1987; Lavi, 2005). Since few could speak from beyond the grave, a whole new study of near death experiences was medically investigated in attempts to prove this hypothesis (Lavi 2005, p. 64). Although incorrect, Munk’s hypothesis challenged fundamental Christian beliefs that,

pain in general, and the pain of dying in particular, has had a privileged place within Christian belief. The belief in the redeeming virtues of pain, the idea that suffering individuals were closer to Christ, that their anguish could be offered in penitence for earthly sins, or even that God put only his elected few through terrible trails were recurrent themes throughout Christian literature (Lavi, 2005, p.65).

Munk’s hypothesis undermined the doctrine of Christian religions in attempting to establish a theory on suffering that not only devalued its importance, but questioned its existence.

An opposing theory, presented by doctor Samuel D. Williams, over a decade earlier in his 1873 essay “Euthanasia”, makes the first reference to a potential coupling of medicine with an

assisted-death procedure (Dowbiggin, 2005). Williams who according to Lavi was otherwise an unspectacular businessman, wrote in his essay that in cases “of hopeless and painful illness it should be the recognized duty of the medical attendant, when so desired by the patient, to administer chloroform” so to, “put the sufferer to a quick and painless death” (2005, p.4; Williams, 1873). Williams’ essay was largely rejected within the Western medical community based on its defiance of Christian morality since it embraced the notion that not all suffering has meaning and dismissed dominant beliefs in posthumous rewards for suffering in an afterlife. “Euthanasia” also went against the popular medical argument of the time, as highlighted by Munk, that the dying do not suffer. This is an example of arguments contrary to those of the Church that question the existence of suffering, and thus the foundation of the majority of religious institutions.

Lavi’s insightful contribution to the literature on assisted-death does not however distinguish between pain and suffering using them interchangeably. In doing so Lavi does not acknowledge the multi-layered and expansively distinct possibilities of human suffering as outlined by preceding social scientists (Young, 1997; Asad, 1997). Lavi neglects to consider the deeper social implications of suffering that extend beyond somatic symptoms (e.g. psychiatric, social or existential suffering), treating suffering as if it were solely based on pain. That being said, Lavi problematizes the legal-ethical preconditions of unbearable pain and hopelessness of improvement frequently required to be granted access to assisted-death. Such requirements of an undefined pre-condition reduce patients’ ability to make decisions concerning their end-of-life to a strict set of necessary circumstances (Lavi, 2005). Thus, the right to assisted-death cannot be said to reflect individual autonomy or self-determination because a patient’s ability to make the

choice to end their life might not match eligible circumstances for gaining access to such a procedure.

The historical narration of medicalized assisted-death lends to a greater understanding of how the right to die as a modern movement has grown to an attempt to divorce the coupling of dying and suffering. However, the existence of suffering is not exclusive to immediately impending death, especially with the possibility of radical life extension. Therefore, more recent inquiry into assisted-death goes beyond dying to establish at what point does life no longer become tolerable in relation to suffering.

(Un)Bearability⁸

The pre-condition of unbearable suffering, whether in terminal or non-terminal cases, is a requirement in Belgian end of life laws and also in most, if not all, countries who allow for assisted death, but with the added clause of imminent death (Herremans, October 2015). However, within the Benelux countries (Luxembourg, Belgium, and the Netherlands), irreversible and unbearable suffering are the only pre-conditions to being granted medical euthanasia (Wijsbek, 2010; Youngner & Kimsma, 2012). Unbearable suffering, at its most basic level, refers to a degree or condition that is so extreme that it is no longer tolerable to the individual experiencing it. The use of the term as a standard for who should be permitted to gain access to assisted-death and who should not has been problematized by some euthanasia practitioners who disagree with its standardization.

Certain Advocates prefer the term 'intolerable'⁸ as unbearable implies a threshold of suffering linked to a scale of severity as opposed to intolerable that reflects an individual's personal ability to handle the suffering (Bernheim 2015)

Although the anthropological literature speaks of various subjective forms of suffering that cannot fully be understood by another individual (Throop, 2015), the need to determine the bearability of suffering is based on practical implications. With the medicalization of assisted-death and unbearable suffering as the main pre-condition to gaining access to the procedure, necessity to create a method of determining who is eligible has become a point of major debate.

An international group of experts on end of life practices, including one of my participants Dr. Jan Bernheim, Professor of Medicine and member of the End-of-life Care Research Group based out of the Free University of Brussels, argue against this pre-condition as it implies that unbearable suffering can be objectively determined through forms of measure (as opposed to subjectively interpreted). Bernheim et al. believe that the subjective self-assessment by the patient is of the greatest importance in end of life decision-making (2014). Moreover, the article argues that currently there does not exist a properly developed measure for unbearable suffering and following the current model allows physicians to determine the validity and speak to the suffering of their patient.

The inability to measure suffering (besides various theories concerning the measurement of pain) is directly linked with the absence of a mutually agreed upon base definition of unbearable suffering. In his article, “The Subjectivity of Suffering and the Normativity of Unbearableness” Philosopher Henri Wijsbek focuses on the lack of a standardized conceptualization of unbearable suffering within the context of medical euthanasia. He contrasts this to the concept of irreversible or incurable suffering that can reasonably be determined by physicians in explaining that,

the absence of any prospect of improvement can generally be determined straightforwardly; it simply means that the condition underlying the suffering is incurable according to accepted medical standards and that there is no reasonable prospect of alleviating the symptoms. Unbearableness, on the other hand, is one of the most intractable elements in the practice and regulation of Dutch euthanasia. In view of the fundamental role of this criterion and the practical difficulties it tends to cause, it is surprising to find that the literature on this topic is virtually all but non-existent (Wijsbek, 2010, p. 319).

It is the pre-conditions of an observable form of both irreversible and unbearable that most often play a deciding factor in whether a patient is granted access to an assisted death. It is due to the importance of unbearable suffering as criteria of assisted-death that Wijsbek expresses his surprise at the lack of literature on unbearableness.

Wijsbek is not alone in complaining that there is a massive intellectual hole on the subject of unbearable suffering. One of my participants, Psychiatrist Dr. Lieve Thienpont, a specialist who provides consultation and administers euthanasia for those experiencing psychological suffering, acknowledges in a recent article that the concept of unbearable suffering has not been properly defined and exists in a state of flux (Thienpont et al., 2015). Dees et al. similarly argue that the concept of unbearable suffering lacks elaboration, claiming that “patients, physicians, members of the assessment committees, as well as the general public, politicians, philosophers, theologians, and ethicists constantly add their own perspectives” in formulating its conceptualization without any fundamental parameters (2010, p. 340). Therefore, the understanding of ‘unbearable suffering’ largely differs depending on what perspective it is being defined from.

Although at the time of this dissertation there does not appear to exist a history of the usage of ‘unbearable suffering’, the term first appeared in the 19th century. As early as 1874

“The American Journal of Medical Sciences” published a case, “surgical operation for the relief of unbearable suffering which the patient endured” (Maury & Duhring, p. 29). A few years later Professor of Medicine Thad A. Reamy wrote to the “Half-yearly Compendium of Medical Science” endorsing the, “value of chloral hydrate in certain cases of labor” especially when, “pains of cervical dilation produce unbearable pain” (1879).

In 1876, a short story titled *Ploughed by Moments* by Mary Cecil Hay was published in the literary magazine ‘Belgravia’ and referred to unbearable suffering through a non-medical lens. Hay portrays the tortured life of a man living through extended solitude in a small village bearing a deep dark secret. In the story the author writes that the character’s life had been “almost unbearable suffering of those 20 years” (Hay 1876, p. 109). Her reference to unbearable suffering provides a contextualization for the term’s use outside of a strict medical definition, and acknowledges of the distress of another’s life experience, which can be understood as existential.

The category of ‘unbearable suffering’ creates a dichotomy of severity between patients who are able to handle experiences of suffering and those who cannot. In a practical sense, the situation is complicated by the need for the patient to convince their physician of the degree of suffering they are experiencing although numerous social scientists, as reviewed in the previous chapter, have argued of the impossibility of adequately explaining suffering through language.

An understanding of unbearableness becomes complicated when the bar of what is considered no longer bearable is left unset and loosely defined. Therefore, physicians' subjective interpretations of another's suffering is the determining factor in absence of a form of measure within a discipline organized around objective forms of measurement.

In recent years, medical philosophers Youngner & Kimsma have argued that the existing definitions of suffering are in general too simplistic and narrow. They are often based on the patient's inability to tolerate great amounts of pain thus not adequately conceptualizing the multifaceted aspects of the experience (2012). Dees et al. go further stating that there are no mutually agreed upon definitions of what is meant by 'unbearable suffering' due to the multifaceted "medical, psychological, existential, and social dimensions" that provide varying motivations for such a state (2010, p, 350). Attempting to properly explain unbearable suffering, as the European Oncology Nurses Society cleverly wrote in their Fall 2010 newsletter, is the same as, "defining a concept with undefined parameters" (p. 30). Otherwise put, an attempt to embark on a mission to standardize an experience that by its own subjective nature cannot be universally conceptualized. Although a fluid definition provides a larger eligibility for who can access assisted-death, it also makes it harder for medical professionals to understand those implications and more importantly to recognize various manifestations of unbearable suffering.

The push to further explore the notion of unbearable suffering is predicated on the concern that medical professionals cannot properly identify all forms of suffering and therefore do not acknowledge the potential validity of a patient's request. Wijsbek questions how physicians are to appreciate the concept of 'unbearable suffering' within a medical system that provides limited guidelines; "one cannot look for the poles of the earth until one knows what a

pole is that is, what expression ‘pole’ means, and also what counts as finding a pole of the Earth” (2012, p.319). The emergence of euthanasia and assisted suicide laws in Benelux countries since 2002 has in recent years led to increased research projects focusing on the concept of ‘unbearable suffering’ within the context of assisted-death.

In the article “Concept of unbearable suffering in context of ungranted requests for euthanasia: Qualitative interviews with patients and physicians” Pasman et al. look at the Dutch euthanasia model, focusing on one of the six requirements that a patient must meet before euthanasia can be administered: unbearable suffering (2009). The study was based on interviews from patients who were either denied euthanasia or did not go through with their request. The article attempts to provide a representation of accounts on how these patients’ perception of their suffering reflected that of the physicians who presided over those cases, the goal being to find what discrepancies exist in interpretation of suffering.

Such studies on the perception of suffering are significant in relation to statements such as the Royal Dutch Medical Association’s mandate, claiming that, “unbearable suffering is not limited to physical suffering, the suffering must at least be recognizably unbearable for the physician, and unbearable suffering is subjective” (Pasman et al. 2009, p. 1235). This definition is equally as open-ended as it is ambiguous in providing guidance in acknowledging a state of ‘unbearable suffering’. Part of the study undertaken by Pasman et al. attempts to identify what unbearable suffering means to Dutch patients who had requested euthanasia, but who had either been denied or who had not yet had the procedure performed.

One of the patients interviewed in the study explained that, for her, unbearable suffering is the notion of being alive, yet not living and only being labeled alive because you are breathing.

She further elaborated that living for her was, “being part of everyday life. For instance, if I can read, see a play” (Pasman, 2009, p.1236). The inability to do activities such as reading can be considered an unofficial marker of when a person is truly experiencing unbearable suffering; where a patient’s ability to read has, not once, been used as a determining factor in physicians denying assisted-death (Herremans, October 2015). For most of the patients interviewed, pain was a part of their suffering, but not the factor that made it unbearable, rather they were more concerned with the social and psychological elements of suffering (consistent with observations by Allan Young who understood physical pain as being the catalyst or overlapping with psychological, existential and spiritual forms of suffering). Other patients explained that although their suffering was unbearable it was not consistently unbearable, allowing them to perform certain activities, however they still maintained a death wish.

In a research article co-investigated by one of my research participants, Dr. Lieve Thienpont focuses on how psychological suffering comes to be and examines its origins from both somatic or mental disorders. This significant research project since 2002 in the Netherlands, Luxembourg and Belgium has gradually interpreted psychological suffering as a valid legal condition for receiving access to euthanasia (Karlsson, Milberg, & Strang, 2012). The paper is the result of a study analyzing 100 cases of people who requested euthanasia in Flanders⁹ and Belgium between October 2007 to December 2011 (Thienpont et al., 2015). The study found, as mentioned earlier, that euthanasia requests were rarely based solely on physical pain, but based on the hopelessness of the situation. Moreover, the findings provided by Thienpont et al.

⁹ Dutch speaking region of the Netherlands

attempts to give legitimacy to the validity of unbearable suffering that is not rooted in pain, but that has a deeper existential and psychological dimension.

Dr. Thienpont's recently published book *Libera Me* (2016/2015)¹⁰, based on her own experiences as a physician specializing in euthanasia for psychological suffering and the testimonials of her patients, argues for a looser interpretation of unbearable suffering that is identified through listening to patients. In the forward to her book, Johan Braeckman, Professor of Philosophy at the University of Ghent, writes that,

In reality, however, all pain is subjective, no matter what its origin. It is experienced exclusively in the consciousness, irrespective of whether it is caused, for example, by a person's inability to cope with a grievous loss or by a somatic illness. This means that in essence there is no difference between physical suffering and psychological suffering (2016/2015, p.21).

His argument addresses the irrelevance of a division of suffering as either psychological or physical if they equally cause a person to lose purpose and no longer consider life bearable. The greater recognition of somatic suffering (as opposed to others) can be seen as an inherited biomedical philosophy that gives credibility to the seemingly objective manifestation of suffering.

Thienpont et al. further investigate the concepts of unbearable and untreatable suffering as a legitimate reason for assisted-death based on psychological suffering. They argue that unbearable suffering is largely understood as a subjective experience that is, "determined from the perspective of the patient himself or herself, and may depend on his or her physical and mental strength and personality" (2015, p. 2). The authors explain that, as defined by current

¹⁰ *Libera Me* is Latin from 'deliver me' or 'set me free'. The title is taken from the Catholic hymn traditionally sung before burial (Thienpont, 2016/2015, p.264).

laws within Belgium, the notion of whether suffering is unendurable remains to be determined between the physician and patient. The question of whether the medical condition is untreatable, on the other hand, is understood by the research team as an objective matter. All other reasonable treatments must be attempted on the patient prior to euthanasia for psychiatric suffering.

Thienpont et al. explain that alternative treatments must meet the guidelines set out by the Dutch Psychiatric Association, requiring first that the treatment must offer a real prospect for the patient's improvement. Second, the treatment cannot take an unreasonable amount of time before administration. Third, there must be a reasonable balance between expected treatment results and the strain it causes to the patient (Thienpont et al., 2015).

According to Thienpont et al. the concept of unbearable suffering is of significant importance for arguing in favour of psychiatric related euthanasia requests. The importance lies in establishing that the suffering of psychiatric patients can be equally unbearable as that of somatic patients. However, the main difference for physicians is that somatic suffering can sometimes be measured through brain scans (Brown et al., 2011) along with somatic symptom scales (Gierk et al., 2014), while psychological suffering is based on the individual's subjective interpretation of their experience.

In her book, Dr. Thienpont is skeptical of the efficacy of measuring somatic pain, adamantly stating that, "there are no effective tools to measure the intensity of physical or psychological suffering" (2015, p.54). She is therefore arguing that determining suffering comes from listening to the patient rather than technological devices. This approach has parallels to Arthur Kleinman's explanatory models (1988; 2013) whose purpose is for the physician to gain a greater understanding of what the patient is experiencing so as to validate their subjective

experience of suffering. However, whereas Dr. Thienpont advocates for listening as a primary method in determining suffering, explanatory models are described as being complementary to objectively diagnosing diseases.

In her book, Dr. Thienpont takes the argument even further by advocating that there should not be a distinction between physical and psychological forms of suffering (not requiring a pre-condition of disease or injury). In this way, existential suffering is given a clearer position within the euthanasia framework” (2015, p. 407). Thus, Dr. Thienpont is arguing that in fact all forms of severe suffering, whether psychological or physical, are at the core existential. However, existential suffering is rarely a recognized categorization for euthanasia and thus more pragmatic categorizations were required.

Following the arguments provided by Dr. Thienpont, assisted death requests for whatever reasons would have a deeper layer of existential suffering. In his article “To thine own self be true: On the loss of integrity as a kind of suffering”, Wijsbek indirectly identifies existential suffering in describing the account of a woman he refers to as Mrs. Boomsma, who lost both her adult sons and father within a short time span. Following these tragic events, Mrs. Boomsma was diagnosed with a “major depressive disorder, single episode, severe, without psychotic features, as part of a complicated bereavement process” (Wijsbek, 2012, p. 2). Due to both the extended length of her suffering and her life’s loss of significance, she requested assisted-death. The existential aspect of her death, surpassing temporary grief, is based in the meaninglessness that Mrs. Boomsma felt towards the continuation of her life.

Mrs. Boomsma’s situation resonates with Professor of Public Health and physician Eric Cassell’s understanding of suffering as occurring, “when an impending destruction of the person

is perceived; it continues until the threat of disintegration has passed or until the integrity of the person can be restored in some other manner” (1991, p. 33; Wijsbek, 2012; Kimsma, 2012). It represents a state of distress that eats away at elements that compromise personhood. Cassell’s conceptualization of suffering incorporates more than pain and sadness, but goes on to acknowledge suffering as an attack on an individual’s personal sense of self. This view of suffering can be further understood in relation to what Dr. Balfour M Mount considers the, “opposite extreme [of unbearable suffering] a sense of wholeness, personal integrity and inner peace” that are often considered attributes of a good life (2003, p. 40). The understanding of existential suffering as the overarching reason -encompassing other forms of suffering - can still be considered a minority perspective within the greater right to die movement.

The concept of unbearable suffering is can be considered a slimy snake in that it is ever elusive and very difficult to pin down. Right to die advocates themselves have various definitions of what can be considered unbearable and thus directly indicative of the validity of suffering. Advocates more open to a looser interpretation of unbearable suffering consider it a term referencing a vast array of subjective experiences that otherwise cannot be put into language. The purpose of keeping unbearable suffering open-ended is not to pigeonhole subjective experiences of suffering into a normalized standard that falls into the dominant medical paradigm.

Medical Gaze:

The quest to gain a deeper conceptualization of how physicians perceive suffering has emerged through interdisciplinary works in direct relation to the right to die’s entry into the

medical framework. In places where assisted death models appear through the health system, doctors are given the role of gatekeepers to the access of legitimated death. Therefore, literature on suffering attempts to understand how medical practitioners as decision makers understand its manifestation and more importantly how physicians perceive unbearable suffering.

Physician and Medical Philosophers Youngner & Kimsma argue that the current methods of assessing suffering are not representative of patients' needs and impose a system of medical paternalism. In their article "Assessment of Unbearable and Hopeless Suffering in Evaluating a Request to End Life" Youngner & Kimsma follow up on a recommendation presented by the KNMG (Royal Dutch Medical Association) urging euthanasia evaluations to focus more on patients' experiences and less on perceptions of medical professionals (Youngner & Kimsma, 2012). In doing so they attempt to integrate a joint (patient and physician) perspective that ideally leads to a mutual understanding on whether assisted death should occur. As discussed later in the chapter, Youngner & Kimsma use this recommendation as a springboard to further investigate how Dutch practitioners have conceptualized suffering in relation to euthanasia.

In a similar vein, anthropologist Frances Norwood conducted her fieldwork in the Netherlands while euthanasia and physician-assisted death were in the process of legalization.¹¹ In her book, *The Maintenance of Life: Preventing Social Death Through Euthanasia Talk and End-of-Life Care - Lessons from the Netherlands*, Norwood discusses the expectation for Dutch doctors to determine whether a patient is experience both a lasting and unbearable suffering - referring to it as the mandating of an "impossible task" (2009, p. 148). She further argues that

¹¹ Norwood performed her fieldwork in 2001-2002

unbearable suffering cannot be translated into objective measurement and is therefore difficult to determine.

Norwood observes that the presentation of unbearable suffering, or *ondraaglijk* in Dutch, can be a major determining factor for whether a patient is granted access. The manner in which euthanasia is requested must convince the physician of unbearable suffering. Norwood observed that this made it harder for those claiming psychological suffering to access euthanasia since it is not always acknowledged as unbearable or even a valid form of suffering. This most often affected categories of suffering whose validity cannot always be understood such as older generations who claimed to be 'weary of life'¹² or immigrants who were not as well versed in Dutch and therefore were often excluded from the discourse (Norwood 2009). Meanwhile Norwood points to cancer as the ideal disease for determining unbearable suffering due to predictable symptoms of decline, pain and discomfort.

The behaviour of patients as viewed by the medical practitioner plays a large role in determining who will be deemed eligible for assisted death requests. Pasman et al. interviewed Dutch assisted-death practitioners in order to determine why certain requests had not been accepted; he examined what patient behaviour tended to be considered incompatible with unbearable suffering, such as a sense of humour or physical fitness (2009). These situations can be compared to the previously mentioned example of a patient reading and thus are not considered to be suffering severely enough.

¹² Also known as 'tired of life' refers to those "who wish to terminate their worldly existence because of the declining quality of that existence, caused, for example, by increasing lack of mobility or an increasing dependence on others" (Thienpont, 2015, p. 292). Although usually requested by elderly individuals it is not necessarily restricted by age.

Such examples can be understood in relation to the concept of ‘the sick role’ that permits the patient to be excused from regular activities and communicates abnormality of the situation to the medical practitioner (Ember & Ember, 2004, p. 201). Therefore a patient who does not appear to be exhibiting the appropriate ‘sick role’ may be suspected of not actually experiencing suffering.

Pasman et al. in their study discovered that a majority of physician participants admitted that signs of physical suffering were taken more seriously in determining unbearable suffering than those not somatic (2009; Karlsson et al. 2012). The article recommends, similarly to the KNMG, that physicians should move past a strict definition of unbearable suffering that does not take into consideration the subjective nature of suffering. The authors further ask: how can patients consider their suffering to be so severe that they no longer wish to live, but not consider it to be unbearable?

In Dr. Bernheim’s co-authored article with other assisted-death experts, an attempt is made to respond to commonly misunderstood questions concerning euthanasia. One of the main questions within this article is: “How do doctors feel after performing a euthanasia?” The article responds by providing accounts of physicians accompanied by a sense of satisfaction due to having relieved a patient from suffering or in the reduction in anxiety that accompanies the promise of euthanasia, should there be need of it (Bernheim et al., 2015). Following Bernheim et al. and Pasman et al. it appears that physicians’ attitude toward performing an assisted death procedure can be directly linked to their own conceptualizations on suffering.

In acknowledging that suffering is understood subjectively and therefore different based on who the suffering subject may be, Youngner & Kimsma argue that people in the West have

fashioned a collective understanding of what suffering looks like based on mediatized representations of extreme human misfortune and pain (2012). Youngner & Kimsma's assertion has strong parallels to the writing of Kleinman & Kleinman (1996) which does not consider mediatized depictions of suffering as accurate of one's suffering because they depict misrepresentations of a decontextualized experience. Mediatized representations of human misfortune, generating a popularized understanding of suffering, create an environment in which it becomes easier to deny the existence of distress that does not appear to meet those same representations (Youngner & Kimsma, 2012).

According to Youngner & Kimsma, the denial of suffering represses the emotional anxiety that occurs when humans confront another's vulnerability and mortality (2012). Human attempts to minimize suffering creates "a formidable obstacle to accurate moral understanding. It leads us to underrate the evilness of suffering, and consequently the urgency of eliminating it" (Youngner & Kimsma, 2012, p. 339). Those who deal with suffering on a frequent basis such as physicians can sympathize with suffering to an extent, however there are still differing views within the right to die community on what unbearable suffering looks like and how it should be dealt with.

Cassell further elaborates that attempting to have empathy for another's suffering has different implications than analyzing medical data since it requires an emotional commitment (1992). However, the degree of empathy and level of awareness required to properly assess a patient's suffering is a topic of debate within the medical profession. Following the precepts of Cartesian dualism, biomedical practitioners have been taught to separate the body and mind in medical assessment. Cartesian dualism within biomedicine works against the notion of non-

visible suffering since it cannot be objectively measured and relies on subjective patient accounts. The integration of Cartesian dualism within biomedicine still dominates physicians' attitudes in favouring an 'objective' form of empirical inquiry characterized by "unbiased, impersonal and unsympathetic observation and measurement" (Mehta, 2011, p. 2). Objective diagnosis is thus still largely considered the most effective medical technique that attempts to distance the practitioner from the patient's lived experience in the belief that this will provide an unbiased assessment.

Attempts to bridge the gap between objective medical attitudes towards suffering and patient subjectivity can be found in the 2007 Annual Report of the Dutch Euthanasia Review Committee (ERC). The report writes that a physician's consideration for euthanasia must satisfy two conditions: the presence of a patient's voluntary and reflected upon request as well as unbearable suffering without prospect of improvement (Youngner & Kimsma, 2012). Here Kimsma draws attention to the Dutch word *invoelen*, which he believes is crucial in attempting to understand Dutch physicians' conceptualization of suffering. *Invoelen*, for which there is no direct English translation, means "to grasp and understand intuitively and rationally after identifying with the object of perception" (Youngner & Kimsma, 2012, p. 336). This term is used to underline how the review committee perceives the importance of the physician-patient relationship in pursuing euthanasia.

Furthermore, the Euthanasia Review Committee's 2007 report problematizes its own conceptual framework of 'the person in medicine'; a term describing how a human is comprised of physical, mental, social and existential aspects in forming personhood. The ERC further states

that human interpretation of suffering is subjective and as such is beyond the comprehension of others. The report goes even deeper and boldly claims that,

the medical concept of the human being is in itself sufficiently broad and abstract to identify the most common symptoms of disease and abnormal behaviour, but it is too limited to help us understand all the main elements of a phenomenon as complex as suffering. Finding a definition of suffering means describing an experience that involves a threat to intact existence and the decay or disintegration of the personality (ERC, 2007, p.17).

In arguing that suffering is never limited to objectified or medically contained understandings, the report expresses an acknowledgement of existential anguish that is linked to human expectations of future purpose (2007). The perceived loss of meaningfulness cannot be divorced from patients' understanding of unbearable suffering.

The ERC's report emphasizes the unfeasibility of tightly defining suffering so as not to create an exclusionary framework and establish a puzzle of never-ending ambiguity. As a result, right to die advocates appear to be stuck in a double-bind in which they are attempting to make aware the existence of suffering that often cannot be properly communicated, understood by another, nor measured with modern medical methods, yet must be accommodated within the healthcare system in allowing assisted death. The right to die movement can be considered as the antithesis of Weber's version of theodicies which promotes faith in something better that awaits as a justification to present suffering. In fighting for access to legitimized mastery over death, advocates support the embrace of not being able to know the unknown so as to alleviate present or anticipated suffering.

Right to die advocates' response to suffering which attempts to take control over death and personal agency, raises questions around both meaninglessness of suffering and how life can

be considered no longer worth living due to that suffering. The complexities of this response become further entangled when put into a framework requiring physicians to determine what constitutes unbearable suffering (a term lacking concrete definition or tangible criteria) that qualifies for assisted-death. The incommunicability of suffering and the inability to fully understand, as discussed in both chapters one and two, additionally add to the challenge of establishing the existence of something that cannot be objectively measured.

Attempts to gain a deeper understanding of the ever expanding and subjective experience of suffering along with how such suffering can be recognized and appropriately validated continue to be debated. According to Youngner & Kimsma, a more general response to the problem of human suffering must be informed through an inquiry into ‘moral anthropology,’

that recognizes humans as beings who live in time, have awareness of time and future, and are composed of both a body and a mind that interact in many ways; it must recognize humans as both individuals – persons who have their own ways of experiencing the world – and beings who interact with others and whose lives involve a social context (2012, p. 342).

This approach is a proposed attempt to address suffering as universal among humans, yet distinct in experience and interpretation; it proposes a case by case response to individual suffering.

Youngner & Kimsma’s callout to be informed by ‘moral anthropology’ is similar to anthropologist Nancy Scheper-Hughes assertion to call on anthropology to address misconceptions about suffering. In doing, it would establish situation specific methods for dealing with unnecessary suffering (e.g. reconciliation in post-apartheid South Africa). However, Scheper-Hughes also draws attention to what she understands to be the source of suffering violence.

Other anthropologists have come to similar conclusions as Scheper-Hughes concerning suffering emerging from violence. Wilkinson & Arthur Kleinman, in exploring the unequal distribution of suffering, elaborate on the concept of social suffering which has become an analytic tool used to explain suffering resulting from situations of disparity (2016). Paul Farmer also combines the concepts of structural violence and social suffering in writing about his field research in rural Haiti to explain why the poor are more likely to be in situations of suffering. Veena Das writing on violence resulting in negligence in the aftermaths of major disasters in Vietnam and India, elaborates what extent the incommunicability of suffering can cause consequences in healthcare, and in legal and political matters concerning victims. Furthermore, Das unpacks how the absence of theodicy to provide a justification has led to the development of sociodicy which explains suffering as a necessary evil for human progress.

These anthropological inquiries, although on different circumstances and subjective experiences of suffering, are attempts to understand various responses to the problem of suffering. The right to die movement, through mastery over death and respect for personal agency, is a response to the perennial issue of suffering where the unexplained evil of suffering can be accepted as being exactly that - an experience that can be unnecessary and meaningfully useless.

CHAPTER THREE: ADVOCATES' PERSPECTIVES: WHAT IS MEANINGLESS SUFFERING?

Following the first two chapters outlining the literature on 'anthropology of suffering' and analyzing 'assisted death and suffering,' this third chapter shall examine these two subjects in the context of my own fieldwork which took place in Ontario, Quebec and Belgium. The purpose of this chapter is to provide an understanding of how right to die advocates that I met with conceptualize assisted death as a response to suffering, and furthermore to position suffering as an argument for assisted death. In this chapter, I will make frequent reference to right to die advocates who are the participants in my fieldwork and supporters of current or expanded legal forms of assisted death. This chapter will also make reference to assisted-death practitioners who are not only advocates for the right to die, but act as healthcare professionals performing end of life procedures.

The subject of suffering in assisted-death, as described by advocates, has many complexities and often lacks a general coherence due to the interconnected nature of the debates. Therefore, to best represent my participants, I have chosen to organize this chapter into five sub-sections: *Observing suffering*, *Validity of suffering*, *Subjectivity of suffering*, and *Meaning(ful/less) of suffering*. Through these sub-sections, my goal is to give my reader an understanding of how advocates in Belgium and Canada are currently conceptualizing suffering in relation to assisted death.

Section one of this final chapter entitled *Observing suffering* explores how right to die advocates I met view the suffering of others and what experiences compelled them to ultimately involve themselves. Furthermore, it touches on how advocates, specifically assisted death practitioners, relate to the act of ending a life, and the importance of patient/doctor relationships.

The relationship, differing from familial support, is predicated on the physician's medical advice regarding a patient's suffering so as to help the patient make an informed decision concerning whether to pursue assisted-death or not. The second section entitled *Validity of suffering* problematizes the notion of measurable suffering as an experience that cannot be quantified or measured. Through analyzing the debates within the movement on who should have access to assisted death, it dissects the validity of certain forms of suffering over others as well as explanations regarding such arguments. Section three called *Subjectivity of suffering* will examine how right to die advocates conceptualize suffering as being a purely personal experience grounded in an intersubjective or common discourse. This part will also lend voice to how advocates for assisted death are pushing away from a paternalistic form of medical intervention.

The fourth section *Meaning(ful/less) suffering* looks at the underlying notion shared by all right to die advocates that some suffering is useless and its presence outweighs maintaining a life at all costs. This section will furthermore examine the forms of suffering that are perceived to be meaningless by advocates.

Observing Suffering:

How can the observer understand another's suffering? This question is if we consider the two previous chapters paradoxical in nature. Understanding another's suffering implies a level of subjective empathy allowing to feel the other person's experiences. Such a level of empathy would need to be somehow communicated from the sufferer to the observer, however

attempts to transmit experiences of suffering have been deemed incomplete and can misrepresenting, as discussed in the two previous chapters (Arendt, 1968; Weber, 1958 Kleinman & Kleinman, 1996; Wilkinson, ND; Kimsma, 2012). Despite the inability to accurately measure (Thienpont, 2015) or understand another's experiences, there continues to be an ever-growing global movement that believes in recognizing such forms of suffering.

In the first few days of August 2015 I met Marcel Boisvert, a retired physician from Quebec, outside a closed café in the Place des arts complex in downtown Montreal. I soon learned that the doctor had spent nearly an hour arriving at our rendez-vous point for our meeting as he lived off the island an impressive feat given he was in his mid-80's carrying with him an immense stack of documentation and books that he brought to show me. Sitting at the back of a Montreal café, Dr. Boisvert explained to me how, "having our life prolonged is a poisoned gift" (August 2015). By this he means the technological ability to extend human life has led to unforeseen outcomes that may in fact cause more suffering (an argument similar to that of Kaufman's that attributes technological innovation to the origins of assisted-death politics). Boisvert's sentiment echoes that of another research participant, Canadian Member of Parliament Steven Fletcher (now a former MP), who passionately states,

people are living much longer with ailments that we never encountered in the evolution of the human species. And for the most part this is a good thing, because you know, we've doubled life expectancy from 40 to 80 and it may increase by another twenty years by mid-century. You know, your grandkids can probably expect to live to 100. But there will be, when you do that, there's also more risk of encountering situations where the extra years are just insufferable. Like, I make a very important distinction between life and living. I want to live life. Life is just a form of existence (January 2015).

Fletcher, who has been a quadriplegic since his early 20's due to an automobile collision with a moose, is open about his commitment to quality of life over quantity. His distinction between life and living encapsulates Boisvert's comment that extending life at all costs can be an undesirable gift.

Fletcher's statement points to a concern, shared by a majority of my participants, that prolongation of suffering often accompanies medical extension of life, and therefore an alternative needs to exist (Desmet, October 2015; L'Esperence, August 2015). Since biomedical innovation that allows for a longer life is generally considered a positive advancement, right to die advocates had to re-conceptualize such advancements in relation to its potential to cause unforeseen suffering. Therefore, the perceived intolerable suffering of others (in whatever capacity) can be found in the arguments of my participants *the right to die* could just as easily be called *the right not to suffer needlessly and meaninglessly*. The variance in what is meaningless and needless suffering is a topic of internal debate within the movement, yet there is a general consensus among my participants that life extending medical technologies often lead to patient suffering.

The right to die advocates I encountered could often point to a defining moment in their life when their way of viewing the suffering of others became more patient focused and moved away from paternalistic medical attitudes. Dr. Gerald Ashe, a physician living near Ottawa and closely affiliated with Dying with Dignity Canada, explained to me and my co-investigator Elijah Herrington when his advocacy began. For him, becoming involved with a right to die

organization came after one of his patients, in the later stages of ALS¹³, requested withdrawal of treatment and a morphine drip to reduce physical pain. During the interview, Dr. Ashe expressed that for him this was a major turning point in how he conceptualized suffering and when he, “realize[d] that...you know, how can you really help a person who is suffering and has...no other available outlet. I mean he was at the point that he couldn’t have committed suicide” (January 2015). Having witnessed this situation in which his patient could not access euthanasia and was forced go through a withdrawal of treatment to die changed the way he thought about assisted death.

I followed up by asking Dr. Ashe if he would be willing to perform euthanasia for all forms of suffering. He responded by placing himself in relation to the right to die organization Final Exit¹⁴ and further explained that he supported the right to die for non-terminal reasons as he believes it to be an individual decision. Dr. Ashe reflectively attempts to clarify,

I’m not there yet. You know what I mean? I’m not, I’m a physician. I want to help people right now with terminal disease that we know they’re going to suffer. Those individuals are tired who feel that their useful life is over. And I can, I certainly see that everyday in my practice where you see elderly people who have multiple illnesses. They’re not, maybe not physically suffering, but they are emotionally diminished, you know (January 2015)

Dr. Ashe’s understanding of who should be granted access to assisted death, and therefore his conceptualization of what types of suffering have merit, did not reflect upon his willingness to provide an assisted death in all cases (at least not at the time of the interview).

¹³ Amyotrophic lateral sclerosis (ALS) also known as Lou Gehrig's disease. Is a physically debilitating neurological disease.

¹⁴ Final Exit is an American right to die organization that advocates for very limited restrictions on assisted death access.

I understood his response as being intellectually open to the idea of intolerable suffering taking place in non-terminal forms, yet personally not being comfortable with performing assisted-death in those circumstance (ex: due to psychological suffering). This discrepancy between degree of advocacy (in what circumstances assisted death should be available) and type of suffering (when they themselves are willing to perform the euthanasia procedure) can be understood on a range depending on the participants - trying to pigeonhole them into two distinct categories would be useless.

I first met Dr. Desmet through a referral from another Belgian doctor involved in the right to die movement. Dr. Desmet could be considered as an rather uncommon right to die advocate (he does not believe he is one at all) as the head of a palliative care unit who does not perform assisted-death procedures on principle, yet he has given his approval and overseen euthanasias. His puzzling involvement (and implied support) for assisted-death based on principles of compassion in the face of suffering while simultaneously actively representing the Catholic church (an institution whose stances on the redemptive value of suffering are in opposition to the right to die) initially complicated my view of a right to die advocate.

When I asked him his reasons for deciding not to perform assisted-death procedures, he first joked that as a Catholic Priest, performing euthanasias would be a scandalous move. However, his more earnest answer reframed my entire question. He responded, “reasons, maybe reason is a limitation or a certain way of asking the question. I think in the first place it is something existential” a statement that he contextualized by providing an anecdote of how his conviction not to practice assisted-death was tested. A few years earlier, a close friend of Dr. Desmet’s had personally asked him to perform her euthanasia and he was torn by the request. To

him his friend's request represented an ethical quandary since he was not opposed to the practice, but he still had misgivings about ending someone's life. In the end he found another doctor who was a stranger to her, but Dr. Desmet attended the procedure off-duty. Dr. Desmet's willingness to acknowledge suffering in others that he may not understand, yet his refusal to perform the act himself provides a deeper level of complexity to how certain advocates conceptualize suffering.

During our interview, Dr. Desmet explained that rather than see himself as a right to die advocate, he considers himself neutral on the topic of assisted-death but takes suffering seriously. He elaborated on his rationale stating that as a Jesuit he finds the issue of euthanasia, "more interesting than the simple response that it is forbidden to kill people who are demanding [assisted death] because they are suffering" (Desmet, 2015). For him it is more beneficial to take suffering seriously, which, "means a lot, it means not only taking [into account] the suffering of the individual, but also requires you to take into account the fact that in a society many many people suffer" (Desmet 2015). Dr. Desmet's perspective on suffering extended not only to individuals but expanded to view the greater social ramifications of patients not being allowed to make the choice themselves. Following my meeting with Dr. Desmet I became increasingly aware of the infinite and seemingly minute distinctions in how right to die advocates conceptualize meaningless suffering.

Dr. Desmet broke the rules of how I imagined right to die advocates to conceptualize suffering since as a Jesuit priest, it is unlikely he believed in a post-theodicy existence. Rather, from my understanding, Dr. Desmet simply disagreed with the Catholic notion that suffering has redemptive qualities that bring one closer to God. Therefore, for Dr. Desmet the belief in the existence of meaningless suffering was not mutually exclusive to being a practicing Catholic.

During my fieldwork I realized that assisted-death practitioners who are often right to die advocates had a separate experience, not only supporting the principle of belief in access to assisted-death, but distinguishing their personal comfortability with ending human life. Some practitioners such as Dr. Jan Bernheim, a retired Professor of Medicine at UZ Brussels and one of Belgium's first assisted-death advocates, personally felt that euthanasia can be compared to delivering a baby (as mentioned in the introduction) (Bernheim, 2015). Dr. Bernheim's perspective took into account that death is inescapable and that certain individuals will no longer wish to continue suffering. This view values the importance of appreciating a life well lived and dignified death over the loss of life.

Although assisted death procedures have been portrayed as satisfying for the practitioner who is liberating the individual, other doctors describe the experience differently. For Dr. Desmet, euthanasia requests he has received have at times felt overwhelming and demoralizing, especially when he it seemed that, "everyone wants to die" (2015). In such situations he has tried to remind himself that the wish to die is how, "people express their existential spiritual [suffering] in our culture" and is thus important to take seriously (October 2015). This worldview sees the loss of significance in life as a form of existential despair that often comes about through somatic or psychological forms of suffering. Thus, Dr. Desmet understands requests for assisted-death as symptomatic of severe human suffering, resulting from various circumstances, he believes they need to be taken seriously by medical practitioners.

As an assisted-death practitioner, Dr. Thienpont, provided me with a more nuanced answer to the question of how performing a euthanasia procedure affected her. She explained that

it depends, but usually her primary feeling was relief. Dr. Thienpont elaborated this answer stating that,

performing a euthanasia is [about] the patient themselves, but also the family, because it is the end of a long story of suffering, and more suffering. Even parents who are able to let go of their child in peace and love, because they saw for years how bad the suffering was, but of course there are always mixed feelings as it is also a sad moment when people say goodbye and often I am crying too, just by standing there, but most important is the relief also afterwards I feel peaceful (Thienpont, October 2015).

Her response is ambivalent, since on the one-hand it provides a deliverance of relief from an unimaginable form of suffering that cannot be empathized with by others (at least not according to the current anthropological literature), yet the elimination of suffering through assisted-death is inevitably accompanied by the end of life. Dr. Thienpont clearly understood this less than ideal pairing of liberation from suffering and death. This is why she insists that euthanasia requests have to genuinely come from the patient. Also, there needs to be a clear assertion of an individual's wish to take control over their suffering through death.

During my interview with Dr. Thienpont, she explained that the genesis of her involvement with euthanasia emerged from her time working in the psychiatric unit of a hospital where there were patients who felt “that there is no solution anymore, that they could not get better anymore and that their quality of life was no longer human” (October 2015). Dr. Thienpont and her spouse, Professor of legal ethics Dr. Tony Van Loon, believe that not all people experiencing psychological suffering can be adequately treated (October 2015). This realization led to their creation of ‘The Vonkel’ (meaning listening house in Dutch), a clinic that

provides consultations for those interested in the ‘euthanasia question’ along with support for patients and their family before and after the procedure.

Dr. Thienpont’s emphasis on doctor-patient relationships, predicated on listening to the patient, is meant to facilitate medical consultations that serve to inform the patient of possibilities rather than dictate a form of treatment for them. Emphasis on listening to patients was supported by the vast majority of advocates I encountered. This held true for even more controversial members of the assisted-death community. Such is the case with Dr. Marc Van Hoey who I met in October 2015 at his medical cabinet in downtown Antwerp.

Dr. Van Hoey is a physician who began his career studying tropical plants in numerous South American countries before going to work in Geriatrics, where he encountered people who were facing slow and debilitating diseases. Having witnessed extended suffering of the elderly, he became convinced that, “people should have a greater self-decision right and be able to decide what is going to happen to their lives” (Van Hoey, October 2015). Dr. Van Hoey has become controversial within the Belgian right to die community due to his ideological belief in minimal limitations to accessing medical euthanasia and has thus performed euthanasias that other practitioners do not approve of, notably that of Hugo Claus¹⁵.

During my interview with Dr. Van Hoey, he highlighted the importance of a doctor-patient relationship so as to better understand the sufferer’s experience. He elaborated, “if I am 95 years [with] multiple small diseases, but I have had it with my life; in those cases I think it is

¹⁵ Hugo Claus was a Belgian writer whose euthanasia was performed by Van Hoey for dementia. It was controversial among advocates since there was a belief that his procedure was done too early and that Claus could have lived longer in a state of lucidity. A few weeks following our encounter, Dr. Van Hoey became the first assisted death practitioner in Belgium to have the Federal Euthanasia Commission disagree with one of his decisions (Hamilton, October 29, 2015).

important to consider the relationship between the doctor and his patient” (Van Hoey, October 2015). As I had never heard of euthanasia for numerous minor ailments, commonly referred to as ‘weariness of life’, I asked Dr. Van Hoey how did this meet the legal standards of ‘unbearable suffering’. To which he bellowed, “who should decide, who should be the judge in saying what is unbearable! Incurable: that is something you can easily judge as a doctor, but unbearable, who is to be the judge? Is it the doctor or is it the patient or are you going to discuss it together” (Van Hoey, October 2015). From this strong reaction it became clear to me that the concept of unbearable suffering for Dr. Van Hoey was based on the patient’s individual and subjective criteria that neither should nor could be externally determined without undermining its validity. This is conceptualization of suffering is entirely understood through the patient’s perspective.

The shift in attitude noted by my participants delineated a conscious effort to move away from a paternalistic centred mode of medical practice to one more focused on consultation. Right to die advocates in distancing themselves from past top-down principles of medicine do not consider their practice any less valid, if anything they perceive it to be more effective in aiding the patient. As Dr. Boisvert explains, “doctors cannot define themselves without looking at other individuals” and thus in accepting assisted death, “are not renouncing their principles, but rather are looking compassionately at others, which may force me to do something that I do not want to do. However, I feel an obligation to perform the act in order to help my patient with whom I have a bond with” (August 2015). Boisvert’s comment delivers a pointed critique of past attitudes toward doctor-patient relations, arguing that medical focus should be on the will of the patient as opposed to the abstract knowledge of the medical establishment. Boisvert’s argument can be understood in relation to previously cited Younger & Kimsma (2012) who believe that current

methods of accessing suffering and recommending treatment are not consistent with patient's best interests.

The notion of doctor-patient care and personal autonomy can thus be understood as the reversal of principles that were foundational to clinical medicine. Although relief of suffering is the purpose of medicine, it became secondary to the objectification of body parts and their treatment. The strong emphasis on patient-centred care can be understood as a response to what Foucault describes in *Birth of the Clinic* as the 'medical gaze'. The 'medical gaze' is characterized by the emergence of clinical care in the 19th century along with an objectification of human suffering that embraces a mind-body dualism (Fouacalt, 1994/1963). Right to die advocates who acknowledge the deeper dimensions of suffering through placing priority on the patient-doctor relationship can be understood as dismantling medical attitudes of objectification and paternalism identified in the 'medical gaze'.

Boisvert goes a step further to argue for the benefits of medical practice based on collaboration, explaining that, "the bond between doctor and patient is crucial, as both members are autonomous and need to work together to make a decision" (August 2015). His emphasis on autonomy reflects a consideration for the subjective nature of suffering that, as believed by other advocates, should be only determined by the patient. However, the belief in suffering as a subjective experience based on personal frames of reference and thus only understood by patients themselves is still contested, even in places where assisted death has been accessible for some time.

Subjectivity of Suffering:

The concept of suffering is considered by right to die advocates as being subjectively understood and interpreted, thus creating the need for believing the patient's narrative.

Anthropological literature concerning the subjectivity of suffering has been touched upon in chapter one (Throop 2015; Klienman 1998, 2003) along with interdisciplinary research found in chapter two (Wijsbek 2012, Pasman et al. 2009). In this chapter, the subjectivity of suffering will be addressed in relation to how right to die advocates understand the suffering of others and in opposition to the approach of medical paternalism. That being said, even within the right to die community, differing understandings exist as to what conditions merit access to assisted death.

Assisted-death laws, more often than not, lean on the concept of patient autonomy that shifts away from medical paternalism or a 'doctor knows best' attitude. During our interview, Dr. Boisvert recalled how when he first started working as a physician, older medical professionals would authoritatively insist treatments without considering listening to the patient's perspective. He explained that this attitude was so prevalent in the medical community that, "It took me five years before I felt a certain discomfort towards the way we dismissed the patients' perception of their experiences" (Boisvert, August 2015). This arrogant attitude does not lend much credence to certain forms of suffering that cannot be understood, creating a lack of belief in the patient's narrative.

Stories of medical paternalism that leave patients in situations of extended suffering are prevalent among my participants who would passionately speak against such attitudes. Pierre Vincke, whose daughter Edith died of suicide after being repeatedly put in psychiatric institutions, and was quite open about her intention to end her life and angrily recounted to me

the story of having met a psychiatrist who spoke dismissively of his patients' perspectives. Vincke remembered that, "after listening to him for about fifteen minutes I realized that he was speaking from his point of view and at no point did he mention the point of view of the patient" (October 2015). When Vincke asked about the patients' perspectives, the psychiatrist replied, "if only you knew all that the patients told me, they are sick and should not be listened to" (October 2015). At this point in our interview Vincke was clearly quite distressed and paused for a moment before explaining that it pained him greatly to think that such attitudes were still prevalent within psychiatry, and that his daughter's request for euthanasia, based on psychological suffering, had not been taken seriously.

Prior to the change in Belgian law in 2002, the medical system maintained a life at all costs model of healthcare that did not officially allow patients to be granted assisted death. Dr. Lieve Thienpont spoke with what I would characterize as sorrow about time before the law. She recalled how patients had been asking for euthanasia,

I remember a woman. She was at the exit of the hospital sitting there and every evening she would ask me 'when will you help me to die?', every evening. We could not do more than what we did for here and the quality of life was very low, very very low. Every evening she would ask and I would say, 'I can't, I really can't, but I want to inside me' and so she jumped off the tower in town. We had many such situations and it has touched me very much because I believe that jumping off a high building or jumping in front of a train or hanging yourself or drinking something or taking pills are not dignified [death] (Thienpont, October 2015).

For Dr. Thienpont and Dr. Van Loon, the need to listen and acknowledge another's suffering is paramount to guiding a patient through their options and working together to find the most suitable form of treatment. Pierre Vincke, who met them following the death of his daughter, claims that speaking to Dr. Thienpont was the first time he, "felt truly listened to as a father who

had lost his daughter” (October 2015). The notion of listening becomes incredibly important following an extended history of medical paternalism towards patients. Johan Braeckman, Professor of Philosophy at the University of Ghent writes in the forward to *Libera Me*,

the medical practitioners were the only ones who possessed the necessary knowledge to heal, and they applied this knowledge without consulting the patient. Paternalism and patronization were the order of the day. Patient participation and self-determination were almost non-existent (Braeckman, 2016/2015, p. 28).

Listening is meant to work against this model of medicine by not only placing greater emphasis on doctor/patient relations, but also by putting greater trust on the patient’s ability to decide for themselves.

Similarly, Dr. Gerald Ashe disagreed with medicine as solely being tasked to keep patients alive at all costs. For him, “medicine is often about dying, because everybody is going to die and there are many, many times when we just don’t have the ability to heal. So it is not all about getting people better. It’s about looking after people and getting them through whatever it is at that time” (January 2015). What Dr. Ashe described is a fairly contested position within the medical community, but one shared by most right to die advocates to varying degrees. They believe not all conditions can be remedied and attempting to do so may cause increased suffering, rather than relief from it.

Dr. Ashe’s quote can be directly traced to a critical medical outlook (or in-look) who consider the need to move medicine towards greater patient centred care. Similarly, Dr. Desmet explained to me his observations relating to this transition within biomedicine. From his experiences, working with dying patients he related that patients and doctors, “used to have a holy respect for the will of God, and now the will of God what is that? It shifted to the will of the

patient. There is a kind of reverence” towards their wishes, even if that means an early death (Desmet, October 2015). Dr. Desmet’s observations add another layer of context of past medical paternalism steeped in moral values stemming from Christian ideology. Therefore, it is unsurprising that in large, opposition to assisted-death and greater patient autonomy comes from religious organizations.

For Dr. Ashe understanding individual patient perspectives was necessary to discern the distinctive experiences of suffering. In his words, patient suffering,

can be very subjective, but there still has to be a discussion with that individual about how they’re suffering and why they want to end their lives. Like, when you talk about mental illness it is a really tough one. But there are some people with mental illness, depression in particular, who don’t get better. Horrible lives. Horrible depression. They are suffering (Ashe, January 2015).

Dr. Ashe’s quote recognizes the ability for others to suffer severely and in a manner that he himself may have never experienced nor fully can understand. In reflecting back to the work of Throop (2015) and Scarry (1985), that characterizes the suffering of another as incomprehensible to the observer, Dr. Ashe’s quote becomes taken as sympathy towards the unknown, rather than empathy.

Although some practitioners have claimed to feel empathy, a profound sense of understanding, towards their patient’s suffering, this claim in itself undermines the argument that an individual’s suffering cannot be completely understood by another. Dr. Jan Bernheim nuances the observer’s capacity to understand the experience in stating,

I defend this position, in that true compassion etymologically is very close to empathy. It is to feel what other persons feel and it is the capacity and the willingness, but also the propensity to put oneself in another person’s situation. Compassion understood like that will include and attempt to understand what the other person suffers or feels, but also I sympathize to your right to autonomy, and that is compassion (October 2015).

Compassion can therefore be seen as not so much the observer's complete understanding of the other's suffering, but rather as the desired attempt to listen to the patient and place themselves in that person's experience. Right to die advocates recognize the limits of their own capacity to comprehend another's experience. However, advocates' conceptualization of suffering differs in the degree of compassion for various forms of suffering.

Validity of Suffering:

The ability to recognize another's suffering, as opposed to doubting its severity, is not practiced as commonly as many of my participants would like. Jacqueline Herremans is the President of *L'association pour mourir dans la dignité* (the French speaking Belgian right to die organization) and a lawyer passionate about Belgium's assisted death access. I met Herremans at her law office in Brussels on a Sunday evening. The office was completely deserted except for herself; I later learned that she was preparing to travel to Southern France the following day as part of Dr. Nicolas Bonnemaïson defence counsel¹⁶. She also sits on the Federal Euthanasia Review committee which oversees all reported assisted death procedures in Belgium.

When we met Herremans spoke to me about cases where a patient's suffering was not taken seriously meaning the physician had not listened to the patient when they were greatly suffering. These situations occur, according to her, because aspects of the euthanasia law in Belgium have advanced rapidly along with the general attitude towards assisted death, "but then

¹⁶ Nicolas Bonnemaïson was accused of ending the lives of seven dying patients. A few days following my meeting with Jacqueline Herremans, Dr. Bonnemaïson was handed a two year prison sentence for one count of homicide, while being acquitted for the other six charges. As of 2016 France has no legislation around assisted death.

suddenly stopped on the ability to sympathize with the suffering of others, especially that of a young person who has a life ahead of them” (October 2015). As of 2014, minors (under the 18 years of age) in Belgium have the right to access medical euthanasia for terminal conditions. However, numerous advocates I encountered are concerned that assisted death is often discouraged for younger individuals who are severely suffering; their experiences are not given the same validity as an elderly person’s.

Dr. Van Hoey describes the case of a woman, Eva, who in her early 30’s requested access to euthanasia for psychological suffering. Since Eva was in relatively good physical health, she attempted to have the procedure take place in a hospital so that she could donate her organs. Even though she had more than the necessary number of approvals needed for a euthanasia procedure (under federal law you need three), the hospital’s ethical committee demanded that she attempt another form of treatment. According to Van Hoey, this was too much for Eva who had already spent years of her life in various treatments and seeking official approvals for her death(October 2015). She had the euthanasia procedure done at home instead of at the hospital and did not donate her organs¹⁷. Eva’s case represents a story of discriminatory attitudes within medical communities where suffering is not recognized as being equally valid to that of others based on age and the nature of suffering.

Dr. Van Hoey’s story does not stand alone in speaking out against discriminatory practices within the euthanasia law. Pierre Vincke, when he recounted the story of his daughter’s life Edith reflectively told me that he considered it a personal mistake to listen to psychiatrists

¹⁷ Eva’s euthanasia was depicted in the documentary “End Credits” (2013) about the right to die laws in Belgium.

who immediately advised him against inquiring further about the possibility of euthanasia for his daughter. Vincke only later realized that these psychiatrists had made recommendations without properly understanding his daughter's lived experience, but similarly to Eva, dismissed her suffering because it was for psychological reasons and due to her youth. Vincke took this in a somewhat stoic reaction, "people love [the young] not because they are beautiful, but because they have an entire life ahead of them" (October, 2015). I understood Vincke's words to mean that he was able to sympathize with the attitudes from which this prejudice originated; the death of a young person, especially at their own behest, is considered not only the loss of life already lived, but more importantly the ceasing of the potential life to be lived.

Another form of discrimination that remains 'a grey zone' for assisted death laws is the question of mental capacity¹⁸ to make a decision concerning death. The most politically controversial form is dementia since it puts into question the ability for the individual to make a voluntary choice. Alzheimer's, the most common form of dementia, is characterized by memory loss and severe disorientation that has been argued to lead to both anticipatory suffering of decline and suffering through lack of human dignity. Jaqueline Herremans explained the specifics of what allowed it to be included in the end of life legislation. When asked if it qualified as a disease that was severe and incurable, Herremans responded,

For the time being yes. We can see signs of somatic or psychic suffering as a result. I would say both. There are vital functions that can be reduced by Alzheimers, there are problems of physical, yet psychic. Because a person who is experiencing Alzheimers eventually realizes that they are no longer themselves (Herremans, October 2015).

¹⁸ The question of mental capacity or necessary sanity to make important decisions remains debated.

Her argument presents the slow decline of cognitive abilities as a form of suffering characterized by anticipation of further decline and the lack of ability to perform tasks significant to human dignity. Although the Belgian Federal Commission on Euthanasia ruled in favour of allowing patients with dementia to access assisted-death, the procedure has to be performed while the person is still lucid. This caveat is to ensure that the person voluntarily accepts the procedure up until the moment of death.

The disappearance of lucidity can decline unpredictably in dementia patients. Currently in Belgium those who do not want to be alive in a state of forgone dementia must have their euthanasia performed at an early stage of their mental degeneration to ensure the legal requirement of full lucidity, but at cost of losing months/years of potentially enjoyable life (Herremans, October 2015). Advanced directives (documents stating what a patient wants done should they be unable to make such a decision) are not accepted in Belgium for dementia since they have the potential of euthanizing someone who is unaware of the situation and does not want to die.

The suffering that often accompanies those with dementia, on a surface level, differs from psychological and physical based suffering. The fear of further cognitive decline, as Dr. Desmet describes, “it is what I will call anticipatory suffering, you will suffer through the anticipation of what will come, but it goes very far and that is one of the evolutions” (October 2015). Anticipatory suffering is unique in that it is based on suffering that has yet to arrive, but the knowledge of this can cause existential anxiety. Therefore, the fear of total loss of mental cognition in the future can cause anticipatory suffering in the present. Such suffering is often combined with the increased inability to do activities that were once meaningful to the person.

Since dementia is a degenerative disease, it means that symptoms overtime become increasingly more pronounced and periods of lucidity become rarer. Herremans explained that people with dementia lose the, “knowledge of how to do the most basic of tasks. Opening a door or tying a shoe. What do we do when we no longer know how to do these things. It is this aspect which is destabilizing” Herremans provides the example of how, “Hugo Claus’ wife would ask him to turn off the light and he no longer knew how to do it. He understood what she was asking of him, but just did not know how” (October 2015). For her, this notion of gradual mental decline can cause suffering in its very nature of dependence on others and loss of dignity that separates a person from who they once were.

When I asked Dr. Thienpont and Dr .Van Loon if there was anything they would want changed in Belgium’s euthanasia law they both looked at each other knowingly and brought up the problem of advanced directives and euthanasia. Since these directives are not acknowledged for patients with dementia who do not want to live, they are left with a short window; they are lucid often enough, but will soon cease to be able to make such a decision. Dr. Thienpont provided the example of writer Hugo Claus who was diagnosed with Alzheimer’s disease. She explained that according to them, Claus, “was afraid that if he was a little bit more demented he would miss his euthanasia, so maybe he had to die a little bit too early. With dementia that is always the problem either it is too early or it is too late” (Thienpont, October 2015). For Dr. Thienpont and Dr. Van Loon, respecting advanced directives that concern an informed individual not wanting to live through the decline of their cognitive abilities nor the anticipation of the decline are most reasonable.

Similarly, other right to die advocates I met in Belgium, spoke in favour of respecting advanced directives in cases of mental degeneration. Dr. Marc Van Hoey argued for a more illicit approach, stating that, “a doctor should respect the law, but if you know a patient very well and you know what he or she wants or has said should we really wait until this person no longer knows anything” and if the patient makes their intentions clear, “why should a doctor not act upon that euthanasia?”(October 2015). For him the law is nonsensical since it negates the patient’s initial wishes and their fear of impending suffering.

However, attitudes in favour of assisted-death in circumstances of mental degradation are not considered legitimate by all right to die advocates. Some advocates I encountered during my fieldwork have a more specific or exclusionary understanding of what circumstances of suffering deserve access to assisted death. The degree of compassion towards those who are inflicted by various forms of suffering cannot be said to stay consistent among all right to die advocates. During my fieldwork, I came across advocates who were skeptical about the extent to which assisted-death laws should encompass non-somatic forms of suffering. One of these participants was Ghislain Leblond, a former civil servant in the Quebec government who was forced to retire early due to his chronic muscle degenerative condition that over the last twenty years has limited his physical movement. I met Leblond at his Quebec City suburban home at the end of July.

Since his retirement, Leblond co-founded a small Quebec right to die organization that he called *Le collectif de mourir digne et libre*. This group was formed in divergence to the political goals of *l’Association québécoise de mourir dans la dignité* (AQDMD)¹⁹. Leblond explained

¹⁹ l’Association québécoise de mourir dans la dignité (AQDMD) is the main Quebec right to die organization

that his organization simply had a “different philosophical approach” to assisted-death²⁰ (July 2015). For him, assisted-death should only be accessible to those who are terminally ill and he spoke against non-terminal cases stating that it, “is not like a root canal at the dentist, it’s a fatal procedure and it’s serious” (July 2015). His cautionary words imply a rejection of conditions of suffering that are not deemed terminal.

Similarly, Steven Fletcher took issue with a vision of the law that would encompass non-physical suffering or as he puts it, “I’m not talking about the teenager who had a bad hair day or someone who is clinically depressed. No, these are competent adults in obviously very difficult circumstances” (January 2015). Fletcher’s comments can be understood as an attempt to undermine the validity of those experiencing psychological suffering by characterizing them as young people who want to end their life for illogical reasons. In fact, Fletcher’s conceptualization of who should have access (at the time of the interview) proposed a law that appeared to be more exclusive than inclusive. In Fletcher’s words, “if they’re clinically depressed for example, it’s probably not going to fly and if you have dementia you wouldn’t be eligible. Kids, you know, you have to be 18 and over,” yet, he leaves it open for the catastrophically injured (Fletcher, January 2015). The perceived validity of suffering, as recognized by the observers, thus becomes transformed into eligibility and access towards assisted-death.

²⁰ Leblond outlined that *Le collectif de mourir digne et libre* first and foremost focused on assisting in someone’s death within the criminal code so as to focus on end of life suffering. Secondly, Leblond and Yvon Bureau (his associate) believed in advocating for assisted death legislation on a federal level as opposed to only in the province of Quebec.

The imagined models of eligibility for assisted death that both Leblond and Fletcher propose have striking similarities since they appear to only recognize physical and near death suffering²¹. It may be important to remind to the reader that both these men, at the time of their interview, were confined to their wheelchairs and with limited mobility. Both Leblond and Fletcher are open about the fact that their advocacy comes from their own respective physical conditions. Therefore, it seems barely surprising that their conceptualization of suffering and who should be eligible is based on their own perceived notions of validity and potentially on their own medical conditions.

Validity and eligibility can be understood as two sides of a coin; validity of suffering is determined by an observer based on their own frames of reference and subjective experiences, while eligibility creates a framework for who should be granted access to assisted-death that is rooted in perceived validity of suffering. Identical points of inquiry have been raised in works on assisted-death and suffering where a physician's conceptualization of suffering will often correspond to what they consider to be a valid form of suffering (Bernheim et al., 2014; Pasman et al. 2009). Therefore, in attempting to gain insight on how right to die advocates conceptualize suffering and who is 'really' suffering, it becomes quite easy to determine their imagined validity/eligibility towards assisted-death.

Besides Leblond and Fletcher, other advocates were unconcerned about the potential for other forms of suffering to be granted access to assisted-death. However, certain advocates, generally those in Canada, were hesitant to express unwavering support for other forms of suffering being included in assisted-death legislation. So I asked Dr. George L'Espérance, the

current head of *l'Association québécoise de mourir dans la dignité* (AQDMD) who for 30 years worked professionally as a neurosurgeon and in recent years as a specialist in medical-legal affairs, where he thought the line should be between those who should be eligible and those who should not. He responded that in principle, he took no issue with assisted-death for minors and those suffering psychologically, but strategically the association did not (at that time) advocate for a law that would incorporate non-terminal suffering. His philosophical approach to the association's platform was, "evolution is better than revolution" a line he repeated many times during our interview (August 2015). Otherwise put, Dr. L'Espérance believed that it was important to start with a limited law and allow for a gradual progression of societal values rather than fighting caveats that would make people uncomfortable²².

Furthermore, Dr. L'Espérance argued that, at least for the time being, assisted-death must remain within a medical framework, explaining, "I don't know what will happen in 50 years and I will no longer be there, but it should be absolutely doctors because beside that you will have sad stories such as Latimer²³ who is a good man who loved his daughter and if only he had doctors willing to help him" (August 2015). L'Espérance's insistence in maintaining assisted-death within a medical framework is based on, "safety and legitimacy" to avoid the potential for further suffering (August 2015). However, he underlines the potential for assisted-death to move

²² Although L'AQDMD's official stance initially made no mention of assisted-death for non-terminal reasons they would later shifted their stance following much political and media attention of the issue in May-June 2016. A year after the interview with Dr. L'Espérance the organization's website stated that, "L'AQDMD compte poursuivre ses démarches pour que l'aide médicale à mourir puisse s'appliquer aux personnes devenues inaptes" (AQDMD website, July 2016). A vague, yet open statement.

²³ Robert Latimer was a wheat farmer in Saskatchewan whose daughter, Tracy, had cerebral palsy. Latimer terminated his daughter's life in October 1993 and served a six year sentence.

away from medicine in the future. Although most of my participants would be weary of non-medical assisted-death, there has been an increasing push for eligibility for issues that are less medical and more existential such can be considered the case with ‘weariness of life’. Norwood draws attention to ‘weariness of life’ (2009) in chapter two as a state that is comprised of many smaller ailments and therefore rarely considered a valid form suffering to the observer.

Yet, the vast majority of advocates I encountered favoured a broad inclusivity of what types of suffering qualified for assisted-death within a medical model. For Herremans, *l’Association pour le droit de mourir dans la dignité* in Belgium wonders how to make others more sympathetic of non-terminal suffering and euthanasia. She believes that, “you need to have the experience of somatic pain to accept the idea that mental illness can have space in within the [euthanasia] law. There is no exclusion for psychological suffering” (Herremans, October 2016). Herremans is arguing that many doctors are unable to accept psychological suffering before having themselves experienced physical pain. Her statement is predicated on the idea that once someone experiences more serious pain they become familiar, even if briefly, with the psychological and existential forms of suffering that accompany it.

Herremans’ argument has parallels to that of medical anthropologist Allan Young, whose work is discussed in the first chapter. He elaborates on how psychological suffering can be the result of and overlap with physical suffering creating both causation and simultaneous forms of suffering (1996). Young does not however link forms of psychological and somatic suffering to an overarching existential suffering that strips the individual of significance as certain Belgian right to die advocates have done. Although many advocates would maintain that psychological,

somatic, and anticipatory suffering are only symptoms of a deeper existential suffering, these distinctions are used politically to either expand or reduce who can gain access to assisted-death.

The politics of deservingness of assisted-death and suffering are complex as there is no consensus on basic determining factors for access to assisted-death. Certain advocates believe that suffering should be determined by degree (e.g. mild to intolerable). According to Dr. Lieve Thienpont, due to the subjective nature of suffering, it cannot be measured unlike somatic pain that can be measured for severity. She says that, “we have scales, but no scales that deals with everything we just talked about, existential suffering” (October 2015). Dr. Thienpont’s argument is based on the premise that the loss of meaning in life is personal and differs depending on the individual. However, only loss of meaning that is symptomatic, or eligible forms of suffering, is considered valid.

Dr. Thienpont, along with numerous other practitioners and advocates, does not believe parceling symptoms of existential suffering into categories to determine whether their suffering is valid. She considers listening to be the most effective form of determination. However, Dr. Thienpont considers the permanency of suffering as an important determining factor to whether that individual should be given access to assisted-death. This is a loose criteria that looks to establish if there is a reasonable possibility for treatment. Dr. Thienpont gives the example of losing a lover which can initially be unbearable but over time gets better. She claims that, “we would never help a person who was ill before and lost a child we would never help them with euthanasia and I mean [for] 2-3 years, even if it is unbearable”²⁴ (Thienpont, October 2015). A

²⁴ This quote is a indirect criticism of Dr. Marc Van Hoey who performed a euthanasia procedure on a woman who had lost her daughter a few months earlier.

decision is based on the foreseeable chances of recovery from existential suffering based on the patient's life circumstances. Dr. Thienpont, along with many other practitioners, would not agree to perform an assisted-death procedure if the suffering was considered temporary (e.g. grief).

The permanence of suffering is a form of safeguard for practitioners so as to not perform assisted-death procedures on those who may be experiencing temporary unbearable suffering. However, according to Dr. Van Loon, promise of future treatments that do not yet exist or only provide temporary relief are not acceptable in considering a patient as suffering temporarily (October 2015). Treatments must have a reasonable time of return, therefore the promise of health improvements after five years may not be reasonable to someone who is suffering unbearably. Patient's can refuse treatment, without hindering their chances of accessing assisted-death, if health improvement cannot be produced within a reasonable time. Also, treatments that may have severe negative impacts on the individual, such as Electroconvulsive therapy (ECT), can be refused due to their risk of further increasing the patient's suffering.

Since suffering is considered subjective in terms of the individual's experience and their tolerance of it - so can the observers conceptualization of validity, and therefore eligibility of assisted-death is subjectively determined. Does the Canadian Parliament's decision not to include eligibility for assisted-death to those experiencing psychological suffering mean that their suffering is thus less valid²⁵? Right to die advocates, like any other observers to suffering, have their own conceptualizations of what valid suffering entails. Advocates with a more open conceptualization of suffering consider that assisted-death, as decided by the patient, is always

²⁵ Bill C-14 - June 2016

valid no matter what category of suffering they fall into (e.g. psychological, somatic, existential, etc) since unbearable suffering is caused by a perceived meaninglessness of existence.

Meaningful/less suffering:

Participants for my research such as Dr. Marc Desmet spoke dismissively of somatic pain being considered the main qualifier for assisted death, not because it was not a valid, but because it did not make sense to him. From his experience he believed that, “in some way pain is the easiest problem, pain is exactly the problem that we can solve in many cases, not always entirely, but sufficiently” (Desmet, October 2015). Dr. Desmet is clearly implying that pain is rarely the reason people request euthanasia, rather what is “most decisive is the psychological and existential state” (October 2015). That being said, pain is often present in suffering. This claim echoes the view shared by many advocates that the loss of significance in life is due to existential suffering, yet pain to contribute to this state.

Dr. Desmet provided the example of a middle-aged woman who had been diagnosed with, “terminal bilateral lung cancer and although she was no doubt in pain, her main concern was that she was dying, leaving behind a son and her husband” (Desmet, October 2015). Drawing from this example, Dr. Desmet characterized such incidents of suffering as being a psycho-existential issue, rather than based on the inability for a person to handle pain. He further explained that, “one of the most malignant traits of suffering is that it has the capacity to separate people from the things they love most...oh this is very profound. Of course suffering can also enhance solidarity, but it can also separate people from each other” (Desmet, October 2015). This is when I understood what he was trying to say; pain in itself is not what makes people want

to end their lives, it is the lack of purpose and dependence that accompanies these situations that can lead to a sense of meaninglessness.

Following this interview with Dr. Desmet it became more clear to me what some of the other advocates had been saying to me sometimes suffering is irreversibly meaningless and thus continuation in that state eliminates a person's perceived sense of significance in life. I write 'perceived sense of significance' since my participants were adamant that suffering is a subjective experience. In Dr. Thienpont's words, her patient with MS, "was only able to move their head and they wanted to live. I saw a patient who could not move his legs and he wanted to die, so it is very subjective for what kind of situation you want to live or you want to stop living...that is the subjective element" (October, 2015). The subjectivity of human suffering is thus mixed with the subjectivity of what signifies a meaningful life. It forces a person to ask themselves what conditions or state of being would make you want to end your life?

So I asked Dr. Thienpont what she considered to be the main reason for which patients would consider euthanasia. She responded by describing a hypothetical process of how an individual's psychological suffering can take away meaning to their life. Dr. Thienpont contextualized that many people who are suffering psychologically have been separated from their families (thus often lack a support system) and have lost their jobs, which makes them feel worthless. To put it in her own words,

Socially they are also put in a corner due to financial consequences of [unemployment], they do not have money anymore, they are living in a small house, their relationships are broken, they don't see their children anymore. So there are a lot of consequences from their [mental] illness...and it is all that together that makes patients ask for euthanasia (Thienpont, October 2015).

Mental illness can thus be considered a factor in potentially worsening what Dr. Thienpont describes as the vicious spiral of meaninglessness in life.

In her experience, Dr. Thienpont noted that often those born with disorders such as autism and Aspergers syndrome are more prone to fall into these spirals through difficulties in communicating with their families and functioning within social structures (October, 2015). Such situations can be characterized by social isolation and lack of resources that further perpetuate feelings of meaninglessness plunging the individual, “deeper into depression and this continues” (Thienpont, October 2015). The spiral of meaningful/meaninglessness can be imagined as a person’s sense of self moving upwards or downwards on a metal spring standing upright; various factors (e.g. mental illness, life events, treatments, etc) have the potential to move a person in either direction. Dr. Thienpont believed that for people experiencing severe psychological suffering, there is sometimes the possibility to reverse the downward spiral through therapy and stability in their life, but often things are too far gone and they become tired of struggling (October, 2015). Once a person reaches a certain point of hopelessness they often lose their will to continue living while unbearably suffering thus experiencing an existential lack of meaning.

The underlying belief that right to die advocates share, a belief in the existence of meaningless suffering, considered a justification for assisted-death and has emerged in opposition to the idea of suffering as existentially meaningful or redemptive. Canadian Federal politician (now former MP) Steven Fletcher explained the common existence of such beliefs in describing how a few hours before our interview he had attended a morning prayer breakfast with other Members of Parliament and considered the fact that many would disagree with his

views of suffering. He believed many of his colleagues would have said that, “well the suffering is part of the gig. You know Jesus suffered and you suffer and, you know, and that’s part of the deal...you know, the context of being human” (Fletcher, January 2015). Fletcher suspected that there is a significant portion of the population that is convinced that all suffering is an essential aspect of being human and brings one closer to God.

The logic behind this is that through end-of-life, suffering humans can approach themselves to God and repent for past sins. According to Dr. L’Espérance, the redemptive value of suffering “is a religious point of view” and furthermore agrees with the general premise that, “suffering is part of life, but it is not a mandatory part of life. When you go to the dentist do you not want to feel the drill in your mouth? Of course not, but no one thinks that because of that you are going to heaven and sit on the side of God, no!” (August, 2015). For him, redemptive suffering is flawed in that it only applies to severe suffering and not to lesser forms of suffering. Dr. L’Espérance concludes his response by explaining that the entire story of human technological advancement is motivated by the desire to minimize human pains and make life easier.

I received a similar response concerning the redemptive value of suffering from Dr. Ashe, who responded in a tone of frustration, “suffering is part of life that is correct, but for suffering to be mandatory to access to another life is completely stupid and if they believe that well, good for them, but do not impose that on other people” (January, 2015). For Dr. Ashe, the notion of severe suffering as a spiritual key to an envisaged post-life paradise is unacceptable since it forces everyone to consider life as sacred.

Ashe goes further to explain another justification for suffering that he has encountered during his years as a family physician. He describes how sometimes loved ones will encourage the person suffering to persist through their condition, even if there is little or no hope of improvement. Dr. Ashe, drawing from his experiences, characterizes this phenomenon as if a close one, “suffers through a horrible ignominious death...those around them are being somehow strengthened, because ‘oh gee Dad was great he fought that thing and you wouldn’t believe the pain he was in’, versus at some point deciding that you’re gonna get most of your family around you and you’re gonna take that overdose and die a comfortable death” (January, 2015). Dr. Ashe’s account of how often loved ones will encourage those around them to continue suffering, with varying religious connection, depicts an imposed meaning of suffering that in its existence rejects a hastening of death.

The participants that I encountered rejected any notion that severe suffering can have meaning and needs to be part of the human experience. That being said, none of my participants felt that all suffering was completely meaningless as some experience can have value in them - the classic example being childbirth.

I became curious to better understand at what point life became meaningless to people. For Dr. Bernheim it is the, “loss of dignity and dependence on others” that contribute to the inability to perform daily acts that provide that individual with a sense of significance (October 2015). He explains that for someone who is immobilized in bed, “bedsores and suffocation become the everyday suffering” that can lead to a sense of dependence and potentially meaninglessness (Bernheim, October 2015). Dependence on others has the capacity to create

suffering based on a lack of purpose or ability to do the things that once brought that individual significance.

The issue of existential meaninglessness can also be characterized through Fletcher's distinction between life and the act of living. Similarly, Dr. Desmet claims that, "suffering is much more about I don't want to be a burden, this is meaningless, I don't want to be dependent of others...they will not say it but the fact that they are burnt out" (October 2015). Thus the inability of the person to live life in a way that brings meaning and the dependence on others can lead to a state of existential suffering removing previous purpose in existence and replacing it with inexplicable torment. For right to die advocates, the belief that certain suffering is simply without reason can be considered the main motivator for their involvement in the movement and is inextricably tied to their support for access to assisted-death.

The main thread of this dissertation seeks to determine how suffering, as a concept, relates to those who wish to have legal access to end their life. This worldview is shared by right to die advocates based on the conviction that some suffering is void of meaning and therefore has no greater purpose, thus presenting profound implications in relation to assisted-death.

Advocates, in believing that extended forms of suffering do not present any hope for an enhanced post-life experience, nor anything of a divine nature, consider whether life under current or worsening conditions of suffering is worth living. The question is a dilemma for it presents two distinct and unfavourable options - death or continued suffering.

To gain a greater understanding of this movement, and the intellectual arguments that support it, this dissertation began (in chapter one - *Anthropology of suffering*) with anthropological literature reviewing the works that address how humans have responded to the

existence of suffering and the meaning that has been attributed to it. Supported by anthropological literature, the second chapter positions the question of suffering to the modern medical response of assisted-death as a means for humans to gain mastery over death. In situating the existence of suffering in relation to right to die advocacy, chapter two *Assisted-death and suffering* draws on works debating this coupling to gain insight into what motivates such a response to suffering.

This chapter -*Advocates' perspective: What is meaningless suffering?*- is meant to contextualize the central argument of this dissertation - that right to die advocates' belief in the existence of meaningless suffering shapes their conceptualization of assisted-death practices (who is eligible and how should assisted-death be undertaken). Drawing from the two previous chapters, it provides the narrative of right to die advocates and attempts to elaborate on both the diversity and nuances that exist around how right to die advocates perceive what characteristics represent valid suffering (e.g. form of suffering, age, method, terminal/ non-terminal, etc). These various understandings of when assisted-death should be permitted become interpretations of what is a valid form of suffering and is intrinsically tied to the question of 'when is one's life no longer worth living'.

CONCLUSION:

Suffering is a curious term; on one level it describes a state of being that translates into numerous languages, occurs to all humans, and has been widely used within art. Yet, it is an experience that is personally subjective and whose meaning is so fiercely debated that entire ways of thought have been created in response. The right to die is yet another response to a perennial human discussion on what the meaning of suffering is and how it should be addressed. Advocates for assisted-death, in opposition to many religious organization and the biomedical status quo, are unified in a conceptualization of suffering as at times unnecessary, somewhat arbitrary, and meaningless to one's greater existence.

Access to assisted-death (in whatever form) translates into an acknowledgement of human suffering so great that it removes the will to continue living. As outlined earlier, and adamantly argued by nearly all my participants, suicide differs from assisted-death based on both the approach towards death - fear and shame versus an anticipatory resoluteness and the ramifications on those who remain. Advocates argue that assisted-death can often provide a sense of closure and understanding of the wish to die, while suicide leaves close ones with questions as well as trauma (Thienpont, October 2015; Bernheim, October, 2015). However, assisted-death, as with suicide, can be considered as individual human responses to unbearable existential suffering - a state in which a person no longer considers their life meaningful.

In his chef d'oeuvre *The Myth of Sisyphus* Algerian-French writer Albert Camus' opens with the claim that, "there is but one truly serious philosophical problem and that is suicide. Judging whether life is or is not worth living amounts to answering the fundamental question of philosophy. Therefore all other questions must follow this one" (2005, p. 11). This profound

statement puts aside other human inquiries in relation to the basic question of whether one wishes to live or not. Camus provides the example of Galileo who withdrew his discovery that the earth revolved around the sun when the Catholic church threatened his life.

Camus' rationale to Galileo's reaction was that, "he did right" in recanting since, "whether the earth or the sun revolves around the other is a matter of profound indifference" as it is put in opposition to the fundamental question of whether life is worth living for Galileo it clearly was (2005, p. 13). Camus observes the paradoxical element of beliefs based in values (e.g. religions) that defend the meaning of life and construct explanations for human suffering, promoting life at all costs, yet historically have killed "for the ideas or illusions that give them reason for living" (2005, p. 11). An example is Galileo's dilemma choosing between denouncing a scientific discovery that had the potential to undermine an established set of religious beliefs, which promised an answer for both human suffering and the meaning behind life, versus Pope Urban VIII's threat of Galileo's torture and death. The history of religious inquisitions, persecutions, purges, etc is riddled with death in defence of the 'true' explanation behind life and suffering.

Camus' writing moves past belief in speculations of theodicies (both secular and religious) in focusing on the question of whether individuals consider their life meaningful enough to continue living and thus choose death. For him, "one kills oneself because life is not worth living, that is certainly a truth - yet an unfruitful one because it is a truism" and is thus seemingly self-evident (2005, p.15). Therefore, the notion of a divine acting as, "hope of another life one must 'deserve' or trickery of those who live, not for life itself, but for some great idea that will transcend it, refine it, give it meaning, and betray it" transforms lived human suffering

into a symbol of greater significance (2005, p.15). For Camus, an individual's realization that human suffering is a social construct can be devastating and as a result there is an, "absence of any profound reason for living, the insane character of that daily agitation and the uselessness of suffering" which can become a form of suffering in itself (2005, p.15). The burden 's weight is held in its ability to unveil the hollowness behind perceived human meaning.

Similarly to Camus, French philosopher and playwright Jean-Paul Sartre understands this reaction to the sudden comprehension of the meaninglessness of life as a sense of 'nausea'. French literature professor Robert Zaretsky explains that in Sartre's novel *Nausea* he asks, "what other response can we feel when we discover that events, once imbued with meaning, are in fact arbitrary; that our acts, once invested with intention, are only mechanical; and that the world, once our home, is simply alien" (2013, p. 16; Sartre, 1964/1938). This realization at once alters one's understanding of life, yet can be equally devastating in its shattering of previously held conceptualizations of life's meaning.

In recognizing the lack of significance of existence beyond human life itself the question of suffering is thus disrobed from its post-life dimensions. In his book *Mortality's Muse: The fine art of dying* D.T. Siebert writes that,

Suffering is a universal constant of being alive, and resolving to do what little we can while realizing its ultimate futility is part of the existential absurd. Any attempt to explain away or justify suffering is sophistry, an anesthetic for our sympathy, even anguish, for the pain of others. We must not think about such things, but they have a way of intruding upon our consciousness (2013, p.31)

In taking on the belief that there is no greater significance beyond life itself, suffering loses its meaning of redemption and means of coming closer to the divine. Thus, the lack of meaning in

human suffering allows for human choice of its elimination even at the cost of life itself, which no longer holds a construed sacredness.

Even though many of my participants would disagree with the existentialist perception of human existence as meaningless beyond life itself, right to die advocates embody an understanding of suffering that can be considered parallel to that of Camus and Sartre - a conceptualization that strips any imposed meaning onto severe suffering therefore condoning its elimination through a dignified end of life. However, unlike existentialists, right to die advocates are not restricted to conceptualize human existence as completely void of meaning or even religious beliefs, but rather the perspective is that suffering does not always have purpose it's evil is rooted in its absurd and arbitrary nature. Furthermore, advocates present an elaborate response to Camus' fundamental question - Is life worth living?

Conceptualizations of an established level of suffering where life loses significance - unbearable suffering (although from this thesis it should be clear that unbearable suffering rests undefined and without parameters) present an attempt to determine exactly when life no longer becomes meaningful. In casting assisted-death as doctor delivered, or doctor assisted, the act of death becomes one of healthcare a treatment when all others have failed. The desire no longer to live becomes a medicalized issue whose core purpose is to eliminate suffering. In doing so, right to die advocates attempt to provide an answer to Camus' question through a framework of medicalization that demands evidence for the validity of suffering that would justify a death wish. Consequently, assisted-death becomes a regulated form of control over who is 'truly' existentially suffering to a such a degree that their life can be considered not worth living.

The model attempts to provide the patient with a dignified alternative to suffering - death - on the condition that the patient can demonstrate the undignified circumstances of their life.

Through the course of my research with right to die advocates, my own conceptualization of suffering has greatly shifted. Although personally I would not consider myself a right to die advocate, mostly due to my lack of political activity, it has become clear to me that there are human experiences of unbearable suffering that I cannot conceptualize, yet I believe are valid. Certainly spending time with numerous advocates who spoke at length about their convictions, observations of suffering as well as the compassion they feel towards others has shaped my own conceptualizations of suffering and assisted-death. However, perhaps even more significant to my re-conceptualization of suffering came from my own encounters with depression during this project.

Prior to beginning graduate research I had been largely unaware, and lacked the ability to even comprehend the concept of 'mental illness' beyond a surface level definition of the term. Depression, for me, had been a black-boxed term that represented a state of sadness associated with undesirable abnormality. My Catholic origins and education further perpetuated the belief that mental illness was to be pitied from a distance, yet remained unvalorized as a form of redemptive suffering (unlike physical suffering that has taken on comparable dimensions with Christ on the cross). Though I had long ceased to consider myself a practicing Catholic, my conceptualization of suffering remained limited to my own experiences and mediatized representations.

A good portion of this thesis has been dedicated to deconstructing the views of right to die advocates and various scientists on the the incommunicability of suffering tied with the

difficulty of recognizing another's suffering. Therefore, I shall not attempt to convey my own experiences besides quoting a short poem from one of Dr. Thienpont's participants, whose words I feel are quite relevant,

A duel with myself.
Deep, grey and sombre.
No grip, no balance.
Not wanting to do anything. But doing it anyway (2015, p. 89).

It was only through my own recent experiences of invisible suffering that I was able to conceive of the existence of unimaginable suffering and by this I by no means claim to understand it.

Through my own feelings of confusion, loss of control and fear of my experiences being invalidated through disbelief, it became clear that such inexplicable experiences could exist for anyone. The invisibility of suffering thus makes it that much worse in that it does not seem tangible and it is hard to prove its existence, especially to one's self.

A reason I write about myself is to differentiate between suffering that still allows one to live meaningfully and suffering that removes the significance of life from the individual. It is clear to me that my experiences have been that of the latter, my life is still very meaningful. The existence and more importantly recognition of my depressive tendencies have further pushed me to explore the question of what constitutes a meaningful life in relation to suffering. Through acknowledging the significance of my own life, despite/because of a form of suffering, I have the capacity to believe in the existence of a suffering that is hopeless and one where there are no new paths towards a meaningful life. Advocates similarly refer to such a recognition of another's suffering, while acknowledging the inability to fully comprehend their experience as compassion. Compassion moves between the borders of sympathy and empathy so as to

understand that certain forms of suffering cannot be shared, yet trusts that another is experiencing the force of its existence.

It is my personal opinion that compassion is a major pillar of the right to die, yet not universal within the movement since numerous advocates are choosy in their willingness to acknowledge severe suffering in others based on external symptoms. However, beyond divisions in what constitutes a valid form of suffering or, otherwise put, whose life can be self-understood as no longer being worth living, right to die advocates are united in a general understanding that life, due to suffering, can become meaningless to the individual.

The meaninglessness of suffering can thus makes the experience of suffering more hopeless in that it removes one's expectation for any future. The embrace of death, without future hope referred to as anticipatory resoluteness thus focuses on a satisfaction with one's life. So, although advocates argue that severe suffering is neither meaningful nor significant, it is their own experiences and observations of suffering which prompt them to advocate for a legitimized conceptualization of suffering that does not oblige the belief in the unwavering sacredness of life. Therefore in my opinion, advocates' views of how they believe assisted-death policies should look like are shaped by their conceptualization of suffering rooted in their own experiences or close encounters with suffering.

It is my hope that this dissertation will contribute to the literatures on both suffering, as a concept that is constantly in flux, and assisted-death, as a response to various understandings of what makes up suffering. The research I present focuses on how the concept of suffering is understood in relation to requested death, but does little to address the sources of suffering themselves. It would be interesting for future research to explore what are the factors that lead

people to determine that their lives are no longer worth living going beyond categorized forms of suffering (e.g. psychological, somatic or existential) and investigating what creates loss of meaning.

The future of how assisted-death policies shall progress in years to come remains unclear, however what is clear is that the right to die movement has become increasingly popular in a number of places all over the world. Future policies will surely be written in relation to emerging biomedical technologies extending human manipulation over biological life and through the way in which suffering becomes conceptualized. Considering this perhaps the reader should ask themselves - Why is your life worth living?

Bibliography:

- Arendt, H. (1968). *Men in dark times*. New York: Harcourt, Brace & World.
- Asad, T. (1993). *Genealogies of religion: Discipline and reasons of power in Christianity and Islam*. Baltimore: Johns Hopkins University Press.
- Asad, T. (1997). On Torture, or Cruel, Inhuman, and Degrading Treatment. In A. Kleinman, V. Das, & M. M. Lock (Eds.), *Social Suffering* (285-308). Berkeley: University of California Press.
- L'Association Québécoise pour le Droit de Mourir dans la Dignité. (2015). *Manifest de L'AQDMD*. Retrieved from <http://www.aqmdm.qc.ca/page10.php>
- Ashe, G. (2015, February 1). Fieldwork Research [Personal interview].
- Aviv, R. (June 22, 2015). The Death Treatment: When Should People With non-Terminal Illness be Helped to Die. *The New Yorker*, 56-65. Print.
- Badham, P. (2009). *Is there a Christian case for assisted dying?: Voluntary euthanasia reassessed*. London: SPCK.
- Bennet, G. (2014, August 18). *Goodbye & Good Luck*. Retrieved from <http://deadatnoon.com>
- Bernheim, J. L., Distelmans, W., Mullie, A., & Ashby, M. A. (2014). Questions and Answers on the Belgian Model of Integral End-of-Life Care: Experiment? Prototype? *Journal of Bioethical Inquiry Bioethical Inquiry*, 11(4), 507-529.
- Bernheim, J., & Vermeersch, E. (2015, June 26). Overhaaste euthanasie? Geloof niet alles wat 'The New Yorker' schrijft. *De Morgen*.
- Bernheim, J. (2015, October 7). Fieldwork Research [Personal interview].
- Boisvert, M. (2015, August 2). Fieldwork Research [Personal interview].
- Braeckman, J. (2015). Forward: The moral relevance of the subjective. In L. Thienpont (Author), *Libera Me: About euthanasia and psychological suffering* (15-25). Antwerp: Witsand.
- Brown, J. E., Chatterjee, N., Younger, J., & Mackey, S. (2011). Towards a physiology-based measure of pain: Patterns of human brain activity distinguish painful from non-painful thermal stimulation. *PLoS ONE*, 6(9), 1-8.
- Camus, A. (2005). *The myth of Sisyphus*. London: Penguin.

- Canadian Medical Association. (2014). *Euthanasia and Assisted Suicide Update*. Retrieved from policybase.cma.ca/dbtw-wpd/Policypdf/PD07-01.pdf.
- Cassel, E. (1992). The nature of suffering and the goals of medicine. *Annals of Internal Medicine*, 116(12), 1038-1055.
- Daniel, D., V. (1997). Suffering nation and alienation. In A. Kleinman, V. Das, & M. M. Lock (Eds.), *Social Suffering* (309-358). Berkeley: University of California Press.
- Das, V. (1997). Language and body: Transactions in the construction of pain. In A. Kleinman, V. Das, & M. M. Lock (Eds.), *Social Suffering* (67-92). Berkeley: University of California Press.
- Das, V. (1997). Suffering, theodicies, disciplinary practices, appropriations. *International Social Science Journal*, 49(54), 563–572.
- Davis, J. (1992). The anthropology of suffering. *Journal of Refugee Studies J Refugee Stud*, 5(2), 149-161.
- Dees, M., Vernooij-Dassen, M., Dekkers, W., & Weel, C. V. (2010). Unbearable suffering of patients with a request for euthanasia or physician-assisted suicide: An integrative review. *Psycho-Oncology*, 19(4), 339-352.
- Desjarlais, R., & Throop, C. J. (2011). Phenomenological Approaches in Anthropology. *Annual Review of Anthropology*, 40(1), 87-102.
- Desmet, M. (2015, October 13). Fieldwork Research [Personal interview].
- Dowbiggin, I. R. (2005). *A concise history of euthanasia: Life, death, God, and medicine*. Lanham, MD: Rowman & Littlefield.
- Farmer, P. (1997). On Suffering and Structural Violence: A View from Below. In A. Kleinman, V. Das, & M. M. Lock (Eds.), *Social suffering* (pp. 261-284). Berkeley: University of California Press.
- Farmer, P. (2003). *Pathologies of power: Health, human rights, and the new war on the poor*. Berkeley: University of California Press.
- Fassin, D. (2012). *Humanitarian reason: A moral history of the present*. Berkeley: University of California Press.

- Fitz-Henry, E., & Kleinman, A. (2007). The experiential basis of subjectivity: How individuals change in the context of societal transformation. In A. Kleinman & J. G. Biehl, B. Good, & A. Kleinman (Eds.), *Subjectivity: Ethnographic investigations* (52-65). Berkeley: University of California Press.
- Fletcher, S. (2015, January 29). Fieldwork Research [Personal interview].
- Foucault, M. (1994). *Birth of the clinic: An archaeology of medical perception* (A.M. Sheridan Smith.). New York, NY: Vintage. (Original work published 1963)
- Gandsman, A., Herrington, E., & Przybylak-Brouillard, A. (2016). Mourir comme mode de vie : être-vers-la-mort et la phénoménologie de l'activisme du droit de mourir. Manuscript submitted for publication.
- Geertz, C. (1973). *The interpretation of cultures: Selected essays*. New York: Basic Books.
- Gierk, B., Kohlmann, S., Kroenke, K., Spangenberg, L., Zenger, M., Brähler, E., & Löwe, B. (2014). The Somatic Symptom Scale–8 (SSS-8). *JAMA Internal Medicine JAMA Intern Med*, 174(3), 399-407.
- Good, B., & Kleinman, A. (2007). Introduction: Rethinking subjectivity. In J. Biehl (Author) & J. Biehl, B. Good, & A. Kleinman (Eds.), *Subjectivity: Ethnographic investigations*. (1-24). Berkeley: University of California Press.
- Gootjes, J., Zuurmond, W., & Perez, R. (Autumn 2010). Unbearable suffering: Defining a concept with undefined parameters. *European Oncology Nursing Society Newsletter*, 28-30.
- Hamilton, G. (October 29, 2015). 'Suicide with the approval of society': Belgian activist warns of slippery slope as euthanasia becomes 'normal'. *National Post*. Retrieved from <http://news.nationalpost.com/news/canada/suicide-with-the-approval-of-society-belgian-activist-warns-of-slippery-slope-as-euthanasia-becomes-normal>
- Han, C. (2012). Life in debt: Times of care and violence in neoliberal Chile by Han, Clara (E. B. Taylor, Ed.). *Social Anthropology*, 20(4), 506-507.
- Han, C. (2013). Suffering and pictures of anthropological inquiry. *HAU: Journal of Ethnographic Theory*, 3(1), 231.
- Hay, C. (1876). Ploughed Moments. *Belgravia*, (28), 104-110.
- Herremans, J. (2015, October 11). Fieldwork Research [Personal interview].

- Karlsson, M., Milberg, A., & Strang, P. (2011). Suffering and euthanasia: A qualitative study of dying cancer patients' perspectives. *Supportive Care in Cancer*, 20(5), 1065-1071.
- Kaufman, S. (2000). In the Shadow of "Death with Dignity": Medicine and Cultural Quandaries of the Vegetative State. *American Anthropologist*, 102(1), 69-83.
- Kelly, T. (2013). A life less miserable? *HAU: Journal of Ethnographic Theory*, 3(1), 213-216.
- Kleinman, A. (1988). *The illness narratives: Suffering, healing, and the human condition*. New York: Basic Books.
- Kleinman, A., & Kleinman, J. (1996). The appeal of experience; the dismay of images: Cultural appropriations of suffering in our time. *Daedalus*, 125(1), 1-23.
- Kleinman, A., Das, V., & Lock, M. M. (1997). Introduction. In A. Kleinman, V. Das, & M. M. Lock (Eds.), *Social Suffering* (vii-ix). Berkeley: University of California Press.
- Kleinman, A. (1998, August 13-16). *Experience and Its moral modes: Culture, human conditions, and disorder*. Address presented at The Tanner lectures on human values, Stanford.
- Kleinman, A. (2012). Culture, bereavement, and psychiatry. *The Lancet*, 379 (9816), pp. 608-609.
- Kleinman, A. (2013). From Illness as Culture to Caregiving as Moral Experience. *New England Journal of Medicine*, 368(15), 1376-1377.
- Kleinman, A. (2013, September 10). *Three more social theories: Social suffering, biopower, and local moral worlds*. Lecture presented at Societies of the World 25, Cambridge, MA.
- Lock, M. (2000). The quest for human organs and the violence of zeal. In V. Das, A. Kleinman, M. Ramphela, and P. Reynolds (Eds.) *In remaking a world: Violence, social suffering, and recovery*. (pp.271-295). Berkeley: University of California Press.
- L'Ésperence, G. (2015, August 3). Fieldwork Research [Personal interview].
- Larue, G. A. (1996). *Playing God: Fifty religions' views on your right to die*. Wakefield, RI: Moyer Bell.
- Lavi, S. J. (2005). *The modern art of dying: A history of euthanasia in the United States*. Princeton, NJ: Princeton University Press.

- Leblond, G. (2015, July 31). Research Fieldwork [Personal interview].
- Lossignol, D. (2015, October 5). Research Fieldwork [Personal interview].
- Leibniz, W. L. (1999). *Essais de théodicée, sur la bone de Dieu, la liberty de l'homme, et l'origine du mal*. Paris: Flammarion. (Original work published 1710).
- Levinas, I. (1986). Useless Suffering. In R. Cohen (Ed.), *Face to Face with Levinas*. New York, NY.: State University of New York Press.
- Marx, K., & Engels, F. (1961). *Capital Volume I* (Moore, S., & Aveling, E. B. Trans.). Moscow: Foreign Languages Pub. House. (Original work published 1867)
- Maury, F., & During, L. (1874). Art. II. Case of Exsection of the Brachial Plexus of Nerves for the Relief of Painful Neuroma of the Skin. *The American Journal of the Medical Sciences*, 68;(135), 29-37.
- Mehta, N. (2011). Mind-body dualism: A critique from a health perspective. *Mens Sana Monographs*, 9(1), 202.
- Morgan, D., & Wilkinson, I. (2001). The problem of suffering and the sociological task of theodicy. *European Journal of Social Theory*, 4(2), 199-214.
- Mount, B. M. (2003). Existential suffering and the determinants of healing. *European Journal of Palliative Care*, 10(2).
- Munk, W. (1887). *Euthanasia: Or, Medical treatment in aid of an easy death*. New York: Arno Press.
- Mystakidou, K., Parpa, E., Tsilika, E., Katsouda, E., & Vlahos, L. (2005). The Evolution of Euthanasia and Its Perceptions in Greek Culture and Civilization. *Perspectives in Biology and Medicine*, 48(1), 95-104.
- Nietzsche, F. W., & Large, D. (1998). *Twilight of the idols, or, How to philosophize with a hammer*. Oxford: Oxford University Press.
- Norwood, F. (2009). *The maintenance of life: Preventing social death through euthanasia talk and end-of-life care: Lessons from the Netherlands*. Durham, NC: Carolina Academic Press.
- Pasman, H. R., Rurup, M. L., Willems, D. L., & Onwuteaka-Philipsen, B. D. (2009, November 28). Concept of unbearable suffering in context of ungranted requests for euthanasia:

- Qualitative interviews with patients and physicians. *British Medical Journal*, 339, 1235-1237.
- Paul II, J. (1984, February 11). *SALVIFICI DOLORIS* [Letter to To the Bishops, to the Priests, to the Religious Families and to the Faithful of the Catholic Church on the Christian meaning of human suffering]. Saint Peter's, Rome.
- Petryna, A. (2002). *Life exposed: Biological citizens after Chernobyl*. Princeton: Princeton University Press.
- Phan, R. (2016, June 17). Senate votes to pass unconstitutional Bill C-14 through Parliament. Dying with Dignity Blog. Retrieved from http://www.dyingwithdignity.ca/bill_c14_passed
- Reamy, T. (1879, May). The immediate operation for laceration of the female perineum. *Half-yearly Compendium of Medical Science*.
- Regional Euthanasia Review Committees (April, 2008). *2007 annual report* (Rep.). Retrieved from <http://www.livinganddyingwell.org.uk/publications/research/dutch-regional-euthanasia-review-committees-2007-annual-report>
- Sartre, J. (1964). *Nausea* (L. Alexander, Trans.). New York: New Directions Publishing. (Original work published 1938)
- Scarry, E. (1985). *The body in pain: The making and unmaking of the world*. New York: Oxford University Press.
- Scheper-Hughes, N. (1992). *Death without weeping: The violence of everyday life in Brazil*. Berkeley: University of California Press.
- Scheper-Hughes, N. (1998). Undoing: Social suffering and the politics of remorse in the New South Africa, *Social Justice*, 25(4), 114-142.
- Siebert, D. (2013). *Morality's muse: The fine art of dying*. Newark, NJ: University of Delaware Press.
- Sinha, A., & Gibbs, T. (2004). Social Stratification and Health in the Western Context. In C. R. Ember & M. Ember (Eds.), *Encyclopedia of medical anthropology: Health and illness in the world's cultures* (Vol. I, pp. 188-191). New York: Kluwer Academic/Plenum.
- Taylor, C. (1989). *Sources of the self: The making of the modern identity*. Cambridge, MA: Harvard University Press.

- Thienpont, L., & Van Loon, T. (2015, October 10). Fieldwork Research [Personal interview].
- Thienpont, L., Verhofstadt, M., Loon, T. V., Distelmans, W., Audenaert, K., & Deyn, P. P. (2015). Euthanasia requests, procedures and outcomes for 100 Belgian patients suffering from psychiatric disorders: A retrospective, descriptive study. *British Medical Journal Open*, 5(7), 1-8.
- Thienpont, L. (2016). *Libera Me: About euthanasia and psychological suffering* (I. Connerty, Trans.). Antwerp: Witsand. (Original work published 2015)
- Throop, J. (2015). Sacred suffering: A phenomenological anthropological perspective. In C. Houston & K. Ram (Eds.). *Phenomenology in anthropology: A sense of perspective* (68-90). Bloomington: Indiana University Press.
- Van Hoey, M. (2015, October 13). Fieldwork Research [Personal interview].
- Vincke, P. (2015, October 12). Fieldwork Research [Personal interview].
- Ware, N. C., & Kleinman, A. (1992). Culture and somatic experience: The social course of illness in neurasthenia and chronic fatigue syndrome. *Psychosomatic Medicine*, 54(5), 546-560.
- Weber, M., Gerth, H., & Mills, C. W. (1958). *From Max Weber: Essays in sociology*. New York: Oxford University Press.
- Weber, M. (1963). *The sociology of religion*. Boston: Beacon Press.
- Wijsbek, H. (2010). 'To Thine Own Self Be True': On The Loss Of Integrity As A Kind Of Suffering. *Bioethics*, 26(1), 1-7.
- Wilkinson, I. (2001). Thinking with suffering. *Cultural Values*, 5(4), 421-444.
- Wilkinson, I. (2005). *Suffering: A sociological introduction*. Cambridge, UK: Polity.
- Wilkinson, I., & Kleinman, A. (2016). *A passion for society: How we think about human suffering*. Oakland, CA: University of California Press.
- Wilkinson, I. (n.d.). Social Suffering as an Approach to Human Understanding. *Academia Education*. Retrieved September 25, 2016, from http://www.academia.edu/2521946/Social_Suffering_as_an_Approach_to_Human_Understanding
- Williams, S. D. (1873). *Euthanasia*. London Edinburgh: Williams and Norgate.

Wright, W. (2000). Peter Singer and the lessons of the German euthanasia program. *Issues in Integrative Studies*, 18, 27-43.

Young, A. (1997). Suffering and the Origins of Traumatic Memory. In A. Kleinman, V. Das, & M. M. Lock (Eds.), *Social Suffering* (245-260). Berkeley: University of California Press.

Youngner, S. J., & Kimsma, G. K. (2012). *Physician-assisted death in perspective: Assessing the Dutch experience*. Cambridge: Cambridge University Press.

Zaretsky, R. (2013). *A life worth living: Albert Camus and the quest for meaning*. Cambridge, MA: The Belknap Press.