

Drawing the Line: Advance Requests for Medical Assistance in Dying

Broad Considerations with a Special Focus on Dementia

by

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Abstract

This thesis considers the issue of whether to expand Medical Assistance in Dying (MAiD) legislation to include advance requests (ARs) broadly, with particular consideration for the dementia condition. The goal is to provide a deeper understanding of the value tensions involved in a decision of if and how ARs for MAiD should be extended to the Canadian population. To date, much of the discussion of the ethics of advance requests for MAiD focuses on those with dementia. This condition poses particular challenges in that it will, at some point, certainly cause a loss of capacity and living with such loss of capacity may be considered unbearable suffering to some individuals. The question of whether to legalize ARs for MAiD hinges on notions of the self and the nature of autonomy, both of which are affected by dementia. This thesis aims to address some of these challenges with a view to understanding whether and under what circumstances an AR for MAiD might be justified. This thesis provides suggestions and arguments aimed specifically at whether ARs for MAiD ought to be legalized and does not suggest whether MAiD ought to be legalized for individuals with mental illness as a sole underlying condition. Further, the scope of this thesis focuses on the moral and ethical considerations and implication that ought to be considered in potential expansion of legislation, not the resulting implications of actually expanding such legislation. Overall, the thesis focuses on the ethics of the potential legalization of ARs for MAiD in general, with a sub-focus on dementia, as the condition poses unique challenges as mentioned above.

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Table of Contents

| | |
|--|-----------|
| Abstract | 1 |
| Acknowledgements | 2 |
| Table of Contents | 3 |
| List of Abbreviations | 5 |
| | |
| Chapter 1: MAiD in the Canadian Context | 6 |
| Section 1—Thesis Road Map..... | 7 |
| Section 2— History and Background of MAiD Legislation..... | 10 |
| Chapter Conclusion..... | 16 |
| | |
| Chapter 2: MAiD in the Global Context | 17 |
| Section 1—Current legislation across Jurisdictions..... | 19 |
| Subsection 1—Netherlands..... | 19 |
| Subsection 2—Belgium..... | 22 |
| Subsection 3—Luxembourg..... | 26 |
| Subsection 4—Colombia..... | 28 |
| Subsection 5—Switzerland..... | 31 |
| Subsection 6—Germany..... | 33 |
| Subsection 7—United States..... | 35 |
| Chapter Conclusion..... | 38 |
| Summary Chart..... | 40 |
| | |
| Chapter 3: Theoretical Considerations | 43 |
| Section 1— Notions of the Self..... | 44 |
| Subsection 1: Dworkin..... | 45 |
| Subsection 2: Dresser and McMahan..... | 48 |
| Subsection 3: Chapman and The Ecology of Dementia..... | 51 |

| | |
|---|------------|
| Chapter Conclusion..... | 56 |
| Chapter 4: Key Viewpoints and Tensions..... | 59 |
| Section 1— Advantages of Expanding MAiD Legislation..... | 60 |
| Section 2—Disadvantages of Expanding MAiD Legislation..... | 65 |
| Section 3—Major Areas of Tension..... | 70 |
| Subsection 1: Autonomy..... | 70 |
| Subsection 2: Anticipation of Suffering and The Disability Paradox..... | 74 |
| Subsection 3: Vulnerability and Stigma..... | 76 |
| Chapter Conclusion..... | 78 |
| Chapter Five: Normative Argument and Recommendations..... | 79 |
| Section 1—Three Degrees of Expansion..... | 80 |
| Subsection 1—ARs for MAiD when Already Eligible..... | 81 |
| Subsection 2—ARs for MAiD Before Eligibility but After Diagnosis..... | 84 |
| Subsection 3—ARs for MAiD Before Diagnosis..... | 89 |
| Section 2—Drawing the Line..... | 92 |
| Subsection 1: Scenario One..... | 93 |
| Subsection 2: Scenario Three..... | 98 |
| Subsection 3: Scenario Two..... | 103 |
| Chapter Conclusion..... | 108 |
| Thesis Conclusion..... | 109 |
| Bibliography..... | 114 |
| Appendix A: Frailty and Cognitive Impairment..... | 122 |

List of Abbreviations:

ALS: Amyotrophic lateral sclerosis

AR: Advance Request for Euthanasia

BCCLA: British Columbia Civil Liberties Association

CACL: Canadian Association for Community Living

CCA: Canadian Council of Academies

CIHI: Canadian Institute for Health Information

CMPA: Canadian Medical Protective Association

CSPCP: Canadian Society of Palliative Care Physicians

DMD: The Foundation for the Right to Die with Dignity

DNR: Do not resuscitate

EPOLRCC: External Panel on Options for a Legislative Response to Carter v. Canada

MAiD: Medical Assistance in Dying

LTC: Long-term care

PTEAG-PAD: The Provincial-Territorial Expert Advisory Group on Physician-Assisted Dying

SCC: Supreme Court of Canada

SDM: Substitute decision-maker

SJCPAD: Special Joint Committee on Physician-Assisted Dying

WFRtDS: The World Federation of Right to Die Societies

Chapter 1: MAiD in the Canadian Context and Thesis Road Map

Medical assistance in dying (MAiD) has been a hotly debated topic across much of the western world for several decades. With the passing of Bill C-14 in Canada on June 17, 2016, MAiD became legal. Medical assistance in dying can include voluntary euthanasia, where a patient requests that a medical doctor or nurse practitioner administer a lethal substance, or medically-assisted suicide, where a medical doctor or nurse practitioner prescribes a lethal substance to the patient which the patient can then self-administer (Nicol and Tiedemann, 2016). MAiD, under varying legislation, is also legal in several U.S. states, the Netherlands, Belgium, Luxembourg, Switzerland, Columbia, and Germany. The comparative features of Canada's legislation with other jurisdictions will be outlined in Chapter 2.

Under the current interpretation of the legislation as presented by the Canadian government, individuals afflicted with cognition impairments, such as dementia, are *not* eligible for MAiD. Patients are also *not* eligible to include MAiD in an advance directive. These exclusions are currently being examined by expert committees in conjunction with the Canadian Council of Academies (CCA), whose report will be referred to at multiple points throughout this thesis. Note that the report provides no recommendations regarding whether or not to expand the legislation, as this was not their mandate. Through the commission of the CCA report, and others referenced in this thesis, it is clear that federal government already anticipates that the legislation might need to be expanded. Three particular issues are being considered and discussed, with one of the issues being the creation of an AR for MAiD.

The consideration of whether to legalize ARs for MAiD, particularly for those with dementia, is an important area to research and discuss, as dementia impacts 1 in 11 Canadians over the age of 65, and this figure is expected to double by 2038 (CIHI, 2011). Polls estimate between 77% and 84% of Canadians support assisted suicide for those with terminal illness. Given that media articles tell the stories of numerous individuals who may have taken their lives sooner than preferred due to the illegality of ARs (Hounsell, 2018; Tutton, 2017; Van Dyk, 2019; Hill, 2018; Proudfoot, 2016), this is a controversial and complex area of ethical discussion. Further, the civil case of *Lamb v Canada* (*Lamb v Canada*, 2016) illustrates that the law is already being challenged in regards to the criterion that the individual's death must be "reasonably foreseeable" ¹. Timely and diligent thought and discussion of MAiD, advance directives and dementia is key before any further changes to Canada's legislation take place. This thesis aims to contribute to this discussion.

This thesis provides the landscape of how MAiD legislation has developed, from its current state nationally and globally including considerations around future expansion. Specifically, this exploration will focus on the existing or potential inclusion of MAiD in advance directives, known as advance requests (ARs), broadly and for individuals diagnosed with dementia. In this thesis I explore notions of the self and autonomy, with a view to developing a justification for AR for MAiD under specific circumstances.

¹ Since the writing of this thesis, note that *Lamb v. Canada* was adjourned after she was found to in fact be eligible for MAiD in September 2019.

Section 1: Thesis Road Map

Chapter 1 outlines the current landscape of MAiD legislation in Canada, including the political and historical context in which the legislation was developed. Chapter 2 explores current legislation within jurisdictions where MAiD is legal, including the Netherlands, Belgium, Luxembourg, Switzerland, Columbia, Germany, and the United States. The content of the legislation in each of these jurisdictions, along with the political and historical context in which the legislation was developed are compared and contrasted with other jurisdictions, including Canada. There are three jurisdictions in which ARs for MAiD are already legalized. Chapter 3 explores some of the key theoretical considerations regarding the issue of whether to expand MAiD legislation to include advance requests (ARs) for euthanasia for individuals with dementia. Two notions of the self are discussed, along with the types of interests each self has. Various arguments and critiques by Dworkin, Dresser, and McMahan are presented regarding which self, and corresponding interests, ought to have authority. I suggest that each theorists' position contains convincing and unconvincing aspects and discuss each of these aspects. The concept of the ecology of dementia is also introduced and I argue that the concept provides a new perspective from which to view the issue of whether or not to expand MAiD legislation to include ARs. The theories, and my corresponding arguments, presented in this chapter set the framework for my discussion and arguments to come in later chapters.

Chapter Four explores the key viewpoints and tensions associated with expanding MAiD legislation to include ARs broadly, with particular consideration for the dementia condition. The first two sections of Chapter 4 describe the key arguments in support of, and against, the expansion of MAiD legislation. Section three explores the major areas of tension within these

contrasting arguments, including conceptions of autonomy, anticipation of suffering and the disability paradox, and vulnerability and stigma. I suggest that both arguments for and against expansion of the legislation to include ARs for MAiD have merit, and we ought to strike a balance between providing equitable access to MAiD for individuals with different conditions in order to express their critical interests, while minimizing the potential for error, abuse, and perpetuation of stigma, in order to give importance to experiential interests.

Chapter Five presents my own normative arguments and recommendations regarding the legalization of ARs for MAiD. Section One outlines three possible contexts in which ARs for MAiD could be legalized in Canada. These potential contexts include the creation of an AR when: (i) the individual has a diagnosis of a grievous and irremediable condition and is already eligible for MAiD; (ii) the individual has a diagnosis of a grievous and irremediable condition but is not yet eligible for MAiD; and (iii) the individual does not have a diagnosis of a grievous and irremediable condition and is not eligible for MAiD. I outline the major concerns with potentially legalizing ARs for MAiD in the context outlined in each scenario listed above, provide recommendations on how to mitigate such concerns, and discuss whether such concerns can be sufficiently mitigated. I argue that there is an increasing level of uncertainty in scenarios one to three, respectively, regarding whether an individual would have changed his/her wish to receive MAiD if he/she were still competent. This level of uncertainty is foundational to my arguments in Section Two.

The final section presents four moral arguments as to where to draw the line regarding in what circumstances, in relation to the three scenarios outlined, ARs for MAiD ought to be legalized in Canada. I support these positions by applying the evidence, discussions, and

arguments in the previous four chapters of this thesis. First, I argue that ARs for MAiD ought to be legalized for individuals diagnosed with a grievous and irremediable condition who are already eligible for MAiD or are reaffirming a previously created AR. I argue that ARs ought not to be legalized for individuals without a grievous and irremediable diagnosis who are not eligible for MAiD. I argue that individuals ought to be able to create an AR at any time, whether before or after diagnosis or before or after eligibility for MAiD, if the sole criterion for implementation is that the individual is irreversibly unconscious. Finally, I argue that ARs ought not to be legalized for individuals who have a grievous and irremediable diagnosis but are not eligible for MAiD.

Section 2: History and Background of MAiD Legislation in Canada

Suicide and assisted suicide were both deemed illegal in Canada's Criminal Code of 1892 under Section 241(b) (Marshall, 2017). Although suicide was decriminalized in Canada in 1972, assisted suicide and euthanasia remained illegal (Marshall, 2017). Following the decriminalization of suicide, much debate ensued regarding whether individuals have the right to assisted suicide, particularly those afflicted with disabilities who are unable to commit suicide without assistance.

Before delving into some of Canada's landmark cases, it is important to draw the distinction between euthanasia and assisted suicide. The distinction lies in how actively involved a physician or another person (e.g. under Canadian legislation nurse practitioners are also permitted to participate) is in the termination of life. Assisted suicide is when one provides an individual with the means to end his/her own life. Euthanasia involves actively ending an

individual's life. For example, consider the prescription of a lethal medication. If a physician provides a patient with a prescription for a lethal dose of medication but the patient self-administers the drug, then it is considered assisted suicide, whereas if the physician administers the drug to the patient, it is considered euthanasia. In any given jurisdiction which permits some form of assisted death legislation, one practise may be legal while the other is not.

In the early 1990s, Sue Rodriguez challenged the prohibition of assisted suicide under Section 241(b) of the Criminal Code, claiming that it was unconstitutional (*Rodriguez v Canada*, 1993). She claimed the legislation violated her Section 7 rights to life, liberty, and security of person because she was not free to end her life with the assistance of a physician. Rodriguez was affected with amyotrophic lateral sclerosis (ALS), which would render her unable to commit suicide herself at a time when she no longer wanted to live. While able bodied Canadians could end their lives at any time, Rodriguez argued that her disability limited her ability to exercise this right at a time of her own choosing. Therefore, she argued that she had a right to assisted suicide due to her disability. Rodriguez took her case to the Supreme Court of Canada (SCC) after losing her challenge before both the Supreme Court of British Columbia and the British Columbia Court of Appeal. In 1993, the SCC upheld the law, maintaining that it was constitutional and does not violate Canada's Charter of Rights and Freedoms². Despite assisted suicide remaining illegal, Rodriguez received assisted suicide from an anonymous physician in 1994 (Beaudoin, 2018).

² While the majority of the SCC acknowledged that Sec. 241b violated Rodriguez's Sec 7 Charter Rights, they held that Sec. 1 of the Charter, which stipulates that other subsequent rights could be overridden if there was a greater public interest in doing so, still prevailed. That is, the majority of the SCC who ruled against SR argued that there was an overriding public interest in not granting SR her request, even though they acknowledged her Sec 7 rights would be violated.

Controversy over assisted suicide and euthanasia in Canada was heightened when Robert Latimer was charged with the murder of his severely disabled daughter in 1993 (*R v Latimer*, 2001). Affected with brain damage and recurring seizures that required medication and painful operations, Latimer asphyxiated his daughter with the fumes from the exhaust of his truck to relieve her of any current or future distress (*R v Latimer*, 2001). He was found guilty of second-degree murder in 1994, and again found guilty upon retrial, as ordered by the SCC, in 1997 (Butts, 2016). While many sympathize with Latimer, the key difference between Latimer's case and Rodriguez's is that Latimer performed non-voluntary euthanasia, to which his disabled child could not consent, while Rodriguez was voluntarily requesting assisted suicide as a competent adult (Butts, 2016).

Attempts were also made to legalize MAiD in a private Bill. Bill C-407 was introduced in 2005 and ended by the 2006 Canadian federal election (Bill C-407, 2004-5). The bill was reintroduced in a slightly revised version as Bill C-562, which was again ended by the election in 2008 (Bill C-562, 2007-8). Another private Bill, C-384, was introduced in 2009 and debated in the House of Commons (Bill C-384, 2009). However, the Bill failed to advance to the Justice and Human Rights committee by a vote of 59 to 228 (Canada, 2010).

In 2011, the law against assisted suicide was again challenged on the grounds that it was unconstitutional and violated Canada's Charter of Rights and Freedoms. That lawsuit was filed by the British Columbia Civil Liberties Association (BCCLA) on behalf of the families of Kay Carter, who had degenerative spinal stenosis, and Gloria Taylor, who had ALS (*Carter v Canada*, 2015). This time, The Supreme Court of British Columbia ruled in favour of the plaintiff.

However, the Court of Appeal for British Columbia overturned the ruling. BCCLA then appealed the decision to the SCC.

On February 6 2015, the SCC voted unanimously to allow physician-assisted suicide on the grounds that the existing law prohibiting assisted suicide violates the Canadian Charter of Rights and Freedoms. Specifically, “prohibition on physician-assisted dying infringes the right to life, liberty and security of Ms. Taylor and of persons in her position, and that it does so in a manner that is overbroad and thus is not in accordance with the principles of fundamental justice” (*Carter v Canada*, 2015, para. 56). One of the key differences between the 1993 challenge and the 2011 challenge is that by 2011 several European countries and American states had legalized assisted suicide or euthanasia under some circumstances, whereas in 1993 only Switzerland had legalized assisted suicide. Further, Quebec legalized MAiD in June 2014, which set a precedent locally and contributed to increased public support for legalization in Canada (Bill 52, 2014). Currently, there are three jurisdictions where ARs for MAiD are legal, each with different limitations and eligibility criteria. There are many important lessons to be learned from other jurisdictions across the world that have legalized MAiD, particularly those jurisdictions that have already legalized ARs for MAiD. This will be further explored in Chapter Two.

On June 17, 2016, Bill C-14, known as the Medical Assistance in Dying Act, became law (Bill C-14, 2015-16). The Bill sets out five eligibility criteria and many safeguards to protect those requesting MAiD. These four criteria include that individuals requesting MAiD: (1) are eligible to receive health services in Canada; (2) have a grievous and irremediable condition; (3) have made a voluntary request for MAiD that is free from external pressure; and (4) give

informed consent to MAiD after being informed of alternatives, including palliative care (Bill C-14, 2015-16). The criterion requiring a grievous and irremediable condition also has its own qualifying criteria set out in the legislation (Bill C-14, 2015-16). One of the most contested criteria is that an individual requesting MAiD must have a grievous and irremediable medical condition, where their *natural death* has become *reasonably foreseeable*. The *Criminal Code* has subsequently been amended this requirement by stating, “their death has become reasonably foreseeable, taking into account all of their medical circumstances, without a prognosis necessarily having been made as to the specific length of time that they have remaining” (Criminal Code, 1985). This leaves it up to the judgement of the nurse practitioner or physician when determining, in the case of dementia, if an individual’s death is reasonably foreseeable.

Further, the legislation also sets out numerous safeguards to prevent error and abuse in the provision of MAiD (Bill C-14, 2015-16). These safeguards include: (1) having two independent witnesses to the request for MAiD who cannot benefit in any way from the individual’s death; (2) the requirement of two independent medical opinions from physicians or nurse practitioners who agree that the individual meets the eligibility requirements including that the illness is grievous and irremediable, the patient has capacity, and has made a voluntary request to undergo MAiD; (3) the necessity of a waiting period of 10 days from the time of signing and dating the original request for MAiD until the provision of the procedure; (4) the individual must be informed of palliative care; and (5) express consent must be acquired right before the provision of MAiD (Bill C-14, 2015-16). The safeguard requiring that the individual is competent at the time of request and immediately before the provision of the procedure

restricts anyone with cognitive impairment from accessing MAiD. Other exclusions under Bill C-14 include minors, individuals with mental illness as a sole underlying condition, and those not eligible to receive health services funded by a government in Canada.

MAiD was legalized through Canada's legislative process wherein a public bill is developed and introduced, is considered and passed in the House of Commons and then the Senate before the bill receives Royal Assent to become law (Bill C-14, 2015-16). This traditional process emphasizes legal rights based on a top down approach, where members of government determine the fate of a particular law. This process may not accurately represent the views of Canada's population overall in a way that a referendum might, where Canadians can vote in favour of, or against, a particular law. However, given that there were several previous attempts to challenge assisted suicide legislation since the 1990s, there has been growing public interest in the area and many Canadians express concern about how they will die and the wish to control when and how their lives will end (*Rodriguez v Canada*, 1993; Bill C-407, 2004-5; Bill C-562, 2007-8; Bill C-384, 2009). This trend of increasing public interest combined with the legalization of assisted suicide in several other countries in the early 2000s likely contributed to the Supreme Court's ruling in favour of the legalization of MAiD in Canada.

Debate as to whether Bill C-14 actually reflects the ruling in the case of *Carter vs. Canada* exists. In Justice Smith's ruling, there is no mention of a requirement that the individual have a terminal illness or be near death (*Carter v Canada*, 2015). Yet, the MAiD legislation passed by the Trudeau government includes the stipulation that death must be "reasonably foreseeable" (Bill C-14, 2015-16). Although the law has been amended to capture a broader interpretation of reasonably foreseeable, as highlighted above, controversy remains regarding

whether the existence of this criterion is constitutional³. Whether or not the reasonably foreseeable criterion ought to be removed or not is beyond the scope of this paper. However, it does cause us to reflect on the appropriateness and subjectivity of the reasonably foreseeable death requirement.

Chapter Conclusion

This chapter outlines the road map for this thesis and provides background information on MAiD in the Canadian context. In Section One, I outline that the aim of this thesis is to set the current landscape of MAiD across jurisdictions, including Canada, in order to provide comparisons and suggestions for potential expansion of legislation to include ARs for MAiD. Further, I raise moral, legal and practical concerns with the expansion of ARs for MAiD and providing recommendations to mitigate such concerns. Ultimately, I explore notions of the self and several types of autonomy in order to develop a justification for the legalization of ARs for MAiD under specific circumstances. In Section Two, several landmark cases that challenged the law restricting assisted suicide and provoked public interest in the matter were discussed. These include *Rodriguez v British Columbia*, *R v Latimer*, and ultimately *Carter v Canada*, from which Bill C-14 was developed. Canada's MAiD legislation sets out five eligibility criteria and many legal safeguards to prevent error and abuse in the provision of MAiD. The legislative process through which MAiD was legalized in Canada indicates a top-down approach from government that emphasizes legal rights and may not represent the view of Canada's

³ Since the writing of this article, The Quebec Superior Court found on Sep 11 2019 in *Truchon and Gladu v. Canada* that restricting medical assistance in dying to individuals whose deaths are "reasonably foreseeable" is unconstitutional.

population overall. However, public interest has grown in discussing MAiD and many Canadians advocate their wish to have heightened control over the timing and circumstances of their death. Further concerns and challenges to the existing law are already in motion, as evidenced by the *Lamb v Canada* civil claim challenging the reasonably foreseeable death requirement. It is clear that this controversial and complex topic warrants further ethical discussion.

Chapter 2: Current State of Assisted Suicide and Euthanasia Worldwide

This chapter aims to set Canada's current situation with regard to MAiD legislation within the broader international context through comparison of legislation across jurisdictions that have already legalized assisted suicide or euthanasia. These countries include: the Netherlands, Belgium, Luxembourg, Switzerland, United States, Germany, and Columbia. Three of these jurisdictions, Netherlands, Belgium, and Luxembourg, have legalized ARs for MAiD in varying capacities. Note that this chapter aims to provide an overview of the legislation in each jurisdiction and is not intended to be a complete historical account or legal analysis.

I begin by highlighting some major commonalities in the legislation across jurisdictions. First, virtually every jurisdiction requires that a request for assisted suicide or euthanasia be voluntary and without external pressure. Generally, the right to assistance in ending one's life stems from a common desire to support individual autonomy surrounding the circumstances of one's death. Therefore, the requirement that a request be voluntary is a fundamental aspect of assisted suicide legislation. In each jurisdiction, a competent individual with decision-making capacity must voluntarily request assisted suicide or euthanasia, whether contemporaneously or via an advance directive. It is this latter point (i.e. the availability of making a request for assisted suicide through an advance directive) that is particularly relevant to the ongoing discussion here. Only three jurisdictions allow ARs for euthanasia, two of which require that the individual be irreversibly unconscious in order to implement the AR.

Further, all jurisdictions require that a physician be the individual who provides the MAiD procedure, with two notable exceptions. In Canada, a nurse-practitioner may also assess

an individual's decision-making capacity and carry out the MAiD procedure (Bill C-14, 2015-16). This exception was granted out of concern for individuals living in rural areas who may have difficulty accessing a physician, particularly a physician who does not conscientiously object to MAiD. In Switzerland, however, there is no requirement that a healthcare practitioner provide MAiD (Criminal Code, 1937). This responsibility has largely been taken up by nongovernmental organizations (Andorno, 2013). However, note that a physician is still required in order to assess an individual's eligibility for MAiD, including decision-making capacity, and to write the prescription for the lethal drug (Andorno, 2013).

All jurisdictions, with the exception of Switzerland and Colombia, require an additional physician (or nurse practitioner) to assess an individual's eligibility for MAiD. Colombia requires that a physician present the case to a committee which then determines the individual's eligibility. In Switzerland, there is no requirement for an additional physician to be consulted.

The final commonality between all jurisdictions, with the exception of Switzerland, is the restriction against suicide tourism ("Zurich votes", 2011). Although not explicitly stated in the legislation of the various jurisdictions identified earlier, most jurisdictions make it difficult for non-residents to gain access to assisted suicide or euthanasia. Some achieve this through requiring that the individual requesting assisted suicide or euthanasia have a long-standing relationship with the physician while others, including Canada, require that individuals are eligible to receive health services in that jurisdiction. Switzerland is the only jurisdiction where suicide tourism is legal, meaning a non-resident can travel to Switzerland to undergo assisted suicide ("Zurich votes", 2011). Since 1998, 64 Canadians have availed of assisted suicide

through Dignitas, one of the major nongovernmental associations providing assisted suicide services in Switzerland (Dignitas, 2019).

Section 1: MAiD in the Global Context

Subsection 1: Netherlands.

The Termination of Life on Request and Assisted Suicide (Review Procedures) Act came into effect in April 2002 and stipulates that euthanasia is still considered illegal in the Netherlands unless physicians have complied with all due care criteria (Termination of Life on Request and Assisted Suicide (Review Procedures) Act, 2002). Adherence to these criteria is determined by a regional review committee after the physician has completed the procedure. The Act contains many of the same eligibility criteria and due care criteria set out in Canada's legislation. However, Dutch legislation does not include any provision that natural death must be reasonably foreseeable. Individuals can also include a MAiD request in an advance directive. Specifically,

If the patient aged sixteen years or older is no longer capable of expressing his will, but prior to reaching this condition was deemed to have a reasonable understanding of his interests and has made a written statement containing a request for termination of life, the physician may carry out this request. The requirements of due care, referred to in the first paragraph, apply *mutatis mutandis* (Termination of Life on Request and Assisted Suicide (Review Procedures) Act, 2002, Article 2.2).

With parental consent, minors aged 12 and older are eligible to access euthanasia and can create a legally valid advance directive. Further, MAiD could be approved with mental illness as

the sole underlying condition as long as the physician believes the patient's suffering is lasting and unbearable (Termination of Life on Request and Assisted Suicide (Review Procedures) Act, 2002, Article 2.1.b). There is no requirement that an individual be in the terminal phase of illness. The Dutch euthanasia law also does not exclude access to MAiD for minors or non-citizens. However, the assessment requirement implies that a well-established relationship between physician and patient is required in order to prevent euthanasia tourism (Netherlands Ministry of Foreign Affairs, 2010). Overall, the Dutch Euthanasia Act is less restrictive than Canadian legislation. In 2017, 6585 people received assisted suicide or euthanasia in the Netherlands, which is 4.4% of the total deaths that year (Regional Euthanasia Review Committees, 2017, p. 9). This is up 0.4% from 2016, where 6091 people received assisted suicide or euthanasia (Regional Euthanasia Review Committees, 2017, p. 9).

Although the Netherlands legalized assisted suicide and euthanasia in 2002, the procedure and requirements had been routinely offered in the Dutch medical community for almost 30 years prior. This is because case law had been developing since 1973 wherein physicians would not be prosecuted if they acted carefully and considerately. The landmark case of 1973 was known as the Postma case, where Andries Postma, a Dutch physician, provided euthanasia to her severely disabled mother (Sheldon, 2007). Postma injected her mother with a fatal dose of morphine after her mother repeatedly begged Postma to end her life (Sheldon, 2007). Although Postma was found guilty of violating the law against euthanasia, she was given just 12 months probation and a one-week suspended prison sentence (Sheldon, 2007). This lenient sentence resulted from the courts accepting, for the first time, that euthanasia may be defensible under certain circumstances, which include a patient who has

an incurable illness, is suffering intolerably, and has repeatedly requested euthanasia. The Postma case, along with three others (Schoonheid, Chabot, and Brongersma), set a precedent and helped to define the 2002 legislation (Sheldon, 2007).

From 1973 to the mid- 1980s, the euthanasia and assisted suicide debate focused mainly on cases where the individual explicitly requested termination of life. However, the Rummelink report was released in 1991, which was the first official government study of assisted suicide and euthanasia (van Delden, Pijnenborg, and van der Mass, 1993). The most controversial finding in the report was that assisted suicide or euthanasia was provided without explicit request in 1,000 cases, which was 0.8% of all cases reported (van Delden, Pijnenborg, and van der Mass, 1993). As a result, further public debate ensued regarding whether assisted suicide and euthanasia should be legalized or remain criminal acts in the Penal Code with specific due care criteria that must be fulfilled to avoid prosecution. Further, debate centred on the definitions and parameters of the due care criteria. For example, in the Chabot case of 1994 the Supreme Court ruled that unbearable suffering can also result from mental suffering, such as from a psychiatric illness, rather than just physical suffering (Griffiths, 1995). In such cases, the individual must be assessed by at least two other physicians, including at least one psychiatrist. Further, the Supreme Court ruled that there are instances where assisted suicide or euthanasia may be justifiable even if the individual is not in a terminal stage of illness (Griffiths, 1995, p. 896).

The expansion of the due care criteria to include permissibility of advance requests for euthanasia has only occurred recently, in 2016. Few details are available in English regarding the challenge that prompted this change. Given that the Netherlands is the only jurisdiction

that has allowed the provision of euthanasia on the basis of advance directives, this will be a key jurisdiction of interest to Canada as we grapple with our own considerations of expansion.

The legislative process through which the Netherlands created legislation to maintain assisted suicide and euthanasia as illegal except when due criteria have been fulfilled, is very similar to Canada's legislative process for legalization of assisted suicide and euthanasia. However, the Netherlands generally adjusted its due care criteria in response to the Supreme Court rulings of cases where a physician was found guilty of violating the euthanasia law, including the Postma, Schoonheid, Chabot, and Brongersma cases mentioned above. In contrast, in Canada, challenges to the existing law largely came from individual advocates who were requesting assisted suicide or euthanasia, including the Rodriguez, Carter, and Taylor cases mentioned previously. While the legislative process resulting from Supreme Court rulings emphasizes a legal rights approach, the Netherlands has clearly demonstrated an openness to discussing difficult moral issues, and, as a result, regulating potentially problematic behaviours and acts, such as prostitution and abortion. The public interest in the assisted suicide and euthanasia debate in the Netherlands since the 1970s and beyond, combined with a national value centred on legalization and regulation, suggests that assisted suicide and euthanasia are supported by the population of the Netherlands as a whole. Where debate remains, however, is on the question of where to draw the line.

Subsection 2: Belgium.

The Belgian Act on Euthanasia has been in place since May 2002 (Belgian Act on Euthanasia, 2002). Note that the Belgian Act does not mention assisted suicide; euthanasia is

decriminalized but assisted suicide is not (Saad, 2017). The Act has many common features with Canadian legislation, where a time period between the successful request and the provision of MAiD is required. However, the waiting period of one month in Belgium only applies to individuals who are not terminally ill (Saad, 2017). Note that there is no requirement for an individual to be terminally ill or for their death to be reasonably foreseeable in order to access euthanasia. Further, until 2014, minors were not eligible to access euthanasia, unless they are emancipated. However, this aspect of the legislation was amended to allow a person of any age to access euthanasia or assisted suicide, as long as "the patient has attained the age of majority or is an emancipated minor, is competent or is still a minor who is capable of judgment, and is conscious at the time of making the request" (Saad, 2017, p. 199).

Many of the due care criteria established in Belgian euthanasia legislation are also shared with Canadian legislation. Belgium also shares aspects of its legislation with the Netherlands. The patient's death does not have to be reasonably foreseeable and patients with mental illness as a sole underlying condition are eligible. Individuals can include a request for MAiD in an advance directive only if they are the age of majority or an emancipated minor, in contrast to the Dutch legislation. One requirement for the advance directive to be followed in Belgium is that the individual must be irreversibly unconscious (Belgian Euthanasia Act, 2002, Section 4.2). This excludes many individuals from accessing euthanasia until they are in an acutely terminal phase of illness, including those afflicted with mild and severe dementia. The Act does not prohibit non-citizens from accessing euthanasia, and European citizens can use their European Union health insurance card to access euthanasia free of charge (Saad, 2017). In Belgium, when a physician provides euthanasia to a patient, the physician must submit a

registration form to the Federal Control and Evaluation Commission within four working days (Saad, 2017). The commission, comprised of sixteen individuals, then determines whether the euthanasia was performed in accordance with the criteria set out in the Act (Saad, 2017).

Similarly to the Netherlands, assisted suicide and euthanasia were prevalent before its decriminalization in 2002 (Saad, 2017). In fact, it is estimated that at least 4.4% of all deaths in Flanders, Belgium in 1998 were achieved illegally through the provision of euthanasia, assisted suicide, or ending the patient's life without his/her request (Deliens et al., 2000). In contrast to the Netherlands, however, the legislation was not based in case law because physicians were rarely prosecuted for performing euthanasia prior to 2002. Nine private euthanasia bills were submitted to Belgian Parliament between 1984 and 1996, all of which were unsuccessful (Saad, 2017).

The Federal Committee on Bioethics was formed in 1996 to provide an advisory role through presenting options representative of popular opinion, rather than providing recommendations (Meulenbergs & Schotsmans, 2002). One of the most significant initiators of the decriminalization of assisted suicide and euthanasia was the election in June 1999 (Saad, 2017) in which the Christian Democrats were defeated after nearly 40 years in power. Led by Liberals, in a coalition with Socialist and Green Parties, decriminalization moved quickly. By July 1999 several prior private bills were resubmitted to government and in December 1999, three bills were proposed by senators (Saad, 2017). The bill as presented underwent hundreds of amendments and after being accepted by the Joint Commission, the House of Representatives, and the Senate, the euthanasia bill was passed into law (Meulenbergs & Schotsmans, 2002).

Following decriminalization in 2002, there have been two amendments to the Act. The first amendment, enacted in 2005, decriminalizes the dispensing of a lethal prescription by a pharmacist, as long as the pharmacist is assured by a physician that due process has been followed (Nys, 2006). The second, and more notable amendment was enacted in 2014, which removes the restriction that an individual must be 18 to receive assisted suicide or euthanasia (Dan, Fonteyne, & de Cléty, 2014).

According to the most recent available data, there were 1807 reported deaths from euthanasia in 2013, which is in trend with a steady year-to-year increase since decriminalization in 2002. Of all of the reported cases since decriminalization in 2002, 62 cases involved an individual afflicted with dementia, and of those 62, only eight received euthanasia as a result of an advance euthanasia directive (Dierickx, Deliens, Cohen, & Chambaere, 2017).

The legislative process through which euthanasia was legalized in Belgium emphasizes legal rights, as euthanasia was ultimately legalized through the passage of a private bill. However, euthanasia legalization comes as no surprise to a nation that has been performing euthanasia for decades. Rather, it is likely one manifestation of a change in a societal moral belief. Prior to the decriminalization of euthanasia, the lack of prosecution of physicians performing illegal euthanasia, combined with formation of pro-euthanasia societies, demonstrates public interest in supporting euthanasia. Further, the nine private bills submitted to parliament between 1984-1996 demonstrate the positive political attitude towards euthanasia and an intensified public awareness of euthanasia. At the time, there was growing acceptance of euthanasia across Europe, which also coincided with a rapid decline in religiousness in Belgium (Cohen et al., 2006). Despite public interest in, and acceptance of,

euthanasia, the desire to change the law came largely from members of parliament. Although consultation of physicians and the general public took place, it was over a much shorter time period than consultation in the Netherlands, and physicians were largely excluded from the legislative process (Saad, 2017). Overall, it is clear that there is some tension and discrepancy between the practice of euthanasia and the formal legislation in Belgium.

Subsection 3: Luxembourg.

Following the Netherlands and Belgium, Luxembourg was the third jurisdiction to legalize euthanasia. The conditions set out in the *Loi du 16 mars 2009 sur l'euthanasie et l'assistance au suicide* are similar to that in Belgium's Euthanasia Act (Commission Nationale de Contrôle et d'Evaluation, 2017). In Luxembourg, legalization occurred on March 19, 2009 and legalizes both euthanasia and assisted suicide (Loi du 16 mars 2009 sur l'euthanasie et l'assistance au suicide, 2009). Prior to legalization, euthanasia was provided in secret or individuals would travel to Switzerland or the Netherlands to end their lives (Watson, 2009).

Unlike in the Netherlands and Belgium, where legislation was introduced by government, the euthanasia bill in Luxembourg was drafted and tabled by an MP and party deputy in 2002 (Watson, 2009). The bill passed narrowly by vote due to the dominant force of the Christian Socialist party, which was opposed to legalization (Watson, 2009). Following the vote, the current reigning monarch of the time, Grand Duke Henri, would not sign the bill into law, so the parliament amended the constitution to reduce the monarch's power (Watson, 2009). Ultimately, legislation came into force in April 2009.

Euthanasia posed particularly controversial and divisive debate prior to legalization in Luxembourg. As with all of the previous cases discussed, euthanasia legislation was passed through the traditional parliamentary legislative process, where a bill is drafted, tabled and voted upon by parliament. A notable difference in the case of Luxembourg is that the monarch still had the ultimate veto power in passage of a bill into law, which had to be amended in Luxembourg's constitution. Heated debate also ensued as the Catholic church launched a campaign against the legislation, while the young population largely supported the legislation (Watson, 2009). Despite the narrow pass in the parliamentary vote and opposition by the lead monarch, over 70% of the population supported legalization according to opinion polls (Watson, 2009).

Individuals are eligible to access euthanasia or assisted suicide if they are experiencing unbearable suffering as a result of a serious, incurable or irreversible condition. An additional physician must be consulted to confirm that the patient's condition is incurable. Individuals requesting euthanasia or assisted suicide must have capacity and make the decision free of external pressure. As a result of the requirement that individuals must have capacity, minors are not eligible to access euthanasia or assisted suicide. However, individuals can create an AR for euthanasia that can be enacted if the individuals end up in a state of irreversible unconsciousness.

The requirement that an advance directive only be invoked if the individual is unconscious is shared with Belgium's legislation (Nicol & Tiedemann, 2017, p. i). However, unlike in Belgium where the limit on the validity of an advance directive is five years, there is no such limit in Luxembourg (Nicol & Tiedemann, 2017, pp. 15-17). In Luxembourg, advance

directives are registered with the government, whose responsibility includes ensuring that every five years the advance directive is still reflective of the individual's wishes (Nicol & Tiedemann, 2017, p. 17). Although there is no requirement that the individual accessing euthanasia or assisted suicide be a citizen of Luxembourg, it is required that the physician must have been caring for the patient for a continuous and sufficient length of time (Nicol & Tiedemann, 2017, p. 17).

Since legalization in 2009, there have been a total of 52 euthanasia or assisted suicide cases, with ten of those occurring in 2016, and only one of the 52 deaths followed an AR (Commission Nationale de Contrôle et d'Evaluation, 2017). Of the ten reported cases in 2016, nine were considered euthanasia while one was considered assisted suicide (Commission Nationale de Contrôle et d'Evaluation, 2017). Within eight days of completing a euthanasia procedure, the attending physician must submit a questionnaire to a national committee consisting of nine members (Watson, 2009). The committee then determines whether the legislation was appropriately adhered to.

Subsection 4: Colombia.

Colombia is the only Latin American country where euthanasia has been legalized. The Constitutional Court declared euthanasia legal in 1997 (Judgement C-239, 1997). However, the Court did not order the Health Ministry authorities to develop guidelines for physicians to perform euthanasia until April 2015 (Resolution 1216, 2015). Without these guidelines in place, physicians refused to perform euthanasia out of fear of prosecution.

The Constitutional Court was formed in 1991 to review the constitutionality of any challenges or norms, but does not have any legislative power (Benavides, 2018). Given the ruling that euthanasia and assisted suicide ought to be legalized, the Court urged the Congress of Republic to pass legislation. However, no regulation was formed until the matter was reopened in the Constitutional Court T-970 ruling in 2014 (Judgement T-970, 2014). The ruling was in response to a man who was denied euthanasia by a health entity because it had not yet been regulated (Benavides, 2018). The T-970 ruling urged the Congress of the Republic to formulate legislation that regulates euthanasia in Columbia and the Health Ministry to develop practice guidelines accordingly (Judgement T-970, 2014). This resulted in the development of Resolution 1216 (Resolution 1216, 2015). One article states that 28 euthanasia cases have been reported to date, but a media source reports approximately 40 (Benavides, 2018; Trivino, 2018). I was unable to find any published data by the Colombian government, and I was limited to information translated to English.

Eligibility requirements include that the patient is an adult with capacity, and is in the terminal phase of his/her illness. Under judgement T-544 from the Constitutional Court in 2017, the law was amended to allow euthanasia for minors seven years and older (Judgement T-544, 2017). For cases where the minor is between seven and twelve years old, both parents must agree. For minors aged 12 to 14, if there is a discrepancy between the parents' wishes, the minor's wishes prevail. For minors aged 14 and older, the minor's wishes prevail (Resolution 825, 2018).

The law excludes those with degenerative conditions, such as dementia, from accessing euthanasia or assisted suicide (The World Federation of Right to Die Societies [WFRtDS], 2015).

If the patient is unconscious, there must be proof of a previously stated preference for euthanasia (WFRtDS, 2015). This is the same requirement as in Belgium and Luxembourg. There is no requirement that an individual must be a citizen to access euthanasia (WFRtDS, 2015). If the patient insists on euthanasia after being informed of all treatment options, the physician must then present the case to a committee comprised of a medical expert, a lawyer, and a mental health professional (WFRtDS, 2015). The committee then has 10 days to determine whether the patient is eligible for the procedure, and, if approved, the hospital then has 15 days to facilitate the euthanasia procedure (WFRtDS, 2015).

Colombia is the only jurisdiction where committee approval is required prior to provision of euthanasia. The Foundation for the Right to Die with Dignity (DMD) provides a document that covers treatment options for various illnesses and allows individuals to state their preference of euthanasia (WFRtDS, 2015). The document requires two witnesses to sign (WFRtDS, 2015).

Given that legalization of euthanasia occurred through the Constitutional Court, it is unknown whether this represented a majority of the populations' views on the issue. Euthanasia in Colombia is not a widely published or discussed topic. However, understanding the unique context of the healthcare system in Colombia is key. Colombia has very poor palliative care services, and as a result many patients die with unnecessary suffering and without appropriate support (Mendoza-Villa & Herrera Morales, 2016). Additional factors include lack of appropriate training for practitioners and poor communication or understanding due to educational or social barriers (Mendoza-Villa & Herrera Morales, 2016). Without adequate palliative care services, individuals may feel that euthanasia is their only option,

rather than viewing euthanasia as one possible option. It is also possible that only those who are privileged economically or socially may have the ability to choose palliative care and/or euthanasia services. These are crucial considerations for Canada as we look to potentially expand current legislation.

Subsection 5: Switzerland.

Switzerland has a unique position on assisted suicide. The Swiss Criminal Code of 1937, which came into force in 1942, considers assisted suicide illegal only if the motive is selfish. Article 115 of the Code states:

Any person who for selfish motives incites or assists another to commit or attempt to commit suicide is, if that other person thereafter commits or attempts to commit suicide, liable to a custodial sentence not exceeding five years or to a monetary penalty (Criminal Code, 1937, Art. 115).

This means that it is legal to assist someone in suicide as long as the individual's motives are unselfish. Notably, there is no stipulation that the assistance must be provided by a physician (Criminal Code, 1937). This means that the law separates the permissibility of assisted suicide from the determination of who ought to provide it. In contrast, several other jurisdictions require that physicians (and nurse practitioners in Canada) can provide MAiD for patients. In these jurisdictions, the law combines the permissibility of euthanasia or assisted suicide with the determination of who ought to provide it.

In principle, anyone can provide assistance in suicide in Switzerland. Physicians do not themselves actually provide direct assistance in suicide. Rather, the physician's role is limited to

prescribing the lethal drug and assessing the patient's decisional capacity. Since the 1980s, assisted suicide has been provided by volunteers working for nongovernmental organizations, such as Dignitas. Since these organizations do not, in principle, have any selfish motive for assisting someone to commit suicide, their activities are not illegal.

Interestingly, however, euthanasia remains illegal in Switzerland. Article 114 in the Swiss Code stipulates:

Any person who for commendable motives, and in particular out of compassion for the victim, causes the death of a person at that person's own genuine and insistent request is liable to a custodial sentence not exceeding three years or to a monetary penalty (Criminal Code, 2917, Art. 114).

Articles 114 and 115 contrast that it is legal to assist an individual in ending his/her own life, but illegal to directly cause the individual's death, even at his/her explicit request. The Code specifies that the individual is required to have capacity at the time of the request, so assisted suicide cannot be included in an advance directive in Switzerland. This condition restricts minors and those with psychiatric conditions deemed to lack capacity from accessing assisted suicide.

When assisted suicide occurs in Switzerland, it is considered an "unnatural death" and reported to police (Hurst and Mauron, 2003). An inquiry takes place, and the case is dismissed unless there is evidence of a selfish motive or doubt is raised regarding whether the individual was competent to make an autonomous choice (Hurst and Mauron, 2003). Since there is no requirement that assisted suicide must be completed by a physician or that the individual must

be a non-foreigner, Switzerland has become a common place for assisted-suicide tourism, including for Canadians. This resulted from a referendum in 2011, where Zurich voters heavily rejected a ban on suicide tourists (“Zurich votes”, 2011). Notably, even with Canada’s existing MAiD legislation, some who are not eligible under current Canadian legislation are travelling to Switzerland to end their lives (Hill, 2018).

Although assisted suicide was legalized more than 75 years ago in Switzerland, two referendum votes in the canton of Zurich in 2011 showed strong support for the continued legalization of assisted suicide and amending the law to allow foreigners to access assisted suicide in the country (“Zurich votes”, 2011). This is a strong indication that Switzerland’s assisted suicide legislation is representative of the majority of the populations’ beliefs. In the most recent report published by the Swiss government, 742 cases of assisted suicide were reported in 2014, which accounted for 1.2% of all deaths that year (Federal Statistical Office, 2016). There were 26% more cases in 2014 compared to 2013, and this figure has increased every year since 2008 (Federal Statistical Office, 2016).

Subsection 6: Germany.

Before Bill 18/5373 was passed in 2015, several bills were developed, but none entered German Parliament (Team Germany 1, 2016). A bill in 2006 and 2010 were initiated by several counties to the Lower House of German Parliament, meanwhile a bill in 2012 was initiated by government itself (Team Germany 1, 2016). Several bills entered German Parliament in 2015 (Team Germany 1, 2016). The first aimed to legalize assisted suicide in the German Civil Code with strict requirements, but this bill could not win a majority of votes in Parliament (Team

Germany 1, 2016). The next approach was to develop a completely new code rather than amending the current Civil or Criminal Code, but again the bill was not passed (Team Germany 1, 2016). Bill 18/5373 was ultimately passed and was similar to the bill proposed in 2012 in that it prohibited commercial assisted suicide (Team Germany 1, 2016). The successful bill emphasized the legal distinction between assisted suicide and euthanasia, and the importance of palliative care (Team Germany 1, 2016).

Prior to the amended criminal code, assisted suicide was not strictly criminalized and therefore was left unregulated (Team Germany 1, 2016). Rather, acceptable acts were determined from existing law and its interpretations set out in cases and the guidelines set out by medical and physician associations (Team Germany 1, 2016). Due to the lack of regulation and risk involved, most Medical Associations' codes of conduct prohibited assisted suicide (Team Germany 1, 2016).

One notable example of the interpretation of the prior law is demonstrated in the *Sirius* case of 1983, where an individual convinced another individual that he/she would be reincarnated into a better life if he/she committed suicide (Bohlander, 2008, pp. 157-158). After the individual attempted suicide, the accused was charged with, and convicted of, attempted murder (Bohlander, 2008, pp. 157-158).

In July 2015, Bill 18/5373 was passed by German Parliament (BT-Drs. 18/5373). In November 2015, German parliament amended its criminal code so that section 217 exempts anyone from prosecution who promotes or procures suicide for another person provided they do not do it for commercial or business means (StGB, section 217). This is similar to

Switzerland's legislation, in that assisted suicide is legal if assistance is not provided for commercial means. An individual cannot be prosecuted for suggesting voluntary suicide or for assisting an individual through the provision of resources such as lethal drugs (Team Germany 1, 2016). This also means that there is no requirement that physicians solely can provide assisted suicide. In fact, physicians may be fearful that they may be prosecuted in such cases if garnering a fee or profit for their services could be viewed as assisting suicide via commercial means (Zenz, Rissing-van Saan & Zenz, 2017). Despite assisted suicide being legalized, euthanasia remains illegal as defined in section 216⁴ (StGB, section 216).

Given that assisted suicide legislation was proposed by the government and passed in German Parliament, it is uncertain whether the legislation represents the majority of the German populations' views. Given that Germany is a pluralistic society with varying morals and beliefs, even within religious groups, it was key to form legislation that could accommodate this pluralism. No published data could be found regarding the number of assisted suicide cases to date.

Subsection 7: United States.

Bills proposing legalization of assisted suicide in the United States began as early as 1906 in Ohio (Emanuel, 1994). Assisted suicide re-entered the public eye in the 1990s when Dr. Jack Kevorkian assisted suicide for more than 40 individuals in Michigan (Angell, 1997). Although he was charged with murder, the charges were dropped in 1990 because there were

⁴ The amended version of the German criminal code was referenced using Google translate, as there is no official English translation available. As a result, the information provided above may not completely match the intended wording.

no laws against suicide or assisted suicide (Angell, 1997). Further, the *Glucksberg vs Washington* case filed in 1994 saw several physicians and patients, and a non-profit organization, challenge the ban on assisted suicide in Washington (521 US 702, 1997). Although the ban was upheld by the Supreme Court in 1997, the case confirmed that individual states can determine their own legislation. Oregon provides the first example of state legislation, as the Death with Dignity Act was first voted to pass by referendum in 1994, and voters chose to retain the Act in 1997, resulting in the law coming into force (Oregon Health Authority, 2019).

Assisted suicide legislation in the United States has been developed at the state level rather than the federal level. Six states have legalized assisted suicide via legislation: California, Colorado, Washington, Hawaii, Oregon, and Vermont, while Montana legalized assisted suicide via court ruling in 2009 (Oregon State Legislature, 1994; Washington State Legislature, 2009; *Baxter v Montana*, 2009; Vermont State Legislature, 2013; California State Legislature, 2015; Colorado Secretary of State, 2016; Hawaii State Legislature, 2018). Although it is not considered a state, Washington DC also legalized assisted suicide via legislation in 2016 (District of Columbia Council, 2016). The law was first adopted in Oregon in 1994, followed by Washington State and Montana in 2009, Vermont in 2013, California in 2015, Colorado in 2016, and Hawaii in 2019.

Upon examination of the various pieces of legislation just referenced, it is noted that the legislation is very similar in each of the states. For example, all stipulate that the illness must be in its terminal stage, with death expected within 6 months and only residents of the specific state are eligible to receive assisted suicide within that state. Most notably, physicians cannot actively be involved in the assisted suicide, meaning the individual must self-administer the

lethal drug. The role of physicians is limited to the prescription of the lethal drug and assessment of the patient's decisional capacity. Assisted suicide cannot be included in an advance directive, and is restricted from minors and those with a mental illness who are deemed to lack capacity. After two oral requests by the patient with a waiting period between each request and the individual is approved by a physician, the individual picks up the prescription from a pharmacist and administers the medication to him/herself in the individual's own home. This contrasts with other jurisdictions where the physician is present when the individual self-administers the lethal medication.

All assisted suicides must be reported in the State where the death occurred and this information is compiled into detailed annual reports. Oregon and Washington have the most data, as assisted suicide has been legal for the longest period of time in these states. Data shows that there has been a consistent increase in death by assisted suicide every year since legalization, with 143 cases in Oregon and 177 in Washington in 2017 (Oregon Health Authority, 2018; Washington State Department of Health, 2018). A majority (75%) of individuals accessing assisted suicide have cancer and tend to be older, white, and well-educated (Oregon Health Authority, 2018; Washington State Department of Health, 2018). Crucially, commonly cited motives for accessing assisted suicide are loss of dignity and quality of life through not being able to enjoy day-to-day activities, rather than inadequate pain control (Oregon Health Authority, 2018; Washington State Department of Health, 2018). This suggests that the desire for assisted suicide is not due to a lack of access to palliative care services, as 88-90% of individuals were enrolled in hospice care when they ingested the lethal medication (Oregon Health Authority, 2018; Washington State Department of Health, 2018).

As noted earlier, Montana legalized assisted suicide via Supreme Court ruling but has not yet developed legislation. Vermont, California, Washington DC, and Hawaii legalized assisted suicide through legislation, while Oregon, Colorado, and Washington State legalized assisted suicide via referendum. It is clear that the assisted suicide legislation in Washington, and Colorado is supported by a majority of the population, as voters enabled the bills to be enacted via referendum. It is more difficult to determine the populations' beliefs in other states that developed legislation without a public vote. However, a 2017 poll determined that 73% of Americans overall are in favour legalizing assisted suicide (Wood & McCarthy, 2017).

Chapter Conclusion

This chapter outlined the current assisted suicide or euthanasia legislation in the eight countries that have legalized one or both of these practices, and provides an overview of the similarities and differences in assisted suicide and euthanasia legislation across the globe. Some of the political and social history behind each jurisdiction's legislation is described, along with any key cases and the legislative process through which assisted suicide or euthanasia became legal. The current legislation is explored in detail, including eligibility criteria, legal safeguards, and key amendments to the legislation since its inception. These pertinent details are also summarized in Table 1 on the following page. This deep knowledge of the history and details of assisted suicide and euthanasia legalization across the world is key when considering some of the major concerns and potential ways to mitigate such concerns associated with whether to expand MAiD legislation to include ARs.

Overall, three jurisdictions have legalized ARs for MAiD, including the Netherlands, Belgium, and Luxembourg. Belgium and Luxembourg allow ARs for MAiD to be created only if the sole criterion for implementation is that the individual irreversibly unconscious. This requirement does allow individuals with dementia to create an AR. However, it would only be implemented if the individual becomes irreversibly unconscious. The Netherlands has no requirement that the individual be irreversibly unconscious. ARs for MAiD were legalized only recently in 2016, so this will be an important jurisdiction to watch closely.

Note that each of the three countries listed above allow the provision of MAiD for individuals with dementia, without the requirement of an AR. This is because there is no requirement in these jurisdictions that the individual's death be reasonably foreseeable. In Belgium, Luxembourg, and the Netherlands, individuals with early stage dementia can access MAiD, as long as they meet all other due care criteria as set out earlier in this chapter. This is another potential avenue for individuals with dementia to access MAiD; however, it is not within the scope of this thesis.

Summary Chart⁵

| | Canada | Netherlands | Belgium | Luxembourg | Switzerland | United States | Colombia |
|--------------------------------|--|--|--|---|---|---|--|
| Assisted Suicide or Euthanasia | Both | Both | Euthanasia | Both | Assisted Suicide | Assisted Suicide | Both |
| Year of Legalization | 2016 | 2002 | 2002 | 2009 | 1942 | 1997, 2009 (2), 2013, 2016 (3), 2019 | 1997/2015 |
| Legislative Process | Supreme Court Ruling (Patient) | Supreme Court Ruling (Physician) | Parliament via Private Bill | Parliament via Private Bill | Swiss Criminal Code | Referendum, Supreme Court Ruling | Constitutional Court Ruling |
| Eligibility Criteria | <ol style="list-style-type: none"> 1. Eligible for Canadian health services 2. 18 years old with capacity 3. Grievous and irremediable medical condition defined by: <ul style="list-style-type: none"> -serious and incurable illness -advanced state of irreversible decline | <ol style="list-style-type: none"> 1. Unbearable suffering 2. Voluntary and persistent request 3. Fully aware of condition, prospects, and options 4. No reasonable alternative 5. Consult at least one other physician | <ol style="list-style-type: none"> 1. Age of majority, emancipated minor, or minor capable of judgement 2. Well-considered, repeated request without coercion 3. Unbearable mental or physical suffering resulting from | <ol style="list-style-type: none"> 1. Legally competent at time of request 2. Voluntary, repeated request without external pressure 3. Unbearable physical or mental pain and incurable condition 4. Physician must discuss other alternatives, | <ol style="list-style-type: none"> 1. Unselfish motive for assisting suicide 2. Fully competent adult | <ol style="list-style-type: none"> 1. Competent adult (18+) 2. Terminal illness with less than 6 months to live 3. Two oral requests with a 15-day waiting period 4. Two day waiting period between final request and | <ol style="list-style-type: none"> 1. Terminal illness 2. If unconscious, must show previous preference for euthanasia 3. Voluntary consent 4. Physician must present all other options 5. Physician must present |

⁵ Germany was not included in this chart due to lack of an English translation of the Criminal Code or other government published information.

| | Canada | Netherlands | Belgium | Luxembourg | Switzerland | United States | Colombia |
|---------------------------------------|--|--|--|--|-------------|-----------------------|--|
| | Intolerable suffering -reasonably foreseeable death 4. Voluntary request 5. Informed consent, including palliative care | 6. Death carried out with physician present 7. At least 12 years of age (with parental consent) | incurable disorder 4. Discuss options including palliative care and determine no acceptable alternative 5. Consult additional physician and nursing team (if applicable) | including palliative care 5. Consult additional physician | | dispensing medication | case to committee to determine eligibility |
| Minors | No | Yes, 12+ | Yes | No | No | No | Yes, 7+ |
| Mental illness as sole condition | No | Yes | Yes | No | Yes | No | No |
| Advance directive | No | Yes, 12+ | Yes-must be unconscious | Yes-must be unconscious | No | No | Yes-must be unconscious |
| Terminal Illness Required | Yes- "reasonably foreseeable death" | No | No | No | No | Yes- <6 months | Yes |
| Physician only | No- also NP | Yes | Yes | Yes | No- anyone | Yes | Yes |
| Voluntary and Well-Considered Request | Yes | Yes | Yes | Yes | Yes | Yes | Yes |

| | Canada | Netherlands | Belgium | Luxembourg | Switzerland | United States | Colombia |
|-----------------------------------|--------------|---------------------------------|------------------------------------|---------------------------------|-------------|--|--|
| Unbearable Suffering | Yes | Yes | Yes | Yes | No | No | No |
| No Reasonable Alternative | Yes | Yes | Yes | Yes | No | No | Yes |
| Consult Additional Physician | Yes | Yes | Yes | Yes | No | Yes | No-present to committee |
| Waiting Period | Yes- 10 days | No | Yes- 1 month if not terminally ill | No | No | Yes-15 days | Yes- within 15 days after committee approval |
| Residency Requirement | Yes | Yes (Not explicitly in the law) | Yes (Not explicitly in the law) | Yes (Not explicitly in the law) | No | Yes-state | No |
| Number of Successful Cases (Year) | 2704 (2017) | 6585 or 4.4% (2016) | 1807 (2013) | 10 (2016) | 742 (2014) | 143 in Oregon and 177 in Washington (2017) | No reliable data |

Chapter 3: Theoretical Considerations

This chapter explores the theoretical considerations at the root of whether or not to expand legislation to include ARs for MAiD, with particular consideration of the dementia condition. At the heart of this discussion is differing notions of the self, including both the stable and dynamic self. The way in which these notions of the self relate to interests and autonomy will be outlined as conceptualized by Dworkin, Dresser, and McMahan. I suggest that some aspects of each theorists' positions are convincing, while others are unconvincing, and highlight each of these aspects. The concept of the ecology of dementia⁶ is also presented and discussed, which is a systems approach wherein the notion of the self both shapes and is shaped by an entire network including loved ones, the healthcare team, and society more broadly. I suggest that this systems approach provides the optimal framework from which to view individuals in a relational and holistic manner, and support ongoing identity changes associated with a loss of capacity. This approach provides a new and more nuanced perspective from which to view the issue of whether or not to expand MAiD legislation to include ARs in Canada, with particular consideration of individuals with dementia.

The conceptualizations of Dworkin, Dresser, and McMahan shape and inform my concerns and recommendations provided in Chapter Four regarding the potential legalization of ARs broadly, with particular consideration of the dementia condition, and my arguments regarding to what extent ARs for MAiD ought to be legalized in Canada, provided in Chapter

⁶ The ecology of dementia is not a normative theory, but rather a social-psychological construct that aims in the first instance to be descriptive in nature. This means that it explains the nature of the evolving self within a broader ecosystem approach. While this description may have normative implications, the ecological perspective is not a normative theory per se.

Five by establishing a balance between the prioritization of the former competent self's critical interests and the current incompetent self's experiential interests. The concept of the ecology of dementia grounds the thoughts and ideas presented throughout Chapters Four and Five by viewing the individual within the context of a network, and thus emphasizing relational autonomy.

Section 1: Notions of the Self

The notion of the self has long been discussed and debated in philosophy (Gevirtz, 2014). In the context of formerly competent individuals, there are two notions of the self at play: the current self and the former self. Formerly competent individuals include those who once had decision-making capacity, referred to as the former self, but have lost capacity as a result of a condition such as dementia. As a result of the condition, the current self no longer has capacity. In such cases of formerly competent individuals, it is widely accepted that respect for autonomy trumps beneficence or the 'best interests' of an individual whenever possible (Jaworska, 2017, sec. 1).

If, ordinarily, we ought to respect patient autonomy rather than impose our own judgments on patients, we ought to respect autonomy even after the patient has lost decision-making capacity; and we can do so by following or reconstructing, as best we can, the autonomous decision the patient would have made himself when faced with the current circumstances (Jaworska, 2017, sec. 1).

From this perspective, certain aspects of the self are considered stable, giving force to the idea that “the self is malleable, susceptible, and created by the workings of the body and the mind, but there is only one self and it stays with the person” (Gevirtz, 2014, p. 16).

The position prioritizing respect for autonomy for formerly competent individuals has challenges, namely the concern that the earlier competent self and the current incompetent self may have conflicting interests. This challenge is particularly relevant for those with dementia, because their decline in cognition can cause drastic changes in interests. Dworkin, a legal scholar, was the first to conceptualize these interests, which he termed critical and experiential interests (Dworkin, 1993). According to Dworkin, critical interests are the goals and hopes that lead to meaning and coherence in our lives, such as raising children, achieving success in a job, or completing an AR (Dworkin, 1993). Experiential interests are those activities or day-to-day moments from which we simply derive enjoyment, such as playing baseball or eating ice cream (Dworkin, 1993).

Subsection 1: Dworkin

Dworkin believes that the former mature, older adult self has special authority over the current self. Dworkin argues that the individual affected with dementia retains his/her critical interests, because all day-to-day experiences affect the value of his/her life as a whole, even when he/she is incompetent (Dworkin, 1993, pp. 236-7). For example, if the individual experiences a great degree of suffering and fear, these experiences impact the individual’s value of life as a whole even if the individual is no longer competent and no longer has the capacity to value. Dworkin supports his argument through discussion of three ethical principles:

precedent autonomy, beneficence, and dignity. Precedent autonomy is one way of expressing critical interests, as currently competent individuals can set out their wishes, such as treatment preferences, for their future incompetent self in a living will. Respecting an individual's precedent autonomy supports Dworkin's argument that former decisions, as set out in an AR (or other method of expressing critical interests), "remain in force because no new decision by a person capable of autonomy has annulled it" (Dworkin, 1993, p. 227). Thus, he argues, treating a patient in contradiction with his/her previously set out wishes fundamentally violates his/her autonomy. The duty of beneficence, as Dworkin presents it, requires that we honour the individual's life narrative through respecting, rather than overriding, the individual's directives. Dworkin also appeals to human dignity. Although individuals with advanced dementia no longer have critical interests, he argues that we must treat individuals as if they retain these critical interests, in an appeal to the human dignity owed to all persons. Overriding an individual's critical interests denies him/her human dignity (pp. 235-6).

There is a threshold at which point the former self has authority over the current self, where the former self is the individual when still competent and the current self is incompetent. For Dworkin, this threshold is reached when the current individual no longer has the capacity for autonomy. Despite Dworkin's clear assertion of such a threshold, determining whether the former competent self or the current incompetent self takes priority is nuanced and challenging. For example, Dworkin argues that individuals with dementia and those in a vegetative state are in the same position, with one important difference:

"I can think about my best interests were I to become permanently vegetative with no concern about any conflict of interests: if I am convinced that it would spoil my life to be

kept alive for years as a vegetable, I can act on that conviction with no prospect of conflict—by signing a living will directing that I be allowed to die. But I know that if I become demented, I will probably want to go on living, and that I may then still be capable of experiential interests” (Dworkin, 1993, p. 230).

I find Dworkin’s point above regarding those who are irreversibly unconscious convincing with respect to the lower level of potential conflict. Unlike with the high variability in experiences with dementia, any individual can consider what it would be like to be irreversibly unconscious and reflect on whether this is a quality of life with which they would like to live. Also, unlike those with dementia, individuals who are irreversibly unconscious have no experiential interests that could possibly conflict with their critical interests, as set out in a living will or AR when they were still competent. This critical difference is central to my argument set out in Chapter Five that at any time, whether before or after a grievous and irremediable diagnosis or before or after MAiD eligibility, it ought to be legal for an individual to create an AR where the sole criterion for implementation is that the individual is irreversibly unconscious.

In his priority given to critical interests, Dworkin fails to address the time-sensitive nature of critical interests. This is because the critical interests set out by individuals when they were eighteen years old are almost certainly no longer applicable to a seventy-year-old individual with dementia. In giving priority to critical interests, it is crucial that the critical interests are still relevant to the current notion of the self. Time, and the strength of the psychological ties between the former and current self, are crucial in considering which interests to give priority. This consideration of time and psychological ties is where McMahan’s

prudential concern (to be discussed below) is superior to Dworkin's complete priority of the critical interests of the former self.

Subsection 2: Dresser and McMahan.

Dresser offers several insights in response to Dworkin's argument that critical interests ought to take priority over experiential interests (Dresser, 1995). Dresser argues that precedent autonomy should be assigned less moral authority than contemporaneous interests because Dworkin's endorsement of strict adherence to critical interests "leaves no room for the changes of heart that can lead us to deviate from our earlier choices" (Dresser, 1995, p. 35). For example, if a competent individual creates an AR for MAiD, with the AR set to be implemented once the individual no longer has capacity, the individual no longer has the ability to change his/her mind. Given that individuals are poor predictors of how they will cope with certain living conditions and that others rate the quality of life of certain individuals with a condition lower than the individual rates his/her own quality of life when living with the particular condition⁷, I find Dresser's concern in this regard highly compelling. This level of uncertainty regarding whether an individual lacking capacity may have changed his/her wish to receive MAiD if he/she had capacity is fundamental to my arguments surrounding whether MAiD legislation ought to be expanded to include ARs. This concern, and potential recommendations for mitigating such concerns in various contexts are suggested in Chapter Four, and the resulting level of uncertainty is used as reasoning in Chapter Five regarding whether Canada ought to expand MAiD legislation to include ARs broadly, and particularly for those with dementia.

⁷ See page 74 for discussion.

Further, Dresser challenges Dworkin's claim that most people want their lives to have narrative coherence, as expressed through critical interests. Rather, Dresser (1995) suggests that "the goal of establishing a coherent narrative may be a less common life theme than the simple effort to accept and adjust to the changing natural and social circumstances that characterize a person's life" (p. 36). This is a significant consideration in the context of dementia, because the nature of the condition itself results in significant psychological and identity changes. According to personal identity theory, the psychological changes caused by dementia may produce a new person with a weak connection to whom they once were (Dresser, 1995, p. 35). Dresser's argument establishes that the significant psychological changes associated with dementia result in an individual who is fundamentally no longer the same person, and therefore, the former competent self can have no authority over the current self. This is at odds with Dworkin's notion of the self, where some aspect of an individual remains stable. Dresser's challenge supports a notion of the self where psychological changes, such as those resulting from dementia, can result in a completely changed self where the interests of the former self are not relevant to the current self.

In a similar vein, McMahan (2002) applies the concept of prudential concern to the weak psychological ties between the former and current self. Prudential concern is a unique type of concern for our past, present, and future selves (McMahan, 2002). McMahan argues that one's prudential concern over two different stages of one's life ought to decrease in proportion to the decrease in psychological ties between the two stages of life. This means that the greater psychological change that occurs between the former and current self, the less prudential concern the former self can have over the current self. Given the significant

psychological change associated with conditions such as dementia, the former self generally has very little authority over the current self due to the limited prudential concern the former self had for the current self. Therefore, McMahan suggests that the interests of the former self be treated independently from the interests of the current self (McMahan, 2002). However, he does note that in cases where the interests of the former self conflict with those of the current self, the former self's interests ought to take priority because the former self's interests are more substantial given that the cognitive abilities of the current self prevent the individual from having substantial interests (McMahan, 2002, pp. 502-3). In this way, McMahan applies a distinct notion of the self from Dworkin and Dresser, wherein the individual has a stable self, but the significant psychological changes associated with dementia mean that the dynamic aspects of the self have stronger moral authority.

McMahan's concept of prudential concern is more compelling than Dresser's take on the psychological changes experienced by those who lose capacity, particularly with dementia. I find that Dresser's argument that the psychological changes undergone in the dementia condition result in a completely changed self is problematic. An individual's physical self remains stable and many loved ones still view an element of the individual as stable that goes beyond the physical. If loved ones viewed the individual as having a different self, or being a different person, it is unlikely they would continue visiting with them and treating them as a loved one might. This is contrary to the many experiences by devoted loved ones in continuing to care for their family member afflicted with dementia. Further, when individuals contemplate their future as an individual lacking capacity, the individual still sets out plans and wishes for that time when they no longer have autonomy. This means that individuals also view some

central aspects of themselves as stable, even with significant psychological changes, such as those resulting from dementia. It is crucial to recognize the individual as the same person, yet also recognize that the former competent self may have little prudential concern over the current competent self. This is because time and differing life stages weaken the concern that the former self can have over the current self. McMahan's concept of prudential concern is applied to my argument in Chapter Five that, as the legislation currently stands, we ought not to legalize ARs for individuals with dementia. The concept is also applied to support my argument in Chapter Five that ARs ought to be legalized for those who have a grievous and irremediable diagnosis and are already eligible for MAiD (this group inherently excludes those with dementia).

Subsection 3: Chapman and The Ecology of Dementia.

Michael Chapman, a geriatrician and palliative care physician, argues that dementia cannot be understood comprehensively as an experience of individuals (Chapman, Philip, & Komesaroff, 2019). The concept of the ecology of dementia suggests that rather than being an individual's disease, dementia is an ecological state involving interaction between systems and their environment (Chapman, Philip, & Komesaroff, 2019). The changes in roles and responsibilities reshape and redefine the identities of the individuals, family, and healthcare team, and the meaning between these connections is influenced by broader social factors and beliefs (Chapman, Philip, & Komesaroff, 2019). As such, dementia is experienced by entire networks of people, rather than just the individual (Chapman, Philip & Komesaroff, 2019).

The concept of the ecology of dementia is distinct from Dresser, Dworkin, and McMahan's positions regarding which notion of the self ought to be prioritized in one important way: the self is not viewed as an individual. Rather, the ecology of dementia views the individual as entirely relational within a larger network of family, friends, and outward to greater society. Dworkin, Dresser, and McMahan treat individual life narratives as largely an individual story, and their debate is about which stage of that narrative ought to take precedence in the discussion about ARs for MAiD. Chapman, on the other hand, sees individual narratives as intimately connected to a broader context of other life narratives (i.e. an ecological conception) such that the issue of which life stage or notion of the self should take precedence has less significance to the discussion. A further issue, however, might be whether or how to gauge what a healthy or functional ecology is compared to an unhealthy or dysfunctional ecology. This is not within scope of this paper.

To help illustrate the ecology of dementia at work, Chapman, Philip and Komesaroff (2019) examined fifteen dementia networks that revealed stable changes, known as first order changes, and transformative changes, known as second order changes. First-order stable changes reinforce existing structures or views. For example,

Ken, a senior academic, responded to his dementia diagnosis with denial, disregarding it as a "fad". Sarah, his wife, continued to assume that his capability was unchanged and structured her life around their ongoing independent lifestyle. Meanwhile the minimally involved geriatrician assumed that just providing the diagnosis, as was the focus of her view of her role, had met the needs of these capable people. The perturbation of status changes associated with the diagnosis thus resulted in a first-order change process that

stabilised current views of the independence and capacity of the “individuals” within the system (Chapman 2018, p. 3).

In contrast, there are significant changes in structures and meaning within networks that undergo second-order transformative changes. For example,

Here Frank, the person with dementia's, decline was becoming more certain but differences in how this was interpreted exposed a network transformation. Frank felt confident that his death would bring him closer to his god. Julie worried about how frustrating she now found Frank, and wished he would die quickly to avoid further changes. And, Tony was confident that Julie and Frank wouldn't be able to cope with the challenges ahead and would be unable to learn from them spiritually. In this case, the perturbation of dealing with the future was associated with a re-interpretation of what was understood and valued by the network, without a unified resolution (Chapman, 2018, p. 3).

These examples are simply static snapshots in time. System changes are constant and fluid, and are also experienced and influenced by communities. The determination to understand those with dementia speaks to the fundamental relational aspect of people. Systems thinking, therefore, provides a way to reflect on how we contribute to dementia through culture and language, such as referring to dementia as a monster, the “war on dementia”, or simply as absence of self (Chapman, Philip & Komesaroff, 2019). Rather than trying to find a static or unchanging person with dementia, Chapman et al argue we must view the individual as though their identity is constantly changing. “Autonomy” on this view functions more as reactive engagement rather than independence (Chapman, Philip & Komesaroff, 2019). This means that rather than viewing autonomy as a decision of a sole

individual in an isolated context, we must view autonomy as being influenced by, and reactive to, the entire network surrounding the individual. As a result, the concept of individual is not overly useful. Rather, relational autonomy⁸ provides a better conceptualization for understanding and supporting the decision-making process.

The ecology of dementia relates closely to Dresser's critique in that it emphasizes the dynamic notion of the self through the significant psychological changes associated with dementia. While the concept of ecology of dementia is not a direct critique or outlook on the ethics of ARs for those with dementia, it does suggest a perspective that gives authority to the current self, where the dynamism ought to be embraced. This means that the changing identity and its corresponding impact on autonomy ought not to be considered a loss but merely a change that requires accommodation and support by the wider network. In contrast to Dresser's argument that the personal identity of the individual changes as a result of the psychological changes brought on by dementia, the perspective espoused by Chapman, Philip and Komesaroff (2019) challenges the "simplistic approaches to dementia that seek to represent it as a threat to the identities or personhood of those affected by it" (p. 2).

The ecology of dementia perspective is in clear contrast to Dworkin's emphasis on capacity as the threshold of autonomy. Legal and medical frameworks often emphasize the determination of whether an individual has the capacity to make decision. However, the ecology of dementia perspective suggests that, "reducing the impact of dementia to a "yes" or "no" question framed within an individualist cultural context, contributes to a depreciation of

⁸ See pages 73-74 for more discussion on relational autonomy.

the multiple rich formations of agency and identity within illness” (Chapman, Philip & Komesaroff, 2019, p.2). Though useful in certain contexts, reducing the capacity to make decisions to a “yes” or “no” response overlooks the holistic experience of the individual and does not enable the surrounding network to support the individual through significant identity changes. The ecology of dementia calls us to shift our perspective of dementia illnesses and those afflicted with them, as growth of those with dementia is possible and ought to be recognized and embraced.

A systems-thinking approach provides a new perspective from which to examine the issue of whether to expand legislation to include ARs for those with dementia. Though, like any other theory or concept, it does not provide an answer one way or the other, it can provide a tool for examining the issue. For example, viewing an individual as changing and having autonomy in the form of reactive engagement can support a shift in our thinking regarding autonomy and capacity. Individuals with dementia who have lost capacity, as it is traditionally defined, may still engage with those in their network regarding their preferences and wishes, such as MAiD. However, viewing an individual’s identity as in constant flux raises the concern of whether an individual can create an AR that has authority over their future self when experiencing the dynamism and changes induced by dementia. Further, a systems-thinking approach emphasizes that the creation and implementation of an AR would have an impact on the entire network through changing roles and identities. Although it’s the ‘individual’s’ decision, it requires involvement and has an impact on everyone in the network, including the wider community. These impacts must be considered carefully by the government and citizens of Canada. A systems-thinking approach may aid individuals in considering whether the

creation of an AR is the right choice given its potential impact on their loved ones, healthcare team, and community and society more broadly.

Overall, critical interests are fundamental to who we are as individuals and what gives us meaning and purpose in life, as opposed to the simple pleasures derived from experiential interests. As the 'final scene of the play', how individuals die matters because it is part of the larger trajectory of their lives and is desired to be consistent with who they are. However, due to the fact that those with dementia are no longer competent, only their day-to-day experiential interests can be expressed contemporaneously. This is because individuals with dementia gradually lose the capacity to make autonomous decisions, so they cannot express the critical interests that underlie such autonomy. The fact that the former competent self's critical interests cannot be expressed contemporaneously, but the current incompetent self's experiential interests can be expressed contemporaneously, results in two different, and often competing, notions of the self (former and current). Dworkin, Dresser, and McMahan have all responded to this conflict in unique ways. Most recently, the ecology of dementia perspective also sheds new insight onto the notion of the self for those living with dementia.

Chapter Conclusion

This chapter explored the former and current notions of the self and provides arguments and critiques by Dworkin, Dresser, and McMahan regarding which self ought to have authority when the interests of the former self compete with the interests of the current self for individuals with dementia. I have identified and described key aspects of each theorists' positions that I find either convincing or problematic. My analysis in regard to these theorists'

positions lays the groundwork for the recommendations regarding concerns of expanding ARs for MAiD which will be outlined in Chapter Four and the moral argument regarding whether ARs for MAiD ought to be legalized in Canada which are presented in Chapter Five. I agree with Dresser's concern that ARs leave no room for an individual to change his/her mind, but accept Dworkin's prioritization of critical interests when individuals are irreversibly unconscious. However, I find McMahan's prioritization of prudential concerns with regard to the various stages of the self over time to be informative as well. Together these various notions inform my own position set forth in Chapter Four. In my view no single theorist's position is sufficient to address every situation or concern associated with ARs for MAiD. This informs the position set forth in Chapter Four. The advantages and disadvantages of expansion and underlying tensions discussed in Chapter Four ought to be considered and balanced in a way that provides equitable access for individuals with various conditions to assert their critical interests through creation of an AR for MAiD, while providing due weight to experiential interests in a manner that minimizes uncertainty regarding whether the individual would have changed his/her wish to receive MAiD.

The concept of the ecology of dementia is also introduced, where the individual is viewed within the context of an entire network consisting of loved ones, the healthcare team and society more broadly. I suggest that this systems approach enables a shift in thinking regarding autonomy and capacity that emphasizes relational autonomy and provides a new and more nuanced perspective from which to view the issue of whether or not ARs for MAiD ought to be legalized in Canada. The concept of the ecology of dementia provides a framework for the concerns raised and recommendations made regarding the potential legalization of ARs for

MAiD in Chapter Four. This is because such concerns must be looked at within the context of an entire network, as the creation of an AR for MAiD, particularly with dementia, has wider impacts on family, friends, and society more broadly. Further, my positions regarding which context ARs for MAiD ought to be legalized set forth in Chapter Five, are influenced by this notion of the ecology of dementia in that it expands our focus to include potential impacts on relationships and broader society, rather than simply focusing on the individual.

Chapter 4: Key Viewpoints and Tensions

Chapters One and Two have outlined the current landscape of MAiD legislation within Canada and across the globe, where three jurisdictions (the Netherlands, Belgium, and Luxembourg) have legalized ARs for MAiD and two of these (Belgium and Luxembourg) require that the individual be irreversibly unconscious. The basis of expansion of legislation in each of these jurisdictions is key in considering potential models of expansion in Canada and the legislation and evidence from these jurisdictions support my arguments regarding which circumstances ARs for MAiD ought to be legalized. Chapter Three has explored more closely various theorists' positions regarding which notion of the self ought to be prioritized for individuals with dementia and introduced a framework (the ecology of dementia) in which to view the self holistically. I have suggested that no one theorist's position is adequate for considering all concerns and potential contexts in which ARs for MAiD may be legalized. The ecology of dementia perspective provides a more nuanced understanding of the self, and thus a more nuanced consideration of the issues at play. Together these perspectives provide the basis for my position in Chapter Four that there are both advantages and disadvantages of legalization and these must be delicately balanced in light of the evolving notion of the self when determining the circumstances in which ARs for MAiD ought to be legalized.

Within the Canadian landscape, there are some individuals and organizations who advocate for expanding MAiD legislation, while others strongly warn against the expansion. The first two of the following sections will outline these two contrasting positions, while the third describes the major areas of tension between them. I suggest that the points raised in the contrasting positions and the underlying tensions ought to be considered and balanced in such

a way that aims to provide equitable access for individuals with various conditions to assert their critical interests, while minimizing potential for error or uncertainty regarding whether the individual would have changed his/her wish to receive MAiD. The quest to seek this balance is foundational to the arguments made in Chapters Four and Five.

Section 1: Advantages of Expanding MAiD Legislation

There are many potential positives of expanding MAiD legislation. Canadians largely believe that they ought to have the autonomy to determine their own quality of life and level of suffering, and ultimately the circumstances of their death. Notably, surveys of the Canadian public demonstrate that there is general support for expanding legislation to allow the inclusion of MAiD in advance directives (EPOLRCC, 2015; Forum Research 2016; Ipsos Public Affairs & Dying with Dignity Canada, 2016). Legalizing advanced euthanasia directives would enable individuals to maintain their individual autonomy in the form of precedent autonomy.

Precedent autonomy means that the interests of the individual expressed while competent take precedence over the interests of their future incompetent selves. The balance between precedent and current autonomy will be further discussed in the section outlining the major tensions between the pro and against arguments. From a pro-expansion perspective, if individuals express a sincere and persistent wish to end their lives, assuming they meet the legal criteria to receive MAiD, providing an option to request MAiD in advance enables individuals' autonomy to be supported.

One of the key requirements for accessing MAiD is that the individual must be experiencing unbearable suffering. This requirement follows from the idea that MAiD

eliminates suffering. By expanding the legislation to include advance directives for those diagnosed with dementia, the individual's suffering will be eliminated, and thereby could reduce suffering in the overall population. Further, if the individual's AR is set out clearly, it may also reduce the burden on the family, who would ordinarily be left to make end-of-life decisions for their loved one (Cheng, 2017). The reduction of individual suffering and family burden would also act to reduce health care costs incurred through futile or unwanted medical care, and offering supports for the individual and/or family⁹ (Turner & Findlay, 2012; Alzheimer Society of Canada, 2016a; Manuel et al., 2016).

At a societal level, it has been argued that MAiD safeguards are effective in protecting vulnerable groups (Battin, van der Heide, Ganzini, van der Wal, & Onwuteaka-Philipsen, 2007). However, this is a point of contention, as some groups also argue that the current safeguards are not sufficient (CCA, 2018, p. 42; CACL, 2017). Legalization, and discussion around its expansion, is enabling Canadian society to become more comfortable discussing and planning for end-of-life issues. One study conducted in the Netherlands from 1992 to 1997 concluded that the bereaved family and friends of cancer patients who received MAiD, coped better with respect to grief symptoms due to: (i) the opportunity to say goodbye while patients were still fully aware; (ii) family and friends being more prepared for the way of death and day of death; and (iii) the ability to talk openly about death after the patient made the request for medical assistance in dying (Swarte, Van Der Lee, van der Bom, Van Den Bout, & Heintz, 2003). Physicians may be more likely to discuss end-of-life care with patients and their families in

⁹ Note the appeal to consequentialism in this line of reasoning.

jurisdictions where MAiD is legal (Dying with Dignity Canada, 2019). Further, it may cause physicians and nurse practitioners to reflect upon, and improve knowledge and communication skills for advance care planning and end-of-life concerns broadly, including palliative care. A study completed in Oregon five years after legalization that surveyed hospice nurses and social workers concluded that, “most respondents rated Oregon physicians as showing improvements in knowledge and willingness to refer and care for hospice patients” (Goy et al., 2003, p. 215). Legalization has shed new light on the importance of barriers to, and limitations of accessing palliative care. There was significant and consistent growth in investment in palliative care following legalization of euthanasia in Belgium and the Netherlands (Bernheim, Chambaere, Theuns, & Deliens, 2014). The norm in which death, and discussion of it, is taboo is slowly shifting and this could aid in supporting a better death for all Canadians, whether or not MAiD is involved.

A potential advantage of expanding the legislation for individuals who wish to receive MAiD but have lost capacity is that an SDM could drive the process if provincial and territorial legislation does not prohibit it (CCA, 2018, p. 48). No jurisdiction in the world currently allows a substitute decision-maker to request assisted suicide or euthanasia on behalf of someone else without a prior written request from that individual (CCA, 2018, p. 48). Currently, only a competent individual without external influence may request MAiD for him/herself. A substitute decision-maker cannot advocate for MAiD on behalf of another individual. However, if legislation were expanded to include ARs, the SDM could be a key part of the process in confirming that the AR is consistent with the individual’s wishes and that the current circumstances match those outlined in the AR. This supports a systems approach, such as the

ecology of dementia, to the experience of dementia through heightened focus on relationships and relational autonomy of the individual within a wider network¹⁰.

One of the most notable arguments for the expansion of MAiD legislation is the prevention of early MAiD. Some individuals who are already eligible for MAiD elect to have the procedure earlier before they lose competence. Since it is often very difficult to predict when loss of competence will occur, it may lead to individuals accessing MAiD earlier than they otherwise would have if they were able to set out an AR for MAiD¹¹. This is the reasoning provided by The Provincial-Territorial Expert Advisory Group on Physician-Assisted Dying (PTEAG-PAD) in its recommendation that ARs be legally permissible for individuals diagnosed with a grievous and irremediable condition (PTEAG, 2015). There have also been several notable cases in the media, as mentioned earlier, including a Halifax woman named Audrey Parker who ended her life earlier than she would have preferred out of fear of losing mental capacity (Hounsell, 2018). This is very similar to the original violation resulting from SCC ruling on the *Carter v. Canada* case, wherein an individual's right to life is violated because they may end their lives earlier than necessary, knowing that they are unable to do so independently at a later time (*Carter v Canada*, 2015, para. 57).

There are several prominent individuals and organizations in support of advance requests for MAiD for individuals with dementia. As already noted, the Canadian population is generally in support, with two polls consisting of a representative sample of the Canadian population demonstrating between 62% and 74% supporting access to an assisted death if they

¹⁰ As discussed in Chapter 3.

¹¹ This reasoning is used in partial support of my position outlined in Chapter Five.

have advanced dementia and an AR (EPOLRCC, 2015; Forum Research 2016; Ipsos Public Affairs & Dying with Dignity Canada, 2016). The PTEAG-PAD and the Special Joint Committee on Physician-Assisted Dying (SJCPAD) recommended expansion for those diagnosed with a grievous and irremediable condition (SJCPAD, 2016). Parkinson Canada “supports the use of advanced consent for medical assistance in dying when suffering becomes intolerable later in the disease course whether or not the person has competency” (Parkinson Canada, 2016). Dying with Dignity Canada also cites persistent suffering as its reasoning for supporting advance requests for MAiD for individuals with dementia (CCA, 2018, p. 42; Dying with Dignity Canada, 2017).

Jocelyn Downie is a Professor in the Faculties of Law and Medicine at Dalhousie, James Palmer Chair in Public Policy and Law, and Pierre Elliott Trudeau Foundation Fellow. Downie was also a member of the PTEAG-PAD, which, as already noted, recommended inclusion of ARs within Canada’s legislation. In a discussion on *CBC The Current*, Downie proposes that those who are competent after being diagnosed with a grievous and irremediable condition ought to be able to create an advance request that remains legally in force even if they become incompetent (CBC Radio, 2018). Downie’s argument aligns with the common concern that the current law forces some individuals, such as in the case of Audrey Parker, to choose to end their lives sooner out of fear of losing capacity or relying on an advance directive that declines assisted eating and drinking, which can result in a slow and unpleasant death. She notes that Parker’s situation is among the easiest circumstances in which an AR is justifiable. She argues that the individual who created the AR bears the risk of not being able to change her mind

following a loss of capacity, rather than a third party, such as the physician or nurse practitioner providing MAiD.

In the same discussion, Dr. Ken Rockwood, a Geriatrician and Professor of Geriatric Medicine at Dalhousie, notes that in some circumstances advance requests for MAiD could be beneficial for a particular patient population that he serves, but the line must be drawn when individuals with dementia set out circumstances that they now believe they would find intolerable, but which are not actually circumstances that cause them to suffer upon reaching that point (CBC Radio, 2018). Clearly, Rockwood believes that there must be some indication that the individual is suffering in a manner described in their AR, as there is a discrepancy between what individuals believe they would define as intolerable suffering in the future and how they actually cope when faced with such a situation. This can be particularly difficult to determine in individuals with dementia, as they may not be able to clearly convey their suffering (CBC Radio, 2018).

Section 2: Disadvantages of Expanding MAiD Legislation

There are many potential disadvantages to expanding MAiD legislation and it is crucial to consider these before any recommendation is issued or action take place. Although allowing ARs may decrease the burden of suffering on caregivers in some ways, it may also increase the burden in others (CCA, 2018, p. 142). Advising when a loved one is suffering and aiding in determining the appropriate time to provide MAiD through interpretation and application of an AR is certain to be a challenging and emotional task. Further, family members may disagree about the appropriate time to provide MAiD based on the interpretation of the AR, thus

potentially creating greater family conflict than if the individual were still competent and could give contemporary consent. Similarly, determining the appropriate time to provide MAiD in alignment with an individual's wishes places additional burden on physicians, nurse practitioners, and potentially the entire care team. A large contributor to the additional burden for family and care providers is determining the exact moment when MAiD ought to be provided. Due to the inherent fluctuation in dementia, it may be possible to still experience glimpses of the individual as they once were, such as remembering a love one's name, yet impossible to predict if or when these glimpses may reappear.

The difficulty in determining when to provide MAiD also relates closely to the criterion requiring intolerable suffering. As the legislation currently stands, the individual determines if they are suffering intolerably. However, once an individual lacks capacity in the case of dementia, it may become very difficult for the individual to express that they are suffering. Therefore, determining if the individual is suffering intolerably, if maintained as an eligibility criterion, will have to be corroborated with the written instruction of the individual by the caregiver or healthcare provider. This leaves potential room for error. Several studies have found that individuals with dementia rate their own quality of life higher than their SDM does (Buckley et al., 2012; Hongisto et al., 2015; Bravo et al., 2017). The caregiver's own burden likely contributes to this lower quality of life rating (Nyst, 2018).

Further, without clear guidelines and legal safeguards for healthcare practitioners, there may be unfounded prosecution of physicians and may result in few physicians willing to provide MAiD based on an AR. The Canadian Medical Protective Association (CMPA) has emphasized concerns about the legal liability for healthcare practitioners providing MAiD based on an AR.

The organization stresses the need for safeguards against civil or criminal prosecution for physicians who follow an AR and provide MAiD in a reasonable manner (CCA, 2018, p. 155; CMPA, 2017). This is especially true in situations where there is disagreement between family members regarding whether and when an AR should be followed for a loved one. Also, lack of knowledge about MAiD legislation by physicians may limit an individual's ability to make appropriate and meaningful end-of-life decisions and physicians may be found legally liable, for example, if they offer MAiD as an option to an individual who is not eligible (Bartlett, 2017; CCA, 2018, p. 149). This legal liability may contribute to the position taken by some physicians and physician groups that the provision of MAiD is counter to the role of the physician as healer and protector of vulnerable individuals.

Since physicians currently have a duty not to harm their patients and are considered protectors and advocates of the vulnerable, there is concern that legalizing ARs for MAiD could cause a drastic change in the social meaning of physicians (Jansen, Wall, & Miller, 2019). For example, in June 2019 the American Medical Association upheld its view that, "Physician-assisted suicide is fundamentally incompatible with the physician's role as healer, would be difficult or impossible to control, and would pose serious societal risks" (Howard, 2019). As discussed previously, the experience of living with an illness such as dementia causes ongoing changes in the individual, which impact the entire network surrounding the individual, including the physician. Therefore, it follows, that the individual's experience of requesting and receiving MAiD will give force to changes in the physician's identity. These changes then impact the entire network surrounding and interacting with the physician, including larger society. Thus, changes in the social meaning of physicians are continually ongoing and subject to changes in

much the same way as individuals. While this concern governs attention due to its involvement in the wider dementia network, the concern regarding social meaning of the physician raises issues different from the ones focused on throughout this thesis on the nature of the self and the role of autonomy, and is beyond the scope of this thesis.

Concern over expansion of MAiD legislation also arises when considering the potential for coercion and abuse through pressuring an individual to create an AR out of greed, malice or bias rooted in ageism (Gastmans & De Lepeleire, 2010). For example, an SDM may be motivated to pressure the creation or implementation of an AR for financial reasons (e.g. to avoid ongoing healthcare expenses or because of a potential inheritance), lack of adequate and appropriate support services, or difficult behaviour (CCA, 2018, p. 148). This concern is at the heart of why an SDM cannot request euthanasia on behalf of their loved one without a prior written request. Pressure is potentially more likely to mount from the individuals themselves through internalizing societal values and their social surroundings (Gastmans & De Lepeleire, 2010). For example, there is still great stigma against individuals with dementia and the risk of being discriminated against may drive some individuals to create an AR. Also, if individuals lack access, or fear a lack of access, to appropriate care services including palliative care and dementia support services, then they may create an AR (CSPCP, 2017; CCA, 2018 p. 147). This internalized stigma and pressure highlights a broader societal concern about whether expanding legislation to include ARs for those with dementia may alter the way society views and values such individuals¹². Specifically, individuals with dementia may feel they have a moral

¹² This concern regarding stigma is explored more closely in Chapter Five and is in partial support of my position regarding whether or not to expand ARs for MAiD.

obligation to create an AR to avoid becoming a burden to family members or the healthcare system as a whole (Gastmans & De Lepeleire, 2010).

Notable organizations that are against expanding legislation to include ARs for those with dementia include the Alzheimer's Society of Canada and the Canadian Association for Community Living (CACL). These organizations are concerned that fear of inadequate support services and being a burden to others drives individuals to select MAiD as an option (CCA, 2018, p. 42; CACL, 2017). Notable physicians and academics who warn against expansion of MAiD in advance directives include Trudo Lemmens and Harvey Max Chochinov. Trudo Lemmens is Professor and Scholl Chair in Health Law and Policy at the University of Toronto Faculty of Law and was a member of the Expert Panel Working Group for Advance Requests by the CCA. Lemmens argues that the criterion of a reasonably foreseeable death is not overbroad and we ought to be concerned about expansion on an individual and societal level (Lemmens, 2018). On an individual level, Lemmens argues, individuals need the opportunity to adjust to their situation and to change their minds if necessary (Lemmens, 2018). From a societal perspective, Lemmens is concerned that expansion would devalue the quality of life of those with dementia, and the resulting impact on how societal perceptions of cognitive disabilities in general (Lemmens, 2018). Further Lemmens highlights that, "it is also reasonable to be concerned about what it means to create an expectation that doctors ought to be able to provide this type of service even when patients can no longer comprehend what is being done to them and have no memory of their request to die in those circumstances"¹³ (Lemmens, 2018, p. 494).

¹³ Each of these concerns and arguments by Lemmens is addressed in Chapter Five.

Lemmens advocates examining the discussion ongoing in the Netherlands and Belgium, which involves two major concerns: (i) euthanasia practice is expanding in ways that many find objectionable, and (ii) it's difficult to constrain small groups from moving the legislation in a direction it was not intended (Lemmens, 2018). Dr. Harvey Max Chochinov holds similar concerns, as a distinguished professor of psychiatry at the University of Manitoba and the only Canada research chair in palliative care. Dr. Chochinov advocates for earlier discussion on advance care planning and that "there is good data to demonstrate that compassion, a gentle touch, respect, and patience can benefit even those patients with moderate to severe dementia" (Chochinov, 2016).

It is clear from sections one and two that there are both advantages and disadvantages to expanding MAiD legislation to include ARs which ought to be considered and balanced. This is the task taken up in Chapter Five.

Section 3: Major Areas of Tension

Subsection 1: Autonomy.

The first area of tension in the outlined contrasting positions from the previous two sections is the weight given to autonomy. Arguments in favour of expansion place a high level of importance on individualistic autonomy. In this way, autonomy is self-determination without controlling interference from others or any barriers that limit meaningful choice (Beauchamp and Childress, 2013, p. 101). Arguments that prioritize individual autonomy apply the reasoning that individuals have a right to end their own lives with the assistance of another person, known as the right to autonomy and self-determination (Dworkin, 1993). Arguments against

this include that this positive right, to have another individual assist someone in ending their life, goes too far and is outweighed by other ethical principles or obligations, such as nonmaleficence and beneficence (van Delden, 2004).

Arguments in favour of expanding MAiD legislation to allow ARs extend this positive right to include autonomy over their future self, even if they are no longer competent. This is the essence of precedent autonomy, which is a well-established concept giving force to advance directives (Dworkin, 1993). Currently, it is legal and within an individual's rights to describe the treatment or procedures that they do not wish to have, should they become incompetent (CCA, 2018). Such procedures or treatment may include a do not resuscitate (DNR) order, no antibiotics, or no assisted eating and drinking.

The distinction between advance directives and an advance request for MAiD is that an advance directive, such as including a DNR order may hasten natural death, but does not actively cause death, as in the case of advance requests for MAiD (CCA, 2018). This parallels arguments for and against assisted suicide when the individual is competent. However, when an individual is incompetent, there is an added level of uncertainty¹⁴ surrounding whether they would have changed their mind if they were competent, even with an advance request in place. With assisted suicide and euthanasia in Canada, an individual has to reaffirm their wishes immediately prior to the procedure (Bill C-14, 2015). However, advance requests mean that an individual is not competent to do so immediately prior to the procedure so there is some

¹⁴ Note that throughout Chapters Four and Five the level of uncertainty refers to the level of uncertainty regarding whether an individual would have changed his/her wish to receive MAiD if he/she were still competent.

uncertainty as to whether the individual may have wanted to change their mind or if the circumstances accurately represent intolerable suffering as they would define it (CCA, 2018).

The level of uncertainty associated with the implementation of an advance request for MAiD depends on the current state or competency of the individual (CCA, 2018, pp. 60-1). The uncertainty largely stems from whether the individual may have changed his/her mind between the time of loss of capacity and provision of MAiD. For example, if an individual remains competent, then their contemporaneous wishes take complete priority over their precedent autonomy. This is because contemporaneous decisions made with capacity take priority over decisions made in the past, as the individual may have changed his/her mind in response to new information or context. In contrast, if an individual is irreversibly unconscious, then they have no contemporaneous autonomy or experiential interests. Under such circumstances, the individual's precedent autonomy, in the form of an AR, would take priority. For example, if the individual set out in their AR that if they become irreversible unconscious, this quality of life is not acceptable to them and they wish to undergo MAiD, then this decision takes priority¹⁵. The clarity of lacking any contemporaneous autonomy or experiential interests is why it is legal to follow an AR in Belgium and Luxembourg only if the individual is unconscious (Loi du 16 mars 2009 sur l'euthanasie et l'assistance au suicide, 2009; Belgian Act on Euthanasia, 2002). A grey area is introduced, requiring extensive judgement, when individuals have an AR and remain conscious, but have lost some level of decision-making capacity and react in ways that counter the wishes set out in their AR. In these situations, it becomes very difficult to balance the

¹⁵ This reasoning is used in partial support of my position outlined in Chapter Five regarding whether to legalize ARs for MAiD.

precedent autonomy of the individual with their contemporaneous wishes. This balance ought to be struck through determining the level of suffering the individual is experiencing. This means that the more readily apparent it is that the individual is suffering, the more weight ought to be given to an individual's precedent autonomy¹⁶. For example, if an individual set out in their AR that they consider it to be unbearable suffering once they can no longer recognize their family members, and therefore wish to undergo MAiD, other aspects of suffering ought to be given consideration. If the individual is otherwise content and still derives enjoyment from experiential interests, then less weight ought to be given to their precedent autonomy (the prior decision to undergo MAiD). However, if the individual spends much of their day-to-day life agitated, confused or in fear, then greater weight ought to be given to their precedent autonomy (prior decision to undergo MAiD).

There is also tension surrounding whether assisted suicide is truly an individual choice. As human beings, we are fundamentally connected to one another, our circumstances and context. This connection is the basis of relational autonomy, which establishes that every autonomous choice occurs in the context of social relationships and socio-cultural and political context¹⁷ (Sherwin, 1998). This means that discussion and involvement of family and healthcare providers is essential to the decision-making process with consideration of the broader access to, and delivery of, healthcare services in Canada. The relationality of MAiD is twofold, where both the decision to undergo MAiD and the procedure itself are fundamentally relational. It has

¹⁶ As noted earlier, this assessment is subjective to some degree.

¹⁷ This aligns closely with the ecological perspective.

been argued, that because MAiD requires both physician and patient to complete the procedure, it is a fundamentally relational act (Gastmans & De Lepeleire, 2010).

The relationality of MAiD extends much deeper beyond simply the involvement of both physicians and patients. Individuals decisions regarding MAiD are deeply influenced by the social environment, since values, identities, and perceptions are largely socially constructed (Sherwin, 1998). Similarly, the decision to create an advance request for MAiD would be a relational act, as it would also require deep involvement of an SDM to verify that the individual's wishes set out in their advance request match their current circumstances, and lengthy discussion and intimate knowledge of the individual while they were competent. Again, on a deeper level, the decision to create an advance request is fundamentally relational, in that the decision is largely shaped by the individual's social environment. This relationality of both the decision and act of creating an AR and providing MAiD closely aligns with the ecology of dementia, as the entire network impacts and is impacted by the individual's decisions, including the physician, family members and friends, and society more broadly¹⁸.

Subsection 2: Anticipation of Suffering and The Disability Paradox.

To date, the possibility that individuals with dementia suffer is scarcely acknowledged (UK Department of Health, 2013). However, there are many ways in which those with dementia may experience suffering. Suffering can result from emotional, physical, existential, or social pain, including a combination of these factors (Bartlett, Windemuth-Wolfson, Oliver, & Dening, 2017). For example, as individuals progress further on the dementia trajectory, gaps in memory

¹⁸ This is fundamental to the concern surrounding internalized stigma and value judgements on the worth of a life without capacity, as discussed in Chapter Five.

or moments of insight can cause fearful feelings and experiences (Bartlett et al., 2017). There may also be a lack of any control or sense of autonomy over one's life, especially in hospitals and long-term care homes where boredom, malnourishment, or mistreatment may occur (Bartlett et al., 2017). Social factors can also contribute to suffering when the individual's social networks shrink due to continuing stigma of dementia. This will be further addressed below.

While all illness involves suffering to some degree, the key eligibility criteria for MAiD in Canada is that the suffering is considered intolerable and irremediable. After the creation of an AR and loss of capacity, an individual may no longer be able to communicate the presence or degree of suffering that they are experiencing. Further, it is difficult to project and define the future circumstances under which you would suffer intolerably. It can be difficult to predict how an individual may experience dementia in their unique personal and social context. Therefore, it is difficult to know whether anticipated suffering as set out in an AR will match lived experience. This relates closely to a notion called the disability paradox, wherein there is a well-established discrepancy between the anticipated quality of life for a potential condition and the actual quality of life rating by an individual living with the condition (Albrecht & Devlieger, 1999). Particularly, those anticipating a potential future condition rate quality of life lower than those actually living with the condition (Ubel et al., 2005). This holds true for an individual prior to having a condition and once they have it.

Tension between arguments for and against expansion of legislation to include ARs exists because arguments against suggest that individuals are unreliable predictors of their future suffering and quality of life. Unreliable prediction could potentially lead many people to change their mind about wanting MAiD. However, since they are no longer competent, MAiD

could be provided to an individual who may no longer wish to access the service. Arguments for expansion acknowledge this limitation, but note that just because an individual with a particular condition may rate their quality of life higher, this does not rule out the possibility that they are suffering intolerably (CCA, 2018, p. 53). Further, dementia is a condition wherein an individual loses control over their body and mind, which is a strong indicator of low quality of life ratings in those with disability (CCA, 2018, p. 53). An individual may make a sincere AR for MAiD based on projected quality of life through knowledge of the dementia trajectory through discussion or witnessing another individual's experiences with dementia (CCA, 2018, p. 53). Therefore, we ought not to discount all projections regarding quality of life. Once again, a balance must be struck between recognizing that suffering and quality of life is difficult to predict, while also recognizing that the nature of the dementia condition causes a loss of control particularly linked to suffering and low quality of life, which can result in sincere ARs for MAiD (Albrecht & Devlieger, 1999).

Subsection 3: Vulnerability and Stigma.

The vulnerability of and stigma towards individuals with dementia creates another defined area of tension. There are two types of vulnerability: inherent and situational (MacKenzie et al., 2014). Lack of capacity, as a result of dementia, for example, is an inherent vulnerability wherein the individual has to rely on others to make decisions for them that are in their best interests. This is especially pertinent when creating ARs in order to ensure that vulnerable individuals are protected from coercion or external influence. Inherent vulnerabilities can also intersect with situational vulnerabilities, of which the CCA outlines three particularly relevant sources: stigma, caregiver burden, and inadequate access to support

services (CCA, 2018, p. 55). As mentioned previously, stigma towards those with dementia still persists and can deplete an individual's social networks. There is concern that being treated differently by family, friends, and care providers in response to dementia may be internalized by the individual, thus decreasing their sense of purpose and self-worth (Herrmann et al., 2018). Further, family members caring for a loved one with dementia experience a high degree of stress and burnout, which can create situational vulnerability for both the carer and the individual with dementia.

Due to several factors, including that long-term care and home care are not considered medically necessary under the *Canada Health Act*, there is disparate access to these services across the country. In general, health care services provided in long-term care are covered under provincial and territorial governments, while the individual pays for room and board out-of-pocket, which may be subsidized depending on the individual's income (Government of Canada, 2018). This also creates vulnerability and there is concern that an individual may make an AR out of fear of inadequate care services, which may result in decreased quality of life, such as through unmanaged pain. Overall, vulnerability creates tension in that arguments against expanding legislation to include ARs for MAiD may point to the need to protect vulnerable populations from coercion or creating an AR out of fear of lack of access to services or internalized stigma from society. This type of vulnerability and related concerns are outlined in discussion of euthanasia in Colombia in Chapter Two.

On the other hand, arguments in favour of expansion may point out that to systematically exclude an entire group of individuals, such as those with dementia, from a right that others can exercise is unjust. Simply because dementia causes loss of competence, no individual with

dementia as a sole underlying condition is able to access MAiD in Canada, which is now a legal right. A delicate balance must then be struck between protecting vulnerable populations affording individuals the same opportunity to access MAiD no matter their specific type of condition.

The tension between opposing perspectives on legalizing ARs for MAiD must be considered and reconciled in a way that minimizes concern over error, abuse, and a shift in societal values, while recognizing that the right to access MAiD ought not to be contingent on the type of illness an individual has, over which they have no control.

Chapter Conclusion

The first two sections of this chapter delve into the key advantages and disadvantages of expanding MAiD legislation to include ARs generally, and for those with dementia. The third section explores the major areas of tension between these two contrasting positions. I suggest that the concerns raised in the positions in favour of and against expansion of MAiD legislation to include ARs both have merit. As such, the advantages and disadvantages of expansion and underlying tensions discussed above ought to be considered and balanced in such a way that aims to provide equitable access for individuals with various conditions in order to assert their critical interests, while minimizing uncertainty regarding whether the individual would have changed his/her wish to receive MAiD. The quest to seek this balance is foundational to the arguments made in Chapter Five.

Chapter Five: Normative Argument and Recommendations

Chapter Five begins by presenting three potential scenarios in which MAiD legislation could be expanded to include ARs. The chapter is divided into two sections, where the first section has two aims: (i) to identify concerns or challenges posed by each of three potential scenarios in which ARs could be legalized; and (ii) to argue that scenarios one to three carry increasing levels of uncertainty, respectively. In section two, I argue that ARs for MAiD ought to be legalized in two ways: (i) in scenario one, where individuals have a diagnosis of a grievous and irremediable condition and are already eligible for MAiD or have become eligible for MAiD and are re-affirming a previous request; and (ii) where the sole allowable criterion for implementing the AR and providing MAiD is that the individual is irreversibly unconscious. The moral arguments presented in Chapter Five tie together the evidence, analysis, and previous arguments made throughout this thesis suggesting that there are some circumstances in which ARs for MAiD ought to be legalized. The key evidence, analysis and previous arguments include: (i) the successful legalization of ARs for MAiD in certain contexts in three other jurisdictions, as set out in Chapter Two; (ii) balancing the conflict of the former competent self's critical interests and the current incompetent self's experiential interests through a critique of various theorists' positions and through the application of the ecology of dementia, as set out in Chapter Three; (iii) balancing the need for equitable access of ARs for MAiD for individuals with various conditions in order to express and prioritize their critical interests while minimizing the uncertainty that individual would have changed his/her wish to receive MAiD in order to prioritize their experiential interests, as set out in Chapter Four.

Section 1: Three Degrees of Expansion

The CCA outlined three scenarios in which ARs could potentially be legalized. The three scenarios include: (i) an individual creates an AR when they are already eligible for MAiD; (ii) an individual creates an AR after diagnosis of a serious illness but before being eligible for MAiD; and (iii) an individual creates an AR before diagnosis of a serious illness (CCA, 2018). These scenarios are discussed with the aim of identifying any concerns or challenges posed by each scenario and proposing potential solutions to the concerns by applying the concepts of critical and experiential interests, relational autonomy, prudential concern and the ecology of dementia. I argue that scenarios one, two and three carry an increasing level of uncertainty, respectively, regarding whether the individual would have changed his/her wish to receive MAiD given three main considerations: (i) to what degree the patient's circumstances match those set out in their AR; (ii) to what degree the patient has repeatedly communicated their wishes for MAiD in specific circumstances; and (iii) family members and care providers know that the AR exists and are familiar with its contents. The greater the time period between creation of the AR and its implementation, the less likely each of these factors is to be satisfied. These considerations are developed from the underlying tensions outlined in Chapter Four, including the disability paradox and autonomy and the corresponding level of uncertainty stems from the potential conflict between the former competent self's critical interests and the current incompetent self's experiential interests¹⁹. The greater the potential level of conflict, the greater the level of uncertainty that an individual may have changed his/her wish to receive

¹⁹ This builds on theoretical discussion in Chapter Three regarding the notions of the self and critical and experiential interests.

MAiD. My arguments regarding the level of uncertainty of whether the individual would have changed his/her wish to receive MAiD after losing capacity in each scenario is central to my argument in section 2 of this chapter regarding if, and to what degree, MAiD legislation ought to be expanded to include ARs.

Subsection 1: ARs for MAiD when Already Eligible.

There are two criteria in Canadian MAiD legislation that may drive an individual to create an AR (CCA, 2018, p. 63-4). The first is the requirement for a 10-day waiting period between when the MAiD request was signed and witnessed and the provision of the procedure. If the individual loses capacity at any time in this 10-day waiting period, the request is null. In anticipation of potential loss of capacity, due to the illness itself or treatment such as pain medication, individuals may be driven to create an AR as a way to ensure that they receive MAiD even if they lose capacity. Recall that, with the exception of Columbia, Canada is the only jurisdiction where there is a required waiting period for a terminally ill individual before they can receive euthanasia²⁰. The second criterion is that the individual must be competent to give consent immediately prior to the procedure in order to have the opportunity to change their mind. Therefore, individuals who are concerned that they may lose capacity any time between signing and witnessing the MAiD request and undergoing the MAiD procedure may wish to create an AR so that their request is not nullified. This scenario effectively excludes individuals with dementia because, as the legislation currently stands, they would never meet eligibility criteria unless an assessor deemed their death reasonably foreseeable while they were still

²⁰ See the summary of legislation across jurisdictions immediately following Chapter Two.

competent. Given that the life expectancy of dementia is typically eight to ten years and decision-making capacity slowly declines, it is unlikely that the individual will remain competent when death is deemed reasonably foreseeable (CCA, 2018, p. 62). This is because the individual may lose capacity several years before their natural death, and this length of time is generally not accepted as a reasonably foreseeable death, as determined by the subjective judgement of the assessing physicians and nurse practitioners²¹. The scenario where an individual creates an AR once already eligible for MAiD applies more closely to conditions such as brain cancer or cancer that has metastasized to the brain, or recurring strokes because they are more likely to have capacity at the time of being assessed as eligible to receive MAiD than those with progressive degenerative conditions affecting the brain, particularly dementia. This condition also applies to individuals who are taking medication, such as for pain, that may reduce their cognitive capacity during the 10-day waiting period. The 10-day waiting period can be waived in circumstances where there is an imminent loss of capacity; however, Canada's legislation does not stipulate whether the imminent loss must be as a result of the individual's condition, or whether it also includes imminent loss as a result of treatment, such as through opioid pain management or other medication (Downie & Chandler, 2018). Given that individuals suffering intolerably can experience high levels of pain, it is very likely that medication may be provided to manage the pain. However, strong pain medication, such as opioids, can result in lowered consciousness or loss of capacity. As a result, there is potential that individuals may waive this pain management in an attempt to maintain capacity so that their request for MAiD is not

²¹ Note the vagueness of the reasonably foreseeable death requirement as mentioned on pages 13-14.

nullified. This potential abstinence from pain medication means that the illegality of ARs for those already deemed eligible for MAiD may in fact cause increased suffering.

Allowing ARs for MAiD for individuals who are already eligible for the procedure bypasses the criteria that an individual must be competent for the entire ten-day waiting period, and immediately prior to the procedure. The major concern raised here is that the individual loses the opportunity to change their mind once they are no longer competent²² (CCA, 2018, p. 64). The concern highlights the difficulty in assigning priority to an individual's critical interests over their experiential interests, because if the individual were competent at the time of providing MAiD, they may assess their contemporary critical and experiential interests and decide that they no longer wish to receive MAiD. However, the more certain the assessors are that the individual won't change their mind, the more this concern would be mitigated. This means that if the assessor is convinced that the individual would retain their decision to undergo MAiD given their current experiential interests, then the concern that the individual would change his/her mind is greatly reduced. Due to the eligibility criteria for MAiD requiring that an individual be suffering intolerably and the request be voluntary where the individual finds no other treatment alternatives acceptable, if an individual has already been assessed as eligible for MAiD, then both the individual and assessors have a high degree of certainty that the individual is suffering intolerably and no longer wishes to live in this state. Therefore, allowing the creation of ARs for MAiD by individuals who are already eligible for the

²² See Chapter Three for my argument that this concern is espoused by Dresser and is highly compelling.

procedure involves the least amount of uncertainty of the three scenarios regarding whether the individual would have changed his/her wish to receive MAiD after loss of capacity.

Subsection 2: ARs for MAiD Before Eligibility but After Diagnosis.

Individuals who are not yet eligible for MAiD may wish to create an AR for MAiD if they are concerned that they may lose capacity from an ongoing or recurring condition, such as a stroke, or have been diagnosed with a condition where they are certain that they will lose capacity, such as dementia. Given that there is a wide range of conditions and circumstances that apply to this scenario, some cases will be more difficult for family and healthcare providers to determine the appropriate course of action than others. In this scenario, there is more uncertainty involved than if the individual were already eligible for MAiD, because they have not progressed as far in their disease and death is not imminent, so there is greater chance that the individual may change their mind, or adapt to their condition. If an individual adapts to his/her condition, this may mean that, despite his/her predictions, he/she is not suffering unbearably in the current state of his/her illness. According to relational autonomy and the concept of the ecology of dementia, an individual's identity is undergoing constant changes as they shape and are shaped by the network surrounding them²³. These identity changes may result in an individual who may find a renewed sense of purpose in their suffering or simply derives pleasure from the fulfillment of their day-to-day experiential interests in a way that they did not anticipate. The individual may discover new coping strategies and better adjust to

²³ These concepts are discussed at greater length in Chapter 3.

their current state. Given that they are able to cope and adjust with the given circumstances of the illness, the individual may no longer wish to receive MAiD.

This added uncertainty in creating an AR before any diagnosis regarding whether than individual would have changed his/her wish to receive MAiD may be mitigated by ensuring the AR is well-informed (CCA, 2018, pp. 67-8). It is crucial that individuals have had multiple discussions with family and healthcare providers in order to fully understand their condition and its trajectory, and their end-of-life options. The ecology of dementia perspective highlights how an individual shapes, and is shaped by, an entire network, including family, care providers, and the wider social environment. Discussion between those in the network is key to understanding and relating to one another within the network²⁴. Multiple discussions are also crucial in supporting the individual's relational autonomy, and practically speaking, it may be difficult for a family member or care provider to interpret the individual's AR without prior discussion of the individual's wishes. The individual also needs sufficient time to consider and accept their condition. Relational autonomy views selfhood as an ongoing process, rather than static or fixed (Sherwin, 1998). Following diagnosis, an individual's identity may change significantly, as demonstrated in the fifteen dementia networks examined by Chapman, Philip and Komesaroff (2019)²⁵. Therefore, an AR created immediately following a diagnosis may not carry the same moral and practical weight as an individual who created an AR several years after diagnosis.

²⁴ Note the potential increased role for SDMs in ARs for MAiD, particularly with the ecology of dementia perspective, as discussed on page 62.

²⁵ See pages 45-46 for a brief summary of this work.

Further, there is concern over whether an individual sets out clear enough criteria in an AR for family or care providers to apply the AR with certainty (CCA, 2018, pp. 69-70). This may result from lack of discussion with family or care providers. However, it may be difficult for individuals to predict the circumstances in which they will find themselves and it can be very difficult to be specific. This difficulty stems from the underlying tension regarding the disability paradox in Chapter Four. For example, an individual may include the inability to recognize family members as a criterion for when they would like MAiD administered. It is unclear whether this means when the individual can no longer remember their names or when they no longer have any reaction or familiarity upon seeing family. This lack of clarity also highlights the tension between the former and current self, which manifest as critical and experiential interests²⁶. Further, since dementia can cause fluctuation in states, an individual may be able to remember a name or recognize a family member one day but not the next. The question then presents itself if any consistency in lack of recognition is required. However, if an individual creates an AR that is too specific, it may not capture circumstances in which the individual would want MAiD. Morally speaking, a balance ought to be struck between creating an AR that is specific enough for family and care providers to interpret and apply it, while being broad enough to capture all of the circumstances in which the individual would want MAiD. Practically speaking, this may be difficult to achieve.

Another concern with the creation of ARs after diagnosis is that the individual's preferences may change, resulting in the AR becoming outdated and not representative of their

²⁶ See pages 40-41 for discussion of these concepts.

wishes²⁷ (CCA, 2018, p. 70). This concern is especially true with illnesses like dementia, where there may be a long period of time between the creation of the AR after diagnosis, and the potential implementation of the AR. The creation of an AR gives priority to critical interests over their future experiential interests in specified circumstances. As such, the less up-to-date the AR, the less force critical interests ought to be given. This is because even when no longer competent, an individual may have experiences to which their AR does not readily apply, and these also need to be considered. For example, an individual may exhibit significant wandering behaviours, often confused, agitated, and trying to 'escape' at night but is content during the day. An individual's AR may be ill-informed or outdated and focus solely on the ability to recognize family members as a criterion for unbearable suffering, as the individual did not anticipate such wandering behaviours or agitation at night. However, the wandering behaviours and agitation ought to be considered in the individual's overall quality of life and assessment of suffering. This concern may be mitigated by requiring individuals to revisit and update their AR as necessary while they remain competent. In Belgium, an AR is only valid for five years and then must be updated by the individual, while in Luxembourg the government maintains a registry which automatically requires individuals to update the AR every five years²⁸. By keeping an up-to-date AR, the AR is more likely to be well-informed, specific, and relevant to the individual's ongoing condition. In such a case, the individual's critical interests have more force. In the example of the individual with wandering behaviours, it is possible that the individual was not aware that certain types of dementia can cause a person to exhibit wandering

²⁷ Note that this concern is not specific to the creation of ARs after diagnosis and will also be referred to during the discussion of scenarios two and three.

²⁸ See Chapter Two for further information and discussion.

behaviours. Upon realization of this knowledge and potential applicability to the individual, they ought to update their AR accordingly.

Cases become increasingly more complex and more uncertainty is introduced when an individual who is no longer competent expresses preferences that differ from, or contradict, the criteria set out in their AR. This is particularly difficult if the individual resists at the time of the MAiD procedure. Resistance at the time of procedure is the clearest example of the individual's critical interests conflicting with their experiential interests. If the criteria set out for unbearable suffering in an individual's AR are fulfilled, then the critical interests of the individual dictate that MAiD ought to be provided. However, if the individual verbally or physically indicates their wish to live or resists the MAiD procedure in any way, then their experiential interests dictate that MAiD ought not be provided. Again, this must be considered in the context of the case and situation rather than be disregarded. It is integral to the process that family and care providers use their judgement to balance the individual's precedent autonomy set out in their AR, and their contemporaneous wishes when no longer competent. This high degree of involvement is consistent with the ecology of dementia perspective, as the individual ought to be viewed within the context of the entire network, and, as a result, the role of the SDM is highly emphasized. The parameters of the role are not within the scope of this paper. The requirement for judgement and decision-making by the family member or care provider on behalf of an individual raises the concern over whether family members are responsible for determining or confirming intolerable suffering on behalf of the individual. This raises concern because suffering is a subjective experience and allowing a third-party to determine intolerable suffering may mean that an AR is overridden (CCA, 2018, pp. 71-2).

Further, individuals may create an AR where intolerable suffering is not the predominant criterion. Based on this uncertainty, family members and care providers alike may find it difficult to follow through with an AR set out by an individual (CCA, 2018, p. 73). Overriding an AR is controversial because the nature of an AR is that it is a legal document protecting an individual's wishes.

It is clear that creating an AR after diagnosis but before being eligible for MAiD involves a greater degree of uncertainty around interpreting and implementing the AR than scenario one, where the individual is already eligible for MAiD.

Subsection 3: ARs for MAiD Before Diagnosis.

There are several reasons any individual may wish to create an AR for MAiD before any diagnosis. First, if an individual closely resonates with the right to MAiD, they may set out circumstances that they would find intolerable, regardless of diagnosis. One concrete example is the affliction of a traumatic brain injury, such as from a car accident, where the individual may wish to make it clear that if they require assisted feeding or drinking or cannot recognize loved ones, he/she would like MAiD. Further, individuals may have witnessed a loved one experience a particular illness or set of conditions that they find intolerable and set out an AR to safeguard against having those same experiences. Particularly, with the availability of genetic testing and/or witnessing a blood relative experience a disease, the individual may perceive themselves to be at elevated risk of such condition, further fueling their desire to create an AR.

Many of the same concerns arise about creating an AR before diagnosis as were discussed previously in scenarios one and two. However, I argue that these concerns cannot be

mitigated as effectively as in scenarios one and two, and therefore there is even greater uncertainty regarding whether the individual would have changed his/her wish to receive MAiD in scenario three. Due to the more limited circumstances under which an AR would be created and implemented before any diagnosis, one could argue there may be a lesser degree of uncertainty involved regarding the applicability of the AR to the individual's future condition. This is because without any diagnosable condition, there are few things that may cause an individual to lose capacity so suddenly. These circumstances would largely be contained to traumatic brain injuries or sudden strokes. However, I argue that there is still great variability in the functioning and experience of individuals with these conditions and without any lived experience with the condition, the uncertainty that the individual may have wanted to change his/her mind is too great. This uncertainty is supported by the evidence²⁹ that individuals are poor predictors of how they will cope with a specific condition. Since evidence also shows that individuals overestimate the suffering of other individuals afflicted with a particular condition, the argument that individuals can gain personal experience with a condition through a loved one's experience with the illness is also not sufficient to mitigate the concern that an individual may change his/her wish to receive MAiD. Without personal life experience with the condition, I argue that the concern regarding whether an individual may change his/her wish to receive MAiD cannot be sufficiently mitigated in the context of scenario three.

Where even greater uncertainty may be introduced, is if an individual creates an AR before any diagnosis, is subsequently diagnosed with a terminal or irreversible condition and

²⁹ See pages 72-73.

does not update the AR. If the AR is not specific to the current illness or condition of the individual, family members and care providers may have an even more difficult time determining if the AR is applicable in the individual's specific set of circumstances³⁰. When creating an AR before any diagnosis, there is a greater degree of uncertainty as to whether the individual could make an informed AR without any personal experience of living in that specific situation, as mentioned above. Also, even without any diagnosis, if there is a long period of time between the creation of the AR and its implementation, its relevance to their current circumstances may be questioned. All of these concerns were discussed previously.

Creating an AR, whether prior to or after diagnosis, also carries the concern of whether the individual's loved ones know that the AR exists, and have discussed its contents (CCA, 2018, pp. 76-7). This concern could be mitigated by requiring a witness during the creation of an AR. This witness need not be a family member or SDM, but must be someone the individual trusts and with whom the individual has discussed his/her wishes. Care providers may also not know that the AR exists if the individual's condition occurs suddenly, such as from a car accident. One way to mitigate this concern is through the creation of an AR registry, similar to that in Luxembourg³¹. However, only the individual can discuss the AR with loved ones to ensure that they are informed of their wishes. Many other practical concerns are raised, such as if an individual creates the AR in one province but is located in another at the time of implementation of the AR, or whether the AR takes precedence if an individual has both an AR

³⁰ The concern is addressed more closely in the context of dementia on page 82.

³¹ See page 26

and advance directive (CCA, 2018, pp. 77-80). These concerns will not be dealt with in the context of this thesis.

Overall, this section demonstrates that scenario three entails the greatest level of uncertainty around whether the individual would change his/her mind regarding MAiD after losing capacity, as compared to scenarios one and two. These uncertainties are developed from the underlying tensions outlined in Chapter Four, including the disability paradox and autonomy. At the root of the varying levels of uncertainty is the conflict between the former competent self's critical interests and the current incompetent self's experiential interests. Further, I present recommendations regarding how to mitigate these uncertainties. The level of uncertainty in each scenario is related to three main factors: (i) to what degree the patient's circumstances match those set out in their AR; (ii) to what degree the patient has repeatedly communicated their wishes for MAiD in specific circumstances; and (iii) family members and care providers know that the AR exists and are familiar with its contents. The greater the time period between creation of the AR and its implementation, the less likely each of these factors is to be satisfied. The level of uncertainty regarding whether the individual would have changed his/her wish to receive MAiD after losing capacity in each scenario is central to my argument in section 2 of this chapter regarding if, and to what degree, MAiD legislation ought to be expanded to include ARs.

Section 2: Drawing the Line

This section ties together the moral arguments presented throughout the thesis suggesting that there are some circumstances in which ARs for MAiD ought to be legalized. In

this section, I argue that ARs for MAiD ought to be legalized in two ways: (i) in circumstances where the individual has a diagnosis and is already eligible for MAiD or becomes eligible and reaffirms a previous advance request; and (ii) in circumstances where the criterion for implementing the AR is that the individual is irreversibly unconscious. I argue that ARs for MAiD ought not to be legalized for individuals who are not yet eligible for MAiD, whether or not they have a diagnosis of a grievous and irremediable condition. My arguments are supported by balancing the potential risks and harms with the potential benefits on an individual and societal level as discussed in Chapter Four, employing the various theoretical concepts discussed in Chapter Three, applying prior recommendations of Canadian reports and sources, and the *Carter v Canada* ruling, and relating to the experience in other jurisdictions that have legalized ARs for MAiD as outlined in Chapter Two.

Subsection 1: Scenario One.

Scenario one entails the creation of an AR after diagnosis and after the individual has been deemed eligible to receive MAiD. This scenario may also entail an individual who becomes eligible for MAiD and reaffirms an advance request created prior to becoming eligible. Canada ought to legalize ARs in the context of scenario one, where individuals are already eligible for MAiD or are reaffirming a previous advance request and wish to have MAiD even if they lose capacity. I support this position by building upon three arguments in Chapter Four and Section One of this chapter suggesting that there is a low level of conflict between the former and current self, resulting in minimal uncertainty as to whether the individual would have changed his/her wish to receive MAiD. I further support this claim of minimal uncertainty by

applying McMahan's concept of prudential concern³², suggesting that there are strong psychological ties between the former competent self and the current incompetent self over a short span of time, such as the ten-day waiting period between determination of MAiD eligibility and provision of the procedure. I further support the argument that ARs for MAiD ought to be legalized in the context of scenario one, because the prohibition against ARs may force an individual to take his/her life earlier than he/she otherwise would. Legalization of ARs in this context can provide an appropriate safeguard against such early deaths.

If an individual is already eligible for MAiD when they create an AR or reaffirms an advance request upon becoming eligible, it mitigates or eliminates many of the concerns regarding ARs where there is a conflict between the former competent self's critical interests and the current incompetent self's experiential interests. Examples of such concerns include: (i) the individual's lack of knowledge or experience living with the condition; (ii) no longer wishing to receive MAiD as a result of adaptation to the condition; and (iii) a significant length of time between creation and implementation of the AR. Allowing the creation of ARs after an individual is already eligible for MAiD supports Dworkin's prioritization of critical interests, while addressing Dresser's concern regarding the lack of opportunity for an individual to change his/her mind. This is because, as discussed in the previous section of this chapter, the individual fully understands the nature of their condition and is unbearably suffering. Their request is well-considered and repeated and has already been thoroughly discussed and assessed by two independent practitioners. Therefore, it is very unlikely in these circumstances that individuals

³² See Chapter Three

would change their minds if they are also creating an AR that would ensure their wishes are followed, even if they become incompetent. Overall, in scenario one, there is minimal potential conflict between the former competent self's critical interests and the current incompetent self's experiential interests.

Time is certainly an important consideration when weighing the likelihood of the individual changing his/her mind. Although time is a relative construct and relational autonomy and the ecology of dementia both support identity as continually changing, it is highly unlikely that an individual's identity could change so significantly within ten days living in a terminal state (the legal waiting period for MAiD) as to cause the individual to change his/her mind regarding the wish to receive MAiD. I support this claim by applying McMahan's concept of prudential concern³³, where he argues one's prudential concern over two different stages of one's life ought to decrease in proportion to the decrease in psychological ties between the two stages of life. Over a ten-day period, I argue that there are strong psychological ties between the former competent self, and the current incompetent self. Therefore, the individual has high prudential concern over their imminent death, and this ought to give force to the former self and his/her critical interests, as expressed through the creation of an AR. For example, if an individual is approved for MAiD, has all paperwork completed, and loses competence before the end of the ten-day waiting period, there must be very strong justification for nullifying the individual's request and extending their suffering. A fair and appropriate safeguard, therefore,

³³ See page 45 for a more in-depth discussion of prudential concern.

could be in the form of an AR, where the individual sets their precedent autonomy into a legally binding document.

Despite the fact that many of the concerns regarding ARs are mitigated when the individual is already eligible for MAiD upon creation of the AR, one could argue there is still a small risk that individuals would have changed their minds if they were competent. This must be weighed against the potential harm of overriding individuals' precedent autonomy and prolonging unbearable suffering if they become incompetent some time after being deemed eligible for MAiD. Given that the individuals have already been deemed legally eligible for the procedure a short time before becoming incompetent, the greater of the two harms would be removing eligibility from individuals suffering intolerably as a result of loss of competence. Further, in accordance with informed consent, the individuals must understand that once they lose capacity, they will no longer be able to change their mind. Given this consent, and that the AR is a legally binding document, individuals are accepting any legal and moral risk associated with being unable to change their minds once they lose capacity.

One of the strongest arguments in support of the view that ARs ought to be legalized if the individual is already eligible for MAiD is that the individual is using the AR as a means of avoiding ending their life too soon. In the *Carter v Canada* decision, Justice Smith concluded that, "Ms. Taylor's right to life was engaged insofar as the prohibition might force her to take her life earlier than she otherwise would if she had access to a physician-assisted death" (*Carter v Canada*, 2015, para. 30). Similarly, in the case of ARs, it would be seen to infringe on the individual's right to life because the prohibition against ARs may force her to take her life earlier than she otherwise would.

The premature decision to end one's life is evident in cases such as the recent attempted double suicide of an elderly couple when the wife, afflicted with dementia, in a moment of lucidity, asked her partner to help her die (van Dyk, 2019). A longitudinal study from Denmark found that, after controlling for mood disorders, hospital-diagnosed dementia was associated with a higher risk of suicide (Erlangsen, Zarit & Conwell, 2008). An individual who does not wish to live in state of unbearable suffering, such as from the inability to recognize loved ones, may commit suicide while still competent or in a moment of clarity, as noted above. In this example, unbearable suffering means the current anticipation that one will not be able to recognize loved ones in the future, and from an ecology of dementia perspective, includes the potential suffering of loved ones when the individual with dementia can no longer recognize them. In anticipation of such suffering, the illegality of ARs may cause individuals to die prematurely via suicide, and therefore, legalizing ARs under certain circumstances could provide an appropriate safeguard. An Australian study examining suicidal behaviour in individuals with dementia concludes that, "The challenges of living with dementia can result in some people requesting euthanasia or assisted suicide before the dementia becomes too severe and there needs to be an active public discourse about the moral dilemmas that this poses to society" (Draper, 2015, p. 1608). This elevated risk of suicide may be alleviated through the legalization of ARs for MAiD, as individuals can create an AR to safeguard against living in a state of unbearable suffering without the capacity to request MAiD as their contemporaneous self.

In this subsection I have argued it ought to be legal in Canada for individuals to create an AR, after they are already eligible for MAiD or if they are reaffirming a previous advance

request, as set out in scenario one. I support this argument by applying Dworkin's prioritization of critical interests, minimizing Dresser's concern that ARs remove the opportunity for individuals to change their mind, applying McMahan's concept of prudential concern, while viewing the individual within an entire network, which is consistent with the ecology of dementia perspective. When weighing the balance between the potential harm of restricting the individual's precedent autonomy and the potential harm of providing MAiD to an individual who may have wished to change his/her mind, the scale is tipped in favour of the individual's precedent autonomy. This argument builds on the crucial underlying tensions outlined in Chapter Four, including autonomy and the anticipation of suffering, and the level of uncertainty of the potential for an individual to change his/her mind argued in Section One of Chapter Five. Note that individuals with dementia are not eligible under scenario one to create an AR because, as the current legislation stands, they are never considered eligible for MAiD. This issue will be further addressed in subsection three.

Subsection 2: Scenario Three.

In contrast to my argument in scenario one, I argue that ARs ought not to be legalized in the context of scenario three, where the individual has no diagnosis, because the potential harm of providing MAiD to an individual who would no longer wish to receive it outweighs the potential harm of restricting the autonomy of individuals who wish to create an AR before any diagnosis. I support this position by building upon my arguments in Chapter Four and Section One of this chapter suggesting there is a high level of conflict between the former and current self, resulting in great uncertainty as to whether the individual would have changed his/her wish to receive MAiD. I further support the position that ARs ought not to be legalized in the

context of scenario three using a consequentialist argument that justifies the prohibition of ARs for MAiD for small segments of the population. In response to a limitation of this consequentialist argument, I suggest that ARs for MAiD ought to be legalized if the sole criterion for implementation is that the individual is irreversibly unconscious. I support this argument with the successful legalization and implementation of ARs in this context in Belgium and Luxembourg, and Dworkin's position establishing that there is no conflict between the former competent self's critical interests and the current incompetent self's experiential interests, as an unconscious individual has no experiential interests.

As demonstrated in my argument in Section One, Subsection Three of this chapter, there is a high degree of uncertainty associated with scenario three regarding the possibility of an individual changing his/her wish to receive MAiD. My argument addressed concerns regarding a conflict between the prior competent self's critical interests and the current incompetent self's experiential interests. Specifically, some of the strongest of these concerns include: the lack of an informed AR, the possibility of changing one's mind, and the limited applicability of the AR to contemporary circumstances. Without a grievous and irremediable diagnosis, it is unlikely that an individual has adequate information and experience with a particular illness to create an informed AR. Further, even with an informed decision, if the individual does not yet have a grievous and irremediable condition, it would be much more difficult to spell out specific circumstances in the AR in which the individual would like MAiD. This limits the applicability of many ARs that are created before any diagnosis. Further, creating an AR before any diagnosis increases the length of time between creation of the AR and its implementation. The longer this time period, the lesser the prudential concern, and the

stronger the argument that the individual may wish to change their mind. If an AR was created many years ago, there is a stronger argument that it may no longer reflect the individual's preferences. Note that this is consistent with the legislation in both Belgium and Luxembourg, where the AR either expires or is required to be updated after five years. Each of these practical concerns outlined above informs the greater moral concern of conflict between the former competent self's critical interests and the current incompetent self's experiential interests. The concerns outlined align closely with Dresser's prioritization of experiential interests, as ARs leave no room for individuals to change their mind and contrast Dworkin's prioritization of critical interests, as critical interests can lose their relevancy over time or with significant identity changes³⁴.

In the context of scenario three, there is great potential for harm to the individual, including his/her surrounding network, due to the uncertainty of whether he/she would have changed his/her wish to receive MAiD. This uncertainty could result in providing MAiD to an individual who would not wish to receive it³⁵. The potential harm to the individual's network includes the emotional and psychological burden of aiding in ending a loved one's life without knowing for certain that he/she would have wanted MAiD in such circumstances. The same burden may impact the healthcare team. There may also be impacts on wider society of providing MAiD in circumstances where it is not certain that the individual would have wanted the procedure, such as through reinforcing fear or stigma of an illness³⁶.

³⁴ See Chapter Three for a more in-depth discussion of these positions.

³⁵ This raises the question of to what degree an individual who no longer has capacity can be harmed by a practice to which he/she can no longer consent, and will not be addressed in the context of this paper.

³⁶ This is further discussed in Chapter Four and applied in the next section of Chapter Five.

One must also consider that there remains the potential harm of restricting the autonomy of individuals who are prohibited from creating³⁷ an AR prior to any diagnosis, subsequently lose capacity, and therefore would not be able to access MAiD through an AR. However, this potential harm resulting from restriction of autonomy in a few circumstances is outweighed by the potential harm of uncertainty in many cases that may lead to providing an individual with MAiD against their wishes³⁸. This is because there are very few circumstances where an individual would be able to create an AR before diagnosis but not after. Such examples might include car accidents that leave an individual with a traumatic brain injury where they no longer have capacity to create an AR. However, given that the majority of illnesses enable individuals to have capacity at the time of diagnosis, the restriction impacts only a small segment of the population. Note the consequentialist line of reasoning.

One limitation of such consequentialist reasoning is that the rights of small segments of the population, often consisting of vulnerable individuals, are sacrificed for the greater good of the whole. In recognizing this potential exclusion of a small segment of individuals, I propose we ought to legalize the creation of ARs where the sole allowable criterion for the creation and implementation of an AR is that the individual is in a state of irreversible unconsciousness. Here, I am suggesting a legal compromise wherein some level of precedent autonomy can be supported for those who wish to create an AR before any diagnosis, while also mitigating

³⁷ There is a potential discrepancy between whether it can be considered illegal to *create* an AR versus illegal to *honour* an AR. In the scope of this thesis, an AR is taken to mean a formal document that is legally binding where the default is to honour the AR. This means that where I have written about the legality or illegality of the creation of an AR, I am also referring to honouring the AR.

³⁸ This resonates closely with principlist and utilitarian reasoning through the weighing and balancing of harms to produce the least harm.

concerns associated with whether the individual would have changed his/her mind. For example, if an individual acquires a traumatic brain injury to the extent that he/she is considered irreversibly unconscious by an assessor, then the individual's AR would be implemented and MAiD could be provided. This compromise is less morally problematic than broad legalization before diagnosis because when an individual is unconscious, the individual's current self has no contemporaneous autonomy or experiential interests. Therefore, the individual's critical interests, as established through the AR, take priority and the individual ought to receive MAiD³⁹. Although I have introduced this argument for legalization of ARs for individuals who are irreversibly unconscious in the context of scenario three (before any diagnosis), this type of AR can be created at any time, whether before or after diagnosis and before or after eligibility for MAiD.

Further, ARs for MAiD for individuals who become irreversibly unconscious have been successfully legalized and implemented in two other jurisdictions: Belgium and Luxembourg. From 2003-2013 in Belgium, the number of euthanasia cases resulting from an AR ranged from 0.4% in 2003 to 4% in 2006 (Dierickx, Deliens, Cohen, & Chambaere, 2016). The total number of euthanasia cases resulting from an AR range from 1 case in 2003 to 44 cases in 2012 (Dierickx, Deliens, Cohen, & Chambaere, 2016). From 2002 to 2013, eight euthanasia cases were reported wherein an individual with dementia was euthanized as a result of an AR (Dierickx, Deliens, Cohen, & Chambaere, 2017). Clearly, dementia cases account for a very small number of the total cases of euthanasia in Belgium resulting from an AR. The legalization, relatively low

³⁹ Note the exposition of this line of reasoning earlier on pages 69-70 and Dworkin's conceptualization in Chapter Three.

occurrence, and reliable data collecting and monitoring suggests that ARs can be an effective and safe way for individuals in an irreversible coma⁴⁰ to give force to their critical interests and exercise their precedent autonomy.

Subsection 3: Scenario Two.

Thus far, I have argued that ARs in the context of scenario one, where individuals are already eligible for MAiD ought to be legalized, while ARs in the context of scenario three, where individuals do not have a grievous and irremediable diagnosis and are not eligible for MAiD, ought not to be legalized. Also, in recognition that some individuals with certain afflictions are excluded altogether from creating an AR, I argue that we ought to also legalize ARs where the criterion to implement the AR is that the individual is irreversibly unconscious.

This subsection focuses on scenario two, where individuals have been diagnosed with a grievous and irremediable condition but are not yet eligible for MAiD, and presents the challenge of where to draw the line regarding legalization of ARs. My response to this challenge lies in weighing the potential harms of allowing versus restricting ARs for those diagnosed with a grievous and irremediable condition but who are not yet eligible for MAiD. The potential harm associated with not legalizing ARs in the context of scenario two is the restriction of the autonomy of individuals with certain illnesses. There is also potential individual and societal harm in (i) providing MAiD to individuals who can no longer consent and may have changed their mind if they were still competent and (ii) creating an AR as a result of internalized stigma regarding the worth of a life without capacity and the potential for perpetuating this stigma⁴¹. I

⁴⁰ Here I take the term irreversibly unconscious to be synonymous with being in an irreversible coma.

⁴¹ This builds on the underlying tension discussed in Chapter Three regarding vulnerability and stigma.

argue that these potential harms to the individual and society outweigh the potential harm of restricting individual autonomy. As a result, I argue that ARs for MAiD ought not to be legalized for individuals with a grievous and irremediable condition who are not eligible for MAiD.

There is deep concern that allowing ARs too broadly would reinforce existing societal attitudes and stigma towards individuals with certain illness such as dementia (Schutten, 2016; CACL, 2017). The reasoning for this argument outlines that creating an AR for MAiD in anticipation of a loss of mental capacity implies that individuals and larger society approve of the notion that a life without capacity is a life not worth living, which contributes to and perpetuates the stigma associated with conditions such as dementia. In other words, allowing ARs for those with dementia inherently makes a value judgement about the worth of those individuals. It is difficult to provide evidence of such claims, as it is difficult to measure stigma and attribute any potential increases in stigma to euthanasia. Interestingly, one study, which completed a discourse analysis and philosophic inquiry of the use of Alzheimer's disease as a potential framing device in the public policy debate surrounding euthanasia for those with dementia (Johnstone, 2011). The study found that stigmatizing language and discussion surrounding Alzheimer's disease is used in order to skew public opinion and the public policy debate to support legalization of MAiD as a "solution to the disease" (Johnstone, 2011, p. 377). The concern about reinforcing stigma causes us to question the root cause of why an individual, particularly with dementia, may want to create an AR for MAiD. One reason may be that,

"Because of being terrorized by the mere thought of 'getting' Alzheimer's disease – of being 'invaded by an alien', of being overwhelmed by 'tidal waves of dementia rolling

through the generations' – people become disposed to seek out those, anyone even, who they believe will offer a reprieve, a redemption, a remedy, a 'final solution' that will rescue them utterly and completely from their terror (Johnstone, 2011, p. 388 paraphrasing Becker, 1973).

It is crucial to recognize that individuals, particularly with stigmatized illnesses like dementia, may internalize stigma and societal value judgements of the worth of a life without capacity. The argument restricting individual autonomy by not allowing ARs for MAiD appeals to the greater good and protects individuals from making a decision that they may not even realize is rooted in stigma and value judgments of their societal worth. This societal influence is supported by the ecology of dementia perspective, as the ongoing changes experienced by individuals also impact the surrounding network, including the social environment, while the social environment also has significant impact on the decisions and identity changes experienced by individuals. Given the potential for internalized stigma to contribute to the decision to create an AR and the evidence demonstrating the misuse of stigmatizing language surrounding dementia in the euthanasia debate, I suggest we ought to work towards further understanding and supporting dementia and those it impacts, and thereby reduce stigma associated with the condition, before legalizing ARs for those with dementia⁴². This stigma regarding the worth of an individual's life when lacking capacity may be internalized by individuals with conditions other than dementia who create an AR after diagnosis but before eligibility due to a fear of loss of capacity, even if it is subtler or to a lesser extent than that

⁴² With the exception of an AR created with the condition of irreversible unconsciousness as a criterion for implementation, as argued in the previous subsection.

experienced by individuals with dementia. Thus, I argue we ought not to legalize the creation of ARs after diagnosis but before eligibility for any condition, including dementia⁴³.

Here, it is tempting to work through an ideal case where an individual can create an AR after diagnosis but before MAiD eligibility that is informed and adequately fits their contemporaneous circumstances when the AR is implemented. In the ideal case, there would be little to no uncertainty by the physician and family members. However, as noted in a recent article,

If the ideal case is not representative of the kinds of cases that will be affected by the policy, then it will tell us little about whether the policy is well considered. Paternalistic restrictions on PAD, for this reason, must be group-centred and based on a realistic assessment of the situation (Jansen, Wall & Miller, 2019, p. 194).

Since the typical case of creating an AR after diagnosis but before eligibility involves a moderate level of uncertainty⁴⁴ regarding whether the individual would change his/her mind and the high potential for an individual to create an AR as a result of internalized stigma of the worth of a life lacking capacity, we ought not to legalize ARs in this scenario even if there are a few cases where the uncertainty is low enough to justify allowing the creation of an AR. This is because if the majority of cases involve high potential for harm to the individual and society more broadly, it is justifiable to restrict the autonomy of individuals in a few cases for the protection and greater good of all individuals in such circumstances, and society more broadly. Since there is

⁴³ Again, with the exception of an AR created with the condition of irreversible unconsciousness as a criterion for implementation, as argued in the previous subsection.

⁴⁴ As argued in section one of this chapter.

no research yet available on the ‘typical’ cases falling under the context of scenario two, the legalization of ARs in the Netherlands in 2016 ought to be watched closely by Canada and the issue reconsidered as more information becomes available.

Although I argue against the legalization of ARs in the context of scenario two given current legislation, there is one potential context in which some individuals with dementia may be able to access MAiD via ARs. If the current challenges to the legislation regarding the criterion that death is “reasonably foreseeable” are successful, some individuals with dementia may be eligible for MAiD if they fulfill all other criteria. Given that individuals’ circumstances now fit into scenario one, they could create an AR to set out when they want to receive, and ensure that they receive, MAiD. However, this would require two amendments to the legislation: (i) removing the requirement that death be reasonably foreseeable; and (ii) legalizing the creation of an AR for individuals already eligible for MAiD. I have already argued that the latter amendment noted above ought to be legalized in section two, subsection one of this chapter. The former amendment, removing the requirement that death be reasonably foreseeable, would not only impact individuals wishing to create an AR, but other individuals in circumstances much different than the ones discussed in this thesis, including minors, those with mental illness as a sole underlying condition and those without a diagnosable terminal condition, to name a few. Due to its significant impact on all populations seeking MAiD, the argument of whether or not the reasonably foreseeable death requirement ought to be removed or not is not within the scope of this thesis. I hope to merely point out that other potential alterations to the current legislation may have significant impacts on individuals wishing to create ARs for MAiD, particularly for those with dementia.

Chapter Conclusion

Chapter Five ties together the evidence, analysis, and moral arguments set out in the previous four chapters by providing further moral arguments and recommendations surrounding the level of uncertainty of whether an individual would have changed his/her wish to receive MAiD in each potential scenario of legalization of ARs, the ways to mitigate such concerns, and the circumstances in which ARs for MAiD ought to be legalized in Canada. The chapter is divided into two sections, where the first section has two aims: (i) to identify concerns or challenges posed by each of three potential scenarios in which ARs could be legalized; and (ii) to argue that scenarios one to three carry increasing levels of uncertainty, respectively. In section two, I argue that ARs for MAiD ought to be legalized in two ways: (i) in scenario one, where individuals have a diagnosis of a grievous and irremediable condition and are already eligible for MAiD or are reaffirming a previous advance request; and (ii) where the sole allowable criterion for implementing the AR and providing MAiD is that the individual is irreversibly unconscious. I also argue that ARs for MAiD ought not to be legalized in two contexts: (i) when the individual is not diagnosed with a grievous and irremediable condition and is not eligible for MAiD; and (ii) when the individual is diagnosed with a grievous and irremediable condition and is not eligible for MAiD.

Thesis Conclusion

Broadly, this thesis has set the landscape of MAiD legislation in Canada and other jurisdictions including the Netherlands, Luxembourg, Belgium, Switzerland, Columbia, Germany, and the United States. Chapters One and Two explore the historical and political context in

which the legislation was developed, and compare this legislation across jurisdictions. Key information is summarized immediately following Chapter Two. Chapter Three addresses some of the theoretical considerations of potentially expanding MAiD legislation to include ARs for those with dementia. Two notions of the self, including the current and former self, along with the self's corresponding interests, including critical and experiential, are discussed. Arguments and critiques regarding which notion of the self and interests ought to have authority are presented from scholars including Dworkin, Dresser, and McMahan. I highlight the aspects of each theorist's position that I find convincing or unconvincing. The concept of the ecology of dementia is also introduced and I suggest that this concept provides a new perspective from which to view the issue of whether or not to expand MAiD legislation to include ARs. Aspects of each theorist's positions along with the concept of the ecology of dementia provide a framework to support my arguments presented later in the thesis.

The fourth chapter explores the key viewpoints and tensions associated with expanding MAiD legislation to include ARs. The first two sections of the chapter outline arguments for and against the expansion of MAiD legislation to include ARs, while the third section highlights the major areas of tension within these arguments. These major areas of tension include autonomy, the anticipation of suffering and the disability paradox, and vulnerability and stigma. I suggest that both arguments for and against expansion of the legislation to include ARs for MAiD have merit, and we ought to strike a balance between providing equitable access to MAiD for individuals with different conditions, while minimizing the potential for error, abuse, and perpetuation of stigma.

Chapter Five presents recommendations and normative arguments regarding the legalization of ARs for MAiD. Section one outlines three possible contexts in which ARs for MAiD could be legalized in Canada. These potential contexts include the creation of an AR when: (i) the individual has a diagnosis of a grievous and irremediable condition and is already eligible for MAiD; (ii) the individual has a diagnosis of a grievous and irremediable condition but is not yet eligible for MAiD; and (iii) the individual does not have a diagnosis of a grievous and irremediable condition and is not eligible for MAiD. I outline the major concerns with potentially legalizing ARs for MAiD in the context outlined in each scenario listed above, provide recommendations on how to mitigate such concerns, and suggest whether such concerns can be sufficiently mitigated. I argue that there is an increasing level of uncertainty in scenarios one to three, respectively, regarding whether an individual would have changed his/her wish to receive MAiD if he/she were still competent. This level of uncertainty is foundational to my arguments in section two.

The final section of Chapter Five presents my argument as to where to draw the line regarding in what circumstances, in relation to the three scenarios outlined, ARs for MAiD ought to be legalized in Canada. I support these positions by applying the evidence, discussions, and arguments in the previous four chapters of this thesis. I argue that scenario one, where an individual has a diagnosis and is already eligible for MAiD or is reaffirming a previously created advance request, ought to be able to create an AR for MAiD for three reasons. Scenario one involves the least level of uncertainty regarding whether the individual may have changed his/her mind. If an individual is already eligible for MAiD, they are suffering intolerably and have lived with the condition for a sufficient length of time that further adjustment to the condition

is unlikely. Second, the potential harm of restricting or violating the autonomy of the individual by removing an individual's eligibility for MAiD outweighs the potential harm of an individual changing their mind. Third, creating an AR for MAiD in scenario one can be used to prevent ending the individual's life too soon. This aligns closely with the reasoning provided by Justice Smith in the *Carter v Canada* decision.

I argue that MAiD legislation ought not to be expanded to include ARs in the context of scenario three, where the individual is not eligible for MAiD and has no diagnosis of a grievous and irremediable condition. In this situation, there is a significant potential for conflict between the former competent self's critical interests and the current incompetent self's experiential interests. As a result, there is a high level of uncertainty regarding whether the individual would have changed his/her wish to receive MAiD. I argue that high level of uncertainty means that the risk of harm to the individual and society outweighs the risk of restricting individual autonomy. I further support the position that ARs ought not to be legalized in the context of scenario three using a consequentialist argument that justifies the prohibition of ARs for MAiD for small segments of the population. In response to a limitation of this consequentialist argument, I suggest that ARs for MAiD ought to be legalized if the sole criterion for implementation is that the individual is irreversibly unconscious.

In the context of scenario two, I argue that, for now, MAiD legislation ought not to be expanded to include ARs. I argue that there are ideal cases in which the uncertainty is low enough to outweigh the potential harm to the individual and society. However, given that the typical cases present a moderate level of uncertainty, the potential harms are too great to the individual, who may have changed his/her mind, and to society, which may further stigmatize

and reinforce the vulnerability of those with dementia. I suggest that Canada watch the Netherlands closely and collect information and data on the cases that occur in this region, as ARs for MAiD were only legalized in 2016.

Note that changes in political positions and parties may have a significant impact on whether MAiD legislation is expanded to include ARs. For example, in a recent cabinet shuffle in February 2019, David Lametti replaced Jody Wilson-Raybould as Justice Minister. Although Wilson-Raybould made it clear in November 2018 that expanding the law was not under consideration, Lametti was one of few Liberal MPs who voted against the 2016 MAiD legislation, as he felt that it was overly restrictive. In response to the legislation, Lametti noted, “as a professor of law in Canada for 20 years and a member of two Canadian Bars, I also worry about passing legislation that is at serious risk of being found to be unconstitutional. On these grounds, I was not able to give it my vote in good conscience” (Bryden, 2019, para. 4). Given that there are only a few months until the 2019 federal election, it is unlikely any changes will be made in the near future. However, Dying with Dignity Canada plans to launch a campaign urging the government to implement “Audrey’s amendment”, so that an individual in scenario one could create an AR (Bryden, 2019). Given the current political climate with Lametti as justice minister, the pressure from individuals and advocacy groups in Canada, and the low uncertainty that an individual would have changed his/her wish to receive MAiD associated with developing an AR when already eligible for MAiD, I predict it is reasonably foreseeable that the creation of ARs for those in scenario one will be legalized. This brief prediction aims to highlight that the legality of issues such as the expansion of MAiD legislation is highly impacted by the political climate of the jurisdiction at the time. This is clearly demonstrated in Chapter

two where several jurisdictions legalized MAiD or expanded the legislation following change in government leadership, such as in Belgium, or lowering the legislative power of a reigning monarch, such as in Luxembourg. As a result of such political influence, the moral arguments made in this thesis do not necessarily translate to if and how they may actually be legalized in Canada.

It will be fascinating to witness the direction in which MAiD legislation takes us. No matter whether the legislation is extended to include advance directives or not, value tensions and controversies will continue to prompt and necessitate thought-provoking ethical discussion. I look forward to actively participating in these future conversations.

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Appendix A: Frailty and Cognitive Impairment

Frailty is a state of increased vulnerability, with reduced physical reserve and loss of function across multiple body systems. This reduces ability to cope with normal or minor stresses, which can cause rapid and dramatic changes in health (Canadian Frailty Network, 2019). MAiD legislation has broad implications for how we support and empower frail older adults at the end-of-life, and as such has potentially significant impacts on frail older adults, their families and caregivers, and their healthcare providers. Dementia may be one contributing factor to the loss of function and can have significant effects on other body systems, while reduced function in other body systems can also impact the dementia. In order to determine whether or not MAiD legislation ought to be expanded to be included in advance directives for individuals diagnosed with dementia, it is crucial to understand what dementia is, its causes, and progression.

Dementia is defined by an irreversible and progressive degeneration of brain cells resulting from one of many possible diseases, of which the most common is Alzheimer's disease (Alzheimer's Society of Canada, 2019). These changes to the brain depend on the specific disease afflicting the brain and the parts of the brain damaged, but often include memory loss and difficulty with thinking, language, or problem-solving (Alzheimer's Society of Canada, 2019). For example, individuals may have difficulty remembering recent events, completing higher level daily functions such as cooking a meal, following conversation, judging distance, and orienting themselves (Alzheimer's Society of Canada, 2019). Individuals afflicted with dementia may experience changes in mood, visual hallucination, and/or delusions (Alzheimer's Society of

Canada, 2019). The Alzheimer's society of Canada lists nine types of dementia and many other rarer conditions that can lead to dementia (Alzheimer's Society of Canada, 2019).

The type of dementia is just one factor contributing to the unique experience and needs of individuals afflicted with dementia. Other factors include the lived environment and caregiving supports (Alzheimer's Society of Canada, 2019). The variability in experience results from the progressive nature of the disease because each individual is affected differently (Alzheimer's Society of Canada, 2019). Therefore, it is difficult to predict the types and onset of symptoms, or the speed at which symptoms progress. The illness trajectory for frailty and dementia is similar, with a great degree of unpredictability (Murray, Kendall, Boyd & Sheikh, 2005). This unpredictability has repercussions for the practical considerations of implementing an AR, because the implementation of an AR is contingent upon the fulfillment of criteria for unbearable suffering that the individual has set out. Therefore, the great fluctuation and unpredictability of the frailty and dementia illness trajectory makes it challenging for healthcare providers and family to determine the appropriate time to provide MAiD.