

Concerns with Expanding Access to Medical Assistance in Dying

A Review of Evidence

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Introduction

This paper reviews a wide body of research and evidence to critically consider expanding access to medical assistance in dying (MAiD) in the Canadian context. In adopting amendments to the *Criminal Code* in June 2017, Parliament committed to studying implications of expanding access to MAiD by providing for eligibility for mature minors, through advance directives and based solely on a mental health condition, which would mean removing the end of life requirement currently in the legislation.

The paper reviews literature from academic sources in psychology, bio-ethics, clinical studies, social policy and disabilities studies. As well, it draws on a wide range of policy research. The aim of this paper is to focus on literature and evidence which raises concerns with expanding access.

The review is organized into three main sections:

- Concerns with Access through Advance Euthanasia Directives
- Concerns with Access by Mature Minors
- Concerns with Access Based Solely on Mental Illness

I. Concerns with Access through Advance Euthanasia Directives

Advanced directives (ADs) are statements and/or directions written by an individual about which medical treatments should or should not be performed if the individual becomes incapable of decision making (Downie & Lloyd-Smith, 2015). ADs have been developed to ensure that an individual's autonomy and preferences are respected throughout their life (de Boer, Droës, Jonker, Eefsting, & Hertogh, 2010b). ADs can offer individuals comfort and reassurance that they will retain control of their end-of-life health care, even when they are no longer able to communicate (Gastmans & De Lepeleire, 2010). ADs can be useful tools in advancing Supported Decision Making; they allow individuals to make medical treatment decisions in advance, that is, for a time when their decision-making capacity may be impaired. In this sense ADs help support Supported Decision Making's principle of autonomy.

ADs are justified as a mechanism both to protect exercise of negative liberty rights – i.e., refusing specific intervention – and to protect positive rights to specific interventions (de Boer et al., 2010b). ADs have been critiqued based on lack of clarity, ability of individuals to predict their future wishes, and possible interference with a physician's judgment, although some suggest that about certain interventions and situations ADs can be justified to respect individual autonomy (Gastmans, 2013; Hertogh, de Boer, Droës, & Eefsting, 2007; Mitchell, 2010).

In the context of assisted dying, Advanced Euthanasia Directives (AEDs) are a means to exercise positive rights: they request physicians to perform interventions intended to cause death at a certain point in the future. The Netherlands is the only country in which AEDs can be carried out for patients with advanced dementia (Belgium allows for AEDs but the individual must no longer be conscious and the AED must have been written at least five years before the start of

incapacity) (Downie & Lloyd-Smith, 2015). Netherland's *Termination of Life on Request and Assisted Suicide Act 2002* states that an individual deemed capable can draft an AED to be carried out when they reach a state of unbearable suffering, and that physicians may follow the directive so long as the due-care criteria set out in the act are met (Bolt, Snijewind, Willems, van der Heide, & Onwuteaka-Philipsen, 2015; van Delden, 2004).

In the case of AEDs, in which death is the specific intent (compared to non-treatment directives that permit the potential of death), it has been argued that these concerns are intensified and the potential for harm is too great to overcome (Francis, 1993; Vogelstein, 2017). These arguments draw on the concept of the sanctity of life, concluding that it is worse to end someone's life when they did not explicitly consent to its termination, than not end their life when they wanted it to end (Vogelstein, 2017).

Thus, there is a crucial difference in both legal and moral terms between ADs and AEDs. While it is legally acknowledged that patients have the right to refuse treatment, the positive right to have an intervention performed that is intended to cause a person's death constitutes a weaker claim on the state. Moreover, the rights of physicians to refuse to perform a treatment they believe is ethically inappropriate or harmful is an ethically stronger claim (Vogelstein, 2017).

Most literature and research on AEDs focuses on how they are to be applied to individuals with dementia and whether an individual should be permitted to draft an AED that requests MAiD to be carried out when they reach an advanced stage of dementia and no longer have the capacity to make the request or provide informed consent for the intervention.

The research and ethics literature points to seven main concerns with allowing AEDs for individuals with dementia.

1. Continuous Identity and Respecting Past vs. Present Wishes

There is an unresolved philosophical question (based on Ronald Dworkin's (1993) concepts of critical and experiential interests) about whether the person making the AED at a certain point in time can bind their future self to its terms when it is impossible to anticipate how that future self will change through the various stages of dementia (Dresser, 1995; van Delden, 2004). Dworkin's well-known argument suggests that the self making the AED has absolute authority to make decisions for future selves, even if they may develop a different set of desires and values (Menzel & Steinbock, 2013; Mitchell, 2010). However, there is clear evidence that an individual may adapt and be content to live in an advanced stage of dementia that they previously thought would be intolerable (Cohen-Almagor, 2016; de Boer Droës, Jonker, Eefsting, & Hertogh, 2010a; Dresser, 1995; 1999).

Biomedical and psychological research do not provide conclusive evidence to justify the moral and legal authority of AEDs; in fact, quite the opposite. Research shows that people are limited in their ability for affective forecasting (predicting future emotional states), often underestimating how quickly they cope with negative circumstances when confronted with them in the future (Gastmans, 2013; Halpern & Arnold, 2008; Wilson & Gilbert, 2005). Research

has found that persons with dementia have reported that the experience of their condition was not what they feared it would be (Bolt, Pasman, Deeg, Onwuteaka-Philipsen, 2015; Cohen-Almagor, 2016; Hertogh, 2009; Menzel & Stenibock, 2013).

Moreover, studies in the Netherlands have found that physicians and relatives of persons with dementia report hesitation about what to do if the patient seems to have adapted to their situation and also uncertainty about determining the exact moments to carry out AEDs (de Boer et al., 2010a; Kouwenhoven et al., 2015; Tomlinson, Spector, Nurock, & Stott, 2015). Physicians and family members are thus placed in an almost impossible position. How are they to determine whether the current situation meets the criteria set by the person who authorized the AED in the past, at a time they were unable to anticipate what would come to pass, or to anticipate their experiential interests at an undetermined point in the future (Gastmans, 2013; Hertogh et al., 2007)? Given these obvious concerns, most physicians in the Netherlands choose only to use the AED as a non-treatment, or withdrawal of treatment, directive (de Boer, Droës, Jonker, Eefsting, & Hertogh, 2011).

2. Others Interpreting Intolerable Suffering

The *Medical Assistance in Dying Act* states that an individual must be experiencing “intolerable suffering” to be eligible for assisted death, but the term is never clearly defined. Concerns have been raised about such wide scope for interpreting eligibility criteria in the context of assisted death, because it can lead to manageable levels of suffering being considered intolerable (Hertogh, 2009). Even if strictly defined, establishing the presence of intolerable suffering is difficult, particularly in the case of dementia patients, who may not be able to express themselves in ways that others understand (Hertogh et al., 2007; Rietens, van Tol, Schermer, & van der Heide, 2009). This places immense pressure on family members and physicians to determine whether an individual is truly suffering from their condition, as they feared they would be when they drafted the AED, and whether the suffering can be relieved through other means, such as expanded and enriched social relationships and rehabilitation interventions (Goering, 2007; Rietens et al., 2009). Moreover, AEDs reference an undetermined future in which the directive can be carried out, which increases the scope for uncertainty in interpretation and application (Francis, 1993; Franklin, 2015; Mitchell, 2010).

3. Questioning Dementia as a Cause of Suffering

The idea that dementia is the cause of unbearable suffering can also be questioned. It can be argued that it is not the condition itself that causes suffering to be unbearable but rather the lack of inclusion and societal attitudes towards the elderly and those requiring assistance that lead to feelings of hopelessness and loss of dignity (Goering, 2007; Mitchell, 2010). Studies on interventions and therapies that promote the inclusion of persons with dementia, such as music programs, contact with nature and their neighbourhood, and life story workshops, show that quality of life can be enhanced and sense of dignity can be preserved (Eldirdiry Osman, Tischler, & Schneider, 2016; Gillard & Marshall, 2011; McKeown, Clarke, Ingleton, Ryan, & Repper, 2010; Phinney, Kelson, Baumbusch, O’Connor, & Purves, 2016; Tranvåg, Petersen, & Nåden, 2015).

4. Communication and Determining Moment of Carrying Out AED

The *Medical Assistance in Dying Act* states that individuals must be able to express consent immediately before MAiD is carried out. For individuals with advanced-stage dementia, this is often not possible, as they are often unable to communicate fully and may be lacking the cognitive abilities and insight to fully understand the nature and consequences of the decision. Physicians in the Netherlands report that adherence to the due care criteria set out in the law rests on their ability to communicate with the patient and go through a process of shared decision making, but that such communication is impossible in cases of patients with advanced dementia (Bolt et al., 2015; de Boer, Droës, Jonker, Eefsting, & Hertogh, 2011). This lack of communication makes it difficult for physicians to determine when the AED should be carried out and whether the individual's current state resembles the situation described in the AED (Gastmans & De Lepeleire, 2010; Hertogh, 2009; Mitchell, 2010). It opens up the very real risk that MAiD could be carried out against an individual's contemporaneous wishes (Gastmans, 2013; van Delden, 2004).

5. Conflicts of Interest

Studies in the Netherlands have found that physicians work with family members to determine whether to carry out AEDs and when to do so (de Boer et al., 2010b). This raises the potential that family members with something to gain from the death of their relative choose to carry out an AED too early. The gain may be tangible, such as an inheritance, or it may be intangible, and even unconscious, such as the relief from providing care, feelings of guilt, or ongoing loss of their relative.

6. Balancing Autonomy and Right to Life of Vulnerable Persons

Respect for an individual's autonomy is an important goal in decision making, but it must be balanced with the recognition that persons with advanced-dementia are vulnerable. AEDs have the potential to increase the vulnerability of an individual because they give relatives and physicians power to determine when MAiD should be performed (Gastmans, 2013; Gastmans & De Lepeleire, 2010; van Delden, 2004). As well, AEDs can potentially increase the vulnerability of persons with dementia as a whole, particularly those that live in group living settings; if one person chooses to write an AED, it may weaken the resiliency of those around them with a similar condition by promoting the idea that life with advanced dementia is not worth living. The legalization of AEDs may also increase the prevalence of the idea that those with dementia are burdens and have a "duty" to society to choose to die, which could in turn work to further increase the stigma against persons with dementia in our society and work to threaten the provision of quality of care, thus pressuring persons who would not normally choose to write an AED to do so (Benbow & Jolley, 2012; Gastmans & De Lepeleire, 2010; Gastmans & Denier, 2010; Johnstone, 2013). Indeed, a recent survey of caregivers of people with Alzheimer's in Quebec found that 91 percent of respondents supported MAiD for individuals with dementia who are at the terminal state of their illness, showing signs of distress and who have an AED and that 77 percent of respondents reported that they would write an AED if diagnosed with dementia, signaling that this trend may already be taking root (Derfel, 2017).

7. Gaps in Service

Research suggests that individuals may be motivated to draft AEDs because of the quality of care and/or gaps in needed services which can underlie fears that dementia brings an inevitable loss of dignity, a burden to relatives, and social stigma. An AED motivated by such fears may not accurately reflect the wishes of an individual (Cohen-Almagor, 2016; Gastmans, 2013; Mitchell, 2010). Significant investment in and transformation of services and supports for individuals with dementia is required to diminish the concerns associated with dementia in the current context (Franklin, 2015; Gastmans & De Lepeleire, 2010; Menzel & Steinbock, 2013).

II. Concerns with Access by Mature Minors

The legal ability of minors to make decisions regarding medical treatment varies across Canada. Quebec and New Brunswick have legislated the age of medical consent to be 14 and 16, respectively. In the other provinces and territories there is no defined age of consent and the “mature minor doctrine” is generally applied (MacIntosh, 2016). In legal terms, this means that minors between 16 and 18 years old are usually considered capable of making medical treatment decisions (Schuklenk, van Delden, Downie, McLean, Upshur, & Weinstock, 2011). This capability is questioned when the decision is considered to be at odds with the minor’s best interest (most often this involves cases of treatment refusal). In such cases, the court may override the minor’s decision if it believes that the minor does not appreciate the nature and consequences of their decision (Arshagouni, 2006; MacIntosh, 2016). The most relevant legal case in Canada is *A.C. v. Manitoba*, in which a 15-year-old refused consent to a life-saving treatment. The Supreme Court decided that the right to make decisions varies in accordance with a minor’s level of maturity and the degree to which the maturity is scrutinized intensifies in accordance with the severity of potential consequences of the treatment and its refusal (*A.C. v. Manitoba*, 2009).

The research points to three over-riding concerns about extending access to mature minors.

1. Capacity for Discernment and Decision Making

The *Medical Assistance in Dying Act* requires that an individual be able to give “informed consent” before receiving MAiD. In order to provide informed consent, one must have the capacity to understand and fully appreciate the situation they are in and the consequences of their decision. However, psychological and neuroscience literature questions whether mature minors can fully meet this test because of an inherent lack of life experience, especially when it comes to major life decisions like MAiD. (Cuman & Gastmans, 2017; Friedel, 2014; Giglio & Spagnolo, 2014; Raus, 2016). This evidence suggests that compared to adults, minors may lack the experiential knowledge, stability of values and preferences, and sense of self that is necessary to make decisions about MAiD (Kaczor, 2016; Siegel, Sisti, & Caplan, 2014; Wolf, 1998).

Furthermore, evidence from neuroscience and brain development suggests that minors tap into different patterns of brain structures and pathways in making decisions than adults. Because

the frontal lobe (the area responsible for governing executive functions such as decision-making and abstract reasoning) develops last and after earlier developing limbic system responsible for emotional response, minors tend to over-rely on the latter structures for decision making. It has been found that minors have a propensity to discount long-term consequences and have more difficulty regulating emotional systems in their decision making. Therefore, even though a minor may have the capacity to understand the circumstances of their situation, they may not have the ability to fully reason and make informed judgments about life and death situations (Arshagouni, 2006; Diekema, 2011; Mendelson, 2014).

2. *Vulnerabilites Specific to Minors*

The economic and emotional dependence of minors on parents and other relatives makes them particularly vulnerable to coercion and influence, which may lead to choosing MAiD (Giglio & Spagnolo, 2014; Wolf, 1998). Even if parents do not explicitly tell their child to request MAiD, a minor may feel pressure to relieve their parents of emotional and financial burdens (Cuman & Gastmans, 2017; Kaczor, 2016). As well, a child who has yet to fully develop executive functions associated with frontal lobe development may be more sensitive to the opinions of their parents and want to satisfy their parents' expectations (Kaczor, 2016; Keeling, 2017). For children and youth with disabilities these concerns are compounded as they have been found to be more likely to be in the child welfare system (Lightfoot and Hill, 2009), have suicidal ideations and behaviour (Gianni, et al., 2010), and live in households dealing with poverty (Statistics Canada, 2008).

3. *Gaps in Service Motivate Requests*

Pediatric palliative care and mental health services for youth have been found to be under serviced (Dan, 2015; Friedel, 2014; Widger et al., 2007). Physicians argue that if better palliative care and mental health services were provided, minors would not be compelled to request MAiD (Cuman & Gastmans, 2017; Giglio & Spagnolo; Khader & Mrayyan, 2017; Silva & Nunes, 2015).

III. Concerns with Access Based Solely on Mental Illness

Research points to six main concerns in providing access to MAiD based solely on a mental health condition.

1. *No Conclusive Evidence that Mental Health Conditions are Irremediable*

An extensive literature on mental illness and the question of irremediability of conditions suggests that the apparent 'futility' of medical psychiatric treatments in a particular case should not be equated with a conclusion that the condition is in and of itself irremediable (Bilkshavn, Husum, & Magelssen, 2017; Broome & de Cates, 2015; Claes et al., 2015; Kim & Lemmens, 2016; Miller, 2015; Olié & Courtet, 2016; Rousseau, Turner, Chochinov, Enns, & Sareen, 2017; Shaffer, Cook, & Connolly, 2016). Cases in the Netherlands and Belgium have highlighted the impossibility of making a conclusive finding that an individual's condition is treatment-resistant. Many individuals whose request has been approved later withdraw their request after receiving

alternative treatment and/or therapy (Claes et al., 2015; Dierickx et al., 2017; Kouwenhoven, 2013; Lemmens, 2016).

The Canadian Mental Health Association has recently issued a background paper informing its position that access to MAiD should not be provided solely on the basis of a mental health condition (Canadian Mental Health Association, 2017). The basis of its position is that the research evidence is simply not conclusive that any mental health condition is by definition irremediable.

2. Capacity to Consent is Often Compromised

No blanket statement is justified that mental health conditions, by definition, undermine capacity to consent, and jurisprudence in Canada and internationally affirms this. However, particular conditions, for specific individuals, in certain circumstances can compromise an individual's ability to assess a situation and make reasoned decisions (Charland, Lemmens, & Wada, 2016; Claes et al., 2015; Lemmens, 2016; Shaffer, Cook, & Connolly, 2016). Clinical depression has been found to interfere with an individual's weighing of short-term and long-term consequences and judgment of their circumstances (Broome & de Cates, 2015; den Hartogh; Frati, Gulino, Mancarella, Cecchi, & Ferracuti, 2014; Kim & Lemmens, 2016; Olié & Courter, 2016).

In this context, it might be assumed that the standards for informed consent and capacity assessment become more rigorous. However, evidence about practice suggests the opposite. While physicians report difficulties in determining whether individuals with mental health conditions have the capacity to consent to assisted death, reviews of such cases have found that physicians generally require only a low threshold be met before a request for MAiD is approved (Doernberg, Peteert, & Kim, 2016).

Concerns have also been raised about cases where an individual, whose initial request had been denied by their primary physician, is later approved for assisted death another physician less familiar with the person and their situation. As well, there are cases in which physicians have disagreed about an individual's capacity to consent and/or their prognoses, but an medically-assisted death was nonetheless administered (Kim, De Vries, & Peteert, 2016).

Cognizant of these concerns, both the Royal Dutch Medical Association and the Dutch Association of Psychiatry have issued guidelines calling for extreme caution when dealing with requests for assisted death from individuals with mental health conditions. There is inherent indeterminacy in judging decision-making capacity in these situations, and especially in a context where evidence suggests psychoanalytic transference and counter-transference with presiding physicians can operate to compromise the process of obtaining informed consent free of inducement or external pressure (Pols & Oak, 2013).

3. Vulnerability Cannot be Adequately Assessed or Addressed without an End-of-Life Criterion

In the regimes for assisted death in Belgium and the Netherlands, individuals with mental health conditions are permitted to request assisted death solely on that basis. In Belgium, in addition to fulfilling the general criteria of being in a state of constant and unbearable suffering that cannot be reasonably alleviated as deemed by two physicians and possessing full competence, individuals with a mental health condition must also undergo consultation with an independent psychiatrist and wait at least one month between the date of the written request and the date the request is carried out (Lemmens, 2016; Naudts et al., 2006).

In the Netherlands, assisted death for individuals with mental health conditions has been permitted officially since 2002, but had been practiced prior based on jurisprudence authorizing the practice (Cowley, 2013; Pols & Oak, 2013; Kissane & Kelly, 2000). The 2002 legislation set out no additional criteria for individuals with mental health conditions to meet. General criteria are applied in all cases, including: that the individual's request is voluntary and well considered; the individual is suffering unbearably without prospect of improvement or reasonable treatment alternative; the individual is informed about their situation; and, at least one other physician has been consulted (Kim, De Vries, & Peteet, 2016).

In Belgium, from 2002 when the practice was legalized, to 2013, there were 117 reported cases in which a psychosocial disability was the sole diagnosis, with an uptake in cases being reported in more recent years (Dierickx, Deliens, Cohen, & Chambaere, 2017). In the Netherlands, 66 cases of assisted death were reported for individuals with mental health conditions between 2011 and 2014 (Doernberg, Peteert, & Kim, 2016). In both countries, depression and personality disorders are the most common disability reported, but cases of individuals with Asperger's Syndrome, ADHD, intellectual disability and eating disorders have also been reported (Charland, Lemmens, & Wada, 2016; Dierickx et al., 2017; Thienpont et al., 2015; Kim, De Vries, & Peteet, 2016).

In the study of the cases in the Netherlands (Kim, De Vries and Peteert, 2016) many vulnerability factors were observed, including the prominence depressive disorders, post-traumatic stress disorder and anxiety disorders. The majority of those who were euthanized under the system had already attempted suicide, and 80% had been hospitalized previously for psychiatric conditions. Social isolation and loneliness characterized those making the requests.

This and other research evidence points to social determinants motivating requests and compounding the suffering associated with the medical condition, including such factors as concern about being a burden on others, fears about losing autonomy, lack of support, and confinement to institutional facilities.

Thus, it is the societal response (or lack thereof), that can result in intolerable suffering for people living with mental health and other disability-related conditions. Research from the Netherlands, Belgium, and Switzerland find that individuals are turning to assisted death because of inadequate social and community support and because it is becoming an acceptable solution to challenges faced by vulnerable populations, particularly individuals with disabilities and the elderly (Snijdewind, van Tol, Onwuteaka-Philipsen, & Willems, 2016). Findings from the

recent survey in Quebec (Derfel, 2017) suggests that prospectively we could anticipate similar outcomes if the end-of-life condition requirement were no longer in place.

In a system for MAiD where eligibility can depend only on mental health conditions, what prevents those most at risk of suicidal ideation and behavior because of a lack of social determinants of health in their lives – persons with disabilities, indigenous persons and transgender youth to name just three of many examples – from accessing the system to die?

4. Access Based Solely on Mental Health Conditions Would Undermine Equality of People with Disabilities and Promote Ableist Stereotypes in Violation of MAiD Objectives

Providing access to MAiD based solely on a mental health condition would mean radically changing a key component of the definition of a “grievous and irremediable medical condition” as it is defined in the *Medical Assistance in Dying Act* – that, among other criteria, a person must be in a condition in which their natural death is “reasonably foreseeable.” For advanced dementia or a mental illness to be considered eligible grounds to receive MAiD, the criterion of the reasonable foreseeability of natural death would have to be removed. The presence of this eligibility criteria currently works to limit a number of otherwise serious and incurable conditions as eligible grounds for receiving MAiD. Removing this criterion would open the possibility that any incurable and irremediable long-term condition—including a disability condition—could be considered grounds for MAiD, if the person finds their suffering intolerable.

Although any disability can be managed if supported, persons with disabilities can suffer intolerably when proper support and social inclusion is lacking. Accepting that a disability condition is a reason for ending a life would, as a consequence, reinforce the ableist notion that life with disability is not worth living. Even if such a policy did not result in explicit coercion of people with disabilities to request MAiD, it would reinforce discriminatory attitudes and negative social stigma toward people with disabilities (Gill, 2010). Further, the “choice” of MAiD might reduce the pressure on society to provide services and support for persons with disabilities and their families (Golden & Zoanni, 2010).

5. Charter Equality Rights Could Not Constrain Access Only to People with Mental Health Conditions

While there is discussion in the Canadian context of whether access to MAiD should be extended to people solely on the basis of mental health conditions, expanding access on this basis could not likely be constrained to those parameters in the context of *Charter* equality rights.

Evidence from Switzerland, Belgium and the Netherlands shows alarming consequences of expanding access beyond end-of-life requirements. In the Netherlands and Switzerland, any suffering that is unbearable and without any prospect of improvement is an eligible criterion, and there is no requirement for a diagnosable condition (Fischer et al., 2009; Legemaate & Bolt, 2013). Belgian law does require evidence that the persistent and unbearable suffering (physical

or psychological) stems from a serious and incurable condition, but that condition does not need to be an end-of-life condition (Raus & Sterckx, 2015).

The consequence of these broad eligibility criteria has been that individuals with a range of physical and mental disabilities and even vague conditions have been able to request—and receive—assisted deaths. In all three countries, reviews of cases have found that interpretation of the criteria have now expanded to include individuals whose claim of being “tired” or “weary” of life has been used to justify assisted death (Miller, 2016; Rurup et al. 2005). Other documented reasons in these jurisdictions for requesting and receiving assisted death are weariness of treatment, social isolation, decreased capacity to engage in activities, loss of concentration, loss of self, fear of future suffering, increased dependency, loss of autonomy, becoming a burden, loneliness, and hopelessness (Dees, Vernooij-Dassen, Dekkers, Vissers, van Weel, 2011; Fischer et al., 2009, Frei et al., 2001; Snijdewind, Willems, Deliens, Onwuteaka-Philipsen, & Chambaere, 2015). Assisted death is also being approved for persons with a range of disability-related conditions including Asperger’s Syndrome, autism, ADHD, intellectual disability and eating disorders.

Under *Charter* equality rights there would be a very strong case to be made that that restricting access only to people with mental health conditions is discriminatory on the grounds of mental and physical disability. The evidence from Switzerland, Belgium and the Netherlands makes clear that a much broader range of disability-related conditions can be associated with suffering sufficient to legally justify assisted death in those jurisdictions. Crossing the threshold of access based on mental health conditions in the Canadian context will inevitably open up access on a much broader basis, with the very likely result that internal and socialized stigma based on disability will have very fertile ground.

6. Expanded Access Risks Major Unintended Social Consequences

It is also critically important to contextualize consideration of expanded access in an historic context. There are other points in history in which public health goals have been equated with the termination of certain forms of life, in the name of population health, compassion and reduction of suffering. These examples teach that delivering on such aims can have unintended social consequences. These examples do not necessarily imply that widespread termination of life of people with disabilities would be inevitable if, for example, the reasonable foreseeability criterion was removed from the legislation, but they do encourage pause, and serve as a reminder that what may first appear to be valid public health goals can have unintended and negative consequences.

The first example is the eugenics movement of the 20th century. In Canada, support for eugenics—that is, the notion of improving a population by controlled breeding—came from the belief that eugenic interventions (i.e. forced sterilization of certain individuals could rid the population of “feeble-mindedness” and mental deficiency, considered as they were to be causes of social ills (McLaren, 2015). This understanding led to persons with disabilities being unjustly and forcibly subjected to segregation and sterilization (Acevedo Guerrero, 2015; Grekul, Krahn, & Odynek, 2004).

The second example is the Nazi eugenically-based extermination program, which took these policies further; the program, which began with the goal of carrying out acts of mercy on persons with disabilities (Gallagher, 1990) and started with forced sterilization, ended with the mass murder of hundreds of thousands of persons with disabilities and individuals with mental illnesses (Bachrach, 2004; Strous, 2006).

The third example is the use of prenatal testing for genetic disability-related conditions which has been used to encourage termination of certain fetuses thought to be carrying disability-related traits (de Graaf, Buckley, & Skotko, 2015; Steinbach, Allyse, Michie, Liu, & Cho, 2016). Social assumptions about what constitutes pre- and post-natal 'normalcy' strengthen the social foundations for viewing people with disabilities as abnormal and deficient, thus contributing to pervasive stigma which people can internalize in self-judging ways (Asch, 1999; Asch, 2000; Browner & Press, 1995; Hubbard, 2013; Saxton, 2000).

Understanding of the inherent value of lives of people with disabilities has progressed since the eugenics movement and Nazi programs, but, as the termination of fetuses with disability traits shows, persons with disabilities still face discrimination, exclusion, and a prevailing societal belief that their life is something to be avoided. Clearly, lessons from history can, and should be applied to critically considering MAiD and its expansion (Frazee, 2017).

Conclusion

The Supreme Court of Canada in the *Carter* decision required that Parliament, in designing a system for exemptions to the prohibition on assisted suicide, strike a balance between the right to autonomy of a competent adult with a grievous and irremediable medical condition experiencing intolerable suffering, and the need to protect vulnerable persons (*Carter v. Canada*, 2016, para. 2). Evidence reviewed in this paper clearly suggests that expanding access through advance directives, approval of requests from mature minors, and eligibility solely on the basis of a mental health condition would pose significant risk to managing that balance in practice. Moreover, the removal of the "reasonable foreseeability of natural death" criterion that would come with providing access solely on the basis of a mental health condition would itself significantly expand access far beyond mental health conditions. The equality rights framework in Canada would undoubtedly be used to successfully challenge restricting access to mental health conditions, once the end-of-life criterion is removed. This would pose significant structural and long-term disadvantage to the status of people with disabilities in the Canadian context.

The research reviewed for this paper points to a large body of evidence that overwhelmingly finds that the intolerable suffering motivating requests for assisted death is often caused by social factors amenable to intervention. Deeply entrenched and for many, internalized, social stigma still equates loss of physical and psychic independence, and dependency on others for personal care, with inherent indignity and loss of autonomy. These equations are by no means inevitable. Rather, they result from well-documented, persistent gaps in access to needed

disability-related supports and palliative care and lack of valued social and economic status for those defined by disability-related conditions. Expanding access to MAiD in the name of public health would appear, in fact, to significantly risk further entrenching the negative disability-related stereotypes that the MAiD legislation explicitly seeks to guard against in its statutory objectives. Thereby, and based on evidence from other jurisdictions, the very criteria for eligibility and access to MAiD would come to constitute social norms that devalue the lives and needs of people with disabilities. This would be a tragic outcome for a group whose equality rights were to be protected and whose structural and historic disadvantage was to be redressed, not further entrenched, under Canada's *Charter of Rights and Freedoms*.

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