

Medical Assistance in Dying and Disability Rights

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Abstract

Until 2015, the Criminal Code of Canada prohibited the aiding and abetting of suicide. Then came the Carter v. Canada case which recognized that the suffering caused by certain illnesses was leading to the premature taking of life, and that the prohibition against assisted dying infringed on the Canadian Charter of Rights and Freedoms (Browne & Russell, 2016). New legislation was developed to allow medical assistance in dying (MAID) in exceptional cases. This controversial legislation garnered significant backlash, especially from disability rights activists. This paper will outline the processes of obtaining MAID, consider criticisms from a disability rights perspective, reflect on these criticisms, and then discuss the implications on social work practice.

Introduction

Until 2015, the Criminal Code of Canada prohibited the aiding and abetting of suicide. Then came the *Carter v. Canada* case which recognized that the suffering caused by certain illnesses was leading to the premature taking of life, and that the prohibition against assisted dying infringed on the Canadian Charter of Rights and Freedoms (Browne & Russell, 2016). New legislation was developed to allow medical assistance in dying (MAID) in exceptional cases. This controversial legislation garnered significant backlash, especially from disability rights activists. This paper will outline the processes of obtaining MAID, consider criticisms from a disability rights perspective, reflect on these criticisms, and then discuss the implications on social work practice.

The MAID Process

McLean and Williamson (2007) point out that access to MAID is not the right to die. Human beings are certain to die; MAID is the right to choose a preferred death. Those seeking MAID must be at least 18 years of age and capable to make health care decisions for themselves. Their choice needs to be voluntary, and they need to be eligible for governmental health services. Recipients also need to have a “grievous and irremediable medical condition” (Government of Canada, 2016, p. 9) which meets all the following four criteria: (1) the “illness, disease or disability” must be serious and incurable; (2) the person must be in “an advanced state of irreversible decline in capability”; (3) the person is “experiencing enduring physical or psychological suffering, due to the illness, disease, disability or state of decline, that is intolerable to the person and cannot be relieved in a manner that they consider acceptable”; and (4) their “natural death has become reasonably foreseeable” (Government of Canada, 2016, p. 9).

Those close to the MAID process are generally in favour of it. In a 15 person qualitative study querying the loved ones of MAID recipients, all of them were supportive. Those who disclosed initial opposition changed their perspective once they observed the suffering of their loved one. While there was a reported strangeness to the procedure, the death itself was deemed peaceful and more advantageous compared to a natural death (Holmes et al., 2018). Nurses tend to see providing MAID as an expansion of their traditional role: providing holistic care without judgment, advocating choice, and supporting a good death. While there exists some opposition in this profession, it is typically value-based and religiously driven (Beuthin et al., 2018). These groups broadly support MAID, and the only concerns of loved ones tend to revolve around operational issues such as a lack of clarity over the process or scheduling challenges, and the shame associated with being judged by clinicians and peers (Hales et al., 2019).

The majority of those who access MAID are not a typically vulnerable group, and thus their decision is unlikely to be influenced by marginalizing factors. They are statistically younger, more likely have a higher income, more likely to be married, and less likely to live in an institution than the decedents within the general population (Downar et al., 2020). They choose MAID because their quality of life is unacceptable: they struggle with their health and function, they have lost the

ability to participate in meaningful activities, and they have lost a sense of purpose in the activities they used to enjoy (Nuhn et al., 2018). Physical pain is not a prevailing factor in people's choice for MAID (Nuhn et al., 2018), and this suffering is predominantly existential. Indeed, the majority of those who access MAID are being followed by palliative care, leading Downar et al. (2020) to reinforce that physical pain is not a strong determinant in MAID requests.

There are possible changes that may be implemented into the MAID process. These include allowing mature minors to access MAID, its inclusion in advance directives, and access for those for whom a mental disorder is the sole underlying condition (Chochinov, 2016). Some of these changes were recommended during the Carter hearing but were not implemented during the initial legislation (Browne & Russell, 2016). While there are safeguards associated with these new changes, such as a 90-day waiting period for those for whom death is not reasonably foreseeable, Chochinov (2016) worries that a lack of vulnerability assessments to rule out coercion and the lack of a clause that necessitates the exhaustion of all available options for those whose death is not reasonably foreseeable may lead to avoidable deaths within the new system.

As of this writing, the Canadian Senate has passed legislation that would extend eligibility to those whose death is not reasonably foreseeable, make advance requests for assisted death, and impose an 18 month limit on assisted dying for those suffering solely from a mental illness (Bryden, February 17, 2021). The Liberal government made some modifications to this legislation, such as a rejection of the advance directive clause and an extension to a two year wait for those suffering solely from a mental illness, and the bill will be returned to the senate for a potentially final review (Bryden, February 23, 2021). While there are some who prefer fewer restrictions, others see permissiveness in MAID as a direct threat.

Criticisms from a Disability Rights Perspective

Disability rights activists worry that MAID risks devaluing the lives of disabled people (Reel, 2018). There are fears that the prevalence of MAID will result in increased deaths within this population; not due to individual choices, but from the pressures of a society that sees suffering and disability as interchangeable (Riddle, 2017). Most able-bodied people find it difficult to imagine life with an impairment, and believe themselves in a preferable position without one. This can incline the able-bodied to make negative assumptions about the quality of life of disabled people (McLean & Williamson, 2007). Given MAID's links to subjective suffering, there is a risk that these stereotypes might be internalized within medical staff who might then unknowingly pressure a disabled patient toward MAID (Riddle, 2017). When disabled life is considered less worth living, death becomes easier to justify.

This pressure is already taking place. While some believe that the safeguards in other countries with relaxed restrictions on MAID have been mostly effective in protecting vulnerable populations (McLean & Williamson, 2007), others see pressure still taking place (Riddle, 2017). In Canada, Stainton (2019) highlights instances of pressure happening locally. Disabled populations require

greater support in the community and protection from subtle pressure, but these needs are difficult to obtain when the gatekeeper to these things are often healthcare workers with their own perceptions of what suffering means. There are concerns that able-bodied patients will receive appropriate counselling and support when they express a wish to die while those with a disability whose lives are assumed to be more tragic will receive less support when they seek the same (McLean & Williamson, 2007).

Disability rights activists applying the social model of disability argue that while there may be suffering that is associated with some forms of impairment, what is more debilitating is the disablement that comes as a result of social exclusion and oppression and the lack of access to reasonable and necessary support that fosters quality of life (McLean & Williamson, 2007). Social determinants of health have a significant impact on the lives of people with disability which can vastly undermine the legitimacy of choice when disabled people are considering MAID (Reel, 2018). A lack of resources or an alternative functionality may prevent access to needed supports and may result in systemic coercion that pushes people toward MAID as their only option (McLean & Williamson, 2007). While recent statistics show that 89.8% of MAID recipients who required disability services were receiving them (Health Canada, 2020), the quality of those services and the 3.9% who received nothing are worth questioning. Canada is the only country that has neglected to enforce a mandate of exhausting all reasonable options of support prior to ending a patient's life (Lemmens & Krakowski-Broker, 2020). Reel (2018) asks if the request for MAID is really a request for needs to be met, and perhaps it would be better for society to lift the barriers that make life unbearable rather than facilitating an easier death (Wallace, 2017).

While those with a disability often report a higher quality of life than able-bodied people expect of them (Reel, 2018), it can sometimes take a while for purpose to develop in a newly disabled person. If the new legislation were to pass that would eliminate reasonably foreseeable death as a requirement for MAID, then the length of the protective waiting period needs to be examined. It takes approximately 120 days for a person to be reviewed for the Canadian Pension Plan Disability Benefit; it takes approximately 5.5 months for a specialized pain clinic; and for some injuries, it takes longer than 90 days before physical healing even begins (Lemmens & Krakowski-Broker, 2020). It can take time to develop a new perspective on life, and for those at the beginning of that journey, it is unjustifiable to have a lack of supports be the reason for MAID (Stainton, 2019).

Criticism Reflection

This is a complex issue. Habilitation and rehabilitation can go for years without any noticeable improvement, resulting in some conditions being viewed as irreversible or irremediable. While there may be many disabled persons who are able to tolerate and even find meaning in their pain and frustrations, this does not suggest identical conclusions for everyone in the same position. Those whose death is not reasonably foreseeable would thus be expected to expose themselves to treatments they may not find palatable, wait an indeterminate length of time for a cure, continue suffering, or end their own lives as evidenced in the higher incidence of suicide by disabled persons

(Dembo et al., 2018). If MAID is not available, people can still deny life-saving treatment, refuse food and drink, or perform more conventional suicides to retain a degree of autonomy over their own deaths (Reel, 2018); however, these methods can result in greater suffering and stigma that is removed in the legitimacy and efficiency of MAID. A desire to control one's ultimate destiny will always be present regardless of legislation, and MAID provides a humane option to meet that desire.

While society is comfortable with a soft paternalism that overrides incompetent choices like that of person suffering from dementia, going against the capable decision of a person requesting MAID requires a much stronger adjudication (Dembo et al., 2018). This is where the argument of a vulnerable population requiring additional legal protection demands greater examination. Vulnerability exists as a deficiency of power that relies on external forces for support: if one group is powerless, then a benevolent power must intervene to shelter them. The question becomes whether this vulnerability is inherent in the group, or is contingently based on their social environment (Arstein-Kerslake, 2021). If people with disabilities are inherently vulnerable, then they would require paternalistic interventions to accommodate that. If their vulnerability is created by outside forces, then limiting those forces would reduce that vulnerability.

When vulnerability is ascribed to a group of people, it creates a dichotomy of the fragile powerless and those "invulnerable enough to have their autonomy largely respected" (Arstein-Kerslake, 2021, p. 120). While being seen as vulnerable might result in increased funding for social programs (Arstein-Kerslake, 2021), having that label says damaging things about the abilities of disabled people and their need to be protected. Believing that the disabled population requires additional protection from MAID due to their vulnerability could be seen as suggesting that they are incompetent, easily coerced, and naturally-inclined toward death (McLean & Williamson, 2007). Denying legal capacity to a population typically increases that group's vulnerability by assuming a lack of agency and reinforcing the stereotype of helplessness (Arstein-Kerslake, 2021), and enabling the autonomy of the disabled community to choose their preferred death may actually decrease vulnerability by increasing their power to choose. If people with disabilities are seen as capable, then allowing them the power to exercise that capability rejects the paternalism of vulnerability gatekeeping.

There is much risk associated with such a controversial topic. Does liberalizing MAID increase the risk of avoidable deaths among the disabled community? Riddle (2017) points to the risks associated with daily living, such as the risk of infection inherent in going to a hospital's emergency room, but these are measured against their benefits. When observing abortions in the United States, Black and Hispanic women receive a disproportionate number compared to their White counterparts (Jones & Jerman, 2017). If it is agreed that abortion is not intrinsically a racist operation despite the racial discrepancy in its outcome, then discrepancy in the outcome of MAID is not necessarily discriminatory either. Pointing to individual cases of harm does not necessarily condemn an entire practice, much in the same way that the adverse effects of a hospital visit does not conclude with the abolition of modern medicine (Riddle, 2017). When social determinants of

health lead to unjust outcomes, the solution is not to force individuals to endure great suffering while they wait for systemic change; it is to reduce harms. When death is considered the lesser harm, it may be the case that the person does not in fact want to die if systemic change might reduce their suffering, but these may simply be the options that the immediate circumstances make available.

Implications for Practice

Riddle (2017) argues that showing respect for disabled people does not mean denying them access to MAID, but allowing them the same choices as others. Article 12 of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), which Canada ratified in 2010, declares that, “States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life” (Convention on the Rights, 2006). Injustice may exist for people with disabilities, but that injustice is not inherent in the idea of MAID (Riddle, 2017). Despite the complexity of MAID within the disabled community, the social worker has an important role in supporting disabled clients understand MAID and supporting their decision making capability. Social workers also have a role in ensuring the ableist attitudes of others – health professionals, care workers and/or family members and friends – do not usurp or unduly influence a disabled person’s decision to access MAID. Social workers may take systemic discrepancy into account, but someone’s capability to decide is always individual-specific (Dembo et al., 2018).

The suffering that is informing a patient’s decision can only be determined by the person themselves. Social workers have no way to measure it outside of the perspective delivered by the patient (Reel, 2018). Because of the stigma that may influence an outsider, it is key that the patient is the one making their own decisions. As McLean and Williamson (2007) point out, it is not the legislation that causes injustice, but the improper behaviour of those in positions of power. Social workers are important advocates for patient-driven care, and must ensure that all available options are provided to mitigate systemic coercion that might induce someone to an early death.

Conclusion

There have been over 5,000 deaths from MAID since November 1, 2018, and just under half of those requests came from individuals needing some form of disability supports (Health Canada, 2020). However, McLean and Williamson (2007) argue that MAID’s gestalt centres on choice, so despite the disproportionate number of disabled people seeking access, disability may not be central to the debate at all. Illness and disability are moot when the severity of suffering can only be qualified by the sufferer (Dembo et al., 2018).

Just as Black and Hispanic women deserve the right to abortions, so too does the disabled community deserve access to MAID. The UNCRPD warns against undue influence in the exercising of legal rights and urges appropriate and effective safeguards against abuse, but it still

demands equal access (Convention on the Rights, 2006). The social determinants of health that amplify unequal outcomes will not be resolved by restricting harm reducing services. The prolongation of suffering impacts not only the individual, but their family as well (Reel, 2018). It is up to the social worker to empower patients to determine how they wish to move forward.

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