

A Disabled Bioethicist's Critique of Canada's Medical Assistance in Dying (MAID)

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A Disabled Bioethicist’s Critique of Canada’s Medical Assistance in Dying (MAID)

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Many disabled individuals adamantly oppose medical assistance in dying, quite rightly referencing pervasive ableism and, euthanasia’s dark history in the Aktion T4 program of Nazi Germany in which disabled people were involuntarily euthanized and sterilized because they were deemed “unworthy of life” (Grodin, Miller, and Kelly 2018; Hudson 2011). Other countries, including the US and Canada, also flirted with eugenics, euthanasia and, sterilization practices for disabled individuals during the nineteenth and twentieth centuries (Pfeiffer 1994). Furthermore, medical professionals carried out these infamous practices in support of the “common good.” Today, people who live in disabling contexts routinely confront social and medical prejudices which presume that their lives are of poor quality and are not worthy of medical effort or salvage (Atkins and Das 2021). (This ableism is also expressed as “inspiration porn” in which a

disabled person is viewed as heroic for simply being alive.) But even within this somber context, as a Canadian academic and bioethicist with a neuromuscular disease, the possibility of having control over the conditions of my final exit seems attractive—MAID tempts me with the promise of having some “control” over my mortal exit. However, like Daryl Pullman, I have concerns about the manner in which MAID is being carried out in my country (Pullman 2023). Unlike Pullman, I believe that the problem with Canada’s implementation of MAID lies in its original schema rather than its method of delivery. Bill C-7, the law enacting MAID, has been badly conceived and, the guidelines and practices which have emerged out of the federal legislation can easily violate the human dignity of the individuals involved.

The legislation specifies that: a person seeking medical assistance must “make a voluntary request that is

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not the result of external pressure, have a serious and incurable illness, disease or disability (excluding a mental illness until March 17, 2024), be in an advanced state of irreversible decline in capability, have enduring and intolerable physical or psychological suffering that cannot be alleviated under conditions the person considers acceptable.” Bill C-7 outlines “safeguards” which require written requests and the ability to withdraw consent at any time. These precautions also demand that “two independent doctors or nurse practitioners must provide an assessment and confirm that all of the eligibility requirements are met” (“Medical assistance in dying: Overview” 2023).

One of the primary faults of Bill C-7 is that it relies on health care professionals to act as the sole arbiters of MAID procedures and implementation, thus prioritizing a medical epistemology which is imbued with ableist tropes about living with “dysfunction” and disability. MAID should not be a purely medical decision because there are so many social and economic factors which come into play when considering whether life is worth living. Currently, Canadians are using MAID when they’ve lost access to accessible or affordable housing or care. While the act requires that the patient “must be informed of available and appropriate means to relieve their suffering, including counseling services, mental health and disability support services, community services, and palliative care, and must be offered consultations with professionals who provide those services,” media accounts reveal that Canadians have opted for MAID when they couldn’t secure appropriate or affordable housing (Sebastian, Els, and Fan 2022). Given that disabled people are some of the poorest members of our community, they are far more likely to fall prey to social and economic pressures when facing their illnesses than others with more resources. Two people confronting the same medical facts will assess and live with them differently depending on their social situation. MAID, it seems, is being used as a solution to social problems. The law denotes intractable suffering as a key standard, but suffering is more than physical pain and other factors need to be articulated, considered and, resolved. Lack of adequate and appropriate housing, transportation, care and financial resources can make someone with a particular disease or syndrome suffer far more greatly than someone with the same illness who has these needs met. MAID only stipulates that a person be “informed” about possible resolutions for their complaints but, the language and intent of the law needs to be stronger. The needs of the individual

patient should be truly addressed and efforts to do so should be enforced prior to any approval. Further, lay community members and social workers, and not just health care professionals, should be a part of the MAID process. (The Netherlands, which has one of the longest experience with medically assisted death, employs interdisciplinary committees.)

A second fallibility lies in that MAID is characterized as “treatment.” The psychiatrist Dr Scott Kim, argues that the physicians offer MAID as part of an array of treatment because the Canadian Association of MAID Assessors and Providers encourages practitioners to bring it up unsolicited as part of their professional duty and as a “care option that is medically effective.” Scott argues “Even when MAID is legal, it should be an exception to the practice of medicine, not something taken into its very bosom.” (Kim 2023) I agree. Offering medically-assisted suicide as effective treatment denies patients the possibility of re-visioning their lives and their autonomy in the midst of difficulty. The gerontologist and bioethicist, Tom Koch, writes that his studies about disability “demonstrate that cognitive, physical and sensory limits can be surmounted when we learn to accept that total autonomy is a myth” (Koch 2023). Confronting morbidity is difficult—great art and literature tries to grapple with it—medicine should not be offering a formulaic solution to the challenge that illness and, changes in function, pose to all humans. MAID should be a last resort once treatment options are absent or no longer palatable.

Thirdly, the practice of MAID also falls prey to latent ableism in our society. Disabled lives are often portrayed as tragic (or conversely as heroically enduring the unendurable). These views contribute to a view that all non-typical functioning is intolerable. As a person with a disability, I fear that if I even mentioned MAID in a moment of despair, well-meaning clinicians might obliging facilitate it in the name of my “autonomy” and in their unconscious ableism. People often remark that they are “awed” by my ability to persist and to lead a full life. In an ableist society, MAID can be easily offered as a remedy by those who have difficulty conceptualizing leading a meaningful life in a disabled context.

Finally, Canada suffers from a lack of transparency around MAID. In 2021 legislators revised the law demanding more robust data collection of applicants belonging to vulnerable groups and, further specialist consultations for those whose death is not foreseeable (Canada Gazette 2023). Further, because MAID is characterized as “treatment,” it remains a part of a patient’s

confidential medical record. As such, families and friends have no access to the file after the individual's death. This lack of transparency creates problems for families particularly when their loved-one may have had previous suicidal episodes. Currently, it is very difficult for a family, and the general public, to know that an assisted death has been properly assessed and carried out. Families want to confirm that the professionals involved understood all the relevant details and gave proper consideration to the case. A seeming facade of oversight in Canada is leading to an erosion of trust that MAID is being carried out ethically.

When comparing euthanasia in California and Canada—two jurisdictions with comparably sized populations—Daryl Pullman draws attention to the vast discrepancy in assisted dying between California (0.15% of deaths) and Canada (2.5% of deaths) during 2021. He proposes that the American state's use of oral medications via self-administration, rather than IV dosages by medical personnel, is the basis for the divergence. Consequently, he suggests that oral medication become the primary method of euthanasia administration in Canada. But it is not clear whether he proposes this as a way of removing medical professionals from being a part of the death-seeking process or, because he believes patients will be more reluctant to undertake the swallowing of a pill themselves rather than receiving an infusion from clinicians. His article infers that the two different methods account for the vast difference in assisted-death frequency between the Californian and Canadian cases. But the link he draws is correlative rather causative. I would argue that the current language (and its interpretation) of Bill C-7 along with the medical characterization of MAID as treatment in Canada is more at fault than the method of delivery.

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