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What’s missing from the conversation about assisted death

We talk a lot about helping the sick, elderly and disabled to die, but we should be starting with what we can do to help them live.

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(This article has been translated into French.)

The Quebec Superior Court recently expanded access to medical assistance in dying (MAiD). If higher courts uphold the decision or if the federal government does not appeal it, people with severe disabilities or illnesses in Canada will be able to access MAiD even if their natural death is not imminent or foreseeable.

But there’s been a major omission. Like the Supreme Court of Canada in a 2015 judgment, the Quebec Superior Court did not discuss ableism, ageism, “disease-ism” or socio-economic vulnerability in relation to MAiD — factors that provide the context for what it’s like to live with a disability in our society. In fact, the Quebec court stated (at paragraph 252) that belonging to a group that has historically suffered from denigration or marginalization is irrelevant to the rights to life, security and liberty.

By ignoring the impact of oppression — including disempowerment, stigmatization and discrimination — in the provision of MAiD, our courts and legislators fail to properly protect the autonomy of vulnerable persons. In our society, we help vulnerable people to die before we properly enable the conditions for them to live.

The Canadian public has heard a lot over the last five years from people who have brought the government to court because Canadian criminal law prevented them from receiving help in dying. They include Lee Carter and Gloria Taylor, Julia Lamb, Jean Truchon and Nicole Gladu. These people have explained how their state of great dependence, pain, loss of ability to pursue meaningful activities, their bedridden state and/or the fear of an "ugly death…wracked with pain," in the words of Gloria Taylor, has made their lives unbearable.

These cases have strategically emphasized reasonable motivations to die, for reasons that no amount of medical help or social accommodation could remedy. These cases illustrate the least ethically problematic requests for MAiD one could imagine.

But much less media attention has been given to other kinds of reasons to die: those that state interventions could change. Individuals such as Archie Rolland, Sean Tagert, Natalie Jarvis and Arleen Reinsborough have all ended or considered ending their lives because society failed to provide them with proper health care or financial and social support. "The current system is inhuman," Rolland said in 2018. "It's hard to be human to someone seen as valueless," Reinsborough said early in 2019.

People can find themselves in hopeless conditions not only because of a grave medical condition but also because of their social context. Disability studies have taught us over the last 50 years that disability is not just a medical issue. It is also the result of oppression; that is, of a failure to provide a social environment that would enable — rather than disable — people with medical conditions.

MAiD debates are replete with the indignity of living in a defective body, but too little is said about the indignity of living in a defective society.

Canada has a duty to examine whether the failure to better help people contemplating MAiD is the result of oppression, such as the ableist or ageist belief that the lives of disabled, sick or old people matter less than the lives of able-bodied, productive members of society.

What can be done?

First, researchers and legislators need to understand how oppression impacts the available resources and resiliency of people contemplating MAiD. Many individuals with a disability have internalized oppression to the point of despising their impairments while lacking access to rewarding activities that could help improve their daily life.

The monitoring structures currently in place for those who seek MAiD in most of Canada do not provide sufficiently detailed data. Data from Oregon and Quebec indicate that individuals want to end their lives for several reasons: they are losing autonomy and control; they are less able to engage in activities that make life enjoyable; they feel they are burdens on family, friends or caregivers; they are concerned about inadequate pain control; they have a diminished self-image; and they experience a lower quality of life.

A more thorough description of the specific sources of existential suffering would enable researchers and policy-makers to better address the needs of vulnerable populations. We know how to offer assistance in dying, but we lack data to offer assistance in living.

How can we make the lives of people contemplating MAiD more tolerable, pleasurable and meaningful? Do available social programs, opportunities and care encourage them to believe that choosing “to live in a damaged body in a world where pain is meant to be gagged” (in the words of American poet Adrienne Rich) is a dignified choice?

We have set up medical and legal frameworks that enable sick, old and disabled people to access death, and our de facto policy is not to monitor whether we could have helped them to live. Since “what gets measured gets done,” this depoliticized picture of MAiD as oppression-free excuses us from doing anything.

Why we ought to do it

Canada’s obligations to monitor the impact of oppression on people contemplating MAiD and to take effective measures to alleviate this impact are a matter of stringent constitutional rights.

It is small-minded to say that the money society spends on the most vulnerable of our citizens facing the greatest suffering could be better spent on sick children and curable adults. Such calculations underscore an ableist and ageist premise that the state should spend its budget on lives that matter — productive lives — rather than on old, irreversibly sick, disabled humans who seem but honorary members of our society. Administrative convenience and reduction of expense are not sufficient reasons for the state to override constitutional rights to equality, life, security and liberty.

Civil rights organizations have contributed to constitutional challenges to ensure that vulnerable people have access to a means of dying. I suggest they also engage in challenges that ensure equal access to social, economic and medical means of living more tolerably. After all, the same rights are involved.

Courts have so far accepted an argument that resembles blackmail. The argument is that, if the state does not give claimants access to MAiD, claimants will end their life while they still can. The state would be violating their right to life by giving them no option more tolerable than an early death.

Why would courts not accept the same argument when socially vulnerable people in a similar situation would claim that, if the state does not give them access to basic forms of support that would render their life minimally tolerable, they will opt for MAiD? Therefore, the state would violate their rights to life, security and liberty by leaving them no other tolerable option.

We do not refrain from talking about the political and social dimensions of suicide in the case of veterans, Indigenous populations, youth and prison inmates. We should not shield MAiD from such scrutiny because just a portion of MAiD users are gravely oppressed or because it is state-sponsored — if anything, state sponsorship should heighten our scrutiny.

We all want a humane death. But oppressed people have never, historically speaking, had difficulty with accessing death (or indeed, tragically, with being killed). A much greater challenge for our society is to help oppressed people access the means to live a worthwhile life in a society that has given up on them. Discussing MAiD expansion before discussing oppression puts the cart before the horse.

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