

Who gets access to “medical aid in dying”?
Or, when is it rational to want to die?

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The state provincial and national legislation regarding end of life issues like euthanasia and physician-assisted suicide is changing at a rapid pace. In June 2014, the Quebec National Assembly passed Bill 52, "An Act respecting end-of-life care," which outlines the conditions under which certain ill patients may request medical aid in dying. On the national stage, MP Steven Fletcher has introduced a private member's bill (Bill C-581) that would amend the criminal code and decriminalize physician-assisted suicide under specific conditions. Fletcher's proposed amendment actually follows fairly closely to what had previously been set out by Bill 52, meaning that both pieces of legislation present similar problems. I am going to concentrate here on one problem in particular: the issue of who gets access to medical aid in dying or physician-assisted suicide.

There are at least two important assumptions underlying legislation like Bill 52 or Bill C-581. First, saying that physician-assisted suicide or euthanasia is permissible assumes that there are situations in which a desire to die can be considered rational. This assumption is necessary in order to hold that physician-assisted suicide or euthanasia could be permitted in a society that treats suicidal ideation (generally) as a symptom of mental illness, and therefore treats suicide as something that (typically) ought to be prevented from occurring. Second, saying that access to physician-assisted suicide or euthanasia ought to be limited to the terminally or seriously ill and disabled assumes that the rationality of a desire to die can be determined by considering the physical condition of the person who wants to die.

I do not necessarily have a problem with the first assumption, but I do think that the second is problematic. We cannot legitimately posit that "being ill or disabled" is simply one of the criteria to consider a suicide rational; we have no justification for doing so. The other option is to attempt to explain how the presence of illness or disability indicates that one of the criteria for rational suicide is met, but doing so reveals a problem with the legislation that has been proposed: it doesn't give us enough time to determine whether or not individuals who qualify for physician-assisted suicide or euthanasia are actually making a rational choice.

Quebec: Bill 52 [1]

26. Only a patient who meets the following criteria may obtain medical aid in dying:

- (1) be an insured person within the meaning of the Health Insurance Act (chapter A-20);
- (2) be of full age and capable of giving consent to care;
- (3) be at the end of life;
- (4) suffer from a serious and incurable illness;
- (5) be in an advanced state of irreversible decline in capability; and
- (6) experience constant and unbearable physical or psychological pain which cannot be relieved in a manner the patient deems tolerable.

Canada: Bill C-581 [2]

3. In order to be eligible to make a request for physician-assisted death, a person must:

- (a) be eighteen years of age or older;
- (b) be a citizen or permanent resident of Canada as of the date of the request;
- (c) have been diagnosed by a physician as having an illness, a disease or a disability (including disability arising from traumatic injury) that causes physical or psychological suffering that is intolerable to that person and cannot be alleviated by any medical treatment acceptable to that person, or the person must be in a state of weakening capacities with no chance of improvement; and
- (d) be of sound mind and capable of fully understanding the information provided to him or her under subsection 6.

Margaret Battin has suggested that two conditions, made up of five criteria, have to be met in order for a suicide (or, I would argue, any request for death) to be considered rational [3]. The first condition is nonimpairment, and three criteria must be met in order for an individual to be unimpaired: they must have (1) the ability to reason, (2) a realistic worldview, and (3) adequate information. This condition appears to speak directly to whether or not an individual has the capacity necessary to make the decision to die. The second condition has to do with satisfaction of interests, and a rational suicide both (4) serves an individual's interests and (5) prevents that individual from being harmed. While meeting the first condition determines whether or not an individual has the capacity to make a decision of this kind, the satisfaction of interests condition appears to speak more to the *reasons* that an individual has for wanting to kill themselves. And this second condition, I believe, is the more interesting of the two: what counts as a good reason for wanting to die?

Genuinely central interests

With respect to this criterion, Battin herself admits that we should limit ourselves to talking about central interests and fundamental ground projects that “cannot simply be dropped, replaced, or forgotten whenever circumstances arise that make their satisfaction impossible” [3]. This means, simply, that genuinely central interests of the relevant kind reflect an individual's deeply held values are consistent with the way that they have, until now, lived their life.

The obvious problem with this is that “genuinely central interests are going to be highly subjective and will vary greatly from one individual to another. This means that there is no reason to suspect that only illness or disability threatens an individual's genuinely central interests: the interests in question might be different in each case, but as long as they are based on deeply held values and consistent with the way that the individual has lived their life they are equally valid.

Subjectivity is not the only issue: we also have to deal with the fact that, sometimes, ground projects that were once fundamental are abandoned, and values that were once deeply held are replaced. While we could say that expressing distaste when confronted with the notion of change indicates that a genuinely central interest is in play, two categories of individuals are going to find the idea of abandoning projects or values distasteful: those whose suicides would be rational, as well as individuals who are merely “fearful or defensive about altering relatively peripheral interests or adjusting to losses” [3]. These latter individuals are experiencing what Battin calls “failed life transitions,” and while they may, at this moment, have a strong desire to commit suicide they can be helped to adjust with enhanced social support and adequate psychotherapy: their desire to die will, with time, disappear.

My worry with the current wording of the legislation is that it does not capture the idea that individuals can be helped to adjust to their new situations. Bill C-581 is especially problematic in this regard because individuals do not have to be “at the end of life” in order to access physician-assisted suicide and could, potentially, live long and productive lives.

I am dying. I do not want to, but I am going to die; that is a fact. I can accept death because I recognize it as a part of life. What I fear is a death *that negates, as opposed to concludes, my life*. I do not want to waste away unconscious in a hospital bed. I do not want to die wracked with pain. It is very important to me that my family, and my granddaughter in particular, have final memories that capture me as I really am—*not as someone I cannot identify with and have no desire to become*.

-Gloria Taylor [4, italics added]

Avoiding harm

We might say that death can both cause and prevent harm: it causes harm by depriving an individual of future goods that they may have experienced, while preventing harm by helping them to avoid future pain. Whether or not any particular death is harmful, therefore, depends on how the goods that are deprived compare to the pains that are avoided.

Saying this, however, begs a couple of questions. First, what goods and harms are we weighing against each other? We ought not limit ourselves to physical pain, but should also consider psychological suffering as harmful, but adding psychological suffering into the mix means that we must defer judgment about whether a particular state is harmful to the individual who wants to die. It is up to them to determine whether or not they will experience any psychological suffering when they are forced to abandon their fundamental ground-projects or central values.

Second, how do we weight the goods against the pains? This, again, requires deferral to the patient: only they can tell us whether physical or psychological suffering will outweigh any goods that they may experience in the future, and each individual will weigh things just a little bit differently. For some people the psychological suffering involved in giving up their fundamental ground-projects or central values will not outweigh the goods of continued life.

People with illness or disability are statistically more likely to have feelings of suicide, especially in the early period after the onset of significant disability because of psychosocial issues, such as feeling like a burden on family and fear about future loss of function associated with increases in disability. However, research overwhelmingly shows that *after an adjustment period*, people with disabilities rate their own quality of life as high or higher than the general public.

-Richard Radtke [5]

The importance of time

Given the connection of future pain to fundamental ground-projects and central values, and the fact that some individuals who express distaste at the idea of change are merely experiencing “failed life transitions,” it seems as though we need time to determine if a particular individual’s desire to die is rational. That individuals can, and do, adjust to lives that they initially thought would not be worth living is a point that has been repeatedly expressed by members of the disability community, and is a fact that legislation needs to take into account.

Given this, my suggestion is that the adjustment period (period between requests for physician-assisted suicide or medical aid in dying) required by legislation like Bill 52 or Bill C-581 ought to be two tiered. First, in cases of strictly terminal illness it makes sense to allow timely access to medical aid in dying in order to prevent undue suffering: these are individuals with a limited amount of time left in their future, and it is therefore easy to determine whether the number of goods present in their short future will be outweighed by physical or psychological suffering.

In other cases, however, I think it would be prudent to require a greater amount of time to pass, in order to ensure that individuals who have been diagnosed with *severe but non-terminal* conditions have an appropriate amount of time to adjust to their new circumstances. Only with time will they be able to determine whether these new lives are, in fact, unacceptable: therefore it is only with time that we can determine whether they are making a rational choice.

It is one thing to feel as though change would cause an unbearable amount of suffering; whether or not it actually does is quite another. The common refrain among disability advocates is, simply, it's not as bad as you think it's going to be: "it is possible for a person to create a perfectly delightful life under conditions that they never would have wished for. Your previous, naïve lack of imagination...is no barrier to the quality of your new life" [6]. However, if suffering does persist in spite of time and support, then the individual in question should be allowed to access medical aid in dying or physician-assisted suicide.

References

- [1] Quebec National Assembly, *Bill 52: An Act respecting end-of-life care* (Quebec Official Publisher, 2013)
- [2] Parliament of Canada, *Bill C-581: An Act to amend the Criminal Code* (House of Commons of Canada, 2014)
- [3] Margaret Pabst Battin, *Ethical Issues in Suicide* (Englewood Cliffs: Prentice-Hall, 1995)
- [4] *Carter v. Canada (Attorney General)* (British Columbia Supreme Court, 2012)
- [5] Richard Radtke, "The Case Against Physician-Assisted Suicide," *Journal of Disability Policy Studies* 16, no. 1 (2005): 58-60.
- [6] Ron Amundson and Gayle Taira, "Our Lives and Ideologies: The Effect of Life Experience on the Perceived Morality of the Policy of Physician-Assisted Suicide," *Journal of Disability Policy Studies* 16, no. 1 (2005): 53-57.

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