REFLECTION

MAID and Mental Illness: Critical Thoughts, Constructive Thoughts

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The current law on Medical Assistance In Dying (MAID) says that as long as a mental illness is the sole source of a person's suffering, MAID will not be provided. I believe the policy is extreme and needs refinement. To support my belief, and to suggest some revisions, I make the following points:

(1) A mental illness does not automatically deprive someone of capacity for making the MAID decision that is right for them.

Writing in Health Ethics Today (24:1, August 2016, pp. 6-8), Navjeet Gill and Paul Byrne assert, "Mentally ill patients ... may have the capacity to make end of life decisions. ... A thorough capacity assessment done by a professional is key to determining whether or not a patient's decision is truly their own and in line with their beliefs and values."

Indeed, if a revised law meant that MAID was no longer out of the question, that fact alone could improve patients' decision-making ability. Currently they are often weighed down by a feeling of "foreverness", brought on by the knowledge that they may have to suffer through several decades until bodily breakdown occurs, when in some cases they have already endured many years of torment. A high degree of desperation often results, greatly impairing their capacity for making wise decisions.

To prevent the foreverness feeling and the resulting desperation, we could establish an evidence-based protocol such as one that said patients would be accepted for MAID if they had:

a) endured 5 or more years of treatment without adequate improvement, and/or
b) tried more than 6 different drugs/therapies without adequate improvement, and/or
c) received a standard course of treatment from 3 or more different professionals without adequate improvement.

The patient would be the one to decide what did or did not constitute adequate improvement.

The numbers might need adjusting, in the light of experience. For instance, if it turned out that many patients were suiciding violently after only 3 years of treatment, the first number could be revised downward.

It is important to remember that capacity has domains or spheres – someone can be incompetent to make decisions in Domain A but quite competent to make decisions in Domain B. For instance, patients may be incompetent to make judgments about which treatment is most likely to help them, but quite competent to assess the net value of a given course of treatment (improvement, if any, versus side effects or other "downsides"). And the patient is probably the best-qualified person in the world to answer the question ,"Can I bear any more of life like the one I am having, which seems to be the only kind I can have?"

(2) With a mental illness, irremediability (the first variable noted by the Supreme Court) is different from what it is with a physical illness.

With a grievous physical illness, it usually means you will be afflicted with death. With a grievous mental illness, it currently means you will be afflicted with life. You will remain available to have increasingly unpromising therapies tried on you, suffering physically from side effects and psychologically from repeated disappointments.

Although "irremediable" is the word used by the Supreme Court, the words "intractable" and "refractory" are more common in the world of medicine, along with the phrase "treatment futility". In a 2010 paper, psychiatrist Justine Dembo writes, "I would ask ... whether acknowledging futility could ever be helpful for the patient, for the physician, and for the therapeutic alliance, and whether refusing to acknowledge futility could ever be harmful." (Journal of Ethics in Mental Health 5(1) Nov. 2010)

If a psychiatric patient who seems to have arrived at the treatment-futility stage expresses interest in MAID, it may happen occasionally that their doctor will feel able to designate them as meeting the requirements (assuming there is no longer an absolute exclusion of people whose suffering stems solely from a condition labelled as mental). But doing this would often be hard on the doctor – it would feel like saying, "I was not good enough at my job."

One solution could be to have a doctors' college or other group set up committees of experts in the various mental diseases which frequently lead to MAID requests. The experts would prepare an outline of what they considered to be a minimal standard treatment regimen. If the patient's records were checked against this, and passed muster, the patient would be accepted for MAID.

Another solution would be to set ceilings for treatment variables such as length of time or number of drugs, as was suggested under Point 1 above.

In acknowledging that an exit was among the possibilities, and need not be avoided at all costs, psychiatrists could re-conceptualize their role as that of "decision-making coach". (Probably most marriage counselors no longer consider that their goal is to prevent divorce; instead they see their role as helping the couple make the decision that is best in their case.)

As long as death remains "the thought which must not be thunk", patients will tend to keep quiet about the fact that they are interested in it. They will see the doctor as a potential jailer, if they consider hospitalization to be a dreadful fate, as many of them do. Once MAID

is put on the table, they can start to see the doctor as a partner, working with them on making the most important decision they will ever make.

One area in which useful data could be gathered by a helping professional is what might be called the graphing of the patient's symptoms. Some mental illnesses, notably bipolar disorder, involve fluctuation in the type or the intensity of the suffering. Ideally, patients would keep a diary in which they recorded a "score" (e.g. from 1 to 10 or from -5 to +5) for their depression or whatever, several times each day. But many disorders make the person too scattered to be methodical about such a project. Someone from their coaching staff could phone them at regular intervals and get a reading to enter into the log (even a "no answer" or a busy signal might be worth recording). The information thus gathered would be helpful in evaluating treatments. It could also help reveal the periodicity of the patient's condition. Then, if MAID is eventually settled on as the best option, it could be scheduled for the phase the patient wanted – perhaps at a time which is likely to be near the end of an "up" phase, or perhaps at a different time.

(3) Intolerability (the second criterion suggested by the Supreme Court) has more scope to develop with a mental illness than it does with a physical illness.

Many mental-illness patients suffer through decades of torment. Even if they have had interludes of relative wellness, the recurring nature of their attacks has made peace and hopefulness impossible. They feel like a mouse being killed by a cat. Eventually the distress caused by this vulnerability may accumulate to the extent that during their next interval of calmness they apply for MAID.

Risk-benefit analysis, common in the world of public policy, is useful here. There is a real risk that exhausted and desperate patients will make their exit alone and in a violent way. Often the alternatives to be compared are not death versus life, but solitary and painful death versus gentle death which can truly benefit the patients and those who love them.

However, patients themselves may want to do some analysis. What if they want to compare the benefits of death with the benefits of continued life? Of course, the comparison could not involve real death, which is permanent. But for the sake of stretching our minds a little, let us imagine that we offer them a simulation. They would be given continuous deep sedation, along with technology to take care of nutrition and elimination, for a week or whatever other interval would be safe for their bodies. They would agree to make a film record of their pre-sleep thoughts and feelings, then another one upon regaining consciousness, responding to open-ended questions such as, "How did you feel when you woke up?" Some patients might discover that they felt relieved, but others might feel bitter disappointment. This information would be quite valuable both to the patients and to their caregivers. And we would be doing error prevention in the proper way: saving people only from acts which would be mistakes by their own standards, not from acts which would be mistakes solely by the standards of outsiders. Just a little creative thinking...

(4) Moving from what the Court said to what it did not say, the phrase used was "medical condition", not "physical condition".

Even if the Court had said "physical condition", mental illnesses would have been included – they stem from structural and electrochemical abnormalities in the brain – but many readers would have taken the wording to exclude mental illnesses.

The kingdom of mental illness has fuzzy boundaries. One border is with neurological conditions such as Parkinson's disease, which are treated by neurologists and whose most prominent symptoms are sensory/motor. However, patients may also develop disorders of thoughts and feelings, often considered the hallmark of psychiatric diseases.

The other neighbour is psychological disorders, which are treated by psychotherapists and whose difference from psychiatric disorders is a matter of degree – they are not quite severe enough to interfere drastically with a person's ability to manage everyday life, whereas psychiatric disorders are.

The fuzzy-borders problem, and the matter-of-degree problem, create difficulties for lawmakers' assumption that "mental illness" can always be delineated with clarity and certainty. To the extent that its delineation may sometimes be difficult, it is poorly qualified to be the basis for a major legal distinction, as it tries to be in the current version of C-14.

The problem is not even delineation, sometimes. Real mistakes can occur. For instance, a person experiencing a cardiovascular event such as atrial fibrillation or a transient ischemic attack may get diagnosed (at least fleetingly, e.g. in an emergency room) with panic disorder, one of the many psychiatric diseases currently identified by symptoms alone. Once a notation about a psychiatric condition has been made in a person's file, there may be difficulties for that person if at some future time an application for MAID is filed. Even if the law disqualifies only applicants whose desire for death stems solely from a mental condition (as the current law does), adjudicators who get a "whiff" of mental illness could well be put off, and be inclined to reject the person's application.

A final problem is that psychiatry as a specialty appears to suffer occasionally from what could be called growing pains (to be charitable) or immaturity (to be less charitable). Sometimes the discipline looks like rather a frail reed to bear responsibility for such a sweeping disenfranchisement as the current C-14 entrusts to it

As an example of what many people would call immaturity, consider the usual response when psychiatric patients feel pain – not just sorrow or tension or fear, but actual throbbing or stabbing or burning pain. Their doctors often resort to discounting the patient's experiences, if no explanation or cure is obvious to them, labelling the pain with minimizing terms such as "psychogenic" or "somatoform". They may deny that they are calling the pain unreal, but to most laypeople (probably including the patient) the word psychogenic means "imaginary". The term somatoform is even worse. It suggests that although the pain feels as if it is in the patient's body, it really isn't, and the patient just doesn't have the wit to grasp the fact. (So as to avoid being purely negative, I offer a substitute label: "rogue pain". This

term too casts aspersions, but it casts them on the pain, not on the patient.)

(5) Continuing with things the Court did not say, in this case probably because they thought it would be assumed: access to MAID must be governed by the Charter of Rights and Freedoms.

The Charter says that people must not be discriminated against because of things they have no control over, such as their gender or their age or their ethnicity.

In most cases people also have no control over what diseases they develop. There is often a large genetic component in illnesses, including refractory mental illnesses. Victims ask, "Conceived without our consent, saddled with genes we did not choose, situated within communities that are still a long way from being able to nurture and protect every one of their members, how can we possibly have a duty to live? And how can our fellow citizens have a right to make us act as if we do?" American state lawmakers were the first to claim this right, when they said people had to wait until they were only six months away from death. Then Quebec legislators followed suit by inserting "en fin de vie" ("at the end of life") into the original Bill 52. And now Canadian federal legislators have effectively copied the Americans, though without the same degree of numerical precision.

Some people have been dealt a very bad hand. Since they did not join the game voluntarily – indeed none of us did – they should not be punished for their misfortune. And continued life, rather than death, is what constitutes punishment in their case.

The BC Civil Liberties Association is preparing a court challenge to C-14, stating that the present version violates the Charter by giving preference to people with fast-moving conditions such as cancer and doing disservice to people diagnosed with slow-moving conditions which can cause great suffering over a period of years, long before death is "reasonably foreseeable". A similar injustice occurs when people with a mental-illness diagnosis are barred from receiving MAID. Diagnosis should not be grounds for discrimination.

Supporters of discrimination against mental patients may say it is a necessary protection. But although these patients can sometimes benefit from a temporary withdrawal of their civil rights, a permanent abrogation enshrined in law is excessive.

(6) Parliamentarians, including the Minister who has been the most strenuous defender of C-14 as currently written (Jody Wilson-Raybould), like to note that Courts make judgments, but laws are made by Parliament.

In the Carter decision the Supreme Court made what could be termed a recommendation for a law governing MAID. Their thinking was shaped by the voluminous research and testimony they had received, and indirectly by the even-more voluminous research and testimony which had been reviewed by Justice Lynn Smith in B.C., whose decision the SCC was considering. It is doubtful that Wilson-Raybould has been informed by materials of

comparable quantity and quality. News reports from June 1 of 2016 suggest that she was moved quite substantially by a desire to avoid having Canada's policy be "the broadest in the world".

But many Canadians would not share her fear of that.

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