

Medical Assistance in Dying and Mental Illness under the New Canadian Law

Jocelyn Downie MLitt SJD FRSC FCAHS

University Research Professor, Faculties of Law and Medicine, Dalhousie University, Halifax, Canada

Justine Dembo MD FRCPC

Medical Director, Reconnect Trauma Center, Pacific Palisades, California, USA

Keywords: medical assistance in dying; legislation

On June 17, 2016, *An Act to amend the Criminal Code and to make related amendments to other Acts (medical assistance in dying)* came into force.¹ In the lead-up to the introduction of the legislation, the issue of whether mental illness should be an exclusion criterion for access to medical assistance in dying attracted considerable attention (i.e., excluding both patients with a mental illness and some other co-morbidity, and patients whose sole underlying condition is a mental illness). The Provincial-Territorial Expert Advisory Group on Physician-Assisted Dying and the Federal Special Joint Committee of the House and Senate on Physician Assisted Dying both heard testimony on each side of this issue, but both ultimately recommended against having mental illness as an exclusion criterion.² Intending to go against these recommendations in part, the government attempted to exclude all individuals whose sole underlying condition is a mental illness. However, after a review of what the legislation actually says and means, as well as the scientific literature on mental illness, we conclude that, despite the government's intention and statements to the contrary,³ the legislation does not actually exclude all individuals whose sole underlying condition is a mental illness. The government should therefore stop giving the public misleading and incorrect information. By disseminating misinformation, the government ensures that individuals (by definition experiencing enduring and intolerable suffering) may be denied access to medical assistance (by health practitioners who have been misled by the misinformation) when they are entitled to such access under the legislation passed by Parliament.

Before proceeding with the analysis that led us to our conclusion, a comment on scope is in order. Arguments have been made, for example by Dianne Pothier, that *Carter v. Canada (Attorney General)*⁴ excluded individuals whose sole condition is a mental illness.⁵ Barbara Walker-Renshaw and Margot Finley point out that arguments have been made in the alternative to the effect that *Carter* "leaves open the possibility that it would be unconstitutional to bar a capable adult from making the fundamentally important and personal medical decision that he or she can no longer tolerate the irremediable suffering of a treatment-resistant, severe mental illness."⁶ The leading authority on this point is *Canada (Attorney*

General) v EF in which the Alberta Court of Appeal unanimously rejected Pothier's and the Attorney General of Canada's arguments and interpreted the *Carter* decision as not excluding individuals with mental illness as a sole underlying condition.⁷ In paragraph 59, the court writes: "As can be seen, in *Carter 2015* the issue of whether psychiatric conditions should be excluded from the declaration of invalidity was squarely before the court; nevertheless the court declined to make such an express exclusion as part of its carefully crafted criteria. Our task, and that of the motions judge, is not to re-litigate those issues, but to apply the criteria set out by the Supreme Court to the individual circumstances of the applicant. The criteria in paragraph 127 and the safeguards built into them are the result of the court's careful balancing of important societal interests with a view to the Charter protections we all enjoy. Persons with a psychiatric illness are not explicitly or inferentially excluded if they fit the criteria." The Attorney General of Canada chose not to appeal this decision. We do not attempt to resolve this debate here but focus on what the legislation establishes, rather than what the Supreme Court of Canada decision in *Carter v Canada (Attorney General)* requires – that must remain the subject of a future paper.

1. What does the legislation say with respect to mental illness?

The legislation establishes criteria for access to medical assistance in dying. Several elements of the criteria are particularly relevant to our discussion of medical assistance in dying and mental illness.⁸

First, s.241.2(1)(b) requires that individuals be "capable of making decisions with respect to their health."

Second, 241.2(1)(c) requires that individuals have a "grievous and irremediable medical condition." S.241.2(2) then states:

(2) A person has a grievous and irremediable medical condition only if they meet all of the following criteria: (a) they have a serious and incurable illness, disease or disability; (b) they are in an advanced state of irreversible decline in capability; (c) that

illness, disease or disability or that state of decline causes them enduring *physical or psychological suffering* that is intolerable to them and that cannot be relieved under conditions that they consider acceptable; and (d) their natural death has become reasonably foreseeable, taking into account all of their medical circumstances, without a prognosis necessarily having been made as to the specific length of time that they have remaining.

Explicitly with respect to mental illness, s.9.1(1) of the Act establishes:

The Minister of Justice and the Minister of Health must, no later than 180 days after the day on which this Act receives royal assent, initiate one or more independent reviews of issues relating to requests by mature minors for medical assistance in dying, to advance requests and to *requests where mental illness is the sole underlying medical condition*.

Section 9.1(2) then establishes:

The Minister of Justice and the Minister of Health must, no later than two years after the day on which a review is initiated, cause one or more reports on the review, including any findings or recommendations resulting from it, to be laid before each House of Parliament.

2. What does the legislation mean with respect to mental illness?

a. The government's interpretation

According to various documents and public statements, the government would have Canadians believe that individuals whose sole underlying condition is a mental illness are excluded from access to medical assistance in dying. In its online glossary re: terminology used in the legislation, the government states the following:

Reasonably foreseeable death

“Natural death has become reasonably foreseeable” means that there is a *real possibility of the patient's death within a period of time that is not too remote*. In other words, the patient would need to experience a change in the state of their medical condition so that it has become *fairly clear that they are on an irreversible path toward death, even if there is no clear or specific prognosis*. Each person's circumstances are unique, and life expectancy depends on a number of factors, such as the nature of the illness, and the impacts of other medical conditions or health-related factors such as age or frailty. Physicians and nurse practitioners have the necessary expertise to evaluate each person's unique circumstances and can effectively judge when a person is *on a trajectory toward death*. While medical professionals do not need to be able to clearly predict exactly how or when a person will die, the person's death would need to be *foreseeable in the not too distant future*.

In terms of the *Carter* decision, the concept of reasonable foreseeable death is consistent with the factual circumstances of *Carter* and persons in the situation of Ms. Taylor and Ms. Carter i.e., taking into account all of the patient's medical circumstances, they were *on an irreversible trajectory toward death*. In all of the medical circumstances of the person, it is fairly clear to the medical practitioner/nurse practitioner (and the second confirming practitioner) that the person is *on an irreversible trajectory toward death, even if the practitioner cannot give a specific period of time for the prognosis*.⁹

Advanced state of irreversible decline in capability

When combined with the requirements that death be reasonably foreseeable and that the person be suffering intolerably, the requirement to be in an advanced state of irreversible decline ensures that medical assistance in dying would be available to those who are *in an irreversible decline towards death, even if that death is not anticipated in the short term*. This approach to eligibility gives individuals who are in decline toward death the autonomy to choose their preferred dying process.¹⁰

It should be noted here that the government's glossary definition does not even include the word “capability.” It should because the use of that term introduces serious ambiguity into the legislation – capability to do what? I can be in an advanced state of irreversible decline in capability to see (i.e., I am blind as a result of macular degeneration) or to regulate my blood sugar levels (i.e., I have adult-onset diabetes). Have I met this criterion? Furthermore, the text of the definition of the phrase “advanced state of irreversible decline in capability” literally adds nothing beyond that which is included in the definition of “reasonably foreseeable death.”

The government's glossary does not offer a definition of “incurable” and the online information provided by the government about the new legislation (posted after it came into force) inexplicably leaves out the element of “incurable” in its description of the eligibility criteria.¹¹ However, conclusions can be drawn about what the government intended to capture from testimony provided during the process of Parliament reviewing the draft legislation. According to the government, “incurable” means something other than its dictionary definition, i.e., “cannot be cured by any means.” Rather, it means, to paraphrase Minister of Health Jane Philpott, “cannot be cured by any means available and acceptable to the patient, not contraindicated for the patient, and not inappropriate.” When asked about the meaning of “incurable” in the bill when appearing before the Senate, Minister Philpott said:

On the matter of curability, there are a lot of reasons why something is incurable. Sometimes it's because no cure is known. Sometimes it's because, for the cure that is available, the patient has a contraindication to whatever that treatment might be. Sometimes there's no access to that treatment in a particular country. Sometimes it's a matter that the doctor and the patient make the decision that that particular treatment is inappropriate given the circumstances. Sometimes people are not able to be cured because of the fact that there's a requirement in the

relationship between a provider and a patient of informed consent and that a patient needs to consent to accept a treatment.

All of those situations need to be necessary for someone to be able to avail themselves of a cure. This is a way of being able to define the specific circumstance in which the doctor is looking at this patient and saying, “I cannot cure this patient’s problem, and therefore they meet the criteria.”¹²

Focusing on the definitionally limiting feature of “acceptable to the patient,” Joanne Klineberg, Senior Counsel, Criminal Law Policy Section, suggested in testimony before the Senate Standing Committee on Legal and Constitutional Affairs that “incurable” must be understood as being limited to treatments that are acceptable to the patient as, under the criminal law, no person should be compelled to undertake a medical treatment without their consent even if such treatment might be curative:

Finally, I would conclude that the criminal law itself prohibits administering a medical substance to a person against their wishes. That is the crime of assault. The criminal law has to be interpreted consistently, as a whole. So it’s not possible to interpret “incurable” in Bill C-14, were it to pass, as though it would require a person, compel a person, to undertake a medical treatment that they otherwise don’t consent to. That is one section of the Criminal Code compelling what is criminally prohibited by virtue of another section of the Criminal Code.

I think our answer would be that “incurable” has to be interpreted in this context in light of standard medical practice. So the willingness of the patient to undertake a medical treatment is part of determining whether or not the condition is incurable.

...

This word has to be understood in a manner that’s consistent with the rest of the Criminal Code. It can’t be interpreted to require individuals to take treatments that they don’t want. That would be counter to other provisions of the same act. That would be an interpretation that I don’t think could be sustained.¹³

In other words, the government testified that the criterion should be understood as “incurable by any treatments available and acceptable to the patient, not contraindicated for the patient, and not inappropriate.”

Turning to the application of the legislation to individuals whose sole underlying condition is a mental illness, the government’s online explanation claims that:

[p]eople with a mental illness are eligible for medical assistance in dying as long as they meet all of the listed conditions. However, you are *not eligible* for this service if:

- you are suffering *only* from a mental illness;
- death is not reasonably foreseeable when considering all the circumstances of your medical condition; or

- a mental illness reduces your ability to make medical decisions.¹⁴

Further evidence that the government believes the legislation excludes patients whose sole underlying condition is a mental illness is the statutorily mandated review and reporting back to Parliament on the issue of “requests where mental illness is the sole underlying medical condition.”¹⁵ S.9.1(1) places these requests in the same category as requests by mature minors and advance requests, which are both excluded by the Act.

During the period of debate over Bill C-14, the Ministers of Health and Justice both reiterated the government’s position that individuals whose sole underlying condition is a mental illness would not qualify for medical assistance in dying under the legislation.¹⁶

b. An alternative interpretation

Contrary to the government’s interpretation of the role of mental illness under the legislation, it can be argued that the legislation does *not* exclude all individuals whose sole underlying condition is a mental illness. This is because it is possible for a person whose sole underlying condition is a mental illness to meet the eligibility criteria set out in the legislation. 1) A person with mental illness *can* have decision-making capacity. 2) Mental illness *can* a) be incurable, b) have brought the patient to an advanced state of irreversible decline in capability, and c) cause the patient enduring physical or psychological suffering that is intolerable to them and that cannot be relieved under conditions that they consider acceptable. 3) The “natural death” of a patient whose sole underlying condition is a mental illness *can* be “reasonably foreseeable.” Furthermore, a person whose sole underlying condition is a mental illness can simultaneously meet all of the criteria (as is required for eligibility). Consider each of these claims in turn.

Capacity

Persons with mental illness *can* be capable of making decisions with respect to their health – even where the consequences of the decision are death.¹⁷

Canadian law has a long history of embracing this conclusion.¹⁸ The Canadian Psychiatric Association has recognized that patients with psychiatric illness can have capacity to consent to treatment that carries a risk of death, or to refuse treatment even where the inevitable consequence is death.¹⁹ One illustrative Canadian case report describes a patient with end-stage severe anorexia nervosa in which clinicians allowed the patient to refuse life-sustaining treatment on the grounds that she was highly likely to die from the illness and that her suffering was unbearable.²⁰ Similar decisions have been made by other treatment teams on the grounds that anorexia is an example of a chronic treatment-refractory and terminal illness with, in some cases, a deteriorating course that leads to physiological collapse, starvation, and death.²¹ Other authors have noted that even in the presence of severe depression, a decision that one’s life is intolerable may not just be a symptom of the illness, and that some treatment refusals in the context of depression, even if they result in death, may be legitimate decisions made by a competent individual.²² The concept of a rational suicide, when there is a realistic appraisal of the prognosis and treatment

options, has also been extended to people with schizophrenia.²³ Indeed, even some of the most vigorous critics of permitting access to medical assistance in dying to individuals with mental illness concede that at least some patients with mental illness have capacity for MAiD.²⁴

Finally, in *Canada (Attorney General) v EF*, the physicians testified and the trial judge found that a patient with severe conversion disorder had decisional capacity for medical assistance in dying.²⁵ As noted by the Court of Appeal,

While her condition is diagnosed as a psychiatric one, her capacity and her cognitive ability to make informed decisions, including providing consent to terminating her life, are unimpaired. ... Her mental competence is not in dispute.²⁶

Incurable

Mental illness *can* be incurable.

Most studies that examine treatment for psychiatric illness focus on those who benefit from the treatment, and yet there are always patients who do not respond. The Sequenced Alternatives to Relieve Depression (STAR*D) trial, a rigorously conducted and evidence-based trial funded by the National Institute of Mental Health (NIMH), illustrated that only 70 percent of participants responded, altogether, following four sequential medication trials.²⁷ This left 30 percent of patients still unwell. More disheartening is that one year later, 71 percent of the responding patients had relapsed.²⁸

STAR*D involved outpatients, who are, relatively speaking, a less severely ill population. Another study, using inpatients, took place in a tertiary care centre specialized in treatment-resistant mood disorders; here, 39.8 percent did not achieve remission.²⁹ Further, in a 2010 clinical trial using one of the most invasive treatment techniques, anterior capsulotomy, in the most carefully controlled trial conditions, only 50 percent of patients with refractory depression responded; these patients had already failed an average of eight antidepressant medications from four classes, plus an average of two courses of electroconvulsive therapy (ECT).³⁰

Although psychiatric treatment continues to advance, there remains a very significant proportion of patients who do not recover despite high quality psychiatric care. The above statistics focus on individuals with depression, but similar statistics apply to numerous other psychiatric illnesses. Obsessive-compulsive disorder can also develop into a severe, chronic, and disabling condition in which, of those who do not respond to first- and second-line treatments, less than half benefit from invasive treatments such as deep brain stimulation and capsulotomy.³¹ Over 20 percent of patients with anorexia follow a very severe and chronic course despite treatment,³² and despite high quality treatment, many patients with borderline personality disorder continue to have severe depressive episodes and experience ongoing distress, anger, relationship dysfunction, and an underlying dysphoric state.³³

The recent development of the subspecialty of palliative psychiatry is further evidence of the fact that some psychiatric illnesses are incurable.³⁴

Recent papers on the legal regulation of MAiD in Canada for persons with mental illness also concede or acknowledge the fact that some mental illness is incurable.³⁵

Finally, we can turn again to *Canada v EF*. In this case, the physicians testified and the trial judge found that EF's severe conversion disorder was "irremediable." For example, the Court of Appeal noted:

Physician B, a medical doctor with 40 years' experience who is competent to provide physician assistance in dying, deposed that, in her opinion, there are no further treatment options for the applicant that would offer any hope of improvement in her condition, or meaningful reductions in her symptoms. She stated: 'Given the length of time the symptoms have been present, the treatment history and her lack of response, I considered her condition to be irremediable.'³⁶

In addition to the above cases in which a mental illness was incurable by any means, there are even more cases in which a mental illness is incurable by any means acceptable to the patient. Given the position on the meaning of "incurable" taken by Minister of Health Jane Philpott and the Department of Justice senior counsel Joanne Klineberg described earlier, it is important to recognize that some treatments for individuals with mental illness are intolerable to patients.

Indeed, in psychiatry, there are times when clinicians agree to shift the goals of care away from cure or active treatment toward palliative care. Most publications on palliative care for mental illness are in the treatment of refractory anorexia nervosa. Here repeated attempts at re-feeding can become too painful and intolerable to the patient: both nasogastric tube and gastrostomy tube insertions are invasive and painful; patients often struggle during insertion and experience extreme distress; feedings themselves can cause both physical and psychological discomfort; and this type of forcible treatment not only can be terrifying and traumatic, but can also rupture the precious therapeutic alliance. Therefore, at times in anorexia, the course of the illness is too severe, death is the likely outcome, and palliative care is seen to be the only humane alternative.³⁷

Of note, it is often the case that the more invasive therapies, such as ECT, deep brain stimulation, and psychosurgery, are felt by patients to be unacceptable. Side effects of ECT, a well-evidenced treatment for highly acute or treatment-resistant depression, include the following: headache, nausea, jaw and neck pain, oral lacerations, dental injuries, and persistent muscle pain.³⁸ Most disturbing to some patients, and quite common, are the cognitive effects, which can include acute confusional states, anterograde and retrograde amnesia (usually short-term but sometimes permanent), deficits in autobiographical memory, and word-finding difficulties.³⁹ In one of the most rigorous medication studies for patients with schizophrenia, known as the CATIE trial, 74 percent of patients discontinued treatment over 18 months, largely owing to intolerability of side effects and lack of effectiveness.⁴⁰ In general, as psychiatric illness progresses, the available treatments are overall less tolerable and less effective, and patients must endure more severe side effects, which are often detrimental to their quality of life; with each failed treatment attempt comes further demoralization on the part of patients and their families.⁴¹

Even the courts have recognized the intolerability of some treatments. Consider, for example, the description of side effects provided in *Fleming v Reid*:

[T]he efficacy of the drugs is complicated by a number of serious side effects which are associated with their use. These include a number of muscular side effects known as extra-pyramidal reactions: dystonia (muscle spasms, particularly in the face and arms, irregular flexing, writhing or grimacing and protrusion of the tongue); akathisia (internal restlessness or agitation, an inability to sit still); akinesia (physical immobility and lack of spontaneity); and Parkinsonisms (mask-like facial expression, drooling, muscle stiffness, tremors, shuffling gait). The drugs can also cause a number of non-muscular side effects, such as blurred vision, dry mouth and throat, weight gain, dizziness, fainting, depression, low blood pressure and, less frequently, cardiovascular changes and, on occasion, sudden death.

The most potentially serious side effect of anti-psychotic drugs is a condition known as tardive dyskinesia. This is a generally irreversible neurological disorder characterized by involuntary, rhythmic and grotesque movement of the face, mouth, tongue, and jaw. The patient's extremities, neck, back and torso can also become involved. Tardive dyskinesia generally develops after prolonged use of the drugs, but it may appear after short term treatment and sometimes appears even after treatment has been discontinued.⁴²

It is therefore not surprising that some individuals with mental illness refuse some treatment and, if "incurable" means (as Minister Philpott and senior counsel Joanne Klineberg) "cannot be relieved by a means acceptable to the patient," then two groups will meet the criterion of incurable under the legislation: 1) those for whom there is no treatment available; and 2) those for whom there is a treatment available but who find the treatment to be unacceptable.

Irreversible decline in capability

Mental illness *can* cause an irreversible decline in capability.

As with the term "incurable," "irreversible" might mean "cannot be reversed by any means" or "cannot be reversed by any means available and acceptable to the patient, not contraindicated for the patient, and not inappropriate." The logic of the justification offered by the government for the narrower view of "incurable" applies equally here to "irreversible" and so it seems reasonable to assume that the government, if asked, would define "irreversible" as "cannot be reversed by any means available and acceptable to the patient, not contraindicated for the patient, and not inappropriate." That said, as with "incurable," mental illness can cause a decline in capability that cannot be reversed by any means. It can also cause a decline in capability that cannot be reversed by any means available and acceptable to the patient, not contraindicated for the patient, and not inappropriate." Consider the following examples.

For some persons with bipolar disorder, repeated and uncontrollable manic episodes increase the risk for harm resulting from risky or dangerous behaviours, and can lead to financial and social ruin

with damaging physical consequences. In the case of severe eating disorders, patients may experience the irreversible consequences of malnutrition, which can include organ failure, cognitive decline, and multiple fractures from premature osteoporosis. Clinically, one of the authors has encountered patients who are permanently and severely physically disabled, or are left in the ICU in a permanent vegetative state as the result of repeated suicide attempts. Unfortunately, then, there are times when no effective and acceptable biomedical treatment exists and severe mental illness can lead to a self-perpetuating and deteriorating cycle of irreversibly reduced capability over time.

When mental illness of any kind is severe enough, individuals may cease to eat, drink, or attend to hygiene or other kinds of self-care. They often become increasingly isolated and may become unable to engage in social relationships, which further exacerbates their illness. The risk of homelessness is significant; access to education and job opportunities can diminish as the illness worsens. Individuals with severe persistent mental illness (SPMI) may cease to seek medical attention when these challenges arise; furthermore, they often no longer participate in preventive health care, which then leads to an increased risk of undetected serious illnesses such as cancer and heart disease.⁴³ Although outcomes in Assertive Community Treatment (ACT), considered the gold-standard form of care for people with SPMI, which includes social forms of support (including supported housing, case management, activities, education, substance abuse counseling etc.) are in some ways better than in other models, a considerable number of these patients still do not improve significantly or recover.⁴⁴ Recent data from the Housing First project, with multiple sites across Canada in which patients are provided with ACT plus housing and measured against those receiving "treatment as usual," indicate comparatively improved overall quality of life, stability of housing, and community function in the former group. Even then, only 73% in the former group remained in housing, and there were no significant differences in severity of psychiatric symptoms or substance use between groups; furthermore the effect size for differences between groups with respect to safety was minimal.⁴⁵ In addition, a 2010 Cochrane meta-analysis found no very significant differences in all-cause mortality for patients with severe and persistent mental illness involved in intensive case management (including but not limited to assertive community treatment ACT) versus standard care.⁴⁶ Even this optimized treatment, then, leaves many with severe and life-threatening symptomatology. It is also the case that some patients find the social interventions to be too intrusive or distressing and reject them. Therefore it can be concluded that, at least in some cases, the decline in capability may not be mitigated by social interventions or, where social interventions might be effective, they might not be acceptable to the patient. The decline will therefore again be irreversible.

Enduring intolerable physical or psychological suffering

Mental illness *can* cause intolerable physical and psychological suffering.

Suffering in mental illness can be severe, unbearable, and intractable. The anguish, loss of self, disorientation, anxiety, and loss of perceived meaning in life that contribute to suffering in mental illness can contribute to a state of not just mild and transient suffering, but to severe, constant, and unbearable suffering.⁴⁷

Author David Foster Wallace, who died by suicide in 2008 at age 46 following decades of refractory depression, anxiety, and substance abuse, once described the experience of psychic suffering as follows:

It is a level of psychic pain wholly incompatible with human life as we know it. ... It is a sense of poisoning that pervades the self at the self's most elementary levels. It is a nausea of the cells and soul. [Its emotional character is] ... a sort of double bind in which any/all of the alternatives we associate with human agency — sitting or standing, doing or resting, speaking or keeping silent, living or dying — are not just unpleasant but literally horrible.⁴⁸

In the same passage, Wallace also described depression as an “invisible agony,” which he likened to being trapped in a burning building. One of the authors has witnessed patients with severe and chronic depression attempting to cut out their hearts or other internal organs, which they describe as causing overwhelming physical pain. Other patients with chronic, severe refractory depression have described a sense of being suffocated or strangling, chest pain, generalized burning pain, severe gastrointestinal distress, limb pain, and of generalized pain and weakness, just to name some of the suffering caused by mental illness. Psychiatric illness can also directly cause physical pain in conversion disorder. Patients with certain types of schizophrenia experience chronic and painful somatic delusions and hallucinations — genuine physical discomfort and pain that is the product of psychosis.⁴⁹ This pain can be just as real, and agonizing, as the pain caused by somatic illness, and it cannot always be treated successfully with psychotherapy or medication.

Patients with depression are well known to experience painful somatic symptoms that are unexplained by medical investigations. In an international study, Simon et al.⁵⁰ examined data for 1146 patients with depression selected from a World Health Organization collaborative study and found that 50 percent experienced medically unexplained somatic symptoms, including physically painful symptoms. Similar reports of associated medically unexplained pain and its effects on quality of life exist for generalized anxiety disorder with or without comorbid depression.⁵¹ These symptoms pose a significant burden on quality of life in addition to the burden of the mental illness itself.⁵²

Finally, here again we can turn to the recent case of *Canada (Attorney General) v EF*, in which the Alberta Court of Appeal concluded that a competent woman with a psychiatric condition was indeed experiencing enduring intolerable suffering.

E.F. is a 58 year old woman who endures chronic and intolerable suffering as a result of a medical condition diagnosed as ‘severe conversion disorder,’ classified as a psychogenic movement disorder. She suffers from involuntary muscle spasms that radiate from her face through the sides and top of her head and into her shoulders, causing her severe and constant pain and migraines. Her eyelid muscles have spasmed shut, rendering her effectively blind. Her digestive system is ineffective and she goes without eating for up to two days.⁵³

It can therefore reasonably be concluded that refractory depression and other forms of mental illness can be a source of both physical and psychological suffering.

Reasonably foreseeable

The natural death of an individual with mental illness can be reasonably foreseeable (even in the absence of a co-morbidity).

The lifespan of patients with severe and persistent mental illness is reduced by 10-20 years, with death being sometimes due to what would be described as “natural death” in the context of non-mental illness (e.g., malnutrition and infection).⁵⁴ It should be noted here that while “natural death” is not defined in the legislation, it seems reasonable to assume that it means the same thing as when it is used on medical certificates of death. There it means death not caused by an external event such as homicide, suicide, or accident. Anorexia nervosa is one clear example of a psychiatric condition that can cause “natural death” (i.e., death without a lethal co-morbidity, homicide, suicide, or accident). There is certainly such a thing as “terminal” or “end-stage” mental illness.⁵⁵

It is important to note here the interpretation of “reasonably foreseeable” as it was applied by the ministers of Justice and Health to the facts of Kay Carter (one of the women at the heart of *Carter*). In responding to the debates in the House, the Senate, and the public arena about the legislation, the ministers repeatedly stated that Kay Carter’s natural death was reasonably foreseeable.⁵⁶ However, Kay Carter’s condition was not terminal. She had spinal stenosis and could have lived with that for years. After that fact was pointed out to them, the ministers explicitly based their conclusion that her death was reasonably foreseeable on the fact that she was elderly and frail.⁵⁷ Therefore, on this logic, an individual whose sole underlying condition is a mental illness would meet the reasonable foreseeable criterion *if she was old and frail*.

In addition, the government’s conclusion that Kay Carter’s natural death was reasonably foreseeable rested figuratively if not literally on actuarial tables (given their reliance on age and frailty). The logic of this could see individuals with mental illness meeting the reasonable foreseeability criterion even when not old as Kay Carter since the phenomenon of “premature mortality” is well-established for individuals with mental illness and so an actuarial table for a relatively young individual with a mental illness might place them closer to death than Kay Carter was at 89. For example, the World Health Organization points out that “[p]eople with severe mental disorders on average tend to die earlier than the general population. This is referred to as premature mortality.”⁵⁸ Therefore, even before the onset of some other condition that would cause their death, even discounting for suicide, homicide, or accident, even younger than 89, they could be predicted to have a lifespan as short as Kay Carter’s would have been (as she had no terminal illness).

3. Conclusion

It can be concluded that, under the new legislation, it is simply not the case that patients are not eligible for medical assistance in dying if they are “suffering only from a mental illness.”⁵⁹ The government should therefore amend its published documents and future public statements to correct the misinformation they

have provided to health care providers and the public. If they do not do so, they will be responsible for the extended, enduring, and intolerable suffering of those individuals denied access to the medical assistance in dying, to which they are entitled under the legislation.

Footnotes

1. *An Act to amend the Criminal Code and to make related amendments to other Acts (medical assistance in dying)*, SC 2016, c3.
2. Provincial-Territorial Expert Advisory Group on Physician-Assisted Dying, *Final Report* (30 November, 2015), online: <http://www.health.gov.on.ca/en/news/bulletin/2015/docs/eagreport_20151214_en.pdf>; Senate, Report of the Special Joint Committee on Physician-Assisted Dying, *Medical Assistance in Dying: A Patient-Centred Approach* (February 2016) (Chairs: Kelvin Kenneth Ogilvie and Robert Oliphant), online: <<http://www.parl.gc.ca/content/hoc/Committee/421/PDAM/Reports/RP8120006/pdamrp01/pdamrp01-e.pdf>>.
3. Others have also stated that the legislation excludes individuals whose sole condition is a mental illness. For example, Louis Charland, Trudo Lemmens, & Kyoko Wada, "Decision-Making Capacity to Consent to Medical Assistance in Dying for Persons with Mental Disorders" (2016) 9 J Ethics & Mental Health 1 at 9, online: <www.jemh.ca/issues/open/documents/JEMH_Open-Volume_Benchmark_Decision_Making_to_Consent_to_Medical_Assistance_in_Dying-May2016-rev.pdf> [Charland et al.]. However, in this paper we focus on what the government should do in response to our arguments (i.e., change official documents and statements so as not to mislead practitioners and the public). Government documents and statements will be taken as more authoritative and have more of a chilling effect on practice.
4. *Carter v Canada (Attorney General)* 2015 SCC 5 [Carter].
5. See, for example, Dianne Pothier, "The Parameters of a Charter Compliant Response to *Carter v. Canada (Attorney General)*, 2015 SCC 5" (2016) Social Science Research Network at 9, online: <http://papers.ssrn.com/sol3/papers.cfm?abstract_id=2753167>.
6. See Barbara Walker-Renshaw and Margot Finley, "*Carter v. Canada (Attorney General)*: Will the Supreme Court of Canada's Decision on Physician-assisted Death Apply to Persons Suffering from Severe Mental Illness?" (2015) 9 J Ethics & Mental Health 1 at 5, online: <www.jemh.ca/issues/open/documents/JEMH_Open-Volume_Benchmark_Assisted%20Death-Nov20-2015.pdf>.
7. *Canada (Attorney General) v EF*, 2016 ABCA 155.
8. In what follows, all italics within quotations has been added by the authors for emphasis.
9. Canada, Department of Justice, "Medical Assistance in Dying" Glossary (20 June 2016), online: <<http://www.justice.gc.ca/eng/cj-jp/ad-am/glos.html>> [Glossary].
10. Glossary, *supra* note 9.
11. See Canada, Health Services, *End of Life Care, Medical Assistance in Dying*, "Who is eligible for medical assistance in dying" (20 July 2016), online: <<http://healthycanadians.gc.ca/health-system-systeme-sante/services/palliative-palliatifs/medical-assistance-dying-aide-medicale-mourir-eng.php#a3>> [Who is eligible]. The eligibility criteria state: "To be considered as having a grievous and irremediable medical condition, you must meet all of the following conditions. You must:
 - have a serious illness, disease or disability
 - be in an advanced state of decline that cannot be reversed
 - be suffering unbearably from your illness, disease, disability or state of decline; and
 - be at a point where your natural death has become reasonably foreseeable, which takes into account all of your medical conditions."
12. *Debates of the Senate*, 42nd Parl, 1st Sess, Vol 150, No 41 (1 June 2016) at 1650 (Dr. Jane Philpott), online: <http://www.parl.gc.ca/Content/Sen/Chamber/421/Debates/041db_2016-06-01-e.htm> [Debates of the Senate].
13. Senate, Standing Senate Committee on Legal and Constitutional Affairs, "Evidence" (6 June 2016) (Chair: Bob Runciman), online: <<http://www.parl.gc.ca/content/sen/committee/421/LCJC/52666-E.HTM>>.
14. Who is eligible, *supra* note 11 (emphasis added).
15. *An Act to amend the Criminal Code and to make related amendments to other Acts (medical assistance in dying)*, SC 2016, c3, ss 9.1(1), (2).
16. See, for example, *Debates of the Senate*, 42nd Parl, 1st Sess, Vol 150, No 41 (1 June 2016) at 1410 (Jodi Wilson-Raybould), online: <http://www.parl.gc.ca/Content/Sen/Chamber/421/Debates/041db_2016-06-01-e.htm> [Debates of the Senate, Wilson-Raybould]; Laura Stone, "Jane Philpott 'Concerned' about Senate Changes to Assisted-Dying Bill," *Globe and Mail* (9 June 2016), online: <<http://www.theglobeandmail.com/news/politics/jane-philpott-concerned-about-senate-changes-to-assisted-dying-bill/article30387436/>>.
17. Here we do not engage with the argument put forward by Charland et al., *supra* note 3. This is because they are not arguing that patients with mental illness can never have capacity for a decision to access medical assistance in dying (MAiD), which is what would need to be argued for individuals with mental illness as a sole underlying condition to be excluded under the legislation as drafted. Rather, they are arguing that, because of problems with capacity assessments, such patients should not be permitted to have access. Their argument has a fatal flaw, the "paralyzing theoretical sting" which they believe sinks access to MAiD for individuals with mental illness as the sole underlying condition, also strikes refusals of potentially life-sustaining treatment by individuals with mental illness as the sole underlying condition. Unless they are prepared to argue that the law on refusals of treatment should be changed to prevent respecting refusals, then their argument that the law should not permit access to MAiD fails. Fleshing out this response to Charland et al., however, must remain a project for a future paper.
18. See, for example, *Starson v Swayze*, [2003] 1 SCR 722, 2003 SCC 32; *Fleming v Reid*, 4 OR (3d) 74, 1991 CanLII 2728 (ON CA) [Fleming].
19. Grainne Neilson & Gary Chaimowitz, "Informed Consent to Treatment in Psychiatry (Position Statement)" (2015) 60:4 Can J Psychiatry 141 at 8.
20. PC Hebert & MA Weingarten, "The Ethics of Forced Feeding in Anorexia Nervosa" (1991) 144:2 Can Medical Association J 141.
21. Joel Yager, "Management of Patients with Chronic, Intractable Eating Disorders" in Joel Yager & Pauline Powers, eds, *Clinical Manual of Eating Disorders* (Arlington: American Psychiatric Publishing, 2007) 465; Amy Lopez, Joel Yager & Robert Feinstein, "Medical Futility and Psychiatry: Palliative Care and Hospice

- Care as a Last Resort in the Treatment of Refractory Anorexia Nervosa” (2010) 43:4 *Intl J Eating Disorders* 372 [Lopez et al.]; Amy Campbell & Mark Aulisio, “The Stigma of ‘Mental’ Illness: Anorexia and Treatment Refusal” (2012) 45:5 *Intl J Eating Disorders* 627 [Campbell & Aulisio].
- 22 Mark Sullivan & Stuart Youngner, “Depression, Competence, and the Right to Refuse Lifesaving Medical Treatment” (1994) 151:7 *American J Psychiatry* 971; Samuel Brown, C. Gregory Elliott, & Robert Paine, “Withdrawal of Nonfutile Life Support after Attempted Suicide” (2013) 13:3 *American J Bioethics* 3.
- 23 Jeanette Hewitt, “Rational Suicide: Philosophical Perspectives on Schizophrenia” (2009) 13:1 *Medicine, Health Care and Philosophy* 25.
- 24 Scott and Lemmens caution: “A further concern is that some patients who request assisted dying because of a psychiatric illness may not meet the criteria for mental capacity. Although *psychiatric diagnoses should not be equated with incapacity, some conditions* (e.g., psychotic illnesses, neurocognitive disorders, severe depression, anorexia nervosa and intellectual disability) *may increase the risk of incapacity*” (emphasis added). See Scott Y.H. Kim & Trudo Lemmens, “Should assisted dying for psychiatric disorders be legalized in Canada?” (21 June 2016) *Can Medical Assoc J*. Similarly, Charland et al. argue, “These stipulations provide a safeguard based on a recognition that psychiatric disorders *may compromise the patient’s decision-making capacity*” (emphasis added). See Charland et al., *supra* note 3.
- 25 In *Carter v Canada (Attorney General)*, 2016 SCC 4, the Supreme Court of Canada established that patients could get judicial authorization for medical assistance in dying for the period of the extension on the suspension of the declaration of invalidity of the Criminal Code prohibition on medical assistance in dying, so long as the patient met the eligibility criteria set out the SCC in *Carter*, *supra* note 4.
- 26 *EF supra* note 7 at para 7.
- 27 Sidney Zisook et al., “Sequenced Treatment Alternatives to Relieve Depression (STAR*D): Lessons Learned” (2008) 69:7 *J Clinical Psychiatry* 1184.
- 28 A John Rush et al., “Acute and Longer-Term Outcomes in Depressed Patients Requiring One or Several Treatment Steps: a STAR*D Report” (2006) 163:11 *American J Psychiatry* 1905.
- 29 Abebaw Fekadu et al., “Prediction of Longer-Term Outcome of Treatment-Resistant Depression in Tertiary Care” (2012) 201:5 *British J Psychiatry* 369.
- 30 David Christmas et al., “Long Term Outcome of Thermal Anterior Capsulotomy for Chronic, Treatment Refractory Depression” (2011) 82:6 *Neurology, Neurosurgery & Psychiatry* 594.
- 31 J Pepper, MHariz, & L Zrinzo, “Deep Brain Stimulation versus Anterior Capsulotomy for Obsessive-Compulsive Disorder: a Review of the Literature” (2015) 122:5 *J Neurosurgery* 1028.
- 32 Hans-Christoph Steinhausen, “The Outcome of Anorexia Nervosa in the 20th Century” (2002) 159:8 *American J Psychiatry* 1284.
- 33 D. Mercer, “Review lecture on personality disorders” (Lecture delivered at the EK Koryani Review Course), University of Ottawa, 16 February 16 2011) [unpublished].
- 34 M Traschel et al., “Palliative Psychiatry for Severe and Persistent Mental Illness” (2016) 3:3 *Lancet Psychiatry* 200; JS Dembo, “Addressing Treatment Futility and Assisted Suicide in Psychiatry” (2010) 5:1 *J Ethics in Mental Health*; M Berk et al., “Palliative Models of Care for Later Stages of Mental Disorder: Maximizing Recovery, Maintaining Hope, and Building Morale” (2012) 46:2 *Australian & New Zealand J Psychiatry* 92 [Berk et al.].
- 35 For an implied concession, see Charland et al., *supra* note 3: “psychiatric disorders ... are often treatable” (i.e., not “always treatable”). For an explicit acknowledgement, see Mona Gupta, “A Response to ‘Assisted Death in Canada for Persons with Active Psychiatric Disorders’” (2016) 9 *J Ethics in Mental Health* 1 at 1, online: < www.jemh.ca/issues/open/documents/JEMH_Open-Volume-Commentary_Response_Assisted_Death_in_Canada-June2016.pdf>. She contends: “There are times in the course of clinical care of a medical problem or set of problems when there is nothing left to offer to alleviate a patient’s suffering from that very problem. This is as true in psychiatry as it is in any other area of medical practice.”
- 36 *EF supra* note 7 at para 63.
- 37 Lopez et al., *supra* note 21.
- 38 C Wijeratne, GS Halliday, & RW Lyndon, “The Present Status of Electroconvulsive Therapy: a Systematic Review” (1999) 171:5 *Medical J Australia* 250.
- 39 Sidney Kennedy et al., “Canadian Network for Mood and Anxiety Treatments (CANMAT) Clinical Guidelines for the Management of Major Depressive Disorder in Adults: IV Neurostimulation Therapies” (2009) 117:1 *J Affective Disorders* 2009S44.
- 40 Jeffrey Lieberman et al., “Effectiveness of Antipsychotic Drugs in Patients with Chronic Schizophrenia” (2005) 353: 12 *New England J* 1209; National Institute of Mental Health, *Clinical Antipsychotic Trials of Intervention Effectiveness (CATIE) Investigators*, online: <<http://www.nimh.nih.gov/funding/clinical-research/practical/catie/index.shtml>>.
- 41 Berk et al., *supra* note 34.
- 42 *Fleming, supra* note 18.
- 43 Theodore Stern et al., *Massachusetts General Hospital Comprehensive Clinical Psychiatry*, 2nd ed (Amsterdam: Elsevier 2016) [Stern et al.].
- 44 Dieterich M; Irving CB; Park B; Marshall M. “Intensive Case Management for Severe Mental Illness” [review], (2010) 10 *Cochrane Database of Systematic Reviews* CD007906 <http://onlinelibrary.wiley.com/doi/10.1002/14651858.CD007906.pub2/abstract;jsessionid=886CEA1DE79C1C7C71D79B91EA796EC4.f01t01>. Aubry T, Tsemberis S, Adair CE, Veldhuizen S, Streiner D, Latimer E, et al. “One-year outcomes of a randomized controlled trial of Housing First with ACT in five Canadian cities” *Psychiatric Services* 2015; 66(5): 463-9.
- 45 Aubry et al., *supra* note 44.
- 46 Dieterich et al, *supra* note 44.
- 47 R Berghmans, G Widdershoven, & I Widdershoven-Heerding, “Physician-Assisted Suicide in Psychiatry and Loss of Hope” (2013) 36:5-6 *Intl JL & Psychiatry* 436.
- 48 David Foster Wallace, *Infinite Jest* (Boston: Little, Brown and Company, 1996) at 692-998.
- 49 Recall the discussion of, and references on, capacity provided earlier in this paper – even with the extreme suffering, the patients described in this section **can** have decision-making capacity.
- 50 Gregory E Simon et al., “An International Study of the Relation between Somatic Symptoms and Depression” (1999) 341 *New England J Medicine* 1329.
- 51 I Romera et al., “Generalized Anxiety Disorder, with or without Major Depressive Disorder, in Primary Care: Prevalence of Somatic Symptoms, Functioning and Health Status” (2010)

- 127:1-3 J Affective Disorders 160-8.
- 52 Jong-Min Woo et al., "Importance of Remission and Residual Somatic Symptoms in Health-Related Quality of Life Among Outpatients with Major Depressive Disorder: a Cross-Sectional Study" (2014) 12:1 Health & Quality of Life Outcomes 1, online: <<http://www.hqlo.com/content/12/1/188>>; A Brnabic et al., Frequency and Outcomes of Painful Physical Symptoms in a Naturalistic Population with Major Depressive Disorder: an Analysis of Pooled Observational Studies Focusing on Subjects Aged 65 and Older" (2012) 66:12 Intl J Clinical Practice 2012 1158.
- 53 EF, *supra* note 7 at para 7.
- 54 Stern et al, *supra* note 43 at pages 704-708.
- 55 Campbell & Aulisio, *supra* note 21.
- 56 See, for example, Debates of the Senate, Wilson-Raybould, *supra* note 16 at 1420; Peter Zimonjic & Catherine Cullen, "Liberals May Accept Senate Amendment to Pass Assisted Dying Bill" *CBC News* (1 June 2016), online: <<http://www.cbc.ca/news/politics/assisted-dying-justice-minister-senate-1.3611337>>.
- 57 Debates of the Senate, Wilson-Raybould, *supra* note 16 and *CBC News*.
- 58 World Health Organization, *Information Sheet: Premature Death Among People with Severe Mental Disorders* (2014), online: <http://www.who.int/mental_health/management/info_sheet.pdf>.
- 59 Who is eligible, *supra* note 11 (emphasis added).

Acknowledgements: *The authors thank Brad Abernethy for helpful comments on earlier drafts of this paper and Kate Scallion for her meticulous editorial assistance.*

Competing interests:

Jocelyn Downie MLitt SJD FRSC FCAHS

Relevant previous roles:

- Member of plaintiffs' legal team in *Carter v. Canada* (Attorney General)
- Member of Provincial-Territorial Expert Advisory Group on Physician-Assisted Dying
- Member of Royal Society of Canada Expert Panel on End of Life Decision-Making
- Special Advisor to Senate Committee on Euthanasia and Assisted Suicide

Competing interests:

Justine Dembo MD FRCPC

Affiliations:

- Member of Physician Advisory Council, *Dying With Dignity Canada*
- Member of Medical Advocates group for *Compassion & Choices*
- Member of Joint Centre for Bioethics MAID Task-Force and Mental Health Subgroup

Address for Correspondence: *Jocelyn.Downie@Dal.Ca*

Date of publication: November 18 2016

ADDENDUM

Since the publication of this paper, the Minister of Justice and Attorney General of Canada as well as Health Canada have taken steps that have confirmed that An Act to amend the Criminal Code and to make related amendments to other Acts (medical assistance in dying) does not exclude all individuals whose sole underlying condition is a mental illness.

In a letter to one of the authors (Downie), the Minister of Justice and Attorney General of Canada provided the following statement:

In crafting the legislation, the Government intended to make medical assistance in dying available to all competent adults who are in decline and approaching the end of their natural lives, in order that they may have the choice of a peaceful death instead of a painful, prolonged, or frightening one. Our policy was to treat the specific reasons underpinning the final stage of an individual's life as irrelevant to his or her eligibility.

Accordingly, the eligibility criteria in the Act, including the definition of "grievous and irremediable illness" found in subsection 241.2(2) of the Criminal Code, were framed around the overall medical circumstances of a patient, viewed holistically, as opposed to focusing on the presence or absence of specific medical conditions or types of conditions. Moreover, the criterion requiring that an individual have a "serious and incurable illness, disease or disability" is stated in general terms, with no delineation between different types of conditions. The Act does not impose any requirement to demonstrate a particular or singular explanation for an individual's advanced state of irreversible decline (241.2(2)(b)), nor why his or her natural death has become reasonably foreseeable (241.2(2)(d)).

Under the Act, the eligibility criteria require an individualized assessment of a person's medical circumstances by his or her medical practitioner(s). It is therefore not possible to make broad generalizations concerning whether a particular condition or illness qualifies or does not qualify someone for medical assistance in dying, as the person's disease or illness is only one medical circumstance, albeit an important one, relevant to his or her eligibility. For example, the degree to which a particular condition has progressed, the efficacy of treatments on the individual, the person's other medical circumstances, including his or her susceptibility to life-threatening infections or complications, the presence of other unrelated medical conditions, and overall frailty, along with other medical factors, are also relevant when considering an individual's eligibility for medical assistance in dying.

I wish to be clear that the Government's intention with this legislation was and remains that a person who meets all of the eligibility criteria may receive medical assistance in dying. As long as all of the criteria are satisfied, the legislation is silent with respect to whether a person's medical condition is a mental illness.

ADDENDUM

The Government's policy intentions as described above are reinforced by the Minister's description of the scope of the independent reviews mandated by s.9.1 of the Act.

This review [in relation to requests for MAiD where a person's mental illness is their sole underlying medical condition] is intended to focus on circumstances in which individuals with mental illnesses are not nearing a natural death and are not in a state of irreversible decline, and thus are not eligible for medical assistance in dying. The review is not intended to focus on cases where an individual with mental illness, in combination with other medical circumstances, would already qualify for medical assistance in dying, such as a competent person with incurable cancer in an advanced state of decline who also experiences mental illness, or where a mental illness, such as an eating disorder, is at such an advanced stage that the individual will die as a result.

Furthermore, the Health Canada website no longer states that "you are not eligible for this service (MAiD) if: you are suffering only from a mental illness." Rather, it now states the following:

About mental illness and physical disability

If you have a mental illness or a physical disability and wish to seek medical assistance in dying, you may be eligible. Eligibility is assessed on an individual basis, looking at all of the relevant circumstances. However, you must meet all the criteria to be eligible for medical assistance in dying, which means:

- your natural death must be foreseeable in a period of time that is not too distant
- you must be mentally competent and capable of making decisions at the time of your request
- you must also be mentally competent and capable of making decisions immediately before medical assistance in dying is provided
- the physician or nurse practitioner must ask you to confirm your choice before administering the service

You can withdraw your consent at any time and in any manner

The government is to be commended for resolving the confusion. All those who advise or educate patients and healthcare providers should now ensure that their materials accurately reflect the fact that the Act does not exclude all individuals whose sole underlying condition is a mental illness.

Jocelyn Downie
May 25, 2017