

Evidence Against Expanding Access to Euthanasia and Assisted Suicide

Backgrounder to the EFC's submission to

the CCA Expert Panel on Medical Assistance in Dying

October 2, 2017

Background

The Council of Canadian Academies (CCA) set up an Expert Panel to conduct a study on expanding access to medical assistance in dying. The Panel will report its findings back to Parliament by December 2018. These independent studies on expanding access to mature minors, to those for whom mental illness is the sole underlying medical condition, and by advance requests were mandated in Bill C-14, the legislation allowing euthanasia and assisted suicide, passed in June 2016.

The CCA Expert Panel on Medical Assistance in Dying has been tasked to answer the following question:

What is the available evidence on, and how does it inform our understanding of, medical assistance in dying (MAID) in the case of mature minors, advance requests, and where mental illness is the sole underlying medical condition, given the clinical, legal, cultural, ethical, and historical context in Canada?

The CCA asked for stakeholder input on expanding euthanasia and assisted suicide (EAS) with a 1000-word limit for submissions.

Given the CCA's word limit for stakeholder submissions, the EFC has prepared this backgrounder that provides additional information on the points made in the EFC's submission.

Introduction

The Evangelical Fellowship of Canada (EFC) is the national association of evangelical Christians in Canada. The EFC upholds respect for human life and care of vulnerable persons. Expanding access to EAS would place the most vulnerable Canadians at risk and further undermine societal respect for life.

In this background document, the EFC outlines some key concerns with expanding euthanasia and assisted suicide (EAS) to mature minors, to those with mental illness as the sole underlying medical condition and by advance request, and provides academic references.

The EFC holds that all human life has intrinsic worth. Allowing EAS treats some lives as less worthy than others. As this article on the underlying assumptions of physician-hastened death articulates:

The value of life in this framework becomes correlated to desired experience and is not something of intrinsic worth. Conceptually, if such a stance is adopted, life worth is established according to a spectrum, and those with more or less suffering in their lives have lives that are more or less worthy. Life is not itself a sufficient criterion warranting protection but must consist of certain experiences. Certainly, if this is the case, the

ending of a life should pose no qualms if experience is poor because within this view, life is meaningless in and of itself and only retains worth when certain conditions are met.¹

Guidelines and requirements for carrying out EAS can lack clarity, even in cases not involving mental illness, mature minors and advance directives. (For example, in the Netherlands in 2010, 23% of EAS cases were not reported by physicians because they did not consider their actions to fall under the EAS guidelines²). The potentially more complicated cases which are the subject of this study involve some of the most vulnerable Canadians, providing a greater potential for abuse, and would be more difficult to govern.

Mental illness

Canadians affected by mental illness are a vulnerable and stigmatized population.

Persons experiencing mental illness can be particularly vulnerable to suicidal ideation. As one study states about depression, "Indeed hopelessness, closure of the future, and suicidal ideation are key features of the illness."³

Mental illness may impair or annul the ability to give informed consent to death. One study states, "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."⁴

Another study points out that legal decisions on capacity involving depression are sparse, compared to other psychiatric disorders. It goes on to state that the competence assessment tool "MACCAT-T articulation of appreciation has proven difficult to apply with severely depressed patients."⁵ It explains that patients may lose the ability to make decisions about the future because they lose the ability to see the future as "open" or "yet-to-be-determined." The available futures all manifest themselves as normatively 'flat.'

An article that noted evidence from clinical ethics and empirical studies indicating that decisionmaking capacity is often impaired in those with severe depressive illness, went on to recommend: "In contrast to other areas where capacity is assumed as a default, that in these cases it should be assumed to be absent unless assessed thoroughly."⁶

Capacity can be difficult to assess. A study of psychiatric EAS cases in the Netherlands, from 2011 to 2014, indicates there was a disagreement among the consultants in one-quarter (24%)

¹ Liao and Chan, "Physician-Hastened Death in Young Children," 182.

² Onwuteaka-Philipsen et al., "Trends in End-of-Life Practices before and after the Enactment of the Euthanasia Law in the Netherlands from 1990 to 2010," 908, 913.

³ Broome and de Cates, "Choosing Death in Depression," 587.

⁴ Kim and Lemmens, "Should Assisted Dying for Psychiatric Disorders Be Legalized in Canada?," 3.

⁵ Owen et al., "Temporal Inabilities and Decision-Making Capacity in Depression," 178.

⁶ Broome and de Cates, "Choosing Death in Depression," 587.

of the requests.⁷ The study goes on to note that EAS proceeded with the disagreements unresolved for most cases.

Research and resources on evaluating capacity are lacking. As commentary in the *Canadian Medical Association Journal* pointed out, "Discussions, much less evidence-based guidance, of how to evaluate people who request assisted dying because of prolonged grief, autism, schizophrenia, or personality disorders are lacking."⁸ The same article discusses a survey of consultant psychiatrists, most of whom reported that assessing decision-making capacity is a challenging task and that training in making evaluations is suboptimal.

It went on to state: "When the consequence could be premature death, assessments of decision-making capacity need to include rigorous thresholds with carefully articulated justifications. Evidence, however, indicates that this is not necessarily the case."⁹

The preservation of hope is absolutely paramount. Hope has been described as "a quintessential prerequisite for recovery" in positive psychology.¹⁰ However, extending the option of euthanasia or assisted suicide (EAS) implies there is no hope of recovery for those suffering from mental illness.

One study stated, "While many patients will be disheartened by a series of unsuccessful treatments, it is critical that they are not given a sense that their doctor has 'given up'."¹¹

One of the key problems that arises with respect to euthanasia in patients with intolerable suffering due to a psychiatric condition, as Vandenberghe noted, is that: "The process of carefully evaluating a euthanasia request inevitably takes time, in the meantime undermining hope and orientation toward life, both crucial to safeguard the chances for partial recovery."¹²

Mental illness may not follow a predictable progression. With depression, for example, remission is always a possibility and there is hope as new treatments are developed. As one study stated, "Epidemiologic research has consistently shown that severe mental illness is not always a lifelong or even a chronic condition; substantial numbers of people with severe mental illness have a reduction of both symptoms and associated secondary impairments over time."¹³

As another study noted, the thesis that "an 'end-stage' psychiatric disorder exists and can be reliably diagnosed is clinically unsubstantiated and ethically problematic, and therefore futility judgments are inappropriate."¹⁴

¹³ Whitley, Palmer, and Gunn, "Recovery from Severe Mental Illness," 951.

⁷ Kim, De Vries, and Peteet, "Euthanasia and Assisted Suicide of Patients With Psychiatric Disorders in the Netherlands 2011 to 2014."

⁸ Kim and Lemmens, "Should Assisted Dying for Psychiatric Disorders Be Legalized in Canada?," 2. ⁹ Ibid., 4.

¹⁰ Park and Chen, "Positive Psychology and Hope as Means to Recovery from Mental Illness," 35.

¹¹ Berk et al., "Palliative Models of Care for Later Stages of Mental Disorder," 95.

¹² Vandenberghe, "P-647 - Euthanasia in Patients with Intolerable Suffering due to a Psychiatric Condition."

¹⁴ Geppert, "Futility in Chronic Anorexia Nervosa," 36.

Mental illness is experienced by many in Canada, but there is limited treatment available. As CAMH's factsheet on mental health statistics notes, only half of Canadians experiencing a major depressive disorder receive "potentially adequate treatment." An estimated 75% of children with mental disorders do not access specialized treatment services. Wait times in Ontario average 6 months to a year. ¹⁵

As a nation, we must not offer death in the absence of treatment. Without a viable alternative, it is arguably not a 'free' choice.

Mature minors

The EFC absolutely rejects the idea that EAS should be made available to minors. Children are a vulnerable population. Children are influenced and may be pressured by adults in numerous ways. As this article in the *Journal of Medical Ethics* noted, "even a small amount of pressure by an authority figure will typically have disproportionate actual force on any child, particularly a sick child... Children rightly merit extra protection because they are generally more sensitive than adults."¹⁶

Canada's first priority must be to provide high quality medical care for children. To consider expanding EAS to mature minors in the absence of widely available, high quality mental health services and palliative care would be unethical. In Canada, less than 25% of children with mental health disorders receive specialized treatment services.¹⁷

There is no agreement about whether minors have a capacity to consent to EAS. One study on adolescent decision-making states: "Given that the psychological and neurological data have already been interpreted to support opposing conclusions on this question, it seems prudent at least to reserve judgment about what the data actually reveal about the quality of adolescent decision-making."¹⁸ It goes on to state: "We haven't yet agreed on a stable definition of capacity in this population, much less a reliable instrument for measuring capacity."¹⁹

The law sets an age at which Canadians may make significant decisions, such as the right to vote or to purchase alcohol or cigarettes. It is only appropriate and reasonable that a life-ending decision should be restricted to a similar age.

¹⁵<u>http://www.camh.ca/en/hospital/about_camh/newsroom/for_reporters/Pages/addictionmentalhealthstatistics.</u> <u>aspx</u>

aspx ¹⁶ Kaczor, "Against Euthanasia for Children."

¹⁷ Waddell et al., "A Public Health Strategy to Improve the Mental Health of Canadian Children."

¹⁸ Salter, "Conflating Capacity & Authority," 34.

¹⁹ Ibid., 35.

At the Special Joint Committee on Physician-Assisted Dying, Dr. Dawn Davies of the Canadian Paediatric Society stated that no consensus exists on an age of consent to treatment. She went on to say:

In general, the less weighty the outcome of the decision, the more we allow the minor to play a role in that decision. For example, for a very young child, it may be asking which arm they would like their intravenous started in because the risk of harm is so low. However, a child not wanting potentially life-saving chemotherapy if they have a good prognosis or not wanting any further treatment if they have just suffered from a terrible car accident, for example, are the cases that are much more difficult to assess.²⁰

In general, the less weighty the outcome, the more a minor plays a role in the decision. EAS cannot be undone or mitigated, it is intended to kill, and thus it cannot be considered like any other type of medical treatment over which minors may have legal decision-making power.

As an article on euthanasia and children states, "The weightiest decision of all is the choice to die. Virtually all other choices can be reversed or mitigated." ²¹

Another article explains: "Making a decision to administer antibiotics differs from making a decision to end a life. In the former case, recovery from a misguided decision is possible, and the very goal is to respect and preserve natural life. This cannot be said of the latter case"²²

There is a moral and ethical difference between refusing or withdrawing treatment and EAS.

In cases where a minor participates in a decision that results in his or her death, the minor is refusing treatment, not consenting to a lethal injection. Hastened death is categorically different than end of life care, including palliative or continuous sedation in the last days or hours of a patient's life. The intention to end a life, rather than to alleviate pain, makes euthanasia and assisted suicide fundamentally different than end of life care.

As Dr. Mary Shariff of the Canadian Paediatric Society explained to the Special Joint Committee on Physician-Assisted Dying:

... the argument is being made that the law has already allowed mature minors to make medical decisions even if doing so would result in their death. But let's think about that a little more closely. In those death cases, the decision is about rejection of treatment whereby if the child rejects treatment, the child runs the risk of dying. This is an entirely different consideration for children than is children being expected to consent to lethal injection.

... we also see from those cases in the Canadian case law that if the odds of survival are good with treatment, the court will override a minor's refusal.²³

²⁰ "Evidence - PDAM (42-1) - No. 11 - Parliament of Canada."

²¹ Kaczor, "Against Euthanasia for Children."

²² Liao and Chan, "Physician-Hastened Death in Young Children," 182.

Advance requests

The requirement that a patient be competent at the time of EAS is a critical safeguard against abuse and involuntary euthanasia. The EFC opposes allowing the use of advance directives to request EAS.

Advance directives are very complex and difficult to carry out because of the nuances and specifics of complicated medical conditions and interventions.

The person writing the advance request cannot anticipate the details of their future state and their future desires. As one study notes, a person diagnosed with dementia "does not have full knowledge to make decisions about subsequent events."

As Dr. Blackmer of the Canadian Medical Association stated to the Special Joint Committee on Physician-Assisted Dying in reference to advance directives:

What I can tell you is that in real-life practice, putting advance directives into action is incredibly complex and difficult, because it's very hard to capture all of the nuances and the specifics of a very complicated medical condition and intervention. Even in the best of situations, physicians have a lot of difficulty actualizing an advance directive.²⁴

Predictions about future suffering are speculative. As a study on dementia and euthanasia noted: "Dementia affects each individual differently, in part due to the area and magnitude of the damage to the brain, but also because of the uniqueness of each individual. Some sufferers of dementia may retain their personality while others may experience dramatic personality changes; there is simply no way to know how the disease will affect a person or how the person will feel about their quality of life once the disease has set in."²⁵

Advance requests put significant additional responsibility on the physician, who must decide at what point a patient's life will end. Currently the doctor carries out the request of the patient. With advance directives, the doctor must identify the particular time at which the patient would want to die. It is an interpretive role but also a progression in role. The doctor goes beyond carrying out the patient's request to interpreting the request, possibly in the midst of unforeseen circumstances and complications, and deciding on the timing.

According to a study from the Netherlands, "In case of advanced dementia, many physicians point out that it is impossible to determine whether a patient is suffering unbearably, due to a lack of meaningful communication."²⁶ The same study notes that many Dutch elderly care

²³ "Evidence - PDAM (42-1) - No. 11 - Parliament of Canada."

²⁴ "Evidence - PDAM (42-1) - No. 6 - Parliament of Canada."

²⁵ Franklin, "Physician-Assisted Death, Dementia, and Euthanasia," 568.

²⁶ Bolt et al., "Can Physicians Conceive of Performing Euthanasia in Case of Psychiatric Disease, Dementia or Being Tired of Living?," 596.

physicians "state it is impossible to determine at what moment an advance euthanasia directive is to be carried out if the patient can no longer specify this. Also, it is probable that physicians cannot conceive of performing euthanasia in a patient with dementia who might not fully comprehend what is happening."²⁷ In such instances, decisions are not based on the individual's autonomous decision in the moment, but on the determination of others.

People change their minds. As one study noted, half of the terminally ill patients who had seriously considered EAS for themselves changed their minds after a few months. Patients with depressive symptoms were more likely to change their minds about desiring EAS.²⁸

Conclusion

The EFC opposes all euthanasia and assisted suicide. However, in a context in which these practices are legal, we advocate for stringent safeguards to provide the strongest possible protection for vulnerable Canadians and to minimize the potential for abuse.

This brief summary points to compelling evidence of numerous problems with expanding access to EAS to mature minors, to those with mental illness as the sole underlying factor, and by advance requests. To expand access to EAS in these ways would place some of the most vulnerable Canadians at unacceptable risk.

Our focus as Canadians must be on extending and improving high quality palliative care and treatment for mental illness.

²⁷ Ibid., 596.

²⁸ Emanuel, Fairclough, and Emanuel, "Attitudes and Desires Related to Euthanasia and Physician-Assisted Suicide Among Terminally III Patients and Their Caregivers."

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