



Strengthening Safeguards and Avoiding MAID Based on Advanced Directives

Submission to the House of Commons Standing Committee on Justice and Human Rights on Bill
C-14, Medical Assistance in Dying
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In submissions to the Joint Parliamentary Committee (JPC) and in a recent publication, I discussed why a restrictive reading of *Carter* is appropriate and I provided substantial evidence of problems with a Belgian/Dutch-style regime.¹ The combination of open-ended criteria and reliance on competency assessment by physicians without tools to prevent doctor shopping is resulting in these jurisdictions in an expansion of problematic MAID practices. This has particularly come to light in the last 5 years. Parliament should be critical of the claim that this evidence has been assessed (e.g. in the *Carter* case) and that no problems were identified. This is incorrect. Even without access to the more recent evidence, the trial judge in *Carter* recognized potential problems. The Bill's definition and focus on end-of-life will help reduce the risk of similar problems while providing access to those like the applicants in *Carter*. I therefore strongly support the definition of 'grievous and irremediable', which provides an appropriate balance between competing Charter rights.

In light of the open nature of the concept of 'reasonable foreseeable' death, prior independent review with administrative or judicial oversight remains important. This would contribute to accountable precedent-development and provide guidance in the interpretation of the concept. I urge Parliament to at least study the option and to permit provinces to use prior review systems. These can be flexible and offer additional protection. Here I want to focus on the Bill's procedures for determining access to MAID, i.e. assessment of competency and informed consent, and briefly also on the appropriate exclusion of advanced directives (AD).

1. Assessment of Access to MAID Procedure: Competency and Informed Consent Standard

The Bill's key safeguards are informed consent and competency (capacity) assessment. They promote patient autonomy, but they are not fail-proof. The problems with these tools are heightened in the context of MAID, where the procedure (the ending of life) is irreversible. Some other exceptional end-of-life practices (e.g. withdrawal of life support) are also irreversible, but MAID measures are ethically and legally distinct. They are an exception to a criminal code prohibition that reflects a rejection of the idea that people ought to receive the power to deprive others of life. MAID will change the dynamic of the doctor-patient relation. Informed consent and competency assessments become more important as protective tools against premature life-ending practices. Yet the protective value of the measures is weakened because the same professionals who perform the life-ending practice conduct the assessments. The current clear professional commitment to save the patient's life leads at times to over-treatment, but also provides protection against premature death. Finally, more people who are not as close to the end of life as in situations of treatment-withdrawal or treatment-refusal will request life-ending interventions. All this makes a more careful assessment of the existing challenges of competency and informed consent practices essential.

Physicians recognize that they are not well trained in assessing competency, which is inherently complex.² In situations where MAID is sought, emotional, physical and contextual factors interact,³ which makes assessments even more difficult. Mental health issues may affect people's ability to understand and appreciate the information provided. Physicians often fail to diagnose, for example, how depression affects the judgment of people diagnosed with a catastrophic illness. Physicians' own values influence whether they deem patients competent.⁴

Challenges with obtaining informed consent for MAID overlap with competency assessment concerns.⁵ There are 'translational' challenges: the person who provides the information determines what and how information is presented. Emotional and contextual factors may undermine the voluntariness of MAID requests. These include financial factors, family dynamics, absence of proper home or palliative care, and quality of life concerns.³

The Bill's safeguards should better reflect the preamble's emphasis on the need to prevent errors and abuse, to protect people from being (consciously or unconsciously) induced, and to protect those who are vulnerable. It is essential to determine whether absence of palliative and other needed health care, or familial, financial or other contextual factor impact on competency or undermine the voluntary nature of the request. These concerns should be addressed before MAID is performed.

- Section 241.2 (1)(d) only refers to external pressures. It should be revised to state: "they have made a voluntary request . . . that, in particular, is not affected by inducement, undue influence, coercion, quality of life or health care related concerns, or external pressures"

- Section 241.2 (3) with regards to safeguards should include a duty to refer for further professional assessment when, after an initial evaluation, a medical practitioner has reason to believe that other factors may impact on the competency and informed consent of the patient. New subsections should be added in section 241.2(3): [the medical practitioner and nurse practitioner must]:

g(a): ensure that palliative care has been offered to the patient and, if not, refer the patient for specialized palliative care counseling. Palliative care counseling has to focus on determining whether palliative care or other health care services can relieve the suffering of the patient in a way that is acceptable to the patient.

g(b) refer the patient to specialized counseling if a medical practitioners is of the opinion that the capacity of the patient may be compromised, for example as a result of a mental health condition; or that the patient's consent may be compromised by inducement, undue influence, coercion, quality of life or health care related concerns, or external pressures.

To enable proper post-factum review of MAID practices, the Bill should provide more detail about the information that has to be reported. It should require a detailed report with details about clinical diagnosis, assessment procedures, additional counseling, whether palliative care was offered, whether other contextual factors or pressures were identified, and how these issues were addressed.

2. Binding Advanced Directives and MAID

The JPC has recommended allowing advanced directives (AD) prepared after people have been diagnosed with a grievous and irremediable medical condition. Dementia is a clear example of a disease targeted by that option. I laud the government for not opening the door to the practice of AD

in the context of MAID. Ending people's lives on the basis of an AD is ethically problematic as it will largely be impossible to determine the voluntary nature of the practice. People may have a very hard time coping with a diagnosis of disease like dementia. They often cannot imagine that they will still have a quality of life once the disease progresses and that they may develop very different interests and reasons to live. When AD's for MAID are prepared after a person is diagnosed with cognitive impairment, as the JPC recommends, competency risks to be compromised.⁶ People with dementia often maintain a good quality of life for a significant period of time. Changes in the brain are accompanied by personality changes, which affect their values and their appreciation of life. They are no longer the person they once were. Yet, since they would have lost competency, they would no longer be able to change a request for MAID, prepared at a time of significant stress, when they could not imagine how they would appreciate their future life. Allowing ADs for MAID would put family members and health care providers before a terrifying moral dilemma: respect a person's past wishes and terminate her life even if she may still enjoy daily activities, or respect the person's current interest in remaining alive. In such situations of uncertainty about what the person wants, the best interest of the person in remaining alive should prevail. Much can be done to address the health care and emotional needs of people who have become incompetent without actively ending their lives. Legally confirming that a person's life can legitimately be ended when intellectual capacities have declined and the person can no longer withdraw the AD-based request compromises our societal commitment and Charter-based duty to protect the lives of those with intellectual disabilities. It also opens the door to abuse of those who can no longer consent.

The most liberal regimes, Belgium and the Netherlands, which legalized euthanasia in 2002, are much more restrictive than what the JPC recommended. Belgium allows AD-based euthanasia, but with strict criteria, including that the person must be irreversibly unconscious. In the Netherlands, ADs are an element of decision-making, but they are not binding for euthanasia. Health care providers and family members do not have to follow them. ADs are only very rarely used for euthanasia practice, and when they have been used, they have sometimes resulted in [serious controversy](#).⁷ Parliament should avoid creating the ethical and legal minefield associated with ADs for MAID.

¹ T. Lemmens, "The conflict between open-ended access to physician-assisted dying and the protection of the vulnerable: Lessons from Belgium's euthanasia regime in the post-Carter era." In C. Régis, L. Khoury, & R. Kouri (eds.), *Les grands conflits en droit de la santé* (Montréal: Yvon Blais, 2016) 261-317.

² L. Charland, T. Lemmens, K. Wada, "Decision-making Capacity to Consent to Medical Assistance in Dying for Persons with Mental Disorders" *J. Ethics & Mental Health* (forthcoming 2016). See also See T. Lemmens, "Why Canada Should Avoid A Belgian-Style Regulatory Regime for Physician Assisted Dying" Memorandum for the Joint Parliamentary Committee on Assisted Dying, January 27, 2016 and references there.

³ Canadian Association for Community Living, *Assessing Vulnerability in a System for Assisted Death in Canada* (1996) online: <http://www.vps-npv.ca/news-and-resources> & D. Baker, G. Sharpe & R. Lauks "Federal & Provincial Responsibilities to Implement Physician Assisted Suicide." *Health L. Canada* (2016) 36(3) 148.

⁴ Linda Ganzini et al, "Evaluation of Competence to Consent to Assisted Suicide: Views of Forensic Psychiatrists" (2000) 157 *Am J Psychiatry* 595

⁵ T. Lemmens, "Informed Consent" In Y. Joly & B. M. Knoppers (Eds.), *Routledge Handbook of Medical Law and Ethics* (London: Routledge, 2015) 27-51

⁶ O. Okonkwo et al. "Medical decision-making capacity in patients with mild cognitive impairment." (2007) 69(15) *Neurology* 1528-35.

⁷ T. Lemmens, "Dangers of a Lax Assisted Death Regime" *Impact Ethics Blog Dalhousie University*, online: <https://impactethics.ca/2016/03/03/dangers-of-a-lax-assisted-death-regime/> & links there to Dutch editorials.