



Critical Reflections on Bill C-14 on Medical Assistance in Dying

Submission to the Senate Standing Committee on Legal and Constitutional Affairs, Re Bill C-14, Medical Assistance in Dying

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I thank the Senate Committee for inviting me to comment on the Government's Bill C-14 on Medical Assistance in Dying. My comments are informed by focused research on euthanasia law and practice in Belgium and the Netherlands, and my 20 years as a professor of bioethics and health law, during which I have published and taught on issues including end-of-life law, the law of informed consent, and professional regulation.

1. Bill C-14's precise definition: the importance of specific access criteria.

I support Bill C-14's definition of the terms grievous and irremediable. The Supreme Court identified these terms as parameters, to be followed by the legislator when developing a more detailed regulatory scheme with stringent safeguards. By defining specific criteria in Bill C-14 the government is ensuring access to MAID to those in situations like the applicants of the *Carter* case, while also respecting in line with *Carter* its Charter-based obligations to those who may be vulnerable to premature death. In a recently published chapter¹ and in earlier submissions to the Joint Parliamentary Committee,² I provided arguments about why a precise and end-of-life focused definition is in line with *Carter* and respects the Charter. Colleagues specialized in Constitutional law have also provided strong arguments to that effect, pointing to the need to balance competing rights in this challenging end-of-life context.³

Providing a precise definition is not only in compliance with the Charter. It is also the right thing to do from a health policy and ethical perspective. In my earlier submissions and in my chapter, I provide substantial evidence of the pitfalls of open-ended criteria, particularly when it is left up to physicians or other health care providers to determine access to MAID on the basis of individual competency and informed consent assessments, without additional independent review. The combination of open-ended criteria and reliance on competency assessment by physicians without tools to prevent doctor shopping is resulting in jurisdictions like Belgium and the Netherlands in an expansion of MAID practices in a direction that I trust most Canadians and most Parliamentarians do not want to take. Problems with the Belgian and Dutch regimes have particularly come to light more recently. Several controversies in the last couple of years have stirred significant debate, with Belgian and Dutch commentators, academic scholars, medical professionals, and politicians now arguing for a strengthening of their systems. Senators should be critical of the claim that this evidence has been seriously evaluated in the *Carter* case and by several Canadian committees and that this reveals that

there are no serious problems in these countries. This is incorrect. Much of this evidence, and particularly the evidence that has become public in the last five years, has not been assessed by the trial judge in *Carter*. Yet, even without access to this more recent evidence, the trial judge explicitly recognized that there could be problems in a Belgian system. The Supreme Court further explicitly ruled that it did not have to consider more recent evidence from Belgium because, so it stated explicitly, it was not dealing with MAID involving people suffering from mental health conditions, children, or people suffering from minor conditions. The Supreme Court also indicated that our Parliament could avoid the problems associated with a system like the Belgian system by enacting a regime that would offer less discretion in the interpretation of safeguards. It thus indirectly cautioned Parliament to design a better regulatory system than what Belgium's parliament came up with.⁴ Providing more specific criteria that allow for less discretion, as the Bill now does, is an essential step to avoid the problems associated with these regimes.

It would in my view be irresponsible for Canada to introduce an open-ended regime for MAID precisely at a time when countries like Belgium and the Netherlands are struggling with an expansion of practices in controversial areas and are discussing how to curb this expansion. I encourage the Senators to take these concerns seriously when proposals are made to expand the Bill's appropriately narrow criteria and to read the evidence of problems, some of which has only recently been made available or discussed in English.⁵

The evidence from Belgium and the Netherlands indeed confirms that vulnerable patients are put at risk when the option of doctor shopping and expandable access criteria make access to MAID all too easy. MAID is in those countries not only exponentially increasing in numbers (from 347 cases in 2004; to 822 in 2009; 1,926 in 2014; and 2021 in 2015), which may in and of itself suggest a shift in practice. It is also increasingly performed on people who are lonely, or who are concerned about becoming dependent on others or on becoming demented. It has been performed on couples who want to die together; people who are blind and deaf; people who were struggling with gender identity; and more generally people who are tired of life.

Particular concerns are raised in the Belgian and Dutch open-ended regimes by the increased use of MAID for people suffering from mental health conditions. Two recent studies published in established medical journals and other data, discussed in more detail in my submission for the SJC, reveal how a fast growing number of people struggling with mental health issues request access to euthanasia.⁶ These requests not only involve people with long histories of treatment-resistant depression, which is often cited as the key reason why people with mental health disorders should be able to access MAID. It also includes people who have personality, post-traumatic stress, anxiety and eating disorders; schizophrenia; addiction; autism and even complicated grief. The studies reveal the challenges of relying on individual physicians' competency assessment for access to MAID for people with mental disorders. They also highlight the serious difficulty of identifying what constitutes an irremediable condition or 'treatment resistance' in the context of mental health disorders. I discussed the problems of providing access to MAID solely on the basis of mental health disorders in more detail in my submissions to the Joint Parliamentary Committee and in my chapter. Other publications focusing on this particular topic will be coming out in the near future, highlighting the challenges of opening up MAID as a method to provide (indeed final and irreversible) relief for people with psychiatric disorders.⁷ I urge the Senators to avoid opening up the access criteria to

include more widely MAID on the basis of psychiatric disorders. It would put among the most vulnerable people in our society at very serious risk of premature death. Improved mental health services are required to address the serious problems people with mental health issues face. Providing access to MAID risks seriously undermining the treatment and support people need, and may in the end create a disincentive to address significant deficiencies in our mental health care system.

2. Prior Review

With a more precise definition, the Canadian legislation will avoid many of the problems associated with the open-ended Belgian and Dutch Regimes. However, particularly in light of the concept of ‘reasonably foreseeable’ death that is put forward in the Bill, prior independent review with administrative or judicial oversight is desirable. A flexible prior review system has been recommended by a broad coalition of health advocacy, health professions and disability rights organizations⁸ and by other colleagues who have drafted a legislative proposal based on an existing federal review structure.⁹ It would contribute to accountable precedent-development and provide guidance in the interpretation of the concept of reasonably foreseeable death. It would also provide protection against possibly sloppy or over-zealous physicians who may be negligent in the assessment of competency and informed consent or be too flexible with the interpretation of the access criteria. Problems with the integrity of professional practice exist in any area of health care practice. There is no reason to think that this would suddenly be different in the end-of-life context. Independent prior review provides an additional protection in an area where professional error and negligence have inevitably fatal consequences. Evidence in Belgium and the Netherlands suggests here again that these concerns are realistic. I therefore urge Parliament to at least study the option and to permit provinces to use prior review systems.

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

The Bill’s key safeguards are informed consent and competency (capacity) assessment. These two concepts are interconnected. Competency is one of the pillars of the doctrine of informed consent. Both aim at promoting patient autonomy, but they are not fail-proof. They reflect an ideal, with practical challenges limiting the extent to which that ideal can be achieved. The inherent limitations of these tools become more significant 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 one of the cornerstones of our liberal, human rights committed society: the rejection of the idea that people ought to receive the power to deprive others of life. Any exception to this fundamental societal commitment to respect life should be carefully crafted, based on a clearly established need, and accompanied by significant safeguards to prevent misuse and error.

MAID will change the dynamic of the relation between health care provider and patient, a change that may have consequences that are hard to predict. As with all fundamental changes to established professional practice, it is important to be prudent in the implementation of such a change. It is true that health care providers are already involved in making decisions and performing actions that indirectly end the patient’s life (e.g. withdrawal of life-support), but in most end-of-life situations

the role of health care providers remains marginal and of a supportive nature. Legalizing MAID will make it more common for health care providers to be confronted with requests for their active involvement in life-ending interventions. As a result, consent and competency assessments become more important as protective tools against premature life-ending practices, and its existing limitations and flaws become more problematic. The protective value of the measures is also weakened when 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 physicians who may become too casual about ending people's lives, or against physicians who become sloppy. All this makes a more careful assessment of the existing challenges of competency and informed consent practices by individual physicians essential. It is also worth pointing out that the limitations and shortcomings of competency and informed consent practices become so much more serious when we are not limiting MAID to end-of-life situations. In that case, errors in assessing competency and failures in identifying factors that may impact on the voluntary nature of the request for MAID will result in the premature death of people who still would have had many years of life.

Physicians recognize that they are not well-trained in assessing competency, which is inherently complex.¹⁰ The science behind competency assessment is indeed still in its infancy.¹¹ In situations where MAID is sought, emotional, physical and contextual factors interact,¹² which makes assessments even more difficult. Mental health issues often 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.¹³

Challenges with obtaining informed consent for MAID overlap with competency assessment concerns.¹⁴ 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.

The Bill's safeguards should in my view 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) of the Bill 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 could 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 practitioner 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.

4. The need for detailed information gathering

To enable proper post-factum review of MAID practices, the Bill or subsequent regulations should indicate more detail about the information that has to be reported. A report should be required 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.

The evidence from Belgium and the Netherlands confirms the importance of data gathering and reveals the limitations of the reporting systems in these countries. First, the evidence suggests that after-the fact reporting systems may provide a false reassurance. It is not because data are being gathered that they are fully reliable (e.g. significant underreporting remains a challenge, particularly in Belgium), and that the data give us sufficient information to make an assessment of the appropriateness of the cases that are reported. Second, the evidence also reveals how important it is that reporting systems provide publicly accessible information in order to create public accountability and enable meaningful public monitoring of the practice and of how the regulatory system functions. This is, for example, not the case in Belgium, where in the context of several controversies even family members of people whose lives were terminated were unable to obtain information about how the physicians had determined that access criteria were met. In some of these cases, family members only learned about the death of their loved ones after the fact, yet they were unable to obtain direct information about why the physicians thought that they satisfied the access criteria. Third, it reveals the importance of having sufficiently detailed information about what the conditions are under which individual physicians provide access to MAID, in order to be able to monitor MAID practices and study the developments of the practice. Even in the Netherlands, where information on specific cases is made publicly available, the information remains limited and often raises questions about how specific problems are dealt with (e.g. disagreements about competency among physicians).¹⁵

It is important to understand, for example, why people request access to MAID. When statistics reveal that most request for MAID involve patients suffering from cancer, that does not tell us how many of these patients were close to death. Many could potentially have had significant periods of quality of life ahead of them. Some have attempted to study this through anonymous surveys, but it would be important to include detailed obligatory data gathering in the regulatory system itself to enable further research on the practices.

Transparency of data reported by those who have a vested interest in presenting that they respected all relevant criteria and procedures can create false reassurance and may lead to

complacency. Prosecution in Belgium and the Netherlands is indeed quasi non-existent, in part because the criteria are so vague that any situation can fit the bill. Moral concerns tend to be brushed aside because ‘legal criteria for euthanasia were respected.’

5. Avoiding (Binding) Advanced Directives for 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 may also already be compromised.¹⁶

People with dementia often maintain a good quality of life for a significant period of time. They undergo personality changes as a result of changes in the brain, which affect their values and their appreciation of life. They are no longer the person they once were. Yet, since they have lost competency, they would not be able to change a request for MAID, prepared at a time of significant stress, when they could not imagine how they would enjoy their future life. Allowing ADs for MAID would put family members and health care providers before a terrifying moral dilemma: respect their family members’ past wishes and terminate their life even if they may still enjoy daily activities, or respect their current interest in remaining alive. In the context of dementia, it is often particularly hard for family members of the patient to cope with the disease and to accept that their loved-one is no longer the person he or she was. As is also often the case with those looking from the outside at the experience of people with catastrophic illness or disabilities, family members may have a tendency to presume loss of meaning and quality of life and have themselves difficulty accepting the (real or perceived) suffering of their loved ones. It makes it problematic to rely on family members or even impose on them the duty to determine when certain AD criteria are met and when precisely the person’s life should be ended. When there is uncertainty about what the person currently experiences, it seems essential to err on the side of life. Much can be done to address the health care and emotional needs of people who have become incompetent without actively ending their lives.

It is also important to recognize that 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 does compromise our societal commitment and Charter-based duty to protect the lives of those with intellectual disabilities and those who are incompetent. It also opens the door to abuse towards those who can no longer consent.

The most liberal regimes, Belgium and the Netherlands, which legalized euthanasia in 2002, are still more restrictive than what the JPC recommends. 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 can refuse to follow them. ADs are only very rarely used for euthanasia practice, reflecting the difficulty for health care providers and family members of acting on the basis of AD.¹⁷ When they have been used, they have sometimes resulted in [serious controversy](#).¹⁸ There is no reason for Canada to create the ethical minefield associated with ADs for MAID.

Concluding Remarks

In this debate over how to legislate MAID, powerful testimonies have been heard from people who requested access to MAID. They join the testimonies of people like Sue Rodriguez, Gloria Taylor, and Dr. Donald Lowe, who have movingly testified in the past about their desire to gain some control over the manner and timing of their death and their desire to see some legislative changes. Since the Government's bill came, we have heard about people who might not have immediate access to MAID because of the requirement of a reasonably foreseeable death, or of family members who are suffering from dementia and who are not eligible for MAID because they were unable to provide consent to the practice. These testimonies reveal the hardship many individuals and family members face as a result of serious health challenges and in the context of end-of-life. They reflect also the unavoidable difficulty of confronting our own suffering and mortality and the suffering and mortality of loved ones. No law will solve all the issues we face at the end of life or when confronted with catastrophic illness, disabling conditions, and other sources of suffering. The legislative process that is now taking place sometimes appears to be seen as a panacea, as if it should provide solutions to all forms of health-related suffering that cannot immediately be addressed in our health care system. This is reflected, for example, in statements such as: "It is incredibly frustrating and disappointing that the government has drafted legislation that's going to exclude potentially thousands and thousands of Canadians who will be suffering from dementia"¹⁹ I really hope that no one is seriously contemplating that all suffering associated with a disease like dementia can be addressed by expanding the criteria of a MAID bill.

The use of powerful emotional narratives about people who we perceive to be suffering and do not have access to MAID often appear to sway people into thinking that MAID legalization will do more than it could and should do. Some of these narratives in fact reveal why many are worried about how some demands for open-ended MAID legislation reflect peculiar views about the value of people's lives when they are suffering from disease, have lost some of their capabilities, or when they are disabled. Legally permitting, for example, MAID on the basis of AD for dementia patients when they are no longer recognizing their loved ones or when declined intellectual capacities prevents them from enjoying literature, as has also been suggested in one media report, does send a societal message about the value of the lives of those with diminished intellectual capacities. I am confident that this does not reflect the values most Canadians adhere to.

We should, therefore, be very cautious in moving ahead with sweeping legal changes in response to these narratives. We should also be cognizant that there are very different narratives and experiences out there in systems that have already introduced open-ended access to PAD. These narratives are not as widely known here, first because many recent reports and documentaries have been published in a different language, and because it is easier to ignore and disconnect from what is happening in another country. But these narratives are also less known because many of the

experiences remain hidden even in the countries in which they occur. They often involve already stigmatized and vulnerable people who end up with death, and are thus not in a position to publicly evoke our sympathy. They often also involve traumatized family members, who may feel very uncomfortable about what happened to their loved ones, and may be reluctant to share their grief in public. And they involve powerful professionals and a regulatory system that may have difficulty admitting that the system does not function as it should. I therefore urge Senators to pay attention to several case reports from Belgium and the Netherlands. Some of the ones that have come to the surface more recently powerfully capture the problems I pointed out above.²⁰ These are the cases we would be confronted with here in the future if we introduce an open-ended system.

We owe it to those who are vulnerable to create a cautious, prudent regime. It will be much more difficult to return to the drawing table if a regime appears too open-ended, than it is to start more cautiously and expand if need be. I truly hope that the Senate will support a legislative framework that is perhaps narrower than some find desirable, but that provides a balance between the rights of some to have access to MAID and the rights of others who are vulnerable to be protected against premature death. Considering the risk associated with having no legislative regime that provides additional protection (which the Supreme Court clearly appeared to find crucial), preventing the timely adoption of legislation is not a responsible option.

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 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 [Memorandum]; and T. Lemmens, “Response to comments made during the Committee Hearing of January 28, 2016” Memorandum for the Joint Parliamentary Committee on Assisted Dying, February 2, 2016.

³ Dianne Pothier, “The parameters of a Charter compliant response to Carter v. Canada (Attorney General), 2015 SCC 5” (2016) *Social Science Research Network*. Online:

http://papers.ssrn.com/sol3/papers.cfm?abstract_id=2753167; and Jacques Fremont, “Some Thoughts Concerning Parliament’s Legislative Leeway in a Post-Carter Era.” (2016) *Social Science Research Network*. Online: http://papers.ssrn.com/sol3/papers.cfm?abstract_id=2760574

⁴ See the discussion in Lemmens, *supra* note 1, in particular at 270-278.

⁵ See *idem*, in particular 287-314; see also 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 Belgian and Dutch editorials and reports.

⁶ See S.Y.H. Kim, R. De Vries, & J.R. Peteet, “Euthanasia and Assisted Suicide of Patients With Psychiatric Disorders in the Netherlands 2011 to 2014.” (2016) 2887 *JAMA Psychiatry* 1–7.

doi:10.1001/jamapsychiatry.2015.2887; L. Thienpont et al, “Euthanasia Requests, Procedures and Outcomes for 100 Belgian Patients Suffering from Psychiatric Disorders: A Retrospective, Descriptive Study” (2015) 5:7 *BMJ Open* 1. Available online: <http://bmjopen.bmj.com/content/5/7/e007454.full>. See the more detailed discussion of these studies in 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.

⁷ 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).

⁸ Vulnerable Person Standard. (n.d.) online: <http://www.vps-npv.ca/>

⁹ D. Baker, G. Sharpe & R. Lauks, “Federal and Provincial Responsibilities to Implement Physician Assisted Suicide,” (2016) 36(3) *Health Law in Canada* 148.

¹⁰ See Charland, Lemmens, Wada, *supra* note 7; and the discussion in Lemmens, [memorandum] *supra* note 2 and references there.

¹¹ Charland, Lemmens, Wada, *supra* note 7.

¹² Canadian Association for Community Living, *Assessing Vulnerability in a System for Assisted Death in Canada* (2016) 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.

¹³ Linda Ganzini et al, “Evaluation of Competence to Consent to Assisted Suicide: Views of Forensic Psychiatrists” (2000) 157 *Am J Psychiatry* 595

¹⁴ T. Lemmens, “Informed Consent” In Y. Joly & B. M. Knoppers (Eds.), *Routledge Handbook of Medical Law and Ethics* (London: Routledge, 2015) 27–51

¹⁵ See the study by Kim, De Vries, Peteet, *supra* note 6.

¹⁶ O. Okonkwo et al. “Medical decision-making capacity in patients with mild cognitive impairment.” (2007) 69(15) *Neurology* 1528-35.

¹⁷ See M.E. de Boer et al., “Advance Directives for Euthanasia in Dementia: How Do They Affect Resident Care in Dutch Nursing Homes? Experiences of Physicians and Relatives” (2011) 59 *J. Am. Geriatr. Soc.* 989; and M. L. Rurup et al., “Physicians’ Experiences with Demented Patients with Advance Euthanasia Directives in the Netherlands” (2005) 53 *J. Am. Geriatr. Soc.* 1138.

¹⁸ Lemmens, *supra* note 5 [Impact Ethics Blog] & links there to Dutch editorials discussing a recent controversy.

¹⁹ Shanaz Gokool quoted in “Families of dementia patients want assisted-dying law reconsidered” CTV News May 2, 2016, online: <http://www.ctvnews.ca/health/health-headlines/families-of-dementia-patients-want-assisted-dying-law-reconsidered-1.2884782>

²⁰ For some of these recent controversies, see Lemmens *supra* note 5 [Impact Ethics Blog] and the links to more detailed discussions of some of these controversies and to translated editorials.