

Wednesday, April 27, 2016

Attention:
STANDING SENATE COMMITTEE ON
LEGAL AND CONSTITUTIONAL AFFAIRS
THE SENATE OF CANADA

RE: Recommended Amendments to Bill C-14

I am honored by the opportunity to share my responses to Bill C-14, for consideration by the Standing Senate Committee on Legal and Constitutional Affairs. By way of background, I am a Distinguished Professor of Psychiatry and the University of Manitoba; Director of the Manitoba Palliative Care Research Unit, CancerCare Manitoba; I hold the only Canada Research Chair in Palliative Care; and perhaps most pertinent to Bill C-14, was the Chair of the External Panel on Options for a Legislative Response to *Carter v Canada*. The following are my recommended amendments to Bill C-14, for the Government's consideration.

Physician assisted suicide versus euthanasia. Bill C-14 makes no distinction between these two forms of Medical Assistance In Dying (MAID)¹. However, international experience reveals they are vastly different in terms of their uptake and lethality. In jurisdictions that offer only physician-assisted suicide, those deaths account for about 0.3% of all deaths i.e. ~3 deaths/1,000 deaths annually. In jurisdictions that offer euthanasia, this form of hastened death accounts for ~3-4% of all deaths i.e. 30-40 deaths/1000 deaths annually.

Extrapolating these figures to Canada and anticipating approximately 260,000 deaths per year, a regime that offers physician assisted suicide exclusively could expect approximately ~800 such deaths annually. On the other hand, a regime dominated by euthanasia could expect approximately 8,000-10,000 such deaths annually. According to experts appearing before the External Panel, this vast difference is largely accounted for by ambivalence. Ambivalence is an important dynamic in considering a hastened death; and while assisted suicide offers the possibility of changing ones mind (~35% of patients in Oregon who receive a prescription do not in fact use it), euthanasia dramatically reduces that possibility once it has been scheduled and expectations are set for a specific time and place.

As such, ***the Government should consider an amendment***, stipulating that MAID will take the form of assisted suicide so long as patients are able to take lethal medication on their own.² Euthanasia would be reserved for instances when patients are no longer able to ingest lethal medication independently. The data is clear; this will ensure that thousands of people each year

¹ MAID is a very unfortunate acronym; which is already being referred to disparagingly as *MAID service*, images of 'being swept under the rug'; and like other acronyms such as MAD (Bill 52), is easily confused with palliative care, which assists patients during the course of their dying. Physician Hastened Death (PHD) is far preferable terminology.

² Patients who are anxious about unintended consequences that might occur while taking a lethal overdose could request the presence of a healthcare provider (physician or nurse) to be present while this takes place. This would have the added benefit of giving the dying person an opportunity to withdraw their request and reconfirm consent (as per 241.2(3)h, Bill C-14).

who are ambivalent about an assisted death will not feel pressured by circumstances to proceed before they are ready to die.³

Palliative Care Consultation: Since eligibility criteria in Bill C-14 stipulates the patient's natural death is reasonably foreseeable, along with being in an advanced stage of irreversible decline in capabilities, the legislation should include a defined role for palliative care. As such, ***the Government should consider an amendment***, requiring a mandatory palliative consultation for all patients requesting a physician-hastened death (PHD). This would be over and above, and distinct from, the duties of the two physicians described in the Bill.

The palliative care consultant would NOT be in a decision-making role regarding whether the patient's request for PHD should proceed. Rather, their role would be in complete alignment with responding to a consultation, framed so that *their opinion is being sought regarding a patient who wishes to pursue a hastened death; and to identify whatever sources of suffering might be moving the patient towards a wish to die, along with any and all suggestions for therapeutic responses that could mitigate the patients suffering.* On the basis of these consultations:

1) Palliative care clinicians would be able to identify all physical, psychosocial, existential and spiritual sources of distress underlying a request to die. *A wish to die can derive from many sources, be they physical, psychosocial, existential and spiritual. Palliative care, more so than any other area of medicine, is committed to a holistic approach to understanding patient experience. Given that the draft legislation stipulates that patients must be anticipating a death that is reasonably foreseeable, palliative care clinicians are ideally qualified to determine if there are alternative approaches might alleviate the suffering underlying a wish to die.*

2) Palliative care clinicians would be able to ensure patients are fully informed of all options that could be initiated on their behalf. *In order for patients requesting a hastened death to give fully informed consent, they MUST be aware of all of their options, and the potential benefits and risks associated with those options, before proceeding with a death hastening intervention.*

3) Palliative care clinicians would be able to enter this anonymized data into a national data base, in order to objectively and prospectively evaluate the benefits and/or problems associated with this new way for Canadians to relieve themselves of suffering. *Bill C-14 stipulates that the Government of Canada is committed to a thorough review in five years. Unless detailed, objective and comprehensive data is collected prospectively, there will be very little upon which Parliament will be able to base its decisions regarding whether C-14 should be narrowed, broadened or rescinded.*

Judicial Oversight: ***The Government should consider an amendment*** requiring judicial oversight and approval for all PHD requests before any death hastening measures are provided. While seemingly counterintuitive, this could increase accessibility for patients seeking PHD under the current criteria, while providing a solid foundation for Parliament's five-year review of the

³ Quebec chose euthanasia for political, not medical or moral, reasons i.e. Bill 52 was designed to fall within the realm of healthcare; this not violating Federal Criminal Code prohibitions in section 241(b). With the advent of Bill C-14, Quebec will likely introduce an amendment allowing for assisted suicide. With the suggested amendment above, euthanasia would be offered only in instances when assisted suicide is no longer feasible.

law, including any considerations for expanded eligibility criteria. Judicial oversight would, 1) remove decision making authority from healthcare professionals, confining their role to the evaluation and treatment of patient suffering; and for those who choose to include PHD within their scope of practice, administering death-hastening measures. This would significantly increase the number of healthcare professionals prepared to engage with patients requesting PHD; hence increasing access; 2) insulate healthcare institutions and professions from any perceived or real hazards associated with PHD (i.e. healthcare institutions would remain *safe spaces*; and allaying concerns regarding the integrity of medicine); 3) yield a precedent-based, consistent and clearly articulated set of benchmarks as to when the proposed eligibility threshold criteria have been met.

Why the safeguards outlined in Bill C-14 are critically important and must be maintained.

Limit availability to patients for whom death is ‘reasonably foreseeable’: Oregon’s Death with Dignity Act allows for physician-assisted suicide only for patients with less than 6 months to live. After 17 years of experience, the External Panel heard that even its strongest proponents object to expanding eligibility to patients with 1 year to live. Quebec also deliberated for several years in arriving at Bill 52. After extensive consultation and public engagement, Quebec landed on criteria that stipulated patients must be at the end of life, suffering from an incurable serious illness and in an advanced state of irreversible decline in capability.

Do not permit access to physician-hastened death on the basis of psychiatric illness alone. While in Oregon, the External Panel met with Dr. Linda Ganzini, an internationally renowned psychiatrist, known for her expertise regarding the interface between psychiatry and a wish to die. She is one of the most published and most cited authors on this particular subject. When asked her advice on how patients with psychiatric disorders should be approached in view of the *Carter* decision, aside from feeling very worried about this prospect, she had no insights to offer whatsoever. She acknowledged that many psychiatric patients have ‘grievous and irremediable’ conditions; that said, she only felt comfortable considering PHD for psychiatric patients within the context of a concurrent condition with a prognosis of less than 6-months.

Last month, the journal JAMA Psychiatry published a critically important paper by Dr. Scott Kim, entitled *Euthanasia and Assisted Suicide of Patients With Psychiatric Disorders in the Netherlands 2011 to 2014*. This article reviewed psychiatric euthanasia and assisted suicide case summaries made available online by the Dutch regional euthanasia review committees as of June 2015. The study included 66 cases, which were described to characterize patients receiving euthanasia or assisted suicide for psychiatric conditions and how the practice is regulated in the Netherlands. The majority of these patients were women; with a combination of issues including personality disorders, depression, psychosis, post-traumatic stress disorder, anxiety, neurocognitive and eating disorders, prolonged grief and autism; with descriptions of being lonely and socially isolated. 27% received the procedure from physicians new to them (most from a mobile euthanasia clinic); 11% had no independent psychiatric input and 24% of cases involved disagreement among consultants. Nevertheless, the review committee found that only one case failed to meet legal due care criteria. This study provides some of the clearest evidence about the problems associated with PHD for psychiatric patients.

Not including Mature Minors: The suffering of children is no less important than the suffering

adults. But before Canada pursues that option, we should be asking those caring for children with life threatening and life limiting conditions what role PHD might play. Input is needed from pediatric specialists (e.g. oncology, palliative care), child psychologists, development specialists or family members of critically ill children themselves. Those voices have not yet been heard.

Excluding Advance Directive Provisions: Jurisdictions that have attempted to include an advance directive provision for dementia have found it completely untenable.^{4 5} Physicians almost always find it 'inconceivable' to comply with these requests, given the patient with dementia is a psychologically different person than the one who completed the advance directive. Physicians are not able to determine the patient's current wishes, feel the patient is not suffering or no longer wants to die. While family members support forgoing life-prolonging treatment, over 70% asked the euthanasia directive not be followed because of uncertainty about the person's current wishes, not being ready for the person to die or not sensing the person is suffering.

I look forward to meeting with your committee and the opportunity to discuss these issues further.

Full signature (including honorifics; and Former Chair, External Panel on Options for a Legislative Response to Carter v Canada)

⁴ ML Rurup et al *Physicians' Experiences with Demented Patients with Advance Euthanasia Directives in the Netherlands*, Journal of the American Geriatric Society (53:1138-1144, 2005).

⁵ de Boer ME et al. Advance Directives for Euthanasia in Dementia: How Do They Affect Resident Care in Dutch Nursing Homes? Experiences of Physicians and Relatives JAGS 59:989-996, 2011.