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Canadian Psychological Association Submission to the External Panel on Options for a Legislative Response to Carter v. Canada

Submission to the External Panel on Legislative
Options to Carter v. Canada
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TERMS AND DEFINITIONS USED IN THIS PAPER:

For the purposes of this paper, we have adopted terms and definitions proposed by the Canadian Medical Association (CMA) in 2014 https://www.cma.ca/Assets/assets-library/document/en/advocacy/end-of-life-care-report-e.pdf (page 5) as follows:

"**Euthanasia:** Knowingly and intentionally performs an act, with or without consent, that is explicitly intended to end another person's life. In the CMA definition, euthanasia includes the following elements: the subject has an incurable illness, the agent knows about the person's condition and commits the act with the primary intention of ending the life of that person, and the act is undertaken with empathy and compassion and without personal gain.

Medical aid in dying: A situation in which a physician intentionally participates in the death of a patient by directly administering a substance themselves or by providing the means whereby a patient can self-administer the substance that causes his or her death.

Physician-assisted dying: The process in which a physician knowingly and intentionally provides a person with the knowledge and/or means required to end his or her life, including counselling about lethal doses of drugs and prescribing such lethal doses or supplying the drugs. This is sometimes also referred to as physician-assisted suicide."

INTRODUCTION

With the Carter vs. Canada decision striking down the legal prohibition against physician –assisted dying, the Supreme Court has initiated a significant change in health care, particularly regarding the care of the terminally ill. Psychologists will be affected by these changes in several ways. As psychotherapists, many of us are involved in counselling individuals who have serious medical problems, who may contemplate asking for a hastened death. As consultants, we are often called on to conduct psychodiagnostic assessments with individuals who have mental health problems that might influence their decision making, including decisions around end-of-life choices. Neuropsychologists, in particular, are consulted to assess the cognitive competence of patients whose capacity may be diminished by neurological impairment. Psychologists also work with families that are experiencing stress or conflict when a loved one is reaching the end of life. As members of interdisciplinary teams, psychologists support the physicians, nurses, and pharmacists who may be involved directly in the provision of euthanasia or physician-assisted dying, some of whom may experience moral discomfort in doing so. In short, we feel that the Carter decision impacts on the practice of Canadian psychologists (Galbraith & Dobson, 2000; Johnson, Cramer, Conroy, & Gardner, 2014). Further, the study and practice of psychology has important contributions to make to how Canada responds to the Carter decision. We appreciate the opportunity to present to the panel.

Psychologists are important contributors to health research in Canada, and as a profession we strive to be evidence-based. Therefore, we have attempted to ground our presentation in research data, and particularly in Canadian data where they are available. One important source of information in this context is the Canadian National Palliative Care Survey (NPCS), which was a national multi-centre study of the quality of life of patients who were receiving palliative care for cancer. The co-principal investigators of the NPCS were Keith Wilson, Ph.D., a psychologist and long-time member of the Canadian Psychological Association, and Harvey Max Chochinov, M.D., who is chair of the External Panel. Among the relevant issues that were examined empirically in the NPCS were the determinants of the experience of suffering, the prevalence and impact of depression and anxiety disorders, the desire for death, and importantly, patients' attitudes toward the practices of euthanasia and physician-assisted dying. The latter term is sometimes referred to as "physician-assisted suicide", but this document will adopt the CMA use of terms as defined in the preface to this paper. The issues examined empirically in the NPCS, as detailed above, are all central to the current panel deliberations.

Our presentation will begin with a review of important points about the distinctions between euthanasia and physician-assisted dying. It will then address what is commonly known as "the slippery slope", which we consider to be a genuine concern, albeit with ramifications that can be anticipated and planned for in proposals for legislation. Finally, we will conclude with special points of consideration regarding the implementation and monitoring of Canadian practice of euthanasia and/or assisted suicide as it evolves over time.

EUTHANASIA VS. PHYSICIAN-ASSISTED DYING

The main distinction between euthanasia and assisted dying is that euthanasia is an act of commission undertaken by one individual to directly end the life of another. In practice, this usually involves the administration of a lethal injection. Assisted dying involves the provision of advice and/or a means by which an individual can take his/her own life and, as mentioned in the preface to this paper, is also called physician-assisted suicide. This typically involves the prescription of medications which, if taken as directed, will result in death. The patient is responsible for ingesting the medications, which may be done at some point in the future, perhaps with no medical personnel in attendance. For some patients, there may be a comfort in knowing that the medications are available in the event their health condition becomes intolerable, even if they never actually take them in the end (Loggers, Starks, Shannon-Dudley, Back, Appelbaum, & Stewart, 2013).

In the current debate, the terms "euthanasia" and "assisted suicide" have sometimes been considered as emotionally laden labels that carry a burden of stigma. Moreover, they may not adequately distinguish between what are intended to be compassionate acts of mercy for the terminally ill, from acts of sheer criminality. For these reasons, euthanasia and assisted dying (as mentioned, often synonymously called assisted suicide) in medical circumstances have been characterized as actions that fall within the purview of "medical aid in dying."

Jurisdictions that permit medical aid in dying each have specific requirements that govern local practice, but a basic broad distinction is that both euthanasia and physician-assisted dying are permissible in some European nations, whereas only physician-assisted dying is permitted in those American states that have endorsed legalization. Bill 52 of the Québec National Assembly more closely resembles the European model in this regard. In the present discussion of the distinctions between euthanasia and assisted dying, we will focus on three main issues: (1) differences in the rates of medical aid in dying in the European vs. United States experience; (2) the attitudes of terminally ill Canadians toward the two practices, as reported in the NPCS, and; (3) precedent with respect to the sometimes unclear categorization of a practice as either euthanasia or assisted dying.

1. The Netherlands vs. Oregon

In this section we will continue to use terms as defined in the preface to this paper. We note, however, that in The Netherlands, the term physician-assisted suicide is used instead of physician-assisted dying. The rates with which euthanasia and physician-assisted dying are conducted in the Netherlands and Belgium are now well-known, as are the rates of physician-assisted dying in Oregon. It is important to note that these rates are very different in Europe vs. the United States. Although cultural variation, both among patients and physicians, may account for some of the difference, it is likely that legal and procedural factors are also involved. The recommendation of the panel that Canadian legislation follow either the European model (permitting both euthanasia and assisted dying), or the American model (permitting only assisted dying), is one of the most important pieces of advice that the panel can provide.

Recent data from the Netherlands show that 2.8% of all deaths now occur by euthanasia, and another 0.1% are due to assisted dying (Onwuteaka-Philipsen, Brinkman-Stoppelenburg, Penning, de Jong-Krul, van Delden, & van der Heide, 2012). Thus, there are 28 euthanasia deaths for each assisted death in the Netherlands. In Flanders, Belgium, the rate of euthanasia is higher, accounting for 4.6% of all deaths. Assisted dying is not addressed specifically in the Belgian legislation, but it reportedly accounts for another 0.05% of deaths (Chambaere, Stichele, Mortier, Cohen, & Deliens, 2015).

Since individuals who die suddenly or unexpectedly are not candidates for medical aid in dying, it can be concluded that the rates of hastened death among traditional palliative care populations are, in fact, substantially higher than the rate reported for all deaths combined. Indeed, in the Netherlands and Belgium, about 1 in 10 patients with advanced cancer now chooses to die by euthanasia (Dierickx, Deliens, Cohen, & Chambaere, 2015), which rises to 1 in 7 among patients with cancer who die at home (Ruijs, Kerkhof, van der Wal, Onwuteaka-Philipsen, 2013).

In Oregon, the situation is quite different. Only about 0.3% of all deaths in Oregon take place with assisted dying. The rates have been increasing steadily since the Death with Dignity Act was enacted in 1997, and may not yet have plateaued (Oregon Public Health Division, 2015). Still, even after 18 years, the rates of hastened death in Oregon remain 9-15 times lower than in the Netherlands and Belgium.

One unequivocal conclusion based on the European data is that when patients have the choice of either euthanasia or physician-assisted dying , they are much more likely to select euthanasia. Although the fact of this imbalance is clear, the reasons for it are not. Perhaps with euthanasia, the end-of-life decision can be put off until later in the trajectory of the disease, closer to the point of natural death. Perhaps having a physician willing to take responsibility for carrying through the technical aspects of the procedure makes it easier for an exhausted patient to pursue a hastened death. In the Netherlands, physicians report that far-advanced medical illness is the primary reason for providing euthanasia rather than assisted dying (Onwuteaka-Philipsen, Mullaer, van der Wal, van Eijk, & Ribbe, 1997). It is estimated that in over 85% of cases, patients' lives are shortened by less than a week (Onwuteaka-Philipsen et al., 2012).

There are other differences in the requirements of hastened death legislation across relevant jurisdictions that could affect the frequency of their use. For example, such protocol requirements as written requests, waiting periods, second opinions, mental health or cognitive capacity assessments, would impact on how quickly a request for medical aid in dying could be implemented. It would be possible, in fact, to recommend a set of legal requirements that was so stringent that only the most determined individuals would have the energy to pursue it, and then only if they initiated the process while they were still medically well enough to participate in a rigorous assessment.

2. Attitudes toward euthanasia and assisted dying in the NPCS:

The NPCS is a unique source of Canadian data because it was a national study conducted across 8 centres, involved patients who were receiving palliative care for cancer, had a relatively large sample by palliative care standards (n = 379), and asked directly about attitudes toward euthanasia and physician-assisted dying (Wilson, Chochinov, McPherson, Graham, et al., 2007). We found that the majority of participants (62.8%) believed that one form or other of medical aid in dying should be legalized. Many participants (39.8%) could envision future circumstances in which they might make a personal request for medical aid in dying, if their worst fears about their illness came true. However, only 22 individuals (5.8%), would have made such a request in their current circumstances at the time of the interview. Of these, 12 individuals would have opted for euthanasia if legally available, 4 would have opted for physician-assisted dying, and 6 were undecided. Although the sample size was small, the statistically significant trend was apparent for patients to report a stronger personal interest in receiving euthanasia over physician-assisted dying.

In the NPCS interview protocol, the distinction between euthanasia and physician-assisted dying was explained carefully to participants, so they were well aware of the differences. They were then asked a general question, "In your opinion, is there any important difference between euthanasia – where the doctor gives a lethal injection – and physician-assisted suicide[i], where the doctor gives the person drugs to commit suicide later on? Is one more acceptable than the other, as far as you are concerned?" Participants provided open-ended, narrative, reasons for their opinions.

The largest group of participants, 33.5%, found the two procedures to be equally acceptable. Another 25.6% found them to be equally unacceptable, and 10% were uncertain about any differences. Interestingly, 21.6% believed euthanasia to be the more acceptable practice, whereas 9.2% believed that physician-assisted dying is more acceptable.

Patients who found euthanasia to be preferable mentioned the technical dimension involved in medication administration, the fact that dying by suicide is actually a difficult thing to bring oneself to do, and a concern with mistakes being made in a self-initiated action. Those who considered physician-assisted dying more acceptable stressed the importance of patient autonomy, reducing the burden on physicians, concerns about the possibility of abuse with euthanasia, and the moral principle that killing is wrong in any form.

In summary, in the NPCS study of terminally ill Canadians receiving palliative care for cancer, there was stronger endorsement for euthanasia than physician-assisted death. For the most part, however, respondents who were in favour of any form of legalized medical aid in dying were supportive of both.

As in the Netherlands, patients who would personally have requested medical aid in dying were more likely to have chosen euthanasia if both methods had been legally available.

3. **Blurring the distinction between euthanasia and assisted dying:**
   Although the distinction between the practices of euthanasia and assisted dying seems clear, it is possible to blur the boundary between them. For example, for a brief period in the 1990s, the Australian Northern Territory allowed physicians to assist terminally ill patients to end their lives. Dr. P. Nitschke developed a “deliverance machine” that required medical support to insert an intravenous line (Street & Kissane, 1999-2000). Once attached to the machine, however, patients used a self-activated mechanism to initiate the administration of the lethal injection. Does the extraordinary degree of external support qualify as euthanasia, or does the patient’s self-initiated button press qualify as assisted dying?

   In Belgium, assisted dying is encompassed under the Euthanasia Law regardless whether the medications are administered intravenously or orally.

SLIPPERY SLOPE

Public opinion may be largely in favour of a permissive approach to the provision of medical aid in dying. However, the general public may lack a full appreciation of the complexity of the circumstances that lead to requests for euthanasia or assisted dying. There seems to be broad public support for providing access to these interventions in scenarios involving terminally ill patients in unremitting physical pain (Emanuel, Fairclough, Daniels, & Claridge, 1996). There is substantially less endorsement for scenarios that involve psychological, social, or existential sources of distress.

A common concern around the provision of medical aid in dying is whether there is a “slippery slope” that leads to progressively less vigilance over the circumstances in which it is applied (Lerner & Caplan, 2015). From this perspective, the starting point for the debate is around the situation of (1) mentally competent (2) terminally ill (3) adults (4) who have clearly identifiable sources of unbearable physical pain and suffering, (5) who are psychologically stable and making a rational request that is (6) consistent over time. The slippery slope concern arises because of the indistinct boundary between that circumstance and other compelling scenarios of human suffering. Debate around these issues has been ongoing in other jurisdictions that have introduced legalization, and they can be anticipated in Canada. Canadian legislation around the following issues should be clear with respect to limits, and well justified on the basis of bioethical principle.

1. **Cognitive competence:**
   Although it would seem to be self-evident that life terminating acts should only be undertaken by those who are competent to request them, there are special considerations that are worthy of specific mention in any legislation proposed around hastening death.

   - *Semi-conscious patients*. Some individuals may, quite reasonably, leave their end of life decisions until late in the course of a terminal illness. It is possible that they may have been competent at the time of an initial request, but lapse into semi-consciousness by the time preparations are in place for completing the procedure. There should be clarity as to whether euthanasia can proceed under these circumstances.

   - *Advance directives.* If an individual has prepared a living will that outlines an advance directive for euthanasia in the event that he/she loses consciousness, will this be regarded as a legitimate request? A special case of advance directive, which is likely to be common, is when the patient has had a prior discussion about end-of-life wishes with the treating team. Will it be permissible for these advance instructions to be granted, even though the patient may not be competent, or even visibly distressed, at the time the life termination is initiated (Menzel & Steinbock, 2013)? In the Netherlands and Belgium, this practice is termed “hastened death without the explicit request of the patient”, and accounts for a further 0.2-1.7% of all deaths (Chambaere et al., 2015; Onwuteaka-Philipsen et al., 2012).

   - *Proxy directives.* There will inevitably be cases in which the patient is not competent to make a request, but the family, perhaps with power of attorney over health decisions, makes the request on the patient’s behalf. Will this be considered an appropriate circumstance to hasten death?

2. **Terminal vs. non-terminal illness or disability:**
   Different jurisdictions have implemented different policies with regard to medical aid in dying for individuals who have illnesses or disabilities that affect quality of life, but are not imminently life-threatening. Some of these conditions, such as cerebral palsy, stroke or spinal cord injury, may result in permanent disability that does not lead to death. Others, such as Parkinson’s disease or chronic obstructive pulmonary disease (COPD), may or may not be an eventual cause of death after a progressive process that unfolds over years. A third category comprises the frail elderly, who may have multiple health problems, chronic pain, and limited social networks. The provision of euthanasia to such individuals who have become “tired of life” does take place in the Netherlands (Snijdewind et al., 2015). Finally, in the European context, the psychological suffering of psychiatric patients is, in some jurisdictions, considered acceptable as the basis for providing medical aid in dying (Thienpont, Verhofstadt, van Loon, Distelmans, Audenaert, & de Deyn, 2015).

   Canadian legislation should be clear as to the circumstances in which these individuals may or may not have access to life-terminating practices. The bioethical question that must be addressed is whether the issue of accessibility to medical aid in dying will hinge on the prognosis that life is limited, perhaps by a prescribed amount of time, or whether the individual's report of a diminished quality of life will suffice, regardless of prognosis.

3. **Adults vs. adolescents and children:**
   If the rationale underlying the provision of medical aid in dying is to act with compassion to relieve the suffering of those at the end of life, is the suffering of terminally ill children any less poignant than that of terminally ill adults? The issue of age of consent has its own unique slippery slope. A minimum age of 18 years, as required for voting in Federal elections, could be seen as appropriate. However, many young people are capable of making well-informed health decisions before this age, and the age of consent for health decisions in most Canadian provinces is below this. If young people under 18 years become terminally ill, should they be denied medical aid in dying? In the Netherlands, euthanasia is available to children as young as 12 years, with parental assent. In Belgium, there is no fixed lower age limit, but a recognition that individual circumstances may call for individual decisions. Again Canadian guidelines should be clear with respect to the age of consent. Legislation might also consider the legitimacy of proxy requests by parents of children who cannot initiate them on their own.

4. **Unbearable pain and suffering:**
   Public opinion polls indicate that for the general public, the debate around euthanasia and assisted dying is largely centered on the relief of unbearable physical suffering, especially because of pain. In reality, the suffering of patients with terminal illness is multidimensional (Wilson, Chochinov, McPherson, LeMay, Allard, Chary, et al., 2007). In the NPCS, physical problems did emerge as the single most important predictors of patients' reports of global suffering, but psychological, existential and social sources of distress were also common and relevant. There are four psychological considerations that are particularly noteworthy in this regard.

   - *Unbearable.* In the Netherlands, the concept of suffering that is "unbearable" is a necessary criterion for medical aid in dying, but in practice it can be a difficult one to pin down (Dees, Vernooij-Dassen, Dekkers, & van Weel, 2010). What is bearable for one person may not be bearable to another. Some visibly obvious sources of physical suffering, such as open wounds, may in fact be bearable, whereas less obvious psychological concerns, such as extreme death anxiety, may be overwhelming. Some research has found that, given a long list of symptoms and problems, almost all patients with advanced cancer report at least one that is very difficult to tolerate (Ruijs, van der Wal, Kerkhof, & Onwuteaka-Philipsen, 2014). Legislation should be informed by a concern that whether a problem is "unbearable" or not is a highly subjective judgement by the patient, and difficult to relate to an external criterion. The judgements of observers, including family members and the treating team, may be equally subjective (van Tol, Rietjens, & van der Heide, 2012).

   - *Suffering.* Surprisingly, however, even in the presence of apparently difficult symptoms, many patients are disinclined to use the language of "suffering" to describe their experience. In the NPCS, about half of the participants reported that they were suffering in a global sense, whereas the others did not (Wilson, Chochinov, McPherson, LeMay, et al., 2007). Although the rates of suffering may increase dramatically as the disease process advances to the final hours of life, by and large most people seem to cope reasonably well for quite a long time.

In a qualitative study conducted among patients with cancer in Toronto, Nissim, Gagliese and Rodin (2009) identified three pathways to the desire for death. One pathway reflected a hypothetical interest in a hastened death as a potential means of maintaining control should the illness eventually become intolerable. These individuals are not necessarily suffering in the moment, but they would like to be prepared to escape possible suffering in the future. A second pathway was characterized by high levels of distress, which Nissim et al. identified as an "expression of despair". It is likely that these highly distressed individuals are indeed suffering. The third pathway is more characteristic of patients who recognize that they have reached the ends of their lives, and they are doing so with a degree of acceptance. Nissim et al. identified their desire for hastened death is a manifestation of "letting go". Their concern is not about the relief of immediate suffering, so much as with achieving a "good death" – the original Greek meaning of euthanasia.

The point is that not all individuals who desire a hastened are suffering at the time they make the requests. Some are acting pre-emptively to avoid the future experience of suffering, and some are opting to die at a time and manner of their choosing, despite good palliative care and well-managed symptoms. The panel should consider whether each of these distinct pathways is an acceptable basis for providing medical aid in dying, regardless of the immediate level of suffering.

- *Self-perceived burden to others.* A consistent reason that patients report for desiring euthanasia or assisted dying is that they feel they have become burdensome to their loved ones (McPherson, Wilson, & Murray, 2007). Some patients see the stress being endured by their family members and believe that they would be better off if the patient was already dead. The importance of this sense of self-perceived burden is underappreciated as a motivation for hastened-death requests. Self-perceived burden is an altruistic concern for the welfare of others, and is a deeply human and noble motive for self-sacrifice. In the medically ill, it is also a powerful predictor of suicidal ideation generally (Wilson, Kowal, Henderson, & McWilliams, 2013). Should the sense of self-perceived burden, in the context of otherwise good symptom control, be acceptable as the basis for providing euthanasia?

- *Loss of dignity.* When physicians in the Netherlands, Oregon or Washington State are asked about the reasons that motivate their patients to request euthanasia or assisted dying, loss of dignity stands out as a reason that is mentioned frequently (Ganzini, Goy, & Dobscha, 2009; Loggers et al. 2013; van der Maas, van Delden, Pijenborg, & Looman, 1991). Indeed, the term "death with dignity" has become a rallying cry for social action around medical aid in dying. Oregon, for example, has framed its assisted dying legislation as a "Death with Dignity Act," and the Seattle Cancer Care Alliance refers to its assisted dying protocol as a "death with dignity program" (Loggers et al., 2013). At its core, loss of dignity is an existential source of suffering rather than a physical one. Moreover there is evidence in one population -- patients with severe COPD – that those with the most significant dignity-related concerns can actually have their dignity restored with treatment (Solomon, Wilson, Henderson, Kowal, & McKim, submitted). Like most psychological and existential concerns, the loss of dignity may not necessarily be a permanent and irreversible state. Again, the importance of existential distress as a source of suffering is an area that should be considered in proposals for legislation.

5. **Rational decision:**
When laws are not explicit about restricting medical aid in dying to individuals with physical or terminal illness, the debate is likely to move to a discussion of the possibility of applying euthanasia or assisted dying to people whose health problems are primarily psychological. Requests for medical aid in dying that are motivated by psychological suffering are considered legally valid in the Netherlands, Belgium, and Luxembourg. Although the practices of euthanasia and assisted dying are uncommon in these circumstances, they do occur (Snijdewind et al., 2015; Thienpont, Verhofstadt, van Loon, Distelmans, Audenaert, & de Deyn, 2015). In a review of 100 Belgian cases of euthanasia requests made by psychiatric patients (48 of which were accepted), the most frequent diagnoses were depressive and personality disorders, although there was a broad spectrum of specific problems and most patients had more than one disorder (Thienpont et al., 2015). In all cases, the patients were considered to be legally competent, experiencing psychological suffering that was chronic, constant, and unbearable, and without prospect of improvement.

In the Carter vs. Canada decision, the Supreme Court ruled that medical aid in dying should not be prohibited if an individual "has a grievous and irremediable medical condition (including an illness, disease or disability) that causes enduring suffering that is intolerable to the individual in the circumstances of his or her condition." This could be interpreted broadly to encompass the suffering of those with persistent mental disorders. If the existence of a terminal illness is not a requirement for medical aid in dying, then Canada's laws should be clear with respect to whether euthanasia or assisted dying will be available to individuals with any chronic health problem (including mental disorders), or to those who have refused treatment. The concerns with mental disorders are similar to any other chronic illnesses or disabilities that are not life-threatening but diminish quality of life. In fact, it may prove difficult to justify permitting medical aid in dying to one condition or disorder but not the other. It will be important to clarify whether any medical condition will be considered "grievous and irremediable" or only certain ones.

A special case is that of medically ill individuals, including the terminally ill, who have a co-morbid mental health problem. For example, it has been estimated that perhaps 25% of patients with advanced cancer have a clinically significant problem with depression (Wilson, Lander, & Chochinov, 2009). Moreover, a recent review concluded that among patients who made explicit requests for euthanasia or assisted dying in either the Netherlands or Oregon, 8-47% have high levels of depression (Levene & Parker, 2011). Despite this, very few patients who seek medical aid in dying receive referrals for formal psychiatric or psychological evaluation (Oregon Public Health Division).

It is also clear that the global experience of suffering, including suffering due to physical symptoms, is much more pervasive among terminally ill patients who are depressed than among those who are not depressed (Wilson, Chochinov, Graham, et al., 2007). In the Netherlands, Dees et al. (2011) have reported that only patients with a comorbid diagnosis of a mental disorder suffer unbearably all the time. Hence, it is likely to be a common scenario for depressed terminally ill patients to make requests for assistance in ending their lives. To prepare for this, legislation should be informed by certain clinical realities.

- *Depression and competence.* A mere diagnosis of a depressive disorder does not necessarily mean that someone is incompetent to make critical health decisions. Especially severe depression, however, may result in negative attitudinal biases that distort rational decision making around medical aid in dying (Blank, Robison, Prigerson, & Schwartz, 2001).

- *Diagnosing depression.* The assessment of depression can be difficult, however, in individuals who are medically symptomatic, have reduced nutritional intake, and limitations in mobility. This can be a particular issue when there is a motivation to conceal symptoms, as might sometimes happen with people who believe that a diagnosis of depression may impede their access to medical aid in dying (Street & Kissane, 1999-2000).

- *The depression paradox.* There is a "depression paradox" with respect to euthanasia and physician-assisted dying. Jurisdictions that permit these practices usually justify them as a way of providing relief from suffering. The research is clear, however, that the experience of suffering is much more frequent and severe among terminally ill individuals with comorbid psychological disorders (Wilson, Chochinov, Graham, et al., 2007); yet in the Netherlands these patients are less likely to have their requests granted (Haverkate, Onwuteaka-Philipsen, & van Der, 2000; Jansen-van der Weide, Onwuteaka-Philipsen, & Van der Wal, 2005). On the one hand, it seems to defeat the purpose of medical aid in dying if the practice is withheld from those who suffer most egregiously simply because they are depressed at the end of life. On the other hand, depression is usually considered to be a treatable disorder, and is an important focus of palliative care (Wilson et al., 2009). Admittedly, treatment takes time, and time is a limited commodity for patients near the end of life. Nevertheless, the panel should consider whether the assessment of depression should be a legal requirement, perhaps involving consultation with mental health professionals qualified to make a diagnosis and render an opinion as to whether the depression may be treatable.

6. **Consistent over time:**
Canadian studies have shown that a transient desire to die is relatively common among patients receiving palliative care for cancer (Chochinov, Wilson, Enns, Mowchun, Lander, Levitt, et al, 1995; Wilson, Dalgleish, Chochinov, Chary, Gagnon, Macmillan, et al., in press). In the Netherlands, patients who make requests for euthanasia sometimes rescind them (Snijdewind et al., 2015). In the NPCS, 9.5% of participants reported that they would have requested medical aid in dying at a previous point in their illness, but that they had changed their minds. Most commonly, their reasons included circumstances of uncontrolled pain and physical symptoms. When these problems were treated appropriately, however, the wish to die subsided.

Overall, then, it is clear that the desire for death can sometimes be inherently transient, or occasionally provoked by acute medical problems or social crises. These may often be treatable, or diminish over time. The legislation should be informed by an appreciation of the need for thorough palliative care assessment and intervention prior to initiating a death-hastening action.

In recognition of the potential temporal instability of requests for medical aid in dying, some jurisdictions require that the patient's request be repeated after a specified period of time (e.g., 15 days in the case of Oregon). This allows for reflection as to the stability of the request and the patient's conviction in it. Clearly, however, this requirement imposes an impassable roadblock for someone who has less than two weeks to live.

SUMMARY AND RECOMMENDATIONS

In this presentation, we have reviewed the empirical research around several of the key policy issues that arise in the wake of the Carter vs. Canada decision. We have focused, in particular, on those that are most relevant to psychologists, including euthanasia vs. assisted dying, terminal vs. non-terminal illness, capacity and consent. Medical aid in dying is a divisive issue and there is unlikely to be consensus on any specific policy recommendation, even within the membership of the Canadian Psychological Association.

In the spirit of informing and participating in the debate, however, there are certain key points that we would like to emphasize as the panel moves forward with recommendations for Canadian legislation.

- *"Egregious and irremediable medical condition"* The Supreme Court reference in the Carter vs. Canada decision can be interpreted broadly to encompass many types of medical conditions, disabilities, and mental disorders. Bill 52 of the Québec National Assembly is more specific regarding applicability to end-of-life care. The panel recommendations should be very clear about how broadly this provision will be applied in national legislation.

- *Voluntariness.* Recommendations should be sensitive to the possibility that patients may sometimes feel subtle social pressures to pursue medical aid in dying. Panel recommendations should consider whether the initial request must come spontaneously from the patient, or whether it can be introduced as an option by the treating team. Patients should always have the ability to rescind a request at any point.

- *Assessment.* The provision of medical aid in dying should only occur after thorough assessment of potentially treatable sources of suffering. This would include appropriate medical and palliative care intervention. However, the importance of psychological factors in motivating requests for medical aid in dying should not be underestimated. These factors include diagnosable mental disorders, but also broader psychological, social, and existential concerns among those with medical illness. These factors should be considered central to assessment

- *Second opinion.* Most jurisdictions have found it prudent to include a requirement for second, and even third, opinions before proceeding with medical aid in dying. In cases where psychological considerations may be relevant, interdisciplinary consultation would be appropriate.

- *Opting out.* Some physicians are morally opposed to participating in medical aid in dying. We would support their right to opt out. We would also support the right of nurses, pharmacists, social workers, psychologists, and others to refuse to participate in these actions in their workplaces, if these practices contravene their personal values. This refusal should be permissible without penalty in the place of work.

- *Diversity.* Attitudes toward medical aid in dying vary across ethnic communities and religious groups. Proposals for implementation should be informed by an appreciation of cultural diversity in end-of-life practices.

- *Resources.* Canada has many rural and remote communities that are underserved with respect to health care. Even in urban areas, access to timely care can be a challenge. There may concerns that medical aid in dying is inappropriate when palliative care resources, or other specialized services, are inadequate. Proposals should recognize that medical aid in dying is not intended to supplant palliative care.

There may also be communities where medical aid in dying cannot be implemented because of lack of personnel who are trained or willing to provide it. It can be questioned whether the practice of medical aid in dying should be limited to physicians under these circumstances. It is not clear whether there can be any recourse for individuals who meet the criteria for medical aid in dying, but have no reasonable access. This situation is worthy of consideration by the panel.

- *Follow-up.* Euthanasia and assisted dying have broader impacts beyond the individual patients. Physicians can have mixed emotions about their participation (Haverkate, van der Heide, Onwuteaka-Philipsen, van der Maas, & van Delden, 2001; van Marijk, Haverkate, van Royen, & The, 2007) and families are also affected (Kinsma, 2010). Consideration should be given to follow-up protocols to ensure that there are no unintended psychological consequences to those who have been involved in the provision or witnessing of the death.

- *Evaluation.* There should be guidelines for obtaining and documenting the patient's request. There should also be reporting requirements and a review procedure for ensuring that the legislation is being implemented as intended. As in other jurisdictions that have introduced legislation, utilization data should be maintained and made available in regular reports to the public.

In summary, we recognize the complexities inherent in formulating recommendations for legislation that will be appropriate to the Canadian context. Hopefully, these reflections will be useful to the panel as it moves forward with its deliberations. We appreciate being given the opportunity to participate.

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[i] Here we use the term assisted suicide because that is the term used in the survey question of patients