



Memorandum

To: The Members of the Special Joint Committee on Physician-Assisted Dying, Parliament of Canada
Re: Response to comments made during the Committee Hearing of January 28, 2016
Date: February 2, 2016
From: Trudo Lemmens, Professor and Scholl Chair in Health Law and Policy

Introduction

With this memorandum, I want to respond to comments made during the Committee Hearing of January 28th, and also alert the Committee to some relevant new evidence that has come to light yesterday that confirms the need for a prior review system.

I first want to make a comment in relation to the more general questions the Committee asked about what the *Carter* decision requires Parliament to do. Professor Downie and the Provincial Territorial Advisory Group [PTAG] interpret *Carter* very broadly. They recommend transporting the vague 'parameters' of *Carter* directly into the legislation without need for clear definitions or additional safeguards. They even suggest that precise definitions and prior review are not in line with *Carter*. This Committee should in my opinion be guided by the realization that, as the Supreme Court strongly emphasizes, *Carter* deals with a narrow, exceptional situation, which the Court felt should not have been captured by what is currently an absolute prohibition. The Supreme Court did not enact clear guidance about how to fix this, since it explicitly left it up to Parliament to develop a "very strict regulatory regime with rigorous monitoring to prevent abuse." This system, it stated explicitly, could be more precise and offer more safeguards than the Belgian regime and thus avoid the type of problems that have come to light with respect to a PTAG-style regulation. The general parameters of *Carter* should guide the legislative process, but they are parameters, not detailed legislative rules. To transpose these without any further specification would amount, to quote Justices McLachlin (as she then was) and Iacobucci, to "slavish conformity [that] would belie the mutual respect that underpins the relationship between the courts and legislature that is so essential to our constitutional democracy."¹

The emphasis in the *Carter* decision on the narrow circumstances of the case (a person 'like Ms. Taylor'), the explicit statement that "euthanasia for minors or persons with psychiatric disorders or minor conditions" does not fall within the parameters of the case, and that it is up to Parliament to develop a rigorous system indicate that *Carter* is much more narrow than Professor Downie and some other esteemed colleagues suggest. Moreover, if the Supreme Court had felt that the type of competency assessment the PTAG relies on would be sufficient, it would not have suspended the declaration of invalidity and would not have renewed this suspension while making Quebec—which has a much more narrow PAD system—exempt from the suspension of invalidity.

It is worth noting here that the trial judgment contains a much more precise definition and stricter conditions for who should have access to PAD. The Supreme Court never rejected this narrow definition and never criticized it. It simply left it open to Parliament to come up with the more precise terms and conditions for access to PAD.

I also want to respond to some specific comments. I will first respond to the argument directly in relation to the evidence I presented. I will then say something about specific *Charter*-compliance arguments made by Professor Downie, which I disagree with. I have discussed my arguments with other legal scholars, including constitutional experts, having presented a forthcoming paper laying this out in more detail at our Faculty of Law, and found substantial agreement with my interpretation of *Carter*.

1. The relevance and strength of the Belgian evidence and new evidence:

Professor Downie stated: “what you have to rely on ... in relation to the Belgian data, is the evidence that was tested in court and the empirical evidence from the actual researchers. In *Carter* and at the Supreme Court level it was presented so it was updated.” I disagree. The Committee should look at relevant new evidence, and should also take the liberty to consider the evidence earlier presented in court *for its own purpose* of designing the best regulatory regime. Much of the evidence I presented to the Committee was not discussed at the trial level. In my report to the Committee, I relied specifically on a peer-reviewed study of euthanasia and mental health published in 2015 in the professional medical literature and ongoing research on Dutch euthanasia cases by psychiatrist-bioethicist Dr. Scott Kim. This evidence shows serious problems with relying on competency assessment, determination of access by individual physicians on the basis of vague criteria, and after the fact reporting. These three tools are the main mechanisms for protecting the vulnerable in the PTAG proposal. The Committee should take these reports very seriously, since it reveals how a flexible, open-ended regime as proposed by the PTAG puts people with mental illness at risk.

The Flemish National Radio and Television (VRT) just reported on February 2, 2016 in detail on the case of a woman in her 30s who was diagnosed with autism merely two months prior to the performance of euthanasia, a diagnosis that then was used to support the claim of her suffering from an irremediable disease. The documentary confirms the problems identified in the reports I already discussed with the committee: over-reliance on individual physicians (and doctor shopping); overly broad criteria; easy diagnosis of ‘irremediable’ conditions, failure of independent assessment by specialist, failure of Federal Control and Evaluation Commission to find any problem—the criteria of the law were respected). I recommend reading some of the details of this new troubling report in reference. In response to this case report, a leading psychiatrist commented: “The time following a euthanasia request must, according to the law, be one month. But in fact a year is in such case even too short.” “The law aims primarily at people in terminal situations.... This is about people who suffer psychologically. **Is a prior evaluation not much more reasonable, whereby a commission discusses a case beforehand?**”² This is what it is all about. No one wants to see similar cases happening in Canada. Yet this case would be possible under the PTAG recommended model.

Some—but not all--of the controversial cases I discussed were indeed presented by an expert witness before the Supreme Court. But I provided more evidence on some of these, including information from interviews with physicians involved. The Supreme Court ruled these cases outside of the parameters of *Carter*. In other words: the Court felt it did not have to consider the evidence, since it counted on Parliament to design a system that would be more rigorous and less open-ended than the Belgian system and that *would not allow PAD in such cases*. The PTAG now recommends providing access to PAD on the basis of very open-ended criteria, including for mental health conditions. The evidence thus becomes very important for the Committee to consider.

Finally, in the trial judgment, Justice Smith acknowledges, with quotations from expert witnesses for the plaintiffs, that there may be problems with the Belgian system and that it was difficult to draw a clear conclusion.³ New evidence confirms the problems admitted prudently at the trial level.

2. Specific Comments: Definitions and Charter Compliance:

2.1. Definition of grievous and irremediable condition. The Belgian evidence confirms the importance of a precise definition. The Trial Judge also worked with a more narrow and precise definition. The Supreme Court emphasized repeatedly that its decision was focusing on people in the situation of Ms. Taylor, that it was not saying anything about PAD for psychiatric patients, minors, or for minor conditions. This indicates that the Court was ruling with the narrow definition and precise criteria of trial judge Justice Smith in mind and did not intend to bind the legislature with its overly broad criteria.

Limiting access to instances of “**terminal illness**” has a strong moral basis for access, since it reflects a reasonable balance between the risk of prematurely ending a person’s life, and the benefit of offering compassionate care at the end of life. It is not too vague and can be defined more precisely. This would not violate *Carter*.

2.2. PAD and Mental Illness

Professor Downie argues that excluding mental health as a basis for PAD would violate the *Charter*. I disagree. Obviously, competent adult persons should not be excluded from accessing PAD for the same conditions and under the same circumstances as others because they suffer from a mental illness. But defining ‘grievous and irremediable’ narrowly is not unconstitutional simply because the definition does not include or capture psychiatric diseases. A narrow definition will in fact ensure that there is no confusion about PAD in the context of mental health: people with mental health conditions could have access to PAD when they are competent, but only in situations that are covered by the law. The reference to psychological suffering in *Carter* is with respect to the suffering that accompanies being affected by a grievous and irremediable condition.

As mentioned before, the Supreme Court explicitly stated that Professor Montero’s case-based evidence about the risks of legalizing PAD was irrelevant, because euthanasia for “persons... with psychiatric disorders” was outside the parameters of the case. If the SC had in mind that its broad criteria inevitably included psychiatric diseases, it would *not* have stated this since it

would bring the evidence relevant and within the parameters of its ruling. The complexity of the interaction between mental illness and competency, the difficulty of determining when mental illness is ‘irremediable’ and treatment-resistant, and the potential very negative impact of offering life-ending PAD as a ‘treatment option’ on the clinical care of people with mental illness justify a more protective approach.

Psychiatric diseases can be kept outside the definition of grievous and irremediable, a definition which should focus on ‘*Carter*-like cases’. But it is also perfectly compatible with the *Charter* and in my view even required under equality law to provide additional protection and scrutiny when that is needed to protect those who are more vulnerable (substantive equality approach).

2.3. Age Restrictions

Professor Downie stated: “To exclude individuals on the basis of a specific age flies in the face of established health law, policy, practice, and the charter.” I disagree. It is true that the law recognizes mature minors’ significant decision-making powers in the context of health care, including with respect to treatment refusal. Yet, setting an age limit or differentiating on the basis of age is frequently done in the context of health law and is not a violation of the *Charter*. The *Assisted Human Reproduction Act* prohibits gamete donation under the age of 16, and surrogacy under the age of 21. These restrictions have not been challenged in court.

*AC v Manitoba*⁴ neither stands for the claim that age differentiation is a violation of the *Charter*, nor that mature minors have to be treated as adults. Rather, the case explicitly confirms that when it comes to minors, the best interest of the child is key, which takes account of the growing ability of young adolescents to make autonomous decisions. The complexity of the decisions and the risks involved are key components of a best interest of the child analysis.

In other words: when it comes to minors, additional safeguards and age differentiation are the norm in relation to very complex and risky decisions. There is arguably no other decision that is more ‘life-changing’ than a request to have one’s life terminated. The legislature should explain the rationale for age restrictions or differentiation. It would clearly be compatible with the *Charter* to impose additional protective measures or additional judicial review for access for mature minors and to focus the legislation in principle on adults.

2.4. Binding Advanced Directives

Professor Downie defends the notion of binding advanced directives, specifically in the context of dementia. If one follows her argument, a person who experiences a diagnosis of onset of dementia as creating intolerable suffering can specify in an advanced directive that her life be ended in circumstances she identifies. “This approach prevents [among others] the tragic case of someone having met all the criteria, but being denied medically assisted death because they became incompetent just before it could be provided.”

When you couple this proposal for binding advanced directives with the PTAG’s subjective and open-ended nature of the definitions of “intolerable suffering” and a “grievous and irremediable” condition, this could lead to the following situation: A person specifies at a very early stage of Alzheimer in an advanced directive that they want to be killed with PAD when

they no longer recognize their family members. At that stage, people can still be functional, find pleasure in life, engage meaningfully with their environment, and continue to live for a long period of time. I have trouble understanding how it can be morally defended that physicians can or even should actively end people's lives in those circumstances on the basis of an advanced directive and a quite hollow concept of autonomy (an autonomy fixed on the basis of how the person used to be). It seems to me impossible to deny that accepting active life-ending actions in those circumstances is a direct affront to the inherent dignity of human beings, regardless of their intellectual capacities. Active life-ending actions in those circumstances is further traumatizing for family and health care providers. It should not be allowed. Note that this does not mean that the individual in such a situation would not receive medical assistance and could not be kept comfortable and supported with all available means already at our disposal. The unfortunate nature of an incompetent person not being able to choose the precise timing and circumstances of her death must be weighed with against the significant moral problems I mentioned here.

2.5. Prior Review and *Morgentaler*

Professor Downie objects to prior review systems and suggests that the proposal by David Baker and Gilbert Sharpe would not be in line with *Morgentaler*. David Baker has explained how flexible and fast a prior review panel can and should act (taking into consideration that in some specific circumstances obligatory waiting periods can actually prevent premature life-ending actions). No one proposes undue delays when decisions have to be made fast.

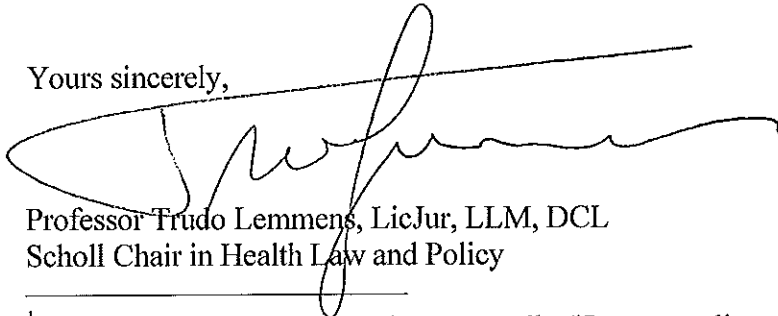
A prior review system for PAD would be *Charter* compliant. The review structure for PAD has a very different purpose and a different impact than the review system held unconstitutional in *Morgentaler*. Decisions related to abortion are not the same as decisions at the end of life. First, in the abortion context, the issue of equality of women is key. Second, in the abortion context, review panels were set up because of "the state interest in the protection of the foetus" and this 'other' interest imposes arguably a burden on a pregnant woman in the context of unwanted pregnancy. In the end of life context, the review aims at protecting the person him or herself. Third, competency issues are in the context of PAD clearly a key concern; not so in the context of abortion. Fourth, in the abortion context, fast intervention is generally important because of the risks and potential trauma of continued unwanted pregnancy and late-term abortions. In PAD, continued suffering can indeed also be traumatizing, but this must be weighed against the risks of prematurely ending a person's existence and the fact that in some cases, if waiting periods are warranted, delay may mean withdrawal of request for PAD because the issues that spurred the request have been addressed.

If the Supreme Court would be faced with a constitutional challenge in relation to a prior review system, I am confident that the Court would distinguish prior review panels in the abortion context from prior review panels in PAD. *Morgentaler* is not a relevant precedent.

For all these reasons, I am fully supportive of the approach proposed by David Baker and Gilbert Sharpe, as well as others, who argue for narrowly defined access to PAD, and for a stringent administrative review system prior to allowing PAD, coupled with a strong reporting system and regulatory monitoring.

I thank you for considering these responses to the issues raised. It has been an honour to be able to participate in this very important debate that affects all Canadians.

Yours sincerely,



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¹ McLachlin & Iacobucci JJ in *R. v. Mills*: "Just as parliament must respect the court's rulings, so the court must respect Parliament's determination that a judicial scheme can be improved. To insist on slavish conformity would belie the mutual respect that underpins the relationship between the courts and legislature that is so essential to our constitutional democracy." At par. 55.

² Quotes (my translation and my emphasis) from "Zussen getuigen over amateuristische euthanasia: Baxter viel op Tines gezicht" *De Morgen* (2 February 2016) online at <http://www.demorgen.be/binnenland/zussen-getuigen-over-amateuristische-euthanasie-baxter-viel-op-tines-gezicht-b92f407b/>. The case was reported in detail in a documentary with interviews on the Flemish National Radio and Television programme *Ter Zake* (a political-social issues show akin to *The Agenda*, which combines panel discussions with short documentaries). It interviewed two sisters of a young woman who was euthanized in 2010, four months after requesting euthanasia. She had been in psychiatric treatment 15 year earlier, but had been able to build a stable life since. Yet, following a break-up, she had a serious mental health crisis, and was in treatment with a psychiatrist for 8 months. Two months before her life was ended, the psychiatrist diagnosed her with autism, and concluded that she had an irremediable illness, and that her psychological suffering was unbearable. She was euthanized in the presence of her family, in problematic circumstances. When her family members inquired with her family physician why he had confirmed the psychiatrist's assessment of the euthanasia request, and whether he was supportive of this, he admitted that he was not in agreement, but that he had no choice. He states (recorded): "I think Tine shopped with too many doctors. I am also a bit angry at the doctor who gave that injection. The way in which he was quickly happy to do certain things. Perhaps there is need for a debate. And a break on people who like to do this technically" The third physician who confirmed the assessment was not a psychiatrist (since it was not a case of terminal illness, a third assessment was required). The case was not reported within the prescribed period of time, but when it was reported, the Federal Control and Evaluation Committee had no problem with it.

³ For example, Justice Smith states: "[672] With respect to Belgium, it is difficult to reach any firm conclusion. In cross-examination, Professor Deliens acknowledged that patients who do not have a psychiatric disorder but who have some level of depression might be vulnerable to being euthanized...". The evidence produced at the trial level was clearly not fully up to date: at par. 548, Justice Smith cites a study that mentions that requests for "patients with a psychiatric disorder were never granted euthanasia." This is clearly not (or no longer) the case.

⁴ *A.C. v. Manitoba* (Director of Child and Welfare Services) [2009] SCC 30

Why Canada Should Avoid A Belgian-Style Regulatory Regime for Physician Assisted Dying

**Memorandum
for the
Special Joint Committee on Physician-Assisted Dying**

Parliament of Canada

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Introduction

With the *Carter*¹ decision, the Supreme Court recognized that the prohibition on PAD unjustifiably deprives some competent adults, in a situation like Ms. Taylor, who suffer from a grievous and irremediable medical condition that causes enduring and intolerable suffering, from their section 7 Right to Life, Liberty and Security of the Person. But it emphasized also that the criminal law is a legitimate tool to protect the vulnerable. Had the Supreme Court been confident that existing practices at the end of life (competency assessment and informed consent) outside the context of Physician Assisted Dying (PAD) were sufficient as safeguards, it could have easily decided not to suspend its declaration of invalidity.

My colleague David Baker will discuss how a ‘very stringent regulatory regime’ with strong safeguards, which the Supreme Court invites Parliament to develop, can look like. I want to highlight here why both strict pre-authorization and after-the-fact review is absolutely crucial. To do so, I want to bring to light some of the key problems of the Belgian regulatory regime around euthanasia. The Supreme Court indicated in *Carter* that Canada could avoid any of the problems Belgium is facing by adopting a strict regulatory regime that allows for less discretion.² With its ‘unique Canadian approach’,³ the Provincial-Territorial Advisory Group recommends, however, a regime that is more flexible, less restrictive, and more open-ended even than the Belgian system. It is therefore essential to understand the essential elements of the Belgian system, how it facilitated the growing controversies around life-ending practices in Belgium, and how it would put Canadians at risk.

The legislative model in Belgium, at least how it developed, represents what has become a largely individual choice-based approach to PAD that gives at the same time enormous powers and responsibilities to individual physicians. Even though PAD requests are in this regime still restricted to specific circumstances and when certain conditions have been fulfilled (there is no explicit recognition of a right to PAD), the vague and flexible criteria coupled with the significant interpretative and evaluative powers vested in physicians, have *de facto* resulted in open-ended access

to PAD; with as protective measures primarily competency and informed consent assessment by individual physicians, and only minimal after-the-fact reporting and evaluation.

PAD has in Belgium expanded significantly beyond the original intentions, both by a flexible interpretation, and by the introduction of legislative changes or regulatory practice that extend PAD (e.g. in Belgium the law now also includes mature minors, albeit under *stricter* conditions than the PTAG recommendations). I will focus on the former.

My analysis is based on: 1) published reports by the official Federal Euthanasia Evaluation and Control Commission; 2) peer-reviewed literature, including analyses of practices by those involved in PAD, and surveys; 3) interviews and media reports in Belgium's official languages (Dutch and French) and in English, which reflect the views and approaches of those involved in and affected by PAD practices. These case reports are particularly relevant because of the limitations of the data based on anonymous surveys and official reports. They shed light on what is happening in the real practice of PAD in Belgium. They provide more detail about some of the practices that are increasingly criticized in Belgium by medical professionals, psychiatrists, ethicists, and legal scholars. At times, I will also expand on comparable developments in the Netherlands.

This evidence reveals: when general and open-ended criteria are used to identify who can have access to PAD, and individual physicians are the main gate-keepers trusted with interpreting these criteria, with only competency assessment and informed consent procedures as safeguards, PAD practices expand in areas that raise serious concern about the protection of the vulnerable, including people with disabilities. The Belgian experience highlights concerns about regulatory regimes that largely rely on post-factum reporting and a limited review of the appropriateness of the practice. It also evokes a culture of normalization of active life ending interventions by physicians that may have long-term consequences that

are hard to predict, for example with respect to the practice of medicine and our societal commitments to patients.

Under the Belgian law patients can ask for PAD when the following combination of objective and subjective criteria are fulfilled: 1. the patient is in a medically hopeless situation; 2. of constant and unbearable physical or mental suffering; 3. that cannot be alleviated; and 4. resulting from a serious or incurable disorder; 5. caused by illness or accident.

Physicians have to consult a second physician and have to report the PAD death to the Federal Control and Evaluation Commission (FCEC). The FCEC looks at a short anonymous summary of the data, and if it has further questions it can obtain access to the specifics of the case (i.e. name of physician and patient). The FCECC can decide with a 2/3 majority to forward the case to the public prosecutor for possible further action. Additional requirements and restrictions exist for patients who are not at the end of life, and for mature minors. When patients are not at the end of life, a third physician (specialized in the condition of the patient or a psychiatrist) has to be consulted and an obligatory wait (reflection) period of 1 month is imposed (which remarkably the PTAG does not even recommend). Under the age of 18, PAD can only be provided for physical suffering at the end of life, and with agreement of the parents (again a restriction that the PTAG does not recommend).

1. Summary of the Problems in Belgium related to an Expansion of the Practice

- 1.1. Total increase in PAD practices or mission creep: what started as a compassionate practice in more exceptional situations at the end of life and *Carter*-like situations, is exponentially increasing:
- a. From 347 cases in 2004; to 495 in 2007; 822 in 2009; 1,133 in 2011; 1,816 in 2013; and 1,926 in 2014; to 2021 in 2015.⁴
 - b. In Flanders, where the number of reported PADs is significantly higher than in the South of the country (80% of reported cases), PAD increased from 3.8

% of all deaths in 2007, to 6.3% in 2013 (1 out of every 16 deaths now involves PAD).

- c. A recent survey of physicians in Flanders suggests a significant increase in the percentage of requests that are granted: from 56.3% in 2007 to 76.8% in 2013.⁵ Physicians are thus not functioning as significant gatekeepers, since $\frac{3}{4}$ of requests are now granted. That makes any shortcoming in their assessment, any limitation in their ability to adequately evaluate a patient very problematic.

1.2. Expansion of the Practice in Problematic Areas: There is growing criticism on the expansion of PAD in areas that are more problematic, including more existential suffering, disabilities, and increasingly also mental health. Many of these conditions were clearly not envisaged when the law was introduced, but the vague criteria enabled expansion in these areas.

This expansion can seriously affect people who are experiencing life-changing disabilities, or situations which are associated with loneliness, isolation, societal stigmatization and rejection, difficulties with managing daily activities, and difficulties functioning independently. In those situations, good support measures and structures can prevent premature death, while all too easy access to PAD can incite life-ending requests. In the context of some diseases, for example severe depression, offering PAD as one treatment option could even more significantly impact on proper clinical care, as it could interfere with suicide prevention. Easy access to PAD can also affect incentives to develop appropriate support structures. It would be naïve to think that once firmly established, the expansion of cost-saving PAD practices could not impact on the government's willingness to invest in potentially more costly support measures.

PAD has been performed in Belgium on people who expressed concern about: becoming dependent on others (e.g. deaf-mute brothers who were becoming

blind)⁶, loneliness and decline of quality of life (e.g. elderly couples who expressed the desire to die together;⁷ and a 85-year old woman who was 'tired of life' after losing her daughter⁸); future dementia;⁹ and the absence of appropriate treatment for sexual deviation in a prison setting¹⁰. Controversies also arose when a transgendered person was euthanized and the doctor involved declared that there had been several requests from transgendered people, including an already granted request for a close friend of the euthanized person.¹¹ Euthanasia practice involving a patient with severe depression without warning of family members has also stirred controversy.¹²

These and several other publicly known, as well as hidden cases (because of the privacy implications, family members often prefer not to publicize their complaints), should not be brushed aside as anecdotal. They are real lived PAD experiences, frequently discussed in detail in public, that have resulted in the death of vulnerable people, may have traumatized family members, and often created moral anguish among health care providers (requests were often initially refused by some physicians). These cases of more 'existential' concerns (albeit often mixed with significant mental health and physical ailments) are said to be increasingly common in Belgium and the Netherlands and have been the subject of growing concern and criticism about expansion of the practice, including by health care providers and some who have been involved in the regulatory review of euthanasia practices.¹³

2. The Mental Health Context.

Specific concerns have been voiced about the expansion of requests for PAD in the context of mental health. The proportion of euthanasia deaths involving neuropsychiatric disorders has increased in Belgium from 1.2% of cases in 2004/05, to 2.8 % (or 58 cases) in 2010/11, to 3.7 % (or 67 cases) in 2013/14. There are also other indications that the number of people with mental illness expressing an interest in PAD is significantly increasing in Belgium.¹⁴

A 2015 study¹⁵ published in BMJ Open documents the practice of euthanasia of people with mental health issues in Belgium. The study involved 100 patients who had requested euthanasia and were assessed in the clinic of one consulting psychiatrist between 2007 and 2011. Patients suffered from a variety of disorders including mood, personality, post-traumatic stress, anxiety and eating disorders; schizophrenia; addiction; autism (Asperger syndrome) and complicated grief, many with co-morbidities.¹⁶ They were all deemed competent, but no information was available about how this was determined in this complex population. The authors also deemed that “[i]n all patients, the suffering was chronic, constant and unbearable, without prospect of improvement due to treatment resistance.”¹⁷ Yet, the outcome of the study (37 patients euthanized; 38 withdrawals of requests, 11 postponing of euthanasia after request granted; 5 independent suicides) raises serious doubts about the original determination of being ‘treatment resistant,’ the absence of possible recovery, and the competency of people with serious mental health conditions.

A group of prominent Belgian psychiatrists, psychologists, and ethicists severely criticized the publication, questioning various components, including the competency assessment, the high number of approved cases, the treatment resistant nature of the conditions, and the fact that the study showed how one psychiatrist can be primarily responsible for a very substantial percentage of euthanasia cases of mental health patients in Belgium.¹⁸

Following this publication, and also in the wake of the exposure of other cases involving euthanasia of depressed people without informing family members, a group of 65 Belgian psychologists, psychiatrists, other health care professionals and ethicists published an open letter in the bulletin for physicians and in leading newspapers, asking that psychiatric conditions be removed from the Euthanasia Law as a basis for PAD, with others responding in support of the current practice.¹⁹ The PTAG recommendations go in the opposite direction, as they even reject an

obligatory wait period in the context of PAD and do not limit PAD for children to somatic diseases.

Problems with mental health euthanasia cases are similar in the Netherlands, where we do have more publically available information. Psychiatrist-bioethicist Scott Kim has been studying the individual case summaries of persons who received PAD for psychiatric disorders in the Netherlands.²⁰ Even though these summaries are public, this appears to be the first time that they have been analyzed in detail, in and of itself remarkable. He has identified several problems that are not reflected in the large-scale surveys of self-reporting of physicians and in official reports. What are the problems he identifies?

One, even though it is often presented as if euthanasia is only practiced in extreme cases of ‘psychiatric suffering’ involving severe depression, as in Belgium, PAD is provided to people with grief, psychosis, cognitive problems, autism, and other disorders. The majority of cases he studied involve socially isolated, lonely people.

Two, there is frequent disagreement in those reports among the ‘expert’ consultants whether the regulatory criteria for PAD are met; but the regional review committees sometimes do not even comment on the disagreements in their reviews. There is also virtually no discussion of any scientific basis for determining someone’s situation as ‘without hope’ or ‘futile’, making any after-the-fact judgment about it virtually impossible.

Three, he identified problems with competency assessment: information on how it is determined is sparse, even in cases where people are more at risk of being incompetent (e.g., cognitive problems, psychosis). The cases are psychiatrically very complex cases. But in over 10% of the cases, there is no independent psychiatrist involved in the evaluation (i.e. the treating psychiatrist assesses competency, and this is not independently verified by an expert). In most cases, the physician is a

general practitioner and not a psychiatrist, with thus no particular expertise in competency.

3. The Challenges of Competency Assessment

The concerns about the practice of PAD in the context of mental health reveal particularly well the overall problematic nature of a regulatory system that relies on competency assessment and informed consent processes by individual physicians. These concerns are worth emphasizing here briefly. Competency Assessment in medical decision-making is notoriously difficult, as mentioned before.²¹ Few physicians, including psychiatrists, are well trained in it, have a good grasp of the concept, and appreciate the difficulties in assessing competency. Competency assessment is influenced, as studies show, by various factors including the nature of the decisions to be made and the risks involved; and even more importantly also the beliefs and values of physicians. Physicians' values and belief systems influence whether they determine someone competent. This has already been documented in the PAD context.²² In the context of end-of-life, or when people are suddenly confronted with a debilitating medical condition or disability, and in situations where patients suffer from a mental health condition that can be accompanied by a desire to die, competency assessment is even much more complex and more likely to vary depending on the physician's commitment to PAD.²³ Physicians who are firmly committed to PAD will more likely find patients competent to opt for PAD, even when they suffer from depression and other mental health conditions. Those who are not familiar with the experience of people with disabilities are more likely to conclude that the choice to end one's life in a situation of disability is a reasonable, competent choice.

With respect to informed consent, the determination whether patients are not unduly influenced by others, by lack of appropriate support structures, by concerns or fears about being a burden or becoming too dependent, and so on, is intertwined with difficulties of competency assessment, and requires appropriate training,

attention and skills, and sensitivity to the specific challenges of each case, which individual physicians often lack. Thus, whether patients' lives will be ended, rather than therapeutic options emphasized and explored, depends in a Belgian-style system too much on the physician who is assessing them, even if a second consult (or in some cases third) by a physician adds some level of extra scrutiny. When it comes to decisions about life-ending actions in very complex situations, a such an assessment is not sufficient.

4. When is There No Hope for Recovery?

Whether there is no hope for improvement, and thus whether a condition is untreatable or 'irremediable' is particularly hard to assess in the mental health context. The concept of 'refractory' or 'treatment-resistant depression,' for example, is in and of itself highly contested.²⁴ People suffer indeed tremendously and often chronically from depression. Yet, studies focusing on 'treatment-resistant depression' indicate that many patients, in one study even 60.2%, fully recover.²⁵ While the evidence of the success rate varies, it is very hard if not impossible to predict who will certainly not recover.²⁶ Mental health treatment often takes time, in particular because finding the right diagnosis is often hard, and the right treatment even harder. The availability of good social support services, easy access to good quality mental health care, and so on, are determinant factors in recovery and improvement. Yet, in many countries, including Belgium, as is the case in many Canadian provinces, good quality mental health care services are in short supply.

5. The Limits of the Reporting System

The Belgian experience also shows that reporting after the facts is limited even with respect to how it promotes transparency and a clear understanding of what is happening. Underreporting and errors in reporting continue in Belgium, with one 2010-study estimating that only 1 in 2 cases of euthanasia are reported.²⁷ Studies also suggest that physicians continue to practice PAD without consent and are

obviously not easily officially reported.²⁸ Thus: hidden practices may have become visible as a result of the de-criminalization coupled with reporting, but other practices remain hidden. What is hidden may simply have shifted.

The reporting system may create, in fact, a false sense of security, a false sense of control over the practice, and lead to an overly bureaucratic assessment of cases on the basis of limited practical information, with little incentives to intervene after the facts. For example, there is often only limited information available about how competency was exactly assessed in individual cases, making it very hard to conduct regulatory and disciplinary follow-up on the basis of the reported information.

Dr. Scott Kim's study of individual case summaries in the Netherlands is thereby again revealing²⁹: Even though these summaries are public, they had not yet been analyzed and publicly discussed. His findings of problems with competency, expansion in problematic areas, serious disagreements among physicians, are not reflected in the data produced by the official review agencies and in large-scale anonymous surveys of physicians.

In Belgium, there have been significant reports, and even public statements of physicians that they were not respecting the reporting requirements.³⁰ Yet, so far, the FCEC forwarded only one file to the public prosecutor, while more than 11,000 patients had their life terminated. Considering the often-public confessions of physicians that they did not respect the requirements, it would be surprising that this is the only case of violation of the rules that merits scrutiny by a public prosecutor.

Conclusion

In conclusion: the Belgian system provides access to PAD on the basis of overly vague and flexible criteria, which gives individual physicians an extraordinary liberty as well as responsibility to determine who has access to PAD and in what situations. It has de facto led to an open-ended access regime that has significantly

expanded, including with respect to the type of situations in which PAD is provided. PAD has expanded in problematic areas, such as the context of mental health where competency is very hard to assess and where physicians may too easily conclude that there is no hope of recovery. The Belgian experience also shows that some individual physicians have become particularly active in providing access to PAD in controversial areas such as mental health, with no regulatory intervention other than limited post-factum review of reported cases, which provide only limited, self-reported information.

For these reasons, I am profoundly concerned that some of my colleagues propose—as in the PTAG report—a regulatory regime that would provide less restrictions, no additional regulatory oversight, and more flexibility than the Belgian regime. Such a regime will put the most vulnerable Canadians at risk. I am convinced this is not what the majority of Canadians want, and what the Supreme Court can have had in mind when it called upon Parliament to develop a strict regulatory regime with rigorously monitored safeguards.

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¹ *Carter v Canada* (Attorney General) [2015] 1 SCR 331

² *Ibid.* “[T]he cases described by Professor Montero were the result of an oversight body exercising discretion in the interpretation of the safeguards and restrictions in the Belgian legislative regime — a discretion the Belgian Parliament has not moved to restrict. These cases offer little insight into how a Canadian regime might operate.” [par. 113]. Note that the Court also indicated explicitly that euthanasia involving minors or persons with psychiatric disorders fell outside the parameters of the decision, two categories arguably included in the PTAG recommendations and in the Belgian system [par. 111].

³ *Provincial-Territorial Expert Advisory Group on Physician-Assisted Dying: Final Report* (Ottawa: Ministry of Health and Long-Term Care, 2015) online:

<http://www.health.gov.on.ca/en/news/bulletin/2015/docs/eagreport_20151214_en.pdf> [PTAG].

⁴ Latest figure released yesterday: “Aantal euthanasia aanvragen overschrijdt grens van 2,000” *De Standaard* (27 January 2016) online <http://www.standaard.be/cnt/dmf20160127_02092952>

⁵ For some recent statistics, see Kenneth Chambaere et al, “Recent Trends in Euthanasia and Other End-of-Life Practices in Belgium” (2015) 372:12 *New England J of Medicine* 1179. See in general also the Reports of the Federal Euthanasia Control and Evaluation Commission, which are posted by LevensEinde InformatieForum, online: <<http://www.leif.be/professioneel/professionelelgids/139-rapportenevaluatiecommissieeuthanasie.html>>.

⁶ See Dirk Verbessem (brother of the euthanized twins) interviewed in “10 jaar LEIF: moet er nog euthanasia zijn?” (November 2013) by Eric Raspoet, online: <http://www.erikraspoet.be/?p=355>: “The Prospect of becoming totally isolated and dependent was too much for them.”

⁷ “Samen Sterven: Anne en François aan de Vooravond van Hun Euthanasie” *Humo* 17 June 2014 online <http://www.humo.be/humo-archief/290374/samen-sterven-anne-francois-aan-de-vooravond-van-hun-euthanasie>. A similar case of PAD of an elderly couple is reported by a physician in a 2009 interview: “One of them”—to use his own words – “because of medical, terminal reasons and the other because of the psychological suffering of being old and having to continue living on her own after having lived nearly in symbiosis” [my translation of: “De ene om medische, terminale redenen en de ander omwille van het psychisch lijden van oud zijn en alleen verder te moeten na bijna in symbiose geleefd te hebben”] quoted in Fred Verbakel, “Niets is zo natuurlijk als sterven” (2009) 2:4 *Relevant* 5 at 6. Available online: <https://www.nvve.nl/files/8513/8753/0895/Relevant_2009-2.pdf>.

⁸ This is in fact the only case so far where the FCEC decided to forward the case to the prosecutor. See Jan Lippens, “De Vrouw Die Niet Zonder Dochter Wilde Leven” *KNACK* (18 November 2015) 68-69; Graeme Hamilton, “Belgian Doctor Facing Possible Murder Charge for Euthanizing Senior Seen as Warning for Canada”, *The National Post* (29 October 2015), online: <<http://news.nationalpost.com/news/belgian-doctor-facing-possible-murder-charge-for-euthanizing-senior-seen-as-warning-for-canada>>.

⁹ See the quote from Dr. Wim Distelmans, co-chair of the FCEC about the euthanasia of well-known Flemish author Hugo Claus: “Like Hugo Claus, dozens of people are euthanized here in the early states of dementia, as a preventive measure.” See *Carter*, *supra* note 1 (Affidavit of Professor Etienne Montero) at para 35.

¹⁰ See “Overplaatsing van Van Den Bleeken naar Nederland zeer onzeker”, *De Standaard* (1 June 2015), online: http://www.standaard.be/cnt/dmf20150531_01707275; “Belgian Serial Rapist will not be Euthanised”, *The Telegraph* (6 January 2015), online: <<http://www.telegraph.co.uk/news/worldnews/europe/belgium/11327541/Belgian-serial-rapist-will-not-be-euthanised-as-planned.html>>; and Tu Thanh Ha, “Belgian rapist’s plea for euthanasia stirs debate on mental health and right to die” *Serial Rapist will not be*

Euthanised", *The Globe and Mail* (1 January 2014), <http://www.theglobeandmail.com/news/world/belgian-rapists-plea-for-euthanasia-stirs-debates-on-mental-health-and-right-to-die/article16157723/>.

¹¹ "Eerste Maar Niet Laatste Euthanasia bij Transgenders", *De Standaard* (2 October 2013), online: <http://www.standaard.be/cnt/dmf20131001_00769803>. "Ook vriendin van transgender Nathan pleegt binnenkort euthanasia", *Het Laatste Nieuws* (October 5, 2013), online: <<http://www.hln.be/hln/nl/957/Binnenland/article/detail/1717203/2013/10/05/Ook-vriendin-van-transgender-Nathan-pleegt-binnenkort-euthanasie.dhtml>>.

¹² See Rachel Aviv, "The Death Treatment" (June 22, 2015) *The New Yorker*, online: <<http://www.newyorker.com/magazine/2015/06/22/the-death-treatment>>. See also the blog by Tom Mortier on the euthanasia death of his mother: Tom Mortier, "How My Mother Died" (4 February 2013), *Mercatornet* (blog), online: <http://www.mercatornet.com/articles/view/how_my_mother_died/11772>

¹³ See *infra* under mental health for complaints by health professionals. Fernand Keuleneer, lawyer and former member of the Belgian FCEC was interviewed about the news that following the PAD permission for imprisoned sex offender Frank van den Bleeken, 15 other prisoners had requested access to PAD: "C'est bien d'examiner le cas de ce criminel, mais pour des milliers de patients lambda, on ne s'est jamais posé la question de savoir si on pouvait développer de nouvelles thérapies. Nous en arrivons à un droit à la mort sur commande, avec la complicité du corps médical..." (Le Figaro 18 September 2014 p.8). In another interview, he supports legalization of euthanasia, but criticizes the developments in Belgium, stating: "Euthanasie is rapidly evolving towards a right to 'die on demand'; when and for the reasons a person determines fully on his/her own, and for which the person can then coerce support by physicians. ... People want to change the soul of medicine" [Euthanasie evolueert snel naar een recht op 'dood op bestelling', wanneer en om de redenen die men volledig zelf bepaalt, en waarvoor men dan de bijstand van artsen mag afdwingen. ... Men wil de ziel van de geneeskunde wijzigen"] Christophe Degreef & Steven Van Garsse, "Fernand Keuleneer, tegendraads anti-splitsingsadvocaat" *Brussel Deze Week* (11 December 2014) online <http://www.brusselnieuws.be/nl/nieuws/fernand-keuleneer-tegendraads-anti-splitsingsadvocaat>.

Theo Boer, a former member of one of the five Dutch Regional Euthanasia Review Committees, who has been and still remains supportive of legalization of euthanasia as a form of exceptional care, recently expressed concern about, among other things, the growing number of people in the Netherlands who ask for euthanasia because of loneliness, or for the fear of being left behind: "Loneliness occurs in 50 out of the last 500 cases that I reviewed before stepping back. Many of these patients could have lived for months, others for years or even decades." See Theo Boer, "Dutch Experience on Regulating Assisted Death" (2015) 65:4 *Catholic Medical Q*, online: <http://www.cmq.org.uk/CMQ/2015/Nov/dutch_experiences_on_regulating.html>.

¹⁴ See e.g. Lieve Thienpont, *Libera Me: Over Euthanasie en Psychisch Lijden [About Euthanasia and Psychological Suffering]* (Witsand Uitgevers, sl, 2015) (at p. 204). Dr. Thienpont, a psychiatrist who is arguably the most active practitioner of PAD in psychiatric patients in Belgium, mentions that in the first 3 years following the 2011 establishment of a

new end-of-life consultancy service which actively supports euthanasia, about 50% of the 900 consultations involved patients with primarily psychiatric problems.

¹⁵ Lieve 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>>

¹⁶ Lieve Thienpont & Monica Verhofstadt, "A Commentary on 'Euthanasia for Psychiatric Patients: Ethical and Legal Concerns about the Belgian Practice' from Claes et al." (2016) 5:7 *BMJ Open*. Available online: <http://bmjopen.bmj.com/content/5/7/e007454.abstract/reply#bmjopen_el_9360>.

¹⁷ In 48 cases the request was approved. While 37 patients were euthanized, 11 postponed their request and were still alive 1 year later. Of the 100 patients, 38 also withdrew their request. In total: 57 people were still alive one year later Lieve 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>> at 5.

¹⁸ Stephen Claes et al., "Euthanasia for Psychiatric Patients: Ethical and Legal Concerns about the Belgian Situation" (2015) *BMJ Open*. Available online: http://bmjopen.bmj.com/content/5/7/e007454.abstract/reply#bmjopen_el_9360 The authors suggest that the psychiatrist involved in the study as first author is certainly responsible for more than 35% and probably close to 50% of all euthanasia cases for psychiatric diseases in Belgium in the period of the study. Yet, if one excludes cases of Alzheimer from the general reported category of 'neuropsychiatric disorders,' the percentage could be even much higher.

¹⁹ Ariane Bazan *et al.* "Euthanasie pour souffrance psychique : un cadre légal discutable et des dommages sociétaux" (2015) 1784-8679 *Le journal du médecin : hebdomadaire réservé au corps médical* 42 online <<http://hdl.handle.net/10067/1280770151162165141>> Ariane Bazan, Gertrudis Van de Vijver & Willem Lemmens, "Schrapp euthanasie op basis van louter psychisch lijden uit de wet", *De Morgen* (8 December 2015), online: <<http://www.demorgen.be/opinie/schrapp-euthanasie-op-basis-van-louter-psychisch-lijden-uit-de-wet-b277b650/>> (my English translation available at: <http://wp.me/p71HQ4-2>); Ariane Bazan et al, "L'euthanasie pour souffrance psychique: un cadre légal discutable et des dommages sociétaux," *Le Soir en ligne* (9 September 2015), online: <<http://www.lesoir.be/985006/article/debats/2015-09-09/l-euthanasie-pour-souffrance-psychique-un-cadre-legal-discutable-et-des-dommages>>. With a response (signed by multiple others) Johan Braeckman, An Ravelingien & Maarten Boudry, "Banaliseer psychisch lijden niet" [Don't trivialize psychological suffering], *De Morgen* (11 December 2015), online: <<http://www.demorgen.be/opinie/banaliseer-psychisch-lijden-niet-bdb8ed05/>> (my translation available at: <<http://wp.me/p71HQ4-S>>); and a reply to the response by Ariane Bazan et al, "Psychisch lijden is nooit banaal" [psychological suffering is never trivial], *De Morgen* (14 December 2015), online: <<http://www.demorgen.be/opinie/psychisch-lijden-is-nooit-banaal-b8e8699f/1CfTcY/>> (my translation available at: <<http://wp.me/p71HQ4-1e>>).

²⁰ Personal Communication

²¹ For a general discussion of the complex nature of and the challenges in competency assessment, see Scott H. Kim, *Evaluation of Capacity to Consent to Treatment and Research* (New York: Oxford University Press, 2010).

²² Linda Ganzini et al, "Evaluation of Competence to Consent to Assisted Suicide: Views of Forensic Psychiatrists" (2000) 157 *Am J Psychiatry* 595.

²³ See Annabel Price: "It is in the grey areas that capacity is the most difficult to determine, and these grey areas are where clinicians' individual values are most likely to affect the process." "Mental Capacity as Safeguard in Assisted Dying: Clarity is Needed" (2015) 351 *BMJ* 11.

²⁴ See discussion in Franklin Miller, "Treatment-Resistant Depression and Physician-Assisted Death" (2015) 41:11 *J of Medical Ethics* 885.

²⁵ See Abebaw Fekadu et al., Prediction of Longer-term Outcome of Treatment-Resistant Depression in Tertiary Care" (2012) 201 *Brit. J. Psychiatry* 369. Other studies show lower rates: David Dunner et al., "Prospective, Long-Term, Multicenter Study of the Naturalistic Outcome of Patients with Treatment-Resistant Depression" (2006) 67(5) *J. Clinical Psychiatry* 688; Francis G. Vergunst *et al.* "Longitudinal Course of Symptoms Severity and Fluctuation in Patients with Unipolar and Bipolar Depression" (2003) 207 *Psychiatry Res.* 143–149.

²⁶ Franklin Miller, "Treatment-Resistant Depression and Physician-Assisted Death" (2015) 41:11 *J of Medical Ethics* 885

²⁷ Tinne Smets et al, "Reporting of Euthanasia in Medical Practice in Flanders: Cross Sectional Analysis of Reported and Unreported Cases" (2010) 341:7777 *BMJ* 819. Available online: <<http://www.bmj.com/content/341/bmj.c5174>>. The authors conclude: "Countries debating legalisation of euthanasia should simultaneously consider developing a policy facilitating the due care and reporting obligations of physicians." Underreporting likely continues. According to Statistics Belgium, there were 61,621 deaths in Flanders in 2013. The study by Chambaere et al, *supra* note 5, suggests that 4.6 % of deaths involved euthanasia. That amounts to 2,834 cases. Yet, the Federal Euthanasia Control and Evaluation Commission received only 1,454 reports of cases in 2013. See Federale Controle en Evaluatie Commissie Euthanasie, *Zesde Verslag aan de Wetgevende Kamers* (2012-2013) 19 August 2014, available online: <<http://www.dekamer.be/flwb/pdf/54/0135/54K0135001.pdf>>.

²⁸ Kenneth Chambaere et al, "Characteristics of Belgian 'Life-Ending Acts Without Explicit Request': A Large-Scale Death Certificate Survey Revisited" (2014) 2:4 *CMAJ Open* E262. See also the comments on the study, the reply by the authors, and further correspondence online: <http://www.cmaj.ca/content/186/18/1368.full/reply%23cmaj_el_726624/reply#cmaj_el_728013>. See statement by Dr. Wim Distelmans, co-chair of the FCEC: ""There is always still a *dark number* : physicians who practice euthanasia but do not register, because of which we do not have a view on the real number" [translation of [E]r is nog altijd een *dark number*: artsen die euthanasie toepassen, maar niet registreren, waardoor we dus geen

zicht hebben op het werkelijke aantal.” *De Standaard* (27 January 2016) online <http://www.standaard.be/cnt/dmf20160127_02092952>

On the concerns of the prevalence of life-ending actions without explicit request in Belgium, see in general the discussion by Raphael Cohen-Almagor, “First Do No Harm: Intentionally Shortening Lives of Patients Without Their Explicit Request in Belgium” (2015) 41(8) *J Med Ethics* 625.

²⁹ See *supra* note 20.

³⁰ See *supra* for a study indicating the low report rate. For a public statement, see for example an interview in *De Standaard* with Dr. Mark Cosyns, a palliative care specialist who has performed many PADs. When he is asked “Dr. Cosyns, you are still not reporting euthanasia to the Commission?” his answer is: “No, not when they are our own patients. I do everything on the basis of the Act on Patient’s Rights [another piece of legislation]. We also don’t have to justify each time we do an operation why this doesn’t constitute assault.” [“Nee, niet als het om onze eigen patiënten gaat. Ik doe alles op basis van de wet op de patiëntenrechten. We moeten toch ook niet voor elke operatie verantwoorden dat we geen opzettelijke slagen en verwondingen toebrengen”] Veerle Beel & Lieven Sioen, “In de VS zat ik al lang achter de tralies. En jij samen met mij” [In de VS I’d already be in prison a long time ago. And you with me] *De Standaard* (21 December 2013), online:

http://www.standaard.be/cnt/dmf20131219_00896009.> For a paper outlining some of the significant problems with reporting and other obligations in Belgium, see Raphael Cohen-Almagor, “First Do No Harm: Pressing Concerns Regarding Euthanasia in Belgium” 36(5-6) *Int’l J. of L. & Psychiatry* 515 [Pressing Concerns].