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Introduction

The House of Commons Bill C-14 defines a "grievous and irremediable medical condition" as requiring that the patient's death be "reasonably foreseeable" and thus limits the availability of physician-assisted death (PAD) to those who are on "a trajectory towards their natural death."[1] In contrast, others (as reflected in the Special Joint Committee [SJC] and the Provincial-Territorial Expert Advisory Group [PTEAG] reports) would permit PAD for non-terminally ill patients, including persons who seek PAD on the basis of suffering due to psychiatric disorders as the primary reason (for brevity, I will refer to this practice as "psychiatric PAD" or **PPAD**). Although the House of Commons Bill excludes psychiatric disorders as a primary basis for PAD, it does not exclude psychiatric patients who are otherwise eligible for PAD.[1] That is, no one whose death is reasonably foreseeable is excluded merely on the basis of their disorder, psychiatric or otherwise.

The purpose of this submission is to discuss the evidence relevant to evaluating the potential impact of a PAD regime that includes psychiatric PAD.

The analysis assumes there are several factors that raise the risk that people suffering from severe psychiatric conditions could wrongly receive PAD if legalized. None of these factors should be controversial, regardless of whether one supports PPAD.

First, psychiatric patients are often stigmatized—they are often made to feel that they are unwanted, culturally and socially, as well as materially in terms of resources devoted to their care. Second, because the psychiatrically ill are often seen as "other," most people—even non-psychiatric physicians in my experience—have limited understanding of the nature of severe psychiatric disorders. Third, the very nature of some psychiatric disorders—indeed, one of the most painful aspects of such disorders—is that the exercise of the patient's judgment is often affected (even if he or she is legally competent) by illness-driven perceptions and feelings. For example, severe depression can cause feelings of despair and hopelessness (which in turn can cause a sense of helplessness in others, that nothing can be done for the patient) and psychotic disorders can cause various distortions of reality that are often not so easy to detect.

As the Legislative Background to Bill C-14 notes, the Special Joint Committee's report fairly closely follows the Belgian and Dutch models. Thus, evidence from those countries may be useful in evaluating the proposals such as those from the SJC which would permit PPAD.

Current state of evidence on psychiatric PAD

In the Netherlands, there were 110 reported cases of PPAD from 2011-2014; prior to that, there had been about 2-5 cases per year.[2] In Belgium, PAD for neuropsychiatric cases (which include non-terminal neurologic as well as psychiatric disorders) were numbered in the single digits until

2007; in 2012-2013 there were 101 cases of PPAD.[3] Although the numbers are small, the trend is clear.

Except for a report in 1997[4] describing 11 cases in the Netherlands, very little was known about the practice of psychiatric PAD in the two countries. Data consisted mostly of media reports and quantitative summaries in the respective review bodies' annual reports.

There have been two recent studies that have analyzed PPAD with some detail, such as descriptions of various diagnoses and other patient characteristics. Dr. Lieve Thienpont, a Belgian psychiatrist, and her colleagues published a case series of 100 consecutive requestors of PPAD from her own private psychiatric practice from 2007 to 2011.[5] Our group has been reviewing the reports of 66 cases (of 85 reported at the time of our study—during 2011 to part of 2014) of completed PPAD from the Netherlands, providing an overview of the characteristics of the patients who received PPAD, how the physicians evaluated them, and how the euthanasia review committees viewed the cases.[2]

Who receives psychiatric PAD?

Although normative arguments surrounding permissibility of PPAD almost entirely focus on 'treatment resistant depression,' the reality is rather more complex.

Thienpont study

In Dr. Thienpont's personal case series of 100 requestors of PAD, 73% were women, and mean age was 47. 58 patients presented with 'treatment resistant depression' (48 unipolar and 10 bipolar). However, patients also had other conditions (some had more than one diagnosis): post-traumatic stress disorder (n=13), schizophrenia and other psychotic disorders (n=14), anxiety disorders (n=11), eating disorders (n=10), substance use disorders (n=10), somatoform disorders (n=9), Asperger syndrome (n=7), attention deficit hyperactivity disorder (n=1), obsessive–compulsive disorders (n=7), dissociative disorders (n=7), and complicated grief (n=6), among others. It also appears that when Dr. Thienpont undertook further evaluation of the patients, additional persons were given a diagnosis of autism (n=12). Half of the patients had personality disorders. She does not report the diagnostic breakdown for those who actually received PAD.

The PAD request acceptance rate is reported as 48%. Of those 48 persons, 11 postponed or cancelled PAD, and 2 committed suicide by other means. Thus, 35 persons received PAD. But 38 of 100 withdrew their requests *before* a PAD decision was made so that the actual acceptance rate may be 77% (or perhaps even as high as 86% because six others may have died before a decision was made).

After 1 to 4 year follow up (depending on when the patient was evaluated), they found that of the 57 persons who were alive at the end of their initial evaluation period, all were still alive: "In nine cases their requests were still in process and no decision had been reached. In 48 cases, their requests were on hold because they were managing with regular, occasional or no therapy."

One final note about the Thienpont study is that during the time that 35 of her patients received PAD, the FCEC (the Belgian euthanasia review commission) received reports of PAD in 76 cases of non-terminally ill neuropsychiatric disorder patients. Because the Belgian commission does not break down the numbers between psychiatric and neurologic disorders, it is not possible to tell what proportion of psychiatric PAD cases in Belgium were Dr. Thienpont's cases.

The potential range is 46% (35 of 76, if we assume no neurologic cases) and 100% (35 of 35, if we assume that 41 cases were neurologic). Since PAD for Alzheimer's has generally outnumbered psychiatric PAD where data are available (the Netherlands), it is possible that most or nearly all cases of PPAD in Belgium during 2007-2011 were cases involving Dr. Thienpont.

Psychiatric PAD in the Netherlands

In our study of Dutch PPAD cases, 70% were women, and the patients were considerably older than the Belgian group in Dr. Thienpont's study. Depressive conditions were the primary psychiatric issue in 36 cases (55%) and over 70% had some form of depression. 16 of 66 (24%) patients had some form of psychosis. PTSD-related and other anxiety disorders were prominent (28 of 66 patients, 42%). Notably 4 persons (6%) had cognitive impairment; one patient had a legal guardian (but was judged competent by consultants, including one psychiatrist). Four women had a chronic eating disorder with borderline personality disorder.
Other aspects of the study are described below.

Summary

As noted above, virtually all arguments and debate about legalizing PPAD use a paradigm case of treatment resistant depression. Thus, there have been lively scholarly debates about how to think about the ethics of PAD for persons with treatment resistant depression.[6,7] Discussions of the conditions under which PAD would be permissible for disorders such as prolonged grief, autism, schizophrenia, mental retardation, or personality disorders are either rare or non-existent, even in the bioethics literature. Public policy discussions about how a physician should address these other psychiatric disorders in the PAD context are rare; I am not aware of any.

The only document that I am aware of that attempts to provide sustained guidance on this issue (Dutch Psychiatric Association Guidelines[8]) primarily provides guidance on how to interpret the legal due care criteria for psychiatric patients in general. In terms of addressing clinical issues that may arise for specific disorders, the document recommends that subspecialists of particular disorders be consulted. As noted below, the Dutch system does not follow this recommendation.

Thus, it seems fair to say that legalization of PAD on the basis of various psychiatric disorders has been proposed (and practiced) with relatively sparse literature to guide clinicians.

What are the social circumstances of the patients receiving psychiatric PAD?

In a majority of the Dutch cases, patients had characteristics that tend to compromise the ability to cope with adversity: significant personality difficulties, social isolation, or feelings of loneliness. 52% (34 of 66) had personality disorders or problems and 56% (36 of 66) were socially isolated or said to suffer from loneliness. Some of these patients are described in the reports as follows: "The patient indicated that she had had a life without love and therefore had no right to exist"; "[t]he patient was an utterly lonely man whose life had been a failure."[2] It seems reasonable to assume that these factors contribute to people's desire for PAD.

How is medical futility determined for psychiatric disorders?

The terms "irremediable" and "hopeless"—referring to medical futility—might be reliably applied for incurable conditions that are known to lead to death, as long as the medical diagnosis is correct. Although not perfect, most people might also agree that 'near the end of life' or 'terminal' are terms that have more or less reliable meaning.

Predicting 'futility' in cases that tend to generate feelings of futility: role of evidence
However, when "irremediable" and "hopeless" are applied to non-terminal psychiatric disorders, the situation is much more difficult to assess. Even for the paradigm case of treatment resistant depression, it is not a straightforward task to determine prognosis. Although it is easy to stipulate as a premise in a theoretical argument that a severe psychiatric illness can be untreatable or 'refractory,' it is difficult to determine this in clinical practice. Remission rates of persons with repeated depressions can be quite low 'in the community' where treatment is often suboptimal.[9] But even among persons with far worse prior treatment histories (patients who have histories similar to some of the Dutch cases we reviewed), most can achieve remission if given high quality treatment.[10] A determination of 'irremediable' will therefore often be a clinical impression, not an evidence-based determination. As such, it will also be highly influenced by the personal beliefs and commitments of particular physicians.[11]

Another example might be borderline personality disorder (BPDO) which is the most common personality disorder and figures prominently in both our study and in Thienpont's study. Although BPDO tends to cause considerable turmoil in and around the patient, often generating feelings of futility in all, in fact the long-term prognosis is that most will achieve remission.[12]

Treatment refusals and determinations of futility: treating persons or disorders?
Furthermore, the SJC's recommendation that "irremediable… does not require the patient to undertake treatments that are not acceptable to the individual" could be particularly consequential for psychiatric patients. It is one thing for a patient with a terminal illness to refuse a last ditch effort, or refuse symptomatic treatments whose side effects are more bothersome than their benefits. But it is quite another to set aside a core clinical imperative in psychiatric treatment: compassionately and skillfully helping patients even through periods of sustained suffering in which people often lose the will to live and despair about whether things will get better. It is difficult to reduce this aspect of psychiatric practice—the treatment of persons, not just disorders—into the language of medical futility.

In our review, we found that 56% of patients (37 of 66) refused at least some treatment. The most common reason was lack of motivation. We note that 20% of the patients apparently did not have sufficiently severe illness in their history to require inpatient treatment. Although depression was the primary condition in 55%, only 39% ever received ECT and only 11% had tried an MAO inhibitor.

Overall, in 24% of cases, physicians involved disagreed on whether the patients met all of the eligibility criteria for PAD. The most common point of disagreement was over the medical futility question (occurring in 81% of the disagreement cases).

In her study, Dr. Thienpont states (without explanation) that all 100 consecutive requestors of PAD met the medical illness criterion (futile with intolerable suffering). That is, every presenting patient requesting PAD was deemed to have a medically futile condition.

Summary
The determination of medical futility in psychiatric disorders will be a complicated judgment for several reasons: (1) Even for the paradigm case of treatment resistant depression, the research literature does not provide clear guidance for clinicians; (2) For other diagnoses, many of which are chronic disorders, a rigorous understanding of what would constitute 'medical futility' for the purposes of providing PAD is something that has not received much attention; (3) More often than not clinicians will have to address the tricky issue of patients refusing recommended treatment—are such cases truly "irremediable"?

This does not mean that physicians cannot make determinations of futility in psychiatric disorders. Physicians will do their best if required to do so. However, it does mean that such determinations will not really be based on evidence, or even on shared 'clinical wisdom'; instead they will largely be personal clinical impressions unlikely to be reliable between physicians. The level of disagreement among physicians in the Netherlands is perhaps a reflection of this complexity. (A third of the patients had been refused PAD previously; many found doctors who were willing to assist in mobile euthanasia clinics; and even among those who ultimately received PAD, ¼ of the cases involved physicians disagreeing about eligibility.)

Determination of capacity of patients who request psychiatric PAD

Some background

A common concern about psychiatric PAD is the issue of mental competence or capacity (sometimes called decision-making capacity) of those requesting it.[13] This is because, although psychiatric diagnoses should not be *equated* with incapacity, some neuropsychiatric conditions are known to increase its risk. These include psychotic illnesses,[14] neurocognitive disorders,[15,16] some forms of severe depression,[17,18] anorexia nervosa,[19,20] and mental retardation.[21,22]

Historically, approaches to capacity relied on ill-defined concepts such as 'unsound mind' and the presence or absence of clinical diagnoses, but these constructs have been replaced by modern function-based frameworks that assess capacity-specific abilities such as the abilities to understand relevant facts, apply those facts to oneself, reason and weigh the facts, and evidence a stable choice.[23]

With abilities-based constructs, however, evaluating the capacity of patients is not always straightforward and is widely recognized to be a complex, challenging task—especially by those who are most experienced at conducting capacity evaluations.[13,23,24] Capacity evaluations are guided by only broad criteria even in complex clinical situations, and are influenced by the criteria used,[25] personal views of assessors[26] and the risk-benefit context.[27,28]
It is interesting to note that in our work, clinicians most often called to assess capacity found their training in capacity assessments to be rather mediocre.[27]

As someone who has been studying and teaching both the normative and empirical aspects of decision-making capacity for close to 20 years,[23,29,30] I would state emphatically that anyone who is not worried about the difficulties associated with assessing the capacity of persons with severe psychiatric disorders who are requesting PAD is not basing that view on existing data.

Dutch and Belgian psychiatric PAD cases

It might be thought that in practice, physicians and oversight bodies will be particularly careful and meticulous, applying high thresholds of capacity to ensure that only truly competent persons receive psychiatric PAD. We did not find this to be true.

In Dr. Thienpont's study, all 100 consecutive persons presenting with request for PAD were, in her evaluation, found to be competent. She does not provide any details of how persons who had disorders known to increase risk of incapacity (e.g., chronic psychoses) were evaluated.

In 55% (36 of 66) of cases of Dutch PPAD cases we studied, the case reports' capacity-specific discussion consisted of only global judgments of patients' capacity (that is, simply stating whether or not the person was determined to be capable or not), even in patients with psychotic disorders and other disorders known to increase risk of incapacity. 32% (21 of 66) of cases did include evidentiary statements regarding capacity-specific abilities; but only 5 cases (8%)

mentioned all four of the abilities generally seen as relevant to capacity (understanding relevant information, applying that information to self, weighing or reasoning, and evidencing a choice).

The physicians frequently stated that psychosis or depression did or did not affect the patients' capacity, indicating that they were aware of the need to address the relation between those conditions and capacity. But they provided little explanation regarding their judgments. For example, we found only one or two cases in which physicians actually explain why a psychotic patient, despite prominent psychotic symptoms, is competent (e.g., content of delusions not relevant to PAD request). By and large, physician simply reported their impressions. Physicians in 8 cases (12%) disagreed about capacity status of patients.

Even when physicians agreed, there were surprising details. In a case of a woman in her 70's with severe personality disorder, multiple suicide attempts, mental retardation, and psychotic symptoms, two physicians agreed that the patient possessed intact capacity. The first physician appealed especially to her ability to "weigh pros and cons" as evidence of intact capacity. The second physician, however, specifically noted that the patient's ability to "use information in a rational way was doubtful." In effect, the two physicians agreed on the outcome but with contradictory reasoning.

In the Netherlands where "voluntary and well-considered request" is a legal due care criterion (and which includes the requirement of intact decision-making capacity), the level of capacity that is deemed acceptable in practice for making PAD request is not especially high.

Summary

Capacity evaluations are easy at the ends but difficult in the middle. That is, most persons without neuropsychiatric conditions, even when suffering from a grievous illness, will likely be competent and the issue of capacity will seldom arise. And for persons who are so ill that they are sedated or unconscious, the evaluation is obviously easy.

But when patients are able to communicate but suffer from severe neuropsychiatric conditions, especially when the decision at stake is one about ending the life of a non-terminally ill person, the evaluation will be very difficult. In this 'gray area,' personal beliefs of evaluators (and review committee members) will likely have a significant impact. The way to minimize any bias is to clearly justify how the specific criteria for capacity are met, and to explain how potentially incapacitating conditions do not in fact cause incapacity. We lack evidence that the current regimes in which PPAD is legal do this, and, at least in the Netherlands, the evidence indicates that a high level of scrutiny and justification is not the norm.

Psychiatry in the development and implementation of psychiatric PAD policy?

Despite repeated acknowledgement by the Dutch euthanasia review committees that psychiatric cases are particularly controversial and require special scrutiny, the way in which this is actually implemented is somewhat divorced from the views of those who might be considered experts in psychiatric disorders.

The Dutch euthanasia review committees, until recently, did not have psychiatrist members. Thus, the committees' review of many psychiatric cases, as well as their opinions about how the Dutch euthanasia law should apply to PPAD, generally reflect the opinions of ethicists, lawyers, and non-psychiatrist physician members.

The Dutch review committees, for instance, permit more liberal practices regarding PPAD than what is recommended in the practice Guidelines promulgated by the main Dutch psychiatric organization. (This is not because the Dutch psychiatric association is against PPAD.) For example, the review committee makes it clear that PPAD does not have to involve any truly independent psychiatrists. We found that in 7 of 66 cases, there was no independent psychiatric input. But the Dutch psychiatric society's Guidelines[8] recommend not only an independent psychiatrist in each case but a subspecialist who is an expert on the specific disorder (for example, an eating disorder specialist). In fact, given that the Dutch euthanasia committees generally do not have psychiatrists (or at least not until recently), it appears that the following is possible (and indeed occurs): a psychiatric patient could be euthanized without any independent expert input or oversight (since no independent psychiatric input is required, and even if obtained, the opinion can be ignored), and then the official review of the completed PPAD is conducted with no independent psychiatric expert input either.

The Belgian system does require independent psychiatric consultation. However, there is no requirement that the doctor performing PAD needs to agree with the consultant. There is also no safety system to evaluate whether a particular psychiatrist might be overly zealous in loosely interpreting the due care criteria.

The Canadian proposals that would permit psychiatric PAD appear to share this lack of input from psychiatric perspectives. For example, the SJC, in explaining why the current practice of determining capacity provides sufficient safeguards, even for psychiatric PPAD requests, appears not to have considered the fairly large literature on capacity evaluations (see above) and instead quotes persons without psychiatric expertise to defend their recommendation.[31]

Permanence of death and routinization of PAD

Extreme caution in developing PAD policies is needed not only because premature and unnecessary loss of life is a great harm. It is also needed because death is permanent and the dead cannot file a complaint. When the person who dies is socially isolated and stigmatized as ‘other’ in society (or has alienated or antagonized persons around her, as in patients with personality disorders), there is even less of a chance that someone will speak for her after she is dead. This eliminates a powerful and natural corrective element of any policy.

Evidence from the Netherlands shows that retrospective reviews of even highly controversial practices such as psychiatric PAD become very routine.[2] Every year the reports get shorter. The evaluative parts (the closing section which reviews whether the cases met criteria) of the review committee reports become so routinized that in nearly 2/3 cases, there are no case specific elements at all.[2] Even in cases where the physicians disagreed with each other about the eligibility of the patients (16 cases or 24%), the review committees specifically addressed the disagreement in their overall evaluative statement in only 2 cases.

Since 2002, the Belgian and Dutch euthanasia retrospective review bodies have found only 0.1% of the nearly 50,000 reported cases of PAD to not meet legal standards (and mostly for procedural violations such as not using the correct drug or dose). Less than 1% of psychiatric PAD cases in the Netherlands have been judged to have not met due care, despite significant disagreements among physicians about the patients’ eligibility for PAD.[2]

Limitations of current research and implications

Both Dr. Thienpont's study and our study are limited. Both are small studies. Thienpont's study is essentially a self-report by a doctor who is a well-known advocate of psychiatric PAD. Our study relied on case summaries drafted by the euthanasia review committees using written reports (and rarely oral testimony) from the physicians involved. Better, bigger studies are needed.

In the context of these limitations, two points are worth noting.

First, even with such limitations, it is not difficult to find rather concerning features of the cases (a testament to the integrity and transparency of the Dutch euthanasia committees which made them public). So despite the limitations, our study provides the most systematic and rich description of the practice of psychiatric PAD to date.

Second, it is obvious that the evidence base for legalizing and regulating psychiatric PAD is thin. For a practice that would involve ending the lives of non-terminally ill persons, it is rather sobering to think that such a policy is being proposed (and practiced) with so little empirical data.

Summary/Conclusions

1. Although the policy discussions about psychiatric PAD focus on 'treatment refractory depression,' the impact of legalized PAD goes well beyond depression. There are many conditions about which there has been little or no public discussion, but which have been used as bases for PAD. For example, I am unaware of a discussion in the Canadian debate about whether prolonged grief would be an acceptable basis for PAD and if so, how a clinician would evaluate such a case.

2. Women are more than twice as likely to receive psychiatric PAD. It is not clear why.

3. A majority of people who receive PPAD have personality disorders, and in some that is the main source of suffering for which PPAD is granted.

4. Most people who obtain PPAD are lonely or socially isolated.

5. It appears that many people withdraw their request for PPAD, both before an evaluation is finished and after the request is accepted by the physician. It also appears that those who are alive after the initial evaluation period remain alive several years later.

6. Applying the evidence-base to determine the medical futility of psychiatric disorders will be difficult even for treatment refractory depression. For other conditions, it is even less clear. Dutch physicians often disagree about futility, and most patients are deemed to have medically futile conditions even as they refuse treatments. It appears that not all patients have received all indicated treatments.

7. Experts in the assessment of decisional capacity find it a challenging task. Previous studies (outside the PAD context) show high variability of judgments even among trained clinicians in 'gray area' cases (which will likely be common in the PPAD context). Thus, one might expect that determination of capacity of persons who request PPAD would involve a high level of scrutiny and careful justification; in practice, this does not appear to be the case.

8. The implications of a single psychiatrist in her private practice being involved in most or nearly all of the psychiatric PAD cases in an entire country have not been sufficiently discussed.

A salient point in that discussion might be that she found all 100 consecutively presenting PPAD requestors to have met the two most important eligibility criteria (capacity and medical futility) for PAD.

9. Oversight of even controversial practices such as PPAD is likely to become routinized. Retrospective review bodies of PAD find that virtually no physician violates the due care criteria despite their broad and vague nature. It seems unlikely that this is due entirely to the perfect judgment of physicians.

10. Despite the highly complex psychiatric issues involved, policy development and implementation regarding PPAD are sometimes at odds with psychiatric expertise.

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