

Denying Assisted Dying Where Death is Not ‘Reasonably Foreseeable’: Intolerable Overgeneralization in Canadian End-of-Life Law

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[See table of contents](#)

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Article abstract

The recent change in Canadian law to allow access to medical assistance in dying restricts eligibility, among its other criteria, to those for whom “natural death has become reasonably foreseeable.” A recent review of certain aspects of the law examined the evidence pertaining to extending access to assisted dying in three particular request situations currently denied: requests by mature minors, advance requests, and requests where mental illness is the sole underlying medical condition [1]. The requirement for this review was included in the legislation that introduced medical assistance in dying in Canada. Both the original change in the law and the review itself neglected to consider those with intolerable suffering for whom natural death is not reasonably foreseeable. This paper explores the possibility that access to assisted dying should be extended by removing this limiting criterion. It also considers the ethical challenges this might present for those who work in rehabilitation.

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ARTICLE (ÉVALUÉ PAR LES PAIRS / PEER-REVIEWED)

Denying Assisted Dying Where Death is *Not* 'Reasonably Foreseeable': Intolerable Overgeneralization in Canadian End-of-Life Law

Kevin Reel¹

Résumé

La récente modification de la loi canadienne permettant l'accès à l'aide médicale à mourir en restreint l'admissibilité, entre autres critères, à ceux pour qui « la mort naturelle est devenue raisonnablement prévisible ». Une révision récente de certains aspects de la loi a examiné les preuves concernant l'accès à l'aide médicale à mourir dans trois situations de refus : demandes de mineurs matures, demandes anticipées et demandes pour lesquelles la maladie mentale est la seule condition médicale sous-jacente [1]. L'exigence de cet examen a été incluse dans la loi qui a introduit l'aide médicale à mourir au Canada. Tant le changement initial de la loi que l'examen lui-même négligent la prise en compte de ceux qui ont des souffrances intolérables, et pour lesquels la mort naturelle n'est pas raisonnablement prévisible. Cet article explore la possibilité d'étendre l'accès à l'aide médicale à mourir en supprimant ce critère limitatif. Il considère également les défis éthiques que cela peut présenter pour ceux qui travaillent en réhabilitation.

Mots clés

mort assistée, invalidité, euthanasie, aide médicale à mourir, suicide

Abstract

The recent change in Canadian law to allow access to medical assistance in dying restricts eligibility, among its other criteria, to those for whom "natural death has become reasonably foreseeable." A recent review of certain aspects of the law examined the evidence pertaining to extending access to assisted dying in three particular request situations currently denied: requests by mature minors, advance requests, and requests where mental illness is the sole underlying medical condition [1]. The requirement for this review was included in the legislation that introduced medical assistance in dying in Canada. Both the original change in the law and the review itself neglected to consider those with intolerable suffering for whom natural death is *not* reasonably foreseeable. This paper explores the possibility that access to assisted dying should be extended by removing this limiting criterion. It also considers the ethical challenges this might present for those who work in rehabilitation.

Keywords

assisted dying, disability, euthanasia, medical assistance in dying, suicide

Introduction

When Czesław Miłosz wrote that "the true enemy of man is generalization" [2, p.208], he may have been engaging in an overgeneralization himself. His words, however, pose an ongoing challenge to those crafting changes in law and policy that create limited access to a previously restricted act. It is imperative to strike a just and ethically defensible balance between enabling individual autonomy, imposing paternalistic restrictions, preventing harm and promoting good. This can be an especially controversial task in the context of assisted dying¹, where the outcome that is sought (i.e., a state sanctioned ending of a life) is profoundly significant, irreversible and subject to deeply emotive reactions.

Canada's current approach to assisted dying might be deemed overly general in its exclusions to eligibility [3]. In keeping with the Supreme Court of Canada (SCC) ruling, the criteria include the need to be a capable adult (over 18) and to be experiencing a grievous and irremediable condition that produces physical or psychological suffering that is intolerable to the individual. The eventual amendment to the Criminal Code of Canada departs from the SCC ruling with more limiting specifications of what constitutes 'grievous and irremediable' [4, S.241.2(2)]. The further requirements for eligibility include the additional criterion that the person's "natural death has become reasonably foreseeable" [4, S.241.2(2)(d)]. This requirement to be nearing death is seen by many as a bit of legerdemain to effectively limit eligibility to the 'terminally ill' without using that term itself – given the term is absent from the text of the SCC decision, and arguably the idea was intended to be absent as well.

This restriction to those nearing death was very likely a response to the anxieties expressed by some about 'vulnerability' in the debates around the new law. One very prominent example was the Vulnerable Persons Standard (VPS) [5] – a proposal for specific additional safeguards intended to protect 'vulnerable' persons. The VPS emphasizes the risks its authors see from potential inducement, influence and coercion, and makes the assertion that various factors unrelated to their condition can "make *some* people vulnerable to request an assisted death when what they want and deserve is better treatment – to have their needs for care, respect and palliative and other supports better met" [6] (emphasis added). The VPS expressly demands

¹ The term 'assisted dying' will be used throughout this paper to refer to what the Criminal Code defines as 'medical assistance in dying', commonly abbreviated as MAiD. This legal definition clarifies that in Canadian federal law both self-administered and practitioner (i.e., physician or nurse practitioner) administered forms of actively ending life are no longer criminal offences when carried out within the parameters of the law. The province of Quebec has its own law which uses the term 'medical aid in dying' in English translation, often abbreviated as MAD. The Quebec law permits only physician administered assisted dying. 'Assisted dying' will be understood here to include those practices decriminalized by both the Canadian and Quebec laws. The terminology used is of note: self-administered assisted dying has long been referred to as '*assisted suicide*', where the assistance is the prescribing (and subsequent dispensing) of the required substance which is then ingested by the person seeking to end their own life. Where the practitioner administers the required substances, the long used term is '*euthanasia*', meaning one individual brings about the 'good death' of another. (The Greek roots of the word 'euthanasia' mean good (*eu*) and death (*thanatos*)). Given the history of these terms, many have argued that the use of more specific wording is critical for two reasons. 'Suicide' is a word that might best be limited to the more conventional situation where someone ends their own life, often in a crisis moment, without the information, assessment, reflection and support that is characteristic of an assisted death (See the American Association of Suicidology statement "[Suicide is not the same as 'physician aid in dying'](#)" of October 30, 2017). The word 'euthanasia' carries a strong and more recent history of reprehensible associations, as will be mentioned later in this paper. While this history is of note, distinguishing it from current or proposed legal practice is critical. The assisted dying laws in Canada and Quebec only permit *voluntary* active euthanasia. Healthcare consent law typically allows for voluntary and non-voluntary passive euthanasia – the withholding or withdrawal of life sustaining treatments. Involuntary euthanasia is neither permitted nor proposed.

that eligibility be limited to end-of-life conditions², arguing for the application of a generalized restriction because of the *possible* risk *some* people may experience in this regard. Its additional demand of a vulnerability assessment is, it seems, insufficient to mitigate the possible risk for those particular people.

These generalizations seem simplistically overstated given that the VPS does not address the possibility that some people who are *not* terminally ill might also be suffering intolerably and that this will not change even with the best support conceivable. The fact of such experience is borne out in individual stories that have emerged over many years – experiences which the VPS appears to disregard and effectively deny. The only related notion entertained within the text of the VPS is that these people asking for an assisted death really want something else – to have their needs better met. Canada's current law enshrines this denial of evident self-reported intolerable suffering by individuals not nearing death, and the parameters of the recent review³ of the law [1] continued to disregard the experiences of some people living with *non-terminal* conditions that lead a small minority of them to seek an end to their life.

To explore this situation more deeply, this paper will consider a number of related topics that underpin an argument in favour of making assisted dying available to some individuals for whom their natural death is not reasonably foreseeable. Beginning with an exploration of the idea of vulnerability, a selection of stories in the public realm will be used to illustrate that some claims of non-terminally ill individuals for assisted death might be legitimate. The way in which these claims are excluded by Canadian law and the review of it will then be detailed. In an attempt to evaluate the moral legitimacy of these claims, some commonly held ethical principles in rehabilitation practice will be discussed and applied. Subsequently, the fact of disagreement about assisted dying among those who identify as 'disabled' will be considered. In the face of differing experiences and opinions, it will be argued that individual evaluations of life's meaning and value should rank higher than generalized notions of disability that suggest implicit vulnerabilities. Finally, the role of assisted dying in opening up more equitable choices about the way one's life ends will be explored using the notion of levelling the odds in what is often a lottery – the way life unfolds and how it may end.

Toward a useful understanding of 'vulnerability'

One of the problems of the focus on vulnerability that shaped the Canadian legislation and the review is the variability in conceptions of vulnerability. The word itself has the capacity to evoke very emotive responses. Thus, defining what is meant by it is especially important. A comprehensive exploration of the complexity of understanding vulnerability is beyond the scope of this paper. However, a brief discussion is warranted in order to explain the working definition that will be adopted here.

The VPS states that "[T]o be vulnerable is to have diminished defences, making us more prone to *harm*" [6] (emphasis added), a focus seemingly placed on inherent weakness in defending oneself against the increased likelihood of harms presented by others. Another conceptual definition, informed by the work of the International Bioethics Committee of UNESCO, is offered by Incardona and colleagues as "a common and essential feature of human nature that highlights our shared experience and reciprocal responsibility to each other" [7], giving recognition to the idea that we are each vulnerable in specific ways and rely on each other to mitigate the effects of our vulnerabilities. A more useful and well-studied phrasing is found in the work of Hurst and colleagues, which frames the idea of vulnerability as "having a greater likelihood of being *wronged* – that is, of being denied adequate satisfaction of certain legitimate claims" [8,9] (emphasis added). This last conceptualization conveys the idea that these 'likelihoods' can be greater or lesser, but without any suggestion of inherent weakness. The idea of being *wronged* when '*legitimate claims*' are denied adequate satisfaction creates a much more nuanced understanding on the variable dynamics involved in any instance of vulnerability. This also raises the prospect of having to distinguish legitimate claims from non-legitimate claims – and satisfying them adequately. The task of determining the legitimacy of claims is something that is likely to involve ethical deliberation and clinical determinations on individual bases. This opens up the prospect that one person's legitimate claim may be viewed by another as a harm. This more nuanced, individualized understanding of vulnerability is more likely to avoid the overgeneralization that seems to have characterized Canada's approach to creating, and reviewing, assisted dying law.

To more concretely illustrate the idea that some individuals may be vulnerable to inadequate satisfaction of legitimate claims, rather than vulnerable to inducement and coercion by virtue of their status as 'disabled', a small selection of stories in the public realm will be briefly examined. They can each be explored in greater depth through many sources available to readers, beginning with the references cited.

Claims to assisted death – discomfiting but potentially legitimate

Any request for assisted death should be viewed as lamentable and regrettable. Certain requests are likely to be seen as more lamentable and regrettable than others for various reasons. In the case of non-terminal illness, the prospect of years of living that might be lost inevitably comes to mind. However, for a minority of people with non-terminal conditions that are grievous

² The VPS, perhaps inadvertently, appears to suggest by its reasoning that those who have an end-of-life condition are not as vulnerable as those who might face many years or decades of ongoing suffering.

³ This article was finalized immediately prior to the release of the review. The author does not comment on the content of the recent review, only the limitations as set out by the government when including the requirement for the review in the legislation and subsequently in tasking the Council of Canadian Academies in completing it.

and irremediable, the years of living that might be 'lost' through an assisted death are seen by these individuals as years of suffering. This can be demonstrated by a few stories.

Ramón

Ramón Sampedro lived for decades with a high-level spinal injury. His very public court case in Spain sought access to legal assistance from others to end his life [10,11]. His attempt was unsuccessful. The film [12] based on his experience gives some insights into the remarkable level of function he was able to attain, yet he remained resolute that what he managed to get from life was not enough to warrant continued living. An important comment is made in this fictionalized account of Sampedro's real life story where he is asked if he appreciates that his plea for assisted death means that the lives of people with spinal cord injuries are not worth living. He responds by denying that any such generalization *ought to follow*, clarifying that his request speaks nothing about *people with spinal injuries*, but only about Ramón Sampedro's view of his own life with a spinal injury⁴.

Tony

For Tony Nicklinson, a British man who experienced a catastrophic stroke, his resulting life with locked-in syndrome was a source of intense suffering, both physical and psychological. Most of what had given his life meaning was now lost to him, and the new hallmark of being alive was suffering. It was evident that he could live years longer, even decades. He did not want that. Five years post-stroke, he made an appeal to the courts in the United Kingdom (UK) to be allowed an assisted death. His request was unsuccessful. His story was told in one of the affidavits submitted to the 2011 appeal in the Supreme Court of British Columbia [13] and throughout the plaintiffs' written submissions [14] when Gloria Taylor's initial court victory was challenged by the government of Canada. Tony's wife, Jane, appeared on his behalf before the UK Commission on Assisted Dying. A notable exchange is documented between one of the commissioners and Jane, when she is asked if Tony has had contact with palliative care specialists. Jane replies "He's not dying! He is not dying! That is the problem, you know he is not dying, he would wish to have cancer or something but he is not dying. He could outlive us all." [13, p.28] Tony died soon after his case was lost, after voluntarily stopping eating and drinking (VSED) and contracting pneumonia [15].

Omid

At the time of writing this article, another British man, known only as Omid, is mounting a similar court case. In his mid-fifties, multiple systems atrophy is leaving him progressively more disabled but without a 'reasonably foreseeable death'. Having unsuccessfully tried to end his own life (which would not be illegal) he is no longer able to do that himself. Nor does he want to be unsuccessful again. For him, an assisted death is something he considers a more dignified death that ends the suffering he experiences daily [16].

Julia

In Canada, Julia Lamb is the plaintiff in an impending constitutional challenge to the current restrictions in access to assisted dying [17]. Julia was diagnosed with spinal muscular atrophy at 16 months of age. The condition continues to cause deterioration in her abilities to the point where she may wish an assisted death. However, given the slow progression of her condition, she may be expected to continue to live for years and would thus not be eligible until her natural death is reasonably foreseeable.

Concerns over possible misuse of access to assisted dying have resulted in an overgeneralized restriction that arguably produces vulnerability – an increased likelihood that individuals like Tony and Julia will have denied their potentially legitimate claim to an assisted death. This will leave them open to the harm of many more years of suffering. It also increases their risk of being vulnerable to the alternatives of either a conventional suicide or VSED. Left with no legal option to actively end their lives in a supported manner, they would have to do the former alone, or risk criminal charges being laid against those who might assist. This may require acting sooner than they might wish, given that impending loss of physical abilities would take away even this option. That was the choice made by Nagui Morcos when he ended his own life before Huntington's Disease meant he was unable to do so [18]. For people like Ramon, Tony or Omid, this option is unavailable as it requires physical capacities they no longer have. Without assisted dying, their only legal option is VSED.

Given that any of these people could have opted for that long before they mounted complex high-profile legal cases seeking an assisted death, it is worth pondering why VSED did not seem an adequate satisfaction of their claim to an assisted death. Some might simply suggest they wanted to make a point and change the law, and that may be true. However, it is also true that a legal assisted death implicitly recognizes the validity of the person's assertion that their life has become not worth living. This categorically changes the potential for prejudicial judgments about death by VSED and its moral legitimacy, its relationship to 'suicide' in the conventional sense and the potential for stigma being associated with it afterwards [19]. It also obviates the need to suffer the period of slow decline by dehydration and lack of nourishment. This can include effects on consciousness and cognition. In addition, it requires that family and friends are witness to the slower, uncertain and potentially distressing course of a death by VSED than would be the case in the certain provision of an assisted death. There is, as well, the potentially damaging impact left upon those health and social care professionals who might experience moral distress as they provide

⁴ An interesting, albeit tangential, notion here is the conceptual distinction in international human rights law between rights based on one's individual status as a human versus rights based on one's membership of a group. This is discussed by Philippe Sands in a 2018 [radio interview](#) on the CBC radio program *Writers and Company*.

merely comfort care to some when others are able to opt for a more decisive intervention to minimize suffering. Finally, extending access to assisted dying for those whose natural death is not reasonably foreseeable creates one more option for all, without imposing any duties to either request the option or provide it – the right to abstain on conscience grounds remains for each potential provider. Restricting access to assisted dying imposes more limited options that appear to inadequately satisfy the claims of some individuals who would be eligible except for the near-death criterion.

The legitimacy of these claims was not put in doubt by the decision of the Supreme Court of Canada, which made no reference to the need to be terminally ill or even near death. The legitimacy of these claims was also supported by one of the UK Supreme Court Justices in the Tony Nicklinson case. Lord Neuberger stated that “[q]uite apart from the notorious difficulty in assessing life expectancy even for the terminally ill, there seems to me to be significantly more justification in assisting people to die if they have the prospect of living for many years a life that they regarded as valueless, miserable and often painful, than if they have only a few months left to live.” [20, col1864]

Despite the evident arguments made by numerous individuals living with grievous and irremediable non-terminal conditions, the Canadian law denies their legitimacy. The parameters of the recent review also deny their potential legitimacy, as will now be discussed.

Requests excluded by Canadian law subjected to limited recent review

At the point of publication of this article, December 2018, the review of assisted dying law in Canada was about to be released. It was conducted by a panel assembled at the Government’s request through the Council of Canadian Academies. The Government-set parameters of the review limited it to considering the existing evidence relating to the three types of request: by mature minors, through advance requests, and where mental illness is the sole underlying medical condition [1]. Each request type and the legal criteria that exclude it will be discussed briefly.

Under 18s

Within the current law, the single criterion requiring the person to be 18 years of age expressly excludes minors. This criterion was clearly included in the Supreme Court decision, perhaps curiously given the typical healthcare consent law approach that focusses on capability to decide rather than any age-related limitation.

Advance requests

Distinct from advance directives, advance requests would occur where capacity is expected to be lost – perhaps fairly soon, or possibly at some point in the more distant future. The current criterion for capacity expressly excludes acting on any request after capacity has been lost because it requires capacity at two points in time. There needs to be a capable written request to initiate the assessment and provision process as well as a further, final capable consent at the time of administration of the medications which fulfill the request.

The Canadian law also stipulates a reflective period of 10 days between the request and the assisted death itself but allows for shorter time frames for specific reasons, e.g. where loss of capacity is imminent [5 (S.241.2.3(g))]. This second point where capacity is required excludes anyone who loses capacity in that time between their formal request and its fulfillment. It also requires, in some instances, reducing pain medications to ensure consent can be capably given at the point of the assisted death being provided. More obviously, this criterion excludes anyone from creating an advance directive requesting an assisted death at any time after which they anticipate losing capacity (e.g., in dementia or other degenerative neurological condition).

These considerations of two points of capacity apply more straightforwardly to the situation where a medical or nurse practitioner administers the medications used to end life. The specifics that might arise where a prescription is provided and the medications dispensed for future self-administration without the presence of a professional are not so simply described. This may be, in part, one reason why assisted dying in Canada occurs almost exclusively through practitioner administration – most practitioners prefer to be involved to ensure all proceeds as planned. This practitioner administration is not allowed under any of the laws in the various jurisdictions of the United States where assisted dying is possible.

Mental illness as sole source of suffering

Where mental illness is the sole underlying condition, assisted death is excluded by one or possibly two criteria – irremediability and foreseeable death. Some will argue that mental illness is never to be considered irremediable, so would not qualify on that point. This argument is far from universally accepted as there is evidence that some individuals live with refractory symptoms despite many attempts to provide effective treatment.

The criterion of ‘reasonably foreseeable natural death’ excludes anyone whose sole underlying condition is not bringing them near death. However, there is the possibility that someone with mental illness might also qualify on other grounds (e.g., terminal cancer or ALS). Thus, it might be argued that the law does not discriminate on the ground of mental illness. So, it is odd that the review only examined requests in the context of mental illness and not all requests excluded by this same criterion. This larger group includes anyone who has a non-terminal condition but meets the other criteria. This particular criterion was not part of the Supreme Court ruling but was introduced in the amendments to the law, presumably in response to pressure to

limit access to the terminally ill. In wordsmithing language other than ‘terminally ill’ (which was absent from the Supreme Court ruling), the law allows for slightly broader access by those at least dying *soon-ish*, though this has also introduced a degree of variation in the interpretation of how far that breadth might extend⁵. The review singled out mental health, even though the text of the law does not. Thus, it could not consider individuals such as those people described above (Ramon, Tony, Omid, Julia and Nagui) living with grievous and irremediable non-terminal (or not-yet-terminal) physical conditions.

Some people in these circumstances may wish to have an assisted death, and many see this as a legitimate claim. If one accepts the notion of vulnerability framed as ‘denial of legitimate claims’, then the law arguably increases the likelihood of being wronged in this way. Even by the VPS definition of vulnerability, this would leave these individuals prone to a certain kind of harm – inadequate satisfaction of a legitimate claim, or as more strongly described elsewhere, an imposition of a duty to live [22]. A fuller, fairer and more equitable review would have considered everyone excluded by this criterion. This neglect of the interests of certain individuals who are not near ‘natural death’ is likely based on an overgeneralization of the idea of vulnerability. This overgeneralization disregards the literature highlighting the very individual and malleable experience of vulnerability [8,9,23-25]. Curiously, much of this literature was authored by some of those behind the VPS, prior to the Supreme Court ruling and the conception of the VPS itself.

There is no doubt that vulnerability must be addressed with a nuanced and balanced assessment of each individual’s situation. The Supreme Court of Canada made specific mention of the individual assessment of vulnerability in its *Carter* decision [26, par114-116], considering extant practice adequate for the purposes of assessing the eligibility of requests for assisted dying. This recognizes that healthcare practice is characterized by the application of ethical principles, often outlined in the codes of ethics in each profession. The next section of this paper will examine some of the ethical principles associated with rehabilitation practice – principles such as beneficence, non-maleficence, respect and autonomy. These are often seen to be elements of an overarching principle of client-centred practice.

Applying ethical principles of rehabilitation practice

It is, and should always be, unsettling to ponder the request to end a life that might otherwise continue for years or for dozens of years. For many healthcare professionals, the prospect of assisted dying for a client with so much potential living ahead sits uncomfortably with fundamental values and principles of their chosen profession, such as beneficence. The ‘good’ arising from upholding the principle of beneficence is manifest in roles throughout healthcare. In rehabilitation practice, the focus on enablement, through promoting function and independence, comes up against a particular challenge where a client is seeking an end to all function. Equally, the principle of avoiding harm seems to rule out assisted dying from the start – until one gets to grips with the client’s own analysis that their continued living is doing more harm than good. The client understands that good will come from the ending of their suffering. Lamentably, this also means the end of their life. Here lies the confusing counter-intuition – a person requesting assisted dying likely does not want to die, but recognizes that, for themselves, to die is a lesser harm compared to the suffering that accompanies living.

It is not difficult, however, to imagine that an enduring hope for improvement in a person’s valuation of their own life might lead to a shift away from the option of an assisted death and thus toward further years of meaningful and purposeful life. Such hope is a cornerstone of rehabilitation practice. There may be a point in time, however, where that hope is premised on thinning prospects for meaningful change in function or outlook.

At the same time, many will see the longstanding principle of client-centred practice as primary among ethical principles guiding their work [27]. It is typically interpreted to include respecting and promoting autonomy and treating each client’s situation as unique. Ideally, this means considering the options and outcomes in *similar* client situations as potentially *instructive*, but not as *prescriptive*. Each client’s own assessment of meaning and purpose in life is to be respected. In the context of pondering an assisted death, this is no less than an individual’s assessment of the meaning of life and weighing the goods and harms a life offers. That assessment includes a person’s analysis of whether they are able to maintain valued life roles, activities and connections that give life its meaning for them.

As was mentioned above, considering vulnerability means addressing all claims any individual client may have that are at risk of being denied. It seems important to assert here that the well-intentioned professional inclination toward protective paternalism must also be assessed for its potential to create an unintended vulnerability. Such an unintended vulnerability may arise with the denial of what might be legitimate claims to an assisted death, especially those claims that are likely to be denied because they cause distress to *others*, perhaps by affronting deeply held values about life. Whether these ‘others’ have any legitimate claim to being spared this distress (beyond the conscience rights they retain) is another question to be explored and resolved.

It is possible that rehabilitation professionals are more likely to experience distress than other healthcare providers when non-terminal conditions lead to a request for an assisted death. Those who work in rehabilitation are particularly aware that there are many ways to enrich lives in the context of grievous and irremediable non-terminal conditions. Rehabilitation professionals regularly accompany people through the experience of despair or frustration to an experience of significant improvement,

⁵ The problematic nature of the phrasing of this criterion – which is novel in both law and medicine – has already resulted in one court case to affirm the clinician’s judgement. See the story of AB [21].

greater purpose and restored meaning. Rehabilitation practice, to a greater extent than many other specialized areas of healthcare, adopts a holistic perspective that includes this central regard for purpose and meaning, and their restoration – even where other more concrete sorts of improvement in functional abilities are no longer part of the plan.

For many rehabilitation professionals, the reflex in response to talk of assisted death may be to redouble efforts to make evident what ‘goods’ are still possible within the experience of an individual with some form of disability. This involves the critical work of adapting attitudinal environments to be more receptive of difference⁶. This necessarily involves both promoting independence of individuals and generally challenging discrimination and prejudice, thus asserting the value of *all* lives.

For a small minority of clients, however, it appears that the prospects for recovering enough of what might be of value in life to make it worthwhile are persistently elusive. This judgement of what is valuable is a profoundly personal one, albeit situated in the context of one’s relationships with others. It is premised upon personal moral values and one’s self-identity. Similar ‘functional’ outcomes, measured objectively, in two different life stories may still lead to different individual subjective opinions about the worth of each of those lives. In some situations, an individual can capably⁷ conclude that death is clearly a preferable option from among those that are available. That capable decision must be a fully informed one, and rehabilitation practitioners have a clear role in helping an individual understand and appreciate the options that are available for maximizing engagement, capabilities and the restoration of meaning and purpose.

This role in making options evident may be a key role in responding to requests for assisted death. It may, however, end up serving two seemingly conflicting ends – enlarging the prospects for meaning and purpose in some lives while reinforcing the decision to pursue an assisted death in others. This will, at times, amount to supporting one person’s determination of their own life being not worth living while also maintaining that the value of the lives of others remains intact. It is here that many rehabilitation professionals may find that the idea of client-centred practice is most challenging, as one may see continuing potential for meaning and purpose where a client’s own assessment is very different. This would represent a reversal of the well documented ‘disability paradox’ where people with disabilities report a higher quality of life than external observers [29]. In both situations, the individual living with the grievous and irremediable condition is arguably best placed to judge its quality, meaning and worth – and make the decision about continuing to live or opting for a supported, comfortable and stigma-free end where legally permitted. This tension between differing views will be discussed further in the next section.

The differing views of those with the experience of disability

Most disability advocates and advocacy groups are passionately and vocally opposed to assisted dying, insisting that to offer it in situations beyond the end-of-life (i.e., where death is not reasonably foreseeable) devalues the lives of *all* persons with disabilities. A full review of these perspectives on assisted dying is beyond the scope of this article, but some aspects of typical positions are worthy of mention. Many speak to the tension present in what had been described above – attempting to uphold apparently conflicting legitimate claims. The fundamental concern routinely revolves around maintaining that disabled lives are worth living while pondering that some people with disabilities declare they would prefer to end theirs. There is also reference to the evidence of inequitable access to health services and generally compromised social determinants of health among many of those who live with a disability. This, it is argued, undermines the legitimacy of real choice around assisted dying [30].

Reasoning in these arguments often involves some form of reliance on the idea of slippery slopes – once such practice begins in a limited fashion, it will lead to ever more acceptance of the idea of assisted dying, and ultimately to more indiscriminate practice [31]. A related argument holds that the devaluation of disabled persons’ lives has been used to justify violence and even murder of disabled people, and that making non-terminal disability an eligible condition for assisted dying may further devalue the lives of *all* people living with disabilities [32].

At least one very prominent voice of disability rights in Canada makes what many consider a questionable reference to the Nazi euthanasia program and draws out what they see to be similarities in the intentions and principles put forward to justify assisted dying [33]⁸. Readers can make their own judgement about the usefulness of relying on slippery slopes arguments and Nazi comparisons, which have been critiqued by others [39-42]. Also of note is the choice by most of those advocates referenced above to use the term ‘assisted suicide’ rather than ‘assisted dying’ or ‘assisted death’.

A very concerning suggestion is that in for profit healthcare systems where private companies act as insurers (as opposed to jurisdictions like Canada where healthcare is publicly funded), these insurers will prefer to provide cover for assisted dying over the more expensive option of continuing to live when ongoing life-sustaining or life enhancing interventions are likely [43]. These concerns are very real and do manifest in specific ways in the Canadian context – where individual practitioners make

⁶ A case in point is the unacceptable way in which one person’s healthcare was seemingly influenced by another’s judgment about their life’s quality and value – see [28].

⁷ ‘Capable’ here would be defined as in healthcare consent law within specific jurisdictions. This typically includes the two-part requirement that someone has the ability to understand all the relevant information pertinent to the decision and appreciates how this relates to their specific situation. This would include understanding and appreciating the reasonably foreseeable consequences of their decision or lack of decision after being fully informed about all options available and the consequences of not pursuing a treatment. The individual must also be making the decision freely – without undue influence or coercion.

⁸ Others who do not identify as disabled also make reference to the Nazi euthanasia program. Frazee [33] references Harvey Schipper’s opinion piece in *The Globe and Mail* [34]. Margaret Sommerville references Catherine Frazee’s article (also published in *The Times Colonist* on 15 June, 2017 [35]) in her comment in *The Guardian* on 20 September, 2017 [36]. See also Peter Saunders blog *Christian Medical Comment* [37]. Finally, Gill’s earlier more academic arguments [38], unrelated to Canada’s law, achieve more nuance in perspective, but this is subsequently lost on those commenting in the other opinion pieces listed above.

judgements about someone's quality of life [42] or where systems level resource allocation does not adequately satisfy the needs of some individuals' circumstances, even though an assisted death might be made available [44].

These arguments are not unique to those speaking from a disability perspective. They are echoed in more general opposition to assisted dying – with the restriction of access to the terminally ill being seen as the most important of all safeguards (as in the VPS).

It is clear, however, that not all people who live with or have lived with disabilities share their perspective – given, among others⁹, the stories above. Such divergence of opinion is to be expected when one considers the wide range of experiences of those living with various forms of disability or difference in functioning. In the broadest of brushstrokes, this range varies across admittedly crude categorical divides such as physical/psychological, acquired/lifelong, progressive/static and the visible/unobservable. But more meaningful variations are to be found in the degree of impact on an individual's function and quality of life – which is evaluated in different ways by different people. Some of these factors are variable both over time and with supportive interventions, including attention to the impact of improving the social determinants of health.

It is important to note here that the continuing inequities of opportunity for those living with disabilities are undeniable, and the ongoing societal obligation to create a more equitable society and healthcare system endures¹⁰ [47]. That these persisting inequities are sufficient reason to deny as illegitimate *all* claims to assisted dying where disability is implicated is not a conclusion universally accepted by all of those who live with these disabilities. How best to serve the differing interests of all remains the complex, nuanced challenge of addressing vulnerability in a less generalized fashion. In the context of assisting to end the life of an individual who has been deemed it to be so replete with suffering as to be not worth living, this includes adequate safeguards to enable satisfaction of legitimate claims according to appropriate eligibility criteria.

The fundamental basis of the ethical reasoning for making legal assisted dying possible is the minimizing of suffering. Such suffering can manifest in many ways for many reasons – often happenstance. A just legal framework for assisted dying would make it available to as many as is ethically defensible and administratively workable. The next section examines a trio of situations where the current law seems to opt for continuing the lottery of happenstance rather than seeking a well-reasoned, appropriately safeguarded fairness in access.

Safely levelling the odds in the (end of life) 'lottery'

There are multiple dimensions associated with an individual's determination of the overall value of their own life. These include many aspects of life and health and dying and death that are more or less distributed by chance, a kind of 'lottery'. The specifics of each person's experience are always unique, hence the need to avoid overgeneralized approaches to the restricting of options like assisted dying. Given this endless variation in life experiences, pondering them all is impossible. In an attempt to achieve some form of overview, it is worth engaging in another limited form of generalization – considering just three 'archetypal' situations. These categorizations will be necessarily simplistic and are intended to focus on and compare only the broadest, but most pertinent, elements involved. In response to any particular request for an assisted death, many details would need to be explored individually.

The first archetypal scenario is one where a hallmark feature is the ongoing need for a particular life-sustaining intervention, like a ventilator or dialysis. This reliance on a life-sustaining intervention leaves the individual with the option to capably choose to withdraw that intervention at any time, bringing about their own death. In the case of a ventilator, this may involve air hunger and anxiety. General fatigue, potential pain and breathing difficulties would likely accompany dialysis withdrawal. Such a choice would typically be accompanied by comprehensively compassionate care that minimizes the physical and psychological distress ensuing after the withdrawal.

A second generalized scenario unfolds differently, without any particular 'critical dependency'. Instead, there is slow loss of various bodily functions, perhaps increasing pain, decreasing functional independence and progressing overall decline towards eventual death. There is no single life-sustaining intervention that can be refused and discontinued. Certain cancers can create this experience, as can multiple systems atrophy or other degenerative neurological, cardiovascular or advanced arthritic conditions. Each of these conditions will produce a unique constellation of symptoms for each individual who lives with them. For some, but not all, there may be points of complication or acute illness that present the option of withholding the treatment that would keep them alive – an acute pneumonia or septicemia, for example.

A third situation to consider involves living with potentially profound, but much more static, limitations, losses or other differences of function. For some people, these will give rise to physical or psychological suffering. This sort of situation may result from lifelong or acquired neurological conditions – cerebral palsy, acquired spinal injury, stroke or meningitis. There may be lifelong habituation to the difference in function if it has been present since birth or early childhood (e.g. cerebral palsy or spina bifida), or the change might be sudden and traumatic after unexpected onset or a precipitating event (e.g. stroke, spinal cord injury).

⁹ The perspective of Canadian Steven Fletcher, former Conservative Member of Parliament, is also worth noting here [45].

¹⁰ The column cited here was also submitted to and quoted in the final report of the External Panel on Options for a Legislative Response to *Carter v. Canada* [46].

To compare across these situations, recall that for those who have the ‘perverse luck’ of the first situation, the option of withdrawal of a life-sustaining treatment has been legal for decades. This bit of ‘luck’ may eventually appear in the lives of those living in something like the second scenario, after a period of worsening symptoms finally presents the option of withholding a new life-sustaining intervention or later withdrawing it. For those living in the third type of situation, there may be little prospect of the option to withhold or withdraw life-sustaining treatment for many years, even decades.

As discussed above, it is often noted that for anyone in any situation there is the possibility of capably deciding to stop eating and drinking in order to bring one’s own life to an end. In a strange, if not absurd twist, this approach has been used in order to achieve eligibility for an assisted death under current Canadian law [48,49]. Equally, for those who are physically capable, other more immediate forms of ending one’s own life are possible. These would be classified with the conventional label of ‘suicide’, rather than assisted death owing to an underlying condition, with this reflected in the death certificate. However, it seems more perverse than the lottery itself to suggest that these extreme options be the only ones available to everyone excluded by the current criteria. While ‘suicide’ may be a legal option, it does not make it the most ethical option, given it carries other harms. These include the isolating and distressing task of planning how to end one’s life with no assistance whatsoever, stigma and trauma for family and friends, further disability or illness where the suicide is unsuccessful as well as further burden for family and friends and healthcare providers who must then respond to the resultant situation. Equally, if the physical ability to end one’s own life is seen to render the eligibility to medical assistance in dying invalid because assistance is not actually required (as some have argued in the case of mental illness in particular [50,51]), it would likely follow that even in cases where natural death is reasonably foreseeable this exclusion must also hold if physical abilities exist to effect one’s own death by unassisted means. This argument would invalidate many, if not most, of the assisted deaths in the author’s experience – where natural death was reasonably foreseeable.

The reasons for the recent change in Canadian law to allow assisted death were primarily to enable the possibility of a more humane ‘helping hand’ from a physician or nurse practitioner where a legitimate claim to that helping hand can be made. The practice of assisting death is, from one perspective, a matter of intervening to make this perverse lottery slightly more equitable – by offering an intervention where there is nothing to readily withhold or withdraw.

For many people who might find themselves in the second sort of situation, and for all those who would be in the third, this helping hand option is unavailable because of the ‘foreseeable death’ criterion. The varying options available to different individuals in these three types of situation appear to present by chance, despite the possibility of similar levels of suffering and equally poor possibilities for remediation. Presumably, though, when one finds oneself in the first type of situation, the decision to withhold or withdraw a life-sustaining treatment immediately gives rise to a reasonably foreseeable death and one can be provided with the more immediate, comfortable and certain option of an assisted death. And, as discussed earlier, VSED can eventually bring about the desired death, but it also opens up the option of assisted death before that.

A law that perpetuates this sort of ‘perverse lottery’ and supports only those that make the choice to withdraw or withhold life-sustaining treatment or hydration/nutrition seems something of a perversion itself.

Proscribing personal choices – ethical and professional considerations

Ultimately, the infinite variability in the experiences of living with differences/disabilities arguably brings the principle of client-centred practice to the foreground in deliberations on the matter of the meaning and purpose of life and the reasons for bringing about its end. The answer to this question is ultimately a personal and highly individual one. Wherever such a person opts, capably, for ending their life, the meaning of the principle of client-centred practice is placed into stark relief for any healthcare professionals hoping to enable deeper engagement in life [52]. The best judgements, needs and wishes of clients and those of professionals might come into apparent conflict. However, professionalism requires respecting the autonomy of a capable and informed client, and recognizing that over-attending to one’s own misgivings, hesitations and distress can increase the likelihood that the legitimate claims of others will not be satisfied (i.e. vulnerability will be created) [53]. Where the professional’s own discomfort about assisted dying is given primary weighting, this may lead some to prioritize their own moral comfort over the reported suffering of others [41].

In considering the possibility that some grievous and irremediable non-terminal conditions could or should be included under Canada’s law, it will be important to consider the sorts of claims that might be made and what specific safeguards are needed to distinguish those claims that are legitimate from those that are not. These safeguards will need to be constructed carefully so that they are neither overly broad nor indefensibly disproportionate, otherwise they would be exclusive to the point of being discriminatory. A broader legal eligibility might also be supported by more refined clinical practice guidelines that speak to evidence based, standardized approaches to capacity evaluation and determination of ‘irremediability’ applied in any individual situation. This may involve outlining a conceptual process of collaboration between the capable person requesting an assisted death and the practitioners involved in their care. In considering the question with respect to some specific conditions, there may be a requirement for critical periods of time to pass prior to the determination of irremediability [54,55]. Specific interventions focused on quality of life might be identified as minimum baselines before a client can be considered capable, fully informed and the criterion of irremediability be declared with adequate assurance [56-58]. The task of creating these will be an unsettling one as there will always be some degree of uncertainty, and the lure of hope for further gains and future

treatment options will linger. It will also be a lamentable task as it will require considering and accepting the fact of the limitations of rehabilitation practice at any point in time. It is, however, arguably better to grapple with this endeavour presently. If it is postponed, there may likely be another court challenge [59] requiring a sudden change of practice for which many may not be psychologically prepared.

With high regard for individual lived experience, and a great deal of ethical deliberation, the legal and practice framework for assisted dying in Canada can become an enemy to fewer individuals who suffer intolerably and indefinitely with no reasonably foreseeable death. Those among them who make an eligible request can be compassionately and safely liberated from that highly over generalized category of 'the vulnerable', and consequently from their suffering.

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