


BRIEF REPORT

Operationalizing the Intolerable Suffering Criterion in Advance Requests for Medical Assistance in Dying for People Living with Dementia in Canada

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Abstract

In Canada, there is interest in expanding medical assistance in dying (MAID) to include advance requests (AR) for people living with dementia (PLWD). However, operationalizing the intolerable suffering criterion for MAID in ARs for PLWD is complicated by the Canadian legal context—in which MAID is understood as a medical intervention and suffering is conceptualized as subjective—and the degenerative nature of dementia. ARs that express a wish to receive MAID when the PLWD develops pre-specified impairments are problematic because people are unlikely to accurately predict the conditions that will cause intolerable suffering. ARs that express a wish to receive MAID when the PLWD exhibits pre-specified behaviors that likely represent suffering are problematic because they are inconsistent with the subjective conceptualization of suffering. Further research is required to determine whether adopting an objective conceptualization of suffering is justified in these cases and, if so, how to reliably identify intolerable suffering in PLWD.

Keywords: advance requests; dementia; Canada; medical assistance in dying; suffering

Introduction

In 2015, the Supreme Court of Canada's (SCC) decision in *Carter v. Canada* overturned the prohibition of medical assistance in dying (MAID) in Canada.¹ In 2016, Bill C-14 legalized MAID in Canada, limiting access to MAID to individuals (1) who were suffering intolerably from a grievous and irremediable medical condition, and (2) whose death was reasonably foreseeable (see [Box 1](#) for full Bill C-14 MAID eligibility criteria).² In 2019, Bill C-7 was passed, expanding MAID eligibility criteria to include individuals whose death is not reasonably foreseeable (see [Box 2](#) for full Bill C-7 MAID eligibility criteria).³

Since Bill C-14, advance requests (AR) for MAID have been identified as an area of potential expansion of MAID in Canada.^{4,5,6} An AR for MAID is defined as “a request for MAID, created in advance of a loss of decision-making capacity, intended to be acted upon under the circumstances outlined in the request after the person has lost decisional capacity.”⁷

Special attention has been paid to ARs for MAID for people living with dementia (PLWD).^{8,9} However, it is unclear how ARs for MAID for PLWD ought to be operationalized. Manifold factors warrant consideration, including the moral authority of advance consent, the availability of care services, the role of substitute decision-makers, the stigmatization of PLWD, the protection of vulnerable members of society, and the nature of suffering.^{10,11}

In this article, I focus on the operationalization of the intolerably suffering criterion in ARs for MAID for PLWD in Canada. I limit my discussion to ARs for MAID that are created when the PLWD has

Box 1. Bill C-14 MAID eligibility criteria (2016–2021)

- (1) A person may receive medical assistance in dying only if they meet all of the following criteria:
- a) they [patients] are eligible—or, but for any applicable minimum period of residence or waiting period, would be eligible—for health services funded by a government in Canada
 - b) they are at least 18 years of age and capable of making decisions with respect to their health;
 - c) they have a grievous and irremediable medical condition;
 - d) they have made a voluntary request for medical assistance in dying that, in particular, was not made as a result of external pressure; and
 - e) they give informed consent to receive medical assistance in dying after having been informed of the means that are available to relieve their suffering, including palliative care.
- (2) A person has a grievous and irremediable medical condition only if they meet all of the following criteria:
- a) they have a serious and incurable illness, disease, or disability;
 - b) they are in an advanced state of irreversible decline in capability;
 - c) that illness, disease, or disability or that state of decline causes them enduring physical or psychological suffering that is intolerable to them and that cannot be relieved under conditions that they consider acceptable; and
 - d) their natural death has become reasonably foreseeable, taking into account all of their medical circumstances, without a prognosis necessarily having been made as to the specific length of time that they have remaining.

Box 2. Bill C-7 MAID eligibility criteria in Canada (2021–Present)

- (1) A person may receive medical assistance in dying only if they meet all of the following criteria:
- a) they [patients] are eligible—or, but for any applicable minimum period of residence or waiting period, would be eligible—for health services funded by a government in Canada;
 - b) they are at least 18 years of age and capable of making decisions with respect to their health;
 - c) they have a grievous and irremediable medical condition;
 - d) they have made a voluntary request for medical assistance in dying that, in particular, was not made as a result of external pressure; and
 - e) they give informed consent to receive medical assistance in dying after having been informed of the means that are available to relieve their suffering, including palliative care.
- (2) A person has a grievous and irremediable medical condition only if they meet all of the following criteria:
- a) they have a serious and incurable illness, disease, or disability;
 - b) they are in an advanced state of irreversible decline in capability; and
 - c) that illness, disease, or disability or that state of decline causes them enduring physical or psychological suffering that is intolerable to them and that cannot be relieved under conditions that they consider acceptable.

decision-making capacity and is not suffering intolerably. I begin by arguing that—because MAID is seen as a medical intervention in Canada’s legal context—the moral authority of patient autonomy in ARs for MAID is circumscribed by healthcare practitioners’ (i.e., physicians and nurse practitioners) duty of care. Second, I argue that the intolerable suffering eligibility criterion for MAID is necessary because it allows MAID to be provided in accordance with the duty of care. Third, I argue that operationalizing the intolerable suffering criterion for PLWD is complicated by (1) the SCC’s subjective conceptualization of suffering, and (2) the degenerative nature of dementia. Finally, I explore two potential ways to operationalize the intolerable suffering criterion in ARs for MAID for PLWD.

Patient autonomy and the duty of care

The moral authority of patient autonomy is central to the ethical justification of MAID. In 2011, the Royal Society of Canada Expert Panel on End-of-Life Decision-Making argued that autonomy grounds

the primary ethical justification for MAID: “[t]he commitment to autonomy, which as we have seen is a cornerstone of our constitutional order... yields a prima facie right to choose the time and conditions of one’s death, and thus, as a corollary, to request aid in dying from medical professionals”.¹² Similarly, in *Carter v. Canada*, autonomy was the central justification in the SCC’s decision to overturn the prohibition of MAID in Canada.¹³

However, the moral authority of patient autonomy in medical decision-making is not absolute; it is circumscribed by healthcare practitioners’ duty of care. The duty of care is grounded in the principle of beneficence. It requires healthcare practitioners to protect and promote their patients’ medical interests.¹⁴ Autonomy grounds patients’ right to choose between or decline indicated treatments, but it does not ground a right to demand treatments that fall outside the scope of professionally validated treatment: “patients may be denied treatment options when those options violate the bounds of acceptable practice.”¹⁵ For example, patients with high blood pressure may choose one of the first-line medications for high blood pressure (e.g., beta-blockers, calcium channel blockers, or angiotensin-converting enzyme inhibitors); but they may not demand opioids to treat this condition because, for this medical problem, prescribing opioids would be inconsistent with the duty of care.

In *Carter v. Canada*, the SCC conceived of physician assistance in dying as a medical intervention that exists along a continuum of care with other end-of-life treatment options:

The law allows people [who are enduring intolerable suffering caused by a grievous and irremediable medical condition] to request palliative sedation, refuse artificial nutrition and hydration, or request the removal of life-sustaining medical equipment, but denies them the right to request a physician’s assistance in dying. This interferes with their ability to make decisions concerning their bodily integrity and medical care and thus trenches on liberty.¹⁶

Understanding MAID as a medical intervention means that healthcare practitioners must only provide MAID if it is concordant with the duty of care. The eligibility criteria for MAID help define these circumstances (Box 2).

Intolerable suffering

Intolerable or unbearable suffering is an eligibility criterion for MAID in every country in which MAID is legal, including Canada.¹⁷ This criterion is necessary because it allows healthcare practitioners to prescribe MAID in accordance with the duty of care. To see how, suppose death represents well-being of zero. When patients experience irremediable, intolerable suffering, their well-being is worse than death. In such cases, MAID is concordant with the duty of care because it promotes patient well-being.

Unlike the other MAID eligibility criteria, which are open to assessment by others, in Canada, the intolerable suffering criterion is understood to be subjective. The *Carter v. Canada* decision specifies “enduring suffering that is intolerable to the individual in the circumstances of his or her condition” as a key eligibility criterion for MAID.¹⁸ This is consistent with a subjective conceptualization of suffering because the suffering must be intolerable “to the individual.” By contrast, the “reasonable person” standard is typically used in objective legal tests.¹⁹ If the SCC had conceptualized suffering as objective, then the intolerable suffering eligibility criterion would have been something to the effect of “enduring suffering that would be intolerable to a reasonable person under similar circumstances.”²⁰

The SCC’s conceptualization of suffering in *Carter v. Canada* aligns with Eric Cassell’s widely accepted view of suffering. He argues that an individual’s experience of suffering depends on their interpretation of their situation in relation to their values, beliefs, social roles, relationships, and life course.²¹ This means that if two patients experience the same physical pain, mental anguish, living environment, and social support, one may judge their suffering to be intolerable, while the other may not.

Understanding suffering in this way places substantial moral weight in the patient's interpretation of their lived experience. To some extent, patients decide when their suffering meets the threshold of intolerability.

Intolerable suffering in dementia

The intolerable suffering criterion is difficult to apply to PLWD. The degenerative nature of dementia complicates the evaluation of suffering in two ways. First, dementia can cause people to lose the ability to evaluate their own suffering. Deciding that suffering has met the threshold of intolerability is cognitively complex; on Cassell's view of suffering, it requires contemplation of one's values, physical condition, and circumstances. Dementia can erode people's ability to think in this complex way. And second, dementia can interfere with people's ability to communicate. Even if a PLWD has the cognitive capacity to determine that their suffering is intolerable, they may not be able to convincingly communicate this opinion to healthcare practitioners.

But deciding when to enact an AR for MAID for a PLWD hinges on whether intolerable suffering is occurring. Like the autonomy of patients with decision-making capacity, the moral authority of ARs for MAID is circumscribed by the duty of care. As argued above, MAID is only concordant with the duty of care if the patient is suffering intolerably at the time of the provision. Past suffering or hypothetical future suffering is insufficient to justify the provision of MAID. Therefore, ARs for MAID for PLWD need to be designed in a way that helps healthcare practitioners determine whether intolerable suffering is occurring.

Operationalizing the intolerable suffering criterion

In this section, I outline and analyze two ways that the intolerable suffering criterion might be operationalized in ARs for MAID for PLWD in Canada's legal context.

Option 1: Pre-specified impairments

One option is to allow PLWD to pre-specify a set of impairments that they believe will cause them to suffer intolerably. For example, a PLWD could specify that "not being able to recognize [their] family members, being bedridden, or not being able to eat... would constitute their intolerable suffering".²²

This approach is problematic because it is not reasonable to expect people to be able to accurately predict the conditions that will cause them to suffer intolerably. There are two reasons to doubt a person's ability to predict this accurately.

First, many people might be biased against living with dementia. The "disability paradox" refers to the well-documented phenomenon wherein some people living without disabilities underestimate the quality of life of people living with disabilities.^{23,24,25} For example, people who do not have a colostomy tend to overestimate the negative impact of a colostomy, relative to what people living with a colostomy self-report.²⁶ Remarkably, even people who previously lived with a colostomy tend to overestimate the negative impact of a colostomy.²⁷

Some evidence suggests that similar biases might exist when it comes to living with dementia. A survey in the United Kingdom recently showed that Alzheimer's disease has overtaken cancer as the most feared disease.²⁸ Further, family members and healthcare practitioners who care for PLWD tend to rate the quality of life of PLWD significantly lower than the PLWD self-reports.²⁹ These prevalent prejudices cast doubt on people's ability to predict how they will adapt to living with dementia and thereby give us reason to question their ability to accurately predict the impairments that will cause them to suffer intolerably as their dementia progresses.

Second, dementia may change people's experience of suffering. Emily Walsh argues that dementia may be a "cognitive transformative experience," defined as an experience "which alters a person's cognitive capacities in such a way that may change the way the person thinks about their preferences,

values, and beliefs.”³⁰ These unpredictable changes might change a person’s subjective experience of suffering. For example, for someone who is cognitively well, the idea of losing the ability to recognize family members is understandably distressing. But for a PLWD who has lost the ability to recognize family members, concurrent changes in preferences, values, and beliefs might alter their perception of suffering such that they are no longer distressed by the loss of this ability.

For these reasons, designing ARs for MAID for PLWD to have pre-specified impairments that attempt to predict the occurrence of intolerable suffering is not a satisfactory solution.

Option 2: Pre-specified negative behaviors

Another option is to design ARs for MAID for PLWD that allow PLWD to express a wish to receive MAID when they exhibit pre-specified negative behaviors that are likely to represent intolerable suffering, such as recurrent agitation that requires chemical or physical restraints.

This approach is problematic because it is inconsistent with the SCC’s subjective conceptualization of suffering. If we understand suffering as subjective, then outside observers cannot, in principle, determine whether another person’s apparent suffering meets their personal threshold of intolerability. If our commitment to the subjective conceptualization of suffering is absolute, then ARs for MAID for PLWD that express a wish to receive MAID when they exhibit pre-specified negative behaviors are, in principle, unacceptable.

However, adopting an objective conceptualization of suffering for these cases could allow us to move forward with ARs for MAID for PLWD. Up to 80% of PLWD develop behavioral and psychological symptoms of dementia (BPSD), such as hallucinations, physical and verbal aggression, apathy, and agitation.³¹ These behaviors are commonly viewed as manifestations of suffering. A variety of health measurement scales exist for scoring the severity of BPSD.^{32,33,34} Scoring BPSD could be a fruitful method for operationalizing the intolerable suffering criterion in ARs for MAID for PLWD.

But this approach would be challenging. In cases of severe, treatment-resistant BPSD, it seems uncontroversial to conclude that the PLWD would meet the criterion of intolerable suffering. Otherwise, determining the threshold of intolerable suffering based on BPSD is logistically and ethically fraught. None of the BPSD health measurement scales have been validated for this application, and it is unclear how to determine what frequency and severity of BPSD ought to qualify as intolerable suffering. Further conceptual research is required to determine whether an objective conceptualization of suffering should be applied in this circumstance. And, if so, further empirical research is required to develop health measurement scales capable of reliably capturing intolerable suffering.

Conclusion

The SCC’s decision in *Carter v. Canada* conceptualizes MAID as a medical intervention. In this context, the intolerable suffering eligibility criterion for MAID is necessary to ensure that MAID is provided in accordance with the duty of care. But the SCC’s subjective conceptualization of suffering is incompatible with the operationalization of ARs for MAID for PLWD. Further conceptual research is required to determine whether adopting an objective view of suffering is justified when evaluating patients who cannot assess or express their own suffering. If adopting an objective conceptualization of suffering in these cases is acceptable, then further empirical research is required to develop health measurement scales that can reliably identify intolerable suffering among PLWD who have lost the capacity to express themselves.

Acknowledgments. The author gratefully acknowledges the assistance of Jess du Toit, Cory E Goldstein, Nicholas Murphy, Pepijn Al, Anand Sergeant, Matthew Tse, Caitlin Lees, Melissa Andrew, Cesar Palacios-Gonzalez, and Charles Weijer. The author would also like to thank the anonymous peer reviewers for their insightful feedback.

Competing interest. The author declares none.

Notes

1. *Carter v. Canada (Attorney General)*, 2015 SCC 5, [2015] 1S.C.R. 331 [Carter].
2. *An Act to amend the Criminal Code and make related amendments to other Acts (medical assistance in dying)*, SC 2016, c3 [Bill C-14].
3. *An Act to amend the Criminal Code (medical assistance in dying)*, SC 2021, c2 [Bill C-7].
4. See note 2, *Bill C-14* 2016, Preamble.
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7. See note 5, Council of Canadian Academies 2018, at 5.
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16. See note 1, *Carter* 2015, [66].
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20. See note 19, Government of Canada 2015. The text in quotations is not a direct quote from the cited source, but the idea originates from the cited source.
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