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Résumé de l'article

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COMMENTAIRE CRITIQUE / CRITICAL COMMENTARY (ÉVALUÉ PAR LES PAIRS / PEER-REVIEWED)

Advanced Requests for MAID: Are They Compatible with Canadian Medical Practice?

James Mellett^a, Cheryl Mack^{a,b}, Brendan Leier^{a,c}

Résumé

L'adoption récente du projet de loi C-7 a placé les directives anticipées d'aide médicale à mourir à l'ordre du jour législatif du Canada. Nous discutons de la façon dont ces directives anticipées peuvent créer des défis éthiques et pratiques pour la pratique médicale canadienne.

Mots-clés

aide médicale à mourir, directives anticipées en matière de soins de santé, demandes préalables, droit canadien de la santé, capacité, consentement, meilleurs intérêts

Abstract

The recent passing of Bill C-7 has placed Advance Requests for MAID (ARMs) on Canada's legislative agenda. We discuss how ARMs may create ethical and practical challenges for Canadian medical practice.

Keywords

medical assistance in dying, advanced healthcare directives, advanced requests, Canadian health law, capacity, consent, best interests

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INTRODUCTION

On 17 March 2021, Bill C-7 received Royal Assent (1). Bill C-7 modifies Canada's federal medical aid/ assistance in dying (MAID) regulatory framework, notably removing the criteria that those eligible for MAID have a death that is 'reasonably foreseeable.' It also eliminates the requirement that a patient give consent for MAID directly before its provision. This 'final consent deferral waiver' amendment allows MAID candidates to maximise remaining quality time without the fear and anxiety of losing capacity, and with it, their eligibility for MAID. However, for patients to use a written waiver to receive MAID in lieu of final consent, their death must be 'reasonably foreseeable.' The Bill then also directed that a parliamentary review begin within thirty days to examine whether MAID requests should be considered within the context of Advanced Healthcare Directives (AHD), i.e., Personal Directives, Living Wills, etc. Conceptually, these legal tools are seen by some as a natural extension of the final consent deferral mechanism, allowing those with a capacity-diminishing illness, such as dementia, to receive MAID without themselves having to trade quality time (2).

We discuss how AHD requests for MAID, commonly referred to as Advance Requests for MAID (ARMs), may create unintended and problematic challenges for Canadian medical practice, especially when applied to patients with dementia. We hope to describe how ARMs are likely not compatible with AHDs as they are currently designed and practiced, and identify significant conceptual and practical problems that ARMs could pose to the best-interests of patients, as well as to physicians and patients' families. We close by providing suggestions for more ethically and practically sound alternatives for those diagnosed with dementia who seek MAID.

THE ARGUMENTS FOR ADVANCED REQUESTS

While advanced requests for assisted dying are rare and legal in only four countries worldwide (3), the concept has its proponents. Arguments in favour of advanced directives centre on notions of autonomy, control, and the relief of distress and suffering (3). Supporters argue that ARMs enhance patient autonomy, allowing patients diagnosed with a capacity-diminishing illness to articulate and action their preferences on an acceptable quality of life and the circumstances of their death. An extension of this argument, proponents believe that ARMs would also relieve patients of the existential suffering of facing a chronic illness with a long and potentially debilitating disease trajectory by knowing that they could receive MAID. Moreover, proponents argue that ARMs would relieve patients in later disease stages from suffering brought by the disease and their illness experience. Lastly, supporters feel that ARMs relieve patients from facing a distressing dilemma: receiving MAID while they still have capacity but are enjoying an acceptable quality of life, or continuing to wait until their quality of life declines at the risk of losing capacity and not being able to receive MAID. There is concern that patients have addressed this dilemma by receiving MAID while they still have quality time remaining, or by committing suicide on their own (3). While the inclusion of a 'final consent waiver' in Bill C-7 relieves many patients of this concern, it is unclear how much it will benefit those diagnosed with dementia.

ARE ADVANCED REQUESTS FOR MAID COMPATIBLE WITH THE CURRENT USE OF ADVANCED HEALTHCARE DIRECTIVES?

The clearest and most beneficial role of AHDs are to stipulate levels or types of medical interventions that patients would find unacceptable. The power of these directives, particularly the capacity to refuse treatment, is derived from the medical/legal standard of consent (4). Canadian case law, which informed subsequent legislation, creates clear expectations of the process by which healthcare providers interact with patients to make decisions over treatment (5). There are two important aspects of consent for medical treatment that warrant examination in the context of ARMs. Firstly, the criteria necessary to establish consent: capacity, disclosure, and voluntariness. Secondly, recognition that capable patients have the right to refuse or withdraw *any* form of medical intervention, even if that intervention is life-sustaining or life-saving, with no rationale necessary to justify that decision.

This second aspect of consent creates an interesting asymmetry in understanding and expectations surrounding consent and by extension AHDs (6-12). For the most part, the explicit patient request, or more appropriately, a patient's withdrawal of consent of ongoing treatment, requires a physician to stop said treatment, with no argument or rationale from the patient necessary. A request for treatment, however, is not a sufficient condition to proceed with said treatment. As requests occur in the context of AHDs, descriptions of limiting treatment, stopping treatment, or refusing treatment we will refer to as *negative requests*. Requests for specific forms of treatment such as ventilation, hemodialysis, artificial feeding and hydration, etc., or requests for particular levels/philosophy of care, we will refer to as *positive requests*. The consent asymmetry we identified presents itself in this way: While negative requests from competent patients must be considered at face value (though good clinicians will always attempt to explore a patient's rationale), the provision of positive requests for treatment must fulfill two subsequent steps. Firstly, the three necessary criteria of consent: 1) patients must have the capacity to make the particular decision in question; 2) physicians must disclose the nature of the patient's condition, the proposed treatment, and harms associated with accepting or refusing the treatment; and 3) The patient must be free to make the decision, i.e., they must not be coerced by others or otherwise constrained or compelled. Secondly, positive requests must pass the test of medical justifiability: the intervention must be therapeutically beneficial to the patient, and more importantly, must not be disproportionately harmful to the patient. So, ideally, positive requests are a shared decision and the joint responsibility of patient and physician. In this shared decision-making model, the physician discloses information to the patient relevant to the medical decision, presents reasonable options, and the patient in turn takes their decision by incorporating this information with their values and preferences.

Negative requests, then, fit seamlessly into AHDs as they require little to no interpretation, and most importantly, are not subject to tests of best-interest, medical or otherwise, as they are grounded in a patient's inviolable right to express sovereignty over their body. On the other hand, positive requests, for MAID or any treatment, are not unilaterally binding. They are subject, not only to the consent process, but to the willingness of a physician to deem the intervention therapeutic and not disproportionately harmful (13). An AHD request to provide MAID to a patient lacking capacity would certainly fall into the category of a positive request. However, the determination that MAID would be therapeutic for a particular patient with later stage dementia would be difficult. As dementia progresses, the connection to prior personal identity, and the preferences associated with that past person are weakened; they can become inconsistent or substantively changed (14,15). Also, at advanced stages of dementia some patients experience anosognosia, or a lack of awareness surrounding their neurological condition, which can diminish the experience of existential suffering present at earlier stages (15). While MAID is not a traditional medical treatment per se, physician responsibilities for its administration remain the same. It is still critical that its provision not impose a disproportionate harm to patients (16). A positive request AHD, in this case an ARM, may likely then fail both criteria required for administration of a medical procedure. First, the details of the patient's future illness experience cannot be thoroughly disclosed given uncertainty over the cognitive changes that will occur, and consent cannot therefore be obtained. Secondly, these cognitive changes make it unclear whether a future physician could find MAID to be an intervention in the patient's best interests.

IS IT POSSIBLE TO WEIGH AND RESPOND TO THE INTERESTS OF THE PAST AND PRESENT PATIENT?

Determining the best interests of the present patient in an advanced state of dementia includes an assessment of the preferences, degree of suffering, and even if capacity is lost, the assent (for MAID) of the current patient. As described above, while advance requests may reduce the existential suffering of patients diagnosed with dementia at the time of diagnosis, it is unclear whether MAID is still in the best interests of the patient when it is time for them to receive MAID. A physician may then consider where their own fiduciary duty lies: with the patient's previously competent self, for whom MAID could provide a favourable best interests assessment, or with the present patient, for whom the best interests determination is less certain or is likely unfavourable (17). The concept dignity is often used to connect the favourable best interests assessment of the past patient with the patient of present. However, the current person who is now subject to a prior ARM is a bearer of rights, and as such, is as deserving of moral obligations as anyone. Thus, the present self, even in its current mental state, deserves considerations equal to that accorded the past self. The present patient is also the person whose interests physicians are traditionally required to maximize through the consideration of the physician's fiduciary duty.

The changes to identity, preferences, cognitive function, and experience seen with dementia pose a further challenge: how should physicians and families decide on the appropriate time to execute an ARM? While a patient may specify in their ARM

a threshold of quality of life at which they would like to receive MAID, providing MAID once the patient meets this threshold may still prove ethically challenging (15,18). For example, the patient's preferences may have changed, they may be inaccessible, they may not exist, or the patient, on the whole, may not demonstrate signs of significant physical or existential suffering. Such situations would place an enormous burden on the family and doctor to decide on timing.

While patients who create an ARM hope that the document will provide certainty to their end of life and dying experience, the demands may also conflict with the current medical practice of respecting a patient's explicit refusal for treatment, even in individuals who have lost capacity. Physicians are highly reluctant to force treatment on patients who have no capacity but maintain volitional behaviour. Common examples would include, for instance, patients extubating themselves of nasogastric tubes or refusing dialysis. Legally speaking, a surrogate can consent to any of these interventions. However, practically, clinicians respect, for the most part, the refusal of all the aforementioned. That is the culture of healthcare, based on a practical ethic of the proportionality of benefits of treatments with the harms of forcing them. Even the initial modifications of the Canadian MAID legislation included a preference to respect the refusal of volitional but incompetent patients who refuse MAID (1). The one strength/benefit of the personal directive request ideally is to assure the capable patient's desire is respected. However, the reality and culture of medicine means that the execution of an ARM would be far from certain.

THE EXPERIENCES OF JURISDICTIONS THAT ALLOW ARMS

The experiences of international jurisdictions that permit ARMs highlight the importance of these concerns. A review of assisted suicide reports from Dutch euthanasia committees found that many ARMs were ambiguous, with some requests not actioned due to the absence of sufficient suffering (19). Studies on the experiences of Dutch physicians found that ARMs have created numerous challenges. Physicians felt that ARMs had increased their emotional burden (20). They found it difficult to craft an ARM with patients given the uncertainty regarding the dementia disease process, they struggled with interpreting Dutch law surrounding ARMs, and encountered difficulties to manage the pressure applied by patients' families surrounding ARMs, notably, to execute an ARM (21).

LOOKING FORWARD: BALANCING ACCESS TO MAID FOR THOSE WITH DEMENTIA WITH THE CHALLENGES OF ARMS

As we have described, there are potential benefits for patients who are not faced with the burden of correctly timing one's death to avoid "missing the window," whereby one may no longer have the capacity to consent. As such, we commend the inclusion of a "final consent deferral waiver" into Canada's MAID framework. However, ARMs are likely incompatible with AHDs as they are currently designed and implemented in clinical practice, with the potential to create several ethical and practical problems. That said, those diagnosed with dementia should not be condemned with the prospect of a quality of life intolerable to them, or for them to trade large segments of "good time" to ensure the facilitation of MAID. Greater emphasis should be placed on supporting and enhancing the autonomy of those diagnosed with dementia, including on how healthcare decisions made for these patients can be most responsive to their preferences and experiences as the disease progresses (22). Patients with mild and moderate dementia are able to articulate preferences surrounding end-of-life care (23). Despite this, there are often discrepancies between caregiver beliefs on the content of these preferences, and those reported by patients themselves (24). Increased exploration of these preferences by physicians and families, and the use of existing MAID mechanisms where appropriate, would be a more ethically and pragmatically suitable alternative to ARMs. Working with patients and their families to identify and elaborate a patient's current end of life preferences promises a smoother ethical path than that offered by ARMs, including potential pressure placed on physicians from family members to execute an ARM. For without ARM legislation, physicians would be unable to execute an ARM regardless of family pressure. Use of the 'waiver of final consent' may even be appropriate if the patient may soon lose capacity, depending on interpretation of the term 'reasonably foreseeable' (25). Should a person's death from dementia be considered 'reasonably foreseeable,' then the patient may be eligible for a final consent waiver under Canada's current MAID legislation (1). Under the final consent waiver, the patient may be able to receive MAID shortly after losing capacity given that they, when capable, had articulated in writing that they would waive final consent to receive MAID should they lose capacity before receiving MAID on their chosen date.

CONCLUSION

As Canada continues to evaluate and modify its framework for MAID, it is essential for the medical and general communities to assess the potential benefits and harms of proposed amendments. Such an evaluation of advance requests for MAID highlights several ethical and practical challenges for patients, physicians, and patients' families. While those diagnosed with dementia should not be excluded from the option of MAID, there are more appropriate alternatives than ARMs for these patients and their caregivers that focus on supporting and actualizing a patient's current preferences.

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