DISCUSSION AND DEBATE

Commentary: Ethics and Advance Requests for MAiD: Thresholds and Applicability

Commentaire : Éthique et demandes anticipées d'AMM : seuils et applicabilité

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Abstract

We seek to highlight key ethical considerations that arise as Canada considers an expansion of medical assistance in dying (MAiD) to include advance requests. To do so, we will first highlight the ethical and practical concerns that arise with advance care planning and advance directives in general and then draw attention to the unique considerations that arise with advance requests for MAiD. Finally, we will take a closer look at the concerns that will arise with an expansion to include the population with dementia. We will argue that the stakeholder concerns for a vulnerable population such as dementia patients are significant. Legislative frameworks will need to address these concerns to ensure the safety of individual patients and support the role of surrogates and healthcare providers in this process.

Résumé

Nous cherchons à mettre en évidence les principales considérations éthiques qui se posent alors que le Canada envisage d'élargir l'aide médicale à mourir (AMM) pour y inclure les demandes anticipées. Pour ce faire, nous soulignons d'abord les préoccupations d'ordre éthique et pratique qui découlent d'une planification préalable de soins et de directives anticipées, en général, puis nous attirons l'attention sur les considérations particulières aux demandes anticipées d'AMM. Enfin, nous examinons de plus près les préoccupations qui découlent de l'élargissement de la demande anticipée aux personnes atteintes de démence. Nous soutenons que les préoccupations des intervenants concernant les populations vulnérables, comme les patients atteints de démence, sont importantes. Les cadres législatifs devront répondre à ces préoccupations pour assurer la sécurité des patients et pour mieux soutenir le rôle des mandataires et des fournisseurs de soins de santé dans ce processus.

Introduction

Advance care planning is an integral part of facilitating future medical care that aligns with a patient's values, life goals and preferences (Sudore et al. 2018). Advance care planning is not limited to persons who are facing complex medical journeys and a possible life-limiting diagnosis. As such, they can be written well in advance of any changes in a person's health status. Advance directives are legal documents that can be written in isolation from, or as part of, a more comprehensive advance care plan. Both advance care plans and advance directives are designed to support surrogates and healthcare teams tasked with making decisions in the patient's best interests. In theory, these documents help develop a patient-centred philosophy of care that extends autonomous decision making when a patient has lost the capacity to communicate their preferences.

An advanced request for medical assistance in dying (MAiD) (ARM) is a special form of advance directive but with a focus on the request for, and the timing of, an end-of-life (EOL) intervention. In Quebec, an ARM cannot be made as part of an advance directive and is subject to a distinct process (Government of Quebec 2024). An ARM can only be made by a person who is diagnosed with a "serious and incurable illness leading to incapacity" (Government of Quebec 2024), such as Alzheimer's disease. ARMs, while giving rise to distinct ethical considerations, are subject to many of the concerns that have been raised with both advance care planning and advance directives.

Strengths and limitations of advance care planning and advance directives

There are practical challenges to advance care planning and advance directives that stem from the non-contemporaneous nature of decisions being made. In any complex medical journey, there is a level of uncertainty involved in the construction of an advance care plan. At best, the patient can be informed about what that journey "might" look like based upon similar, but never identical, experiences. This limitation means that an advance directive cannot reach the standard of an informed consent. Surrogates and medical teams are often required to rely upon judgement to interpret the applicability of an advance directive in the context of a particular decision. This can lead to disagreements regarding levels of care being provided (Hall 2015; Pope and Richards 2015).

It is not uncommon for acute, potentially reversible changes in health status to occur alongside a more progressive palliative diagnosis. In such circumstances, it may be reasonable for an advance directive to be revisited and potentially adjusted in a time-limited manner. It may also be the case that some previously expressed preferences, taken together, may not be compatible and choices will have to be made. Ideally, any adjustments or choices occur with as much involvement from the patient as possible. The intention of revisiting an advance care plan is to help ensure that goal-concordant care is being provided.

Such challenges mean that studies looking at the outcomes associated with advance care plans have yielded mixed results (Jimenez et al. 2018; Malhotra et al. 2022; McMahan et al. 2021). Part of this concern arises from the types of patient outcomes that are used as key indicators and a mixed methodology that has often relied upon retrospective approaches. Given the role of advance care plans in extending autonomy, preference congruence with care delivery should be a priority goal (Rietjens et al. 2017; Sudore et al. 2018). However, as highlighted, mixed results will be expected to arise from the inherent complexity of health that is difficult to capture via the nature of advance care planning: a longitudinal process that involves a complex and uncertain medical trajectory, many stakeholders and a cross-section of clinical environments (Cohen et al. 2019; McMahan et al. 2021; Udelsman et al. 2020).

Regardless of these challenges, there is consistent evidence that advance care planning is considered important by critical stakeholders (Fulmer et al. 2018; Johnson et al. 2016; McMahan et al. 2013). Working through possible scenarios with knowledgeable healthcare providers can help patients articulate their current preferences and ask difficult questions. These conversations are an opportunity for building trusting therapeutic alliances between a patient and their caregivers. Advance care planning should be best understood as an ongoing process of shared decision making (Malhotra et al. 2021, 2022; McMahan et al. 2021; Sudore and Fried 2010).

Advance requests for MAiD: specific considerations

The importance of safeguards as protective measures for the effective implementation of an ARM is a key consideration (Espericueta 2025). Importantly, what is being safeguarded against must be clarified. We will concentrate on the concerns that arise fundamentally from the nature of an ARM, focusing on patients with dementia. These concerns would need to be addressed by any framework that will be developed to support the implementation of ARMs.

Understandably, facing an uncertain future of progressive illness and cognitive decline is distressing for patients and their carers (Yates et al. 2021). An ARM potentially relieves the existential suffering that can accompany a capacity-diminishing illness (Mellett et al. 2021). As it currently stands in Quebec, there is no necessity for ARMs to be integrated into discussions that will develop into a more comprehensive advance care plan. For such patients, it is important to inform them that an ARM represents just one final decision along a care path that likely will require many weighty decisions to be made. Without this integration, patients will still be vulnerable to a number of potentially burdensome, life-prolonging medical interventions that may not be concordant with their overarching philosophy of care. Without attention to all the domains of caring, other key preferences that will play a role in a patient's overall quality of life may be missed (Wehrmann et al. 2021).

The ability to articulate preferences on what constitutes an acceptable quality of life and make plans for the timing of MAiD when that threshold is lost is a key consideration that supports ARMs. However, with the proposal of an ARM, further autonomy concerns arise in the context of cognitive decline, particularly what ought to be within one's decisional scope. This scope cannot become so limited as to force people to live out their remaining days in an intolerable state, but simultaneously, there is a need for protections so that the vulnerable are not placed into a position of coercive, unwanted or ad hoc MAiD provisions.

The possibility of preference instability occurring alongside cognitive decline and capacity loss is an autonomy concern that will arise in ARMs. The experience of illness and cognitive decline can be transformative, with the potential to fundamentally alter our interests in ways that likely no document can account for (Walsh 2020). Evidence has demonstrated that EOL preferences can be unstable and change over time even when patients face serious, life-altering illness (Malhotra et al. 2022). The loss of capacity does not necessarily equate to a loss of valuing. How should surrogate decision makers and healthcare providers weigh the preferences and evaluations documented in an ARM if they no longer align with what is being expressed or demonstrated by the patient?

We must consider the well-being, interest and needs of the patient in front of us. This requires that we communicate with the patient and involve them as much as possible in the care they are receiving. This patient-centred care is consistent with the professional obligations of healthcare providers and with the duties of surrogate decision makers (Mellett et al. 2021). Prior capable wishes are respected but also need to be applicable in the context they are going to be applied. Relevant context to consider is whether the MAiD provision will conflict with the expressed wishes of a not wholly competent patient who nonetheless demonstrates opposition. It may be a "no," pulling away or simple facial expressions that lead us to question whether this is something the patient wants. Unless we arrive in a room wherein the patient is no longer an experiencing subject, our obligation to the patient in front of us, and their preferences, demands further exploration.[1] In these situations, what work does the ARM do? It seems that an advanced consent in many cases may be insufficient.

ARMs: safeguards

A robust system of safeguards would seek to protect first and foremost the interests of the patient but also the interests of surrogates and healthcare providers involved. Yet, critically, what has not been settled is how to understand the interests of the patient with dementia (Hall 2015; Pope and Richards 2015). How are surrogates and healthcare providers supposed to understand their obligations? Who is the patient is a legal question, but ethically it is clear; it is the patient in front of us. How we view and care for persons with dementia at the EOL impacts caring beyond this context. Valuing the patient in front of us is not a trivial obligation to be decided in a moment or in a court of law. Do we see a way forward? It seems an ARM ought best to be understood as a request for future MAiD consideration – a permission for a consultation triggered by the parameters identified within the document. The applicability of the request can then be assessed. This assessment would likely require input from healthcare providers with expertise in the patient population, clinical ethicists and legal professionals. Essentially, it would also seek to include input from the patient in front of us. Ultimately, the scope of the parameters in an ARM, the threshold setting itself, will require a broader discussion of what constitutes reasonableness, given a recognition that the interests of a person with dementia matters.

Note:

1. While the ability to have preferences and to be subject to one's life is paramount for decision making, the practicalities of communication mean that while some may be subjects, they may lack any ability at all to communicate preferences. As such, there is some threshold wherein barriers may modify the obligations we have to explore and what can reasonably be accommodated.

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