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Résumé de l'article

La législation canadienne sur l'aide médicale à mourir (AMM) a changé en 2021 ; les personnes n'ayant pas de mort naturelle raisonnablement prévisible (MNPR) peuvent désormais être éligibles à l'AMM et doivent attendre au moins 90 jours avant leur intervention. Ce changement législatif a soulevé une nouvelle question éthiquement complexe, que nous explorons dans ce commentaire, à savoir : Où les personnes qui ne sont pas en état de MNPR doivent-elles attendre (pendant 90 jours) dans un système de santé financé par l'État?

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

Where Do I Go to Wait? Ethical Considerations During the 90 Day Reflection Period for MAiD

Kesi Disha^a, Andria Bianchi^{a,b}, Ruby Shanker^{a,b}, Nikolija Lukich^c

Résumé

La législation canadienne sur l'aide médicale à mourir (AMM) a changé en 2021 ; les personnes n'ayant pas de mort naturelle raisonnablement prévisible (MNPR) peuvent désormais être éligibles à l'AMM et doivent attendre au moins 90 jours avant leur intervention. Ce changement législatif a soulevé une nouvelle question éthiquement complexe, que nous explorons dans ce commentaire, à savoir : Où les personnes qui ne sont pas en état de MNPR doivent-elles attendre (pendant 90 jours) dans un système de santé financé par l'État?

Mots-clés

aide médicale à mourir, AMM, bioéthique, réadaptation, polyphonie

Abstract

Canada's Medical Assistance in Dying (MAiD) legislation changed in 2021; persons without a reasonably foreseeable natural death (RFND) could now be eligible for MAiD and would have to wait at least 90 days before their intervention. This legislative change caused a new ethically complex question to arise, which we explore in this commentary, namely: Where should individuals without a RFND wait (for 90 days) in a publicly funded health system?

Keywords

medical assistance in dying, MAiD, bioethics, rehabilitation, polyphony

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INTRODUCTION

The topic of Medical Assistance in Dying (MAiD) is fraught with ethical complexity. Some specific areas of MAiD with documented ethics implications involve individual and/or institutional conscientious objection/abstention (1-3), capacity to consent in advance (4-6), and whether MAiD should only be permitted for people whose desire to hasten death is motivated by physical ailments (7-10).

Although MAiD has been legally available for over two decades in some jurisdictions (e.g., Belgium), it became legal in Canada in 2016. Recent amendments to the legislation in 2021 broadened the eligibility criteria; more people now qualify for MAiD, including individuals whose natural death is not reasonably foreseeable. Further, insofar as all eligibility criteria are met, a person whose natural death is not reasonably foreseeable must wait a minimum of 90 days before their MAiD intervention.

The purpose, here, is to highlight and respond to a pressing, though potentially underdiscussed, ethical question that three of the authors (NL, RS, AB) have asked of them, as practising healthcare ethicists (PHEs)¹, in non-acute care settings: In a publicly funded healthcare system, where *should* patients who want to receive MAiD spend their 90 day reflection and assessment period? As demonstrated in the sections below, this seemingly simple question is fraught with ethical complexity, and an ethical decision-making process is necessary by way of response.

We begin by briefly describing the development of Canada's MAiD legislation with a focus on the reasonably foreseeable natural death (RFND) criterion, or lack thereof. We introduce a hypothetical scenario that exemplifies the complexity involved in determining where a person ought to spend their 90-day assessment and waiting period, followed by an exploration of the ethical dilemma and potential options to consider in response to the scenario. We conclude by arguing that the most ethically defensible space for patients to spend the reflection period will be context-dependent – we propose some key questions and procedural suggestions to help healthcare workers and administrators reflexively respond to varying contexts.

It is important to note that each author of this paper embodies diverse identities, experiences, and perspectives, which inevitably influences our approach to the ethical concerns we describe. Each of our distinct voices come together to create what may sometimes be referred to as *polyphony*. Polyphony is the “multiplicity of independent and unmerged voices and consciousnesses... each with equal rights and its own world [that] combine, but do not merge, into the unity of an event.” (11) When diverse yet independent voices interact, they create polyphony, much like how individual musical instruments come

¹ Practising Healthcare Ethicist (PHE) is the preferred Canadian reference for bioethicists or ethicists working in a clinical setting. This title was developed during the professionalization movement in the early 2000s by the Practising Healthcare Ethicists Exploring Professionalization (PHEEP) (18), which is now called the Canadian Association of Practising Healthcare Ethicists – Association canadienne des éthiciens en soins de santé (CAPHE-ACCESS). In Canada, most PHEs still practice under the title of Bioethicist or Ethicist depending on their place of employment.

together to create a symphony of sounds. This process of polyphony, of recognizing and learning from varying perspectives and identities, of piecing together a justifiable discourse, is crucial to ethically defensible decision-making.

AN OVERVIEW: MEDICAL ASSISTANCE IN DYING IN CANADA, 2016-2021

In 2016, Canada legalized MAID (12), and from 2016-2021 a person who wanted MAID was only eligible if they met a narrow set of criteria. In order to qualify, a person needed to be: eligible to receive funded health services in the jurisdiction of the MAID intervention; at least 18 years of age; capable of consenting; have a grievous and irremediable condition; and provide a voluntary request (12). Additionally, death needed to be reasonably foreseeable. After meeting these criteria, a person needed to wait at least 10 days until the intervention and give informed consent at the intervention time.

In 2021, Canada's MAID legislation underwent important changes, the most significant arguably being the condition(s) for which a person may be approved. Currently, a person no longer needs to have a condition with a RFND. One can now be approved if they: a) have a serious illness, disease, or disability (excluding mental illness); b) are in an advanced state of irreversible decline; and c) experience unbearable physical or mental suffering as a consequence of their condition and which cannot be alleviated in a manner that is acceptable to the person (12). This means that a number of individuals who previously would not have qualified for MAID may now be eligible. For instance, under the initial legislation, a 30-year-old with a newly acquired spinal cord or brain injury would not have been eligible for MAID based on suffering caused by the injury. However, this same person may now qualify if they meet all other criteria. Similarly, an active 70-year-old with no comorbidities and who recently had a hip fracture requiring surgery might not previously have been eligible for MAID but may now qualify.

The expanded MAID legislation has received substantial criticism. A primary point of contention is that some people with acquired disabilities may experience unbearable suffering because society fails to be accessible (13,14). The argument is that if we had a society that was more inclusive (e.g., universal design), then fewer individuals with disabilities would experience unbearable suffering and, consequently, not request MAID (14,15). Along the same lines, there is a concern that Track 2 patients will skip waitlists in order to see a specialist or gain access to expensive resources during their 90-day reflection and assessment period in order to prove that they have tried other treatments. This sheds light on a healthcare system with insufficient resources to potentially alleviate a patient's suffering, causing them to pursue MAID. These examples carry many ethical questions which should be considered but which are beyond the scope of our paper.

In order to help ensure that people *without* a RFND only proceed with MAID for legislatively appropriate reasons, a 90-day waiting and assessment period was implemented as a safeguard. During this period, any relevant support and services must be offered, and may be trialled with the individual's consent (12). Ultimately, the goal is to augment a person's autonomous and fully informed final decision to pursue MAID.

AN UNANTICIPATED ETHICAL DILEMMA

The expanded legislation has brought forward some novel, and perhaps unanticipated, concerns and considerations, including the following question: *In a publicly funded system, where should patients who want to receive MAID spend their 90-day reflection and assessment period?* Many factors are important to consider when determining where a patient can and should wait for MAID, including personal preferences, hospital resources (e.g., bed availability), and degree of medical assistance/support required for the patient.

For instance, suppose a 50-year-old, Patient X, with a spinal cord injury and paraplegia as a result of a recent motor vehicle accident, was transferred to a rehabilitation program after acute care. In rehab, they were mostly supported by allied health professionals who helped them learn how to navigate aspects of life using a wheelchair. Medical support was available to help with pain management, in addition to treating their underlying, long-standing depression. Meanwhile, Patient X and their partner have had a tumultuous relationship, and their partner was seldom present.

After being in rehab for two months, Patient X regained some strength and could ambulate using a wheelchair. They were still receiving physiotherapy and required support for some activities of daily living (ADLs). However, it was determined that limited publicly funded support could be provided at home, and the assistance of a caregiver (i.e., familial/spousal presence) could supplement their current level of function. At this point, the care team determined that Patient X was ready for discharge, particularly since they already had an accessible apartment. However, as discharge planning began, Patient X requested MAID. The patient expressed gratitude for the team's support and noted that their pain was under control, but ultimately decided that their injury resulted in intolerable suffering that could not be alleviated in a manner acceptable to them. After making the request, two independent clinicians offered a MAID assessment. Both deemed Patient X capable and determined that eligibility criteria were met, albeit without RFND. Patient X acknowledged the 90-day waiting and assessment period before the intervention and requested to have MAID in-hospital.

The team continued to plan for a discharge and explained that Patient X would only be able to receive MAID in their home through community referrals once discharged. The hospital would not be able to provide MAID if they were not an inpatient. Upon learning this information, Patient X asked if they could spend their 90 days in the rehab facility, where they had a positive relationship with the staff and felt well-supported.

EXPLORING THE OPTIONS: RESPONDING TO THE DILEMMA

Cases such as Patient X's are occurring in places such as rehabilitation facilities, where patients may be medically stable and clinically ready for discharge, yet want to wait in-hospital for 90 days until MAID. As such, healthcare providers, administrators, and PHEs must determine whether and when to honour patient preferences if waiting at-home is not their preferred option.

As ethicists, we recognize that there is not one right response to the question of where patients should wait for MAID. A starting point, however, may be to clarify what practical options typically exist in scenarios such as Patient X's. Based on our experiences, patients can typically wait for MAID in spaces such as an active inpatient hospital unit (e.g., a rehabilitation or acute care bed), a transitional care unit (TCU), or at home. Each of the options have potential benefits and drawbacks.

The initial option of allowing someone like Patient X to remain in-hospital for 90 days is plausibly the most person-centred since it would accord with their expressed desire. Additionally, this option may respond to some of Patient X's psychosocial needs while awaiting MAID, as the care team may provide emotional support and safety; this may be of particular significance given Patient X's long-standing depression. Although a care team would be available on a TCU, Patient X developed a positive rapport with current staff and would want them present. Having a trusted support network available as one waits for MAID is presumably important, and although waiting at home may provide some patients with a space of safety, comfort, and compassion, this may not always be the case.

The option of honouring patient preferences to wait in-hospital may be the most person-centred, but it may also be the most burdensome for hospital resources and/or the public. Allowing Patient X to remain in a hospital bed for 90 days means occupying a publicly funded hospital bed (i.e., a bed that is paid with taxpayer dollars) *even though there exists a home to which Patient X can safely return*. Allowing patients to remain in-hospital based on preferences means that there is one less bed available for patients requiring timely access to necessary resources for their care needs. Hospitals with limited resources can be ill equipped to care for population-wide crises. The COVID-19 pandemic demonstrated that Canadian hospitals are easily overwhelmed, and hospital bed shortages are a significant issue (16). The demand for hospital beds and resources will almost always outweigh the scarce supply in hospitals, which will inevitably create untenable pressure on hospital staff. On a more specific note, someone like Patient X remaining in-hospital means that a specialised spinal cord injury rehab bed is occupied.

An alternative option might be to send Patient X to a TCU for the 90-day period and then back to the rehab centre for the MAID intervention. Although spending 90 days in the TCU would not align with Patient X's expressed preference, it would allow for continued medical monitoring and align with their ultimate preference not to go home. Additionally, this option would alleviate pressures on specialised rehab resources. However, pressures may be redirected to TCU resources and, consequently, the healthcare system as a whole. TCU beds are typically used for patients who require an alternative level of care ("ALC patients") and/or who do not have a secured discharge destination (e.g., waiting for long-term care); neither condition applies to Patient X. If a TCU bed is offered to Patient X, an ALC patient might be unable to transfer to a TCU and may unnecessarily occupy an acute care bed for a longer period of time. Downstream effects ensue on our health system based on the decision of where Patient X resides. In short, significant pressures on our health system make it such that using a hospital bed when alternative options exist could pose detrimental consequences for others.

The third option of going home would not align with Patient X's initial preference to remain in and receive MAID in-hospital, nor would it allow for ongoing medical monitoring and support (particularly given the tumultuous relationship with their partner). One benefit of this option, however, is that it allows for publicly funded hospital beds to be available for those in-need, which is significant given healthcare constraints. Another benefit may be that a discharge home would allow Patient X to experience life outside of a hospital environment. The last time that Patient X was *not* in a hospital was prior to their traumatic accident; Patient X has never lived with a spinal cord injury outside of a medicalized space. Living independently may pose anxieties that Patient X wants to avoid, yet it may also help to ensure that they have all the information needed to make a fully informed decision about MAID. As indicated in their 2020 article related to spinal cord injury and MAID, Tchajkova, Ethans, and Smith found that it may be difficult for people to make a fully informed decision about ending their life shortly after a spinal cord injury (17). It is frequently the case that suicidal ideation is experienced shortly after the injury, and taking time to receive rehabilitation, peer mentorship, and re-integration into one's community can help promote necessary reframing about living vs. ending one's life. Based on this information, it seems possible that living with an injury in the community may exceed some of Patient X's assumptions; the only way to know is by trialling the experience. So, although discharging Patient X to their home may not *seem* person-centred, it may be a worth pursuing if it will enable them to make a more informed choice about receiving MAID.

AN ETHICALLY DEFENSIBLE PROCESS

As demonstrated above, there are a number of less-than-ideal options that can be pursued in response to Patient X, and each has strengths and challenges. Insofar that there exists no 'right' place wherein a person should wait for MAID, we ultimately advocate that those persons responsible for managing cases like Patient X's pursue an ethically defensible *process*. Responding to every patient request in the same way (e.g., every patient will be allowed to wait in-hospital for MAID, every patient will be discharged) fails to consider nuances that may contribute to determining the most defensible option for each

patient. A process that attends to such nuances may provide some assurance that an ethically defensible and fair outcome has been achieved, even if some may agree to disagree that the outcome is 'right' in and of itself.

In contemplating what factors may be relevant when determining where a person should wait, particularly in circumstances such as the COVID-19 pandemic, keeping Patient X in-hospital would pose significant, potentially imminent, risks to them, to other individuals, and to the healthcare system. It is difficult to justify the allocation of a scarce resource (a bed and associated staff) when a safe, alternative discharge plan exists. In other contexts, however, it may be difficult to defend a decision *not* to allocate a bed.

Sometimes, exceptions might be granted to otherwise blanket policies and processes. For instance, although MAID is not typically offered at Patient X's rehab facility for outpatients, might an exception be logistically possible? And, if possible, is it defensible? Taking into consideration Patient X's preferences, lack of familial support, as well as available healthcare resources may be helpful when deciding whether and when to grant any exception.

In addition to considering societal and healthcare contexts, a significant part of ethical decision-making involves considering various individual perspectives. Depending on their expertise and history, each member of the healthcare team brings with them a unique view. By offering individuals a safe space to offer and consider varying perspectives, a justifiable discourse may be embarked upon towards a holistic final decision. As briefly mentioned in the Introduction, the term polyphony may help clinicians and administrators work through an ethically defensible decision-making process; a process of polyphony would encourage all persons to come together in their professional roles, to give equal weight to different perspectives, and to work towards a consensus. In the case of Patient X, this may involve a discussion with the discharge planner, social worker, physiotherapist, occupational therapist, recreation therapist, physician, as well as Patient X and anyone in their support network. Offering everyone a space to share perspectives allows for a fuller appreciation of contexts, and an ethically defensible and proportional response to be achieved through dialogue. For instance, upon hearing how the decision to remain in-hospital may variably affect access to necessary care for other patients, perhaps Patient X may opt to go home, or vice versa.

It ought to be noted that a process of polyphony should be used in conjunction with an ethical decision-making framework that may otherwise be the exclusive method to resolving dilemmas in some healthcare organisations. Taking time to deeply consider which voices have been dominant, which ones excluded, and which ones need to be further sought while working through each stage of the framework would align with a polyphonic process. Ultimately, exploring and assessing all available options, contemplating the benefits and drawbacks based on the context, and listening to varying voices and perspectives in an effort to achieve polyphony may allow us to determine where patients like Patient X should wait for MAID in a publicly funded system. Although ethical decision-making processes are always important, they may be of particular significance when immensely value-laden, complex, and final decisions like MAID are on the line. It seems plausible that a person's location may influence their quality of life and/or decision-making in the 90 days leading up to their anticipated death. As such, it is worth taking the time to approach this new, important question of where one should wait, in an ethically defensible manner.

CONCLUSION

Our purpose, here, was to explore where a patient without a RFND should wait for at least 90 days pre-MAID-intervention in a publicly funded health system. Cases involving this question are occurring in non-acute-care settings, and establishing an ethically defensible response is necessary. In offering an ethics analysis on the hypothetical case of Patient X, it becomes clear that there is no 'right' answer in terms of where, specifically, a person should wait. As is typically the case in response to ethical dilemmas, various contextual factors need to be considered. Upon considering these factors and options available, we ultimately conclude that an ethically defensible *process* may allow for a defensible outcome to be achieved. An ethical process ought to include hearing all voices and exploring all options in relation to the context. The concept of polyphony may be helpful to delve further into how discourse unfolds towards this type of decision-making process, in which various equally weighted voices can be heard in order to achieve consensus on where those like Patient X should reside for 90 days.

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