DISCUSSION AND DEBATE

Advance Requests for Medical Assistance in Dying in the International Context: Some Legal Issues for the Canadian Case

Demandes anticipées d'aide médicale à mourir dans le contexte international : enjeux juridiques pour le Canada

LUIS ESPERICUETA, MA, LLB, PhD (C)
Department of Philosophy I
University of Granada
Granada, Spain

Abstract

An advance request for medical assistance in dying (MAiD) (ARM) is a document that allows individuals to request euthanasia if they lose their decision-making capacity. Currently, it is available in all countries where MAiD is permitted for individuals suffering from a serious and incurable illness whose natural death is not reasonably foreseeable, except in Canada. In this country, various citizen and parliamentary initiatives are considering the inclusion of this document in national legislation. This article presents for the first time a compilation of all ARM regulations worldwide. Analysis of the international framework suggests that the requirements for drafting an ARM could influence the effective implementation of patients' wishes.

Résumé

La demande anticipée d'aide médicale à mourir (AMM) est un document qui permet aux personnes de demander l'euthanasie si elles perdent leurs capacités décisionnelles. Actuellement, cette mesure est disponible dans tous les pays où l'AMM est autorisée pour les personnes atteintes d'une maladie grave et incurable dont la mort naturelle n'est pas raisonnablement prévisible, sauf au Canada. Dans ce pays, diverses initiatives citoyennes et parlementaires envisagent l'inclusion de ce document dans la législation nationale. Cet article présente pour la première fois une compilation de l'ensemble des réglementations concernant la demande anticipée d'AMM dans le monde. L'analyse de ce contexte international laisse croire que les exigences

relatives à la rédaction d'une demande anticipée d'AMM pourraient influencer la mise en œuvre efficace de ce que souhaitent les patients.

Introduction

Medical assistance in dying (MAiD) has been legally allowed in Canada since 2016. Over the past eight years, this medical practice has undergone continuous modifications through court rulings and legislative amendments (Downie 2022). Initially, it was available only to individuals whose death was reasonably foreseeable, but it has since been extended to those not facing imminent death but experiencing severe suffering.

In this context, one of the most debated changes was the amendment allowing persons suffering solely from a mental disorder to be eligible for MAiD (MAiD MD-SUMC), although its implementation has been postponed to 2027. Nevertheless, this recent expansion of criteria for MAiD contrasts with the legal impossibility of using advance requests for its application. This discrepancy is particularly notable when we consider that some may view the use of advance requests for MAiD (ARM) as less controversial. For example, a 2021 survey of Canadians found that 17% of respondents opposed the use of ARM, while 35% were against the implementation of MAiD MD-SUMC, which is double (IPSOS 2021). Support for ARM was also reflected in a 2015 survey, in which 62% of a representative sample of Canadians agreed, and 22% disagreed, that they should have access to MAiD if they suffer from advanced dementia and have an ARM outlining their desire for assisted death at that stage of the illness (EPOLRCC 2015).

An ARM is a document "created in advance of a loss of decision-making capacity, intended to be acted upon under circumstances outlined in the request after the person has lost decisional capacity" (The Expert Panel Working Group on Advance Requests for MAID 2018: 5). The use of this document is especially important in cases of severe dementia[1] and impaired consciousness. However, with the exception of Quebec[2], it is not permitted in Canada, as the law requires the patient to explicitly confirm their consent immediately before receiving MAiD. Only when a person is at risk of losing capacity and their natural death is reasonably foreseeable does the law allow them to waive final consent through a written agreement with their healthcare provider (Parliament of Canada 2021). It is notable that of the six countries in the world where euthanasia is currently practised without the requirement of terminal illness, only Canada does not permit the use of ARM.[3]

Although bioethical and philosophical issues are varied (Wijsbek and Nys 2022), some health professionals in Canada appear to support the legal use of ARM by patients with advanced dementia. According to a survey conducted in Vancouver, most dementia care specialists favour allowing ARM for these patients, although they express ethical and logistical concerns about its use (Nakanishi et al. 2021). There is also political interest in addressing the use of ARM safely. Senator Chantal Petitclerc's remarks during the second reading of *Bill C-7* are illustrative:

> It requires us to consider safeguards for two completely distinct acts that may be many years apart – the making of the document setting out the wish for MAID and the provision of MAID for a person who can no longer consent on the basis of the earlier document (Petitclerc 2020: 672).

For this reason, it is useful to examine the procedures followed in the six jurisdictions (the Netherlands, Belgium, Luxembourg, Colombia, Spain and Quebec) where access to ARM is permitted.

Who can draw up an ARM in other jurisdictions?

Regarding the profile of individuals, we found that two of the six jurisdictions studied allow minors to make an ARM. Specifically, the minimum age in the Netherlands is 16 (Law Bank 2002), while in Colombia, it is 14. In Colombia, however, this is only permitted if the minor has a "diagnosis of terminal illness or life-threatening condition" (Ministerio de Salud y Protección Social 2018). Once the individual reaches the age of 18, they must create a new document without diagnostic restrictions. In both Colombia and the Netherlands, MAiD is available for minors. In Spain, by contrast, the age of majority is required to complete an ARM. In some autonomous communities, emancipated minors or those aged 16 and over can make advance requests for situations outside of MAiD (BOE 2002). Nevertheless, MAiD is prohibited for minors throughout the country without exception (BOE 2021).

A different situation exists in Belgium, where an emancipated minor can make an ARM (Moniteur Belge 2002). However, regardless of age, an ARM applies only if the patient, in addition to suffering from a serious and incurable illness or injury, is in a state of irreversible unconsciousness according to current scientific knowledge. As a result, while Belgian law does not explicitly address the case of dementia, it indirectly excludes it. A similar situation occurs in Luxembourg, where an ARM can only be used when the patient has irreversibly lost consciousness (Ministre de la Santé et de la Sécurité sociale 2009). In Luxembourg, only adults, not emancipated minors, can complete this document. With respect to the province of Quebec, only individuals of legal age are allowed to make an ARM (Assemblée Nationale du Québec 2023).

Regarding the health status of the person, it is important to note that, with the exception of Quebec, no jurisdiction explicitly requires a prior diagnosis. This means that an ARM can be made by an individual who is not ill and can cover any scenario in which they wish to express their will. In contrast, Quebec law stipulates that, in order to complete an ARM, a person must suffer "from a serious and incurable illness leading to incapacity to give consent to care" (Assemblée Nationale du Québec 2023: 10).

In addition, although the ARM document must be in writing in all countries, the requirements for its preparation differ. In the Netherlands, for example, it is recommended that it be drawn up with the assistance of a medical professional (Supreme Court of the Netherlands 2020). In contrast, both Spain and Colombia offer three options: to formalize

the document in the presence of a notary, medical personnel or witnesses (in Spain, two or three depending on the region; in Colombia, two). Both countries have different criteria for witnesses concerning their relationship to the person signing the ARM. In Spain, witnesses cannot be related up to the second degree of kinship or affinity, nor can they have any economic relationship with the person. In Colombia, anyone can be a witness unless they have been disqualified by a court decision or have an economic or employment relationship with the person. In Belgium and Luxembourg, however, an ARM must be signed in the presence of two witnesses of legal age. In Belgium, "at least one of them will have no material interest in the death of the declarant" (Moniteur Belge 2002).

In Quebec, on the other hand, the law requires that a patient making an ARM be assisted by a competent professional during the drafting process. The ARM must then be formalized in the presence of either a notary or two witnesses. The witnesses must be of legal age and capable of giving informed consent.

How long is an ARM valid in other jurisdictions?

The validity of an ARM is unlimited in the Netherlands, Colombia, Spain, Belgium and Quebec. Nevertheless, it is important to note that, according to the Regional Euthanasia Review Committees (2022: 38), in the Netherlands, "the older the directive, the more doubt there may be as to whether it still reflects the patient's actual wishes." Meanwhile, in Colombia, as previously mentioned, an ARM made by individuals aged 14 to 18 must be replaced once they reach the age of majority. In Belgium, an ARM had to be renewed every five years until April 2, 2020. However, the "Loi du 15 mars 2020 visant à modifier la législation relative à l'euthanasie" (Moniteur Belge 2020) stipulates that ARMs issued after this date are valid indefinitely. Luxembourg is the only country where ARMs must be renewed every five years (Ministre de la Santé et de la Sécurité sociale 2009).

Who can invoke an ARM in other jurisdictions?

Once the person is in the situation described in the document, the procedure can vary significantly from country to country. In Spain and Colombia, there is no complete certainty about the effective implementation of an ARM. Indeed, depending on how the document is signed, there may be unforeseen complications if the patient is unable to indicate the existence of an ARM. For example, a document formalized in front of witnesses would rely on one of them delivering it to a physician in time. Similarly, if it were notarized, it would be essential for the patient to have informed someone of its existence so that it could be retrieved and presented in a timely manner. Therefore, since it is not mandatory to register the ARM or include it in the patient's medical record nationwide, the proper fulfilment of the patient's wishes would depend on various circumstances. As a result, the regulations in these countries do not provide sufficient certainty regarding who can invoke the existence of an ARM.

In Belgium and Luxembourg, an ARM must be completed in the presence of two witnesses. The laws emphasize that one or more "trusted persons" can be designated when

drafting the document to communicate the patient's wishes to the attending physician. Belgian law also suggests that it is preferable to designate several persons and rank them in order of preference. In this way, "each trusted person replaces the one who precedes them in the declaration in the event of refusal, incapacity, disability, or death" (Moniteur Belge 2002). It should also be noted that Belgium explicitly prohibits doctors familiar with the patient's case from being designated as a "trusted person." Only in Luxembourg does the law require that an ARM be registered with the *Commission Nationale de Contrôle et d'Évaluation*. Any doctor treating a patient in a medical situation eligible for MAiD under the law must consult this register.

In the Netherlands, in cases where the ARM is prepared with the attending physician, it is understood that this document will be included in the patient's medical record. This helps avoid unnecessary delays and intermediaries that could compromise the effectiveness of the ARM. In addition, it is recommended that the document be prepared with the involvement of someone close to the patient and that the patient communicates their wishes to their family (KNMG 2021). This safeguard ensures that the patient's trusted persons can verify that the medical staff appropriately carries out the patient's wishes in a timely manner.

In Quebec, the law requires that all ARMs be recorded by the professional assisting the patient or by the notary in a register established by the ministry of health (Assemblée Nationale du Québec 2023). In addition, the law recognizes the role of trusted persons, who are not permitted to serve as witnesses at the same time. These provisions serve as safeguards, allowing both professionals and individuals close to the patient to invoke an ARM in a timely manner.

What events trigger an ARM in other jurisdictions?

Finally, concerning the elements justifying the activation of an ARM, in Belgium and Luxembourg, it is the irreversible loss of consciousness. In the Netherlands and Colombia, it is the finding of unbearable suffering in the patient – which may exclude cases where the person with dementia appears happy (Asscher and van de Vathorst 2020). Whereas in Spain, it must be proven that the patient has limitations in his physical autonomy and ability to relate to others as well as constant physical or psychological suffering (BOE 2021). In Quebec, on the other hand, the law specifies that the patient must be incapable of giving consent to care due to a serious and incurable illness. In addition, the patient must consistently exhibit the clinical manifestations related to their illness described in the request; be in a state of advanced, irreversible decline in capability; and experience, in the judgement of the competent professional, "enduring and unbearable physical or psychological suffering that cannot be relieved under conditions considered tolerable" (Assemblée Nationale du Québec 2023: 16).

What advice can we draw from international framework?

Since the question of allowing MAiD for minors is under consideration in Canada (Comité mixte spécial sur l'aide médicale à mourir 2023), it would be important for the country to determine the minimum age required to sign an ARM and to develop appropriate safeguards

if this right is extended to this population. In addition, legislators must carefully consider whether to require a specific health condition to draw up an ARM, as is the case in Quebec, which contrasts with international practices. In this context, the possibility of making an ARM without a prior diagnosis is a controversial issue, as there are concerns about an individual's ability to accurately project current preferences onto future events or situations (van den Bosch et al. 2021).

Another essential point will be specifying the appropriate way of signing an ARM and the individuals involved. There are at least four models for policy makers to consider: the Hispanic–American model, which we consider to be less protective; the Belgian–Luxembourg model, which reduces uncertainty by clearly defining the roles of the witnesses and trusted persons involved in the effective implementation of the ARM (Luxembourg, in particular, provides a key safeguard by establishing a dedicated ARM register); the Dutch model; or the Québécois model, which incorporates several of the safeguards of the other models and is considered by us to be more protective. Indeed, clearly defining who can activate an ARM could significantly influence whether key logistical and ethical issues, such as the timing – the precise moment to administer MAiD (Mellett et al. 2021) – can be effectively addressed.

Finally, Canada should consider how to verify the elements that must be met in order to access MAiD through the ARM. In particular, it will need to address how to apply the criterion of "physical or psychological suffering that is intolerable to them and that cannot be relieved under conditions that they consider acceptable" in the current law (Parliament of Canada 2016: 6). One option could be to follow Quebec's approach, considering both the patient's personal circumstances under which they wish to receive MAiD and the medical judgement of the competent professional. The correct wording of the ARM and effective communication between the patient, family and healthcare professionals will be crucial in this task.

Conclusions

Considering the various international models, the requirement that the advance request be drafted with the assistance of the competent professional and trusted persons seems to offer one of the best safeguards. The more thoroughly and precisely the ARM is prepared, the more reliable and effective its implementation could be. The competent professional, the caregivers and the patients' trusted persons play a key role in the drafting and eventual interpretation of the ARM. Therefore, it is also essential to record this document in a traceable and searchable register. Finally, the inclusion of appropriate safeguards will help not only to ensure that the rights and wishes of patients are respected in all circumstances but also to strengthen public trust in the system.

Funding

This study was funded by the Spanish Ministry of Science and Innovation, MICIU/AEI/10.13039/501100011033 and ESF+; INEDyTO II project: Bioethics and practices related to the end of life (PID2020-118729RBI00); "ayudas para contratos predoctorales"

(PRE2021-098759); and Ariadna project PPJIB-2024-55 (University of Granada).

Ethical Approval

Ethics committee approval is not required.

Notes:

1. Dementia generally progresses through three main stages: mild, moderate and severe. In the severe stage, individuals experience significant cognitive decline, marked functional limitations and noticeable behavioural changes. In addition, advanced dementia often results in difficulties with eating and swallowing, requires assistance with walking and demands continuous support for personal care. It also increases the susceptibility to infections (Clifford et al. 2024).
2. In June 2023, the Assemblée Nationale du Québec amended the law regulating medical assistance in dying (MAiD) to allow individuals to make an advance request of MAiD (ARM) under certain conditions. This new provision took effect on October 30, 2024.
3. In 2024, Ecuador judicially decriminalized MAiD for individuals with terminal or serious chronic illnesses (Espericueta 2024). Soon, the Ecuadorian parliament will need to pass a law, at which point we will know whether it will allow ARMs.

Correspondence may be directed to Luis Espericueta by e-mail at espericueta@ugr.es.

References

Asscher, E.C.A. and S. van de Vathorst. 2020. First Prosecution of a Dutch Doctor Since the Euthanasia Act of 2002: What Does the Verdict Mean? *Journal of Medical Ethics* 46(2): 71–75. doi:10.1136/medethics-2019-105877.

Assemblée Nationale du Québec. 2023. *Bill 11 (2023, Chapter 15), An Act to Amend the Act Respecting End-of-Life Care and Other Legislative Provisions*. Retrieved February 15, 2024. <https://www.publicationsduquebec.gouv.qc.ca/fileadmin/Fichiers_client/lois_et_reglements/LoisAnnuelles/en/2023/2023C15A.PDF>.

BOE. 2002. *Ley 41/2002, de 14 de noviembre, básica reguladora de la autonomía del paciente y de derechos y obligaciones en materia de información y documentación clínica*. Retrieved February 15, 2024. <https://www.boe.es/buscar/act.php?id=BOE-A-2002-22188>.

BOE. 2021. *Ley Orgánica 3/2021, de 24 de marzo, de regulación de la eutanasia*. Retrieved February 15, 2024. <https://www.boe.es/diario_boe/txt.php?id=BOE-A-2021-4628>.

Clifford, K., M. Moreno and C.M. Kloske. 2024. Navigating Late-Stage Dementia: A Perspective From the Alzheimer's Association. *Alzheimer's and Dementia* 16(1): e12530. doi:10.1002/dad2.12530.

Comité mixte spécial sur l'aide médicale à mourir. 2023. *L'aide médicale à mourir au canada: les choix pour les Canadiens*. Retrieved February 15, 2024. <https://aqdmd.org/wp-content/uploads/2023/02/amadrp02-f.pdf>.

Downie, J. 2022. From Prohibition to Permission: The Winding Road of Medical Assistance in Dying in Canada. *HEC Forum* 34(4): 321–54. doi:10.1007/s10730-022-09488-6.

Espericueta, L. 2024. Analysis of the Legal Situation Regarding Euthanasia in Ecuador, Colombia, and Peru: Towards a Latin American Model of Medical Assistance in Dying? *Developing World Bioethics*. Early Release. doi:10.1111/dewb.12457.

External Panel on Options for a Legislative Response to Carter v. Canada (EPOLRCC). 2015. *Consultations on Physician-Assisted Dying: Final Report*. Government of Canada. Retrieved February 15, 2024. <https://www.justice.gc.ca/eng/rp-pr/other-autre/pad-amm/pad.pdf>.

IPSOS. 2021. *Support for Medically-Assisted Dying in Canada*. Retrieved February 15, 2024. <https://dyingwithdignity.ca/wp-content/uploads/2022/03/DWD_Canada_MAID_Feb_2021.pdf>.

KNMG (The Royal Dutch Medical Association). 2021. *KNMG Position. End-of-Life Decisions*. Retrieved February 15, 2024. <https://data.maglr.com/3230/issues/27397/360234/downloads/knmg_standpunt_levenseinde_interactieve_downloadversie.pdf>.

Law Bank. 2002. *Termination of Life on Request and Assisted Suicide Law*. Retrieved February 15, 2024. <https://wetten.overheid.nl/BWBR0012410/2021-10-01>.

Mellett, J., C. Mack and B. Leier. 2021. Advanced Requests for MAID: Are They Compatible With Canadian Medical Practice? *Canadian Journal of Bioethics* 4(2): 78–81. doi:10.7202/1084453ar.

Ministerio de Salud y Protección Social. 2018. *Resolución 2665 de 2018 (por medio de la cual se reglamenta parcialmente la Ley 1733 de 2014 en cuanto al derecho a suscribir el Documento de Voluntad Anticipada)*. Retrieved February 15, 2024. <https://www.minsalud.gov.co/sites/rid/Lists/BibliotecaDigital/RIDE/VS/PP/abece-voluntad-anticipada.pdf>.

Ministre de la Santé et de la Sécurité sociale. 2009. *Loi du 16 mars 2009 sur l'euthanasie et l'assistance au suicide*. Retrieved February 15, 2024. <https://legilux.public.lu/eli/etat/leg/loi/2009/03/16/n2/jo>.

Moniteur Belge. 2002. Loi du 28 mai 2002 relative à l'euthanasie. Retrieved February 15, 2024. <https://etaamb.openjustice.be/fr/loi-du-28-mai-2002_n2002009590.html>.

Moniteur Belge. 2020. Loi du 15 mars 2020 visant à modifier la législation relative à l'euthanasie. Retrieved February 15, 2024. <https://www.ejustice.just.fgov.be/cgi/article_body.pl?language=fr&caller=summary&pub_date=20-03-23&numac=2020040680>.

Nakanishi, A., L. Cuthbertson and J. Chase. 2021. Advance Requests for Medical Assistance in Dying in Dementia: A Survey Study of Dementia Care Specialists. *Canadian Geriatrics Journal* 24(2): 82–95. doi:10.5770/cgj.24.496.

Parliament of Canada. 2016. *An Act to Amend the Criminal Code and to Make Related Amendments to Other Acts (Medical Assistance in Dying). Bill C-14*. Retrieved February 15, 2024. <https://www.parl.ca/Content/Bills/421/Government/C-14/C-14_4/C-14_4.PDF>.

Parliament of Canada. 2021. *An Act to Amend the Criminal Code (Medical Assistance in Dying). Bill C-7*. Retrieved February 15, 2024. <https://www.parl.ca/DocumentViewer/en/43-2/bill/C-7/royal-assent>.

Petitclerc, C. 2020. *Sponsor's Speech. An Act to Amend the Criminal Code (Medical Assistance in Dying)*. 2nd Session, 43rd Parliament. Retrieved February 15, 2024. <https://sencanada.ca/content/sen/chamber/432/debates/pdf/020db_2020-12-14-e.pdf>.

Regional Euthanasia Review Committees. 2022. *Euthanasia Code*. Retrieved February 15, 2024. <https://english.euthanasiecommissie.nl/the-committees/documents/publications/euthanasia-code/euthanasia-code-2022/euthanasia-code-2022/euthanasia-code-2022>.

Supreme Court of the Netherlands. 2020. *Judgment ECLI:NL:HR:2020:712*. Retrieved February 15, 2024. <https://uitspraken.rechtspraak.nl/#!/details?id=ECLI:NL:HR:2020:712>.

The Expert Panel Working Group on Advance Requests for MAID. 2018. *The State of Knowledge on Advance Requests for Medical Assistance in Dying*. Council of Canadian Academies. Retrieved February 15, 2024. <https://cca-reports.ca/wp-content/uploads/2019/02/The-State-of-Knowledge-on-Advance-Requests-for-Medical-Assistance-in-Dying.pdf>.

van den Bosch, G.J., R.A.N. Roos, R. Otten, C. Bockting and Y.M. Smulders. 2021. Are Patients Accurate Forecasters of Their Emotional Response to Medical Conditions? A Scoping Review on Affective Forecasting. *BMJ Open* 11(12): e053370. doi:10.1136/bmjopen-2021-053370.

Wijsbek, H. and T. Nys. 2022. On the Authority of Advance Euthanasia Directives for People With Severe Dementia: Reflections on a Dutch Case. *Hastings Center Report* 52(5): 24–31. doi:10.1002/hast.1418.