BRIEF

House of Commons Special Joint Committee on Medical Assistance in Dying
(AMAD)

ACCESS to MEDICAL ASSISANTANCE IN DYING in CANADA: END DISCRIMINATION

Natalie Le Sage, MD, LMCC, CSPQ, PhD

Physician devoted to medical assistance in dying

Full clinical professor, Faculty of Medicine, Université Laval

Submitted as an individual

May 2022

EUTHANASIA: etymology

From the Greek

"eu": good

"thanatos": death

A gentle and easy death

"What gives meaning to life gives meaning to death." *Antoine de Saint-Exupéry*

Thank you for the invitation to testify as part of this important study on expanding eligibility for access to medical assistance in dying (MAID).

I have practised and taught emergency medicine for more than 30 years at the CHU de Québec-Université Laval (tertiary trauma centre/neurosciences and psychiatric emergency). I am also a clinical researcher and sat on my institution's research ethics committee for seven years. I am therefore familiar with the many legal and ethical aspects of medical practice, particularly the **right to self-determination, shared decision making and informed consent**.

At the twilight of my career, I am devoting my full clinical time to working in MAID.

Having lived through many upsetting situations closely related to the issues being discussed today, I wish to share my thoughts with you.

1. Advance request for MAID following a diagnosis of major neurocognitive disorder (MNCD)

Under certain conditions, Bill C-7 already provides for the possibility of waiving final consent for persons eligible for MAID. In other words, Parliament recognizes that a capable person can waive final consent to receive MAID if they become incapable.

I agree with the Report of the Select Committee on the Evolution of the Act concerning End-of-Life Care:[1,2] allow for an advance request for MAID following an MNCD diagnosis. This recognizes the distinct nature of the progression of these illnesses: they inevitably compromise capacity to consent.

Here are some brief answers to questions raised by some opponents.

Could a decision made in advance no longer match the patient's desire at the time of MAID?
To avoid making a decision about a hypothetical and far-off situation, it's important that the advance request for MAID be signed once the diagnosis is made, as is the case in the current act.

The "anticipated" assessment of suffering?
There are many types of suffering.[3] There are the many forms of physical suffering: pain, fatigue, weakness, shortness of breath, exhaustion, nausea, lack of appetite, etc. Then there is psychological suffering, which can result from anticipating a morbid and intolerable situation, or the inability to do what gives meaning to life. It's undoubtedly this ability to anticipate suffering that makes 80% of Canadians support an advance request for MAID in cases of MNCD.[4]

What about happy dementia?
For those who believe that dementia can be "happy," this can be discussed with the capable patient at the time of their request. Specific directives on this matter can be made when signing the advance request.

What if scientific research offers a new treatment?
There is currently no cure for an MNCD, and it inevitably progresses in all patients. By the time a person loses their ability to function, brain damage is already advanced and irreversible, which is why new treatments are aimed at the earlier stages of this disorder.

What if our health care system provided better care for people with decreasing independence?
Like many Canadians, I'm requesting my right to express my choice following an MNCD diagnosis:[4]

- even if I'm promised delicious food by the spoonful, beautiful music and walks knowing I'm safe if I wander off at night…
- even if I'm assured of adequate medication to relieve my irritability, agitation, anxiety and difficulty sleeping…

- even if someone smiling and pleasant makes sure to change my diaper immediately after it's soiled and turns me every two hours to avoid bed sores…
- even if some people feel that I'm not in pain because I don't show any reaction…

An individual's self-determination with respect to their health must remain the focus.

2. MAID where a mental disorder is the sole underlying medical condition (MD-SUMC)

It is unacceptable that mental illness is not considered the same as any other so-called "physical" illness, and I believe that patients with MD-SUMC are currently being discriminated against.

Let me explain. In medicine, we generally recognize our limitations when faced with the impossibility of curing certain illnesses. This precept is readily accepted for so-called "physical" illnesses where the prognosis is poor and treatment is non-existent or ineffective. Why should mental illness be an exception? It's possible to adequately evaluate the incurable nature and irreversibility of a mental illness, and I refer you here to the paper published by the Collège des Médecins du Québec (CMQ).[5]

3. MAID and children

On this issue, I refer you to expert pediatricians[6] and distressed families.[7,8] However, I can tell you that, as a MAID provider, I am quite comfortable providing MAID to children whose cases have been assessed within the guidelines. Like most people, I am unable to watch a child suffer when medicine is powerless. I therefore fully endorse the position of the CMQ[5] on this matter.

Recommendations

- Allow an advance request for MAID following a diagnosis of major neurocognitive disorder, with final consent waived

- Expand eligibility to patients where a mental disorder is the only underlying condition who otherwise meet all MAID eligibility criteria

- Expand eligibility to children aged 0 to 1 with life-threatening conditions and to those aged 14 or older who otherwise meet all MAID eligibility criteria

References

1. Assemblée-Nationale-du-Québec (2021). Rapport de la commission spéciale sur l'évolution de la loi concernant les soins de fin de vie. http://www.assnat.qc.ca/fr/document/179287.html.
2. National Assembly of Quebec (2021). Report of the Select Committee on the Evolution of the Act Respecting End-of-Life Care. http://www.assnat.qc.ca/en/document/179287.html.
3. Groupe-de-recherche-sur-la-souffrance-psychique-et-l'AMM (2017). Exploration de la souffrance psychique dans le cadre d'une demande d'aide médicale à mourir. http://www.cmq.org/pdf/outils-fin-de-vie/exploration-souffrance-psychique.pdf.
4. L'aide médicale à mourir dans les cas de maladie de type Alzheimer au stade avancé - L'opinion des Canadiens - Rapport d'un sondage exclusif réalisé pour Capsana (Léger, 2019). https://leger360.com/wp-content/uploads/2019/06/Rapport-71227-021-V2-16.04.2019-Final.pdf.
5. Collège-des-Médecins-du-Québec (2021). Recommandation de positionnement du groupe de réflexion sur l'aide médicale à mourir et les soins de fin de vie. http://www.cmq.org/publications-pdf/p-7-2021-12-13-fr-recommandation-positionnement-groupe-reflexion-sur-amm-et-soins-fin-de-vie.pdf?cs=8.
6. Davies, D. (2018). Medical assistance in dying: a paediatric perspective. Paediatrics & Child Health, Volume 23, 125–130, https://cps.ca/en/documents/position/medical-assistance-in-dying.
7. Des parents résignés à laisser mourir leur bébé atteint d'une maladie rare, 2021. https://ici.radio-canada.ca/nouvelle/1806516/shawinigan-aide-medicale-a-mourir-famille-enfant-mort.
8. Charles Gignac, en souvenir d'une étoile filante, 2021. https://www.lequotidien.com/2021/08/14/charles-gignac-en-souvenir-dune-etoile-filante-3fb2812999e21c61cdebab4da1b8fbe5?utm_campaign=lequotidien&utm_medium=article_share&utm_source=email.