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October 15 – 18, 2024 | Palais des Congrès de Montreal



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Medical assistance in dying for incompetent people with neurocognitive disorders:

Perspectives of people living with neurocognitive disorders, caregivers, healthcare professionals and ethicists.

- Preliminary results -

Presented by Vanessa Finley-Roy

Under the supervision of: Prof. Marie-Ève Bouthillier

Co-researchers: Prof. Gina Bravo, Catherine Perron, Phd, Téo Mérard, Intern in clinical ethics



Conflict of Interests Declarations



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Presenter: Vanessa Finley-Roy

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Patents for drugs or devices: **None**

Other: **None**

Learning Objectives



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At the conclusion of this presentation, participants will be able to :

- Identify stakeholders' perceptions regarding advance MAiD requests for incompetent people living with neurocognitive disorders (NCD)
- Identify promising practices and potential ethical issues



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Background



Expert panel – created 2017



Commission spéciale sur l'évolution de la loi concernant les soins de fin de vie - 2021



Bill 38 - 2022



Bill 11 – 2023 – October 30



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ASSEMBLÉE NATIONALE DU QUÉBEC

PREMIÈRE SESSION

QUARANTE-TROISIÈME LÉGISLATURE

Projet de loi n° 11
(2023, chapitre 15)

**Loi modifiant la Loi concernant les
soins de fin de vie et d'autres
dispositions législatives**

Présenté le 16 février 2023
Principe adopté le 4 avril 2023
Adopté le 7 juin 2023
Sanctionné le 7 juin 2023

Legislative changes - overview



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At the moment the advance request (AR) is drafted



Person must suffer from a serious and incurable illness leading to incapacity to give consent to care



Must be accompanied by a competent professional at the time of the drafting



Clinical manifestations described in the AR must:
be medically recognized as being clinical manifestations of the disease
be observable by a competent professional

Legislative changes - overview



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At the moment of the evaluation:



Exhibit, on a recurring basis, the clinical manifestations related to their illness that they described in the request;



Be in state of advanced, irreversible decline in capability and experience enduring and unbearable physical or psychological suffering that cannot be relieved under conditions considered tolerable.



Refusals must be respected and it is prohibited to disregard them.



Philosophical and ethical debate concerning AR-MAiD

Under representation of people living with NCD

In the Netherlands:

Validity and effectiveness of AR-MAiD

Experiences and needs of Dutch physicians

In Canada:

Quantitative studies on attitudes and opinions (older adults, clinicians, caregivers)

Research question



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How do various key stakeholders reflect on and explore the issue of implementing AR-MAiD in clinical practice?

Assessing the acceptability of AR-MAiD among various stakeholders;
Exploring stakeholders' perspectives on the legislative provisions governing AR-MAiD;
Identifying promising practices and potential ethical issues.

Methodology



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Exploratory
qualitative study



Focus groups and
semi-structured
interviews



Purposive sampling,
snowball sampling



Thematic analysis

Participants



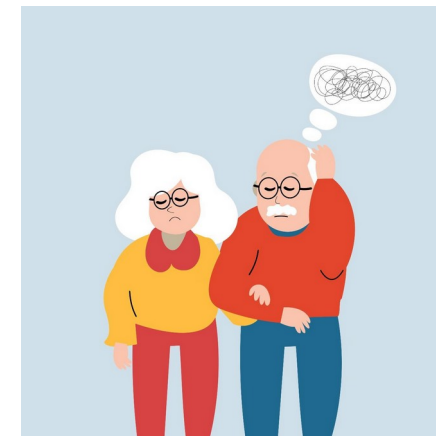
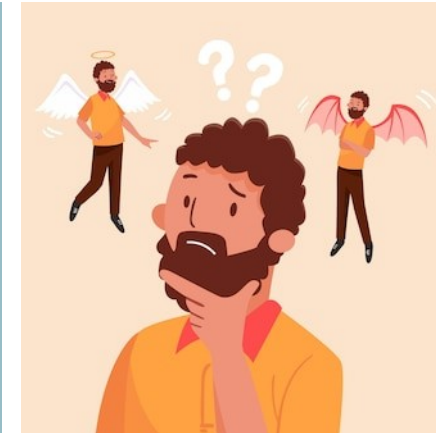
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N = 31

- **Healthcare professionals (n=10)**
 - Physicians (n=4)
 - Social worker (n=1)
 - Neuropsychologist (n=1)
 - Nurses (n=4)
- **Ethicists (n=6)**
- **Caregivers (n=10)**
- **People with NCD (n=5)**



Results - Themes



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**Advance
consent**



**Evaluation of
suffering**



**Resistance
and refusals**

Advance consent



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Healthcare professionals & Ethicists:

- 1) Timing
- 2) Happy dementia
- 3) Expertise
- 4) Refusal

Caregivers:

- 1) Timing
- 2) Happy dementia

People with NCD:

- 1) Timing
- 2) Support



Evaluation of suffering



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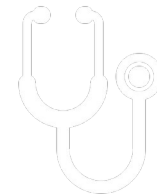


Healthcare professionals, Caregivers & Ethicists:

- 1) Concerns regarding the process
- 2) Happy dementia
- 3) Observable and refractory symptoms

People with NCD

- 1) Happy dementia



Refusals and resistance



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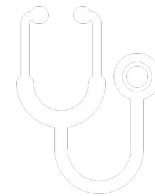


Healthcare professionals, Ethicists & Caregivers

- 1) Must respect refusals
- 2) Unease with sedation

People with NCD

- 1) Must honor precedent autonomy/ AR-Maid
- 2) Sedation is acceptable / necessary



Reasons for drafting an AR-MAiD



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Loss of functional autonomy

Loss of meaningful activities

Fear of being a burden

Loss of identity



Conclusion



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- The closer stakeholders are to clinical practice, the more concerns and potential ethical dilemmas emerge
- Echoes the discussions during public consultations & expert panels regarding the evaluation of suffering
- Consensus regarding the need for support during the process of drafting of an AR-MAiD
- Importance of including wishes regarding refusals/resistance in the AR
- Need for raising public awareness regarding end-of-life care and advance care planning
- Importance of including people with NCD in research