

Medical aid in dying where a mental disorder is the sole underlying medical condition: perspectives of patients, relatives, and healthcare practitioners for ethical care

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BACKGROUND INFORMATION

- **Medical aid in dying (MAiD)** is a process through which an authorized doctor or nurse practitioner provides or administers medication that intentionally brings about a person's death, at that person's request (1,2). To be eligible to MAiD, the requestor must meet the **eligibility criteria** (2).
- In Canada, people whose mental disorder is the sole underlying medical condition will become eligible to MAiD in **March 2023** (3).

RESEARCH PROBLEM AND MAIN OBJECTIVE

- In order to ensure **ethical support** for people who will deal with this upcoming reality, resources adapted to their needs and experiences must be developed.
- Hence, this participatory action research (4) project **aims to involve relevant stakeholders in the co-construction of a support tool** to help people living with mental disorders, their relatives and their healthcare practitioners as they experience moral concerns related to MAiD.

FOUR PHASES OF THE RESEARCH PROJECT

PHASE 1 - Project development & Literature reviews

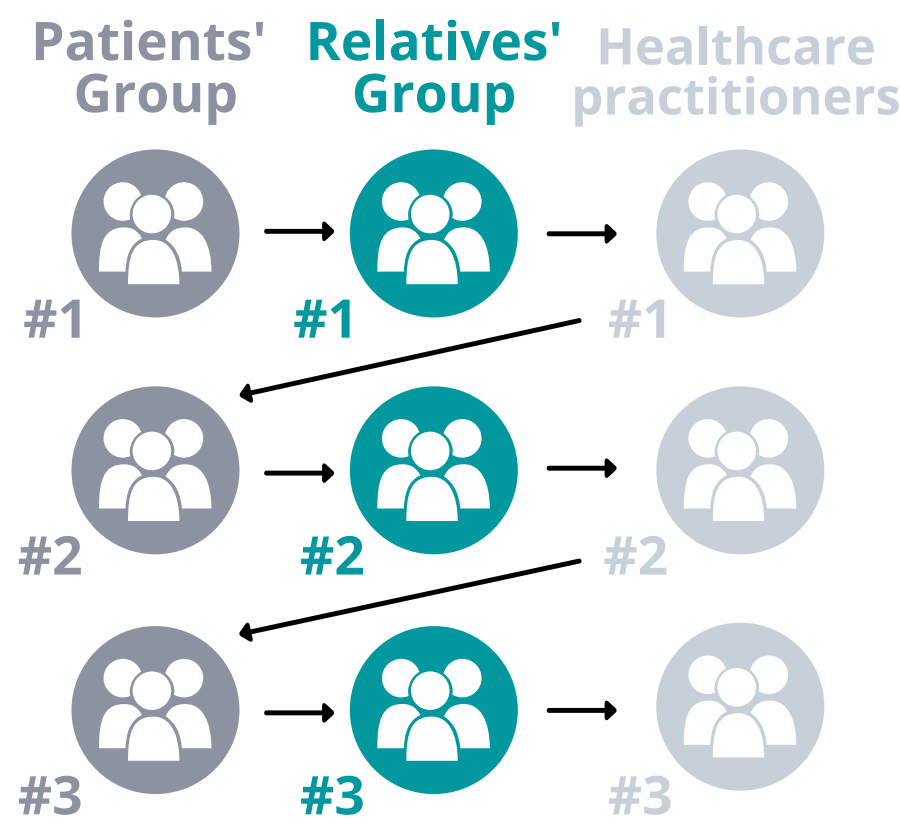
Aim: To explore relevant literature to prepare for the next steps

First Review - Which moral concerns related to MAiD for people with mental disorders are reported in the scientific literature?

Second Review - What support tools, guidelines, practices, guides (and others) have been developed in response to such moral concerns?

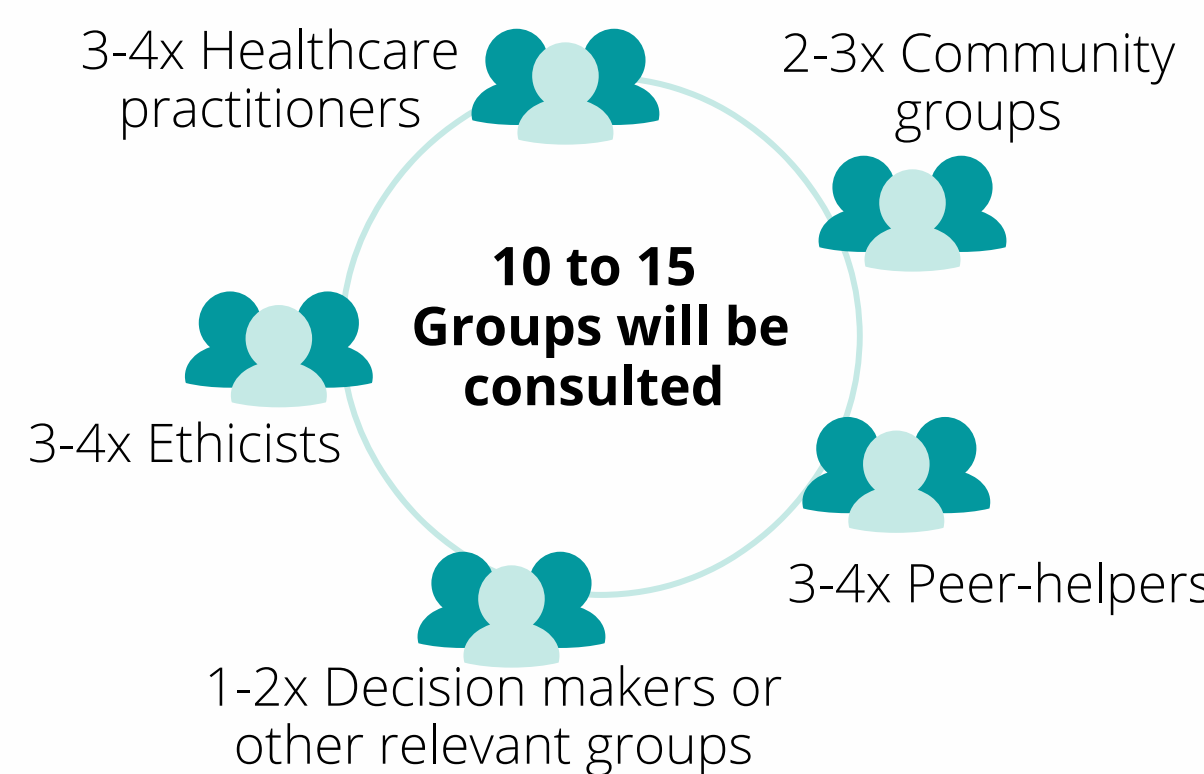
PHASE 2 - Focus-groups with stakeholders

Aim: To identify relevant moral concerns & draft a support tool



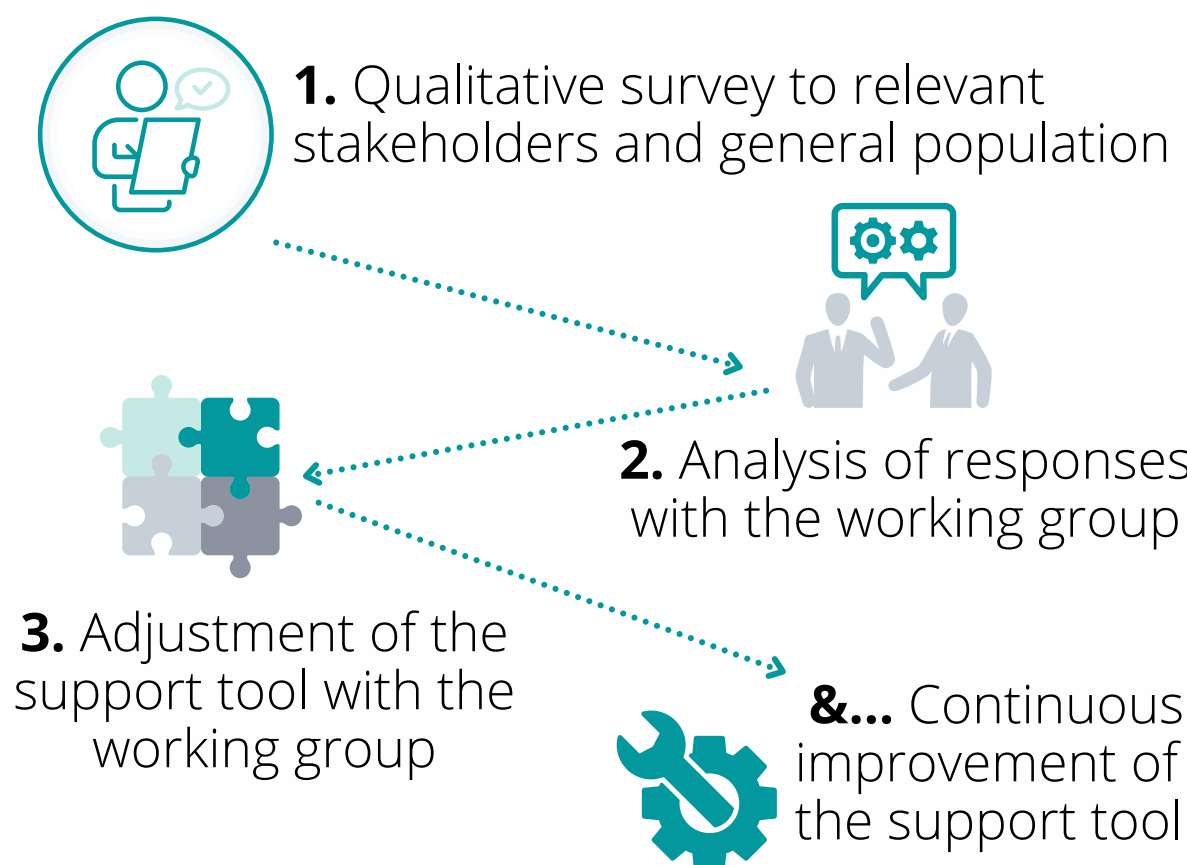
PHASE 3 - Community consultation

Aim: To complete the support tool



PHASE 4 - Evaluation of the support tool

Aim: To improve the support tool



RESULTS OF THE FIRST PHASE OF THE PROJECT

SOCIETY

4 key moral concerns:

- Stigma & discrimination
- Social determinants of health
- Public opinion & lack of trust
- Concerns related to policy making

HEALTHCARE SYSTEM

5 key moral concerns:

- Lack of resources
- Lack of training & expertise
- Lack of access to care & services
- Suicide prevention
- Limits of medical knowledge

CONTINUUM OF CARE

5 key moral concerns:

- Answering patients' needs
- Quality of care
- Hope for recovery
- Treatment goals
- Patient-clinician relationship

STAKEHOLDERS' EXPERIENCE

4 key moral concerns:

- Challenging care experiences
- External factors influencing the MAiD request
- Dealing with MAiD requests
- Transference & countertransference

PRACTICES

3 key moral concerns:

- Evaluation of MAiD requests
 - Capacity assessment
 - Unbearable suffering
 - Irremediable condition
- Quality of the process & oversight
- Repercussions

IDENTIFIED NEEDS AND POTENTIAL SOLUTIONS TO TACKLE THOSE MORAL CONCERNS

Raise awareness of the reality of mental disorders

Involve stakeholders in societal discussions & policy making

Inform people about MAiD

Improve social determinants of health

Develop resources and training for healthcare practitioners

Improve access to adequate mental healthcare

Invest more resources in mental health care

Nurture the patient-clinician relationship

Adapt treatment goals to patients' needs and preferences

Maintain hope

Work towards practice improvement & better quality of care

Facilitate difficult discussions between stakeholders

Develop support tool to help stakeholders deal with MAiD

Make sure MAiD requestors are feeling seen and being heard

Develop guidelines to help healthcare practitioners with MAiD assessment

Follow up on people whose MAiD request is rejected

Develop resources to support grieving relatives & healthcare practitioners involved in MAiD

OBSERVATIONS & IDEAS TO EXPLORE

- There is a **lack of empirical qualitative studies** in the scientific literature
- We noticed a lack of space for the **voices of patients and their relatives**
- Most of the potential solutions mentioned in the literature are oriented towards **"what" to do**. The next step is to find **"how" to do it**.
- **An idea:** We could start by asking "how can we promote the well-being of stakeholders who experience these moral concerns?" and consult with those stakeholders to better understand their needs and perspectives.

CONTRIBUTION OF THE FIRST PHASE OF THE PROJECT

- **Contribution to current knowledge:** The literature review highlighted important knowledge gaps, key moral concerns and potentiel ways to tackle them.
- **Contribution to the project:** The literature review helped us to develop the discussion guide for the focus-groups and it will allow for the support tool to be based on evidence from the literature as well as on stakeholders' experiences.
- **Next steps going forward:** We are currently recruiting people living with mental disorders, relatives of people living with mental disorders and healthcare practitioners for the "Focus-groups" phase of the project.

PROJECT CONTRIBUTION TO INS 2022 CONFERENCE TOPIC

- The support tool will likely take the form of a guide to facilitate difficult discussions on MAiD or to raise awareness on important issues, to ease the experience of difficult situations. **This project is therefore a step towards building meaningful and living ethics in MAiD.**

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References: (1) Act respecting end-of-life care. CQLR, c. S-32.0001. (2) An Act to amend the Criminal Code and to make related amendments to other Acts (medical assistance in dying). S.C. 2016, c. 3. (3) An Act to amend the Criminal Code (medical assistance in dying). S.C. 2021, c. 2. (4) Schneider, B. (2012). Participatory action research, mental health service user research, and the hearing (our) voices projects. International Journal of Qualitative Methods, 11(2), 152-165.