

End-of-life care and social services for people with neurodegenerative diseases

Rationale

The Quebec Commission on end-of-life care recently asked the Institut national d'excellence en santé et en services sociaux (INESSS) to conduct a series of reflections on the state of practices in care and social services at the end-of-life in the context of integrated proximity care.

Implications

Results of this review will help INESSS and the Quebec Commission on end-of-life care develop a series of quality indicators to identify care trajectories leading to clinic excellence in end-of-life for patients with neurodegenerative diseases. This project is a starting point to allow the reflection and implementation of actions to improve end-of-life quality of care in Quebec and Canada.

Link to protocol registration:

TBD

For more information, please contact

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Background

- In Canada, neurodegenerative diseases are one of the leading causes of disability and death in the aging population. It is essential to better understand and take into account the health care needs and preferences of these patients and their families in the context of end-of-life care.

Objective

- This review aims to better understand the evidence on end-of-life care and social services for people with neurodegenerative diseases and to highlight best practices in the field.

Methodology

- **Review design: Systematic review**
- **Eligibility criteria (PICO):** **Participants:** Anyone with a neurodegenerative disease at the end of life and their family caregivers. **Intervention:** Any clinical or organizational interventions in end-of-life care. **Comparator:** Any or no comparator. **Outcomes:** Any outcome related to the improvement of the quality of care and social services will be considered and prioritized in partnership with our knowledge users. **Study design:** Any study design will be included initially. However, we will exclude books, conference abstracts, thesis, protocols, comments and editorials. No language or year restriction.
- **Literature search:** An experienced librarian will conduct comprehensive literature searches of electronic bibliographic databases in Medline, EMBASE, CINAHL, PsycINFO, CDSR and CENTRAL. The search strategy will be peer-reviewed by another librarian using the PRESS checklist.
- **Study Selection/Data Abstraction:** We will develop standardized forms for study selection and data extraction. Pilot exercises will be conducted within the review team for all steps. Study selection and data extraction will be conducted by pairs of two reviewers independently. Discrepancies will be resolved by discussion or by a third reviewer (senior). Risk of bias in trials and observational studies will be evaluated by pairs of two reviewers using the GRADE approach.
- **Synthesis:** Data synthesis will focus on providing information to our knowledge users regarding end-of-life care and social services for people with neurodegenerative diseases. Literature will be summarized according to the type of population, intervention, comparators, and outcomes identified. Outcomes will be categorized according to the harmonized approach of global value assessment as described in the statement of principles of the INESSS institutional framework of evaluation. This approach includes the dimensions (clinical, population, economic) of the health and social services system triple objective, to which are added the organizational and socio-political dimensions.

Knowledge Translation Strategy

- Knowledge users will be involved in all review stages.
- A manuscript will be submitted to a scientific, peer-reviewed journal.