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QUERY 43-20: End-of-life care and social services for people with neurodegenerative diseases

Protocol for a Systematic Review

Prepared for the Institut national d'excellence en santé et en services sociaux (INESSS)

Submitted [Pick the date]

Prepared By:

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Review title and timescale

1 Review title:

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

2 Anticipated or actual start date:

June 1st, 2020

3 Anticipated completion date:

May 31st, 2021

4 Stage of review at time of this submission:

This review has not yet started

Review stage (Please check all that apply)

Started **Completed**

Preliminary searches

✓

Piloting of the study selection process

Formal screening of search results against eligibility criteria

Data extraction

Risk of bias (quality) assessment

Data analysis

Provide any other relevant information about the stage of the review here: Not applicable

Review team details

5 Named contact

Annie LeBlanc

6 Named contact email

Annie.LeBlanc@fmed.ulaval.ca

7 Named contact address

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8 Named contact phone number

418-663-5712

9 Organisational affiliation of the review

VITAM – Centre de recherche en santé durable

10 Review team members and their organisational affiliations

Give the title, first name and last name of all members of the team working directly on the review. Give the organisational affiliations of each member of the review team.

First name

Last name

Credentials

Role

Affiliation

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| | | <i>e.g. MSc, PhD</i> | <i>e.g. PI, co-I</i> | |
|---------------|-----------|----------------------|----------------------|---|
| Annie | LeBlanc | PhD | PI | Department of Family Medicine and Emergency Medicine, Laval University, and VITAM |
| Denis | Roy | MD, MPH, MSc, FRCPC | Co-I | INESSS |
| Andrée-Anne | Poirier | PhD | Review Lead | INESSS |
| Michèle | Dugas | MSc | Review Lead | VITAM |
| Catherine | Vandal | MBA | Coordinator | VITAM |
| Benoit | Mailhot | PhD(c) | Reviewer | VITAM |
| Valérie | Carnovale | PhD | Reviewer | VITAM |
| Audrey | Turmel | | Reviewer | VITAM |
| Marie-Pier | Déry | BSc | Reviewer | VITAM |
| Jean-Philippe | Lavoie | | Reviewer | VITAM |
| Khalil | Moqadem | MBA, PhD | Reviewer | INESSS |
| Becky | Skidmore | MLS | Librarian | SPOR Evidence Alliance |

11 Funding sources/sponsors

The Institut national d'excellence en santé et en services sociaux (INESSS) and A. LeBlanc research team will co-fund this study. The SPOR Evidence Alliance will provide in-kind support.

12 Conflicts of interest

No conflicts of interest to declare.

Review methods

13 Review question(s):

What are the clinical and organizational interventions that have demonstrated a favorable or unfavorable impact on the quality of health care and social services for people with neurodegenerative disease at the end of life?

14 Literature Search:

An experienced librarian will conduct comprehensive literature searches of electronic bibliographic databases in MEDLINE, EMBASE, CINAHL, PsycINFO, The Cochrane Database of Systematic Reviews (CDSR), and The Cochrane Central Register of Controlled Trials (CENTRAL). The search strategy will be peer-reviewed by another librarian using the PRESS checklist.

15 URL to search strategy:

N/A

16 Condition or domain being studied:

End-of-life care for people with a neurodegenerative disease

17 Participants/Population:

Anyone with a neurodegenerative disease at the end of life and their family caregivers.

Neurodegenerative disease is defined as: Alzheimer's disease / dementia, Parkinson's disease, Multiple

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sclerosis, Amyotrophic lateral sclerosis (ALS, Lou Gehrig's disease, Charcot disease) or Huntington's disease.

End of life is defined as: 12 to 24 months before death.

18 Intervention(s)/Exposure(s):

Any clinical or organizational interventions in end-of-life care for people with neurodegenerative diseases and their family caregivers.

19 Comparator(s)/Control(s):

Any or no comparator.

20 Types of study to be included initially:

Any study design. We will however exclude books, conference abstracts, thesis, protocols, comments and editorials.

21 Context:

Any context will be considered.
No language or year restriction.

22 Primary outcome(s):

Any outcome related to the improvement of the quality of care and social services for people with neurodegenerative diseases at the end of life will be considered and prioritized in partnership with our knowledge users.

23 Secondary outcome(s):

N/A

24 Data extraction (selection and coding):

We will develop standardized forms for study selection and data extraction. The review team will conduct pilot exercises for all steps. Pairs of two reviewers will conduct the study selection and screen titles, abstracts and full text articles independently. Pairs of 2 reviewers will conduct the data extraction independently. A third reviewer (senior) or discussion will resolve discrepancies.

We will extract data relating to:

- **Study description** (ex: study aim, design, country, funding sources)
- **Participants** (ex: inclusion/exclusion criteria, method of recruitment, number of participants, age, sex and race/ethnicity)
- **Intervention** (ex: description, setting, duration of the intervention, timing, providers, fidelity)
- **Results** (ex: study conclusions, outcomes data)

25 Risk of bias (quality) assessment:

Pairs of two reviewers will evaluate the risk of bias in trials and observational studies using the GRADE approach. A third, senior, reviewer or discussion will resolve discrepancies.

26 Strategy for data synthesis:

We will synthesize the data focusing on providing information to our knowledge users regarding end-of-life care and social services for people with neurodegenerative diseases. We will summarize the literature according to the type of population, intervention, comparators, and outcomes identified. We will categorize the outcomes according to the harmonized approach of global value assessment as described in the

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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.

27 Analysis of subgroups or subsets:

-

Review general information

28 Type of review

Select one of the following:

Review Type

Scoping review

Rapid review

Systematic review

Other: _____

29 Language

Any language

30 Country

Canada

31 Other registration details

We will register our protocol on PROSPERO in July 2020.

32 Reference and/or URL for published protocol

TBD

33 Dissemination plans:

We will hold a meeting to present review results to our knowledge users and stakeholders (before writing the final report) to get their feedback on the results and discuss the potential implications of these results. Following this, we will share a one page, standardized, policy brief with knowledge users, partners of the SPOR Evidence Alliance, and broadly (through the SPOR Evidence Alliance Website). We will hold a meeting with stakeholders from the INESSS. We will submit a manuscript to a scientific, peer-reviewed journal for publication.

Do you intend to publish the review on completion?

Yes

No

34 Keywords

End-of-life, neurodegenerative diseases

35 Details of any existing review of the same topic by the same authors.

N/A

36 Current review status

Ongoing

37 Any additional information:

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We will involve knowledge users throughout the review process (i.e., development of protocol, development of the forms, prioritization of outcomes to extract, and presentation of results).

38 Details of final report/publication(s):

TBD