



THE INCLUSION OF INFORMAL CAREGIVERS IN THE PALLIATIVE AND END-OF-LIFE CARE OF OLDER ADULTS: RESULTS FROM A SCOPING REVIEW

Auclair, I.,^a Bourbonnais, A., Lavoie, A.^a & Leclerc-Loiselle, J.^b

Correspondance: isabelle.auclair.2@umontreal.ca

a) Faculté des sciences infirmière, Université de Montréal; b) Faculté de médecine et des sciences de la santé, Université de Sherbrooke

1. Introduction

Population ageing increases demands for quality palliative and end-of-life (EOL) care

"Interprofessionnal care to improve quality of life and relieve suffering (social, physical, emotional, spiritual) of people facing life-limiting illnesses and their informal caregivers" ¹

An important part of older adults' palliative and EOL care is the inclusion of their informal caregivers ^{1, 2}

- Reviews on the topic are specific to a health condition/setting

To identify best practices and priorities for improvement...

3. Methods: Scoping Review (Levac et al., 2010) ³

1) Research questions

Older adults, informal and formal caregivers...

- Experiences?
- Interventions?
- Influencing factors?
- Nature of inclusion?

2) Relevant publications

Key selection criteria

Population: Family/friends of ≥60yrs old with a terminal illness

Inclusion: Words and/or actions by informal caregivers to support older adults, understand palliative and EOL care, and influence care; Support of professionals in these aspects

Context: All settings and countries

- All publications (exc., social media, abstract, protocol)
- No time limit

Sources of information

Databases (9); Search engines; Reference lists

3) Selection

Reviewers (2) independently assessed for relevance (title, abstract, full text)

4) Charting the data

Template for data extraction included:

- Type
- Design
- Country
- Setting
- Purpose
- Sample
- Data collection & analysis methods
- Quality (JBI)
- Results - Questions

5) Collating, summarizing, and reporting the results

Descriptive summary of publications

Qualitative content analysis ⁴

Themes

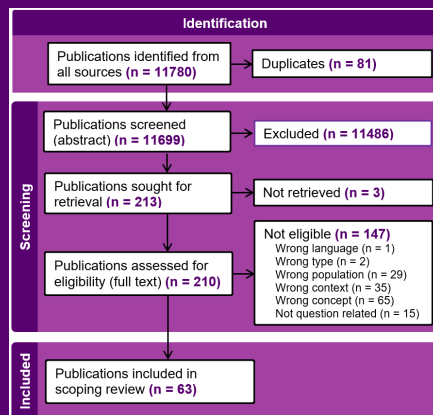
2. Aim



Map the extent of knowledge on the inclusion of informal caregivers in the palliative and EOL care of older adults

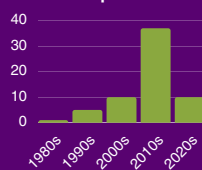
4. Results

PRISMA Flowchart

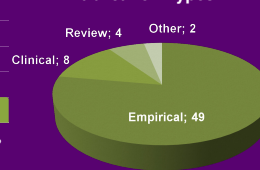


Descriptive summary of publications (n = 63)

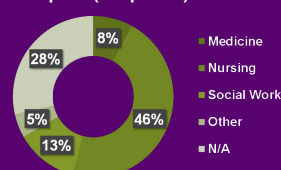
Decade of publication



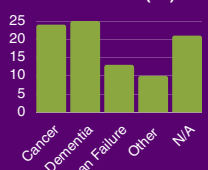
Publication Types



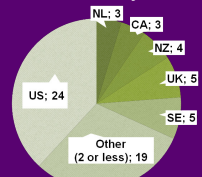
Discipline (if reported)



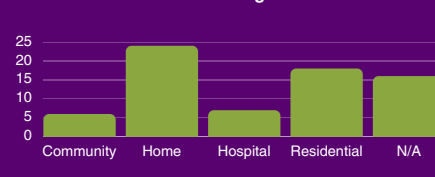
Terminal illness(es)



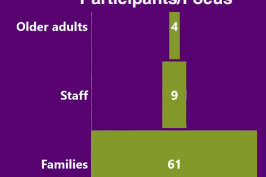
Country



Settings



Participants/Focus



Themes

Multifaceted: Physical, social, emotional

1. Activities of daily living (ADLs) and instrumental ADLs
2. Care related to nursing tasks
3. Communication
4. Constant emotional investment (thoughts, feelings)
5. Advocacy

Mainly at home

Most prevalent

Predominance of the experience of relatives

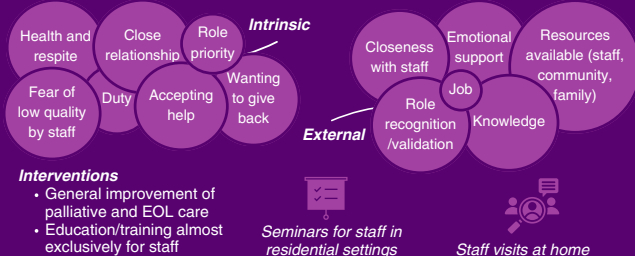
Older adult and staff: Scarce, but mostly positive

- Conflicts between staff and relatives
- Staff's knowledge of older adult
- Quality of care
- Relief of suffering
- Wishes honored

Relatives: Comprehensive and mixed

- Burden (emotional, social, physical, financial)
- Health deterioration
- Personal neglect
- Time consuming
- Role tensions (work, family)
- Emotionally rewarding
- Closer relationships
- Knowledge and skills
- Preparedness

Some ways to promote the inclusion of family and friends



5. Conclusions

The scope of relatives' inclusion is vast, and this is particularly evident in publications that focus on the home environment.

The inclusion of relatives in palliative and EOL care can have many psychosocial benefits, while most negative experiences can be mitigated with the help of health care professionals

No intervention specifically aims to promote the inclusion of relatives in palliative and EOL care, regardless of care setting

Intrinsic and external factors are avenues to promote the involvement of relatives and improve their experience:

- Clinical practices
- Development of interventions



Key references

1. World Health Organization. (2014). Global atlas of palliative care at the end-of-life.
2. Radbruch, L., De Lima, L., Knaul, F. et al., (2020). Redefining palliative care: A new consensus-based definition. *Journal of Pain and Symptom Management*, 60(4), 754-764. <https://doi.org/10.1016/j.jpainsymman.2020.04.027>
3. Levac, D., Colquhoun, H. & O'Brien, K. K. (2010). Scoping studies: Advancing the methodology. *Implementation Science*, 5, article: 69. <https://doi.org/10.1186/1748-5908-5-69>
4. Miles, M. B., Huberman, A. M. & Saldaña, J. (2020). *Qualitative data analysis: A methods sourcebook (4e)*. SAGE



CHAIRE DE RECHERCHE EN SOINS INFIRMIERS À LA PERSONNE AGÉE ET À LA FAMILLE

Université de Montréal



CANADA RESEARCH CHAIRS CHAIRES DE RECHERCHE DU CANADA

Centre de recherche iugm Institut universitaire de gériatrie de Montréal



RQSPAL RÉSEAU QUÉBÉCOIS DE RECHERCHE EN SOINS PALLIATIFS ET DE FIN DE VIE

Université de Montréal et du monde.

CHAIRE DE LA FAMILLE BLANCHARD POUR L'ENSEIGNEMENT ET LA RECHERCHE EN SOINS PALLIATIFS Faculté de médecine Département de médecine de famille et de médecine d'urgence

Fonds de recherche Santé Québec

Éducation et Enseignement supérieur Québec

We acknowledge the funding source