

BMJ Open Inclusion of informal caregivers in the palliative and end-of-life care of older adults: a scoping review protocol

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ABSTRACT

Introduction Palliative and end-of-life (EOL) care will increasingly be required in years to come as a result of an ageing population. An important component of this type of care is the inclusion of informal caregivers, who are family members or friends offering unpaid assistance to older adults with a terminal illness. Although systematic reviews were conducted on topics related to the inclusion of informal caregivers in the palliative and EOL care of older adults, several gaps remain as they were specific to a health condition and/or setting. The purpose of our scoping review is to map the extent of knowledge on this subject.

Methods and analysis We will conduct our scoping review following Levac's methodology. We will gather publications of various types through nine databases, manual searches in journals and search engines and reference lists. The selection process will be conducted by two independent reviewers and consist of screening by title and abstract, followed by reading the full text to confirm eligibility. An independent reviewer will then extract data and assess quality from included publications. Data extracted from different publication types will be synthesised together in the Excel software using a content analysis method, with quantitative data transformed into a qualitative description. Results will be presented through descriptive statistics and themes. During different steps of the review, we will also consult informal caregivers and health professionals for feedback as stakeholders.

Ethics and dissemination The conduction of this scoping review requires no ethical approval. Results will provide an overview of the state of knowledge on the inclusion of informal caregivers in palliative and EOL of older adults, which could help guide clinical practice, the development of interventions and policy and further research. We will disseminate these results by publishing an article, presenting in conferences, and discussing findings with stakeholders.

INTRODUCTION

Palliative and end-of-life care in the context of an ageing population

In 2019, 1 billion people were aged 60 years and older, and this number is estimated to double to about 2.1 billion in 2050; while the proportion of people aged 80 years old and over is expected to triple.¹ Population ageing leads to an increase in people living

Strengths and limitations of this study

- Our scoping review will be strengthened by a comprehensive search of the literature, as different publication types will be identified through multiple data sources.
- Literature included will be appraised for quality to consider the strength of evidence when making recommendations.
- Publications will be limited to those targeting older adults aged 60 years and over, in French or English.

with multimorbidity and serious illnesses who require palliative and end-of-life (EOL) care to manage their symptoms or the oncoming death.² The demand for this type of care will, therefore, increase in the coming years in settings such as hospitals, ambulatory services, long-term care facilities, palliative care centres and patients' homes.³

Palliative and EOL care refers to interprofessional care provided to improve quality of life by meeting individual needs and relieving suffering (physical, emotional, social, spiritual) of people facing life-limiting illnesses and their informal caregivers (ie, family members and friends offering assistance freely to someone with a health condition or limitation).⁴ Recently, a new definition on palliative care, based on feedback from 450 health professionals working in this field, broadens the scope to people living with severe illnesses or injuries of any kind causing suffering, but not necessarily terminal.⁵ This inclusive way of viewing palliative and EOL care can be beneficial to increase access to palliative care, although some health professionals criticise it as being too broad and as generating confusion for providers and policymakers.⁵ To avoid these mentioned difficulties and considering that the context of severe illnesses/injuries compared with terminal illnesses can bring different care issues, this review remains specific to the

latter. Moreover, the context of terminal illness is not limited to the last months of life, but more broadly refers to palliative and EOL care provided from the moment the diagnosis is received.

The importance of the inclusion of informal caregivers in the palliative and EOL care of older adults

An important role of health professionals in palliative and EOL care is to include informal caregivers.⁶ The nature of their inclusion in care can take the form of consultation (receiving information on care planning and decisions), involvement (influencing care planning and decisions by sharing opinions, experiences, etc) or partnership (care planning and decisions are fully made in collaboration).⁷ Also, Andershed and Ternstedt⁸ convey how the inclusion of informal caregivers in palliative and EOL care is not limited to shared information; they may directly participate in care or be present for the person with a terminal illness. 'Inclusion' is, therefore, used as a concept to encompass all terms and possible ways informal caregivers can take part in palliative and EOL care.

Informal caregivers can play key roles in palliative and EOL care by contributing to the well-being of the dying person (eg, physical or psychosocial relief), helping in activities of daily living (eg, getting dressed, personal hygiene, housekeeping), participating in care planning and decision-making (eg, communication with staff, promotion of autonomy) in addition to ensuring continuity of care.⁹ For instance, the participation of informal caregivers in care is common in non-institutional settings, especially in developing countries where older adults are mostly cared for by family members at home with sometimes little help from health professionals.¹⁰ Nevertheless, the role of informal caregivers caring for older adults with terminal illnesses differs from other populations, given that disease trajectories related to advanced age, such as organ failure and frailty, can often be unpredictable.¹¹ Additionally, older adults frequently live with multiple comorbidities requiring complex care, and, thus, they may need specific help from their informal caregivers to compensate for loss of physical and cognitive autonomy.¹²

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

There is an abundance of literature on various aspects related to the inclusion of informal caregivers in the palliative and EOL care of older adults, reflected by many reviews conducted on topics associated.

Experiences relating to the inclusion of informal caregivers

Systematic reviews addressed experiences relating to the inclusion of informal caregivers (eg, positive and negative consequences, unfulfilled needs),^{13–17} among others in the context of older people living with a major neurocognitive disorder in long-term care facilities¹³ and older adults with advanced cancer.¹⁸ However, these reviews are specific to a condition and/or setting. They do not

reflect the spectrum of experience of informal caregivers included in palliative and EOL care of older adults, which could be useful to identify shortfalls or strengths in care provided in different healthcare settings.

Nature of the inclusion of informal caregivers

As for the nature of the inclusion of informal caregivers in palliative and EOL care (ie, how informal caregivers include themselves and how they are included by health professionals), we identified a systematic review on this aspect, but it was not specific to older adults, did not have a comprehensive search strategy and dates back to more than 6 years ago.⁹ A recent narrative review did offer insight into the nature of the inclusion of informal caregivers, although in the context of EOL care provided to older adults living in long-term care facilities.¹⁹ Establishing with a systematic approach the scope of informal caregiver' inclusion in the palliative and EOL care of older adults, who have unique characteristics, could inform health professionals working with this population on opportunities they can offer to increase informal caregivers' potential of participation.

Factors influencing the inclusion of informal caregivers

Another narrative review synthesised studies on factors influencing the inclusion of informal caregivers in the palliative and EOL care of older adults,²⁰ but results provide limited knowledge considering it was again specific to long-term care facilities and not a systematic review. Identifying facilitators and barriers to inclusion would be useful to guide the development of strategies and interventions aiming to promote the inclusion of informal caregivers in palliative and EOL care.

Interventions promoting the inclusion of informal caregivers

Finally, two recent systematic reviews were identified on interventions intended to support informal caregivers in the context of palliative and EOL care, although they were not specific to the care of older adults.^{21–22} While a systematic review aimed to identify avenues for improvement in the EOL care of older adults, it was not in regards to promoting the inclusion of informal caregivers.²³ Because the role of informal caregivers to older adults approaching death can be particularly challenging as stated above, it would be important to review if interventions target this population and what are their characteristics.

In short, reviews on topics related to the inclusion of informal caregivers in the palliative and EOL care of older adults are specific to a health condition and/or a setting, or they are not targeting older adults, who have unique palliative and EOL care characteristics. No review identified the extent of the state of knowledge on the inclusion of informal caregivers in palliative and EOL care of older adults. Such a knowledge synthesis across all care settings and that considers various types of publication would be relevant to inform clinical practices of health professionals and future research. Indeed, establishing

the extent of literature on the subject could help build on what is already known to identify best practices and priorities for improvement. A scoping review would allow to reach such a goal.^{24–26}

PURPOSE

The purpose of this review is to map the extent of knowledge on the inclusion of informal caregivers in the palliative and EOL care of older adults. This review will answer four research questions described below.

METHODS AND ANALYSIS

Review method

We will conduct a scoping review to identify available knowledge, its purpose being to ‘systematically map the literature available on a topic’.²⁷ Furthermore, this type of knowledge synthesis is useful for large and heterogeneous subjects.²⁸ We will use the method by Levac, Colquhoun,²⁴ defined by six steps: (1) identifying the research questions, (2) identifying relevant studies, (3) study selection, (4) charting the data, (5) collating, summarising and reporting the results and (6) consultation. This specific method was chosen given its clarity and the fact that stakeholder consultation is an integral part of the process while remaining flexible. In this review, stakeholders refer to informal caregivers or health professionals with experiences on the inclusion of informal caregivers in palliative and EOL care. Our scoping review protocol is organised according to the six methodological framework steps, and with respect to relevant items of the Preferred Reporting Items for Systematic Review and Meta-Analysis Protocols (PRISMA-P).²⁹ We estimate that the scoping review will take about 1 year based on previously reported time frames³⁰ and our systematic approach.

Step 1: identifying the research questions

We identified four broad research questions that will guide the scope of inquiry. From the perspective of informal caregivers, older adults and health professionals, what is the state of knowledge on: (1) the experiences relating to the inclusion of informal caregivers in care? (2) the nature of the inclusion of informal caregivers? (3) the factors influencing the inclusion of informal caregivers? (4) the interventions developed to promote or support the inclusion of informal caregivers and their characteristics?

Step 2: Identifying relevant studies

Inclusion and exclusion criteria

Population: we will consider publication reporting on informal caregivers of older adults receiving palliative and EOL care, regardless of the type of terminal illness that led them to require this type of care. As presented above, informal caregivers in this review are family and friends offering unpaid assistance, while older adults are defined as people aged 60 years and over in accordance

with the WHO report on ‘ageing and health’.² We will exclude publication if results are not specific to this population, such as publications on older adults with severe illnesses that are not terminal, or if they do not provide a definition for the term ‘older adults’.

Concept: the concept of inclusion of informal caregivers in the palliative and EOL care of older adults is defined as encompassing all forms of inclusion described in previously mentioned frameworks by Carman *et al*⁷ and Andershed and Ternstedt⁸: consultation, involvement, partnership, presence, participation in tasks or care. It can be summarised as words and/or actions by informal caregivers to support older adults, understand palliative and EOL care and influence care provided; or, words and/or actions by health professionals to encourage informal caregivers’ participation in the aforementioned aspects, in addition to supporting them in their experience. To be included in the scoping review, publications should provide answers to one or more of the four research questions on the inclusion of informal caregivers in the palliative and EOL care of older adults (experiences, nature of inclusion, influencing factors, interventions).

Context: we will place no restriction on the country of publication or type of care settings.

Type of records: we will include all types of publication in French or English (ie, research articles, theoretical articles, professional articles, book chapters, thesis, guidelines, grey literature). As for grey literature, we will consider letters, editorials, governmental reports and magazine articles. We will exclude posts on blogs and social media platforms since they are not reliable records and relevant content on the inclusion of informal caregivers will likely be found also in other types of publication. Furthermore, we will exclude conference abstract and protocols in favour of the full studies they are referencing. We will apply no limit on time to ensure the exhaustiveness of the selection process.

Methods used to identify publications

Sources of information: we will maximise the identification of publications by using many sources of information as suggested by Cooper.³¹ Seven health science databases will be searched: Cumulative Index to Nursing and Allied Health Literature (CINAHL), PubMed, PsycINFO, Embase, Trip, ProQuest Dissertation & Theses Global, Cochrane Database of Systematic Reviews. We will also identify grey literature using two databases: Open Grey and Grey Literature Report. In addition to searching these nine electronic databases, we will perform manual searches in search engines (Google Scholar, Web of science) as well as in journals of key articles identified. Health professionals with expertise in palliative and EOL care and/or geriatrics will be solicited for additional publications, especially grey literature such as guides for clinical practices. Finally, we will examine the references list of relevant articles to find publications not collected via other information sources. We have direct access to most publications and journals through our institution’s

resources, but, if necessary, we will use the interlibrary loan service or contact authors to obtain full texts. To include very recent publications, we will conduct a second search in the databases shortly before submitting the results of the scoping review.

Search strategy: to carry out searches in the databases, we developed a strategy using keywords and descriptors in collaboration with a librarian to ensure balance between sensitivity and specificity on the topic. It includes three major concepts: ‘informal caregivers’, ‘palliative and EOL care’ and ‘older adults’. We grouped ‘palliative and EOL care’ into one concept since we are targeting publication that addresses either palliative care or EOL care (Boolean operator OR). We did not include ‘inclusion’ as a concept following the librarian’s recommendation. This was justified by the fact that words without any meaning on their own (eg, influence, effects, increase) are not useful to identify relevant publications. Instead, we specified that each major concept had to be present in either the title, the abstract or the keywords. [Table 1](#) presents an example of the search strategy, as conducted in the CINAHL database.

Step 3: Study selection

As recommended by Levac *et al.*,²⁴ we will proceed to the selection of publication on the Covidence platform, where teams of two people will independently evaluate if publications meet the eligibility criteria. Disagreements will be resolved by a third person. We will first assess the relevance by the title and abstract of papers. Selected publications will then be read fully to determine eligibility. Levac *et al.*²⁴ suggest meeting in the beginning, middle and end of this selection process to discuss uncertainties and refine inclusion and exclusion criteria. Therefore, we decided to assess the same 20 publications at the beginning of each stage of the selection process (title and abstract, full text) to have a big enough sample of publications to ensure teams of reviewers have the same understanding of criteria and refine them if necessary. We will complete a flow diagram to show the number of articles obtained throughout the different stages of the selection process and the reasons for exclusion.³²

During the selection process, duplicates will first be removed with the EndNote function before importing references in the Covidence platform. Duplicates identified by Covidence after references import will also be removed. Finally, we will manually exclude any duplicate that would remain.

Step 4: Charting the data

We will also use the Covidence platform to extract data from included publications. To guide this extraction, we will develop a template informed by our team’s expertise in palliative and EOL care and/or geriatrics. Preliminarily, the extracted data will include: type of publication (research article, theoretical article, literature review, grey literature, etc), country where the research took place or where the first author originated, conflicts of

interest (presence or not, nature), theoretical framework (name of the framework, if any), purpose, design, setting, sample (size, type of participants, sociodemographic characteristics, eligibility criteria), data collection and analysis methods, results related to research questions on the inclusion of informal caregivers (experiences, nature of inclusion, influencing factors, interventions), strengths and limitations as described in the publication. We will also extract data on the quality of publications. Although Levac *et al.*²⁴ are neutral about quality appraisal in scoping reviews, we plan to assess quality as it allows to identify knowledge gaps based on low-quality evidence and to consider the rigour of the literature when making recommendations.³³ Therefore, the purpose of this quality assessment is not to exclude publications, since we aim to map all available knowledge, but to take into account the quality of the available knowledge in the conclusions of our review and for its implications for research and practice. We will use the appraisal tools from the Joanna Briggs Institute as they are validated and will allow for quality assessment of different types of publication (both empirical and non-empirical), while also providing instructions that guide this assessment.³⁴ For mixed methods studies, we will use the Mixed Methods Appraisal Tool,³⁵ since there is no Joanna Briggs Institute quality appraisal checklists for this type of study.

Data extraction will be conducted by one person, following a calibration in 10 studies of all those involved in the process.²⁴ This strategy will be used to ensure consistency from one person to another in the way the data are extracted, in addition to pilot test the template and discuss possible adjustments.

Step 5: Collating, summarising and reporting the results

Data extracted from different types of publications will be synthesised together by IA through qualitative content analysis in the Excel software using the method suggested by Miles *et al.*³⁶ This method is characterised by three steps: (1) data condensation, (2) data display, (3) drawing and verifying conclusions. In short, IA will code relevant data, transform any quantitative data into a qualitative description, interpret patterns and verify that conclusions are grounded in the original data. The research team will then be invited to comment the content analysis in Excel and make their own interpretations. Discrepancies will be resolved by consensus.

Results will be presented with a descriptive numerical summary on the characteristics of publications and a description of themes based on the synthesis of data extracted from the articles. We will use visual representations to support the organisation of results, for example, a figure could show knowledge gaps, or a table could detail characteristics of publications. IA will draw the preliminary results and consult the research team as well as stakeholders (ie, informal caregivers and health professionals) for feedback on the organisation and interpretations of results.²⁴ Stakeholders will be asked, for example, to indicate if some findings need clarification and identify

Table 1 Search strategy conducted in the CINAHL database

Concepts	Informal caregivers	Palliative and end-of-life care	Older adults
Keywords	Family-ies Caregiver-s Caregiving Spouse-s Wife-ves Husband-s Brother-s Sibling-s Sister-s Son-s Daughter-s Child-ren Relative-s Offspring-s Grandchild-ren Next of kin	End-of-life care End-of-life treatment EOL care EOL treatment Palliative care Palliative approach-es Palliative therapy-ies Palliative medicine Palliative treatment-s Palliative Surgery-ies Palliative sedation Palliation Surgical palliation Supportive Care Terminal care Terminal treatment-s Terminal therapy-ies Terminal sedation Terminally ill patient-s Terminal illness-es Hospice care Hospice treatment-s Hospice therapy-ies Hospice practice-s Hospice programs Hospice patients Suicide assisted care Assisted death-s Assisted dying Assisted suicide-s Euthanasia MAID (medical assistance in dying) Medical aid in death Medical aid in dying Dying care Dying measures Dying patients	Older adult-s Old person Old people Older people Old age Aged Elderly Elder-s Senior-s Centenarian-s Nonagenarian-s Octogenarian-s Septuagenarian-s Sexagenarian-s Geriatric-s Gerontology Gerontologic
CINAHL descriptors	(MH "Family+") (MH "Caregivers") (MH "Caregiver Support") (MH "Caregiver Burden") (MH "Caregiver Attitudes") (MH "Professional-Family Relations") (MH "Decision Making, Family") (MH "Family Centered Care") (MH "Family Attitudes+") (MH "Family Nursing") (MH "Patient-Family Conferences") (MH "Family Role") (MH "Family Assessment") (MH "Dependent Families")	(MH "Hospice and Palliative Nursing") (MH "Terminally Ill Patients+") (MH "Terminal Care+") (MH "Attitude to Death") (MH "End-of-Life Comfort Questionnaires")	(MH "Aged+") (MH "Gerontologic Care") (MH "Gerontologic Nursing+") (MH "Gerontologic Nurse Practitioners") (MH "Geriatric Psychiatry") (MH "Geriatric Nutrition")

Continued

Table 1 Continued

Concepts	Informal caregivers	Palliative and end-of-life care	Older adults
CINAHL search combining keywords and descriptors	(Family OR Families OR Caregiv* OR Spouse* OR Wife OR Wives OR Husband* OR Brother* OR Sibling* OR Sister* OR Son OR Sons OR Son's OR Daughter* OR Child* OR Relative OR Relatives OR Offspring* OR Grandchild* OR "Next of Kin" OR (MH "Family+") OR (MH "Caregivers") OR (MH "Caregiver Support") OR (MH "Caregiver Burden") OR (MH "Caregiver Attitudes") OR (MH "Professional-Family Relations") OR (MH "Decision Making, Family") OR (MH "Family Centered Care ") OR (MH "Family Attitudes+") OR (MH "Family Nursing") OR (MH "Patient-Family Conferences") OR (MH "Family Role") OR (MH "Family Assessment") OR (MH "Dependent Families")) AND (("End-of-life" OR "EOL") OR Palliat* OR "Supportive care" OR (Terminal* N2 (care OR treatment* OR therap* OR sedation OR ill*)) OR Hospice OR ((Care OR Treatment*) N2 (withdraw* OR withhold* OR cessation)) OR (Assist* N2 (death* OR dying OR suicide*)) OR Euthanasia OR ("Medical aid" N2 (death* OR dying)) OR "MAID" OR (Bereavement N3 (care OR support*)) OR (Dying N2 (care OR measure* OR patient*)) OR "Death care" OR (Attitude* N2 (death* OR dying)) OR "Final stages of life" OR (MH "Hospice and Palliative Nursing") OR (MH "Terminally Ill Patients+") OR (MH "Terminal Care+") OR (MH "Attitude to Death") OR (MH "End-of-Life Comfort Questionnaires")) AND ((Old* N2 (adult* OR person OR people OR age OR individual*)) OR Elder* OR Senior* OR Aged OR Centenarian* OR Nonagenarian* OR Octogenarian* OR Septuagenarian* OR Sexagenarian* OR Geriatric* OR Gerontolog* OR (MH "Aged+") OR (MH "Gerontologic Care") OR (MH "Gerontologic Nursing+") OR (MH "Gerontologic Nurse Practitioners") OR (MH "Geriatric Psychiatry") OR (MH "Geriatric Nutrition"))		

research gaps based on their experience. This will allow to further refine our results as well as help identified possible implications.

Patient and public involvement

This review protocol was written with no patient or public involvement. We plan to involve informal caregivers and health professionals with experiences on the inclusion of informal caregivers in palliative and EOL care when conducting the scoping review and disseminating its results. More precisely, these stakeholders will be consulted for identification of publications, feedback on organisation and interpretation of preliminary results and informed of the scoping review's final results.

DISCUSSION

This scoping review will map the extent of the literature on the inclusion of informal caregivers in the palliative and EOL of older adults, relating to experiences, nature of inclusion, influencing factors and interventions. Results will provide an overview of the state of knowledge, including research gaps. They could increase awareness on informal caregivers' experiences of being included or not in palliative and EOL care of older adults and the individual and organisational factors influencing this practice. These results could, therefore, offer valuable information to inform clinical practice and the development of interventions and policy. By identifying knowledge and evidence gaps on informal caregivers' inclusion in palliative and EOL care of older adults, this scoping review will help guide further research on the subject.

Many methodological steps will contribute to the quality of our scoping review, the majority drawn from recommendations by Levac *et al*²⁴: the use of multiple data sources to identify publications, the participation of

a librarian in the conception of the search strategy, the selection of publications by two independent reviewers, calibration between reviewers for the selection, extraction and quality assessment processes and the participation of stakeholders who have personal or professional experiences with the inclusion of caregivers in palliative and EOL care. The latter will contribute to the clinical relevance of findings.

Limitations of our scoping review include language as only publication in French or English will be considered. Additionally, some relevant documents could be excluded on the basis that results are not specific to adults aged 60 and above or if age is not specified.

ETHICS AND DISSEMINATION

As this is a review and per Article 2.1 of the Canadian Tri-Council Policy Statement, no approval is needed from an ethics committee for the consultation of stakeholders in a systematic review as they are not themselves the focus of the research questions.³⁷

We intend to maximise the dissemination of results by submitting the results of our scoping review in an international peer-reviewed journal with a target audience of interdisciplinary health professionals and researchers. We will write the article presenting our results in accordance with the items of the PRISMA extension for scoping review to ensure reporting quality.³⁸ Additionally, we will disseminate results by presenting in conferences and sharing them with stakeholders (ie, informal caregivers and health professionals who participated in the scoping review). These stakeholders could in turn help disseminate the results to other health professionals they work with.

Contributors IA drafted the manuscript, while AB, AL and JL-L contributed meaningfully to the conceptualisation and editing of the introduction, review questions, methods and analysis and discussion. All authors approved of the final manuscript.

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Competing interests None declared.

Patient and public involvement Patients and/or the public were involved in the design, or conduct, or reporting, or dissemination plans of this research. Refer to the Methods section for further details.

Patient consent for publication Not applicable.

Provenance and peer review Not commissioned; externally peer reviewed.

Data availability statement No datasets as it is a scoping review protocol.

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