End-of-life care in long-term care homes: A scoping review protocol

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Abstract

Background: Quality end-of-life (EOL) care is essential in long-term care homes (LTCHs), as the average survival time of newly admitted residents is estimated to be around 2 to 2.5 years. However, significant challenges exist when it comes to providing EOL clinical care in LTCHs, and the available empirical evidence does not offer a clear idea of the best practices to adopt.

Aim: To systematically map the state of knowledge on EOL clinical care in LTCHs, as it relates to people receiving care, family care partners, health care professionals, the characteristics of the organization, the social context, and the implementation of guides.

Methods: The scoping review method by Levac et al. (2010) will be used. Data will be collected from multiple sources, including eleven databases using a combination of keywords and descriptors, references list, prospective and manual searches, and by consulting clinicians and managers from LTCHs for additional publications. The literature from 2012 and onwards will be selected if it directly concerns EOL care in LTCHs, with no restriction on the age of residents or on the type of health care professionals or family care partners. The screening and data extraction will be performed by two people independently and any discrepancies will be resolved by consensus. We will also assess the quality of publication with the critical appraisal tools developed by the Joanna Briggs Institute. We will synthesize the extracted data using content analysis and consult stakeholders in LTCHs when a first version of the data synthesis is available to enhance the interpretation of the results based on their experience. We will present results in narrative form with tables and graphs.

Discussion: The results will provide evidence-based recommendations for clinical practice when available findings are conclusive and will allow identifying knowledge gaps to orient future research programs focusing specifically on EOL clinical care in LTCHs.

Keywords: Nursing home, palliative care, dying, systematic review, family, health professional, residents, intervention, experience

Background

According to the World Health Organization (WHO), end-of-life (EOL) care refers to physical, psychological, social, and spiritual support offered by health professionals to dying people in an effort to increase their comfort and dignity (World Health Organization, 2020). EOL care also encompasses the management of symptoms and the support of the family care partners by health care professionals (World Health Organization, 2020). EOL care is a form of palliative care. Palliative care focuses on the prevention and relief of multifaceted suffering (physical, psychological, social, spiritual) in people with life-limiting illnesses through the early identification, assessment, and treatment of suffering. EOL care specifically aims to provide this type of care to people who are considered in a terminal phase of their illness or are imminently dying (Fowler & Hammer, 2013).

The importance of long-term care homes (LTCHs) staff delivering high quality EOL care has been recognized for decades (Goodridge et al., 2005). This is even more relevant nowadays as LTCHs are caring for increasingly frail older adults, also affected by multiple comorbidities and complex health conditions (Matthews et al., 2016). In fact, the average survival time upon admission in LTCHs was estimated between 2 and 2.5 years in America and Scandinavia, with annual deaths of around one third of the residents (Vossius et al., 2018). Furthermore, data from 17 countries across 4 continents (America, Europe, Oceania, Asia) shows that close to 20% of deaths of older adults aged 65 years and older occurred in residential aged care, including LTCHs (Broad et al., 2013). The percentage of deaths only increases with age, with an average of 32% of people over 85 years old dying in these settings (Broad et al., 2013). Therefore, this demographic and health context indicates the need for timely integration of quality EOL care in LTCHs.

Empirical evidence and clinical practice attest to persisting obstacles when it comes to EOL care in LTCHs. These obstacles include the lack of recognition of the fatal nature of certain conditions frequently encountered in LTCHs, such as major neurocognitive disorders (Robinson et al., 2014), and the challenges of assessing signs and symptoms encountered at the EOL (Smets et al., 2018). These difficulties can lead to suffering for residents and their family members or friends (hereafter called family care partners) (Bokberg et al., 2019), as well as contribute to moral and emotional distress in health care professionals (Brorson et al., 2014; Lundin & Godskesen, 2021; Saint-Arnaud, 2018).

Although publications can be found about EOL in LTCHs, the state of knowledge remains to be established. Knowing this state of knowledge is essential to provide evidence-based recommendations for clinical practice and allow identifying knowledge gaps to orient future research programs focusing specifically on dying adults in LTCHs and their family care partners. Recently, authors conducted a scoping review on the models of palliative and EOL care in LTCHs (Kaasalainen et al., 2019). While the review is specific to LTCHs, it focused only on organizational models and their content (e.g., models using external consultants at the LTCHs

or offering this care locally). Another scoping review was carried out on organizational aspects related to EOL care provided to older adults, but without specifically targeting LTCHs (Threapleton et al., 2017). In addition, the search strategy in that review included only two databases, an important limitation considering scoping reviews aim to explore the existing publications broadly and sensitively. Although these two reviews are relevant, their results focused only on organizational aspects. They do not offer a clear overview on available knowledge on EOL clinical care provided to people in LTCHs or their family care partners. These settings have specific characteristics in terms of organization of care (e.g., routinized work, but unpredictable), of professionals (e.g., mainly registered nurses, licensed vocational nurses, and nurse aides), of people being cared for (e.g., multimorbidity) (Bedin et al., 2013; Leppa, 2004), and family care partners who support them (e.g., significant change in the role) (Williams et al., 2012). Recent reviews in LTCHs that address clinical aspects have focused on advance care planning before the EOL and not on EOL care directly (Flo et al., 2016; Gilissen et al., 2017; Martin et al., 2016).

To better understand the state of knowledge on EOL care in LTCHs, we will carry out a scoping review targeting the clinical and psychosocial context, that will draw on numerous data sources and on the assessment of the quality of publications. Our results will make it possible to better identify clinical and research needs to guide research development and issue clinical recommendations to optimize quality of EOL care in LTCHs.

Aim and Research Questions

We aim to conduct a scoping review to map the state of knowledge on EOL clinical care in LTCHs. The following six questions underlie our review. What is the state of knowledge on EOL care concerning:

1) People receiving care?
2) Family care partners?
3) Health care professionals?
4) Characteristics of the setting (LTCHs)?
5) Social-cultural context?
6) The implementation of EOL care guides in LTCHs?

Methods

We will use the scoping review method described by Levac et al. (2010) because it clearly explains the various steps and promotes the participation of stakeholders. It also considers this type of review as an iterative process that allows adjustments to the protocol as the state of available knowledge becomes clearer. As recommended in this method, the review will be conducted by a team consisting of experts on the content (EOL care, geriatrics, LTCHs) and the methodology of interest (scoping reviews). This method includes various types of publications (empirical, theoretical, grey literature) and has 6 steps: 1) identifying the research

questions; 2) identifying the literature; 3) selecting the literature; 4) extracting the data; 5) presenting the results; 6) consulting with stakeholders. As it is not possible to register the protocol for a scoping review and to ensure transparency in our process (Allers et al., 2018; Moher et al., 2009), it will be published in an open access online research platform. This protocol will thus serve as a basis for highlighting and documenting the changes made during the iterative process.

Identifying the Literature
Information Sources
As suggested by Cooper (2010), we will use several data sources to identify publications, namely 1) databases (CINAHL [EBSCO], APA PsycInfo [Ovid], MEDLINE [Ovid], Embase [Ovid], Cochrane Database of Systematic Reviews [Ovid], Global Health [Ovid], Dissertations & Theses Global [Ovid], Sociological Abstract [ProQuest], Web of Science [Clarivate], Gray LiteratureReport [The New York Academy of Medicine], MedNar [Deep Web Technologies]); 2) references from key publications; 3) prospective searches of key references in Google Scholar and Web of Science; 4) contacting key authors to identify non-indexed publications; 5) consultation of knowledge users to identify other relevant publications.

Search Strategy
For database searches, the initial MeSH descriptors will be: ("Hospice and Palliative Nursing" OR "Terminally Ill Patients+" OR "Terminal Care+" OR "Attitude to Death") AND ("Nursing Home Patients" OR "Nursing Home Personnel" OR "Nursing Homes+"). The strategy will be refined by undergoing a search in CINAHL in collaboration with a librarian, to add descriptors and keywords. We will use descriptors and keywords for the concept "palliative care" in the search strategy as this concept is often interchanged by authors with EOL care. When the strategy is considered effective, we will carry out the search in the other databases (see Annex for example of the search strategy in CINAHL).

Data Management
We will import reference into EndNote™ 20, and remove duplicates. We will use Covidence web platform to proceed with the screening and extraction processes by two independent persons.

Selecting the Literature
Eligibility Criteria
To meet the aim of this scoping review, the literature that meets the following population-concept-context (PCC) criteria will be included in the review.

Population. We will include literature on people receiving EOL care or on their family care partners and/or staff or health care professionals if it allows for answering the review questions. We will exclude literature on residents (their family care partners or professionals) with COVID-19, HIV or AIDS as those health conditions are not representative of the usual context in LTCH or usual current population.

Concept. The core concept of this scoping review is EOL clinical care (defined in the background section). This includes care provided to terminally ill residents, care provided to residents in their last months or days of life, philosophical or ethical aspects of EOL clinical care, outcomes on transfers of dying residents to hospital settings, and predictors for initiating EOL care.

We will exclude literature focused on organizational models (including external hospice services), costs (including Medicare policies), legal aspects, staff or student training, or a topic related to or prior to EOL clinical care (bereavement, advance directives, advance care planning, good death, mortality predictors). We will also exclude literature were EOL care is not the central concept of the publication, for example by not being mentioned in the aim of the study.

Context. We will include literature concerning explicitly and exclusively LTCH or similar settings (e.g., skilled nursing facilities) if they offer the presence of nurses 24 hours a day. We will exclude publication about or including other types of settings offering mainly personal assistance (e.g., assisted living facilities). We will include literature from all countries.

Type of Records. The search strategy will be limited to English, French or Spanish literature published in the last 10 years (2012 and onwards). This is because the characteristics of LTCH residents have changed in recent years. LTCH are now admitting older adults who present more severe disability, including being more cognitively impaired, and more complex multimorbidity (Barker et al., 2021). This changes the nature of care in those settings. Older literature would likely not represent the current clinical or research context. Also, based on preliminary searches in databases, there seems to be a large body of literature on EOL care in LTCH in recent years.

All types of literature will be considered. This includes, for example, primary studies (e.g., quasi-experimental, experimental, qualitative, and mixed-method designs), literature reviews (e.g., narrative reviews, meta-analysis, systematic reviews), grey literature (e.g., governmental reports, theses), as well as theoretical articles. To focus on scientific and clinical literature with sufficient content to help answer our research questions, we will exclude conference abstracts or proceedings, protocols, editorials, expert opinions, commentaries, letters, summaries of an

article, book reviews, books, book chapters, magazines, publications without an author, personal story, personal blogs, media, and social media.

Screening Process

We will start by screening publications by title and abstract based on the eligibility criteria above and review questions. We will classify the publications as relevant (included), irrelevant (excluded) or uncertain relevance (maybe). We will read publications considered uncertain or relevant in full to validate their relevance. We will document reasons for exclusions at the full-text review stage. The screening and full-text review will be carried out by two independent persons in duplicate, one of them always being the research assistant (IA) or the principal investigator (AB). Conflicts between two screeners will be discussed between the research assistant and the principal investigator to reach a consensus. The other research team members will be involved, if needed, to resolve the remaining conflicts and iteratively adjust the protocol, as expected in a scoping review (Levac et al., 2010).

To contribute to consistency between reviewers, we will undertake a calibration process using at least 5 publications before screening and full-text review. The results of the calibration processes will be discussed with all team members. If needed, this step will be repeated with another number of publications until the screening process is clear.

Extracting the Data

Once the screening and full-text review processes are completed, two independent team members will independently extract the data in duplicate. Consensus will be resolved by one of the extractors with the research assistant or principal investigator. If there are more than 20 publications to extract, the first 20 will be extracted independently by two people in duplicate and the following ones will be done by only one person with uncertainties tagged to be discussed and resolve by consensus with members of the team. This is justified by the little additional value to independent extraction after many publications have been extracted. As Levac et al. (2010) recommend extracting only five to ten publications independently, our protocol is more stringent to ensure similar extraction between extractors. Also, a calibration process using 4 documents will be undertaken before starting data extraction ensuring the clarity and completeness of the extraction template. The results of the calibration processes will be discussed with all team members in order to reach a consensus (Li et al., 2015).

We will extract data using a template built in Covidence which includes the following aspects:
1. General data: title, year of publication, first author surname, the discipline of the first author, country of the first author's affiliation, type of literature (i.e., primary study, literature review and its type, grey literature, theoretical article), aim/research questions of the study, type of participants/context (person receiving care, family care partners,

health care professionals, managers, sociocultural context, institutional characteristics, end-of-life guide, other);

2. Theoretical data: explicit use of a framework to identify relevant variables, guide the design or development of an intervention, guide the conduct of the study, or explain the relationship between variables, if mentioned;

3. Methodological data (if an empirical study): research design (i.e., randomized trial, non-randomized experimental study, cohort study, descriptive study, correlational study, qualitative study, mixed-methods study, case study, case report, case control study, action research, other), number of participants recruited, participants' characteristics (i.e., mean, [and standard deviation] or median [and interquartile range]) age of participants, the proportion of female participants (versus male), time before death, inclusion or not of people with a major neurocognitive disorder or their family care partners, name of data collection tools and measures timing;

4. Results data: results on factors, characteristics, needs, experience/perceptions, predictors or intervention (nature of the intervention described based on the following items of the TIDieR checklist, i.e., name, procedure, provider, modes of delivery, number of times administered [Hoffman et al., 2014], as well as effects) associated with EOL clinical care.

While the quality assessment of publications is not required in a scoping review (Levac et al., 2010), identifying areas where sufficient evidence is available to support recommendations for clinical practice is a goal of this project and must be based on the quality of evidence. We will judge each publication as having good, moderate, or poor methodological quality. We will use the quality assessment tools proposed by the Joanna Briggs Institute (JBI) (2021) since they are specific to each type of publication (e.g., qualitative, quantitative, systematic reviews and opinion text) (Aromataris et al., 2015; Lockwood et al., 2015; McArthur et al., 2015; Moola et al., 2020; Munn et al., 2020; Tufanaru et al., 2020). These tools are based on the type of research design and were approved by the JBI Scientific Committee following extensive peer review. They include questions (between 6 and 13) that allow for an overall judgment on the quality. As the JBI does not offer a critical appraisal checklist for mixed studies, these studies will be appraised using the checklist for qualitative research and the one corresponding to the quantitative design in addition to the five questions specific to mixed studies (section 5) of the Mixed Methods Appraisal Tool (MMAT) (Hong et al., 2018; Pace et al., 2012). If the study is an action research, the checklist corresponding to the type of assessment will be chosen.

Presenting the Results

Following data extraction, we will analyze data using content analysis techniques inspired by Miles et al. (2014) which include the following steps: 1) data condensation; 2) data display of similarities and differences; and 3) drawing and verifying conclusions (noting themes and subthemes). We will present results in narrative form accompanied by tables and graphs. The

results will be presented based on the Preferred Reporting Items for Systematic Review and Meta-Analysis extension for scoping reviews (PRISMA-ScR) (Tricco et al., 2018).

Consulting With Stakeholders

When a first version of the results and recommendations for EOL clinical care and research in LTCH is available, we will consult stakeholders (clinicians, care partners and managers) that have expertise on the topic. We will share with them the list of the references from which data were extracted as well as the eligibility criteria to invite them to propose additional references that would be missing, especially grey literature. In addition, we will invite them to comment a synthesis of those main results and recommendations based on their experience. We will ask them specific questions in writing, or if their prefer, by discussing with the research assistant or principal investigator. This will allow us to improve the interpretation of the results and, mostly, identify essential elements to discuss regarding clinical EOL care and research development, including aspects that are not reported in publications but that would be important.

Discussion

To our knowledge, our scoping review will be the first to map the state of knowledge on EOL clinical care in LTCHs. Conducting such a review is fundamental considering EOL clinical care contributes to the wellbeing of dying adults in LTCHs and their family care partners, and since this setting will be increasingly called upon in the context of an aging population. Multiple rigorous methodological steps will enhance the quality of our scoping review, including an exhaustive search of publications, a systematic approach to screening and extracting data with two independent reviewers, and the consideration of the quality of publications when making recommendations. We will also consult stakeholders working in LTCHs to contribute to the depth, relevance and applicability of the scoping review synthesis. Results obtained could help guide health care professionals in their clinical practice in LTCHs, as well as inform of priority areas for future research based on the observed knowledge gaps and the needs of the multiple stakeholders. Therefore, results will be key in order to inform a research program focusing specifically on EOL clinical care in LTCHs.

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Annex: Complete search strategy to be conducted in CINAHL

Concepts	End-of-life care	Residential and long-term care centres
Keywords	Assisted death-s	Aged care center-s (centre-s)
	Assisted dying	Aged care establishment-s
	Assisted suicide-s	Aged care facility-ies
	Attitude to dying	Aged care home-s
	Attitudes to death	Aged care residence-s
	Attitudes to dying	Extended care center-s (centre-s)
	Care withdrawal-s	Extended care establishment-s
	Death Attitude	Extended care facility-ies
	Death Attitudes	Extended care home-s
	Death care	Extended care residence-s
	Dying care	Extended patient care center-s (centre-s)
	Dying measures	Extended patient care establishment-s
	Dying patient	Extended patient care facility-ies
	End-of-life care	Extended patient care home-s
	End-of-life treatment	Extended patient care residence-s
	EOL care	Home-s for the aged
	EOL treatment	Home-s for the elderly
	Euthanasia	Long term care center-s (centre-s)
	Final stages of life	Long term care establishment-s
	Hospice care	Long term care facility-ies
	Hospice patients	Long term care home-s
	Hospice practice-s	Long term care residence-s
	Hospice programs	Long term use facility-ies
	Hospice therapy-ies	Nursing home-s
	Hospice treatment-s	Residential and long-term care centre-s
	Medical assistance in dying (MAID)	Residential care center-s (centre-s)
	Medical aid in death	Residential care establishment-s
	Medical aid in dying	Residential care facility-ies
	Palliation	Residential care home-s
	Palliative approach-es	Residential care residence-s
	Palliative care	Skilled nursing center-s (centre-s)
	Palliative medicine	Skilled nursing establishment-s
	Palliative sedation	Skilled nursing facility-ies
	Palliative surgery-ies	Skilled nursing home-s
	Palliative therapy-ies	Skilled nursing residence-s
	Palliative treatment-s	
	Suicide assisted care	
	Supportive care	

	Surgical palliation Terminal care Terminal illness-es Terminal sedation Terminal therapy-ies Terminal treatment-s Terminally ill patient-s Treatment cessation Treatment withdrawal-s Treatment withholding	
Descriptors (CINAHL)	(MH "Attitude to Death") (MH "End-of-Life Comfort Questionnaires") (MH "Hospice and Palliative Nursing") (MH "Terminal Care+") (MH "Terminally Ill Patients+")	(MH "Nursing Home Patients") (MH "Nursing Home Personnel") (MH "Nursing Homes+")
Full strategy	((MH "Hospice and Palliative Nursing") OR (MH "Terminally Ill Patients+") (MH "Terminal Care+") OR (MH "Attitude to Death") OR (MH "End-of-Life Comfort Questionnaires") OR ("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 (Dying N2 (care OR measure* OR patient*)) OR "Death care" OR (Attitude* N2 (death* OR dying)) OR "Final stages of life") __AND__ ((MH "Nursing home Patients") OR (MH "Nursing Home Personnel") OR (MH "Nursing Homes+") OR ("Long term" N2 (center* or centre* or residence* or facilit* or home* or establishment*))OR ("Aged care" N2 (center* OR centre* OR residence* OR facilit* OR home* OR establishment*)) OR ("Residential care" N2 (center* OR centre* OR residence* OR facilit* OR home* OR establishment*)) OR (("Extended care" OR "Extended patient*") N2 (center* OR centre* OR residence* OR facilit* OR home* OR establishment*)) OR ("Skilled nursing" N2 (center* OR centre* OR residence* OR facilit* OR home* OR establishment*)) OR ((Nursing or aged or elderly) N2 home*))	