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Adults' End-of-Life Wishes Beyond Clinical and Legal Tools: Scoping Review Protocol

Volontés de fin de vie des adultes au-delà des outils cliniques et juridiques : protocole de revue de la portée

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end-of-life wishes; health preferences; advanced care planning; personal priorities; socio-spiritual well-being

Abstract

Introduction: Research on end-of-life wishes (EoLW) primarily focuses on the elderly or ill individuals, limiting reflection to specific moments within life trajectories. Drawing on Patterson and Hazelwood (2020), this article proposes 4 dimensions of EoLW: medical care, legal considerations, personal priorities, and socio-spiritual well-being. While numerous knowledge syntheses explore EoLW, they primarily focus on the first 2 dimensions, overlooking aspects that are nonetheless essential to true person-centered end-of-life planning. **Objective**: To map the extent and nature of knowledge on personal priorities and socio-spiritual well-being dimensions of EoLW and to identify trends, gaps, and implications for research and practice. **Method**: This scoping review follows the 6-step methodology of Levac et al. (2010) and queries scientific (CINAHL Complete, Érudit, MEDLINE, PsycINFO, Social Sciences Abstracts, Social Work Abstracts and Web of science) and grey literature (Dissertations & Theses Global and Sociological Abstracts) databases. Literature published from 2015 onwards, in English or French, will be systematically identified and selected through an independent double anonymous review process. **Discussion and Research Spin-offs**: We will identify the contexts in which these 2 dimensions are operationalized, the research methodologies used and any knowledge gaps in the current state of research. Engagement with key stakeholders in the 6th stage of this scoping review will facilitate the synthesis of critical insights to better inform practice, influence policy development, and guide future research.

Résumé

Introduction : Les recherches sur les volontés de fin de vie (VFV) se concentrent principalement sur les personnes âgées ou malades, limitant la réflexion à certains moments des trajectoires de vie. Inspiré de Patterson et Hazelwood (2020), cet article propose 4 dimensions des VFV : les soins médicaux, les considérations juridiques, les priorités personnelles et l'épanouissement socio-spirituel. De nombreuses synthèses de connaissances explorent les VFV, mais elles se concentrent principalement sur les 2 premières dimensions, laissant dans l'ombre des aspects pourtant essentiels à une planification de fin de vie centrée sur la personne. **Objectif** : Cartographier l'étendue et la nature des connaissances des priorités personnelles et du bien-être socio-spirituel des VFV, afin d'identifier les tendances, les lacunes et les implications pour la recherche et la pratique. **Méthode** : Cette revue de la portée suit la méthodologie en 6 étapes de Levac et al. (2010) et interroge plusieurs bases de données scientifiques (CINAHL Complete, Érudit, MEDLINE, PsycINFO, Social Sciences Abstracts, Social Work Abstracts et Web of Science) et de littérature grise (Dissertations & Theses Global et Sociological Abstracts). Les écrits publiés à partir de 2015, en anglais ou en français, seront systématiquement identifiés et sélectionnés selon un processus en double insu indépendant. **Discussion et retombées anticipées** : Cette revue de la portée permettra d'identifier les contextes dans lesquels ces 2 dimensions s'opérationnalisent, les méthodologies de recherche utilisées et les lacunes dans l'état des connaissances sur le sujet. Durant la 6e étape de cette revue, l'engagement avec des parties prenantes facilitera la synthèse d'informations critiques afin d'éclairer les pratiques, d'influencer l'élaboration de politiques et d'orienter les recherches futures.

Mots-clés

volontés de fin de vie; préférences en santé; planification préalable de soins; priorités personnelles; épanouissement socio-spirituel

INTRODUCTION

Most research on end-of-life planning focuses on older adults and/or individuals with chronic or terminal illnesses (Cox et al., 2013; Robinson et al., 2019). However, emotions surrounding death and the disclosure of a grim prognosis are often perceived as unfavorable circumstances for initiating discussions on end-of-life planning (Brooks et al., 2017; Othman et al., 2019). Furthermore, in recent decades, factors such as aging population, demographic growth, increasing life expectancy, and the rising prevalence of chronic diseases (Leeson, 2014; Sallnow et al., 2022; United Nations Population Fund, 2024) have raised concerns about end-of-life planning, even among healthy individuals (Robinson et al.). When end-of-life planning is delayed, caregivers and loved ones are often compelled to make difficult decisions on behalf of individuals, raising profound ethical concerns, particularly with respect to personal values and the principle of beneficence (Akdeniz et al., 2021; Spoljar et al., 2020).

Thus, as many research teams recommend, end-of-life discussions should begin as early as possible in our life trajectories, regardless of our health condition (Brooks et al., 2017; De Panfilis et al., 2020; Fan et al., 2019; Macedo et al., 2023; Othman et al., 2019; Park et al., 2019; Robinson et al., 2019; Sallnow et al., 2022; Tan et al., 2024). Anticipating one's end of life can serve as a lever for improving both quality of care and overall quality of life, promoting person-centered care by supporting their self-determination, facilitating decision-making for loved ones, contributing to early access to palliative care and reducing the use of aggressive end-of-life measures (Organisation for Economic Co-operation and Development, 2023; Othman et al.; Van Pevenage et al., 2024).

Various clinical and legal tools are available to help individuals articulate their end-of-life choices, all of which present significant variations across countries and even among healthcare institutions. In Quebec (Canada), for example, individuals can choose to complete advance medical directives (AMD), a protection mandate, or establish care objectives (Institut national d'excellence en santé et en services sociaux, 2016; Saint-Arnaud and Roigt, 2024). These tools are recognized as key levers for ensuring quality of care, fostering self-determination, supporting caregivers, improving access to palliative care and reducing the use of unwanted end-of-life interventions (Prince-Paul and DiFranco, 2017; Rietjens et al., 2017; Sedini et al., 2022; Van Pevenage et al., 2024). These tools are often seen as the culmination of advance care planning (ACP): a discussion process between an individual, their loved ones, and their healthcare team, aimed at predetermining the individual's care objectives and preferences in case of incapacity (Prince-Paul and DiFranco; Rietjens et al.). Although ACP is not initially designed to focus solely on care, it often does, reaffirming both the priority given to medical care in end-of-life contexts and the dominance of biomedical knowledge over experiential knowledge (Noonan et al., 2016).

Furthermore, most research on end-of-life wishes focuses on AMD (Hopping-Winn et al., 2018); however, their completion rate varies between 0.5% and 34%, depending on the country (Macedo et al., 2023). This highlights the limitations of clinical and legal tools in adequately addressing individuals' needs in end-of-life planning. These shortcomings may stem from the inability to anticipate every possible medical intervention within these tools (Brown, 2017; Prince-Paul and DiFranco, 2017; Sedini et al., 2022) or to the fact that they overlook many non-medical needs.

Opening discussions about the end of life to plan for it requires more than legal or medical tools: it involves a broader set of personal, interpersonal, and societal skills. To extend the scope beyond medical and legal considerations, "end-of-life wishes" (EoLW) is presented here as a dynamic framework encompassing four key dimensions: 1) medical care, 2) legal considerations, 3) personal priorities, as well as 4) socio-spiritual well-being that actively shape end-of-life reflection, as outlined by Patterson and Hazelwood (2022). However, Patterson and Hazelwood do not provide a precise definition of these. While numerous knowledge syntheses explore EoLW, they primarily focus on the first two dimensions (e.g., Borovecki et al., 2022; De Panfilis et al., 2020; Plaisance, Morin, et al., 2023;

Plaisance, Tapp, et al., 2023), allowing us to define them as follows: **Medical care** refers to decisions regarding desired or refused interventions and treatments (e.g., intubation, intravenous nutrition, cardiopulmonary resuscitation), as well as the preferred location of end-of-life care. ACP, care objectives, and levels of care, for example, fall within this dimension of EoLW. **Legal considerations** encompass legal arrangements related to end-of-life planning, such as drafting AMD, appointing a proxy, or writing a will. These measures aim to ensure that EoLW are respected within a legal framework.

To our knowledge, although personal priorities and socio-spiritual well-being are explored in certain studies on end-of-life conversations (Meier et al., 2023; Omori et al., 2022), there is no widely accepted definition for these two EoLW dimensions. For the purposes of this research, we define them as follows: **Personal priorities** refer to aspects of an individual's personality and lifestyle that they wish to maintain at the end of life. For example, this may include the importance they place on outdoor walks. **Socio-spiritual well-being** refers to activities that allow individuals to ensure their spiritual well-being (e.g., religious matters), maintain social relationships (e.g., connections with loved ones), and find meaning in life up to the moment of death.

OBJECTIVE

This project therefore aims to map the extent and nature of knowledge on EoLW dimensions beyond clinical and legal aspects by exploring personal priorities and socio-spiritual well-being. The goal is to identify trends, gaps, and implications for research and practice. This will help determine, for example, the contexts (e.g., moments of life, people involved) in which these two EoLW dimensions are operationalized, the various research methodologies used to study them, and any knowledge gaps.

This protocol is registered on the Open Science Framework platform, an open access protocol registration platform that promotes transparency in research, at the following link: https://doi.org/10.17605/OSF.IO/B6HC9

METHOD

Scoping reviews (ScR) are a knowledge synthesis method particularly suited for mapping the scope and nature of knowledge on a given subject, identifying gaps and assessing their implications for stakeholders (Arksey & O'Malley, 2005; Levac et al., 2010; Peters et al., 2020). Since the initial methodology proposed by Arksey and O'Malley, several authors have introduced refinements and updates (Levac et al.; Peters et al.; Tricco et al., 2018).

This ScR will follow the methodology of Levac et al. (2010). It enhances transparency and systematization in the research process by providing specific recommendations for each step. At the same time, it maintains greater flexibility in iterative refinements than subsequent updates. Levac et al. describe six steps: 1) identification of the research question, 2) identification of relevant studies, 3) literature selection, 4) data extraction, 5) synthesis and presentation of results, and 6) stakeholder consultation.

It is relevant to note that Levac et al. (2010) have all contributed to the development of ScR methodologies, including that of The Joanna Briggs Institute (Tricco et al., 2018), whose reporting guidelines have been used to structure this protocol (Appendix 1, Table 1). Levac et al. conceptualized ScR as an iterative methodology, and as such, the evolution of this ScR may lead to adjustments to the present protocol, which will be explicitly detailed and justified in the final article presenting the results of this ScR. As this article goes to press, stages 1, 2 and 3 are already underway.

STEP 1: IDENTIFICATION OF THE RESEARCH QUESTION

Given the objective of this ScR, the following research question has been formulated: "What is known about the dimensions of end-of-life wishes (EoLW) that extend beyond clinical and legal aspects, particularly those related to personal priorities and socio-spiritual well-being, including how they are operationalized, studied, and applied in various contexts ?"

STEP 2: IDENTIFICATION OF RELEVANT STUDIES

The search was conducted on February 25, 2025, across seven scientific databases: CINAHL Complete (EBSCO), Érudit (strategies in French and English), MEDLINE (Ovid), PsycINFO (Ovid), Social Sciences Abstracts (EBSCO), Social Work Abstracts (EBSCO) and Web of Science. Additionally, grey literature was consulted through Dissertations & Theses Global (ProQuest) and Sociological Abstracts (ProQuest). Once the relevant literature has been selected from these databases, their references will be screened for additional sources according to the selection criteria.

The search strategy was based on the Population-Concept-Context model (The Joanna Briggs Institute, 2015): 1) Population: adults (18 years and older), 2) Concepts: wishes related to personal priorities or socio-spiritual well-being, and 3) Context: end of life. A preliminary search within the selected databases helped identify relevant keywords for each element. A search strategy was developed with the assistance of a health sciences librarian. This strategy focused on the concept and context, while the population component will be refined according to the selection criteria. Whenever possible, a thesaurus was used within each database to identify appropriate descriptors, which were then combined with keywords extracted from the title, abstract, and keyword sections of the literature (Appendix 1, Table 2).

STEP 3: LITERATURE SELECTION

As recommended by Levac et al. (2010), a team-based approach was used to establish the inclusion and exclusion criteria for literature selection. References identified in the databases were imported into Covidence (Veritas Health Innovation, 2025), where duplicates were automatically removed. A manual verification of the records will be conducted by sorting them based on author names to identify duplicates not detected by the software.

Covidence facilitates independent, double anonymous screening, ensuring that each record is assessed by two reviewers without knowledge of the other's decision, as recommended by Levac et al. (2010). The selection process follows two consecutive stages: 1) screening based on titles and abstracts, and 2) full-text review. Prior to each phase, a calibration process is conducted: a sample of records (20 for the first phase, five for the second) is independently reviewed by all the members of the research team, using a detailed selection guide (the selection guide is available upon request to authors). A meeting is then held to ensure a shared understanding of the selection criteria and to refine them if necessary (Levac et al.). The selection process will only begin once at least 75% agreement is reached during the calibration phase (Tricco et al., 2018). At the end of each stage, disagreements will be discussed and resolved collectively by the members of the research team. If no consensus is reached, an experienced independent researcher will be called to decide based on the study protocol.

INCLUSION CRITERIA

Records will be included if they explicitly address both dimensions of EoLW under study: 1) personal priorities and 2) aspects of social and spiritual well-being.

Due to ongoing legislative changes related to end-of-life care, only literature published in the last ten years, beginning in January 2015 (as some journals do not publish monthly), will be included.

Considering the importance of individuals' social networks (e.g., close relatives, care providers) in EoLW-related reflections, records presenting their perspectives will be included, provided they discuss their contributions to individuals' EoLW. Additionally, only primary research and meta-analyses presenting new results will also be included.

EXCLUSION CRITERIA

Records that focus exclusively on the clinical or legal aspects of EoLW (e.g., AMD, Physician/Medical Orders for Life-Sustaining Treatment, Do Not Resuscitate order, Medical Orders for Scope of Treatment, protection mandate, objectives of care, living will) will be excluded, as numerous recent knowledge syntheses have already addressed these topics (e.g., Burks et al., 2023; Canny et al., 2023; Institut national d'excellence en santé et en services sociaux, 2024; Macedo et al., 2023; Park et al., 2021). Records focusing on post-mortem wishes (e.g., funerals, organ donation) or exploring the topic in populations under 18 years old will be excluded. Indeed, the ethical and legal issues related to end-of-life in minors differ substantially from those concerning adults, requiring distinct considerations that fall outside the scope of this review.

To ensure the relevance of the results to the research question, the following types of records will be excluded: media entries, blogs, book reviews, letters to the editor, editorials and conference abstracts. For resource-related reasons, any records in languages other than French or English will also be excluded.

Knowledge syntheses (excluding meta-analyses) will be excluded, as they constitute secondary data analyses. However, they will be tagged accordingly in Covidence, allowing researchers to verify whether any pertinent articles were missed during the initial selection process. This tagging will also enable the team to identify and document any relevant information.

Similarly, research protocols will also be excluded yet tagged accordingly in Covidence to facilitate gaining access should this be required.

If the full-text version of a record is unavailable, the first author will be contacted twice via email. If no response is received, the record will be excluded.

STEP 4: DATA EXTRACTION

The same calibration process will be applied in the selection phase using a sample of five to 10 records. Data extraction will be carried out by one researcher and subsequently validated by a second reviewer. Covidence will again be used to extract data relevant to the analysis. The extracted data will include: 1) general data, 2) methodological data, and 3) findings related to EoLW under review (personal priorities and socio-spiritual well-being). Table 3 presents a draft of the matrix indicating the data to be extracted. As extraction is an iterative process, the nature of the collected data may be reassessed based on the study's evolution (Levac et al., 2010).

Although this step is optional according to Levac et al. (2010), we will conduct a quality assessment of the empirical studies included. Considering that this ScR will include studies from various methodologies, we will use the French version of the Mixed Methods Appraisal Tool to evaluate methodological quality (Hong et al., 2018). This evaluation will not be used to exclude studies, but rather to enrich the mapping of existing literature and identify gaps in the current knowledge. Results will be presented in a double entry table, indicating which criteria fulfills or fails to meet.

STEP 5: SYNTHESIS AND PRESENTATION OF RESULTS

This step consists of three phases (Levac et al., 2010): data analysis, presentation of results and meaning in a broader context.

DATA ANALYSIS

The data will be exported into an Excel spreadsheet for content analysis following the three-step process described by Miles et al. (2014):

1) Data condensation, that is, initial coding based on key ideas;
2) Pattern identification, e.g., exploring similarities, differences, contradictions, counterexamples;
3) Categorization, which groups ideas into categories and subcategories.

Additionally, descriptive statistics will be used to summarize the nature of the existing knowledge (e.g., distribution of writings by country, study design, population) (Levac et al., 2010). While no theoretical framework is predetermined, one may be introduced during analysis if it helps interpret complex findings or supports a deeper understanding of the results (Levac et al.).

PRESENTATION OF RESULTS

The findings will be presented in a structured article following the PRISMA-ScR guidelines (Tricco et al., 2018), summarizing identified evidence, including research gaps. The article will be presented in a narrative format, supplemented with tables, diagrams or graphs to enhance clarity. Special attention will be given to methodological transparency and reproducibility. Indeed, the study selection process will be illustrated using a PRISMA-ScR flowchart (Tricco et al.). Any discrepancies between this protocol and what has been achieved will be stated and justified at this point.

MEANING WITHIN A BROADER CONTEXT

We will explore the broader implications of our results, particularly for research, health policies and clinical practice (Levac et al., 2010). For example, we will explore how our results align with public health policies on palliative and end-of-life care, as well as research aimed at supporting individuals' self-determination throughout their life trajectories.

The results will specifically inform a subsequent doctoral research project aimed at modelling the process leading to the expression of EoLW among the adult population of the city of Montreal (Quebec, Canada).

In addition, as all the authors have disciplinary expertise in nursing sciences, we will use the next consultation step to explore the practice implications of our results, particularly regarding care quality and life experiences.

STEP 6: STAKEHOLDER CONSULTATION

Although optional, this final step aligns with the social-constructionist epistemology underlying this project. This philosophical perspective considers that knowledge is co-constructed, thanks in particular to interaction between people, through language (Burr, 2024). This step will help contextualize the findings, enhance their interpretation, and ensure their relevance in addressing the needs of key stakeholders (Levac et al., 2010).

After analyzing the results and prior to dissemination, we will consult key stakeholders involved in the EoLW process: a palliative care specialist, a representative of a community organization supporting caregivers, a family caregiver, a person living with a chronic illness and a healthy one. These stakeholders will participate in a focus group, during which we will present our preliminary findings and facilitate discussions around three key questions based on Levac et al.'s (2010) recommendations:

1) "How do these findings align with your experience?"
2) "How could these findings be applied to better support knowledge users (professionals, researchers and the public)?"
3) "Which of these findings should be prioritized for future research, knowledge dissemination, and policy advocacy?"

DISCUSSION AND RESEARCH SPIN-OFFS

To our knowledge, no ScR has yet mapped the scope and nature of knowledge on personal priorities and socio-spiritual fulfillment in EoLW. We believe that this ScR will help broaden the perspectives of research on EoLW from a systemic approach while integrating both individual and community aspects.

The composition of the research team represents both a key strength and a potential limitation of this ScR. On the one hand, as our team consists exclusively of experts in nursing sciences, this may limit the interdisciplinary scope necessary for a comprehensive analysis of the topic. However, the consultation phase will help mitigate this limitation. On the other hand, the experiential diversity within our team will likely enrich our analysis. Additionally, the team's strong experience in knowledge synthesis and integrating the expertise of a librarian at the outset of this project will help ensure methodological rigor throughout the ScR.

This research aligns with a broader health perspective, advocating for a collective and societal approach to death and dying rather than a strictly biomedical one, as recommended by a recent Lancet report (Sallnow et al., 2022). Beyond the first author's doctoral project, the findings may inform other future research adopting a public health approach to palliative care (Kellehear & Sallnow, 2011).

Through the consultation step, we will generate key insights and recommendations to guide future research, knowledge dissemination and practical applications. The knowledge mapping will also help identify gaps in literature, while the quality assessment of the selected literature will assist in prioritizing further research directions.

Authors' contribution: This protocol is part of the literature review for the first author's (CC) doctoral thesis,

supervised by EA. CC designed the protocol and the article and wrote the entire first draft under the supervision of EA. ABP, SSR, TT and CLP contributed to refining the manuscript by providing methodological, theoretical, conceptual, and editorial feedback. More specifically, ABP proposed substantial changes to the search strategy and revised the translated version, SSR reshaped the problem statement, TT suggested methodological clarifications and produced the first English translation, and CLP suggested conceptual clarifications. All authors reviewed and approved the final version of the manuscript and will participate in conducting the scoping review.

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Ethical considerations: No ethics certificate number is necessary for this scoping review.

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Appendix 1

Table 1

Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) Checklist (Tricco et al., 2018)

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
TITLE			
Title	1	Identify the report as a scoping review.	Abstract (ENG) + Résumé (FR)
ABSTRACT			
Structured summary	2	Provide a structured summary that includes (as applicable): background, objectives, eligibility criteria, sources of evidence, charting methods, results, and conclusions that relate to the review questions and objectives.	Abstract (ENG) + Résumé (FR)
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known. Explain why the review questions/objectives lend themselves to a scoping review approach.	"Introduction"
Objectives	4	Provide an explicit statement of the questions and objectives being addressed with reference to their key elements (e.g., population or participants, concepts, and context) or other relevant key elements used to conceptualize the review questions and/or objectives.	"Objective" "Step 1"
METHODS			
Protocol and registration	5	Indicate whether a review protocol exists; state if and where it can be accessed (e.g., a Web address); and if available, provide registration information, including the registration number.	"Objective"
Eligibility criteria	6	Specify characteristics of the sources of evidence used as eligibility criteria (e.g., years considered, language, and publication status), and provide a rationale.	"Step 3: Inclusion criteria"
Information sources*	7	Describe all information sources in the search (e.g., databases with dates of coverage and contact with authors to identify additional sources), as well as the date the most recent search was executed.	"Step 2"
Search	8	Present the full electronic search strategy for at least 1 database, including any limits used, such that it could be repeated.	"Appendix 1, Table 2"
Selection of sources of evidence†	9	State the process for selecting sources of evidence (i.e., screening and eligibility) included in the scoping review.	Introductory paragraphs to "Step 3"
Data charting process‡	10	Describe the methods of charting data from the included sources of evidence (e.g., calibrated forms or forms that have been tested by the team before their use, and whether data charting was done independently or in duplicate) and any processes for obtaining and confirming data from investigators.	Introductory paragraphs to "Step 3" + "Step 4" + "Appendix 1, Table 3"
Data items	11	List and define all variables for which data were sought and any assumptions and simplifications made.	s/o

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
Critical appraisal of individual sources of evidence§	12	If done, provide a rationale for conducting a critical appraisal of included sources of evidence; describe the methods used and how this information was used in any data synthesis (if appropriate).	End of "Step 4"
Synthesis of results	13	Describe the methods of handling and summarizing the data that were charted.	"Step 5"
RESULTS			
Selection of sources of evidence	14	Give numbers of sources of evidence screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally using a flow diagram.	s/o
Characteristics of sources of evidence	15	For each source of evidence, present characteristics for which data were charted and provide the citations.	s/o
Critical appraisal within sources of evidence	16	If done, present data on critical appraisal of included sources of evidence (see item 12).	s/o
Results of individual sources of evidence	17	For each included source of evidence, present the relevant data that were charted that relate to the review questions and objectives.	s/o
Synthesis of results	18	Summarize and/or present the charting results as they relate to the review questions and objectives.	s/o
DISCUSSION			
Summary of evidence	19	Summarize the main results (including an overview of concepts, themes, and types of evidence available), link to the review questions and objectives, and consider the relevance to key groups.	s/o
Limitations	20	Discuss the limitations of the scoping review process.	"Discussion and research spin-offs"
Conclusions	21	Provide a general interpretation of the results with respect to the review questions and objectives, as well as potential implications and/or next steps.	s/o
FUNDING			
Funding	22	Describe sources of funding for the included sources of evidence, as well as sources of funding for the scoping review. Describe the role of the funders of the scoping review.	End of text, before the references

JBI = Joanna Briggs Institute; PRISMA-ScR = Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews.

* Where *sources of evidence* (see second footnote) are compiled from, such as bibliographic databases, social media platforms, and Web sites.

† A more inclusive/heterogeneous term used to account for the different types of evidence or data sources (e.g., quantitative and/or qualitative research, expert opinion, and policy documents) that may be eligible in a scoping review as opposed to only studies. This is not to be confused with *information sources* (see first footnote).

‡ The frameworks by Arksey and O'Malley (6) and Levac and colleagues (7) and the JBI guidance (4, 5) refer to the process of data extraction in a scoping review as data charting.

§ The process of systematically examining research evidence to assess its validity, results, and relevance before using it to inform a decision. This term is used for items 12 and 19 instead of "risk of bias" (which is more applicable to systematic reviews of interventions) to include and acknowledge the various sources of evidence that may be used in a scoping review (e.g., quantitative and/or qualitative research, expert opinion, and policy document).

From: Tricco, A. C., Lillie, E., Zarin, W., O'Brien, K. K., Colquhoun, H., Levac, D., Moher, D., Peters, M. D. J., Horsley, T., Weeks, L., Hempel, S., Akl, E. A., Chang, C., McGowan, J., Stewart, L., Hartling, L., Aldcroft, A., Wilson, M. G., Garritty, C., Lewin, S., … Straus, S. E. (2018). PRISMA Extension for Scoping Reviews (PRISMA-ScR): Checklist and Explanation. *Annals of internal medicine*, *169*(7), 467–473. https://doi.org/10.7326/M18-0850

Table 2

Concept Plan and Research Strategy (in Alphabetical Order)

Equations with thesaurus and keywords		
CINAHL Complete (EBSCO)		
Equation with thesaurus	Concept 1: wishes related to personal priorities or socio-spiritual well-being	Concept 2: end of life
	(MH "Personal Values") OR (MH "Attitude to Death") OR (MH "Spirituality") OR (MH "Support, Psychosocial+") OR (MH "Personal Satisfaction") OR (MH "Life Style")	(MH "Terminally Ill Patients")
Equation with keywords - concept 1 Fields: (TI, AB, MW)	((Wish* OR Will* OR Values OR Preference* OR Priorit* OR Attitude* OR Expectation* OR Desire OR Aspiration* OR Fulfil?ment) N2 (Personal OR Social OR Spiritual*))	
Equation with keywords - concept 2 Fields: (TI, AB, MW)	((Terminal) N1 (Ill*)) OR "End of life" OR "End-of-life" OR Dying	
Érudit (English Strategy)		
Equation with keywords - concept 1	((Wish* OR Will* OR Values OR Preference* OR Priorit* OR Attitude* OR Expectation* OR Desire OR Aspiration* OR Fulfillment OR Fulfilment) AND (Personal OR Social OR Spiritual*))	
Equation with keywords - concept 2	("End of life" OR "End-of-life" OR Dying OR "Terminal* ill*")	
Final equation	(Titre, résumé, mots-clés : ((Wish* OR Will* OR Values OR Preference* OR Priorit* OR Attitude* OR Expectation* OR Desire OR Aspiration* OR Fulfillment OR Fulfilment) AND (Personal OR Social OR Spiritual*))) ET (Titre, résumé, mots-clés : ("End of life" OR "End-of-life" OR Dying OR "Terminal* ill*")) ET (Publié entre 2015 et 2025) ET (Langues : ['Anglais', 'Français']) ET (Fonds : ['Érudit', 'UNB', 'Persée', 'FRQ'])	
Érudit (French Strategy)		
Equation with keywords - concept 1	((Souhait* OU Volonté* OU Valeurs OU Préférence* OU Priorité* OU Attitude* OU Attente* OU Désir* OU Aspiration* OU Accomplissement*) ET (Personnel* OU Socia* OU Spirituel*))	
Equation with keywords - concept 2	("Fin de vie" OU Mourir)	
Final equation	(Titre, résumé, mots-clés : ((Souhait* OU Volonté* OU Valeurs OU Préférence* OU Priorité* OU Attitude* OU Attente* OU Désir* OU Aspiration* OU Accomplissement*) ET (Personnel* OU Socia* OU Spirituel*))) ET (Titre, résumé, mots-clés : ("Fin de vie" OU Terminal* OU Mourir)) ET (Publié entre 2015 et 2025) ET (Langues : ['Anglais', 'Français']) ET (Fonds : ['Érudit', 'UNB', 'Persée', 'FRQ'])	
MEDLINE (Ovid)		
Equation with thesaurus	Concept 1: wishes related to personal priorities or socio-spiritual well-being	Concept 2: end of life

	Social Values/ or Patient Preference/ or Attitude to Death/ or exp personal satisfaction/ or spirituality/	Terminally ill/
Equation with keywords - concept 1 Fields: ab, kf, ti.	((Wish* or Will* or Values or Preference* or Priorit* or Attitude* or Expectation* or Desire or Aspiration* or Fulfillment or Fulfilment) adj2 (Personal or Social or Spiritual*))	
Equation with keywords - concept 2 Fields: ab, kf, ti.	((Terminal) adj1 (Ill*)) or "End-of-life" or "End of life" or Dying	
PsycINFO (Ovid)		
Equation with thesaurus	Concept 1: wishes related to personal priorities or socio-spiritual well-being	Concept 2: end of life
	Personal values/ or death attitudes/ or expectations/ or aspirations/ or Social Identity/ or Exp social Support/ or exp spirituality/	terminally ill patients/ or "Death and Dying"/
Equation with keywords - concept 1 Fields: ab, id, ti.	((Wish* or Will* or Values or Preference* or Priorit* or Attitude* or Expectation* or Desire or Aspiration* or Fulfillment or Fulfilment) adj2 (Personal or Social or Spiritual*))	
Equation with keywords - concept 2 Fields: ab, id, ti.	((Terminal) adj1 (Ill*)) or ("End-of-life" or "End of life" or Dying	
Social Sciences Abstracts, H.W. Wilson (EBSCO)		
Equation with keywords - concept 1 Fields: (TI, AB, SU)	((Wish* OR Will* OR Values OR Preference* OR Priorit* OR Attitude* OR Expectation* OR Desire OR Aspiration* OR Fulfillment OR Fulfilment) N2 (Personal OR Social OR Spiritual*))	
Equation with keywords - concept 2 Fields: (TI, AB, SU)	((Terminal) N1 (Ill*)) OR "End of life" OR "End-of-life" OR Dying	
Social Work Abstracts (EBSCO)		
Equation with keywords - concept 1 Fields: (TI, AB, SU)	((Wish* OR Will* OR Values OR Preference* OR Priorit* OR Attitude* OR Expectation* OR Desire OR Aspiration* OR Fulfillment OR Fulfilment) N2 (Personal OR Social OR Spiritual*))	
Equation with keywords - concept 2 Fields: (TI, AB, SU)	((Terminal) N1 (Ill*)) OR "End of life" OR "End-of-life" OR Dying	
Web of Science		
Equation with keywords - concept 1 Fields: (Topic)	((Wish* OR Will* OR Values OR Preference* OR Priorit* OR Attitude* OR Expectation* OR Desire OR Aspiration* OR Fulfillment OR Fulfilment) NEAR/2 (Personal OR Social OR Spiritual*))	
Equation with keywords - concept 2 Fields: (Topic)	"End of life" OR "End-of-life" OR Dying OR ((Terminal) NEAR/1 (Ill*))	
Grey literature - Dissertations & Theses Global (ProQuest)		
Equation with thesaurus	Concept 1: wishes related to personal priorities or socio-spiritual well-being	Concept 2: end of life

	Exact("social support" OR "social support groups" OR "preferences" OR "desire" OR "social attitudes" OR "values" OR "expectation" OR "spirituality" OR "spiritual development" OR "cultural values" OR "aspiration" OR "expectations" OR "wills")	Exact("terminal illnesses" OR "terminal illness" OR "death & dying")
Equation with keywords - concept 1 Fields: title, abstract, subject	((Wish* OR Will* OR Values OR Preference* OR Priorit* OR Attitude* OR Expectation* OR Desire OR Aspiration* OR Fulfillment OR Fulfilment) NEAR/2 (Personal OR Social OR Spiritual*))	
Equation with keywords - concept 2 Fields: title, abstract, subject	((Terminal) NEAR/1 (Ill*)) OR "End of life" OR "End-of-life" OR Dying	
Grey literature - Sociological Abstracts (ProQuest)		
Equation with thesaurus	Concept 1: wishes related to personal priorities or socio-spiritual well-being	Concept 2: end of life
	MAINSUBJECT.EXACT("Life goals" OR "Expectations" OR "Death attitudes" OR "Priorities" OR "Preferences" OR "Life satisfaction" OR "Values" OR "Desire" OR "Attitudes" OR "Aspiration")	MAINSUBJECT.EXACT("end of life" OR "dying" OR "terminal illnesses" OR "dying" OR "death/deaths" OR "end of life decisions" OR "terminal illness" OR "death & dying")
Equation with keywords - concept 1 Fields: title, abstract, subject	((Wish* OR Will* OR Values OR Preference* OR Priorit* OR Attitude* OR Expectation* OR Desire OR Aspiration* OR Fulfillment OR Fulfilment) NEAR/2 (Personal OR Social OR Spiritual*))	
Equation with keywords - concept 2 Fields: title, abstract, subject	((Terminal) NEAR/1 (Ill*)) OR "End of life" OR "End-of-life" OR Dying	

Notes. AB: abstract, ID: article identifier, KF: keyword heading word, MH: exact subject heading, MW: word in subject heading, SU: subject, TI: title.

Table 3

Draft Data Extraction Table

									Sample			
	Title	Authors	Year of publication	Country	Objective	Theoretical approche	Study design	Context of the study	Age	Health criteria (if applicable)	n	Measurement Tool (if applicable)
Paper 1												
Paper 2												
(…)												

	Findings	
	Related to personal priorities	Related to socio-spiritual well-being
Paper 1		
Paper 2		
(…)		