

Review Article

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Palliative and end-of-life care practices for critically ill patients and their families in a peri-intensive care setting: A protocol for an umbrella review

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Abstract

Objectives. This umbrella review will summarize palliative and end-of-life care practices in peri-intensive care settings by reviewing systematic reviews in intensive care unit (ICU) settings. Evidence suggests that integrating palliative care into ICU management, initiating conversations about care goals, and providing psychological and emotional support can significantly enhance patient and family outcomes.

Methods. The Joanna Briggs Institute (JBI) methodology for umbrella reviews will be followed. The search will be carried out from inception until 30 September 2023 in the following databases: Cochrane Library, SCOPUS, Web of Science, CINAHL Complete, Medline, EMBASE, and PsycINFO. Two reviewers will independently conduct screening, data extraction, and quality assessment, and to resolve conflicts, adding a third reviewer will facilitate the consensus-building process. The quality assessment will be carried out using the JBI Critical Appraisal Checklist. The review findings will be reported per the guidelines outlined in the Preferred Reporting Items for Overviews of Reviews statement.

Results. This umbrella review seeks to inform future research and practice in critical care medicine, helping to ensure that end-of-life care interventions are optimized to meet the needs of critically ill patients and their families.

Introduction**Rationale**

In hospital settings, patients often receive disease-modifying treatments until the end of life, undergo inappropriate life-sustaining interventions, are referred to palliative care late, and lack advanced care planning and anticipatory directives for end-of-life care (Becker *et al.* 2007; Bentur *et al.* 2014; Curtis *et al.* 2002; Nakano *et al.* 2012). Approximately 10–36% of adult intensive care unit (ICU) patients die, yet many receive costly and uncomfortable interventions despite a lack of benefits (Mani *et al.* 2012). Providing personalized, quality care to individuals nearing the end of their lives is crucial. It is a comprehensive approach that is versatile and universally applicable in addressing physical, psychological, social, spiritual, and existential symptoms. It ensures that individuals can die in their preferred location with the aid of a trained healthcare professional while receiving palliative care (Ellershaw and Ward 2003; Smith 2000; Steinhauser *et al.* 2000). ICUs have traditionally prioritized life-extending treatments for critically ill patients (Pan *et al.* 2023). However, recognition of the complex and unique needs of these patients has led to a shift toward a more holistic approach that includes palliative care (Pan *et al.* 2023). Efforts to integrate palliative care were in response to the limitations of a purely

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curative model of care in the ICU (Hua and Wunsch 2014). Studies have shown that early integration of palliative care leads to enhanced patient and family satisfaction, reduced symptom burden, and improved alignment of care with patient's values and goals (Rao et al. 2022).

Before writing this protocol, a scoping search of the literature on systematic reviews in ICU palliative and end-of-life care was conducted. It showed that there are published systematic reviews related to types of ICUs like burns (Ribeiro et al. 2023), surgical and trauma (Newsome et al. 2023), cardiac (Kim et al. 2022), neonatal (Abuhammad et al. 2023; Kim et al. 2019), pediatric (Bennett and LeBaron 2019; Howes 2015; Short and Thienprayoon 2018), geriatric (Da Fonseca et al. 2012; Roczen et al. 2016), and cancer (Martins et al. 2017). Furthermore, there were systematic reviews related to the palliative care process in ICUs that include the consults (Grabda and Lim 2021), family meetings (Singer et al. 2016), eliciting preferences (Alyami et al. 2019), decision-making (Johal et al. 2022; Oczkowski et al. 2016; Spoljar et al. 2020; Visser et al. 2014), and communication (Schram et al. 2017; Zante and Schefold 2019). A few systematic reviews focused on palliative care interventions (Araujo et al. 2023; Aslakson et al. 2014; Noome et al. 2016; Velarde-García et al. 2016), education (Baltazar and Popejoy 2023; Hewitt et al. 2023), and quality improvement (Lo et al. 2020; Tanaka et al. 2023) in ICU settings, and a few focused on outcomes like family perception (Chen et al. 2020; Desanto-Madeya and Safizadeh 2017), satisfaction (Hinkle et al. 2015), experience (Coombs 2015), length of ICU stay (Kyeremanteng et al. 2018; Liu et al. 2017), and utilization (Khandelwal et al. 2015). One systematic review focused on low- and middle-income settings (Rao et al. 2022) and another on the impact of culture on palliative care delivery in ICUs (Brooks et al. 2019). Although palliative and end-of-life care practices were synthesized in these systematic reviews, they were not the review's primary objective, nor was the synthesis concerning these practices comprehensive, necessitating the conduct of this umbrella review. The existing related umbrella reviews have focused on palliative care needs for people with dementia (Wendrich-van Dael et al. 2020), patient-centered end-of-life care (Hatzikiriakidis et al. 2023), and advanced care planning in the elderly population (Park et al. 2021). This umbrella review will focus on synthesizing the palliative and end-of-life care practices in peri-intensive care settings by systematically reviewing the systematic reviews in ICU settings.

N.B. The peri-intensive care includes the time before admission to the ICU, during the ICU stay, and after discharge from the ICU or death.

Review question

What are the practices for providing palliative and end-of-life care to critically ill patients and their families in a peri-intensive care setting?

Review objectives

1. To identify the palliative and end-of-life care practices provided to patients with critical illness and their families in the peri-intensive care setting.
2. To identify the factors that facilitate or hinder the provision of palliative and end-of-life care in a peri-intensive care setting.
3. To determine the relationship between the palliative and end-of-life care practices and the outcomes for the patients and their families.

Materials and methods

The protocol for the umbrella review was developed following the Preferred Reporting Items for Systematic Review and Meta-Analysis Protocols (PRISMA-P) (Shamseer et al. 2015) and is provided as Supplementary File 1. The umbrella review will adhere to Joanna Briggs Institute (JBI) guidelines for umbrella reviews (Aromataris et al. 2020) and registered on PROSPERO 2023 CRD42023463718. Modifications, if any, to this protocol will be documented in the final review along with plausible explanations justifying the necessity for these alterations.

Eligibility criteria

Inclusion criteria

- The review will consider systematic reviews of adult patients receiving ICU care and their families.
- The review will include a systematic review that addresses all gender, ethnicity, and geographic settings, irrespective of the disease conditions of the patient.
- The setting for this review will include multidisciplinary or disease-specific ICUs, high-dependency units (HDUs), or areas designated by the hospital for critical care.
- Systematic reviews discussing palliative and end-of-life care practices provided in Table 2 in a peri-intensive care period will be included.
- Systematic reviews with or without meta-analysis, qualitative systematic reviews, scoping reviews, and mixed-method reviews will be included.

Exclusion criteria

- Review will exclude systematic reviews with pediatric and neonatal age groups, as well as formal or paid caregivers.
- Critical or intensive care provided at a hospital ward, home, or facility not categorized as an ICU or HDU setting will be excluded.
- Narrative reviews and all reviews that have not been conducted following a systematic and structured methodology will be excluded.

The review eligibility criteria are provided in Table 1, and a detailed list of possible practices that facilitate end-of-life care provision in ICUs is provided in Table 2.

Information sources

Our review will involve an exhaustive search of 7 electronic databases: Cochrane Library, SCOPUS (Elsevier), Web of Science (Clarivate), EBSCO (CINAHL Complete), Medline (PubMed), EMBASE, and PsycINFO (Ovid). This diverse range of sources will enable us to gather insights and findings that align with our review objectives.

We plan only to include systematic and scoping reviews per our eligibility criteria. However, systematic/scoping reviews in this overview might have included gray literature. Hence, for this overview, gray literature search will not be carried out.

Search strategy

To search the published literature, we divided the review question into search concepts (palliative and end-of-life care practices that

Table 1. Eligibility criteria

	Inclusion	Exclusion
Population	Adult patients receiving ICU care and their families All gender, ethnicity, and geographic settings All disease conditions	Pediatric and neonatal age groups Formal or paid caregivers
Setting	Multidisciplinary or disease-specific ICUs, HDUs, or areas designated by the hospital for critical care	Critical or intensive care provided at a hospital ward, home, or at a facility not categorized as an ICU or HDU
Phenomenon of interest	Palliative and end-of-life care practices provided in Table 2 in a peri-intensive care period	
Types of study	Systematic reviews with or without meta-analysis Qualitative systematic reviews Scoping reviews Mixed-method reviews	Narrative reviews and reviews that have not been conducted following a systematic and structured methodology

HDU = high-dependency unit; ICU = intensive care unit.

Peri-intensive care period denotes the time before admission to the ICU, during the ICU stay, and after discharge from the ICU or death.

Table 2. Practices that facilitate end-of-life care provision in intensive care units

Practices	
Prognostication	Physician prediction Survival estimates Recognition of palliative care needs and triggers for referral Recognition of end-of-life phase or dying, prognostication methods, tools, or scales
Communication	Family meetings, serious and critical illness conversations, breaking bad news, disclosure of information, and family counseling
Decision-making	Discussions on clinical futility and potentially inappropriate treatments, goals of care discussions, shared decision-making, decision-making styles and preferences, surrogate decision-making, place of care, and nature of care
Care planning	Comprehensive care plan; anticipatory care plan; advance care plan; resuscitation; resuscitation preferences; do not attempt resuscitation; withholding, withdrawing, foregoing, or limiting life-sustaining treatment; palliative care referral; withholding non-beneficial treatment; and time-limited trial
Care facilitation	Ethical and legal considerations, documentation, guidelines and guidance documents, procedures and protocols, capacity to provide care, symptom management, palliative or end-of-life care education and training, drug availability, advocacy, policy on discharges against medical advice, and family presence during the care process
Care evaluation	Quality of death, family perception and satisfaction of care, cost of dying and economic evaluation of end-of-life care, access to palliative and end-of-life care, and individual and societal perception of good death

facilitate end-of-life care provision in a peri-intensive care period, systematic reviews, and intensive care setting). We conducted a scoping search to determine the key search terms for each concept.

Supplementary File 2 outlines the search concepts utilized in this study. From these concepts, we will develop free-text and thesaurus terms. We also used an index paper (McGlinchey *et al.* 2023) to broaden our search terms and identify additional free-text and thesaurus terms relevant to the scope of the review (Ramer 2005). The thesaurus terms are specific to the subject-specific databases we searched, such as MEDLINE, CINAHL, EMBASE, and PsycINFO. We will use Boolean operators to search the free-text and thesaurus terms together (Chang *et al.* 2006). To further enhance our review, we will examine the bibliographies of the full-text articles and conduct citation searches using Google Scholar and Web of Science to identify more articles (Eyers 1998). We will continue to check the citations of the included publications until no additional relevant reviews are found (Hinde and Spackman 2015). Furthermore, we will hand search relevant journals for additional citations. We will not limit the search to any specific date and database-specific filters. The preliminary search performed on PubMed (Supplementary File 3) will undergo further refinement and tailoring for use with other databases.

Study records

Data management

The data management for this review will be done using Rayyan software (Ouzzani *et al.* 2016), wherein the citations from all the databases will be imported for identifying duplication and screening. The reference management tool Endnote Version 20 will be employed for in-text citations. The extraction of data will be executed using Microsoft Excel.

Selection process

After eliminating duplicates, the records will undergo a two-stage identical screening process. In the first stage, the title and abstracts of each article will be independently evaluated by 2 reviewers based on the predefined inclusion and exclusion criteria ([Table 1](#)). The citations deemed relevant at the title and abstract screening will be fully retrieved. In the second stage, the full texts will be carefully reviewed in detail, adhering to the eligibility criteria, by 2 reviewers independently. At both stages, disagreements regarding the article's eligibility will be resolved using a consensus approach between the reviewers. However, a senior reviewer will be consulted to decide if a resolution cannot be reached. The results of the database search, screening, and the reasons for exclusions during the full-text screening stage will be presented in a PRISMA flow chart (Page *et al.* 2021).

Data collection process

Data extraction from the selected studies will be carried out independently by 2 reviewers. In case of any discrepancies between the reviewers, a third reviewer will mediate the discussion to reach a consensus. We have adapted the JBI template for data extraction specifically designed for umbrella reviews (Aromataris *et al.* 2020).

To reduce the likelihood of errors, the data extraction form will undergo adaptations in consultation with subject experts and through a pilot exercise. The reviewers will thoroughly deliberate the data extraction approach and test specific items to ensure it aligns with our review objectives and to retrieve the pertinent data in sufficient detail. As a result, necessary modifications will be made before advancing to the final data extraction phase. In addition, an attempt will be made to contact the review authors to obtain additional or missing data. A preliminary data extraction form is provided in Supplementary File 4.

Data items

The data collection form will encompass specific data items on

- Review characteristics: authors, year of publication, review types, objectives, country, and setting.
- Methodological attributes: eligibility criteria, reporting guidelines, databases and sources searched, timeframe, screening methods, data extraction, risk of bias, quality assessment tools, and review synthesis methods.
- Findings: number of studies included, quality of evidence, quantitative and qualitative data related to palliative and end-of-life care practices, barriers and facilitators, patient outcomes, quality of evidence (GRADE assessment), review limitations, conclusions, and funding.
- Critical appraisal: The data on 11 items of the JBI tool for critical appraisal checklist for systematic reviews and research syntheses will be extracted.

Outcomes and prioritization

The specific outcomes for which the data will be extracted are as follows:

- The palliative and end-of-life care practices related to prognostication, communication, decision-making, care planning, care provision, and evaluation.
- Factors that hinder or facilitate the palliative and end-of-life care practices in a peri-intensive setting. Several key factors can influence palliative and end-of-life care practice, including the patient, the involvement of healthcare professionals and family members, the healthcare setting, and the broader political and economic context.
- The range of outcomes linked to palliative and end-of-life care practices. These outcomes encompass aspects like the quality of life for patients, the management of symptoms, levels of depression and pain, caregiver burden and distress, the quality of life for patients' family members, the financial cost of care, the acquisition of knowledge and skills, support during bereavement, as well as the participation of both patients and caregivers.

The compilation of practices, factors, and outcomes for end-of-life care and palliative care has been refined through consultation with subject matter experts and derived from existing literature (Mani et al. 2012; Myatra et al. 2014). This list will further undergo alterations due to the findings made in this umbrella review.

Risk of bias assessment

Two independent reviewers will assess the quality of the included systematic reviews, employing the JBI critical appraisal checklist for systematic reviews and research syntheses (Aromataris et al. 2015). The tool comprises 11 questions guiding the evaluation of systematic reviews or meta-analyses, with responses categorized as "yes," "no," "unclear," or "not applicable (NA)." The findings from the critical assessment will be presented both in a descriptive narrative and in a tabular format. Including a review in this umbrella, the review will be independent of the quality assessment. Any reviewer disagreement concerning the methodological quality will be resolved by involving a third reviewer.

Data synthesis

The key characteristics of all included reviews will be tabulated, accompanied by a narrative synthesis and descriptive statistics. The framework for categorizing the primary outcome of this review, which is palliative and end-of-life care practices, will be adapted from the guidelines for palliative and end-of-life care provided by the Indian Society of Critical Care Medicine (Mani et al. 2012; Myatra et al. 2014). The outcomes associated with each practice will also be captured along with methods.

Factors reported as influencing palliative and end-of-life care practices, both as barriers and facilitators, will be categorized into major themes. The most frequently occurring themes will be organized into overarching categories (Saunders et al. 2023). We will describe the factors through a systems approach to health-care delivery involving 4 levels: (1) the individual patient; (2) the professional care providers and family members; (3) the organization; and (4) the political and economic environments (National Academy of Engineering et al. 2005).

We will create a descriptive overview of the practices, outcomes, hindrances, and enabling factors, categorizing them based on geographical region, specific settings, and the perspectives of different stakeholders, including patients, families, caregivers, and health-care providers. Through an iterative discussion process, we will explore the connections between various practices, contributing factors, and the outcomes experienced by patients and their families. This exploration aims to create a model representing best practices for engaging in palliative and end-of-life care within the peri-ICU setting. We will depict possible commonalities or overlaps among the primary research studies within the included syntheses.

Reporting of the umbrella review

The umbrella review will be reported using Preferred Reporting Items for Overviews of Reviews statements of healthcare interventions (Gates et al. 2022).

Meta-bias(es)

This review aims to map practices, factors, and patient outcomes. Under our umbrella review, all kinds of reviews (quantitative/qualitative/mixed methods, scoping, and rapid) will be included. Meta-bias(es) identified in the included systematic reviews will be reported.

Confidence in cumulative evidence

We will retrieve GRADE and GRADE CERQual assessments if provided in the reviews included. We only plan to report the GRADE assessment if the authors of the included reviews carried it out.

Ethics

Ethical approval is not required for conducting this overview as it is based on already-existing, publicly available published literature.

Dissemination

The findings of the overview will be shared with pertinent stakeholders through workshops focused on knowledge dissemination,

Table 3. Review timeline

Steps	Scoping review steps	Timeline	Status
Step 1	Identifying the research question	July 2023	Completed
Step 2	Identifying relevant studies		Completed
	Inclusion and exclusion criteria and Identification of search terms	August 2023	Completed
	Preliminary search	September 2023	Completed
	Final search	30 September 2023	Completed
	Review registration	October 2023	Completed
Step 3	Selection of eligible studies	October 2023	Completed
	Title and abstract screening	October 2023	Completed
	Full-text screening	October–November 15 2023	Completed
Step 4	Data extraction and charting	16 November–17 December	Ongoing
Step 5	Data analysis and report writing (first draft)	18–31 December	To be completed by 31 December 2023

as well as through publications, conference presentations, easy-to-understand summaries, policy briefs, and similar means.

Review timeline

The review timeline is depicted in [Table 3](#).

Discussion

Evidence supports the importance and impact of implementing optimal end-of-life care practices in the ICU (Aslakson *et al.* 2017; Iguina *et al.* 2023; Martz *et al.* 2020; Melville *et al.* 2017; Patel and Stone 2021; Su *et al.* 2016; Zhang *et al.* 2017). Prioritizing early and compassionate communication with patients and their families is critical, and ensuring that their values and preferences shape decision-making is essential (Baltazar and Popejoy 2023; Davis and Nunn 2023; Markiewicz *et al.* 2023; O’Kane *et al.* 2023). Multiple studies have consistently demonstrated that integrating palliative care into ICU management, initiating timely conversations about care goals, and providing psychological and emotional support significantly enhance end-of-life care quality (Adler *et al.* 2017; Hamdan Alshehri *et al.* 2020; Mun *et al.* 2016; Noizet-Yverneau *et al.* 2019; Poi *et al.* 2023; Ribeiro *et al.* 2019). By adhering to such practices, needless and aggressive interventions that offer little or no benefit can be minimized, leading to increased patient and family comfort and overall satisfaction (Schram *et al.* 2017). Emphasizing shared decision-making, symptom management, and ethical considerations is vital to delivering the best possible end-of-life care in the ICU (Blot *et al.* 2016; Clemens and Klaschik 2009; Mittel and Hua 2019; Schildmann and Schildmann 2014). Research in this field is continuously refining these practices, leading to better outcomes for patients and their families.

This umbrella review focuses on synthesizing palliative and end-of-life care practices in peri-intensive care settings by providing an overview of systematic reviews. It represents a significant novel contribution to the intersection of palliative and critical care medicine as it will provide a comprehensive synthesis of the current practices and potential future directions for end-of-life care interventions for critically ill patients in peri-intensive care settings. It will draw on a range of systematic reviews to provide an evidence-based account of the current state of research in this area. By doing so, it seeks to inform future research and practice in critical care medicine, helping to ensure that end-of-life care interventions are optimized to meet the needs of critically ill patients and their families.

Supplementary material. The supplementary material for this article can be found at <https://doi.org/10.1017/S1478951524000130>.

Data availability statement. The data produced or examined during this research have been incorporated into the published article or are available as a supplementary file.

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Author contributions. Naveen Salins: Conceptualization, methodology, supervision, writing – original draft, writing – review & editing, and funding acquisition. Arathi Rao: Conceptualization and writing – review & editing. Vijay Shree Dhyani: Conceptualization, methodology, writing – original draft, and writing – review & editing. Ashmitha Prasad: Methodology and writing – review & editing. Mebin Mathew: Methodology and writing – review & editing. Anuja Damani: Writing – review & editing. Krithika Rao: Writing – review & editing. Shreya Nair: Writing – review & editing. Vishal Shanbhag: Writing – review & editing. Shwethapriya Rao: Writing – review & editing. Shivakumar Iyer: Writing – review & editing. Roop Gursahani: Writing – review & editing. R K Mani: Writing – review & editing. Srinagesh Simha: Writing – review & editing. Guarantor: Dr Naveen Salins.

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Competing interests. We have no conflict of interest to declare. The salaries of 2 research associates, A.P. and M.M., were funded by the ELICIT, a not-for-profit task force for advancing end-of-life care in India.

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