Review

Improving Intensive End-of-Life Care for Infants and Children: A Scoping Review of Intervention Elements

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Highlights

What are the main findings?

- This review catalogued elements of end-of-life care interventions in the pediatric intensive care unit.
- Most interventions target clinician knowledge as a primary outcome.

What is the implication of the main finding?

- Findings underscore the need for interventions that target family outcomes, especially parental empowerment.
- More interventions should assess family outcomes and aim to integrate families in development.

Abstract

Background/objectives: High-quality pediatric critical care includes supporting children nearing the end-of-life (EOL) and their families. Cataloging existing interventions for children dying in the pediatric intensive care unit (PICU) establishes critical areas for future research. In this scoping review, we evaluated characteristics of PICU EOL interventions. **Methods:** A librarian guided a search of OVID Medline, CINAHL, OVID PsycINFO, OVID Embase, Cochrane Central, and Web of Science, plus backwards and forwards reference searching. We included interprofessional interventions, defined as any systematic change (e.g., educational programs, symptom management, electronic medical record, etc.), for children dying from any cause. Studies were independently screened by two reviewers. Data were extracted by one team member and reviewed by a second. We extracted intervention elements, contextual factors, and implementation barriers/facilitators and generated frequencies from qualitative coding. **Results:** Of 11,643 screened articles; 44 met inclusion criteria. Most were in neonatal ICUs (28/44, 64%) and general PICUs (10/44, 23%). Most interventions aimed to improve clinician knowledge (25/44; 57%), augment clinical structures and processes (11/44; 25%), or enhance communication (N=8/44; 18%). Common delivery methods included clinical practice changes (N=25/44; 57%; e.g., protocols, order sets [N=12]) and educational sessions (N=20/44; 45%). Outcomes included clinician knowledge (N=17/44; 39%), qualitative feedback (N=18/44; 41%), feasibility/acceptability (N=12/44; 27%), or treatment utilization (N=11/44; 25%). Few examined families' mental health (N=3; 7%) or bereavement (N=2; 5%). Few reported implementation facilitators or barriers. **Conclusions:** Most included studies targeted clinician outcomes through education. Designing, testing, and implementing interventions focused on family outcomes is a critical next step.

Keywords: pediatric critical care; interdisciplinary; end-of-life care; palliative care

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1. Introduction

A child's death is life-altering, leading to life-long grief for their families [1–7]. Many children and families navigate the terminal phases of an illness or injury in the pediatric intensive care unit (PICU) [8–10]. A multidisciplinary, team-based approach is crucial to addressing end-of-life needs in the PICU, including tending to a child's symptoms, family spiritual and emotional needs, and meaning-making opportunities [7,11,12]. Parents who self-report feeling unprepared for end-of-life (EOL) more frequently perceive EOL suffering, or experience decisional regret and decreased social functioning [13–15]. As the clinicians most frequently at the bedside, nurses are well-positioned to support and prepare families for EOL. Interprofessional EOL care that fully leverages nurses' roles is therefore critical to supporting patients and families.

To date, studies of family and clinician experiences illuminate several gaps in PICU EOL care that exacerbate parental distress [16–19]. These include fragmented communication, strained relationships within and between clinical teams and families, and limited structural support for families and clinicians, among others [16–19]. Generally low pediatric mortality rates mean that clinicians may rarely apply palliative and EOL skills learned during pre-licensure training, instead learning on the job. Thus, there is a pressing need for supportive EOL interventions that can be readily integrated into routine PICU care to address these known barriers to high-quality EOL care.

Although EOL care interventions are increasingly common, systematic evaluations of their components — including who, how, and when interventions are delivered and implemented — remain lacking. Systematically cataloging existing interventions is necessary to ensure all dying children in the PICU receive compassionate, evidence-based care from well-trained clinicians. We therefore conducted a scoping review to evaluate interventions for children nearing EOL in the PICU.

2. Materials and Methods

2.1. Design

This scoping review [20] followed Arksey and O'Malley's method [21] and the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines [22]. The review protocol was registered on Open Science Foundation (https://doi.org/10.17605/OSF.IO/7ST2E). The following research question guided the review: How are pediatric EOL interventions designed and delivered, who delivers and receives them, what outcomes do they aim to effect, and what factors facilitate or inhibit their implementation?

2.2. Search Strategy

A medical librarian (JB) and the first author (EGBA) developed a search strategy that was peer-reviewed by another medical librarian (Supplement 1). Electronic databases included Ovid MEDLINE(R) ALL, OVID APA PsycINFO, OVID Embase, CINAHL, Cochrane Central, and Web of Science. Search terms included both controlled vocabulary and synonymous free text to capture these concepts: population (children with life-threatening conditions), care settings (intensive care units) and interventions (intervention, education, training, etc.). We used citationchaser [23] to identify additional articles using backward and forward reference searching.

2.3. Selection Criteria

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To capture interprofessional interventions, articles with the search terms in the title, abstract, or subheadings and the word "nurse" within the full text were included. We included reports of empirically evaluated interventions designed to support EOL care for children (i.e., last days of life) dying from any cause in any intensive care setting (e.g., neonatal, pediatric, and cardiac). We sought to include interventions that meaningfully involved nurses in their implementation and impact. We defined intervention broadly as any practice change focused on bedside EOL care (e.g., educational programs, symptom management, communication training, order sets, electronic medical record modifications, etc.). Eligible articles formally evaluated the interventions using quantitative, qualitative, or mixed methods, with outcomes reported by patients, families, or clinicians. We included all research designs and quality improvement efforts.

To capture as many interventions as possible, we made no exclusions based on publication year, location, or language. We translated articles published in languages other than English using Google translate [24] or ChatGPT (OpenAI) if needed. Studies were included if they reported results specific to ICU populations or if > 50% of patients died in the ICU. Studies not explicitly focused on the EOL period were included only if >50% of patients died during the study period. We excluded reviews, opinion articles, dissertations, and editorials. Articles describing practice changes without formal evaluation were excluded.

2.4. Screening and Data Management

Search results were uploaded and deduplicated in EndNote (version 20 – Thompson Reutres) then uploaded into COVIDENCE systematic review software (Veritas Health Information) [25]. Two reviewers from a team of four authors (EGBA, NO, SEW, IJEU) independently screened study titles and abstracts. Discrepancies were resolved by a third reviewer from the team of four. Full texts studies that met criteria were reviewed using the same process and team.

2.5. Data Extraction and Quality Appraisal

We developed and pilot tested a standardized data extraction form in REDCap [26,27]. Three authors (EGBA, NO, or SEW) independently extracted article information and reviewed extracted data, with discrepancies resolved through discussion. We extracted intervention elements, contextual factors, and implementation barriers and facilitators (Supplement 2). Intervention elements (Figure 1: Box 1) included development processes, goal or intended impact, delivery methods, interventionists and recipients of the intervention, and outcome measures (quantitative metrics and qualitative questions). Contextual factors included sample characteristics, ICU type (neonatal, general PICU, cardiac PICU), and hospital characteristics. Unit- and hospital-level intervention implementation facilitators and barriers were based on the Consolidated Framework for Implementation Research [28]. We extracted palliative care focus — physical, psychological, spiritual/existential, and/or social [29]. We evaluated methodological rigor using the Mixed Methods Appraisal Tool (MMAT; Supplement 3) [30]; we did not evaluate quality improvement, program evaluation, or implementation project rigor given their small number and heterogeneous designs.

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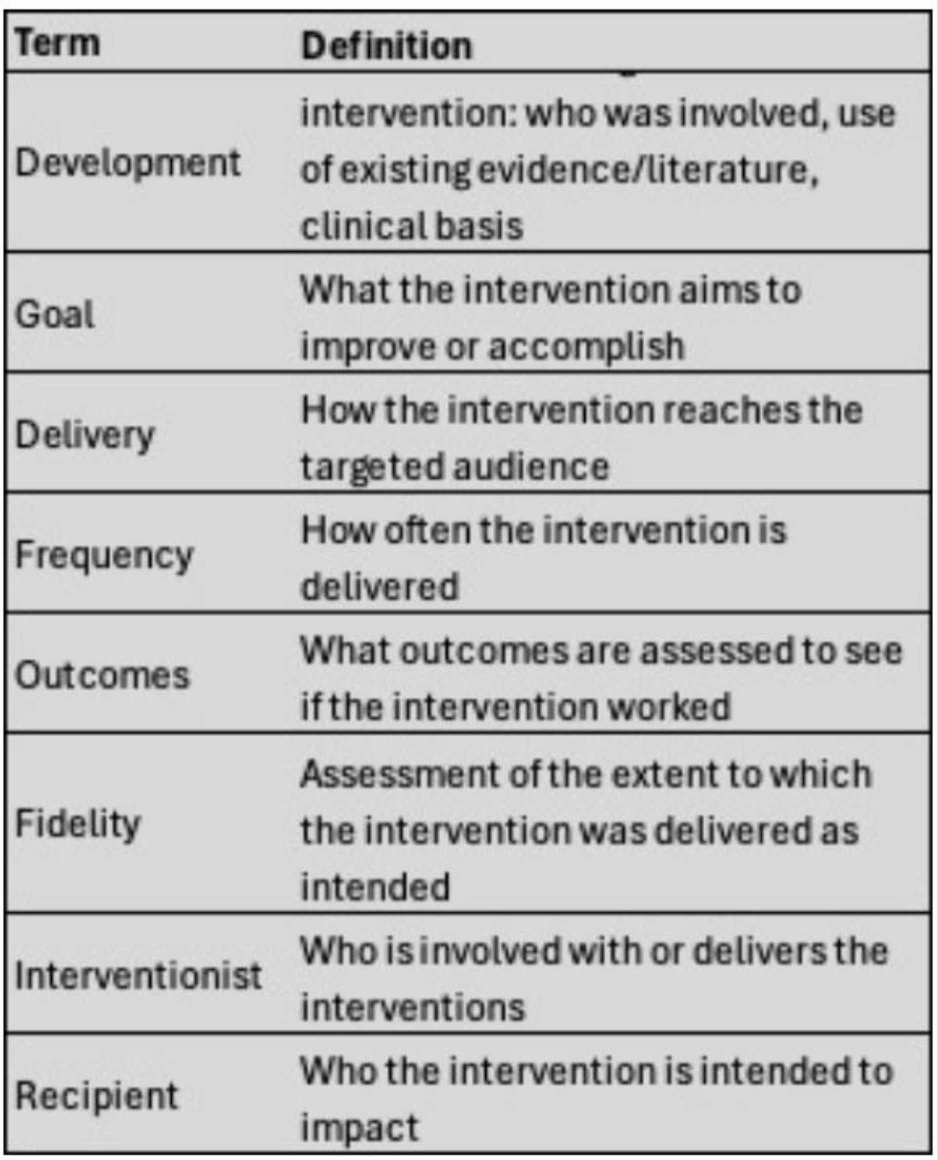

Term	Definition
Development	intervention: who was involved, use of existing evidence/literature, clinical basis
Goal	What the intervention aims to improve or accomplish
Delivery	How the intervention reaches the targeted audience
Frequency	How often the intervention is delivered
Outcomes	What outcomes are assessed to see if the intervention worked
Fidelity	Assessment of the extent to which the intervention was delivered as intended
Interventionist	Who is involved with or delivers the interventions
Recipient	Who the intervention is intended to impact

Figure 1. Extracted intervention elements. Alt text: A text box containing definitions of intervention elements.

2.6. Analysis:

Quantitative data were summarized in STATA [31] using frequencies for categorical and means/medians for continuous variables. For qualitative data, the coding team (EGBA, NO, SW, IJEU) generated descriptive categories from extracted free text about intervention elements and implementation barriers and facilitators,[28,32] then collaboratively coded 10% of articles in Dedoose [33] before proceeding independently with all coding verified by the first author (EGB). Code frequencies describing intervention elements and implementation barriers and facilitators were generated. Categories were not mutually exclusive and thus do not sum to 100% in reporting.

To assess if interventions targeted parent priorities, we mapped intervention goals and outcomes to parent-identified gaps in EOL care. Based on two systematic reviews of parent PICU EOL experiences and one qualitative study of bereaved parents recommendations for PICU EOL care [16,19,34], we identified seven parent-identified gaps from these three articles: communication and information sharing, comfort and symptom management, family psychosocial and spiritual care, structural support (e.g., visitation policies), meaning making (e.g., memento-making), grief and bereavement care, and parental role acknowledgement and empowerment. Among the total sample of articles in our review, we tabulated the number addressing each of these gaps and intervention goals/outcomes.

3. Results

We screened 11,643 articles, assessed 286 full texts for eligibility; and 44 met inclusion criteria (**Figure 2**). Most research teams used non-randomized quantitative (17/44, 39%) or quantitative descriptive designs (12/44, 27%); see **Table 1**. The neonatal ICU was the most common site (28/44, 64%) followed by general PICU (10/44, 23%). Four (9%) studies were conducted in pediatric cardiac ICUs. Most interventions focused on multiple palliative care domains (38/44, 86%).

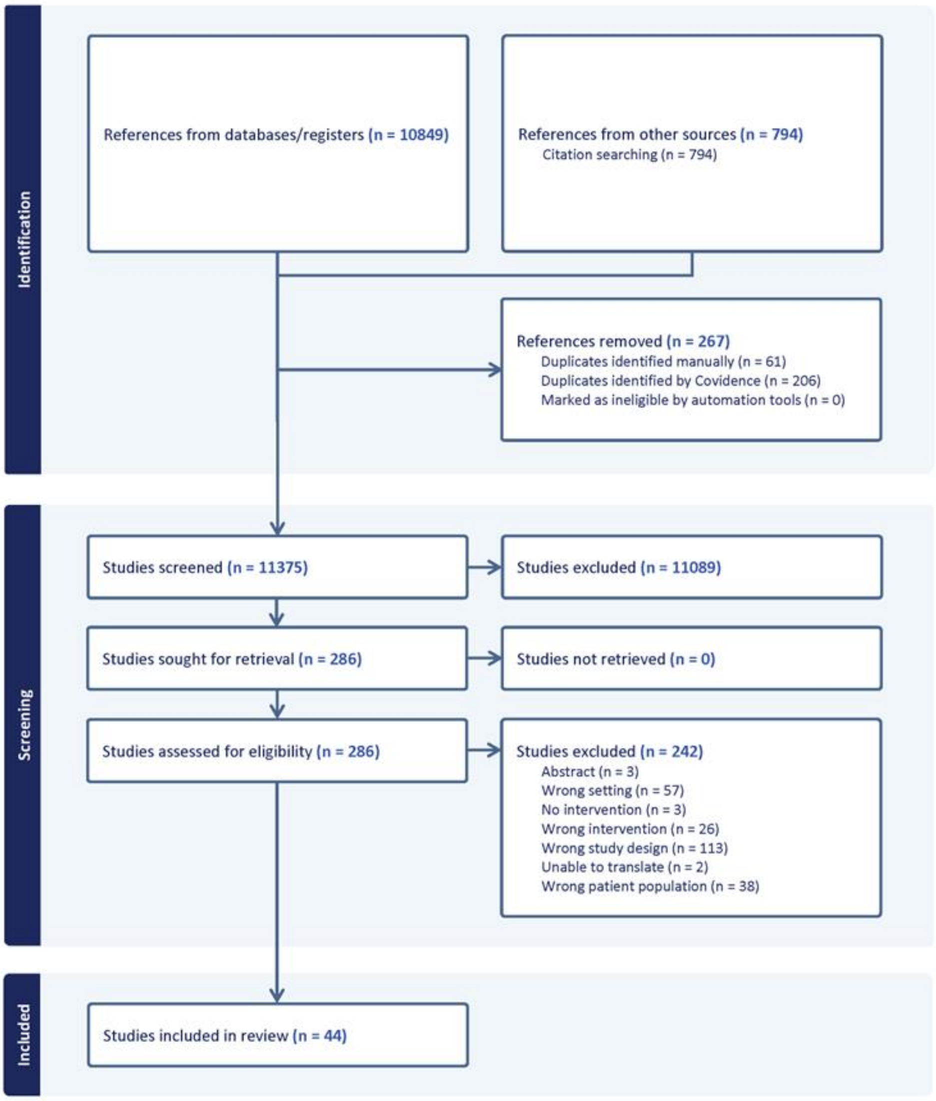

Figure 2. Preferred Reporting Items for Systematic Reviews and Meta-Analyses Flowchart. Alt text: A flowchart of review screening and study selection procedures.

Table 1. Aggregate Study Characteristics.

Category	Variable	N (%)
Total		44
Study design	Mixed Methods	3 (7%)
	Other[1]	8 (18%)
	Qualitative	4 (9%)
	Quantitative descriptive	12 (27%)
	Quantitative non-randomized	17 (39%)
Unit type[2]	General PICU	10 (23%)

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	PCICU	4 (9%)
	NICU	28 (64%)
	Other unit type	2 (5%)
Palliative care domains*	Physical	34 (77%)
	Physical alone	5 (11%)
	Emotional/psychological	38 (86%)
	Emotional alone	1 (2%)
	Spiritual Domain	25 (57%)
	Spiritual alone	0
	Social Domain	30 (68%)
	Social Alone	0
	Multiple	38 (86%)
Interventionist Role[3]	Interprofessional team + family	2 (5%)
	Research team	4 (10%)
	Supportive care consultants	7 (17%)
	Physician	6 (14%)
	Nurse	3 (7%)
	Interprofessional team	10 (24%)
	ICU clinical team	5 (12%)
	Palliative care team	2 (5%)
	External education team	3 (7%)
	Nurse(s) involved	18 (41%)
Sample*	Patients	14 (32%)
	Parent/family	10 (23%)
	Clinicians	28 (64%)

[1] Other designs included implementation, quality improvement, informal evaluation, multimethod. [2] Other unit types include interventions where all pediatric units were eligible and over half of intervention participants were in intensive care setting. [3] 2 interventionist roles were unreported or unclear. *indicates categories that are not mutually exclusive.

3.1. Intervention Elements

Here we summarize intervention elements, contextual factors, implementation facilitators and barriers, and study rigor. Appendix 3: Table of Evidence contains study details and all citations.

Development: Eleven of 44 (25%) interventions were developed from prior evidence (e.g., based on prior research, adapted existing interventions) and 5 (11%) were informed by clinical experience. Eighteen interventions (41%) engaged key partners (e.g., clinicians) in study development; three (7%) involved family members. For example, Zhang et al. engaged bereaved parents to develop a protocol for transferring infants to a specified NICU room with parent sleeping space [35]. Development processes were not explicitly reported in 21/44 (48%) articles.

Goals: Most (25/44; 57%) interventions focused on improving clinician knowledge or comfort with EOL care. Eleven (25%) interventions focused on improving clinical structures and processes. For example, Younge et al. integrated a palliative care protocol, order set, nursing care plan, and comfort medication guidelines into NICU EOL care [36]. Eight (18%) interventions aimed to enhance communication within clinical teams and with families, by increasing regular case discussions [37] or bereavement debriefings for families [38]. Six interventions (14%) integrated palliative care into the PICU; two (5%) supported decision-making, [39,40] such as through meetings about discontinuation of life-sustaining treatments [40]. Nine (20%) interventions focused on staff debriefing. Interventions addressing patient and family experiences (12/44; 27%) included symptom management (N=5; 11%), [36,41–44] memento-making activities (N=4; 9%), [35,45–47] and support for parents (N=3; 7%) [35,48,49].

Delivery: Most interventions were delivered through clinical practice changes (25/44; 57%). These included protocols/pathways (N=12; 27%), team/family meeting processes/structures (N=9;

20%), order set or medication administration instructions (N=4; 9%),[36,41,42] electronic health records (N=2; 5%),[50,51] or environmental modifications (N=4; 9%) [35,48,49,52]. For example, Carter et al. incorporated EOL content into NICU morbidity and mortality conferences [53]. Other delivery methods included educational sessions (20/44; 45%) and simulations (N=6; 14%). Ten of 44 (23%) interventions used reflective debriefings, such as peer support [54], emotional debriefing sessions for staff [52,55–59] or follow-up meetings with families [38,60]. Some interventions (7/44; 16%) were delivered by preparing specific personnel (e.g., champions, palliative care teams).

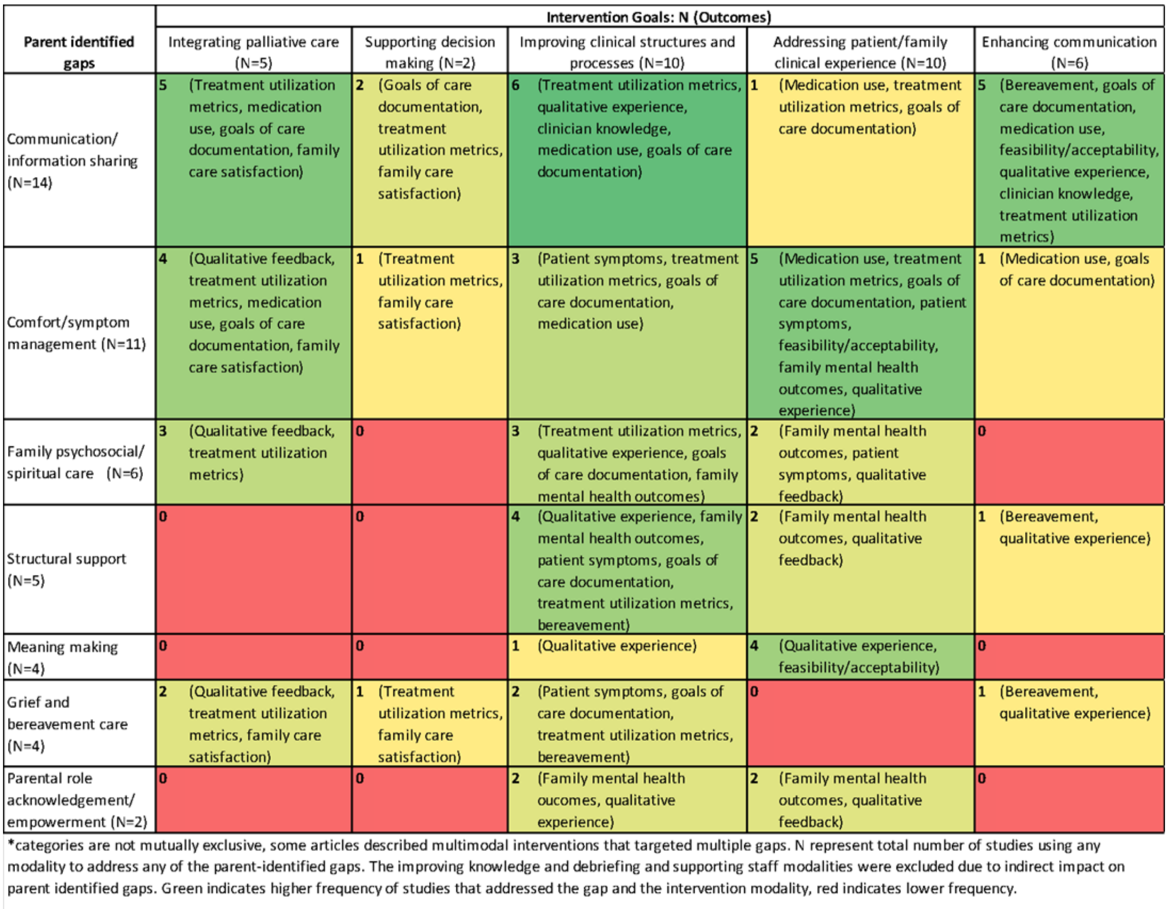
Timing and frequency of interventions: Some interventions were integrated (N=20/44; 45%) or separate (N=24/44; 54%) from clinical processes. Four of 44 (9%) interventions occurred once (e.g., singular memory-making experience) [35,45–47], and 16 (36%) repeated changes within the practice setting, (e.g., medication administration over the last days of a child's life) [41]. Eleven (25%) interventions occurred once outside clinical practice (e.g., a one-time simulation) [61] and thirteen (30%) included multiple events outside clinical practice (e.g., simulations throughout PICU fellowship) [62]. Four interventions (9%) included post-mortem processes (e.g., a reflective debriefing, family bereavement meeting) [38,58–60].

Interventionists: About a quarter (24%) of interventionists included multiple disciplines (e.g., medicine, nursing, social work), and 5 (12%) used ICU-based teams. Three (7%) had nurse interventionists [41,48,63] and 2 (5%) interventionist teams included parents (**Table 1**) who completed intervention procedures such as photography [47] and educational content [64].

Subspecialty palliative care: Thirteen (39%) studies explicitly involved subspecialty palliative care in intervention development or delivery. In two (5%), no palliative care team was available [65,66], while three (7%) mentioned palliative care teams that were not part of the study [44,49,57]. Nineteen (43%) did not reference palliative care team involvement.

Summary of outcomes: Clinician knowledge, attitudes, or beliefs about palliative and EOL care practices were evaluated in 17/44 (39%) studies. Eighteen (41%) studies examined qualitative feedback. Twelve (27%) studies evaluated treatment utilization metrics (e.g., mechanical ventilation at time of death) [39]; twelve evaluated feasibility/acceptability (27%). Four (9%) evaluated medication use [36,42,43,65]. Five (11%) projects evaluated goals of care documentation or meetings [36,40,51,65,67], and/or patient symptoms/experience [41–44,67]. Three (7%) studies evaluated clinician mental health (e.g., burnout), [54,56,59] and three (7%) evaluated family mental health [35,39,44]. Two (5%) studies examined parent bereavement (e.g., meaning making [38], grief experience [52]).

Mapping to parent-identified gaps: Parent-identified gaps with the most corresponding interventions (**Figure 3**) were communication and information sharing (14 interventions) and comfort/symptom management (11 interventions). Six interventions addressed family psychosocial and spiritual support, through integrating palliative care or improving clinical processes like psychosocial consultations. These were evaluated using treatment utilization metrics (N=3) [35,51,68], or patient/family experience, (e.g., parent depression/anxiety (N=2)) [35,44]. Five interventions addressed structural support for parents through clinical structures/processes, addressing family experience (e.g., specific spaces for EOL) [35,49,52], or enhancing communication (e.g., increasing family conferences) [52]. Structural interventions evaluated family outcomes, treatment utilization metrics, and/or qualitative data.



Parent identified gaps	Intervention Goals: N (Outcomes)				
	Integrating palliative care (N=5)	Supporting decision making (N=2)	Improving clinical structures and processes (N=10)	Addressing patient/family clinical experience (N=10)	Enhancing communication (N=6)
Communication/ information sharing (N=14)	5 (Treatment utilization metrics, medication use, goals of care documentation, family care satisfaction)	2 (Goals of care documentation, treatment utilization metrics, family care satisfaction)	6 (Treatment utilization metrics, qualitative experience, clinician knowledge, medication use, goals of care documentation)	1 (Medication use, treatment utilization metrics, goals of care documentation)	5 (Bereavement, goals of care documentation, medication use, feasibility/acceptability, qualitative experience, clinician knowledge, treatment utilization metrics)
Comfort/symptom management (N=11)	4 (Qualitative feedback, treatment utilization metrics, medication use, goals of care documentation, family care satisfaction)	1 (Treatment utilization metrics, family care satisfaction)	3 (Patient symptoms, treatment utilization metrics, goals of care documentation, medication use)	5 (Medication use, treatment utilization metrics, goals of care documentation, patient symptoms, feasibility/acceptability, family mental health outcomes, qualitative experience)	1 (Medication use, goals of care documentation)
Family psychosocial/ spiritual care (N=6)	3 (Qualitative feedback, treatment utilization metrics)	0	3 (Treatment utilization metrics, qualitative experience, goals of care documentation, family mental health outcomes)	2 (Family mental health outcomes, patient symptoms, qualitative feedback)	0
Structural support (N=5)	0	0	4 (Qualitative experience, family mental health outcomes, patient symptoms, goals of care documentation, treatment utilization metrics, bereavement)	2 (Family mental health outcomes, qualitative feedback)	1 (Bereavement, qualitative experience)
Meaning making (N=4)	0	0	1 (Qualitative experience)	4 (Qualitative experience, feasibility/acceptability)	0
Grief and bereavement care (N=4)	2 (Qualitative feedback, treatment utilization metrics, family care satisfaction)	1 (Treatment utilization metrics, family care satisfaction)	2 (Patient symptoms, goals of care documentation, treatment utilization metrics, bereavement)	0	1 (Bereavement, qualitative experience)
Parental role acknowledgement/ empowerment (N=2)	0	0	2 (Family mental health oucomes, qualitative experience)	2 (Family mental health outcomes, qualitative feedback)	0

*categories are not mutually exclusive, some articles described multimodal interventions that targeted multiple gaps. N represent total number of studies using any modality to address any of the parent-identified gaps. The improving knowledge and debriefing and supporting staff modalities were excluded due to indirect impact on parent identified gaps. Green indicates higher frequency of studies that addressed the gap and the intervention modality, red indicates lower frequency.

Figure 3. Heat Map of Intervention Goals and Outcomes vs. Parent Identified Gaps in End-of-Life Care. Alt text: Heat map showing how often different intervention types addressed parent-identified gaps in pediatric end-of-life care. Green indicates more studies addressing a gap with a modality; red indicates fewer.

Four interventions supported meaning making through memento-making activities which were evaluated qualitatively [45–48]. Four interventions included grief and bereavement care, through integrating palliative care (N=2) [39,69], supporting decision making (N=1) [39], improving clinical structures (N=1) [67], and/or enhancing communication. [52] For example, Morillo Palma et al.'s palliative care protocol included systematic bereavement follow-up for families. [67] Two interventions [35,48] helped support parental role empowerment by improving clinical structures and processes and addressing patient and family clinical experience, evaluated through family mental health outcomes and qualitative feedback. Specifically, Kymre et al. evaluated nurse-facilitated parent skin-to-skin opportunities for dying neonates. [48]

3.2. Contextual Factors

Most studies (25/44; 57%) were conducted in academic institutions. Thirteen (30%) were in freestanding children's hospitals and 6/44 (14%) in community or government hospitals. Six of 44 studies (14%) described multisite approaches.

3.3. Implementation Barriers and Facilitators

Unit-level implementation facilitators included high volume (12/44; 27%); existing family-centered, palliative, or EOL care infrastructure (8/44; 18%); invested individuals (8/44; 18%); and staff enthusiasm (2/44; 5%) [44,57]. Unit-level implementation barriers included technology or procedural issues (10/44; 23%); scheduling (10/44; 23%); lack of palliative or EOL care infrastructure (3/44; 7%); [61,70,71] and individual hesitations (2/44; 5%) [41,60]. For example, nurses who used an oral or transmucosal comfort medication protocol in Drolet et al.'s study reported discomfort interrupting families' privacy [41].

Hospital-level implementation facilitators included committed intervention champions (7/44; 16%), support for required time/resources (4/44; 9%) [59,68,70,72], established hospital EOL, palliative, or bereavement programming (7/44; 16%). Barriers included lack of programming (4/44; 9%) [50,65,69,70]. Many studies (26/44; 59%) did not report about hospital-level implementation factors.

3.4. Study Rigor

Common threats to rigor included potential selection or sampling bias (Appendix 3: MMAT Results). Many studies (15/44; 34%) did not report sample demographic data. Most studies utilized a quasi-experimental design, often without a control group, introducing the potential for confounding.

4. Discussion

This scoping review cataloged EOL care intervention elements and implementation considerations in neonatal and pediatric ICUs. Most interventions aimed to improve clinician knowledge about palliative and EOL care through educational programming or improved clinical processes (e.g., team meeting procedures or assessment protocols). Few studies examined family outcomes. Parent-identified gaps of communication and comfort/symptom management were addressed by >10 interventions, whereas just two interventions addressed parental role empowerment. Implementation facilitators included structural factors like established palliative or bereavement programs. Barriers often included scheduling or operational challenges. These findings highlight common strategies used to enhance EOL care in the PICU and illuminate critical areas for future research and family engagement.

Most interventions relied on educational sessions, simulations, or protocols to improve clinicians' knowledge about palliative and EOL care. Educational interventions tailored to the PICU are critical to upholding quality EOL care since most pre-licensure EOL care education focuses on non-pediatric populations, and pediatric ICU mortality is low, meaning clinicians may not receive much on-the-job PICU EOL training [73–76]. The impact of educational interventions depends on successful integration into complex clinical workflows [77–79]. Yet, many studies did not routinely consider implementation facilitators or barriers, which may limit interventions scalability or integration into clinical care [77,78].

Mapping intervention goals and outcomes to EOL care gaps reported by parents [16,19,34] revealed important future priorities. Many parents recount issues with how information was shared during their child's terminal hospitalization [16,19,34]. We identified fourteen studies focused on improving information sharing during clinical care, through integrating palliative care, supporting decision making, improving clinical structures, and enhancing communication. However, outcomes were mostly clinician perspectives or medical record data, rather than family reports. Few interventions focused on enhancing parental role empowerment, [35,48] despite perceived importance by bereaved parents [34,80]. Prior qualitative findings retrospectively articulate how clinicians can effectively partner with parents during serious illness [81] and EOL care [4,12,80]. However, prospectively operationalizing and implementing family role empowerment during the uncertainty of PICU EOL care is complex and warrants careful design and evaluation of family-driven interventions.

Many studies support early palliative care during a child's serious illness [82,83]. However, few studies in our sample included subspecialty pediatric palliative care in the development, design, or implementation of intervention studies. Fostering research collaborations between PICU and palliative care teams to develop and test family-centered interventions may be a critical step to strengthen the evidence base for PICU EOL care. While 41% of intervention teams included nurses, only 3 (%) studies evaluated nurse-led interventions, and most interventions did not impact routine nursing practice. Given nurses' uniquely close involvement with children and families during EOL, future interventions should consider leveraging nursing workflows to enhance EOL care.

Limitations of Included Studies

Most screened articles were excluded for describing EOL care without implementing an intervention. No randomized trials met our inclusion criteria; most studies used quantitative non-randomized or descriptive designs, often without control groups or detailed demographic data. These study features limit generalizability or transferability to other populations outside the study context. While randomized controlled trials may be challenging to conduct during intensive EOL care, alternative designs, such as pragmatic trials, cluster and hybrid effectiveness trials, or causal approaches such as interrupted time series analysis may be feasible [78,84]. Additionally, few studies engaged families in intervention design or study procedures.

Strengths and Limitations of Review

This scoping review followed a comprehensive, peer-reviewed search strategy and rigorous methodological standards. However, our findings should be interpreted considering several limitations. Publication bias limits our analysis to interventions that have been evaluated and reported in published literature. The search terms we used were comprehensive and corresponded with leading causes of mortality but may not have captured all causes of death. We limited our sample to interventions conducted in PICUs and NICUs using interprofessional interventions and contained the word nurse in the report. Intervention studies conducted in other settings, such as pediatric oncology, or that did not use an interprofessional approach, could have applicable elements. We limited our focus to last days of life; studies focused on earlier serious illness communication, advanced care planning, or shared decision making could be informative to designing EOL interventions. Although assessing intervention effects was outside of the scope of this review, future studies should aim to analyze outcomes to inform evidence-based EOL practice.

5. Conclusions

Empirically evaluated EOL interventions in pediatric and neonatal intensive care units are scarce. Most published EOL care intervention studies focus on improving clinician knowledge of palliative and EOL care using educational approaches or clinical practice changes evaluated with pre-post designs. Few interventions target parent-reported gaps in EOL care, especially parental role empowerment, include families in intervention development, use designs that account for selection bias or confounding factors, or consider implementation barriers/facilitators. These are important areas of future research to strengthen EOL care.

Supplementary Materials: The following supporting information can be downloaded at the website of this paper posted on Preprints.org, Supplement: Search strategy, Extraction form, Table of Evidence, Mixed Methods Appraisal Tool Results.

Author Contributions: EGBA: 1) study conceptualization, 2) data acquisition, analysis, interpretation, 3) manuscript original draft and edits, 4) accountable for manuscript. **NO**: 1) study conceptualization, 2) data acquisition, analysis, interpretation, 3) manuscript original draft and edits, 4) accountable for manuscript. **SW:** 1) study conceptualization, 2) data acquisition, analysis, interpretation, 3) manuscript original draft and edits, 4) accountable for manuscript. **IJEU**: 1) study conceptualization, 2) data acquisition, analysis, interpretation, 3) manuscript original draft and edits, 4) accountable for manuscript. **JB:** 1) study conceptualization, 2) data acquisition, 3) manuscript edits, 4) accountable for manuscript. **DKC**: 1) study conceptualization, 2) manuscript edits, 3) accountable for manuscript. **SF**: 1) study conceptualization, 2) data interpretation, 3) manuscript edits, 4) accountable for manuscript. **JS:** 1) study conceptualization, 2) data interpretation, 3) manuscript edits, 4) accountable for manuscript

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Abbreviations

The following abbreviations are used in this manuscript:

PICU	Pediatric Intensive Care Unit
EOL	End-of-life
ICU	Intensive care unit
NICU	Neonatal intensive care unit

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