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Midwifery practice in perinatal palliative care: A scoping review and conceptual framework

Federica Caminiti [a], Cristina Lumia [b,*,1], Sara Tomaselli [b], Elisabetta Colciago [a], Marzia Serafini [a], Simona Fumagalli [a,b], Antonella Nespoli [a,b]

[a] Fondazione IRCCS San Gerardo dei Tintori, Monza, Italy
[b] University of Milano-Bicocca, School of Medicine and Surgery, Monza, Italy

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ABSTRACT

Background: Perinatal palliative care (PPC) is a multidisciplinary, family-centred approach aimed at improving the quality of life and comfort of newborns with life-limiting conditions, and their families. Midwives can play a crucial role in supporting these pathways. However, their specific contribution within PPC remains underexplored in the scientific literature.
Aim: To map the available evidence on the role and contributions of midwives in perinatal palliative care and to explore how midwifery practice is integrated into care strategies for pregnancies complicated by life-limiting fetal conditions or uncertain neonatal prognosis.
Methods: This scoping review was conducted in accordance with the Joanna Briggs Institute Manual for Evidence Synthesis and reported following the PRISMA-ScR guidelines. Comprehensive searches were performed across PubMed, CINAHL, PsycINFO, EMBASE, and Google Scholar (May-September 2025). All English-language primary studies were included, with no restrictions on publication year or country.
Results: Eleven studies met the inclusion criteria. Most focused on professional education and healthcare professionals' experiences and clinical recommendations from professional organizations. Findings highlight several domains - communication, emotional support, birth planning, breastfeeding counselling, and bereavement care - where midwifery competencies align with the principles of PPC. Based on the synthesis of the included studies, a conceptual framework was developed to illustrate how core domains of midwifery practice align with key components of perinatal and neonatal palliative care across the antenatal, intrapartum, and postnatal continuum.
Conclusion: Midwives hold professional, relational, and educational competencies that position them ideally to contribute to perinatal palliative care. However, the lack of formal recognition and structured training in this area highlights the need for policy guidance and further research to clearly define, strengthen, and standardise their role.

Statement of significance

Problem:

Perinatal palliative care is increasingly recognized as a key component of neonatal care; yet the role of midwives in these care pathways has been insufficiently explored.

What is already known:

Midwives provide personalised, continuous, and family-centred care throughout pregnancy, childbirth and the postpartum period. Their professional roles in communication, emotional support, and collaborative decision-making closely align with the principles of palliative and end-of-life care.

What this paper adds:

This scoping review consolidates global knowledge about midwives' roles and contributions, highlighting their integration into multidisciplinary care pathways and emphasizing the need for structured education and professional recognition in this field.

* Correspondence to: School of Medicine and Surgery, University of Milano-Bicocca, Via Cadore n. 48, Monza 20900, Italy.
E-mail address: c.lumia2@campus.unimib.it (C. Lumia).
[1] ORCID iD: https://orcid.org/0009-0007-9091-009X

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1. Introduction

A substantial proportion of pregnancies are affected by fetal conditions associated with life-limiting or uncertain prognoses [1]. Life-limiting conditions are defined as disorders for which no curative intervention exists and which are likely to result in miscarriage, stillbirth or neonatal death [2]. These conditions include chromosomal abnormalities such as trisomy 13 or 18, as well as major congenital anomalies including anencephaly, renal agenesis, congenital diaphragmatic hernia and severe cardiac malformations [3]. Following a prenatal diagnosis, parents are offered counselling to support informed decision-making among different care pathways, which may include fetal surgery, neonatal life-extending interventions, pregnancy termination or perinatal palliative care [4].

Perinatal palliative care (PPC) is a systematic, multidisciplinary and family-centred approach that provides obstetric and neonatal management options across the prenatal, intrapartum and postpartum periods, prioritising quality of life and comfort for both the newborn and the family while addressing physical, emotional, social and spiritual dimensions of care [2,5,6]. Increasing availability of PPC services has been associated with a growing number of families choosing to continue the pregnancy despite severe fetal conditions [7]. This choice requires coordinated care delivered by an interdisciplinary team capable of supporting parents through complex clinical decisions and ensuring continuity across care settings [8]. PPC extends from the antenatal period across multiple contexts - including outpatient services, hospital care and community settings - and encompasses prenatal testing and counselling, specialist consultations, advance care planning, intrapartum and postnatal care, end-of-life and post-mortem support, as well as emotional, psychological and spiritual support for bereaved families [9,10]. Effective, empathetic and culturally sensitive communication is essential to facilitate shared decision-making and respect family values throughout this process [11].

In the literature, the terms perinatal and neonatal palliative care are sometimes used interchangeably, although they refer to partially overlapping scopes. Neonatal palliative care typically focuses on care provided after birth, primarily within neonatal intensive care or hospital settings, whereas perinatal palliative care encompasses a broader continuum that begins at the time of prenatal diagnosis and extends through pregnancy, birth, neonatal care and bereavement [5,11,12]. In this review, the term perinatal palliative care is adopted to reflect this longitudinal and integrated model of care, while acknowledging that some included studies focus predominantly on the neonatal phase.

Existing research has primarily explored parents' experiences and the perspectives of healthcare professionals, as well as the development of clinical guidelines and conceptual models. Qualitative studies focusing on parents have described the profound emotional impact of receiving a prenatal diagnosis of a life-limiting condition, characterised by shock, grief, guilt and fear, alongside the desire to experience parenthood through meeting, holding and caring for their baby, even for a limited time [13,14]. Across these studies, parents consistently emphasised the importance of empathic and non-judgemental communication, continuity of care, involvement in decision-making, and sensitive support for memory-making activities such as photographs, footprints and memory boxes [13,14]. These findings highlight relational and continuity-based dimensions of care that are central to high-quality PPC and directly inform professional practice.

In parallel, studies focusing on healthcare professionals have documented challenges related to preparedness, emotional burden, ethical uncertainty and organisational constraints when delivering PPC [15–19]. Confidence and comfort in providing palliative and bereavement care appear to be associated with prior training, clinical exposure and structured institutional support [15–17]. Conceptual and guideline-based publications further frame PPC as a holistic and family-centred continuum of care, while also warning against excessive medicalisation and limited visibility of relational and caregiving roles within prevailing models [20–22].

Despite this growing body of literature, the specific contribution of midwives within perinatal and neonatal palliative care remains insufficiently described. Midwives are frequently included under broader professional categories or grouped with nursing roles, and explicit analysis of midwifery contributions, responsibilities and scope of practice in PPC is scarce [23]. Moreover, most published studies originate from high-income Western countries, particularly the United States, raising questions about the generalisability of findings across different cultural, regulatory and organisational contexts [23]. This fragmentation limits the ability to clearly identify common elements of midwifery involvement in PPC and to inform education, practice and policy development at an international level.

Given the alignment between core midwifery values - such as continuity of care, family-centred practice, relational support and shared decision-making - and the foundational principles of perinatal palliative care, a comprehensive mapping of the existing evidence is warranted. This scoping review was therefore conducted to: (1) map and synthesise the available international literature on midwives' involvement in perinatal palliative care; (2) identify knowledge gaps related to midwifery roles, contributions and training needs; and (3) explore how midwifery practice is currently integrated within palliative care pathways across different healthcare settings. By providing an overview of existing evidence and highlighting areas for future research, this review aims to support the development of more coherent, equitable and midwifery-informed models of perinatal palliative care.

2. Methods

The existing literature on the role of midwives within perinatal and neonatal palliative care pathways was delineated, examining how midwifery practice integrates into the continuum of care for pregnancies affected by life-limiting or uncertain prognostic conditions for the fetus and/or newborn. The protocol was registered on the Open Science Framework (OSF) on June 6, 2025 (registration ID: osf.io/3wtnk).

This scoping review was conducted following the Joanna Briggs Institute (JBI) methodology for scoping reviews [24], in combination with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) guidelines [25]. The review also adhered to the methodological framework proposed by Arksey and O'Malley [26], encompassing five key stages: 1) identifying the research question; 2) identifying relevant studies; 3) study selection; 4) data charting; and 5) collating, summarising, and reporting results.

2.1. Stage 1: Identifying the research question

Based on gaps identified in the literature, the primary research question was formulated: *"How does midwifery care integrate into and support neonatal palliative care pathways?"*.

Although the research question refers to neonatal palliative care, the broader term perinatal palliative care is used throughout the manuscript to reflect the continuum of care beginning at prenatal diagnosis and extending through pregnancy, birth, neonatal care and bereavement.

2.2. Stage 2: Identifying relevant studies

The Population, Concept, Context (PCC) framework (Table 1) was used to define inclusion criteria. No date or geographical setting restrictions were applied. Only studies published in English were included.

The search strategy was developed in consultation with an information specialist, using the Medical Subject Headings (MeSH) database to identify relevant index terms, synonyms, and keywords. Systematic searches were then performed from May to July 2025 across PubMed, CINAHL, PsycINFO, EMBASE, and Google Scholar for grey literature. Full search strings for each database are detailed in Appendix 1.

Table 1
Inclusion and exclusion criteria.

Population	Midwives, newborns, and families involved in neonatal/perinatal palliative care pathways.
Concept	Role, responsibilities and contributions of midwives within perinatal/neonatal palliative care and comfort care pathways.
Context	Setting: Perinatal and neonatal palliative care settings across antenatal, intrapartum, and postnatal care; hospital and community environments; interdisciplinary care pathways. Study design, inclusion, and exclusion criteria: All primary studies, including qualitative, quantitative, and mixed-methods designs, were eligible for inclusion. Relevant grey literature and the most recent clinical guidelines were also consulted to ensure comprehensiveness. Research protocols, systematic reviews, and scoping reviews were excluded.

2.3. Stage 3. Study selection

The conclusive search approach retrieved 79 results from all databases. Twenty-two articles were eliminated as duplicates, providing fifty-seven unique studies eligible for screening. Two reviewers (CL and ST) independently evaluated titles and abstracts to ascertain eligibility for full-text review. A third reviewer (FC) was designated to resolve disagreements; however, this was unnecessary as consensus was always achieved. A total of 23 studies were considered suitable for full-texts evaluation.

The same reviewers (CL and ST) independently assessed eligibility based on predefined inclusion and exclusion criteria. Disagreements were resolved with an independent third reviewer (FC). Ultimately, eleven papers were removed for population irrelevance and one for inappropriate publication type, yielding a total of 11 research articles included in the final scoping review. The study selection procedure is illustrated in the PRISMA flow diagram (Fig. 1).

The software Rayyan was used to support the processes of study screening and selection.

2.4. Stage 4. Charting the data

A data extraction spreadsheet was developed in Microsoft Excel to systematically record key information from all included studies. The extracted data included authors, publication year, country, study design, methodology, study aim, participant characteristics, and main findings.

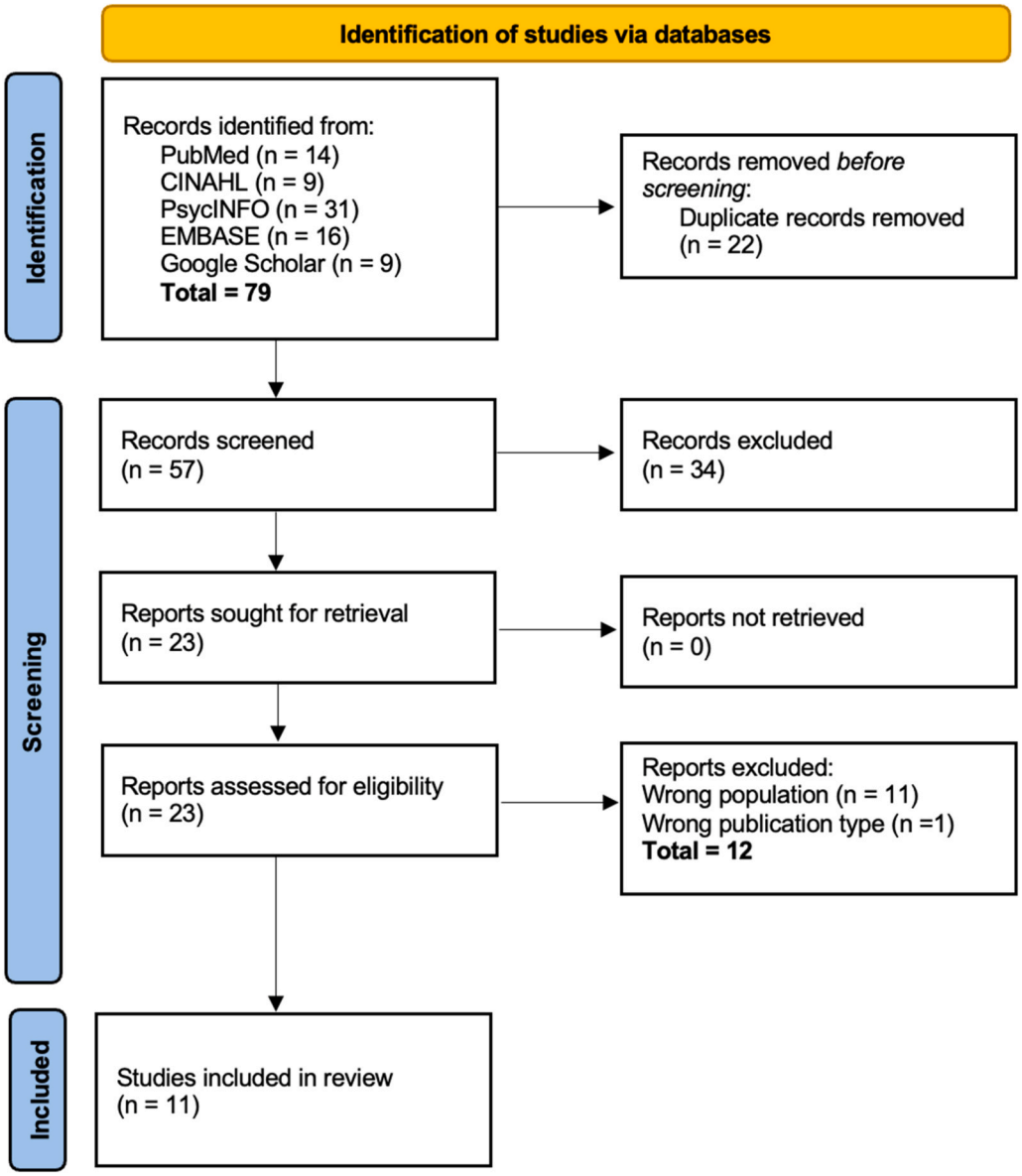

Fig. 1. PRISMA flow diagram.

The data extraction form was piloted by all reviewers on two included studies to assess clarity, consistency, and feasibility. After this pilot period, minor modifications were implemented to improve the structure and comprehensiveness of the tool. To ensure reliability, the extraction process was discussed by the review team, and the final version of the form was shared among all reviewers. The gathered data were then used to facilitate the narrative synthesis, identify recurring themes, and map the existing literature on the topic.

The main characteristics of the included studies are presented in Table 2, whereas the key findings are reported in Table 3.

2.5. Stage 5. Collating, summarising, and reporting results

The findings of this scoping review were systematically collated, mapped, and reported. A comprehensive numerical summary was initially conducted to include the characteristics of the identified literature, including year of publication, geographical distribution, study design, and methodological approach. The data were presented in tables to illustrate the evolution and distribution of research in neonatal palliative care.

The extracted data were further analysed to identify recurring themes related to perinatal and neonatal palliative care and midwifery practice. Although not all included studies focused explicitly on midwives, studies addressing perinatal and neonatal palliative care more broadly were also considered, as they described practices, processes and relational dimensions closely aligned with midwifery role. These studies were therefore mapped alongside midwifery-focused literature to provide a comprehensive understanding of how midwifery practice may be integrated within palliative care pathways across the perinatal continuum. As part of the data synthesis process, a conceptual framework was developed through an iterative, interpretative approach based on the findings of the included studies. It was constructed to organise and represent key aspects of midwives' roles in perinatal and neonatal palliative care across the antenatal, intrapartum, and postnatal continuum, and informed by patterns identified in the data and supported by existing conceptual models and international perspectives on midwifery care.

Significant theme areas were identified through descriptive comparison and categorization to illustrate how the role of midwives has been represented across different contexts, populations, and study designs. This mapping provides a conceptual and descriptive overview of the literature, rather than a formal thematic analysis.

The findings are presented using a combination of descriptive tables and narrative synthesis, facilitating a comprehensive assessment of the structural aspects of the evidence and the conceptual domains emerging from the study.

According to the scoping reviews methodology, no formal critical appraisal was conducted.

Table 2
Characteristics of included studies.

Author, Year, Country	Study Design	Methodology	Participants	Aim
American College of Obstetricians and Gynaecologists (2019) - USA	Expert consensus Clinical guideline	Narrative expert consensus based on multidisciplinary evidence	Healthcare professionals involved in perinatal care and pregnant women with life-limiting fetal diagnoses and	To provide clinical guidance on the organisation and offer of perinatal palliative (comfort) care for pregnancies affected by life-limiting fetal conditions.
Engler et al. (2004) - USA	Cross-sectional descriptive study	Quantitative survey	190 neonatal nurses and advanced practice neonatal nurses working in NICUs.	To explore neonatal nurses' perceptions, comfort, and roles in bereavement and end-of-life care for families of critically ill and dying infants
Banazadeh & Rafii (2021) - Iran	Concept analysis	Dimensional analysis of literature	46 published studies (2001–2018) on neonatal palliative care	To clarify and define the concept of neonatal palliative care within nursing practice.
Geurtzen et al. (2023) - Netherlands	Cross-sectional multicentre study	Nationwide online survey	769 perinatal healthcare professionals (including obstetricians, neonatologists, clinical midwives, obstetric and neonatal nurses).	To explore Dutch perinatal healthcare professionals' preferences regarding prenatal and postnatal decision-making with parents facing extremely preterm birth.
Wool (2013) - USA	Cross-sectional study	Online survey using the Perinatal Palliative Care Perceptions and Barriers Scale (PPCPBS)	212 clinicians: physicians (n = 66) and advanced practice nurses (APNs, n = 146), including certified nurse midwives, nurse practitioners and clinical nurse specialists.	To examine clinicians' perceptions, comfort and confidence in providing and referring patients to perinatal palliative care.
Peng et al. (2018) - Taiwan	Cross-sectional study	Questionnaire-based survey using a modified Comfort Level Caring for Dying Infants Scale (CLCDI)	154 neonatal clinicians (119 neonatal nurses; 35 neonatologists) from 4 Level III NICUs.	To evaluate factors associated with professional confidence and personal comfort of neonatal clinicians in providing neonatal palliative care.
Mendel (2014) - USA	Narrative review / educational article	Narrative synthesis of literature and clinical perspectives	Neonatal nurses (focus on NICU nursing practice).	To discuss the role of neonatal palliative care in reducing moral distress among NICU nurses and identify barriers to its effective implementation.
Wool (2015) - USA	Cross-sectional survey	Web-based survey using the Perinatal Palliative Care Perceptions and Barriers Scale (PPCPBS); quantitative analysis with *t*-test and Mann-Whitney U	212 clinicians: 66 physicians and 146 advanced practice nurses (including midwives) involved in perinatal care.	To measure and compare perceived barriers to providing and referring families to perinatal palliative care among physicians and advanced practice nurses.
Marchuk (2016) - USA	Case study / Conceptual paper	Application of Comfort Theory as a conceptual framework	Theoretical/clinical application to neonatal end-of-life care in the NICU.	To demonstrate how Comfort Theory and its taxonomic structure can be used as a conceptual framework for nurses and midwives providing end-of-life care to neonates and their families.
Knowles et al. (2021) - USA	Meeting abstract	Conference abstract presentation	Case/context of planned home birth with neonatal life-limiting condition (LLC) supported by hospice.	To describe the role of perinatal palliative care consultation and home hospice in the context of a planned home birth in a newborn with a life-limiting condition.
Kain & Chin (2020) - USA and Australia	Conceptual paper	Narrative literature review with thematic analysis (using NVivo)	13 peer-reviewed articles + 6 institutional definitions related to neonatal and children's palliative care.	To propose a conceptual definition of neonatal palliative care (NPC) by identifying and synthesising key concepts and themes from the literature.

Table 3
Key findings of included studies.

Author & Year	Key Findings
ACOG, 2019	Highlights the importance of communication, shared decision-making, birth planning, continuity of care, and bereavement support in perinatal palliative care. Although midwives are not explicitly named, these areas strongly align with core midwifery competencies.
Engler et al., 2004	Neonatal nurses reported good levels of comfort in providing bereavement and end-of-life care, particularly in supporting parents around the time of the infant's death. Higher comfort and involvement were associated with greater clinical experience and the presence of unit policies on bereavement care. Cultural and language differences were perceived as barriers to effective family support. Education and specific training in end-of-life care were identified as key factors influencing confidence and professional engagement.
Banazadeh & Rafii, 2021	Neonatal palliative care is conceptualised as a multidimensional process including five key dimensions: perspective (family-centred care), context, conditions, process, and outcomes. The concept emphasises holistic care, symptom control, communication with families, support for parents, professional advocacy, and structured end-of-life care for neonates.
Geurtzen et al., 2023	Most professionals favoured shared decision-making in counselling parents of extremely preterm infants. Fifty-three percent preferred presenting early intensive care and palliative comfort care as equally valid options. Sixty-one percent supported discussing a conditional trial of intensive care as a third option. The majority (78%) believed healthcare professionals should initiate postnatal discussions about continuation or withdrawal of intensive care. Considerable variation existed regarding definitions of severe long-term outcomes.
Wool, 2013	Physicians and advanced practice nurses showed similar ethical perceptions of perinatal palliative care but differed significantly in self-reported comfort and confidence. Physicians reported higher levels of comfort with providing and referring to perinatal palliative care and greater overall confidence. Perceived barriers, personal comfort, years of practice, and referral comfort were significant predictors of clinician confidence.
Peng et al., 2018	Clinicians' confidence was significantly associated with age, marital status, years of experience, and prior palliative care training. Comfort levels were significantly associated with educational degree, marital status, and professional experience. Professional confidence and personal comfort were positively correlated ($r = 0.47$; $p < 0.001$). Supportive workplace environments were significantly correlated with higher confidence ($r = 0.286$; $p < 0.001$) and comfort ($r = 0.521$; $p < 0.001$). No significant differences were found between nurses and physicians in confidence or comfort.
Mendel, 2014	Neonatal nurses experience high levels of moral distress during end-of-life care, particularly when care is perceived as futile or not aligned with the infant's best interests. Consistent and well-implemented neonatal palliative care, supported by structured education in communication, symptom management, and ethical decision-making, was identified as a key strategy for reducing moral distress. The study highlights a lack of training, inconsistent communication, and the absence of dedicated palliative care teams as major barriers to effective neonatal palliative care.
Wool, 2015	Clinicians reported multiple barriers to perinatal palliative care (PPC) provision. Nurses reported significantly more system-level barriers (difficulty securing administrative support and interdisciplinary collaboration). Physicians reported greater confidence in counselling families. Both groups described distress and helplessness when caring for families with life-limiting fetal or neonatal diagnoses. The most frequently reported barrier across both groups was a lack of societal understanding and support for PPC.
Marchuk, 2016	Applying Comfort Theory and its taxonomic structure as a conceptual framework for end-of-life care in the NICU may support the standardisation and improvement of care for dying neonates and their families, providing a structured approach to comfort care in neonatal end-of-life contexts.
Knowles et al., 2021	Hospice-assisted home birth in cases of fetal life-limiting conditions presents specific clinical and organisational challenges. Effective care requires close collaboration between midwives and community hospice organisations to ensure immediate access to symptom management and end-of-life care for the newborn following birth.
Kain & Chin, 2020	Five major themes underlying definitions of neonatal palliative care were identified: philosophies of care, support, culture and spirituality, the team, and clinical management. NPC is defined as an active, holistic, and family-centred approach beginning at diagnosis, provided by a multidisciplinary team, aimed at maintaining quality of life, alleviating suffering, supporting a "good death", and providing ongoing family support, including bereavement.

3. Findings

A preliminary mapping of the included studies was conducted to describe the existing body of evidence concerning midwifery within perinatal palliative care. Most publications explored neonatal and perinatal palliative care from multidisciplinary or institutional perspectives, while only a limited number explicitly addressed the role of midwives. For this reason, the inclusion criteria required that studies provided a clear discussion of midwives' roles, competencies, or involvement in perinatal or neonatal palliative care from a professional perspective. Publications primarily focusing on parental experiences, clinical case management, or broader programmatic aspects of perinatal palliative care without an explicit focus on midwifery practice were not included in the analytical synthesis.

3.1. Characteristics of the included studies

Eleven papers published between 2004 and 2023 met the inclusion criteria. Most studies were published after 2010, with a marked increase in publications over the last decade, reflecting growing academic attention to perinatal and neonatal palliative care.

Six studies [15–19,27] explored the perspectives and experiences of healthcare professionals involved in neonatal or perinatal palliative care, while five articles [12,20–22,28] contributed to clinical guidance and conceptual frameworks related to neonatal palliative care.

Only a limited number of studies specifically addressed midwives [14,16,17,19,21,28], whereas the majority examined neonatal palliative care from broader professional or institutional viewpoints, often grouping midwives within multidisciplinary teams.

Reported healthcare settings included neonatal intensive care units (NICUs) [15,16,19,21,27], hospital-based perinatal services [17,20,24,25], community and hospice services [22], and planned home birth context [28].

Based on semantic and content similarities across the included studies and through iterative discussion within the research team, two descriptive domains were identified:

1) Professional experiences, preparedness, and organisational context.
   This domain includes studies exploring training, preparedness, confidence, and the emotional and professional impact of providing neonatal and perinatal palliative care as part of this competence.
2) Professional and organisational frameworks guiding practice.
   This domain refers to publications describing professional guidance, standards, and organisational models shaping neonatal and perinatal palliative care.

3.2. Domain 1. Professional experiences, preparedness, and organisational context

Six studies examined the education and professional experiences of healthcare professionals involved in neonatal palliative care [15–19,27]. These studies primarily explored professionals' perceived readiness, emotional experiences and barriers in providing care. Participants included midwives, neonatologists, obstetricians, neonatal nurses, and advanced practice nurses. Across these studies, three recurrent constructs were described: confidence, comfort, and distress.

Confidence referred to professionals' perceived ability to provide appropriate clinical and emotional support to families experiencing perinatal loss or navigating palliative care pathways [16]. Comfort described the degree of ease professionals experienced while providing care in sensitive end-of-life contexts [29]. Distress - particularly moral distress – was described in situations where clinicians perceived a misalignment between institutional practices and their personal or professional values, especially in ethically complex decision-making situations involving life-limiting conditions [18].

Higher levels of confidence and comfort were reported among professionals who had received prior education or training in neonatal or perinatal palliative care [16,17]. Working in high complexity NICUs, characterised by more frequent exposure to critically ill newborns and end-of-life care, was also described as contributing to greater confidence in bereavement support [15]. Moreover, structured organisational support, such as institutional protocols and clearly defined care pathways, was reported as reducing uncertainty and supporting professional stability. Less experienced professionals emphasised the importance of interprofessional education and mentorship models to strengthen both clinical competence and emotional resilience when supporting families experiencing neonatal loss [15–17]. Within this context, midwives reported that limited consultation time during antenatal care restricted opportunities for holistic counselling and the development of meaningful relationships with families [16].

Several barriers related to professional practice and organisational context were also identified. Professionals reported that cultural and language differences posed challenges to effective communication and shared decision-making when adequate training, interpretive resources or institutional support were lacking [15]. Additionally, time constraints, especially within maternity care settings, were described as limiting relational continuity and reducing opportunities for emotional support [19].

3.3. Domain 2. Professional guidance and clinical frameworks

Five studies provided clinical, conceptual, and practice-oriented guidance on neonatal and perinatal palliative care [12,20–22,28]. The articles included conceptual analysis, expert opinions, and professional recommendations. Neonatal palliative care was consistently described as a dynamic, holistic, and family-centred approach that may begin during pregnancy and continue through birth, death, and bereavement, emphasizing comfort, emotional support, and shared decision-making [20,22]. Several publications have raised concerns regarding the potential medicalization within neonatal palliative care models, noting limited explicit recognition of nursing and midwifery contributions, despite their pivotal role in providing comfort and relational support [22]. The American College of Obstetricians and Gynaecologists distinguish perinatal palliative care from perinatal comfort care. While perinatal palliative care is described as a comprehensive and longitudinal model that may be provided alongside life-prolonging treatment [12], perinatal comfort care refers specifically to an end-of-life–focused approach centred on newborn comfort, symptom management and family support, when the goal of care is no longer life prolongation [30]. This option is presented alongside other reproductive care pathways, including life-prolonging treatment or termination of pregnancy [12,30].

4. Discussion

This scoping review shows that neonatal and perinatal palliative care is consistently described in the literature as holistic, family-centred, multidisciplinary and focused on comfort and relational care. These features emerged across two main analytical domains: professional experiences and preparedness, and organisational frameworks guiding practice [12,20–22,28]. Together, these dimensions position PPC as a longitudinal process that may begin at the time of diagnosis and extend across pregnancy, birth, neonatal care and bereavement, rather than being confined to end-of-life alone [12,31,32].

Across the included studies, healthcare professionals involved in neonatal and perinatal palliative care reported a substantial emotional and moral burden. Ethical uncertainty, complex decision-making, and institutional constraints were frequently associated with moral distress, emotional exhaustion and professional vulnerability [33–36]. These challenges were particularly evident in contexts where professionals felt inadequately supported or where organisational practices conflicted with their professional values or the needs of the families. Similar dynamics have also been described in studies exploring parental experiences and decision-making processes following life-limiting fetal diagnoses [37].

A consistent finding across the literature was the presence of educational and organisational gaps. Several studies reported limited formal training in neonatal or perinatal palliative care, with professionals feeling insufficiently prepared to manage both the clinical and relational demands of care [38,39]. In contrast, prior education, clinical exposure and access to structured institutional support were associated with greater confidence and comfort in providing palliative and bereavement care [33,39]. These findings underscore the importance of integrating PPC content into undergraduate, postgraduate and continuing professional education, alongside organisational strategies that support ethical reflection, emotional well-being and interdisciplinary collaboration [40].

Although midwives were not consistently identified as a distinct professional group within the included studies, the challenges described - particularly those related to relational work, continuity of care and emotional labour - closely reflect core midwifery practice domains. This suggests that the professional experiences reported in the literature are highly relevant to midwifery, especially in antenatal and intrapartum settings where midwives often accompany families following a life-limiting fetal diagnosis.

In parallel with professional experiences, the literature highlights the role of professional guidance and organisational models in shaping neonatal and perinatal palliative care. PPC is increasingly described as a planned, multidisciplinary approach integrating obstetric and neonatal care to prioritise quality of life and comfort for the fetus or newborn and the family [12,31]. Integrative reviews and practice frameworks emphasise that effective palliative care encompasses not only symptom management, but also psychosocial and spiritual support, memory-making, bereavement care and staff support, particularly when delivered through coordinated and continuous programmes [30,31,41–43]. Within these models, family-centred care emerged as a central organising principle. Parents consistently valued honest and sensitive communication, meaningful involvement in shared decision-making, continuity of care and sustained emotional and relational support [13,14]. These elements strongly shaped parental perceptions of care quality and were associated with more supported bereavement experiences [44,45]. Conversely, fragmented communication and discontinuity of care were linked to increased distress, confusion and dissatisfaction [20,46]. The relational dimension of care, characterised by professional presence, empathy and respect for parental values, was repeatedly identified as integral to high-quality care rather than an optional or secondary component [47,48]. Bereavement-related practices and supportive care pathways described in the wider literature further illustrate how families experience and navigate perinatal loss within palliative care

contexts [49].

Despite this, explicit articulation of midwifery roles within neonatal and perinatal palliative care frameworks remains limited. This gap is notable given the close alignment between the principles underpinning palliative care and the philosophical foundations of midwifery, particularly continuity, relational care and family-centred practice. Addressing this disconnect may represent an important step towards more integrated and equitable models of perinatal palliative care.

4.1. Relationship with previous literature

The findings of this scoping review are consistent with, and extend upon, previous literature describing the marginal yet significant positioning of midwives within perinatal and neonatal palliative care. Across the included studies, midwives were primarily described in terms of relational, communicative, and continuity-of-care functions rather than as clearly delineated professional actors within palliative care models. Structural constraints, such as limited consultation time in antenatal settings, were frequently reported as limiting opportunities for holistic counselling and sustained relationship-building with families [16]. Similar to other professionals, midwives were also exposed to emotional strain, low confidence, and ethical tension when supporting families facing life-limiting fetal or neonatal diagnoses, particularly lacking structured education and organisational support [15–17,19]. These experiences align with broader patterns of moral distress and professional vulnerability documented among healthcare professionals working in neonatal palliative care [15,18,27].

In line with our findings, a recent US scoping review [23] highlighted that midwives' roles in perinatal palliative care remain poorly represented and under-theorised in the literature. Most included studies in that review were descriptive or case-based, and midwives were often grouped under generic professional categories or positioned at the margins of interprofessional teams. When explicitly described their contribution encompassed both direct clinical care (antenatal, intrapartum, postnatal, neonatal and bereavement care) and care planning and coordination activities (birth planning, team communication, and community/continuity of care). However, that review also identified insufficient preparation for these roles as a recurrent issue, reflecting the educational gaps described in the studies included in the present review [15–17].

Furthermore, conceptual and guideline-oriented papers on neonatal palliative care continue to prioritise medical and institutional perspectives, with limited explicit recognition of midwifery contributions. Warning against excessive medicalisation of palliative care models [21] resonates strongly with our findings, as midwifery roles often remain under-recognised despite their centrality in presence and relational care. This limited visibility contrasts with parents' accounts, which consistently emphasise empathy, continuity, non-judgemental support, shared decision-making, and sensitive facilitation of memory-making and bereavement, all domains that closely reflect midwifery philosophy and practice [6,7,13,22,29].

4.2. Implications for midwifery practice and research

The findings of this scoping review suggest that midwifery practice is closely aligned with the core dimensions of perinatal and neonatal palliative care identified in the literature, including holistic and family-centred care, interdisciplinary collaboration, individualised comfort-focused care, and sustained relational presence [9,20,22,23,31,43]. This conceptual alignment is also reflected in international professional standards [50,51] and midwifery literature, which emphasise continuity [52], shared decision-making [53] and communication [54] in complex and sensitive situations, including bereavement. Despite this conceptual consistency, perinatal and neonatal palliative care continues to be only partially integrated within several midwifery regulatory and educational frameworks. The lack of explicit recognition might contribute to the ongoing underrepresentation of midwives in clinical palliative care services and in scientific research.

From a practice perspective, the literature described in this review indicates that midwives appear particularly well positioned to contribute across the perinatal palliative care continuum, beginning from the antenatal counselling following a life-limiting fetal diagnosis, to continuity of support during labour and birth. These components are consistently recognised as central aspects in midwifery practice.

From a research perspective, there remains a clear need for studies explicitly focusing on midwives' roles, competencies, and educational needs in perinatal and neonatal palliative care. Current evidence is largely derived from neonatal, paediatric, or general nursing perspectives, with limited midwifery-specific empirical research [13,19,22,24,26]. Future studies should explore midwives' experiences across different care settings (antenatal services, birth units, postnatal wards, and community or home-based perinatal palliative care), examine the impact of midwifery-integrated or midwifery-led palliative models of care on parental and family outcomes, and support the development of structured educational pathways within undergraduate and postgraduate midwifery curricula [13,25,31]. Strengthening the evidence base in this area is essential to ensure the systematic and explicit integration of midwifery within perinatal and neonatal palliative care services, moving beyond its current predominantly conceptual recognition.

These findings also have important implications for midwifery education. Integrating perinatal palliative care into undergraduate and postgraduate curricula could strengthen midwives' preparedness to support families facing life-limiting fetal conditions, particularly in areas such as communication, shared decision-making, bereavement care, and interdisciplinary collaboration.

4.3. Framework for midwifery practice

The framework was developed through an iterative interpretative process based on the synthesis of the literature included in this scoping review and informed by international midwifery standards and conceptual models of midwifery care. Addressing the gap between midwifery values and their limited representation in perinatal palliative care policies and research is essential to develop more equitable, relational and family-centred models of care for families facing life-limiting fetal and neonatal conditions. The Midwifery Framework (Fig. 2)

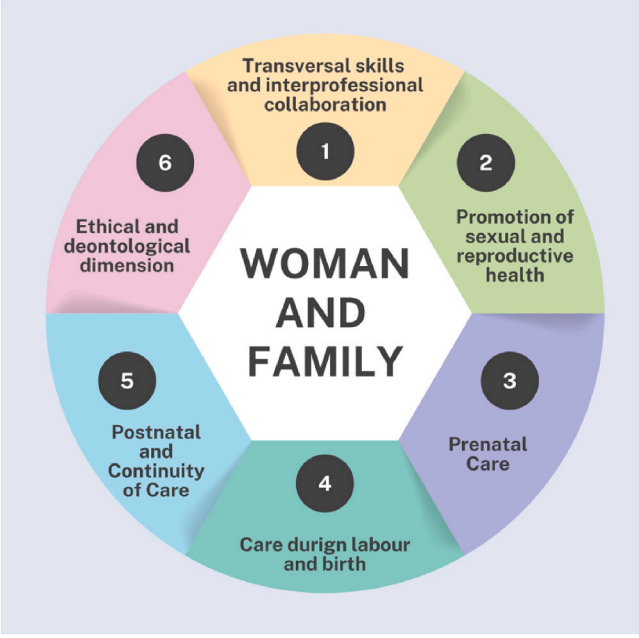

Fig. 2. Midwifery Framework for perinatal and neonatal palliative care.

proposed in this study conceptualises midwifery contributions to perinatal and neonatal palliative care as a multidimensional, continuous and woman-family centred model of care, grounded both in international midwifery standards and in the empirical evidence mapped in this review.

In the framework, the woman and her family are placed in a central position, surrounded by five interrelated domains of midwifery practice: 1) transversal competencies and interprofessional collaboration; 2) sexual and reproductive health promotion; 3) antenatal care; 4) intrapartum care, and 5) postnatal care and continuity of care.These domains are permeated by a sixth overarching dimension of ethical and deontological responsibility.

This structure reflects how midwifery practice, even beyond explicitly palliative settings, is inherently embedded in longitudinal, relational, and holistic care - dimensions consistently identified as central to perinatal and neonatal palliative care in the literature. For these reasons, the proposed framework does not synthetically "add" palliative care to midwifery practice but rather shows how palliative principles are already intrinsically aligned with its core domains. In addition to programmatic models such as the NCCP, several studies included in this review describe specific clinical practices and organisational approaches that reflect these domains in practice. Examples such as advance birth planning and interdisciplinary care coordination, breastfeeding counselling and milk donation pathways following perinatal loss, and educational initiatives designed to prepare midwives to support families facing life-limiting fetal diagnoses. These examples further illustrate how the relational, continuity-based and family-centred components of midwifery care can be operationalised within perinatal palliative care pathways.

When applied to a perinatal palliative care context, each component of the framework corresponds with key elements of existing care models. For example, the Neonatal Comfort Care Program (NCCP) at Columbia University [30] demonstrates how continuity of care from diagnosis through birth and bereavement, relational support, family presence, and interdisciplinary collaboration are fundamental to high-quality palliative care. These elements closely align with antenatal, intrapartum, and postnatal domains represented in the framework, particularly in relation to birth planning, rooming-in, feeding support, memory-making, and bereavement follow-up.

Similarly, the Midwifery Partnership Model [55] emphasises a sustained, reciprocal relationship between the woman and the midwife, based on trust, shared decision-making, empowerment, and continuity across the reproductive trajectory. These principles resonate strongly with the needs of families living through perinatal loss or life-limiting fetal diagnoses, where relational stability, presence, and advocacy are repeatedly identified as core components of a meaningful care experience. Within this framework, this partnership philosophy is reflected not only in the antenatal and intrapartum domains, but also in the transversal dimension of communication, ethical practice and interprofessional collaboration.

Importantly, aligning this framework with real-world programs such as the NCCP also highlights a critical paradox emerging from the findings of this scoping review: despite midwifery competencies, values and philosophies are highly congruent with perinatal palliative care principles, midwives remain inconsistently recognised, formally integrated and trained within these models. The NCCP itself acknowledges the growing need for a dedicated midwife to ensure continuity of care, facilitate communication, support birth planning, promote skin-to-skin contact and feeding, and provide postnatal follow-up and bereavement support [30]. This reinforces the relevance and applicability of the framework, not only as a theoretical contribution but also as a practical tool to inform service design and workforce development.

Overall, the integrated midwifery framework proposed represents a conceptual link between midwifery theory, international professional standards, and the operational models of perinatal palliative care currently implemented in specialised centres. It therefore offers a structured lens through which to reinterpret existing neonatal palliative care practices, positioning midwives not as outside contributors, but as central relational, clinical, and coordinative figures across the entire perinatal trajectory: from diagnosis to bereavement.

4.4. Strengths and limitations

Several limitations should be acknowledged. First, the current evidence base appears fragmented and geographically concentrated, with most studies conducted in high-income Western countries. This limits the generalisability of the findings to other healthcare settings and cultural contexts. Therefore, there is a clear need for future research that is more culturally sensitive and inclusive of diverse healthcare systems. In addition, many of the included studies did not explicitly differentiate midwives from other healthcare professionals (e.g., nurses or advanced practice nurses, making it challenging to isolate midwifery-specific contributions.

However, this scoping review provides a comprehensive mapping of the existing literature on neonatal and perinatal palliative care with a specific focus on the potential role of midwives. A key strength lies in the use of a transparent and rigorous methodological framework consistent with JBI and PRISMA-ScR guidance, which ensured a systematic search, selection, and synthesis process. Moreover, adopting a midwifery lens allowed us to highlight relational, continuity-based, and family-centred aspects of care that are often underrepresented in predominantly medical or nursing literature.

5. Conclusions

Perinatal palliative care is increasingly recognised as an essential care pathway for families facing life-limiting fetal and neonatal conditions, yet its integration into routine practice remains inconsistent. This scoping review shows that while the literature mainly addresses parental experiences and healthcare professionals' perspectives, the specific role of midwives is still insufficiently explored and undertheorised.

However, the core dimensions emerging from the evidence strongly aligned with midwifery roles and professional contributions. The literature suggests that midwives are uniquely positioned to support families across the continuum of diagnosis, birth and bereavement, offering care that integrates both clinical and relational dimensions.

These findings highlight the need for stronger recognition of perinatal palliative care within midwifery education, professional standards and clinical pathways.

Ethical approval

Not required.

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CRediT authorship contribution statement

FC, CL and ST: Conceptualization, Methodology. CL and FC: Data curation, Writing - original draft. ST: Investigation, Visualization. AN and MS: Supervision. AN, SF, EC and MS: Validation. SF, EC and CL: Writing – review and editing. All authors contributed to manuscript revision and approved the final version.

Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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Appendix A. . Search strings for each database

Database	Strings
PubMed	(Palliative Care OR Hospice and Palliative Care Nursing OR Palliative Medicine OR Terminal Care OR End-of-life OR Euthanasia OR Bereavement) AND (Infant, Newborn OR perinatal OR neonate OR neonatal) AND comfort care (midwi* OR midwifery OR midwife OR midwives)
CINAHL	(MH "Palliative Care" OR MH "Palliative Care Nursing" OR MH "Palliative Care Nurses" OR MH "Palliative Medicine" OR MH "Hospice Nurses" OR MH "Hospice Nursing" OR MH "Hospice Patients" OR MH "Hospice Care" OR MH "Terminal Care+" OR MH "Euthanasia+" OR MH "Bereavement+") AND (MH "Infant, Newborn+" OR MH "Perinatal Death" OR MH "Perinatal Care" OR MH "Perinatal Period" OR MH "Perinatal Nursing+" OR MH "Neonatal Nurses+" OR MH "Neonatal Nursing+") AND comfort care AND (MH "Midwifery+" OR MH "Midwives+" OR midwi*) (Palliative Care OR Palliative Care Nursing OR Palliative Care Nurses OR Palliative Medicine OR Hospice Nurses OR Hospice Nursing OR Hospice Patients OR Hospice Care OR Terminal Care OR end-of-life OR Euthanasia OR Bereavement) AND (Infant, Newborn OR Perinatal OR Neonatal OR Neonate) AND comfort care AND (Midwifery OR Midwives OR midwife OR midwi*)
PsycINFO	(Palliative Care OR Euthanasia OR Hospice OR Terminal* OR Bereavement OR Grief OR end-of-life) AND (Neonatal OR Perinatal OR baby)
EMBASE	(palliative OR terminal OR euthanasia OR bereavement) AND (newborn OR perinatal) AND comfort AND care AND midwi*
Google Scholar	Palliative care AND Midwife

References

[1] J.M. Lorenz, C.V. Ananth, R.A. Polin, M.E. D'Alton, Infant mortality in the United States, J. Perinatol. 36 (10) (2016) 797–801, https://doi.org/10.1038/jp.2016.63.
[2] E. Parravicini, Neonatal palliative care, Curr. Opin. Pedia 29 (2) (2017) 135–140, https://doi.org/10.1097/MOP.0000000000000464.
[3] M.E. Doherty, L. Power, R. Williams, N. Stoppels, L. Grandmaison Dumond, Experiences from the first 10 years of a perinatal palliative care program: a retrospective chart review, Paediatr. Child Health 26 (1) (2019) e11–e16, https://doi.org/10.1093/pch/pxz089.
[4] K.L. Marc-Aurele, Decisions parents make when faced with potentially life-limiting fetal diagnoses and the importance of perinatal palliative care, Front Pedia 8 (2020) 574556, https://doi.org/10.3389/fped.2020.574556.
[5] A. Zanin, A. Salerno, M.E. Cavicchiolo, C. Daicampi, B. Martini, A. Marinetto, S. Salvadori, F. Benini, A systematic review of perinatal palliative care models: challenges and opportunities for the future, Eur. J. Pedia 184 (11) (2025) 678, https://doi.org/10.1007/s00431-025-06459-0.
[6] J. Bennett, J. Dutcher, M. Snyders, Embrace: addressing anticipatory grief and bereavement in the perinatal population: a palliative care case study, J. Perinat. Neonatal Nurs. 25 (1) (2011) 72–76, https://doi.org/10.1097/JPN.0b013e318208cb8e.
[7] L. Hostalery, B. Tosello, Outcomes in continuing pregnancies diagnosed with a severe fetal abnormality and implication of antenatal neonatology consultation: a 10-year retrospective study, Fetal Pedia Pathol. 36 (3) (2017) 203–212, https://doi.org/10.1080/15513815.2017.1296519.
[8] A. Postier, K. Catrine, S. Remke, Interdisciplinary pediatric palliative care team involvement in compassionate extubation at home: from shared decision-making to bereavement, Children 5 (3) (2018) 37, https://doi.org/10.3390/children5030037.
[9] C. Wool, A. Catlin, Perinatal bereavement and palliative care offered throughout the healthcare system, Ann. Palliat. Med. 8 (1) (2019) S22–S29, https://doi.org/10.21037/apm.2018.11.03.
[10] S. Lord, R. Williams, L. Pollard, L. Ives-Baine, C. Wilson, K. Goodman, A. Rapoport, Reimagining Perinatal Palliative Care: A Broader Role for Support in the Face of Uncertainty, J. Palliat. Care 37 (4) (2022) 476–479, https://doi.org/10.1177/08258597221098496.
[11] R.J. Anderson, S. Bloch, M. Armstrong, P.C. Stone, J.T. Low, Communication between healthcare professionals and relatives of patients approaching the end-of-life: a systematic review of qualitative evidence, Palliat. Med 33 (8) (2019) 926–941, https://doi.org/10.1177/0269216319852007.
[12] American College of Obstetricians and Gynecologists. Perinatal palliative care, ACOG Comm. Opin. No. 786. Obstet. Gynecol. 134 (3) (2019) e84–e89.
[13] K. Tewani, R. Singh, C.P.Y. Wendy, H. Jia Huan, P. Jayagobi, I. Teo, Understanding the experiences of mothers receiving perinatal palliative care: a qualitative study, Palliat. Med. 37 (9) (2023) 1379–1388, https://doi.org/10.1177/02692163231171182.
[14] K. Branchett, J. Stretton, Neonatal palliative and end of life care: What parents want from professionals, J. Neonatal Nurs. 18 (2) (2012) 40–44.
[15] A.J. Engler, R.M. Cusson, R.T. Brockett, C. Cannon-Heinrich, M.A. Goldberg, M. G. West, W. Petow, Neonatal staff and advanced practice nurses' perceptions of bereavement/end-of-life care of families of critically ill and/or dying infants, Am. J. Crit. Care 13 (6) (2004) 489–498.
[16] C. Wool, State of the science on perinatal palliative care, quiz E54-5, J. Obstet. Gynecol. Neonatal Nurs. 42 (3) (2013) 372–382, https://doi.org/10.1111/1552-6909.12034.
[17] N.H. Peng, H.F. Liu, T.M. Wang, Y.C. Chang, H.Y. Lee, H.F. Liang, Evaluation of comfort and confidence of neonatal clinicians in providing palliative care, J. Palliat. Med 21 (11) (2018) 1558–1565, https://doi.org/10.1089/jpm.2018.0102.
[18] T.R. Mendel, The use of neonatal palliative care: reducing moral distress in NICU nurses, J. Neonatal Nurs. 20 (6) (2014) 290–293.
[19] C. Wool, Clinician perspectives of barriers in perinatal palliative care, MCN Am. J. Matern Child Nurs. 40 (1) (2015) 44–50, https://doi.org/10.1097/NMC.0000000000000093.
[20] M. Banazadeh, F. Rafii, A concept analysis of neonatal palliative care in nursing: introducing a dimensional analysis, Compr. Child Adolesc. Nurs. 44 (3) (2020) 209–234, https://doi.org/10.1080/24694193.2020.1783029.
[21] A. Marchuk, End-of-life care in the neonatal intensive care unit: applying comfort theory, Int. J. Palliat. Nurs. 22 (7) (2016) 317–323, https://doi.org/10.12968/ijpn.2016.22.7.317.
[22] V.J. Kain, S.D. Chin, Conceptually Redefining Neonatal Palliative Care, Adv. Neonatal Care 20 (3) (2020) 187–195, https://doi.org/10.1097/ANC.0000000000000731.
[23] R. Schafer, J.A. LoGiudice, P. Hargwood, A. Wilpers, The role of Midwives in US perinatal palliative care: a scoping review, J. Midwifery Women's. Health 69 (6) (2024) 875–887, https://doi.org/10.1111/jmwh.13664.
[24] M.D.J. Peters, C. Godfrey, P. McInerney, Z. Munn, A.C. Tricco, H. Khalil, Scoping reviews, in: E. Aromataris, C. Lockwood, K. Porritt, B. Pilla, Z. Jordan (Eds.), JBI Manual for Evidence Synthesis, JBI, Adelaide, 2024.
[25] A.C. Tricco, E. Lillie, W. Zarin, K.K. O'Brien, H. Colquhoun, D. Levac, D. Moher, M. D.J. Peters, T. Horsley, L. Weeks, S. Hempel, E.A. Akl, C. Chang, J. McGowan, L. Stewart, L. Hartling, A. Aldcroft, M.G. Wilson, C. Garritty, S. Lewin, C. M. Godfrey, M.T. Macdonald, E.V. Langlois, K. Soares-Weiser, J. Moriarty, T. Clifford, Tunçalp Ö, S.E. Straus, PRISMA extension for scoping reviews (PRISMA-ScR): checklist and explanation, Ann. Intern. Med. 169 (7) (2018) 467–473, https://doi.org/10.7326/M18-0850.
[26] H. Arksey, L. O'Malley, Scoping studies: towards a methodological framework, Int. J. Soc. Res. Method. 8 (1) (2005) 19–32.
[27] R. Geurtzen, L. De Proost, A.A.E. Verhagen, I.K.M. Reiss, M. Hogeveen, E. J. Verweij, Dutch professionals' discussion preferences with the parents of extremely premature infants varied, but the trend was towards shared decision-making, Acta Paediatr. 112 (7) (2023) 1200–1208.
[28] G. Knowles, T.M. Vente, J.T. Fry, Hospice home birth, Pediatrics 147 (3_MeetingAbstract) (2021) 533, https://doi.org/10.1542/peds.147.3MA6.533a.
[29] A. White, From comfort zone to performance management: understanding development & performance, White & MacLean Publishing, Baisy-Thy (Belgium), 2009.
[30] C. Wool, E. Parravicini, The Neonatal Comfort Care Program: Origin and Growth Over 10 Years, Front Pedia 8 (2020 Oct 30) 588432, https://doi.org/10.3389/fped.2020.588432.
[31] L. Dombrecht, K. Chambaere, K. Beernaert, E. Roets, M. De Vilder De Keyser, G. De Smet, K. Roelens, F. Cools, Components of perinatal palliative care: an integrative review, Child. (Basel) 10 (3) (2023) 482, https://doi.org/10.3390/children10030482.
[32] English NK, Hessler KL. Prenatal care and birth planning for a woman carrying a fetus with a life-limiting diagnosis, J. Midwifery Women's. Health 58 (5) (2013) 589–592, https://doi.org/10.1111/jmwh.12049.
[33] M. Mills, D.E. Cortezzo, Moral distress in the neonatal intensive care unit: what is it, why it happens, and how we can address it, Front Pedia 8 (2020) 581, https://doi.org/10.3389/fped.2020.00581.

[34] S. Han, H. Min, S. Kim, NICU nurses' moral distress surrounding the deaths of infants, Nurs. Ethics 30 (2) (2023) 276–287, https://doi.org/10.1177/09697330221134978.
[35] Z. Rezaei, M. Nematollahi, N. Asadi, The relationship between moral distress, ethical climate, and attitudes towards care of a dying neonate among NICU nurses, BMC Nurs. 22 (1) (2023) 303, https://doi.org/10.1186/s12912-023-01459-7.
[36] M. Sakai, K. Tanaka, K. Nagata, R. Ichinoyama, Moral distress in the neonatal intensive care unit experienced by nurses caring for critically ill neonates: a phenomenological study, J. Adv. Nurs. 81 (7) (2025) 4160–4171, https://doi.org/10.1111/jan.16625.
[37] T.L. Kauffman, F.R. Hauck, B. Mandleco, Development of a perinatal palliative care program, MCN Am. J. Matern Child Nurs. 35 (6) (2010) 343–349, https://doi.org/10.1097/NMC.0b013e3181f0fd0a.
[38] Y. Yan, J. Hu, F. Hu, L. Wu, The knowledge, attitude and behavior on the palliative care among neonatal nurses: what can we do, BMC Palliat. Care 23 (1) (2024) 164, https://doi.org/10.1186/s12904-024-01470-y.
[39] B. Brichard, M.L. Roux, B. de Terwangne, D. Bellis, N. Crasselts, M.C. Nassogne, C. Hocq, Perceptions and needs of NICU professionals regarding pediatric palliative care: a qualitative study compared with international literature, BMC Palliat. Care 24 (1) (2025) 256, https://doi.org/10.1186/s12904-025-01900-5.
[40] J.A. LoGiudice, O'Shea E. Perinatal palliative care: integration in a United States nurse midwifery education program, Midwifery 58 (2018) 117–119, https://doi.org/10.1016/j.midw.2017.12.024.
[41] C. Buskmiller, S. Ho, M. Chen, S. Gants, E. Crowe, S. Lopez, Patient-centered perinatal palliative care: family birth plans, outcomes, and resource utilization in a diverse cohort, Am. J. Obstet. Gynecol. MFM 4 (6) (2022) 100725, https://doi.org/10.1016/j.ajogmf.2022.100725.
[42] A. Chimenea, L. García-Díaz, A. Ferrari, et al., Perinatal palliative care: from fetal to neonatal life, BMJ Support. & Palliat. Care 14 (2024) e314–e315.
[43] P. Lago, M.E. Cavicchiolo, F. Rusalen, F. Benini, Summary of the key concepts on how to develop a perinatal palliative care program, Front Pedia 8 (2020) 596744, https://doi.org/10.3389/fped.2020.596744.
[44] C. Kenner, J. Press, D. Ryan, Recommendations for palliative and bereavement care in the NICU: a family-centered integrative approach, J. Perinatol. 35 1 (1) (2015 Dec) S19–S23, https://doi.org/10.1038/jp.2015.145.
[45] K.L. Meert, L. Keele, W. Morrison, R.A. Berg, H. Dalton, C.J. Newth, R. Harrison, D. L. Wessel, T. Shanley, J. Carcillo, A. Clark, R. Holubkov, T.L. Jenkins, A. Doctor, J. M. Dean, M. Pollack, Eunice Kennedy shriver national institute of child health and human development collaborative pediatric critical care research network. end-of-life practices among tertiary care picus in the united states: a multicenter study, Pedia Crit. Care Med 16 (7) (2015) e231–e238, https://doi.org/10.1097/PCC.0000000000000520.
[46] E.R. Currie, B.J. Christian, P.S. Hinds, S.J. Perna, C. Robinson, S. Day, K. Meneses, Parent perspectives of neonatal intensive care at the end-of-life, J. Pedia Nurs. 31 (5) (2016) 478–489, https://doi.org/10.1016/j.pedn.2016.03.023.
[47] K. Saint Denny, K. Lamore, J.L. Nandrino, S. Rethore, C. Prieur, S. Mur, L. Storme, Parents' experiences of palliative care decision-making in neonatal intensive care units: an interpretative phenomenological analysis, Acta Paediatr. 113 (5) (2024) 992–998, https://doi.org/10.1111/apa.17109.
[48] J. Jansens, K. Faes, M. De Coninck, J. Gilissen, L. Van Kelst, A qualitative study of bereaved parents and healthcare professionals on perinatal loss, Eur. J. Midwifery 8 (2024), https://doi.org/10.18332/ejm/194159.
[49] J.C. Cole, J.S. Moldenhauer, T.R. Jones, Milk donation after perinatal loss in a perinatal palliative care program, Breast Med 13 (6) (2018) 424–427, https://doi.org/10.1089/bfm.2017.0199.
[50] World Health Organization, WHO Recommendations on Maternal and Newborn Care for a Positive Postnatal Experience, WHO, Geneva, 2022.
[51] International Confederation of Midwives, ICM Essential Competencies for Midwifery Practice, International Confederation of Midwives, The Hague, 2024.
[52] J. Sandall, C. Fernandez Turienzo, D. Devane, et al., Midwife continuity of care models versus other models of care for childbearing women, Cochrane Database Syst. Rev. 4 (4) (2024) CD004667, https://doi.org/10.1002/14651858.CD004667.pub6.
[53] S. Egenberg, G. Skogheim, M. Tangerud, et al., Clinical decision-making during childbirth in health facilities from the perspectives of labouring women, relatives, and health care providers: A scoping review, Midwifery 140 (2025) 104192, https://doi.org/10.1016/j.midw.2024.104192.
[54] P.A. Murphy, T.L. King, Effective communication is essential to being with woman: midwifery strategies to strengthen health education and promotion, J. Midwifery Women's. Health 58 (3) (2013) 247–248, https://doi.org/10.1111/jmwh.12080.
[55] S. Pairman, K. Guilliland. Midwifery Partnership: A Model for Practice, 1st ed., New Zealand College of Midwives, Wellington, 2003.