



Barriers influencing nurses' attitudes towards palliative care in the neonatal intensive care unit: a scoping review

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Abstract

Objectives

To identify the barriers that influence nurses' attitudes towards palliative care in the neonatal intensive care unit.

Background

Neonatal nurses play a crucial role in caring for the newborn suffering from a complex chronic illness or who is at the end of life and needs palliative care. In the neonatal intensive care unit, the implementation of palliative care is inconsistent due to the existence of barriers that influence nurses' attitudes when faced with the need to make decisions related to newborns' end-of-life or the suspension of curative treatments.

Methods

Following the methodology designated by the Joanna Briggs Institute and the PRISMA-ScR as a complementary checklist, this scoping review was conducted in three phases and 10 databases were searched for relevant primary research studies, systematic reviews and meta-analyses, in English, Portuguese, French, and Spanish from 2016 to 2021. The data obtained through the extraction process were gathered in a table, and included the study characteristics, the population involved, the key findings related to the barriers influencing the nurses' attitudes towards the provision of palliative care in the neonatal unit and the instruments used to assess those attitudes.

Results

Sixteen studies met the inclusion criteria. The main barriers identified by the studies are related to the absence of training in palliative care, difficulty in communication with parents and between health professionals, and the absence of policies related to the provision of neonatal palliative care. The semi-structured interview has been the most common and widely used instrument for qualitative studies. Questionnaires were selected for quantitative studies, with the NiPCAS being the most commonly used in the NICU.

Conclusion

The barriers influencing nurses' attitudes towards the implementation of neonatal palliative care are identified by the scientific literature, however care remains inconsistent. The definition of training strategies and organizational policies can reduce the impact of barriers faced by neonatal nurses in the provision of palliative care.

Keywords

Attitudes; Barriers; Intensive Care Unit; Neonatal; Nurse; Palliative Care.

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Background

The survival of premature newborns at the limit of viability and other newborn with very serious pathology is due to the evolution of technical and scientific knowledge in the field of Neonatology. However, if survival rates are higher, the potential for well-being and a healthy life decreases due to morbidity, disability and complex chronic diseases (CCD) leading to unpredictable levels of health difficult to manage, which may influence the newborn development in the short, medium and long term.¹

Palliative care (PC) needs in the neonatal population are mainly important in situations of pre or postnatal diagnosis of life-limiting and/or life-threatening conditions (e.g. bilateral renal agenesis, anencephaly, trisomy 13 and 18...), when there is a high risk of morbidity or death (e.g. severe bilateral hydronephrosis, hypoplastic left heart syndrome, neurological disease...), when newborns are at the threshold of viability (22-23 weeks' gestational age), postnatal situations with high risk of sequelae and compromised quality of life (e.g., severe hypoxic-ischemic encephalopathy, severe peri-intraventricular haemorrhage), or postnatal situations causing great suffering and no possibility of cure (e.g., severe necrotizing enterocolitis) or no cure.² Thus, in the context of neonatal intensive care, it is necessary for health professionals, specifically nurses, to develop skills in palliative care (PC) in order to support the newborn and his/her family^{3,4} by providing holistic, active, and total family-centred care from diagnosis, throughout the newborn life, at death, and beyond. Neonatal palliative care (NPC) encompasses physical, emotional, developmental, social and spiritual elements, and focuses on enhancing the newborn quality of life and supporting the whole family, including management of distressing symptoms, end-of-life care and bereavement support.⁵

The decision to initiate PC to the newborn should involve the multidisciplinary team and consider the relevant facts related to the newborn clinical situation, the opinion of caregivers, including parents, and, if necessary, the opinion of an PC expert team and the Ethics Committee.⁶

The literature and practice show that the implementation of NPC is inconsistent⁷⁻⁹, often due to the emotional distress and ethical dilemmas that nurses experience when faced with the need to make decisions related to the newborn end-of-life or the suspension of curative treatments.^{4,10} The assessment of neonatal nurses' attitudes toward the implementation of NPC has been carried out through instruments that enabled researchers to identify barriers to the provision of NPC.^{3,11,12} Some of those barriers include human resources with inadequate ratios and lack of training in PC, an unfavourable physical environment, technological imperatives, difficulty in communication between team members and with parents, and unrealistic parental expectations.

The use of instruments highlights the impact that nurses' attitudes may have on the provision of palliative care for newborns, and enable the implementation of policies that help health professionals make consistent and holistic decisions in a constant search for improved quality of care.

A preliminary search conducted in the Joanna Briggs Institute Database of Systematic Reviews and Implementation Reports, Cochrane Library, MEDLINE and CINAHL, did not identify a scoping review on this topic. Scoping reviews aim to map the main concepts that underpin an area of research and the main sources and types of evidence available.^{13,14} Therefore, this approach was considered a useful way to map and examine the scientific evidence on the barriers influencing nurses' attitudes towards PC in NICU.

Aim

The aim of this scoping review is to identify and map the literature about the barriers that influence nurses' attitudes towards palliative care in neonatology.

This scoping review will focus specifically on the following questions:

What are the barriers that influence nurses' attitudes towards palliative care in neonatology?

What instruments have been used to assess nurses' attitudes toward palliative care in neonatology?

Methods

The scoping review strategy followed the recommendations of the Joanna Briggs Institute (JBI) methodology, namely, identification of research objective/s and question/s, developing the inclusion criteria, searching for the evidence, evidence selection, evidence extraction, analysis of the evidence, presentation of the results, summarizing and reporting results.^{14,15} The Covidence® software and the Preferred Reporting Items for Systematic Reviews extension for Scoping Reviews (PRISMA-ScR) reporting guideline and checklist¹⁶ were used to support data management. Assessment of methodological limitations or risk of bias of the evidence included within this scoping review was not performed because it is not generally recommended in scoping reviews.¹⁴ This study is registered in the Open Science Framework: osf.io/phcm7

Search Strategy

The search considered studies written in Portuguese, English, French and Spanish, published between 2016 and 2021. All scientific articles addressing the study objective of a quantitative, qualitative or mixed nature, and those unpublished (grey literature) were included.

In a first stage the search was limited to four databases, namely CINAHL Complete, MEDLINE Complete, COCHRANE Database of Systematic Reviews (via EBSCOhost), and Joanna Briggs Institute EBP Database via OVID, whereby analysing the words contained in the title and abstract of the studies, the indexing terms (MeSH 2020 descriptors and keywords) were identified. The second stage was carried out in the databases referred to in the first stage, as well as Academic Search Complete (via EBSCOhost), b-on, BioMed Central, Science Direct for Elsevier publications, PubMed, Scopus, and Biblioteca Virtual da

Saúde. In a third stage, the references of the identified documents were analysed in order to identify some additional bibliography. The literature search included the following combination of MeSH headings and Keywords searching: (“barriers”) AND (“nurse” OR “nurses” OR “nursing”) AND ((MM “palliative care”) OR (“end of life”)) AND ((MM “neonatal intensive care unit”) OR (“NICU”)). The CINAHL Headings descriptors used were (“barriers”) AND (MH “nurses+”) AND ((MM “palliative care”) OR (“end of life”)) AND ((MM “intensive care units, Neonatal”) OR (“NICU”)).

Eligibility

The eligibility criteria are described in table 1.

After the identification of the relevant studies, they were imported into the Covidence® software. Duplicates were removed using this software and, after applying the inclusion and exclusion criteria, the studies were screened, first by analysing the title and abstract, and, in a second phase, by reading the full text. The process of study selection and data extraction was independently performed by two reviewers and with a third reviewer who intervened whenever a conflict arose in the selection of studies.

Table 1 – Eligibility Criteria

| Eligibility criteria | |
|--|---|
| Inclusion Criteria | Exclusion Criteria |
| All studies in which the participants are nurses who provide care in the NICU. | All studies whose focus of interest is not on neonatal nurses. All studies whose participants include healthcare professionals other than neonatal nurses. |
| All studies whose phenomenon of interest is related to the barriers, challenges or any impediments influencing nurses' attitudes towards PC in the NICU. Studies exploring attitudes, perceptions, and experiences of neonatal nurses in relation to NPC. | |
| All studies developed at the NICU, regardless of their level of differentiation or complexity. | All studies whose context of care is not the NICU, such as in the Paediatric Intensive Care Unit or Hospices |
| Studies in English, Portuguese, French, and Spanish from 2016 to 2021. | |

Data extraction and synthesis

Following the JBI methodological guidance for scoping reviews on the data extraction instrument¹⁵, at the protocol stage the authors developed a charting table to register the information of the records, specifically the authors, country where the study was developed, year, title, aims, methodology and topics that would provide answers to PCC. Once the data extraction table was completed, the main key findings were extracted in a synthesis table (Table 2). This table contains the participants, the context, and the barriers identified as those influencing nurses' attitudes toward palliative care in the NICU and the instruments

used by the authors to assess these attitudes. The data extraction was performed by one reviewer, and a second one verified the extracted data. Where there was a conflict, a third reviewer intervened to ensure that the data extraction remained consistent with the objective and questions outlined. A word cloud was generated in order to extract the most relevant topics from the studies, and a narrative analysis was performed.

Table 2 - Synthesis table with key findings of the studies included in the review (n=16)

| 1 st Author Studies | Participants Context | Barriers | | | Instruments |
|------------------------------------|------------------------|---|--|--|---|
| | | Parents | Nurses | Health Institution | |
| Razeq, N. 2019/Jordan Quantitative | Nurses (n=289) NICU | Difficulty in interpreting Parents' attitudes | Insufficient time to make decisions; difficulty in establishing a prognosis | Lack of policies; conflicts between NICU policies and those of each professional | Parents' information and ethical decision making in neonatal intensive care units: staff attitudes and opinions |
| Forouzi, M. 2017/Iran Quantitative | Nurses (n=57) NICU | ----- | Inappropriate nurse/newborn ratio; absence of PC training | Inadequate environment; absence of protocols | Neonatal Palliative Care Attitude Scale (NiPCAS) |
| Beckstrand, R. 2019/USA Mixed | Nurses (n=121) NICU | Difficulty in communication with parents | Conflicts with parents; Inconsistency in medical staff decisions; therapeutic futility | Inadequate environment; lack of privacy | National Survey of NICU Nurses' Perceptions of End-of-Life Care |

| | | | | | |
|---|---------------------------|--|--|--|--|
| Chin, S. 2020/USA Mixed | Nurses (n=200) NICU | Non-inclusion of Parents in decisions; requirement for continuation of treatment | No understanding of the goals of neonatal PC; stigma; staff use life support technology beyond what is comfortable | Lack of support for neonatal PC by society; protocols; the physical environment of the NICU; lack of privacy | NIPCAS Questionnaire with open questions |
| Cerratti, F. 2020/Italy Quantitative | Nurses (n=347) NICU | Suboptimal communication between parents and healthcare professionals; families are not aware of neonatal palliative care options | Inability to share personal views; clinicians felt out of tune with parents' requests to prolong infants' lives; unsatisfactory previous experience in providing care in a palliative setting | Physical environment not appropriate; shortage of resources; for palliative care; lack of formal end-of-life policies and neonatal palliative care in-service education for staff | NIPCAS |
| Kilcullen, M. 2017/Australia Qualitative | Nurses (n=8) NICU | Family is far away from the hospital; no use of technology to communicate | Lack of experience in PC; emotional distress; difficulty in changing the model of care from curative to palliative | Lack of privacy; lack of recommendations, procedures and policies, absence of evaluation | Semi structured, individual interviews |
| Kim, S. 2019/ South Korea Qualitative | Nurses (n=20) NICU | Communication with parents; demands for the continuation of treatment; parental expectations | Lack of experience in PC; difficulty in supporting parents; conflicts about deciding between comfort care and curative care; therapeutic futility | Inadequate environment, lack of privacy; restriction of visits; performance of administrative functions | Semi structured, individual interviews |
| Oliveira, FC. 2018/Brazil Qualitative | Nurses (n=9) | ----- | Emotional distress; identification with families; lack of skills to provide PC; lack of education/formation; emotional disengagement, repression of feelings and thoughts, avoidance | Limited institutional support for PC; inconsistencies in hospital policies; lack of standardized PC and protocols | Semi structured, individual interviews |
| Gibson, K. 2018/Australia Review of the Literature | Nurses | Decisions made by parents to continue treatment; irrational expectations relating to the long- term outcomes of infants | Moral distress; sense of powerlessness; prolonged emotional involvement with families; avoidance; lack of knowledge, experience, and competence; lack of palliative care education | Inadequate environment; NICU guidelines on palliative care poorly reflect the values and ideals of staff or the community | |
| Kachlová, M. 2021/Czech Republic Quantitative | Nurses (n=109) UCIN | Parental demands to continue curative treatment | Lack of training in PC; lack of emotional support | Inadequate ratio of human resources; Inadequate environment; Lack of support for training | NiPCAS |
| Sadeghi, N. 2021/Iran Qualitative | Nurses (n=12) UCIN | Parents do not accept death of the infant; parents' presence | Inadequate ratio of nurses; emotional stress; medical indication for continue treatment | Inadequate environment | Semi-structured in- depth interviews |
| Salmani, N. 2018/Iran Review of the Literature | UCIN | Requirement for continuation of treatment; culture and religion | Health professionals' negative attitude toward death; religion; lack of training in PC; ethical dilemmas | Absence of training courses; Inadequate environment; low nurses/infant ratio | |
| Kim, S. 2017/South Korea Qualitative | Nurses (n=20) UCIN | Denying the infant's medical situation; discourage the creation of memories by grandparents | Emotional stress; beliefs and cultures; inadequate ratios; work overload | Absence of protocols and recommendations; inadequate environment; absence of team of specialists' in PC | Semi-structured interviews |
| Silva, I. 207/Brazil Qualitative | Nurses (n=8) UCIN | Parents not aware of palliative options | Lack of PC training; lack of dialogue between medical and nursing teams; impossibility of expressing opinions in end-of-life decisions | NICU organization; routines; dealing with the rules established by institutions | Semi-structured interviews |
| Silva, E. 2017/Portugal Qualitative | Nurses (n=15) UCIN | Conflicts with parents and between the couple; difficulty in decision-making | Lack of communication; inability to provide support; therapeutic boundaries; lack of consensus | Inadequate environment; lack of privacy; absence of protocols | Semi-structured interviews |

| | | | | | |
|--|--------------------|---|--------------------------------------|---|----------------------------|
| Carvalhois, M. 2019/Portugal Qualitative | Nurses (n=15) UCIN | Difficulty in decision-making; parents' suffering | Lack of PC training and PC education | Absence of protocols, recommendations; diminished psychological support | Semi-structured interviews |
|--|--------------------|---|--------------------------------------|---|----------------------------|

Results

Search Results

According to figure 1 (PRISMA 2020 flowchart of the study selection process), the search conducted in 10 databases identified 483 records. Of these, 75 records were removed by Covidence® for duplication. The screening of the title and abstract of the remaining 408 records was

performed and 370 were excluded for not meeting the inclusion criteria, leaving 38 reports for eligibility. After reading the full text, 22 reports were excluded for not meeting the inclusion criteria, namely the context, the population, and not making reference to the study design. Therefore, 16 studies were included in this scoping review.

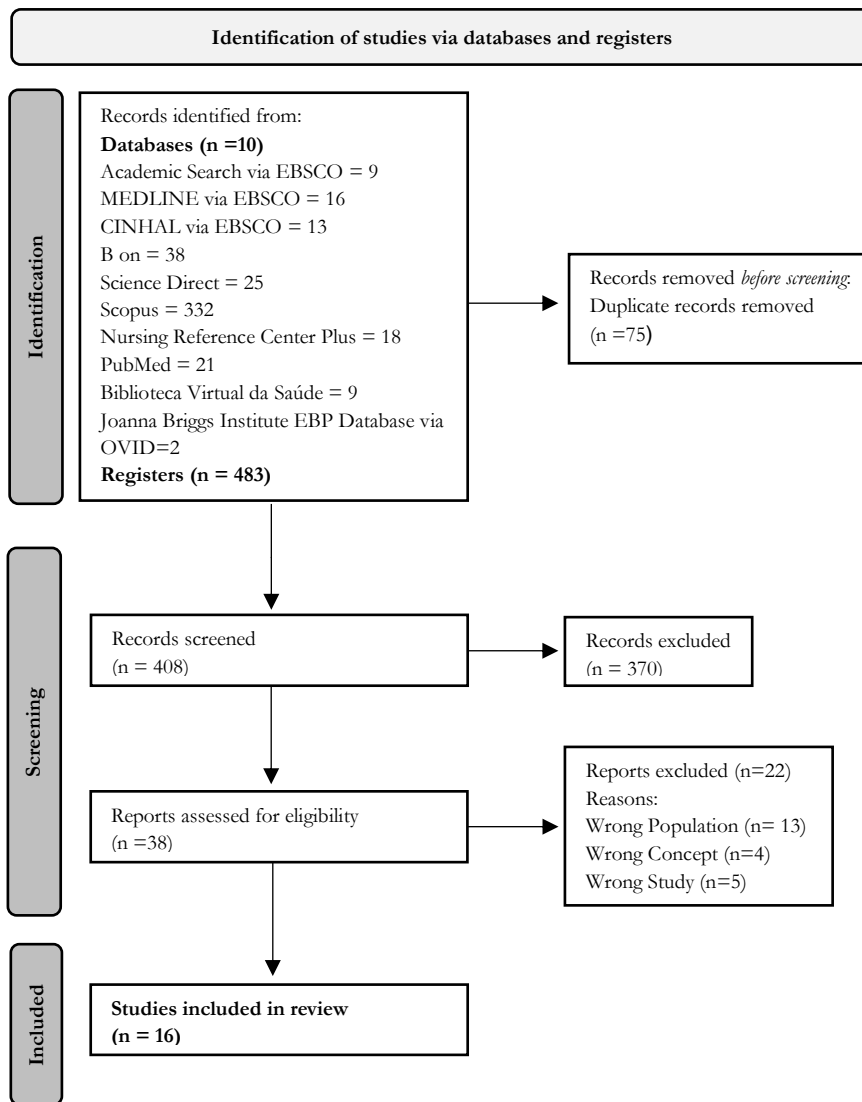


Figure 1 - PRISMA 2020 flowchart of the study selection process

Characteristics of the studies included

In relation to the year of publication, there was a continuum from 2016 to 2021. The year 2018 included 5 studies, 2017

and 2019 included 3 studies respectively, 2020 and 2021 with 2 studies respectively, and 2016 with only 1 study. The studies were conducted in European countries (n=4), North America (n=2), Middle East (n=4), South America (n=2),

Asia (n=2) and Oceania (n=2). The 16 studies analysed adopted as methodological strategy the qualitative approach (n=8) and the quantitative approach (n=4). Academic dissertations with a mixed approach (n=2) and Literature Reviews (n=2) were also identified. All studies elected the NICU as context, and nurses as participants (n=16). The main research objectives focused on exploring the experiences^{9,17-19}, perceptions, and^{3,20-22} attitudes²³⁻²⁶ of nurses towards the implementation of neonatal palliative care and the challenges^{24,27} or barriers that exist.

Thematic analysis

Using the NVivo® software, a thematic analysis of the 16 studies was carried out and four themes

(figure 2) emerged reflecting the barriers influencing nurses' attitudes towards palliative care in the neonatal intensive care unit, namely, (1) the nurses' experience in providing palliative care to newborn and their families; (2) the nurse's communication with the multidisciplinary team and parents; (3) the unfavourable conditions in which palliative care is provided, (4) the institutional and organizational support through the existence of protocols, guidelines, policies, and expert teams in palliative. A word frequency counts of the 16 studies included in the review was carried out, and a word cloud was generated (Figure 3). The most frequent topic was "experience" (0.54%), followed by "environment" (0.29%), "experiences" (0.28%), "healthcare" (0.24%), "guidelines" (0.18%) and "perceptions" (0.17%). These words reflect some barriers that may influence nurses' attitudes towards palliative care in the NICU.

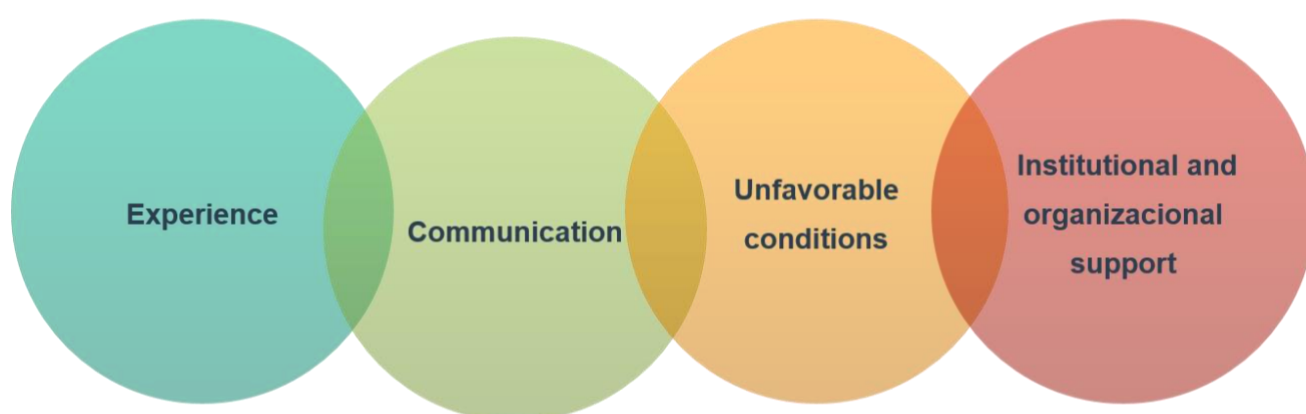


Figure 2 - Thematic analysis of the studies included in the scoping review (n=16)



Figure 3 - Word cloud analysis of studies included in the scoping review (n=16)

Instruments that enable the assessment of nurses' attitudes towards palliative care in the NICU

Regarding the second question, “*What instruments have been used to assess nurses' attitudes toward palliative care in neonatology?*”, from the analysis of the 16 studies included in the review, eight (n=8) used the interview to identify the barriers that influence nurses' attitudes toward NPC.^{3,7,17,19,21,22,29,30} Six studies used scales and questionnaires, namely *parents' information and ethical decision-making in neonatal intensive care units: staff attitudes and opinions*²⁴ (n=1), the *National Survey of NICU Nurses' Perceptions of End-of-Life Care*⁷ (n=1) and the *Neonatal Palliative Care Attitude Scale - NiPCAS*^{12,20,25,31} (n=4). *The Parents' information and ethical decision-making in neonatal intensive care units: staff attitudes and opinions* is a questionnaire dating from 1997 and was used as an instrument for the European study EURONIC.³² It was constructed to record data on the organization and NICU policies, to survey the opinions and attitudes of health professionals regarding the transmission of information to parents, and the ethical decision-making process in the NICU in relation to the social, cultural, legal and ethical backgrounds of different countries. The *National Survey of NICU Nurses' Perceptions of End-of-Life Care*, used in a mixed study, is a questionnaire aimed to identify nurses' perceptions of end-of-life care. It was based on four similar questionnaires applied to nurses in adult intensive care units, emergency departments, oncology units and paediatric intensive care units. The *Neonatal Palliative Care Attitude Scale - NiPCAS*¹¹ was developed to examine neonatal nurses' attitudes towards palliative care, attitudes which may constitute barriers or facilitators to PC in the NICU. It is a five-point scale (1 to 5) ranging from strongly disagree to strongly agree. It assesses three dimensions, namely organization, resources, and clinicians. This scale has been used in several studies, translated and validated for other countries^{12,25,31,33,34} and the results obtained are very similar, i.e., the barriers identified are related to the lack of training in PC, lack of communication with parents, lack of institutional support, the existence of an environment not conducive to the practice of PC and the imperatives related to technology.

Discussion

In the vast majority of studies, the barriers influencing nurses' attitudes towards palliative care in the NICU relate to lack of experience in providing NPC, lack of training, lack of skills/competencies in communicating with parents and among health professionals, difficulty in dealing with one's own emotions and difficulty in decision-making.

Not having experience in providing palliative care to the newborn, or having had bad experiences, may increase emotional stress and promote situations of avoidance and difficulty in communicating with the family.^{9,26,28}

Nurses' little experience in PC combined with lack of knowledge about the philosophy, principles, and practices of PC, is one of the barriers that influence their attitudes towards the implementation of palliative and support measures for the newborn and their family.^{3,9,19,30,31,35,36}

Therefore, nursing schools curricula³⁷, health services and institutions²⁷ should promote PC training at different levels and create a culture that promotes and supports the philosophy of PC^{3,9,38}, and nurses' professional and personal development.

As a very demanding and specific area, NPC requires theoretical education, technical preparation and training in order to ensure quality care that is culturally sensitive and meets the needs of the newborn and the family. There are recommendations³⁹ for nurses' training in the area of PC at basic, intermediate and specialized level. The purpose of this training is to understand the concept of PC, assess and manage the symptoms, pain, and discomfort experienced by newborn, children and young people, acquire communication skills with these age groups and their families, and understand suffering, the dying process, death, and grief. Obtaining knowledge on symptom control, namely pain control, is essential to ensure the comfort of the newborn and the reduction of parental stress. PC training provides tools and skills that allow demystifying the use of certain medications for pain relief in newborns, namely the use of opioids. The health team learns to recognize the signs and symptoms of pain and discomfort, objectively assesses the level of pain and justifies the use of opioid, analgesic and sedative drugs, promoting the quality of life of the newborn and his/her family and, finally, the reduction of the emotional distress of the health professionals caring for the triad.

Another key issue in training and acquisition of PC skills is communication of bad news, including those related to end-of-life. Nurses consider it a challenge and a complex intervention to give bad news to parents⁴⁰, a procedure causing emotional distress, but essential for decision-making centred on the needs of the parents and the newborn. Communication is the foundation stone of PC and family-centred care (FCC), and may be a barrier that influences the attitudes of nurses towards PC at the NICU since there may be conflicts between parents and the health team²², and within the health team itself.^{31,36–38} Language, culture, and religion of the parents (but also of the health professionals) may be an obstacle^{27,36}, hindering the transmission of information on the newborn clinical condition, diagnosis, and decision-making regarding curative versus palliative care options.³¹ Parents may not understand and accept the decision to initiate PC, demanding that active treatment and life support be continued^{22,27,36,38,41}, presenting to the healthcare team ethical dilemmas and emotional distress that may hinder the change from curative to palliative care. According to the FCC philosophy, the information parents receive should be consistent, honest, and realistic⁷, and parents should be incorporated into the definition of the anticipatory care plan^{4,30,34}, allowing them to adapt to difficult situations, as parental stress levels may decrease if the health team consistently adheres to FCC practice, reducing inconsistencies in the implementation of interventions and fostering the use of the “same language” by the health team.

Another theme described as a barrier influencing nurses' attitudes towards NPC is the unfavourable conditions in

which palliative care is provided.^{3,7,27,31,34–36,41} An unsuitable environment that does not allow for privacy^{3,7,23,25} is perceived by nurses as a barrier to the provision of palliative care. his/her family. The vast majority of NICUs are characterized by being a large, open space, where newborn, parents and health care team coexist, thus reducing the parents' privacy and comfort. The possibility of caring for newborn with PC in a room separate from the NICU would allow parents to enjoy the support of other relatives and also to release their emotions and feelings regarding the process of suffering that they are experiencing. However, this option would require structural and physical changes to the NICU itself and an increase in the nurse ratio, which may not be possible due to organizational issues.^{27,38} The shortage of nurses promotes a reduction in the nurse/newborn ratio, which makes it difficult for nurses to be available to accompany and be with parents, to respond to parental wishes and provide all the comfort care they need.^{12,18,27}

Institutional and organizational culture and support may be a barrier that influences nurses' attitudes towards the implementation of NPCs.

The absence or lack of recommendations, protocols, standards, and policies favours the ad hoc implementation of NPC^{42,43} because decision-making, tasks to be developed, and responsibilities in the different phases of the process depend on the attitude of each member of the healthcare team towards NPC^{3,9,17,41,44}, promoting inconsistency of care and increased stress for parents and health team. The lack of guidelines, protocols or organizational policies^{9,21,22,24,26} may promote situations where decision-making is not based on the needs of the newborn and his family.

The existence of recommendations, standards, and policies together with the possibility of consulting a team of experts in PC can reduce barriers and favour decision-making. Also, the hospital institutions should create an Intra-Hospital Paediatric Palliative Care Support Team, scaled to local characteristics and needs, which can provide direct care and guide in the execution of the individual care plan for children and young people in a situation of complex chronic illness and their families, whenever their intervention is requested.

One barrier associated with the implementation of NPC is related to the use of the word *end-of-life* and the effect it has on care provision. The word end-of-life^{7,17,19,30,35,44}, relates PC with dying and death. This relationship between PC and death promotes ethical dilemmas and moral distress in nurses²⁷, since they experience feelings of personal failure³⁷ in the face of death and parents' expectations and demands^{27,34,38,41}, adopting interventions related to therapeutic futility, therapeutic distress and the difficulty in changing the model of curative care to palliative care.^{7,19,30,34,41} However, the focus of NPC is not entirely on end-of-life and death, but rather on life and the possible transition of the newborn home. This way of being enables newborn and families to live their lives to the fullest while coping with complex medical conditions⁴⁵, promoting parenting and parental roles, positive experiences and

memories for the whole family for as long as life lasts.

Regarding the identified instruments, the interview is one of the techniques used in qualitative research and gather information about participants' experience and views. Knowing that providing NPC in neonatal unit can place an emotional burden on nurses, the interview is a suitable tool to explore the complex problems nurses experience in their practice and to understand how and why their attitudes impact the provision of palliative care.

With regard to quantitative studies, in this scoping review only one instrument was identified to assess nurses' attitudes towards palliative care in the NICU – NiPCAS.¹¹ The barriers to the provision of NPC, namely attitudinal, educational, environmental and institutional barriers, identified through the interview in studies with a qualitative approach are similar to the barriers identified by studies that used a quantitative approach using questionnaires or scales.

Limitations

In this scoping review only neonatal nurses were considered as participants and other health professionals were excluded, which may have offered a different perspective on the barriers influencing nurses' attitudes towards palliative care in neonatology. The content of some instruments, such as the interviews, was not available, so the analysis of the studies may have been incomplete.

Conclusion

This scoping review included 16 studies whose focus was on identifying the barriers influencing nurses' attitudes towards palliative care in the neonatal intensive care unit and the instruments that enable the assessment of nurses' attitudes towards palliative care in the NICU. Our findings reinforce the need for neonatal nurses to respond not only to technological demands, but also to the newborn and parent's personalized demands and to those posed to themselves as people. Neonatal nurses face a number of barriers that may influence their attitudes towards neonatal palliative care. The lack of experience and training in palliative care and the deficit of communication between the healthcare team and the one established with parents were considered to be the major barriers to the provision of neonatal palliative care. Thus, we may say that it is urgent and important to develop and boost training programmes related to palliative care, namely those directed to the area of neonatology, define policies and protocols that specify the tasks and responsibilities that each professional develops in the different phases of the care process, to reduce the moral distress and ethical dilemmas faced by nurses, decrease parental stress, and allow for interventions focused on the newborn and the family. Different instruments are used to assess nurses' attitudes towards neonatal palliative care, however, only one of these instruments is dedicated to the area of Neonatology. Further research with other health professionals is important to adjust interventions and promote the improvement of neonatal palliative care.

References

1. Wolke D, Johnson S, Mendonça M. The Life Course Consequences of Very Preterm Birth. *Annu Rev Dev Psychol* [Internet] 2019 [cited 2021 Jan 15];1(1):69–92. Available from: <https://www.annualreviews.org/doi/abs/10.1146/annurev-devpsych-121318-084804>
2. Sataloff RT, Johns MM, Kost KM. Integrating palliative care and symptom relief into paediatrics: a WHO guide for health care planners, implementers and managers. [Internet]. Geneva: World Health Organization; 2018 [cited 2021 Mar 27]. Available from: <https://www.who.int/health-topics/palliative-care>
3. Kilcullen M, Ireland S. Palliative care in the neonatal unit: Neonatal nursing staff perceptions of facilitators and barriers in a regional tertiary nursery. *BMC Palliat Care* [Internet] 2017 [cited 2021 Jan 3];16(1):1–12. Available from: <https://widgets.ebscohost.com/prod/customerspecific/ns000290/authentication/index.php?url=https%3A%2F%2Fsearch.ebscohost.com%2Flogin.aspx%3Fdirect%3Dtrue%26AuthType%3Dip%2Cshib%2Cuid%26db%3Dcmedm%26AN%3D28490381%26lang%3Dpt-pt%26site%3Dedslive%26scope%3D>
4. Quinn M, Gephart S. Evidence for Implementation Strategies to Provide Palliative Care in the Neonatal Intensive Care Unit. *Adv Neonatal Care* (Lippincott Williams Wilkins) [Internet] 2016 [cited 2021 Jan 3];16(6):430–8. Available from: <https://pubmed.ncbi.nlm.nih.gov/27775989/>
5. Dickson G. A Perinatal Pathway for Babies with Palliative Care Needs [Internet]. Bristol: 2017 [cited 2021 Mar 27]. Available from: www.togetherforshortlives.org.uk
6. Alshehri H, Olausson S, Öhlén J, Wolf A. Factors influencing the integration of a palliative approach in intensive care units: A systematic mixed-methods review. *BMC Palliat Care* [Internet] 2020 [cited 2021 Feb 20];19(1). Available from: https://www.researchgate.net/publication/343148653_Factors_influencing_the_integration_of_a_palliative_approach_in_intensive_care_units_a_systematic_mixed-methods_review/link/5fc235aca6fdcc6cc677c24f/download
7. Beckstrand RL, Isaacson RF, Macintosh JLBB, Luthy KE, Eden L. NICU Nurses' Suggestions for Improving End-of-Life Care Obstacles. *J Neonatal Nurs* [Internet] 2019 [cited 2021 Jan 7];25(1):32–6. Available from: <https://www.scopus.com/inward/record.uri?eid=2-s2.0-85054506367&doi=10.1016%2Fj.jnn.2018.08.004&partnerID=40&md5=090eca08aea9a90f01877bd0680cd41>
8. Kain V, Wilkinson D. Neonatal palliative care in action: Moving beyond the rhetoric and influencing policy. *J Res Nurs* [Internet] 2013 [cited 2021 Feb 5];18(5):459–68. Available from: https://www.researchgate.net/publication/258155898_Neonatal_palliative_care_in_action_Moving_beyond_the_rhetoric_and_influencing_policy
9. Oliveira F, Cleveland L, Darilek U, Silva A, Carmona E. Brazilian Neonatal Nurses' Palliative Care Experiences. *J Perinat Neonatal Nurs* [Internet] 2018;32(4):E3–10. Available from: https://www.researchgate.net/publication/328499453_Brazilian_Neonatal_Nurses'_Palliative_Care_Experiences
10. Martin M. Missed opportunities: A case study of barriers to the delivery of palliative care on neonatal intensive care units. *Int J Palliat Nurs* [Internet] 2013 [cited 2021 Jan 20];19(5):251–6. Available from: https://www.researchgate.net/publication/256098015_Missed_opportunities_A_case_study_of_barriers_to_the_delivery_of_palliative_care_on_neonatal
11. Kain V, Gardner G, Yates P. Neonatal palliative care attitude scale: Development of an instrument to measure the barriers to and facilitators of palliative care in neonatal nursing. *Pediatrics* 2009;123(2).
12. Forouzi A, Banazadeh M, Ahmadi R. Barriers of Palliative Care in Neonatal Intensive Care Units: Attitude of Neonatal Nurses in Southeast Iran. *Am J Hosp Palliat Med* 2017;34(3):205–11.
13. Arksey H, O'Malley L. Scoping studies: Towards a methodological framework. *Int J Soc Res Methodol Theory Pract* 2005;8(1):19–32.
14. Peters MDJ, Marnie C, Tricco AC, Pollock D, Munn Z, Alexander L, et al. Updated methodological guidance for the conduct of scoping reviews. *JBIEvid Synth* [Internet] 2020;18(10):2119–26. Available from: https://journals.lww.com/jbisrrr/Fulltext/2020/10000/Updated_methodological_guidance_for_the_conduct_of_a.4.aspx
15. Peters M, Godfrey C, McInerney P, Munn Z, Tricco A, Khalil H. Scoping Reviews. In: Aromataris E MZ, editor. *JBIE Manual for Evidence Synthesis*. JBI; 2020. page 406–51.
16. Tricco A, Lillie E, Zarin W, O'Brien K, Colquhoun H, Levac D, et al. PRISMA extension for scoping reviews (PRISMA-ScR): checklist and explanation. *Ann Intern Med* 2018;169(7):467–73.
17. Pereira A. End of life in neonatology: experiences of health professionals in neonatal palliative care. *Millenium - J Educ Technol Heal* [Internet] 2019 [cited 2021 Jan 5];2(9):91–8. Available from: <https://revistas.rcaap.pt/millenium/article/view/17098>

18. Sadeghi N, Hossein H, Seyyd A, Sadeghi S, Sadeghi M. Barriers to Palliative Care in the Neonatal Intensive Care Unit from Nurses' Perspective: A Qualitative Study. *Medical-Surgical Nurs J* [Internet] 2021;10(2):1–8. Available from: <https://search.ebscohost.com/login.aspx?direct=true&AuthType=ip.shib&db=ccm&AN=153832714&lang=pt-pt&site=ehost-live>
19. Kim S, Savage TA, Song M-KMK, Vincent C, Park CG, Ferrans CE, et al. Nurses' roles and challenges in providing end-of-life care in neonatal intensive care units in South Korea. *Appl Nurs Res* [Internet] 2019 [cited 2021 Jan 7];50(October):151204. Available from: <https://www.scopus.com/inward/record.uri?eid=2-s2.0-85074521131&doi=10.1016%2Fj.apnr.2019.151204&partnerID=40&md5=9d54a24d6a5f3ca9ccd8de7c9ea15e18>
20. Chin S, Paraszczuk A, Eckardt P, Bressler T. Neonatal Nurses' Perceptions of Palliative Care in the Neonatal Intensive Care Unit. *MCN Am J Matern Child Nurs* [Internet] 2021;46(5):250–7. Available from: <https://search.ebscohost.com/login.aspx?direct=true&AuthType=ip.shib&db=ccm&AN=152213416&lang=pt-pt&site=ehost-live>
21. Kim S. Nurses' Perceptions of End-of-Life Care Practice in Korean Neonatal Intensive Care Units. *Nurses' Perceptions End-of-Life Care Pract Korean Neonatal Intensive Care Units* [Internet] 2017;1. Available from: <https://search.ebscohost.com/login.aspx?direct=true&AuthType=ip.shib&db=ccm&AN=130413253&lang=pt-pt&site=ehost-live>
22. Silva E, Silva M, Silva D. Perception of health professionals about neonatal palliative care. *Rev Bras Enferm* [Internet] 2019 [cited 2021 Jan 7];72(6):1707–14. Available from: <https://www.scielo.br/pdf/reben/v72n6/0034-7167-reben-72-06-1707.pdf>
23. Azzizadeh Forouzi M, Banazadeh M, Ahmadi JS, Razban F. Barriers of Palliative Care in Neonatal Intensive Care Units. *Am J Hosp Palliat Med* 2017;34(3):205–11.
24. Abdel Razeq NM, Razeq A, Nadin M, Abdel Razeq NM. End-of-life Decisions at Neonatal Intensive Care Units: Jordanian Nurses Attitudes and Viewpoints of Who, When, and How. *J Pediatr Nurs* [Internet] 2019 [cited 2021 Jan 7];44(xxxx):e36–44. Available from: <https://search.ebscohost.com/login.aspx?direct=true&AuthType=ip.shib&db=ccm&AN=134252881&lang=pt-pt&site=ehost-live>
25. Kachlová M, Bužgová R. The attitudes of neonatological nurses to providing perinatal palliative care. *Kontakt* [Internet] 2021;23(4):240–6. Available from: <https://www.scopus.com/inward/record.uri?eid=2-s2.0-85124468341&doi=10.32725%2Fkont.2021.036&partnerID=40&md5=e0a5fb97ab8520b6fdafc8a199281824>
26. Cerratti F, Tomietto M, Della Pelle C, Kain V, Di Giovanni P, Rasero L, et al. Italian Nurses' Attitudes Towards Neonatal Palliative Care: A Cross-Sectional Survey. *J Nurs Scholarsh* [Internet] 2020;52(6):661–70. Available from: <http://10.0.4.87/jnu.12600>
27. Salmani N, Rassouli M, Mandegari Z, Bagheri I, Tafti BF. Palliative Care in Neonatal Intensive Care Units: Challenges and Solutions. *Iran J Neonatol* [Internet] 2018;9(2):33–41. Available from: <http://10.0.86.22/iin.2018.25521.1337>
28. Gibson K, Hofmeyer A, Warland J, Ahern K. Nurses Providing End-of-Life Care for Infants and Their Families in the NICU: A Review of the Literature. *Adv Neonatal Care (Lippincott Williams Wilkins)* [Internet] 2018;18(6):471–9. Available from: <https://search.ebscohost.com/login.aspx?direct=true&AuthType=ip.shib&db=ccm&AN=134450524&lang=pt-pt&site=ehost-live>
29. Oliveira F, Cleveland L, Darilek U, Borges Silva AR, Carmona E. Brazilian Neonatal Nurses' Palliative Care Experiences. *J Perinat Neonatal Nurs* [Internet] 2018;32(4):E3–10. Available from: <https://www.scopus.com/inward/record.uri?eid=2-s2.0-85055611682&doi=10.1097%2FJPN.0000000000000361&partnerID=40&md5=058f74ad287e620ff160380043d644d8>
30. Silva IN, Salim NR, Szylyt R, Sampaio PSS, Ichikawa CR de F, Santos MR dos. Knowing nursing team care practices in relation to newborns in end-of-life situations. *Esc Anna Nery* 2017;21(4):1–9.
31. Cerratti F, Tomietto M, Della Pelle C, Kain V, Di Giovanni P, Rasero L, et al. Italian Nurses' Attitudes Towards Neonatal Palliative Care: A Cross-Sectional Survey. *J Nurs Scholarsh* [Internet] 2020 [cited 2021 Jan 7];52(6):661–70. Available from: <https://doi.org/10.1111/jnu.12600>
32. Cuttini M, Nadai M, Kaminski M, Hansen G, De Leeuw R, Lenoir S, et al. End-of-life decisions in neonatal intensive care: Physicians' self-reported practices in seven European countries. *Lancet* [Internet] 2000 [cited 2021 Feb 23];355(9221):2112–8. Available from: <https://pubmed.ncbi.nlm.nih.gov/9373868/>
33. Jung HN, Ju HO. Comparison of the Attitudes of Nurses and Physicians toward Palliative Care in Neonatal Intensive Care Units. *Korean J Hosp Palliat Care* [Internet] 2021;24(3):165–73. Available from: <http://10.0.56.139/jhpc.2021.24.3.165>

34. Kyc SJ, Bruno CJ, Shabanova V, Montgomery AM. Perceptions of Neonatal Palliative Care: Similarities and Differences between Medical and Nursing Staff in a Level IV Neonatal Intensive Care Unit. *J Palliat Med* [Internet] 2020 [cited 2021 Jan 7];23(5):662–9. Available from: <https://pubmed.ncbi.nlm.nih.gov/31808706/>
35. Nurse S, Price J. ‘No second chance’ – Junior neonatal nurses experiences of caring for an infant at the end-of-life and their family. *J Neonatal Nurs* [Internet] 2017 [cited 2021 Jan 7];23(2):50–7. Available from: <http://dx.doi.org/10.1016/j.jinn.2016.04.008>
36. Dombrecht L, Piette V, Deliens L, Cools F, Chambaere K, Goossens L, et al. Barriers to and Facilitators of End-of-Life Decision Making by Neonatologists and Neonatal Nurses in Neonates: A Qualitative Study. *J Pain Symptom Manag* [Internet] 2020 [cited 2021 Jan 7];59(3):599. Available from: <http://10.0.3.248/j.painsymman.2019.10.007>
37. Marc-Aurele KL, English NK. Primary palliative care in neonatal intensive care. *Semin Perinatol* [Internet] 2017 [cited 2021 Jan 3];41(2):133–9. Available from: <http://dx.doi.org/10.1053/j.semperi.2016.11.005>
38. Ismail MSM, Mahrous E, Mokbel RA, S. Mahrous E, Mokbel RA. Facilitators and Barriers for Delivery of Palliative Care Practices among Nurses in Neonatal Intensive Care Unit. *Int J Nurs Heal Sci* [Internet] 2020 [cited 2021 Jan 5];6(01):18–28. Available from: https://www.researchgate.net/publication/339377481_Facilitators_and_Barriers_for_Delivery_of_Palliative_Care_Practices_among_Nurses_in_Neonatal_Intensive_Care_Unit
39. World Palliative Care Alliance. Global atlas of palliative care at the end of life [Internet]. 2nd ed. London: 2014 [cited 2021 Feb 10]. Available from: <http://www.who.int/cancer/publications/palliative-care-atlas/en/>
40. Marçola L, Zoboli I, Polastrini R, Barbosa S. Breaking bad news in a Neonatal Intensive Care: the parent’s evaluation. *Rev Paul Pediatr* [Internet] 2020 [cited 2021 Mar 15];38:6. Available from: https://www.scielo.br/pdf/rpp/v38/pt_1984-0462-rpp-38-e2019092.pdf
41. Chin SDN. Neonatal Nurses’ Perceptions of Providing Palliative Care in the Neonatal Intensive Care Unit. 2020;
42. Catlin A, Carter B. Creation of a neonatal end-of-life palliative care protocol. *J Perinatol* [Internet] 2002 [cited 2021 Jan 5];22(3):184–95. Available from: <https://www.nature.com/articles/7210687.pdf>
43. Carter BS. Providing palliative care for newborns. *Pediatr Ann* [Internet] 2004 [cited 2021 Jan 5];33(11):770–7. Available from: https://www.researchgate.net/publication/8167038_Providing_Palliative_Care_for_Newborns
44. Razeq A, Nadin M. End-of-life Decisions at Neonatal Intensive Care Units: Jordanian Nurses Attitudes and Viewpoints of Who, When, and How. *J Pediatr Nurs* [Internet] 2019 [cited 2021 Jan 7];44:e36–44. Available from: <https://doi.org/10.1016/j.pedn.2018.10.014>
45. Himelstein BP. Palliative care for infants, children, adolescents, and their families. *J Palliat Med* [Internet] 2006 [cited 2021 Feb 15];9(1):163–81. Available from: https://www.researchgate.net/publication/7343352_Palliative_Care_for_Infants_Children_Adolescents_and_Their_Families