

STRATEGIES FACED SITUATIONS OF TERMINALITY AND DEATH IN NEONATAL INTENSIVE CARE: NURSING PERSPECTIVES

ESTRATÉGIAS FRENTE SITUAÇÕES DE TERMINALIDADE E MORTE EM TERAPIA INTENSIVA NEONATAL: PERSPECTIVAS DA ENFERMAGEM

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ABSTRACT: The objective of this study was to analyze the scientific evidence on strategies used by the nursing team when facing situations of terminality and death in the Neonatal Intensive Care Unit. This was an integrative literature review conducted in September and October 2024 in the MEDLINE, PubMed, SCOPUS, EMBASE, Integrated BVS, Web of Science, and CINAHL databases, including original articles carried out in neonatal intensive care units, available online, with no time or language restrictions. A total of 26 studies were analyzed, predominantly quantitative, and the evidence highlighted the conceptual differentiation between end-of-life care and palliative care, the importance of continuing health education for professional preparedness, and the individual and collective strategies adopted by the nursing team to cope with these situations. The findings point to the need for permanent health education for professionals and for the parents and families of neonates, as well as the importance of collective coping, multiprofessional action, inclusion of spirituality, open dialogue, and the implementation of care protocols.

KEYWORDS: Nursing Team. Perinatal Death. End-of-Life Care. Intensive Care Units.

RESUMO: O objetivo foi analisar as evidências científicas de estratégias utilizadas pela equipe de enfermagem frente situações de terminalidade e morte em Unidade de Terapia Intensiva Neonatal. Revisão Integrativa de literatura realizada em setembro/outubro de 2024 nas bases MEDLINE; PubMed; SCOPUS; EMBASE; BVS integrada; *Web of Science* e CINAHL. Incluíram-se artigos originais realizados em Unidade de Terapia Intensiva neonatal, disponíveis on-line, sem recorte temporal e idiomático. Foram analisados 26 estudos, majoritariamente quantitativos, em que as evidências apontaram a diferenciação conceitual entre cuidados de fim de vida e cuidados paliativos; a importância da educação permanente em saúde para o preparo dos profissionais; e as estratégias individuais e coletivas da equipe de enfermagem para o enfrentamento destas situações. Aponta-se a necessidade de educação permanente em saúde com os profissionais e com os pais/familiares dos neonatos, a importância do enfrentamento coletivo, atuação multiprofissional, incluindo a espiritualidade, diálogo e implementação de protocolos assistenciais.

PALAVRAS-CHAVE: Equipe de Enfermagem. Morte Perinatal. Terminalidade. Unidades de Terapia Intensiva.

INTRODUCTION

It is well known that, in hospitals, death is a frequent occurrence among patients admitted to intensive care units (ICUs).¹ In the specific context of neonatal ICUs (NICUs), data indicate that death rates have been declining recently. However, it should be noted that most deaths still occur after life support is withdrawn, representing an increase compared to previous decades. In addition, there has been a reduction in deaths due to chromosomal abnormalities, complications related to prematurity, and severe neonatal asphyxia.²

Globally, from 1990 to 2019, the number of deaths from neonatal disorders decreased by 37.38%, particularly in Central Europe and East Asia.³ In Brazil, this downward trend was also identified in early and late neonatal mortality⁴. However, reducing neonatal mortality from preventable causes remains one of the key highlights in promoting well-being and health. It is one of the Sustainable Development Goals in Brazil, as outlined in the 2030 Agenda⁵.

Still in the Brazilian context, there are ministerial initiatives already implemented to improve maternal and child health conditions, focusing on ensuring access to quality health care in prenatal, childbirth, and postpartum care, resulting in the prevention of complications in the neonatal period, such as the *Rede Cegonha* (Stork Network)⁶, highlighting the importance of health promotion and disease prevention in the impact of outcomes in neonatal intensive care. However, even with measures to combat mortality, it is noted that Brazil still has significant rates of newborns with serious illnesses in the daily routine of NICUs, especially extreme prematurity, low birth weight, and congenital malformations.⁷

In this perspective, caring for newborns (NBs) admitted to NICUs becomes especially challenging, since technological advances have enabled the survival of babies with congenital diseases, birth sequelae, prematurity, and chronic medical conditions. Given this scenario, working in the process of terminal care and neonatal death requires preparation and sensitivity for the healthcare team.⁸ Given the above, nurses play a central role in conducting the terminal care process and in supporting families before, during, and after the death of the NB.⁸

In this role, nursing professionals must develop strategies to cope with the process of terminal illness and the death of newborns, both individually and collectively. At the individual level, strategies include mechanisms of acceptance, consolation, silence, avoidance, isolation, denial, and helplessness. At the collective level, as a nursing team, strategies may involve spirituality, dialogue, and multidisciplinary collaboration.⁹

However, it is observed that research on this study primarily focuses on the types of care provided by nursing professionals in NICUs, such as end-of-life care and palliative care (PC). However, there are gaps in scientific production regarding the strategies used by these professionals, both individually and collectively, when faced with terminal situations and death, especially when related to the critical and sensitive environment of the NICU.

It is assumed that scientific evidence recommended for nursing practice in NICUs has the potential to minimize the effects of loss on nursing staff and contribute to the promotion of healthy work environments. Given the above, this study aims to analyze the scientific evidence of strategies used by nursing staff when dealing with terminal situations and death in NICUs.

METHODOLOGY

TYPE OF STUDY

This is an integrative literature review (ILR), which enables the synthesis of results from multiple studies related to a specific problem, thereby contributing to a more profound understanding of the researched topic and facilitating informed decision-making. Furthermore, it is defined as a research method derived from secondary data in which studies related to the topic are summarized, allowing general conclusions to be drawn from the compilation of several studies.¹⁰

The study went through five stages, which were identification of the theme and formulation of the review question; establishment of criteria for inclusion and exclusion of articles; selection process and definition of the information to be extracted from the selected articles/categorization; evaluation; interpretation of the results; and synthesis of the evidence.¹⁰

To ensure the methodological rigor necessary for a critical and reliable report of the results, the recommendations of the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) were followed.

IDENTIFYING THE TOPIC AND DRAFTING THE REVIEW QUESTION

The guiding question for this review was defined in accordance with the chosen theme and study objective¹⁰, and was developed based on the PICO acronym, as shown in Chart 1.

Chart 1. PICO strategy for developing the research question.

Acronym	Definition	Description
P	Population	Nursing team
I	Phenomenon of Interest	Terminality and death situations
Co	Context	Neonatal Intensive Care Units

Source: The authors.

In this regard, the following review question was outlined: “What strategies are used by the nursing team when faced with terminal and death situations in the Neonatal Intensive Care Unit?”

ESTABLISHMENT OF CRITERIA FOR INCLUSION AND EXCLUSION OF STUDIES

The inclusion criteria were original articles (from primary studies) conducted in a neonatal ICU setting, available in electronic format online, and that addressed the review question. The exclusion criteria were articles from secondary sources (review studies, theoretical studies, reflections, opinion articles), editorials, and letters to the editor. Duplicate articles were counted only once. There were no time or language restrictions.

MAPPING TERMS AND DEFINING INFORMATION SOURCES

To operationalize the searches, controlled and uncontrolled terms were defined and extracted from the Health Sciences Descriptors (DeCS) vocabulary: “Nursing Team,” “Perinatal Death,” “Terminality,” and “Neonatal Intensive Care Units”; and Medical Subject Headings (MESH): “Nursing, Team,” “Terminal Care,” “Death,” and “Intensive Care Units, Neonatal,” using their respective synonyms and entry terms. The terms were searched in the databases mentioned above using a combination of the Boolean operators “OR” and “AND”.

The search was conducted in September/October 2024, using specific advanced strategies in the following data sources: Medical Literature and Retrieval System Online (MEDLINE), PubMed; SCOPUS (Elsevier); EMBASE (Elsevier); Integrated Virtual Health Library (BVS); Web of Science Core Collection (Clarivate analytics) and CINAHL (EBSCO), with the number of references found in each database being 89, 269, 3, 191, and 3, respectively.

PROCESS OF SELECTING AND DEFINING THE INFORMATION TO BE EXTRACTED FROM THE SELECTED STUDIES/CATEGORIZATION

First, the titles and abstracts (phase 1) of all items that responded to the primary search were read. Subsequently, the full texts were read (phase 2). Reference management was performed in *Rayyan* for the screening and selection of relevant studies. The study selection process was carried out in a double-blind manner, with access to a third review in cases of disagreement. This phase is represented in Figure 1.

For the studies' categorization phase, a synoptic table (Chart 2) was developed using Microsoft Word 2010, which contained variables related to the references and characterized the articles according to these variables.

EVALUATION, INTERPRETATION OF THE RESULTS, AND SYNTHESIS OF THE KNOWLEDGE OBTAINED

This phase required an organized and orderly approach to the evidence. The information in the databases was analyzed systematically and rigorously, following selection criteria based on the research question and the inclusion and exclusion criteria for articles.¹⁰

The Evidence Levels (EL) of the primary studies were classified according to the type of clinical question addressed by the studies. Thus, four classifications of evidence levels were considered for the analysis: treatment/intervention (when the research question is focused on the evaluation of a clinical health intervention); diagnosis/testing (when the research question is focused on verifying a particular phenomenon or exposure); prognosis, prediction, or etiology (when the research question is intended to infer the etiology or probability of specific outcomes occurring); and meaning (when the research question is focused on understanding experiences surrounding the disease or the feelings involved).¹¹

The results were presented through descriptive analysis, including absolute (N) and relative (%) frequencies, as well as a narrative summary. The results listed in the summary table were analyzed to identify the main thematic categories. At this stage, the categorization process was also carried out, aligning the results with the research objectives.

As the research did not involve human beings, it was not necessary to obtain approval from the Ethics Committee; however, the copyright and reliability of the selected works were respected.

The methodological flowchart illustrating the process of synthesizing the search and mapping the eligible and included scientific productions according to PRISMA is shown in Figure 1.

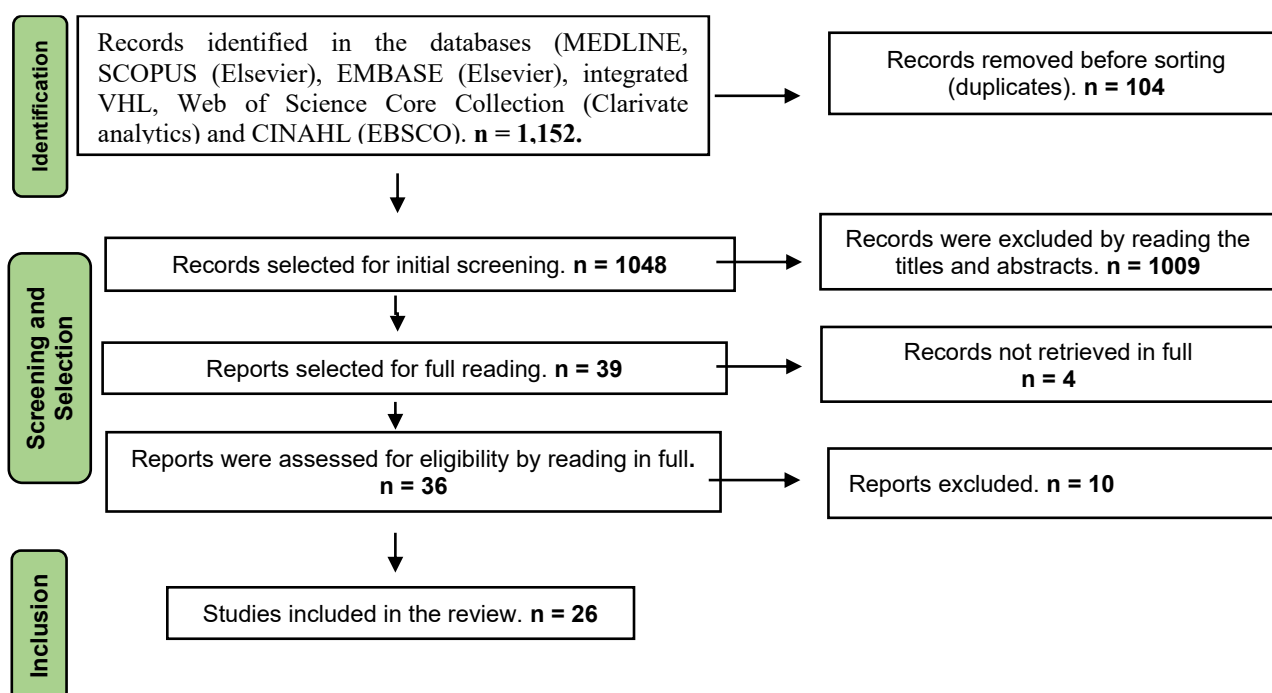


Figure 1. Flowchart for selecting scientific productions for the review, adapted from the Preferred Reporting Items for Systematic Review and Meta-Analyses (PRISMA). Source: the authors.

RESULTS

Of the total studies found, 26 met the eligibility criteria and were selected to compose the corpus of the integrative review. Regarding the geographical location of the 26 studies included in this review, the United States of America^{1,12-19} (34.6%; n=9) prevailed, followed by Australia^{8,20,21} (11.5%; n=3). Brazil^{9,22}, Korea^{23,24}, and Taiwan^{25,26} had two studies each (7.7%; n=2 each). The United Kingdom², Jordan²⁷, Canada²⁸, Croatia²⁹, the Netherlands³⁰, Portugal³¹, the Iberian Peninsula³², and Iran³³ each had one study (3.85%; n=1 each).

Regarding the year of publication of the studies, production began in 1984¹⁵, followed by 2004¹⁶, 2006²¹, 2008^{18,20}, 2011³¹, 2012²⁶, 2013²², with a significant concentration between 2015 and 2016^{8,9,14,17,19,28} (23%; n=6). Furthermore, there has been a growing trend in publications about this study over the last five years (2018-2024)^{1,2,12,13,23-25,27,29,30,32,33}, with the most recent publications on the subject concentrated in this period (46%; n = 12).

Regarding methodological designs, quantitative cross-sectional studies (57.7%; n = 15) and qualitative studies (42.3%; n = 11) were employed. Regarding Levels of Evidence (LE), the studies predominantly presented clinical questions focused on prognosis, prediction, or etiology with LE=IV^{2,13-17,20,21,24,26,27,30-33} (57.7%; n=15) and LE=II^{1,8,9,12,18,19,22,23,25,28,29} (42.3%; n=11).

Based on the analysis of the studies, considering objectives, results, and conclusions, three thematic categories were listed, namely: conceptual differentiation between end-of-life care and palliative care; the importance of continuing education in health; individual and collective strategies of the nursing team when faced with terminal illness and death in neonatal intensive care; and procedures performed by the nursing team when faced with terminal illness and death in neonatal intensive care.

Chart 2. Characterization of the corpus in terms of objective and main results (N=26).

Cod.	Objective	Main results (strategies of the nursing team in the face of terminality and death in neonatal intensive care)
A1	Analyze the use of palliative care in pediatric intensive care nursing.	- Prenatal palliative care can help parents make decisions when a life-threatening diagnosis is presented or a disease-modifying treatment for a chronic condition no longer provides benefit. - The clinical information that care teams may find upsetting is the information parents need to make effective decisions about their child's care.
A2	Describe the efforts of the End-of-Life Nursing Education Consortium (ELNEC) project and its Pediatric Curriculum to provide this education and describe the efforts of nurses to implement the training in practice settings.	- The ELNEC Pediatric Palliative Care (ELNEC-PPC) project is a train-the-trainer educational program and evidence-based curriculum. - Conducting an online course or training on symptom management, care at the time of death, and bereavement support for families. - Implement the curriculum to improve care.
A3	Develop a family-centered end-of-life care protocol and evaluate its feasibility.	- The 71-item protocol was based on an integrated model of end-of-life care and the concept of family-centered care, consisting of main guidelines, communication during end-of-life care, and five sub-stages according to changes in a baby's condition. - The protocol was feasible and improved nurses' competence and attitude in providing end-of-life care for babies and their parents. It also had a positive impact on the well-being of parents who had suffered the loss of their babies in neonatal intensive care units and improved family-centered care within the units.
A4	To examine how clinical decisions are made at the end of life for NBs with specific fatal and disabling conditions in NICUs in Jordan, from the perspectives of neonatal health professionals.	- Doctors were the central decision-makers at the end of NB's life in 83% of situations. - Parents, nurses, ethics committees, and NICU managers were less involved. - Age, importance of religion, having children of their own and involvement in research activities were factors that significantly predicted nurses' perceived levels of involvement in decision-making.
A5	To explore how end-of-life care is carried out in NICUs in Ibero-America.	- 86% of neonatal nursing professionals are responsible for providing end-of-life care, although 48% of them said they had received no training on the subject. - Need for investment in care protocols: only 17% say that the NICU where they work has a protocol for carrying out end-of-life care. - The actions implemented during end-of-life care are globally infrequent in all the items explored and very infrequent concerning allowing free access to family members, having privacy, providing psychological assistance, helping with bureaucratic processes, or providing a bereavement follow-up plan.
A6	Analyzing the nursing experience using art therapy with parents facing the death of a newborn baby	- Art therapy strategy aimed at parents to encourage them to express their inner emotions through writing memoirs and diaries and their participation in companionship. - Nursing care provided to the patient: maintenance of individualized physical functions and maintenance of physical integrity during the end-of-life period.
A7	Demonstrate how comfort theory and its associated taxonomic structure can be used as a conceptual framework for nurses and midwives providing end-of-life care to neonates and their families.	- Application of comfort theory tends to improve the provision of end-of-life care in the Neonatal ICU;
A8	To describe the roles and challenges perceived by NICU nurses when providing end-of-life care in South Korea.	- Nurses' roles during end-of-life care were grouped into four categories: providing information and support, increasing the bond between parents and babies, providing direct care for the baby, and completing documentation.
A9	To describe the decision-making conditions for terminally ill babies and the cultural effects on the infant death process in the neonatal intensive care unit	- 82% of the records documented a do-not-resuscitate order, and 16% of the parents allowed ventilatory support to be discontinued when they realized the futility of continued care. - In 30 nursing records, parents and their terminally ill NBs were given a quiet place to say goodbye. In 10 cases, the nurses accompanied the parents and allowed them to express their emotions. - Great external expression of religion now of death. Cultural issues affected both the families' grieving process and their babies' dying process.
A10	To evaluate changes in end-of-life care after the start of a palliative care program in a neonatal	- The Palliative Care Program consisted of medication guidelines, a set of individualized orders, a nursing care plan, and staff education.

Cod.	Objective	Main results (strategies of the nursing team in the face of terminality and death in neonatal intensive care)
	intensive care unit.	- Eighty-two babies died before (Era 1), and 68 babies died after the implementation of the program (Era 2). - Do-not-resuscitate orders and family meetings were more frequent among Era 2 babies with activated palliative care orders (n=21) compared to babies without activated orders (n=47).
A11	To investigate the influence of perceptions of death, stress in end-of-life care and emotional intelligence on attitudes towards end-of-life care among neonatal intensive care unit nurses.	- The factors that influenced NICU nurses' attitudes towards end-of-life care were academic degree, the number of times the nurse had experienced the death of a patient, negativity towards death, anxiety towards death, and emotional intelligence. - More positive attitudes towards end-of-life care were associated with higher academic grades, more frequent experiences of a patient's death, less negativity towards death, less anxiety towards death, and higher emotional intelligence.
A12	Analyzing the ethical dilemmas of the newborn: nursing attitudes in intensive and intermediate care	- ICU nurses were more likely than intermediate care nurses to favor passive and active euthanasia. - ICU nurses were more likely than intermediate care nurses to see ending life support for a sick baby as a necessity. - ICU and intermediate care nurses agreed, however, that the decision to end a baby's life support should be made jointly by the child's parents and doctors.
A13	To describe the nurses' efforts to create normality in the face of sadness and grief at the death of a child in a pediatric/neonatal ICU.	- Four themes emerged from the thematic analysis: respecting the child as a person; creating opportunities for family involvement/connection; collecting memories; and planning for death. - The activities enabled parents to participate in caring for their children as death approached.
A14	To assess whether neonatal nurses could be helped in their knowledge and comfort through an educational intervention provided by members of the hospital ethics committee and specialists in palliative care.	- There were higher levels of comfort and knowledge in caring for terminally ill babies in the areas of ethical/legal issues and symptom management after the educational programs. - Although not statistically significant, mean scores were higher after the educational sessions on pain management, spirituality/anxiety, and preventing compassion fatigue. - The scores for the communication/culture module were lower in the post-test application.
A15	To describe neonatal nurses' perceptions of bereavement/end-of-life care for families of seriously ill and/or dying babies.	- Comfort and role scores correlated significantly with the number of years as a neonatal intensive care nurse. - Respondents agreed with many essential aspects of their roles with patients' families, especially the importance of providing daily support to families. - Most respondents identified caring for a terminally ill baby, the actual death of a baby, and linguistic or cultural differences as influential factors in the level of their involvement with families.
A16	To learn about the resistance strategies adopted by nursing professionals when faced with newborn deaths.	- The individual strategies for coping with the death of a newborn were related to mechanisms of acceptance, consolation, silence, avoidance, isolation, denial, and impotence, highlighting the possible lack of success. - The collective strategies were the cult of spirituality, dialogue, and teamwork.
A17	To understand the experiences of nurses regarding the death/dying process of children admitted to the Neonatal Intensive Care Unit.	- The conflict between what is idealized and what is experienced (when faced with the death of a child, the nurse may be conflicted because she feels she has failed in her mission and wonders what else could have been done). - The experience of negative feelings (fear, guilt, sadness, a sense of emptiness, anguish, and frustration). - Sharing the death process with the family (they experience their grief and find it challenging to give them the news of the death, feeling their sadness).
A18	To investigate the perceptions, experiences and challenges that health professionals face when dealing with end-of-life decisions in neonatal and pediatric intensive care units.	- Two main themes: "critical illness" consisted of the following sub-themes: the child, the family, and other professionals. - The "end-of-life procedures" theme consisted of the following sub-themes: breaking point, decision-making, end-of-life procedures. The perceptions and experiences of end-of-life issues among nurses and doctors working in NICUs and PICUs share many common characteristics. High variability in the end-of-life procedures applied and various difficulties faced during the sharing and decision-making processes were observed.
A19	Comparing neonatal deaths and end-of-life decisions	-The median age of death was three days in the NICU and eight days in the PICU, and mortality despite full intensive care was 4% and 25%, respectively. Intensive care was discontinued due to low chances of survival in 25.1% of NICU cases and 52.8% of PICU cases, and care was redirected due to the expectation of poor quality of life in 70.9% and 22.2% of cases, respectively.
A20	Evaluating changes in causes of death and end-of-life care over	- Involvement of the specialized PC team. However, a small proportion of deaths were referred to PC. Specialist involvement in PC is only sought if the

Cod.	Objective	Main results (strategies of the nursing team in the face of terminality and death in neonatal intensive care)
	almost four decades	dying process is prolonged, if PC takes place in the community, or if a specialized symptom management plan is required.
A21	Document changes in the causes of death and their management over the last two decades	-In period 1, 132 children died in 1,362 hospitalizations, and in period 2, there were 111 deaths in 1,776 hospitalizations. Approximately three-quarters of the children died after life-sustaining treatment was withdrawn in both periods. There was a significant reduction in the proportion of deaths due to chromosomal abnormalities and neural tube defects in epoch 2.
A22	To evaluate the care provided to terminally ill newborns and their families and the changes that have occurred a decade later.	-The 2002-2005 cohort had more requests for a spiritual advisor, a greater number of family members with permission for free visitation, and more clinical meetings with neonatologists. The interventions of parents, health professionals, and ethics committees during decision-making were not documented. Only eight written orders regarding therapeutic limitations and the adoption of palliative care were documented; seven (87.5%) were from the 2002-2005 cohort. Parental presence during death was more frequent in the last four years, but only 21.5% of parents wanted to be present at the time.
A23	To analyze personal care options for bereaved parents of newborns at the end of life.	- Parents prefer various options for the personal care of their baby at the end of life. - Emerging themes were the need for guidance from the medical team, the creation of memories, the feeling of care and respect from the team, and regret related to missed opportunities.
A24	Determine nurses' attitudes towards caring for terminally ill newborns and their families.	Nurses had the most positive attitudes towards the items "nursing care should also include the family of the terminally ill patient" and "the caregiver can prepare the patient or their family for death". Nurses had the least positive attitude towards the item "the time spent caring for terminally ill patients creates a feeling of frustration in me". The average score for NICU nurses' attitudes towards caring for terminally ill NBs and their families indicates the need to improve this attitude.
A25	Exploring the end-of-life experiences of nurses and doctors in the neonatal intensive care unit	Participants described their experiences through a general theme of "creating the best possible experience" for parents. To support this theme, there were three sub-themes (building relationships, preparing for the end of life, and creating memories). However, nurses and doctors articulated their roles and obligations differently within these sub-themes. Three sub-themes were found through which providers described their personal experiences, and these included moral distress, parental readiness, and autopsy consent.
A26	Examine the symptoms presented by neonates at the end of life and the treatments used to control these symptoms, as documented in the medical record during the last 24 hours of life.	Inadequate documentation in the medical records resulted in missing data, which prevented us from fully exploring aspects of symptom management during the last 24 hours of life. Importantly, this study revealed a difference in how neonates approach the end-of-life period. Other findings were that many NBs in the study received pain medication, although pain scores were rarely documented. There was also a lack of documentation of the non-pharmacological interventions used at EOL.

ICU: Intensive Care Unit. NICU: Neonatal Intensive Care Unit. PICU: Pediatric Intensive Care Unit. PC: Palliative Care. Source: Research data.

DISCUSSION

CONCEPTUAL DIFFERENTIATION BETWEEN END-OF-LIFE CARE AND PALLIATIVE CARE: THE IMPORTANCE OF CONTINUING HEALTH EDUCATION

This summary of evidence points to the inseparability of the object of study (end-of-life process and death in NICUs) from end-of-life care and PC, given that both have an impact on important quality benchmarks to be considered in NICUs. Therefore, the studies analyzed were primarily focused on end-of-life care, using various terms, including "end-of-life care" and "neonatal end-of-life care."^{13,16,27,28,32}

The provision of quality end-of-life care is recommended when a newborn is dying in a NICU, and it is recommended that the individual needs of the newborn, as well as the contextual and cultural needs of their family, be considered.²⁸ Regarding its implementation, a cross-sectional study with 400 nursing

professionals from 11 NICUs highlighted the leading role of this professional category in the responsibility of directly providing end-of-life care, accounting for a total of 86% of respondents.³²

However, almost half (48%) reported that they had not received prior training on the subject,³² which points to the need for Continuing Health Education (CHE) that covers end-of-life care in the terminal process, post-death, and bereavement.¹⁶ CPE is conceived as learning on the job, where learning and teaching are integrated into the daily routine of health organizations and work, based on meaningful learning and the potential for transforming professional practices.³⁴

Following the CHE premise that the transformation of professional practices must be based on dialogue and critical reflection on the actual practices of professionals working in health services, this strategy proved beneficial for nurses' comfort in caring for families of critically ill and/or dying newborns.³⁴

Health education is also promising for improving nurses' attitudes toward end-of-life care. Content planning should be designed to enhance these professionals' emotional intelligence, focusing on reducing negative perceptions and promoting positive perceptions of death. Additionally, hospitals should provide administrative and institutional support to facilitate such initiatives.²⁴ Furthermore, it is recommended that content on grief/end-of-life care be included in nursing curricula at both the technical and higher levels.¹⁶

Studies indicate that it is impossible to elaborate on terminality and death in the ICU environment without recognizing the interface with PC.^{1,12,20} Furthermore, regarding the establishment of PC in the NICU, it is known that, historically, the goal of care in this sector has been to do everything clinically possible to cure diseases or prolong life. When curative therapies were no longer appropriate, the approach was to resort to end-of-life care. However, this scenario has changed, and today there are newborns surviving diseases that previously resulted in death or significant disability, with repercussions on quality of life. It is in this context that PC comes in, as an approach also used in pediatric populations to improve quality of life, clarify treatment decisions that align with the child's goals and values, and minimize suffering, as evidenced in this evidence summary.^{1, 12}

PCs offer the opportunity to ensure quality of life for newborns during their stay in the neonatal ICU, while also providing meaning for parents. Through this type of care, it becomes possible to openly discuss which strategies may be effective in improving the quality of life of newborns, presenting interventions that work in this direction or that do not offer benefits and are therefore unnecessary.¹

PCs aim to enhance the quality of life for patients and their families experiencing a life-threatening illness. Although this type of care is well established internationally, in Brazil, it was only officially recognized through a resolution by the Ministry of Health.³³ In this context, PCs constitute an approach to individuals in the early stages of progressive, advanced, and incurable diseases.³⁶ The goal is to prevent and alleviate suffering through early identification for the treatment of painful symptoms and interdisciplinary care for physical, psychological, psychosocial, and spiritual conditions.³⁷

To this end, the role of nurses is reinforced through a health education strategy, with actions aimed at informing parents and family members of hospitalized newborns about the available treatment options.^{1,20} It is assumed that teaching and learning activities carried out by PC specialists in the NICU tend to help nurses feel comfortable caring for newborns in the terminal phase and dying.²⁰

However, although the importance of PC in the NICU is recognized, a study has shown that this approach was only used in a small proportion of cases. This finding may be explained by the fact that neonatal intensive care physicians are qualified to provide end-of-life care per international recommendations for perinatal palliative care.² However, specialized PC care is only sought if the dying process lasts longer than expected or if PC is instituted through home care services.²

INDIVIDUAL AND COLLECTIVE STRATEGIES OF THE NURSING TEAM IN THE FACE OF TERMINALITY AND DEATH IN A NEONATAL INTENSIVE CARE UNIT

Based on the analysis of the *corpus* of this ILR (N=26), it was possible to classify the strategies adopted by nursing professionals when faced with a terminal illness and the death of newborns in the ICU into individual^{9,22}, and collective strategies. Strategies are considered normal by nursing professionals working in NICUs, who believe that this situation is part of the expected progression of their patients' condition and has become routine.⁹

The study participants also use mechanisms of acceptance, consolation, silence, avoidance, isolation, denial, and helplessness. These have proven unsuccessful in coping with the process of terminal illness and the death of the NB in an ICU. A study highlighted that professionals often adopt an escape strategy, avoiding discussion of the subject, which tends to have negative repercussions.⁹

The use of denial strategies to cope with the situation and reports of helplessness by nursing professionals demonstrate their difficulty in dealing with situations of death, in which frustration and sadness are intensified. Thus, it can be inferred that individual strategies are less effective than collective ones.⁹

Still, from an individual perspective, in line with the above, study²² points out that there is a disconnect between what is idealized and what is experienced by nursing professionals working in NICUs. This is because they idealize the stereotypical mission of nursing to "save lives" and yet suffer from performing invasive procedures that they consider contradictory in the face of the certainty of the child's death. It is also because they believe they have failed as professionals, and this has repercussions on the difficulty of deciding when to stop trying to resuscitate the child and certify their death.

As a result, terminality and death stir up negative feelings in nursing professionals, which are reflected in sadness, guilt, emptiness, anguish, and frustration.²² In addition to individual feelings, there is the issue of professionals sharing the process of terminality and death with the newborn's family, experiencing their grief, and sharing feelings of sadness, with difficulty in delivering the news of death.¹⁹

Collective coping is considered more effective than individual coping when it comes to dealing with terminality and death in the NICU.^{9,22} This can be achieved through intra-team coping strategies, which revolve around the cultivation of spirituality, dialogue, the implementation of care protocols^{13,24,32}, multidisciplinary action²⁷, art therapy²⁵, family-centered care^{17,25}, and Comfort Theory.²⁰ These are considered decisive protective factors for nursing professionals facing situations of terminality and the death of newborns.⁹

CARE PROTOCOLS

It is assumed that care protocols have a positive impact on the well-being of parents who have lost their babies in the NICU and improve family-centered care within the units.^{13,32} Based on this technology, the aim is to standardize conduct in the face of situations of terminality and death in the neonatal ICU, seeking to standardize the management of parents, with reproducible clinical reasoning, although in clinical practice this is a care technology that is little used.

In line with this, a study found that 17% of nurses report that the NICU where they work has a protocol outlining a strategy for end-of-life care.³² However, there is a need to make progress in this area because the actions implemented during end-of-life care are generally infrequent ($\leq 50\%$) in all items explored.³²

A 71-item protocol was also developed based on an integrated model of end-of-life care and the concept of family-centered care, consisting of three sections: main guidelines, communication during end-of-life care, and five sub-steps according to changes in the condition of a newborn.¹³ This proved to

be feasible and improved the competence and attitude of nurses in providing end-of-life care for newborns and parents who needed support due to the loss of their babies.¹³

Therefore, care protocols are considered technologies that are integral to the organization of nursing work and constitute an essential tool for health management.³⁸ In addition, they are used to organize services, optimize work, and standardize procedures, incorporating them into care practices. In this sense, protocols based on scientific evidence provide a systematization of the actions performed and autonomy for professionals in decision-making regarding the best healthcare, which is a key recommendation of this evidence synthesis.

MULTIDISCIPLINARY ACTION

This summary of evidence highlights the importance of multidisciplinary care in situations of terminal illness and death in NICUs, beyond the exclusive role of nurses.^{20,27} Meanwhile, the study found that the centrality of conduct remains guided by the biomedical model; in other words, in 83% of situations, it was the doctors responsible for caring for the babies or the doctors on duty who were accountable for end-of-life decision-making for newborns with fatal or incapacitating conditions. Nurses, parents, ethics committees, and NICU heads were less involved, which points to the need for these decisions to be more focused on the real needs of families and based on multidisciplinary teams.²⁷

Considering that when parents are faced with an unfamiliar and stressful situation, they rely heavily on guidance from the multidisciplinary team, studies reiterate the importance of assertive communication between healthcare professionals and the parents of hospitalized newborns.¹⁷ Effective strategies for multiprofessional practice also include conducting interviews after the death of each newborn, multidisciplinary team meetings, and lessons learned sessions on cases of infant death.²⁰

FAMILY-CENTERED CARE AND ART THERAPY

The strategy of art therapy aimed at parents was mentioned in the provision of care in the face of newborn death in the NICU.²⁵ The benefits were related to the possibility of expressing their inner emotions through writing memories and diaries. The use of art therapy demonstrates the family-centered care strategy and shows how the family was successfully assisted during the crisis.²⁵

Another study recommends that counseling on family-centered care options for newborns in the terminal and dying stages should be provided early, concerning the diagnosis of imminent death. Providing this information to families promptly is vital in several ways.¹⁷

COMFORT THEORY

Another strategy listed in the *corpus* concerns the application of Comfort Care, which offers direct benefits in end-of-life care at the NICU.²⁸ This is a medium-range theory, conceived by Katharine Kolcaba, which aims to promote holistic comfort for both patients and their families. It can be applied in clinical practice to different populations and at various points of care.³⁹

According to this theory, there are several levels of discomfort, which can be physical, spiritual, social, and environmental. To this end, studies suggest that in all situations, the patient's perception as the recipient of comfort care should be considered, along with their needs, so that care can be directed effectively in the practice of CPs.³⁹ From this perspective, the primary purpose of Comfort Theory is to go beyond the management of distressing symptoms and physical pain, seeking to achieve comfort as an experience so that the patient's needs for relief, tranquility, and transcendence are met in the four main contexts, namely,

physical, psychospiritual, social, and environmental.³⁸ In the specific case of the NICU and the newborn, this can be extended to their family and the newborn as relief from pain and physical discomfort³⁹.

PROCEDURES CARRIED OUT BY THE NURSING TEAM IN THE FACE OF TERMINALITY AND DEATH IN A NEONATAL INTENSIVE CARE UNIT

The work of the nursing team when dealing with terminal situations and death in the NICU is divided into three main areas. These initiatives provide information and support to parents, strengthen the bond between parents and babies, and offer direct care to the baby by maintaining individualized physiological functions and integrity.^{23,25}

This summary of evidence identified the centrality of studies that discuss the humanization of care in the NICU in preparing for the death of newborns. In these situations, it is recommended that the family be included and that parents or family members be allowed to participate in preparing the patient for death.^{17,18}

The study confirms nurses' concerns with family members in preparing for death, how to present the child to the parents in the best way, and the possibility of family involvement, including the creation of memories.¹⁷ These memories include locks of hair, hand and footprints, memory boxes, and hospital identification bracelets. One study found that the practice of taking photographs of the baby or child before and after death is standard and helps to preserve memories and give meaning to the experience of parents after the loss of a child.⁸

A study recommends that parents create memories with their newborns, considering that evidence shows missed opportunities to create additional memories were the predominant component of parents' wishes and regrets.¹⁷ Procedures involving parents in the face of newborn death are evaluated positively by them when the team demonstrates sensitivity, attention, and clear communication with understandable explanations.⁸

Therefore, when NICU health professionals demonstrate care in other ways that go beyond their professional role and care demands, the parents' experience is also improved. This can be achieved through actions that recognize how important and special the child was, such as free access to family members, providing private time for parents with their child, and encouraging them to care for the child before death.⁸ However, it is worth noting that nurses had a less positive attitude toward the item on time spent caring for terminally ill patients, which leads to a feeling of frustration among these professionals.¹⁸

Another strategy listed in the corpus of this IR regarding terminality and death in the NICU to minimize the effects of loss on the family and the team concerns providing psychological assistance, recording the process in the medical records, assisting with bureaucratic processes, or providing a grief support plan, although this was very infrequent.³²

In this regard, scientific literature indicates that, over the last four years, there has been a trend toward increased parental presence during the dying process. However, only 21.5% of parents wanted to be present at this time.³¹ Nevertheless, there is a gap in the records of interventions carried out by health professionals and ethics committees regarding decision-making in terminal and end-of-life situations. During this period, only eight written orders were documented regarding therapeutic limitations and the adoption of palliative care.³¹

Above all, some challenges must be overcome to achieve effective nursing care in these situations. These include environmental and physical restrictions on the admission of parents, dilemmas and conflicting and/or ethical situations during this period, and the provision of end-of-life care by professionals who lack sufficient prior experience and knowledge.²³ In contrast, comfort scores

correlated significantly with longer nursing experience in the NICU.¹⁶ Another factor that influences the care of newborns in the terminal and dying process concerns linguistic and/or cultural differences that interfere with the involvement of nursing professionals with families.¹⁶

Regarding the implications for care practice, the restructuring and ongoing qualification of care processes in the NICU context are notable. Terminality in neonatology involves not only highly complex clinical decisions but also emotional and communication challenges that require technical preparation and sensitivity from the professionals involved. In this sense, the importance of continuing education is evident, as it has proven essential in updating knowledge, developing skills, and enhancing professionals' ability to address situations of suffering and engage in shared decision-making with families. Furthermore, this action should be carried out in a coordinated manner, with a focus on the family but with a multidisciplinary approach. Another significant contribution is the institutionalization of specific protocols for dealing with terminal illness and the neonatal death process, since standardizing procedures makes it possible to offer best practices, providing dignity and relief from suffering in the care provided.

CONCLUSION

The evidence suggested an inseparability between the conceptual approaches to end-of-life care and palliative care, which were found to be intrinsic to the study's object. In both cases, it is necessary to broaden the view beyond the newborn, considering the individual, contextual, and cultural needs of each family. However, nursing professionals are not adequately prepared and do not feel comfortable caring for newborns in the terminal phase and dying. To this end, continuing health education was identified as an essential strategy for the work process of these professionals.

Individual strategies, mechanisms of acceptance, consolation, silence, avoidance, isolation, denial, and helplessness have proven unsuccessful in coping with terminal and death situations in NICUs. Therefore, collective strategies are recommended as protective factors for nursing professionals in dealing with these situations. These include spirituality, dialogue, teamwork, the use of care protocols, and multidisciplinary action.

The findings highlighted the leading role of nurses in all types of care, as well as their central role as mediators in the communication process between the multidisciplinary team for planning and managing care in NICUs.

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