

Bioethics as a decision-making tool in neonatal palliative care

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Abstract

Technological advancements in neonatology contribute to the care and maintenance of newborns' lives; however, its overuse is associated with increased morbidities and suffering. Having bioethics as its theoretical framework, this systematic literature review elucidates the provision of neonatal palliative care. Results analysis resulted in four categories: 1) poor inclusion of palliative care and bioethics in neonatal specialization curricula; 2) professionals' inability to communicate with family members; 3) exclusion of family members from decision-making; and 4) need for further studies and discussions regarding neonatal and home palliative care and organ donation. Palliative care contributes to people's quality of life and death, despite being taboo in the case of newborns.

Keywords: Palliative care. Neonatology. Bioethics. Decision making.

Resumo

Bioética como ferramenta nas decisões de cuidado paliativo em neonatologia

Os avanços tecnológicos da medicina perinatal contribuem para o cuidado e a manutenção da vida dos neonatos, entretanto a utilização demasiada da tecnologia está associada ao aumento de morbidades e sofrimento. Tendo em vista a bioética, esta revisão sistemática da literatura objetivou esclarecer como estão sendo ofertados os cuidados paliativos em neonatologia. Os resultados foram divididos em quatro categorias: 1) fragilidade curricular das especializações em neonatologia referente a cuidados paliativos e bioética; 2) inabilidade dos profissionais na comunicação com familiares; 3) exclusão dos familiares na tomada de decisão; e 4) necessidade de aprofundamento dos estudos e discussões acerca de cuidados paliativos perinatais, domiciliares e doação de órgãos neonatais. Concluiu-se que os cuidados paliativos contribuem para a qualidade de vida e de morte dos indivíduos, embora ainda seja um tabu no caso de neonatos.

Palavras-chave: Cuidados paliativos. Neonatologia. Bioética. Tomada de decisões.

Resumen

Bioética como herramienta en las decisiones sobre cuidados paliativos en neonatología

Los avances tecnológicos en medicina perinatal contribuyen al cuidado y al mantenimiento de la vida de los neonatos, sin embargo, el uso excesivo de la tecnología se asocia a un incremento en la morbilidad y el sufrimiento. Desde la bioética, esta revisión sistemática de la literatura pretendió aclarar cómo se ofrecen los cuidados paliativos en neonatología. Los resultados se dividieron en cuatro categorías: 1) Deficiencias en los planes de estudios de las especialidades de neonatología respecto a los cuidados paliativos y la bioética; 2) Inhabilidad de los profesionales para comunicarse con los familiares; 3) Exclusión de los familiares en la toma de decisiones; y 4) Necesidad de más estudios y debates sobre los cuidados paliativos perinatales y domiciliarios, y la donación de órganos neonatales. Los cuidados paliativos contribuyen a la calidad de vida y de muerte de las personas, aunque siguen siendo tabú en el caso de los neonatos.

Palabras clave: Cuidados paliativos. Neonatología. Bioética. Toma de decisiones.

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Technological advancements in perinatal medicine have notably enhanced the care and maintenance of newborns' lives, even though 40% of infant deaths still occur within the first four weeks of life¹. While technology has enabled the survival of children, its use is often associated with severe disabilities. This juxtaposition is noteworthy: while mortality rates have decreased, the use of technology has led to an increase in morbidity, bringing forth ethical dilemmas surrounding potential therapeutic obstinacy leading to suffering^{2,3}.

Such life-limiting situations are identifiable during prenatal care, at birth, or afterward, and palliative care could provide significant benefits in such cases. Decision-making and conveying distressing news are major challenges, primarily stemming from uncertainties regarding the prognosis of the fetus or newborn. Determining the terminal phase of biological life is challenging, leading parents to endure profound emotional distress¹.

Consequently, health professionals proficient in perinatal palliative care play a vital role in alleviating the social, spiritual, and psychological suffering experienced by these families¹. Embracing palliative care within this framework may prove strongly beneficial for patients, families, and healthcare practitioners⁴.

Since 1990, the World Health Organization has acknowledged palliative care, although its definition has evolved over time. The most current version of the concept emphasizes its role in preventing and alleviating the physical, psychological, spiritual, and social suffering of both adults and children facing potentially fatal diseases, along with their families⁵. However, dispelling the misconception that palliative care signifies an imminent death sentence remains crucial. Instead, it should be viewed as a specialized form of care tailored to the individual needs of the patient, prioritizing comfort and rational therapeutic measures⁶.

Perinatal palliative care primarily involves ethical and empathetic support for seriously ill children and their families, provided by a specialized multidisciplinary team. This approach aims to enhance comfort and quality of life for all

involved, extending from end-of-life care for the child to support during the mourning period^{1,6}.

In the context of an intensive care unit (ICU), the primary goals encompass improving the quality of life, optimizing pain and symptom management, facilitating sensitive communication of difficult news, and engaging in shared decision-making processes. Additionally, these goals encompass providing ongoing care and furnishing emotional, psychosocial, and logistical support for patients, families, and the ICU team staff^{2,4}.

Facilitating orthothanasia (meaning "good" death) poses a formidable challenge, particularly concerning children. Perceptions about death vary widely among individuals experiencing this situation, including family members, friends, healthcare professionals, and other caregivers involved in end-of-life patient care. Assessing a "good death" involves evaluating both the moment and manner of death and considering the dying process or the timeframe until life ceases⁷.

The concept of a "good death" typically involves pain management, the physical presence of family members, empowerment in end-of-life decisions, comprehension of the dying process, reflections on a life lived well, the opportunity to resolve unresolved matters, bidding farewell, and leaving a legacy⁷. Philosophical insights significantly inform palliative care practices, making a "good death" seemingly attainable for adults. However, literature and discussions concerning a "good death" for children are notably scarce compared to adults⁷.

Commonly, death is perceived as tragic rather than something desired, especially when involving children and newborns. The complexities of perinatal care make it challenging to conceptualize a "good death" for children. Unlike adults, children might not have the opportunity to resolve personal issues, bid farewell, leave a legacy, engage in play, or fulfill their aspirations. Consequently, what should be a joyous occasion for families—welcoming a new life—often transforms rapidly into profound grief over loss⁷.

Adding to the complexity of defining a "good death" is the principle of the sanctity

of life, driving the use of technologies to prolong life, even when it leads to keeping patients in a vegetative state devoid of quality of life³. Prolonged hospitalizations of critically ill newborns due to extensive resuscitation efforts and active treatments significantly heighten the risk of serious and enduring neurological complications³.

The application of such medical practices has sparked considerable tension and controversy, prompting ongoing discussions and shifts in paradigms regarding complex decisions concerning the initiation, suspension, or continuation of new therapeutic approaches. Ethical dilemmas are pervasive in issues surrounding the extension of lives for children with bleak prognoses and in managing chronic illnesses where the outcome remains unchanged, despite interventions lacking curative potential².

Consequently, challenges surface in fostering discussions and contemplating the conclusion of children's lives, particularly newborns. These struggles impact not only parents and family members but also the healthcare professionals tasked with their care, who serve as mediators between care provisions, diagnosis, prognosis, and the collaborative decision-making process concerning end-of-life care. Amidst this landscape, this study was undertaken to delve deeper into discussions on this subject matter and address the fundamental question: How is palliative care in neonatology being provided from a bioethical perspective?

Method

The systematic literature review conducted in May 2022 encompassed databases such as PubMed, SciELO, and the Virtual Health Library (VHL). The search utilized Health Sciences Descriptors (DeCS) in Portuguese, English, and Spanish, namely: neonatology, palliative care, newborn, bioethics, and neonatal intensive care units. The inclusion criteria encompassed articles published within the last decade (2012-2022) that were available

in full text. Taking into account the objectives presented, the search strategy used the Boolean operator AND to combine the descriptors into three specific combinations: 1) "*neonatology and palliative care and bioethics*"; 2) "*infant, newborn and palliative care and bioethics*"; and 3) "*intensive care units, neonatal and palliative care, and bioethics*."

Exclusion criteria comprised duplicate articles across databases, articles diverging from the study's objective, and those that were incomplete or had restricted access. Following the initial screening, selected articles were thoroughly reviewed in their entirety. The PICO strategy (*patients, interventions, control, outcomes*) was used to develop the guiding question for the search presented.

Results

In total, 72 articles were found—30 in PubMed, 30 in SciELO, and 12 in the VHL. 29 studies were excluded in the initial selection stage due to duplication, while six articles were excluded as they were not available in their entirety. Subsequently, the review process continued, involving exclusion based on title (14 studies), abstract (seven articles), and full-text review (nine articles). Eventually, this process led to the retention of seven articles for inclusion in this study (Figure 1).

Out of the seven selected studies, three⁸⁻¹⁰ were conducted in the United States, while one study each originated from Austria¹¹, the Netherlands¹², Spain¹³, and Brazil¹⁴. Notably, the majority of publications within the last four years (2018-2022) amounted to five studies, indicating a growing trend in expanding discussions on the subject matter. Among these studies, those employing a mixed methodology were predominant. These methodologies combined a literature review with the development of other research approaches, such as semi-structured interviews, case discussions, and expert consensus within the relevant field (Table 1).

Figure 1. Flowchart of the study selection process for the systematic review

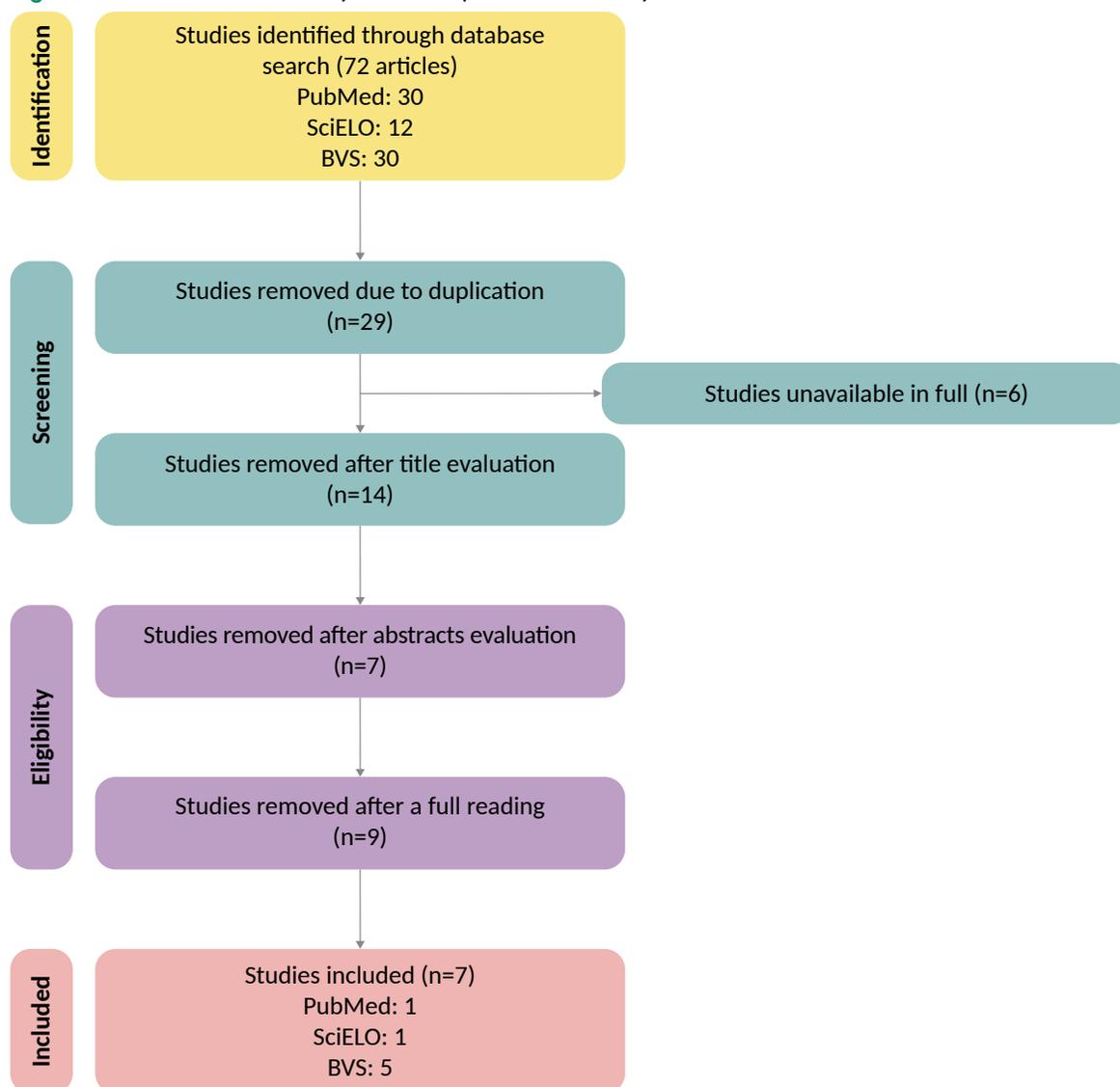


Table 1. Characteristics of the studies included in the systematic review.

Author/year	Title	Type of study	Country	Journal	Main findings
Herbst, deSante-Bertkau; 2020 ⁸	“Ethical dilemmas at the beginning and end of life: a needs-based, experience-informed, small-group, case-based curriculum for pediatric residents”	A trio of small group discussions based on cases on artificial nutrition and hydration, fertility, and ethical considerations in neonatology	United States	<i>MedEdPORTAL</i>	Evidence of deficiencies in medical ethics. It demonstrated an enhancement in the comfort levels and self-reported attitudes of pediatric residents and medical students following conversations about ethical dilemmas at the onset and end of life

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Table 1. Continuation

Author/year	Title	Type of study	Country	Journal	Main findings
Richards and collaborators; 2018 ⁹	“Physicians perceptions of shared decision-making in neonatal and pediatric critical care”	Semi-structured interviews and content and thematic analysis	United States	<i>American Journal of Hospice & Palliative Medicine</i>	Shared decision-making might be affected by various factors, including power differentials between physicians and family members, clinical uncertainties regarding the optimal approach to balancing the interests of the family and the child. Furthermore, the values and preferences of families might not be integrated into end-of-life decisions and conversations concerning care objectives.
Carter; 2018 ¹⁰	“Pediatric palliative care in infants and neonates”	Literature review	United States	<i>Children</i>	Need to add palliative care to intensive care, and not just in the terminal phase of children’s lives. Takes the incorporation of palliative care in the management of fetal diagnosis into consideration as a futuristic action
Stanak, Hawlik; 2019 ¹¹	“Decision-making at the limit of viability: the Austrian neonatal choice context”	Mixed: literature review and semi-structured interviews	Austria	<i>BMC Pediatrics</i>	Communication strategies regarding therapeutic options can significantly impact decisions, the survival rate, and the neuropsychomotor development of infants. Potential influencing factors on decision-making included professional biases, parental comprehension, and how information was conveyed.
Willems, Verhagen, van Wijlick; 2014 ¹²	“Infants’ best interests in end-of-life care for newborns”	Mixed: literature review and consensus meetings in a multidisciplinary committee of experts	Netherlands	<i>Pediatrics</i>	Current recommendations from the Netherlands regarding end-of-life decision-making for newborns suggest that treatment be conditional. In case of failure, it must be abandoned and palliative care for the child and their family must be initiated.

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Table 1. Continuation

Author/year	Title	Type of study	Country	Journal	Main findings
Arnaez and collaborators; 2017 ¹³	“La bioética en el final de la vida en neonatología: cuestiones no resueltas”	Synthesis of studies and conferences plus the experience of professionals and information from databases such as PubMed, Embase, and Cochrane	Spain	<i>Anales de Pediatría</i>	It emphasizes the necessity of educating professionals in bioethics, the deliberative method, communication proficiency, and the handling of moral distress, ensuring prudent and rational decision-making. It underscores the dearth of advancements in perinatal and home-based palliative care within hospitals catering to newborns and the absence of protocols guiding neonatal organ donation
Gazzola, Leite, Gonçalves; 2020 ¹⁴	“Comunicando más noticias sobre malformações congênicas: reflexões bioéticas e jurídicas”	Update	Brazil.	<i>Revista Bioética</i>	The significance of effective communication and a strong doctor-patient relationship cannot be overstated in preserving the right to autonomy and the receipt of information. Failure to adhere to these standards could lead to civil and ethical-professional liabilities.

Discussion

The main results of the studies were categorized into four major themes, namely: 1) weaknesses in neonatology education curriculum; 2) professionals’ challenges in communicating with family members; 3) exclusion of family members from decision-making processes; 4) studies and discussions: an in-depth study of neonatal palliative care.

Curricular weaknesses in neonatology: palliative care/bioethics

The challenges surrounding ethical dilemmas at both the onset and end of life were deemed the most complex aspects of medicine, despite the presence of medical ethics and palliative medicine aimed at aiding this process⁸. Pediatric residents encountered significant difficulties in managing internal ethical conflicts—uncertainties regarding the appropriate course of action in specific situations—and external conflicts arising from disagreements with others regarding their decisions⁸. This difficulty

stemmed from the inadequacies within the curricula of pediatric residency programs that focused on medical ethics, providing minimal training concerning death and end-of-life care. As a result, this lack of education led to significant limitations in comprehending and effectively addressing ethical dilemmas at the end of life⁸.

A Spanish study¹³ further emphasized the existing gap in the clinical bioethics training of healthcare professionals, highlighting that the deliberation process could be beneficial in neonatal clinical decisions and pointing to the need for further knowledge and practical application. Moreover, this research emphasized that such a tool was not restricted to ethics committees but could greatly assist professionals, particularly in conflict situations or amidst ethical uncertainties, shedding light upon the ongoing need for professional training.

Professionals’ challenges in communicating with family members

The right to information stands as an essential foundational principle within the doctor-patient

dynamic, and healthcare professionals may face civil and ethical-professional liabilities if this right is breached¹⁴. Private autonomy should form the foundation of this relationship, prioritizing inclusion rather than withholding information from family members, as employing optimal communication techniques is essential in effectively sharing information¹⁴. Conversely, achieving consensus in decisions involving newborns eligible for palliative care within neonatal intensive care units (NICU) poses a significant challenge for medical teams, entailing cultural, socioeconomic, and religious considerations among others. This occurs within a context marked by deficient communication quality between the parties involved¹¹.

A plausible explanation for this scenario is the substantial gap in curriculum guidelines addressing effective communication of challenging news in neonatology specializations¹¹. Furthermore, inadequacies in communication with parents may be attributed to professional and personal biases, informational prejudices, and the varying levels of parental (mis)understanding¹¹.

Hence, professionals are recommended to cultivate self-awareness regarding their biases, exercise sound judgment, and deliver tailored information to family members. Additionally, integrating internal training initiatives for NICU professionals is proposed to enhance their communication proficiencies¹¹.

Behavioral sciences underscore the pivotal role of communication in decisions, directly influencing parental assessments regarding survival or the consideration of palliative care in neonatology¹¹. Arnaez and collaborators¹³ emphasize the significance of honing both verbal and non-verbal communication skills, along with demonstrating dedication, active listening, empathy, and patience toward parents. These traits aid in fostering understanding and acceptance of the situation and its future implications. Clarity and precision in information delivery are paramount, discouraging practices aimed at persuading or convincing families¹⁴.

Another commonly utilized strategy in clinical settings for conveying difficult news is the SPIKES protocol, as outlined by Buckman¹⁵. The acronym delineates six steps to follow during communication: S (setting up), P (perception), I (invitation), K (knowledge), E (emotions), and S (strategy/summary)¹⁴.

Moreover, the multidisciplinary team should remain attentive to prior agreements with parents to mitigate inconsistencies or disputes in communication and care provision¹³. Equipping the team with training to offer support and emotional assistance to parents, alongside the essential involvement of psychologists and social workers, stands as a cornerstone for providing proper guidance and nurturing critical judgment concerning the realities of decisions that need to be made¹⁴.

Exclusion of family members from decision-making processes

Relatives of critically ill patients often exhibit symptoms indicative of acute and post-traumatic stress disorder, potentially impacting communication and hindering their ability to make decisions¹⁶. Thus, adopting a family-centered care approach has proven beneficial for both children and their families, empowering and enabling families to participate in the care of their hospitalized child⁹.

In their research, Richards and collaborators⁹ observed that in situations where doctors were uncertain about the prognosis, they assumed that families shared the same objectives as healthcare professionals, leading to the initiation of treatment without restrictions towards the unrestricted maintenance of children's lives. Similar conclusions were drawn by Willems and collaborators¹², who emphasized that while treatment initiation occurred, the medical path should not be regarded as final. Health professionals must remain vigilant against the practice of medical paternalism and should integrate and respect parental decisions. This approach can mitigate conflicts between familial preferences and medical opinions. In cases of disagreement, institutional ethical bodies mediate the final decision within the healthcare setting¹⁴.

Studies and discussions: an in-depth study of neonatal palliative care

Carter¹⁰ highlighted that the recent adoption of palliative care during the neonatal and perinatal periods has proven beneficial for children with complex chronic conditions and special health needs. The primary criteria guiding the adoption of palliative care in the neonatal period encompass three categories: 1) infants born at

the threshold of viability or vulnerable due to prematurity; 2) those with congenital anomalies threatening vital functions; and 3) newborns who received intensive care but reached a point where the benefit from continued care became costly and inadequate¹⁰. However, there is no consensus in the literature regarding the best time or situation to start palliative care.

Palliative care may be introduced during prenatal care, at childbirth, or within the ICU. However, the limited acceptance of neonatology care might be attributed to the interdisciplinary team's limited involvement, societal challenges in understanding and embracing neonatal palliative care, as well as professionals' inadequacy in clinical communication and uncertainties surrounding prognosis, among other factors¹⁰.

Final considerations

Palliative care significantly enhances the quality of life and end-of-life experiences for individuals, yet these advantages remain a sensitive and challenging topic, particularly concerning newborns. The primary obstacles stem from the difficulty in

determining the optimal timing for commencement, exacerbated by prognostic uncertainties that overshadow routine NICU practices.

Understanding what a "good death" would be for newborns poses a complex dilemma, given that the extremes of life are condensed within a brief timeframe: the onset of biological life *versus* the premature cessation of vital organ functions. This context reveals the inadequacies in neonatal palliative care, notably in professional curriculum compositions within neonatal care, ethical quandaries regarding the end of neonatal life, communication strategies for conveying challenging news, and the collaborative decision-making process.

Therefore, it is imperative to reform professional training methods and provide ongoing education for multidisciplinary teams involved in NICU care while aligning with a compassionate and family-centric approach to facilitate shared and equitable decisions regarding palliative care. Furthermore, emphasizing the necessity of further research in less-explored areas, such as home-based neonatal palliative care and neonatal organ donation, underscores the need for expanded studies in this field.

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Brenda Silveira Valles Moreira was the main researcher, responsible for the literature search, data analysis, writing and final review of the text. Andréia Patrícia Gomes was responsible for guiding the article construction, critical review, and final review of the text.

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