



## Early palliative care to decrease suffering in neonatal intensive care unit: narrative review

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### Abstract

**Objective:** The objectives of this review are to ascertain the diseases that result in palliative care in neonates in NICU and whether such care can ease the suffering of the child or the family. **Methods:** This is a narrative and descriptive literature review carried out in MEDLINE, PUBMED, VHL, and LILACS BVS databases during November 2020 to May 2021. Descriptors used are “Intensive Care Units,” “Ethics,” “Palliative Care,” and “Newborn,” which are related to Boolean descriptor “AND.” Articles published in English and within the last five years were included in this article. **Results:** The respiratory diseases and distress, prematurity, congenital abnormalities, and patients at risk of neurological injury represents some of the reasons to refer the patient to the ICU. Beyond that, the three most life-timing complex chronic conditions are neurological, neuromuscular, and cardiovascular diseases. The research emphasizes that the relief in the neonatal ICU is an important factor, in this way, palliative care should be focused mostly on the patient. **Conclusion:** To date, palliative care is appropriate from the moment when a serious diagnosis is made, otherwise it requires the creation of a protocol that guides patients to healthcare professionals. Regardless, to improve the life quality of the neonates during development, their care must be maintained at all moments of the therapeutic intervention.

**Keywords:** Palliative Care. Infant. Neonate. Intensive. Care Units.

### Introduction

The World Health Organization (WHO) defines palliative care as a multidisciplinary assistance provided

to patients and their families in order to improve their quality of life when diagnosed with a life-threatening disease [1]. This approach makes it possible to provide comprehensive and expert care, assisting in the best possible way those who are living in terminal or chronic situations and placing their wishes and particularities above any other therapeutic resource [2].

According to the European Association for Palliative Care, those who need this type of treatment can be divided in four different groups: life-threatening conditions, when access to palliative care services may be necessary alongside with attempts at curative treatment methods; conditions, when premature death is inevitable and there may be long periods of intensive life-prolonging treatments; progressive conditions without curative treatment options, when treatment is only palliative; and irreversible but non-progressive conditions with complex healthcare needs, leading to complications and likelihood of premature death [3].

In neonatal (period consisted of four weeks after birth) [3], there is great difficulty in defining, with criteria, a chronic patient for palliative care [4]. On the other hand, palliative care is needed for dying infants, mostly prenatally diagnosed [3]. When including this type of care, we can find some aspects to consider, including the approach to terminally ill neonates [5]. As technology advances, we have access to data that can suggest the diagnosis of some diseases still during the gestational period, preparing the medical team and the family for possible prognosis [5].

Furthermore, Liben et al. defined neonatal palliative care as a subspecialty that seeks the best quality of life and this care should also focus on psychological, physical, spiritual, and social well-being [6]. Moreover, the World Health Organization mentions

the need for a multidisciplinary approach, which can be combined with community resources, and it also cites the main differences in relation to adult care in this area: prognosis, life expectancy, association with other methods of therapy, guilt among family members, and consideration of the child's emotional during the setting of conduct [1].

Additionally, diseases such as congenital anomalies and changes incompatible with life during pregnancy, may result in palliative care as a therapeutic option, in which there are several management options, including pregnancy termination [5]. Even with remedial measures, quality of life is considered above life prolongation, focusing on comfort and relief of the neonate's suffering, as well as on the family's beliefs and values [4,5,7].

One of the first cares to take with all patients is pain control. Unfortunately, research on pharmacological analgesia is limited in the neonatal population, so medications are available but used with caution [5,7,8]. Many find that non-pharmacologic means of comfort are very effective [5,7,8]. On the other hand, the relief of suffering is essential and done by means of the maintenance of body temperature, contact with family members, good nutrition, and the removal of stress factors, with the purpose of attenuating the neonate's discomfort and bringing comfort to the family [5,7,8].

Perinatal palliative care, despite the same bases of conduction as the neonatal palliative care, is directed to those from twenty-two completed weeks of gestation to seven days of birth. This refers to care of pregnant women, whose expected infant has a condition that indicates the start of palliative care and the care of the newborn [9].

As soon as the fetal diagnosis is made and a therapeutic plan is established, a birth plan is needed to be drawn in order to guide the delivery and prenatal components [10]. Prenatal testing will be important to provide the parents with understanding regarding the presumed life-limiting diagnosis. The plans for assessment and care of the newborn should, ideally, be discussed before delivery and be available for further review [10]. Moreover, the intrapartum monitoring is deferred because of fetal indications and cesarean delivery, which is sometimes needed, may entail maternal risks with the prospects of neonatal demise. The decisions should be individualized and tailored to address each case and specific parents wishes [10].

According to the UK organization "Together for Short Lives", neonatal palliative care includes fetus, neonate, or infant with life-timing conditions. These conditions embrace physical, emotional, social, and spiritual life during this practice [11].

The objectives of this review were to ascertain the diseases that result in palliative care in neonates in NICU and whether such care can further alleviate the suffering of the child or the family.

## Methods

This is a descriptive narrative literature review study carried out from November 2020 to May 2021. The bibliography for this article was compiled from Medical Literature Analysis and Retrieval System Online (MEDLINE), PUBMED, Virtual Health Library (VHL) and Latin American and Caribbean Literature on Health Sciences (LILACS). In addition, as paper inclusion criteria, this study presents a selection of the articles that best fit the proposed subject, using the descriptors "Neonatal Intensive Care Units", "Neonatal ICU", "NICU", "Ethics," "Palliative Care", and "Perinatal" found in the database "Health Science Descriptors." It is relevant to mention that search words were combined using the Boolean operator "AND", except "Neonatal Intensive Care Units", "Neonatal ICU", "NICU" which have been combined with the Boolean operator "OR". This method of research was used to delimit the articles with the theme Neonatal Palliative Care.

Due to being a relatively new subject and to evaluate how much it has been discussed for the past 5 years, which is considered a small period of time in the scientific area, another criterion applied was the time frame between January 2015 and November 2020. On the other hand, NICU palliative care was chosen because it was the purpose of this article to focus only on this population. Furthermore, articles that were repeated among the research databases and those that did not address the subject studied or that did not establish ethical criteria of medical confidentiality were excluded.

Moreover, all the articles needed to be about the neonatal population in palliative care, indexed in the research databases, approved in ethics committees in English or Portuguese language, and the quality of the articles were considered according to Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA).

## Results

A total of 29 articles were found in the PUBMED database; 22 articles were found in the VHL database, of which one article was selected from LILACS and the other 21 articles from MEDLINE, and 10 articles were found in the BVS, all from MEDLINE. However, only 22 articles were selected for this review. There were 14 articles that were not consistent with the theme addressed in this study or did not respect medical

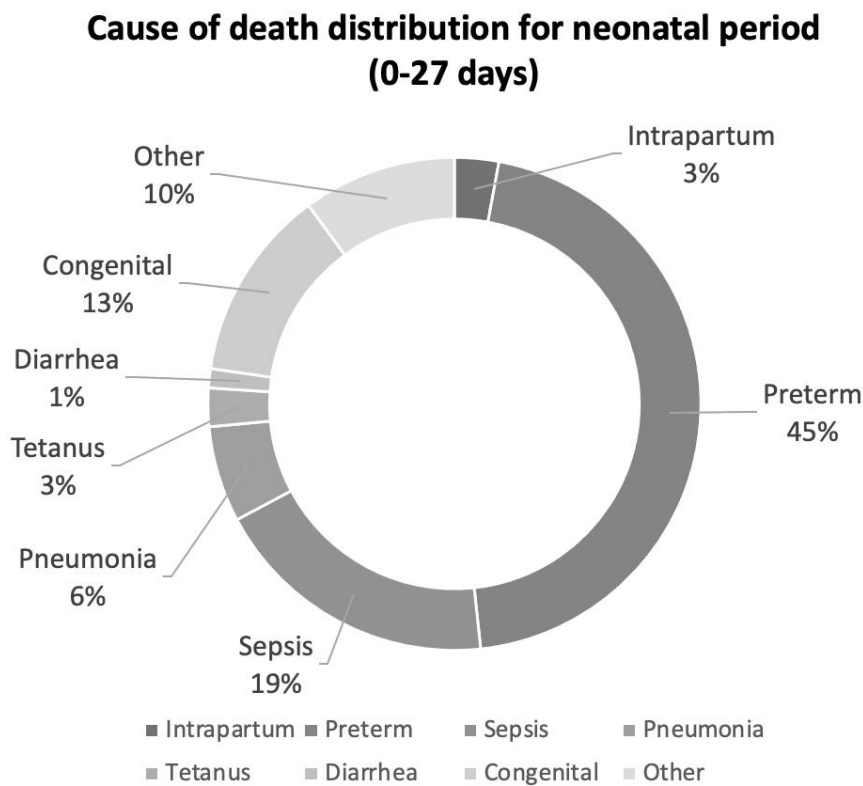
confidentiality. Also, there were 19 articles that were repeated among the researched databases. The total amount of articles discarded was 46.

The life-threatening diseases of neonates that prompt palliative care of the present study are summarized in **Table 1, Figure 1 and 2.**

**Table 1.** Life-threatening disease of neonates that prompt palliative care.

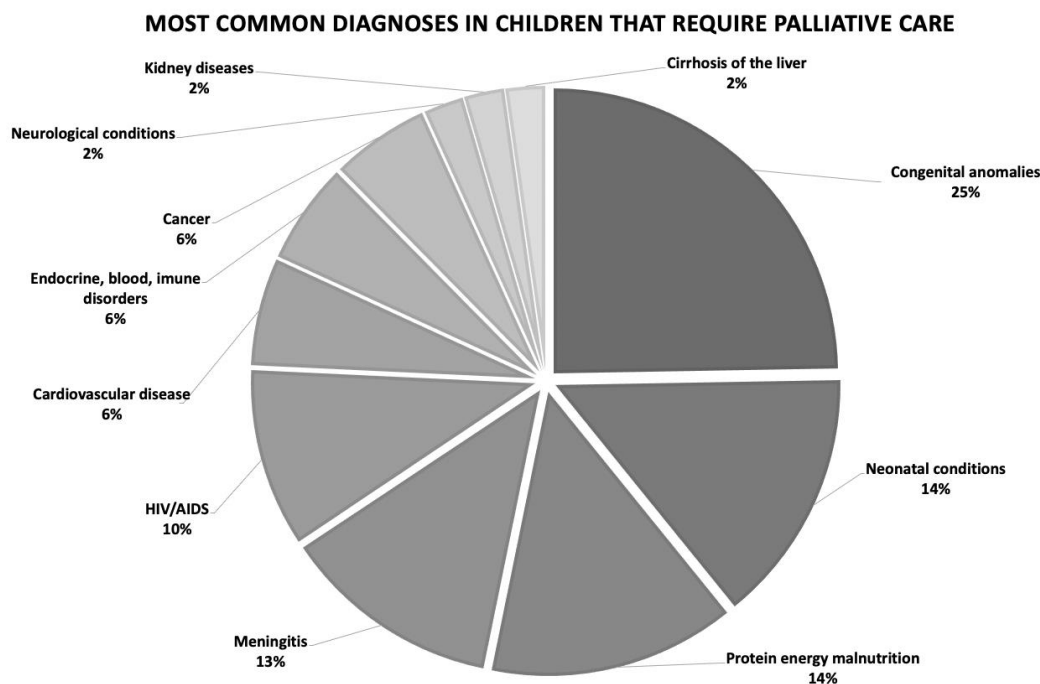
Lam V, et al. [19] and Janvier A et al. [20]	Neurodegenerative Disease
Boer JC, et al. [9] and Hellmann J, et al. [10]	Extreme Prematurity
Boer JC, et al. [9], Hellmann J, et al. [10] and Janvier A et al. [20]	Respiratory Failure
Hellmann J, et al. [10]	Sepsis, Multiorgan Failure
Boer JC, et al. [9], Zimmermann K, et al. [18], Lam V, et al. [19], Janvier A, et al. [20], Nayeri F, et al. [21]	Congenital Syndrome or Anomaly (Down and Edwards Syndrome)
Hellmann J, et al. [10], Zimmermann K, et al. [18] and Lam V, et al. [19]	Congenital Heart Disease
Lam V, et al [19].	Congenital Diaphragmatic Hernia, Abdominal Wall Defect, Renal Abnormalities, Neural Malformation, and others.

**Figure 1.** Distribution of cause of death for the neonatal period (the first 27 days).



Source: Progress, priorities, and potential beyond survival [54].

**Figure 2.** Represents the most common diagnoses in children that required palliative care. Most of them died from congenital anomalies, followed by neonatal conditions, protein energy malnutrition, meningitis, HIV/AIDS, and cardiovascular diseases.



Source: Global Atlas of Palliative Care at the End of Life [56].

Respiratory diseases and distress, prematurity, congenital abnormalities and patients at risk of neurological injury represent some of the reasons to refer the patient to the ICU [15,16,19,23]. Beyond that, the three most life-timing complex chronic conditions (CCC) are neurological, neuromuscular and cardiovascular diseases [16,21-23]. Prentice T. et al. [31] emphasizes that the relief in the neonatal ICU is an important factor, therefore palliative care should focus mostly on the patient.

Despite these factors, the conduct to be taken is chosen in association with the family, mostly commonly with the parents, who often choose to save their child "at all costs" [17,20,31,32]. In addition, the multidisciplinary team of health care empathize with the patient situation because they are in direct contact and want to provide palliative care corroborating with the wishes of the patient's parents, but that doesn't always happen [12,19,23,33].

Furthermore, neonatal palliative care in the ICU aims to relieve suffering, improve quality of life and facilitate shared decision-making [14-17,25,32,34]. Other than that, palliative care is appropriate from the moment when a serious diagnosis is made [15]. This care can be classified as "integrative", which is the usual care for the patient, and "consultative", which is the care to particularly complex cases [15]. Besides that, the environment of the ICU should focus extra attention

to deliver consistent, comprehensive, and personalized care [14,15]. Marmion PJ et al, highlight withholding relevant information while presenting a very negative message induces parents to choose palliative care [30].

Moreover, Aujoulat I et al quote "The Groningen Protocol" developed in the Netherlands, which refers to a systematic approach to make decisions based on a predefined number and objective criteria for Euthanasia in Newborns, is inconsistent with the goals of palliative care [20]. In this article, all 58 neonatologists make antenatal decisions, concerning whether to resuscitate at birth on the basis of the clinical assessment of the baby's maturity, its vitality at birth, and the presence of malformation not detected during the pregnancy. In addition, it is worth mentioning that the parents are usually involved in the decision [20]. Moynihan KM et al emphasize the approach with prolonged ventilation, tracheostomy or cardiopulmonary resuscitation are not compatible with shared decision making, and this topic should be decided in the antenatal period with the parents or family [17].

Besides that, Zimmerman K et al found that the median time between diagnosis of the life-timing in CCC and death was one month, therefore patients underwent several interventions and received a considerable amount of medications compared to others researches with the same profile diagnosis. Other than that, the most common intervention was surgery [21].

Kaempf JW [18] and collaborators developed a consensus guideline to help physicians choosing whether or not to use palliative care and, taking into account the gestation weeks, obstetric care, newborn care, and significant neurological disability. Thus, palliative care can be used, mostly, before 25 gestation weeks, after that, resuscitation or NICU care are indicated [18]. Proving this, Lam V et al in his research found that the lower of the gestational age is associated with, more is the primary reason for admission in the NICU care [22].

Prentice et al in his research developed the "Neonatal Intervention Score (NIS)", which is useful to highlight the relative illness severity and dependency on life-sustaining interventions or clinical trajectory of the patients [29].

About conduct, Mendes J et al evidenced that the treatment plans may include oxygen therapy, antiepileptics, antireflux medication and, if the newborn is able to eat, access to milk or formula [16]. Otherwise, Nayeri F et al demonstrated physicians are more inclined to treat the group with acceptable levels of survival, but these professionals are not inclined to treat aggressive measures in infants with severe asphyxia and advanced abnormalities [13,24].

## Discussion

The World Health Organization (WHO) defines palliative care as "an approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with life-threatening illness [35]. It prevents and relieves suffering through the early identification, correct assessment, and treatment of pain and other problems, whether physical, psychosocial or spiritual [35,36]. Therefore, neonatal palliative care is a set of actions and support to children and their families, usually proposed when the neonate is diagnosed with life-threatening conditions [1,37-39].

Many neonates die despite the great effort of the medical and nursing teams in Intensive Care Units (ICUs), but the best plan for the patient should always be considered in order to respect the patient's quality of life, as well as legal and ethical conditions such as beneficence, non-maleficence, justice, and autonomy, expressed, in this case, by the parents or legal representatives [12-17,40]. Once ethical and legal issues have been considered and care has transitioned to palliative care, comfort should remain the goal despite the healthcare team wanting to preserve life [18,40-43].

In this group of individuals, not only progressive diseases that pose a threat to life from the time of diagnosis suggest the start of palliative care, but also

diseases in which curative treatment cannot resolve the problem or in which death is foreseeable, as well as non-progressive diseases with severe disability [12,13,18-24]. Furthermore, this population also includes extreme preterm infants [12-14,20,25,26].

Some examples of the first situation are major polymalformative syndromes, genetic diseases (trisomy 13 and 18), neurodegenerative diseases, severe hypoxic-ischemic encephalopathy with poor prognosis, severe central nervous system malformations or with severe neurological sequelae, certain complex heart diseases, and certain metabolic diseases; examples for the second situation are very severe meconium aspiration syndrome, sepsis with multiorgan failure and no clinical improvement, extremely severe diaphragmatic hernia with no clinical improvement or with short bowel plus severe absorption problems; and for the third situation, severe cerebral palsy with complex health needs or severe pulmonary sequelae [13,19,21-23,27].

There are several clinical situations that suggest a poor prognosis of the neonate, which might be included in palliative care, such as severe neurological lesions [43,44]. The risk of impaired neurodevelopment of the child increases with the duration of ICU hospitalization [28]. Therefore, to estimate the infant's initial counseling during birth, healthcare professionals can use the National Institute of Child Health and Human Development (NICHD) Calculator and the Prematurity Risk Evaluation Measurement (PREM) Score, although these measures do not cover clinical changes in the neonate after ICU admission [29]. In addition, other methods that can be used for palliative care counseling include the Score for Neonatal Acute Physiology version II (SNAP-II) and the Score for Neonatal Acute Physiology with Perinatal Extension version II (SNAPPE-II), which consider physiological parameters to predict both mortality and resource utilization of referral units, although these criteria can only be used up to the end of the first 24 hours of life of the newborn [29].

There is also the Neonatal Therapeutic Intervention Score System (NTISS), which covers the severity of the disease according to the intervention performed, but it is valid only for the first few days of the patient's life [29]. Nevertheless, the ICU staff usually considers gestational age, birth weight, gender, expected antenatal steroid use, and whether the baby was born in a hospital with no ICU [28-30].

Prentice and collaborators developed the Neonatal Intervention Score (NIS), which describes the disease severity and prognosis [29]. The authors of this tool express the utmost importance that it brings to the therapeutic discussion, stating that the patient's clinical status should not be disregarded [29]. Another fact to

be highlighted is the need for the validation process of this score in other institutions. Despite all these scores developed to help in the therapeutic choice for the neonate, usually the prognosis is unpredictable, especially in neonatal ICUs [14]. Moreover, Limbo R and collaborators demonstrated in their book categorized palliative care in hospitals, which is divided in three ranks based (basic skills, mid-level, advanced skills) on the resources of the hospital [9].

Notwithstanding all the ethical measures and care in communicating with the family, there is still a need for great evolution of this practice in healthcare institutions [13]. Nayeri and collaborators demonstrated in their study that the decision to propose palliative care usually rests with the physician in charge of the case, which interferes directly with society, creating space for the debate on the need for intensive care [24]. Therefore, factors such as prognosis and suffering of the child, religion, ethics, legal aspects, cultural beliefs of family members, and professionals involved may interfere in the palliative approach [13-17,21,23,28,29,31].

Moreover, the child's treatment is always discussed with other health professionals before the options are presented to the family [16-18,25,43-46]. Boer and collaborators suggested a structured, multi-professional, and ethical medical system, characterized by meetings with professionals from different healthcare areas to assist medical decisions regarding the therapy of the neonate patient in the ICU [12]. Family counseling occurs in the presence of the doctor, the nurse, and a social worker [12,14,47,48]. Another ethical measure that should not be forgotten is the signature of the Term of Consent by the patient's legal representatives [13,20].

The choice of therapy for the newborn is always made by the child's legal representatives with the help of the medical team [12,14,15,17,49,50]. However, there is a limit to the parents' decision-making authority when it represents great harm compared to the alternative recommended by the healthcare team, which means that the state must intervene to provide adequate care for the patient [14,51].

Hellmann and collaborators demonstrated in their study that most of the physicians in charge of neonatal patients offered palliative care therapy with withdrawal of life support equipment to avoid or prevent survival with poor quality of life, as a result from the consensus between the decision of the child's legal representatives and the opinion of the healthcare team [13]. Nevertheless, three studies reported the regularity of moral stress in neonatal ICUs due to the existence of disagreement in the therapies carried out in these units [23,31,32]. In spite of this inconsistency, the moral stress experienced

by healthcare professionals can be considered an expression of humanity, and it interferes in the relationship between the family and the healthcare agents [19,31,52].

For the patient with uncertain prognosis, the baby may concurrently get both curative and palliative care, until the baby's outcomes become clear [5,19,20,22]. This may include surfactant, ventilatory support, parental nutrition, and advanced surgical techniques besides palliative care, the latter classified as integrative when incorporated by all unit providers, or consultative when it has a sub-specialized team in such care, particularly in complex cases [15,19,20,22] (Table 2). Likewise, neonatal care in these units aims to relieve the patients' suffering, improve their quality of life, facilitate shared decision-making, and coordination of care for the families in cases of serious illnesses, in addition to helping the family get through situations in which the patient's diagnosis is uncertain [15,16]. It is important to consider that curative and palliative propaedeutics can coexist by merely changing to end-of-life care, which focuses on the control of the neonate's symptomatology [16].

**Table 2.** Strategies in pediatric palliative care.

<i>Place of caring</i>	<i>Conduct</i>
Maternity room	Heat, Minimum stimulation, Kangaroo care, Swaddling, Non-nutritive sucking
	Acetaminophen, Midazolam, Lorazepam, Morphine, Oral sucrose
ICU	Heat, Minimum stimulation and pain procedures, Swaddling, Non-nutritive sucking, Noise and Light reduction, Kangaroo care, Massage, Music, Nesting
	Acetaminophen, Midazolam, Lorazepam, Morphine, Oral sucrose, Gabapentin, Clonidine, Fentanyl, Baclofen
<i>Home</i>	Heat, Swaddling, Nutritive or non-nutritive sucking, Kangaroo care, Massage, Music
	Acetaminophen, Midazolam, Lorazepam, Morphine, Oral sucrose, Gabapentin, Clonidine, Fentanyl, Baclofen

Source: Lemmon ME, et al [15].

According to Zimmermann and collaborators, early initiation of pediatric palliative care allows planning and implementation of specialized care at home in a way that promotes family relief and improves the patient's quality of life [21]. Thus, before the child is born, palliative care focuses on the emotional, psychosocial,

and spiritual state of the parents, providing spiritual and cultural support [16,17]. Also, it is the woman's and her family's right to have psychological assistance in dealing with depression, post-traumatic stress disorder, and anxiety arising from the loss of a newborn [16]. Another aspect is palliative care in the ICU aimed at family care, so that parents or family members are allowed to hold their children in their final moments and with the cardiorespiratory monitors turned off to focus the family's attention on the child. Hence, the conclusion is that palliative therapy serves all individuals involved, such as health professionals, parents, and the child itself [22].

Healthcare professionals should be properly trained in palliative care so that, when approaching the family, they can empathize with them and call the neonate by the name; conversations with relatives should be individualized and adapted to the psychosocial situation of the family; the child's guardians should know what the diagnosis means and what therapeutic options exist so that, together with the ICU team, they can decide on the best course of action [18,23,33,34,53-55].

## Conclusions

Neonatal palliative care is provided by a range of treatment improvements that will ensure the survival and the quality of life of those who were born extremely premature or with severe diseases/malformations. Moreover, this activity focuses on the infant and his or her family, including, specially, the mother. Palliative care cure-oriented and disease-modifying care intensify when curative therapies are no longer beneficial or appropriate. This research shows important development factors of the NICU. In this way, doctors can improve their conduct in the day-to-day medicine practice in this area, always maintaining a deep respect for human dignity. Thus, further studies are needed on the subject and the development of a protocol for health professionals to follow, integrating the patient's family in this care. In addition, knowledge about palliative care must be disseminated in order to provide a more humanized medicine, especially in Neonatal Intensive Care Units. For this purpose, the care unit must provide training for these agents.

Neonatal palliative care involves the care of neonates and their families, ensuring the transition between life and death of this child to be as painless as possible. Also, each step in the medical course of action involves the family members so that they are aware they have done everything possible, and do not burden themselves with a sense of guilt.

However, the healthcare team should always

prioritize the best procedure in favor of the patient's well-being until the last moment, even if this is initially contrary the parents' wishes, who have chosen intensive therapy in contradiction to the rights of quality of life. Therefore, negatively influencing the course of the psychological, social, and physical development of the neonate. Palliative care aims primarily at relieving the child's suffering by focusing on the control of the symptomatology.

In conclusion, even though caring for the neonate is the priority, his or her loved ones should also receive assistance, as they do suffer with the illness of their child as well.

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## Informed consent

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No additional data are available.

## Conflict of interest

The authors declare no conflict of interest.

## Similarity check

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## References

1. World Health Organization [internet]. Palliative Care; c2021 [access on January 12, 2021]. Available at: <https://www.who.int/health-topics/palliative-care>.
2. Evangelista CB, Lopes MEL, Costa SFG, Batista PSS, Batista JBV, Oliveira AMM. Palliative care and spirituality: an integrative literature review. *Rev Bras Enferm.* 2016; 69 (3): 554-63.
3. Cherny NI, Radbruch L, The board of the European Association of Palliative Care. *European*

- Association for Palliative Care (EAPC) recommended framework for the use of sedation in palliative care. 2009; 23(7): 581-93.
4. Ranallo L. Improving the Quality of End-of-Life Care in Pediatric Oncology Patients Through the Early Implementation of Palliative Care. *J Pediatr Oncol Nurs*. 2017; 34 (6): 374-80.
  5. Parravicini E. Neonatal Palliative Care. *Curr Opin Pediatr*. 2017; 29 (2): 135-40.
  6. Liben S, Papadatou D, Wolfe J. Paediatric palliative care: challenges and emerging ideas. *The Lancet*. 2008; 371 (9615): 852-64.
  7. Valadares MTM, Mota JAC, Oliveira, BM. Cuidados paliativos em pediatria: uma revisão. *Rev Bioét*. 2013; 21 (3): 486-93.
  8. Bellazzi JL, Vieira MRR, Cury PM, Augusto MT. Cuidados Paliativos e Doença Crônica na Infância: Quem são as crianças?. *Revista de Cuidados Paliativos*. 2016; 3 (2): 71-80.
  9. Limbo RK, Wool C, Carter BS. *Handbook of Perinatal and Neonatal Palliative Care: a guide for nurses, physicians, and other health professionals*. Springer Publishing Company, LLC. New York. 2020.
  10. Perinatal palliative care. ACOG Committee Opinion No. 786. American College of Obstetricians and Gynecologists. *Obstet Gynecol* 2019; 134:84-9.
  11. Paravicini E. Neonatal Palliative Care. *Current Opinions in Pediatrics*. 2017; 29(2): 135-40.
  12. Boer JC, Gennissen L, Williams M, Dijk M, Tibboel D, Reiss I, et al. Children's outcomes at 2-years follow-up after 4 years of structured multi-professional medical ethical decision-making in a neonatal intensive care unit. *J Perinatol*. 2017; 37 (7): 869-74.
  13. Hellmann J, Knighton R, Lee SK, Shah PS. Neonatal deaths: prospective exploration of the causes and process of end-of-life decisions. *Arch Dis Child Fetal Neonatal Ed*. 2015; 101 (2):102-7.
  14. Krick JA, Hogue JS, Reese TR, Studer MA. Uncertainty: an uncomfortable companion to Decision-making for Infants. *Pediatrics*. 2020; 146 (1): 13-7.
  15. Lemmon ME, Bidegain M, Boss RD. Palliative care in neonatal neurology: robust support for infants, families and clinicians. *J Perinatol*. 2015; 36 (5): 311-7.
  16. Mendes J, Wool J, Wool C. Ethical considerations in Perinatal Palliative Care. *J Obstret Gynecol Neonatal Nurs*. 2017; 46 (3): 367-77.
  17. Moynihan KM, Jansen MA, Liaw SN, Alexander PMA, Truog RD. An ethical claim for providing medical recommendations in pediatric intensive care. *Peatr Crit Care Med*. 2018; 19 (8): 433-7.
  18. Kaempf JW, Dirksen K. Extremely premature birth, informed written consent, and the Greek ideal of sophrosyne. 2018; 38 (4): 306-10.
  19. Oliveira FC, Cleveland LM, Darilek U, Silva ARB, Carmona EV. Brazilian neonatal nurses' palliative care experiences. *J Perinat Neonatal Nurs*. 2018; 32 (4): 3-10.
  20. Aujoulat I, Henrard S, Charon A, Johansson AB, Langhendries JP, Mostaert A, et al. End-of-life decisions and practices for very preterm infants in the Wallonia-Brussels Federation of Belgium. *BMC Pediatr*. 2018; 18 (1): 206.
  21. Zimmermann K, Cignacco E, Engberg S, Ramelet AS, Weid N, Eskola K, et al. Patterns of paediatric end-of-life care: a chart review across different care settings in Switzerland. *BMC Pediatr*. 2018; 18 (1): 67.
  22. Lam V, Kain N, Joynt C, Manen MA. A descriptive report of end-of-life care practices occurring in two neonatal intensive care units. *Palliat Med*. 2016; 30 (10): 971-8.
  23. Janvier A, Farlow B, Baardsnes J, Pearce R, Barrington KJ. Measuring and communicating meaningful outcomes in neonatology: a family perspective. *Semin Perinatol*. 2016; 40 (8): 571-7.
  24. Nayeri F, Asghari F, Baser A, Janani L, Shariat M, Eabrhim B. Views and Decisions of Physicians in Encountering Neonates with Poor Prognosis. *Arch Iran Med*. 2017; 20 (3): 172-7.
  25. Kaempf JW, Tomlinson MW, Touhey J. Extremely premature birth and the choice of neonatal intensive care versus palliative comfort care: an 18 years single-center experience. *J Perinatol*. 2016; 36 (3): 190-5.
  26. Jaworski M, Janvier A, Lefebvre F, Luu TM. Parental Perspectives Regarding Outcomes of Very Preterm Infants: Toward a Balanced Approach. *J Pediatr*. 2018; 200: 58-63.
  27. Mendes J, Silva LJ. *Consenso Paliativos e Neonatais e em fim de vida*. Access on: January 12, 2021. Available at: [https://www.spneonatologia.pt/wp-content/uploads/2016/11/2013-Cuidados\\_paliativos.pdf](https://www.spneonatologia.pt/wp-content/uploads/2016/11/2013-Cuidados_paliativos.pdf)
  28. Ferrand A, Gorgos A, Ali N, Payot N. Resilience rather than medical factors: how parents predict quality of life of their sick newborn. *J Pediatr*. 2018; 200: 64-75.
  29. Prentice TM, Janvier A, Gillman L, Donath S, Davis P. Providing clarity around ethical discussion: development of a neonatal intervention score. *Acta Paediatr*. 2019; 108 (8): 1453-9.



30. Marmion PJ. Perivability and the "god committee". *Acta Paediatr.* 2017; 106 (6): 857-9.
31. Prentice TM, Janvier A, Gillman L, Davis PG. Moral distress within neonatal and pediatric intensive care units: a systematic review. *Arch Dis Child.* 2016; 101 (8): 701-8.
32. Prentice TM, Gillman L, Davis PG, Janvier A. Always a burden? Healthcare providers' perspectives on moral distress. *Arch Dis Child Fetal Neonatal Ed.* 2018; 103 (5): 441-5.
33. Forouzi MA, Banazadeh M, Ahmadi JS, Razban F. Barriers of Palliative Care in Neonatal Intensive Care Units. *Am J Hosp Palliat Care.* 2017; 34 (3): 205-11.
34. Menin GE, Pettenon MK. Terminally child life: perceptions and feelings of nurses. *Rev Bioet.* 2017; 23 (3): 608-14.
35. World Health Organization [homepage na Internet]. WHO definition of palliative care. Access on: January 10, 2021. Available at: <https://www.who.int/news-room/fact-sheets/detail/palliative-care>.
36. Lima RPG. Palliative care: challenges for the health systems. *Rev Latino Am Enfermagem.* 2011; 19(2): 227-8
37. Summer LH, Kavanaugh K, Moro T. Extending palliative care into pregnancy and the immediate newborn period. *J Perinat Neonat Nurs.* 2006; 20(1): 113-6.
38. Boss R, Kavanaugh K, Kobler K. Prenatal and Neonatal Palliative Care. In: Wolfe J, Hinds P, Sourkes B. *Textbook of interdisciplinary pediatric palliative care.* Philadelphia: Souders; 2011.
39. Liben S, Wolfe J. Paediatric palliative care: challenges and emerging ideas. *The Lancet.* 2008; 371(9615): 852-64.
40. Mancini A, Bluebond-Langer M. Training neonatal staff for the future in neonatal palliative care. *Seminars in Fetal and Neonatal Medicine.* 2013; 18(2): 111-5.
41. Committee on Bioethics and Committee on Hospital Care. *Palliative Care for Children.* American Academy of Pediatrics. 2021; 106(2): 351-7.
42. Carlet J, Thijs LG, Antonelli M, Cassel J, Cox P, Hill N. Challenges in end-of-life care in the ICU. *Intensive Care Medicine.* 2004; 30: 770-84.
43. Gavrin J. Ethical considerations at the end of life in the intensive care unit. *Critical Care Medicine.* 2007; 35(2): 85-94.
44. Himelstein BP. Palliative care for infants, children, adolescents, and their families. *Journal of Palliative Medicine.* 2006; 9(1): 163-81.
45. Bhatia J. Palliative care in the fetus and newborn. *J Perinatol.* 2006; 26: 24-6.
46. Becker SP. Wilderness Therapy: ethical considerations for mental health professionals. *Child & Youth Care Forum.* 2010; 39: 47-61.
47. Heyland DK, Allan DE, Rocker G, Dodek P, Pichora D, Gafni A. Discussing prognosis with patients and their families near the end of life: impact on satisfaction with end-of-life. *Open Med.* 2009; 3(2): 101-10.
48. Mizrahi T, Abramson JS. Collaboration between social workers and physicians. *Social Work in Health Care.* 2000; 31(3): 1-24.
49. Heimer CA. Competing institutions: law, medicine, and family in neonatal intensive care. *Law & Society Review.* 1999; 33(1): 17-66.
50. Kirkbride V. Managing complex ethical problems on the neonatal unit. *Medical ethics.* 2013; 9(2): 66-70.
51. Kukura E. Birth conflicts: leveraging state power to coerce health care decision-making. *University of Baltimore Law Review.* 2018; 47(2): 247-94.
52. Choe K, Kang Y, Park Y. Moral distress in critical care nurses: a phenomenological study. *Journal of Advanced Nursing.* 2015; 71(7): 1684-93.
53. Osterweis M, Solomon F, Green M. *Institute of medicine (US) committee for the study of health consequences of the stress of bereavement.* Washington (DC): National Academies Press (US); 1994.
54. Thomas TA, Reed PA. Ethics: a historical perspective. In: Mazur KA, Berg SL. *Ethical issues in pediatric hematology/oncology.* Houston: Springer; 2020.
55. Lawn JE, Blencowe H, Oza S, You D, Lee AC, Waiswa P et al. Every Newboen: profess, priorities, and potential beyond survival. 2014; 384(9938):185-205.
56. Connor SR et al. *Global Atlas of Palliative Care,* 2nd edition. World of Health Organization. 2020. Available at: <http://www.thewhpc.org/resources/global-atlas-on-end-of-life-care>.

