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ORIGINAL ARTICLE

Facilities and difficulties of palliative care in neonatology: nurses' experiences

Facilidades e dificuldades dos cuidados paliativos em neonatologia: vivências dos enfermeiros

Instalaciones y dificultades de los cuidados paliativos en neonatología: experiencias de enfermeros

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Abstract

Objective: To learn the experiences of nurses in front of the facilities and difficulties for palliative care in neonatology. **Method:** A qualitative research was carried out with nurses in neonatal intensive care units. We used the methodological reference Discourse of the Collective Subject. **Results:** Eight central ideas (IC) emerged, grouped into three themes: Experiences of nurses in palliative care (IC1 End-of-life palliative care; IC2 Confronting palliative care and curative measures); Facilities for the implementation of neonatal palliative care (IC3 Knowledge and congruence in conduct); Difficulties of the team to perform palliative care (IC4 Importance in offering training; IC5 Gaps in the definition of criteria; IC6 Palliative versus curative decision-making; IC7 Communication of bad news; IC8 Inadequate environment). **Conclusion:** Nurses report differences in behavior and non-acceptance as barriers. However, they saw that the training and multidisciplinary discussions and the inclusion of the family can facilitate the implementation of palliative care in neonatology.

Descriptors: Palliative Care; Newborn; Neonatal Intensive Care Units; Neonatal Nursing.

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Resumo
Objetivo: Apreender as vivências dos enfermeiros frente às facilidades e dificuldades para os cuidados paliativos em neonatologia. **Método:** Pesquisa qualitativa realizada com enfermeiros em unidades de terapia intensiva neonatal. Utilizou-se referencial metodológico Discurso do Sujeito Coletivo. **Resultados:** Emergiram oito ideias centrais (IC), agrupadas em três temas: Vivências dos enfermeiros nos cuidados paliativos (IC1 Cuidados paliativos no fim da vida; IC2 Confrontando cuidados paliativos e medidas curativas); Facilidades para implantação dos cuidados paliativos neonatais (IC3 Conhecimento e congruência na conduta); Dificuldades da equipe para a realização dos cuidados paliativos (IC4 Importância em ofertar capacitação; IC5 Lacunas na definição de critérios; IC6 Tomada de decisão paliativista versus curativa; IC7 Comunicação de más notícias; IC8 Ambiente inadequado). **Conclusão:** Os enfermeiros referem divergências de conduta e a não aceitação como barreiras. No entanto, vislumbraram que a capacitação e discussões multidisciplinares e, a inclusão da família podem facilitar a implantação dos cuidados paliativos em neonatologia.

Descritores: Cuidados Paliativos; Recém-nascido; Unidades de Terapia Intensiva Neonatal; Enfermagem Neonatal.

Resumen
Objetivo: Aprehender las experiencias de los enfermeros frente a las facilidades y dificultades para los cuidados paliativos en neonatología. **Método:** Investigación cualitativa realizada con enfermeras en unidades de cuidados intensivos neonatales. Se utilizó el referencial metodológico Discurso del Sujeto Colectivo. **Resultados**: Surgieron ocho ideas centrales (IC), agrupadas en tres temas: Vivencias de los enfermeros en cuidados paliativos (IC1 Cuidados paliativos al final de la vida; IC2 Confrontando cuidados paliativos y medidas curativas); Facilidades para la implantación de cuidados paliativos neonatales (IC3 Conocimiento y congruencia en la conducta); Dificultades del equipo para la realización de los cuidados paliativos (IC4 Importancia en ofrecer capacitación; IC5 Lagunas en la definición de criterios; IC6 Toma de decisiones paliativa versus curativa; IC7 Comunicación de malas noticias; IC8 Ambiente inadecuado). **Conclusión:** Los enfermeros mencionan las diferencias de conducta y la no aceptación como barreras. Sin embargo, vislumbraron que la capacitación y discusiones multidisciplinarias y la inclusión de la familia pueden facilitar la implantación de cuidados paliativos en neonatología.

Descriptores: Cuidados Paliativos; Recién Nacido; Unidades de Cuidados Intensivos Neonatales; Enfermería Neonatal.

Introduction

With technological advancements and improvements in neonatal care, there has also been an increase in survival rates for this population group. However, due to the great fragility of premature newborns (PNBs), they still suffer from adverse outcomes, with high morbidity and mortality rates in the Neonatal Intensive Care Unit (NICU), with irreversible sequelae that increase the baby's length of stay and consequently the suffering of the entire family.[1,2]

With a focus on the comfort of the RNP and their family, the philosophy and practice of Palliative care (PC) is an important topic to be discussed and is gaining ground in the field of neonatology.[1,3] PC should maximize the quality of life and comfort of the newborn and their families, supporting the relief of suffering when affected by a life-threatening illness.[3,4]

In Brazil, in 2018, regulations were established to guarantee palliative care within the Unified Health System (SUS), considering any individual with a life-threatening illness, whether in an acute or chronic diagnostic condition, eligible for palliative care and therefore entitled to multidisciplinary assistance to improve the quality of life of the patient and their family through the prevention and relief of suffering. Early identification, impeccable assessment, and treatment of pain and other physical, social, psychological, and spiritual symptoms.[5] Thus, when we turn our attention to the newborn (RNP), in their serious clinical situation, at risk of death, or outside of therapeutic treatment, they must be assisted with the purpose of obtaining comprehensive care and humanized[1,3,5], guaranteeing access, welcoming and effective solutions at different levels of care.

One of the shortcomings of palliative care in neonatology stems from the limited space for discussions among the multidisciplinary team in end-of-life and death situations, a complex experience that potentially aggravated in this NICU environment by the difficulty of facing death early in life.[1]

To achieve safe and comprehensive care, specific attention and training are necessary, as well as insight and sensitivity on the part of the healthcare team, which assists newborns admitted to the NICU who are in a state of dependency, frailty, and instability.[6]

There are descriptions of a variety of perinatal and palliative care programs in neonatology, but most focus exclusively on end-of-life care. Furthermore, there is a great need to standardize practices and obtain quality measures of follow-up to achieve a state of comfort, with a family-centered care approach.[7] Therefore, a multidisciplinary team is recommended to address the needs of the babies, as well as the grieving process of the parents and the suffering of the healthcare professionals.[1]

The nurse plays an important role in the set of actions for babies and families, with the other professionals in the context of the multidisciplinary team[7], given that care is the foundation of this professional's work, therefore the present study aims to understand the experiences of nurses in the face of the facilities and challenges for palliative care in neonatology.

Method

This cross-sectional, qualitative study, grounded in the conceptual basis of palliative care, was conducted with nurses working in NICUs at three hospitals located in the northern region of the state of Paraná, Brazil. The guidelines of the Consolidated Criteria for Reporting Qualitative Research (COREQ) were adopted.[8]

The conceptual basis adopted was palliative care, defined as the prevention and relief of suffering, improving quality of life, facilitating informed decision-making, and assisting in coping with problems associated with potentially fatal diseases.[9]

The inclusion criteria adopted for the study were nurses with a minimum of six months of experience in the NICU; professionals who were absent due to vacation or leave during the data collection period were not included.

Initially, there were 25 nurses who could participate in the research, according to the inclusion criteria. However, 20 nurses participated, as three refused and two interviews were disregarded due to failures in the recording.

The research setting consisted of three NICUs located in hospitals accredited by the Brazilian Unified Health System (SUS), which were designated, for this study, as hospitals A, B, and C. Hospital A – a public service considered a Regional Reference Center, Hospital B – a philanthropic institution, a model of care for high-risk pregnant women, and Hospital C – a philanthropic institution with exclusive care for the pediatric population and serving various health insurance plans. Only in Hospital A is there a movement towards the implementation of palliative care in the neonatology service; however, at the time of data collection, implementation had not yet occurred.

Data collection took place between November 2019 and January 2020, following a pilot test lasting an average of 30 minutes, including the initial interaction and the interview.

To schedule the interviews, prior telephone contact was made directly to the nurses' work departments, explaining the research objective, the need for a private location for data collection, and the approximate duration. After acceptance, the date and time for data collection were scheduled. The interviews were conducted by the principal researcher on the institution's premises, during the nurses' working hours audio was recorded and, later transcribed in its entirety. At the end of each interview, the audio was made available to the nurse, who could make changes if deemed necessary.

The individual interview technique and a semi-structured interview guide were used containing two parts, the first related to the characterization of the professionals and the second with questions related to the research topic, such as: Have you experienced or do you remember any situation involving babies who were being cared for in your service and who received palliative care? (tell me what the baby's condition was and what measures were taken that, for you, constituted palliative care); Even if your service does not adopt or have criteria for palliative care, what would be the greatest difficulties and advantages in working with palliative care in neonatology?

To understand the experiences of nurses and the advantages and disadvantages of palliative care in neonatology, the Collective Subject Discourse (CSD) was the method chosen for constructing meaning, allowing for a closer understanding of the phenomenon under study. The CSD proposes the organization and tabulation of qualitative data in a discursive manner, seeking to clarify the thoughts or experiences of a given population on a particular topic. In this study, three methodological figures were used: the key phrase, the central idea (CI), and the DSC.12

The key phrase is the methodological figure that reveals the essence of the testimony, that is, what the subject said about a given topic. The key phrase consists of describing the meaning present in the key phrase. In the DSC (Discourse Synthesis), qualitative data are presented through a synthesis discourse, written in the first person singular and elaborated with the most significant extracts from meaningful testimonies similar.[10]

To this end, following the transcription of the interviews, an exhaustive reading of each individual response was carried out, highlighting the most significant passages that reveal the essence of the content of the individual discourses, referred to as key expressions. Then, the central ideas, those that succinctly describe the meaning of the key expressions, were identified and separated. With this, synthesis discourses were constructed, in the first person singular; that is, the thought of the group or collectivity appears as if it were an individual discourse. In this way, linguistic vices were removed and connectors were used to give meaning to the synthesis discourse, without altering the meaning of the sentence elaborated by the participant.

This research has been approved by the Ethics Committee for Research Involving Human Beings under opinion number 3.665.201, CAAE number 14997219.1.0000.5231. All interviews began after reading and clarifying the objectives, inclusion criteria, and procedures for conducting the research and the signing of the Informed Consent Form (ICF) by the participant, with a copy remaining with the participant. In order to preserve the anonymity of the participating nurses and to better understand the analysis performed, their names were replaced by the initials Nurse, followed by the numerical sequence, based on the order in which the interviews were conducted, and the letter corresponding to the hospital where they work.

Regarding the timing for stopping data collection, sample saturation was not used; instead, all nurses who met the inclusion criteria were guaranteed participation in the study. This precaution was taken due to the scarcity of knowledge on this topic, which has emerged in recent times.

Results

Participants in this study included 20 nurses, 13 of whom were between 20 and 30 years old, 14 with less than 5 years of experience in NICUs, 18 with postgraduate degrees (lato sensu) and 2 with stricto sensu (master's) degrees.

From the analyzed discourses, eight key insights (CIs) emerged, which were grouped into three themes: 1 – Nurses' experiences in palliative care (CI1 – Palliative care at the end of life; CI2 – Confronting palliative care and curative measures); 2 – Facilitating the implementation of neonatal palliative care (CI3 – Knowledge and congruence in conduct); 3 – Team difficulties in providing palliative care (CI4 – Importance of offering training; CI5 – Gaps in defining criteria; CI6 – Palliative versus curative decision-making; CI7 – Communicating bad news; CI8 – Inadequate environment).

Theme 1 – Experiences of Nurses in Palliative Care

In general, palliative care is experienced by nurses as being geared towards end-of-life care, the period approaching the end of life. This approach can vary depending on the professional providing the care, with the physician being responsible for determining the extent to which therapeutic intervention should occur and when to initiate palliative care.

IC1 – Palliative Care at the End of Life

DSC1: *I recall a few cases, and they generally do not last long. For example, the case of a baby who was considered cardiac arrest after birth because he was born in a condition incompatible with life, and although he remained with his mother for only a short time, he was soon brought to the NICU where he received mainly comfort care and instructions not to resuscitate in case of cardiorespiratory arrest. There are many extremely premature babies in this situation, and within hours or days, they die. Depending on the on-call physician, cardiac arrest only begins at a very advanced stage of the disease, through drug reduction, non-resuscitation, and waiting for specialists; that is, it is not a path to be followed during the lifespan, but is associated with babies in imminent danger of death (Nurse 1A, Nurse 4A, Nurse 8B, Nurse 12A, Nurse 18B).*

DSC2: *I did not experience palliative care in the NICU, only attempts at it. I believe that palliative care is not being carried out, as some actions and interventions taken were unnecessary. I have doubts because we try to offer comfort to all babies, regardless of the severity and imminence of death. Depending on the on-call physician, we reduce interventions, do not perform resuscitation maneuvers, and increase contact with the family (Nurse 5A, Nurse 9A, Nurse 10C, Nurse 11A, Nurse 13A, Nurse 14B, Nurse 16C, Nurse 17B).*

In other situations, nurses mentioned palliative care as a process that only begins when invasive measures have been exhausted.

IC2 - Confronting Palliative Care and Curative Measures

DSC3: *I think many babies are referred to the pediatric ward after a period of invasive measures, until the prognosis is determined by the team or even after a request from the parents, and from that conversation, they prioritize comfort, focusing mainly on pain control and reducing unnecessary interventions (Nurse 2A, Nurse 3A, Nurse 15B, Nurse 19A, Nurse 20A).*

DSC4: *There was a case of a baby who returned from the ward intubated after stopping breathing during breastfeeding, and tests showed that she would have sequelae. From that moment on, when antibiotics were no longer effective, they opted for this care, allowing the parents greater contact. The Kangaroo Method was used all day, with sedation, pain control, and breathing only with the help of a ventilator until the end.* (Nurse 2A, Nurse 3A, Nurse 15B, Nurse 19A, Nurse 20A).

Topic 2 – Facilitating the Implementation of Neonatal Palliative Care

Professional training regarding the meaning of CP (Comprehensive Care) enables teams to understand their role and become more collaborative, and, coupled with the convergence of the multidisciplinary team in decision-making, facilitates implementation as represented by nurses.

IC3 – Knowledge and Congruence in Conduct

DSC: *I believe that several factors favor the provision and implementation of CP, highlighting the training of the multidisciplinary team, working in a hospital linked to academia and with a large circulation of residents from different areas connected to teaching and research (Nursing 1A, Nursing 2A, Nursing 3A, Nursing 4A, Nursing 5A, Nursing 6C, Nursing 7C, Nursing 8B, Nursing 9A, Nursing 12A, Nursing 14B, Nursing 15B, Nursing 19A, Nursing 20A).*

DSC6: *I think it's necessary to establish a team to carry out these training sessions, as well as clearly define the criteria and routines, and improve communication, encouraging discussions about the "new" practices so that the procedures are consistent across the entire team regardless of shifts, and after that, include the family in the baby's care during this complicated time.*(Nurse 1A, Nurse 2A, Nurse 3A, Nurse 4A, Nurse 5A, Nurse 6C, Nurse 7C, Nurse 8B, Nurse 9A, Nurse 12A, Nurse 14B, Nurse 15B, Nurse 19A, Nurse 20A).

DSC7: *When teams are well-informed and have defined care measures, especially the nursing team, they tend to be more collaborative. I find it easier to deal with situations when the doctor shares my mindset and is focused on the child's well-being, putting themselves in the child's shoes. We have a doctor who is doing a master's degree and is sensitizing everyone* *to this issue; this is one of the advantages of working in a teaching hospital, in addition to receiving newly graduated nurses with new knowledge. It would be much easier if all professional categories were working together and speaking the same language (Nurse 1A, Nurse 2A, Nurse 3A, Nurse 4A, Nurse 5A, Nurse 6C, Nurse 7C, Nurse 8B, Nurse 9A, Nurse 12A, Nurse 14B, Nurse 15B, Nurse 19A, Nurse 20A).*

DSC8: *The nursing team is quite sensitive and has a more palliative care-oriented approach compared to the medical team, although this is gradually improving. When we are aware and understand that it is truly best for the baby and the family, I personally feel relieved and I think that offering palliative care would greatly facilitate our work in communicating with the family and would increase their bond with the team, in addition to witnessing the patient's well-being, with more comfort, pain relief and less investment at any cost, saving time and suffering for the family, the baby and ourselves, easing the stress on the team. Inclusion in this care would avoid discrepancies in care and medication practices through established measures and awareness campaigns related to diet, family visits, holding the child, and truthfully explaining to the parents that their child unfortunately has a malformation, for example, and that we could work on this issue, providing them with comfort (Nurse 4A, Nurse 5A, Nurse 9A, Nurse 11A, Nurse 13A, Nurse 14B, Nurse 17B, Nurse 18B).*

Topic 3 – Team Difficulties in Providing Palliative Care

In neonatal care, palliative care is often portrayed by nurses as a difficult task to perform due to a lack of professional training.

IC4 – Importance of Offering Training

DSC9: *One of the difficulties is the lack of staff training; it's not enough to implement it, training is needed, including explaining and making everyone understand the concept of palliative care. We need health education to align both the approach and the management across specialties, to think alike and reach a consensus. I believe it is important to start talking about palliative care in clinical case discussions that we already have, together with the medical and nursing team, with more concrete exchanges. I did not have this preparation during my undergraduate studies; there's a lack of subjects and courses, and often, the search for information on the subject occurs out of personal interest. There's a lack of an active team clarifying what palliative care is and how to do it (Nurse 1A, Nurse 2A, Nurse 8B, Nurse 9A, Nurse 12A, Nurse 14B, Nurse 18B, Nurse 19A, Nurse 20A).*

For these nurses, a lack of knowledge and doubts about the criteria for discussing palliative care in neonatology presented a barrier.

IC5 – Gaps in the Definition of Criteria

DSC10: *In neonatology, the greatest difficulty is the lack of a protocol, a simple flowchart outlining the profile of children requiring palliative care, identifying diagnoses, defining the necessary care, and establishing general criteria through health education that would bring together all those involved to reach a consensus on knowledge, both in how to address and handle certain questions that family members may ask the medical or nursing staff (Nurse 9A, Nurse 15B, Nurse 17B, Nurse 19A, Nurse 20A).*

Resistance from the team and difficulty in communicating about palliative care, especially in early life, is an obstacle mentioned by nurses.

IC6 – Palliative Versus Curative Decision Making

DSC11: *It is truly difficult to deal with the end of life at the beginning of life, both for the staff who end up having a psychological barrier and for the parents in accepting the care. Today, I see great difficulty with one doctor in particular, who does not accept palliative care, being very interventionist and giving too much hope to the mother of a disease that has no prognosis. In addition to the lack of support for the other members of the multidisciplinary team who also have little expertise related to the subject. So, in neonatology, we do not know how the children will grow, develop; even with exams we cannot see everything completely, what the future will be like, and this is one of the difficulties, including for the medical team. I think defining criteria to determine that some babies deserve differentiated care will be very difficult here. Babies are very surprising; they have their whole lives ahead of them, so forcing a diagnosis by saying they won't invest [in treatment] causes discomfort, and* *you think: "Ah, but what if I had given them an antibiotic or drained that chest?" and you think about why a child who has just been born is susceptible to death? (Nurse 1A, Nurse 2nd, Nurse 3A, Nurse 5A, Nurse 11A, Nurse 12A, Nurse 14B).*

DSC12: *I think working with neonatal palsy is not easy, due to the population size and the resistance from the medical team because they are intensivists. It is very complicated! It involves many people, that is why I believe its implementation is difficult, and that is also why there are few studies on the subject (Nurse 10C, Nurse 16C).*

The differences and difficulties in approaching the delivery of bad news in neonatology were represented by the nurses in the following statements.

IC7 – Communicating Bad News

DSC13: *Perhaps the way to approach the family needs to be very well thought out and started during prenatal care, because people strongly believe that babies are not born to be in the palliative care unit. How do you tell the mother that there is nothing more that can be done for her child? If it were an elderly person, they would have already lived and enjoyed life, but the mother, in this case, did not take the baby home and never held it. Because of this, I believe the team tends to take more heroic measures to save the baby, due to the uncertainty of a poor prognosis, in addition to the divergence between the on-call doctors, some being more palliative than others. We are caught in the crossfire even knowing that this decision should be made as a team, resulting in conflicting statements and even, in the terminal stage, indications of hope for improvement (Nurse 3A, Nurse 5A).*

DSC14: *I believe that many families do not accept CP very well, because talking to them about it and them accepting it is like a death sentence; however, I have never seen the medical team explaining what CP itself is. We end up creating a bond with some mothers, there was a case of one who stayed in the support house for months and had a lot of faith and hope, so how can you look at her knowing the real situation of the baby? I feel sorry, especially for those families who do not understand properly, they have no idea of the problems the child will have if they go home (Nurse 4A, Nurse 5A, Nurse 13A).*

In addition to communication barriers, the environment of neonatal units was cited by some nurses as hindering the implementation of palliative care.

IC8 – Inadequate Environment

DSC15: *I have a lot of difficulty with the physical/structural environment; I have little space here in the ICU to perform palliative care with family members. If I put a mother there, I will have little space to provide care (Nurse 1A, Nurse 10C).*

Discussion

The results indicate that nurses experience palliative care (PC) in the care of preterm infants, and this experience is permeated by both ease and difficulties in coping with its implementation in the NICU and the day-to-day management of PC.

For some nurses, the experience of palliative care (PC) is related to end-of-life actions, associated with differing approaches among the multidisciplinary team, with the physician being responsible for the decision to provide such care or not. This reality may be related to the lack of implementation of PC in neonatology services in the hospitals that were part of this investigation. From this perspective, a contradiction is observed with what is recommended for the implementation of PC, since it should be offered by a multidisciplinary team[1,7] that includes at least: physicians, nurses, social workers, and psychologists, thus ensuring, in a broad and optimistic way, the relief of suffering for the newborn and support for their family.[11]

The nurses highlighted that, for the implementation regarding the promotion of CP in neonatal services, several factors facilitate this process, such as the link between teaching, research, and professional practice, keeping professionals always up-to-date; the implementation of care protocols; the inclusion of the family in care with a focus on Family-Centered Care (FCC); an informed and engaged team, highlighting the broad discussion among the multidisciplinary team in the pursuit of congruence in the team's conduct, and the possibility of providing comfort care.

The need for effective communication between healthcare professionals and between them and the patient and family, placing them as protagonists in the decision-making process and expanding the possibility of understanding.[7.12] It should be one of the cornerstones in the implementation of CP, as well as the existence of protocols, because when protocols are lacking, uncertainty arises in diagnosis and prognosis, and consequently, difficulty in discussing care options and the decision-making process, which is directed towards palliative care, becomes compromised.[13]

The gaps regarding the situations that qualify for palliative care are represented by nurses as a barrier that generates conflict between professionals and family members. However, the decision to adopt palliative care should be shared and may encompass several ethical conflicts to be faced by the healthcare team.[14]

Uncertainty regarding the concepts of palliative care hinders decision-making, making it necessary to discuss life-support and palliative care treatment options. Another important issue is the lack of parental involvement in this process, observed in several cases, as healthcare professionals lead the discussion and parents are left to reactively express their opinions.[13]

The difficulty in addressing the issue and consequently the lack of clarification for the entire team and family about the true meaning of CP becomes a barrier. Therefore, the availability and ability of the multidisciplinary team to clarify doubts and offer support throughout the illness process until its end become essential for the family's acceptance of this context.[13,14] Thus, care must be proportional to the clinical condition and the baby's real possibility of response.[14] A team-developed coping plan can help families engage in activities that build memories and bonding, as well as offer opportunities for support during early and ongoing bereavement.[6]

Regarding the nurses' statements highlighting the need for palliative care after several invasive procedures, it is similar to other studies in which infants hospitalized in a NICU who died were not considered for palliative care. In those studies, it was detected a large proportion of newborns with serious illnesses and health conditions that would meet the eligibility criteria for palliative care were found, yet such cases were not even discussed.[15,16] It was noted that the quality of death was poor and that on the day of death there was a high level of therapeutic investment, with the use of several invasive devices and the presence of poorly controlled pain.[16] Unnecessary measures and interventions should be avoided when the newborn is part of a palliative care plan.[5,17]

The lack of dialogue with the medical team, the inability to have a say in end-of-life decisions, and the lack of preparedness to deal with such situations are obstacles that affect the care relationship. Therefore, continuous training and the creation of spaces for professionals to share their anxieties are fundamental.[13] However, training for the care team is necessary in order to provide quality care for newborns who are beyond therapeutic possibilities.[15,17]

For nurses, deficiencies in their training and continuing education within the services presented a barrier to understanding and, consequently, implementing palliative care in neonatology services, thus persisting in their work environment.

It is necessary that the topic of palliative care be included in the undergraduate education of professionals; moreover, it highlights the role of the institutions where this care is needed, in the process of continuing education and support for professionals. Among the main difficulties faced by nursing professionals regarding palliative care are: lack of professional experience and involvement of the nurse in end-of-life decision-making, lack of team collaboration, lack of active participation in the suffering of the patient and family, and morale.[17] In Brazil, there has been a growing number of courses offering training in palliative care; however, the training of healthcare professionals in this area is still deficient.[18]

It is essential that the multidisciplinary team involved in care converges on their approaches so that the implementation of neonatal palliative care proceeds smoothly, involving and informing all members, which makes a patient eligible for palliative care.[14,19]

The difficulty in communicating bad news by professionals was another issue raised by nurses, leading to resistance from some professionals in offering palliative care. Overwhelmed by feelings of helplessness, fragility, and sadness, death is considered a difficult and inevitable event, which is potentially aggravated when experienced in the first moments of life. The loss of a child alters the natural cycle of life and, consequently, the search for reasons and meaning for this change becomes more intense and complex1, therefore it is essential to ensure that parents are informed of all possibilities.[20]

Therefore, it is necessary to involve parents in discussions of all possible events after birth and to review the care plan after reassessment of the newborn in the NICU, respecting their final wishes and ensuring the reduction of the newborn's suffering. It is necessary that more inclusive approach, involving parents and the entire multidisciplinary team, should become the standard of care in perinatal and neonatal practice, building a longitudinal therapeutic relationship, focusing on CCF.[6,13]

The NICU environment itself already presents an obstacle to the family's connection with their infant who is beyond the possibility of a cure. This situation is exemplified by some nurses who believe that the current structure of their service hinders the full implementation of palliative care.

While the NICU provides advanced technologies, it can also have negative impacts on the physical and psychological needs of newborns, their families, and the staff who work there, as it is a stressful environment. The most frequent negative impacts include intense light, noise, constant handling by professionals, and little social interaction.[2]

This research was limited by the participation of only one professional category, namely nurses, and therefore it was not possible to compare the behaviors and opinions of the multidisciplinary team in neonatology services. It is known that the implementation of palliative care requires the involvement of at least one nurse, one doctor, one psychologist, and one social worker.

Conclusion

It was understood that nurses experience palliative care situations, some with positive outcomes, even though many of them have numerous doubts about it. The main obstacle to implementing this care is the lack of understanding of the meaning of palliative care itself.

Given this context, the factors facilitating the implementation of palliative care in NICUs are related to the presence of protocols, the inclusion of the family in the decision-making and care process, and the discussion of cases among the multidisciplinary team. Barriers to the implementation of palliative care are related to a lack of technical and scientific training, gaps in knowledge regarding eligibility criteria, situations of divergent decision-making, and communication failures between professionals and family members, leading to non-acceptance of palliative care.

In this regard, it is recommended that neonatology services continuously provide training through continuing education programs, assisting in the implementation of the CP and the establishment of a committee in the area that includes at least one nurse, one doctor, one social worker, and one psychologist, who are integrated within these units and monitor the entire palliative care process.

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