



EXPERIENCES AND FEELINGS EXPERIENCED BY THE NURSING TEAM IN NEONATAL PALLIATIVE CARE

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ABSTRACT

Objective: to describe the experiences and feelings attributed by the nursing team in the palliative care provided to newborns in the Neonatal Intensive Care Unit. **Method:** descriptive, exploratory study with a qualitative approach, conducted with the nursing team of a neonatal intensive care unit in a federal hospital. The data collection took place through semi-structured interviews, transcribed in full and submitted to content analysis between the months of December 2023 and February 2024. **Results:** the sample consisted of nine nursing technicians and seven nurses. From the interviews, 72 units of meaning were extracted and grouped into three categories: Neonatal palliative care: understanding attributed by the nursing team; neonatal palliative care: lived experience of the nursing team; neonatal palliative care: feelings attributed by the neonatal nursing team. **Final thoughts:** the neonatal palliative care is experienced by the nursing team as an emotionally challenging process for emerging feelings of sadness, pain and anxiety before the finitude, but the empathy that allows these perceptions is also the motivational factor for a responsible and humanized care.

Keywords: Neonatal nursing. Intensive care units, neonatal. Infant, newborn. Palliative care.

INTRODUCTION

The end of the twentieth century brought significant changes in the care of newborns (NB) hospitalized in Neonatal Intensive Care Units (NICU). These changes allowed the survival of extreme premature NB and/or with severe congenital malformations that may limit their development. In this context, palliative care (PC) acquires an important space concerning parental decision-making, influence of the health team, legal regulations and acceptance by both the general population and professionals who interact on the subject⁽¹⁻³⁾.

The World Health Organization (WHO) defines PC as a care approach that improves the quality of life for patients and their families facing life-threatening disease problems and alleviates suffering through early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial

or spiritual⁽⁴⁾, offered from the initial diagnosis, providing support and integral follow-up to the person and his/her family throughout the disease process⁽⁵⁾.

Technological advances and the development of neonatology have allowed an increase in the survival rates of extreme premature NB with congenital malformations, severe bone alterations and anencephaly, chromosomal abnormalities and heart diseases^(6,7). However, this same premise brings with it the possibility of life extension and sometimes the need for palliative care. For the effective evolution of this type of care, it is recommended to plan actions that involve the family and the multiprofessional team, in order to ensure the improvement of the patient and his/her family members who experience the contrasts between technological advances and existential issues related to finitude, dignity and quality of death^(4,8,9).

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PC intended for NB in conditions that limit life represent active approaches, from diagnosis or recognition, through life and death, encompassing physical, emotional, social and spiritual elements, focused on improving the quality of life of this life cycle, extended to family support. For the execution of palliative care, measures that monitor distressing symptoms, provision of short breaks and care during death and mourning are necessary⁽⁹⁾.

With interdisciplinary features, PC is composed of a health care system with the purpose of anticipating, preventing and managing physical, psychological, social and spiritual suffering, optimizing the quality of life of patients, their families and caregivers in any care environment with the collaboration of professionals in an extended way to an integrated network of care and respect for decisions for the end of life, in an interdisciplinary perspective of care described as holistic, dynamic and extensive that run through pregnancy, birth and mourning, prioritizing the respect and dignity of the patient and family^(9,10).

Regarding the nursing team that acts in these scenarios, studies point to the need for education and training in PC to favor the empowerment of the exercise of ethical and sensitive care that these patients require at this existential moment⁽⁹⁻¹²⁾. The literature indicates that the greatest difficulty in providing PC to the NB is due to inadequate training of the nursing team⁽⁸⁻¹⁰⁾. Studies indicate that the nursing team reveals uncertainty, discomfort about the prognosis of the disease, management and treatment of symptoms, and the appropriate time for the transition from curative care to PC^(11,12). Studies indicate that neonatal PC is widely guaranteed as an essential aspect in the NICU, but inconsistencies and barriers are observed in this environment regarding the lack of experience with end-of-life care of the NB, specifically in the management of symptoms^(13,14).

In addition to the need for training of professionals evidenced in the literature, there are sufferings and emotional difficulties involved in the provision of PC, which can bring harm to the mental health of professionals and a direct negative impact on the quality of care^(1,7,10).

Understanding the experiences and feelings experienced by the nursing team can signal new discoveries of intervention needs and bring clarity on how to train professionals technically and emotionally for the challenges of neonatal palliative care.

Given the above, the present study presented the following main question: how does the nursing team that works in neonatal intensive care units experience and feel the neonatal palliative care? Thus, the objective of the study was to describe the experiences and feelings attributed by the nursing team in front of the NB in palliative care hospitalized in the Neonatal Intensive Care Unit.

METHOD

This is a descriptive, exploratory study with a qualitative approach. To ensure better validity of methodological aspects, the recommendations of the Consolidated Criteria for Reporting Qualitative Research (COREQ)⁽¹⁵⁾ were followed. The study was conducted with nursing professionals in a Pediatric and Neonatal Intensive Care Unit (PNICU) of a federal teaching network hospital, accredited to the Unified Health System (UHS), which offers medium and high complexity hospital care to 27 municipalities in the interior of the state of Minas Gerais-Brazil.

The study unit has 24 active beds and the nursing team consists of 22 nurses and 54 nursing technicians. The sample was of the non-probabilistic type and the selection of participants was by convenience, according to the inclusion criteria established: nurse and/or nursing technician working in the NICU during the research period, inserted in the work scale, with participation in the care of the newborn admitted to the unit. The exclusion criterion was: nurses and/or nursing technicians who, although fully active in the unit at the moment, report not having enough experiences in neonatal PC to express experiences and feelings useful to the research.

To define the number of participants, the response saturation criterion was used, represented by the absence of new data that contributed significantly to the study outcome⁽¹⁶⁾. The professionals were approached

during the work schedule and, at that time, the objectives of the research were presented, and the researchers waited for the manifestation on participation in the study. After the demonstration of interest in participating in the study, day and time for the interview were scheduled. To guarantee the methodological rigor, the Informed Consent Form (ICF) was presented. Each consent was signed after reading the ICF, before the beginning of each interview.

The data collection took place in the months of December 2023 to February 2024, carried out by means of semi-structured individual interviews at a location provided by the unit's coordination. The interview script was divided into two parts, with the first part formed by sociodemographic issues such as sex, age and professional qualification. The second part of the interview consisted of questions with open-ended answers: What do you understand by neonatal palliative care? How is it for you to care for a newborn in palliative care? How was it for you to experience neonatal palliative care? Would you like to say something else?

The average duration of each interview was approximately 12 minutes. Each interview was conducted in only one meeting, being all recorded with the help of a smartphone model that adds functions for editing on computers, adapted to this type of equipment. Then, the interviews were transcribed in full text to Microsoft Office Word 2016, printed and validated by each participant of the survey, who had the opportunity to make the observations they deemed necessary and, after this procedure, were organized for analysis.

The data were analyzed based on Bardin's referential⁽¹⁷⁾, considering three phases: 1) pre-analysis, with repeated reading of the interviews (floating reading), carried out between five and ten times, in order to systematize the information collected for the understanding of the studied phenomenon; 2) exploration of the material from an exhaustive reading to highlight the most relevant and significant aspects of the discourses in units of meaning based on the study objectives; and 3) treatment and interpretation of the units of meaning that culminated in the construction of the categories. After these phases, the results

were analyzed in accordance with references evidenced in studies on the subject.

The research was approved by the Research Ethics Committee of the Clinical Hospital of the Federal University of Triângulo Mineiro, under CAAE: 30946820.7.0000.8667. Opinion number 4.062.920. The ICF and the guarantee of anonymity were presented to all participants, by means of coding the speeches: nurses were identified with the acronym "NUR", and nursing technicians, "NT", followed by the number corresponding to the order of the interviews.

RESULTS

The sample consisted of nine nursing technicians and seven nurses (n = 16). There was a predominance of females, with 15 participants. As for the age group, seven were in the age group between 27 and 39 years, and nine between 40 and 59 years. About the time of professional activity in neonatology, ten worked with up to five years of experience, six between five and 15 years. In relation to the professional qualification, nine had incomplete higher level; seven, *Lato Sensu* post-graduation; one (6.25%) *Stricto Sensu* post-graduation. As for the nursing technicians, three were nursing graduates. From the 16 interviews obtained, 72 units of meaning were extracted, grouped in three categories, namely:

Neonatal palliative care: understanding attributed by the nursing team

In the speeches extracted through the interviews, participants report how they understand care and how it should be established before a prognosis of finitude:

I understand that the patient does not have a life prognosis, [...] but there is a care that establishes in the best way the survival he has, even if not much [...], but of better quality (NT2).

[...] these are the necessary care for the patient [...]the care we have to do in our routine service (NT3).

[...] it is care when the child no longer has a prognosis [...] it is care for comfort and meeting the baby's basic needs until the moment of death (NUR9).

[...] palliative care in my perception would be comfort and pain relief [...] it is care for the patient who does not have a survival prognosis, but while they are alive we have to provide comfort, mainly pain relief, basically that is it (NUR10).

[...] neonatal CP is about meeting the patient's basic needs (NUR11).

The participants see palliative care as care without a life expectancy:

[...] it is care without perspective [...] for me it is the care that has to be done, it is as if it had to be done on someone else, but we know that there is no perspective [...] for me it is all the necessary care (NT4).

[...] I understand that it is a care to generate a certain comfort for the child [...] children who have no prospect of improvement [...] or who are affected by diseases, degenerative or chronic, right, [...]. A better quality of life for them, right, during the time they had here (NT5).

[...] it is when the child no longer has [...] perspective [...] we have to take care so that he does not feel pain [...] to have quality of... care [...] so that he does not suffer [...] that is how I understand it (NT6).

In the words of one of the participants, palliative care is a humanized way of assisting the newborn and the family:

[...] I believe that it is a humanized care for the child, in a dignified way [...] allowing him to die peacefully, but without failing to provide assistance [...] with everything possible [...] the family has to be informed of everything that is happening (NT7).

In the speech of one participant, an attempt to conceptualize palliative care can be observed:

[...] the terminology of the word itself [...], the palliative term itself would be to alleviate suffering, only [...], to comfort in a moment that can be long or short, only in one way [...] in one of the symptoms that the patient is presenting at the moment, no more than that, that's how I see it (NUR13).

Neonatal palliative care: lived experience of the nursing team

In this category, participants report

experiences regarding the palliative care provided, difficulties and psychological pressures faced with the impossibility of the NB's life.

[...] for me, taking care of a newborn in PC is quite a complicated thing psychologically (NT1).

[...] always with a lot of responsibility [...] attention [...] with a lot of affection, because it's complicated [...] (NUR14).

One of the participants reported that, although there is suffering, the experience is understood as a form of positive learning for this care:

[...] somehow the newborn has to rest [...] I learned to face the experience in a more positive way (NUR15).

The speeches indicate that, through their experiences, they become aware of the family:

[...] for me, caring for a newborn means providing better conditions for the child to have a loving end to life [...] real care [...] is staying close to the family [...] and this newborn was the result of an expected pregnancy [...] it is a significant experience [...] (NT9).

[...] I am particularly sensitive to the family, to this father, to the mother, who will return home with empty arms [...] as a professional, I always put myself in the mother's shoes [...] (NUR16).

Neonatal palliative care: feelings attributed by the neonatal nursing team

In the reports, the professional and personal difficulties in dealing with the situation bring out feelings in different ways:

[...] you never get used to losing a child [...] it's difficult [...] living with the family all that sadness [...] the situation of loss is difficult [...], I believe that you never get used to it [...] the situation that stays with us is a psychological burden (NT1).

[...] it's very sad because we know that parents wait so long [...] they wait nine months and then when they leave, they get home and the child isn't with them, the newborn isn't with them (NT6).

[...] I suffer sometimes [...] I feel very down when I see my family suffering, because then I suffer because of the family's suffering (NT9).

[...] I'll say it's bad [...] I cry, that I suffer when I see the family suffering [...] I wish I could take care of that suffering heart [...], I think it's a continuation of life (NUR10).

[...] this causes insecurity, anxiety, even in us. (NT9).

[...] exhausting [...] painful, but we do it with a lot of love (NUR13).

[...] it's a constant pain (NUR15).

DISCUSSION

The understanding of palliative care by the nursing team is supported by fundamental and necessary pillars for the provision of quality care, but among health professionals, including this research, the concept of palliative care remains intensely associated with the finitude of human life, as the last phase of the natural process of existence^(3,6,7,18).

The care portrayed by professionals consists of measures aimed at providing comfort, analgesia, hydration/nutrition, as pointed out in studies on the subject^(1,3,7,13,19). Two participants reported that they understand the PC as any other assistance, however, the literature points out that an adequate understanding of the fact that PC is not routine is indispensable for applicability without life extension and interventions that disadvantage the quality of life of the patient⁽¹⁹⁾, which indicates the need for improvement on the subject.

Studies on the subject indicate weaknesses related to professional qualification, as well as issues in the environment of spaces for the applicability of PC, which may directly affect the assistance to be offered to the patient and family^(2,3,7). A study conducted with nursing professionals pointed out gaps in training, highlighting the need for professional training with a view to quality care^(20,21).

In this sense, there is a need for preparation and qualification for best practices, given a significant increase of NB under these conditions^(18,21). The professional qualification contributes to a better professional conduct and affects a quality care both for the NB and the family, and reflects in a greater professional security in its performance as the principles of the PC. Although studies and protocols are

important in professional practice, there is a shortage of literature on the subject^(20,22).

The participants stated in accordance with the literature that PC is a humanized way of assisting the NB and the family, since the palliative principles aim at relieving pain and suffering^(1,2,6,8). The speeches reinforce the importance of mutual dialogue between members of the care team and the family. It should be emphasized that palliative practices focus not only on symptomatology, but also seek to cover the psychological aspects and communication with the NB's family, offering integral and individualized care within the therapeutic possibilities required^(8,23). In this context, the need for investment in education is intensified to facilitate these processes and instrumentalize professionals^(10,12).

The speeches demonstrate that empathy, despite bringing suffering, is one of the motivations for providing humanized and responsible care, which corroborates studies that understand empathy as a central competence of PC and that is associated with a series of benefits, as Patient-Centered Care, better management of chronic conditions, pain reduction and increased satisfaction with care⁽²⁴⁾.

Most of the units of meaning identified in the research demonstrate team suffering, difficulties in admitting the end of life of the NB, understood as a psychologically challenging experience. It is expected that, in the PC, many experiences arise from the life history of each one, mobilizing meanings and feelings of attachment and sadness, emerging during the care of the NB before the imminent death so close to birth⁽²²⁻²⁵⁾. Studies carried out with a multiprofessional team pointed to the need for strengthening communication, teamwork and a space to discuss terminality^(25,26).

The participants of this research admit that the intensity of feelings does not change over time, they do not get used to the process even with a lot of experience. On the other hand, a study shows that, over time, professionals can separate the professional from the personal life and learn to deal better with the feelings arising from the assistance in PC⁽²⁶⁾. This finding indicates that studies that identify which factors

contributed to the professionals who improve their negative feelings with increased experience are necessary to develop strategies in order to instrumentalize other professionals for this confrontation.

It is important to highlight that, although the script of the interviews did not direct the answers to the emotional scope, allowing free reflection on the experience in the provision of PC, no professional involved ideas in their speeches regarding job satisfaction, difficulties regarding physical space, structure, equipment or techniques and procedures, but they focused their speeches on emotional experiences and suffering, indicating as a primary subject for their perceptions in PC.

The way each individual responds to stressors is personal, being influenced by individual differences and coping strategies, which may be related to the resolution of the factor causing discomfort or focused on the emotions of how he/she perceives, controls and faces his/her feelings⁽²⁶⁾.

Regardless of the individuality in coping capacity, professionals admit that there is always suffering involved in PC assistance. Research shows that strategies in which professionals perceive as beneficial are team meetings with the focus on externalizing emotions, exposing doubts, opinions and positions⁽²⁵⁻²⁷⁾.

The emotional embracement and psychological support to the team, especially to nursing professionals who deal with more frequency and constancy in the assistance of neonatal PC, is essential to promote mental health, which will have a direct impact on services and quality of care^(26,27).

Public and institutional policies are prerogatives for the support and assistance in coping with the suffering arising from PC assistance, such as strategic scales for adequate team rotation, group offer and therapies, appropriate workload, rest structures, adequate

remuneration, in addition to recognition when the professional needs an individualized follow-up in order to deal with the feelings^(26, 27).

FINAL THOUGHTS

The results of how the nursing team experiences and feels the palliative care of newborns indicates that there is a need for improvement and personal training so that, with greater understanding of the concepts, objectives and practices related to palliative care, professionals can be better prepared and feel safer for a care without unnecessary interventions and without anxiety, insecurity and exacerbated psychological impacts.

In this sense, the results point to the need for professional support services and collective and individualized coping strategies, so that the team perceives embracement, a safe place of sharing and reflections and, in this way, experience the minimized suffering and have real possibility of overcoming.

Despite the reports of suffering, the findings of this study demonstrate that the empathy generated in the relationship with the NB in PC and the family is a support for a responsible, humanized assistance that brings direct benefits in pain relief and satisfaction of care.

The generalization of this study is limited, since the research is restricted to the nursing team that works in a single NB care center in PC. Nevertheless, it contains important findings that allow comparison with other studies on the subject and basis for the elaboration and development of efficient and reliable instruments that allow the investigation on a large scale of the frequency, intensity of suffering, as well as the confrontation of nursing teams in neonatal PC, thus supporting effective strategies focused on team or macro interventions and public policies that bring training, relief, comfort and coping before neonatal palliative care.

EXPERIÊNCIAS E SENTIMENTOS VIVENCIADOS PELA EQUIPE DE ENFERMAGEM NO CUIDADO PALIATIVO NEONATAL

RESUMO

Objetivo: descrever experiências e sentimentos atribuídos pela equipe de enfermagem diante dos cuidados paliativos prestados aos recém-nascidos na Unidade de Cuidados Intensivos Neonatal. **Método:** estudo descritivo, exploratório, com abordagem qualitativa, realizado com a equipe de enfermagem de uma unidade de

terapia intensiva neonatal de um hospital da rede federal de ensino. A coleta de dados se deu por meio de entrevistas semiestruturadas, transcritas na íntegra e submetidas à análise de conteúdo entre os meses de dezembro de 2023 e fevereiro de 2024. **Resultados:** a amostra foi composta por nove técnicas de enfermagem e sete enfermeiros. Das entrevistas, foram extraídas 72 unidades de significado e agrupadas em três categorias: Cuidado paliativo neonatal: compreensão atribuída pela equipe enfermagem; cuidado paliativo neonatal: experiência vivida da equipe de enfermagem; cuidado paliativo neonatal: sentimentos atribuídos pela equipe enfermagem neonatal. **Considerações finais:** observou-se que o cuidado paliativo neonatal é vivenciado pela equipe de enfermagem como um processo emocionalmente desafiador por emergir sentimentos de tristeza, dor e ansiedade diante da finitude, porém a empatia que permite essas percepções é também o fator motivacional para uma prestação de cuidados responsável e humanizada.

Palavras-chave: Enfermagem neonatal. Unidades de terapia intensiva neonatal. Recém-nascido.

EXPERIENCIAS Y SENTIMIENTOS VIVIDOS POR EL EQUIPO DE ENFERMERÍA EN CUIDADOS PALIATIVOS NEONATALES

RESUMEN

Objetivo: describir experiencias y sentimientos atribuidos por el equipo de enfermería ante los cuidados paliativos prestados a los recién nacidos en la Unidad de Cuidados Intensivos Neonatal. **Método:** estudio descriptivo, exploratorio, con enfoque cualitativo, realizado con el equipo de enfermería de una unidad de cuidados intensivos neonatal de un hospital de la red federal de enseñanza. La recolección de datos se realizó por medio de entrevistas semiestruturadas, transcritas en su totalidad y sometidas al análisis de contenido entre los meses de diciembre de 2023 y febrero de 2024. **Resultados:** la muestra estaba compuesta por nueve técnicas de enfermería y siete enfermeros. A partir de las entrevistas, se extrajeron 72 unidades de significado y agrupadas en tres categorías: Cuidado paliativo neonatal: comprensión atribuida por el equipo de enfermería; Cuidado paliativo neonatal: experiencia vivida del equipo de enfermería; Cuidado paliativo neonatal: sentimientos atribuidos por el equipo de enfermería neonatal. **Consideraciones finales:** se observó que el cuidado paliativo neonatal es vivido por el equipo de enfermería como un proceso emocionalmente complejo por surgir sentimientos de tristeza, dolor y ansiedad ante la finitud, pero la empatía que permite estas percepciones es también el elemento motivador hacia una prestación de cuidados responsable y humanizada.

Palabras clave: Enfermería neonatal. Unidades de cuidados intensivos neonatales. Recién nacido. Cuidados paliativos.

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Submitted: 29/07/2024

Accepted: 21/04/2025