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Nursing team's conceptions about palliative care in newborns

Concepções da equipe de enfermagem sobre cuidados paliativos em recém-nascidos

Concepciones del equipo de enfermería sobre los cuidados paliativos en los neonatos

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ABSTRACT

Objective: to describe nursing staff's perceptions of palliative care for newborns in a Neonatal Intensive Care Unit. **Method:** in this exploratory, qualitative, descriptive study, 16 nurses were interviewed using a semi-structured script. Data were treated using Bardin content analysis. **Results:** the following categories emerged: "Neonatal palliative care: the nursing team's view"; "At the bedside: nursing and palliative neonatal care"; and "Challenges and limitations in providing palliative care for newborns and their families". **Conclusion:** talking about palliative care seems to be taboo also among these health professionals, who presented dissonant narratives. Palliative care needs to be discussed in the academic and professional spheres, in order to qualify nursing teams confronted daily with neonatal cases with no prospect of cure.

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

RESUMO

Objetivo: descrever a percepção da equipe de enfermagem acerca dos cuidados paliativos ao recém-nascido em uma Unidade de Terapia Intensiva Neonatal. **Método:** estudo qualitativo de caráter descritivo exploratório, realizado a partir de um roteiro de entrevista semiestruturado com 16 profissionais de enfermagem. Para tratamento dos dados foi utilizado o método de análise de conteúdo de Bardin. **Resultados:** emergiram as seguintes categorias: "Cuidado paliativo neonatal: o olhar da equipe de enfermagem"; "À beira leito: a enfermagem e o cuidado paliativo neonatal"; "Desafios e limitações para a implementação dos cuidados paliativos ao RN e sua família". **Conclusão:** falar sobre cuidados paliativos também parece ainda configurar-se como um tabu entre os profissionais, que apresentaram narrativas dissonantes. É necessária a discussão de cuidados paliativos no âmbito acadêmico e profissional, a fim de qualificar as equipes para o enfrentamento cotidiano de casos neonatais onde não há perspectiva de cura.

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

RESUMEN

Objetivo: describir la percepción del equipo de enfermería sobre los cuidados paliativos al neonato en una Unidad de Cuidados Intensivos Neonatales. **Método:** estudio cualitativo de carácter exploratorio descriptivo, realizado a partir de un guión de entrevista semiestructurado junto a 16 profesionales de enfermería. Para el tratamiento de los datos se utilizó el método de análisis de contenido de Bardin. **Resultados:** surgieron las siguientes categorías: "cuidados paliativos neonatales: la mirada del equipo de enfermería"; "Al lado de la cama: enfermería y cuidados paliativos neonatales"; "Desafíos y limitaciones para la implementación de cuidados paliativos al neonato y su familia". **Conclusión:** hablar sobre cuidados paliativos también parece ser un tabú entre los profesionales que presentaron narrativas disonantes. Es necesario discutir los cuidados paliativos en el ámbito académico y profesional, con el fin de capacitar a los equipos para el enfrentamiento diario de los casos neonatales donde no hay perspectivas de cura.

Descriptores: Enferméria Neonatal; Unidades de Cuidado Intensivo Neonatal; Recién Nacido; Cuidados Paliativos.

INTRODUCTION

Advances in neonatal care have been significant in recent years, enabling the survival of clinically severe newborns (NBs). A percentage of these NBs evolve to death or develop dismal prognoses, requiring special health care and, often, Palliative Care (PC)[1-3].

The World Health Organization (WHO) defines PC as the provision of assistance aimed at preventing and alleviating suffering, providing better quality of life to people who have potentially fatal diseases, without any possibility of curative therapies. This care must cover physical, psychological, social and spiritual aspects with inclusion of the family in the care provided[4].

In neonatal care situations where there is no prospect of a cure, it becomes necessary to develop care strategies that prioritize the quality of life, dignity and well-being of the NBs and their family[5].

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PC is easily confused with end-of-life care, not only by society in general, but by health professionals themselves. Both are related, but they should not be seen as synonyms, since they bring together different intervention modalities[6]. End-of-life care is provided when the individuals receive, near death, care in the last stage of their life[7].

Elucidating this paradigm has been a challenge for the health professionals who monitor patients through all the life cycles. Every day, the health teams working in Neonatal Intensive Care Units (NICUs) are faced with situations of seriously-ill NBs, dealing with stress, anguish, uncertainty, suffering and death. Nursing provides direct care to the NB in the NICU, being a category involved in the dialog between the team and the family[8].

The counterpoint of PC is therapeutic obstinacy, an expression that can also be used as a synonym for futile and useless treatment, which results in a slow and prolonged death, accompanied by suffering. It is the medical attitude that, aiming to save the life of terminal patients, submits them to significant distress. With this course of action, life itself is not prolonged, but the process of dying[9].

The study is relevant, as it can expand knowledge about Palliative Care in the neonatal area, since this is a relatively new topic, still little explored and often associated with Oncology.

Thus, the general objective of this study is to describe the perception of the Nursing team about PC for NBs in the NICU.

THEORETICAL FRAMEWORK

The provision of PC promotes the quality of life of patients and families facing a potentially fatal disease, through prevention and relief of suffering. It requires early identification, assessment and treatment of any physical, psychosocial or spiritual problems. Its purpose is to relieve pain or other symptoms, defending life, without hastening or delaying death. It integrates psychological and spiritual aspects in the care provided, in addition to offering a support system both for the patients and for the families[3,4].

A significant number of NBs present conditions that limit them, threaten their life or imply uncertain prognoses. When extension of life is no longer a goal, it is fundamental to plan care aimed at the NB's comfort[10].

Resolution 41 of October 31st, 2018, provides guidelines for the organization of PC, in the light of integrated continuous care, in Brazil. It should be offered as early as possible in the process of any fatal disease, with a focus on quality of life and relief from physical, psychological, social and spiritual distress up to the grieving process. It is guided by the principles of reasserting life and death as a natural cycle, quality of life, early identification, assessment and treatment of pain along with other signs and symptoms[11].

Neonatal Palliative Care (NPC) is unique and specific, in addition to requiring different skills when compared to adults. NBs do not speak and present behavioral expressions that require interpretation skills and sensitivity on the part of the team. In addition to professional training for holistic and sensitive care, the representation of PC is different with people belonging to the same professional category and workplace, since their perception about the subject matter takes into account personal experiences, religious aspects and academic content received in their training[12].

The health team, especially the Nursing team, is continually faced with ethical dilemmas in Neonatology, as families and society expect all possible measures to be taken to save the NBs, regardless of the birth conditions or deterioration. The feeling of frustration and moral distress permeates the work process in the NICU when it is known that the provision of certain care is futile and can cause harms to the NBs[13].

COFEN's Resolution No. 564/2017 highlights in a single paragraph, in article 48 that, even in cases of incurable and terminal serious diseases with imminent risk of death, in line with the multi-professional team, Nursing must offer all available PC measures to ensure physical, psychological, social and spiritual comfort, respecting the person's or legal representative's will[14].

Nursing professionals who stay in daily care play the important role of taking care of the NB from the beginning to a dignified end of life, promoting quality of life through beneficial care, without causing harms or suffering, in addition to offering support and being sensitive to the family.

METHOD

This is a qualitative, descriptive and exploratory study, in which Bardin's theoretical framework was used to analyze the interviews. The method aims at systematizing and describing the phenomenon beyond the level of common sense and subjectivism, under critical surveillance of the communiqué, whether in documents, literary texts or interviews, among others. The description of the content of the messages is given by a thematic indicator, paying attention to the manifest perceptions about objects and their phenomena, seeking unity of meaning, the theme[15].

It was developed in the NICU of a State University Hospital, located in the municipality of Rio de Janeiro. This maternity hospital is a health care reference for pregnant women at high maternal-fetal risk. The NICU has 15 active beds, ten for intensive care and five for intermediate care.

Data collection was carried out from May to June 2019, in a reserved room of the NICU and the study participants were 8 nurses and 8 nursing technicians working in the unit of the aforementioned hospital, totaling 16 participants. The sample was intentional and for convenience, according to the availability of the researcher and of the day service professionals. Those who were willing to participate signed the Free and Informed Consent Form (FICF). Resident nurses, nurses and nursing technicians who were on vacation, medical leave or bonus at the time of data collection were excluded from the study.

The project was submitted to *Plataforma Brasil* for analysis and consideration by the local Research Ethics Committee (*Comitê de Ética em Pesquisa*, CEP) and was approved through Opinion No. 3,766,475, in accordance with Resolution No. 466 of December 12th, 2012[16].

The study risks were minimal and, if the participant felt uncomfortable or embarrassed during the interview, it would be interrupted, and its data removed from the research, which was not necessary.

The Consolidated criteria for reporting qualitative research (COREQ) were followed. As data collection instrument, a semi-structured interview script was developed containing closed-end questions to outline the participants' profile and open questions about the investigated object: “How do you perceive neonatal PC in the unit?” and “How do you provide PC to a NB in the unit?”. The answers were audio-recorded and transcribed in full into a Word document. The interviews were only recorded after the participants had signed the FICF.

Data analysis was carried out after a thorough reading of the transcripts, identification and separation of the central themes of the speeches in analytical categories, based on Bardin's content analysis[15].

RESULTS AND DISCUSSION

The entire sample consisted of female participants. Among them, 31.2% were aged between 30 and 39 years old and 68.8%, between 40 and 59. With regard to training time, 75% have more than 15 years of training in Nursing and 25% have between 10 and 15 years of training. As for the length of professional experience in Neonatology, 62.5% have more than 15 years of experience and 37.5%, between 10 and 15. As for professional qualifications, 12.5% of the sample has incomplete higher education; 62.5% have *Lato Sensu* graduate studies; 18.7% have a Masters/PhD degree and 6.3% have technical level. That is, even among the technicians, the vast majority have a degree in Nursing and specialization in the neonatal area, configuring an experienced and specialized team.

From the 16 interviews, 84 registration units (RUs) emerged, which were divided into 8 units of meaning (UMs), being grouped into 3 categories, namely: “NPC: the perspective of the Nursing team”, “At the bedside: Nursing and NPC” and “Challenges and limitations for the implementation of Palliative Care for NBs and their families”.

Category 1: Neonatal Palliative Care: the perspective of the Nursing team

In the speeches represented by nurses (N) and nursing technicians (NT), the association of PC with the disease and the imminent condition of neonatal death was evident:

> *I see how to provide better conditions for the child to have a more affectionate end of life... (NT6)*
>
> *[...] there's a disease and that disease is already progressing to death. (N2)*
>
> *It is care provided to a patient in a terminal condition... (NT7)*

From the statements above, we notice that the team members confuse the “end-of-life care” and PC concepts. End-of-life care is only one aspect of Palliative Care, being the last phase of care, when it is known that death is near and inevitable, often due to the clinical deterioration of the NB[7]. On the other hand, Palliative Care must be offered from the moment when the onset of a progressive and incurable disease is determined, together with other treatments relevant to the disease and symptoms[5,16].

Speeches also emerged that recalled the concern with the quality of life of the NB and the family:

> *[...] to improve the quality of life of the patient and the family. (N5)*
>
> *Also care for his family, who are seeing him being taken care of and to offer the maximum comfort possible, satisfy the basic needs, leave him hemodynamically stable, offer security, quality. (N7)*

The word quality permeates the proposal of Palliative Care: targeted and assertive care is able to promote quality of life. Care centered on relief of symptoms, comfort, maintenance of the metabolism and psychological support to the family should be the goals of a Palliative Care plan[17].

Category 2: At the bedside: Nursing and Neonatal Palliative Care

This category reveals the Nursing team's concern with the NB's comfort measures, pain relief, physical and psychological distress.

> *[...] we take care to alleviate the child's suffering, in the sense of pain, of comfort... (N1)*
>
> *[...] It's care that we do not for curative purposes, but to alleviate the suffering she may have during her time hospitalized in the ICU. (N4)*
>
> *This is assistance care to avoid suffering, pain, psychological distress. (NT8)*

The participants' speeches are in line with what the literature states about the care to be provided to a NB. However, when asked about having already provided care to the NB without any therapeutic possibility and if they considered that Palliative Care should be provided, they reveal lack of preparation, difficulties and institutional limitations. An Australian study conducted with eight neonatal nurses[16] also presented similar difficulties regarding the recognition of patients eligible for Palliative Care, in addition to institutional problems.

The absence of a well-established protocol in the unit, which could define the selection criteria for decision-making, was also an aspect recalled by the team:

> *I've already provided assistance to patients without any therapeutic possibility, but there's no institutionalized Palliative Care for NBs. (NT8)*
>
> *[...] I don't understand that Palliative Care was provided, no, because I think it's very difficult for people to accept that, so what we did was try our best to maintain life and not let it go with quality. (N6)*

Adopting a framework that guides the professional conduct, not only in Nursing, and the search for qualification in the area, would exert a positive impact on the care provided, satisfaction of the families and comfort for the NB itself. With regard to policy, in another Australian study, the nurses perceived lack of contribution to the unit's guidelines for Palliative Care, lack of evaluation of the unit and the need to update ideas and values on the provision of care[17].

Category 3: Challenges and limitations for the implementation of Palliative Care for NBs and their families

The need for the qualification of a specialized multi-professional team to provide Palliative Care was recurrent in the participants' speeches:

> *I don't consider, I think that neonatal ICU, mainly, it's very difficult for the professionals to face that the patient has no therapeutic possibility. [...] they always invest and with procedures that are sometimes more painful, trying to somehow prolong the life of this child, not thinking about suffering and about alleviating pain." (N4)*
>
> *... I don't see this care implemented within the neonatal ICU, neither of my two work experiences showed that, that there is some specific care for patients in Palliative Care" (NT4)*

The professional and personal difficulties in dealing with bereavement are products of our experiences and end up interfering with the assistance provided, as they bring out some feelings such as frustration, sensation of failure, impotence and inability, which prevent the professionals from exercising their proper role. Nurses who work in NICUs stay at the patient's side in a more intense and permanent way and, for this reason, they must be prepared to watch the entire process, monitor the patient's finitude and offer support to the family members. Therefore, dignifying and humanizing the final stage of life and death becomes a challenge for the health professionals who work in intensive care units[18,19].

The literature shows that there is still a gap in the academic training of health courses in terms of end-of-life support and Palliative Care. These are topics little explored in undergraduation, although they are increasingly recurrent in the clinical practice[20].

In addition to the need for academic training, professional qualification must also be built through constant updates and permanent health education in the service.

This practice promotes teaching and learning in the daily work, provides training and improvement of professional skills and improves care quality as it seeks new ways of learning, educating, assisting and caring.

Neonatal PC involves elements such as offering warmth, human contact, pain relief and the dignity of “leaving” without suffering. The health professionals' role is to offer options to the parents, preparing them for death, when inevitable, comforting the family and, at the same time, supporting the NB[17].

Thus, continuing education of the professionals, protocols and team engagement with the insertion of a palliative culture seem to be fundamental elements to support the NB and the family, perceived by the members of the Nursing teams.

Study limitations

We consider the following as study limitations: the fact that it was developed in a single reality and that the unit does not yet have a protocol for neonatal PC.

CONCLUSION

The research also showed that there are conceptual conflicts between “palliative care” and “end-of-life care” among the members of the teams interviewed.

The lack of uniformity in the narratives can imply that each professional takes care of the NBs according to their knowledge, beliefs and previous experiences, revealing a poorly systematized local care.

As the unit does not yet have a PC protocol, we present the need to elaborate it and expand the multi-professional discussion on the topic, in order to formalize local management, further engaging the PC teams.

We can also suggest expanding the discussion of PC in the academic and professional scopes, in order to qualify professionals for the daily confrontation of neonatal cases where there is no prospect of a cure.

REFERENCES

1. Ministério da Saúde (Br). Secretaria de Atenção à Saúde. Departamento de Ações Programáticas Estratégicas. Atenção à saúde do recém-nascido: guia para os profissionais de saúde / Ministério da Saúde, Secretaria de Atenção à Saúde, Departamento de Ações Programáticas Estratégicas. – 2. ed. – Brasília: Ministério da Saúde, 2012. [cited 2021 Jul 6]. Available from: https://bvsms.saude.gov.br/bvs/publicacoes/atencao_saude_recem_nascido_v1.pdf.
2. Alves AMF, França MLR, Melo AK. Entre o nascer e o morrer: cuidados paliativos na experiência dos profissionais de saúde. Rev. Bras. Promoç. Saúde [Internet], 2018 [cited 2021 Jul 6]; 31:1-10. Available from: https://periodicos.unifor.br/RBPS/article/view/6712/pdf.
3. Forouzi MA, Banazadeh M, Ahmadi JS, Razban F. Barriers of palliative care in neonatal intensive care units. American Journal of Hospice and Palliative Medicine [Internet], 2015 [cited 2021 Jul 14]; 34:205-11. DOI: http://journals.sagepub.com/doi/10.1177/1049909115616597.
4. World Health Organization. Global Atlas of Palliative Care at the End of Life [Internet], 2014 [cited 2021 Jul 21]. Available from: https://www.who.int/nmh/Global_Atlas_of_Palliative_Care.pdf.
5. Burlá C, Py L. Palliative care: science and protection at the end of life. Cad. Saúde Pública [Internet], 2014 [cited 2021 Jul 15]; 30(6):1139-41. Available from: https://www.scielo.br/scielo.php?pid=S0102-311X2014000601139&script=sci_arttext&tlng=pt.
6. Conselho Federal de Enfermagem. Resolução COFEN nº 564/2017. Brasília, DF [Internet], 2017 [cited 2021 Jul 21]. Available from: http://www.cofen.gov.br/resolucao-cofen-no5642017_59145.html.
7. Ministério da Saúde (Br). Biblioteca Virtual em Saúde. "Meu cuidado. Meu direito": 12/10 – Dia Mundial dos Cuidados Paliativos [Internet], 2019 [cited 2021 Jul 15]. Available from: http://bvsms.saude.gov.br/ultimas-noticias/3047-meu-cuidado-meu-direito-12-10-dia-mundial-doscuidados-paliativos.
8. Silva IN, Natália S, Salim R, Szylit R, Sampaio PSS, Ichikawa CRF, Santos MR. Knowing nursing team care practices in relation to newborns in end-of-life situations. Escola Anna Nery Revista de Enfermagem [Internet], 2017 [cited 2021 Jun 20]; 21(4):1-8. DOI: https://doi.org/10.1590/2177-9465-EAN-2016-0369.
9. Pessini L. Dystanasia: How long to draw out the life? São Paulo: Editora do Centro Universitário São Camilo: Loyola; 2001.
10. Parravicini E. Neonatal palliative care. Curr. Opin. Pediatr. [Internet], 2017 [cited 2021 Mar 10]; 29(2):135-40. DOI: https://doi.org/10.1097/MOP.0000000000000464.
11. Ministério da Saúde (Br). Secretaria de Atenção à Saúde. Portaria nº. 3.519/GM/MS, de 29 de outubro de 2018. Diretrizes para a organização dos cuidados paliativos, à luz dos cuidados continuados integrados, no âmbito Sistema Único de Saúde (SUS) [internet], 2018 [cited 2021 Jul 26]; Seção 1,(225). Available from: https://portalarquivos2.saude.gov.br/images/pdf/2018/novembro/23/RESOLUCAO-N41.pdf.
12. Lee MC, Chen YC, Chen CH, Lu FL, Hsiao CC, Peng NH. Comparison of the Educational Needs of Neonatologists and Neonatal Nurses Regarding Palliative Care in Taiwan. American Journal of Hospice & Palliative Medicine [Internet], 2013 [cited 2019 Jul 6]; 33(3):264-71. Available from: http://www.researchgate.net/publication/236918244_The_educational_needs_of_neonatal_nurses_regarding_neonatal_palliative_care.

13. Oliveira FC, Cleveland FM, Darilek U, Silva ARB, Carmona EV. Experiências em cuidados paliativos de enfermeiras neonatais brasileiras. J. Perinat. Neonat. Nurs. [Internet], 2018 [cited 2021 Jul 26]; 32(4):3-10. Available from: https://journals.lww.com/jpnnjournal/Abstract/2018/10000/Brazilian_Neonatal_Nurses__Palliative _Care.17.aspx.
14. Conselho Federal de Enfermagem. Resolução 0564/2017 [Internet], 2017 [cited 2021 Jul 26]. Available from: http://www.cofen.gov.br/wp-content/uploads/2017/12/RESOLU%C3%87%C3%83O-COFEN-N%C2%BA-564-2017.pdf.
15. Minayo MCS. Qualitative analysis: theory, steps and reliability. Ciênc. Saúde Coletiva. 2012 [cited 2021 Jul 26]; 17(3): 621-6. DOI: https://doi.org/10.1590/S1413-81232012000300007.
16. Brasil. Resolução nº 466, de 12 de dezembro de 2012. Dispõe sobre diretrizes e normas regulamentadoras de pesquisas envolvendo seres humanos. Diário Oficial da República Federativa do Brasil, Brasília, DF [internet], 2013 [cited 2021 Jun 10]. Available from: http://bit.ly/1mTMIS3.
17. Kilcullen M, Ireland S. Palliative care in the neonatal unit: neonatal nursing staff perceptions of facilitators and barriers in a regional tertiary nursery. BMC Palliat Care [Internet], 2017 [cited 2021 Jul 21]; 16:32. DOI: http://doi.org/10.1186/s12904-017-0202-3.
18. Ministério da Saúde (Br). Instituto Nacional do Câncer (INCA) [Internet]. Cuidados Paliativos Pediátricos [Internet], 2018 [cited 2020 Nov 10]. Available from: http://www.inca.gov.br/tratamento/cuidados-paliativos-pediatricos.
19. Marchetti D, Moreira MC. Experiences of prematurity: has the acceptance of the real child assumed the deconstruction of the imaginary baby? Revista Psicologia e Saúde [Internet], 2015 [cited 2021 Jun 6]; 7(1):82-9. Available from: http://www.pssa.ucdb.br/pssa/article/view/408/529.
20. Gonçalves JTRBO, Nunes NAH. Palliative care: lack of qualifications of general practitioners. Revista UNINGÁ [Internet], 2016 [cited 2020 Nov 10]; 50:27-30. Available from: http://revista.uninga.br/index.php/uninga/article/view/1318/937.