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Original article

Care-educational guide to neonatal death management: Production based on Freire's Research Itinerary*

Guia cuidativo-educacional manejo do óbito neonatal: produção a partir do itinerário de pesquisa freiriano

Guía educativa y de cuidados para el manejo de la muerte neonatal: Producción a partir del Itinerario de Investigación de Freire

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Abstract

Objective: to produce a care-educational guide for and with health professionals in an Intensive Care Unit, based on an understanding of their practices in neonatal death management. **Method:** a qualitative and methodological study guided by Paulo Freire's Research Itinerary, consisting of three stages: Thematic investigation; Coding and Decoding; and Critical Unveiling. It was carried out at a public maternity hospital in Manaus, Amazonas, Brazil, with the participation of 24 professionals. **Results:** the guide was organized into three chapters on care and preparation of the neonate; guidelines for the health team on what to do in the face of neonatal loss; support for the team; and maternal rights facing the loss. **Conclusion:** the technology was produced with a methodological strategy that contributed to understanding care practices in neonatal death management, marked by traumatic feelings, which collectively encouraged the participants to seek systematized, welcoming and humanized interventions.
Descriptors: Infant Mortality; Intensive Care Units, Neonatal; Educational Technology; Patient Care Team; Nurses

Resumo

Objetivo: produzir um guia cuidativo-educacional para e com os profissionais de saúde de uma Unidade de Terapia Intensiva, a partir da compreensão de suas práticas vivenciadas no manejo do óbito neonatal. **Método:** estudo metodológico, qualitativo, guiado pelo Itinerário de Pesquisa de Paulo Freire, constituído por três etapas:

Investigação temática, Codificação e Descodificação e Desvelamento crítico. Realizado em uma maternidade pública em Manaus, Amazonas, Brasil, com a participação de 24 profissionais. **Resultados:** o guia foi organizado em três capítulos sobre os cuidados e preparo do bebê; orientações para a equipe de saúde do que fazer diante da perda neonatal; apoio a equipe e direitos maternos diante da perda. **Conclusão:** a tecnologia foi produzida com uma estratégia metodológica que contribuiu para a compreensão das práticas de cuidado no manejo do óbito neonatal, marcadas por sentimentos traumáticos, que de forma coletiva, os participantes se sentirem estimulados a buscar intervenções sistematizadas, acolhedoras e humanizadas.
Descritores: Mortalidade Infantil; Unidades de Terapia Intensiva Neonatal; Tecnologia Educacional; Equipe de Assistência ao Paciente; Enfermeiros

Resumen

Objetivo: crear una guía educativa y de cuidados para y con los profesionales de la salud de una Unidad de Cuidado Intensivo, a partir d comprender las prácticas que experimentan en el manejo de la muerte neonatal. **Método:** estudio metodológico y cualitativo, guiado por el Itinerario de Investigación de Paulo Freire, constituido por tres etapas: Investigación temática, Codificación y Descodificación, y Desvelamiento crítico. El estudio se realizó en una maternidad pública de Manaus, Amazonas, Brasil, con participación de 24 profesionales. **Resultados:** la guía se organizó en tres capítulos sobre los cuidados y la preparación del neonato; pautas para el equipo de salud sobre qué hacer frente a una muerte neonatal; apoyo para el equipo; y derechos maternos frente a la pérdida. **Conclusión:** la tecnología se produjo con una estrategia metodológica que ayudó a comprender las prácticas de cuidado en el manejo de la muerte neonatal, marcadas por sentimientos traumáticos y que, en forma colectiva, los participantes se sintieran estimulados a buscar intervenciones sistematizadas, acogedoras y humanizadas.
Descriptores: Mortalidad Infantil; Unidades de Cuidado Intensivo Neonatal; Tecnología Educacional; Grupo de Atención al Paciente; Enfermeros

Introduction

The neonatal period corresponds to the time between birth and the twenty-eighth day of life, when human beings adapt and survive in the extra-uterine environment, with greater susceptibility to acute health problems and development of respiratory infections, especially in premature, low birth weight newborns (NBs), who may need to be admitted to a Neonatal Intensive Care Unit (NICU).[1]

Neonatal deaths have presented a slow reduction when compared to infant mortality (in children under five years old). Globally, the Neonatal Mortality Rate (NMR) fell from 37 deaths per 1,000 live births (LBs) in 1990 to 19 deaths per 1,000 LBs in 2016. However, this decline is not observed in a heterogeneous way in much of the world, especially in countries with low development levels such as sub-Saharan Africa and South Asia, where children are nine times more likely to die during the first month of life than in developed countries.[2]

In Brazil, from 2007 to 2017, the mean NMR was 9.46%/1,000 LBs. Among the Brazilian regions, the North had the highest rate, with 11.02%/1,000 LBs, whereas the lowest rates occurred in the South (7.8%/1,000 LBs). Higher rates were observed in premature indigenous NBs with extremely low birth weight.[3] Among the main causes of neonatal death are infectious deaths and complications

related to labor and birth.[4]

The NICU is a hospital environment that provides complex care and is intended for the hospitalization of high-risk NBs, mostly premature, who are exposed to environmental stressors such as the use of electronic equipment with alarms and beacons, invasive devices, excessive handling by the health team and others related to the therapy adopted. In addition, depending on their birth and physiological conditions, NICU admission can result in the interruption of a healthy life, greater susceptibility to complications and even neonatal death.[5]

Providing intensive, integrated care to NBs admitted to a NICU requires the work of a multiprofessional health team, duly trained and prepared to transform this space for assisting newborns into a humanized, welcoming and supportive environment for the family/guardians, in order to involve them in the therapeutic processes, stimulating the creation of bonds and minimizing separation between mother and newborn.[6]

The health team is oftentimes unprepared to deal with pain at the time of a neonatal death in the NICU, living daily with a situation of imminent death due to the unstable conditions and therapeutic needs for the survival of NBs, and also with the presence of parents who, despite recognizing the seriousness of their newborns, are not or have not been prepared to experience the loss.[6] As a result, there is a need to consider biopsychosocial and spiritual dimensions in the care of NBs and their families/guardians, emphasizing the importance of professional training to understand the death and mourning experienced in the NICU routine, especially by nurses, who spend most of their time caring for the neonates.[7-9]

Scientific studies carried out through the development of health technologies for care mediation, more specifically those that bring care and education closer together, such as Care-Educational Technologies (CETs) understood as a set of scientific knowledge/know-how based on the routine experienced by professionals in a caring/educating and educating/caring process for themselves and others, considering human praxis, i.e., professional practice carried out in a conscious and guided manner.[10-11]

In this area, their use is identified in the creation of technological products in health and nursing, methodological development studies in complementarity with qualitative research and participatory interface, with application of different group research techniques. These proposals encourage knowledge co-creation in the development of technologies together with the target audience, with the participants taking part in the construction process as active subjects who discuss and define the content of the technology in question.[11-12]

Thus, for producing the CET in the form of a guide on neonatal death management, it is considered appropriate to apply Paulo Freire's Culture Circles methodological strategy, adapted for the health area as Paulo Freire's Research Itinerary, used by national researchers and research groups, mainly in the southern region of the country. As envisioned by Freire, Culture Circles are understood as spaces for dialogues between people who come together to reflect on a given topic, sharing knowledge and practices from realities they have experienced and who, in collaboration with each other, problematize and search possibilities for interventions in different contexts, especially in the education and health care areas.[13]

The objective is to produce a care-educational guide for and with health professionals in an ICU, based on an understanding of their practices in neonatal death management.

Method

A qualitative and methodological study, with a participatory interface and based on Paulo Freire's Research Itinerary.[12-14] This type of research can be developed through different stages consisting of situational diagnosis, literature review, production-construction of the technology, face and content validation by expert judges and pilot testing (evaluation and/or application). However, in order to reach all the stages, continuity research studies are required to ensure the effectiveness and expected impact of a given technological production.[12] In this case, as it comes from an MSc thesis, it was possible to reach its production-construction, in complementarity with the methodological strategy proposed by Paulo Freire, carried out through Culture Circles, making up three interdependent stages: Thematic Investigation; Coding and Decoding; and Critical Unveiling, as presented in Figure 1.[14]

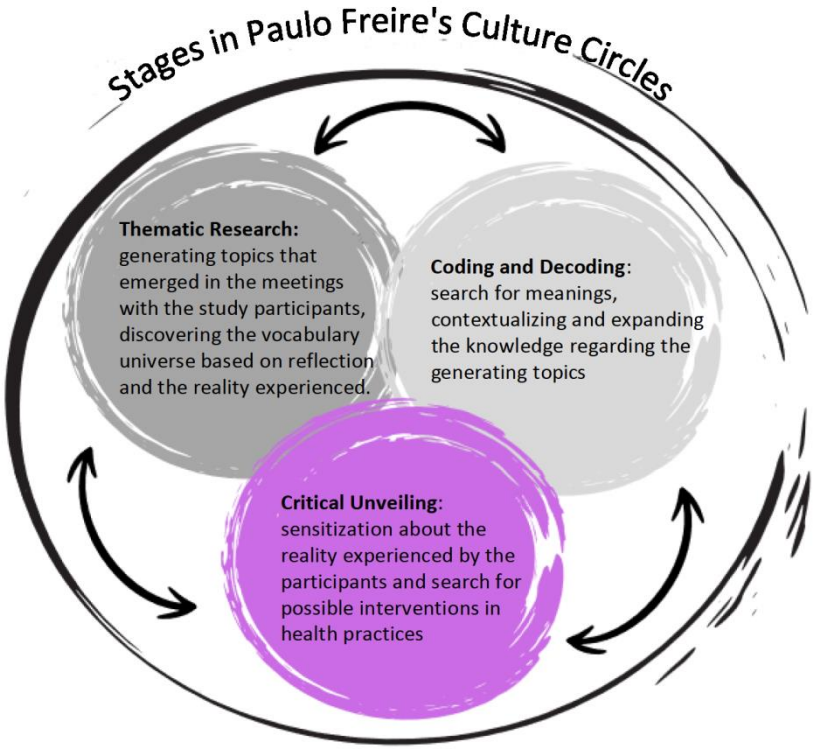

Figure 1 - Paulo Freire's Research Itinerary Stages, Manaus, Amazonas, 2023.

The study was carried out at a public maternity hospital in the city of Manaus, Amazonas, a reference for high-risk neonatal and maternal care, which serves the population of the capital Manaus and the state inland.

The participants were 24 professionals working in the maternity ward's NICU, including five nursing technicians, ten nurses, two physicians, two psychologists, two social workers, two speech therapists and one physiotherapist, as well as the two researchers that played the role of hosts, and a research assistant who recorded additional information in the field diary.

The inclusion criterion was a minimum of one year of professional experience in the maternity ward's NICU. Professionals who were away from work at the collection moment and those who reported having experienced a personal neonatal loss or one among close family members were excluded, so that there was no interference from feelings that were not strictly professional.

The researchers first carried out a Narrative Literature Review (NLR), with the objective of stimulating reading and gathering prior knowledge about the theme. An NLR is a critical theoretical and contextual analysis of the literature, which makes it possible to deepen diverse knowledge of a given topic in various sources of scientific production, not necessarily by establishing a systematic description of the studies investigated.[15] The databases used were as follows: *Literatura Latino-Americana e do Caribe em Ciências da Saúde* (LILACS), *Base de Dados de Enfermagem* (BDENF) and

National Library of Medicine (PubMed), covering publications indexed and made available in full in the last 10 years. The search was guided by the following descriptors: Neonatal Mortality; Neonatal Intensive Care Units; Educational Technology; Health Team; and Nurses, in English, Portuguese and Spanish.

To produce the data, the Culture Circles were applied in a second stage. Firstly, the researchers took part in a training course run by the Health Promotion and Education Research Laboratory of the Amazonas State University (*Laboratório de Pesquisa em Promoção e Educação em Saúde/Universidade do Estado do Amazonas*, LAPPES/UEA), on Paulo Freire's Research Itinerary methodological strategy. The researchers then entered the research field to recognize and observe the health team's work process. It should be noted that one of the researchers had already worked in the NICU of the maternity hospital.

At the time, the managers of the service and the coordination of the NICU were contacted and the team was invited via a social network group (WhatsApp), created to strengthen communication and interaction with potential participants. An invitation was sent to the group via a link to register on the Doity platform. After agreeing to take part in the study, they were sent the Informed Consent Form (ICF) in an electronic form built on the *Google Forms* platform to fill in their identification details and sign.

The meetings were agreed upon in advance, with dates and times depending on the participants' availability, and were held in the institution's auditorium, a spacious and comfortable environment. Colored brushes were used to hold the meetings, as well as sulfite paper of various colors to make folders, brown paper, a flip chart easel, adhesive tape, folders, pens, a notebook, a datashow, an audio recorder to record the testimonies and a field diary for additional notes.

At the first meeting, the researchers presented the research, the objectives and the methodological strategy of the study, encouraging bonding based on a dialogical relationship, as proposed by Freire. We tried to position the participants in a circle so that they could see and look at each other, in order to ease open dialog and interaction. In the thematic investigation stage, a script containing three guiding questions was used: What does neonatal death management mean to you (health team)? What do you understand about care in neonatal death management? Which are the limits, difficulties and potentialities found in the development of practices in relation to neonatal death management?

In the second meeting, the researchers presented the topics that emerged from the thematic

investigation and the coding/decoding stage took place. As soon as the participants recognized and contemplated the topics, they coded them by critically analyzing the reality of their professional practice in the NICU, creating a view of the whole observed by the professionals. As they resumed the dialogue in an action process, in an attempt to contextualize, signify and re-signify each generating topic, the whole was divided into parts in a back and forth movement during the group discussions about the existential situation, which until then had been covered by the generating topic.[14,16] Decoding takes place through construction of different perspectives, expansion of knowledge about reality and search for an understanding of the generating topics that have already been coded, culminating in an action-reflection process.[14,16] In decoding, new topics may emerge to be coded and decoded.

At the third meeting, the team was encouraged by the researchers to create a synthesis chart describing the generating topics, in order to reduce their number and contextualize each one. For this activity, the participants were given colored pens and paper to draw a picture of the meaning of neonatal death.

At the fourth meeting, the critical unveiling stage took place and the topics generated were apprehended by the participants as concrete realities experienced, at which point they became aware of the reality underwent in the daily routine of their practices and, in collaboration with each other, they sought possibilities for dealing with the situations, intervening positively in health care transformation, in order to complete the action-reflection-action process.[14] The synthesis chart was then resumed, structured and organized according to the opinions, ideas and desires reported by the team, and systematization of care was proposed regarding neonatal death management in the NICU.

Based on the needs discussed and reflected on during the Culture Circles, a preliminary script for the Guide was produced with the health team and the researchers, establishing the main textual topics for describing step-by-step care in the event of a neonatal death.

At each meeting, the researchers got together to transcribe, read, re-read and organize all the information in the field diary. In Paulo Freire's Research Itinerary, the investigation stages are interdependent and production and analysis are carried out simultaneously, with this methodological strategy having its own technique for data analysis and interpretation.[14,16]

Also in the fourth meeting, based on the needs discussed and reflected on during the Culture Circles, a preliminary script for the Guide was produced with the researchers and the health team, establishing the main topics and subtopics for the textual composition of version 1.0 of the technology, which was divided into three chapters. In addition, theoretical information from the NLR

was used for scientific support. The image content was made up of images drawn by the professionals and others created with the help of a graphic designer, who vectorized the images and laid out the text using *Adobe InDesign* and *Adobe Illustrator*. Data collection and analysis took place from December 2022 to March 2023.

This study is part of a project entitled "Organizational and structural aspects of maternity hospitals that assist women who experience pregnancy losses in Manaus, Amazonas" approved on July 22nd, 2022, by the UEA Research Ethics Committee under opinion No. 5,540,012. The recommendations set forth in Resolution 466/12 were complied with. The participants signed the informed consent form, were informed of the objectives, importance and contributions to their work and the health service's, and were free to withdraw from the research at any moment and to have confidentiality of their identities preserved. The participants' names were identified by the first letter of their professional background and the respective ordinal numerical order of participation (Example: P2, N1, NT1, SW1...).

Results

Based on the NLR eligibility criteria, 74 articles were selected to read their abstracts, resulting in 23 for full-reading and only six considered relevant for further studying theme.17-22 The articles dealt with assistance aspects regarding the complex care to be provided to neonates in the death process, being part of the everyday practices of the multi-professional team in the NICU, interactional aspects involving affective relationships, welcoming, empathy, bonding and dialog between health professionals and family members, spiritual aspects with experiences related to human beliefs and needs in the search to overcome death situations, and administrative, normative and institutional aspects on the event of neonatal death in the NICU.17-22

It is noted that only one article referred to the creation and validation of a theoretical construct.17 Therefore, there was scarce literature on the production of educational and health technologies on the theme researched.

In the Culture Circle meetings, 28 generating topics emerged from the three guiding questions in the thematic investigation stage, which were reduced to 16 in the coding/decoding and critical unveiling stages, as shown in Figures 2, 3 and 4.

In the Thematic Investigation stage, the generating topics were discussed based on the feelings experienced by the team in the NICU, in which they sympathized with the family's feelings of

loss (Figure 2).

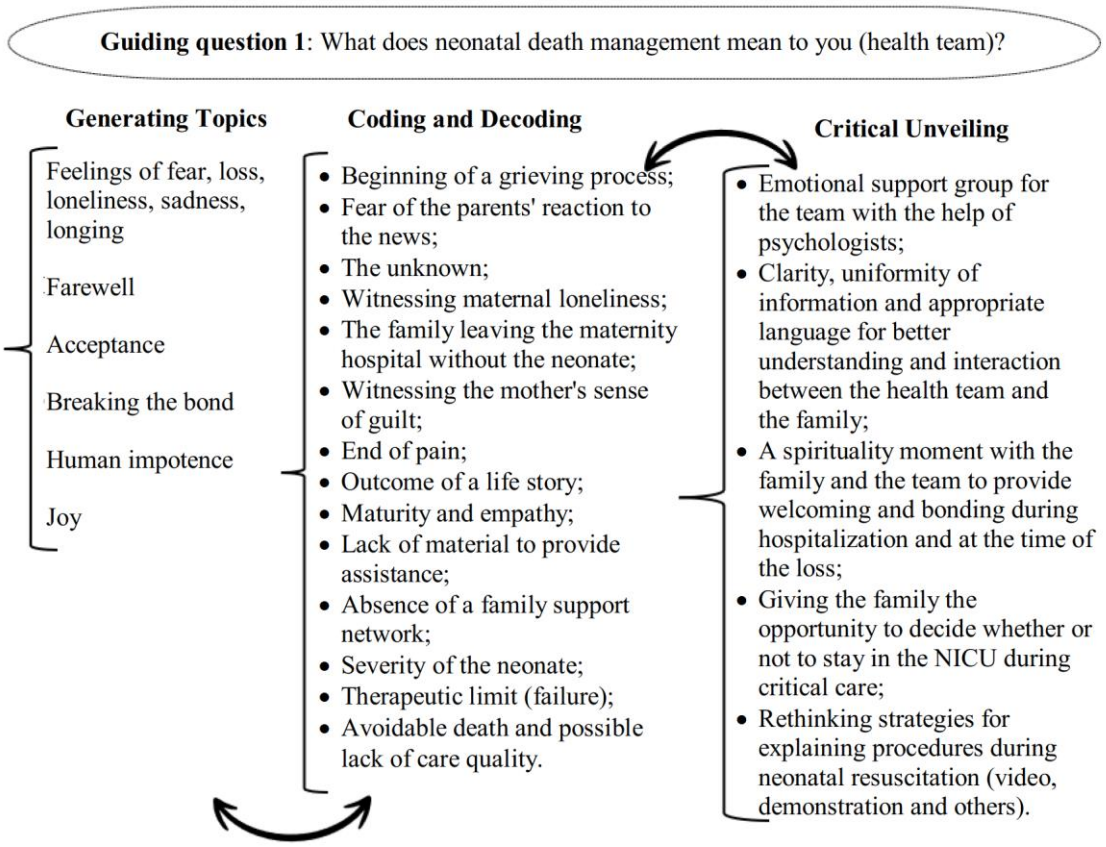

Figure 2 - Synthesis of Research Itinerary stages for guiding question 1, Manaus, Amazonas, Brazil, 2023.

Also in the thematic investigation, in the discussions on guiding question 2 (Figure 3), the understanding of care in neonatal death management revealed certain concern about handling and preparation of the stillborn body and how the death news would be given to the parents; they recognized that there was no adequate or specific space in the NICU for the family to be informed and to say goodbye to the neonate.

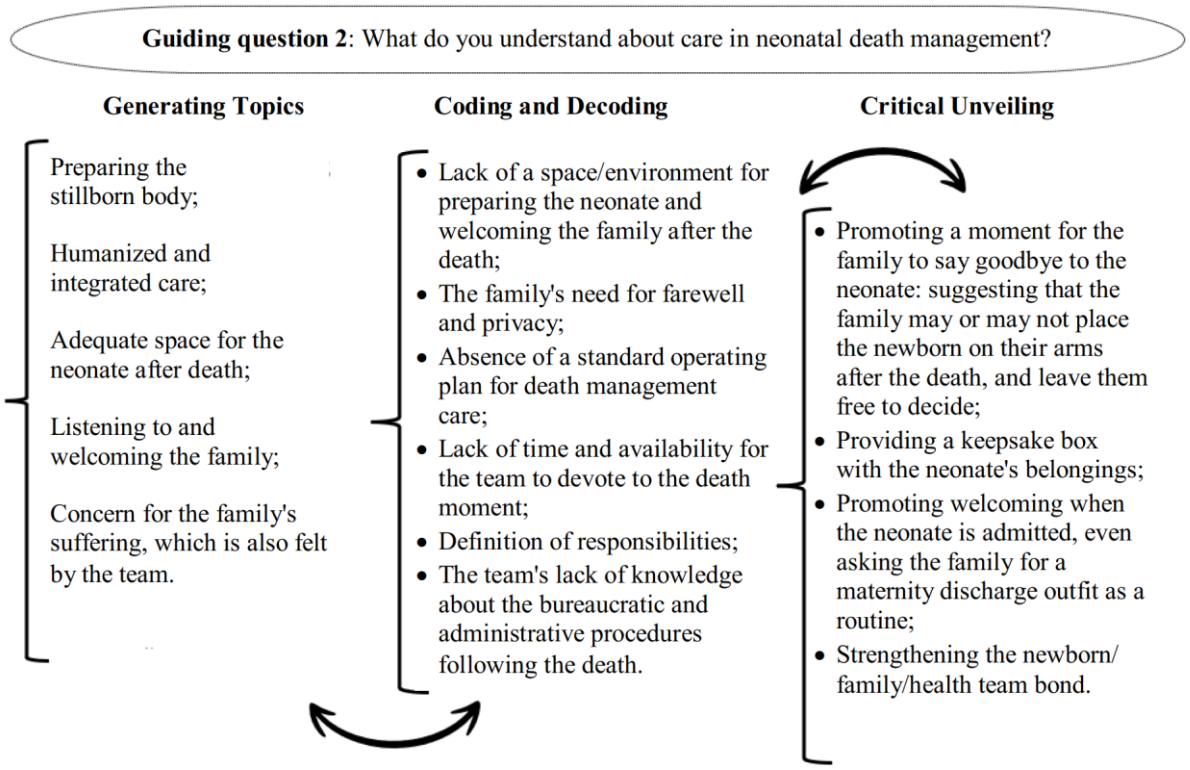

Figure 3 - Synthesis of Research Itinerary stages for guiding question 2, Manaus, Amazonas, Brazil, 2023.

The limitations, difficulties and potentialities found in the development of death management practices were revealed among the participants in the midst of the perception that they did not feel prepared to deal with neonatal death situations in the NICU. In addition to that, they pointed out the absence of a standardized and systematized instrument to guide the team on how to proceed in the event of death, containing the necessary procedures to be followed. The feeling of relief, bonding with the neonate and the family and good interaction between the health team members were considered by the participants as potentialities (Figure 4).

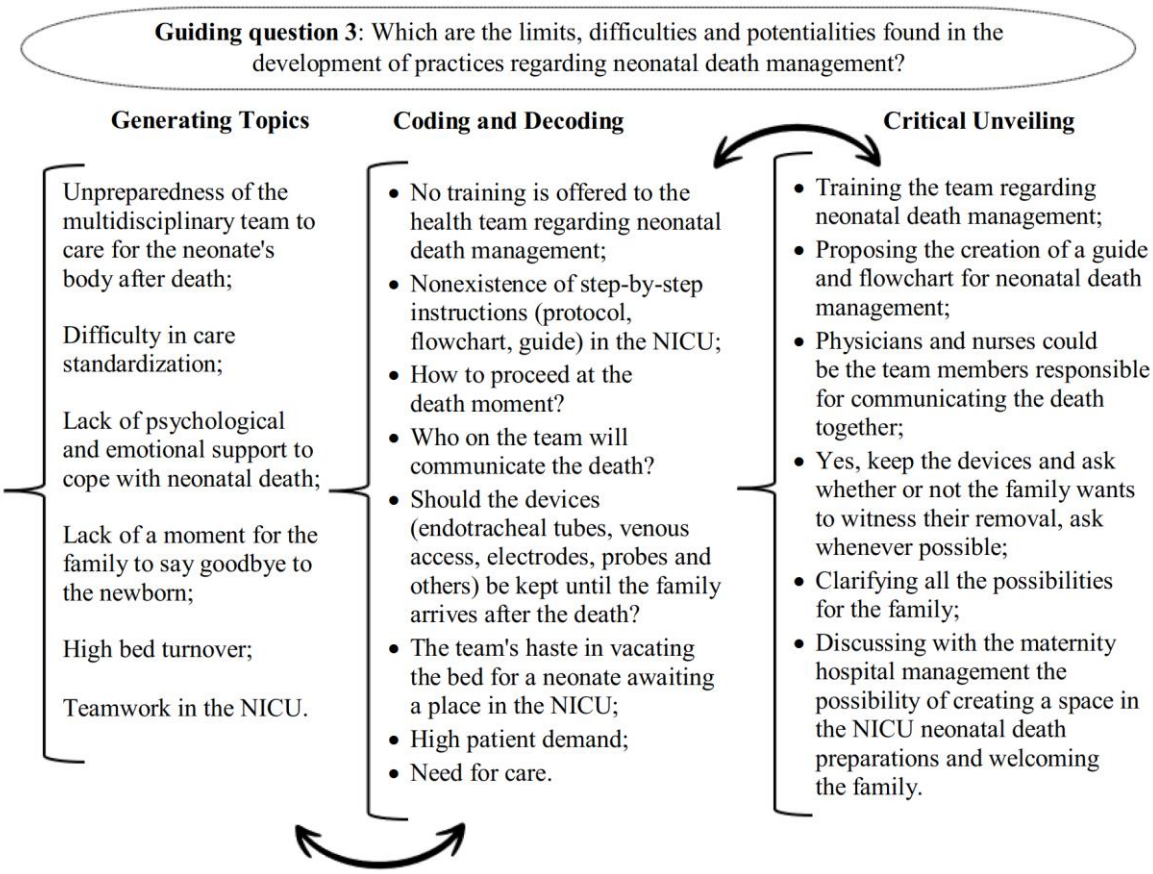

Figure 4 - Synthesis of Research Itinerary stages for guiding question 3, Manaus, Amazonas, Brazil, 2023.

In the Coding and Decoding stage, the professionals showed sensitivity towards the family and were concerned with providing warmth and care to the neonate.

In the Critical Unveiling stage, they pointed out the need for emotional and psychological support to deal with the loss of a patient, as a bond had already been established during the care process, both with the newborn and with the family. Through a critical and reflective process on the reality of the practices in the NICU, they experienced apprehension of knowledge and recognition of the process experienced, which allowed them to search for interventions and possibilities to face the neonatal death care and management practices.

The proposals put forward included the following: having an emotional and psychological support network for the health team available through the institution; having an exclusive space for the professionals to talk to the family and provide a moment to say goodbye to their newborn; and having a guide on neonatal death management, in order to instruct the team in conducting systematized care.

Produced with the professionals' participation, the guide was materialized in 66 pages, in digital format and containing three chapters and their respective subtopics: Chapter 1. The health team's understanding about neonatal death (Practicing care humanization; Care and preparation of

the neonate; Preparing memories); Chapter 2. Guidelines for the health team (Step-by-step instructions on what the team should do in the event of neonatal death; Legal point of view on the necessary documents, responsibilities and competencies of the professionals; and What care should the institution guarantee? Communicating neonatal death); Chapter 3. Dealing with neonatal death (Support for health professionals; Maternal and family rights in the face of neonatal loss); and finally, a separate topic, in which a care checklist for neonatal death management in the NICU was described.

Purple and lilac were predominantly used, considering the color as alluding to prematurity, a condition that is the major cause of neonatal death. In general, the images used are representations created by the participants themselves at one of the data collection meetings. A technical language accessible to the professionals was used, always seeking lightness, dynamism and creativity in the material to make it easier to read and grasp (Figure 5).

Figure 5 - Illustrations from the Neonatal death management guide for Neonatal Intensive Care Unit health teams, Manaus, Amazonas, Brazil, 2023.

Discussion

As experienced by the participants, neonatal death involved a series of issues that went beyond health care and also encompassed psychological, social, cultural and spiritual aspects within the NICU care process, both for the family and for the health team. The first Culture Circle meeting with the professionals made it possible to get to know and recognize the generating topics, based on

an existential and concrete situation experienced in the practice. This process was only possible as a result of having established interactive and dialogical relationships, which allowed identifying the problems encountered, the limit-situations imposed as challenges to be faced.[14]

These limit-situations represent barriers/obstacles that require political action on the part of people. They can be seen as challenges to be overcome or as situations of powerlessness in the face of reality.[14] The feelings of loss, loneliness and sadness revealed by the participants at the event of a neonatal death represented not only weaknesses, but also solidarity and empathy with the bereaved family. Although this situation is common in the NICU environment, there are few studies that discuss this issue.[23-25]

A study carried out in northeastern Brazil aimed at analyzing how the death was communicated and bereavement support for women who had lost their infants during the puerperal period, and found that the participants expressed suffering and anguish at the loss and that, in some cases, these feelings were aggravated by the absence of support offered and the way in which the news was transmitted by the health team, revealing the professionals' unpreparedness in neonatal death situations, as revealed in this study.[24]

Another research study which also found that the teams were unprepared for the process of dying in the NICU highlighted the absence of spaces for discussion in hospital environments about the need to train professionals, even in the academic scope.[25] Emotional support, provision of a suitable place to communicate the news to family members, support from the multiprofessional health team, and reflection and understanding of the feelings experienced during care were all strategies observed.

It is emphasized that the health team needs to develop effective communication skills and make good use of them during the process of caring for newborns, making it humanized, welcoming and ethical. In addition to that, they should encourage building of memories and emotional bonds with the deceased newborn and their family members, undergoing the mourning experience in a shared way, providing confidence and security to overcome the loss.[9,24] Discovery of the generating topics on the representation of neonatal death management, carried out collectively and interactively among the participants in this study, sparked encouragement for the co-production of the first chapter of the guide, ranging from care, death notification, handling the news, welcoming, identification and preparation of the stillborn.

The concept of care in neonatal death management also referred to difficulties preparing the stillborn body, as the team is usually prepared to "save lives" and not to deal with death. Lack of a time and of a physical space in the NICU to say goodbye to the newborn with the family were negative

factors expressed by the professionals. NICUs need to have a comfortable and supportive place to welcome the family in the event of death, as the high demand and turnover of patients result in a rush to vacate the bed and having to remove the neonate to the morgue before the family even receives the news. This practice was identified as strictly technical, mechanized and inhumane, imposed by the reality experienced by the professionals.[1]

Advance guidelines to family members about the possible neonatal loss, psychosocial support in groups, involving parents in the death procedures, strategies such as having a multiprofessional team available to help prepare the family and the use of cold cribs as a way of preserving the neonate's color, smell and characteristics, have all contributed to raising awareness, humanizing and establishing a bond between the professionals and the neonates' family members.[1,8-9,26]

Paulo Freire's Research Itinerary enabled the NICU health team to understand their practices in neonatal death situations, as the dialogic relationship established in the Culture Circle meetings mediated by the researchers allowed the study participants to take a new approach to doing/caring, moving from naive thinking to critical, political and liberating awareness.[14]

At each meeting, the professionals progressively problematized and reflected on significant dimensions of their realities (generating topics), which contributed to a proactive stance in the face of the limit-situations revealed in their care practices regarding neonatal death management.[14]

In this way, it was possible to use this methodological strategy with a participatory interface in producing the Care-educational guide to neonatal death management for the multiprofessional health team, with the NICU professionals as co-producers, who were part of the process as protagonists in the care provided to neonates and their families. At a national level, it is noted that methodological studies have used Knowledge Translation as a conceptual model, in which the technological product is created with the participation of the target audience. In addition, in participatory methodological research, "high density" participation is considered to be when the target audience not only determines the content of the technology, but is also part of its production.[12,27]

The limitations of this research are the scarcity of studies on the theme and the difficulty bringing participants together outside the workplace to hold the Culture Circles, due to the professionals' intense workload. It is expected that, on future occasions, the next stages in production of the technology will be carried out, which will be validation and evaluation of this Guide. Although the checklist is incorporated into the guide as a complement to care, if it is to be used in the practice, it

will need to be validated and institutionalized with NICU managers and coordinators.

The Guide was produced to support professionals in providing standardized care that is aligned with the needs and experiences of the team and the bereaved families. Its content includes what to do and how to do it in neonatal death management in the NICU. It is not merely a product materialized digitally or otherwise, but involves internal elements that reflect the feelings, aspirations, perceptions, difficulties, limitations and potentialities experienced by the target audience.[28-29]

CETs should be seen as products that incorporate educational processes in their production, which are intended to ease health education and care, in order to contribute to professional practices, especially for nurses, who take on heavy workloads in neonatal intensive care.

Conclusion

The "Care guide to neonatal death management", produced in conjunction with a participatory methodological strategy, is characterized as an important tool with the potential to support multiprofessional health teams in the NICU, especially nurses, with regard to care for neonatal death management. In addition to that, it contributes to care humanization and minimizes the family's feelings of loss in the face of neonatal death.

The health team's understanding of their practices in neonatal death management was marked by traumatic feelings of sadness, fear, loneliness, acceptance, impotence and even joy at the relief of pain. The results showed that the professionals did not feel prepared to experience the death moment and expressed empathy and concern about communicating the news to the family. As limits and weaknesses, they pointed to fear of the parents' reaction to the news, witnessing maternal loneliness, lack of a family support network and difficulty establishing a routine and rules on how to deal with the death. The potentialities perceived by the professionals were feeling of relief, bonding with the neonate and the family, and teamwork.

The spaces for dialog and reflection provided by the Culture Circles enabled the health team to collectively seek to overcome limit-situations with a critical and political stance. The possibilities for interventions materialized through production of the guide referred to the need for clear and sensitive communication; preparation of the neonate and adequate space for welcoming the family members; freedom of decision for the family to say goodbye to the newborn; and the possibility of offering a keepsake box with personal objects of the deceased NB.

Paulo Freire's Research Itinerary proved to be an applicable option for the participatory development of health technologies, especially in the Nursing field. The importance of conducting

more studies on the topic is noted, with problematizing, creative and innovative approaches to guide the health team's work process in terms of systematizing their practices in preparing the neonates and welcoming the bereaved family.

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