



BETWEEN BIRTH AND DEATH: PALLIATIVE CARE IN THE EXPERIENCE OF HEALTH PROFESSIONALS

Entre o nascer e o morrer: cuidados paliativos na experiência dos profissionais de saúde

Entre el nacer y el morir: hwecuidados paliativos a partir de la experiencia de profesionales sanitarios

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ABSTRACT

Objective: To understand how the health professionals of a neonatal intensive care unit (NICU) in a high-risk maternity hospital experience neonatal palliative care. **Methods:** Qualitative study carried out using the critical phenomenological method and with the unstructured interview as instrument, performed from October to December 2015, with participation of eight health professionals of the said NICU. Four categories arose: Experiencing palliative care; Giving meaning to the baby with no prognosis; The families of the babies and the affectation of professionals; and Traversing death in the lived experience of the professionals. **Results:** The main findings of the study indicate that palliative care for the professionals can be portrayed from different aspects. For them, looking and caring for babies without prognosis are intertwined with the onset of affective involvement; the experience of contact with the family also appears as a way of being affected, as feelings that had not emerged before arise; and the moment of the baby's death is a challenge full of difficulties to face. **Conclusion:** It is perceived that, even without the palliative care program at the institution, there is the initiative to perform a practice that approaches that kind of care, especially with regard to seeking comfort for the baby and greater inclusion of the family, what already demonstrates that they are sensitized awareness to this perspective.

Descriptors: Intensive Care Units, Neonatal; Health Personnel; Palliative Care.

RESUMO

Objetivo: Compreender como os profissionais de saúde de uma unidade de terapia intensiva neonatal (UTIN), em um hospital-maternidade de alto risco, experienciam os cuidados paliativos neonatais. **Métodos:** Estudo qualitativo, realizado com método fenomenológico crítico, tendo como instrumento uma entrevista não estruturada, realizada no período de outubro a dezembro de 2015, do qual participaram oito profissionais de saúde da referida UTIN. Surgiram quatro categorias: Experienciando cuidados paliativos; Significando o bebê sem prognóstico; As famílias dos bebês e a afetação dos profissionais; e O atravessamento da morte na experiência vivida dos profissionais. **Resultados:** Os principais achados do estudo indicaram que os cuidados paliativos para os profissionais podem ser retratados a partir de diferentes aspectos. Para eles, o olhar e o cuidar dos bebês sem prognóstico estão entrelaçados ao surgimento do envolvimento afetivo; a experiência de contato com a família também aparece como uma forma de serem afetados, pois surgem sentimentos não antes emergentes; e o momento da morte do bebê é um desafio cheio de dificuldades para enfrentar. **Conclusão:** Percebe-se que, mesmo sem o programa de cuidados paliativos na instituição, existe a iniciativa de realizar uma prática que se aproxima desses cuidados, principalmente ao buscar conforto para esse bebê e maior inclusão da família, o que já mostra sensibilização para tal perspectiva.

Descritores: Unidades de Terapia Intensiva Neonatal; Pessoal de Saúde; Cuidados Paliativos.



RESUMEN

Objetivo: Comprender cómo los profesionales sanitarios de una unidad de cuidado intensivo neonatal (UCIN) de un hospital-maternidad de alto riesgo vivencian los cuidados paliativos neonatales. **Métodos:** Estudio cualitativo realizado con el método fenomenológico crítico con la entrevista no estructurada como instrumento de recogida de datos realizada en el periodo entre octubre y diciembre de 2015 en la cual participaron ocho profesionales sanitarios de la referida UCIN. Surgieron cuatro categorías: Vivenciando los cuidados paliativos; Significando el bebé sin pronóstico; Las familias de los bebés y la afectación de los profesionales; y El cruce de la muerte en la experiencia vivida por los profesionales. **Resultados:** Los principales hallazgos del estudio indicaron que para los profesionales los cuidados paliativos pueden ser retratados a partir de distintos aspectos. Para ellos, la mirada y el cuidar de los bebés sin pronóstico están entrelazados con la aparición del involucramiento afectivo; la experiencia del contacto con la familia también surge como una forma de ser afectado pues surgen los sentimientos que antes no emergieron; y el momento de la muerte del bebé es un desafío lleno de dificultades para afrontar. **Conclusión:** Aunque no haya el programa de cuidados paliativos en la institución, se percibe la iniciativa de realizar una práctica que esté cerca de esos cuidados, principalmente al buscar el confort del bebé y mayor inclusión de la familia lo que muestra la sensibilización para tal perspectiva.

Descriptores: Unidades de Cuidado Intensivo Neonatal; Personal de Salud; Cuidados Paliativos.

INTRODUCTION

The Neonatal Intensive Care Unit (NICU) is intended for the care of a newborn (NB) – child aged 0 to 28 days – in a severe condition or at risk of death, of any gestational age, bearing the following clinical conditions: dependence on mechanical ventilation, or in the acute phase of respiratory insufficiency, with Fraction of Inspired Oxygen (FiO₂) higher than 30%; preterm infants younger than 30 weeks gestational age, or weighing less than 1,000 g; need for major surgeries, or immediate postoperative period of minor and medium-sized surgeries; parenteral nutrition dependence; and specialized care⁽¹⁾.

The United Nations has presented as a main issue for the coming years the reduction in child mortality, which is a concern for the development of the millennium⁽²⁾. However, international studies point out that, despite the technological development that drives the survival of even smaller infants, leaving decreased clinical complications, there are still cases of inevitable deaths, such as babies who are born with extreme prematurity or develop into cases that are incompatible with life⁽³⁾.

In 2016, in Brazil, the number of neonatal mortality was 24,611. Of these, 6,195 were explained as deaths from non-preventable causes⁽⁴⁾. As to the determinants of death, prematurity, congenital malformation and infections prevailed⁽⁵⁾.

Critically ill NBs may have the morbidity and mortality inherent in their clinical condition, which makes them think about the limits on the use and benefits of technology for these patients, an ethical discussion that has permeated neonatology for some time through the philosophy of palliative care (PC)^(6,7). Preterm and/or low-weight patients (<27 weeks and <750 g), who bear congenital anomalies incompatible with life and do not respond to intensive care, may be eligible for PC in neonatology⁽⁸⁾.

The PC perspective focuses on the quality of life, comfort, and relief of physical symptoms of infants facing life-threatening situations, extending to the emotional and spiritual distress of the family, with integrity and respect for cultural aspects and spiritual beliefs even after the death of the NB^(6,8,9). Assistance is based on the principle that professionals attend to the needs of the baby for palliative treatment and to family issues in order to perform the well-deserved embrace, understanding that the health team also experiences difficult moments⁽¹⁰⁾.

There is an intrinsic relationship between the health team, the babies, the family and the environment of the NICU, in which the relations are affected in the perspective that the world is the field of experience of mankind, characterizing a worldly man who constitutes the world and is constituted by the world⁽¹¹⁾. Such conception overcomes the idea of dichotomy and neutrality in the relations in the field of health⁽¹²⁾, which implies that the health professionals of neonatology are part of the NICU and this is part of the professionals, and it is not possible to dissociate them. Therefore, it assumes a multiplicity of contours that surround them, such as social, historical, cultural and biological aspects, among others that permeate this constitution⁽¹¹⁾.

The mention of phenomenology in health problematizes the concept of health production in the community health context, looking at the health-disease relationship⁽¹²⁾, and strengthens the humanization of high-complexity services, promoting the interhuman encounter of professionals, users and relatives⁽¹³⁾, perspectives that corroborate the PC philosophy.

In the present study, there was a specific intention of understanding the lived experience of health professionals of a neonatal intensive care unit, from a critical phenomenological perspective. It is perceptible that there is no PC program⁽¹⁴⁾, although the majority of hospitalized infants have a profile close to those described as eligible for such care. Cases such as those of extremely preterm newborns and/or malformed infants who survive with NICU support, however, with severe sequelae that render them dependent on high technology for their life to last, which leads to questioning whether there is only a postponement of neonatal death to another moment in the child's life, without taking into consideration their dignity and quality of life⁽¹⁵⁾. It is also reflected in the country's current health scenario, mobilizing itself to implement public policies for early childhood care, which aim to promote health through comprehensive care, since pregnancy⁽¹⁶⁾.

Thus, the relevance of this study consists in instigating the PC within this context, understanding that objectifying the quality of life and well-being of the baby with a life-threatening clinical condition is health promotion. For the field of community health, it is fundamental that the subjective aspects involved in the relationship between death, PC and the professionals' experiences be open for discussion, since these professionals often become fragile in the presence of the situation of a baby's death, which makes the subject a health concern for professionals that deal with confronting such condition and with the limitations in knowledge and practice in health.

As part of this perspective, some differentiated attention should be given to the professional who deals with death and understanding of PC, so that they can best develop care at the NICU⁽¹⁰⁾. Thus, this question is raised: In your process of caring for the infant at a NICU, how do you experience palliative care in neonatology?

In view of this context, the objective was to understand how the health professionals of a neonatal intensive care unit (NICU) in a high-risk maternity hospital experience neonatal palliative care.

METHODS

This is a qualitative study conducted between October and December 2015, justified by the objective of understanding PC in the lived experience of the health professional of a NICU. Qualitative research aims at apprehending the phenomena and all the human dimensions involved in them, which can not be stipulated into variables and analyzed by statistics⁽¹⁷⁾. It renders it possible to think about challenges in community health practices, focusing on studies of human processes, getting rid of the accumulation of biotechnology⁽¹⁸⁾.

This qualitative research was delineated as a field study, which took place at a maternity hospital located in the city of Fortaleza, capital of the State of Ceará, classified as tertiary level of care, a referral service in high-risk gestation, acting as a Support Center for Good Practices in Obstetric and Neonatal Care in the Northeast of Brazil and designated as a Baby-Friendly Hospital. The institution's Neonatal Service consists of the NICU (two units) and the Neonatal Intermediate Care Unit (three units), totaling 56 beds for infants⁽¹⁹⁾.

The research participants were the health professionals working in the NICUs of the said hospital, one of each category in the team, assuming the existence of particularities of each nucleus of action. As an inclusion criterion, it was stipulated that the participant should be a professional working daily at the NICU and, as an exclusion criterion, professionals in the process of academic training or graduate studies. Because of the service turnover, there were eight participants: a neonatologist, a nurse, a physiotherapist, an occupational therapist, a psychologist, a social worker, a pharmacist and a nursing technician, who were interviewed following an invitation made by direct contact between the researcher and the professionals, for them to take part in the research.

In order to access the lived experience of the professionals of a NICU, there was the appropriation of the critical phenomenological method from Merleau-Ponty's perspective, which makes it possible to understand that there is no absolute truth in science, this being a movement in constant genesis⁽²⁰⁾. There are different prisms of reality in a variety of experiences, which leads to the realizing that research does not seek some ready concept, but rather the revelation of prisms. This method is a way of accessing the phenomenon in the participant's lived experience⁽²⁰⁾. The lived is defined as something that happens prior to reflection. It is the immediate reaction, even before the conceptualization⁽²¹⁾. The objective of this study was to understand the professionals' experience, not the theoretical concept learned by them. Therefore, the unstructured interview, composed of a guiding question⁽²¹⁾, was used as the instrument of data collection: "In your process of caring for the infant at a NICU, how do you experience palliative care in neonatology?" The interviews were previously scheduled with the collaborators and took place at the very institution, in quiet and private places. These were recorded and transcribed, having their anonymity preserved.

There is an interweaving of the researchers with the research participants and, in order to understand their lived experience, the phenomenological reduction is carried out in the interviews and data analysis (until the last stage), which is the suspension of the "a priori", that is, it is time to let the preconceptions and the familiarity with the world be suspended so as to understand the lived world of the other⁽¹¹⁾. What differentiates it from neutrality is the science that a complete reduction is impossible, since one is rooted in the world, so that it will always be an attempt⁽¹¹⁾.

Without aiming at a synthesis of meanings, data were analyzed in three different moments⁽²⁰⁾: division of the native text (transcription of interviews) into movements; descriptive analysis of the emerging meaning of movement; and "leaving the parentheses", articulating the professionals' lived experience with the theoretical path made from what emerged in the interviews, when the researchers were allowed to position themselves.

From the reading of the native text and its division into movements, according to the methodological proposal⁽²⁰⁾, the following emergent themes were listed: PC experience in neonatology; Pediatric and adult PC; Possibilities of assistance in PC in neonatology; PC practice in the institution's neonatology; Viability of the baby; Health professional - family relationship; Communication of bad news to the family; Dealing with death; Self-care and death-related care; Work dynamics in the maternity ward; Working condition; Acting in other contexts; Training course; Relation with the team; Personal experience.

With the emerging themes, they were grouped into categories based on the affinities with the study objective⁽²⁰⁾: Experiencing palliative care; Giving meaning to the baby with no prognosis; The families of the babies and the affectation of the professionals; Traversing death in the lived experience of the professionals.

It is emphasized that this research was in compliance with Resolution 466/2012 of the National Health Council, which addresses research involving human beings, with the approval of the Ethics and Research Committee (ERC) of the institution surveyed under Approval no. 1253641. Participants signed the Informed Consent Form. In order to maintain anonymity, the participants were given fictitious names: Gabriela, Clara, Laís, Victória, Samile, Jasmim, Paloma and Ana. These were chosen by one of the researchers, referring to children's names, but without identification, who had crossed their professional history and died as a result of clinical conditions in which death was inherent, with the intention of paying homage to their existence in the world.

RESULTS AND DISCUSSION

Here we present the categories that have emerged from the study, discussing them from the excerpts of the native text and getting them theoretically articulated.

Experiencing palliative care

In this category, we present the experience lived in PC by the participants through their own understandings in relation to such care.

PC is portrayed by means of different experiences: routine care, impending death care and pain relief measures:

“But the PC that you're talkin' about are in relation to the baby, isn't it? [...] no, it's ... (pause) PC is not ... Really hard [...] no, like this (pause) what we, when I, you talk about PC, it reminds me, it comes to my mind a person who is in a terminal state, isn't it, you only do PC isn't it, use only comfort measures for that person not to feel no pain isn't it, but so, I'll speak in a general way, because here with the babies, most of the babies, at least there is a big chance of them surviving” (Samile).

In the case of PC, it is common to remember often the elderly persons who are at the end of life, because of the belief that children should not perish before the adults⁽²²⁾. This was seen in Samile's statement regarding the way she experiences neonatal PC. For her, PC is intended to give comfort in the terminal stage, to prevent pain, at the same time, she contradicts herself, when she mentions that the babies will have a great chance to survive, despite being children of NICU.

It is possible to differentiate “end-of-life care” from “palliative care”. End-of-life care represents the final step, when death becomes irreversible, and is a phase comprised in the PC⁽²³⁾.

As another movement, the participants discussed their experiences in PC in the NICU taking place from the team and the family coping process:

“In my little experience of working inside a NICU, it's ... Here, in this hospital, it's like, those few babies who have needed PC, it is, it was very important for that child's quality of life [...] and we really do whatever possible for that baby, it is very important to give some comfort in life” (Ana).

“I think PC in neonatology is something that ends up facing some resistance, right? [...] and besides the professionals' resistance, there is a resistance on the part of the the families, isn't it?” (Laís).

The reported experiences approach the definition of this care, in the similarity of having an active approach that is centered on the child's quality of life⁽⁸⁾. However, there is resistance related to the child's own developmental condition, which implies constant changes, and thus renders it difficult for the team and the family to accept the limited prognosis⁽²⁴⁾, and it is necessary for those involved (care team and family) to have knowledge of the baby's process of dying, understanding the “how, where and why”^(6,25).

The professionals described possibilities for PC work: the expansion of visits, the inclusion of family and religion, and the need for a structure with a protocol:

“But then, in my little experience in that period, which is really about quality in whatever you can do, while that baby is here, isn't it? Yes, there has already been a situation when a pastor came here, the doctor spoke of the severeness itself and then we have supported that process ... so, then, to have the aunt in, to have others in, other family members, brother, pastor, and so” (Clara).

“I think there should be a structure, that there should be a team, indeed, involved in the process, isn't it, in which (pause) first to classify, to see which patient would be taken into that, which patient would enter the protocol, the way it would be done; I think we need to have everything formalized and need people who do it with the necessary kindness” (Laís).

There is an emphasis on the quality of doing in the proximity of death, an expansion of the forms of action, corroborating the literature, which points out that care should be focused on the needs of the baby and the family, thus providing the support required by them, including the spiritual support, an important dimension in this context^(6,15), as well as the parents' persistence alongside the babies at the end of life⁽²²⁾.

It is fundamental to provide space not only for family members, but also for professionals to express the affectation of the child's life and death⁽²⁵⁾. It is also pointed out the importance of a specific team to manage the PCs and that the professionals benefit from this support⁽⁹⁾, given their own demands in the statements and the non-specific training, as evidenced.

The PC practices in the maternity hospital investigated, currently, indicate that there is no specificity in the practice of PC, nevertheless, it is explained that there is an ongoing reflection on the limit to the viable:

"That's why I'm telling you. PC like that, indeed palliative, I don't know whether here at the Neo this question 'we won't try anymore' would apply, because of non-viability, since here, from what I see, trying lasts until forever; until we realize that the baby won't come back, understand? Thus, our palliative is to give a little more quality of life but, even so, even when they collapse, resuscitation is attempted" (Ana).

"In recent times, I think this has grown, we have seen several patients that we have started to discuss this, patients we know are non-viable, that bear some genetic syndrome that is incompatible with life, and we have started talking about it, talking to the families, showing that there is a limit to caring, that there is a limit to what can be done" (Lais).

The limit to the viable gives rise to questioning what the life and the way of living of these children are. Phenomenology encompasses a complex discussion about human existence – not intended to be achieved in this study – pertinent to be pointed out hereby, for promoting the understanding that life exists imbricated to death, enabling an expanded compression of the finitude. Prior to the essence of who the participant is, there are the conditions of their existence⁽²⁶⁾. It leads to thinking about the life-death of the baby, the conditions they are in at the NICU, supported by technologies and procedures that cause discomfort, and in this context, the way the relationship with the world is constituted and even the way parents and families are affected, which is the basis of the PC philosophy⁽²⁷⁾.

Regarding the implementation of PC in neonatology, it is imperative to have a guideline for standardization of the practice, with patient eligibility criteria, with established parameters, with conducts to be performed, steps to be followed, among others. It is necessary to plan, train and involve all participants, including the prenatal care team, management personnel and the family^(9,27).

In order to admit the PC specification in neonatology, the barriers and facilitations experienced by the health professionals, as well as the technical knowledge, must be validated. This is a philosophy that can provoke professional self-reflection in several aspects, as it involves their beliefs, values and culture, when faced with the possibility of death⁽¹⁰⁾.

Giving meaning to the baby with no prognosis

In this category, a discussion about these babies has emerged, portraying how the professionals perceived and conceived them, and how it felt to care for them, attributing different meanings.

The following excerpts describe caring for babies with no prognosis in two different ways: as those who are avoided and as those who are cared for as any other:

"[...] they are the last ones to have their medicines prescribed; they are the last to be examined; they are the ones that the resident doctors don't want to see; they are the remainders; they are hidden from ourselves, and this is not just regarding the doctors, I guess it all has got to do with that, isn't it so? It's that, that pain that no one wants to see, right?" (Lais).

"I keep caring for them the same way, like for any other that could be aged many years of life, because there is a life there, isn't it? So we must give him the best while he lives, while he's there. I'm not saying that 'oh, he's going to die tomorrow', no way, I don't think so, that because he won't have a life, I won't do it, God forbid such a thing, because it's a life and the way it must be dealt with, as a human being who could live many, many years ..." (Paloma).

Avoiding the baby can be a way of denying the existence of that baby. Caring for them like for any other baby is questioned, whether this would be a denial of the condition of his inherent death. Denial of death can occur when there is a prolongation of life, in an attempt to control death and escape the suffering that results from it⁽²⁸⁾, or even when, in those care, the individuality of the clinical situation, in which death is imbricated, is not considered. The denial is a healthy transient defense mechanism, since facing death all the time is not bearable, especially for the health professionals, and it is problematic to crystallize this denial⁽²⁹⁾.

The participants described the aspects imbricated with this experience: putting oneself in the place of the parents, feeling for the baby, the presence of the baby, among the existing multiplicity of meanings:

"[...] then I feel compassionate; it doesn't hinder me at work, doesn't stop me from working, but I have, I feel compassionate for the mother, the baby ..." (Samile).

"But for me, what has become very clear is that, while the baby is there, you have to give your attention, your care, your touch, your hope [...]" (Clara).

The concept of humanization in community health by means of phenomenology concerns this intertwining professional-user relation, rendering neutrality in health relations impossible. There is an understanding of the professional-user-world encounter constituting the care process, which is not disease-centered⁽¹²⁾. Humanization in the NICU enables the encounter between health professional and newborn, admitting the environment in which the family and the clinical framework of the child are present, the life history of the professional, among the several aspects that constitute this relationship, without being restricted only to the proximity of dying, also encompassing it, though.

The participants expressed the way they see these babies, giving meaning to them, within the experience they live in caring for the infants. They report that the child feels the care and the presence of the mother and reflect on the child as a symbol for the family:

"I believe that the baby, despite not speaking, he feels, feels the care, he knows that it's the mother who is there, he knows" (Paloma).

"Even if the individual weighs half a kilo, because he's an individual, he's a being, he's a small being, but he's a being for those families ..." (Lais).

"There are those who say the opposite, but I think he feels, right, when he is allowed [by the family] to go" (Clara).

In all the speeches, it is understood that the babies were placed as subjects, who feel and have a place in the family. It is fundamental to consider the condition of establishing the attachment of the mother to the fetus, which generates expectations and fears since the gestation period, which appears imbricated in the relationship with the neonate, threatened with death, arising feelings previously unknown to the mother and that must be recognized within the perspective of PC. The story of this child in the world becomes clear, no matter how brief the time is⁽²⁵⁾.

The NICU professionals should include the family with the baby in their health care, as recommended by the PC philosophy, aiming at a comprehensive care for the baby and including the multidimensional needs it presents and the family's demands⁽⁶⁾.

The families of the babies and the affectation of the professionals

In this category, the families of the babies and the affectation of the professionals are movements that explain how the collaborators experienced the family of the babies during the hospital stay and in the situation of having a baby without prognosis. It shows the way professionals experienced the relationship with the family, how they are affected and how they perceived what that relationship should be. The way the contact with the family unfolds or even its absence was described:

"... We even begin to create a bond with this mother and start to follow and know a baby's history, and we deal with expectations, with dreams, with so many things" (Gabriela).

"No. With the family, we usually do not have contact [...] Except when the father or mother is by the side of the incubator and we need the medical chart and they approach us, as they would do to any other health professional, wanting to be informed about the baby, then [we] take a look at the medical chart and see if we can be of help, but the recommendations, really, the doctor and the nurse are the ones who are most appropriate to give guidance regarding the therapy that we see, isn't it? Right?" (Viktória).

Professionals can access the family's emotions when they facilitate a channel of fluent communication with them⁽⁶⁾. The relationship of the team with the family is based on the emotional conditions and the professional's coping in dealing with the family's suffering in the speech addressing the performance and procedures. There is a difference, in the phenomenological perspective, between talking about aspects in a theoretical way, without becoming involved in what is being said, and expressing one's experience, what happens to someone in its totality, movement prior to the thought proximity of dying. When suffering is unbearable, there is a distancing from the relatives, either as hostility or as non-involvement⁽³⁰⁾.

It is noticed that there is a difficulty on the part of the collaborators in expressing themselves, during the interviews, showing their perception, their feelings and emotions, being always inclined to be reflective⁽¹¹⁾.

The lived experience of the professional, encompassing the theoretical aspect and the actual experience, is intertwined with the encounter between them and the family. With the view of humanization articulated to phenomenology, this relationship is based on the recognition of the subjectivity of both involved. There is a co-responsibility in the care, in which there is autonomy and production of the family member's health, and it is up to the professional to promote this perspective, being aware of the barriers to such encounter, unveiling possibilities of their way of acting in care⁽¹²⁾.

In the professionals' practice with the families of infants hospitalized at NICU, the following actions were presented: inclusion of families in care, promotion of family contact with the baby, ludic activities (cut and paste, beads, drawings etc.) and support to the family:

"Because, right in the beginning, when she was, when she was like... not more severe, but... when it was possible to change her diaper, see, to hold the diet, I tried to include her in the care, she already had the little girl in her arms, even if she is intubated, then we try to create this - not only I, but the entire ICU team - try to create that bond, to tighten this bond between the mother and the little baby, even if the little baby was not viable" (Samile).

"[...] then, she used to say that she was upset, that the baby had gotten worse, but she was not the type of person who likes to talk; we brought some activity [therapeutic resources developed by the occupational therapist] for her to do, she did all the activities, all of them. She followed me everywhere to do the activities [...]" (Jasmim).

The insertion of parents in the care and the encouragement to coexistence with the infant facilitates the parent-child relationship, reducing suffering and bringing benefits to the infant, the family and the team, which also share the responsibility for care⁽⁶⁾.

Traversing death in the lived experience of the professionals

This experience portrays the presence at the time of baby's death, starting from the way of dealing with death and up to the recognition of the need to work in order to cope with the situation.

In the following excerpts, the professionals express the experience of being present and accompanying this moment:

"It was very sad. It was sad, because I was seeing there that there was no coming back, there was no return, that she was very severe [...] that it was tried, a lot was tried, in resuscitation and everything, but she didn't come back ... A feeling of sadness indeed, what a pity" (Ana).

"Oh, it was terrible, because, being aware of the involvement, she [the baby's mother] was a difficult person, but it was not because she was a difficult person that she did not love her son, she would not suffer, it was a scene that has been in my head for many years now, she rocking that dead baby [...]" (Jasmim).

The professionals get involved in their relationship with the patient and feel their death. The finitude of the baby is considered even more difficult to cope with than the adult's, because of the connotation of tragedy due to the shortness of life⁽²⁴⁾.

It is noted, through the interviewees' statements, how moving it was to experience the baby's death, which can trigger a conflict by feeling this pain and not knowing how to take a stand, since they have been taught, from the beginning of the academic training, not to establish bonds, and there is a need to have their emotions validated. The way of coping with death is intertwined with three dimensions: personal history (deaths previously faced, losses already felt and previous processes of mourning); culture (representations of death, space for expression of pain and the perception of mourning); and academic training and professional qualification⁽³⁰⁾.

The importance of the sensibility present in this process was also expressed:

"[...] and, then, I don't want to lose the thing, despite feeling this, because I think it's important, too, like this ... I don't want to naturalize it, to say 'oh, in time, it will become natural'. No, it's not like that, I think that, even as a way of being close to the other, one should not lose that sensitivity even so, the sensitivity thing of somehow being understanding that moment" (Gabriela).

"[...] but I think that, as a professional, we have to work on this issue in ourselves, to keep it, to avoid becoming intolerant, but rather, but another baby that, like that, inevitably departs, but we feel the loss, but we are working on this issue and everything [...]" (Ana).

The implication for the feeling is associated with the creation of bonds of the professionals with the newborns, since they know the child's history and family as a security support to perform care as a life investment, but also at the moment of death. For humanization and comprehensiveness in the care for the baby, the professionals must encompass the process of dying in the practice of the NICU⁽²⁴⁾.

The dimension of developing the resources to support the confrontation of death, without distancing oneself from the feelings and trivializing the situation, was brought to light. The need to work the issue of dealing with death was questioned:

"... because death is always a moment of mourning, isn't it? Of rupture, it is hard, There's no easy death, right? (pause) But at least, may it be a little less hard, a little easier, and may it be understood in such a way, that the families don't ... (pause) no, that they get to show love, they get to show affection, get... (pause) that this is not something so (pause) so little tangible" (Laís).

“... because you have to give room for the other to experience mourning and, if you do not work yours, you don't give room to others, do you? You interrupt it, due to your anguish, your fear. How will the other react, since you can not cope with it?” (Clara).

By means of phenomenology, the notion of worldly beings is admitted, without separation between the interior and the exterior, and the experiences of professionals, the baby and the family are intertwined⁽¹¹⁾. The professional must examine their reactions, how their expression is present in the patient and interferes in his process, a prism that promotes greater growth and maturation for the very professional when they look at themselves⁽²³⁾.

The notion of death intrinsic to life allows the understanding of this anguish with the finitude that is inherent to the being. Not to deny this strangeness makes it easier to cope with the process of dying, starting from broadening the look to all the aspects that involve this process, such as culture, life history, moral values, among others⁽²⁶⁾.

The ways of working death so that the professionals be strengthened and have self-support to deal with it were explained in two interviews:

“Well, I've had some therapy; right now, I'm not having it, but I've already had therapy, I've processed mournings several times before, even with losses of loved ones” (Clara).

“[...] then, so, I even think that I have to become more qualified professionally, isn't it, to be able to contribute in a more qualitative way, because this is, I think, one of the most difficult issues today, as a professional, to be dealing with such situations [...]” (Gabriela).

The PC philosophy points out that it is essential to work on this theme with the professionals acting in the context starting from groups of discussion and support, enabling the expression of feelings and doubts⁽⁶⁾, as well as the psychological on-call modality, as it is constituted of a psychological service suitable to moments of crisis. Leisure activities are also recommended, aiming at the interpersonal approach of the team and the construction of friendships⁽³⁰⁾.

It is understood the need to further discuss this issue, the unknown of the dimension of death and the pain of experiencing life being interrupted⁽²⁴⁾, especially when it comes to the end-of-life care of a NB⁽⁹⁾.

When death is admitted as a phase of life, it is possible to integrate PC into the healthcare levels, and it is necessary to insert it as a form of care and assistance, aiming at promoting health and preventing illness with invasive and painful procedures⁽³¹⁾. Community health aims at an expanded view of the health-disease process, with the concept of being comprehensive⁽¹²⁾, which corroborates the PC philosophy.

It is understood that one of the pillars to improve PC in neonatology is to associate it with health promotion, since this is the primordium of all care. It involves providing the patient with well-being, whatever their clinical condition. It is necessary to draw more attention to this field of community health in order to overcome the issue of the harms that occur with health technologization, valuing the subject, their family and the professionals.

Finally, it is understood that the experience lived by the health professionals is endless in possibilities, as well as the PC is a wide field of assistance, which problematizes several aspects of the practice of neonatology, and this study can not manage to cover such complexity in full, this being its limit. It stands out the importance of further research on this assistance, with the development of research to support the practice and to expand the access of the philosophy in the field of neonatology starting from the training of health professionals.

CONCLUSION

It was possible to identify, in the statements of the participants of the present research, practices consistent with the palliative proposal in some cases. It can be seen that, despite lacking the palliative care program in the institution, there is an initiative to carry out a practice that approaches such care, mainly when seeking comfort for the baby and greater inclusion of the family, which already shows awareness of this perspective.

The challenges were described as difficulty in admitting the death of the baby. The experiences of health professionals at the Neonatal Intensive Care Unit (NICU) appeared with their multiplicity of differences, based on the life history of each one. As a similarity, the reports on how moving it is to care for the baby at the NICU, because of the fear of impending death so close to birth. The feelings of attachment and sadness, emerging during the care; the perception of the baby as a subject and belonging to a family; and the mechanism of denial of the child's condition appeared.

The professionals expounded on their relations with relatives. For some, the involvement with the family demonstrates an interest in learning of the history and, for others, the detachment, which has been understood as a measure to avoid suffering. The establishment of bonds and the validation of the professionals' expression were pointed as important in palliative care, which should be discussed since the academic training levels, having professionals provided with support for recognition of such needs in this implication. Through the expression of their experiences, the participants brought death as a difficult event to be

experienced, with a sense of sadness and loss, and the need for self-care in order to face this moment, in addition to professional training for it.

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