

Family centered-care at the neonatal intensive care unit (NICU): nurses' experiences

**Cuidado centrado na família na unidade de terapia intensiva neonatal (UTIN):
experiências de enfermeiras**

**Cuidado centrado en la familia en la unidad de terapia intensiva neonatal (UTIN):
experiencias de enfermeras**

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Abstract: Introduction: Family-Centered Care in the Neonatal Intensive Care Unit is a practice based on scientific evidence to provide wellness and relief from suffering. This practice must be constant in an environment where family members accompany their preterm or risky newborns; and the nurse, due to a strong relationship of proximity with the patients, assumes the role of assisting these families in most cases. Main objective: to understand the experience of nurses in the development of the family-centered care of hospitalized newborns in the Neonatal Intensive Care Unit. Specific objectives: to describe the Nursing care offered to families during the hospitalization of newborns in the Neonatal Intensive Care Unit; and to describe the nurses' perception about the care taken with families during the hospitalization of neonates in the Neonatal Intensive Care Unit. Methods: a cross-sectional research study with a qualitative and interpretive approach. Ten nurses working in the NICU participated. In-depth interviews were conducted. Data analysis followed the steps of the Narrative Research method and had Symbolic Interactionism as its theoretical reference. Results: the categories referring to the background, conditions, actions and outcomes perceived in the care process for newborns and their families were identified in the narratives. Conclusion: the nurses understand the importance of family presence for the recovery of newborns and for the development of parenthood; however, there are still some conceptual limitations regarding the understanding of the meaning of family-centered care and to consolidate this approach in the practice.

Keywords: family-centered care; newborn; family; neonatal intensive care unit

Resumo: Introdução: o Cuidado Centrado na Família na Unidade de Terapia Intensiva Neonatal é uma prática baseada em evidências científicas com o objetivo de proporcionar alívio do sofrimento e bem-estar. Essa prática deve ser constante em cenários, onde familiares acompanham seus recém-nascidos prematuros ou de risco e a enfermeira, pela forte relação de proximidade com estes, assume, na maioria das vezes, a função de assistir as famílias. Objetivo geral: compreender a experiência das enfermeiras no desenvolvimento do cuidado centrado na família de neonatos hospitalizados na unidade de cuidados intensivos neonatais. Objetivos específicos: descrever o cuidado de enfermagem ofertado à família durante a hospitalização do neonato na unidade de cuidados intensivos; descrever a percepção das enfermeiras sobre o cuidado desenvolvido com a família durante a hospitalização do neonato na unidade de cuidados intensivos. Métodos: pesquisa transversal de abordagem qualitativa e interpretativa. Participaram dez enfermeiras que atuam na unidade de cuidados intensivos neonatais. Foram realizadas entrevistas abertas em profundidade. A análise dos dados seguiu os passos do método de Pesquisa de Narrativas e teve como referencial teórico o Interacionismo Simbólico. Resultados: foram identificadas nas narrativas categorias temáticas referentes aos antecedentes, às condições, às ações e aos resultados percebidos no processo de cuidado ao RN e sua família. Conclusão: as enfermeiras entendem a importância da presença familiar para a recuperação do neonato e para o desenvolvimento da parentalidade, entretanto ainda existem limitações conceituais quanto à compreensão do significado de cuidado centrado na família e para consolidação dessa abordagem na prática.

Palavras-chave: cuidado centrado na família; recém-nascido; família; unidade de terapia intensiva neonatal

Resumen: Introducción: la atención centrada en la familia en la Unidad de Cuidados Intensivos Neonatales es una práctica basada en evidencia científica para aliviar el sufrimiento y el bienestar. Esta práctica científica debe ser constante en un entorno como la UCIN donde los miembros de la familia acompañan a sus recién nacidos prematuros o riesgosos, y la enfermería, debido a la fuerte relación de proximidad con los usuarios, asume el rol de ayudar a estas familias en la mayoría de los casos. Objetivo general: comprender la experiencia de las enfermeras en el desarrollo de la atención centrada en la familia de neonatos hospitalizados en la Unidad de Cuidados Intensivos Neonatales. Objetivos específicos: describir la atención de enfermería ofrecida a la familia durante la hospitalización del neonato en la Unidad de Cuidados Intensivos Neonatales; describir la percepción de las enfermeras sobre el cuidado que se toma con la familia durante la hospitalización del neonato en la Unidad de Cuidados Intensivos Neonatales. Métodos: investigación transversal con enfoque cualitativo e interpretativo. Participaron diez enfermeras que trabajan en la UCIN. Se realizaron entrevistas en profundidad. El análisis de los datos siguió los pasos del método de Investigación Narrativa y tuvo como referencia teórica el Interacionismo Simbólico. Resultados: las categorías temáticas relacionadas con los antecedentes, las condiciones, las acciones y los resultados percibidos en el proceso de atención para el neonato y su familia se identificaron en las narraciones. Conclusión: las enfermeras entienden la importancia de la presencia familiar para la recuperación del recién nacido y para el desarrollo de la paternidad. Sin embargo, todavía existen limitaciones conceptuales con respecto a la comprensión del significado de Unidad de Cuidados Intensivos Neonatales y para consolidar este enfoque en la práctica.

Palabras clave: atención centrada en la familia; recién nacido; familia; unidad de cuidados intensivos neonatales

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Introduction

Birth is a moment of several changes for a family as it demands a redefinition of roles and responsibilities assumed until then so that the challenges brought by the arrival of a child can be dealt with. However, when this newborn child goes through complications and needs to be hospitalized, feelings of fear and vulnerability arise in the parents as a result of the distancing imposed to them by the loss of autonomy in the care of their children and the insecurity triggered (1).

Then, to approximate and deal with these negative feelings that arise in family members during the hospitalization period of a child in the Neonatal Intensive Care Unit (NICU) at the same time that the newborn receives proper care, Family-Centered Care (FCC) comes on the scene.

The philosophy of FCC requires nurses to meet not only clinical, but also emotional, affective, and social needs in order to develop a relationship with the families based on respect and dignity. This care perspective contains, then, the ability of knowing how to listen to patients and their family members, unrestricted access to the children, information, choice, flexibility of care, autonomy of the people involved, collaboration, and support at all stages of the provision of services (2, 3).

Family-centered care in the neonatal intensive care unit is a comprehensive and holistic approach with recognized benefits for the newborn, the family, professionals, and institutions (4). Some of the main consequences related to the newborn are the following: reduction in the hospitalization time and of the number of rehospitalizations in the NICU, promotion of the connection with the parents, better neurological stability, safety, meeting of all their needs, pain relief and reduction of analgesic use, as well as long-term benefits, such as improvement in physical, behavioral and neurological developments with positive cognitive impacts. The consequences related to the families include the following: increase in emotional wellness, better adjustment to the condition, increase in self-esteem, independence, sense of control, and meeting their needs. Additionally, there is stress reduction, increase in the autonomy and responsibility to make decisions, logical understanding of the newborn conditions, satisfaction, and self-confidence to proceed with the care actions at home. Regarding the benefits for professionals and institutions, the following stand out: economic results (reduction in hospital expenses), promotion of social skills, inter-professional cooperation, qualification, professional satisfaction, and increase in the knowledge and recognition about the care provided (4).

Recent studies show that there is a constant claim of parents in Brazilian neonatal unities to be part of their children care, coupled with the difficulties in the interpersonal relationship with health care teams, emphasizing that FCC is not yet a reality in most of the hospital institutions in Brazil. This happens because nurses, in particular, do not seem to have understood, in their

majority, the importance and the meaning of caring for the family, nor did they manage to reorganize their work process when compared to the expansion of their object of work (1, 5).

Family participation in the care of a hospitalized child started in Brazil in the late 1980s, a fact that received important support with the publication of the Statute of the Child and Adolescent (*Estatuto da Criança e do Adolescente*, ECA) in 1990, reinforcing the right to integral permanence of one of the parents or legal guardian when a child or adolescent is hospitalized, as well as the provision of proper conditions for their permanence (6).

However, despite the fact that the provision of family-centered care is not a reality in most of the Brazilian neonatal unities, it is possible to notice that there is certain sensitization by some professionals who, when caring for an individual, provide humanized care to the family and seek to do their activities in order to involve them in the assistance. The lack of support from the health institution is also an aggravating factor for the non-provision of this type of care. So, the non-involvement of the family with the care provided is the great difficulty that some parents present when dealing with the hospitalization of the preterm and risky NB (7, 8).

Therefore, as NBs are part of a whole (family), which is responsible for the health care of all their members, Nursing teams should be concerned that a proper welcoming is essential in this process to provide efficient care and help families overcome fears and insecurities related to the hospitalization of the newborn child that is at risk (1).

Considering the aforementioned, this study has the following questions: *How have nurses experienced family-centered care during the hospitalization of a newborn in the Neonatal Intensive Care Unit (NICU) and in the Neonatal Intermediate Care Unit (NIMCU)? How is family-centered care defined? What are the actions developed and their perceptions of family-centered care?*

So, by recognizing the role of families as a priority in care, nurses will be able to, with them, identify their weaknesses and strengths, helping with health care and promoting planning that aims at meeting their needs.

Accordingly, the objectives of the research were as follows: to understand the experience of nurses in the development of the family-centered care of newborns hospitalized in the NICU; to describe the nursing care offered to families during the hospitalization of a newborn in the NICU; and to describe the nurses' perception on the care developed with families during the hospitalization of newborns in the NICU.

Methodology

This is a cross-sectional research study with a qualitative and interpretive approach. The qualitative method of research favors the presence of the researchers in the field of study and their inter-subjectivity related to social groups promoting a temporal and local analysis, which can be seen through expressions and meanings that people give to their experiences (9).

The interpretive approach allows the researcher to get close to the conceptions, habits, and practices of people through their narratives and actions, thus understanding human experiences and their meanings (10).

The study was carried out in the Neonatal Intensive Care Unit of a School Hospital in Brasília, Federal District, Brazil. Such hospital has the title "Child-Friendly" since 1997 for promoting, protecting, and supporting breastfeeding and the effective health of children and women through the implementation of the Kangaroo Method (KM), for example (11). The

environment is subdivided into three sectors: Obstetric Center, Rooming-in, and Neonatal Intensive Care Unit composed of ten (10) hospital beds.

Ten (10) nurses who work in the NICU took part in the research. They have more than one year of experience in the institution, thus being more familiar with the routine of the unit. The following was defined as exclusion criterion: nurses who are temporary or assigned to other sectors did not participate in the research.

The approach to nurses occurred on an individual basis, in an appropriate location, moment, and condition by means of clear and simple language. After introducing herself, the researcher stated her interest in conducting the research, by informing about the procedures, objectives, approaches, and implications; and, after verifying understanding, the invitation was made and time was given to each participant to think and decide if they were going to participate or not, respecting their autonomy if there was any refusal. Thirteen (13) nurses were approached and all of them accepted to participate in the research, but only ten (10) met the inclusion criteria and signed the Free and Informed Consent Form.

The data collection strategy was an open interview in order to obtain the nurses' narratives. From this perspective, the narratives recommend in their collection instrument the generating or guiding question of the study, with minimum interference of the researcher. This way of approaching the research participants suggests obtaining speeches through a quite different position from the semi-structured interview that uses semi-structured scripts with defined questions in which the aim is to circumscribe a given object to be investigated. Interferences with specific questions to clarify doubts, more directed to the focus of the content investigated, are made after the end of the narrative. This is because deep understanding requires from the interviewer the ability of listening to statements, pauses, silences, rhythms, and the scenario itself that is being configured during a story that is being told. Therefore, the deeply comprehensive, relational, reflective, and ethical nature of this data collection process is emphasized (9, 12).

Considering the assumptions of this framework, the interview started with a broad guiding question. In this study, the following question was chosen: *Can you describe your care relation with the families of newborns during their hospitalization in the NICU?*

The interviews were conducted from July 25th, 2018 to August 3rd, 2018, lasting a mean of fifteen (15) minutes. The audios were recorded and transcribed in full, preserving the integrity of the content.

The methodological framework adopted for data analysis was Narrative Analysis. Narrative Analysis is a proposal for dialog between the researcher and the participant. It does not intend to rebuild the participant's story, but to understand the context of their experiences told and the factors that produce changes and encourage the interviewees' actions (12, 13).

Accordingly, the analysis of the narratives occurs as follows: 1st) Transcribing the material; 2nd) Separating the material with rational content (indexed) from the material with subjective content (not indexed); 3rd) Using the material indexed, organize the facts of each individual (experience); 4th) Investigating the dimensions not indexed of the text; 5th) Grouping and comparing the individual experiences; 6th) Comparing and establishing similarities between the individual cases, thus enabling the identification of collective experiences (12).

Interpretive analysis was supported by the Theoretical Framework of Symbolic Interactionism (SI). The theoretical framework that supported the analytical process of the qualitative subproject was Symbolic Interactionism, as this framework aims at knowing the foundations and causes of human actions and at assuming that human beings define and act in

situations according to meanings established at that moment, which are processed and adjusted in social interaction. The definition of reality occurs during each experience and, based on that, actions are materialized and influenced by the *self* (14, 15).

The research was approved by the Ethics Committee of the School of Health Sciences (*Comitê de Ética da Faculdade de Ciências da Saúde, CEP/FS*) (CAAE 89394318.9.0000.0030, opinion number: 2,705,687). Regarding the ethical procedures in research studies involving human beings, this study followed the Brazilian standards required by the National Health Council included in Resolution No. 466 of 2012 (16).

Results

The analysis of the nurses' experiences allowed identifying thematic categories representing the backgrounds (beliefs and concepts), conditions (standards, structure, work dynamic), actions (expression of family-centered care), and outcomes noticed (effects of the care provided) by the nurses in the process of caring for newborns and families in the Neonatal Intensive Care Unit (NICU).

Beliefs and Concepts of Family-Centered Care

They refer to the perspectives used by the nurses to attribute meanings to the interactions with newborns and families during hospitalization. The set of meanings is built based on their personal beliefs and concepts developed or reasserted in previous experiences with the families of newborns in the NICU, which shape the definitions and behaviors of nurses when providing care.

The nurses' narratives reveal beliefs and concepts that approximate to and distance from family-centered care.

Beliefs and concepts that distance from family-centered care

They express a set of meanings and definitions built by nurses based on beliefs, values, and previous experiences that restrict, distance, or hinder the approximation and implementation of family-centered care.

Sometimes, nurses identify actions that, from their perspectives, contribute to the development of comprehensive assistance to the newborns' families. However, conceptual divergences are perceived. The perspective of fathers and mothers as visitors, for example, triggers actions that create certain distancing from the assumptions of family-centered care.

“And when the father can visit, the moment when he can visit, he can come that his entrance is authorized” (Nur. 1).

Among these ideas that culminate in the distancing of families is the control of the parents' access to their hospitalized children, which is exercised by the nurse. In most of the situations, nurses consider themselves as capable of determining the moments for the approximation and physical interaction between parents and children to start. This control is based on the risk indicators of the NB. Therefore, clinical improvement and weight gain are considered by the nurses to allow for the touch and presence of the parents.

“We need to be careful with big families in here, very big from the beginning and these care actions are being progressively developed, differently, according to the gestational age of the baby” (Nur. 1).

“[...] if he can touch his child, what moment he can or can't [...]” (Nur. 2).

“Then over time, during the recovery of the baby, it’s also going to depend on the gestational age of the baby, you know, if the baby is too premature, we advise the mother not to keep opening the incubator because it’s an extreme premature baby, you know [...]” (Nur. 1).

“[...] as much as it’s a customary procedure and it’s for good, this is faced as an aggression, because the baby’s going to react, you know [...] then in these moments we prefer not to have the presence of fathers or mothers. We excuse ourselves, ask them to leave, and then when it’s done they return” (Nur. 8).

Also in an attempt to get close to the family members, but with unfavorable results, the nurses try to insert families into the NB’s care plans as providers and not as receptors of the assistance. Despite the fact that this practice is related to a form of care with an approach specially focused on the neonate, nurses believe that including fathers or mothers in the care actions is a way of meeting the needs of these family members.

“[...] it’s her baby, right, so I think it’s really important that she participates, that she’s present” (Nur. 10).

“[...] even though we don’t monitor t mothers, care is up to them, right, we’re there to support [...]” (Nur. 3).

Beliefs and concepts that approximate to family-centered care

They express a set of meanings and definitions built by the nurses based on beliefs, values, and previous experiences that promote an approximation to family-centered care.

The nurses working in the NICU show in their speeches beliefs that the NBs are part of a network, their family, which also needs to receive care. Additionally, they assert that neonates who have participative parents improve more quickly than those whose parents are not so present. For this reason, they feel sad when they cannot promote approximation, as wished, between parents and children during hospitalization.

“It makes all the difference for the baby, for the prognosis of this newborn, for the clinical evolution of the patient. It’s important to involve this family in the care actions, encouraging and empowering mothers and fathers, the family, because they’re a support network, right [...]” (Nur. 6).

“So that’s how we see it, that babies recover better when the parents are involved” (Nur. 3).

The nurses acknowledged the importance of welcoming the families at the initial moments of the hospitalization of NBs, because it is going to open doors for a relationship with more intimacy and reliability among both. By establishing bonds that allow for more approximation to the family members, nurses feel capable of better understanding the pain and vulnerability experienced by the families.

“[...] as nurses, in each shift, we welcome this mother, we have a first moment of welcoming introducing the team and telling her about the unit routine, how the ICU works” (Nur. 6).

“[...] during the assistance, we try to create a bond with this mother, always being available. [...] and always concerned about empowering, encouraging this mother, the father also in the care of the baby” (Nur. 6).

By means of conversations, the nurses strengthen the parents, involve them in the care actions, teach, inform, detect needs, and understand that there are difficult moments when they must be quiet and express love. With these actions, they value the presence of the parents not as visitors, but as co-responsible individuals for the care of the NB by asserting that the work

developed in the NICU is only possible if there is involvement of the entire family. So, according to them, not being concerned about the wellness of the family is not thinking about the wellness of the neonate, and, then, all care would be in vain.

“I even got very emotional. The mom of a little baby here that I’m taking care of his little feet and I got really involved with this mom when he went to surgery. We prayed for him, the wound is getting really better, you know. It’s so rewarding! The mom is very happy and we are happy with this too” (Nur. 1).

“[...] if we don’t consider the parents’ view, don’t get concerned about their wellness, don’t be careful with them, you know, you are not taking care of the child, the child needs them [...], how do you take care of a child and don’t take care of the child’s caretaker who is always going to be the mom, right? (Nur. 9).

“So we see that this family participation is important because if the family doesn’t participate, it’s as if care had been in vain” (Nur. 1).

“Our work with newborns only happens if it is for the whole family” (Nur. 7).

In order to implement effective care, by understanding that NBs need their families and vice-versa, the nurses try to carry out work focused on the training of parents for taking care of their newborn after discharge, reducing fears and possibilities of a new hospitalization. For this reason, it is very important for them that the families are open to the instructions that are offered.

“But it’s continuity work. Certainly, the mom who doesn’t come, who doesn’t participate in the care actions here in the NICU is a mom who’s going to have a lot of difficulties out there, difficulties even to hold, to position the baby, and to put it in the crib, so the NICU is really a preparatory unit” (Nur. 3).

“[...] if we don’t prepare the family, how is it going to be, right? The patient, he may return, he’s going to return to us, he’s going to return to the pediatric ICU” (Nur. 1).

Conditions which Favor and Hinder Family-Centered Care

The care provided by the nurses to neonates and families is influenced by the context of the NICU, by the clinical condition of the NB, and by the institutional regulations. These elements interfere in structures and work processes of the professionals, promoting approximation to and distancing from family-centered care.

Regulations that distance from family-centered care

The NICU has rules and routines that organize the activities of the sector and that shall be obeyed both by the professionals and by the families of the newborns.

However, the intense and constant care required by premature and at-risk neonates, added to the paternal and maternal wishes to monitor their children at all times, indicate a behavior frequently observed in family members, which is the difficulty of following the rules established in the NICU. The times to be observed for the care of the neonate, the teachings that the nurses try to explain to the parents about how to take care of their children, and the absence of family members during some procedures are examples of how the family-nurses relationship is affected.

“[...] we have difficulty in making the mother understand, making her understand that we have times, we have rules, the fathers, the family as a whole when it’s related to care, teaching the mother and for her to accept or learn, some mothers don’t want to, they don’t accept this learning and for many reasons sometimes we have conflicts with the families that are difficult to deal with” (Nur. 7).

And just like the work process is necessary for the assistance, the physical structure is also important for care. The nurses emphasize the lack of an environment especially intended for welcoming as a difficulty for the implementation of family-centered care.

“[...] and the difficulty is that we still don't have a more reserved place, you know, I would even say that it's the place, a more reserved place to have this first conversation with this mother” (Nur. 6).

The routine, in its turn, as an unfavorable condition for family-centered care, is aggravated by the overload of daily activities that are attributed to the Nursing team. The nurses know that it is necessary to devote some time to the neonates' parents, but this is not always possible. As a result, their actions become more and more automated and less humanized.

“[...] sometimes we even have difficulties in having greater contact with the parents because of the work that is sometimes very exhausting” (Nur. 1).

Regulations that favor family-centered care

They refer to elements of the structural organization of institutions that promote the implementation of family-centered care, considering the principles of quality and humanized care for the newborn.

The physical space of the NICU studied is based on standards established by Ordinance No. 930 of 2012, of the Ministry of Health. It is a small-sized NICU. The nurses reported that this feature favors the approximation of the family members.

“[...] we are around the unit where they are all the time with the nurse, doctor, technician all the time together [...]” (Nur. 2).

“We end up having a closer relationship, you know, with the mothers, because they can be here and have access to the ICU [...]” (Nur. 4).

The Nursing Mother space, for example, is devoted to the accommodation of women who accompany their children full-time during hospitalization and makes it easier for them to approximate to their children, to the nurses, and to the other professionals of the health care team. The fathers do not have a specific place to stay; however, they have free access to the NICU 24 hours a day so that their bond with their children is not affected.

“[...] we have the Nursing Mother here, right, it's where we give support for the moms to stay here 24 hours, so she can sleep, eat, you know, she can stay in the NICU anytime she wants to” (Nur. 1).

“[...] we make it clear to the mother and father that they're not considered visitors, that they have access to the unit 24 hours a day” (Nur. 6).

In addition to the presence of the parents, the nurses know that the participation of siblings and other family members of the newborns is important to their care.

“[...] a routine of siblings' visits is being established [...]. And also, the visit of the parents, of the grandparents too, right, the uncles, I think this is very important” (Nur. 8)

Moreover, as reported by the nurses, the Hospital has as an institutional policy to value their employees' work by allowing them to criticize, evaluate, and propose improvements in the care provided. So, they feel motivated to provide their services in the best way possible.

“Yes, we have this hospital structure. We sometimes make a suggestion and they always try to help us. So I think that this is what we need, it's not only about earning money, we need to give our best” (Nur. 2).

Approximation and distancing actions of Family-Centered Care

They are related to a set of attitudes derived from beliefs and definitions of the nurses that reveal the expression of family-centered care in the clinical practice.

Actions that distance from family-centered care

They portray care actions provided by Nursing that distance families from a direct or indirect contact with NBs during their hospitalization in the NICU, also reflecting a relational distancing of nurses from families.

The instability of newborns in the NICU generates in the parents the desire of being informed all the time about the health condition of their children. However, as rule of the unit, it is the physicians' role to discuss and inform families about the progress of the child, which ends up restricting the functions of Nursing.

Despite their relation of natural proximity with the families, by supporting and trying to insert them into the care actions, nurses allow that the mothers play a central role during the provision of care to their children, such as breastfeeding and bathing and, sometimes, the professionals are not aware or ready to recognize signs of pain and physical and emotional fragility in the parents. These signs create an important feeling of insecurity in the parents and are expressed by physical and emotional distancing from the NBs.

“Sometimes, as nurses, we can't identify some signs of risk, aggressiveness, or lack of concern about the baby, and the technicians, who are in most constant care with the babies, they identify and tell us, so we look for some assistance, you know, for the baby to be fine [...]” (Nur. 3).

“So we need to try to have this control of understanding, of caring, and even of knowing if the mother is fine because sometimes you don't notice when a mother is crying a lot, a mother that sometimes shows pain in her face [...]. You need to have this look to pay attention to the mother and take care of her, right [...]” (Nur. 9).

Therefore, to reduce insecurities and the distancing that might exist between families and nurses, or between parents and newborns, the nurses try to share with family members whatever they can about the health condition of the neonates. However, the lack of knowledge and the emotional condition of the family members hinder this process of approximation and understanding of what is said.

“They have a lot of questions about the diet, sometimes the baby is really in a bad shape and they want to know what the baby is eating, if it's peeing, pooping, even when they can't understand because of the fact that you're dealing with an acute disease [...] the family sometimes can't, you know, even if we try to tell them about the situation, about the severity, sometimes the family can't understand that very well, you know [...]” (Nur. 8).

“[...] you usually see that the mother sometimes doesn't have a lot of knowledge about a pathology of the child and she's going to have to take the child home and take care of the child. So it's the time you have to speak with a lot of love, explain, and help [...]” (Nur. 9).

The control practices adopted by the nurses are considered attitudes that distance from the assumptions of family-centered care. In this context, the nurses' decision about the best moment to allow physical contact between parents and their NBs stands out again.

Actions that approximate to family-centered care

They represent the work practices and processes of the nurses in the NICU together with actions that approximate to the family-centered care of hospitalized NBs.

Communication and information are assistance tools present in the execution of Nursing care actions. The welcoming to families that just arrived at the NICU is done by the nurses, who also use this moment to provide a set of information regarding the routine of the unit and the services provided, among other essential instructions for the proper development of the neonates and for the participation of the families.

“Initially care is provided by means of guidance” (Nur. 1)

“We summarize all the routine, all the protocols that are followed when the baby is hospitalized here in the ICU, you know. We talk to them about the visit times, about the visit of siblings [...], we make it very clear for the mother and for the father that they are not considered visitors [...], about the breast milk bank. So we tell them about this routine through a form, a form where the nurse welcomes them at this first moment, he signs, the mother or the legal guardian too” (Nur. 6).

In the interim between the NB admission and discharge, the families continue to receive information about everything involving their children and how they are supposed to act. This is the moment when the parents start being part of the care provided to the neonate. The information provided at this moment refers to procedures adopted, devices connected to the neonate, diet and eliminations, the importance of recognizing risk signs, and the importance of touching, among others. That is to say, it is the period when the parents are prepared to go from the NICU to the Kangaroo Intermediate Care Unit (*Unidade de Cuidado Intermediário Canguru, UCINCa*). However, the independence and autonomy of the parents to provide care to the NB is more appreciated in the UCINCa.

“[...] it’s important that we always tell them about what’s going to be done to this child in the unit and some procedures, mainly those that are painful” (Nur. 2).

“And procedures that we can let her watch and be with us, we try to allow, it’s even a preparation for when she leaves here and goes to the kangaroo ward, then she arrives there and is not so insecure about taking care of her child and managing to do it well [...]” (Nur. 2).

For hospital discharge, apart from a good clinical condition, it is necessary that the family is well structured and emotionally prepared. Therefore, the close look of the Nursing team is essential to identify family needs and to activate the necessary services and supports, always aiming at the wellness of the families.

“[...] if some subjective situation happens and this mother needs to be accompanied by another member of the interdisciplinary/multi-professional team, we make this connection, it can be with the social service, with psychology. I understand that this work is only possible because it’s an inter- and multi-professional work” (Nur. 6).

Additionally, it was noticed that the bond created between nurses and mothers/families worked as a source of support for them during the difficult moments of the hospitalization. The nurses remember the mothers’ statements showing appreciation and gratefulness, emphasizing that the moments of conversations, prayers and information are ways of showing sensitivity and helping them to overcome fears and insecurities.

“The mothers who are here for a long time, yesterday a mother hugged me, she left and hugged me. Like this, we see how important we are for them, you know, in this sense we don’t even realize it until when this happens, we see how they consider us” (Nur. 1).

“[...] we meet them all the time so we build friendships, you know, we end up being their psychologists and they are ours too” (Nur. 4).

In order to promote a method of family-centered care and to conquer quality assistance, the nurses encourage the implementation of the Kangaroo Method (KM). The KM is a practice that should be adopted in the first days of the NB's life and continue for as long as possible. It is recognized that, beyond its therapeutic purposes, the KM is a technique of humanization of the care provided to the NB in order to intensify the affective bond between parents and children.

“We seek to have a close look at the family because that baby came from a family, right, he came from a network that also needs to be cared for, both for him to improve and for people in this network to be fine. So, when we accept this baby, we are accepting a family and we try to bring this family, involve them in the care, involve them in the participation in the therapy offered to the baby” (Nur. 5).

Perception of the Outcomes of the Family-Centered Care(less) Actions

They refer to a set of interpretations made by the nurses about the effects and outcomes of the actions directed to the care of neonates and families, as well as of the limitations identified in the non-implementation of practices of approximation, understanding, and meeting of family needs during the hospitalization of the NB in the NICU.

Perception of the effectiveness of family-centered care.

The nurses define effective care as the one that meets, in addition to the needs of neonates, the needs of the family members. By implementing a broadened and sensitive care approach to the specificities of each family, the nurses verify a good outcome of their actions in different ways, either by the verbalization of the family members, by the self-recognition of their functions, or by an assessment where they verify practices that require improvement.

“[...] all the mothers that leave here say that they were well received [...]” (Nur. 2).

“So, we see, we don't often see the return of this, you know, from mothers who come here, but we see it in the recovery of the baby, you know?” (Nur. 3).

The fact that the mothers have free access to the NICU and keep daily contact with the team enables the emergence of a bond of trust. This affectivity developed is a facilitator and strengthening feature of the care actions performed by the Nursing team, since the closer they are, the easier for nurses to recognize signs of vulnerability in the families and, therefore, intervene with love and respect.

However, this bond and this affectivity do not happen randomly. The parents need a reference professional with whom to identify. Accordingly, the nurses reported that they relate closely to some families due to better identification, to the way they are received, or to their mood at the moment of interaction with the parents, for example.

After hospital discharge, however, this contact and continuous Nursing care are almost always interrupted. So, it is common that nurses, as well as families, express both feelings of fear and loss, as well as of gratefulness and happiness for the work done.

Generally, the learning and the recognition of these nurses' work by the mothers is an encouragement so that these professionals continue to provide a care that makes the difference for whom is being taken care of.

“Well, it's so good to know that we can help people by giving our best and being recognized for what we do” (Nur. 2).

2). *“It’s not about what we earn, you know? It’s about seeing the result of our work”* (Nur. 2).

In addition, the nurses believe that, to achieve good results, they should not only be based on empathy, but also get scientifically prepared. The nursing team of the NICU understands that experience and continuing training are important in the preparation of professionals who want to address the concept of family-centered care in their practices.

“I believe that it must be a technique frequently approached through trainings, daily care, training in the service itself, during work, and there’s also the experience, right, over time we gradually get this perception, this handling of how to deal with the family” (Nur. 5).

Perception of limitations in the outcomes of family-centered care

Despite considering the participation and involvement of families in the care of neonates as important, many nurses notice that, in their practice, they prioritize the stability and recovery of the at-risk NB.

However, this does not prevent them from often predicting the closure of some cases and the impact on the corresponding families. This happens because the experience that these nurses acquire over time enables them to develop such ability, even if they do not completely devote themselves to the care of NB’s parents.

The arrival of a NB to the NICU encompasses various factors that go against the efforts of the Nursing team to implement a care plan including the NB and the family. The insecurity of the parents is one of them.

When the parents are insecure, the NB is at risk because they do not feel capable of meeting the needs of their child and often convey this feeling to the professionals. Therefore, it is important that nurses are secure and prepared people not to let this fear interfere in their care actions nor in their relationship with the neonate’s parents.

“Sometimes I feel some insecurity at first from this mother in relation to the baby, but mainly in the situations when the baby is premature, has low weight, you know [...]” (Nur. 6).

It is common that the family members initially present resistance to the care actions and instructions of the Nursing team, resulting in a fragile and complicated relationship. According to the nurses’ reports, the barriers imposed by the families are often defense mechanisms to overcome the difficult moment that they are experiencing. In contrast, according to the nurses, those parents who are little collaborative are sometimes seen as burdens, a source of more work than that required by the NB.

Frequently, the emotional state of these families, especially of the mothers, is harmfully affected, as long periods of hospitalization are almost always associated with stress, nervousness, and anxiety. Accordingly, it is essential that the nurses are aware of the signs of vulnerability in the family members.

“[...] but there are some cases that I think are always going to happen in the ICU, the mothers who are hospitalized for a long time start being stressed, nervous, anxious to go home and then they start being impatient when they are taking care of the baby [...]” (Nur. 3).

There are moments that must also be worked on by the nurses because they represent a challenge in comprehensive family care. Situations of complications in the NB are an example. The nurses report that, in circumstances of urgency and emergency, neonates become the center of attention, and it is often difficult to deal with families in these situations. For the parents, this sounds like carelessness and absence of welcoming.

Therefore, by understanding the gains of comprehensive care provided to the NBs and their families, as well as the losses that the lack of this type of care causes, the nurses believe that their practices need to be improved. They report that there is still a gap to be filled between knowledge and practice.

“[...] I think that maybe people know that it is necessary to take care of this family, but maybe this preparation isn't real, you know, about how to deal with the pain of mothers, fathers, families, how to deal with this care [...]. Maybe we know that it's necessary, but we don't have a preparation” (Nur. 5).

“[...] we end up being a little mechanized, in the daily routine, so maybe we're not so humanized when we face the problems with the mom [...] or we forget a little in the daily routine because of the work rush” (Nur. 7).

Discussion

Prematurity and low birth weight are some of the several complications that can be present during the perinatal period and, thus, interfere with the natural development of the neonate. Such complications present themselves as a need for more attention in the care of these newborns in order to ensure their survival with quality of life and health. In addition to offering life support and continuous care to the neonates, the professionals of a neonatal care unit must also be ready to meet the needs of the NB's family members (17).

The Brazilian Neonatal Units (Neonatal Intensive Care Unit, NICU; Neonatal Intermediate Care Unit, NIMCU; Conventional Neonatal Intermediate Care Unit, UCINCo; and Kangaroo Intermediate Care Unit, UCINCa) shall comply with the standards established by Ordinance No. 930 of 2012 of the Ministry of Health, (18) which “defines the guidelines and objectives for the organization of a comprehensive and humanized care to newborns in severe or potentially severe conditions and the criteria of classification and capacity of hospital beds of Neonatal Unities in the scope of the Unified Health System (*Sistema Único de Saúde, SUS*)”.

This ordinance does not only recommend the principles of humanization in the care of newborns, but also contributes to the provision of family-centered care through a pre-established physical and functional organization of the units (staffing of professionals, number of hospital beds, specification of equipment, procedures, professional categories, physical structure, determination of the minimal clinical conditions for the permanence of newborns in each sector of the neonatal unit, and rooming-in for mothers, among other features) (18).

Therefore, the neonatal unit considered for this study complies with the principles of the aforementioned ordinance regarding physical structure and functionality, with an emphasis on the Nursing Mother space, which is devoted to the comprehensive stay of the mothers of hospitalized newborns. However, despite the importance of the paternal figure, fathers do not have a place like the Nursing Mother space, but they are allowed to accompany their children with no restrictions as long as they follow the internal permanence rules of the NICU/NIMCU.

As much as the humanization policies for newborns value the care of the families and the School Hospital of this study tries to adequate to these principals, the work process of the NICU and NIMCU can still be improved. The implementation of the Kangaroo Method (KM) in the unit is a big step forward in this process, but the care practice itself, in an integrated manner with the entire health care team to the newborns' family members, is the most important aspect and can still be improved.

The fragility of an at-risk NB demands specialized care in a neonatal unit. The hospitalization of a child immediately after birth interrupts an important family moment of affective bonding. During this hospitalization period in the intensive care unit or intermediate care unit, the family experiences a combination of quite intense positive and negative feelings; however, the negative ones are more present, as noticed in the report of the nurses working in the NICU of the University Hospital of Brasilia for this study (19, 20).

Family-centered care emerges as a way to work on these feelings together with the clinical aspects of the NB. The provision of this care is not so simple, since factors like concepts and beliefs of the people involved and the organizational culture of the hospital institution interfere with the process of parenthood in the NICU. Even if various feelings and situations help the parents face the process of hospitalization of their children in a less traumatic manner, different situations interfere negatively with family wellness and impair the family-neonate and family-health professionals interactions (21).

The NICU environment itself and the difficult relationship with the health professionals, for example, are unfavorable elements in the process of parenthood. The clinical condition of the NBs and their dependence on devices and other technological resources can limit the interaction between parents and children to the point of hindering physical contact between them and, consequently, hamper their insertion the direct care provided to the NBs during hospitalization and after discharge (21).

As a consequence of these complications that culminate in a not so efficient approach to the family, the parents feel insecure and vulnerable because they cannot be present as they wished to do activities that usually represent maternal and/or parental care, that is, actions that make them truly feel as parents of that neonate. In addition, physical fatigue and emotional stress are factors that jeopardize the wellness of NB's family members, complicating even more the provision of care to the neonate (20, 21).

In face of the challenge of meeting the demands of the family and of the NB as receptors of care, nurses are seen as individuals capable of defending and supporting the role of the parents, ensuring that they are effectively inserted in the relations of the care provided to the NB, even if in some situations their active involvement is confused with the Nursing actions. In short, nurses are capable of helping and organizing their work so that they can meet not only the needs of the neonate, but also the needs of each mother/father (22).

These professionals also experience difficulties in implementing family-focused assistance, although they recognize the benefits of this practice and its inevitability as detected in the narratives of the nurses interviewed for this study. A number of research studies show that the greatest difficulties are related to the lack of material, infrastructure, and human resources; to the lack of team discussions to plan and evaluate the care offered; to the difficulty in relating with the family members; and, mainly, to the contradictory notion of providing specialized care but, at the same time, judging the parents' capacity for participating in these actions. Therefore, as it is not so common to implement care for the family as a care unit in Brazilian institutions, it is admitted that, when it is put into practice in a neonatal unit, there are some Nursing professionals with a higher training level regarding the principles of family care in this environment, as they are more sensitive to the parents' needs and more conscious about the benefits of family-centered care (21, 22).

Accordingly, the importance becomes clear of nurses taking into account the participation of parents in the care of children in the NICU for the clinical evolution of neonates, as well as the benefits yielded for the family unit. However, this participation should happen in a way that the

family members are really empowered of their rights as parents, that is, that they have free access to their children, that there is a relationship of equality between health care teams and families aiming at cooperation and collaboration, and that there is a change of values and behaviors both in the professionals and in the parents in order to develop good quality care and environment for all – which does not occur in a large number of neonatal intensive care units over the country. At the same time, it is necessary to be alert so that the parents are not overwhelmed, that is, there must be a balance in the application of the principles of family-centered care so that it acts as a foundation for the inclusion of the parents in the care provided from the admission of the NB in the NICU and that it does not become a burden (23, 24).

It is common that, in intensive or intermediate care units, the health care team treats fathers and mothers in a different manner, despite the efforts for fighting against the stigma of the father as a visitor. During the interviews, it was possible to perceive that the nurses not always have the same thoughts about the presence of fathers. Some of them defend that fathers are important for the care provided and that their presence is essential, while others still spread the paternal figure as that of a visitor, someone who is not so present. For many health professionals, fathers are only seen as observers, infection vehicles, or intermediate links between mothers and health care teams (24).

The experience of seeing a child hospitalized and receiving care and complex treatments in an environment like the NICU makes parents not feel able to provide basic care (which they believe necessary) to their children if the actions performed by the professionals do not involve them since the welcoming stage. A number of research studies show that the families, especially the mothers, experience a gradual process of approximation to their child until the moment in which they are ready to provide care with confidence. In the first days after the birth of a NB, the parents need to learn to take care of their child, with the presence of the Nursing team being essential to teach, support, and guide (24).

A research study carried out with fathers and mothers of NBs hospitalized in a neonatal unit of a Portuguese hospital showed that, when they go home, the parents present concerns about the future of their children in terms of development, financial expenses related to the children's health, risk of a new hospitalization, and how to take care of their children without the help of health professionals and machines. Doubts like these are common, but if the family, during the hospital period, is welcomed and involved in the planning of actions regarding the improvement of the neonate, they will be more prepared and calmer at the time of discharge (20).

In order to provide increasingly qualified and effective assistance, nurses must use all the available resources in their provision of services, among them, the Systematization of Nursing Care (SNC). The SNC consists of a process of work organization that enables the professional to have the autonomy, during the care provided, to assess the outcomes of the actions implemented and to conduct the necessary interventions/changes, always considering the individualities of the person being cared for (25, 26).

In Neonatology, the SNC enables to combine scientific knowledge with the needs and the singularities of the NBs and their families, that is, humanization of care. Recent research studies reveal that many nurses avoid putting the SNC into practice, although they thoroughly know what it is and how to apply it. In a research study carried out by Oliveira and Borges (25), it was verified that the excessive demands in the sector (NICU/NIMCU) and the internal organizational culture of the service direct the actions in such a way that the SNC becomes a bureaucratic and devalued activity.

It was evidenced in the speeches of the nurses interviewed for this study that the overload of functions that they perform does not allow them to always have time to meet the demands of the families. However, the sector has the routine for the nurses of the night shift to perform the SNC. So, there are questions about the efficacy of this systematization of care targeted to the families since that, even in the interviews, the nurses who work the night shift reported that they do not have much contact with the NB's family members.

Accordingly, the Nursing actions are not complete when they are not implemented or performed in the expected manner (dissociated from practical actions – addressing all the elements that compose family-centered care). That is, it becomes more difficult to really put family-centered care into practice, the practices become more and more technical, tending to recover the biomedical model of care, and the reflections and discussions about scientific actions get increasingly scarce and restricted to the academic environment (25).

Family-centered care involves the neonatal team, considers the parents' experiences, and requires changes in the practices to create an environment to support the parental needs and to promote active participation in the care provided to hospitalized children (27). Despite the fact that some research studies highlight the benefits of FCC for parents and neonates, in practice this support remains challenging and inconsistent (27,28). Such evidence reinforces the need of a structure for the development of a family-centered care that has as foundation its philosophy and a process of continuous education which guides the practical guidelines supporting the nurse-family and family-neonates relationships (27).

Partnership is a central concept in FCC. An effective partnership between nurses and families in the NICU can be achieved by developing and constructing mutual knowledge, as well as by developing competences in role negotiation. Developing and maintaining a balanced partnership is a dynamic process. However, nurses have the power to reduce and eliminate many of the barriers identified to enable a successful partnership with the parents in the NICU (28).

Considerations, limitations and recommendations of the study

From this study it was possible to know the way in which the nurses of a neonatal unit perceive the presence of families of hospitalized neonates and how they experience the care provided to them. Most of the nurses have the perception that the presence of the NB's parents is essential both for the recovery of the neonate and for the development of parenthood in the family members; however, they do not completely understand the meaning of family-centered care so as to put it into practice.

As a contribution to the existing studies in this area, this research highlighted the perception of nurses regarding the parental needs and the vulnerability experienced during a critical period of fragility in their child but, at the same time, important for the creation of bonds, for learning, for the legitimation of fathers/mothers, and for family empowerment.

In spite of the importance of the theme addressed and of it being little developed so far, the study presented some limitations. It was carried out in an NICU of a Brazilian School Hospital with a sample of 10 nurses from a total of 13. It is a small-sized unit that may not portray the perceptions and attitudes of nurses working in large neonatal unities.

Therefore, it is recommended that new research studies are carried out focused on the development and the implementation of family-centered Nursing care with a broad look at the needs and vulnerabilities derived from the experience of an at-risk birth and of the hospitalization

of a neonate in the NICU. The development is recommended of models of Systematization of Nursing Care that allow for the incorporation and implementation of the FCC philosophy.

It is believed that the provision of family-centered care following the steps of the SNC will have greater probability of effectively meeting the demands of neonates and their families, as well as that the continuous practice will allow nurses higher levels of sensitivity, knowledge, and professional qualification.

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