

EXPERIENCES OF MOTHERS WITH THE NEWBORN IN NEONATAL INTENSIVE CARE UNIT¹

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ABSTRACT

This study aimed to know the perception of family members about their stay with the newborn in the Neonatal Intensive Care Unit. We conducted a descriptive exploratory research with a qualitative approach with 10 mothers of newborns admitted to a Neonatal Intensive Care Unit of a university hospital in southern Brazil. Data collected in the fall of 2018 through semi-structured interviews and submitted to content analysis. This study identified the areas to prepare the family for coping; Family preparation for the care and difficulties experienced by the family as important aspects experienced by these families during the period of stay in the hospital. The family prepares to face development and care; it goes through many difficulties such as changes in family routines and some structural and organizational aspects that made it difficult to transition through this stage. In this sense, it is clear that health professionals have a strong educational role in this process, since the family is prepared for these to face from receiving information that clarifies the cause of hospitalization and care that will be needed.

Keywords: Nursing. Neonatal intensive care units. Family.

INTRODUCTION

The arrival of a child is an intense change in the lives of parents, either by the new roles and responsibilities to be undertaken or the anxieties generated from the responsibilities that emerge⁽¹⁾.

However, not always newborn is discharged shortly after birth, and many negative feelings may occur in the family when there is need for hospitalization of a newborn, especially in a neonatal intensive care unit (NICU). Among them are the insecurity, inexperience, failure, and imbalance on the experienced situation⁽²⁾.

During the first visits to the NICU parents of newborns, when they witnessed this new world, full of specific routines may develop feelings of fear, anguish, and anxiety of the unknown. Faced with this explosion of feelings it is necessary to the reception and orientation of the family, especially by nursing staff to make this experience less painful as possible⁽³⁾.

That host families are of paramount importance given that these parents can develop in addition to the above feelings, a sense of insecurity about their ability to take care of newborns, triggering feelings of guilt by the need for

hospitalization, associated with a disbelief about the future the newborn, especially if the reason for hospitalization for serious illness⁽³⁾.

The family's presence is essential for the child's stay in the NICU is to participate in the care or simply be present during the progress of the infant. In this sense, National Humanization Policy (NHP) proposes the open visit, aimed at facilitating access to inpatient units, providing the relationship between the patient, their social life, and health services. The guarantee of visitation and the accompanying permanence are fundamental to the realization of the extended clinic, promoting autonomy of family and community⁽⁴⁾. However, promoting a pleasant environment in the NICU for an integrated assistance to the family and the newborn is not easy for the nursing staff. It is necessary to understand each situation as unique, plan and foster care by establishing a link, a partnership with the family. One should take into consideration all the manifestations of feelings with the uniqueness of each, their cultural background, beliefs, values, experiences, habits, and customs⁽³⁾.

It is essential the participation of the nursing team, providing the emotional bond between parents and

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newborns and promoting adequate preparation for the family stay in the industry. Such care could foster a less traumatic experience, minimizing the wishes of the family, providing the clarification that may be necessary, valuing the strengthening of parenting with child⁽⁵⁾. The health team should allow the involvement of the family member who is present in the NICU with the care of the newborn, providing information and guidance, thus allowing moments of comfort and guidance on treatment, expectations and results, in an attempt to reduce fear, anxiety, distress, difficulties, valuing the permanence of these patients in the hospitalization environment⁽⁶⁾. Thus, this study had as objective to know the perception of the relatives about their permanence with the newborn in the Intensive Care Unit, justifying the need to reorganize the care practice, expanding the care focus, born to care that encompasses the whole family.

Therefore, the question that guides this study is what is the perception of the relatives about their stay with the newborn in the Intensive Care Unit?

METHOD

A qualitative study carried out in an intensive care unit of a University Hospital of Southern Brazil. Participants were 10 family members of infants admitted to the NICU in July 2018.

Data collection performed through semi-structured interviews, with questions about how they perceive the possibility of their stay with the newborn during hospitalization at the NICU and the feelings generated. The interviews conducted in an audiotaped way and performed in the NICU itself in the meeting room for privacy.

The analysis of the data occurred by Content Analysis, which consists in discovering the sense nuclei that make up a communication whose presence or frequency means something for the intended analytical objective (BARDIN, 2009). The analysis is divided into three stages: 1) pre-analysis (organization stage that aims to operationalize and systematize the initial ideas in order to lead to a precise scheme of research development); 2) exploration of the material (stage of operationalization of the textual analysis systematically in function of the categories previously formed) and 3) treatment of the results, inference and interpretation (in this stage there is condensation and the highlight of the information for analysis, culminating in the inferential interpretations; the use of intuition, reflexive and critical analysis)⁽⁷⁾.

During the preparation and development of this study, the precepts of resolution 466/2012 taken into account and the local Ethics Committee under opinion 20/2018 approved the research. Participants duly informed of the

purpose of the study, justification, methodology, benefits and expected risks and ways of disseminating the results of the study, and their consent to the disclosure of data anonymously requested.

RESULTS

Participants in the study included 10 family members who accompanied the newborns at the NICU during the data collection period. As for the gender, all were female. Their ages ranged from 21 to 39 years, the average being 30 years old. The mean daily NICU stay with the newborn was 8 hours. As for the place of residence, 06 were residents of the municipality where the NICU was located and 04 resided in a neighboring municipality; 06 newborns were the first child.

The analysis of the data generated as categories: the preparation of the family to cope with the hospitalization of the newborn in the Neonatal Intensive Care Unit; the preparation of the family for the care of the newborn in the Neonatal Intensive Care Unit and the difficulties experienced by the relatives during their stay in the Neonatal Intensive Care Unit.

Prepare to combat the newborn hospitalization in the Neonatal Intensive Care Unit

All the participants informed that they had received information regarding the cause of the newborn's hospitalization in the NICU. Some had already foreseen this event even before their birth, when they arrived at the Obstetric Center and told of the need for a preterm birth.

She was born premature with 35 weeks. I developed diabetes in pregnancy. I got sick and I came here to do some tests. Were very changed and labor had to be induced. They took me to the Birth Center again and the doctor was waiting for me. She did an ultrasound and said-Your placenta is all-cool. Let us do a emergency C-section now. There was that, it was all fast and you are there. (F1) I had preeclampsia. Then he had to be born. He was with 27 weeks. When I came to the Birth Center. The doctor told me it was serious, he could not survive. That is all before delivery. (F10)

After the impact of the need for NB internment in the NICU, the family needs to prepare, in some cases, for a long period of hospitalization. In some situations, the expectation of the NB's stay in the NICU is only a few days and the family perceives the severity of the child's clinical condition and its fragility during the hospitalization period.

Actually, at the beginning, he said something, and then it was showing more things, I thought he was going to stay only the first 72 hours that was for evaluation, just because she was premature. W HY her birth weight, it was born with two hundred. Therefore, she was born with weight. She could even

have gone home, but then those 72 hours complicated and appeared this infection, it's okay, appeared yellowing. The picture worsened, then why are we so far and there is no prospect of high soon. (F7)

Mothers reported as important to prepare to face the hospital the existing communication of the child with the professional's health team. This helps in understanding the real situation of the child.

I think they explain all essential and why. I ask all. So much that I asked why the yellowing, if she had stayed four days in the light, and the doctor spoke. Both of them as the doctor explained to me that it is normal to go back, and as she is, taking breast milk can come back. I am never in doubt. I am a person that I do not know I ask, as long as you are going to say is I do not know and I am going to see (F1) information received make all the difference. Helps people understand the situation, which the real gravity of the situation. Because sometimes, we are there hugging and have to drop out. Have to think that everybody is in the same boat let us say so. (F7)

Girls treat us well. At the beginning I was there, I would not eat, in the first three days I did not eat. The girls began to notice, and now they run at mealtime. However, at the beginning I wanted to be there, be there, looking. Now they soothe me. Talk, I guide. Now I am more relaxed, I am eating right; I am getting tickets and going to eat. (F7)

Preparation of the family for the care of the newborn in the Neonatal Intensive Care Unit

All the participants said they invited to help in some care of the newborn, but someone reported that at the beginning but were afraid to touch them children, especially in premature borns, with low weight and that were in incubators.

On the first day they explained to me how, in the second I've helped a little bit. Gradually I will encourage me and doing more things. (F1) Just to hold him on your lap, to change. Not yet, because when he is agitated, he will not stop. He does not like to be moving him, generally who do everything at once. Exchange the blanket, give milk, so he does not get too agitated breathing. I prefer that he stay longer in the incubator for bacterial infections. I prefer even than he is on my lap. Is more protected. (F4) They ask me if I want to touch it. I touched it. I talk to him. (F10)

They emphasized that they always guided on what was to happen, and when they found it capable, they left to feel free to choose whether to participate.

They taught me how to change my diaper, but they asked if I was ready. The first time I said no, but I asked if I wanted to change or just assist, no, I said, just assist. From there on the first day, I just helped. I thought she was very small, very wet, from there with a probe and that little thing in her foot and all this made me insecure to change. There I helped and on the second day, I changed. I changed alone. From the little bath I attended, I still did not. (F1)

No, we could not touch her before. We avoided because we

touched her and she was frightened. The nurse explained that he had to do it all: exchange r, r milk, with band-aid all in the same time because it hurts. Then, we did not move. If we played, she would get scared and start crying. Then, the People left her very quiet, because she was very agitated. Here then was going, it was going, and then the girl asked if I would get that and grab her, tries to be within, there was going was going. Moreover, after she has said to me try looking at the r holds the read r, r starts to make the dressing, because, and then I walk away and know precisely how she does at home. (F2)

Difficulties encountered by family members during the stay in the Neonatal Intensive Care Unit

One of the main difficulties reported by the participants not directly referenced to NICU, but to have to organize in their schedules, since they have other children.

For the sake of the children, a brief study in the morning until the afternoon. A does the course of theatre and ballet and if you have so many fouts loses the job. There is a little difficult. We are trying to go out there to justify her absenteeism. This is my difficulty and each has a routine. One is staying with a neighbor and another with her father, but sometimes they cannot. (F3)

The difficulty I think biggest has to leave my other son with my husband. He had to stop the things that he did to take care of him. There I have to merge. Why I am not coming early here. Because of another older one. (F4)

The question of living far away, I cannot stay 24 hours with her, you understand. I also have another son, have to give some love to not be jealous or anything, you understand. I have to talk to him for a little while. Before I was in NICU from 10 hours to 16 hours. But now I am going to have to stay longer, because she has to suck enough, but there is for a short time. Nevertheless, I talked to my husband that we can fix. (F5)

Many mothers view in the procedures as an assault on their children and can hurt, promote pain and discomfort. Even though it comes to procedures for their evolution, they nevertheless feel embarrassed without floor, helpless and guilty.

It is sad because she is tiny. Be watching her go through it, get all purple, try to get the vein, have to shave her head, did not expect. (F3)

Not that I did not like, it is like it hurts, still felt pain and, thus, look, I was half hurt because of her to be going through this. (F5)

I was floorless. Because we stay, how am I going to explain, as we feel helpless? You cannot do anything, if you could take a piece of you, it hurts me, but it does not hurt. We feel very powerless, when you see them there very small, being judged. Of course, we know what is good, but I say they are not been well treated. The suffering they feel. (F7)

Mothers reported that nursing is careful to ask them to leave the room in the event of an intercurrent event or to perform a more invasive procedure.

I could not see, because they ask us to leave, wait a little bit out

there to do the procedures in children, but it is sad to know that will suffer and we suffer together. (F6)

One mother reported that, although difficult, receptivity and communication made the difference when she was able to make the first visit to the RN in the NICU.

Then I think that on Thursday night I was able to go in alone. I was very scared. I was holding me on the wall, very slowly, I was going, and then I went. It was a night that girls are very, very dear, and asked me if I had ever hold her in her lap. I said no, they have it, and they put it on my lap to hold, was so very good. (F8)

DISCUSSION

From the analysis of the data, it was possible to identify that the perception of the relatives about their permanence with the newborn in the Unit of Neonatal Intensive Care, includes aspects related to the emotional preparation of the family to face the situation; the technical preparation for the development of child care and the difficulties experienced during this stage of hospitalization.

Regarding the preparation of the family to confront the newborn's hospitalization in the Neonatal Intensive Care Unit, it was possible to verify that the team has an essential role during the first impact of the news, until it is the moment of the NICU discharge. On the first visit to the NICU, some mothers find the baby connected to several machines and tubes, weak and fragile. This can cause difficulty to recognize, it is essential that professionals assist parents in the process of adaptation to new RN routine⁽⁵⁾.

It is known that the first moments after birth are essential for the formation of the family bond, but the need for hospitalization of the newborn deprives the child of receiving family care, which are considered to be fundamental for the establishment of this bond, especially skin contact skin, breastfeeding, or simply hearing the voice of parents.

Therefore, it is important that the team advise the family through humanized care, establishing a positive relationship that favors the interaction between the parents and the neonate. Thus, the link constructed by daily instrumentation for family care, through a gradual approach to the mother as to provide safer care for the RN⁽⁸⁾.

Mothers, when not properly attended, may present a distortion of motherhood, especially in cases of premature birth, where there was no preparation for this event. Faced with this experience, the feeling of helplessness appears, making them fragile in any situation, so it is fundamental that the professional understands that not all mothers can interact with the RN, others are only able to observe, and are recognizing it like yours⁽⁹⁾.

Will need for professionals who work in the NICU have the ability to perceive and understand the feelings, so

that they can help the family to face this moment in the best way, as well as promote and stimulate direct contact with the newborn⁽¹⁰⁾. Informing oneself and understanding about the experience of the companion who is experiencing this moment within the NICU, it becomes fundamental for the nursing team to be able to develop and improve humanized and centralized care in the family. With this, there will be resources to promote the necessary emotional support, as well as assisting them in accepting the framework in which the newborn found, fostering a re-organization of the family routine⁽¹⁰⁾.

Regarding the preparation of the family for the care of the NB in the UTI All of the study participants reported that they were invited to help in some NN care, but some reported that at the beginning they were afraid to touch the child, especially those born premature, with low weight and that were in incubators. They emphasized that they always guided about what was going to happen, and when they found themselves capable, they left to choose whether to participate or not in care.

During the newborn's hospital stay in the NICU are indispensable the presence and involvement of the family in providing care see that those family members drive the RN recovery process. Family participation in the care of infants in the NICU may promote the bond and contributes to reduce the time of hospitalization and promote the continuity of home care manipulated form⁽¹¹⁾.

During the hospitalization, the NICU team has the function of minimizing parents' fear, answering their questions, explaining the NB's health status and the treatment that will be performed, besides guiding the care they need to attend the unit⁽¹²⁾.

As a companion, the mother needs to understand that depending on the severity of the clinical situation of the newborn, it cannot be breastfed, but the maintenance of lactation should be encouraged, which requires an increased incentive for the establishment of the mother and RN through the host, and educational activities, fostering an early onset of breast milk, and a close look at the possible negative feelings when they appear. Many mothers use their child's desire for improvement as energy to meet this challenge, which with the passing of days becomes less painful due to the team's incentive rescue the bond and the establishment of strategies to address the hospital, mainly develop skills in nursing, which will be necessary's home in continuity⁽¹³⁾.

The multiprofessional team of the NICU can help reduce the psychosocial impact of hospitalization, and it is present in all stages of hospitalization. It is possible to allow the family to promote comfort and affection for the newborn, minimizing the feeling of abandonment present

by the estrangement of their family and the permanence in a hostile and unknown environment⁽¹⁴⁾. The nursing team should always stimulate the strengthening of the family bond with the newborn; the affections offered by the relatives are between simple gestures like the touch, the look, and the voice of the parents, so the company of the parents to the RN helps in its recovery⁽¹⁵⁾.

The mother should be encouraged to have as close a contact as possible to her child, the ideal is skin to skin, but some newborns have the need to stay in the incubator for several days or instability of body temperature or clinical instability, which would make it difficult or even impossible to approach. In such cases there are alternative techniques to the NICU promotes an improvement in the development and treatment of the newborn, as well as strengthen the emotional bond parents.

Through the maternal touch, the baby is able to present improvement in saturation, decrease in pain, improvement in sleep and facilitation of neurological development, therefore, his clinical progresses and the dreamed up high becomes a closer idea, minimizing the separation of the newborn from the family nucleus⁽¹⁶⁾.

The category concerning the difficulties experienced by the family during their stay in the Neonatal Intensive Care Unit, found that changes occur in family routines as often these families have other children who rely solely on s parents. Thus, many mothers report difficulties in reconciling their personal routine, visiting schedules, difficulties in getting around, traveling time and availability.

The period of hospitalization results in significant changes in the family structure, such as the abandonment of social functions, so feelings of loneliness degrade the family environment, weakening and limiting its members⁽¹⁷⁾. Thus, the hospitalization of the newborn becomes a challenging experience for the family since the NICU is a new, complex, and inhospitable environment, causing the separation of parents and the RN to be as physical as psychologically⁽⁸⁾.

The NICU promotes the follow-up of the parents to the NB during their period of hospitalization, being a right guaranteed by the ECA, but in some hospitals the infrastructure makes this monitoring difficult, some norms and routines can hinder this process, such as rigidity of visitation time. Thus, in order for the RN's right to be ensured, it is necessary that strategies be developed, in order to ensure the permanence of the parents⁽¹⁸⁾.

Reports identified on physical facilities, such as inadequate accommodation for a long stay in the industry; moreover, the father limited dwell time hinders the interaction of this with the RN and the experience of it. Also is dedicated to achieving the well-being of the newborn, but

it is usually an impersonal and even fearsome place for family members who are not accustomed to the unit's routines. The physical and mental health of the family being affected daily by the lack of structure with comfort, excessive noise and alarms, fatigue, emotional stress and lack of time for proper care.

These are factors that can interfere negatively in the life of the hospitalized NB companions, so that the health institutions must invest resources to promote welcoming ambiances, contributing to the care of these relatives. Another important factor to note is the possibility of relaxing the rules and routines, as this is a strategy that provides opportunities for more effective care, unique and pleasurable, leads going to a more subjective care, committed to with the autonomy of families⁽⁹⁾.

Dialogue, listening, and communication are important tools for the empowerment of weak mothers, and these tools become essential for the realization of care, especially when the professional acquires knowledge and sensitivity to the situation of the other. Therefore, the nursing team needs to understand that the hospital environment is not only a work environment but also an environment unknown to the family, leading to insecurity to expose their doubts and fears, especially when using language difficult to understand the relatives⁽⁹⁾.

FINAL CONSIDERATIONS

The study aimed to know the perception of the relatives about their stay with the newborn in the Neonatal Intensive Care Unit, so it was possible to verify that the hospitalization requires, mainly from the mother, a departure from the family context, and an adaptation to new hospital routines, which can be stressful, because most of the time families are not prepared to deal with the new routine, which becomes a daily obstacle.

I can still conclude that the family has a positive perception of the treatment received in the NICU, the different teams working there and that this openness made a difference in the understanding and acceptance of the admission of the RN. The preparation for coping with the hospitalization of the newborn in U TIN begins with the receipt of the news, and extends throughout this period, with guidelines and training regarding the care given to the NB.

The difficulties perceived by the family members during their stay in the NICU relate to the disorganization of the family routine, since many families have other children who depend on care, the limited time of permanence of the father were aspects that hindered the interaction of this with the RN, being perceived as an act of dehumanization.

The data made it possible to conclude that the preparation of the family against the need for hospitalization of the newborn is essential in the process of acceptance and development of early contact with the newborn, promoting attachment and feelings of affection, tenderness, and hope. In this sense, the family providing opportunities whenever possible, for the realization of some care RN, the guidelines and respecting their time and willingness to perform care.

Finally, the family experiences show which is necessary the support of professionals who maintain contact with their parents, helping in structuring and family acceptance, as well as better performance as escort. The host and communication are important working tools because they favor greater permanence of family and active participation of those with the RN in the NICU, fostering their autonomy and empowerment as the acquisition of

skills and expertise to care, especially after discharge.

This study had as limitations the fact that it performed in a single hospital institution in a specific period, and it is not possible to generalize its results. It believed that the study enabled the construction of knowledge about the family staying with the newborn in the neonatal intensive care unit, contributing to a rethink of the nursing team practice for the host necessary to these families.

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VIVÊNCIAS DAS MÃES JUNTO AO RECÉM-NASCIDO NA UNIDADE DE TERAPIA INTENSIVA NEONATAL

RESUMO

Este estudo teve como objetivo conhecer a percepção dos familiares acerca de sua permanência junto ao recém-nascido na Unidade de Terapia Intensiva Neonatal. Realizou-se uma pesquisa exploratória descritiva com abordagem qualitativa com 10 mães de recém-nascidos internados em uma Unidade de Terapia Intensiva Neonatal de um Hospital Universitário do Sul do Brasil. Os dados foram coletados no segundo semestre de 2018 por meio de entrevistas semiestruturadas e submetidos à Análise de Conteúdo. Este estudo identificou os seguintes domínios: a preparação da família para o enfrentamento; preparação da família para o cuidado e dificuldades vivenciadas pela família como importantes aspectos vivenciados por esses familiares durante o período de permanência no hospital. O preparo da família para o enfrentamento e desenvolvimento do cuidado passa por muitas dificuldades, como a modificação das rotinas familiares e alguns aspectos estruturais e organizacionais que dificultaram a transição por essa etapa. Nesse sentido, percebe-se que os profissionais de saúde possuem um forte papel educativo nesse processo, uma vez que a família é preparada por estes para o enfrentamento a partir do recebimento de informações que esclarecem a causa da internação e os cuidados que serão necessários.

Palavras-chave: Enfermagem. Unidades de Terapia Intensiva Neonatal. Família.

VIVENCIAS DE LAS MADRES JUNTO AL RECIÉN NACIDO EN LA UNIDAD DE CUIDADOS INTENSIVOS NEONATALES

RESUMEN

Este estudio tuvo como objetivo conocer la percepción de los familiares acerca de su permanencia junto al recién nacido en la Unidad de Cuidados Intensivos Neonatales. Se realizó una investigación exploratoria descriptiva con abordaje cualitativo con 10 madres de recién nacidos internados en una Unidad de Cuidados Intensivos Neonatales de un Hospital Universitario del Sur de Brasil. Los datos fueron recolectados en el segundo semestre de 2018 por medio de entrevistas semiestruturadas y sometidos al Análisis de Contenido. Este estudio identificó los siguientes dominios: la preparación de la familia para el enfrentamiento; preparación de la familia para el cuidado; y dificultades vividas por la familia como importantes aspectos experimentados por estos familiares durante el período de permanencia en el hospital. La preparación de la familia para el enfrentamiento y desarrollo del cuidado pasa por muchas dificultades, como el cambio de las rutinas familiares y algunos aspectos estructurales y organizacionales que dificultaron la transición para esta etapa. En este sentido, se percibe que los profesionales de salud poseen un fuerte papel educativo en este proceso, puesto que la familia es preparada por ellos para el enfrentamiento a partir del momento que reciben las informaciones que aclaran la causa de la internación y los cuidados que serán necesarios.

Palabras clave: Enfermería. Unidades de Cuidados Intensivos Neonatales. Familia.

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