ABSTRACT

Objective: to learn how parents experience the discharge of the child hospitalized in a Neonatal Intensive Care Unit. Method: a descriptive-exploratory study with qualitative approach, conducted with nine parents, from August to October 2011, through an interview at home from the snowball sample technique. Data were analyzed using content analysis. The research project was approved by the Research Ethics Committee, Opinion on 148.2011.2. Results: three categories emerged: << Feelings in the hospitalization in the NICU >>; << Child care after hospital discharge >> and << Importance of the healthcare team for parents of newborns in the NICU >> Conclusion: the hospital discharge is an expected moment by parents and a period of stress, anxiety and insecurity. During this period, the guidelines/nursing care are relevant, since they prepare parents for the child's care at home. Descriptors: Newborn; Parents; Neonatal Intensive Care Units; Nursing.

RESUMO

Objetivo: conhecer como os pais vivenciam a alta hospitalar do filho internado em Unidade de Terapia Intensiva Neonatal. Método: estudo descritivo-exploratório, de caráter qualitativo, realizado com nove pais, no período de agosto a outubro de 2011, por meio de uma entrevista individual no domicílio a partir da técnica bola de neve. Os dados foram analisados pela técnica de análise de conteúdo. O projeto de pesquisa obteve a aprovação do Comitê de Ética e Pesquisa, Parecer n° 148.2011.2. Resultados: emergiram três categorias: << Sentimentos diante da internação do filho na UTI Neonatal >>; << Cuidando do filho após a alta hospitalar >> e << Importância da equipe de saúde para os pais do RN na UTI Neonatal >>. Conclusão: a alta hospitalar é um momento esperado pelos pais e um período de estresse, ansiedade e insegurança. Nesse período, as orientações/cuidado de enfermagem são relevantes, uma vez que preparam os pais para o cuidado do filho no domicílio. Descritores: Recém-Nascido; Pais; Unidades de Terapia Intensiva Neonatal; Enfermagem.

ORIGINAL ARTICLE

NEONATAL INTENSIVE CARE: FEELING OF PARENTS AFTER DISCHARGE OF THE CHILD

UNIDADE DE TRATAMENTO INTENSIVO NEONATAL: SENTIMENTO DOS PAIS APÓS A ALTA HOSPITALAR DO FILHO

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Objective: to know how parents experience the discharge of the child hospitalized in a Neonatal Intensive Care Unit. Method: a descriptive-exploratory study with qualitative approach, conducted with nine parents, from August to October 2011, through an interview at home from the snowball sample technique. Data were analyzed using content analysis. The research project was approved by the Research Ethics Committee, Opinion on 148.2011.2. Results: three categories emerged: << Feelings in the hospitalization in the NICU >>; << Child care after hospital discharge >> and << Importance of the healthcare team for parents of newborns in the NICU >> Conclusion: the hospital discharge is an expected moment by parents and a period of stress, anxiety and insecurity. During this period, the guidelines/nursing care are relevant, since they prepare parents for the child's care at home. Descriptors: Newborn; Parents; Neonatal Intensive Care Units; Nursing.

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INTRODUCTION

During pregnancy period, parents experience a lot of feelings and sensations that remain until the arrival of the newborn (NB). The birth of a child awakens parents’ expectations and changes in the routine especially when unexpected events happen, as the child hospitalized in the Neonatal Intensive Care Unit (NICU).

The Neonatal ICU is an environment that offers specialized care to the newborns, being complex and high risk cases that require a qualified and committed health team. Being an unknown environment, it is seen as frightening for the parents, and it is difficult to accept having there the hospitalized child. For this reason, the nurse who manages the care and newborn lives with parents during hospitalization may help them in facing this painful moment.

It is relevant the integration between parents and newborns during hospitalization for the emotional bond during pregnancy has continuity, as well as preparing them for the time of hospital discharge. For this, the team must provide a space for them to express their feelings and strengthen the contact with the child.

The hospitalization in the NICU causes parents to feel frightened and weakened by the separation of the child in an unexpected way by any pathology or simply because the baby is premature. This event generates moments of stress, anxiety, as well as expectations about the treatment. The expectation will be mitigated as they are targeted and reported on the state of health of the child.

It is recommended before visiting the child in the NICU, to parents be advised about how they will find the newborn, as well as monitoring of the nurse as a member of the healthcare team in that first contact. Nurses should answer questions from parents soothing their stress to favor feel safe with the professionals who are taking care of their child. The nurse being part of the multidisciplinary health team of NICU, being in full shift, also needs to consider care within the family.

In this study it is emphasized the newborns and their parents, since they need to continue the bond created in the intrauterine environment, that for health reasons, it was hampered by hospitalization. The newborns realize that is not alone, since the presence of their parents provides safety and comfort for them. From this interaction, both feel prepared for the process of hospital discharge and home care. For this to occur, the planning of newborn hospital discharge must be done from the first days of hospitalization providing the emotional bond between parents and babies. Thus, both can feel safe and confident with the care.

Parents experiencing the process of the child many times illness, fear performing routine care in the NICU believing to be a frail child, being necessary the monitoring of the nurse to guide the care and their adaptation in the family. Therefore, nursing professionals should prioritize humanized care not only to the newborn but also to their parents, to meet the individual needs of each case do not feel abandoned. It is important that in practice to emphasize the completeness, uniqueness and particularity to value each situation in context.

Parents when are not guided, show their afflictions to the child, making difficult the adaptation of both at home. This research is justified by understanding that care to the NB and family after admission to the NICU, needs to be discussed and expanded by the health team to assist parents in the discharge of the child, which will help to reduce anxiety and fears.

Based on the above, the question is: “How parents experience the discharge of the child hospitalized in a NICU?” In attempting to answer the question and explained the expectation of enabling interactive looks and committed to caring the newborn and family, inserted in the NICU and after the discharge, the objective is:

- To know how parents experience the discharge of the hospitalized child in the Neonatal Intensive Care Unit.

METHOD

Descriptive exploratory study with qualitative approach, since it aims to provide an overview of a situation that can be considered as the first step in a broader research, since as a result of their findings, strategic action plans can be arranged contributing to the changing reality investigated.

This research was developed at home of nine families who experienced the hospitalization of their child in the NICU. The sample was intentional, through the “snowball” sample technique. Thus, the first parents were asked by one of the researchers, after their child’s discharge from the NICU, who reported other parents who have been hospitalized children in the same period in the unit, and so on. Each family was informed who
appointed her and was invited to participate in the investigation. Inclusion criteria were considered: being a newborn’s parent and have experienced the hospitalization of the child in the NICU for over ten days.

Data were collected through individual interviews, during September and October 2011, with the guiding question: How was for you to take your child home after discharge from the NICU? Data were analyzed by content analysis method. It is to discover the meaning that compose a communication whose presence or frequency add significant perspectives to the study object. The notion of the subject is associated with a claim that relates to a particular subject, and may be presented for a word, phrase or idea.

The operationalization of the analysis process followed the three steps of the method. In the first step, called pre-analysis, we sought to make a thorough reading of the data, then the organization of the material and the formulation of a hypotheses. Following, the exploration of the material was performed seeking to encode the raw data. In the third and final phase, the data were interpreted and defined in themes according to the meanings.

The ethical and legal issues involving research with human beings were considered, according to Resolution 466/2012 of the Ministry of Health. Clarified the objectives and methodology of the survey, participants signed a consent form, and in two copies, getting one with the participants and one with the researchers. The document was guaranteed free access to the data collected. Participants were also informed that their names would not be disclosed and that they could withdraw from the study at any time without restrictions.

The anonymity of the participants was kept and they were identified by flowers names. The project was approved by the Ethics Committee in Research of Franciscano University Centre under the number 148.2011.

RESULTS

From the interviews, three categories were revealed: Feelings on the hospitalization of their child in the NICU; Importance of the healthcare team for parents of newborns in the NICU and caring son after hospital discharge.

Feeling in the child hospitalization in the NICU

Because it is not expected the hospitalization of the newborn and consequently, the separation imposed between parents and children, the family feels fragile, anxious and insecure because they do not know the environment of the NICU and would not know the outcome of their son. The moment the news of the hospitalization in a Neonatal ICU covers a range of feelings, as can be seen in the parental reports, which for some was characterized as a period of anxiety, fear and insecurity.

[...] A difficult period, given the uncertainty we had in relation to the care we should have because it is a newborn, premature and needed special procedures. (Tulipa)

[...] Great uncertainty because my daughter had some complications during hospitalization and had the risk of having sequels in the future. (Rose)

I was very anxious, she was hospitalized for jaundice, and also for being a carrier of Down Syndrome. (Orchid)

After the birth, she was transferred to the NICU, fear and anxiety were part of our life. (Violet)

In the reports, it can be realized that parents are afraid, are distressed and anxious about the complications and care which the child is subjected to and the possible consequences that may have in the future.

Importance of the healthcare team for parents of newborns in the NICU

As the reports below, the health professionals, especially nursing team, help in the formation of the bond between parents and babies in the NICU. This approach is capable of generating feelings of gratification and joy to be able to take care of the hospitalized child with the support of skilled professionals.

Without any doubt, health professionals do all the difference in the lives of all parents who went through an ICU, not only for his technique, but by a set of factors that give us strength, hope and help to deal with the situation. (Tulipa)

The nursing staff was always giving me support, how to deal with it, especially emotional. I left well with all the necessary guidance, not having difficulties in home care. (Orchid)

He was hospitalized 40 days, but the nursing staff helped us, guided us. We were well instructed how to care and love and their affection helped us. I only thank the nursing, guidance and emotional support that primarily helped us overcome this obstacle. (Violet)

When they (referring to hospitalized children) were in the hospital the nurses received enough guidance, I helped to change them. (Glass of Milk)
The hospital discharge generates expectations as the hospitalization, even parents being happy to bring home their child, still characterize it as weak and feel insecure about taking care alone, with important guidance and monitoring of the health team at this moment too. In the reports, it was revealed that the nurses helped significantly in both the inpatient process and post-discharge, as offered emotional support, strength and hope potentiated safety in home care.

**Child care after hospital discharge**

In the statements below, it is seen the importance of the healthcare team, especially nursing, for supporting and guiding parents. They said that this behavior enabled the continuity of safely care for their newborn at home.

**Guidelines were fundamental to the multidisciplinary team, with emphasis on nursing, they gave us during hospitalization and after discharge, as allowed the continued recovery of my daughter, as well as her development. (Tulipa)**

The nursing staff was always giving me support, how to deal with it, especially emotional. I did well with all the necessary guidance, having difficulties in home care. (Orchid)

One family, however, states that feels insecure to care for the child during the first days at home because he fears to happen something wrong and not knowing how to proceed. He stresses the important presence of a professional to guide the main care.

**An orientation that I would have was if he stopped breathing as I could do first aid, since he had apnea. In his first days at home I would like someone to guide me in case of some problem, in his case having something or even some guide of the newborn with tips and guidelines. (Yasmin)**

The continuity care that the multidisciplinary team can provide after discharge may contribute to parents ask their frequent questions, get more security in care and transmit it to the NB, helping, so for that readmissions are avoided because the family did not have follow-up at home.

**DISCUSSION**

The arrival of a newborn featuring an important phase of the life cycle of a family, it is the time when new roles are outlined and relational dynamics are restablished. Thus, when complications during childbirth or after the first hours of life emerge and NB needs to go to a Neonatal ICU, feelings arise not only for the parents, but on the whole family that somehow also involved with the pregnancy, whether planned or unplanned.

In the speeches of many parents feelings emerged. One was the feeling of distress and anxiety from the news that the long awaited child had to be hospitalized in a Neonatal ICU. This moment is difficult, since one NB imagined throughout pregnancy is lost in some way. The mother, in the situation of puerperal goes through a difficult period in which the absence of the child postpartum goes triggers many emotions in her, making it physically and emotionally fragile.

It is understandable that parents feel fear, insecurity and instability for recognizing the risks the newborns are exposed, creating a sense of frustration for the separation imposed for the child hospitalization. This instability requires the understanding and acceptance by the team health, especially nursing, needing to be able to encourage her to overcome the difficulties and facilitate the adjustment of family and recovery of the NB.

When the nursing staff involves the family in care of the newborn, they promote the reduction of stress and anxiety, focusing on continuity in home care. The adequacy of parents during the hospitalization of the child in the NICU, with the experienced circumstance, should be helped by the nursing staff as a guidelines, including the host and the bond that they will be safe in relation to care provided to their child.

In this context, it is relevant to the bond between the healthcare team and the family of the newborn in order to facilitate adaptation to this environment providing both parents not just being passive spectators of the situation, but rather spend the agents in the treatment and reviewers a healthy physical and mental development of the child. In addition, nurses must perform integration of parents with the health care team so that adaptation of both sharing of care to the newborn occurs. Also it is essential that the nursing staff develop a process of teaching and guidance, starting from the time of arrest through interaction both in care of the child so that they feel part of the treatment and recovery process.

Hospital discharge for parents is expected moment to have the assurance that their child is healthy and able to go home, but can also be configured as an occasion to stress, anxiety and insecurity moment. For weeks and/or months, parents felt calm, confident that his son was being cared for by a trained staff that could detect and solve any problems that arose. It is natural that at this moment, they feel unable to perform care alone at home,

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making this period a little messy due to fear and insecurity demonstrated by these in the early care of the NB.

In the interviews, it was noted that nursing guidelines were present throughout the time of hospitalization, which improved to make them feel safe and able to care for their child during hospitalization and post-discharge. This finding was also found in a study conducted in the city of Maringa, which aimed to understand the experiences of parents who had their children in the NICU since their birth.14

In the study, parents reported receiving assistance in cozy moments before the birth of their children as throughout the hospital, thus helping to reduce anxiety and promote the feeling of support and comfort of the mothers.14 Then, it is realized the importance of a committed assistance involving institutions and professionals engaged in the care of newborns in the NICU. It is also necessary to develop some mechanisms that discharge planning can ensure that care initiated during hospitalization, have continued post-discharge.

Such planning will minimize the loss of continuity of care for newborns, when sent home. Therefore, the hospital should be planned with emphasis on comprehensive care, meeting the individual needs of each case and encouraging parents in achieving the childcare.15 Thus, after discharge, parents will have confidence and trust in achievement of care, performing their activities firmly effectively at home.

CONCLUSION

This research reinforces the importance of nursing care in the comprehensive care of infants and parents who experienced the situation of having admitted to a NICU. Respondents reported having experienced various feelings towards the fact that they can take home their child, but the confidence felt by the healthcare team, especially nurses, helped to surpass this difficult time.

When the time of hospital discharge arrives, parents are aware of how to deal with basic child care, since even those who have gone through motherhood have doubts, feeling the need to have to learn everything again. Also because before they had the security of having a qualified staff to monitor any complications with the child quickly solving; at home they will be ahead of meeting the needs that arise.

Nurses should therefore be aware that the NICU, beyond the care given to the newborn, parents also need attention, as they feel frightened, anxious and insecure at the moment they are experiencing. The guidelines can and should have continuity in home care, it is important to avoid readmissions and both feel safe. Thus, it became clear that the nursing staff, as well as multidisciplinary, it is critical for parents to undertake the care of their child naturally.

This study may contribute to health professionals if they monitor and care from parents who experience the admission of their child in the NICU, as well as at home after hospital discharge. That is because this monitoring of the early days is the time when the nursing staff may assist the main needs of the NB reassuring parents in making the care of their child.

It is necessary to pay attention to the public policy of customer assistance focus of research in the health care of the newborn and parents; home visits shall include, without doubt, all the principles of the Health System so that both are treated comprehensively and considering singular completeness, fairness and universality. Besides the tripod - Teaching, Research and Extension - the school should promote the improvement of health care to the newborn in the NICU with proper home care post-discharge.

Finishing this search, it is considered that there is the need for further studies aimed at caring for their newborn and family upon admission to the NICU and post-discharge in order to minimize distress in parents and bring them security potentiating security to the NB care at home.

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