

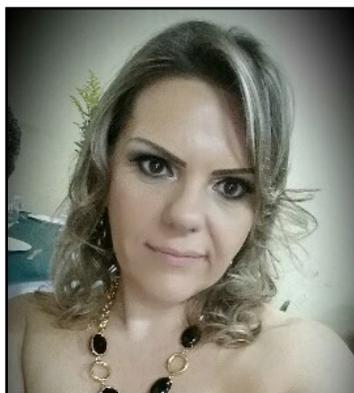


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Original Articles



The early days of the premature child at home: collective subject discourse

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ABSTRACT

Aim: to better understand the experiences of fathers regarding the care of their premature child in the first days after discharge. **Method:** qualitative approach study. Seven parents participated, who had preterm infants hospitalized in a neonatal intensive care unit. Data collection took place in the period from March to June 2015. For data analysis, the methodological reference of the discourse of the collective subject was used. **Results:** the speeches were grouped into three themes: 1) Experiencing the emotions of the first night with the child at home; 2) Taking responsibility for the care of the premature child at home; 3) Putting into practice the care measures learned from the nursing team during the hospitalization period. **Conclusion:** the fathers participated in the care of the child. The nursing team should be prepared to encourage the presence of the father in hospital environments, involving him in the early care practices, so that he can feel more secure when the child is brought home.

Descriptors: Paternity; Patient Discharge; Infant, Newborn; Infant, Premature.

INTRODUCTION

Medical standards categorize newborns with a gestational age of below thirty-seven weeks as premature. Prematurity is considered to be the leading cause of neonatal mortality.⁽¹⁾

Due to the risks to life that prematurity can cause, these infants may be separated from their parents soon after delivery and be taken to the Neonatal Intensive Care Unit (NICU) so they can receive specific care, which may hinder the bond between the baby and the parents⁽²⁾. As a consequence of this, negative feelings such as anguish, sadness, uncertainty and fear of death arise in the family, particularly in parents⁽³⁾.

In this context, health professionals working in NICUs play a fundamental role promoting the formation of this bond and helping to overcome this difficult and delicate stage for parents and newborns. Thus, the team should be carefully trained to take care of the family and suggest actions that can reduce their suffering, promote empowerment, share information and encourage parental participation in the provision of care, whilst also respecting the family's time and limitations.⁽⁴⁾

The care promoted at the NICU to parents can ease the suffering caused by the premature birth of the child, strengthen the child-parent bond, help to create security in the provision of care, and ensure future good care practice after discharge from hospital⁽⁵⁾.

In general, the mother figure is more present in the care, because historically, the woman has played the primary role of caregiver in the home to the children in the family, whilst the father has taken the role of family provider. However, today, with the intense social changes that have taken place, women have entered the labor market in search of new possibilities, new achievements and new models of life⁽⁶⁾, which have caused profound changes in families. These

changes have affected the role of the father, who has started to participate equally and actively in raising children, contributing to the provision of care and sharing responsibilities and decisions about their children⁽⁷⁾.

In general, during the stay at NICU, the father is the first to visit the child and to receive information from the health professionals. Facing the prospect of the hospitalization, he is often responsible for informing the mother about the situation, since she may also be in need of care and thus unable to see her child after birth⁽⁸⁾.

Since the child's birth the father has been taking on new roles within the family every day, such as, dividing domestic activities with his partner, who is often fragile, stimulating and supporting breastfeeding and contributing to its success⁽⁹⁾. In addition to the period of hospitalization, the range of his role widens at home. As a caregiver, he interacts in a different way with the child, introducing new experiences and challenges and contributing to the child's cognitive and empathic development.⁽¹⁰⁾ He may be involved in many ways with the baby: playing, caring, teaching, providing financial support, showing affection and sharing the mother's activities, responsibilities and concerns about the child⁽⁷⁾. Based on these assumptions, the goal of this study was to capture the experiences / opinions of the father regarding the care of their premature children in their first days after the hospital discharge.

METHOD

This is a study which uses a qualitative approach and integrates a broad research project entitled: "The father figure in the care of the premature and low birth weight neonate hospitalized in Neonatal Intensive Care Units".

The study setting was the NICU of a school

hospital located in the northern region of Paraná. Accredited by the Unified Public Health System (SUS), this hospital provides healthcare assistance in practically all medical specialties, human resources training, continuing education, research and technological development and carries out technical and scientific cooperation with the health services network of the city of Londrina. Its structure is composed of medical-surgical and pediatric hospitalization units, as well as maternity, center-surgical, emergency and adult, pediatric and neonatal ICUs. In the neonatal area, the ICU has seven beds and the Intermediate Care Unit has eight beds.

Seven parents, who had preterm children hospitalized in the NICU, participated in this study. They were invited by the researchers to participate in the study, were informed of the research goals, data collection procedures, confidentiality in the treatment of information, potential risks and the possibility of interrupting participation at any time which would not prejudice their child's care provision. As requested they agreed to sign the free and informed consent form.

We used the following inclusion criteria: fathers of children born with a gestational age of less than thirty-four weeks, weighing 1,500g or less and having been discharged from the hospital in the period from March to June 2015. The exclusion criteria adopted were as follows: fathers of children with congenital malformations (one case) or who died during the follow-up period (four cases).

The average duration of the researchers' meeting with the participants was thirty minutes, including the initial interaction and the interview itself.

The interviews were recorded using a digital recorder and a field notebook was used for the researcher's summary notes. At the end of the interview the father was asked to

listen to the recording and to a reading of the summary, providing him with the opportunity to change any information he deemed necessary. The interviews were carried out at the families' homes seven days after the children were discharged.

Data collection was carried out in the period from March to June 2015, through a semi-structured interview. The guiding questions used in the interview to motivate the parents' speeches were the following: "Tell us, how was the first day you spent with your child at home? How has your child's care measures been distributed? Did the guidelines you received at the hospital about your child's care have any influence on you here at home?"

We processed the data according to the theoretical reference of the Social Representations, which constitutes a series of opinions, explanations and affirmations produced from the daily life of the groups. Communication is a prime element in this process. Considered a common-sense theory, because it is created by groups as a way of explaining reality, social representation formalizes a particular type of knowledge whose function is the explanation of behaviors and the communication between individuals⁽¹¹⁾. The methodological framework adopted was the Collective Subject Discourse (CSD), which proposes the organization and tabulation of qualitative data in a discursive way, aims to make clear what an individual thinks or the experience of a certain population on a specific theme.

The CSD proposal consists of analyzing the oral material collected and extracting methodological figures from the speeches. These figures are used to organize, present and analyze the data obtained from the testimonies. The methodological figures that aid in the analysis of the data are the key expressions, central ideas, the collective subject discourse and the hooking⁽¹²⁾.

Collective Subject Discourse is constructed in a first person format, aiming to reconstruct, through pieces of individual discourses, as many speeches-synthesis as are deemed necessary to express the thoughts or social representations of a group of people on a certain theme⁽¹²⁾. The representativeness of the group in an individual's speech occurs because both the social and individual behaviors obey internalized cultural models, although the personal expressions likely present variations in conflict with the traditions. The question of qualitative representativeness reflects the more general and specific historical character of a group⁽¹³⁾.

The study was approved by the Research Ethics Committee of the State University of Londrina - UEL, through CAAE n. 30709814.0.0000.5231, according to Opinion No. 694,303.

RESULTS

Parents ages varied from twenty to forty-four years old. Three fathers had incomplete elementary education, three had completed their secondary education and one had completed his primary education. Regarding their marital status, four disclosed they were married, two were in common-law union (with union time varying from eight months to seven years) and one was divorced. Four were experiencing paternity for the first time, while three already had other children. With reference to family income, three fathers reported earning approximately double the minimum wage, two informed earning three times the minimum wage and two fathers revealed they earned more than three times the minimum wage.

From the empirical material analyzed, six central ideas (CI) emerged, which were grouped

into three themes, as follows: 1) Experiencing the emotions of the first night with the child at home (CI1 - The first night was a calm night; CI2 - No one could sleep in the first night); 2) Assuming responsibility for the care of the premature child at home (CI3 - Effective participation of the father in the provision of care to the child, CI4 - Aid in domestic tasks) and 3) Putting into practice the care measures learned from the nursing team during hospitalization (CI5 - Nurses' guidelines on basic care with the child were important; CI6 - Nurses' advice on the main signs of danger with the premature infant provided peace of mind).

For a better understanding of the analysis performed and preservation of the participants' privacy, parents' names were replaced by the letter P, followed by a numerical sequence based on the order of the interviews.

Theme 1 – Experiencing the emotions of the first night with the child at home

CI1- The first night was a calm night

CSD1- The first night was calm and quiet. It was very good, we've been expecting hospitalization discharge. We were concerned about hospital risk, because of the possibility of contamination. They are fragile and have low immunity. So we were very happy to bring our kid home. It was nice, it was our dream to bring him here. There is no way to describe this joy! **(P1, P4-P7)**

As noted in CSD1, parents perceived children as fragile and mentioned concerns about the appropriateness of the hospital environment. They were worried, particularly about the risk of hospital contamination, which is why they felt happy with the discharge and arrival at home. On the other hand, difficulties in arriving at home were also reported, as stated in CSD2.

CI2- No one could sleep in the first night

CSD2- The first day was a different day. We had a hard time, the baby cried a lot at night and did not let anyone sleep because he had to adapt as the hospital was different, another environment. There was some activity at night, so everyone at home was awake too. It was different, a different experience than normal. **(P1-P4)**

The first day at home with the child, despite being a moment of happiness, was also permeated by feelings of insecurity, as both parents and child needed to adapt to the new home environment and to previously unknown routines...

Theme 2 – Assuming responsibility for the care of the premature child at home

CI3- Effective participation of the father in the provision of care to the child

CSD3- Whenever I can, I help. I try to stay overnight with our baby when I get home from work: I change diapers, I give him his medicine, I help in the bath, I wake my wife when the baby wants to nurse and then I take the baby back to sleep. **(P1-P7)**

The fathers represented the care measures based on daily tasks, such as domestic tasks which they assumed on arrival from work, (CSD3) and performed with the child, to help the wife become free to provide care for the child, as reported in the CSD4.

CI4- Aiding in domestic tasks

CSD4- I also help to take care of the house so that my wife has more time to take care of our baby: I wash the clothes, I do the dishes, do dinner and clean the house... and when my wife is taking care of the house I play with our baby, or stay with him on my lap to help her. **(P2-P5, P7)**

Fathers' assistance in household activities allowed mothers to strengthen the bond with their newborn children and, consequently, marriage bonds are strengthened.

Theme 3 – Putting into practice the care measures learned with the nursing team during hospitalization

The parents represented the care measures learned through the support of the nursing team as caring and comforting the baby, and also the practical actions, such as bathing and changing diapers. They based their needs not only on the fact that they had poor or no experience but also on the special demands preterm infants require, aspects that emerged in CSD5:

CI5- Nurses' guidelines on basic care with the child were important

CSD5- The nurses at the hospital taught us a lot about how to take care of our baby. They taught me how to prepare the crib for him to sleep and feel as if he was still inside mom's belly, how to wrap him up, to place a diaper under his shoulder because his head is bigger than the body ... I learned how to change diapers, to give him a bath with the baby wrapped in the diaper, because if it is done without a diaper he feels lost and how to cover his ears to avoid water. I learned a lot, mainly because I was a first-time father, he's a premature baby and when I went to the hospital I learned that the baby only cries for four things: hunger, dirty diapers with pee or poo or when he is in pain. If he is fed, cleaned and cries, there must be something else. At first my wife and I suffered a lot through the cramps, he used to have a lot of cramps, but then we started to stimulate him with exercises in his abdomen and feet, then he started to poop and get better. After that he slept well. **(P2-P7)**

After experiencing hospital admission of preterm children, parents began to assimilate technical medical terms in their discourse, as stated in CSD6. Understanding the meaning of this language and learning the techniques to meet any uncommon demands is important and reassuring to them.

Cl6- Nurses' advice on the main signs of danger with the premature infant provided peace of mind

CSD6- If every parent had the opportunity I have had, to know what apnea is, what choking is... surely they, too, would be calmer like me. Today I can go to work with peace of mind. The nurses taught us a lot, all the advice was very relevant, because everything I learned from them I use here at home and it always works. **(P4-P7)**

DISCUSSION

With the inclusion of women into the labor market and their contributions to household incomes, men are becoming increasingly close to children and home care. The birth of a preterm child may demand even more participation from the father. This is because the wife will probably need to exclusively play the role of the mother, staying in hospital to be with the hospitalized baby. The father will therefore be expected to undertake domestic tasks in the home and in some cases, to take care of their other children.⁽¹⁴⁾

After discharge, even with the guidelines received, feelings of insecurity, fear and anxiety may arise within the family, since the baby who spent much of its time under the care of health professionals is now exclusively the family's responsibility, without the help of professionals and outside the hospital environment.

During the first night at home, mixed fee-

lings arose among the parents, including some negative emotions, such as tiredness, due to poor sleep. There was also the awareness of the need to change habits to suit the newborn baby, which would directly affect family life. After the arrival of this child at home, several changes can be observed, such as the need to prioritize the baby, his pace and the parents' dedication to him, as the child is totally dependent on the parents⁽⁷⁾.

. It is common that the birth of a child delivers negative changes in marital quality, especially in situations that demand more care, such as in the case of a premature birth. Baby care is very different from pre-birth expectations especially when these expectations are disrupted due to the consequences of preterm births. In addition, adaptation to paternity can often imply a greater commitment to the relationship as a parent than as husband/wife⁽¹⁵⁾.

In contrast to these negative feelings, some parents referred to the first night as "quiet" and even as "expected", since the greatest feeling was the happiness of having the child at home. The hospitalization period, which is often prolonged, generates anxiety for the discharge and the arrival of the child at home. When this discharge occurs, feelings of joy and satisfaction arise⁽¹⁶⁾. Parents with positive expectations before birth in relation to the child, tend to participate more effectively after birth, with marital satisfaction and less stress during this transitional stage⁽¹⁵⁾.

The contrasting positive and negative experiences may be related to the stages of the new parental role. Many of the emotional responses during pregnancy and up to two years after birth are often more negative than positive. Negative emotions such as surprise and confusion, observed in some discourses, are associated with the transition to parenthood, as well as positive emotions, such as joy. Anxiety and sadness are also observed as a mix of feelings

that are typically characteristic of the parenting process⁽¹⁷⁾. The fathers' speeches reveal their increasingly active and frequent participation in the direct care of their children. This corroborates with findings from another similar study that investigated the main activities of baby care performed by the fathers: changing diapers, doing the bath, picking up children to rest on fathers' laps, feeding, preparing and giving the bottle or pasty food, special attention at night and health care measures such as taking the child to medical visit, giving him medicine or observing habits of hygiene and disease prevention⁽⁷⁾.

The study revealed that fathers are not only providing direct care to the child, but also assisting their wives in household activities and thus enabling their wives to spend more time on the child's care⁽¹⁵⁾.

The fathers desire to spend more time with their children is considered positive⁽¹⁷⁾. Activities such as playing, picking up and others are identified as pleasurable and satisfactory for parents⁽⁷⁾.

It is important to emphasize that the nursing team's effective communication with the family favors the creation of a bond of trust and respect, contributing to the quality of care provided to the newborn⁽¹⁸⁾.

The nursing team plays a fundamental role in health education training mothers and fathers to take care of their children. Often because of the child's prematurity and/or risk, parents are fearful of providing inadequate care for them and require the support and guidance of a nursing team to advise them. In this recent study, the support was recognized by parents as an essential measure.

Nurses act in the assessment and direct care of the hospitalized newborn, as well as their family, offering support and listening, guiding and informing them about prematurity and also preparing them for the discharge and home care^(16, 19).

The care advice and guidance from the nursing team to the family during the children's hospitalization were essential to reduce parents' fears and doubts regarding the care provision of their children, allowing them to be part of the care process. This is possible because the nursing team can delegate to the parents the simple care practices and keep responsibility for the more complex, technical procedures. The team must encourage the family in the provision of care to the baby, thus ensuring quality care measures in the future, even after hospital discharge^(5,20).

CONCLUSION

We consider that the goal of the study was achieved, since it was possible to gain the representations of the fathers regarding the care of their premature children in their first days after the hospital discharge. Among the fore front of the fathers' emotions during the infants' first night at home, we observed feelings of happiness and tranquility, but also of stress and difficulties in understanding what the children wanted and why they cried.

An increasing involvement in the direct care of the child emerged from fathers' discourses, who assumed responsibility for the care practices and also assisted their companion in household activities so that she could have more time with the child.

In this study, we observed the relevance attributed by the father to the care measures and guidelines taught by the nursing team in the hospital environment, which contributed to the reduction of fears and anxiety at home...

Thus, it is worthy to note that the fathers have effectively participated in the provision of care to their children. It is the nursing team's responsibility, as well as other professionals working in the neonatal units, to be prepared

to encourage the presence of the fathers in the hospital environment. Early involvement in the care of their children, even with simple care measures, will help ensure they can become familiar with the new family member and therefore strengthen their bond.

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