

Experience of family members in the care of preterm newborns discharged from a neonatal intensive care unit*

Experiência de familiares no cuidado do recém-nascido pré-termo egresso de unidade de terapia intensiva neonatal

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ABSTRACT

Objective: to understand the experience of family members in the care of preterm newborns discharged from the Neonatal Intensive Care Unit. **Methods:** qualitative study, developed with 16 family members of preterm newborns discharged from a neonatal unit through semi-structured interviews. Data were submitted to thematic content analysis. **Results:** three categories were listed: Family members' rearrangements in the care of the preterm newborn at home; recognizing the specific care needs of the preterm child; and care in the face of complications and sequelae resulting from prematurity. **Conclusion:** family members recognize that the preterm newborn requires differentiated care and, therefore, experience a reorganization of their daily lives to promote the care of the child after discharge from the neonatal unit. **Contributions to practice:** this study points out the relevance of the nurse's work with families in neonatal units by strengthening family skills so that they can undertake care, so that it can be offered safely and meet the health demands that arise on a daily basis at home, in addition to guiding them about the need for monitoring the child after discharge.

Descriptors: Family; Parenting; Qualitative Research; Infant, Premature; Intensive Care Units, Neonatal.

RESUMO

Objetivo: compreender a experiência de familiares no cuidado do recém-nascido pré-termo egresso da Unidade de Terapia Intensiva Neonatal. **Métodos:** estudo qualitativo, desenvolvido com 16 familiares de recém-nascidos pré-termo egressos de uma unidade neonatal por meio de entrevistas semiestruturadas. Os dados foram submetidos à análise de conteúdo do tipo temática. **Resultados:** foram elencadas três categorias: Rearranjos dos familiares no cuidado do recém-nascido pré-termo no domicílio; Reconhecendo as necessidades de cuidados específicos da criança nascida prematura; O cuidado ante as complicações e sequelas decorrentes da prematuridade. **Conclusão:** os familiares reconhecem que o recém-nascido pré-termo necessita de cuidados diferenciados e, por isso, vivenciam uma reorganização do seu cotidiano para promover o cuidado da criança após a alta da unidade neonatal. **Contribuições para a prática:** este estudo aponta a relevância da atuação do enfermeiro junto às famílias em unidades neonatais por meio do fortalecimento das competências familiares para que estas possam empreender os cuidados, de forma que estes possam ser ofertados com segurança e atender às demandas de saúde que surgem no dia a dia no domicílio, além de orientá-las sobre a necessidade do acompanhamento da criança após a alta.

Descritores: Família; Poder Familiar; Pesquisa Qualitativa; Recém-Nascido Prematuro; Unidades de Terapia Intensiva Neonatal.

Introduction

Preterm newborns (PTNBs) often need to be admitted to Neonatal Intensive Care Units (NICU) that offer access to specialized and technological care to ensure a satisfactory adaptation to extrauterine life and, consequently, their survival⁽¹⁾. Due to the characteristics of their health conditions, it is common that PIs undergo several therapeutic interventions during their stay in NICUs as well as at the time of hospital discharge, as they depend on assistive technologies and present differentiated care needs when compared to term newborns⁽²⁾.

The transition of PTNB from the hospital environment to home is marked by new experiences lived by the family and permeated by ambiguous feelings, such as fear, anxiety, expectation and joy. This moment is characterized by the perception of difficulties and adaptations in the family environment, where the need to prepare for this transition stands out. Thus, for parents to assume the care of their child at home, it is necessary that the multidisciplinary team starts preparing for this transition from the moment the newborn is admitted to the NICU through information, training and continuous monitoring⁽³⁾.

Although parents are recognized as the main caregivers of their child in a situation of illness, they depend on the offer and understanding of information to satisfactorily perform this role, in order to meet the child's specific needs. In this sense, it is essential to have adequate support provided by NICU professionals, in addition to follow-up services that will provide subsidies for a more effective care, especially after the arrival of the preterm baby at home⁽⁴⁾.

However, some studies pointed out the dissatisfaction of family members regarding the quality of information provided by health professionals before the PTNB is discharged from the NICU, and also the lack of support from these professionals to prepare them for the care to be undertaken at home^(3,5-6). Although the scientific literature recognizes the importance and need to prepare families for the continuity

of care of PTNBs in the home environment, there are still weaknesses that need to be reconsidered in this process. These weaknesses may be mitigated with the approximation of the experience of care provided by the family after hospital discharge, since the identification of weaknesses and potentialities in this context enables (re)directing the care practices of health professionals.

Therefore, the act of bringing evidence that shows the NICU team the importance of preparing the family for care based on the knowledge of their experiences in care after hospital discharge is the justification for this study. In this context, it emerges as a gap of knowledge to be unveiled in this study: what is the experience of family members in the care of PTNB discharged from the NICU at home?

Thus, this study aimed to understand the experience of family members in the care of preterm newborns discharged from the Neonatal Intensive Care Unit.

Methods

This is a qualitative study⁽⁷⁾ developed with families of children born preterm in the municipality of Cuiabá, Mato Grosso, Brazil, and reported according to the Consolidated Criteria for Reporting Qualitative Research (COREQ) protocol.

The following selection criteria were adopted to participate in the study: being the family member of a child born with a gestational age equal to or less than 32 weeks and who was hospitalized in a NICU during the period from January 2018 to July 2019. The choice of this gestational age is justified by the greater complexity and particularities of care arising from the condition of prematurity, which have as a consequence longer hospitalization time. Families of newborns who died after being discharged from the NICU and those whose address was not located by the researcher were excluded.

Initially, a survey of possible participants was conducted with the NICU of a public hospital in the

state capital, using the unit's inpatient record book and medical records. A total of 38 PTNBs were located that met the inclusion criteria of the study and whose family members were later contacted by telephone. During this contact, the main researcher presented the research proposal, addressing the theme, the objectives and how the data would be collected. The interviews were conducted on a previously scheduled day and time with each participant, always seeking to ensure privacy in a calm and reserved environment, in addition to providing clarification about any doubts of the participants regarding the research process.

Upon acceptance, the researcher went to the family home with the Informed Consent Form. There were 27 refusals, which were justified by the family member's unavailability of time to participate in the interview. Five family members were excluded, three because they could not be found at the address and two because the child died soon after discharge. Therefore, 16 relatives of six PTNBs discharged from the NICU participated in this study, being six mothers, three fathers, three grandmothers, two sisters and two aunts.

Data collection was guided by a semi-structured instrument containing the following guiding questions: Tell me about your experience of caring for a child born preterm after discharge from the NICU? Tell me about the child's main care needs after discharge from the NICU and what you did to meet the demands of this care? What places (health services and other care and support spaces) did you seek to meet the child's care demands? The instrument was validated in the first interview, and there was no need for adjustment regarding the questions.

The interviews were conducted by the main researcher, who is close to the studied theme and has an understanding of the guiding principles of the interview technique for obtaining data. It is noteworthy that the interviewer had no ties whatsoever with the research participants. The collection proceeded in a face-to-face and individual way, in the homes of six families, in the period from August to November 2019

with an average duration of 80 minutes, recorded on a smartphone device, offline mode and with a digital recorder application. Then, the material was transcribed in full in Microsoft Office Word 2016® document, forming the corpus of analysis.

The empirical data were submitted to thematic content analysis, anchored in three stages: pre-analysis; exploration of the material and treatment of the results; and interpretation⁽⁷⁾.

To ensure anonymity, the participants were identified with the first letter referring to family composition (M/Mother, F/Father, G/Grandmother, S/Sister, A/Aunt), followed by the letter F for Family member and the number assigned to it based on the order in which they were interviewed, example: MF3 - mother of the third family interviewed.

The research was conducted according to the required ethical standards and was approved by the Research Ethics Committee of the Julio Muller University Hospital under opinion number 2,788,928/2018.

Results

The participants were between 18 and 67 years old. Regarding education: one interviewee reported being illiterate; nine had complete high school education; three had incomplete college education; and three had complete college education. The children had gestational age between 26 and 32 weeks, birth weight between 855g and 1,250g, and the length of stay ranged from 17 to 60 days. Among the six neonates in this study, three were diagnosed with complications of prematurity at the time of discharge, one with hydrocephalus, one with metabolic bone disease, and one with hearing loss. At the time of the interview, the children were aged between four months and one year.

Rearrangements of family members in the care of the preterm newborn at home

After the PTNB's hospital discharge, families experience a reorganization in their daily lives to cope

with the care required by the child. The participation of other family members comes after a few months of life of these newborns, when they have already been at home for some time. In this scenario, there is the participation of aunts, older sisters and grandmothers who take on most of the routine demands so that the parents, especially the mothers, can resume the activities performed before the birth of the preterm child: *I spent 20 days taking care of him there, I bathed him, changed him, fed him, which was every three hours, now it's every two hours because he's starving like a thing (GF3). My mother-in-law and my daughters, because I work the whole day. They take turns, one in the morning and another in the afternoon (MF1).*

The birth of a preterm child, for some families, was accompanied by feelings of fear and insecurity that permeated the rearrangement of these, especially when performing the care of the child at home, even having received the preparation of the health team of the NICU: *It was different, so there [NICU] I knew everything, here [home] it seems that I knew nothing, I did not know how to handle, or how to give the bath, I was already shaking at the base. ...we have that feeling of losing, and anything is not, because he is very fragile we are afraid (MF3). In the first days it is very difficult, I did not even know what to do, I wanted to help, but I did not know how, because they gave us instructions on how to do not let him choke, but you have the fear, you have to stay close, looking all the time, you do not want to leave the vicinity. In fact, it was quite difficult! (SF1).*

Although the participants receive guidance from the health team of the neonatal unit regarding the care of preterm infants at home, the performance of family health teams, especially nurses, during home visits was not mentioned by the family members. In this sense, the family remains in constant vigilance and afraid that some complication or intercurrent may occur at home due to the premature condition, above all, the difficulty in interpreting the signs/demands of the child and in adapting to the new scenario of care, in which they are fully responsible for the care of the child's needs: *I kept looking all the time to see if she was breathing (MF6). Any noise, I would look. I keep an eye on him, I'm scared to death of him choking, when he sleeps and makes a noise I wake up immediately (MF2). When he sleeps I get very ... I can't relax,*

right, I wonder if he is breathing, if he is well, because inside the UCIN-Co (Conventional Intermediate Care Unit) he was monitored in those apparatuses there, isn't it (MF3).

Despite the central role of mothers and female figures in the responsibility for the care of the newborn, as occurs in relation to grandmothers and daughters, it should be noted that, in many moments, such care was also shared with the father who played the most present paternal role in this period, participating directly in the care of the child and offering support to the mother, especially in the involvement of domestic chores: *When she went home I would also give her a bath even though she was little, sometimes I was afraid and since my wife does not give the bath then I would take it and give her a bath without any problem (FF5). Ah! I always helped her (mother) to clean, take care, stay with him and everything, help to give him medicine (FF2). I arrived here [home] around four o'clock in the morning, then I said, give her to me and I will stay with her and then you can sleep, then I stayed with her, then we both stayed here in the living room until six, seven o'clock in the morning watching her, then she [wife] would wake up and say, now go to sleep and I will take care of her, the night sleep here was kind of alternated (FF1).*

Recognizing the specific care needs of the prematurely born infant

The care with the hygiene of the newborn and the environment reinforce the idea that family members have about the fragility of these children in the first months of life, especially regarding the immaturity of the immune system. Initially, the restriction of visits to the child and his stay in the room were precautions taken by parents as preventive measures to minimize the risk of infections, in addition to reproducing at home cleaning and disinfection practices as those performed at the NICU, such as the use of alcohol gel by caregivers, as highlighted in the following statements: *My mother didn't like visits like that, because she (pre-term sister) had a little problem of immunity isn't it, ...my mother was also that psycho like that about cleaning isn't it, she put alcohol gel on everything, so you had to go in there (room) and you had to pass gel even on the foot, on the hand on everything (SF1). So we don't let*

people get it, we had to be careful not to enter the room and not to get it, because she was very small, very young, so we were afraid of infection, of any kind of thing and... If we got home, we took a bath, didn't we, we sanitized well and rubbed alcohol gel on our hands to be able to pick her up (MF5).

The use of medications was described as another care directed to PTNB after discharge. However, the family, despite understanding its importance, has little information about the administration of drugs. When questioned about how this care was performed, emphasis was given only to the routine of not missing and/or offering the medication to the child at the same time: *It was careful with her medications, she couldn't be without (MF1). To give medicine, you don't put it there, you put it here in the corner of the mouth and squeeze that it will go down (GFm3). No, no, then my mother gave it in the syringe, but it was noripurum which was all prescribed there (NICU) (SF1).*

Regarding breastfeeding care, a routine is established with defined schedules in order to prevent preterm babies from losing weight. Furthermore, the mothers' effort to maintain breastfeeding is noticeable through the recognition of its importance for the PTNB: *Ah! the care with him is much more strict, isn't it? The correct feedings every 3 hours... I talk about breastfeeding, which is important for premature babies (MF3). The baby gains weight exactly when he sleeps, when he rests, so he needs all the rest possible, because even his handling could lose an ounce or two and so, every loss for him was bad... so we always took him, bathed him quickly, changed him, breastfed him and put him back in his crib, so he could rest (FF5).*

Care in the face of complications and sequels resulting from prematurity

In the case of children with sequelae or complications resulting from prematurity, the complexity of the family's care increases, to meet their health needs as well as the demand for specialized services and urgency and emergency services.

Families experience moments of anguish when faced with the diagnosis of a sequel resulting from premature birth, besides experiencing moments of denial and difficulty in accepting the child's condition

that culminate in constant access to health services, in order to seek confirmation of the diagnosis or even the resolution of the child's health problem: *Only that he had a little problem that is the hearing problem, I don't know if he hears or not, in the first test he didn't pass and in the second one he didn't, the doctor said that this is one of the sequelae isn't it, that the child really stays. So, this was the most painful sequel for me, to know that my son might not hear. But I will run after him, while there is a solution for him, while he is small (MF3). When we left with this diagnosis, we decided to look for several other doctors, because when you talk about hydrocephalus when you are pregnant and this report would have to be seen during my pregnancy. We went to three neurologists and all three said that she had hydrocephalus and that she had to be followed up and so on (MF1).*

In these cases, the demand for care increases, sometimes requiring appropriation of knowledge by the family and skills to provide specific care, with a view to offering conditions that favor the child's adequate growth and development: *The physiotherapist oriented us to place her, help her to want to walk, like holding her and supporting her little legs. She said to squeeze a ball in her hand, these things like that, to help her development (MF1). She [the physical therapist] oriented her that we have to help her to crawl, because this is the first step that she needs, she doesn't need to walk now, she needs to move her body to crawl. So, but then, that's how she explained it to me (GF1).*

Sometimes, the sequelae are perceived by the family as the child grows and is compared to others born at term. It is also at this moment that the delay in growth and development is identified by the family according to the following narrative: *The development of her throat is not the same as the other children that when they reach their six months can already feed normally, she chokes, and then she gives a lot of reflux, because she stays a long time with her head down, now that she is learning to stay with her neck more upright to be able to feed (MF1).*

Another situation that permeates the daily lives of families are the health complications presented by the child after discharge. It was observed in this study that all the families interviewed faced difficulties in the management of the child's gastroesophageal reflux which, in some cases, led to the search for ur-

gency and emergency services: *Look, there was a moment that I thought was very difficult, it was a day that he choked on milk, then it came out through his nose, and there was that desperation, in these moments then who helped was my husband (MF3). One day he choked and his father had to suck his nose and mouth, because it was an emergency thing, that he didn't even know how it worked (GF3). On this day he kind of vomited, it even came out of his mouth, but then it came back, then he became purple and soft, I got scared, I turned him around and saw that he was not reacting and became very purple, then I called the Mobile Emergency Care Service (SAMU) (MF2).*

It is evident through the speeches the protagonism of the family in the care of children born preterm trying to meet their health needs seeking care in the health care network. However, it is observed that the nurse of the family health strategy was not mentioned, thus showing little action and a fragile bond between these family members and the gateway to health services.

Discussion

In this study, the support network built for the care of PTNB discharged from the neonatal unit occurred after the first days of their arrival at home. Initially, care was assumed entirely by the parents, and later began to be shared among other family members. Studies highlight that nuclear family members such as the father and siblings, and extended family members such as uncles and grandparents are important support network and constitute the main support for the child's care^(3,8).

Social support is an important factor in the adaptation⁽⁹⁾ of parents caring for preterm infants at home. One aspect that may increase the need for support is the fact that newborns have a different sleep pattern than full-term babies. They tend to sleep later and with less total sleep time per night, a factor that may be related to increased maternal stress⁽¹⁰⁾, making the support network even more important in neonate care after NICU discharge.

Considering the complexity of the birth of a PTNB, which involves hospitalization and dischar-

ge from the neonatal unit, a process begins in which the family experiences different emotional reactions, making it necessary to adapt to new demands in their daily routine, which imposes changes in the organization and family dynamics, especially at home⁽¹¹⁾. Feelings of fear and insecurity are common among family members, and the concern with the illness or loss of the child is present in their daily lives⁽¹²⁻¹⁴⁾, making them more attentive to the needs of their children.

The maternal care of the preterm newborn at home reveals that the inefficiency in the process of preparation for discharge may be responsible for feelings of insecurity and fear expressed by the family during this care, however, as the mother receives consistent guidance throughout the child's hospitalization, the process of transition and adaptation to the realization of care at home becomes smoother⁽⁹⁾. The preparation of the family for care should begin during the stay at the NICU and continue after discharge through interventions that will be part of the support network as well as to monitor the family and identify their needs throughout the first years of life of the PTNB.

Parents of PTNB in the first year of life reported greater safety when they received home visits from health professionals and had their doubts answered and offered tips and appropriate advice on activities to, for example, strengthen the baby's motor development. Thus, it is evident that the health team's support must go beyond the hospitalization period⁽¹⁵⁾.

The care of PTNB at home involves several particularities arising from prematurity itself and specific needs of the neonate, and the understanding of family members to consider it fragile and susceptible to complications reflects the way the family provides care at home⁽¹⁶⁾. The father's participation in care shows not only a support to the mothers' experience, but also their involvement in the care of their children. The father also has his load of expectations and stress due to the excess of care that the preterm child may require, they also become vigilant and undergo stress in the interaction with the child, and may present symptoms of depression⁽¹⁷⁾.

The nurse is seen as an educator, whether in the hospital environment or in primary care, and has the potential to become a social support as he promotes integral and resolute care^(11,18-20). However, it was possible to verify in this study that the experience of family members of preterm infants in the care after discharge from the NICU was solitary, remaining evident the protagonism of the family in this care and the absence at various times of health professionals such as nurses, for example. This fact was also identified in other studies, in which parents reported that, without the support of the healthcare team, a feeling of emptiness is produced in the family, which can generate internal conflict and overload during their adaptation to life at home⁽²¹⁻²²⁾.

These professionals are responsible for identifying the needs and vulnerabilities generated by the process of change in the family's daily life with the arrival of the preterm infant at home. Thus, the support of health professionals should begin at the time of admission of the newborn in the neonatal unit, intensifying at discharge and continuing with the Family Health Strategy team, aiming to guide the puerperal woman and make her safer for care, in addition to stimulating the construction of an affective and empathetic support network, valuing the good behaviors and offering help when necessary^(11,20).

Such guidance is still crucial and necessary to ensure continuity of care. In addition to consultations, it is essential that the professionals of the Family Health Strategy seek, through home visits, to contemplate the real needs of the family and cover the care needs of PTNB and identify the parents' ability to meet them, since these children demand greater attention due to their premature condition^(3,16).

Home visits by the Family Health Strategy team are configured as an important tool to provide knowledge and guidance, especially for the parents of prematurely born children. In addition, they can contribute to the family adaptation to the demands of this baby, constituting a source of support for the develop-

ment of care to the newborn and also reducing the occurrence of readmissions⁽²⁰⁾.

To meet the child's needs, the family reproduces the care learned during the period of hospitalization in the neonatal unit. This aspect can be seen through the concern expressed by family members regarding the maturity of the immune system, restriction of visits, search for urgency and emergency services in interurrences, in addition to specialized services to confirm diagnoses of situations and/or diseases as a result of prematurity. Throughout the PTNB hospitalization, parents enunciate different learning needs; however, approaching the NICU discharge, they continue to have doubts about the clinical conditions, feeding and treatment, although the focus has changed to include the interpretation of the baby's symptoms and the management of medical care at home⁽²³⁾. Therefore, based on the knowledge of parents' experiences and needs, the NICU staff should make efforts to prepare them to care for their child according to these needs and thus reduce stress and worries at home.

Regarding complications resulting from prematurity, families experience uncertainty as to the diagnosis, which leads to a greater demand for health services, which is configured as a way to solve the parents' doubts and also to receive guidance. These findings corroborate a study that observed a constant search of families for answers to the complications and sequelae of preterm infants⁽¹³⁾. In this sense, teaching parents about the clinical condition of their preterm child may help them to accept the difficulties resulting from prematurity, when these are identified during the process of growth and development.

A systematized plan to prepare for the discharge of PTNBs from the neonatal unit is configured as an essential strategy to promote safe care after discharge, such as: parental skills for basic or specialized care of the baby; the reality of the home environment; parental notions about the development of the preterm child; knowledge of warning signs; instructions on emergency procedures (especially in case of broncho-

aspiration); family support networks; and access to health services⁽²³⁾. In this sense, educational programs for preterm discharge should be used as a means to ensure best practices and to help guide mothers regarding adequate care after birth and at home. It is up to the family to make the decision about the child's needs, and this process encompasses their experiences and their interaction with the health services that influence the importance that the family attributes to the search for care after discharge⁽¹⁶⁾.

However, it is essential that preterm newborns be accompanied by the health team after discharge from the neonatal unit. The articulation between the neonatal unit and Primary Health Care should be initiated even during hospitalization, in order to know the clinical conditions of the newborn and ensure continuity of care after discharge from the neonatal unit⁽¹⁹⁾.

Study limitations

These are related to the joint analysis of the experiences of families with preterm infants of different gestational ages that had or not permanent complications. These situations may have generated very different care demands and experiences, being necessary to explore this reality in future studies. Furthermore, the study was limited to data collection with preterm families leaving a single hospital service, thus, research in other services is suggested for a more extensive understanding of the phenomenon in different contexts.

Contributions to practice

This study will contribute to the relevance of the nurse who works in neonatal units for the preparation of the family in order to strengthen the family competences to undertake care, so that it can be offered safely and meet the health demands that arise in the daily life at home, in addition to orienting them about the need of monitoring the child after discharge. Furthermore, it reinforces the importance of these

professionals in primary health care to meet the real needs of the preterm infant and the family nucleus in the implementation of care actions at home.

Conclusion

The development of this study allowed an approximation of the reality of family care of the preterm newborn at home as well as knowledge of the experience of families in meeting the different health needs of these children. The participants experienced a reorganization of their daily lives to promote the care of the child after discharge from the neonatal unit, sharing it with other family members, who are the main support to parents in meeting the child's demands.

Family members recognize that the preterm infant requires differentiated care with regard to the restriction of visits, cleaning and disinfection practices, administration of medications and care for the guarantee and maintenance of breastfeeding. Furthermore, it was evidenced that the care of children with sequels or complications resulting from prematurity increases the complexity of care by the family.

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Authors' contribution

Conception or design of the study and interpretation of study data: Silva EFL.

Relevant critical review of the intellectual content: Silva RA, Mufato LF, Viera CS.

Writing of the article and responsible for all aspects of the study, ensuring issues of accuracy or completeness of any part of the study: Bernardino FBS.

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