



## Care of preterm newborns after hospital discharge: investigation of family demands

### *Cuidados com o recém-nascido prematuro após a alta hospitalar: investigação das demandas familiares*

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#### ABSTRACT

This study aimed to investigate the knowledge and demands of family members regarding the care of the preterm newborn after hospital discharge. This is a study with a qualitative methodological approach. Open interviews were conducted with family members of preterm newborns who had been discharged from the NICU of a philanthropic hospital in the southeastern region of Paraná State. The interviews were recorded and then transcribed verbatim and, subsequently, analyzed according to the thematic content analysis. This analysis showed four themes that were raised by family members: feeding, hygiene, feelings and health. There is a need to expand the scientific knowledge of family members, for their empowerment in the care of preterm newborns, using health education instruments.

**Keywords:** Family. Infant, premature. Patient discharge.

#### RESUMO

O objetivo deste trabalho foi analisar o conhecimento e as demandas dos familiares em relação aos cuidados com o recém-nascido prematuro após a alta hospitalar. Trata-se de um estudo de abordagem metodológica qualitativa. Foram realizadas entrevistas abertas com familiares de recém-nascidos prematuros egressos da UTIN de um hospital filantrópico da região sudeste do Estado do Paraná. Elas foram gravadas, transcritas de forma literal e, posteriormente, avaliadas segundo a análise temática de conteúdo. Evidenciaram-se quatro temas levantados pelos familiares: alimentação, higiene, sentimentos e saúde. Verificou-se a necessidade de ampliar o conhecimento científico dos familiares com vistas ao seu empoderamento no cuidado ao recém-nascido prematuro, utilizando-se de instrumentos de educação em saúde.

**Palavras-chave:** Alta do paciente. Família. Recém-nascido prematuro.

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## INTRODUCTION

A baby born alive before 37 weeks of gestational age is considered preterm<sup>1</sup>. The rate of preterm births in Brazil and in the world has been increasing over time: each year there are about 15 million, which is equivalent to more than one preterm birth for every ten babies born alive.

The birth of a preterm baby is a surprise and cause for concern for family members. Often the long-awaited baby cannot be taken home and needs to be admitted to a Neonatal Intensive Care Unit (NICU), where he/she will receive specialized care 24 hours a day. The long period of hospitalization ends up making it difficult to establish the mother-baby bond, resulting in a feeling of insecurity in the mother about the ability to care for her newborn (NB) and feeding the belief that health professionals are those in fact able to do so<sup>2</sup>.

When a preterm infant is born, preterm parents are also born, who are often not yet prepared for the baby's arrival. The newborn desired and idealized by family members ends up being different from the real, fragile baby, who needs special care, and this generates feelings of frustration, guilt and anguish<sup>3</sup>.

A NICU, with all the technological apparatus and with characteristic noises, can represent a frightening place and make mothers and family members of the preterm newborn afraid about his/her real chances of survival<sup>4</sup>. In this moment of doubt and anguish, the support of the multidisciplinary team working in the Neonatal Unit is essential, as these professionals have the possibility to make this hostile environment a little more welcoming, offering emotional and informational support to family members<sup>5</sup>.

During the hospitalization period, the development of skills of family members for the management of premature newborns should occur, with a view to greater empowerment of the family in relation to home care<sup>6</sup>. It is very important that parents and family members are prepared to care for the newborn at this time, as it can reduce anxiety and increase the family's self-confidence in caring for the newborn after hospital discharge<sup>7</sup>.

Hospital discharge is a moment long awaited by family members and surrounded by great joy; however, it is also permeated by anxiety and the fear that something will happen to the baby away from the specialized care offered at the hospital. In the home environment, the preterm baby will demand differentiated care, specific to the needs of a risky newborn<sup>8</sup>. Considering that, from the moment of discharge, parents and family members are responsible for the care of the preterm newborn, which until then was carried out by a specialized team, the study aimed to analyze the knowledge and demands of family members in relation to preterm newborn care in this new phase.

## METHODOLOGY

This is a qualitative study and follows the criteria of the Consolidated Criteria for Reporting Qualitative Research (COREQ)<sup>9</sup>. "The qualitative method applies to the study of history, relationships, representations, beliefs, perceptions and opinions, products of the interpretations that humans make about how they live"<sup>10:57</sup>.

Interviews were conducted with family members of preterm newborns who were discharged from the NICU of a philanthropic hospital in the southeastern region of the state of Paraná in December 2017 to identify what information these users would like to receive about the health of the preterm. Data were collected at the Intermunicipal Health Partnership, where newborns at risk are monitored from hospital discharge to approximately one year of age.

Participants in the present study were the parents and family members who attended the follow-up care of their preterm newborn at the High-Risk Outpatient Clinic of the Intermunicipal Health Partnership. The number of respondents was defined by the criterion of response saturation, when the interviews were closed. Interviews were open, conducted by the main author and by the undergraduate students of the Speech Therapy Program, based on the following guiding question: "Now that you and your family are responsible for baby care, we are interested to know: what are your main fears and doubts about taking care of the baby at home after hospital discharge?"

Inclusion criteria of the participants were: having a preterm newborn (gestational age less than 37 weeks), having remained in the Neonatal Intensive Care Unit and without associated congenital or perinatal pathologies.

Interviews were recorded and then verbatim transcribed. For the investigation, the content analysis technique was used, in the thematic analysis modality, which “consists of discovering the *nuclei of meaning* that make up a communication, whose *presence* or *frequency* means something for the analytical object targeted”<sup>10: 316</sup>. It is carried out in three main stages: pre-analysis, material exploration and inferences/interpretations<sup>11</sup>.

For this research, all participants read and signed the Informed Consent Form (ICF). In order to guarantee their anonymity, families were identified using fruit tree names. The choice for this nomination was made with the intention of poetically putting families as the trees that bear the fruits, which are the newborns. This study was approved by the Research Ethics Committee of UNICENTRO under opinion 2.409.240, CAAE 79390617.0.0000.0106.

## RESULTS

For this study, a pilot interview was initially carried out with the family of a preterm baby to check the effectiveness of the open question proposed in providing the provision of information relevant to the study. Having reached the objective, interviews were conducted with family members (mothers, fathers, grandparents and aunts) of another 25 babies, totaling 29 participants. The interviews lasted a maximum of ten minutes. Preterm babies, whose families took part in the research, are characterized in Box 1 below.

**Box 1.** Characterization of preterm babies, whose family members participated in the study

Characterization of preterm babies		
Sex	Boy	Girl
		n = 15
Gestational age	Minimum	Maximum
	29.6 weeks	36.4 weeks
Birth weight	Minimum	Maximum
	755 g	3.100 g
Type of delivery	Normal	Cesarean
	n = 13	n = 13
NICU length of stay	Minimum	Maximum
	2 days	89 days
Infant's age on the day of the interview	Minimum	Maximum
	10 days	371 days

Source: prepared by the authors.

After a detailed content analysis, four main themes were revealed - feeding, hygiene, feelings and health -, within which subthemes were also identified. All will be described below.

## FEEDING

This theme was the one that generated more doubts, divided into three sub-themes: breastfeeding, complementation and food introduction. Breastfeeding was mentioned repeatedly, mainly in relation to the use of medication to increase milk production, the fear that the infant will choke during breastfeeding or lose weight. Regarding the complementation, the questions that most frequently arose were the use or not of complement and the adaptation of the baby to the change of milk.

As the interviews were carried out with families of older infants (over six months), doubts also arose regarding the food introduction, raising questions about what foods and drinks can be offered to the infant.

Box 2 presents the complete list of questions on the topic “feeding”.

**Box 2.** Questions raised by family members of preterm babies about “feeding”. CIS - Irati, 2017

Feeding	
Breastfeeding	What is the correct attachment to the breast?
	Should I use the silicone nipple shield? How to use it?
	What is the ideal feeding time?
	I am suffering to attach my baby to the breast ... What to do?
	Should I switch breasts at each feeding time?
	I think my milk is not enough to my baby...
	My baby has difficulty breastfeeding ... What to do?
	What is the best breastfeed position?
	Should I use medication to increase milk production?
	What to do when the baby wake very frequently at night to breast-feed?
	My baby sucks more times a day and in less quantity ... Is this normal?
	My baby sucks too much! Is this normal?
	How to wean my baby?
	My baby dropped the breast for the bottle...and now?
	I have a breast infection...What to do?
My nipple is cracked...What to do?	
I am very afraid that my baby will drown...	
My baby vomits too much... What to do?	
I am very afraid that my baby will lose weight ...	
My baby doesn't burp ... Is this normal?	
Supplementing	Should I use complementary feeding?
	My baby has lactose intolerance! And now?
	Should I bottle feed?
	My baby doesn't want a bottle at all ... Now what?
Food introduction	The change of milk can be bad for the baby? How to make the transition from one milk to another?
	What foods can I give my baby? Can I offer tea?

Source: prepared by the authors.

**HYGIENE**

This theme resulted in two sub-themes: diaper change, which raised the fear of hurting the infant during the change as the most cited question; and bath time, which addressed the fear of hurting the newborn because he/she was very “small” and could escape through the hands. Box 3 lists the questions presented by the interviewees on the topic of “hygiene”.

**Box 3.** Questions raised by family members of preterm babies about “hygiene”. CIS - Irati, 2017

Hygiene	
Diaper change	I'm afraid of hurting my baby when changing diapers...
	When is the best time to change a diaper: before or after breastfeeding?
Bath time	I am afraid to bathe my baby, afraid that he/she is limp, tiny, afraid that he/she will escape through the hands.
	What is the ideal baby bath time?
	What is the ideal temperature for the baby's bath? Can I put tea in the baby's bath water?

Source: prepared by the authors.

**FEELINGS**

The theme related to feelings resulted in five questions, the most cited of which was the fear of picking up the baby for being too “small”. Although little mentioned, other questions highlight important issues, such as guilt and hope.

Box 4 shows the complete list of questions on the topic “feelings”.

**Box 4.** Questions raised by family members of preterm babies about “feelings”. CIS - Irati, 2017

Feelings
Is it my fault that the baby was born prematurely?
I'm afraid to pick up my baby ...
Hope that everything will be fine ...
I must remain calm...
I'm afraid of hurting my baby, of not knowing how to take care of him/her...

Source: Prepared by the authors.

**HEALTH**

(Conclusion)

This theme presented the largest number of inquiries, resulting in four sub-themes. The sleep sub-theme brought up as the most cited question the position of the neonate in the cradle. The immunity subtheme raised several questions, and the most cited referred to the low resistance of the preterm infant and the risk of infections, in addition to doubts regarding the visits received by the newborn.

The body temperature subtopic addressed doubts regarding the difficulty in maintaining the ideal temperature for the preterm infant's comfort and thermal stability. The last sub-theme related to health, generated by the interviews, was related to the baby's clinical condition, bringing half of the questions on this topic. The most reported questions were regarding the size of the newborn and colic.

Box 5 lists all the questions about the "health" theme.

**Box 5.** Questions raised by family members of preterm babies about "health". CIS - Irati, 2017

(To be continued)

Health	
Sleep	I'm afraid to leave the baby alone in the crib... What is the best position to leave the baby in the crib? My baby sleeps little... What to do? My baby changes the night for the day... What to do? My baby only sleeps with the light on ... What to do?
Immunity	I'm afraid my baby will get sick... Does my baby have low immunity? Can he/she get an infection? When will I be able to go out with my baby on the street, in the wind? Can I receive visits? What care should I take? Should I use alcohol on my hands every time I touch the baby? Will my baby get more flu than term babies? Should I overprotect my baby?

Body temperature	I don't know how much clothes I should dress my baby... My baby can't be cold, right? Should I use many blankets? I can't overheat my baby, can I?
Clinical condition	I'm afraid my baby will run out of air... My baby cries a lot... What now? My baby is so tiny!!!! My baby has colic...What to do? What is the ideal time for the preterm baby's belly button to dry and fall off? My baby's belly button is popped out!!! And now? What are the risks of prematurity? My baby pees a lot...Is this normal? My baby has reflux...Now what? How should my baby's poop's consistency be? What vaccine reactions are expected? What to do when they happen? My baby cries more quietly...Is this normal? What to expect from my baby's motor and cognitive development? Should I raise my baby like a normal, full-term baby?

Source: Prepared by the authors.

**DISCUSSION**

Parents of preterm newborns frequently have many doubts, even on apparently simple matters such as breastfeeding and bathing. Several times they are not remedied within the NICU, either because of the family members' shame in questioning the professionals, or because of the level of stress these families are under and that leads them to not think about anything other than the newborn's survival. There are also fears (such as the baby choking) and expectations (in relation to his/her development) that affect everyone involved in caring for the infant<sup>12</sup>.

Preterm newborns, due to their immaturity and harmful sensory stimuli experienced in the NICU (such as intubation, aspiration of the upper airways, use of feeding tubes, etc.), have some dietary difficulties, such as choking and food aspiration risk<sup>13</sup>. For this reason, the fear shown by parents that their NB will drown is fully understandable, which is why all families should receive guidance and be prepared to perform first aid if this occurs.

The physiological (natural) weight loss for a term NB is 10% in the first seven to ten days of life, recovering it around the 15th day. "The expected weight gain for a baby on exclusive breastfeeding is 18 to 30 grams per day and at the end of the first month it should be greater than 500g"<sup>14,91</sup>. It is worth mentioning that weight gain in babies on exclusive breastfeeding should be calculated individually, since it depends on birth weight and varies from baby to baby.

Preterm newborns show different growth dynamics in the first months of life. Initially, there is a period of weight loss, which will be inversely proportional to gestational age and birth weight and directly proportional to nutritional restriction and the duration of complications in this phase<sup>15</sup>.

In this study, a major concern of the family members was exactly about the baby's weight loss, which is corroborated by another study with mothers of preterm babies<sup>16</sup>. The authors refer that, even in preparation for hospital discharge, mothers were often anxious about weight gain, as it is a crucial factor for the discharge of newborns.

As for the family members participating in this study, the mothers interviewed in another study<sup>17</sup> questioned whether their milk would be enough to satisfy the infants. They reported knowing about the importance of breast milk, but believed that newborns would be more satisfied if they received the milk formula as a complement.

In a 2013 study, it was found that family members and health professionals have different concepts of "caring". According to the authors, "for mothers, caring is related to the feeling of affection, while professionals relate care to the execution of technical procedures, meeting the child's physiological needs [...]"<sup>18:835</sup>.

As stated in another study, "the care for the preterm newborn is different from the others, being essential that the mother learns this new way of caring"<sup>19:68</sup>. When thinking about care for the newborn, one of the first concerns is in relation to hygiene. For family members of preterm infants, something as simple as bathing can become quite difficult and frightening. In a 2013 survey<sup>20</sup>, 36.7% interviewed mothers reported having difficulty in taking care of their children, and the most frequent one was related to bathing.

In order to minimize the parents' fear regarding the newborn's hygiene, especially when bathing, it will be interesting to use health education strategies that can guide them on how to properly hold the newborn and how to prepare the environment for these occasions. For example, the bath must be in a place without drafts, neutral soap should be used, dry the child with a soft towel and avoid using oils, talc and perfumes<sup>21</sup>.

When a preterm baby is born, preterm parents are also born, who are not prepared for the arrival of the newborn in these conditions. Expectations and plans of family members do not materialize as expected, feeling frustrated and vulnerable<sup>22</sup>. With the unexpected interruption of pregnancy, there is a transition marked by the mourning of the imaginary baby (the one imagined in the dreams and wishes of the parents) and adaptation to the real baby<sup>23</sup>.

In another study<sup>24</sup>, mothers of preterm babies report that they associate their children with a fragile child, susceptible to complications due to their size, which was also listed as a concern of the relatives herein. The perception of the newborn's small size and the fear of not knowing how to care for him/her or even hurting him/her were sometimes mentioned.

Family members participating in another study<sup>25</sup> said that they felt insecure about taking their children home, as they believed that they lacked the knowledge and skills necessary to care for their premature child at home. This insecurity may be related to the fact that, during the period in which the preterm NB is hospitalized, maternal care is mediated by the multidisciplinary team of the NICU, which de-

cides when and how such care can be experienced in the mother-baby binomial<sup>26</sup>.

Guilt is a feeling that appears with some frequency in family members of preterm babies, especially among mothers. They suffer when they see their children in need of ventilatory and nutritional support, staying in an incubator and under so many painful procedures and they wonder if anything they may have done anticipated the baby's birth, who now has to fight for their own survival<sup>27</sup>.

Some family members brought as an important question what would be the best position for the NB to sleep in the crib, an aspect also present in another study<sup>28</sup> in which, in a conversation circle, the participants did not reach a consensus in this regard. This was because they observed the neonate was positioned in all decubitus positions in the NICU, but at home the orientation was that he/she should be kept in the supine position with the head elevated.

In a 2013 study<sup>24</sup>, mothers reported feeling apprehensive about the greater probability that their preterm baby would suffer serious illnesses when compared to a full-term child. Family members interviewed in this study also raised this concern with the health of their infants when questioning whether they would be more predisposed to catching an infection or becoming sicker compared to a full-term newborn (FTNB).

Another aspect reported by family members was related to the exposure of the preterm baby to home visits and hand hygiene. In this 2016 survey<sup>29</sup>, the interviewed parents also raised this issue. As an action to prevent rehospitalization, they highlighted the restriction of the child's contact with people other than the parents, the non-exposure to cold, not letting them have contact with the floor and the adoption of strict hygiene habits.

In this study focused on the father's experience at hospital discharge for the premature infant, the authors refer that the small size of the newborn and its fragility "lead parents to be very afraid to touch and carry the child, as well as to transmit infection to them"<sup>29: 225</sup>.

However, despite all the initial fears and difficulties in caring for preterm NBs, several mothers interviewed in a 2017 study<sup>16</sup> reported that they understand that the premature baby, already recovered from the NICU, would be cared for like any other infant, as also mentioned by one of the families interviewed in this research.

## CONCLUSION

Many of the doubts and questions raised by the participants in this study are similar to data found in the literature. The themes that emerged among family members - feeding, hygiene, feelings and health - involve both an emotional issue and the practice of caring for the baby, and apparently simple tasks become delicate obstacles in the routine of caregivers of preterm babies.

For the transition from hospital to home to occur in a more natural and safe way, in a context of continuity, it is necessary to expand the scientific knowledge of family members, for their empowerment in the care of preterm newborns, using health education instruments. That way, they can feel more secure in this task.

One of the limitations of this study is that the data collected comes from a regional survey, carried out with a small number of family members of preterm newborns who were admitted to the same hospital in the southeastern region of the state of Paraná. For more comprehensive and reliable information about the doubts of family members in the care of preterm newborns after hospital discharge, it will be interesting to replicate this research in other regions of the state and, also, in the country.

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