

**GUIDELINES FOR NEONATAL HOSPITAL DISCHARGE IN A REFERRAL
HOSPITAL: PARENTS' PERCEPTIONS****ORIENTAÇÕES PARA A ALTA HOSPITALAR NEONATAL EM UM HOSPITAL
DE REFERÊNCIA: PERCEPÇÃO DOS PAIS****DIRECTRICES PARA EL ALTA HOSPITALARIA NEONATAL EN UN HOSPITAL
DE REFERENCIA: PERCEPCIÓN DE LOS PADRES**Danielle Bonotto Cabral Reis¹, Adriana Duarte Rocha²

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ABSTRACT

Objective: To verify how parents understand the guidelines given by the multidisciplinary team at the time of neonatal hospital discharge. **Method:** Qualitative and exploratory study with 25 parents who met the inclusion criteria and who agreed to participate in the study. Semi-structured interviews were used for data collection and Content Analysis according to Bardin was used for data processing. **Results:** Three categories emerged: Communication between the multidisciplinary team and parents during the NB's hospitalization in the NICU; Neonatal hospital discharge: questions, doubts and instructions for the care and Participation of the multidisciplinary team in the periods of hospitalization and discharge: bonding. **Final considerations:** This study verified that there is a need for initiatives that favor a relationship of trust and humanized care between the team, NB and family members, thus seeking to strengthen relationships aimed at comprehensive and global care for this family.

Descriptors: Patient discharge; Parents; Patient care team; Intensive Care Units, Neonatal

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RESUMO

Objetivo: Verificar como os pais compreendem as orientações realizadas pela equipe multidisciplinar no momento da alta hospitalar neonatal. **Método:** Estudo qualitativo e exploratório com 25 pais que obedeceram aos critérios de inclusão e que aceitaram participar do estudo. Para coleta de dados utilizou-se a entrevista semi-estruturada e para tratamento dos dados a Análise de Conteúdo segundo Bardin. **Resultados:** Emergiram três categorias: Comunicação entre a equipe multiprofissional e os pais durante a internação do RN na UTIN; Alta hospitalar neonatal: questionamentos, dúvidas e instruções para o cuidado e a Participação da equipe multiprofissional nos períodos de internação e alta: criação de vínculo. **Considerações finais:** Este estudo verificou que é necessário que haja iniciativas que favoreçam uma relação de confiança e cuidado humanizado entre equipe, RN e familiares buscando com isso o estreitamento de relações visando um cuidado integral e global para esta família.

Descritores: Alta do paciente; Pais; Equipe de assistência ao paciente; Unidades de Terapia Intensiva Neonatal

RESUMEN

Objetivo: Verificar cómo los padres entienden las pautas dadas por el equipo multidisciplinario al momento del alta hospitalaria neonatal. **Método:** Estudio cualitativo y exploratorio con 25 padres que cumplieron con los criterios de inclusión y que aceptaron participar en el estudio. Para la recolección de datos se utilizaron entrevistas semiestructuradas y para el procesamiento de datos se utilizó el Análisis de Contenido según Bardin. **Resultados:** Emergieron tres categorías: Comunicación entre el equipo multidisciplinario y los padres durante la internación del RN en la UCIN; Alta hospitalaria neonatal: preguntas, dudas e instrucciones para la atención y Participación del equipo multidisciplinario en los períodos de hospitalización y alta: vinculación. **Consideraciones finales:** Este estudio constató que existe la necesidad de iniciativas que favorezcan una relación de confianza y cuidado humanizado entre el equipo, el RN y los familiares, buscando así fortalecer las relaciones orientadas al cuidado integral y global de esta familia.

Descritores: Alta del paciente; Padres; Grupo de atención al paciente; Unidades de Cuidado Intensivo Neonatal

INTRODUCTION

Neonatal care in Brazil has shown significant advances in technological development, corresponding, in a certain way, to a global trend. The improvement in intensive care offered to newborns (NB) has reduced, in particular, the mortality of at-risk or preterm newborns.¹⁻²

Despite technological advances, it is often observed that the separation of the newborn from its mother and family and the long period of hospitalization can generate

some negative repercussions, such as: reduction of family ties and restriction of the development of maternal skills for caring for the newborn.¹⁻²

Studies show that mothers' lack of preparation in dealing with babies who are hospitalized in neonatal units can have repercussions on the baby's home care.³⁻⁴ Many parents report feelings of insecurity, fear and lack of preparation in routine care for their child, such as hygiene and diaper changing.⁴⁻⁵

When the information received by parents during hospitalization, still in the NICU, is not provided in a standardized and systematic way by the health team, this can generate doubts, uncertainties and insecurity, which can have severe repercussions on the care and health of this baby at home.⁵⁻⁶

A study⁷ highlights the need for discharge planning that involves the NICU health team and those responsible for the newborn, with the aim of mitigating family members' doubts and favoring the development of skills and acquisition of knowledge by parents.

Furthermore, the author emphasizes the importance of creating stimulating strategies for welcoming parents, aiming at a safe neonatal hospital discharge, taking into account the clinical conditions of the newborn and the parents' willingness to learn. According to the author, the development of skills and acquisition of knowledge should come from caregivers through stimulating strategies developed by the team.⁷

Therefore, preparation for discharge should begin as early as possible, since the lack of interaction between the family and the newborn can reflect both the lack of cognitive and emotional skills, which are fundamental for maintaining care at home.^{6,8}

In order to meet the needs of the family and enable them to continue to care for the newborn at home, it is necessary to

develop a discharge planning process. The purpose of this process is to develop the parents' skills in caring for the newborn, reduce the family's stress level, avoid readmissions, and identify community resources available for follow-up after hospital discharge.^{1,5,8}

Faced with such a challenge, it is important to rethink care actions, aiming at comprehensive care, with the moment of discharge defining the relationships between the Neonatal Unit (NU) and the other sectors of the hospital or other health services that will be used by the family for the continuity of care for the newborn.^{1,8}

With these precepts in mind, this article aimed to verify how parents understand the guidelines provided by the multidisciplinary team at the time of neonatal hospital discharge.

METHODOLOGY

Descriptive, exploratory study with a qualitative approach, developed in a neonatal unit of a reference hospital for high-risk babies, located in the city of Rio de Janeiro. Since this is a qualitative research, the methodological guide used was *Consolidated criteria for reporting qualitative research*(COREQ).⁹

The study was approved by the institution's Research Ethics Committee

under number 3,098,916 – CAEE 04636818.9.0000.526.

The population consisted of parents who had their children hospitalized in the aforementioned Neonatal Unit and were about to be discharged from hospital between June 2020 and September 2021.

The convenience sample included a total of 25 interviewees who met the inclusion criteria, which were: parents of newborns who were hospitalized in the unit and who were constantly present in the NICU and who agreed to participate in the study.

It is worth mentioning that the sample size was defined according to the theoretical saturation of data, that is, when no new elements are found and the addition of new information is no longer necessary, as it does not alter the understanding of the phenomenon studied.¹⁰

The semi-structured interview technique was used for data collection. It consisted of two parts: the first with socioeconomic data of the parents (age, marital status, number of children and family income), and the second with guiding questions related to the theme, namely: What guidance did you receive during your baby's hospitalization? Which professional(s) participated in this guidance? What guidance did you receive at the time of discharge? Which professional(s) guided you at the time of discharge? Did you

understand all the information provided? If not, which do you still have doubts about?

The instrument for data collection, with the guiding questions, was created by the authors and was previously submitted to a pilot test between September and October 2019. Based on its results, the instrument was adjusted for its final use. It is worth remembering that the data related to the pilot test were not part of the final composition of this study.

Data collection took place between June 2020 and September 2021. It is worth noting that due to the Covid-19 pandemic, the start of data collection had to be postponed until the institution's health protocols were properly implemented.

This happened as follows: first, the researchers identified the babies who would be discharged from hospital during the multidisciplinary round that takes place daily in the unit, and then the parents were approached.

When they agreed to participate in the research, they were directed to an individual room, where they were informed about the research and signed the Free and Informed Consent Form (FICF). From there, the interviews were recorded following the previously structured script with open and closed questions.

The average duration of each interview was 10 minutes, and after they

were transcribed, the recordings were deleted.

After the collection stage, the data relating to the characterization of the population studied were spreadsheeted using the Microsoft Excel® Program, version 2007 and subsequently analyzed according to the variables involved, through descriptive statistics, in simple percentages.

The subjective data were analyzed according to the content analysis according to a study¹¹, seeking to relate the themes or categories that emerged with the literature related to the theme in order to help understand the discourses.

According to a study¹¹, this type of analysis is organized into three stages: pre-analysis – transcription of interviews, transforming speeches into text, floating, exhaustive reading of the material, to respond to the object of the study; categorization and exploration of the material – apprehension of the nuclei of understanding of the text formulated from the transcription of the interviews, searching for significant expressions, to formulate categories and subcategories; interpretation – inferences and interpretations relating the nuclei of meaning with current literature related to the issue studied.

The participants' statements were identified by the letter M, followed by the cardinal number, as was the case in the interviews, in order to guarantee the anonymity of the interviewees.

RESULTS AND DISCUSSION

Interviews were conducted with 25 participants, of which 100% were female. This fact possibly occurred because data collection took place during a pandemic period where, for health reasons, only one guardian was allowed to be present, hence the female predominance (mothers) within the neonatal unit.

Of these, 56% (14) were single and primiparous and 60% (15) reported that they earned between one and two minimum wages per month (which at the time of the interviews was R\$1,212.00 – the value corresponding to the national minimum wage).

Based on the analysis of the material collected in light of Laurence Bardin¹¹, the first registration units (RU) were defined based on the guidelines that parents received during their baby's hospitalization in order to evaluate their appearance in the interviewees' statements and their influence on the results of the present study, as indicated in table 1.

Table 1 - Guidelines most cited by interviewees during their newborn's hospitalization. Rio de Janeiro (RJ), Brazil, 2022.

REGISTRATION UNITS	UR No.	%
Clinical conditions of the newborn	12	29.3
Surgical issues	7	17.1
Breastfeeding/Feeding	6	14.6
General care for newborns (bathing, diaper changing, GTT, TQT)	5	12.2
NICU Operation	4	9.8
Exams/Treatment	4	9.8
Continuous use of masks	1	2.4
Easy touch	1	2.4
Medication administration	1	2.4
TOTAL	41	100

Source: Reis, 2022

*Legend: RN – Newborn; GTT – Gastrostomy; TQT – Tracheostomy; UTIN – Neonatal Intensive Care Unit

In a second stage of the interview, the mothers were asked about the guidance they received when their children were discharged from hospital, as described in Table 2.

Table 2 - Guidelines most cited by interviewees at the time of hospital discharge of newborns. Rio de Janeiro (RJ), Brazil, 2022.

REGISTRATION UNITS	UR No.	%
Bath/Body hygiene	15	23.1
Breastfeeding/Feeding	14	21.5
Return queries	8	12.3
Medication administration	6	9.2
Diaper change	5	7.7
Warning Signs	4	6.2
Vaccines	4	6.2
Use of health devices (GTT, TQT, among others)	3	4.6
Performing and changing dressings	3	4.6
Temperature measurement	1	1.5
Performance of intermittent bladder catheterization	1	1.5
Avoid using cell phone screens, computers, etc.	1	1.5
TOTAL	65	100

Source: Reis, 2022

In tables 3 and 4, we can observe the professional category that carried out the guidance described above, according to the interviewees' responses, according to the time of guidance – hospitalization and/or hospital discharge.

Table 3. Professionals who participated in providing guidance to parents during the newborn's hospitalization in the NICU. Rio de Janeiro (RJ), Brazil, 2022.

REGISTRATION UNITS	UR No.	%
Nurse	26	37.1
Doctor	22	31.4
Speech therapist	5	7.1
Nursing Technician	4	5.7
Psychologist	4	5.7
Social Worker	3	4.3
Occupational Therapist	2	2.8
Physiotherapist	2	2.8
Nutritionist	2	2.8
TOTAL	70	100

Source: Reis, 2022

Table 4. Professionals who participated in providing guidance to parents at the time of discharge of newborns from the NICU. Rio de Janeiro (RJ), Brazil, 2022.

REGISTRATION UNITS	UR No.	%
Doctor	23	37.7
Nurse	19	31.1
Nutritionist	5	8.2
Speech therapist	5	8.2
Social Worker	3	4.9
Psychologist	3	4.9
Nursing Technician	2	3.3
Physiotherapist	1	1.6
TOTAL	61	100

Source: Reis, 2022

According to the content analysis of the interviewees' responses, three categories emerged that represent the axis around which this study was based, namely: Communication between the multidisciplinary team and the parents during the newborn's hospitalization in the NICU; Neonatal hospital discharge: questions, doubts and instructions for care;

Creation of a bond between the parents and the team

Communication between the multidisciplinary team and parents during the newborn's hospitalization in the NICU

When we began the interviews with the mothers, we found that the idea about the clinical conditions of the babies, followed by the prenatal diagnosis, the

surgical issues and the entire emotional burden on the health of their children was still very strong, even after days of their children being hospitalized, as we can see in the following reports.

[...] he said he had hydrocephalus, that he was going to stay (hospitalized) to have the valve inserted, you know? That he was going to stay there until he recovered, until he could breastfeed. (M16)

Look, I was told that he would be hospitalized here in the ICU because of his encephalocele, right, before my pregnancy, no, during my pregnancy, I already knew that he had a malformation in his skull, right, in his head, and that he would need the ICU. And as soon as he was born, he went to the ICU [...]. (M17)

I was told that he would be a baby with an anomaly, I don't know if that's what it's called, right? A very complicated disease that involved several surgical risks or even at birth, that he could die even before the operation. According to the reports on the problem he had and that he wouldn't come to me at birth, he would be intubated straight away so they could do everything they could, but without much expectation on the part of the man, knowing that it depended solely on how he was going to be born. (M20)

In addition to preterm newborns, the NICU is also the gateway for full-term newborns who require hospitalization, such as: malformations, metabolic, respiratory, neurological, surgical and blood incompatibility disorders, among others.¹²

As it is a reference unit for high fetal risk, it is common for babies to be born and admitted to the NICU with some type of alteration, whether physical, metabolic or genetic, forcing these mothers to adapt to another reality, which they had never foreseen, causing a feeling of disillusionment and anguish.

The hospital environment, especially the NICU, has unique characteristics and is full of technologies to support the life of newborns that are unknown to many parents and family members, especially those who are experiencing it for the first time.¹³

For this reason, as a way of mitigating feelings such as uncertainty, insecurity and anxiety that hospitalization itself generates, it is essential that communication between professionals who provide care to newborns and family members must be as clear as possible, with minimal use of technical terms and/or elaborate, as a way of strengthening ties between staff and parents and valuing these family members' ability to understand the clinical conditions of their newborns.¹³

The people here are very clear, very objective, they are always willing to answer any questions and I received all the guidance I needed for any doubts I had. (M6)

Yes, she was going to stay, right, for a while, due to her surgery, which was delicate, she couldn't go home, and you were going to take care of the dressing, everything properly and you were guiding me, so that I could understand. (M10)

Replacing the overload of information that parents receive during their newborn's hospitalization in the NICU is a task that must be reinforced periodically by the multidisciplinary team, prioritizing dialogue instead of verticalized information, generating mutual trust and thus favoring the care of these parents for their children in the home environment.¹⁴

Another fundamental aspect, identified in the interviewees' statements, was the presence of the nurse as the most active professional in welcoming these parents in their first contact with both the NICU environment and their baby, followed by doctors, speech therapists and nursing technicians.

Yes, the doctor was very attentive, explaining to me the care I will have to take with her at home. To observe her closely, each little breath she takes is a problem with her breathing. She gave me everything written down on a piece of paper, what I have to do if she needs anything, it was very good. (M9)

The nurses also gave me a lot of support, they talked to me and explained things to me too, they took good care of her. (M10)

This finding reinforces the importance of the Nurse throughout the hospitalization and discharge process of the newborn in a NICU, since he or she is responsible for the direct and uninterrupted care of the patient in the unit, and therefore clear and effective communication between these professionals and the parents can be favorable for building bonds and strengthening the guidelines given to these family members.⁶

Neonatal hospital discharge: questions, doubts and instructions for care

It is known that neonatal hospital discharge is the most anticipated moment for parents, and this is accompanied by a mix of feelings that range from the excitement of yet another stage completed, through feelings of doubt, anguish and fear of

experiencing a new stage, of parental autonomy, to the relief of taking their child home.^{6,14}

For a safe discharge, it is important that throughout the newborn's stay in the NICU, the transfer of care to their parents is done in an individualized and complete manner.

It was observed that the main guidelines provided to parents at the time of discharge were related to: bathing and body hygiene, feeding, follow-up appointments, administration of medication, changing diapers, warning signs, among others.

So I had training on bathing, on feeding, on guidance on how they should lie down, burp, breastfeed, medications that they might need... with colic, with earache, with any type of pain, I left here with a medical prescription, if there was any need, yeah... I think that was it! (M6)

They also gave me the medications, they taught me how to administer them to her, and... I don't have to be connected to the machine anymore, because now I can focus on the child. (M21)

Empowering parents regarding the care provided during hospitalization and close to discharge can generate numerous benefits for the post-discharge period, such as: reducing parental stress, increasing confidence and skills in care, and increasing the knowledge of caregivers about the baby's health, signs of discomfort and risk.¹⁵

Since I'm a first-time mother... I was told that as soon as I finished breastfeeding, I should place her close to my lap so she doesn't vomit and not to place her face down in the crib so she doesn't end up getting sick and not to leave anything near her (in the crib): pillow, sheets, anything that won't suffocate

her. Wash your hands before breastfeeding, don't use your cell phone too much so you don't pass an infection to the baby. Be very careful! Wash your hands, use alcohol gel... (M11)

I learned how to change her diaper, you know, they taught me that I was very afraid... how to change her diaper, bathe her, everything was taught well. They taught me that I will need to change her bandage at home. They guided me on how to bathe her, change her diaper, breastfeed her too, the girls at the milk bank taught me a lot. And childcare, which I can't miss because it will help her grow. (M10)

Studies suggest the use of an individualized care plan for newborns admitted to the NICU as a way to clarify doubts and facilitate the resolution of possible conflicts between staff and family members, mainly resulting from long hospitalizations, thus creating a lighter and more inclusive path for parents to participate in the care of their babies until hospital discharge.^{4,6}

It is worth noting that guidance given on the day of hospital discharge may generate even more doubts instead of resolving them, in addition to leading to difficulties in understanding and possible errors at home.⁶

Creating a bond between parents and staff

During the prolonged hospitalization that newborns spend in the NICU, the separation of this baby and his/her family is normally observed, which can generate some negative repercussions, such as: reduction of the family bond and restriction of the development of family and maternal

skills for caring for the newborn, thus making the hospital discharge process difficult.^{4,16}

Therefore, the multidisciplinary team must work together to ensure the best possible care for the newborn and their family until the moment of hospital discharge.

Yes, they guided me on how I should act at home, in relation to food, and... if I had any problem I would have to go back to the hospital, and... about milk too, they... the doctor even gave me a document that I could take to the city hall where I live so I could get milk, since there are three of them. And go for follow-up, the milk bank is always very present here, speech therapists have always helped me a lot.

When taking care of them, during hospitalization, right, they always let the mother do it, so the mother can gain experience. Bathing them, they always helped me with that. (M13)

Observing the bond created between the family and the hospitalized newborn is one of the essential aspects for this care network to be formed. The recognition by the health team of the socio-emotional aspects of these family members is one of the ways to provide support for the development of skills and strengthening the performance of the role of parents during hospitalization, thus increasing the family bond.¹

According to this study, we found that the most active professionals at the time of neonatal hospital discharge, contrary to what was observed at the time of reception, are the doctor, followed by nurses, nutritionists and speech therapists. These professionals

are responsible for closing the newborn's hospitalization cycle in the NICU and are often the ones who most approach parents with guidance or information about the baby's health status at the time of hospital discharge.

Mitigating doubts so that discharge can occur safely is another point that must be verified, as it aims to reduce possible wrong behaviors at home, as well as the readmission of these newborns discharged from the NICU.

[...] I was well guided. The only fear now is the day-to-day of dealing with him, but I was well guided by the hospital, everything went well, thank God! (M2)

[...] they were very clear. Also because they are available, if you have any questions, you can ask them and they will answer. So it was very easy! They use language that is easy to understand, so it was very easy! (M6)

I had a little doubt, but she (the doctor) cleared up my doubts, it was in relation to her feeling pain, even though I didn't want to take her (due to the Pandemic), that I should take her to the emergency room... because of that little breathing she has. Avoid crowds, because of this COVID, because she's a baby, right? Take all precautions, and avoid having a lot of people on top of her without a mask, preferably. (M9)

The set of care pertinent to neonatal hospital discharge, the creation of bonds between parents and children and between family and professionals, as well as systematic and individual planning for discharge are fundamental pieces in the health team's care not only for newborns, but also for parents.¹⁵

FINAL CONSIDERATIONS

The present study found that neonatal hospital discharge generates in parents a whirlwind of paradoxical feelings that range from happiness and excitement at their baby leaving that hostile environment, to feelings of insecurity, anxiety and fear about the new stage that is beginning.

To this end, the multidisciplinary team is responsible for guiding this process, which begins with the newborn's admission to the NICU until their actual discharge, mitigating obstacles, especially those related to communication and guidance to parents, which are so important for the effectiveness of this process.

It is therefore necessary to have initiatives that favor a relationship of trust and humanized care between the team, newborns and family members, thereby seeking to strengthen relationships with a view to comprehensive and global care for this family.

Empowering parents to care for their children can be considered a strong point for a safe and effective transfer of care. Reinforcing guidance day after day is also essential to strengthen learning and reduce doubts that may arise during this process.

Encouraging parents to care for their child while they are still in the NICU and early contact between them are ways to ensure conditions for care and the identification of possible warning signs, and

which should be practiced by the multidisciplinary team.

This study aims to contribute to promoting new research on the subject, aiming at planning and constant improvement in the systematic organization of neonatal hospital discharge carried out by the multidisciplinary team.

As a limitation of this study, we can point out that the Covid-19 pandemic contributed to only one of the newborn's guardians, in this case the mothers, being present at the time of discharge, due to the restrictive measures imposed at that time.

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