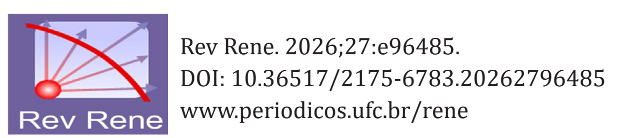
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Original Article

Parental perceptions of care during neonatal intensive care unit hospitalisation

Percepções de pais sobre a assistência durante internação de filhos em unidade de terapia intensiva neonatal

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ABSTRACT
Objective: to explore parents' perceptions of the care provided during their children's hospitalisation in a neonatal intensive care unit. **Methods:** this qualitative study was conducted in a public hospital and included 13 parents whose children required neonatal intensive care. Interview data were analysed using thematic content analysis, while information from medical records was used to characterise the clinical profiles of participants. **Results:** participants reported satisfaction with the humanised care and supportive approach provided by the multiprofessional care team. Dissatisfaction was expressed regarding the presence of other family members, which was considered inappropriate given the vulnerability of the neonates. Parental involvement in care strengthened emotional bonding as well as confidence and a sense of security in handling the infant. Initial feelings of fear and anxiety evolved into hope and gratitude over time. **Conclusion:** care in neonatal intensive care units extends beyond the neonate, encompassing family support and promoting emotional well-being and healthy development. **Contributions to practice:** the findings highlight the need to enhance care practices in neonatal intensive care units by fostering effective communication, providing emotional support, and encouraging parental involvement in care.
Descriptors: Intensive Care Units, Neonatal; Family; User Embracement; Humanization of Assistance; Infant, Newborn.

RESUMO
Objetivo: conhecer as percepções de pais sobre a assistência prestada durante a internação hospitalar de seus filhos em unidade de terapia intensiva neonatal. **Métodos:** estudo qualitativo, realizado em um hospital público, com 13 pais que tiveram filhos submetidos a cuidados intensivos neonatais. Os dados das entrevistas foram submetidos à análise temática de conteúdo, enquanto as informações dos prontuários foram utilizadas para caracterização clínica dos participantes. **Resultados:** os participantes demonstraram satisfação com a assistência humanizada e acolhimento prestados pela equipe. Houve insatisfação quanto à entrada de outros familiares, considerada inadequada devido à vulnerabilidade dos neonatos. A inclusão dos pais no cuidado fortaleceu o vínculo afetivo, a confiança e a segurança no manejo do bebê. Sentimentos iniciais de medo e ansiedade transformaram-se em esperança e gratidão. **Conclusão:** o cuidado em unidades de terapia intensiva extrapola o atendimento ao neonato, abrangendo o acolhimento familiar e promovendo bem-estar emocional e desenvolvimento saudável. **Contribuições para a prática:** evidenciou-se a necessidade de qualificar práticas assistenciais em unidades de terapia intensiva neonatal que promovam comunicação efetiva, acolhimento emocional e participação dos pais no cuidado.
Descritores: Unidades de Terapia Intensiva Neonatal; Família; Acolhimento; Humanização da Assistência; Recém-Nascido.

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Introduction

Every year, around 30 million children worldwide require hospitalisation due to prematurity or pathological complications, and approximately 8-10 million of them require intensive care[1]. Around 300,000-340,000 premature babies are born in Brazil each year, which accounts for approximately 11% of all births[2].

A neonatal intensive care unit provides complex, comprehensive care for critically ill newborns, with a focus on infants from birth to 28 days of life. As a setting designed specifically for specialised care, it is equipped with advanced technology and supported by a qualified multidisciplinary team. The unit aims to deliver the safest and most effective care possible[3]. The main reasons for neonatal admission to intensive care units include preterm birth, low birth weight, and various pathological conditions such as congenital malformations and cardiac diseases, among other diagnoses[4].

Hospitalisation involves providing professional care for both the neonate and their family. This is achieved through open communication, which involves providing information and addressing any concerns about the infant's clinical condition. Such communication is an essential component of care, as it fosters a secure, effective interpersonal relationship between parents and professionals[5].

Throughout the hospital stay in the neonatal intensive care unit, the multidisciplinary team plays a fundamental role in creating a supportive and understanding environment for parents. In addition, the team plans actions aimed at strengthening the bond between parents and their newborns[6]. It is therefore necessary to understand each family considering their social, spiritual, biological, and cultural characteristics in order to plan individualised care[7]. Furthermore, professionals should recognise parents as co-responsible for the care of the newborn, rather than viewing them merely as visitors[8].

However, a prolonged stay in the neonatal intensive care unit may have an adverse effect on the bond between parents and their newborn baby, leading to feelings of fear, concern, anxiety, and insecurity[9]. In this context, high-quality care is essential. Mothers report greater satisfaction when guided by health professionals, and they also feel more confident and capable of caring for their infant. The need for psychological support to help parents cope with this situation and the emotions it provokes is also emphasised[10].

Conversely, negative experiences have been reported by parents who did not participate in their child's hospitalisation process due to invisibility, indifference, and lack of consideration by the multidisciplinary team. This resulted in a lack of knowledge regarding the procedures performed on the newborn and their clinical progression during hospitalisation[11].

Although advances have been made in the humanisation of neonatal care, reinforced by national humanisation policies that promote the inclusion of users and their socio-familial networks in care processes, there remains a need to strengthen welcoming practices and, in particular, communication between professionals and users as well as to value individuals' active role in the production of health[12]. Investigating these gaps will enable the identification of both weaknesses and strengths in care practices, contributing to the improvement of family-centred care strategies. The relevance of this study lies in understanding parents' perceptions of the care received in the neonatal intensive care unit, considering that this experience influences family bonding, emotional well-being, and the care of the newborn after discharge. Therefore, recognising the importance of improving the quality of care provided to newborns, this study aims to explore parents' perceptions of the care provided during their children's hospitalisation in a neonatal intensive care unit.

Methods

Study design and setting

This study represents a subset of a broader umbrella project entitled "Analysis of the Development of

Children Discharged from a Neonatal Intensive Care Unit from the Parents' Perspective." The study adopts a qualitative approach and was conducted and reported in accordance with the Consolidated Criteria for Reporting Qualitative Research. This framework comprises 32 items that guide the reporting of qualitative studies. The checklist was used to ensure transparency and methodological rigour across the stages of study design, data collection, participant characterisation, interview conduct, and description of the analytical process, thereby enhancing the completeness of the information presented in the manuscript[13].

The study was conducted in a public hospital located in the south-west region of the state of Paraná, Brazil. The institution was selected as it is the only neonatal intensive care service in the region, comprising 10 intensive care beds and five intermediate care beds, as well as a multidisciplinary team and technological infrastructure capable of meeting the needs of newborns. The hospital also receives neonates from different regions of the state, with care provided according to individual needs, based on the regulatory system and bed availability, regardless of the risk classification assigned to the pregnant woman during antenatal care.

Inclusion and exclusion criteria

The study included parents of neonates who were born and admitted to the neonatal intensive care unit of the selected institution and who were discharged between 2011 and 2021. Parents who withdrew from the study after initially agreeing to participate were excluded, as were those whose newborns died prior to discharge. This decision was based on the understanding that parental experiences in such cases involve processes of loss and bereavement, constituting a distinct phenomenon from that investigated in this study, which aimed to explore parents' perceptions of care during hospitalisation up to discharge.

Data collection

Initial contact with potential participants was made by psychologists from the institution, using a list of telephone contacts provided by the hospital. Telephone communication was the standard method of contact between the institution and parents for exchanging information regarding the newborn's clinical condition during hospitalisation. Following the provision of the researchers' contact details by the psychologists, parents who wished to obtain further information about the study or participate contacted the research team, who then scheduled a suitable time for the next interaction based on participants' availability and preferences.

Between June and August 2022, data were collected through telephone interviews with parents of children who had been discharged from the neonatal intensive care unit. Additional data were obtained from medical records, including information on the newborn's sex, mode of delivery and reason for admission. These data were used to characterise the clinical and care profiles of the newborns, thereby providing context for the parental experiences reported during hospitalisation.

The interviews followed a guide developed by the research team based on a literature review aimed at identifying key characteristics of neonatal intensive care units in Brazil. Open-ended questions were developed in the form of a questionnaire, including variables related to the newborn and the parents. Additional questions addressed the child's development after discharge, enabling the exploration of parental perceptions of the care received during hospitalisation. No formal pilot testing was conducted due to the exploratory nature of the instrument; however, comprehension of the questions was assessed during the initial interviews, and no modifications were deemed necessary.

Data collected from medical records were com-

plementary to the interviews and served a purely descriptive purpose, contributing to participant characterisation and to understanding the hospitalisation context in which the reported experiences occurred.

The interview instrument was guided by open-ended questions such as: "How do you evaluate the care provided by the neonatal intensive care unit?", "Would you offer any advice to parents whose children require admission to this unit?", and "What experiences would you like to share regarding the neonatal intensive care unit?". Interviews were audio-recorded and lasted approximately 30 min each.

Data collection was concluded based on the criterion of theoretical saturation[13], which was observed after the eleventh interview, when additional accounts only reinforced previously identified meanings and patterns without introducing new conceptual or empirical elements. Two further interviews were conducted to confirm data stability. The indicator of saturation was thematic recurrence, defined as the repetition of expressions, meanings, and perceptions across the analytical categories identified during data exploration[14].

Data analysis

Data were analysed using content analysis without the use of supporting software, following three stages: pre-analysis, exploration of the material, and treatment and interpretation of the results[15]. Each interview was examined individually, sentence by sentence, to segment the data into distinct units and compare them in order to identify similarities and differences, which were then organised into categories. To ensure reliability and consistency in the interpretative process, peer review was conducted during the categorisation stage. The resulting categories were guided by the domains of human development[16].

Ethical considerations

To ensure anonymity, participants were identified by the letter R (for "Respondent"), followed by a numerical code corresponding to the order of the interviews (R1, R2, R3, and so forth). The study was approved by a Research Ethics Committee under protocol no. 5,436,550/2022 and Certificate of Presentation for Ethical Appraisal no. 57796222.9.0000.0109. It complied with the ethical principles outlined in national health regulations. The participating institution authorised the study, and all participants provided informed consent through an online form.

Results

A total of 13 parents (mothers and fathers) participated in the study, representing 16 children (including one case of twins and one case of triplets). Among the newborns, there was a predominance of males (75%) and births by caesarean section (87.5%). The main reasons for admission to the neonatal intensive care unit were prematurity (93.8%) and low birth weight (87.5%). Among the interviewed parents, 62.5% reported that their child did not have chronic conditions. Following hospitalisation, the children continued in multidisciplinary follow-up care, particularly in high-risk paediatrics and physiotherapy.

Based on data analysis and parental perceptions, five categories emerged: i) Satisfaction with multidisciplinary care; ii) Dissatisfaction with care and service organisation; iii) Parental inclusion in neonatal care; iv) Feelings and difficulties experienced in the neonatal intensive care unit; and v) Exchange of experiences and emotional strengthening among parents after discharge from the neonatal intensive care unit.

Satisfaction with multidisciplinary care

This category relates to parents' perceptions of the care provided by healthcare professionals to both newborns and their families during hospitalisation. Interview data revealed a high level of satisfaction with the assistance offered. During procedures, professionals provided explanations regarding the

newborn's diagnosis and clarified parents' doubts, contributing to a sense of support and reassurance. Parents perceived the care as attentive and appropriate. The following excerpts illustrate these findings: *In our ICU, the level of care is very high... gloves, alcohol, masks, and that coat... the gown... they are very careful. They are always attentive; at least when I was there, they were constantly monitoring everything, even when expressing milk to store for the baby. The level of care there is very high* (R12). *My goodness, I even get emotional, you know, because it's outstanding—the highest possible standard. Not only did they care for him, but they also cared for us, for the family* (R13).

Dissatisfaction with care and service organisation

This category highlights parents' dissatisfaction with aspects of care and service organisation. Concerns were raised regarding the presence of extended family members in the neonatal intensive care unit, which was perceived as potentially harmful to the newborn's recovery and as increasing the risk of exposure to unwanted microorganisms. This presence was also considered inappropriate within a critical care environment, as it could create unnecessary situations. The following excerpts exemplify these perceptions: *Visits from grandparents, uncles, cousins, godparents... I don't think that would be ideal because not everyone, sometimes, is completely well, but they don't say anything just to see the baby* (R7). *When I was there, people came from all sorts of places, and they would even answer phone calls inside the ICU, you know? These things are quite complicated. People don't always have that awareness... I think it should be just the mother and father; the rest should not be allowed inside the ICU* (R8).

Parental inclusion in neonatal care

When parents were included in care during hospitalisation, they reported feeling more confident and useful due to their active participation in their child's care. This involvement strengthened interpersonal bonds and contributed to the newborn's development through emotional connection. It also supported the process by which parents gradually assumed their caregiving role.

In some cases, mothers initially felt detached from their newborn, particularly when the infant was admitted immediately after birth, limiting opportunities for physical contact or feeding. However, being present, expressing milk beside the infant, and assisting with feeding through clinical support methods contributed to increasing parental confidence and engagement in care.

These experiences resulted in a sense of well-being among parents, as illustrated in the following excerpts: *The visits, the mothers inside the ICU... it does a lot of good for the babies, and for them too, because they feel they are helping* (R8). *In every way, they taught us how to care... feeding, the affection when feeding, the gentle touch... in many moments...* (R13).

Feelings and difficulties experienced in the neonatal intensive care unit

Upon learning that their newborn required admission to the neonatal intensive care unit, families experienced an intense emotional impact. Although each parent interpreted the experience individually, there was a common report of fear, anxiety, insecurity, and concern.

The environment of the unit was initially perceived as unfamiliar and intimidating, due to its association with critically ill newborns and the presence of numerous complex technologies and procedures. Over time, however, what had initially been perceived as a last resort came to represent hope and the possibility of recovery, transforming into a challenging yet meaningful experience.

The following excerpts illustrate these perceptions: *At first, you feel frightened; so many machines, many beds, many babies, each with their own condition* (R3). *At the same time, there's joy, sadness, and a kind of fear that comes and stays... it's something very intense, a very intense experience* (R8).

Exchange of experiences and emotional strengthening among parents after discharge

Although challenging, the experiences lived by parents in the neonatal intensive care unit were also described as rewarding. They evoked feelings of hope, trust, safety, and support. The perception of not being alone throughout this prolonged and complex journey strengthened both the bond with the healthcare team and the ability to cope with the situation.

Support and encouragement were considered essential for maintaining psychological balance and well-being, providing parents with the strength to care for their newborns and trust in their recovery. These experiences reinforced the belief that their children were receiving appropriate care and would soon return home, enabling healthy development.

The following excerpts exemplify these findings: *I know what we want most is for our children to go home, but they are doing everything so that when they do go home, they won't need to come back. So, what I say is: be patient, because they take very good care of them there* (R5). *It is a very difficult time for parents, but I would say: trust the professionals, because they are doing everything they can, and have faith that everything will be alright* (R6). *That room they have for mothers is very important because we share experiences, we talk, we comfort each other. It's a very good space. Parents need to support each other and be patient, because this phase passes, and afterwards there are many joys* (R9).

Discussion

This study contributes to advancing knowledge in neonatal nursing by exploring a dimension that has been little investigated in literature: parents' perceptions of care during their children's hospitalisation in a neonatal intensive care unit, assessed after discharge. Unlike studies that predominantly focus on the hospitalisation period and the maternal perspective[17-19], this research addresses parental perspectives in the post-discharge context, thereby filling an important gap and contributing to the consolidation of family-centred care practices. It also broadens understanding of the long-term effects of this experience and its influence on family bonding and the evaluation of care received.

The findings indicate that care directed at the newborn extends to the family, contributing both to the infant's recovery and to a more positive experience for relatives during the intensive care period, which is widely recognised as a time of considerable difficulty and challenge.

A high level of parental satisfaction with multidisciplinary care was observed, particularly when communication was clear, care was supportive, and parents were included in the care process. These practices strengthen the bond between families and healthcare professionals and enhance parents' sense of safety and confidence during hospitalisation, an experience often marked by fear, anxiety, and insecurity. In this context, professional support and the sharing of experiences among families emerge as important coping strategies[20].

During pregnancy, families often anticipate a full-term birth without complications. When unforeseen events require admission to a neonatal intensive care unit, this represents a challenging experience, as it disrupts family dynamics and elicits negative emotions. In such circumstances, healthcare professionals play a key supportive role by fostering a welcoming and supportive environment that strengthens the bond between newborns and their parents, particularly in situations involving early separation[7].

The category "Satisfaction with multidisciplinary care" demonstrated that participants evaluated the care provided to both the newborn and the family positively. This was reflected in expressions of gratitude and high ratings attributed to the health care team, which was described as attentive, supportive, and effective, with a strong emphasis on humanised care. These findings are consistent with previous studies indicating that care is often delivered in a compassionate, attentive, and welcoming manner, with family inclusion in daily care and ongoing communication regarding the child's health status[21].

The experience of having a child admitted to a neonatal intensive care unit is characterised by suffering, fear, distress, and uncertainty[1,6,21-22]. A supportive, welcoming approach is essential, and attitudes grounded in respect and trust contribute to the development of strong therapeutic relationships[23]. Parents reported that professionals listened to their concerns and demonstrated understanding of their situation, resulting in satisfaction with the care received[24]. These findings reinforce recommendations that care in neonatal intensive care units should be comprehensive and humanised, respecting the rights of the newborn and promoting parental involvement in care[25].

The role of nurses is particularly significant in this setting. According to parental reports, nursing professionals were perceived as key providers of humanised care, contributing both to the recovery of the newborn and to strengthening the bond between parents and their child. This support also facilitates the development of maternal identity and enhances parents' confidence in providing care[21].

In contrast, the category "Dissatisfaction with care and service organisation" revealed parental concerns regarding the excessive presence of visitors beyond the parents within the intensive care environment. This was perceived as a potential risk, as newborns are exposed to excessive noise, light, and a high number of individuals, which may be harmful[21,25]. These findings highlight an inherent tension within neonatal intensive care: balancing the principles of humanisation, which encourage family presence, with the requirements of biosafety and environmental control. Thus, hospitalisation in this context requires careful management to achieve equilibrium between these dimensions[25].

Within the category "Parental inclusion in neonatal care", parents reported that being involved in care allowed them to feel helpful and engaged in their child's recovery, increasing their confidence and strengthening their bond with the newborn. Direct involvement in care activities, such as touch, nappy changes, and feeding, promotes bonding and enhances parental security[24]. Parental inclusion in the neonatal intensive care environment is therefore a fundamental component of humanised care, extending beyond technical interventions to place the family at the centre of care[16,18]. This approach is associated with benefits such as reduced length of hospital stay and increased parental confidence in the healthcare team[23-25].

The category "Feelings and difficulties experienced in the neonatal intensive care unit" highlighted the intensity of emotions experienced by parents during hospitalisation. These included fear, concern, and anxiety related to the infant's clinical condition as well as distress associated with the unfamiliar and technologically complex environment. The hospitalisation of a newborn in a neonatal intensive care unit is widely recognised as a highly stressful and emotionally challenging experience for the entire family[21,26].

Parents may experience profound emotional responses, including fear of death, distress, sadness, insecurity, helplessness, and, in some cases, guilt regarding the child's condition[5-6,21,26]. Inexperience and uncertainty in caring for a vulnerable infant may hinder interaction, leading to feelings of helplessness and lack of control, particularly in relation to the desire to take the child home or the perceived inability to meet the infant's care needs[6,26].

Clear, appropriate communication, free from excessive technical language, can reduce anxiety, promote a sense of security, and help parents understand the necessity of the care provided and the use of medical equipment[4,21-22]. Empathy and attentive listening are essential to ensure effective communication and to provide reassurance and guidance to parents[5]. The way information is delivered, including sensitivity, honesty, and clarity, contributes to the perception of effective communication, even when conveying difficult news[22]. Conversely, inconsistent communication, which is characterised by insufficient information, complex language, or rushed interactions, is a major source of parental dissatisfaction and anxiety[5,22].

The category "Exchange of experiences and emotional strengthening among parents after dischar-

ge from the neonatal intensive care unit" revealed that sharing experiences among parents fosters feelings of faith, hope, trust, and gratitude, serving as an important source of emotional support during hospitalisation. Participants reported that interaction with other parents and support from family members facilitated coping with the challenges associated with neonatal hospitalisation. These findings are consistent with the literature, which identifies social support and mutual assistance among families as key strategies for reducing negative emotions and strengthening coping, promoting empathy, support, and emotional well-being among individuals undergoing similar experiences[27].

The perception of support and care received was essential for maintaining psychological balance and well-being, providing parents with greater strength to care for their newborns[5,23,26]. Furthermore, the feeling of "not being alone" during the neonatal intensive care journey was fundamental in strengthening both the bond with the healthcare team and the ability to cope with the situation[5].

The findings of the present study, based on parents' accounts following hospitalisation in a neonatal intensive care unit, highlight the importance of encouraging the exchange of experiences among families. This approach constitutes an important psychosocial support strategy. This perception is consistent with findings from recent studies conducted during the hospitalisation period, which highlight the role of the healthcare team, particularly nursing staff, in providing family support and promoting supportive bonds among parents[6,21]. However, by considering the retrospective experience and incorporating the parental perspective, this study expands the existing body of knowledge by demonstrating how these interactions are reinterpreted over time and recognised as a fundamental element in coping with neonatal hospitalisation.

Study limitations

Although the institution investigated is a regional reference centre for neonatal care, the findings cannot be generalised, as they reflect the outcomes of a specific group of participants. This constitutes a limitation of the study.

The retrospective nature of data collection is another aspect that may have introduced limitations, as participants' accounts were based on past experiences related to their newborns' hospitalisation in a neonatal intensive care unit. This approach may be subject to recall bias since perceptions and interpretations can change over time. However, it also enabled an understanding of how parents reinterpret their experiences after discharge, allowing for a broader analysis of emotional impacts and perceptions of the care received.

Contributions to practice

The findings of this study expand understanding of the parental experience following discharge from a neonatal intensive care unit, a topic that remains underexplored in the literature, which typically focuses on the hospitalisation period. By adopting a retrospective perspective on parental perceptions, it is possible to identify aspects related to the persistence of emotional impacts associated with hospitalisation, as well as strategies for family support and parental inclusion in care. These results reinforce the relevance of care practices based on family-centred care and may inform the refinement of institutional protocols aimed at improving communication, emotional support, and parental participation in neonatal care.

Conclusion

The findings indicate that care in neonatal intensive care units extends beyond technical interventions directed at the newborn, encompassing support and care for the family. The inclusion of parents in care, combined with clear communication and support from the multidisciplinary team, may strengthen emotional bonds, increase trust in the healthcare team, and reduce feelings of insecurity during hospitalisation.

These findings underscore the importance of care strategies guided by family-centred principles, including the promotion of parental participation, the improvement of communication, and the organisation of spaces for emotional support, thereby fostering a more humanised care experience in the context of neonatal intensive care.

Author contributions

Conception and design of the study or analysis and interpretation of data; Drafting of the manuscript or critical revision of important intellectual content; Final approval of the version to be published; Agreement to be accountable for all aspects of the manuscript: **Costa LD, Vieira MTF, Deotti YEP, Santos LR, Dalmuth KH, Cavalheiri JC, Schamus's JM**.

Data availability

All data supporting the findings of this study are available within the article.

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