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Research Article

Mothers' Perceptions of the Health Care Provided to their Children during their Hospitalization of the Neonatal Intensive Care Unit in a Public Maternal and Child Hospital

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Abstract

Introduction: The internment of a baby in a Unit of Neonatal Intensive Care (NICU), is usually a traumatic and unexpected experience for families, which breaks into their lives in the form of a vital crisis, with a strong emotional impact. The continued ness of parents within NICuNs and their inclusion in the care of their children brings multiple benefits in terms of growth and development, the establishment of effective breastfeeding, the increase of attachment, and post-discharge safety and confidence; however, it is a measure whose implementation appears to be resisted by health teams. This study describes and analyses mothers' perceptions of care received by newborns during their NICU idenation.

Material and Methods: On-site interviews were conducted with mothers who had had their children interned in the NICU and who met the criteria for inclusion. The stories were analyzed and the thematic axes and categories were determined.

Results: The most relevant categories were: unpredictability of preterm birth, delay to make the first contact with the baby after birth, deficits in accompaniment and containment during the first entry to the NICU, poor communication, restricted parental entry every three hours, limited possibility of participation in the question, non-explicit and contradictory regulations (professional-dependent), difficulties and delays for physical contact with the newborn and infrequent skin-to-skin contact.

Conclusion: Mothers perceive strong limitations related to the entry into the NICU and participate in the care of their inpatient children. In some cases, these limitations are naturalized by mothers who assume that such exclusion is necessary for the welfare of the baby. The time within the Unit was perceived as insufficient and the possibility of entering and remaining as a favor that the institution grants according to certain non-explicit guidelines.

Keywords: *Care; Neonatal Internment; Maternal Perceptions; Participation; Accompaniment; Information*

Introduction

Lowdermilk, Perry and Bobak [2] have claimed for more than a decade that the experience of clinical hospitalization in the NICU provokes mixed reactions in parents, generally intense and disturbing: an emotional impact associated with feelings of newborn loss the healthy and ideal they had projected, the even-to-bun and untimely that sometimes means their child's illness, the drastic changes in the

family dynamics generated by the hospitalization of one of its members and the stress and insecurity helplessness for having to leave their sick children in a NICU.

Objective of the Study

The objective of the present study was to analyze the perceptions of mothers acer- ca of the care received by their children by the health team during their internment in the NICU, in aspects related to communication, entry and permanence within the service and mothers to actively participate in the care of their babies.

Materials and Methods

Qualitative study: Mothers who attended the control of their children in the Preterm Monitoring Office were invited to participate after being discharged from the Neonatology Service of the same institution. Mothers invited to participate had to meet the following criteria for including: (a) that their children had been admitted to the NICU during the period 2015 to 2018; b) for a period of at least thirty days; and c) who had participated in the care by entering the Unit frequently - at least four years a day and staying at least three hours a day total.

The interviews were conducted between January and April 2018, in the Preterm Follow-up Office, which is attended from Monday to Friday, an average of fifteen mothers per day. The invitation was referred to those mothers who, according to the data in the Office, met the criteria of inclusion. The semi-structured interview included some topic on which the story of the mothers was guided (context before birth, birth, impressions and sensations during the first admission, information received, possibility of admission to the Unit and participation in care, time within the Unit, containment by the health team). These interviews were conducted in a privacy area, the anonymization of the data was guaranteed, and the informed consent, which included the permission to record the interview, was collected in each case. A simple analysis was then carried out, identifying the categories and the relations between them, to understand the context and reconstruct the meaning of the collected data. For the analysis of the interviews was highlighted in the most current recommendations for family-centered care and development, embodied in Altimier's model "Advanced model of care for the integral neonatal development of Altimier and Phillips: seven neuro-protective measures of developmental care family-centered" since it was seen as a standard of holistic care, which collects and replaced to many of the concerns obtained during the interviews with the mothers and whose applicability within the Unit is feasible by implementing simple measures that involve, however, profound changes in the current work processes in force. Since the author was aware of the dyno- mica of work for developing her professional work within the institution as a resident of neonatal disease, the study may be tinged with a certain subjectivity, however, the potential advantage that has contributed to guiding the interview, analyzing the data and making recommendations is recognized.

Ethical aspects: The necessary institutional permits were obtained, the Institutional Bioethics Committee was submitted for consideration and informed consents were obtained before proceeding to each of the mothers.

Results

A total of 42 mothers were invited to participate. Fourteen of them refused to do so for reasons of time, two said they were not interested, and four of them were minors and were not accompanied by a representative able to integrate with their consent the Informed Consent (Art. 644 Civil and Commercial Code of the Nation). The mothers who participated stated that they felt very comfortable and appreciated the space they perceived as listening and containment. In some cases, de- de- de- dos to the high levels of distress that manifested itself during the interview, they were advised and accompanied so that they could be evaluated and assisted by the Psychology Service of the Hospital.

3 thematic axes were obtained from the analysis of the data 26 categories (Table 1).

Thematic axes (ET)	Categories (C)
ET1 Birth and its context	C1: experiences before birth; C2 absence of prior information; C3: unpredictability of birth; C4: anguish, bewilderment and breaking the ideal of having a healthy child; C5: feeling guilty; C6: Time elapsed until contact with the baby.
ET2 Experiences within the NICU	C7: prints on first entry; C8: shock; C9: need and often impossibility to have contact physical with the baby; C10: fear of the unknown; C11: ignorance of space and technology used as support; C12: noises; C13: need for information and containment; C14: emphasis placed on the regulatory aspects of the service.
ET3 Participation in care	C15: non-explicit and contradictory legislation; C16: time inside the unit; C17: reception of the entry message by "shifts", every three hours and inability to enter with the father; C18: permits and concessions by the health team; C19: vulnerability, lack of knowledge of the existence of the right that assists them; C20: need to ask permission for any activity related to baby care; C21: confidence in the health team regarding care; C22: inability to touch the baby when it is found in microclimate; C23: copay perceived as extraordinary permission and good reception by mothers (repair care); C24: exclusion from parents and feeling of not being able to share as a family; C25: parents "expelled" from the room (use of the verb: "throw").

Table 1: *Thematic axes and categories.*

The most relevant categories that emerged during the interviews were the following:

1. Pre-birth information: although some of the interviewees reported situations that could anticipate the possibility of a premature birth or with some complications, the information received at this stage seems scarce or even absent.

a) The unpredictability of preterm birth: only some of the interviewees had a pre-natal diagnosis of any pathology and, although their accounts show that they did not seem emotionally prepared, they foresaw an internment in the NICU. In most of the interviewees, the urgency appears, linked to anguish, surprise, disco drastic changes in family dynamics and the loss feeling of the healthy and ideal newborn they had planned.

b) Time elapsed until contact ingesting the baby for the first time: many of the mothers told them that even though they felt physically in conditions, they were unable, under different circumstances, to access to meet their babies as soon as they would have wanted to. Some interviewees seem to challenge the system of institutional rules that are not very clear or explicit but rather subject to the varying criteria of the professionals who interact and take the initiative to approach Neonatology spontaneously and without "asking permission".

Accompaniment and containment in the first entrance: for most parents the NICU is an unknown environment, and their first experience there is usually of deep shock and trauma. This arises bluntly from most of the between the views. The richness of the details and memories in the stories in this aspect gives an account of the deepness with which this experience is experienced by mothers. The word "shock" is repeated very often. The technology used for the care of the baby generally appears to be very frightening. The small size of premature babies will cause fear and bewilderment in many of the interviewees. The containment received during this first entry was highly variable according to each reported experience. In some cases, the first approach of the health team was only linked to the normative aspects (entry times, handwashing) and even with calls for attention not to meet these requirements.

c) Need for containment versus in the aspects of the service: mothers reported needing to receive restraint, pointed in some cases to rewarding experiences, identified the professionals who generated trust and security, and also those with whom they went through situations that generated distress, confusion and bewilderment. When inquiring about containment and information received, some mothers associate it with explanations linked to normative measures, which seem to be insistently marked throughout this

day's day's time in the NICU. In some cases, education to prevent infections is transmitted with resources that seem to generate fear and bewilderment among mothers.

d) Time within the Unit and possibility of participating in the care of your children: all the interviews they stated that they had been informed that entry to the Unit was allowed every three hours, coinciding with the schedule of financial care. The time spent within the Unit was interpreted as limited to one hour and that time should be divided between ambos (mother and father) if they were pre-sent. In general, the time within the Unit was perceived as insufficient and the possibility of entering and remaining as a favor that the institution grants based on certain non-explicit guidelines.

e) Non-explicit and contradictory regulations: this category goes through many of the aspects investigated: entry times, time of stay of the Unit, possibility of entry in conjunction with the father and possibility of participating in the care and remaining within the Unit while carrying out procedures of invasive the baby. It is noted that there are no clear rules and the criteria are variable according to the professional involved. There are no written rules or policies and the messages transmitted are released to the variability of criteria of the issuer of the same.

f) Confidence in the health team regarding procedural skills and abilities: this category was associated with the possibility of being able to stay inside the room during the interventions. Perceptions were variable. Some mothers stated that they were given the opportunity to stay and chose to leave, while other mothers were not offered such a possibility. Some mothers associated the information and the possibility of remaining with some tranquility and bail at the time of making more or less complex interventions to their babies. Here the affinities towards certain professionals emerged because of the qualities perceived in them - delicacy- deza, sweetness, contention- and rejection towards others qualified with qualities perceived as negative - antipathy, lack of delicacy, disinterest. Some specific situations were narrated, living as carelessness or disinterest. These experiments provoked emotions of anger, anguish and bewilderment in mothers. In some cases, they expressed some fear that they had to leave the baby in the care of people who did not build their trust.

g) Impossibility to have physical contact with the newborn and COPAP: there was research on the time and conditions in which mothers were able to make physical contact with their newborns for the first time; it was found that it is usually de- to be de- de- demored in varying times and that this causes high levels of distress in mothers. In those few cases in which COPAP was encouraged and implemented, the experience was described, in general terms, as very rewarding and rewarding.

h) The perceptions of mothers in the face of the different perceived restrictions, carry the subjectivity of each of them, the circumstances and their context. Some mothers reported having "trans-gredido" the limits imposed, empowered from the natural exercise of their parental role. Most, however, accepted and even justified the rules, even though in recounting their experiences they dared to express their desire to have been able to stay longer, participate more actively, and be able to share time within the unit with Dad.

Discussion

Absence of prenatal counseling, a significant articulation between the services involved in a risk yearly; Neonatology service and no prior information, even though, in some cases, it was already planned to be admitted for problems during the course of pregnancy.

Testimonies

- "(...) No one told me anything, they told me that I was going to be born small, that there were many risks and that I had to be at rest, but no one came to me and explained to me that after that I was going to have to be admitted, that I could be at best or a little time (...) but no, no one had explained anything to me..." (E1).
- "(...) It was all like a bucket of cold water because I was told that I had to stay like 40 days, holding back the pregnancy, but she was still going to be born premature, but they were going to try to challenge her... which could not be because it would have been a week and days and there it was born and I really had no idea what premature was" (E7).

- "I had it at ehhh, 10 and a half at night and i went to see him the next day at 10 in the morning. actually at four o'clock in the morning I was lifted out of bed and I wanted to go to neo, I wanted to go to neo, but they wouldn't let me because they were being cared for yet, so I said, well I go at 7, and the baby dad still didn't I had seen in neo, and he said, "i'm going to go to 10 and go together and see it..." (E19).

Prenatal counseling is now widely recommended. According to several studies, this measure has been shown to reduce anxiety, increase family knowledge, facilitate decision-making and establish anti-mental relationships with the Neonatology health team [3].

The specific actions are addressed in some bibliography and contemplate the situation of the interned embrace, recommending: "(... visit of doctors or nurses in Neonatology. They are trained to respond to all mother and family concerns regarding the expected premature birth. It is also recommended to offer parents (or at least the father if the mother has an indication of absolute rest) the possibility of making a visit to the Neonatology Unit where their child will be hospitalized when he is born" [4].

The possibility of a neonatologist joining the prenatal practice in the risk gestations has been suggested by some literature, noting that "... represents the opportunity for this to allow a first contact of parents with the Neonatal Union, anticipate the possible scenarios that may occur at the time of delivery and care for two postnatal, share uncertainties and doubts with parents and agree on a neonatal action plan" [5].

Prenatal counseling is a simple implementation, low-cost measure that could be implied to emotionally prepare parents to get through the NICU stay [4], working with aspects related to the importance of breast milk feeding and initiating the concurrent decision-making truck.

The comprehensive approach to the immediate period before and after birth requires the institutional articulation of several services, since as well it has been stated "... Ideally both obstetric and neonatal equipment should perform counseling together" [3].

From the mother's account we can see the need to implement prenatal counseling in all at-risk pregnancy, improve the articulation between the services involved in the control of pregnancy in the last stage, birth, joint mother/son internment and Neonatology [5]. The difficulties found can be interpreted as a consequence of poor communication between professionals from different disciplines involved at this stage. This aspect assumes different peculiarities and varying intensities within each institution but is usually a common problem. It is clear that this fragmented approach seems to accentuate the scenario of unpredictability that usually characterizes any birth with complications.

First entry in the NICU: The account of the experience lived in the first entry in the NICU is one of the most developed in interviews, full of details that are vividly remembered, expressions of mixed feelings, and the feeling of being an experience that is perceived as unforgettable. During interviews, the mothers used adjectives and various expressions to qualify her as "terrible," "cute," "ugly," "excited," "weird," "crying," "fear," "nerves," "anguish," "I dropped the world," "horrible," "strong," "don't understand anything," "despair." The word that was repeated most often was the expression "shock", used as a qualifier "was in shock" or sotantivo "was a shock".

Testimonies

- "A shock, it kept crying, that is, it is like a mixture of sensations because you are happy because you are seeing your child who was born, because the anxiety that a pregnant woman has is how it will be, it will be stopped to someone, it will be fine, It will have everything perfect...

  Saw? Then it's like a lot of fears..." (E 19).
- "It's a shock, and seeing her there full of tubes, no, it's horrific" (E4).

- "(... It was a half shocking, they took me where he was... and nothing, when I saw it as the world dropped, I didn't know, I was crying, I didn't know, I didn't...)" (E13).

This expression coincides with some studies [6] that have described as "post-traumatic stress disorder" to the experience of some parents after the internment of their babies in Neonatology.

"Babies born prematurely have premature parents, who are generally not ready to deal with the crisis of having their babies in the NICU. Pre-term births are often unexpected (...) For most parents the NICU is an unknown environment, and its first experience in the NICU is usually of a deep shock and trauma. Their babies are wired and equal in a place that is very different from the one they had planned. Parents of these babies are prone to enormous emotional stress, depression and anxiety, uncertainty about the baby's future, financial stress, and even post-traumatic stress compared to newly born-two parents (...) The experience in the NICU impacts the family dynamic, not only during the baby's stay but even in the months and years that followed and can shape the trajectory of long-term relationships and parental perspectives of their roles (...)" [7].

According to the data gathered, it could be interpreted that there is an urgent need to strengthen the containment and accompaniment that is provided to the family at its first entrance to the NICU. In parallel with the shock they often go through, the teachers have expressed lack of contention and a communication focused on emphasizing the normative aspects (timetables, hand washing, infection prevention). In this state, mothers not only do not pay attention to the indications they are referred to, but they need to be 'received' with other types of messages in which the emphasis is on conveying confidence that their child is receiving the best possible care.

Unrestricted entry, time within the Unit, ability to participate in the care of your babies.

Testimonies:

- "(...) I wanted to be with him for as long as I wanted and that he needed me, to be able to leave him idly, to me to leave quietly, that happened to me too, to say "oh no, I have to go now", I did not want to leave, and I would stay and spy, and I would look at it (...)" (E1).
- "(.) Sometimes I felt like they wanted me to leave, were quite strict they said 'good mom already va-we go you saw' and dad did, the dad was marked A lot" (E13).
- "(.) That's where I'd be left for five more minutes, 10 more minutes, and he slept, so I was going out quiet..." (E18).
- "(.) Because they, let's say they told me if I could touch her or not, for what reason, and it was the fear of touching her or further her, or something so I did what, say, the nurses told me, the moment they would let me touch her, all for fear that nothing would happen to her" (E12).

Partnering with parents for baby care is much more than just allowing them to stay within the Unit. It is a philosophy of care that recognizes that it is the parents who have the greatest influence on the development of the child's health and well-being.

"The NICU environment can become a comfortable asset as long as compassionate caregivers are able to encourage parents to stand by their babies, teach them how to understand the keys to their children's behavior and how to provide appropriate position and management for development, provide active listening to parents' pro- stays of shock, anger, and grief for loss of a normal pregnancy and/or a birth of a term/healthy baby, and help them heal the tools caused by the interruption of the bond with their babies" [7].

The data collected in this study suggest that this model is strongly resisted by the health team. Parents are in some cases excluded from their participation, tolerated in others and encouraged to participate in the best of scenarios. The proposal is the creation of a care society with them, in which their protagonist is recognized. The verbs "leave", "allow", used in different conjugations, in positive or affirmative, in the context of "permission for" appear in the real-cough a total of 46 times. Its repetition in the context referred to, could make us infer

quite solidly that the dispensation to the unwritten norm, the power of some in the sense of "doing a favor", is a fairly common perception among parents who have been neonatology in the time that the study lasted. While some mothers managed to "challenge" the retentions, probably feeling supported by the naturally perceived power since the exercise of their parental role, many others accepted these limits without questioning them, even justifying them. It is understood that this passive acceptance of the rules could be related to the vulnerability associated with unawareness and fear.

Conclusion

The mothers interviewed were able to reconstruct their experience within the NICU describing it as an unexpected fact that has a strong impact on family dynamics, as well as highlighting the deficits in communication with the health team, the need to remain unrestricted within the NICU and to participate more actively in the care of their babies internees.

Altimier's model, used as an axis for analyzing the results of this research, makes a compromise between parents and health equipment as "partners" in baby care. The gap between this model and its effective implementation is still enormous. The health team does not seem to have the tools to consistently highlight that the role of parents cannot be replaced by any other professional and that their presence and commitment is indispensable for the recovery of their babies. The gap between the proposals endorsed since the scientific knowledge and recognized as a right, will continue to widen as long as there are no clear institutional policies, collected by the service, embodied in written guides and disseminated among the health team, assuming that all changes in organizational culture are not established "gradual processes" and progressive acceptance, but must always be led by the formal authorities and informed of the institution. Our country has specific guides to adhere to the Safe and Family-Centered Maternity model [8]. Its implementation requires a huge commitment to overcome that transcends formal but empty proclamations of content. Renewing our commitment to the MSyCF model and incorporating the new aspects of the latest research is a challenge more in the field of remodeling the 'soft' skills of professionals. This at-adytum change will only be effective if it impacts the entire team and is consistently and uniformly supported by all staff involved in the care of the neonate's welfare and their families.

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