THE ROLE OF THE FAMILY IN CARE DELIVERY TO HOSPITALIZED NEWBORNS: POSSIBILITIES AND CHALLENGES TOWARDS COMPREHENSIVE CARE

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ABSTRACT: The aim of this qualitative study was to analyze family participation in care delivery to newborns in daily practice at a Neonatal Intensive Care Unit. The study was carried out at five hospitals in Belo Horizonte, Minas Gerais, Brazil. The study subjects were healthcare professionals taking care of newborns hospitalized at the Neonatal Intensive Care Unit and the relatives of these infants. Data were collected through participant observation and daily conversations and analyzed using Content Analysis. The data permitted capturing aspects of family participation in newborn care related to institutional organization, interaction with healthcare professionals and the care process. Different actions favoring mothers' participation in care delivery to their children were identified at the Neonatal Intensive Care Unit. Nevertheless, the study showed that these actions have not been incorporated into the daily activities at the institution, nor into healthcare professionals' practice.

DESCRIPTORS: Family. Infant, newborn. Intensive Care Units, neonatal. Professional-family relations. Comprehensive health care.

A FAMÍLIA NO CUIDADO DO RECÉM-NASCIDO HOSPITALIZADO: POSSIBILIDADES E DESAFIOS PARA A CONSTRUÇÃO DA INTEGRALIDADE

RESUMO: Estudo de abordagem qualitativa que teve como objetivo analisar a participação da família no cuidado ao recém-nascido no cotidiano da Unidade de Terapia Intensiva Neonatal. Foi realizado em cinco hospitais de Belo Horizonte, Minas Gerais. Teve como sujeitos os profissionais de saúde que assistem o recém-nascido internado na Unidade de Terapia Intensiva Neonatal e os familiares desses recém-nascidos. Os dados foram coletados por observação participante e conversas do cotidiano e analisados por meio da técnica de Análise de Conteúdo. Os dados permitiram captar aspectos da participação da família no cuidado ao recém-nascido relacionados à organização institucional, à interação com os profissionais e à realização do cuidado. Identificou-se, nos cenários, a existência de diferentes ações que favorecem a participação da mãe no cuidado do filho na Unidade de Terapia Intensiva Neonatal. Contudo, verificou-se que essas ações não estão incorporadas ao cotidiano institucional e ao fazer dos profissionais de saúde.

DESCRITORES: Família. Recém-nascido. Unidades de Terapia Intensiva Neonatal. Relações profissional-família. Assistência integral à saúde.

LA FAMILIA EN EL CUIDADO DEL RECIÉN NACIDO HOSPITALIZADO: POSIBILIDADES Y RETOS PARA LA CONSTRUCCIÓN DE LA INTEGRALIDAD

RESUMEN: Estudio de enfoque cualitativo que tuvo por objetivo analizar la participación de la familia en el cuidado del recién nacido en la Unidad de Terapia Intensiva Neonatal. El estudio se llevó a cabo en cinco hospitales de Belo Horizonte, Minas Gerais, Brasil. Tuvo como sujetos los profesionales sanitarios en la Unidad de Terapia Intensiva Neonatal y los familiares del recién nacido. Los datos se recolectaron por observación participante y conversaciones del cotidiano y fueron analizados a través de la técnica de Análisis de Contenido. Los datos permitieron captar aspectos de la participación de la familia relacionados con la organización institucional, la interacción con los profesionales y la realización del cuidado. Se identificó la existencia de diferentes acciones que favorecen la participación de la madre en el cuidado del hijo en la Unidad de Terapia Intensiva Neonatal, aún así, estas no están incorporadas en el cotidiano institucional y en el quehacer de los profesionales sanitarios.

DESCRIPTORES: Familia. Recién nacido. Unidades de Terapia Intensiva Neonatal. Relaciones profesional-familia. Atención integral de salud.

INTRODUCTION

Transformations in neonatal care have affected parents' participation in newborn care. In the mid-20th century, new care forms were developed in response to inquiries and studies, addressing the harm the separation between mother and child causes for the development of the infant and family relations. Nevertheless, care delivery at Neonatal Intensive Care Units (NICU) is mechanical and impersonal, centered on techniques and procedures that are capable of guaranteeing premature infants' survival.[1]

The predominant care form at the NICU is important to improve neonatal morbidity and mortality indicators, although it is acknowledge that this care logic is not sufficient to guarantee attendance to newborns' health needs, including the needs related to emotional and social aspects. To guarantee more efficient results in the cure or control process of morbidities and mortalities, health practices need to be used that address individual, family and community singularities in the therapeutic process through knowledge sharing.[2]

Considering newborn care in this perspective leads to the notion of comprehensive care as a guiding principle of health policies and practices. Comprehensive care reveals meanings that cannot be summarized in one single concept, but express different aspirations and values. Independently of the meaning attributed, comprehensive care "[...] implies a refusal of reductionism, a refusal of subjects' objectification and perhaps an assertion of the opening to dialogue".[3:61]

The construction of care comprehensiveness can be recognized in practices that value care and whose conceptions contain the idea-strength of considering users as subjects who need care and whose demands and needs should be respected.[4] Hence, offering NICU care that addresses the meanings of comprehensive care involves the consideration of the family's participation in the newborn care context.

In this study, the definition of family is used as systems of belonging that value the affective bond among people connected by bonds of blood, neighborhood or friendship, based on concepts of reciprocity, solidarity, trust and gift.[5] The family participation perspective we adopt is not restricted to the execution of newborn care, but includes the family's participation in definitions of what care is to be delivered, with team support, in order to enhance family members participation in care delivery to their children and their opportunity to discuss with the team.[6]

The parents' presence at the NICU is a right[7] and their participation in care delivery to the hospitalized child contributes to affective bonding between mother and child, to the reduction of family stress the hospitalization causes and to the family's preparation for childcare at home.[8-9]

A study involving parents of infants hospitalized at the NICU evidences contradictions in their opportunities to participate in care for their child. If, on the one hand, health professionals express their interest in developing ideal care by promoting parents' participation, on the other hand, care delivery to infants at the NICU was centered on routines and technical procedures.[10]

In view of these considerations, the challenge is to seek a mid term in care delivery to newborns hospitalized at the NICU, which permits combining the technology of knowledge, procedures and equipment with welcoming and respect for newborns and families' individualities.

AIM

The aim of this study is to analyze the family's participation in care delivery to newborns, based on daily reality at the NICU.

METHODS

This qualitative research was based on the theoretical-methodological framework of dialectics. Hospitals in the city of Belo Horizonte, Minas Gerais were chosen, which complied with the following inclusion criteria: having a maternity hospital and NICU, besides a multiprofessional team working at the unit. Using the National Register of Health Establishments, 13 institutions were identified, 11 of which were selected based on the criteria set. These institutions were ranked in decreasing order, considering the number of beds, and chosen in view of the institutions' political-administrative range. Five hospitals were defined as the study context, one federal teaching hospital, one state, one municipal, one philanthropic and one private hospital.

Research subjects were health professionals who deliver care to the newborns hospitalized at

the NICU and these infants' relatives. The participants received a letter in which the research was presented and were asked to sign the Informed Consent Form (ICF). Data were collected through participant observation and daily conversations. Observation was guided by a script that was focused on newborn care situations, including care actions, transmission of news among professionals, admission or discharge of the infant, problem or death, parents' first contact with the unit, the mother's participation at the unit and visits to the infant. Daily conversations, which are a communication form in different social spheres, characterized by flexibility in time and space and disciplinary slacking,[11] were captured in daily interactions and registered in a field diary.

The researchers moved into the field on different weekdays and times, collecting data in the morning, afternoon and night, including shift transfers among professionals. Between 15 and 25 hours of observation took place in each context, totaling approximately 100 hours. The aim of the observations was not to cover all neonatal care situations, but to apprehend the range of situations.

The collected data were analyzed through thematic content analysis, which seeks manifest and latent meanings in empirical material.[12] This material was presented to the hospital professionals and managers in a seminar to return the results, validate the results and broaden the analysis.

In the different project phases, the determinations of Ministry of Health Resolution 196/96[13] were complied with, which regulate research involving human beings. The research received approval from the Research Ethics Committee at *Universidade Federal de Minas Gerais* (Opinion 503/07) and the hospitals' research ethics committees.

RESULTS AND DISCUSSION

Data analysis revealed aspects of the family's participation in newborn care, related to the institutional organization, interaction with professionals and care practices, expressed in three categories, which will be presented next.

Institutional organization and its relation with family participation in care

The set of observations and conversations revealed different situations the family experienced while the infant was hospitalized at the NICU, especially regarding institutional initiatives that permit access and offer conditions for the mother and family to stay and support. In the study contexts, the parents have access to two NICUs at all times during the day and night and at three units at pre-established times. Institutions with preset times are attempting to make the parents' entry to the NICU more flexible, as observed, through the entry flow and the information exhibited or delivered to the parents.

At the units with preset times, restrictions were mainly identified with regard to access to the NICU at night. The parents protest against this entry limit as they acknowledge the importance of their presence with their children and are available to spend the whole time with them, according to one of the mothers' reports, registered during the observation: *so they put us here at night... the pressure does not change, there's no apnea when I and the father are here, that does not happen and it does not happen either to all others who are here too… so that's because we're good to the baby, right? So let us stay here twenty-four hours, they* [babies] *will get better* (Conversation at ICU D, date 10/19/2008, 16:00h).

Despite advances in the parents' access to the NICU, mainly the mother's, the same is not the case for the other family members, as observed in a multiprofessional team meeting with the parents, when they *ask about the possibility for other family members, like the uncles, to visit the babies. The pediatrician explains that this is not possible for the sake of the babies' safety as, if she made an exception for one relative, she'd have to make exceptions for everyone, and there would be many people circulating at the unit. The pediatrician also comments that restricting visitors is a way to protect the babies against the risk of infections* (Observation at ICU A, 09/01/2008, 13:05h).

At four out of five NICUs, infrastructure and resources were found that favor the mother's presence with her child at the institution. At one of the institutions, a house was made available near the hospital, offering housing conditions and meals; at another, the mother received resources to pay for transportation; at the other two, the possibility was considered that a bed would be offered to the mother at other hospital sectors, more frequently at the maternity.

The presence of a companion with the newborn hospitalized at the NICU is guaranteed in the

Statute of the Child and Adolescent;[7] however, the way conditions are offered for parents to stay and get access to their hospitalized child is a political-institutional decision. One of the observations reveals that some strategies the institutions adopt for the mother's presence with her child can entail restrictions that interfere in the quality and duration of the parents' stay at the institution as, *during a meeting with the parents of babies hospitalized at the NICU, a comment is made about exhaustion, fatigue. The mothers say that what is most tiresome is bus transport to the hospital* (Observation at ICU A, 09/19/2008, 12:45h).

Despite the institutions' efforts to guarantee accommodation for the mothers' stay, the fathers also face this need and seek alternatives, like staying at relatives' home or at a pension near the hospital.

The importance of the father's presence for the child's development is undeniable; in the daily reality of the institutions where the research was undertaken, emphasis is placed on the mother figure, while the father is somehow ignored in the process. There is a paramount need to acknowledge that, in the context of a premature infant or patient's birth and its implications in family life, the father's presence interferes positively in the construction of bonding between father and child, and to share childcare at the hospital and at home with the mother.

One of the mother's reports reveals the transformations in newborn care at one of the institutions where the study was developed and that these are not restricted to the acknowledged importance of the mother and family's stay with the child, but also relate to the multiprofessional team support they receive to cope with the situation of having a child hospitalized at the NICU. During a meeting with mothers, she commented on *what the hospital was like when she had her first child. At the NICU, the mothers had less contact, the professionals did not work with the mothers, there were more restrictions to entry the ICU. When she had the second child with a problem, she got desperate; but, when she found out about the changes, that she could stay in there, she got calmer* (Observation at ICU A, 09/04/2008, 13:00h).

Besides the existence of formal spaces to offer support to the families, considered as group and individual attendance here, situations are observed that evidence the professionals' opening to welcome the family's needs in daily work at the unit. In the multiprofessional team meeting with the parents, *the nursing coordination reinforced that the mothers do not need to wait for the time of the meetings to explore their problems, she said she was available whenever they needed* (Observation at ICU A, 09/01/2008, 13:05h).

Acknowledging that the families of hospitalized newborns also need care is part of a process under construction, which involves the creation of alternatives to attend to the premature infant's biological and psychosocial needs.[8]

Regarding the support offered to the family, the group with the parents of newborns hospitalized at the NICU is considered an approach that furthers access to information, emotional support and strengthening of parents and family members to cope with the hospitalization of the newborn.[14] Holding regular meetings with health professionals was considered an important form of providing support, besides minimizing maternal suffering and favoring mother-child interactions, reducing the risk of emotional and developmental problems in these children in the future.[15]

Group session observations reveals that they also serve as a space for learning about the health conditions and care delivered to newborns, which can enhance the mother's participation in care.

At some institutions, the support the team offers was not limited to the parents and mothers. Based on the situations observed, this support is extended to other family members, demanding service organization to respond to this family need, like in the situation reported here:

[...] *the visit was suggested and mediated by the psychologist, who talked to the child first* [sister of the newborn] *and suggested that she could make a drawing for the baby. According to the mother, it was a surprise that she was able to stay in the ICU environment, as 'she's afraid of people dressed in white' and 'now she wants to come every day'* (Observation at ICU D, 10/18/2008, 09:38h).

The relation between parents and professionals for newborn care delivery at the NICU

Regarding participation in care delivery to newborns hospitalized at the NICU, the mothers' reports express that health professionals

determine how and when they can take care of their children, when a mother was questioned by the research on *how she participates in care for her daughter. She says: 'I am not taking care, the hospital staff is'. I ask if she has already carried her daughter and she says: 'yesterday was the first time, let's see if they'll allow it today'* (Conversation at ICU A, 08/26/08,10:35h).

Further evidence on the determination of care was found when a *nursing technicians performs procedures on the baby in the bed next to her and, when observing the mother touching the baby, she asks: 'have you already carried the baby?' She answers that she carried her in the morning and smiles. The nursing technician comments: 'you've already held her in the morning so that's enough, right?'* (Observation at ICU B, 04/13/2009, 17:45h).

The situations observed reveal that the team, in turn, reinforces this understanding through care actions, including the mother in these actions or not and using the infant's clinical condition as a guide.

In view of the importance of these professionals' assessment, this decision should be oriented not only by the child's clinical condition, but negotiation should also take place with the mothers in order to identify their condition to be responsible for childcare activities at the NICU.

The inclusion process of the mother in childcare at the NICU depends on the support she receives from professionals, who can create possibilities for participation, even when the child is in severe clinical conditions, like asking the mother to hold or hand over material during procedures and, as the child gets better, encouraging her to deliver care.[16]

The results reveal that the parents' contact with daily care at the NICU and interaction with people working at the unit allows them to gain knowledge on the practices that produce safe and appropriate care for hospitalized newborns. The incorporation of this type of knowledge allows the parents to evaluate and raise questions on care practice, especially when this care puts their children's safety at risk. During the multiprofessional team meeting with the parents, *one of the mothers comments that the fact bothers her that, for the parents to enter the NICU, they need to remove all accessories and wash their hands, while some nursing professionals are reading the newspaper all day. She said that the newspaper contains bacteria and demonstrated concern with the risk for her child* (Observation at ICU A, 09/01/2008, 13:05h).

When the infant is hospitalized at the NICU, the mother attempts to adapt to her child's condition and to the environment at the unit. Over time, she starts to understand the routines and evaluate how professionals take care of the children.[16] The professionals generally direct care based on service routines, while the parents use their perception and knowledge gained to define what is best for their children, further approaching their needs.[10]

The situations observed reveal that, in care, the mother's presence represents a possibility to participate in childcare and, at the same time, reveals a dispute between the professionals' form of care and the mother's form of care, as reporting in a psychology team meeting with the parents, when the *mother discusses the contradiction between the breastfeeding position the professionals advise and what the mothers consider best. She says that, sometime, the way the mother positions the baby is better, but professionals want her to hold the baby differently, bothering* (Observation at ICU A, 09/19/2008, 12:45h).

The report reveals that the health professional ignored the mother's perception and used her professional authority to determine the care form she considers appropriate for the infant. A similar result was identified in another study, in which health professionals tended to set limits, supervise the mothers and, in some cases, reprehend them by positioning themselves as infant care experts.[17]

Situations were observed in which the parents were advised to offer care to contribute to their children's wellbeing, including information on appropriate ways to touch a premature infant and hold him/her on the lap and the importance of mother's milk. In some situations, adjustments were made in the unit's routine to permit this participation.

The nursing technician advises him, saying that he can remove the film and touch the baby [...]. *The father touches the baby with his fingertips. Minutes later, the physiotherapist arrives and advises the father to touch the baby with the hands, as that's how the baby feels tickles* (Observation at ICU C, 02/07/2009, 8:40h).

Records on the situations observed evidence that the parents establish relations with the professionals, in the attempt to respond to their information needs on their children's health situation, like in the following excerpts:

[...] *one mother commented that some nursing technicians do not provide information. The nursing coordinators said that some information really has to be transmitted by the physicians. The mother referred to weight and breastfeeding and the nursing coordinator said that the nursing technicians really could transmit this information* [...] (Observation at ICU A, 09/01/2008, 13:05h).

[Multiprofessional team meeting with the parents] *the father comments that he only believes in the information the physicians transmit. They do not consider the information other professionals provide, like the nursing team* (Observation at ICU A, 09/01/2008, 13:05h)

The situations reported reveal that both parents and team members consider the physicians' information central. In the first situation, this central role is particularly evidence when other team members could provide the information. In the second situation, the parents value and grant credibility to the information the physician provides.

The need to distinguish between communication and information is evidenced, as the need parents' discourse reveals refers not only to the need for information on the child's clinical conditions, but also the need for a dialogical relation that produces welcoming, trust and bonding.

One element that distinguishes information from communication is that, in the latter social bonds are established, which involve not only the subject him-/herself, but also "things and other men".[18:256] Communication refers to "producing, circulating and consuming the social meanings manifested through discourse".[19:167] This concept is supported in another study, in which communication is considered a process that implies interaction and interlocution among the parties involves, allowing them to create, feed and reestablish social bonds.[18]

Newborn care at the NICU by the family

The set of observations and conversations allows us to identify different actions the parents perform while accompanying their children during NICU hospitalization. These actions relate to demonstrations of affection and faith, daily care like offering meals, bathing, diaper changing, skin-to-skin contact and surveillance of the child's evolution and multiprofessional team care.

I see a mother with her newborn on the lap and a father observing the child inside the incubator (Observation at ICU E, 09/30/2009, 14:35h).

Standing next to her child, the mother positions him in the bed. His father is standing on the other side of the bad, sitting on a chair. Father and mother talk to their child, caress him and sing to him [...]. *The mother reports that, in the afternoon, because of the heat, she bathed her son alone. At 18:02h, the parents pray with their hands on the child and soon after everyone says goodbye and leaves the unit* (Observation at ICU E, 09/28/2009, 17:50h).

In these situations, one way the families participate is to spend time with the children, looking at them, talking to them and caressing them. These were identified during observations as the most frequent behaviors during the first hospitalization days. When the children's clinical conditions improve and the parents' get familiar with the environment, as observed, the families, especially the mothers, started to perform other newborn care actions.

The ways mothers participate in care can be understood based on a study that evidences that mothers experience different conditions during their child's hospitalization at the NICU. Some of them rapidly got involved and became partners in care, while others remained strangers across the entire hospitalization period. This transition was influenced by previous maternal experiences, the infant's health condition and the NICU culture. The establishment of a partnership relation was only possible when the health professional participated.[9]

To participate in childcare, besides dealing with the particularities of having a newborn at risk who demands distinguished care, the families face the challenge of getting accustomed to the NICU environment.

The babies went to the NICU soon after birth and the mother reports that the NICU frightened her at first, she was scared when the devices went off, but the professionals calmed her down and explained what was happening (Observation at ICU C, 03/24/09).

The NICU environment increases the stress the mothers experience, which underlines the importance of health professionals' help in the process of adapting to and coping with the situation.[9,20] One way to help the parents is to establish effective communication, mainly during the first hospitalization days, offering information on the protocols and expected results. This will contribute for family members to feel less anxious and favor further interaction between team and family.[21]

Data analysis demonstrates the importance of professionals' activities for the mother to understand NICU events. This indicates the relevance of considering these aspects, related to the adaptation to the environment, in the professionals' interaction with the family and adopting them as a focus of team work.

The mothers presented distancing form the family as one of the difficulties they faced while staying at the institution; their involvement in childcare played a determinant role in their continuation at the hospital though. In the group of mothers, reports mentioned that *staying away from the family is very difficult... 'I got better yesterday when I found out that she needed my milk, then I got more cheerful'* (Observation at ICU C, 03/26/2009, 09:50h). Despite suffering because of their separation from the family, the mothers stay with their hospitalized child because they believe they can offer exclusive care and feel useful when conditions are created that enhance their participation in their child's care.[22]

The mothers' observations and discourse at the different NICUs evidence that professionals particularly stimulate their participation through orientations on milking and the daily food volume the child demands:

[...] *the ICU technician goes to the Maternity to tell the mother that the pediatrician changed her child's diet from every six hours to every four hours and that, therefore, she will have to get a ml. of milk at the milk bank* (Observation at ICU A, 08/30/2008, 9:03h).

The need was identified to stimulate this action, but not limited to the biological space. Instead, this should also be broadened to other aspects of breastfeeding. We believe that the professionals' prioritization of breastfeeding is due to the acknowledged importance of milk for children at risk, but especially because this care is exclusively maternal.

Other forms of maternal inclusion in care happen non-systematically, depending on each professional's availability and interest. Thus, actions like bathing, diaper changing, meal offering, among others, can be incorporated into the set of professionals' activities. Their accomplishment by the mothers is a differential but does not play a determinant role in the care routine. Based on the above, the mother's participation should be part of the newborn care plan at the NICU, but should not be relativized based on each professional's opinion.[23]

As a way to enhance mothers' participation in care, authors defend the inclusion of guided participation into the care plan of newborns hospitalized at the NICU.[9,24] Guided participation is a process through which an experienced person helps another with less experience to perform significant daily activities. In the context of infant care at the NICU, guided participation means that a health professional accompanies the mother while taking care of the infant. According to the authors, guided participation goes beyond orienting and answering questions. It is a way to involve the mother in care and help her to perform tasks related to the practice of motherhood.

CONCLUSION

In the different research contexts, data analysis revealed the existence of actions that favor the mother's participation in the child's care at the NICU. These actions, however, have not been incorporated into the daily tasks of professionals who deliver care to the infants at the units, but remain limited to specific care situations in the contexts observed.

Considering care production at the NICU and parents as a part of this process, this study evidences the existence of a field marked by tensions among models, practices, interests and voices. In most cases, the professionals establish how care will be performed, also defining who takes care and how. This signals the need to incorporate dialogue as a newborn care technology, allowing health professionals and mothers to circulate their interests and be heard. This permits the construction of care that is committed to the subjects' subjectivity, autonomy and alterity.

Recommendations include: granting parents access to the NICU at all times during the day and night; offering infrastructure and resources that favor the mother's presence at the institution, addressing her care needs; increasing the opportunity of the father's and other family members' participation; valuing the family group as a strategy that furthers information access and emotional support; and stimulating other forms to have parents participate in care for their child, besides the provision of mother's milk, through orientation and negotiation.

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