Mother recognition in the Neonatal Intensive Care Unit

Reconhecimento materno na Unidade de Cuidado Intensivo Neonatal

Reconocimiento materno en la Unidad de Cuidado Intensivo Neonatal

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ABSTRACT

Objective: analyze the maternal experience in a neonatal intensive care unit, focusing on relations of recognition. **Method:** a qualitative study, built on the perspective of Gadamer's hermeneutics, based on Honneth's concept of recognition. In-depth interviews were conducted with 10 mothers of children admitted to a neonatal intensive care unit. **Results:** failures were reported in the process of mother recognition in the unit, with consequent feelings of insecurity and obligation to child care, resulting in fragility of self-esteem. **Conclusion:** interactions with health professionals in the NICU and its standards and protocols cause vulnerabilities and affect maternal recognition and autonomy.
Key words: Integrality in Health; Professional-Family Relations; Intensive Care, Neonatal; Humanization of Assistance.

RESUMO

Objetivo: analisar experiências maternas em Unidade de Cuidado Intensivo Neonatal, com foco nas relações de reconhecimento. **Método**: estudo qualitativo, desenvolvido na perspectiva da hermenêutica gadameriana, fundamentado no conceito honnethiano de reconhecimento. Foram entrevistadas, em profundidade, dez mães de crianças internadas em Unidade de Cuidado Intensivo Neonatal. **Resultados**: há comprometimentos no processo de reconhecimento materno na unidade e, como desdobramento, surgem sentimentos de obrigação e insegurança para o cuidado do filho e fragilidades na autoestima. **Conclusão**: as interações com os profissionais de saúde e as normas e protocolos ali existentes promovem vulnerabilidades e comprometem o reconhecimento e a autonomia materna.
Descritores: Integralidade em Saúde; Relações Profissional-Família, Terapia Intensiva Neonatal; Humanização da Assistência.

RESUMEN

Objetivo: analizar la experiencia derivada de la maternidad en la Unidad de Cuidados Intensivos Neonatales, centrándose en las relaciones de reconocimiento. **Método**: estudio cualitativo, desarrollado desde la perspectiva de la hermenéutica de Gadamer, basado en el concepto honnethiano de reconocimiento. Fueron entrevistados en profundidad diez madres de niños ingresados en una Unidad de Cuidados Intensivos Neonatales. **Resultados**: existen deficiencias en el proceso de reconocimiento materno en la UCIN y, por consiguiente, surgen sentimientos de inseguridad y obligación de cuidar de su hijo resultando en debilidades en su autoestima. **Conclusión**: las interacciones con profesionales de la salud en la unidad y las normas y protocolos allí existentes llevan a vulnerabilidades y comprometen el reconocimiento y autonomía materna.
Palabras clave: Integralidad en Salud; Relaciones Profesional-Familia; Cuidado Intensivo Neonatal; Humanización de la Atención.

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INTRODUCTION

The guidelines of the Brazilian Ministry of Health for good healthcare ensure comprehensiveness and humanization in both individual and collective routine assistance[1].

Comprehensiveness involves the practices of health professionals, the health service organization, and the government's response to fulfill the health needs of people and communities[2]. Having comprehensiveness as a value requires an articulation of professional competence with an effective movement of health professionals and users towards care construction[3]. It involves the definition of responsibilities, assistance, and bond as guiding elements of health action and management, based on an effective dialog involving health professionals and users.

The discussion about humanization in healthcare is a movement that broadens and contributes to healthcare comprehensiveness and, specifically in a hospital environment, the National Program of Humanization of the Hospital Assistance (PNHAH) is a milestone[4]. However, although it was created in 2001, the implementation of this program in Brazilian hospitals is still incipient[5].

A study that analyzed national experiences of humanization in Brazilian hospitals[5] reported a gap in relation to the concepts of subject and autonomy from the PNHAH. It identified the prevalence of an individual view of subject and the concept that autonomy is achieved through: 1) providing individuals with training; 2) informational support; and 3) a guarantee of the right to decision in healthcare process. The study pointed out the existence of *a concern about expanding the way health service users are seen*[5], especially in the recognition of singularity and complexity. In the authors' opinion, the health professional-user interaction has some gaps when considering it as a *relationship in which a game of expectation and production is developed*[5] and mutually built.

Routines and regulations in the hospital context impact the health professional-user relationship[5-6]. Among the issues is a failure to promote dialog as an important means to leverage the relationship, produce mutual responsibilities, and favor shared construction of healthcare processes[2,5-6].

This study analyzed healthcare interactions in a neonatal intensive care unit (NICU), a hospital section where techno-scientific developments in neonatology involve incorporating material technologies and the protocols of diagnostic and therapeutic practices into neonate care[6-8]. In NICUs, the interactions are predominantly vertical[9], with insufficient support from families[6-9], constituting a trend that impacts the autonomy of family members in decision making and conducting healthcare processes[6,10].

Based on this, and considering the need to discuss the consequences of healthcare—especially those of highly complexity[11]—in hospital units[5], this study attempted to understand the interactions between mothers and health professionals in one NICU and the impacts on mother care to preterm neonates. The objective of this study was to analyze the maternal experience in one NICU, focused on relations of recognition.

METHOD

This is a qualitative study that seeks to understand the relations between mothers and health professionals, based on the concept developed by Honneth of "*intersubjective recognition*" as a moral basis for sociability and its conflicts.[12] Honneth states that "*for individuals to have autonomy, their needs, legal equality and/or social contributions have to be socially recognized*"[13]. For the author, "*individuals and social groups can only have an identity when they are intersubjectively recognized*"[14]. He states that individual development and self-fulfillment are the true requirements to build equalitarian societies, and that this is possible only with "the intersubjective recognition of individual autonomy, specific needs and particular abilities"[13].

Recognition, according to Honneth, corresponds to a positive form of experience based on the relation with others, processed in three interconnected dimensions: love, rights, and solidarity[12-14]. Situations of non-recognition in one or more of these dimensions are experiences of disrespect which, depending on the degree of sharing and relevance, may encourage collective processes of a search for recognition elsewhere[12-14].

Recognition in the dimension of love is based on the emotions of interpersonal relations[12-13]. It especially refers to the primordial processes of identity construction during personal development and, if successful, it promotes self-confidence and the ability to move with autonomy according to moral rules, which determines self-respect[12,14], interpersonal interaction skills, and participation in public life[12-13]. Maltreatment and violence are examples of disrespect and, therefore, non-recognition[12-13], in childhood or adult life.

In the dimension of rights, Honneth states that individuals need to feel that they are active members integrated in their community[12-14]. "*Subjects in the dimension of rights have to be able to develop their autonomy to allow rational decision about moral issues*"[13]. For this purpose, their rights should not be violated. Situations of violation, that is, lack of promotion or defense of rights, cause feelings of injustice and a fight for recognition[12-14].

The third dimension highlighted by Honneth, solidarity, refers to mutual acceptance among subjects, judged according to the community's values, and leading to self-esteem[12-14]. Values are reference systems for the moral evaluation of personal attributes, whose totality constitutes the cultural self-understanding of a society. Threats to dignity and damaged self-esteem also promote a fight for recognition[12-13].

Appreciating care interactions based on the definition of recognition proposed by Honneth contributes to analysis of practices and knowledge in health care[1] and is relevant to expanding healthcare understanding in the chosen NICU, especially regarding intersubjectivity. This study was based on this perspective.

This study was conducted between May and August 2013, in a municipality in the state of São Paulo whose population is around 222,000, with a similar number of males and females, most of them living in the urban area. In 2010, its municipal

human development index was 0.805 and its illiteracy rate was 3.39%. The unit is located in a philanthropic hospital with up to 10 beds and no national humanization measures in neonate care. It allows continuous access to the unit to breast-feeding mothers during the daytime. Otherwise, mothers and family members have access during visiting hours, that is, two periods of one hour, one in the afternoon and one at night. Brothers or sisters of neonates have no access to the unit. All shifts have one nurse and one physician, and the nursing team has nurse technicians in a ratio of around three beds to every technician. According to information provided by the nurse in charge, users are predominantly premature neonates of low birth weight and their family members from that city and nine other cities in the region, considering that this NICU is a reference to these cities. It has users from the government Unified Health System (SUS) as well as private health plans, but favors SUS users, who represent around 80% of total users.

Ten mothers were interviewed whose preterm neonates had left the NICU less than one month prior to the interview. The inclusion criteria for this study were: mothers of newborns for gestational age of 34 weeks or less according to Capurro's method; without any congenital syndromes; who stayed in the NICU for at least one week. Mothers who had had another preterm child and those with any mental health problem were excluded. Among the 10 participants, five had had their first child and five were multiparas, and one had twins. Seven participants lived with a partner and three were single mothers. All were having preterm neonates for the first time. Six participants were 18-25 years old, three were 25-30, and one was over 40. The gestational age of seven neonates varied from 26 to 30 weeks and from 31 to 34 weeks for the remaining three. Neonates' length of stay in the hospital ranged from 20 to 120 days.

In-depth interviews were conducted based on the following question: "How did you feel in the neonatal intensive care unit while you child was there?" The interviews were conducted at home around one month after the child was discharged from the hospital.

The steps of the hermeneutic approach were followed[15] to produce and interpret the testimonials. The interviews were recorded and transcribed, providing a text used in the dialog. All of the women were interviewed twice, and the second interview started by examining "unusual issues" discovered by the researcher after reading the text from the first interview. Thus, the understanding was based on the offer-support and support-offer axis[15].

Text reading and rereading was conducted, primarily appreciating text fragments, seeking to analyze themes related to recognition of factors identified in the texts. Then, the themes (parts) were correlated with an understanding of the original testimonial and total testimonials (both) and vice versa, expanding the understanding of maternal experiences. Then, significant aspects and portions were interpreted and identified for the understanding acquired in the interviews.

This study followed the recommendations for research with human subjects and was approved by the Research Ethics Committee, document no 115/2012.

RESULTS

The feeling that predominated in the experience with the interviewed mothers when their children were in the NICU can be summarized in three terms: "self-demand"; "insecurity"; and "fragility of self-esteem."

Self-demand

Understanding child care as a mother's obligation is deeply rooted in Brazilian culture[16]. In intersubjective processes in the NICU, especially in interactions with health professionals and through standards and practices in the unit, such understanding was constantly mentioned and demanded of mothers, especially because their children were considered "at risk".

They [nursing team] say: You gave birth; now you have to provide child care. That's the mother's obligation, to provide care, and even more if it's a preterm child. Premature children are weaker and have to be protected. (Mother 1)

They [nursing team] say that all the time: Visiting hours are for that. You have to come; you can't miss it or say you can't come. And when we get there on the first day, they say everything we can or can't do. They give a piece of paper explaining about the ICU and, at the end, they say: These are the visiting hours. There's no exception; the children are at risk and all care may not be enough. (Mother 5)

Mothers interviewed stated that they had child protection in mind and were seeking the security to achieve that. Success in child care is part of the image they build for their role as mothers. However, in interactions with health professionals, they said their behaviors and attitudes were criticized, though they gave no specific details of such situations. The demand to care for the child and be present in the NICU was continuously reinforced and generated in the mothers a feeling that they were disregarded and that their effort to do their best was useless.

My, when I saw him so small, I had that feeling of protection. I just wanted to protect my son. Everything I do is to protect, care for him. They [health professionals] don't understand that. We are afraid they'll die; we just want it to be all right. I'm the mother. (She thinks) They don't see that; they just criticize us. (Mother 3)

Reinforced criticism and the risk to premature children in interactions in the NICU generated the understanding that their children require differentiated attention. In addition, the technological apparatuses in the NICU and the manual skills of health professionals make mothers question whether they will be able to actually fulfill their "obligation" to care for their children.

... I had to care for the child very well, I heard that all the time. (Silence) How, if we feel scared, if that seems so different? How? They do it with just one hand. (Silence) Everything seemed to be from another world to me. I thought

I wouldn't be able, especially because of the weight of demand they put on us. (Mother 6)

In addition to the scenario above, the mothers feel that health professionals, when justifying everything they teach and speak with the "maternal obligation" cliché, seem to doubt mothers will successfully accomplish it, and that they have an obligation to fulfill the challenge imposed by them on mothers.

I always thought: They seem to doubt mothers can do it. (Mother 2)

Insecurity

The testimonials indicated the image of a health professional who points out that he or she is in charge, provides information to mothers, and explains that mothers have to observe their recommendations. The interviewees showed that they wanted to have an active role and, despite their discomfort, they ended up accepting the situation. This contributed to a feeling of insecurity regarding child care, both in the NICU and after the discharge.

A non-conflicting presence and appeal to divine intervention are seen as recourses to such situations and an attempt to perform actions of child protection and care.

We know we depend on them (health professionals). The mother has to obey, do what they say. In the beginning, I asked about everything, then I stopped; they don't like that. They like to speak about what they want to say and explain. Then, I put that in the hands of God, and then in their hands (of health professionals). ... It was the best thing to do to him (her son) (Silence) ... and to me. ... They don't see our pain; they don't feel us. (Mother 1)

Health professionals from the NICU try to control and shape maternal projects based on "intensive" concepts and always reinforce the moral obligation of mothers to provide good care to their children. They train and use brochures, with guidance near the time of discharge to provide security to mothers in child care, believing that this is enough. However, mothers show in their tone of voice and the descriptions of their experience the sensation of having been underestimated or undervalued in their skills, abilities, and need for information and support to overcome fear and insecurity and protect and care for their children.

They give orders all the time and say a good mother is the one that provides good care. Then, they say "Pay attention, learn it, then you'll do it alone." Near the discharge, they give a brochure, a class, etc. I wanted them to see my pain. I tried that many times. They just said "Provide good care and then you'll take the brochure at discharge." But they don't allow us to provide care there (in the NICU), only two or three days before the discharge. (Mother 6)

In the NICU, health professionals tried to alert mothers to the "risks" and need for vigilance while taking care of their child. In interactions in the NICU, health professionals highlighted that improper behaviors by mothers may affect the child's health, survival, and recovery. A very abstract idea of care was transmitted to mothers, in which their personal experiences, values, and concrete conditions seemed to be useless. These mothers said it was because health professionals did not want to have any emotional contact with them. They mentioned some closeness only in the discharge process.

They said all the time I had to remember my son was premature; he could get an infection and get sick easily. You get that idea. And there, in the ICU, I thought, Oh my God, how is it going to be? You know, we feel like that (stretches hands and shakes them). And it seems that nobody notices that. (She thinks) Maybe they notice that. Yes, they notice that. They don't want mothers there with them, they don't want to waste time talking to mothers. (She thinks) You get there and they leave. It was almost all the time just like that. Only at the end, they come and tell us how to take care of the child; they bring a brochure with explanations, stuff like that. You just don't know if you'll do it, if you know how to do it; it's a bad feeling, a fear of taking care. (Mother 7)

Fragility of self-esteem

The interviews showed that mothers had a problem with being understood in their singular experiences and particular realities. They felt that their real effort and their involvement with their child's situation were not recognized.

The evaluation concepts adopted are the mother's presence and acquiescence, showing that dialog and sharing are not the focus of child care. A reported interaction showed hierarchy and lack of room to dialog, seeming to exclusively address guidance to the mother on how to take care of the child. Thus, the mother asked no questions, which increased her insecurity and self-questioning as a mother-woman.

I liked and disliked them [nursing team]. They provided good care for her (daughter), but they were rude to me. They didn't like when I asked things, when I had questions; they seemed to run away when they saw me. (She thinks) ... If you obey, all right, you are a good mother. ... I guess we want some comfort, too. And you don't have it there. You have rules. Rules, rules, and you are there, lost, thinking, "Will I be a good mother?" (Mother 5)

When a health professional showed sensitivity and interest in the particularities and problems of a case and concern about the pain of mother/family, he or she was seen as a different person, someone who went beyond his or her role.

I was lucky; the one who trained me in the nursery was A. She's special, she's more than a health professional, she's someone from another world. She's kind; she talks and tries to understand. The others are tough. She breaks the rules under the table. Some are nicer than others. (Mother 9)

The way a health professional interacts with mothers tends to show rigorous behaviors in child care, leading to autonomy

achieved by reproducing what the professional models, not from recognition of the mother in such care.

I don't know if I would do it this way (the same as in the NICU), it's not my style ... but I feel more secure this way. That's how I saw it, and it works, the way they taught me. (Mother 1)

In the NICU, mothers feel as if they are viewers of their child care, experiencing an observation stage in order to understand, and then they question it and end up accepting it as something inherent to that environment. That contributes to non-recognition of themselves as caregivers, and has negative impacts on their self-esteem.

When he was there in the hospital, they were in charge, but they said the mother had the obligation to provide care. I guess so, but there, it's impossible to know it. They are serious and the rules don't allow it. And then, you keep watching, watching, just watching. Then, you're afraid. I am afraid, I don't know if I provide proper care. (She thinks) I don't know if I provide good care. It's confusing. (Mother 9)

In the NICU, mothers allow themselves to submit to the health professionals' control, although they attempt to show their maternal feelings, angry about the rules and the way they are treated. They feel discomfort and disagree with this, but they accept it. This aspect affects their self-fulfillment, self-confidence, and self-esteem.

I had never been so angry. I couldn't control it anymore. Angry, I was angry because I couldn't do what I wanted with my son, angry about the rules, the way we are seen. But I saw he was receiving good care, he was getting better. Thank God and them, he's here, so handsome. ... But we feel angry about the way they treat mothers. I guess everyone feels the same, angry. They don't want mothers there. They really don't. But we stay there, even if we are angry inside. (Mother 8)

DISCUSSION

In agreement with other national and international studies, hospitalization of preterm children is associated with parent insecurity[6-7,9,17-20] and a tendency toward emotional unbalance[8,16-20]. Maternal difficulties are related to poor support from health professionals[6,18-20] and, according to the results of this study, the hospital rules imposed on them. These results show that the support provided by health professionals involves discomfort, pain, and uncertainty, with negative impacts on the mother's recognition, autonomy, and self-esteem.

Sensitive support encourages mothers and fulfills emotional and information needs[6,19-21]. On the other hand, poor dialog with health professionals, distance, and non-intimacy with the child generate feelings of exclusion[20] and pain[22]. Individual listening and observations, as well as effective and continuous communication, are the best way to achieve maternal care in the NICU[6,20], while disregard and disrespect affect maternal autonomy[6].

The context of premature children requires maternal adjustment and overcoming challenges in order to provide child care[6-7,9]. Such adjustments depend on interactions that promote a favorable experience in the hospital[6,20,22-23]. Continuous reinforcement that child care is a mother's obligation may be understood as maltreatment, especially because it is intersubjectively characterized by professional and institutional suspicion of the mother's ability to provide child care. This experience negatively impacts the mother's self-esteem. In addition, allowing the mother to provide care for her child only near the time of discharge indicates professional and institutional insecurity in relation to the mother.

Based on Honneth's Theory of Recognition, the findings of this study show the importance of the relational dimensions in the child care process and how the disrespect for the presence of others, although involuntary, may produce adverse effects on those attended by the health team, even in a technically and scientifically proper environment.

As a collective process, shared experiences of this type of disrespect or lack of recognition have generated reactions regarding the construction of women's rights, as well as more dialogic and sensitive care in terms of the mother's life and maternity conditions that involve gender, ethics, and socioeconomic issues, among others. Mutual recognition is relevant not only in the dimension of rights and public acceptance, but also when drawing attention to effective healthcare. This study reinforces the fact that successful[24] child care in the studied NICU features an important challenge of inattention to mutual recognition in interpersonal relations in care processes.

CONCLUSION

The comprehensiveness and humanization of hospital assistance is part of the national guidelines on healthcare and should be extended to NICUs. Such guidelines are applied to interactions with health professionals, especially if intersubjective recognition is experienced by everyone involved. The presence of mother-woman in the NICU is guaranteed by law, but it is useless if such commitment is not enforced in the healthcare work effectively performed in these units.

The results of this study point out the relation between the political and legal commitment and mother-woman recognition and the technical process of the work performed in the studied NICU. In the reports by mothers, self-demand, insecurity, and the fragility of self-esteem of mothers as caregivers are clear signs of poor recognition in the interactions taking place in the NICU and have negative impacts on care relations.

The fact that health professionals who maintained a dialogic perspective were identified as "exceptions" or "rule breakers" reinforces the impression that, indeed, recognizing the mother and her singularity was not highlighted in the work effectively performed there.

This study raises a peculiar question that involves ethical, technical, and political aspects: Does the hospital, when searching for technical excellence through protocols and standardized routines in intensive care, need to sacrifice interaction and listening, blocking dialog and support and neglecting recognition of others?

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