NURSES’ PERCEPTION ON PARENTS OF PREMATUARE BABIES IN THE NEONATAL INTENSIVE CARE UNIT

PERCEPÇÃO DE ENFERMEIROS SOBRE OS PAIS DE PREMATUROS EM UNIDADE DE TERAPIA INTENSIVA NEONATAL

PERCEPCIÓN DE ENFERMEROS ACERCA DE PADRES DE PREMATUROS EN UNIDAD DE CUIDADOS INTENSIVOS NEONATALES

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The study aimed to analyze the nurses’ perception on the babies’ parents during the treatment in the NICU. Qualitative research carried out from March to June 2012 through semi-structured interview with nine nurses from a hospital in Recife-PE, Brazil. Data showed that the parents are initially perceived in a state of emotional disorganization, but when they turn to defensive strategies and with the nurses’ aid, which provide clinical information and psychological support, they adjust themselves to the treatment situation. On the other hand, reporting the death of the premature infant is an experience seen as extremely negative. To improve the accomplishment of the humanization of the assistance, the nurses highlight the need for a multidisciplinary approach.

Descriptors: Parents; Infant, Premature; Intensive Care Units; Nurse's Role.

El objetivo fue analizar la percepción de enfermeros acerca de padres durante el tratamiento en UTI Neonatal. Investigación cualitativa, llevada a cabo de marzo a junio de 2012, por entrevista semiestructurada con nueve enfermeros de un hospital en Recife-PE, Brasil. Los datos señalaron que los padres son, inicialmente, percibidos en estado de desorganización emocional, pero, recurriendo a estrategias defensivas, y con auxilio de enfermeros, por ejemplo, a medida que estos profesionales propician informaciones clínicas y apoyo psicológico, se ajustan a la situación del tratamiento. Para mejorar la humanización de la atención, enfermeros destacan la necesidad del abordaje interdisciplinario.

Descriptores: Padres; Prematuro; Unidades de Cuidados Intensivos; Rol de la Enfermera.

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Parenthood represents the assumption of a new social role for both the man and the woman, namely as father and mother. At the same time, it is full of representations that are not limited to the biological aspects, covering others of historical, cultural, social, and especially subjective representations. Experiencing the birth of a child is a personal and relational experience filled with contradictory emotional states – happiness/sadness, security/insecurity, love/anger –, which can be intensified given the aggravations associated with prematurity. The illness and/or death of the child leads to a state of distress in parents, and thus the health professional, considering the parents importance for the treatment development, must also have them as the focus of their care\(^{(1-2)}\).

According to the World Health Organization (WHO), it is assumed the birth of 15 million premature babies (preterm) worldwide, which makes prematurity a public health problem. In Brazil, with the occurrence of 279.000 preterm deliveries per year, it represents, for every 100 live births, a rate of 9.2%. Although technological advances allow a greater and better survival of preterm infants, premature birth remains one of the major causes of perinatal morbidity and mortality, as well as of possible consequences associated with the physical, neurological and mental health of the child\(^{(3-4)}\).

Prematurity is attributed to babies born before 37 weeks gestational age and weighing less than 2,500 grams. With regard to weight, it is possible to classify the newborn in low birth weight (<2,500 g), very low birth weight (<1,500 g) and extremely low birth weight (<1,000g)\(^{(3-4)}\). Furthermore, we also consider the maturity of organs and body systems. Although the etiology is not fully known, we observed, regarding the pregnant women, risk factors such as infections, pregnancy-induced hypertension, smoking, and assisted reproduction\(^{(5)}\).

Due to the anatomical and physiological immaturity of the newborn, there is the need for an environment that provides the basic conditions for their survival, like the one provided by the Neonatal Intensive Care Unit (NICU). The NICU, given the human and material resources available, is essential for the life maintenance of premature infants, thus being necessary to their survival. Despite of its importance, it is a hostile and unfriendly environment to parents, because it contains several pieces of equipment, often unknown, besides the alarm sounds and great luminosity\(^{(6)}\). Therefore, it presents an ambiguous dimension for the parents, because it carries both the chances of recovery and of disease/death of the child, in other words, it may intensify one or the other.

The support and encouragement for parental involvement in the child care should be priorities in neonatal units. It is about strengthening the mother-child and father-child binomials, and thus intensifying the emotional bonds adversely affected by prematurity, which are extremely important for the child's physical and emotional development. Parental involvement proves beneficial, for example, to soften the aggressive and stressful character of clinical procedures used in the NICU, many of them invasive, and may also help to reduce the hospitalization period\(^{(6)}\). On the other hand, it also favors the organization of an environment that allows diminishing the frustration to which parents are submitted by deprivation of contact and care of the child\(^{(7)}\).

The nursing staff is responsible for welcoming the parents during child visit and for the guidance on the care involved in the treatment. Including parents in the care planning and respect their decisions about treatment characterize a type of assistance guided by a listening and an intervention favoring the confrontation of fears, anxieties and doubts. It carries in its essence a
communicative and relational strategy that, empathically, allows expressing the suffering experienced. Caring for a premature child is also caring for their relatives, especially parents, since at that time they are inseparable dyads.

The working process of the nursing staff in the NICU is intense, requiring maximum attention of its members. Besides dealing with the newborn and the machinery that assists them, they also perform clinical procedures, assist parents and collaborate with them. In this context, the present study aims to analyze the nurses’ perception about parents during the treatment in the NICU. With such knowledge, it is possible to better structure the relationship of nurses with parents, helping to minimize the stressful condition that prematurity can trigger on parents and also on the child. The work oriented by cooperative attitudes creates a mental condition favorable to all involved in its development, allowing, in the context of health actions, the development of a humanized approach.

**METHOD**

This study was based on a qualitative approach of descriptive and exploratory type. In the qualitative approach, we prioritize understanding the subjects’ beliefs, concepts, values and attitudes. Focusing on the subjectivity of the subjects individually and collectively, the data collection enables to apprehend the particularities of a certain population by explaining its characteristics.

The research was carried out in the first half of 2012, in a hospital considered a reference in comprehensive health care of children, women and adults, located in Recife, Pernambuco, Brazil. To ensure the collection of the information targeted, the study participants met the following inclusion criteria: (a) work for at least one year in the NICU, (b) belong to the regular team of professionals of the sector, (c) maintain, during assistance, interactive attitudes with the parents of the preterm infant, and (d) have experienced one or more situations of death of premature infants. According to the criterion of content saturation, a purposive sample of nine (09) nursing professionals was composed. All participants were submitted to a structured interview previously tested.

After transcribing the interviews, data were analyzed using the method of the Discourse of the Collective Subject (DCS), whose methodological figures rescue and organize the collective meaning based on the articulation and relationship of those individuals. Therefore, we have the following steps: a) Identification of Key-Expressions (KEs): fragments that best identify and describe the meaningful and common content for several individuals; b) Synthesis of Main Ideas (MIs): synthetic formulas describing the meaning (common, complementary or opposite) present in the speeches; c) Establishment of Anchors (ACs): synthetic formulations resulting from discursive marks that allow identifying and articulating the ideological context, underlying the discourse formulated; and d) Editing of the Discourses of the Collective Subject (DCSs): articulation of KEs and their respective MIs and/or ACs by editing texts in the first-person singular, representative of the individuals and the group.

During the analysis, each researcher conducted individually the preliminary identification of KEs and MIs, which, once compared, led to the establishment of the definitive ones. Based on these, we proceeded initially to the previous editing of the DCSs by each researcher, for then comparing them to perform the final editing. In this context, the MIs/DCSs are synthetic formulations that express, with regard to the parents of premature babies hospitalized in the NICU, the meanings assigned to them by nurses. The content focus, which had targeted the subjective dimension, allowed disregarding the analysis of anchor marks inherent to the speeches.

Thus, considering the nurses’ perception, we
established the following analysis themes: a) Experiences of parents of premature babies in the NICU, and b) Assistance to parents of premature babies in the NICU. For discussion and analysis of each theme, we used the data itself and the scientific literature published on the content identified in the production of the several speeches. The set of interviews allowed formulating a total of twelve MIs and their respective DCSs, with six for each of the themes.

The research was evaluated by a Research Ethics Committee, according to the Resolution 196/96 of the National Health Council, and approved under CAAE No. 2408.0.000.099-11. Before formalizing their inclusion in the study by signing the Informed Consent Form (ICF), and in compliance with the ethical principles, the participants were informed, among other things, about the purpose of the study, the identity confidentiality, the need for recording/de-recording of interviews, and the subsequent publishing with scientific purpose of the answers provided.

RESULTS AND DISCUSSION

The study participants comprised the age group between 28 and 42 years, being all female. As regards to the professional performance in the NICU, they have more than four years working in the area. The choice for this professional field was due to an interest in identifying the type of activity and the clientele: the care of newborns in critical condition. All nurses confirmed the participation in several activities related to the improvement of professional qualifications (courses, conferences, symposia).

Experiences of parents of premature babies in the NICU

The desire for affiliation for men and women, even before conception, is followed by positive expectations about the physical and mental health of the child, and even more so during pregnancy, delivery and postpartum. With prematurity and hospitalization of the newborn in the NICU, these expectations are replaced by negative ones – diseases, sequelae and death – thus, triggering a state of distress(12). The parents, according to the nurses interviewed, experience a situation in which the fraility and dependency condition of the child prevails. Seeing the baby in the NICU, in the incubator, with probes, catheters and monitors, leads to a situation of extreme risk that leaves them emotionally moved:

**MI/DCS 1 – Fears associated with the NICU:**

The name ICU is very frightening, everything is new: the fear of devices, the sector and the questions about the baby’s health, the fear that their child dies. The feelings such as anxiety, disability, worry, sadness [and] despair, as they get worst. Parents are very concerned about their health, restless and anxious for their improvement.

In the context of hospitalization, emerges a situation of frustration, in which parents find themselves unable to provide the child with the care – nursing, cherish, bathe – that allows them to fulfill the desire for affiliation(12-13). However, the nurses observed that despite this desire of practicing the parenthood through care, facing the fragility of the child, for instance, as evidenced by their low body weight, it causes the perception that parents feel inhibited at first contact, particularly physical:

**MI/DCS 2 – Fear of the initial contact with the child:** The first contact with the newborn is full of fears, doubts and insecurity. Many [parents] relate just by looking out of the incubator, afraid to touch them, with the fear of losing them, and also the anxiety to get out of the hospital.

At the beginning of hospitalization, the whole health care team, including nurses, must act not only in the protection of the newborn, but also of parents, providing emotional support to enable them to express and elaborate the fears that inhibit their initial contact with the child: “the shock caused by the hospitalization of a premature baby can be understood, when we see parents being confronted with a stressful and confuse environment, powerless to take care of their child, whose life is at risk”(14:540).
The baby who lives in the minds of parents has a narcissistic dimension that, in a way, is an extension and the high point of the existence of each one, and even a possibility of its continuity, an imaginary overcoming of death\(^{(15)}\). In the nurses’ perception, the reality of prematurity causes a rupture and frustration of this perfectly idealized image, which would be submitted to manifestations of surprise, and sometimes rejection, expressed or hidden towards the child. Likewise, also in a narcissistic perspective of self-recrimination and guilt, they feel responsible for the child’s condition:

**MI/DCS 3 – Prematurity and desidealization of the child:** For them, it is a moment of frustration, because this is not the idealized child, “where did I go wrong?”. Parents are surprised to see their children for the first time; I believe that is due to the difference from the image that was built during pregnancy. In some cases, they reject the children, because we noticed their absence.

The operation of the NICU, with their invasive and unknown procedures, represents for parents an unexpected and threatening situation, which may lead to feelings of loss of control, helplessness, and anger. Nurses show that they are aware that, in this context, they can establish a maladjustment process, causing a state of emotional disorganization. Thus, they suggest that parents experience a speculative identification with the child – by wishing to be in their shoes and feeling their pain –, which makes them suffer and, like the child, feel vulnerable, and at the same time react, defensively, whether by the cathartic expression, such as anger, or by denial, when they move away or avoid participate in treatment:

**MI/DCS 4 – Parents’ emotional mobilization facing treatment:** They feel fear and insecurity due to unknown procedures, afraid that the children are being harmed. For some, it is quite scary to see all those procedures being performed with their baby, who is so small. If they could, they would be in their place, because there would be less pain. They cannot see the children in pain, see them suffering. They get angry. Some parents rarely attend the ward; they do not get much involved with the treatment.

The parents’ state of emotional disorganization, according to the nurses, is not permanent. Gradually, they begin to see the treatment as a concrete possibility for the child’s recovery. Even though they show themselves frustrated with the hospitalization and its impact on their life condition (work, leisure, sociability), they slowly restore their positive expectations and revitalize the desire to accomplish what was planned for the child. For this new representation, there is certainly contribution from the empathetic and embracement attitudes of nurses. The NICU environment, initially threatening, progressively becomes a keeper of hope, and living with its routines allows parents to integrate it into their everyday life:

**MI/DCS 5 – Parents’ positive expectations about the NICU:** It is an environment that fills parents with hope, [in] knowing that the child has a chance of survival. [They feel] a lot of joy when they can take their children alive from the ICU. With the daily routine, the procedures become more accepted, causing a calmer reaction, starting to view these procedures as necessary to the baby’s recovery. Perseverance for those who are often away from their homes, leaving children and husband to take care of this child that needs full attention.

Nurses realize that the parental involvement in the NICU is extremely important to overcome the parents’ emotional disorganization. The mother’s relationship – or the person performing this role, which can also be the father – through the care and attention to the psychological and physical needs of the child, which is called handling, is essential for the psychic structure of this child, because this bond initiates the organization and the intra and inter-subjective functioning\(^{(16)}\). However, it is also important for parents, because, as mentioned before, these cares enables men to practice fatherhood and women to practice motherhood. Encourage parental involvement contributes to the newborn to have a healthy mental development and also to these parents to express the anguishes they are submitted to and that arise in the NICU environment:

**MI/DCS 6 – Importance of parents inclusion in the care:** It means bringing the family together so that they can
give comfort and a better assistance to the newborn and make them feel useful in caring for their own child, letting the parents touch their baby and say that there is no need for fear, that the newborn needs to feel their presence, and guide them to perform procedures like offering food and changing diapers. I ask them to touch him [the child], stimulating them. Encourage breastfeeding or milking, thus increasing the bond.

Encouraging the parental involvement in the child care, since this relationship is emotionally organizer for both, is a perspective that dimensions the psychological approach of prematurity, therefore a focus that goes beyond that exclusively organicist. The NICU, more than a treatment center, is now focused as a nursery, or even as a temporary home. Thus, we also highlight the uniqueness of the individual. Every child admitted to the NICU is seen as a unique case, as an individual that, fragile and unprepared, presents a particular experience of a boundary condition. The parents accompanying the child also get the opportunity to be singularly welcomed, i.e. according to their suffering experienced regarding their child and not as the parents of another newborn, to which a depersonalized protocol is applied.

Assistance to parents of premature babies in the NICU

The lack of knowledge on the technical aspects involving the treatment can intensify the threatening character of the NICU, raising questions and concerns among the parents. The nurses highlighted the importance of providing clarifications and guidelines that explain and justify every action performed by the staff. Also, they must use a communicative strategy that gradually allows gaining trust in the professional, the acceptance of the treatment and the belief in the efficacy of its achievement. Valuing the questions is of the utmost importance, both to build a positive image of the NICU and to encourage an empathetic relationship with the parents:

**MI/DCS 1 – Misinformation on clinical procedures:** Most parents, especially mothers, participate actively in the hospitalization; in most cases, they question and want to know the prognosis. We inform the patient’s bedside, accompanying them to the location. If they are with orogastric tube or CPAP respirator, we inform on the equipment being used, always willing to help and support parents in every situation.

Nurses must provide parents with embracement, in other words, develop physical and affective attitudes that, receiving and considering their emotional condition, allow integrating them into the environment. The clarification of doubts about the clinical condition of the child, the aspects concerning the clinical evolution, and the procedures and apparatus used is certainly a promoting factor of this embracement. These are clarifications that, giving reality parameters, minimize the aggressiveness of the NICU, allowing parents to deal with the situation:

**MI/DCS 2 – Information as embracement strategy:** Always be present, especially in times of distress, clarifying all doubts and concerns, elucidating the situation of the newborn. [They feel] calmer when they are informed about the procedure that needs to be performed.

For both health professionals and parents, the severity of the situation is not an unrealistic situation, is rather real, in which the possibility of sequelae or death is imposed to the child. Living with illness can trigger, in healthcare professionals, a countertransference relationship, i.e. in which the condition of physical and mental weakness of the patient, real and possible, unconsciously triggers fears related to their health and of those with whom they have affective connections. Thus, countertransferentially, facing the distressing context of NICU, the nurses – moved by their desires, experiences, beliefs and representations – can find themselves identified with the parents and their suffering, or rather can imaginatively realize themselves, unconsciously, fearful of a possible, though not necessarily probable, occurrence of sequelae or death of children with whom they maintain emotional bonds, such as children, siblings, nephews:

**MI/DCS 3 – Nurse’s emotional mobilization:**
I see another baby coming into the world so unexpectedly. But they are there, asking for someone to help win another battle. I feel
involved with the suffering of parents and children, but I know I'm there to help them improve and get out of here with quality of life. Over time, we adjust to the routines, we begin to feel important to the parents, who have so much hope on the hospital discharge.

As already mentioned, during the treatment in the NICU, there is the risk that the premature baby develops sequelae, which can be derived from the pathological condition or from iatrogenic occurrences, or, what may be worse, an event with an extreme outcome: death\(^{(18)}\). Such possibilities cause stress in health professionals, particularly in nurses, because they are the ones who systematically maintain contact with the child, establishing a stronger bond than other professionals\(^{(1-2,18)}\). According to the nurses, in the case of death, arises a state of anguish and sadness that can be associated with feelings of professional disability and guilt. A subjective question seems to occupy the imagery of nursing professionals: How to report to parents the death of their child? How to prevent them from such suffering and pain? Which are followed by another defensive question: How to avoid such an occurrence?

**MI/DCS 4 – The pain of reporting death to parents:** It is a very hard time, with a lot of suffering. I wish I never had the obligation to give this type of information to parents, sometimes I even cry with them. It is an awkward moment of pain and much crying. I get very anxious, is just sadness, the feeling that something more could have been done. In most cases, I chose not to be present.

In this situation, as identified, the nurses report the existence of reactions like crying, pain and embarrassment, which express their experiences with the loss of the newborn and to which they feel powerless. Death, as an inevitable step on the human existential cycle, is more acceptable when concerns those who lived their life story, their life cycle. At the same time, with death, nurses are driven to break, more than ending the bond with the child and parents, without the possibility of expressing mourning. With this break, they can work an escape mechanism, which is expressed by the need to avoid the situation – preferring not to be present – which, psychologically, is not the best defensive strategy, since what is not symbolically developed can work as an emotional maladjustment, for example, as a state of stress. Often, we observe disorders, such as depression, in professionals working in the ICU areas, particularly in the NICU\(^{(1,19)}\).

The humanization of health care consists in meeting the needs of everyone involved in the hospitalization process, which in the context of the NICU are both the newborn and their parents. This assistance must identify and recognize, by health professionals, the stressing factors in order to minimize them as much as possible\(^{(6)}\). A condition for the humanization is the emotional availability of nurses for support listening to the suffering experienced by parents:

**MI/DCS 5 – Listening as support for humanized care:** It is about knowing to see, hear and feel the newborn and their parents as a whole and as an individual, knowing to conduct a humanized assistance, where the neonatal unit staff respects every moment of parents, focusing on the clinical situation of the child.

Nurses are aware of the need for empathic listening, directed to emotional support. Besides conducting technical procedures with the newborn, which are unquestionably essential for the treatment, an embracement strategy is needed for the anguish experienced by parents, i.e. the creation of a relational space, inter-subjective, enabling them to express their experiences. The clarification of doubts, previously mentioned, as well as the promotion of guidelines are examples of actions associated with this type of listening\(^{(20)}\). But the bottom line, which should be intrinsic in this or in any other action, is the emotional availability of nurses that, by providing the word to parents, allow them to discursively express their suffering, and thus symbolically elaborate it.

In the NICU, the nursing professional takes on assignments that, besides the direct care to children and their parents, comprise the administrative, bureaucratic and organizational actions, which carry both the interaction with other hospital departments and with

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other health professionals, such as psychologists, physicians, social workers, and physiotherapists. According to this set of attributes and to make possible a full and effective care to children and their parents, nurses indicate leaving behind an attitude of omnipotent care and emphasize the need for another one supported on interdisciplinarity:

**MI/DCS 6 – The importance of interdisciplinary care:** Nursing plays a key role at this moment, so they [the newborns] can get out of this situation with as little sequelae as possible. Having more staff, a psychology service more available in the sector, alongside with nursing; a social service more influent, especially on weekends.

The treatment of premature babies cannot be limited only to offering technological advances and therapeutic processes related; it also needs a professional with a psychosocial training, which should be the case of nurses. In this perspective, the care takes a humanized dimension, and the assistance in the NICU, coming off an organicist approach, becomes also humanized. It is an approach that enables the integration between parents and caregivers, and also as subjects of care.

**CONCLUSION**

The parents, in their relationship with the premature baby in the NICU, are presented, according to the nurses, with a condition of emotional distress characterized by the rupture between the image previously formed and desired, that of a healthy child, and that arising from prematurity: a sickened child and with real possibilities of sequelae or death. Therefore, it is a situation in which the child care process is also willing to face the dramatic repercussions of the hospitalization and the fears, especially for parents, which sometimes can also express difficulties of physical contact with the child.

Nurses, in general, are aware of the need for a balanced and sensible attitude to support parents in their coping with the premature birth of the child. Essentially, they assume a posture based on empathic listening, which favor an adaptive process. Parents who initially experience some emotional disorganization will slowly reorganizing and adapting to the invasive nature of the NICU. Gradually, they stop reacting defensively to treatment and start to realize it as a real possibility for the child’s recovery. Therefore, the nurses emphasize the importance of providing clinical information and welcoming of the expression of the fears experienced by parents. These attitudes allow the elaboration and overcoming of inadequate defensive actions, such as the speculative identification, cathartic expression and denial, and facilitate experiencing the desire for affiliation through the exercise of parenthood.

The work process in the NICU, given the risk situation involved and hence the set of activities demanded, imposes a working stress condition for health professionals, especially nurses, who are responsible for the service organization and the accomplishment of most of the actions developed. This is how the nursing professionals, facing the parents’ suffering, the fragility of premature births and the invasive procedures performed in treatment, identify with them, and thus, in a countertransference relationship, feel emotionally moved, also starting to experience a state of suffering. When the child’s death occurs, the suffering is even greater, and may even lead to feelings of helplessness and guilt. This labor dimension of suffering that permeates the work in the NICU highlights the importance of a professional nursing care to minimize or avoid stress reactions or anxiety, and even depression.

According to reports, the responsibility and labor demand faced by the nursing staff in the NICU do not prevent a humanized approach of the child and their parents, allowing transform it into a welcoming environment, whose assistance is not only organicist and technical. Reinforcing this perspective, we highlight the importance of an interdisciplinary team, which would...
result in a better understanding and intervention also on
the child’s psychological and social development, and
especially their parents’. We must understand that the
process of fragmentation and specialization of care is
historic-ideological, rather than a need. Particularly in
the NICU, the assistance cannot be fragmented, i.e.
directed only to the child and excluding parents, nor an
exclusivity of doctors and nurses, rather an exchange
among professionals, such as psychologists, social
workers and physiotherapists, if we want a
comprehensive and humanized care.

To make a couple of suggestions, the data set
allows us to observe and propose the importance of
implementing a support and discussion group in the
hospital environment, characterized by dialogue between
professionals and parents and among parents, so that,
through the report of the experiences and doubts, they
expose, clarify and elaborate the experiences derived
from the treatment. This group would become a
humanizing action, since, in emphasizing the uniqueness
of the parents, it dimensions each person according to
their socio-emotional condition. It can also be a space
for health professionals, especially nurses, express their
anxieties and thus preserve their mental health against
the risks inherent to the anxiogenic context of the NICU.

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