

HUMANIZATION IN THE NEONATAL INTENSIVE CARE UNIT FROM PARENTS' PERSPECTIVE

A HUMANIZAÇÃO EM UNIDADE DE TERAPIA INTENSIVA NEONATAL SOB A ÓTICA DOS PAIS

HUMANIZACIÓN EN UNA UNIDAD DE TERAPIA INTENSIVA NEONATAL SEGÚN LA PERCEPCIÓN DE LOS PADRES

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ABSTRACT

This study aimed to understand the meanings of humanization of care from the perspective of parents of newborns hospitalized in a Neonatal Intensive Care Unit. A descriptive and exploratory qualitative study was carried out with the parents of newborns hospitalized in a Neonatal Intensive Care Unit of a hospital in the countryside of São Paulo, through a semi-structured interview, in 2014. The methodological approach was the Content Analysis. A total of 14 interviews were carried out. Analyzing them, three categories emerged: "welcoming care to newborns", "relationship with parents" and "behavior of professionals". From the perspective of parents, the humanized care involves welcoming and respectful actions, to consider the uniqueness of individuals, and to understand the family as having an active role in the hospitalization process, but also in need of care.

Keywords: Intensive Care Units, Neonatal; Infant, Newborn; Humanization of Assistance.

RESUMO

Objetivou-se compreender os significados de humanização da assistência sob a ótica de pais de recém-nascidos internados em uma Unidade de Terapia Intensiva Neonatal. Estudo descritivo e exploratório, de natureza qualitativa, realizado com os pais dos recém-nascidos internados em Unidade de Terapia Intensiva Neonatal de um hospital do interior paulista, por meio de entrevista semiestruturada, no ano de 2014. Os dados foram analisados conforme o método da análise de conteúdo. Foram realizadas 14 entrevistas e da análise dos depoimentos emergiram três categorias: "assistência acolhedora aos recém-nascidos", "relacionamento com os pais" e "comportamento dos profissionais". O cuidado humanizado emerge como a maneira que se cuida e pela relação com os profissionais de saúde.

Palavras-chave: Unidades de Terapia Intensiva Neonatal; Recém-Nascido; Humanização da Assistência.

RESUMEN

El presente estudio tuvo como objeto comprender los significados de humanización de la atención desde la perspectiva de los padres de recién nacidos ingresados en una Unidad de Cuidados Intensivos Neonatales. Se trata de una investigación exploratoria descriptiva de naturaleza cualitativa realizada en 2014, a través de entrevistas semiestructuradas a los padres de niños recién nacidos ingresados en la Unidad de Cuidados Intensivos Neonatales de un hospital del interior del estado de San Pablo. Los datos fueron sometidos a análisis de contenido. Se llevaron a cabo 14 entrevistas y del análisis de los informes surgieron tres categorías: "atención acogedora a los recién nacidos", "relación con los padres" y "comportamiento de los profesionales". El cuidado humanizado se vislumbra como la manera cómo se cuida y por la relación con los profesionales de salud.

Palabras clave: Unidades de Cuidado Intensivo Neonatal; Recién Nacido; Humanización de la Atención.

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INTRODUCTION

The birth of a child represents for many families the fulfillment of a dream. All that parents want at this time is a safe, quiet gestation and the birth of a healthy child.

During the gestational period, quarter to quarter, the affective bond between mother and baby is strengthening, especially from the second trimester, when the first fetal movements begin, and for the first time, the woman feels the fetus as a concrete reality within her.¹ At the end of the gestation, several feelings and expectations rise and among them, the anxiety of the first contact with the child and the desire to take the healthy baby home. However, this desired outcome does not always occur, in some cases, it is necessary for the newborn (NB) to receive intensive care as early as the first days of life.

Prematurity, low weight, extreme low weight and some critical and specific conditions are the conditions in which hospitalization in a Neonatal Intensive Care Unit (NICU) may be necessary.^{2,3} Thus, the first contact with the child escapes from what was planned and expected.

Before the hospitalization of the NB in the NICU, the family faces the mourning of the idealized baby. The feelings of fear, insecurity, guilt, worries, and doubts about the prognosis of the newborn invade the life of the parents.⁴ Moreover, in addition to parents who find their child in a fragile, premature, low-weight state and unable to survive without intensive care, they also face the need to obey the hospital rules and routines.^{4,5}

Studies have shown the parents' perception about the NICU, which is defined as a hostile and often inaccessible, unfriendly environment, that causes unpleasant feelings and reactions and excludes parents from caring for their child.^{6,7} Because of this, it is necessary to modify this perception, the common sense, that associates the term ICU with the notion of pain and even the notion of death, and basing the care in the conception that the parents have the right to participate in the care of the child.^{7,8}

To this end, changes have been implemented in such environments in recent years. The theme of humanization was born as a program of the Ministry of Health, focused on the hospital care in 2001, with the objective of establishing guidelines for the implementation, development, and assessment of humanized actions in hospitals.⁹ In 2003, humanization ceased to be a program and has become the National Humanization Policy (NHP), proposing changes in the ways of managing and caring by valuing the human dimension of health practices. The embracement in health services, the expanded and shared clinic, the social participation and participative management are some of the guiding concepts of NHP.¹⁰

However, the humanization of care is a comprehensive and inclusive concept and refers to an initiative that comprises and values excellence in the quality of care, considering the technical point of view, the aspects related to the subjectiv-

ity of the user and also of the professional, the cultural references and the right to health.¹¹ In addition, four discursive axes are correlated in the concept of humanization: humanization as opposed to physical or psychological violence, which is expressed by mistreatment or unmet expectations of patients; humanization as the capacity to implement quality care, which articulates technological advances with a good relationship; humanization as the improvement of the working conditions of health professionals; and, finally, humanization as an extension of the communicational process, which is considered the central guideline of humanization.¹²

Including the family in the process of hospitalization of the newborn and guaranteeing quality care to both the patient and the family are the primary actions of humanization, especially when it comes to the hospitalization of a newborn, since the parents are fundamental characters in the process of growth and development of the child and the parent-child bond should be maintained and encouraged. In this context, the embracement becomes essential in the NICU environment. According to the NHP, the embracement is an ethical stance that involves listening to the user in their complaints, recognition of their role in the health and illness process, and accountability for a resolution, with the activation of knowledge sharing networks. It is built collectively and aims to build relationships of trust, commitment, and a bond between the professionals and the patients/families.¹⁰

Thus, we consider that understanding the meaning of the NICU's humanization for the parents is a necessary condition for seeking strategies and planning a care focused on meeting the real needs of the parents and the NB, to reduce possible damages that may be caused by negative experiences during the hospitalization period in the NICU.

In view of the above, the objective of this study was to understand the meanings of humanization of care from the perspective of the newborn babies (NBs) parents hospitalized in a Neonatal Intensive Care Unit (NICU).

METHOD

A descriptive and exploratory study of a qualitative nature developed at the NICU of a public-school hospital located in the countryside of the state of São Paulo, with a coverage area of 68 municipalities. The NICU has 16 hospital beds and a multi-professional team composed of physicians, nursing staff, physiotherapists, psychologists, and social workers. The parents' stay in the NICU is allowed daily from 10 am to 2 pm and from 3 pm to 8 pm provided that no invasive procedure is being performed in the NBs.

The inclusion criteria for participation in the study were: parents over the age of 18 who had children hospitalized for at

least seven days at the NICU, who agreed to participate in the study after being informed about the purposes, objectives and methods of the study with the guarantee of confidentiality and anonymity, by signing the Free and Informed Consent Term.

The data collection was carried out during the months of July to October 2014, through a semi-structured interview elaborated for this study, with the following guiding questions: "For you, what is the meaning of humanized care?"; "Tell me about your experience regarding the humanized care in this Neonatal ICU."

The interview was held in a single moment in a reserved space within the NICU itself, which guaranteed the privacy of the researcher and the respondent throughout the period, and there was no interruption at the time of the interview. The audio was recorded in its entirety on a voice recorder. The parents, for the purposes of this study, were identified with the numbering assigned to them at the time of the interviews (P01, P02, etc.) to maintain their anonymity.

The sample closure was due to theoretical saturation, i.e., the inclusion of new research participants occurred when the data obtained began to present repetition and redundancy and did not contribute significantly to the study.¹³

For the organization and analysis of the data, Bardin Content Analysis was adopted as a method.¹⁴ The content analysis is a set of communication techniques aimed at obtaining systematic and objective procedures for the description of the content of the messages, allowing the inference of knowledge about the conditions of production/reception of messages that define it as a research technique for objective and systematic description of the manifest content of the communication. The content analysis method is composed of three phases: the pre-analysis, the analytical description and the inferential interpretation.

In the treatment of the results obtained, in the inference and the interpretation, the data were revealed so that they became significant and valid, and the parents' perception regarding the humanization of the care was understood.

The research was carried out after approval by the Committee of Ethics in Research with Human Beings of the Botucatu School of Medicine under the opinion number 670.579, of June 2, 2014, in accordance with the ethical standards required by the Resolution of the National Health Council number 466 of 2012.

RESULTS AND DISCUSSION

A total of 14 parents participated in this study, 12 mothers (85.7%) and two fathers (14.3%). Most of the respondents were white (92.9%), had between 8 and 11 years of schooling (71.4%), were in a common-law marriage (50%) and the average age was 28 years old. In relation to the NB, the mean number of days of life was 38.5 days and the mean number of days of hospitalization was 36.9 days.

The meanings that parents attributed to the humanization of care were classified into three thematic categories which are described below:

CATEGORY 1: CARE PROVIDED TO THE NB

For the parents, the meaning of humanization presupposes that the care provided to the NB is based on human contact, in a welcoming way, and it must also contemplate the comprehensiveness and specificity of each child together with the scientific work of the professionals.

Humanized[...] as I can say[...] Attention care, especially in infants, who are so helpless. (P01)

It's to be considerate and to be there for any little thing, that's all. (P07)

Humanized care, let's say so, specific to each child, not to consider all children equal, each has a peculiarity, something a little different from the other. (P09)

The nurses took good care of her (NB), they were very affectionate, sometimes they even put a little clip on her hair. So, we'd be calm[...] because we knew it was not just a physical care, like changing the dressing, she had a little love too. (P14)

I think it involves the aspect of hygiene and everything to avoid infection, other types of illnesses (P05).

The concept of humanization for parents is strongly related to the concept of comprehensiveness. Comprehensiveness is one of the principles of the Unified Health System (SUS) that assumes different meanings that express desirable attributes for health practices.¹⁶ In the context of the NICU, comprehensiveness should guide the care to contemplate and respect the different dimensions and needs of the NB and their family, seeking a non-fragmented care.

A study carried out in a large hospital in the state of Minas Gerais, in the Pediatric ICU, also identified in family testimonies that the humanized care is related to the fact of receiving help, care, attention, and comfort.¹⁷ Also emerged the technical aspects, such as the cleaning and organization of the sector, the practice of hand hygiene, and the nursing care characteristic of an ICU, a high technology sector for the care of children under critical conditions. The care, therefore, is seen by the companions associated with the relationships of the professionals, the patient, and the family and interspersed with the scenario of intensive pediatric care.¹⁷

In the present study, negative aspects related to care were also experienced:

So, there were days of me staying there and virtually no one entering (in the room). Then [...] there were also days when he was crying very, very much, I would listen from outside e I would get there and there was nobody. In the case [...] there were unoccupied people. Yeah, it was not humanized. (P08)

The technical-scientific efficiency and administrative rationality in the health services, when unaccompanied by principles and values such as solidarity, respect, and ethics in the relationship between professionals and users, are not sufficient for the achievement of quality in health care.⁹

In the NICU, the humanization of the care is worth mentioning because it can be considered as the first step so that the families, mainly the parents, can deal with the hospitalization of their child in NICU in a less traumatic way.^{8,18}

CATEGORY 2: PROFESSIONAL VS. FAMILY RELATIONSHIPS

In this category, humanization meant for the parents to consider the family of the patient also as an object of work, with the need to be informed and treated with a careful and respectful attitude.

[...] besides taking care of the babies, the support that they (health professionals) gave to me and my wife. (P06)

Humanized care [...] care for all people, good care, providing attention[...] (P10)

It is to have respect [...], to be polite and to be kind, right? Because here you are working with people, with little moms and little dads who are going through a moment of suffering. (P03)

My blood pressure was very high and they (health professionals) were always careful, while it did not go down they were always there, on it. It was great for me. (P12)

Humanized[...] is to be treated very well[...]. (P13)

An efficient communication between the health team and the parents has also been cited as humanize care.

[...] because here I have a lot of doubt, right? I always ask a lot of questions and I always have good answers. (P13)

They had always explained her situation to us and how she was doing as soon as we arrived. (P03)

Listening to the fears and concerns of the family members is indispensable and must be the first action of the professionals, before even informing the parents and family about the routines of the unit, about the devices and care provided to the NB. According to the NHP, the qualified listening, that is, active and welcoming, is essential in building a relationship of trust between the family and the health professionals, being an important strategy for the embracement in the health services.^{10,19,20}

The integrative review on studies that address the relationships between health professionals and users during health practices aimed to identify the aspects researched in the daily life of the services about these relationships. The results of the research identified a high index of studies referring to communication as an integral component of the process of humanization of care, emphasizing that it is necessary to value the communication by the professionals with the subjects and their relatives for a humanized practice. They revealed that health service users are looking for qualified, committed professionals, prepared to listen to them and to communicate warmly, with the appreciation of their speeches, and that can respond to their needs.²¹

Efficient communication enables a harmonious care and is the essence for the humanized care. Through communication it is possible to understand and share messages, it is an exchange of messages that influences the behavior of the individuals involved.²²

In view of the hospitalization of the NB in the NICU, it is essential that the communication between family and the health team is efficient, to clarify doubts, the provision of clear, true, and adequate information. In this process, it is important that the health professional has, in each encounter with the relative, intentionality, and consciences in their actions, in addition to respect and empathy.

CATEGORY 3: BEHAVIOR OF THE HEALTH PROFESSIONAL

This category has brought the humanization of care related to the professional's behavior, their attitudes, dedication and, vocation to the activity.

I think that: you feel more secure about some than others. [...] some like to help more, others don't have this care... there are also some who are busier during the day and have no time[...] Humanized [...] is also enjoying what they do, you know, the profession. (P01)

There are some (health professionals) who are more attentive, stay together all the time. (P02)

See[...] 90% I have nothing to complain about. Of course, there will always be exceptions, right [...]. I usually say there is one (health professional) that, when she takes care of my son, I would tell her: 'when my son is with you I sleep peacefully'. (P11)

The professional's behavior and the attention given by the professionals were factors cited by relatives in another study, which identified that when the professional does not respond to the expectations of the family, showing neglect or lack of attention, care is interpreted as not humanized, which allows us to infer that the assessment of humanized care is closely related to the behavior and attitude of the professionals.²³

The concept of humanized care can be understood as a care based on respect, embracement and efficient communication, according to the reports and experiences of the parents of this study, which is in line with the National Program for the Humanization of Hospital Care and NHP, which advocates a dignified reception and differentiated relationship between professionals and users.^{9,10} However, in this study, from the parents' point of view, the physical structure, the equipment, and the environmental conditions were not included in the concept of humanization, although the concept of ambiance appears to create cozy, comfortable spaces that allow changes in the process and respect privacy.¹⁰

The humanized care should not be just a concept, but a practice based on the appreciation of the human and the uniqueness. Thus, the health professional during the care of the NB should be able to perform the technical procedures effectively, which are fundamental and very present in the NICU but also to consider the human issues involved in the whole context, since these are inherent in the care routine. However, it should be emphasized that humanized care is based on a set of individual actions, and therefore should not be cataloged or standardized.²⁴

This study presents as limitations a reduced and non-probabilistic sample, in a single context, that meets the assumptions of the qualitative research. However, it is considered that the study makes an important contribution to the process of reflection and construction of humanized care in these environments.

FINAL CONSIDERATIONS

From the parents' point of view, humanized care emerges as the terms that care is taken and by the relationship with health professionals. The professional's behavior, effective communication, individualized care provided to the NB and the family are factors that must be considered by the health team that seeks to offer humanized care.

It should be emphasized that this care should not only be a concept, but a practice based on the appreciation of the hu-

man and the singularity, and effectively implemented in the care provided to the NB admitted to the NICUs.

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