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A percepção do acompanhante sobre o atendimento humanizado em unidade de terapia intensiva pediátrica

The perception of the companion of the humanized care in a pediatric intensive care unit

La percepción de el compañero sobre el cuidado humanizado en una unidad de cuidados intensivos pediátricos

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ABSTRACT

Objective: To understand the perception of the companion of the hospitalized child about humanized care in the context of pediatric intensive care unit. **Methods:** A descriptive, exploratory study with a qualitative approach, developed in the pediatric intensive care unit of a pediatric hospital in Salvador to interview the caregivers of hospitalized children. The interviews were analyzed using content analysis technique. **Results:** Perceptions of family associate the meaning of humanized care to a greater affection and attention; values the guidance provided by the health team and emphasizes the importance of their presence throughout assistance. Concerns about the “lack of care” are from the suffering inherent in the child’s situation. **Conclusion:** The perception of companions on the concept of humanization involves attention, care, concern and sometimes even an emotional involvement with the patient and to understand their perception means to be alert to the real needs of the patient.

Descriptors: Humanization, Companion, Pediatric Intensive Care Unit.

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RESUMO

Objetivo: Compreender a percepção do acompanhante da criança hospitalizada acerca do atendimento humanizado no contexto da unidade de terapia intensiva pediátrica. **Métodos:** Estudo descritivo e exploratório com abordagem qualitativa, desenvolvido na unidade de terapia intensiva pediátrica de um Hospital Pediátrico em Salvador, onde foram entrevistados os acompanhantes das crianças hospitalizadas. Os depoimentos foram analisados através da Técnica de Análise de Conteúdo.

Resultados: As percepções dos familiares associam o significado de cuidado humanizado a um carinho e atenção maiores; valorizam as orientações dadas pela equipe de saúde e enfatizam a importância da sua presença durante toda assistência. As inquietações acerca do “não cuidado” são oriundas do sofrimento inerente à própria situação da criança. **Conclusão:** A percepção dos acompanhantes sobre o conceito de humanização envolve atenção, zelo, preocupação e muitas vezes até um envolvimento afetivo com o paciente e compreender a percepção deste, significa estar alerta às reais necessidades do indivíduo.

Descritores: Humanização, Acompanhante, Unidade de Terapia Intensiva Pediátrica.

RESUMEN

Objetivo: Comprender la percepción del compañero del niño hospitalizado acerca del cuidado humanizado en el contexto de la unidad de cuidados intensivos pediátricos. **Métodos:** Estudio descriptivo, exploratorio con abordaje cualitativo, desarrollado en la unidad de cuidados intensivos pediátricos de un hospital pediátrico en Salvador para entrevistar a los cuidadores de los niños hospitalizados. Las entrevistas fueron analizadas utilizando la técnica de análisis de contenido. **Resultados:** La percepción de la familia asocia el significado del cuidado humanizado en mayor afecto y atención; valorar la orientación proporcionada por el equipo de salud y hacer hincapié en la importancia de su presencia en la asistencia. La preocupación por la “falta de cuidado” es por el sufrimiento inherente a la situación del niño. **Conclusión:** La percepción de los compañeros en el concepto de humanización implica atención, cuidado, preocupación y, a veces incluso una implicación emocional con el paciente, y entender su percepción significa estar alerta a sus necesidades reales.

Descriptor: Humanización, Compañero, Unidad Pediátrica de Cuidados Intensivos.

INTRODUCTION

Humanize is caring, understanding and valuing the patient. The hospital environment and the hospitalization process are delicate situations for any patient, and has special contours when it comes to an event in the life of defenseless beings, as children and newborns, as it implies the change of routine of the whole family.¹

Brazil only improved over the humanization of child care, after the publication of Law nº 8,069 in 1990, regulating the Statute of Children and Adolescents, which in its Article 12 requires that health facilities should provide conditions for the permanence of a parent or guardian, full-time, in child or adolescent hospitalization cases.²

Humanization policies were implemented in order to improve the care provided by the health services. Thus arose the Humanization Policy of Hospital Care, the Kangaroo

Mother Care Program and the Baby Friendly Hospital. These advances have been intensifying due to the joint efforts of the Ministry of Health and especially of society.

Within this panorama, the humanization of the hospitalized child care currently searches to involve the family increasingly in the care given to the small patient. Parents of these hospitalized children, acting as their legal representatives, can provide important contributions to assist in fault identification committed by the hospital system^{1,3} that invariably end up causing a less effective and erroneous caregiving, that justifies listening to these relatives. Today, the family is more active and more participant, in both planning and assistance, that is why human care to children requires interaction with the family in the most holistic manner possible.⁴

In addition to this importance, in the context of the assessment of hospital care, parents play a key role in the circumstance of childhood hospitalization, as they represent the fundamental reference of the child, as mediators of the therapeutic relationship, the main source of security and warmth, and essential support to face this challenging situation that is disease and hospitalization.^{1,5}

In this sense, the question is: What view does a family of a hospitalized child in an intensive care unit has on humanization of assistance? What is the meaning of humanized care?

This paper aims to contribute with reflections on these questions and seeks to understand the perception of the companion of the hospitalized child about humanized care in the context of the pediatric intensive care unit (PICU).

To answer these questions, the objective of this work is to understand the perception of the hospitalized child companion about humanized care in the context of the pediatric intensive care unit. Thus, one might be able to decode the manner in which the companion perceives the care provided to hospitalized children in intensive care unit from the perspective of humanization.

The results of this study will provide health professionals with a foundation for the practice of humanized care with hospitalized children in PICU in order to propose a reorganization in the hospital so that the focus is centered not only on the child but also on the family.

OBJECTIVE

To understand the perception of the companion of the hospitalized child about humanized care in the context of the pediatric intensive care unit.

METHODS

This is a descriptive study of a qualitative nature conducted in the Pediatric Intensive Care Unit of a pediatric hospital in Salvador, which has 10 beds and has the predominant feature of long-term cases of hospitalization, due to the chronic nature of the diagnoses.

The population of this study was composed of relatives of children admitted to the Intensive Care Unit, regardless of the diagnosis for which they were admitted and the length of stay in that unit. During the period of data collection were interviewed companions who were present at the time of collection and who agreed to participate in the study by signing the Free and Enlightened Term of Consent.

Thus, were excluded from the research family of children who were admitted to units other than intensive care one and also family members of patients admitted to the pediatric intensive care unit that did not meet the criterion of being parents and/or grandparents of patients, and who did not accept to participate in the study or to sign the Instrument of Consent.

Data collection occurred during the months of June and July 2010, during the visit of the family to the intensive care unit. The collection technique used was the semi-structured interview that was to implement a road map consisting of open and closed questions, divided into two sections. The first, related to the identification and socio-demographic characteristics of the study informants and the second composed of broad and open-ended questions, which addressed issues related to the topic under study, including the companion understanding about humanization and the perception they have of humanized care provided in the unit.

The interviews were conducted individually in the unit facilities, recorded and lasted an average of six minutes. Later, they were fully transcribed and coded with names of precious stones.

Content Analysis technic was used for data analysis.⁶ Exhaustive readings from their comments were made, and the information was organized through the following steps: sorting the data collected, re-reading the material and organization of reports and classification of data through categories.

For the construction of the categories, the lines were subjected to a coding process. The significant elements of each of the lines were highlighted, which received a code. Related codes were divided into categories.

At all stages of this research were considered the principles established by Resolution n° 196/96 of the National Health Council, which regulates research involving human subjects in order to comply with the guidelines and standards for autonomy, beneficence, non-maleficence and justice, ensuring the rights of the informants.⁷

All participants were informed about the objectives and relevance of this study, the nature of scientific work, as were guaranteed anonymity and confidentiality of responses. They were informed about their participation, by reading and signing the Free and Enlightened Term of Consent. To the people who agreed to participate in this research, was assured the right to withdraw their participation at any time, at no cost, through contact, available as indicated above, of any of the researchers.

RESULTS AND DISCUSSION

Human care is “an ethical attitude through which human beings perceive and recognize the rights of each other.” In human care, there is a commitment to each other, a responsibility to be in the world.⁸

Caring involves an interactive action grounded in the values and knowledge of the caregiver and care receiver. Care arouses feelings of compassion, solidarity and help. In health, humanized care is aimed at the patient's well-being, their moral integrity and their dignity as person.⁹

From the findings obtained during the research, it was necessary to guide this study through the following aspects: The humanized care; The perception of suffering, all described and presented in their respective categories.

The humanized care

Caring for in a humane way is a current need, as many times it ends up becoming a mere application of techniques. It is, first of all, the realization that the being to which these techniques are being applied is a biopsicosocial agent.¹⁰

Human care involves ethics, principles and values. It cannot be prescribed as it is felt, experienced and exercised. Therefore, care is understood as “an action and a behavior of attendance, management and teaching with zeal, keeping the well-being”.⁸

A comprehensive analysis of the speeches of the interviewed companions allowed the identification of an association between the meaning of humanized care and a greater care and attention.

“I think that humanized care is to be well taken care of.” (Onyx)

“It's when they take really good care, they give affection.” (Amethyst)

At one point in history, health becomes valued as a value above any discussion. Thus, humanizing health implies to accept and recognize that in this area there are still problems and shortcomings. To humanize is not only to “soften” the hospital coexistence but to put oneself in another's place and to give it voice.¹¹

It is of great importance and it is part of a humanized care, the guidance given by the staff on procedures performed on the patient as well as on its situation. The statements underscore the importance of establishing effective communication with family members, using to this end, strategies of verbal and non-verbal communication. One can note in the lines below the importance given to such situation.

“Caring involves responsibility, to be responsible, to listen, to give us information, care in general [...]” (Emerald)

“I think care is everything, even telling us what is going on, what they are doing to help our child [...] and there are many ways to say what is going on, sometimes with a look or by swinging their head they tell us the reality, words are not always needed.” (Diamond)

Thus, the act of humanistic care reveals itself concretely when the nurse, based on its technical competence but without losing tenderness, tries to give this mother the information it needs to calm down.¹²

The lack of information and uncertainty are major sources of anxiety in patients and their companions. The uncertainty often causes apprehension and anxiety in the family, that waits afflicted for the time of the visit to ask about their doubts and preferably receive good news.¹³

“Ever since she got here, they do the possible and the impossible, they give baths, change the saline and watch everything, explaining everything, it helps a lot.” (Ruby)

“I want to know everything I need to know, they have to know how they are going to break the news.” (Crystal)

Most companions considered as a concept for humanized care actions taken by the professionals that provide affection and attention bestowed upon them and the little patients. Another aspect that was highlighted in the speeches was the importance of establishing relationships of trust and respect between the health staff and patients and families.

“Here they treat well. When he feels something there is always someone by his side.” (Onyx)

“They always treat well, they understand the pain of my daughter, understand my pain and respect that. In some, you see they work for love.” (Diamond)

“I feel that my child is well cared for, safe [...]. It is important to trust, isn't it? In spite of all I'm going through, I trust the team.” (Ruby)

Parents perceive the hospitalization of the child through the interaction with members of the healthcare team and the care provided to the child. They value the technology and dedication of the professionals, but above all, attitudes of respect and consideration, judging them indispensable in interpersonal relations.¹⁴

To bring the mother or the responsible to the unit is not a simple matter, because it implies in the reorganization of the work process in theoretical and practical levels. A fact to consider is that the permanence of the parents imprints another dynamic to the process because they are not only

developing technical skills, but getting to know the everyday of the hospital and of the therapy.⁵

This discourse is supported by Emerald's speech, where it states that to humanize is much more than to give affection, is to be present during the entire assistance, playing their caring role.

“It is to be able to participate in this care, to understand the disease, sure, to stay here and see all this is difficult, I have never seen my son like this [...], but I'd rather be here by his side, I couldn't stay anywhere else.” (Emerald)

As parents attend the unit, they come to rely increasingly on the team that provides assistance to the child, thus decreasing the anxiety transmitted by the environment.¹⁵

Thus, confirming the idea found in the speech of respondent companions, to the family, what really matters is the care given to the patient and whether it is loving or not. The stress of the situation itself and the difficulty of coping are ameliorated by the treatment provided to the patient by the team. Consequently, there is no way to promote the humane care without the inclusion of the family.¹⁶

Humanized care will only really exist when the health team develops actions that seek to humanize care. One should understand the child as a being who feels, cries, but does not speak. Moreover, it is part of a household that suffers, still needing protection and support.¹¹

This way, the patient begins to receive the care deserved performed by human hands and that provide him a job worthy of humans.

The perception of suffering

Directing our interest to the experience of the companion and analyzing the dialogues that took place during the interviews, we realized that the concerns about the “lack of care” derive from the suffering inherent in the child's situation.

“It is a lot of exams. He cries a lot.” (Onyx)

“Every day someone comes to draw her blood. That hurts.” (Ruby)

“To see my son no being able to speak, not eating, not even breathing alone, is much suffering for a child.” (Emerald)

The main concern of the companions of hospitalized children refers to the excessive number of procedures to which they are subjected. The expressions reveal that there is no association between suffering caused by procedures and a possible lack of care by the professionals.

The experience of having a hospitalized child is very painful for both the child and their parents. So, the professionals working in this area have a concern regarding

the assistance of the families in a humanized way. In its study, the author demonstrates the need for nurses to be aware of the importance of the support given to parents during this time. By Diamond's speech, it is perceived that this concern is noticed in some professionals.¹⁷

"I don't think there is anything bad, they do everything right [...]. Care about our children, care about us, that's enough." (Diamond)

The combination of technology and humanized care transforms a place of pain and suffering in an environment capable of inspiring hope for a future in which children and their parents have a decent life. To understand the child's and parents' condition is not enough, one must seek to overcome the adversities of the disease process and the hospitalization.¹⁴

CONCLUSION

It was currently found through this study that ICU humanization has a broader horizon, encompassing from the physical environment to the relationship between health professionals and patients/families. The philosophy of humanization is becoming more popular in the perception of intensive care units, and more understood as a location that enables the recovery of patients and not necessarily a place for the patients with no chance of survival.

It was shown that the perception of companions on the concept of humanization involves attention, care, concern, and often even an affectionate involvement with the patient.

They reveal in their testimonies that although it is an ICU, where the stress of work is great, the professionals involved in this work environment act in a humane way, give affection, respect and understand the situation of the child, thus enabling an alliance between the existing technological resources and a more humanistic care.

The perception of the companion contemplated the importance of practical strategies such as comprehensive listening, verbal and nonverbal communication, optimization of information among team members, and with the child/family. Emphasizing the importance of honesty of professionals concerning informations, not hiding anything regarding the treatment of their families.

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