FAMILY CAREGIVER OF HOSPITALIZED CHILD IN THE VIEW THE NURSING TEAM

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ABSTRACT
This study aimed to delineate the concepts of the nursing staff about the family caregivers of hospitalized children. A clinical-qualitative research conducted with 14 nurses at a university hospital in southern Brazil. The data were collected between September and October 2011, through semi-structured interviews and treated by the technique of content analysis, emerging four thematic categories those address the relationship between work and family in the context of children's hospitalization: "The family in children's hospitalization: elements for care", "Hospitalized children: family support and child welfare", "The family caregivers and professional caregivers: similarities and differences in the pediatric inpatient" and "The role of the family in host and care process". One can check that for the nursing staff, the family is central to the monitoring of hospitalized children, contributing to the care and recovery process of health. It is concluded that the process of reflection and continuous training of staff for reception and humane approach of the family is essential to the qualification of pediatric care.


INTRODUCTION

When the first pediatric hospitals came, from the nineteenth century, the presence of accompanying children was allowed by the time that they could have. Records show that the first of these hospitals was implemented in 1802 in Paris and later in London and in the United States in 1850. However, this period was marked by the great spread of infectious diseases, which led to the need to adopt stringent measures, resulting in the restriction of visits and isolation of hospitalized children\(^{(1,2)}\).

After The Second World War and with the discovery of antibiotics, the child is seen as a psychosocial being and who presented a need for special care. The increasingly small number of men in Europe, which affected the economy of the nations, was also an important factor and stiffener of this way of thinking. However, the discussion on the need for rooming for children and their caregivers peaked only in 1943, when researchers showed the beneficial influence of parental presence for the recovery of hospitalized children. In line with this premise, the World Health Organization releases in 1951, reports that relate to maternal absence during children’s hospitalization, as something detrimental to the mental health of children who require hospitalization\(^{(2)}\).

Another milestone in this context was the Platt report, published in the UK in 1959, and also saw the release of the visit of the parents, with no time restriction, as an essential element to promote the emotional and psychosocial well-being of children in hospitals\(^{(2,3)}\).

In Brazil, the program "Mother-participant" of the State of São Paulo, established, through Resolution SS n. 165\(^{(4)}\), was the starting point for the implementation of rooming for pediatric hospitalization. It followed this initiative, the Law 8069 of 1990, which consolidated the Statute of Children and Adolescents\(^{(5)}\), ensuring that clientele, the right to rooming in cases of hospitalization. Later, in 1993, the Ministerial Decree n. 1.016\(^{(6)}\) came to the regulatory standards for implementation of rooming nationwide.

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This new landscape has also brought in its wake a differentiated reality of work for the nursing staff, which shall be an extension of the escort service and demand, not only restricted to hospitalized children.

In this context and based on the assumptions of the Family Centered Care (FCC), arises the need for a paid-for professionals involved in the direct care of the child looks, the presence and encouraging family participation throughout the hospitalization process and the opportunity to clarification of doubts and valuing the specific needs of care throughout the hospitalization period, since the FCC emphasizes the family as the fundamental source of support and considers the involvement of the same essential to promote the health of all members of child and the whole family (3).

The appreciation of the presence of the family, especially the mother in the child care is reflected in the educational process, informative, of two-ways, between escort and indispensable team within reach of an assistant practice really humane and humanizing (7).

Thus, it is essential to understand the child in their family and social context, encouraging the participation of parents and caregivers in child care, offering them the opportunity to express their concerns through active listening as an important resource for a healthy childhood (8).

Thus, despite the knowledge gaps or differences in cultural values that may exist between family and health professionals, the process of communication and effective interaction between these social actors are translated into element of greatest relevance to the quality of the assistance, having a direct impact on treatment success. Based on these assumptions, the present study aimed to delineate the concepts of the nursing staff about the family caregivers of hospitalized children.

**METHODOLOGY**

The study was based on a clinical-qualitative method; theoretical study that interprets the meanings given to phenomena related to the life of the individual is a patient or other person participating in the scenario of health care (9). We believe that this methodology for trying to interpret the interpersonal relationships of individuals (in the case of this study, family caregivers and nursing staff), is suitable for this research, since they can decipher meanings of this relationship and unveiling positives and negatives points.

Nurses and nursing technicians, working in pediatric admissions department of a university hospital in southern Brazil, were invited to participate in the study. From the previous scheduling and telephone contact, the professionals were interviewed in their work schedules. Data were collected between September and October 2011 through semi-structured interviews which were conducted individually in a private room next to the sector, the following guiding question: “What is your opinion about the presence of family caregivers during pediatric hospitalization?”

The interviews were recorded, transcribed and analyzed. For interpretation of the data was chosen for the thematic the content analysis (8). It was chosen to identify reports from participants the most common, frequent and meaningful expressions, following the phases of pre-analysis, material exploration, processing and interpretation of the results. In the first phase, or pre-analysis detailed readings of the articles were made in order to raise the points relevant to the study objective. In the second phase, the exploration of the material, proceeded to the data encoding, the process by which the raw data are systematically transformed and aggregated into units of record. In the last stage, the processing of results, categorization, which consists of classifying the elements according to their similarities and differentiation, with the subsequent reunification on the basis of common features was performed (10). To evidence these common features, it is used a color-coded rating, assigning colors to the same texts with common characteristics (eg. speeches that portrayed the feelings were highlighted in green, depicting the behavior were highlighted in red, and so on).

For presenting the results of the study, and to ensure the anonymity of the subjects, they were identified with the acronym "TEC ENF" for nursing techniques and "ENF" for nurses, followed by Arabic numerals 1-5 for nurses and 1-9 for nursing technicians, according to the order of the interviews.
There were followed the ethical aspects of human research, established by Resolution no. 196/96 of the National Health Council (NHC) and revised by Resolution 466/2012 of the NHC (11). The research project had the approval of the Standing Committee on Ethics in Research Involving Humans, as Opinion nº 648/2011. The agreement to participate in the study was recorded by means of signing the consent form in two copies, becoming one of the routes signed with each partner in the study.

RESULTS AND DISCUSSION

The study involved the participation of five nurses and nine nursing technicians, which perform their functions in the pediatric unit, totaling 14 participating subjects, aged 22 to 56 years old, all female. The operating time in the unit ranged from six months to nine years. Interviews lasted on average 38 min each.

Gives data analysis resulted in four discursive categories: "The family in child hospitalization: elements for care"; "Hospitalized children: family support and child welfare"; "The family caregivers and professional caregivers: similarities and differences in the pediatric inpatient" and "The role of the family in the host and care process."

The family in child hospitalization: elements for caregiving

The child's hospitalization process sometimes requires a longer hospital stay, competing family monitoring the recovery and integration of the child with the hospital and the nursing staff. For the paid care effectively occur, it is necessary to a proper process of communication and cooperation between the family and the professionals who provide care to children.

The family's relationship with the child, I think it has to be a relationship so reliable, so the family must always attend, interact and ask, must always be trying to get information, not leave with doubt. Always seek to dispel doubts, you know? Because from the moment the child is hospitalized in pediatrics, benefit the most from it is the child and family. She has to attend assiduously in treating children, to have more security and also have no doubt (TEC ENF 3).

The focus of pediatric nursing care should not just be hospitalized children, but should include the family, respecting their individuality and unique characteristics. So should seek assist the family in their doubts, anxieties, encourage participation in care, support their initiatives, so as to favor the recovery of the health of the child, taking into account their culture, spirituality, and socioeconomic status (12).

It is very important to establish links between the family and the nursing staff from the beginning of hospitalization, in order to alleviate the stress caused by hospitalization. The emotional support offered to hospitalized children by the companion is in facilitating recovery tool which, if not well crafted, could result in creating a barrier between nursing and child.

The family, I think it's essential! But since we can assess that this family wants to interact with multidisciplinary team ... Because if she wants to learn how to care for the child here, obviously she will want care at home (TEC ENF2).

I think the presence of the family is important, only because most kids must have a continuous (care) at home. So here the family has to continue training at home (TEC ENF 5).

The report of TEC ENF 2 makes us reflect how the nursing staff believes that the family has a certain "duty" in wanting to learn the inherent care for hospitalized children; otherwise it is assumed that it does not provide the necessary care will know when household.

However, the authors (13) reported in their study that the skills for care independent of any specific skills, emphasizing that such skills are dependent on confidence, mental and physical health, level of education, autonomy and also the cultural environment, type work, time available, the family receives help from family and community.

Still, it is of paramount importance to realize that there are different limits for each. That is not always the family caregiver will have physical and / or emotional conditions to provide care, especially in hospitals. In this sense, the nursing staff must respect these limitations, considering that even members of this team, provided with appropriate training, can sometimes come across challenges of care to be provided, the more a family-caregiver that, an hour to the other, takes on the role of responsible for that sick child, having to learn to perform
procedures which never was minimally prepared for this.

Not infrequently, the care in the hospital environment developed by nursing staff has its follow-up at home, where usually the mother is responsible for performing it. The other family members are assigned secondary and distinct roles. In the face of the bond that mothers and children establish themselves from pregnancy and due to the thorough knowledge they possess about the habits, preferences and behaviors of their children, it is almost a natural condition, being mothers, persons elected to monitoring of minors in their experience of hospitalization.

The knowledge of the physical and emotional peculiarities of the child allows the mother to identify signs or reactions presented by his son, assisting the nursing staff, as there is a maternal sensitivity, can consider "cultural" in our society regarding the perception of the first symptoms disease demonstrated by the child. In this sense, the proper care and early involvement of the family and especially the mother in-hospital care process, translates into an essential condition for the successful transition of this care home environment for the child.

The child in the hospital: the family as child welfare support

The permanence of the parents during the child's hospitalization has triggered new forms of organization of care, emphasizing the humanization of it. From this perspective, it is necessary to broaden the focus of hospitalized children, to direct a closer look to the owning family care, beyond the purely clinical care. Thus, care must also encompass the family, allowing their participation in child care, respecting their beliefs and preferences, facilitating their presence, providing the necessary support.

The family spends nurturing, support in many ways and passes security and confidence. Thus, the child feels better and is less stressed... So if you'll change a diaper, it is obvious that she will prefer to replace the mother! If you go to the bathroom, she will feel more comfortable if the mother gives bath. So, it is important yes! Greatly improves and you leave the child less stressed (TEC ENF 6).

The family, as an institution, attends the basic needs of its members, and their responsibility to care for and raise children, including the requirement of food, hygiene, clothing and housing, and has a close relationship and trust with the child. When a child is hospitalized, this relationship extends to hospital.

The relatives and caregivers become intermediaries of child care during hospitalization, facilitating communication between the child and the nursing staff. The absence of family produces insecurity in the child, causing the hospitalization period become something traumatic, slowing the process of recovery and medical discharge.

If the mother is willing to watch your child improve, she will accept whatever is being done to him "a good" quiet, without stop, without creating barrier ... I think this is a wonderful progress, because the mother helps us a lot. Sometimes with medication: have a mother who can give talking to his son. He goes there and takes "a good"! The treatment actually evolves (NFE 1).

Reveals itself through the above account how the nursing staff often put the family as submissive regarding the procedures to be performed aiming at child care. There still exists the perception that mothers, when "barring" the provision of care for their child in the hospital, most often, is because she still did not understand the need to perform this procedure, or because no one explained this to her need (inefficiently explained).

In a study conducted with families of children (six families) who were born weighing less than or equal to 3 Apgar score at 5th min, diagnosed with severe perinatal asphyxia, in the State of Rio Grande do Sul in 2005, 2006 and 2007, the authors found that the information passed to the Professional relatives, most often, were mediated inefficiently, providing care to these children a delay of initiation and various obstacles on the acceptance of the same by the family.

Nevertheless, this recognition of the importance of the family in the therapeutic process and aiming to child welfare, there are situations where this relationship is not established smoothly, and in which there was the acceptance of unfamiliar care or assistance provided. The first contact between family and nursing staff often not perceived positively,
depending on factors such as fear, anxiety, distress, lack of procedures to be performed with the child and the lack of trust in interpersonal relationships\(^{13}\). There are even considering that this first contact is signed in a very familiar environment for members of the nursing team, this is your place of work in their daily lives. But for the family caregiver that internal along with the child, this is a place totally out of context that usually these patients usually attend, with different routines, unfamiliar people and procedures not only unusual, but also often painful.

Moreover, when there is a lack of interaction between parents and nursing, the child is more resistant to care and no cooperation from the child. Usually this is broken, waiting to nonverbal cues from parents, the tangent to how to respond or react to the interventions made by the team. Acceptance of treatment the child is directly linked to the understanding that parents have of this process, and affective input provided by them during this experiment.

They feel safe and secure. Sometimes it's difficult with the family that does not "coordinate" with the child, and therefore not accept a situation. Another thing we see is thus the same clinical picture, have family that gets along but does not accept the situation, then, creates a psychological problem. When there is a social problem, we try to solve ... and will talking, huh? (TEC ENF 1).

In situations where the health of the child is severe, the family caregiver, especially a mother, can appear fragile and feeling helpless to the situation forward, thus needing support and support team. When this support happens, the family feels strengthened and evaluates care as effective\(^{16}\).

In the hospitalized child, therefore, nursing should understand the moments of uncertainty and suffering of family members, seeking to establish an affective and effective dialogic relationship in order to build a bond of trust culminating in the reestablishment of balance and family structure.

The family and the nursing staff as main agents of disease modification/hospital place

Hospitalization or the discovery of a disease is able to disrupt the dynamics within the family. The sick child requires constant attention from the family, especially the mother, making the performance of other household and family chores. If there is a good understanding between members of this family, the new health situation possibly triggers conflicts and misunderstandings, and heavy workloads on the primary caregiver of the sick child. These imbalances may interfere with the child's recovery, which is fragile and takes her caregiver the source of security to meet the challenges posed by their new health status.

When the family is a family gift, the child is right ... She is happy and treatment goes up faster! It's all very calm. But when there is a social problem, a problem with some conflict within the family, gets in the way treatment (ENF 3).

Children and their families experience various difficulties during periods of hospitalization, whether as a result of the separation of family members during hospitalization, whether as a result of profound changes in their daily activities, or even fear of the unknown and death. The nursing staff should provide a calm environment, making them less invasive procedures traumatic for the child, through the establishment of a bond of affection and trust. Thus, the child may feel more secure against care, identifying those who care for them, by their names. When parents or carers feel their children are getting assistance from someone "known", come to rely on their competence and feel safer and more open, better understanding the health condition and treatment. This fosters sense of security to parents, to discuss the opening with the nursing staff your feelings about hospitalization, reducing their anxiety and helping the child in their recovery\(^{15}\).

The role of the family in the host and care process

The family is the first institution known by the child. Within the family, it feels safe and secure the extent to which emotional ties are becoming increasingly strong. When faced with another environment, so it is natural that children experience feelings of fear and threat to this security condition. The hospital environment, particularly, presents itself as extremely threatening in the eyes of the child, either by their physical and organizational characteristics, either because of the strange and strangely dressed people who "inhabit" this place.

In these circumstances, not infrequently the child feels unprotected, punished, and helpless
before the deprivation of their routine, their friends, their anchorages safety and well-being. At this time, the presence of family is fundamental, as a facilitator of this process of transition. The presence of a significant family, especially the mother, coming with and sharing this confrontation with his son, makes this new scenario presents itself less hostile and traumatizing the child. Nursing recognizes the need for monitoring the child's family in the hospital, as an essential support for the physical and psychological well-being of the same:

Family is very important in the child's hospitalization! I see that she has to be present, giving lullaby ... the things we do not have to spend! The affection that the family provides for child support ..., in many ways: security and trust. The child feels better and is less stressed (TEC 6).

Since 1980, in Brazil, it has been thinking about the rights of the child. Thus, it is believed that the inclusion of a family companion during the period of hospitalization of children and their involvement in the therapeutic process provides an understanding of the dynamics of relationships between nursing staff and family (18) to meet with such rights.

The presence of parents in the hospital is the most effective method to reduce the psychological and emotional trauma of hospitalization of the child, presenting as main advantage the fact giving opportunity to the family caregiver, feel physically and emotionally available to your child, so to share this with the difficult experience of hospitalization. For the nursing staff, the advantages are: better interaction with parents and the feeling of greater safety of the child, provided by the presence of a familiar face.

Whereas, for some researchers in the field, nursing is placed featured as "profession that participates in the training of family care, as has training for the education of the clientele attending", a familiar presence gives opportunity to team teach and encourage parental involvement in caring for their children, ultimately allowing these professionals to devote more time to unaccompanied children (20).

**FINAL CONSIDERATIONS**

The theme of family recovery has occupied more space in the center of discussions about health care. Thus, the understanding of man as a holistic, leads to the need for approaches that consider this completeness as well as the influence and importance of the family in the preservation or recovery of health process. This observation becomes more apparent when referring to the health-disease in childhood.

The approach to hospitalized children should consider the preservation of their fundamental rights, with a view to promoting their physical, mental and psychological health; their actions should extend also to the child's family. We have to consider the experience of illness and hospitalization in childhood affects not only the sick child, but has varied effects on the family and family dynamics.

In this perspective, it is the multidisciplinary team which considers this scenario attention, recognizing the familiar role and promoting their effective participation in the care process. Nevertheless, there are numerous evidences on the benefits of family presence in the children's hospital, participation and acceptance of family attention these scenarios are not always appropriately. This study confirms the importance of this recognition by the professionals interviewed nursing. It appears from the analysis of the reports obtained, the ongoing need for investment in education, health care activities in these contexts, with emphasis on the factual information of the families, the appropriate inter-personal communication and the adoption of foster care during the child's hospitalization while strategies for increasing qualification of care.
que tratam das relaciones entre profesionales e familiares no contexto da internación infantil; “A familia na hospitalización infantil: elementos para o cuidar”, “A criança hospitalizada: a família como suporte do bem-estar infantil”, “O cuidador familiar e o cuidador profesional: encontros e desencontros na internação pediátrica” e “O papel da familia no processo de acolhimento e cuidar”. Pode-se verificar que, para a equipe de enfermagem, a família é fundamental no acompañamiento da criança hospitalizada, contribuindo para o cuidado e o proceso de recuperação da saúde. Conclui-se que o processo de reflexão e capacitação continua da equipe para o acolhimento e a abordagem humanizada dos familiares é essencial à qualificación do cuidado pediátrico.


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**RESUMEN**

Este estudio tuvo como objetivo delinear los conceptos del personal de enfermería a cerca de los cuidadores familiares de niños hospitalizados. Una investigación clínico-cualitativa realizada con 14 enfermeros de un hospital universitario en el sur de Brasil. Los datos fueron recogidos entre septiembre y octubre de 2011, a través de entrevistas semi-estructuradas y tratados mediante la técnica de análisis de contenido, produciendo cuatro categorías temáticas que abordan la relación entre el trabajo y la familia en el contexto de la hospitalización de los niños: “La familia en la hospitalización de los niños: elementos para el cuidado” “El niño hospitalizado: la familia como apoyo del bienestar infantil”, “El cuidador familiar y el cuidado profesional: encuentros y desencuentros en la internación pediátrica” y “El papel de la familia en el proceso de acogida y cuidado”. Se puede comprobar que, para el personal de enfermería, la familia es fundamental en la acogida de los niños hospitalizados, lo que contribuye al cuidado y en el proceso de recuperación de la salud. Llega a la conclusión de que el proceso de reflexión y formación continua del personal para la acogida y el enfoque humanizado de la familia es esencial para la calificación de la atención pediátrica.


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Submitted: 09/10/2013
Accepted: 19/03/2014