THE FAMILY NECESSITY IN THE HOSPITALIZATION OF CHILDREN: SUBSIDIES FOR NURSING

A FAMILIA FREnte À NECCESSIDADE DE INTERNAÇÃO HOSPITALAR DA CRIANÇA: SUBSIDIOS PARA A ENFERMAGEM

LA FAMILIA FRENTE A LA NECESIDAD DE INTERNACIÓN HOSPITALAR DEL NIÑO: SUBSIDIOS PARA LA ENFERMERÍA

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ABSTRACT

Objective: to know the experiences and perceptions of family caregivers about the need of hospitalization of the child. Method: it is a descriptive and exploratory study, with qualitative approach with methodological referential of the Theory Based on the Data held in the first half of 2010, at a hospital in southern Brazil, with 15 family caregivers. The production of the data was performed by semi-structured interviews, analyzed by the open, axial and selective encoding. The research project has been approved by the Research Ethics Committee, under CAEE-23116.00352012009 19. Results: from the analysis of the interviews, three categories emerged <<recognizing the lack of sources to care the child at home >>; << Recognizing the lack of ability to care the child at home > and << feeling distressed for the hospitalization >>. Conclusion: the nursing staff needs to be prepared to provide support, guidance and information to children and their families, in order to facilitate the acceptance of hospitalization. Descriptors: Child Hospitalized; Family; Pediatries; Nursing.

RESUMO


RESUMEN

Objetivo: conocer las experiencias y percepciones de familiares cuidadores acerca de la necesidad de la internación hospitalaria del niño. Método: estudio descritivo y exploratorio, de enfoque cualitativo, con referencial metodológico de la Teoría Fundamentada en los Datos, realizado en el primer semestre de 2010, en un hospital en el sur de Brasil, con 15 familiares cuidadores. La producción de los datos fue realizada por entrevistas semiestructuradas, analizadas por la codificación abierta, axial y selectiva. El proyecto de investigación fue aprobado por el Comité de Ética en Investigación, sobre CAEE nº 23116.00352012009-19. Resultados: a partir de los análisis de las entrevistas, emergieron tres categorías << Reconociendo el empeoramiento en el cuadro clínico del niño>>; << Reconociendo la falta de recurso para cuidar del niño en casa >> y << Sintiéndose angustiada frente a la internación hospitalaria >>. Conclusión: el equipo de enfermería necesita estar preparado para dar apoyo, orientaciones e informaciones para el niño y sus familiares, de modo que facilite la aceptación de la internación hospitalaria. Descriptores: Niño Hospitalizado; Familia; Pediatria; Enfermería.

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INTRODUCTION

The family is the first place where the disease occurs and begins to be treated and cured. Generally, the family caregivers are the members who identify the first manifestations of the disease in children, mobilizing to take care of them trying to recover. They are watchers and put into practice their knowledge and resources present in the social and family circle of support.\(^1\) Caregiving the child in case of illness at home is presented itself as a dynamic process, surrounded by signs and symbols interpreted by the family, raising reactions in accordance with the meanings attributed to this experience.\(^5\)

Due to the child's illness, the family can expand, seeking external resources in order to qualify their potential caregiver.\(^7\) They search for help with significant people in the expanded family or neighbors, friends, and health services. In addition to targeted care to the sick body, to minimize the symptoms, it is common the use of popular practices of care, based on common knowledge, but close to the familiar reality, such as the use of teas, sympathies and benedictions.\(^1\) In addition, they usually demand for health services, in the search for new knowledge and resources of the professional system of care to the family care system.\(^3\)

Despite these cares, in some situations, the worsening of clinical picture of the child appeared and once again it is perceived by the family through the identification of new or worsening of pre-existing symptoms. The child is in need of care and resources that the family may not possess. The lack of financial conditions to afford the cost of treatment, a weak network of social support in the community, the lack of help to care for the child, the ignorance about the disease and the severity of the clinical picture are conditions for the family care for the child at home.\(^1\)

Facing the exhaustion of family resources related to the care and worsening of clinical picture of the child, it is strengthened the search for professional care. In the medical opinion about the need of hospitalization of the child, the family feels heavily distressed.\(^4\) They may feel fear and blame for the situation and to present feeling of failure in the mission of promoting the health of the child. However, before the depletion of its resources to care for the child at home, the family resigns to the need of hospitalization of that human being, to recognize it necessary.

Hospitalization is seen as a stressful and distressing situation in people's lives, and points a special outline when it is experienced by children, as it affects the life and family routine, having a change in the life of every family.\(^6\) For the family, the hospitalization enters the child into an environment that often threatens his sense of security and competence.\(^8\) So, as it is an essential foundation for the child, the family needs to be aware of the benefits that such intervention may provide him so that he can accept the need for hospitalization and organize themselves to his care.

Hospitalization, although feared, is presented as the ability to provide specialized care to the child, because the hospital brings together the resources that the child needs and that the family has not.\(^9\) Thus, it is presented itself as a viable solution for the treatment and cure of child. In front of this finding, the family then takes the child to be hospitalized.

In this context, the nursing staff can be recognized as a source of care that enables to identify the bio-psychosocial needs of families and children.\(^4\) In order to assist the family in this moment, it is necessary that the nursing team professionals meet their previous experiences to the hospitalization of the child and perceptions about it. So, the question that has guided this study was: what are the experiences and perceptions of family caregivers about the need for hospitalization of the child? In this sense, the objective of this study was to learn about the experiences and perceptions of family caregivers about the need of hospitalization of the child.

METHOD

The present study has been extracted from the Final Report of the Scientific Initiation Research project/CNPQ/FURG << Family experiences in the hospital during the hospitalization of the child >>, valid from August 2009 to 2010.

This is an exploratory and descriptive study of qualitative approach, developed in the first half of 2010, in a unit of Pediatrics, from a hospital in southern Brazil. The unit has 25 beds, all for children under agreements by the Unified Health System (Sistema Único de Saúde, SUS).

The descriptive and exploratory search addresses the description of the investigated phenomenon, making it possible to meet the problems experienced and deepen their study within the limits of a specific reality.\(^10\) The qualitative approach considers, as a source of study, the perspective of individuals who experience certain phenomenon and their meanings.\(^10\)
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15 family caregivers of hospitalized children participated in the study, in the first half of 2010. They were divided into four groups, two consisting of five family members, one by three and another by two. As criteria for the choice of participants, the following conditions were determined: be a significant caregiver of the child and to provide direct care at the hospital.

The production of the data was collected through semi-structured interviews. The family caregivers of hospitalized children were questioned about their acceptance of the need for hospitalization of the child. The interviews were scheduled with each family and subsequently recorded and transcribed for analysis.

Data were analyzed according to the methodological referential of the Theory Based on Data.11-12 This was operationalized, for the simultaneous analysis of the data, through open codification, which was carried out the examination of the data line by line, cutting the units of analysis; followed by the axial coding with their categorization and, finally, selective encoding, in which they were certain connections between the categories.

The ethical principles of research involving human beings, as the Resolution 196/96, were followed13. The research project was referred to the Committee of Ethics in Research at the Federal University of Rio Grande and approved by the Certificate of Introduction to Ethics Assessment (CAEE) nº 23116.00352012009, receiving assent to its publication under Protocol No 92/2009. The lines have been identified by the letter F, followed by the number of the interview as a way to ensure their anonymity.

RESULTS

From the data analysis emerged three categories: Recognizing the worsening clinical picture of the child; Recognizing the lack of resources to care for the child at home and Feeling distressed for the hospitalization.

◆ Recognizing the worsening clinical picture of the child

The family in front of the child's illness gives them care and are watchers following the evolution of their state of health. From the network of interactions with the child, with the environment in which it operates and to himself, the family realizes the worsening clinical picture.

My daughter has always been healthy, well cared for and then she got sick. When we are faced with the illness, we do everything in our power to take care of her. She coughed a lot and breathed wrong. I took her along with my mom in the center a couple of times to consult, but she only got worse. In seven days, treating her at home, she only got worse. (F1)

I took him to see, I gave him medication, I took care of everything, but he got worse. I brought to see at night. They did a fogging and sent him away. In the morning, I brought him again because he got worse. (F3)

This worsening is recognized through the appearance of new symptoms or worsening of preexisting symptoms, of which families often are unaware of the etiology, they can't cope or are afraid of the consequences, as in the case of high fever or the seizure.

After two bad days, my daughter started with shortness of breath and fatigue. She was tearful, thing that is not. With 40 degree of fever, from 5 p.m. to 2 a.m. I panicked, I feared something worse. (F2) My son had a convulsion at home. I took him to the emergency center. I was so scared that I went in front of the other people who were in the queue. I'm afraid of worsening of his neurological status and his constant respiratory infection. This disease of him [encephalopathy] needs to hospitalized, but I just hospitalize him when there is no way to care for him at home. (F3)

Worsening is still perceived due to not getting the expected effects of the medicines administered to the child or permanent care at home.

He began using stronger medication and had no effect. But he can no longer take antibiotic, so he was worsening. He used syrup, but also didn't work, the flu evolved. He had a lot of phlegm, then pneumonia started again. (F4)

So, when I saw that the diarrhea was not stopping, I tried the packet of serum that my neighbor had at home and gave it to me. It was not good and the diarrhea continued. (F12)

◆ Recognizing the lack of resources to care for the child at home

As the family recognizes the depletion of its resources and its limitations to continue caring for the child at home, they realize that the child needs professional care because it is out of control. Dependent on these resources, the care will be provided at the hospital.

With the worsening of her, I saw that she needed stronger medicine that I could not buy. I used homemade teas, but she got so much worse. Without resources, only hospitalizing. How I would stay with the girl at home like that? (F5)

When she arrived here, the doctor sent her for examinations. Things that out of here I wouldn't be able to do it fast, because it would be more time-consuming. So, she hospitalized. (F13)
The difficulty to consult a physician, in basic health units in the days and times they need, as well as the lack of resources for the purchase of medicines prescribed by him, when consulted, presenting themselves as conditions for proper care to the sick child at home.

I do not possess health insurance. There at the health center, you never get to consult with a doctor because the queue is immense. To go early with him, I have no one to leave the other children with. We can't compete for the consultation, because we don't have any money to pay. (F12)

Where I live, it has a health center, but to take her I have to go very early in the morning. In addition, sometimes we go there and the doctor does not come. (F6)

There's only pediatrician in the health center on Mondays and Thursdays. When I get the consultation, I can't buy the medications. They are very expensive. Most of the medications that my son needs are not provided by the city hall and by health center. (F7)

The lack of help to care for the child at home is a familiar limitation to child care in case of illness. In addition, in some situations, there is a lack of knowledge of the pathology to subsidize the family as caregiver of the son.

I am alone. I have no one to help me to take care of her at home. I don't know how to take care of a child with bronchitis. I don't quite understand why this disease. There are things to watch at home. (F5)

Another difficulty of families becomes evident when these reside in the interior cities, having to find the features of which they do not have to care for the child in another city.

I'm here for five months in the hospital. I came from the city A, because there is not resource to meet child with seizure. There, I leave home and take her on the health center for a consultation, but never had a pediatrician. Then she had this problem and always she has to hospitalize, even with financial difficulty, I come to this town and hospitalize her here. Here there is a neurologist. (F8)

There in city B, they do not meet the most severe cases and, if hospitalize, until the baby bath tub we have to take from home. (F14)

Feeling distressed from the hospitalization

The need for hospitalization of the child showed feeling of distress in the family, carried out by its fear of entering the world of the hospital, as well as the severity of the clinical picture of the child. The hospital is recognized by the families as an unknown world, which is subjected to pain and suffering.

We are distressed and frightened. I'm a little afraid, because here, we're just in the middle of the sickness and routines that I don't know. I suffered thinking that I could lose my daughter [cry]. (F6)

It is very painful for us, as parents, to accept the necessity of hospitalization. We must bring them to hospitalize, although we want to treat them at home. They are not sure what she's got. I'm scared of all this. (F11)

The family presents sadness and despair facing the need for hospitalization of the child. They feel guilty and present profound sense of failure in their role as caregiver and promoting the health and well-being of the child.

We were desperate because we know that meningitis is a very serious disease. I feel that we should have prevented this hospitalization, this disease. I don't know what more we could have done, but I don't accept that he almost died. I know I'm not, but I feel guilty. I see him so helpless, so fragile. Our desire is to protect, to defend him from everything and everyone. It may be an exaggeration, but I feel like this. (F9)

Having a daughter in the hospital is very sad. Oh, no […] to come to the hospital it is have to be just to have a son. (F10)

Another familiar aggravating is the fear of losing control over the situation in which the child is found. Families reveal also mistrust what they can make with his son at the hospital as they feel distant from the care and the health team provides.

Her mother was desperate with the hospitalization. She cried every day, she worsened after hospitalization. The nurses said they could take about 48 hours to give treatment result. I felt with hands tied. I had to wait for her improvement. (F15)

We take care very well at home. She has all the time and the hour. And then he has to hospitalize because of it. We feel very bad. I don't think they're going to take care of her here as at home. And if they give a wrong medication? I need more information. (F11)

Discussion

Child's illness is not an unusual family life case. To care for the child in his illness has been presented as a common practice. To take care of him, effectively the family provides care, become a watcher and search features available on social support network. Parents use various practices contained in their reality, as the use of teas, benediction and sympathies. They make use of...
medications they know and they have fearing of the misfortunes that can cause the disease.\textsuperscript{1,3} They request help from relatives, friends and neighbors, sharing the care, resources and knowledge with them.

When families acknowledge the worsening of clinical picture of the child, due to failure obtaining the expected effects of care at home, they seek for professional assistance.\textsuperscript{3} On the difficulty of access to medical consultations, prescribed medications and information about the pathology of the son, the family tends to recognize their lack of resources to care for the child at home and searches the efficaciousness of hospitals for their health problems.

In the need for hospitalization of the child, the family may feel anxious, fearing that the child worsens presenting sense of guilt and failure by the situation.\textsuperscript{1,6} These feelings can interfere with their ability to care for the child at the hospital.

The family realizes that to look after the child they need help because they fear losing control of the situation in the child disease.\textsuperscript{6} They recognize the need of being help by their families, friends and health team. When requesting professional care for the child they want to share with such care, empowering themselves as caregiver.

At the hospital the family believes that will interact with various professionals, getting from them specialized care for the child, so articulate and cooperative.\textsuperscript{17} Nursing staff professionals should carry out educational practices with the goal of providing family child care, becoming part of their social support network for the care to be small, both in hospital and at home, assisting in the prevention of diseases in children, in its treatment and avoiding the need of hospitalization.\textsuperscript{1}

\section*{CONCLUSION}

The data obtained in this study reveal the experiences and perceptions of family caregivers about the need for hospitalization of the child. It was found that they provide child care at home based on their own caregiving, supported by its network of social interaction.

In front of the illness of the child, it was evidenced that the family seeks professional help with the purpose of enhancing the child care in case of illness. However, it is not always this feature becomes sufficient for child care that requires specialist care. In the lack of resources, the family tends to resign with the hospitalization of the child, as it is to recognize the hospital as the best chance for his care, since this is characterized as an environment where there are the technological resources and professionals that the child needs.

It was concluded that the family needs to be helped to fulfil their role as caregiver, both at home and in the hospital, so that the child does not require any new admission. Basic network professionals and the hospital need to work together so that the health network works. Therefore, it is necessary to reflect on the health care provided to the family and the child in the community, placing the family in the care of the child in the hospital, as well as the acceptance of admission for this dyad.

It is necessary to carry out health education, comprehensively, providing the family knowledge about children's diseases and ways of prevention and care, with the aim of avoiding their deterioration and need hospitalization. There is a need of facilitating access to family health services, enabling early diagnosis of pathologies and features for your treatment. Thus, it is possible to construct a shared care for the child, both at home and in the hospital. We must meet the needs and demands of families, empowering them as caregivers, making it less traumatic time of hospitalization of the child when required.

It is not enough just to be engaged in nursing goal. The multidisciplinary team must be united and focused for such a purpose, because it's not just nursing the family interacts and shares the caution. Need to put efforts in the quest for improving the care that lends itself, by articulated and committed work.

It is the responsibility of the nurse to allow rebuilding their professional practice, from interactions with families that need to be met in their unique needs, both at home and in the hospital. For this, they become needed professionals to support preparations and Humanized, guidelines and information, in order to facilitate the acceptance of the family of the need of child hospitalization.

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