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## ORIGINAL ARTICLE

### THE FAMILY MOBILIZING AGAINST THE MANIFESTATIONS OF CHILD DISEASE A FAMÍLIA MOBILIZANDO-SE FRENTE ÀS MANIFESTAÇÕES DE DOENÇA DA CRIANÇA LA FAMILIA MOBILIZÁNDOSE FRENTE A LAS MANIFESTACIONES DE ENFERMEDADES DEL NIÑO

Giovana Calcagno Gomes<sup>1</sup>, Daiani Modernel Xavier<sup>2</sup>, Aline Campelo Pintanel<sup>3</sup>, Deise Ribeiro Aquino<sup>4</sup>, Dóris Helena Ribeiro Farias<sup>5</sup>, Pâmela Kath de Oliveira<sup>6</sup>

#### ABSTRACT

**Objective:** to know how the family is mobilizing against the manifestations of illness of the child. **Method:** descriptive-exploratory study, of qualitative approach, with methodological referential of the Theory Based on Data held in the first half of 2010, at a hospital in southern Brazil, with 15 family caregivers. Data collection was held by semi-structured interviews, analyzed by the open, axial and selective encoding. The research had the project approved by the Ethics Committee in Research of FURG, CAEE nº 23116.00352012009-19. **Results:** from the analysis of the interviews, emerged the three categories: 1. Realizing the first manifestations of the disease in children, 2. Seeking social support network resources and 3. Looking for health services. **Conclusion:** it is necessary for the nursing staff, with their role as a health educator, to use accessible mechanisms to instrumentalize the familiar, inside every reality, seeking the support networks, thus avoiding the aggravation of the state of health of the child. **Descriptors:** Child Hospitalized; Family; Pediatrics; Nursing.

#### RESUMO

**Objetivo:** conhecer como a família mobiliza-se frente às manifestações de doença da criança. **Método:** estudo descritivo-exploratório, de abordagem qualitativa, com referencial metodológico da Teoria Fundamentada nos Dados, realizada no primeiro semestre de 2010, em um hospital no sul do Brasil, com 15 familiares cuidadores. A coleta de dados realizou-se por entrevistas semiestruturadas, analisadas pela codificação aberta, axial e seletiva. A pesquisa teve aprovado projeto pelo Comitê de Ética em Pesquisa da FURG, CAEE nº 23116.00352012009-19. **Resultados:** a partir das análises das entrevistas, emergiram as três categorias: 1. Percebendo as primeiras manifestações de doença na criança, 2. Buscando recursos na rede de apoio social e 3. Procurando os serviços de saúde. **Conclusão:** faz-se necessário para que a equipe de enfermagem, com o seu papel de educador em saúde, utilize mecanismos acessíveis para instrumentalizar o familiar, dentro de cada realidade, a procurar as redes de apoio, evitando assim o agravo do estado de saúde da criança. **Descritores:** Criança Hospitalizada; Família; Pediatria; Enfermagem.

#### RESUMEN

**Objetivo:** conocer como la familia se moviliza frente a las manifestaciones de enfermedades del niño. **Método:** estudio descriptivo-exploratorio, de enfoque cualitativo, con referencial metodológico de la Teoría Fundamentada en los Datos, realizada en el primer semestre de 2010, en un hospital en el sur de Brasil, con 15 familiares cuidadores. La recolección de datos se realizó por entrevistas semi-estructuradas, analizadas por la codificación abierta, axial y selectiva. La investigación tuvo el proyecto aprobado por el Comité de Ética em Investigación de la FURG, CAEE nº 23116.00352012009-19. **Resultados:** a partir del análisis de las entrevistas, surgieron las tres categorías: 1. Percibiendo las primeras manifestaciones de enfermedad en el niño, 2. Buscando recursos en la red de apoyo social y 3. Buscando los servicios de salud. **Conclusión:** se hace necesario para que el equipo de enfermería, con su papel de educador en salud, utilice mecanismos accesibles para instrumentalizar el familiar, dentro de cada realidad, buscando las redes de apoyo, evitando así el agravo del estado de salud del niño. **Descriptor:** Niño Hospitalizado; Familia; Pediatría; Enfermería.

<sup>1</sup>Nurse, PhD Professor, Graduation/Post-graduate Program in Nursing, Federal University of Rio Grande/PPGENF/FURG. Rio Grande (RS), Brazil. E-mail: [giovanacalcagno@furg.br](mailto:giovanacalcagno@furg.br); <sup>2</sup>Nurse, PhD, Post-graduate Program in Nursing, Federal University of Rio Grande/PPGENF/FURG. Rio Grande (RS), Brazil. E-mail: [daiamoder@ibest.com.br](mailto:daiamoder@ibest.com.br); <sup>3</sup>Nurse, PhD Professor, Nursing Graduation, Federal University of Rio Grande/FURG. Rio Grande (RS), Brazil. E-mail: [acpintanel@furg.br](mailto:acpintanel@furg.br); <sup>4</sup>Nurse, Master degree Professor, Post-graduate Program in Nursing, Federal University of Rio Grande/PPGENF/FURG. Rio Grande (RS), Brazil. E-mail: [deiseaquino@furg.br](mailto:deiseaquino@furg.br); <sup>5</sup>Nurse, Master degree, Post-graduate Program in Nursing, Federal University of Rio Grande/PPGENF/FURG. Rio Grande (RS), Brazil. E-mail: [dorisenf@hotmail.com](mailto:dorisenf@hotmail.com); <sup>6</sup>Nurse, Master degree, Post-graduate Program in Nursing, Federal University of Rio Grande/PPGENF/FURG. Rio Grande (RS), Brazil. E-mail: [pamelakathpko@yahoo.com.br](mailto:pamelakathpko@yahoo.com.br)



## INTRODUCTION

When one of the family members experience the disease process, the structure and family relationships can suffer some changes.<sup>1</sup> In order to overcome this difficult moment, the family reorganizes and rebalances facing the disease.<sup>2-4</sup> The hospitalization of the child is presented to the family as a time of crisis. It can get sick and often feel guilty and powerless against this event.<sup>5-6</sup>

During childhood many diseases appeared, being classified as acute or chronic, and may trigger psychological changes in its bearers.<sup>7</sup> For the family, the disease of the child has a symbolic, moral, social and psychological representation for the family.<sup>8</sup> The hospitalization of the child put the family to moments of fear, doubt, sadness, worry, helplessness and despair and when there is lack of information and of psychosocial support this confrontation becomes harder.<sup>9-10</sup>

Experiencing the disease of the child, the families seek support with the other members of the family, because with them it is possible to carry out an exchange of experiences and feelings, resulting in decreased anxiety and fear. The relationship with the other members of the family expanded, helps in coping with the situation and treatment of the child.<sup>11</sup> When the child gets sick, the first person who realizes what is happening, it is usually the mother. The first attempt to help the child occurs at home and if this attempt is not successful, the family seeks then, professional help. When the state of health of the child remains the same, or worsens, the family seeks other resources to try to solve the problem.<sup>12</sup>

Many times, the mother feels responsible for the child's health status, becoming involved with his illness and treatment so intense that sometimes, she gives up her care needs to support the child in this coping.<sup>13</sup> When this mother has other children, it is important that family members visualize their needs, because they also suffer to see his sick brother and may show jealousy by the lack of attention of parents who prioritize the care of the sick child.<sup>14,15</sup> In this context, it is visualized that with the illness child, the family mobilizes to provide care. So, the guiding question of this study was: How does the family mobilize with the first manifestations of illness of the child? From this questions, the study aims to:

- Know how the family mobilizes with the manifestations of illness of the child.

## METHOD

The present study has been extracted from the Scientific Initiation Research Report/CNPQ/FURG << **Family experiences in the hospital during the hospitalization of the child** >>, from August 2009 to 2010. This is a descriptive and exploratory research with qualitative approach. This kind of research covers the description of the phenomenon investigated, making possible to know the problems experienced and deepen their study within the limits of a specific reality.<sup>16</sup>

It was held in a Pediatrics Unit, from a hospital in southern Brazil. It has 25 beds, all for children under agreements by the Sistema Único de Saúde (SUS). In this study 15 family caregivers of children hospitalized in the first half of 2010 have participated. They were divided into four groups, two sampling consisting of five family members, one by three and another by two. As criteria for the choice of participants, were determined the following conditions: be significant caregiver of the child, provide direct care in hospital and accept to participate in the study.

The data were collected through semi-structured interviews. They were asked about their acceptance of the need for hospitalization of the child. The interviews have been scheduled with each family, recorded and transcribed for analysis.

The data obtained were analyzed according to the methodological referential of the Theory Based on Data.<sup>17-8</sup> It was operationalized by the simultaneous analysis of the data, by open encoding, in which the examination of the data line by line was conducted, cutting the units of analysis; axial coding ensued, with their categorization and, finally the selective encoding in which there were certain connections between the categories.

The ethical principles of the research involving human beings, as the Resolution 196/96 were followed.<sup>19</sup> The research project was referred to the Ethic Committee in Research at the Federal University of Rio Grande and approved by the Certificate of Introduction to Ethics Assessment (CAEE) nº 23116.00352012009-19, receiving opinion 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

The analysis of data generated two categories: Realizing the first manifestations of the disease in children, Seeking social



support network resources and looking for health services.

#### ◆ Realizing the first manifestations of the disease in children

The disease is a common and inevitable episode in the life of any child. It appears suddenly or it is a slow and progressive. The family is the first place where the disease occurs and the child begins to be treated.

*The girl had a fever and bronchitis. She had a strong flu which turned bronchiolitis. (F1)*

*My son's disease performed with difficulty, he wasn't born with this problem, he was after. He was four days old, and then from there, he began the problem of jaundice. With three days I thought he was kind of yellowing, but everything that is child gets kind of yellow. The doctor waited too long and, when he was doing a transfusion, he was already with six days of light bath and, therefore, it did not give more time. He has a cerebral palsy, leaving an injury. (F3)*

The family, due to its proximity and conviviality is who identifies the first manifestations of diseases in children and mobilizes in order to find them. This fact demonstrates the organic and interactional aspect of the family, in the uniqueness of each of its members. The main manifestations of diseases identified by the families of this study were: cold, flu, fever, cough, skin yellowing, mood swings, difficulty swallowing, shortness of breath and pain.

*I noticed that he was very quiet and sleepy. When I saw him, he was with 41-degree fever. I was scared. In the morning, I was laughing and joking and, in the afternoon, he was like that. (F2)*

*He started with a sneeze and cough and I've taken to consult. (F6)*

*My son had Meningitis when she was underage, and stayed with Hydrocephalus, having to put a valve in the head. I noticed that his head began to grow and the eyes were bigger. I was scared. (F5)*

#### ◆ Seeking social support network resources

This category consists of two sub-categories: caring for the child at home and looking for health services.

##### ◆ Taking care of the child at home

Taking care of the sick child at home has been a commonplace activity. The family, usually the mother, when she realizes that his child is sick, she tries to take care of him at home with the resources and expertise available to her, from their previous experiences and of the meanings attributed to them.

She performs careful practices within her reality. The main household care to the child are those carried out with the objective of alleviating the symptoms of diseases, comforting him, and those directed to the sick body, such as caring for the child does not get cold, dress properly, eat well and reduce the fever.

*I take care of her to not be cold. She was feeling sick and did not want to eat. I made chicken noodle soup. I gave it in her mouth. She just wanted to be on my lap. (F4)*

*I really wanted to reduce the fever. I took a wet handkerchief, with natural water, and put it in his forehead. It was what I could do to help. (F7)*

Algumas famílias utilizam-se de práticas da medicina popular, como o uso de chás, benzeduras e simpatias. Também, utilizam medicamentos de que dispõem em casa e que foram utilizados em ocasiões anteriores de doença na família. Medicam a criança com os medicamentos que conhecem ou que lhes foram indicados por pessoas leigas.

Some families use popular medicine practices such as the use of teas, blessings and sympathies. Also, they use medicines available at home that have been used on previous occasions of illness in the family. They medicate the child with the medicines that they know or that have been indicated by a lay person.

*We do everything, when I saw that she had a fever I gave the pill I've ever had at home. I thought it was flu or tooth bearing. I gave her fennel tea. (F6)*

*I always try to medicate at home with what I have. (F7)*

*So, when I saw that the diarrhea was not stopping, I have tried everything: blessings to stop it, leaf tea of Surinam, pomegranate bark tea and sympathy. (F8)*

The family does not stay calm in front of the disease; it is active, dynamic in the pursuit of their right to live. They use the resources present in their social circle, surrounding a social and family support network to assist in the care of the sick child at home. It is verified the existence of parental solidarity that contributes to survival and to the existence of families. This solidarity is through sharing and permanent exchange of services, support all the time and all the problems and knowledge.

In cases of illness, the family expands. Generally, women are mobilizing this support network in people like mother, mother-in-law, sister and neighbors, helping to care for the child directly, by providing knowledge based on their previous experiences with the disease.



*When she got sick, I called my sister because she already has four children and, perhaps, she knew what to do. I said, I'm taking her to the doctor. She said it was silly, that her kids she cares at home. I saw it was ignorance, because she didn't know what to do for shortness of breath of the child. Because my sister doesn't know anything. She doesn't know anything about herbs tea. She said it was bronchitis and Pneumonia. If I go for it, I'm just at home and lose the girl. (F6)*

*We can handle it and when we see that the child gets sick, we do everything to care for him at home. I ask my mother what to do, even, I call the neighbor to help me. O do everything they tell me. I bought and gave the medicine the doctor prescribed. (F15)*

With the illness, the family promotes changes in their daily life, in order to better take care of the child. As strategies, there are the missing service to care for the child at home and do not take the child into school.

*When I saw that she was sick, I call to my job and say I couldn't go because my daughter was sick and just me to take care for her at home. (F10)*

*That day onwards, he was no longer in kindergarten. He only goes when he is really good. (F12)*

#### ◆ Looking for health services

Many times the care provided at home is not enough for the child to recover. In this way, families seek health services. There are several behaviors of families with the child disease, but health services are sought frequently in situations of illness of the child, especially when the family sees the worsening of clinical symptoms.

They seek health services in order to subsidize their care for the child at home. This fact shows that the family is strongly influenced by the professional health care system and it is presented as a promoter of health by aggregating internal and external resources with the disease of their members.

Families use covenants, take the child to consultations in basic health units or in the hospital. According to their judgment about the evolution of the clinical picture of the child, they seek more of a health service and hear the opinion of a medical professional. They repeat this strategy several times, until the resolution of the problem of the child.

*I as a mother, without a health plan, with no other help I brought her in the emergency room to see. (F9)*

*We have an insurance, so I always take, every sneeze I get a consult and I ask for the tests, he does CBC, chest x-rays. Because this illness (encephalopathy) he needs*

*hospitalization, often, but I just don't have domestic way to take care at home. (F14)*

*I called the Pediatrician and took him in the office at the time. I was so scared I was in front of the other people who were in the office. (F11)*

*I took her to see, I gave medicines and take care, but she got worse. I brought her to see at night. They did a fogging and sent us home. In the morning, I brought her again, when she was hospitalized. (F13)*

## DISCUSSION

At first the family is who identifies the first manifestations of disease in children.<sup>20</sup> To encounter these, she mobilizes in order to care for the child with a view to their recovery, according to the meanings that these demonstrations have for them.<sup>4</sup> They stay alert and put into practice their knowledge and resources present in their social and family circle of support, to the child to get better<sup>21</sup>.

The family is the first space where the disease occurs and begins to be treated and cured. When health changes of one of its members are realized, each component of the family interacts with itself, interprets and defines the situation, giving suggestions and meaning and starts the act of seeking for help.<sup>22</sup>

The care for the child in case of illness at home is presented as a dynamic process, surrounded by signs and symbols interpreted by the family raising reactions, as the meanings attributed to this experience. With the illness, the family can expand, seeking external resources, in order to qualify more their potential of caregiver. They search help with significant people in the expanded family or neighbors, friends and health services.<sup>23</sup>

Practically, all cultures have their views on health and disease and their own care behaviors.<sup>22</sup> Besides care directed to the sick body, with a view to minimizing the symptoms, it is common the use of popular practices of care, based on common knowledge, but close to the familiar reality as the use of teas, sympathies and blessings.<sup>24</sup>

The family, commonly, seeks for health services, in the search to add knowledge and resources of the professional system of care to the family system of care. It was found that, sometimes, the family is looking for more than one health service, aiming to expand their resources to care for the child.<sup>3,25</sup>

The family health system is inserted in a sociocultural context that includes the professional and popular system of care which makes exchanges, influencing and being



influenced by them. Despite these care, in some situations, the worsening of clinical picture of the child appears and, once again, it is perceived by the family through the identification of new symptoms or worsening of pre-existing symptoms.<sup>3,24</sup>

The child is needing care and resources that the family may not possess.<sup>5</sup> The lack of financial conditions to afford the cost of treatment, a network of social support of disabled in the community, the lack of help to care for the child, ignorance about the disease, the severity of the clinical picture are conditions for the family care for the child at home.<sup>26</sup>

Facing the exhaustion of resources related to the care and worsening of clinical picture of the child, it is reinforced then, the search for professional care. With the medical opinion, about the need of hospitalization of the child, the family feels heavily distressed. They feel fear and guilt for the situation and presents sense of failure in the mission of promoting the health of the child.<sup>10</sup>

The symbolic representation of hospitalization is danger and risk of life of the son. His feelings and behaviors are based on prior idea of hospital with symbols and meanings constructed throughout its history, in social and family life.<sup>4</sup>

## CONCLUSION

The sick child is a common and inevitable episode. Being the disease of sudden onset or slow and progressive, it is his family, especially his mother, who realizes the signs and symptoms of illness. From the perception of changes in the health of the child, the family establishes measures, initially at home, in an attempt to improve his health.

The care at home is a trivial activity, within the reality that his family is inserted. They uses resources and expertise acquired by their own experience and meanings assigned. The measures established by the family focus, primarily, on the easing of symptoms, comforting the child.

Although establishing measures of care, the family is not liable to the situation, they seek to solve problems by using, initially, characteristics present in their social circle. With the illness of the child, the family passes to experience a new situation needing to reorganize the needs of the child. It is observed that the family situation of disease expands, adding the entire network of support for the welfare of the child.

Even with all the efforts, many times home resources are not enough for the recovery of

the child. Thus, there is a need to seek health services. This is sought in order to subsidize the care provided by viewing the recovery of the child. They take the child in consultations in the Basic Health Units or at the hospital, seeking care at several health services, hear opinions from different professionals, many times repeating this process until the resolution of the problem of child health.

The family of the child, normally makes the identification of the child's health problems, seeking the resolution of it and when they cannot do it or the child shows a worsening of the signs and symptoms of the disease, they search health services aiming at the recovery of the child.

It is necessary to understand how the family mobilizes against the manifestations of illness of the child, so that the nursing staff, with their role as a health educator, use accessible mechanisms to instrumentalize the familiar, inside every reality, seeking the support networks, thus avoiding the aggravation of the state of the child's health and his hospitalization.

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#### Corresponding Address

Daiani Modernel Xavier  
Programa de Pós-Graduação em Enfermagem  
Escola de Enfermagem  
Universidade Federal do Rio Grande  
General Osório, s/nº – Campus da Saúde –  
Centro  
CEP 96201-900 – Rio Grande (RS), Brasil