

**FAMILY EXPERIENCE IN THE HOSPITAL  
DURING CHILD HOSPITALIZATION**Giovana Calcagno GOMES<sup>a</sup>, Pâmela Kath de OLIVEIRA<sup>b</sup>**ABSTRACT**

This study aimed to reveal how family experiences the hospitalization of the child in hospital. The study was performed at the pediatrics ward at a university hospital, in the state of Rio Grande do Sul, Brazil. The methodological approach was based on Grounded Theory. Data were collected through semi-structured interviews, during the first semester of 2010 with 12 companion mothers. They were divided into two sample groups. Comparative analysis of the data generated two categories: negative family experiences during child hospitalization and positive family experiences during child hospitalization. It is known that the experiences of families in the hospital lead us to reflect on our actions when facing them, indicating strategies that professionals can adopt in order to provide a more effective care, they help to experience a healthier hospitalization of the child, reflecting on this process.

**Descriptors:** Family. Child, hospitalized. Nursing.

**RESUMO**

*Objetivou-se compreender como a família vivencia o período de internação da criança no hospital. O estudo foi realizado na Unidade de Pediatria de um Hospital Universitário do sul do país. O referencial metodológico foi baseado na Teoria Fundamentada nos Dados. A coleta de dados foi realizada através de entrevistas semiestruturadas, realizadas no primeiro semestre de 2010, com 12 mães acompanhantes. Estas foram divididas em dois grupos amostrais. A análise comparativa dos dados gerou duas categorias: Vivências Negativas da Família durante a internação da criança no hospital e Vivências Positivas da Família durante a internação da criança no hospital. Conclui-se que conhecer as vivências das famílias, no hospital, nos remete a refletir acerca de nossas ações frente a elas, indicando estratégias que os profissionais podem adotar com vistas a prestar um cuidado mais efetivo que as auxilie a vivenciar a hospitalização da criança de forma mais saudável, refletindo sobre esse processo.*

**Descritores:** Família. Criança hospitalizada. Enfermagem.

**Título:** *Vivências da família no hospital durante a internação da criança.*

**RESUMEN**

*Este estudio tuvo por objetivo conocer cómo la familia vive el ingreso del niño en el hospital. Se realizó en la Unidad Pediátrica de un hospital universitario en el sur de Brasil. El enfoque metodológico se basó en la teoría fundamentada. La recopilación de datos se llevó a cabo a través de entrevistas semiestructuradas en el primer semestre de 2010, con 12 madres con niños. Estos se dividieron en dos grupos de la muestra. Análisis comparativo de los datos generados dos categorías: experiencias negativas de la familia durante la hospitalización del niño en el hospital y la experiencia positiva de la familia durante la hospitalización del niño en el hospital. Se sabe que las experiencias de las familias en el hospital nos lleva a reflexionar sobre nuestras acciones frente a ellos, indicando las estrategias que los profesionales pueden adoptar con el fin de proporcionar una asistencia más eficaz que les ayude a experimentar la hospitalización del niño más sano, reflexionando sobre este proceso.*

**Descritores:** Familia. Niño hospitalizado. Enfermería.

**Título:** *Experiencia de la familia en el hospital durante la hospitalización del niño.*

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## INTRODUCTION

Children hospitalization represents itself as a source of stress for both child and family, which might cause the child to become emotionally traumatized. In this regard, one cannot think of hospitalized children without thinking of the family in this process<sup>(1)</sup>.

“The theoretical, practical and investigational evidence of meaning that the family gives to the welfare and health of its members as well as the influence on the disease, require nurses to consider the family-centered care as an integral part of nursing practice”<sup>(2:13)</sup>. In this assistance approach, the participation of multidisciplinary team enables a globalized care for both the child and his/her family caregiver giving them comfort. By sharing childcare with their family, we will encourage them to develop skills and abilities as caregivers.

When hospitalization occurs, at the same time, a disruption of the usual and familiar occurs drawing a disorganization of all known generating anxiety both in children and in their family caregiver<sup>(3)</sup>. In order to help him/her experience this time in a less traumatic manner, communication and bond may be important tools among health professionals and family caregivers strengthening human relationships in the Pediatric Unit, helping the family in understanding the hospitalization process, helping in the development of complex feelings<sup>(4)</sup>.

The hospital may represent an unfamiliar environment to the child, restricted of opportunities for activities such as play, often being a place of loneliness, sadness, homesickness, missing their family members, friends and colleagues<sup>(5)</sup>. In this context, the caregiver may also go through times of trouble presenting feelings of guilt and loss.

During a child hospitalization, his/her family is the mediator in the hospital and continues to provide care. In this context, the child goes beyond the need of daily care; they need more specific care related to their new demands regarding the cause of his/her hospitalization. The handling of this situation constitutes a complex task for the family, the child and the health team<sup>(6)</sup>. The inclusion of a family member as a caregiver at the hospital requires an open and attentive posture to the interactions and impacts of the experiences that occur in the environment<sup>(7)</sup>.

The family caregiver, while in the hospital will be more or less autonomous from the information

received from the health team. The more informed the caregiver is regarding the diagnosis, treatment and clinical status of the child, the greater will be the chance of an early notice of any changes in the child's clinical status<sup>(8)</sup>.

Through this information, health professionals may instrumentalize them to care for the child, helping them to develop skills and competencies for care. For that to happen, the caregiver must be encouraged by health professionals to participate in child care giving support to their actions and teaching them the necessary care<sup>(9)</sup>.

In the relational game between family, staff and child there is a need to play and reproduce forms of identification, mobilization, negotiation so that necessary actions are made possible providing welfare to all involved. These possibilities emerge respect for others and attentional listening because it is materialized as affectionate work networks in the sense that the essential of them is in fact the creation and manifestation of affection.

We realize that interpersonal relationships that take place in the hospital environment are essential to the success of care actions. Dialogic relationship exists not only as an impersonal encounter, to devoid of affection and emotion, but it actually becomes a real haven of affection<sup>(10)</sup>.

A child's hospitalization represents an interruption of family schedule, also the unusual clutter, the urgency of confronting the doubtful, the fearful, and the unknown. It installs almost always a crisis, determining a tricky time in anyone's life<sup>(3)</sup>. Thus, it is essential for the child to receive, from the professional staff of health, a humanized therapeutic care. Humanization may be achieved without breaking the necessary technologies to help in a humanely way the mankind to be and remain in relationships<sup>(10)</sup>.

The humanized interaction in the hospital, occurs through the therapeutic care that is expressed and based on technical and legal competence, searching for an ethical and aesthetic act, under a transformative and emancipatory conception<sup>(11)</sup>. A humanized therapeutic care requires staff to use a spirit of comradeship, that is, a friendly, happy, relaxed and humorous way to make the hospital a less sad place<sup>(12)</sup>.

The crisis caused by the child's hospitalization may increase the unity and solidarity of the family, because it strengthens their relationships, enriching

its members through the exchange of love, energy and comfort. The interaction of family caregivers with the professional health team is consolidated in small gestures, a receptive look, tone of voice, touch, strengthening the family through a dialogical relationship.

Many children requiring hospitalization have become more tearful and dependent on their parents. Their emotional status tends to worsen, due to the possibility of moving away from home and their families, on behalf of the hospital environment and procedures which will be submitted<sup>(15)</sup>.

This fact may cause the family caregiver to feel afraid of the situation they are in and how they will deal with it will be strongly influenced by their experiences, knowledge, and personal ethical values that will guide their conduct in this context. The disease favors an exhausting process for both the child and their families, and for professionals who work there, where the nursing staff is highlighted by their constant presence<sup>(14)</sup>.

Law No. 8069, which regulates the Statute of Children and Adolescents, provides in Article 12 that “[...] health facilities should provide conditions for the permanence, full time, for a parent or guardian, in cases of hospitalization of children and adolescents”<sup>(15;16)</sup>. However, it appears that the family often does not have their comfort prioritized in the hospital.

In some hospitals, we still see the physical area being organized based solely on the child and for the family they usually offer inappropriate conditions for accommodation. The work process, the rules and routines of the units are generally designed according to the needs of the service and not the customers. Visiting hours, food and others are not suitable to favor the family caregiver, but the convenience of services<sup>(16)</sup>.

The family needs to be considered by health professionals as a co-participant in the child's care. For this, they need to be aided, heard and that their views and wishes are taken into account. It is necessary to seek further instrumentation to work with families in order to understand them and act jointly on their needs in order to benefit hospitalized children in our care.

Therefore, the question that guides this study is: how does the family live hospitalization of children in hospital. Since the goal of this study was to understand how the family experiences the period of hospitalization of children in hospital. This knowl-

edge is important because it may indicate strategies that health professionals can adopt in order to enable the hospital stay of children and their families to be a more productive and balanced, transforming the hospital environment in a more humane place.

## METHODOLOGY

This is a descriptive and exploratory qualitative research. Qualitative research works with the universe of meanings, motives, aspirations, beliefs, values and attitudes. It allows the author to engage directly in the situation, and enables us to observe agents in their everyday living, interacting socially with these<sup>(17)</sup>.

The methodological framework was based on Grounded Theory (GT), this methodology was used in order to enable the development, inductively, of knowledge from own experience lived by families participating in this study<sup>(18)</sup>.

The study was conducted in the Pediatric Unit of a University Hospital (UH) in southern Brazil. The Pediatrics UH has 21 beds for children aged from zero to twelve years of age hospitalized for both clinical and surgical care. The study population was comprised of 12 mothers who were told about the objectives and methodology of the study and who afterwards agreed to sign the consent form. They were divided into two sample groups, each one with six mothers.

Data collection was conducted in the first half of 2010 through semi-structured interviews with each participant, to obtain a better understanding of the reality on the phenomenon under study. The participants of the two sample groups answered the following initial question: How are you perceiving your child's hospitalization? The first sample group of participants were explored on the negative experiences of the family in the hospital and the second sample group, family participants experiences were positively explored in the hospital. All interviews were held in the waiting room of the Child Friend Hospital Programme, because it ensures comfort, privacy and is attached to the Pediatrics; they were recorded and transcribed for analysis. And they lasted about 40 minutes.

The collection and analysis of data were conducted simultaneously, because the constant comparison of data was used to develop and theoretically refine the emerging categories. A comparative

analysis of the data was done using the following steps: environmental knowledge, data encoding, category formation, reducing the number of new categories or groupings, identifying the core category, modification and integration of categories<sup>(18)</sup>. After categorization a discussion on the data using thematic expert authors was held.

The ethical principles of research involving human subjects were respected, under Resolution No. 196/96<sup>(19)</sup>. The research project was submitted to the Ethics Committee of the FURG receiving assent under No. 92/2009. The Consent Form was signed in duplicate. The anonymity and privacy of the family were kept by identifying their quotes with the letter F followed by the interview number.

## RESULTS AND DISCUSSION

The analysis and discussion of the data generated two categories: Negative Family Experiences during child hospitalization and Positive Family Experiences during child hospitalization.

### Negative Family Experiences during child hospitalization

Families reveal negative experiences in the hospital when faced with situations that reflect fear, which are linked to worsening of health status of their children. It also reveals the concern about the risk of the child acquiring nosocomial infection, with possible sequels occurred by procedures and illness with lack of knowledge about the necessary care for the child. They are afraid they are not receiving effective assistance, which is referred as anguish and suffering of other families, and the possibility of the child's death.

*I get a little scared. I even cry. I think I can't take care of my daughter right [...] I'm afraid she gets another disease in here (F 6).*

*I am afraid that she will be always like this. Not for me, I know she will not walk, will not talk. But it is for her, I don't want her to have a sad life, only in bed. I'm afraid she won't get better, that seizures keep happening, that she dies (F 7).*

Another unfavorable factor is the low income, considered by the family, sometimes, as the reason for the hospitalization of the child, given their lack

of condition to conduct a proper treatment at home. Even so, the family has their expenditures increased during child hospitalization, due to transportation costs, food, among others.

*She didn't do the proper treatment at home. The medicine was too expensive. The hospitalization increased our expenditures because I have to come from my house, I'm not with my fridge with my stove. [...] People with a low income have everything planned for the month [...] So the money is going out and not coming in (F 4).*

It has been reported that the unit is organized to provide comfort to the child; the accommodations designed does not provide rest for companions. Moreover, the noises and crying children hinder sleep and rest. These factors combined with the suffering for long periods of hospitalization, and the division between home and hospital, makes the family caregiver feel a burden pushing them to physical and emotional limits.

*[...] We are very uncomfortable. Her bed is good, but the chair for mothers is very hard, very small. The shower is good, but you cannot take long bath. There is noise all the time. We get emotionally tired. I am exhausted (F 8).*

The coexistence between the families of children hospitalized is not always harmonic. They need to share space with other people who may have different hygiene standards and customs.

*[...] sometimes we stay with good people and sometimes they want to know all of our lives. People who want to give their opinion and who say that I am young and want to teach me. Sometimes it's hard to stay together. They can be messy. We even argue (F 7).*

The family in the hospital may notice that the team does not take into account their requests and feels that health professionals ask them to do many things for the care of the child, even when they are not in a position to do so.

*I told the doctor that the kid was in pain. He said no, that it was not what I was saying. I asked this exchange because the drug is making my son ill. The doctor says it has to be that. He is going against me. He doesn't take anything I say into account. (F 9).*

The confinement in the hospital, in which the family see themselves imposed to, causes the

family to prioritize care for the sick child, leaving their own care as a second matter. Furthermore, the confinement of family caregivers in the hospital, makes their living with other family members decrease. When hospitalization is prolonged, the concern for other children increases in relation to their physical and emotional safety, their studies, their health, and other care.

*We're closed here. There are days when I forget to brush my hair, because the priority is his care. We are a second matter. I feel so sleepy, so tired (F 3).*

*If a mother has children who are at home, she also feels guilty about these. Those who are at home, for sure, are not well because they are without their mother. At the same time, the one who is here is sick and need his/her mother more than the others. It is difficult (F4).*

### **Positive Family Experiences during child hospitalization.**

Families reveal positive experience at the hospital when they feel able to develop child care. That is why they value the educational component of the care given by health care team. When they are instrumented and encouraged by health professionals, they occupy their time acquiring skills that make them even more able to care for the child.

*When he was born and got sick, I thought I wouldn't know how to care for him. I thought he was going to die. But in the hospital, each hospitalization, we find out new things, how to do things, how to aspirate, how to grip, how to nebulizer. People are encouraged to take care, ask questions, and receive explanations, and then we learn (F 1).*

Suitable conditions established by a comfortable infrastructure are referred as some accompanying family members as a positive factor during hospitalization of the child. Family members reveal that despite the unpleasant circumstances the hospital environment becomes more warmly by presenting, for example, comfortable accommodation and recreation areas.

Some families recognize that the hospital is organized to bring together all the resources needed for childcare. The presence of materials, equipment, specialized professionals, in the quantity and quality necessary to transform the services into merit of the trust of its users.

*We feel relaxed because we know that we will receive the correct medicine, exams, food [...] especially good service. So it is not only features such as medication, materials, but mostly having care that is the main difference. It is the presence of these professionals around us all the time (F 3).*

Families understand the value of dialogue with the child, with the health care team and with other families, as a way of experiencing the most harmonious time of hospitalization. Through dialogue, sharing experiences, they can adapt better, interact with others and integrate with the hospital setting.

*The dialogue in here is essential. We are lay people, we know what the child sees and feel, so talking with professionals is very important to us. Talking to other mothers also helps people to feel useful and the time goes by (F 4).*

Each family can strengthen their identity as a social group, overcome their weaknesses and vulnerabilities, acting and reacting, fighting and facing the daily challenges that child hospitalization requires them. For some, the changes and situations experienced in this context, reflect feelings of solidarity that accentuate the emotional bonds between family members.

*In my case there was no disruption because my family kept everything the same. [...] But everyone still follows their obligations. [...] The family life that we had, continues. It is even strengthened (F 4).*

The fact that hospitalization units provide food, medicine, materials, equipment and diagnostic tests at no additional cost makes some families not to experience economic problems.

*We don't need to buy medicine, food and diapers, because the hospital gives us everything. You have to spend nothing. (F 5).*

The family reveals that their suffering can be alleviated during hospitalization of the child, when, for example, there is an improvement in the health status of their child and other children, also when they participate in the care and see the commitment of health professionals during hospitalization. At the same time, other simple everyday hospital situations also contribute to ease the anguish of relatives, among them the importance of meals offered by the institution, visits, reading a book,

self-care, chat, meet new people and see child within the recreation unit are highlighted to contribute to ease this anguish.

*The pleasure here is to eat a good meal, hearing his laugh. Pleasure assumes other proportions and meaning. We start enjoying the small things in life daily [...] a visit, reading a book, taking a relaxing bath, having a good conversation with other mothers. These are our pleasures in hospital (F 3).*

Through self-care, the family is strengthened in order to better assist the child, so that they try to take care of their own physical and emotional well being. They also emphasize the importance of maintaining appropriate standards of sleep and rest, proper nutrition and alternative recreation activities that can contribute to overcome the tensions caused by the hospital, as well as the possible situations of pain and suffering experienced during child hospitalization.

*We try to take good care of ourselves too, because I know that my child depends on me. I cannot get sick [...]. I like to walk to relax. When I see that I'm tired, I go for a little walk (F1).*

From these data it appears that in the hospital, the experiences are perceived individually at different stages of the child's hospitalization. When the health state of the child is still delicate, the family lives in the hope of improving their condition and the drugs can make them better. When the health state of the child improves, the experiences come to be understood as good, allowing caregivers to participate in activities, including learning new ways to care<sup>(1)</sup>.

In seeking to understand the meaning of these experiences, it is shown that, even today, we reflect on these without knowing whether it is an object of natural processes or a cultural object<sup>(6)</sup>. These experiences come to be administered by several factors, such as the confinement that affects the control mechanisms leading to overload and disorientation.

The experience of time in hospital seem to be interpreted according to their experiences. When participants recognize their experiences as good, they believe to have lived good times at the hospital. If on the contrary, they recognize they have lived more negative than positive experiences, they can interpret this period as a bad time. In these cases, it

may rise to a feeling of lost time due to the harsh conditions of the hospital, the loss of social contacts and the interruption of a daily work<sup>(5)</sup>.

The child hospitalization is perceived by the child's mother as impregnated with experiences. To be recognized as such good experiences, the family must be guided in welcoming and understanding<sup>(7)</sup> by health professionals. Sharing the childcare with health staff at the hospital may be a period when they can reflect about being a family, and from this experience build a new way of caring for the child. A more instrumental and effective care.

## CONCLUSION

In seeking to understand how the family lives the child hospitalization in the hospital, it was found that each family lives a unique experience, with different meanings from their referential, their interactions and experiences in this context. During hospitalization, the family shares childcare with the healthcare team. This sharing enables humanize the environment.

Understanding how the family lives the child hospitalization in the hospital lead us to reflect on our actions facing them, indicating strategies that health professionals may adopt in order to enable these experiences to be more productive and less traumatic. Among them, we find the possibility of assisting families to reflect on the situation experienced, making the hospital stay less painful, conducting workshops, informal conversations and self-help groups. Using this period in their advantage, building positive interactions allowing them to be creative, express themselves, assign meanings to their experiences and acquire new knowledge, thus promoting family health and especially the child health.

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