

The family living the time during the hospitalization of the child: contributions for nursing

A família durante a internação hospitalar da criança: contribuições para a enfermagem

La familia participando de la hospitalización del niño: contribuciones para la enfermería

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ABSTRACT

Objective: To uncover how the time is experienced by familiar caregivers in the hospital in the hospitalization of the child. **Methods:** Descriptive and exploratory research with qualitative approach, performed in the second half of 2010. It was developed in the Pediatric Unit of a hospital in southern Brazil, with 15 family caregivers. The data collection was performed by semi-structured interviews. The analysis of the data was done by the technique of content analysis. **Results:** It was verified that being part of the hospital world with the child, each family assigns different meanings to the time lived, perceiving it as good or bad, according to their experiences in this period. **Conclusion:** To know the good and the bad times experienced by families in the hospital can lead to nursing staff to reflect on their actions, indicating strategies to be adopted in order to allow that the time in the hospital to be productive and better lived.

Keywords: Family; Hospitalized Child; Length of Stay; Nursing.

RESUMO

O objetivo deste estudo foi desvelar como o tempo é vivenciado pelo familiar cuidador no hospital na internação da criança. **Métodos:** Pesquisa descritiva, exploratória, com abordagem qualitativa realizada no segundo semestre de 2010. Desenvolveu-se na Unidade de Pediatria de um hospital do sul do Brasil, com 15 familiares cuidadores. A coleta de dados realizou-se por entrevistas semiestruturadas. A análise dos dados deu-se pela técnica de análise de conteúdo. **Resultados:** Verificou-se que, ao inserir-se no mundo do hospital com a criança, cada família atribui diferentes significados ao tempo vivido, podendo percebê-lo como bom ou mal tempo, de acordo com suas vivências neste período. **Conclusão:** Conhecer os bons e os maus tempos vividos pelas famílias no hospital pode levar a equipe de enfermagem a refletir acerca de suas ações perante elas, indicando estratégias a serem adotadas de forma a possibilitar que o tempo no hospital seja produtivo e melhor vivido.

Palavras-chave: Família; Criança hospitalizada; Tempo de internação; Enfermagem.

RESUMEN

Objetivo: Comprender la participación del familiar cuidador en el proceso de hospitalización del niño. **Métodos:** Estudio descriptivo, exploratorio, con enfoque cualitativo, realizado en el segundo semestre de 2010. Fue desarrollado con 15 familiares cuidadores en la Unidad Pediátrica de un hospital en el sur de Brasil. La recolección de los datos fue realizada mediante entrevistas semiestructuradas. El análisis de los datos se hizo mediante la técnica de análisis de contenido. **Resultados:** Se verificó que al entrar en el mundo del hospital con el niño, cada familia asigna significados diferentes para el tiempo vivido y pueden percibirlo como un bueno o malo tiempo. **Conclusión:** Reconocer los buenos y los malos tiempos vividos por las familias en el hospital puede llevar al equipo de enfermería a reflexionar sobre sus acciones, indicando estrategias que serán adoptadas con el fin de possibilitar que el tiempo en el hospital sea productivo y mejor vivido.

Palabras-clave: Familia; Niño Hospitalizado; Tiempo de Internación; Enfermería.

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INTRODUCTION

The hospital appears as a complex institution in which patients and accompanying family members live with the pain and disease requiring an effort to adapt the new situation. In this context, they experience the limits imposed by the organization of the work that can disregard their subjectivities, having to adapt to the rules¹.

The patient and his family tend to assume a passive posture in front of the health professionals and of the situations they face in context². In addition, the hospitalization almost always causes the necessity of constructing new interpersonal relationships among patients, family caregivers and health professionals, in the progress of activities and in social welfare, affecting the daily life and the uniqueness of each subject³.

Similarly, the notion of time can be changed due to a number of factors present in this new environment^{4,5}. The time shall be determined by the establishment of rules and limitations with rigid schedules for implementation of the hygiene and visits, the meals, the examinations and procedures, leading patients and families to manage their time from the demands of the institution⁶.

Thus, the hospital, configured as a depersonalized environment becomes a space governed by mechanized actions that usually go unnoticed and fill every moment of the life of the family. In addition, the hospitalization carries significant changes in family life accentuating even more when it comes to the hospitalization of a child who requires the constant presence of an adult carer⁷.

During the stay in the hospital, the family can live favorably with the illness of the child, since in the hospital environment provide stimulus able to qualify the time lived, making this period less stressful, both for the child and for the accompanying family⁸.

Thus, the rhythm, the way they do things and the way of unfolding of actions at the hospital, lead to reflect on an intense experience of the child and the accompanying family in relation to the new situation experienced⁴. The length of stay in hospital is governed by the dynamics of the work, by the way of life of the subjects included in this environment and, above all, by the health professionals, and these contributing to the maintenance and improvement of the infrastructure that sustains the passage of time during the period that the family follows the hospitalization of the child⁶.

As the days pass, the time spent in the hospital, even if this is perceived as a strange and unpleasant environment, it can be regarded as customary, fixed and natural. It appears, therefore, that the time category as predominant factor of the experience of the subject in the place, leads to the naturalization of spaces, objects and situations assimilated through everyday experience⁹.

These considerations refer to the need to establish a space of listening and talking to the family express their experience, referring the health professionals to reflect and mobilize in order to minimize the suffering of the family during the period of hospitalization of the child⁶. So, the question that has guided this study was: how time is experienced by the family caregiver

in the hospital during the hospitalization of the child? From this, in this context, it was aimed to unveil how time is experienced by the family caregiver in the hospital during the hospitalization of the child.

METHOD

This is an exploratory, descriptive type research with qualitative approach. The exploratory, descriptive research deals with the description of the phenomenon investigated, making it possible to meet the problems experienced and to deepen their study within the limits of a specific reality¹⁰. The qualitative approach considers, as a source of study, the perspective of individuals who experience certain phenomenon and their meanings¹⁰.

The study was carried out in the second half of 2010, held on a Pediatric Unit of a University Hospital in the South of the country. This unit has 21 beds intended for the *Sistema Único de Saúde* (Unique Health System - SUS) for children from 0 to 12 years old who are hospitalized for clinical and surgical care.

In this study participated 15 relatives of hospitalized children carer. Inclusion criteria were: to be significant caregiver child and provide direct care at the hospital and accept to participate in the research. This consent was signed in two copies, one copy to each participant.

Data collection was performed by semi-structured interviews with each participant. They were held during nursing consultations. The number of interviews was delimited by the saturation of data and family caregivers were asked about how to realize the experience of time in hospital. The interviews were scheduled with each family member, held in the infirmary, recorded and transcribed for analysis. Despite the nurses being collective, there were no interruptions during the interviews.

The data were analyzed by Proceeded of Content Analysis technique¹¹. Technique in which the focus is the speech of individuals since it considers that there is a correspondence between the type of discourse and the characteristics of the environment or reality where this individual stays¹¹. This method has been operationalized through the pre-analysis steps at which proceeded the empirical material organization. At this stage the data were organized, constituting the *corpus* with the speeches of the subjects. In this step, the empirical material floating readings with the aim of preparing the material was done. In the exploration of the contents step careful and exhaustive reading speeches were carried out and identified units of sense and heat-treating phase of results and interpretation which the results become meaningful and valid, generating empirical categories, revealing the constituent elements of the phenomenon investigated¹¹.

The principles of ethical research involving humans were followed, as the Resolution 196/96¹². The research project was approved by the Ethics Committee of the Federal University of Rio Grande, receiving assent, under Protocol N^o 92/2009. To ensure anonymity the participants were identified by the letter F, followed by the number of interviews.

RESULTS

Two categories were showed: Experiencing a good time at the hospital and Experiencing a bad time at the hospital.

Experiencing a good time at the hospital

The families live a long time in the hospital when they feel able to develop child care. So, they recognize and value the educational component of the care given by the health team. When are instrumented and encouraged by the health professionals, the families occupy their time acquiring skills that make them able to take better care of the child. They feel encouraged to take care, when health professionals clarify their doubts about the child's illness as well as when they receive guidelines that allow improving the care provided to them.

When he was born and got sick, I thought I wasn't going to know to take care of him. I thought he was going to die. But at the hospital, each hospitalization, we're discovering new things, how to make, how to breath, how to hold, how to nebulize. Everyone is encouraged to take care, to take questions, they receive explanations and then they learn (F1).

I know I don't have as much experience in raising children, but I think I take good care of them. We are very encouraged to take care. They look and praising us. They thank for our help (F2).

The appropriate conditions set by a comfortable infrastructure are referred to by some family members as a positive factor during the hospitalization of the child. The relatives reveal that despite the unpleasant circumstances linked to the illness of the child, the hospital environment becomes more welcoming when offers comfortable accommodation and a recreation area. Some families recognize that the hospital is organized in order to aggregate all the resources needed for the care of the child. The presence of materials, equipment, specialized professionals, in the amount and with the necessary quality makes the services worthy of the trust of its users, allowing the time lived to be considered good.

We feel peaceful because we know we are getting the right exams, the food [...] especially good service. So it's not just resource such as medication, materials, but has primarily the care that is the key differentiator. Is the presence of these professionals all have to go back. The weather becomes nice (F10).

The families understand the value of dialogue with the child, with the health team and with other families, as a better way to experience the time of hospitalization. Through dialogue, sharing the situations experienced, interact with different people in the

institution, making it possible to adapt to the new way of caring for and interacting with other people, which may contribute to their integration in hospitals, making the time pass faster and in a positive way.

The dialogue here is crucial, because it has to be on top of everything that's going on. We are lay people, everybody knows who sees the son feel and, therefore, the conversation with the pros is very important to us. We feel more integrated, time passes more quickly. I think it is a positive time for us (F14).

Each family can strengthen its identity as a social group, overcome its weaknesses and vulnerabilities, acting and reacting, fighting and facing daily challenges that the hospitalization of the child imposes them. For some of them, the changes and situations experienced in this context, they reflect feelings of solidarity which accentuate the affective links among its members.

In my case there was no disruption, because in my family was everything the same. [...] But still everyone is following their obligations. [...] The family get-together that we had, we continue having. It maintained and even strengthened. Although we are living here in the hospital this time I'm sure it's fine at home (F4).

The fact of the inpatient units provides supply (also for family caregivers), medication, materials, equipment and diagnostic tests, without additional costs, since the SUS services cover all costs arising with the treatment, causes some families don't experience economic problems during the time of the child's hospitalization.

We do not need to buy medicine, food and diapers, because the hospital gives me everything. You don't spent anything. Then, the fear of having extra expenses during this period, to me, does not exist (F5).

The family reveals that their suffering can be eased during the hospitalization of the child, when, for example, follows the improvement of the state of health of the child and the other children, participate in the care and see the commitment of health professionals during hospitalization. At the same time, other simple situations of everyday life at the hospital, also contribute to alleviating the anguish of families, among them they highlight the importance of meals offered by the institution, the visits, read a book, self-care, chat, to meet new people and to see the child in the recreation space of the unit.

The pleasure here is to eat a good food, to hear his laugh, his health improves. The pleasure takes on other

proportions and sense. We shall take pleasure in the small things of everyday life [...] with a visit, to read a book, to take a relaxing bath, to have a nice chat with other moms. There are our pleasures during this time here in the hospital (F11).

Through self-care, the family becomes stronger to be able to watch better the child, for this the family seeks to take care of their physical and emotional well-being. They highlight the importance of maintaining, wherever possible, appropriate patterns of sleep and rest, proper nutrition and recreation alternatives, activities that can contribute to overcome the tensions caused by the hospital environment as well as the possible situations of pain and suffering experienced during the hospitalization of the child.

We seek to take care of ourselves too, because I know my son depends on me. I can't be sick [...]. We have little time to take care, because the priority is the child care, but I'm looking for a walk to de-stress. When I see that I'm tired, I'm off to take a walk. Thus, relief tensions and time passes faster (F9).

Experiencing a bad time in the hospital

The family is experiencing a bad time in the hospital when faced with situations that reflect a fear, these being linked to worsening of the state of health of the child. Also it shows concern about the risk of the child acquire nosocomial infection, with the possible consequences arising from procedures and of the illness itself, with the lack of knowledge about the care required and specific to the child.

I'm a little scared. I even cry. I think I won't be able to take care of my daughter [...] I'm afraid she get another disease in here. I want this time goes by fast. I want to get back to my house (F6).

I'm afraid she is always like that. [...] It's not for me, I know she won't walk, won't talk. But it is for her, not to have a sad life, only in bed. I'm afraid she's not improve, that the seizures did not pass, she dies. Since we arrived she didn't stop with the seizures. If it happens again at home I don't know what to do (F7).

In some situations the families of hospitalized children are afraid of not receiving effective assistance of the health team in emergency cases. At the same time, they referred to the suffering of anguish with other families, and with the possibility of death of children in most severe state, even their own child.

I'm afraid of him having a crisis and the doctor and the nurses do not see him in time, because his illness is rare (F12).

Now my son is fine, but to see the other mothers crying because their children are not well is difficult. Is suffered watching a child in critical condition. It is a misery, fear of a child died. Because hospital is the place for that to happen (F15).

Another unfavorable factor is the low income, considered by the family. Sometimes, the reason for the hospitalization of the child, attributed to his lack of policies to achieve a proper treatment at home. Even so, the family has their spending increased during the hospitalization of the child, due to the cost of locomotion, feeding, among others.

In this period also the family spending increases. Because you dislocated from your house. You don't have access to the things you need. You're not with your fridge with your stove. [...] Who have a low income have everything right, scheduled to spend the month [...] The husband is not here, he is working these days. So, the money is going out and not coming in. It's a difficult time (F13).

Families report that the unit is organized in such a way as to provide comfort to the child, the carer is meant simple accommodations, usually chairs or seats which do not provide the rest. The noises caused by other family members and the health team, besides the crying of children, hinder sleep and home. These factors combined to suffering by the long period of hospitalization, and the division between home and the hospital, they overload the familiar caregiver making this feel always on the physical and emotional limits.

[...] We stay very badly accommodated. Her bed is good, but the mother's chair is too hard, too small. The shower is good, but you can't take a long bath. So there's no comfort and becomes tiring [...]. We've been here for days at the hospital and it is well experienced in this part. Children cry, it is a coming and going of people that I cannot sleep quietly (F8).

I felt very tired, overloaded. We don't rest, don't sleep, don't eat right. We're emotionally tired. It is from home to the hospital and from the hospital to home. I'm exhausted (F3).

Not always the coexistence between the families of the children hospitalized in the hospital takes place harmoniously. According to these reports, the coexistence becomes difficult when they need to share the care space with other with hygiene standards and customs different from them.

Now, I'm alone in this room and it is being very good, but in previous hospitalizations, I was always with

other moms [...]. Sometimes, we get good people and, sometimes, we get people who want to know all of our lives. People who want to guess and say I'm young and want to teach me. Don't care for the cleanliness and hygiene of the infirmary and children. Sometimes it's hard to stay together. We even have fight (F7).

The family at the hospital can go through difficult situations, when they realize that his team does not take into consideration they request and feel very charged about child care, even when they can't afford to do it.

I said to the doctor that the boy was in pain. He said no, that was not what I was saying. I ask to change the medicine because this is hurting him. The doctor says he has to be that one. He is against me. Don't take anything than I ask. It's very hard to stay here this time (F9).

Confinement in the hospital in which is imposed, causes the family to prioritize the care of the sick child, leaving his own care in the background. In addition, the family reports that the confinement of the familiar caregiver in the hospital causes its coexistence with the other members of the family decreases. When hospitalization is prolonged, the concern of the family with the other children increases, in relation to their physical and emotional security, to their studies, their health, and other care.

The displeasure is total. We're closed here [...], I just want to cry and walk away (F8).

There are days that I forget to comb the hair, because the priority is to care for him. We stay in the background. I feel very sleepy, tired (F13).

If a mother has children who are at home, she also feels guilty about these. Those who are at home, for sure, are not good because they are without their mother. At the same time, they are being advised by someone. This patient is in need of you, more than others. Is the meaning that the disease has for us (F14).

DISCUSSION

From the data it appears that in the hospital, the passage of time is perceived individually in different stages of hospitalization of the child. In this environment, the time is consumed in the actions and interactions made by the family, mainly directed to child care. Study on social support to the family caregiver during the hospitalization of the child showed that the time is interpreted as nice when family relationships are still in effect, harmonics solidarity among its members and with no disruption. Link the experience of a long time in the hospital when they realize the improvement of the health status of the child¹³. In this situation, the

time goes faster, what enables carers participating in activities, including learning new ways of caring.

The time spent is considered good when the family feels potentized to the child care, they find suitable conditions to their comforts and acknowledges the resources available for the care of the child as appropriate, sufficient and quality¹³.

During the hospitalization of the child her familiar caregiver may be required, due to new demands of child care. In this sense, interprets the possibility to invest some time with their self-care, leisure and participation in recreational and educational activities as positive experiences².

Study on the maternal role conflict during the hospitalization of the newborn features that when the state of health of the child is still delicate, the family lives in expectation of improvement of their conditions⁴. During this period, time seems to pass slowly. They interpret as a bad time experienced when they're afraid of the severity of the clinical picture of the child and that this doesn't get the expert assistance they need. Suffering with the pain of other families with which they coexist in the same ward.

They can interpret the time lived at the hospital as bad when it has increased its spending, off balance the family budget^{4,14}. Often, they may recognize the physical area available to the family as inadequate to their rest, sleep and rest, having its physical and mental wear increased^{13,7}. Furthermore, the coexistence with other families in the same ward can be contentious and stressful⁸. A bad time, can also be interpreted when the hospitalization of the child extends, leading to the feeling of confinement, for his live daily life is disrupted and may generate suffering for what might be being lived in a good time⁴.

In a study on the experience of time in the hospital it was verified, with the cross of the days, the time can be denied by the patient. In this environment the clock and calendars seem to lose their meaning, because the biological time and time imposed will not meet. The time is marked by activities undertaken by professionals working in routine, removing the own temporality people, showing the time as something subjective¹⁵. Time seems to be reinvented, because the habits and customs that sustained the temporality of the everyday life of the patient were modified demanding these new validation mechanisms, despite the relentless passing of time¹⁶.

When fetching apprehends the sense of time it verifies that they meditate on it without knowing if it is an object of natural processes or a cultural object. However, in this study we focused on the time lived, spent the interactions made by the family to ensure child care during his hospitalization, which is recognized as a social time in that their notion of duration is governed by several factors, such as in this case, the confinement that affects the mechanisms of control and may lead to a temporal disorientation¹⁵.

The notion of temporal continuity shall be governed by the experiences¹⁷. If the experiences are recognized as good so time can be interpreted. If on the contrary, are recognized as bad as long lived can be understood as bad. There may be a feeling of

lost time due to the harsh conditions of the hospital, the loss of social contacts and the interruption of a daily life of work.

This time lived, full of experiences, needs to be based on the acceptance and understanding of the family by nursing professionals. To share the care of the child with the health team at the hospital can be a time when the family reflect about being family, and from this experience to build a new way of caring, supported and effective care⁴.

The data show that nursing staff create strategies for the inclusion of families and children at the hospital, allowing them to express their anguish and limitations. The time lived by the family on pediatric unit can allow their exploitation and empowerment as a caregiver. In this sense, the nurse should provide information and support network, recognizing their right to decide and intervene in case of child health.

The study showed how limitations do not allow for generalizations. However, I had this goal. He approached the subject from the point of view of family caregivers, further studies are needed in order to check how the nursing staff has contributed to the family caregivers and children hospitalized experience good times at the hospital.

CONCLUSION

When looking for unveiling how time is experienced by the family caregiver in the hospital during the hospitalization of the child it was found that each live a unique experience, with different meanings, from their referential and the interactions that performs at this time. In this context, shall share the care of the child with the nursing staff and experience a good time and/or a bad time.

Experience a good time when they feel able to take care of the child, recognize that the hospital has the right conditions for the care, maintains a dialogical relationship with the nursing staff, maintains a relationship of solidarity with the other relatives, have not increased their spending with the hospitalization of the child, they see the improvement of the clinical picture of the child and can undertake actions of self-care, and leisure.

Experience a bad time when they're afraid of worsening of clinical picture of the child and of his death or of other children hospitalized, have increased their spending with hospitalization, gangly your family budget, don't have your prioritized comfort, increase physical and mental wear and tear, have conflicts with other relatives with whom coexist in the same Ward, are not heard by the team to watch and feel confined when the time of hospitalization of the child extends.

It turns out that knowing the good and bad times experienced by families in the hospital can take nursing professionals to reflect on their actions in front of them, indicating strategies to be adopted in order to allow this time to be productive and best lived. The data of the study point out possible contributions to the performance of nursing with a view to promoting the experience of a good time at the hospital by the family caregiver during the hospitalization of the child.

Among these contributions there is a need to invest in the maintenance of a dialogical relationship between professionals and family caregivers of the child, in order to meet their needs and expectations, conducting educational activities with their views as empowerment caregivers, in an attempt to prevent new hospitalizations and instrumentalize them for the care of the child at the hospital.

It can also improve the ambience of the wards of the inpatient units in order to provide comfort and well-being to family caregivers and children interned, to organize their work processes in order to promote sleep and home repairer so that these do not feel exhausted, promote recreational activities and leisure activities that include also in the quest for promoting their physical and mental health. In addition, it can make rules and routines, favoring the visit and the participation of other family members in case of hospitalization of the child, among other actions to be planned.

When drawing up the therapeutic nursing professionals project need to know the experience of the family at the hospital and provide instruments for the time of hospitalization of the child be effective care. Such actions require changes of paradigms, ways of thinking and take care that empowers the family as caregiver, building harmonic relationships between the same and the nursing staff, rescuing the caregiver dimension of nursing. This aspect needs to be brought to the debate as a possibility for construction of a widened perspective for nursing care, guided on bailout provisions with the family.

The time lived at the hospital may have a meaning and significance. Therefore, this includes being creative, making the experience of new experiences and knowledge, to promote the health of the family and especially the child. It is necessary to assist the families to reflect on the situation experienced by making the length of hospitalization of the child less suffered.

This is a process in construction and introduces himself as a possibility for the experience of a good time, in which both the child and the family feel valued, minimizing possible traumas. A time the child recognize show life experience throughout its growth and development process, being a challenge to be built by nursing professionals to attend.

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