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The experiences of relatives of children hospitalized in an Emergency Care Service

VIVÊNCIAS DE FAMILIARES DE CRIANÇAS INTERNADAS EM UM SERVIÇO DE PRONTO-SOCORRO

EXPERIENCIAS DE FAMILIARES DE NIÑOS INTERNADOS EN UN SERVICIO DE URGENCIAS.

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ABSTRACT

Childhood is a phase that requires much attention from the family and the health service, because family members, besides depending on relatives, are vulnerable to the environment. The objective of this study was to describe the experiences of relatives of children hospitalized in an emergency care service, discuss on how those experiences affect the everyday life of the family and report the aspects that interfere in the nursing care. This descriptive study was performed using a qualitative approach, and was developed in a private emergency hospital. Interviews were performed with ten family members to obtain the data. The data was submitted to thematic analysis, and three categories were elaborated: experiences of the family member, changes in the everyday life of the family, the faith of the family and their closeness as facilitating agents. In conclusion, the person accompanying the patient goes through adaptations, whilst experiencing hospitalization, with changes to the routine of the family. However, because of the conflicts experienced by the family member, nursing should see them as a subject of the extended care.

DESCRIPTORS

Child, hospitalized
Family
Child care
Pediatric nursing
Emergency medical services

RESUMO

A infância apresenta-se como uma fase que exige bastante atenção da família e do serviço de saúde, uma vez que seus integrantes, além de dependerem de familiares, são vulneráveis ao ambiente. Objetivou-se descrever as vivências de familiares de crianças internadas em um serviço de pronto-socorro, discutir como essas vivências influenciam no cotidiano da família e relatar os aspectos que interferem no cuidado de enfermagem. Estudo descritivo, de abordagem qualitativa, desenvolvido em um hospital de urgência da rede privada. Utilizou a técnica de entrevista com dez familiares para produzir os dados. Estes foram submetidos à análise temática, elaborando-se três categorias: vivências do familiar, alterações no cotidiano da família, a fé e a aproximação familiar atuando como agentes facilitadores. Concluiu-se que o ser acompanhante passa por adaptações, ao vivenciar a hospitalização, existindo alterações na rotina familiar. Porém, devido aos conflitos vivenciados pelo familiar, a enfermagem deve compreendê-lo como sujeito do cuidado ampliado.

DESCRITORES

Criança hospitalizada
Família
Cuidado da criança
Enfermagem pediátrica
Serviços médicos de emergência

RESUMEN

La infancia se presenta como una fase que exige bastante atención familiar y del servicio sanitario, toda vez que sus integrantes, además de depender de familiares, son vulnerables al ambiente. Se objetivó describir las experiencias de familiares de niños internados en servicio de Urgencias, discutir cómo esas vivencias influyen el cotidiano familiar y relatar los aspectos que interfieren en el cuidado de enfermería. Estudio descriptivo, de abordaje cualitativo, desarrollado en un hospital de Urgencias privado. Utilizó técnica de entrevista con diez familiares para obtener los datos. Estas fueron sometidos al análisis temático, elaborándose tres categorías: vivencias del familiar, alteraciones del cotidiano familiar, la fe y aproximación familiar actuando como agentes facilitadores. Se concluyó en que el acompañante pasa por adaptaciones al vivir la hospitalización, existiendo alteraciones en la rutina familiar. Sin embargo, debido a los conflictos enfrentados por el familiar, la enfermería debe comprenderlo como sujeto de cuidado ampliado.

DESCRIPTORES

Niño hospitalizado
Familia
Cuidado del niño
Enfermería pediátrica
Servicios médicos de emergencia

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INTRODUCTION

The Brazilian Federal Constitution from 1988 ensures universal, equal and integral rights to the population, establishing various doorways to the health system. Depending on the complexity of their clinical condition, the system's users should seek a unit capable of resolving their health problems. Health problems are characterized according to their severity: elective cases are those that do not require urgent care and treatment can be postponed without harming the patient's health⁽¹⁾; urgent conditions correspond to the occurrence of unexpected illness, with or without a potential risk of death, and that require immediate medical care; emergencies require medical evidence that there is a condition involving imminent risk of death or intense suffering, thereby requiring immediate medical care⁽²⁾.

The context of an emergency department, the unit that takes care of these cases, is different from other hospital units because it offers unrestricted access to the population and receives an excessive number of patients with the most varied levels of severity⁽³⁾. In this context, work overload, irregular physical structure and the scarce availability of human and material resources⁽⁴⁾ are currently inherent to the conditions of emergency departments in Brazilian hospitals. These units receive a large number of cases, which harms the care provided to severe and acute cases since it leads to accumulated tasks, contributes to increased costs and generates a burden for the health team's professionals. Coupled with these problems, these professionals also care for situations of extreme severity that go beyond the services' problem-solving capacity and face counter-referral problems. The observation rooms, which should temporarily serve patients, become hospitalization areas without offering appropriate infrastructure and personnel to provide continuous care⁽⁵⁾.

In the context of caring for children in the emergency department, various factors contributing to the vulnerability of these patients are observed such as the constant risk of children getting involved in accidents such as: mimicking their parents' routine, curiosity, and lack of judgment. There are also diseases prevalent in childhood that can manifest due to the children's fragile immunity, poor hygiene knowledge and actions, or intense contact with other children. Whatever the case, in the presence of such occurrences and depending on the child's general condition, children are taken to emergency departments seeking rapid care and effective solutions. Given the disease and hospitalization, some factors may psychologically affect children and be determinant of children's emotional discomfort such as: not being familiar with the hospital environment; a large number of non-familiar people in this environment with

similar needs; being separated from family; the child's age and personality before being hospitalized related to her/his level of maturity⁽⁶⁾. A hospitalization is a stressful and conflictive situation, which can be alleviated in the presence of someone the child trusts. Therefore, the figure of a companion emerges, a person who represents the patient's social network and who accompanies the child during her/his entire stay in the facility⁽⁷⁾. The presence of a companion is a right acknowledged in the Statute of the Child and Adolescent that establishes in its article 12 that "health care facilities must provide conditions for the full time stay of one of the parents or legal guardian in the case of hospitalization of children or adolescents"⁽⁸⁾.

According to the Ministry of Health, the presence of a relative in the hospital facility is necessary to enable better understanding of the guidance and instructions provided concerning the patient and to help the child in her/his existential moment; to provide the professionals information concerning the child's main problems and needs; to encourage the child's social inclusion in a hostile environment as well as in the community; and to facilitate, from the beginning, the changes triggered by the hospitalization⁽⁷⁾. Hence, having a relative present during hospitalization is a way to ensure the child keeps her/his personal records and those of her/his social life, which makes the patient feel safer and cooperate with the health team, developing improved communication channels and cooperation with the treatment⁽⁹⁾.

The individual accompanying the child during hospitalization also experiences a period in which s/he feels uncomfortable in the environment. The child's condition itself can determine behaviors and attitudes of companions. Children with acute diseases, such as self-limiting diseases and even accidents, go through a relatively short, though intense, experience in which the disease/trauma has a poignant effect on their lives. Hence, the family should abandon its daily activities and make itself fully available⁽⁹⁾.

However, when the occurrence involves chronic diseases or the condition demands a more prolonged time for the patient's effective recovery, both the patient and his/her significant people attempt to adapt to a new socio-cultural world, with life styles that fit within the limits imposed by the situation⁽⁹⁾.

Because the hospitalization is an unexpected and unpredictable event, it may trigger vulnerability in companions, who are, in most of the cases, family members. The meaning of this event may be defined and related to factors capable of reinforcing them, such as: previous experiences, excessive demands, and lack of preparedness to act⁽¹⁰⁾.

...having a relative present during hospitalization is a way to ensure the child keeps her/his personal records and those of her/his social life, which makes the patient feel safer and cooperate with the health team, developing improved communication channels and cooperation with the treatment.

There is a perception, which became a common belief among most health professionals, that there is no need to care for anything beyond the physiological aspect in an emergency department since they deal with the eminent risk of death⁽⁴⁾. Consequently, the psychosocial and psycho-spiritual needs of patients and families are left aside.

Nursing care should not be detached from the family since the hospitalization process is oftentimes incomprehensible for the child and also demands a great amount of availability on the part of those accompanying the patient; the companion has to assume an additional responsibility.

Considering that children are very dependent on their companions, understanding daily situations experienced by these individuals during hospitalization enables health professionals to acquire a better understanding. Children can perceive themselves in a safe environment when a healthy relationship occurs, which encourages the patient's adaptation and recovery. Therefore, health professionals are considered agents of an enlarged care.

OBJECTIVE

Given the preceding discussion, this study describes the experiences of relatives of children hospitalized in the service of an emergency department; how the daily routine of these relatives changed; and reports the aspects that influence nursing care.

METHOD

This is a descriptive study that permitted the researchers to acquire a better understanding of the relation of factors and elements that influence the studied phenomenon⁽¹¹⁾. A qualitative approach was adopted and interviews were used to collect data since the study involved individuals from a social group with their beliefs, values, and meanings⁽¹²⁾.

The study's setting was a small and private urgent care center in Teresina, PI, Brazil. The study's participants were ten companions of children hospitalized for more than 24 hours in the service.

Inclusion criterion was consenting to participate in the study manifested through a signature on a free and informed consent form. Data collection was carried out in October 2008 through semi-structured interviews. A handheld voice recorder was used to register the reports, which were later transcribed. To ensure the participants' confidentiality, the reports were identified by the capital letter I followed by the number of the interview.

Data were analyzed using thematic analysis, which consists of unveiling the core meanings that compose communication and includes three stages: pre-analysis, a stage in which documents are selected; material exploration, in

which meaningful expressions are identified in the obtained reports; and treatment and interpretation of results, the stage in which the information obtained is interrelated with the literature initially presented⁽¹²⁾.

Ethical principles were complied with in all the study's phases, in agreement with the recommendations of the Resolution 196/1996⁽¹³⁾. The study was approved by the Research Ethics Committee at the Federal University of Piauí, Brazil (nº 0113.0.045.000-08).

RESULTS AND DISCUSSION

The interviewees were between 20 and 43 years old; women were prevalent and 80% were mothers. A large part (70%) was from the city of Teresina, PI, Brazil and the remaining from nearby cities. In relation to profession, only one (10%) was housewife, the remaining worked outside of the house.

In relation to the hospitalized children, most were victims of acute diseases such as: Acute Respiratory Infections (ARI), diarrhea and dehydration. Only one had a chronic disease (Non-Progressive Chronic Encephalopathy (NPCE) and asthma). A total of 70% of the preschool aged children were hospitalized for about 30 hours and the remaining for three days.

The data collected from the participants' reports were grouped into three categories presented as follow.

The relative's experience

Once the prevalence of mothers as companions was noted, we observed that they assume the role of official caregiver in the family context. The historical trajectory of the female figure is a consequence of rooted cultural parameters that consider the act of providing care a "natural" feminine responsibility. However, the act of caring is a socially constructed characteristic⁽¹⁴⁾ due to tradition itself and family education.

Mothers consider themselves irreplaceable; hence, no one is up to the task of caring for their children and with equal responsibility. Even the own child elects her as protector and chooses her over other family members⁽¹⁵⁾, as presented in the following report:

[...]He wants to stay with his mother, so he gets whiny [...] (I05).

It is necessary to stress that this perception of the mother as the official caregiver has an important role both in the child's recovery and also for the child's mental development. When children are partially or totally deprived of maternal care, the development of their personality is harmed, since it is the mother who transmits essential information for the child's development in the first years of life. The hospitalized child experiences a rupture in this relationship and may present severe emotional, physical and intellectual disorders in the future⁽¹⁶⁾.

Even though, in social terms, fathers are less expected to assume this role, 20% of the interviewed companions were fathers. This finding allows us to observe that fathers are also sharing responsibility with the mothers. When women began to be included in the job market, they started to share the breadwinner role with men and also the remaining responsibilities. Hence, fathers start to perform activities that were previously within the feminine sphere⁽¹⁷⁾.

The child's relatives may become vulnerable, and physically and psychologically exhausted during the hospitalization. However, caregivers may be reluctant to ask or accept help. Oftentimes, the caregiver does not identify in her circle of significant people someone she trusts and considers dedicated and capable as herself⁽¹⁸⁾. This fact is evidenced in the following reports:

[...] I want to be there. There's someone who can stay in my place, only that I'd rather stay with her myself (I10).

There's no one who can do a mother's job!! (I01).

The parents accompanying the child experience the hospitalization, the disease and the child's pain. The caregiver suffers with the child when perceiving her/his physical pain, which may be a manifestation of the strong bond between them⁽¹⁹⁾.

[...] we experience even more pain than the child at the time of the injection (I07).

These feelings show how costly it is in psychological terms to adapt to the new situation, leaving the family environment and routine, to play a role that requires different behavior. Hence, the nursing diagnosis 'caregiver role strain'⁽¹⁸⁾ is identified among the companions. Such a situation deserves special attention from the health team, especially the nursing team, since care should also be directed to the patients' relatives, clarifying doubts, reassuring them and talking to them to alleviate tension.

Impaired Home Maintenance⁽¹⁸⁾ is another diagnosis identified among the interviewed companions. Those who have other children are obliged to leave their home and remaining family members to care for the one who is currently most susceptible. There is the additional concern with the children deprived of maternal/paternal care. This fact is an extra motive for suffering as evidenced in the following report:

I want to go back home as fast as possible because my other child is as dear as she is [...] (I04).

These children are cared for by other relatives, who understand the importance of the situation and provide important help.

My sister is taking care of the others [...] my mother-in-law also, and the niece of my husband is also helping (I02).

In this kind of situation, the entire family is involved and cares for the house and children of the companion, which is effective help capable of easing the parents' con-

cerns. The priority the family members give to the hospitalized child is apparent.

Changes in the family routine

The situation experienced by the child and companion, mother or father, during the hospitalization is a critical and delicate one that requires adaptation and implies changes in the routine of the entire family⁽²⁰⁾. Consequently the family dynamics need to be reorganized⁽²¹⁾.

Most of the study's participants worked at home and also had a job outside home. Hence, they were obliged to give priority to the care provided to the hospitalized child and sometimes have to abdicate their job as the following report shows:

Yeah, I'm here as a companion, it disrupts my work [...] I have an office and work on my own, but I still have a schedule to fulfill; I've already cancelled some of it. (I05).

Missing work is seen by some as something unavoidable since the individual believes his/her presence is necessary for providing comfort to the child and helps her/him to recover. Indeed, this is the main reason for such a sacrifice. Expecting the child will heal and go back to *normal* life, the child becomes a priority among the other tasks and obligations.

Yeah, but we have to miss work [...], the family has priority (I07).

Hospitalization and the companion role demand physiological and behavioral changes in common daily situations previously performed without problems. Considering the needs of the patient are greater than those of the caregiver, the latter understands that the child is dependent on him/her and therefore disregards his/her own needs. Consequently, the caregiver gives up hours of sleep, social life, leisure time, family time and self-care⁽¹⁵⁾.

You can't sleep, you have to keep an eye on the serum, you cannot bathe, have no time to eat [...] (I09).

The constant surveillance of the child's health condition and the events experienced by the caregiver and the child represent potential risks of psychological weariness in the family sphere, leading caregivers to manifest feelings that accrue from the difficulty of dealing with the situation⁽²¹⁾.

The caregiver is exposed to internal and external pressure. Internal pressure includes factors intrinsic to the individual such as: anxiety, loneliness and guilt, among others⁽²¹⁾. Emotional changes were identified among the interviewed. When asked whether the hospitalization had an affect on the psychological aspect, they answered:

A lot... (I get) concerned, anxious, sad (I04).

She suffers from not knowing what might happen to the child, due to the disease and treatment uncertainties, and also from the possibility that something might go wrong

and she might lose the child. The mother witnesses the child's suffering and suffers along with the child, especially in situations in which the child undergoes painful therapeutic procedures and there is nothing the mother can do to avoid or alleviate the child's pain. The mother also experiences pain from being powerless and incapable of stopping the child's suffering⁽²²⁾.

There are, however, moments in which the caregiver masks his/her emotions so that the child does not perceive them. The caregiver believes these can influence the patient's health condition. The following report confirms this fact:

He needs love, affection...to strengthen him [...] I'll make him feel worse if I get here crying (I03).

Even though this report implies a defensive strategy in coping with psychological suffering that relatives experience when a child is hospitalized, it also reflects the fact that the relative accompanying the child during the hospitalization is aware that manifesting his/her concern may affect the child's recovery. Hence, such a manifestation is avoided⁽¹⁹⁾.

External pressures are related to the hospital environment itself such as uncertainties and the fear of the unknown⁽¹⁹⁾, which is manifested in one mother's report; she was insecure for being alone and far away from home:

It's difficult for me because I live far away, I'm not from here [...] my father helps me and I miss him, I need him here to guide me. Sometimes, I get confused, I don't know much about the health plan, there're things I don't know about, you know [...] (E08).

Even though hospitalization is a solitary experience for the mother (or companion), it is important she receives some kind of support, essential for her to experience her companion role. She feels supported when she can count on the support and solidarity of people who are concerned for the child and herself, that is, family, friends, and some professionals⁽²²⁾.

The nursing team can play an important role in situations like these by keeping a dialog with the companion in order to diminish insecurity and enable emotional and psychological wellbeing.

Faith and family closeness acting as facilitator agents

The experiences of companions of hospitalized children can trigger diverse behaviors and conduct⁽¹⁹⁾. The family members seek alternatives to ease suffering, through faith, clinging to religion in the figure of God. Issues relating to spirituality are very present in people's lives, especially when facing difficult times⁽¹⁴⁾. After all, one needs to believe there is hope and that the child's health condition will improve.

Only one among the interviewees expressed the importance of faith, showing his attachment to religion. It may be related to the fact that his child had a chronic disease for six years. He showed himself strong during the report

but also insecure in relation to the future, seeking hope in God to restructure the family environment.

We have to find strength and courage [...] have faith in God [...] he's getting better, we'll certainly be back home soon (I03).

In order to cope with psychological suffering another need emerges. The companions need support not only from family but they also need to find comfort in God. Having faith means to believe that there is hope the child will improve or be cured⁽¹⁹⁾.

In contrast, the difficulties and suffering experienced during the child's hospitalization can be characterized as a positive aspect because it can promote increased family closeness, especially when the parents work outside of the home. In turn, the mother may become satisfied for being able to accompany the child during the hospitalization, giving her affection and care, which is necessary for the child's health recovery⁽¹⁹⁾. Through lessons about life acquired while experiencing and sharing suffering of other people, the mother begins to deal with life differently⁽²²⁾.

[...] I realized that this was an opportunity to get closer to my daughter, because I have a hectic life; I spend the entire day outside the house (I06).

Hospitalization is a suffering process; hence the companions try to see something good arise from the situation. It is not desirable, however, it becomes bearable since it is a means to ensure the child's health recovery.

[...] you want to treat [...] So it is better she stays hospitalized than wait for it to happen again (I04).

When a child needs to be hospitalized, various factors can hinder or facilitate overcoming the intercurrent, promoting balance and bringing the situation under control. The companions can experience changes in daily routine because they experience emotional upheavals due to the patient's prognosis. However, they acknowledge hospitalization as an essential event, given the already discussed reasons, and are also capable of getting something good from the experience. Faith can act as a driving force capable of justifying and supporting the process of overcoming an obstacle. Hence, the companion seeks balance and becomes capable of experiencing the moment in a positive way.

CONCLUSION

The study's objectives were achieved. The experiences of the relatives of hospitalized children were described and indicated that a child needs a companion s/he trusts to help her/him to experience the unexpected hospitalization, which requires caregivers to adapt to the situation.

Changes that occur and transform the families' entire routine were observed. These were accompanied by emotional changes in all those participating in the process: father/mother and hospitalized child.

Improved knowledge concerning this experience reinforces the importance of the health/nursing team delivering integral care, including the family, the subject of the care, in all the care actions, valuing the need of the child/relative to establish bonds and receive individualized care. The family should be seen as an active actor in the patient's treatment and be supported in order to play such a role. The team should support caregivers so they are able to cope with the situation and deal with their own conflicts, fear and increased responsibilities.

Therefore, it is essential to understand that the professional should, from the beginning of the process, integrate the companion into the hospital environment to promote improved

adaptation. It is, therefore, necessary to focus on the humanization of care. The key point is to involve not only the child in the care process but also her/his relational universe, considering the duality of family-child as a single client.

Finally, we acknowledge that the emergency department is a critical unit, hence, has its limitations when one refers to integral care. However, we believe in the use of guidelines recommended by the Ministry of Health, such as admitting patients in such a way that is consistent with humanized care and classifying them by risk. This procedure has been implemented in Brazilian emergency services to promote appropriate adaptations in order to humanize the care provided in these health units.

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