The needs of families in pediatric nursing from their own perspective

Necessidades das famílias em enfermaria pediátrica: a percepção dos próprios atores

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ABSTRACT: This study aimed at identifying the perception of families on their needs when experiencing the process of child hospitalization. Using the focal group technique, we carried out 11 meetings with a total of 36 family members. We analyzed the data obtained with Thematic Content Analysis and divided it into four categories: psychological exhaustion, changes in routine, hospital environment and support resources. From the given reports, we verified that family members' needs are associated with problems regarding the hospital environment, health professionals, service dynamics, and the disease and hospitalization experience. We concluded that their demands are multidimensional, considering they comprise emotional and organizational matters associated with changes in routine. This way, the patient's family companion needs to be considered in this process, which demands an effective interdisciplinary work, and the occupational therapist can be considered a potential professional to minimize the difficulties mentioned.

KEYWORDS: Family; Hospitalization; Child Care; Humanization of assistance; Patients' riims/standards.

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RESUMO: O presente trabalho visou identificar a percepção de familiares sobre suas necessidades na vivência do processo de hospitalização infantil. Por meio do uso da técnica de grupo focal, foram realizados 11 encontros com um total de 36 familiares participantes. Os dados obtidos foram analisados pela Análise de Conteúdo Temática e agrupados em quatro categorias: desgaste psicoemocional, modificação de rotina, ambiente hospitalar e recursos de suporte. Diante dos apontamentos, verificou-se que as necessidades proferidas pelos familiares vinculam-se a problemáticas relacionadas ao ambiente físico hospitalar, à postura profissional, a dinâmica do serviço e a própria vivência do adoecimento e hospitalização. Concluiu-se que as demandas apresentadas são multidimensionais, visto perpassarem por questões emocionais, organizacionais e relacionadas a rupturas de seu cotidiano. Deste modo, se faz necessário incluir o familiar cuidador na assistência, fator que exige o desenvolvimento de um trabalho interdisciplinar efetivo, sendo o terapeuta ocupacional um profissional potencial para auxiliar na minimização das dificuldades estratificadas.

DESCRITORES: Família; Hospitalização; Cuidado da criança; Humanização da assistência; Quartos de pacientes/normas.

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INTRODUCTION

The disease and hospitalization process is a potentially disturbing event that implies deep changes in the family's routine[1].

The hospitalization of a child causes suffering to all family members, not only affecting them but also the roles played by them, which contributes to the dismantling of the family context[2]. With the hospitalization, the family might face difficulties regarding organization, communication, and the physical conditions and standards of the hospital environment[3].

Factors, such as the lack of adequate accommodation to rest and sleep in the hospital environment, noises from other families and health professionals, in addition to the children's suffering, and the need to alternate between home and hospital, lead to physical and emotional exhaustion of families.

Negative feelings such as anxiety and blame, as well as the sudden change in routine because of hospitalization, affect the family's quality of life and the support offered by them to the patient. The structural conditions offered by hospital to patients' companions directly affect human basic needs, such as sleeping, eating, and personal hygiene.

In general, hospitals organize their physical environment according to children's needs, not considering those from patients' companions. In addition, the work process, rules and routines of units follow their own course, not considering the clients' perspective. Visiting and eating schedules, among others, work according to the needs of the service and not of the families[7]. Rumor and Boehs[8] point out the need to revise institutional regulations according to families' demands, thus contributing to assistance humanization.

Another factor that contributes to emotional exhaustion showed in the literature are conflicts between family members and health professionals during service. According to Collet[9], the relationship between families and health professionals is complex and demands the use of strategies from both parts to overcome potential conflicts. In this context, health professionals need to invest in a dialogical relationship with the children's family to better understand their needs and expectations[4].

We are aware that the families' needs are multidimensional and not always identified and incorporated in health care[6]. Ayvazian[10] reports that, despite being subject of interprofessional discussions, family care is not part of health professionals' practice. Empowering the family with educational actions in the care process might prevent recurrent hospitalizations and improve this relationship[4].

Armond and Boemer[11] say that the search for understanding how family members deal with hospitalization can lead to new care configurations, which implies their inclusion in the care process. The structuring of interventions involving the particularities and potentials of each family contributes to the development of institutional policies based on the reality of patients[8].

The family's experience can become easier with the help of health professionals, with information on the causes and prognosis of diseases, and with the understanding of their vulnerabilities[12].

In the law 8,069 from 1990 on the Brazilian Child and Adolescent Statute, article 12 refers to the duty that health professionals have regarding the offer of conditions for the integral stay of one of the parents or legal guardians of hospitalized children or adolescents[13]. This way, it is important to understand the difficulties faced by family members in the hospital environment considering their previous experiences with the disease.

This study aimed at identifying the perspective of family members of hospitalized children to stratify potential demands in family-centered occupational therapy.

METHODS

This is a cross-sectional study, of qualitative approach[14], in which a focal group was used for data collection and thematic analysis for its organization and description.

This research was conducted in the pediatric nursing of the Santa Casa de Misericórdia hospital, of the state of São Paulo, which serves users of the Brazilian Unified Health System (SUS). Structurally, the nursing rooms are distributed according to different health problems (respiratory, gastrointestinal, pre- or post-surgical, and isolation for infectious cases). The average time of hospitalization ranges between seven and 15 days considering the health conditions of the child.

Participants were family members (or people from the family's support network) whose children were hospitalized from October 2013 to February 2014. During this period, the researcher was in the hospital weekly. After the patient's admission, the institution, with the help of the nursing staff, conducted a survey on the number of patient companions of hospitalized children aged between 0 and 12 years, also inviting them to participate in the group. Family members who refused to participate and some of those who had already participated in the group once were excluded from the study, which affected the group activities for weeks.

We did not consider the family's frequency or period of stay as a patient's companion, because we wanted to gather information on the newcomers and on those who were already there for several days.

The group took place in one of the rooms with meetings of 30 minutes long on average, duration being defined by the dynamics of the pediatric nursing.

Methodologically, the focal group was chosen because, according to Iervolino and Pelicioni[15], this technique is used to understand the different perspectives on facts, practices or services. The focal group can be considered an interview group, comprising the essence of the interaction method between participants and researchers to collect data from the discussion of specific topics[15]. After accepting the invitation and accompanying family members to the room where the group would be carried out, an informed consent form was presented to them and after signing it, the meetings started with a help of a lead in.

The triggered strategy were scenes from soap operas that showed hospitalized children and figures with them accompanied by their parents followed by a guiding question: How is the experience of accompanying the child in hospitalization? These resources helped the participants to start talking about it. The researcher had to stimulate the exchange among people and maintain the subject on focus to be able to listen to their point of views, ensure organization, and stratify the collective perspective on hospitalization difficulties.

Data were registered in a recorder and in field journals. Sessions were transcribed and analyzed along with the field journals by following the "Thematic content analysis" technique[14], in which it is verified the repetition of themes in the analyzed material, based on three steps:

1) Pre-analysis of collected material: the reading of texts from the field diary and transcriptions of recorded audios, followed by its review to verify if these data corroborated or not with the hypotheses of this research.
2) Material exploration: organization of the collected material and report analysis in thematic categories.
3) Results interpretation: from report categorization, data interpretation was carried out based on theoretical references.

To complete data collection, saturation was used[16].

This study was approved by the Human Research Ethics Committee as opinion no. 375,606 and had the consent of the hospital institution (Resolution CNS 466/12).

RESULTS

At the end of the study, we obtained 11 focus group sessions with 36 participants, 30 women and six men, all of them being relatives (parents and grandparents).

We gathered the data into four categories, namely: psychological stress, changes in routine, hospital environment, and support resources.

Emotional exhaustion

In this category, we included the emotions reported regarding the hospitalization experience, the child's medical condition, the adopted medical procedures, among others.

We noted that the family reports expressed different emotions, such as concern, fear, exhaustion, apathy, powerlessness, which comprise a stress framework.

Family members talked about the current and the future health status of their children, expressed stress because of their children's health condition, whether because of disease disclosure, or the adopted medical procedures. They also mentioned the fear of the child's suffering with the disease and with treatment procedures, or even of losing their child. In addition, they pointed out that the anxiety of not having an accurate diagnosis or knowing if the treatment is working as expected contributes to emotional exhaustion.

> *"We feel a lot of things at the same time... it's not just about fear, tiredness... It's about insecurity, discomfort, the anguish of seeing your child in bed and not being able to do anything about it." (C4)*

> *"[If] they will come into the room, we get anxious because we keep waiting for tests results... We don't know how he will be in a while...". (C12)*

Family members also reported resignation, discouragement, and conformity regarding hospitalization, in a way, it seems they do not see any other alternative to this situation besides being there for their children.

> *"We need to get used to it, right?" (C22)*

> *"I don't get sad or happy anymore, I don't feel anything anymore." (C18)*

Some of the relatives expressed empathy and willingness to live the experience in the child's place.

> *Yesterday I was saying to my daughter "Child, let me feel this pain for you! Go home, I stay in your place!" (C15)*

We noted that relatives did not want to show weakness to the child, but to focus on giving them support.

> *"... Like it or not, we have to show strength because of the child." (C20)*

> *"We can only transmit security [...] and that's not possible by crying around him, right? "Trying to make him feel safe." (C36)*

Changes in routine

In this category, we gathered information on absences at work, absences of other children, and lack of self-care, which directly affects the daily routine of the family members.

Because of the sickness and hospitalization processes, many of the participants reported having problems at work; one of them reported having lost the job because of the extended periods at the hospital.

> *"She* [employer] *called me and said: I know it's hard, but if you do not show up to teach, you'll lose your job." (C18)*

> *"... the company doesn't care if you're a parent, at the beginning we have flexibility in the job, but it turns out it only lasts a couple of days, after this time it gets more complicated...". (C35)*

Reports on tiredness seemed to be associated with emotional exhaustion led by hospitalization and lack of a support network. We noted the need for temporary reorganization of the family routine in reports that mention the family's search for support from social figures during their period of stay in the hospital; usually, family members need others to be responsible for accompanying the patient or to do things they are not capable of doing alone. These include personal problems apart from the hospital experience, such as the possibility of losing the job, the need to take care of other children and of household chores in addition to needs such as the replacement of clothes and personal items used in hospitalization.

> *"It makes the child tired, it makes us tired. "There are more children at home, my husband can't go there all the time to take care of them because he works." (C26)*

> *"I'm here but I keep thinking about him [son] there with his brother* [hospitalized]*... If I'm there with them, I keep thinking about them being here...". (C17)*

The mentioned difficulties represent losses in the developing of personal care and work activities. Spending the whole day at the hospital because of the unavailability of other family members to take turns in accompanying the child affects the personal hygiene (to take a shower, brush the teeth, change clothes, among others) of the patients' companions, which makes them more susceptible to psychological exhaustion. Sometimes we noted that parents ignored their own needs to put their child's first.

The family members associated their adaptation problems to the hospitalization routine with practices of child care, considering they reported difficulties of adaptation to food and medication timetables; with a different environment with no possibility of using time productively; as well as the difficulty to rest at night.

> *"He is used to eat almost all the time, and here he can't, because there's a right time for it. He wants milk, you see, they brought some tea, so I had to go there to get some milk." (C4)*

> *"At night, we have to stay right there. The nurses give the medication and we only have to stay there... mothers don't sleep, we just keep watching." (C26)*

Hospital environment

This category has reports on the difficulties regarding the quality of services, tedious routines, and perceptions of environmental inadequacies.

Hospitalization experiences arise the need to express feelings and to fill time with distracting activities that minimize the hospitalization impacts. The lack of occupation and leisure activities made patient companions complain about boredom, which make them more anxious and apathetic.

> *"It's awful to stay here... time doesn't go by...". (C1)*

> *"... here we don't have a TV to get distracted... We bring a computer but we can't work because there's no internet... That's not a luxury, it's a need... Over there there's a playroom, but there's nothing attractive to the child...". (C31)*

Family members criticized the hospital regarding delay in service; professionals that do not explain the procedures, do not give enough attention to patient care and not provide diagnosis or explanations on the subject's health condition; and also reported embarrassing moments they lived with their children because of the quality of service that directly affected their emotional balance.

> *"We only come here in last case, but we want a solution, we want an answer from the doctor.. We have no reason to complain about the doctors, but when something bad happens, like that time when the neurologist didn't receive her and didn't say anything about it... I thought it was ridiculous... As a professional, I would never do such a thing." (C29)*

> *"She was with the hospitalization papers in hand and she stayed downstairs* [at the reception]*, waiting for more than two hours, watching the emergency room entry, horrible things... She was watching all of that [...] there was a boy who had attempted suicide, he was screaming a lot [...] until the officer that was there said 'Wow, what is this girl still doing here?'." (C6)*

Patients' companions often justified the criticism addressed to the service with the poor conditions offered to them: there was just a semi-reclining chair for them to spend day and night. Some rooms had a TV and there was a shared playroom for children only containing some books and a TV. Family members mentioned the lack of cleaning and of certain objects – beds, sheets, chairs – and the reduced comfort in general.

> *"We could have a lot of things... a better place to sleep, because most of these chairs are broken... the dad did not have enough space to sleep, the mother was over there, for the love of God, and the grandmother was here... Poor her! I don't know how they managed to sleep..." (C11).*

However, some participants were satisfied with the care and with professionals, especially nurses. The reports point out the preference for treatment at the hospital rather than at home, which, according to family members, contributes to patient's care and safety.

> *"So, for me, it's easier when she's hospitalized, because there was this time when I brought her here, she stayed around three hours under observation, she came back home and got worse... then she had to go back to the hospital once again... I think the service is a lot better, with intravenous medication... it's way different than taking care of her at home... there's the right time to take the medication, right?" And I work, actually, I was supposed to be working by now, so it's hard for me... but it's way better to have her here". (C34)*

> *"Their service is really good, they're really thoughtful... I believe this is essential to the child... They are not the type of nurse that come in looking grumpy. It's so satisfying when they come in with a smile, even for the child. They play while administering the medication...". (C19)*

The support offered by the health service was relevant for family members. Family members considered things, such as the opinion of doctors and other professionals, the way of conveying information, and handling with patients essential for them to trust in the hospital service and have a more humanized environment.

> *"The day she was hospitalized, the head nurse of the intensive care unit, after seeing that I was freaking out, said "listen, mom, you can't stay here, but I'm a mother as well and I know you're not going to relax before getting some news... She passed the phone number of neonatal and gave me the name of the girl who was going to be on duty so that I could call her to see how my daughter was doing [...] so, I mean, they are really good at what they do." (C4)*

Although some relatives reported a trustworthy and satisfying relationship with health professionals, others reported the opposite. Which was mainly due to the lack of attention in care.

> *"When we got there, the doctor said that everything was okay without even looking at him...". (C10)*

> *"I usually get very scared at the time of giving injections, serum, things like that, because as we see in the newspapers, anything can happen! Let's say you're here with your daughter and they give her the wrong medication and it kills her... I always ask what that is for, why they are applying it... Human beings' life is very fragile...". (C16)*

Support resources

It consisted in the gathering of information on hospitalization support resources.

One of the main resources mentioned by the participants was religion, which helped them accept the recent events, search for direction, stay strong, and hope for the best during hospitalization.

> *"I believe that in moments like this, we can only have faith... She was almost dead when she got here... And she came to be drained and stay at the intensive care unit, but thank God she didn't need to... she had a stroke in her lungs [...] I believe that in a moment like this the family helps a lot as well as the roommates, but God's first, I think that there's no other way besides believing in God." (C5)*

In addition, some reports referred to family and partner support, mentioning visits, alternate shifts as family's companion, phone calls and external support, such as the care of the home and of other children. The fact that their other children were under the care of relatives let family members more relaxed and available to focus on the hospitalized child. Some families said the visit time was insufficient (30 minutes) for the number of visitors or the time the hospitalized child would like to stay with the people who came. Family members pointed out they underwent a bonding process after the child's illness and hospitalization.

> *"The most important thing for a patient's companion is family support [...] we just want someone to say 'you can count on me' because being in the hospital is very difficult...". (C29)*

> *"... I would never imagine it, but they* [family] *are helping a lot, they are struggling to help me. My cousin came, I haven't seen her in years! I didn't believe she was here!". (C27)*

In the mentioned cases, friends, children's caregivers and even roommates became part of the family's support network.

> *"People I thought that wouldn't care and that are helping... people help at times when you need the most... I was surprised!" (C30).*

> *"She* [roommate] *had to look after my boy while I was taking a shower today...". (C23)*

DISCUSSION

The families difficulties mentioned were associated with emotional and relational issues and changes in routine. To this end, we observed that the needs pointed out by family members are linked to issues regarding the hospital physical environment, professional's service, the dynamics of the service, and the experience of disease and hospitalization, considering this is a time of change and uncertainty.

This configuration denotes physical and emotional exhaustion. Ramirez[17] expressed that the disease and hospitalization process require adaptation and preparation to promote psychosocial well-being and quality of life, considering family and social changes are risk factors for the development of psychoemotional disorders.

In this sense, Balling and McCubbin[18] aim at keeping parents aware of the child's prognosis, as well as of the procedures that will be undertaken (exams and treatments) to allow parents to feel they have control over the situation, which decreases stress, anxiety and negative feelings.

Gomes et al.[19] claim that, in addition to family support, the visiting schedule is important, considering it is a time when family members can vent about their fears and anxieties and find the courage to face the situation. This time is essential to reestablish contact with life outside the hospital.

Physical and psychological exhaustion reported by the parents is mentioned in the studies by Santos et al.[5] and Beuter et al.[20] and it generally occurs due to negative experiences with the child's hospitalization. In this context, we observed that people needed an opportunity to vent about their feelings as a way of facing the situation, filling idle time and bonding with other patients' companions, thus creating a more humanized environment.

Hence, we believe the guidelines of the Brazilian National Humanization Policies, such as environment and expanded service, can be potential strategies to minimize the needs found in this study that corroborate with the literature findings.

Particularly, environment refers to the physical social, professional space and interpersonal relationships involved in the care. It should provide a resolutive and human reception, considering the need for comfortable spaces and production of subjectivities among subjects, which can be used as a facilitator of the work process. Achieving this environment is the aim of users and professionals[21].

Warm reception comprises the recognition of the other's needs and is extremely necessary to maintain a good relationship between services and user/staff/population[21].

Nevertheless, the use of support resources by family members, such as religion, help the family and the partner, the roommates' family companions, and the health team, and could be understood as strategies that help them face the situation and reduce the reported difficulties.

Othero[22], as well as Gomes et al.[19] and Beuter et al.[20], see religion as an important support tool in hospitalization, considering that it helps people to overcome suffering. The access to the hospital chapel and the encouragement by health professionals to practices such as praying contribute to the process of recovery and resilience of families.

It is noteworthy that changes in the family routine, such as complaints on the lack of occupation, the adaptation to the environment, difficulties regarding self-care, as well as the reports of changes in occupational roles (absence from work, distance from other children, other appointments), all these being considered potential aspects for the occupational therapist' intervention.

Child's hospitalization: perspectives on family-centered occupational therapy

From this configuration, we obtained enough information on the problems that affect families as an object of intervention for occupational therapy in the hospital environment.

Takatori et al.[23] recognized that family is very important for the hospitalized child's health, also highlighting the occupational therapist as a professional with great potential for developing support actions with family members. The occupational therapist has technical skills to build better coping strategies with family members that involve conflict mediation, empowerment of rights, and individual attendances focused on the particularities of each patient's companion (activities associated with religion, leisure, and self-care).

The use of artistic and relaxation activities can be an important resource to face the hospital experience and promote well-being to some extent. Alvarez[24] presents intervention with art in a highly effective way of reestablishing the creative potential of the individual, developing coping and confidence skills to overcome the negative experiences lived in the hospital environment and develop resilience, which is the capacity of staying strong despite adversities.

The development of proposals in group activities[25] focused on the expression of feelings and emotions brought out during hospitalization also contribute to the family's support demands, considering that such practice offers them a place to be heard, to exchange experiences, and to be closer to health professionals.

The impact that hospitalization has on the job of family members called out our attention. The reports from parents who were almost losing their jobs and that have lost their jobs suggest that, at national level, there is a need for changes in labor policies and, at local level, for more attention from health professionals when addressing this issue with the families. Among the possible actions, we highlight the settlement of agreements with the families during occupational therapy interventions with the child; during a certain period, family members can use this time to take care of themselves (to take a shower, change clothes, brush the teeth), being informed on what was developed with the child while they were gone, being aware of what happened, besides feeling more comfortable and included.

Finally, when it comes to the reports that mentioned the service offered by the health team and the physical environment, we believe there is the need to improve the hospital environment. In this sense, occupational therapists, following the Brazilian National Humanization Policy, can develop actions to raise awareness among health professionals regarding the service offered and the emotional impact experienced by families; they can also contribute to the management of extended visit schedules and to the planning and modification of environments for them to achieve more comfort and functionality.

CONCLUSION

Conducting a focal group in a pediatric nursing in the state of São Paulo allowed us to gather the demands of families at the hospital environment due to the hospitalization of their children. It was possible to verify that families showed difficulties regarding emotional and organizational matters associated with changes in routine, which highlight the need to incorporate such factors in the care practices of the institution.

Family-centered care is present in health professionals' speech; however, family care is still not included in the care practice of many hospitals. From the family difficulties pointed out in this study, we verified a problem of multidimensional order, which implies the need for the elaboration of an effective interdisciplinary care plan.

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