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The (dis)satisfaction of the companions about their condition of staying in the pediatric ward

A (in)satisfação dos acompanhantes acerca da sua condição de permanência na enfermaria pediátrica

La (in)satisfacción de los acompañantes acerca de su condición de permanencia en la enfermería pediátrica

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Abstract

Objective: To describe the needs of hospitalized children's caregivers during their stay at the infirmary, to analyze the strategies the caregivers use to satisfy these needs. **Methods:** Qualitative study. The concepts of Human Motivation Theory and Family Care were used. The data collection technique was the non-directive group interview and the analysis was thematic. The study participants were 11 hospitalized children's caregivers at a pediatric hospital in Rio de Janeiro in 2012. **Results:** Of the five hierarchy levels of basic human needs, most remained on the first level - physiological needs. To fulfill them, participants seek material resources in the support network that exists or was built during the child's hospitalization. **Conclusion:** To attend to all hierarchy levels, caregivers' needs have to be attended to, starting with physiological and safety needs and advancing to subsequent levels, which can avoid frustration and the feeling of impotence.

Keywords: Hospitalized Child; Pediatric Nursing; Social Support.

Resumo

Objetivo: Descrever as necessidades do acompanhante da criança hospitalizada durante sua permanência na enfermaria; analisar as estratégias utilizadas pelos acompanhantes para satisfazer estas necessidades. **Métodos:** Estudo qualitativo. Utilizaram-se os conceitos da Teoria da Motivação Humana e do Cuidado Familial. A técnica para coleta de dados foi a entrevista não diretiva em grupo e a análise foi temática. Os participantes do estudo foram 11 acompanhantes de criança hospitalizada em um hospital pediátrico localizado na cidade do Rio de Janeiro no ano de 2012. **Resultados:** Dos cinco níveis da hierarquia das necessidades humanas básicas, a maioria permaneceu no primeiro nível - necessidades fisiológicas. Para supri-las, os participantes buscam recursos materiais na rede de apoio existente ou construída durante a hospitalização da criança. **Conclusão:** Para atender todos os níveis hierárquicos, os acompanhantes devem ser atendidos em suas necessidades, iniciando pelas fisiológicas e de segurança, avançando aos níveis subsequentes, podendo evitar a frustração e o sentimento de impotência.

Palavras-chave: Criança Hospitalizada; Enfermagem Pediátrica; Apoio social.

Resumen

Objetivo: Describir las necesidades de los acompañantes de niños hospitalizados durante su estancia en el hospital; analizar las estrategias utilizadas por los cuidadores para satisfacer estas necesidades. **Métodos:** Estudio cualitativo. Se utilizaron los conceptos de la Teoría de la Motivación Humana y del Cuidado Familiar. La técnica de recolección de datos fue la entrevista no directiva en grupo y el análisis fue temático. Participaron 11 acompañantes de niños en un hospital pediátrico del municipio de Rio de Janeiro, en 2012. **Resultados:** De los cinco niveles de la jerarquía de las necesidades humanas, la mayoría se quedó en el primer nivel: necesidades fisiológicas. Para cumplir estos requisitos, los participantes buscaron recursos materiales en la red de apoyo existente o en la construida durante la hospitalización. **Conclusión:** El apoyo se debe cumplir en sus necesidades avanzando a los niveles subsiguientes, debiendo evitar la frustración y la impotencia.

Palabras clave: Niño hospitalizado; Enfermería pediátrica; Apoyo social.

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INTRODUCTION

Today, in Brazil, pediatric inpatient services in general offer minimal infrastructure to receive the companions of hospitalized children. It is a fact that the enactment of the Child and Adolescent Statute[1], which entitles children to have a legal responsible serving as a companion during the hospitalization, made hospitals with pediatric beds adapt to maintain the presence of this new element.

Twelve years later, the Resolution of the Board of Directors Nº 50[2], which sets technical regulations for the planning, programming, elaboration and assessment of physical projects of health care establishments. In the items on the minimal characteristics for the Pediatric Inpatient Unit (UIP)[*], the following recommendations are focused on the companions in the support environment: Room for the companion's chair at the child's bedside, bathroom for the companion's exclusive use and living room.

In practice, the matters for the companion's stay are focused on sleep and rest, meals, elimination and hygiene. As verified, RDC Nº 50[2] does not provide the technical descriptions of the spaces and furniture for the companions' use, allowing each institution to offer what to give priority and its financial range.

In view of the relative/companion's extended stay during the child's hospitalization, the hospital infrastructure offered and theinteractions between the family member and the health team in the hospital context, the authors started to study the family member/companion's needs during hospitalization.

An online bibliographic search was undertaken in the following databases: Virtual Health Library (VHL) and Cumulative Index to Nursing and Allied Health Literature (CINAHL), in order to identify the studies that indicated the needs of the hospitalized child's companion.

The bibliographic search was undertaken between March and May 2014, and the following descriptors were used: mother or family and hospitalized child, in Portuguese and English. In addition, research papers whose participants were companions of hospitalized children and which discussed these people's needs were set as inclusion criteria. Studies that did not comply with the inclusion criteria or repeated articles in the databases were excluded. It should be highlighted that only one of the duplicated studies that complied with the inclusion criteria were considered. After reading the title and abstracts, 203 articles were preselected. After reading the full version of these articles and using the inclusion and exclusion criteria, the final sample consisted of three studies.

Two qualitative studies, which involved mothers of hospitalized children, highlight that their needs are multidimensional, and that their care is not acknowledged, valued and informed. In addition, they do not receive appropriate accommodation at the institution. In a quantitative study, 43 needs of people accompanying hospitalized children were presented. Nine of them were present in all participants and related to childcare and information regarding the treatment, which means that, considering the child's right to have a companion, the needs of that person become (in)visible.

Based on the survey, it is verified that the number of studies on the needs of children's companions during hospitalization is insufficient, revealing that the relative/companion is not valued as an individual and not included as a care subject. Therefore, the following objectives were set: to describe the needs of hospitalized children's companions while at the infirmary and to analyze the strategies the companions use to attend to those needs.

The theoretical framework included Maslow's Theory of Human Motivation[3] and Elsen's concept of Family Care[4].

According to the Theory of Human Motivation, individuals share needs that drive their behavior aiming to satisfy those needs, according to the five hierarchical levels, in the following order of needs: basic or physiological; safety; love and/or social; esteem and self-accomplishment. According to the theory, when the individual experiences satisfaction at a given level, (Sh/He soon moves to the next level and so forth[3].

Family Care is specific, based on each family's world of meanings and development in the course of its life process. This care occurs between and inside generations, that is, parents taking care of children and, sometimes, children taking care of parents, evidencing the double meaning of intergenerational care. The redistribution of roles makes family care happen in the course of the family's life process and in its respective steps. The particularities occur according to the family's demand and characteristics[4].

METHOD

A qualitative study was undertaken, approval for the project was obtained from the Institutional Review Board. The study context was the inpatient unit of a pediatric hospital located in the city of Rio de Janeiro.

The UIP consists of six infirmaries, two for infants, one for preschool children, one surgical clinic and one onco-hematology clinic, totaling 46 beds. Each infirmary consists of eight beds, except for onco-hematology with only six beds. Each bed is called a child unit, including a cradle or bed, an armchair for the companion and a bedside table, and each unit is separated by a partition. At the UIP, there are two bathrooms for all companions, including a toilet, sink and shower. For meals, the companions are referred to the canteen on the ground floor.

The study participants were eleven companions of hospitalized children, randomly chosen, and who accepted to participate

in the study by signing the Informed Consent Form. It should be highlighted that nine of the 11 companions were mothers and two grandmothers. Companions from the surgical clinic who stayed with the children for a short period, ranging between few and 48 hours, were excluded from the study.

The data were collected between January and March 2012 through nondirective group interviews, which were recorded and fully transcribed.

The nondirective interview is therefore a client-centered psychotherapeutic technique, originally developed by Carl Rogers. It is based on the interviewee's free discourse, in which the interviewer remains attentive to the informant's verbal and non-verbal communication, providing help and stimulating the free expression, using themes that guide the discourse towards questions of interest for the research. In this group technique, the participation of three to five interviewees is recommended[5].

Two group interviews were held with four participants and one interview with three. The mean length of each interview was 45 minutes. The themes used in the interview were related to the conditions to stay at the infirmary, such as: physical, emotional, spiritual structure, health, social, leisure and interaction with the health team. It should be highlighted that the themes were constructed based on Maslow's theoretical reference framework, whose application was validated in the first interview.

On the day of the data collection, the companions were contacted, informed about the research objectives and consulted about their availability and interest in participating in the research. After the acceptance of three to five participants who were chosen from different infirmaries, they were forwarded to a reserved room near the infirmaries, where the companions were placed on chairs turned towards a board where the themes were displayed. The informed consent form was read and signed, clarified, after which authorization was requested to record the interviews. Next, the participants were introduced and the companions were informed that they could discuss the themes displayed, talking freely and randomly without a preset order.

The fieldwork was terminated when the theoretical saturation of the data was reached. As the data collection is interrupted when no new elements to support the desired theorization come out of the observation field, that is, when the interaction between the research field and the researcher no longer provides elements to deepen the theorization[6].

The empirical matieral produced was subject to the analyses recommended in thematic analysis[7] and, then, the following analysis topics were constructed: The infrastructure at the Pediatric Infirmary to house the companions; Thecare/neglect of the health team in the interaction with the child and his/her companion; and the Support Network of the companion who accompanies the hospitalized child.

RESULTS

The infrastructure at the pediatric ward to welcoming of the companions

This topic discusses issues related to the meals, washing of clothes, conditions of the armchair, the exclusive bathroom for companions and leisure.

Concerning the meals, the companions reports the increased financial expenses:

> *You spend a lot here, when I'm here you need money, because the food here is lousy... (companion 1).*
>
> *Here 50 reais is not enough for a week, because the food here, the husbands think like at home, because 50 reais at home you can pay for up to 15 days. (Companion 2).*

According to companion 2's discourse, independently of the quality of the food offered, she eats at the institution, justified by the lack of or limited financial resources:

> *So, whether the food is good or bad, I eat it, because I don't have money to spend. I prefer to save so my mother does not need to keep on sending money and give food to my other children who are at home. (Companion 2).*

Companion 3 is encouraged by her husband to spend money on meals:

> *My husband calls and asks if I'm eating. He says: eat, eat. If you don't have money I'll take it or buy on the credit card. Thanks God he's very calm about that... (Companion 3).*

Companion 3 highlights the lack of meal options due to the way the institution provides the meals:

> *I don't drink coffee with milk nor bread and butter. I don't eat beans and the food here already comes mixed with beans … I don't eat anything here. (Companion 3).*

As to washing clothes, the companions of the hospitalized children mention that there is no appropriate place for them to wash and dry clothes while staying at the hospital:

> *And the clothes? If we don't go home you can't wash them. (Companion 10).*
>
> *The clothes I take everything home, I wash, I iron it and I come back. (Companion 6).*
>
> *There's no place to wash and there's an alert that you can't wash and place them in the infirmary. (Companion 3).*

The companions living in another city are unable to comply with the hospital standards:

> *As I live in Resende and she doesn't have much clothes, I wash them and let them dry on the bed...(Companion 1).*

Another item regarding the infrastructure is the furniture to rest:

> *The place we lie down is a bit bad, we're accustomed to a bed and here it's a chair, it's hard, it's got a gap that kind of hurts your back (Companion 4).*
>
> *...There's no good place to sleep, because the armchair is all hard... (Companion 5).*

Companion 6 mentions the use of a duvet on top of the armchair:

> *I brought a duvet to put on the armchair for me to sleep, because I'm pregnant and when I get up I'm all crooked (Companion 6).*

The number of bathrooms for the companions to use was also mentioned:

> *Sometimes I want to use the bathroom then I come, it's crowded, I go back. In a while I come back and it's still crowded (Companion 7).*

Regarding leisure, companion 6 mentions:

> *Because over here we just sleep at the child's side, there is nothing to do. Even for us to talk and get to know one another, because you can't get to know one another at the infirmary, because we are taking care of our children there (Companion 6).*

The health team's care for/neglect of the companion while staying in the hospital context

This topic addresses issues related to the health team's care/neglect of the companion while staying at the pediatric infirmary. Situations were discussed related to the interaction, care for the child, the noise the health team provokes and health care ofr the companion.

The interviewees informed being treated well and being consulted before any procedure is done with the child; they also qualify the professionals as polite and thoughtful:

> *I can't complain about the doctors… I can't fight or say bad things about the nurses, they treat me very well… They're always sweet. The professionals often ask if they can do a certain procedure, do you allow us to do that? (Companion 8).*
>
> *...The health professionals, they're all very polite, very thoughtful… the nurses themselves, they get there, give care, medication, check for fever, all the time. (Companion 9).*

Two companions mention doing some activities they consider to be the nursing team's responsibility:

> *...Companion is to accompany, it doesn't matter if I have an auxiliary nurse degree, it doesn't matter if I haven't. I do it when I can help and I'm not obliged to. The obligation in here is for the health professional to give medication… There are groups who sometimes don't even wake me up, then they say: it's okay mom because I'm doing it. Others wake you up and say: mommy the medication is there. Sometimes they wake me up to aspire the child's tracheotomy (Companion 7).*
>
> *Sometimes you're there quiet and calm, then one of them comes and says: mom, look, the medicine. I don't mind at all giving my daughter the medicine… but sometimes we're that tired and I think it's their job and it wouldn't be any trouble to go to the child and give the medicine correctly. Because we're sleeping, because we're tired... (Companion 1).*

Another item the participants appointed is related to the noise at the infirmary, according to two subjects:

> *I think it's very bad that, when the technicians arrive, because there's no time to sleep for us here, when our child is sleeping the other one's awake feeling bad and crying, then we go to sleep at one, two o'clock in the morning. So they arrive 6:30 and they talk really loud, then the child wakes up and immediately starts crying...(companion 5).*
>
> *There's a lot of noise at the infirmary and, in my opinion, it's a great lack of respect. As mother 5 also mentioned.... (Companion 1).*

Also regarding their stay at the hospital, the interviewees mention that there is no health care for them at the institution where they are accompanying the child:

Here at X there's no health support for us at all... (Companion 10).

We have no health care. Sometimes we could ask to measure the pressure and the professionals say: no you can't, you need to go to hospital Y to be able to measure your blood pressure... (Companion 5).

The companions also mention difficulty to get medication at the place of study in case of any symptoms, such as allergy or headache:

I had to take anti-allergic medication and there's none here for companions and there's no pharmacy here around… so you don't get any until a relative comes... (Companion 8).

Even a headache you have, if you ask for a medicine they tell you: no, what if you die mommy...(Companion 10).

As verified, when the companions do not get the prescribed drug, they end up self-medicating.

...I don't bring my dorflex® for myself and to distribute to everyone (Companion 10).

Support Network for companions of hospitalized children

This topic discusses aspects of financial support, accompanying the child at the hospital, washing clothes and spiritual support.

Two companions mention getting financial resources from their family or social programs:

No I don't work, but I get help from my family (Companion 11).

...my son gets the LOAS (Organic Social Welfare Law), it's a minimum wage… my husband is now working autonomously, if he gets back to a regular job I lose it. I even told him to get back and take the risk, beause when you get to the end of the year there's no Christmas bonus, no holiday, everything is very uncertain. So R. needs to assume everything and the spending is very high (Companion 5).

Companion 1 mentions have resigned from her job to accompany her child:

... Before G. got ill I and my husband used to work, but as she got ill I can't help anymore, because I had to stop working to take care of her and we are going through difficulties (Companion 1).

Another type of support mentioned is related to the alternation among the family members to accompany the child:

... because he (husband) stays with him (child) at night and I during the day... (Companion 6).

My mother alternates with me here at the hospital... (Companion 3).

Two companions also inform that their relatives take the dirty clothing and bring them back clean:

... Thanks God there are people who wash my clothes, but there's a girl here who lives in Volta Redonda. The other girl arrived these days and lent her clothes. (companion 3) ...

My clothes when someone comes they take the dirty ones and bring more clean clothes... (Companion 1).

Another aspect the participants appointed was related to spiritual support while accompanying the child. The research institution offers spiritual support, in accordance with companion 8:

... Here at the hospital sometimes a priest comes and an evangelical woman who comes and prays for my daughter too, there's no problem because I think there can never be too much prayer (Companion 8).

DISCUSSION

As verified, the meals the institution offers do not attend to the companion's food preferences, resulting in unforeseen extra spending in the family budget. In addition, in the research context, most of the children are hospitalized over long periods, intensifying these expenses.

Human behavior is determined by and, hence, motivated by needs. The physiological need for food is the starting point for the hierarchy of basic human needs[3].

The non-fragmentation of family care can also be identified, for example, at mealtimes, when there is concern with the different family members' nutritional needs, including the acceptance or rejection of the food and individual preferences[4].

It should be highlighted that the companion's food is a very important factor, as the companions should be well fed and willing to help with the hospitalized children's recovery and care[8].

As for getting clean clothes, most companions get them at home. In some cases, the institutional rule has to be violated, mainly because many of these companions live in other cities in Rio de Janeiro. The hospital does not provide clean and sufficient clothing for the children and a place to wash the companions'

clothing. On the opposite, the institution prohibits that they wash and hang up the clothes at the infirmaries. It is clear that these standards or rules cannot be complied with, as clothing is part of individual physiological needs.

The companions coming from the interior of the State, who have been staying at the service for a long time, as well as companions with children suffering from a chronic condition, are able to violate the standards more frequently, with a certain aquiescence by the team[9].

As regards rest, the use of a reclinable armchair is uncomfortable as, according to the testimonies, the padding is hard and the surface is not linear. When the companions have some resources, they use them, like for example a duvet or mattress to minimize the discomfort. As they spend a long time at the hospital, however, and as the furniture is not a bed, discomfort is a permanent complainings.

In the daily life of the hospitalized children's mothers, the place at the companion's disposal is either uncomfortable or very badly perserved[10]. The companions call for better accommodation during the child's hospitalization[9].

One of the individuals' physiological needs is an appropriate posture to have a good sleep and rest pattern[3]. In a study of school-aged children, hospitalized patients can perceive the companions' irritability and associate this feeling with their hospitalization, blaming themselves for the suffering caused to the companions[11].

As verified, the companions face difficulties to attend to their needs for bodily hygiene and physiological eliminations, due to the insufficient number of bathrooms for these clients at the infirmary.

Although the companions appoint this fact negatively, the institution complies with the standards established in RDC Nº 50/2002[2], which does not specify the number of bathrooms and their dimensions for the number of companions, allowing each institution to offer what is within its reach or what it considers a priority.

As verified, the companions do not have room and/or leisure activities during the child's hospitalization, underlining their social privation and the opportunity to talk about their experiences while in hospital with other companions.

During the child's stay in hospital, the companion does not have any leisure activities. Nevertheless, simple measures can be taken to improve the recreation and the the companions' relation during the child's hospitalization, including: proposal to celebrate special dates; crafts; sewing; handicraft; origamis; making toys; relaxation; dancing and others; which can distract and enhance the companions' wellbeing and, consequently, improving their quality of life during the child's hospitalization[12].

Human beings need to feel integrated and part of a group. The frustration of this social need generally leads to a lack of social adaptation and solitude[3].

As verified, the attention the health team pays to the health team during care leaves the companion with a good impression of the team. It is supposed that the companion is concerned with the child's wellbeing and health promotion, showing family care in the discourse. Family care is also identified concerning food expenses.

Family care represents the family members and the family group's wellbeing, aiming for a movement that irradiates towards health promotion and individual wellbeing[4].

It is interesting to highlight that, in the interactions between the health team and the companion, there is difference in the way they refer to the medical and nursing categories.

It is also acknowledged that the companion is not fully responsible for the care delivered to the children while in hospital and these individuals are dissatisfied when the health professionals wake them up when they are resting to deliver care the professionals themselves could provide.

One of the potential problems interfering in the interaction with the companions in the hospital context is the neglect of their sleeping, eating and relaxation needs. The accommodations to sleep are limited to a chair and their sleep is interrupted by the nursing procedures. Consequently, the companions are unable to maintain a continuous sleep and rest pattern, as their sleep is fragmented[10]. In addition, there is the professionals' erroneous behavior who, when they arrive at the infirmary, to not take into account the problems that may have happened during the night shift, producing bothersome noise.

Individuals need respect from the people around them. When this does not happen, their needs for esteem and valuation are not attended to. The frustration of this need causes feelings of inferiority, impotence, which lead to discouraging reactions[3].

There are difficulties related to medical care for the hospitalized children's companions, as the health system does not provide for care for these clients, no do health policies offer any alternative for this group[13]. The research institution does not offer medical care for the companions, being a pediatric institution. In that sense, they try to self-medicate, using drugs other companions offer.

It should be highlighted that the child is entitled to have a companion while in hospital. In that sense, it is supposed that companions are not considered as parts of health care, intensified by the fact that the research context is specialized in pediatrics.

One of the aspects of the most important support network for hospitalized children's companions is financial support, evidenced as family care[4]. The social support network is constituted and strengthened by relatives, friends and neighbors[4,14].

The family gets organized to maintain a constant income, whether through social programs or informal work, often for the sake of a complementary income. In addition, the study appoints that the companions choose to resign as, during hospitalization, the child needs to be accompanied by a caregiver, often being the mother. The alternation in accompanying the hospitalized child mainly involves close relatives like the child's father and the grandmother.

Family care is recognized through different attributes, including the "presence" of a family member, as shown that being together, accompanying and assuming respnsiblity for the other still involves multiple generations, that is, between generations[4].

To attend to their safety needs, individuals tend to seek a religion and world philosophy that organizes the universe and men into a satisfactorily coherent and significant whole[3]. As verified in the statements, the companions need spiritual support to provide them with strength and hope, independently of the religion proclaimed.

It is fundamental for pediatric nurses to develop skills to take care of the companions as clients, acknowledging their needs, permitting the proposal of interventions that relieve the suffering and promote institutional changes[14,15].

CONCLUSION

In conclusion, while staying with the child in hospital, the companions have needs related to the first hierarchical level of basic human needs, that is, basic or physiological needs. In that sense, they are unable to move to the subsequent levels.

To attend to some of their physiological needs, they are motivated to seek means to satisfy them, including means to minimize the discomfort of the armchair, like using a duvet, violating the institutional standards to get clean clothing, as well as self-medication to minimize the pain and the lack of medical care, besides constructing a social network that provides intra and extra-hospital support in terms of having clean clothers and alternation to accompany the hospitalized child.

The study also appoints that the companions indicate their (dis)satisfaction with the interaction in the care the health team delivers to the hospitalized child; the noise produced by the health professionals; the delegation of care and leisure. The companions with a strong social support network are able to advance to the subsequent hierarchical level (safety), while the companions with a weak support network, like when the family lives in another city for example, reveal greater difficulties to have their needs attended to.

Despite the progressive increase in the number of studies on companions in the pediatric hospital context, there is an urgent need to seek strategies and policies that attend to their needs and the dignity to stay for the child's right to be fully attended to.

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* UIP - This service includes the following areas: infirmaries, isolation room, antechamber to isolation room, rooms for examinations and dressings, bathroom, nursing station, service room, medical prescription room, recreation/leisure/canteen area and classroom[2].