

RESEARCH

O Familiar na Unidade de Terapia Intensiva Pediátrica: um contexto revelador de necessidades

The family member in the pediatric intensive care unit: a developer needs context

El familiar en la unidad de terapia intensiva pediátrica: un contexto revelador de necesidades

Francisca Georgina Macedo Sousa¹, Danilo Marcelo Araujo Santos², Heloisa Rosário Furtado Oliveira Lima³, Dennyse Cristina Macedo Silva⁴, Luciana Palácio Fernandes Cabeça⁵, Ericka Leticia Lima Perdigão⁶

ABSTRACT

Objective: understanding the needs of family members of children admitted to the pediatric ICU. **Method:** a qualitative descriptive study supported on thematic analysis with data collected by unstructured interviews having as subjects eight family members of children admitted to the pediatric ICU of a hospital of reference in the State of Maranhão. **Results:** revealed 11 themes grouped into five needs (safety and comfort, emotional, communication, adaptation and support). **Conclusion:** the illness and hospitalization coupled with the care needs of family members revealed a gap between systems centered on the disease and the centered on the person that encompassed the physical, emotional, spiritual and financial field of the accompanying family member. This perspective demands expansion of the focus beyond the disease reaching the family and its needs. Thus, the ICU professionals shall develop skills and competencies to identify and meet those needs, breaking with the fragmentation of care and suggest meeting that involves the context, the child and family. **Descriptors:** Nursing; Family; Pediatric Intensive Care Unit.

RESUMO

Objetivo: compreender as necessidades dos familiares de crianças internadas em UTI Pediátrica. **Método:** estudo descritivo qualitativo apoiado na análise temática com dados coletados por entrevistas não estruturadas tendo como sujeitos oito familiares de crianças internadas em UTI Pediátrica de hospital de referência no Estado do Maranhão. **Resultados:** revelados 11 temas agrupados em cinco necessidades (segurança e conforto; emocionais; comunicação; adaptação e suporte). **Conclusão:** o adoecimento e a hospitalização aliados ao atendimento de necessidades de familiares revelou um fosso entre um sistema centrado na doença e o centrado na pessoa que englobaram o campo físico, emocional, espiritual e financeiro do familiar acompanhante. Essa perspectiva demanda ampliação do foco para além da doença alcançando a família e suas necessidades. Assim, os profissionais da UTI deverão desenvolver habilidades e competências para identificar e suprir tais necessidades, rompendo com a fragmentação do cuidado e sugerem encontro que envolve o contexto, a criança e a família. **Descritores:** Enfermagem; Família; Unidade de Terapia Intensiva Pediátrica.

RESUMEN

Objetivo: comprender las necesidades de los familiares de niños internados en UTI Pediátrica. **Método:** es un estudio descriptivo cualitativo apoyado en el análisis temático con datos colectados por entrevistas no estructuradas teniendo como sujetos ocho familiares de niños internados en UTI Pediátrica de un hospital de referencia en el Estado de Maranhão. **Resultados:** revelados 11 temas agrupados en cinco necesidades (seguridad y confort; emocionales; comunicación; adaptación y soporte). **Conclusión:** el padecimiento y la hospitalización aliados al atendimento de las necesidades de familiares revelaron u fosso entre un sistema centrado en la enfermedad y el centrado en la persona que englobaron el campo físico, emocional, espiritual y financiero del familiar acompañante. Esa perspectiva demanda ampliación del foco para más allá de la enfermedad alcanzando la familia y sus necesidades. De esa forma, los profesionales de la UTI deberán desarrollar habilidades y competencias para identificar y suplir tales necesidades, rompiendo con la fragmentación del cuidado y sugieren encuentro que envuelve el contexto, el niño y la familia. **Descriptor:** Enfermería; Familia; Unidad de Terapia Intensiva Pediátrica.

¹Nurse, PhD, Professor of Graduate and Post-Graduate Nursing/UFMA, Coordinator of GEPSFCA. ²Nurse Care of the University Hospital/UFMA, Student Academic Master in Nursing UFMA, Member of GEPSFCA/UFMA. ³Nurse Care of the University Hospital/UFMA, Student Academic Master in Nursing UFMA, Member of GEPSFCA/UFMA. ⁴Nurse, Student of Master in Nursing at the Federal University of Paraíba, Member of GEPSCA/ UFPB and GEPSFCA/UFMA. ⁵Nurse Care, University Hospital, UFMA, Student Academic Master in Nursing UFMA, Member of GEPSFCA/UFMA. ⁶Nurse, Student of the Multidisciplinary Residency in Subarea Child Health, University Hospital, Federal University of Maranhão, Member of GEPSFCA/UFMA.

INTRODUCTION

The family needs are conceptualized as something essential, required by the person, when supplied, relieve or decrease the distress and the immediate distress or improves perception and wellness fitness.¹ unmet needs or inadequately answered bring discomfort and periods imbalance that can lead the human being in need of assistance of a qualified professional. This situation can be observed in the intensive care unit, where in addition to the needs presented by inpatient, are the family members who also start to have changes in the balance of their status.²

The Intensive Care Units (ICUs) have technological advances and highly specialized teams that assist in the survival of which there are interneers, mostly from the clinical point of view. However, these do not replace the family, especially the parents,³ whose importance lies in the emotional support to sick children and is mainly seen as an ally in the nursing family health-disease process. On the other hand, the family needs information, clarifications and team support, because they are fragile and vulnerable because of the situation.²

Freitas, Kimura and Ferreira¹emphasize that hospitalization of a family member in the Intensive Care Unit (ICU) generally occurs in acute and inadvertently, leaving little time for family adjustment, which can lead to imbalance in the structure of that family. Faced with this stressful situation, relatives can feel disorganized, helpless and struggling to mobilize, giving rise to different types of needs that can be aggravated by lack of information and prior knowledge on the environment of the ICU's that generate insecurity and fear to family and patients considering treat yourself to a frightening environment, and admission source of stress for people who experience.⁴ In addition to industry expertise, the physical structure, noise, bright light, the equipment and the movement of people contribute as stress generator for the patient and for the family.⁵

Furthermore, family participation in the care for hospitalized children was regulated by the Statute of Children and Adolescents,⁶ ensuring the right for parents to accompany their children throughout hospitalization. Article 12 establishes that hospitals must provide conditions for staying in full-time a parent or guardian in the case of children or adolescents hospitalization.

However, the hospitalization of a child in a Pediatric Intensive Care Unit (PICU) because the family moments of anguish, suffering and despair⁷ and experience a break in its structure and functioning in which the family lost power over the child becomes temporarily belonging to the health team. For Silva⁸ family defines the PICU as a place to die, and the possibility of death causes a great impact on those directly involved in monitoring the child or adolescent. In this context, the whole family is involved and experience intense suffering caused by the child's health condition as well as the experienced interactions with the environment and the professionals who work there.

From this perspective, Ângelo⁹ elaborates the concept of family vulnerability, which is, a sense of threat to autonomy, which is under pressure from the disease, their families and the staff generating uncertainties, impotence, threats, fear and expectations of the outcome of return to previous life. Under these conditions, the familiar vulnerability is characterized by an imbalance in their ability to function, causing disrupts, distance, change in family life and conflicts. Complementing the statement, studies of Inaba, Silva and Telles¹⁰ reveal that the family is weakened by the child's illness and becomes vulnerable to cope with the situations giving rise to different types of needs. The authors assert that many families demands are not met or whether perceived by the team and although the nurse mobilize to include the family in their care plan, not yet feel ready to welcome families in the Pediatric ICU.

However, nursing has always recognized the importance of the family in promoting and maintaining health as having the care unit with emphasis on their answers to the current problems and potential health that is experiencing as well as the meanings constructed symbolically to illness. In this process, the family can reveal a number of needs that must be identified and serviced by professionals. Considering the above assertions wonders: what are the needs of families of children hospitalized in the Pediatric ICU?

The interest in working with the needs of hospitalized children of relatives in ICU emerged in discussions and research projects related to the Group for Study and Research on Family Health, Child and Adolescent/Federal University of Maranhão (GESPFCA/UFMA) than in allowed to approach the subject by growing unrest in understanding family needs in child care hospitalized in ICU considering them as a customer who also need care.

The relevance of the work is linked to the fact that, to work the nursing care of families in hospital, it is necessary to identify and understand the needs felt by family and includes the family in shared child care. Thus, it is important for nurses and other professionals understand that the families, as well as hospitalized children need care. Thus, understanding these needs means realizing the family as care unit and that the knowledge produced about the experience of the family that is with a son hospitalized in ICU, it is important to scale the practice of nursing in this context.

The research aimed to understand the needs of families of children hospitalized in the Intensive Care Unit.

METHOD

Descriptive study with qualitative approach supported by the thematic analysis proposed by Minayo^{11:316} which was to "discover the units of meaning that make up a communication whose presence or frequency mean something to the targeted analytical objective". While the notion of the theme is linked to a "statement about certain subject and can be displayed by a word, phrase of a summary"^{11:315} The review process was guided by the three steps of the method: pre-analysis, exploration of material and treatment of results and interpretation. In the Pre-analysis were performed readings of the interviews followed by the organization of the material (Constitution of Corpus) and the formulation of

hypotheses. In the second step was performed exploitation of material, which consisted of "a classification operation to reach the core understanding of the text" ^{11:317} encoding using the raw data consisting in the reduction of text through meaningful phrases.

In the last step was performed the treatment and interpretation of the results obtained from the option of working meanings rather than statistical inferences.

The study site was an Intensive Care Unit Pediatric (PICU) of a public institution of health state reference to highly complex located in São Luís, Maranhão state capital which has 10 beds. The subjects were relatives of children admitted to the PICU research that met the following inclusion criteria: a period of 24 hours of admission of the child in the PICU; being a father, mother (biological or not), grandparents, uncles, brothers, cousins or people close (with or without consanguineous ties); family aged over 18 years; who have visited the child at least two times; that is in physical, emotional and psychological conditions to attend the interview.

The number of subjects was defined from the data density and scope of the proposed objectives. In this way, eighteen research subjects understood by relatives of children admitted to the PICU for a total of four grandparents, five parents and nine mothers aged between 26 and 48 and average of 37 years old, 50% were from the interior of the state. Children admitted to the PICU during the period of data collection were aged 4 and 96 months, mean 50 months.

Family members were individual guests and personally to participate in the study and were interviewed in a room of one's PICU or nearby places, taking care to be guaranteed absence of noise aiming audio quality. The intimacy and the availability of the family were respected. Coupled with the recording of the interviews of the reactions of respondents notes were conducted through field diary to enrich the analysis process. We used the unstructured interview using the following guiding question: What are your needs from the first day of hospitalization of your son/grandson/nephew in the ICU? The interview was enriched by circular questions, so that the testimony of family heeding the requirements proposed by the investigation.

This study is part of the "Family Needs of Inpatients and Nurse Attention Demands in the Intensive Care Unit," which was approved by the Ethics Committee HUUFMA under the Research N° 092/11. After approval was initiated field research, and obeyed all the ethical principles of the National Health Council Resolution 196/1996.

RESULTS

The data analysis process emerged 11 themes that will be presented descriptively. The themes were nominated from understanding and grouping of needs: Safety and Comfort needs, emotional needs, communication needs, Adaptation and Support Needs (Figure 1).

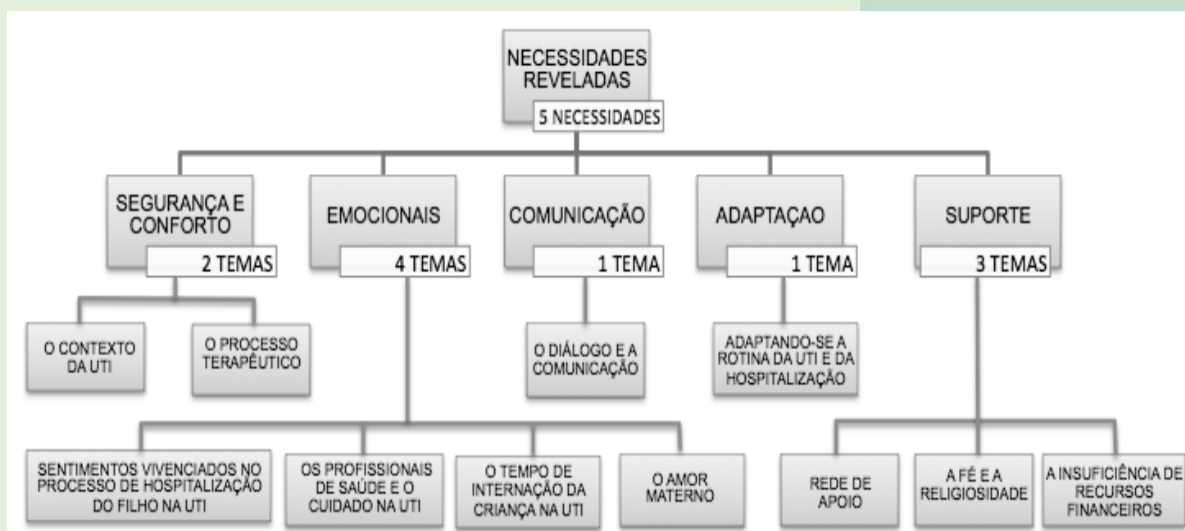


Figure 1. Grouping of subjects according to the needs of families of children admitted in PICU. São Luís - MA, 2011.

a) Safety and comfort needs

Theme 1: The ICU context

This topic describes how the family understands and experiences the context of the PICU. Although the ICU represents an unknown and stigmatized environment, the family, when faced with the reality of illness and hospitalization, begin to recognize it as a safe and supportive environment needed to save the child's life:

[...] He was in the IU that is not an ICU for him and when I got here I was more relieved because here's all he needs. (Carnation)

In the ICU's being good because there where we didn't have any resource and if we hadn't come here he could have died. And here we're better than there. Here he's in a good place. (Rose)

The design of family UTI is a safe space for the child to offer all necessary resources for the care of children. However, the ICU environment and the new routine, coupled with the stress and emotional distress, cause different impacts on the family, giving rise to needs and wants. Among them, the family showed the need for comfort, sleep and rest:

Comfort in a hospital nobody has and here is no different. (Carnation)

In the ICU I miss a cosiness, comfort, because staying the whole day sitting in that chair is bad enough. Now I got an armchair to sleep, but in the early days I slept sitting on plastic chair, kept all night. (Bromeliad)

It is evident that comfort and sleep in the ICU are not satisfactory due to the structural weaknesses of the institution. At the time of the research the unit had six seats for companions, which were next to each bed, the other plastic chairs were available; added to this the sleep disruption due to routine activities of assistance.

Another need detected in the speech of family was the lack of security for personal items by the absence of a cupboard, reinforced by the occurrence of petty theft:

It would be interesting if I had a place that we could keep our stuff, like a file cabinet with lock and key, because I don't carry my things here with fear of being stolen. (Margaret)

Provide local and be safe for safekeeping of personal objects of the family should be considered in areas of Pediatric Intensive Care, from the moment the child's family's stay during the entire period of hospitalization is guaranteed. Disregarding this aspect can enhance/suggest the invisibility of the companion in the hospital context, a fact that compromises the comfort, safety and family welcome.

Theme 2: The therapeutic process

The need for adequate therapeutic support during the child's removal to the ICU and dissatisfaction with the therapeutic process are noted by family members as factors causing insecurity in assistance to critically ill children. The reports of family revealed the difficulties faced by ICU admission, among them, the pilgrimage for several health services, combined with inadequate conditions in inter-hospital transport:

He was admitted to a hospital in the countryside and there suffered a cardiac arrest. Then we went to another city here, and just after we came here without any feature only with the oxygen flask and leave it to another hospital. There he was in IU, that it was not appropriate for him, and then he came here. (Carnation)

This scenario is experienced mainly by children and families from the interior of the State, moved by the child's improvement hope moving to the capital in an attempt to ensure the best treatment. There are words that reveal the lack of structure and therapeutic medical support highly complex in Maranhão cities.

Maruiti and Galdeano¹² assured that the family worries about the patient and experiences fear and insecurity, often a result of uncertainty, regarding the conduct and treatment. Looking more closely those needs, it is understood that the families of children admitted to the PICU resent the lack of care, mainly related to the child's problem:

Yesterday I discussed with them (professionals). I asked the cardiologist to she look at my son. (Carnation)

The doctor looks at my son and says that he is not the neediest. (Bromeliad)

He (medical specialist) not sure what my son has just enough and gives him so. I got angry with him. (Margaret)

Such situations cause dissatisfaction familiar with the therapeutic process of the child in the PICU. Some families come to characterize the attitude of professionals as negligent, and the lack of team care for the child's problem.

At times the family identifies the professional neglect of his patient, increasing their anxiety, lack of answers to their questions.

The need for a more resolute service is also explicit in the statements of family members, where bureaucracy and the delay in performing therapeutic procedures such as surgical tests and procedures, aggravate stress and increases the family's anxiety during hospitalization:

I think the tests that he must make should be done here inside the hospital. Because sometimes he has to get out of here and go to another hospital for examination because there has [...] and sometimes they take too long to do. We're sad here and with the delay of these exams more sad about us. (Rose)

The delay in carrying out tests and procedures deemed essential by the family generates anguish, apprehension and tension, since the family relentlessly seeks answers about the child's clinical condition. The attitudes of health professionals, especially of doctors were judged by the family as of little interest, given the delay in making decisions regarding resources to confirm the diagnosis and therapy of establishment. It is observed so that the satisfaction and quality of care have explicit link with the availability of staff to meet the child's needs.

b) Emotional needs

Theme 3: Feelings experienced in the child's hospitalization process in ICU

The disease and the child's hospitalization are conditions that generate different feelings, uncertainty and doubt, especially as regards the full recovery of child health, generating intense anxiety disorders in family caregivers. Hospitalization is nonetheless a threat to the emotional integrity of the accompanying family member, as this is released suddenly in another world, a threatening world, away from their daily lives, which is the institution, full of rules and rotinas¹³ condition shown in the following speech:

This experience is an experience that I never had passed and I never imagined that one day would pass. It is very hard to be here. It is very difficult to not be sure what my son has. (Margaret)

The relative faces throughout the child's hospitalization in PICU feelings of fear, despair and loneliness caused by separation from family life and the fear of death revealing weaknesses across the situation:

By the time I walked into the ICU I felt alone, I thought I was alone inside without having someone beside me, I thought there was no one by my side. (Margaret)

I felt really scared. Fear of doing something wrong. Will apply a general anesthetic my son die? (Sunflower)

What I miss the most is in the ICU's with my family, I miss my family. (Rose)

I miss them. Miss having my family together in this moment. (Bromeliad)

Subject to these feelings, family emotional support from the healthcare team PICU, however, do not find what they seek in these:

I don't have any support from a psychologist or someone so I can talk, sometimes I feel like I want to talk to someone, someone to listen to me, but here I have nobody. (Margaret)

The reports highlight the PICU as an ambivalent environment. Insurance as a result of scientific and technical support that allows complex interventions and for the recovery of

child health, while cold and unwelcoming, where family members experience feelings of fear of death, loneliness and helplessness. Family members feel the need for support and professional accompaniment to emotional problems caused by the disease process, being away from home and the child's hospitalization. One can understand that the therapeutic action in the PICU is limited, for the most part, the technical and scientific aspects important to the control and cure of serious diseases patients regardless of the threatening aspect of the PICU environment and physical suffering and emotional that cause the family members accompanying the hospitalized child.

The need for support is described by family members when their accounts reveal miss family and to have her at his side. Be close to family means support for coping with the situation. The reports demonstrate the importance of the presence and participation of the extended family as a key element in supporting the child and parents during hospitalization.

Hospitalization is therefore a threat to the physical and emotional integrity of mainly companion resulting in the wake of various feelings that are being discovered and experienced by the family. Melo et al.¹⁴ justify these feelings arising from their own environment and the dynamics of work, living with the child's illness, changes in external and internal structure of the family, as well as dealing with the diagnosis and experience suffering during hospitalization.

Even experiencing this painful process, the feeling of hope that the child will recover is present in the speeches of the family members:

It's hard because it's very serious the problem of my son, but I have hope that he's going to wake up and will improve. (Rose)

The frame is very severe, recovery is very slow, but I have hope that he comes back home. (Jasmine)

The way my son was a healthy child, studied and played never passed through my mind that he could have a tumor in the head and by the time we hit the MRI and discovered he had a tumor, was a very big shock. But I have a lot of hope that he will work out of here. (Hydrangea)

The feeling of ambivalence was identified in the reports of mothers who recognize they have needs, but support them. The mother is not important to supply her needs and yes, the needs of her child:

What I want is that my son gets better soon; because, if I have a chair, I sleep, now he can't, he needs a comfy bed and I see him lying quite comfortable for me OK. (Rose)

I miss having a little money for me, but having everything to my son, I'm satisfied with what is offered. (Hydrangea)

According to Molina and Marcon¹⁵ in a study on the permanence of mothers with hospitalized children, they realize that their presence goes tranquility and security, and may help in the recovery and stability of your child. The suffering and the decision not to give happen simultaneously, which means that on the one hand, the mother suffers, on the other, it does not yield to this suffering:

For the health of the child from us everything else supports and tries to overcome. All I want is my daughter to get well and that we can get out of here. (Bromeliad)

The desire to stay next to the child is related to the role of providing protection for hospitalized children, while remaining vigilant controlling everything that is or is not done with the child:

I don't even like going down a lot because I like to be alone in there with him, enjoying him. So that's my hunger because I get close to him, I'm talking to him. (Rose)

In addition, the anguish due to the perceived severity of the child's illness is also part of the feelings experienced by the family:

What I need is for her to come out of those devices, because I see her linked directly into those devices and I'm sure there's not breathing. (Rose)

The previous report reveals that the observation of children's dependence on mechanical ventilatory therapy and other devices and invasive devices, causes the family accompanying feelings of distress, because the child's inability to perform basic human activities, such as breathing.

Theme 4: Health professionals and care in the PICU

Family of incorporation in child care, professionals adopt key roles in the development of shared care. According to the subjects of the research family, members of the healthcare team in caring role of hospitalized children have knowledge about the health-disease process being able to measure and intervene in the severity of the child:

Doctors examined her and said she was in serious condition, but they were going to try, they wouldn't give me certainty, as they tried to she reacted. (Bromeliad)

The aid from professionals as to the perception of gravity, minimizing the suffering for the acceptance of disease enables gradual adaptation of the familiar to the new child's condition. Family members report feeling welcomed by professionals with emphasis on nursing staff and the psychology service. There is the perception of the approach of these professionals on the family's needs and consider that their needs were adequately met:

The nurses were giving me assistance, were taking care of my daughter, a psychologist came in and introduced herself; then I felt already in another situation. (Rose)

In Leite et al.¹⁶ words, appreciation the establishment of trust relationships between family and professional works as a link between the subjects of hospitalization, transforming the hospital into a place of less discomfort for those involved. The establishment of a plan of care to meet the family's needs by the professional staff of the unit is an effective way to establish trust.

Theme 5: The child's length of stay in PICU

The family of ICU stay is prolonged because the treatment of critically ill patients requires caution, continued treatment is slow and in some cases it is not possible to

estimate the patient discharge this sector. Allied to the needs faced by families have been the valuation given to the days of ICU stay and revealed in the reports:

I'm nine days away from home and it's hard to be here. (Sunflower)

Makes 15 days that I'm here in intensive care, will do a fortnight tomorrow. (Carnation)

Time of hospital stay reveals a need for family, becoming a dichotomous value. On the one hand is an ally to the child's recovery and, on the other, is an aggravating to the situation of stress and social isolation experienced by the accompanying family member.

Theme 6: Maternal love

Mothers revealed in interviews that love for the child overcomes the fear of possible loss and the feeling of comfort is the maintenance of the mother / child even when the child's hospitalization. Mother's love is characterized as unconditional, which causes do not lose hope in her son's recovery. They spoke of the mother's love as a major and specific feeling of the maternal figure:

It's a feeling that has no explanation, because I wasn't scared. Is a love so great that we have, which gives a sense that we're not going to lose hope and I don't lose hope. (Margaret)

The feeling I have is the feeling that every mother feels. Because every mother who creates a child, a grandchild, she has a love so great! It's a great feeling that we have. (Bromeliad)

According Faquinaldo and Collet¹⁷, love and affection for his son make a continued interest object to the mother, and beyond that persistent interest, it offers a range always refreshing, rich and varied life experiences. What makes these so important experiences for the child is the fact that they are interconnected, enriched and characterized by maternal affection. It is essential in childhood, because at this age the affections are of far greater importance than in any other period of life.

c) Communication Needs

Theme 7: Dialogue and communication

The communication between impaired health staff and family was evident when his family reports proved afflicted for answers on the clinical picture of the child:

The doctor arrives and doesn't talk to us, just with the nurses and other doctors with my son and not enough to talk with us what's really going on with him. (Bromeliad)

In the search for information some families report as the main need, to know the diagnosis of the son:

What I want most is to know what my son has. I want to be sure what he has and that is getting the right treatment. I want to see concrete what my son has. What is happening to him. (Carnation)

Have answered questions about the child, a good relationship with the health team of the ICU and be informed and discuss the clinical picture with the health professional needs are evidenced by reports of family members. Allied to these issues to qualified hearing, the interactive dialogue and communication therapy are primary conditions for the care of family while not externalize the need of care, internally calls for attention to psychological, social and biological aspects.¹⁸

d) Need of Adaptation

Theme 8: Adapting to the routine of the ICU and hospitalization

As a result of hospitalization, the family experiences the disruption of their routines and the suffering caused by the limited interaction, both for its conditions such as those imposed by the hospital, experiencing a process of family breakdown to adapt the new routines. The need to adapt the structure and routine of the institution, for example, is quoted by the family:

Have a small bathroom that we use straight. We are six inside of the ICU and this bathroom is for the six of us, everybody wore, the care with the bathroom is ours. Whoever arrives will using, cleaning and leaving. (Margaret)

Adapting to the power supplied by the institution and mealtimes was a difficult aspect experienced by families. In his reports, they said the food provided by the hospital to be of better quality, higher amount to meet their needs and with flexible hours:

The power supply has improved with respect to the taste. The amount is reasonable, you can eat. And I do my meals here, because not every time I have money. (Carnation)

With respect to food the only problem is the time of eating. Because who has the sick son, doesn't have time to eat and sometimes food is served well by the time they are doing some procedure with the son of a people and I don't want to leave near him in those hours. (Rose)

The large family judged as between meals as well as the need to do more than three meals in 24 hours. Thus the family has to complement your food outside the hospital which implies the ICU setting output and withdraw funds to purchase snacks and other foods. To try to solve the problem, the family suggests that there is a snack bar in the institution thus would not need to leave the hospital:

I think it should be served a snack and meal times because then we have to go down for breakfast outside the hospital. Should have a place for the parents could have a snack here inside the hospital. (Sunflower)

I miss a snack, if I did, it would be nice. Because they give just for mothers of babies and I think they should give to everybody, because it's five o'clock [pm] until the seven o'clock the other day without eating. (Bromeliad)

Family members are submitted to hospital routines, which is still present rigid and inflexible manner, in particular with regard to the times and intervals between meals.

At the same time adapting to hospitalization process is a family rehabilitation in the home environment. The family perceives the disruption, with changes in the daily routine mainly because the accompanying family member plays an important role within the family. The family continues to previous responsibilities, which are added financial demands resulting from hospitalization. Generally lies with the father, the home provider function, but during the child's hospitalization father takes two functions: the provider and caregiver. However, the effort is compensatory because of the possibility of standing beside your child:

This experience is being harder because I work, and it is very tiring for me work and I came to the hospital. On the other hand is very good to stay next to my son, the effort to here is too big. (Sunflower)

Furthermore, hospitalization can cause a reversal of roles. If before the family contributed to the costs or was the sole breadwinner now their only role is to sick child's caregiver:

When my daughter got sick, I had to stop working to care for her here in ICU. (Bromeliad)

The speeches of the family revealed the overhead to answer all the roles that are defined as yours. They need to fulfill the duties with the hospitalized child and the other family members, who usually are the other children. As a result feel divided, pressured and overwhelmed:

I have to go home every day because I have two other children to care for. I've got to get some things to wash, wash the diapers of my other sons and when at night I have to come back to the hospital for me to sleep with her. (Rose)

There are utterances that reveal the child's hospitalization abruptly changes the family homeostasis and affects all members of the family system due to changes in their routine and dynamics, causing changes of roles between their members and financial and social difficulties.^{19,20}

e) Needs for Support

Theme 9: Support Network

During the hospitalization of the child, the role of social network / support is essential for the family. According to Hayakawa^{21:441} "networks can be understood as a system composed of several corporate purposes, ie, people, functions and situations that offer instrumental and emotional support to people in their different needs." Family members, friends and neighbors make up this network, which is an important feature in the hospitalization process and provides the feeling of security and support for accompanying child family.²²

My family is always calling to see how he's doing. They can't come here because they live too far away, but still support me very much. (Rose)

Before doing the surgery he cried a lot with longing for the brother. And before the surgery he came down and saw the cousins and his little brother. It was so hot that day, was the family together. (Bromeliad)

Often the support offered by the family concerns related care to other children who stay at home:

I have two other children to care for and while I'm here they are with their grandmother or with the neighbors. (Jasmine)

In an attempt to reorganize the household members seek support to enable greater permanence of parents in the hospital without family everyday damage. In this perspective the family constitutes a primary social support network of its members. The possibility of family participation during the therapeutic process and the child's hospitalization minimizes stress and suffering that pass the family and the child.

The ICU and the continuous coexistence with other families facing the same situation of child hospitalization favor building aid relationships, because they support and share experiences:

I feel alone with respect to my family, but I know there are people here who are with me. We make many friends in here; with the other mothers, fathers, and that makes me feel less lonely. (Rose)

These relationships help in fighting the disease and the child's hospitalization act as support to support family members who, being in the same situation, have many desires and feelings in common, such as the recovery of the child, the desire to return home and the family longing. In addition, by sharing the same experience family members are comprised of mutual form, revealing the need to be heard and to understand each other.

Theme 10: The faith and religiosity

Faith and religion are an important support for the family in coping with the disease and has important role in maintaining and child health recovery. Family members seek through faith hope of cure or ways to cope with less suffering.

I feel in a difficult situation in the ICU. Then I say: My God, only Jesus can give me strength to resist this with my daughter. (Margaret)

I don't lose hope because I trust my God that I follow. (Easter lily)

In the words of family, God is responsible for the health and life of the child. They report that at various times their faith saved the son from great danger conditions:

I'm sure the living God that I follow will get her out of those devices for her breathing with the breath that He (God) gave. (Margaret)

A family when facing a difficult situation or illness tries to find answers to understand everything that is happening in the context in which they live, and most of the time, it is God who keeps him company and help the family understand these situations experienced.

Theme 11: The lack of financial resources

The family reported the lack of financial resources influences the child's disease coping process. The reports show that the family is formed by poor people with little or no money to meet their needs during the hospitalization period, which causes concern, anguish and generates suffering.¹⁶

Certain hours I felt a lot because I had no money so I can buy what I needed. (Margaret)

It is very difficult because there are days that I have a buck, there are days that I do not have. (Bromeliad)

The financial needs experienced by the family members prevent the purchase of toiletries and personal items for them and for the child:

I for example am without flip-flops, without deodorant and don't have money to buy. My son came here just came wrapped in a diaper so I can't really afford a dress for him. I wish I had money to buy some stuff for my son. (Hydrangea)

The lack of resources reported by family members arises as a problem for the child during the hospitalization process in the ICU, making the accompanying family's stay and visits from other family members even more difficult, due to the lack of money for transportation, snacks and other personal needs.

DISCUSSION

The hospitalization of a child involves critical and delicate situation for the child himself, his family and the hospital staff, especially when this occurs in hospital intensive care unit. During this period several adverse events are experienced by the accompanying family member, such as changing the physical and psychological environment, separation from other family members, the interruption of daily activities and arduous period of adaptation to new routines imposed by the hospital setting. To respond to this new need, professionals and work processes also need to be changed providing a reorganization of assistance, including new insights on the family as care unit and "partner" in the shared care of children.

In the context of infant hospitalization family is also affected and has needs generated by the situation. From this context, there are two interactive phenomena: losing control over its operation and seeking a new functioning rhythm performing mutual effects among themselves, trying to regain his balance to take care of the demands that were already part of your experience and new arising in child's hospitalization.²³ These phenomena generate overhead functions which become experienced during hospitalization because play important roles within the family, such as caregiver of other children and provider of home.

The situation of hospitalization of one of his children interferes with the dynamics and family structure causing many feelings like fear, anxiety, hope and insecurity in the family accompanying the child in the ICU. As a coping mechanism, faith and hope arise, beyond unconditional love, which together will make the family be present as long as necessary for the child's recovery.

While I accept and judge required hospitalization in intensive care for your child recovers, the new environment causes physical and emotional suffering, making the family feel ignored their needs. Needs comfort, emotional and adequate food support reveal the structural weaknesses of the institution to accept and install this family.

Doubts about the situation, the answers and solutions not only depend on the family, revolving around the child's health and the effectiveness of treatment and result in a feeling of powerlessness, evidencing the need to have their questions answered.

The family's experience with hospitalization may be facilitated when you can count both with the support of ICU professionals to receive information on the evolution of child health and disease causes the. Another important factor is the family feel valued in their suffering and understood in their vulnerability. For the family, it is necessary that professionals demonstrate availability and reciprocal attention and relational and communication skills, making them essential tools in care practice.

Understanding the needs of caregivers of children admitted to ICU invites a reflection on the care process, while suggesting paths, perspectives and possibilities for transformation of the organization of the practices of those involved. It means rethinking actions and attitudes in order to contribute to the enrichment of both views as of care practices for hospitalized children by inserting the family and the family as care units in a process of true encounter between those who care and those who are cared.

It is a perspective that departs from scientific and technical dimension and approach the subjectivity of personal relationships, the human condition and the value of life. It means thinking of the daily care practices in a social and human perspective of the nature of care. No answer/identify/understand the needs demanded by families may show an oversight and a departure from the true mission of care.

The needs that emerged from the process of sickness and child hospitalization in ICU disclosed herein, should reorient practices, not as a mere reorganization, but as the adjustment look thinking about the people to whom they are intended. It means going beyond the norm, technical, scientific and hospitality "that however necessary they may be, will never be partial aspects".^{24:2}

The process of hospitalization and illness coupled with issues related to care and to meet the multiple and complex needs seem to reveal a gap between a system centered on the disease and person-centered. From this perspective, care is revealed as art with different skills from different professionals, since the true concern is that produced by the complementarity of diverse knowledge. This logic needs to evolve and overcome the certainties and scientific logic.

CONCLUSION

The analyses of the results described in relation to the needs of family members of patients in the Intensive Care Unit showed that being the patient, the focus of care; the needs of family members are diverse and individual. The results showed that the needs include the physical and the emotional field, needing a comprehensive care to the relative.

This care must be planned and executed by all professional team, aiming not only the needs of children, but also their families.

The experience of having a family member hospitalized in an ICU is marked by feelings of fear and insecurity, which could undermine the family structure. In this process it is important that health professionals perceive the emergence of needs by family members, promoting the approach and their involvement with the care for the children.

On the experience of the team that is used to the hospital environment, the situation experienced by the family can be considered common and of simple resolution. Thus, the risk of underestimating the needs presented by the family happens when the professional perceives the family as just another in the hospital and does not interact with it in order to align their actions and cooperate with its strengthening.

To avoid this situation, professionals should open more effective channels of communication with the family informing them about routines, treatment and expected results. This will make the families feel less anxious and fearful in relation to children's health, providing greater interaction with staff. Depending on the attention and care received by the child's family admitted it will be better able to care for the child, whether in hospital or at home.

Despite the relational difficulties with some professional category characterized by indifference, for short and little enlightening dialogues, it is emphasized that no professional should exempt from the caring role and attention to the subject person. So it is not "relevant develop professional concepts and organizational models in which a patient had the responsibility while others are interested only by the disease or a type of organ or function" 24: 46 However, the context of recognized and understood ICU as high technological apparatus in prevailing techniques can cause a split between those who treat and those who care, revealing and reaffirming the fragmentation centered care in a biology model.

But the search will be on to see the focus of attention focused on care. In this sense, the results pointed to the understanding of family needs of children hospitalized in ICU and suggest a meeting involving the environment, the child and the family as voltage producers, feelings, experiences and meanings. A caregiver perspective suggests is a dynamic process that leads the way to the meeting where professionals are invited to dialogue, to reflect, to analyze and identify the elements that determine such needs. This process is not limited to rules and routines, but the sensitivity to identify both the needs and the skills to fill them.

This context suggests listening, availability, compassion, otherness, technical, ethics, commitment and responsibility. Therefore, professionals must be supported by a vast body of knowledge and past experience both professional and personal, heading for knowledge able to establish relationships with multiple elements and situations, so as to act in a creative and sensitive dimension. In short, we need to build "a system that is not only analytical, but understanding; a scientific system, but sensitive"^{25: 18}

The results of the research seem to infer that the health systems and services as well as professionals are more efficient in identifying the disease and treatment than on identifying and efforts to address the needs of family members of the sick person. However, it is recognized that although efficient this approach has limited value, because the "human beings are much more than their bodies".^{25:26}

REFERENCES

1 Freitas KS, Kimura M, Ferreira KASL. Necessidades de familiares de pacientes em unidades de terapia intensiva: análise comparativa entre hospital público e privado. *Rev Latino-am Enfermagem*. 2007 Jan-Fev;15(1):84-92.

2 Baldini SM. Avaliação da reação dos pais à internação do filho em unidade de terapia intensiva e desenvolvimento de uma proposta de apoio psicológico [Tese]. São Paulo: Universidade de São Paulo. Curso de Medicina; 2001.

3 Dazzi MR, Santos BSC [homepage na Internet]. Humanização NA UTIs neonatais: atitudes que salvam vidas. Espírito Santo; 2008. [citado 4 dez 2009]. Disponível em: http://https://encipecom.metodista.br/mediawiki/images/1/1f/Suzana_D._C._Santos_e_Ana_Maria_R._Dazzi.pdf.

4 Lemos RCA, Rossi LA. O significado cultural atribuído ao centro de terapia intensiva por clientes e seus familiares: um elo entre a beira do abismo e a liberdade. *Rev Latino-am Enfermagem*. 2002 maio-jun;15(3):345-57.

5 Bitencourt AGV, Neves FBCS, Dantas MP. Análise de estressores para o paciente em unidade de terapia intensiva. *Rev. bras. ter. intensiva*. 2007 jan-mar;19(1):53-9.

6 Brasil. Estatuto da Criança e do Adolescente. Brasília: MEC; 1998.

7 Bousso RS, Angelo M. Buscando preservar a integridade da unidade familiar: a família vivendo a experiência de ter um filho na UTI Pediátrica. *Rev. Esc. Enferm. USP*. 2001 jun;35(2):172-9.

8 Silva RCC, Sampaio JA, Pinheiro PNC, Neto RGX, Ferreira AGN. Sentimentos das mães durante hospitalização dos filhos: estudo qualitativo. *Rev. Soc. Bras. Enferm. Ped*. 2010 jun;10(1):23-30.

9 Angelo M. Com a família em tempos difíceis: uma perspectiva de enfermagem [Tese]. São Paulo: Escola de Enfermagem da Universidade de São Paulo. Escola de Enfermagem; 1997.

10 Inaba LC, Silva MJP, Telles SCR. Paciente crítico e comunicação: visão de familiares sobre sua adequação pela equipe de enfermagem. *Rev. Esc. Enferm. USP*. 2005 dez;39(4):423-9.

11 Minayo MCS. O desafio do conhecimento: pesquisa qualitativa em saúde. 9ª ed. São Paulo: Hucitec; 2010.

12 Maruiti MR, Galdeano LE. Necessidades de familiares de pacientes de pacientes internados em unidade de cuidados intensivos. *Acta paul. Enferm*. 2007;20(1):37-43.

13 Silva FS, Santos I. Expectativas de familiares de clientes em UTI sobre o atendimento em saúde: estudo sociopoético. *Esc. Anna Nery*. 2010 apr/jun;14(2):230-5.

14 Melo CRM, Villa SG, Silvério NF, Santana RA. Conhecendo os sentimentos e expectativas de mães de recém-nascido em uma unidade de terapia intensiva neonatal. *Rev enferm UFPE on line*. 2010 abr-jun;4(2):739-48.

15 Molina RCM, Marcon SS. Benefícios da permanência da participação da mãe no cuidado ao filho hospitalizado. *Revista Esc Enferm USP*. 2009 dez;43(3):856-64.

16 Leite MF, Gomes IP, Rosin J, Leite MF, Oleveira BRG, Rosin J, Collet N. Condição crônica na infância durante a hospitalização: sofrimento do cuidador familiar. *Cienc Cuid Saude*. 2012 jan-mar;11(1):051-7.

17 Faquino P, Collet N. Vínculo afetivo mãe/criança na unidade de alojamento conjunto pediátrico. *Rev Gaúcha Enferm*. 2003 dez;24(3):294-304.

18 Oliveira BRG, Oliveira MRP, Leite ALT, Collet N, Azevedo ND. Cuidado de Enfermagem a famílias de crianças hospitalizadas por doença crônica. *Cienc Cuid Saude*. 2012 jul-set;11(3):522-8.

19 Schultz LF, Sabatés AL. A família vivenciando a doença e a hospitalização da criança: estudo qualitativo. *Online Braz J Nurs [periódico na internet]*. 2010 [citado em 24 ago 2013];9(2). Disponível em: <http://www.objnursing.uff.br/index.php/nursing/article/view/3054>.

20 Hayakawa LY, Marcon SS, Higarashi IH. Alterações familiares decorrentes da internação de um filho em uma unidade de terapia intensiva pediátrica. *Rev Gaúcha Enferm*. 2009 jun;30(2):175-82.

21 Hayakawa LY, Marcon SS, Higarashi IH, Waidman MAP. Rede social de apoio à família de crianças internadas em uma unidade de terapia intensiva pediátrica. *Rev Bras Enferm*. 2010 maio-jun;63(3): 440-5.

22 Pettengill MAM, Côa TF. A experiência de vulnerabilidade da família da criança hospitalizada em Unidade de Cuidados intensivos Pediátricos. *Rev. Esc. Enferm. USP*. 2011 ago;45(4):825-32.

23 Collet N, Rocha SSM. Criança hospitalizada: mãe e enfermagem compartilhando o cuidado. *Rev. Latino-Am*. 2004;12(2):191-7.

24 Hesbeen W. Cuidar no hospital. Enquadrar os cuidados de enfermagem numa perspectiva de cuidar. *Lusociência: Lisboa*; 2000.

25 Remen RN. O paciente como ser humano. São Paulo: Summus; 1993.

Received on: 01/08/2014
Required for review: no
Approved on: 01/12/2014
Published on: 30/12/2014

Contact of the corresponding author:
Francisca Georgina Macedo Sousa
São Luiz - MA - Brasil
Email: fgeorginasousa@hotmail.com