Experience of family members as a result of children's hospitalization at the Intensive Care Unit

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Abstract

Objective. To describe the experience of family members as a result of children's hospitalization at the Intensive Care Unit (ICU). **Methodology**. Descriptive and cross-sectional study. A structured interview was held with 20 relatives of patients hospitalized at two clinics of the Botucatu Medical School at Universidade Estadual Paulista "Júlio de Mesquita Filho". Information was collected between July and September 2010. **Results.** The main characteristics of the participating relatives were: 80% mothers of the children; 70% low education level and 70% married. Sixty percent of the children were hospitalized at the ICU for the first time. Eighty percent of the interviewees believe that the children's behavior changes inside the unit and 85% consider that visiting hours are sufficient. The predominant negative feelings are fear (50%) and insecurity (20%), while the predominant positive feelings are hope (50%) and the expectation of discharge (25%). The professional who most supported the relatives was the nurse (35%). **Conclusion.** The family members' experience as a result of the children's hospitalization at the ICU involves positive and negative aspects, which also affect the child's behavior at the unit.

Key words: intensive care units, pediatric; family relations, child

Experiencia vivida por los familiares con la internación de niños en la Unidad de Cuidado Intensivo

Resumen

Objetivo. Describir la experiencia vivida por los familiares con la internación de niños en la Unidad de Cuidados Intensivos (UCI). **Metodología**. Estudio descriptivo de tipo transversal. Se realizó una entrevista estructurada a 20 familiares de pacientes hospitalizados en dos clínicas de la Facultad de Medicina de Botucatu de la Universidade Estadual Paulista "Júlio de

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Mesquita Filho". La información se recolectó entre julio y septiembre de 2010. **Resultados.** Las principales características de los familiares participantes fueron: 80%, madres de los niños; 70% tenía escolaridad baja y el 70% estaba casado. Fue la primera hospitalización en la UCI en el 60% de los niños. El 80% de los entrevistados cree que hay cambio en el comportamiento del niño dentro de la unidad y el 85% considera suficiente el tiempo de visita. Los sentimientos negativos predominantes son el miedo (50%) y la inseguridad (20%), mientras que los positivos son la esperanza (50%) y la expectativa del alta (25%). El profesional que más apoyo brindó al familiar fue el enfermero (35%). **Conclusión.** La experiencia de los familiares con la internación del niño en UCI tiene aspectos positivos y negativos, que incluso, afectan el comportamiento del niño en la unidad.

Palabras clave: unidades de cuidado intensivo pediátrico; relaciones familiares, niño.

Experiência vivida pelos familiares com a internação de crianças na unidade de terapia intensiva

Resumo

Objetivo. Descrever a experiência vivida pelos familiares com a internação de crianças na Unidade de Terapia Intensiva (UTI). **Metodologia**. Estudo descritivo de tipo transversal. Realizou-se uma entrevista estruturada a 20 familiares de pacientes hospitalizados em duas clínicas da Faculdade de Medicina de Botucatu da Universidade Estadual Paulista "Júlio de Mesquita Filho". A informação se coletou entre julho e setembro de 2010. **Resultados**. As principais características dos familiares participantes foram: 80% eram mães das crianças, 70% tinham escolaridade baixa e o 70% estavam casados. Foi a primeira hospitalização na UTI em 60% das crianças. 80% dos entrevistados creem que há mudança no comportamento da criança dentro da unidade e 85% considera suficiente o tempo de visita. Os sentimentos negativos predominantes são o medo (50%) e a insegurança (20%), enquanto os positivos são a esperança (50%) e a expectativa do alta (25%). O profissional que mais apoio brindou ao familiar foi o enfermeiro (35%). **Conclusão.** A experiência dos familiares com a internação da criança na UTI tem aspectos positivos e negativos, que inclusive, afetam o comportamento da criança na unidade.

Palavras chave: unidades de terapia intensiva pediátrica; relações familiares, criança.

Introduction

The Intensive Care Unit (ICU) is a facility designed for care delivery to patients in potentially serious conditions or failure of one or more functional systems, who need intense medical and nursing support. Intensive care and individual, continuous and complete observation according to the patients' needs are aimed at their recovery and also help to reduce mortality. The ICU is a stressful environment because of the permanent anticipation of emergency situations, patients in unstable clinical conditions and constant activities of professionals working in this field, lights, noises, specific and complex equipment and visiting restrictions.[1-4] In 1988, the Hospital das Clínicas de Botucatu created the Pediatric Intensive Care Unit (PICU) for care delivery to children in serious conditions. One of the problems experienced in this unit, however, is the separation of the children from their families because, due to the unit features and institutional policy, the right of children to have a support person during their treatment is not respected.[3-6]

According to the Child and Adolescent Statute, healthcare facilities should provide conditions for parents and/or legal guardians to remain with

the hospitalized children or adolescents.[7] At the ICUs, on the other hand, the issue of infections or contaminations due to the excessive number of people is also raised. Therefore, the institution sees fit that parents and/or support people remain close to the children when procedures and/or assistance by the unit healthcare team are not being performed. The illnesses of the children subject the families to an extreme state of pain, due to the importance they represent in the family unit, which ranges from the fulfillment of dreams to the response to the parents' expectations and the future projection of the children. Their children's illnesses affect all of these meanings and require the internal and external mobilization of the families, as well as drastic adjustments in various aspects of life, such as the structural (change of city, house), financial, social and emotional points of view, among others. These circumstances may entail negative consequences, such as separation of the parents and among the members of the family, friends and even removal from social life. Within this scenario, situations of fear, concern, insecurity and even loneliness may occur.[3,4,8,9]

Hospitalization is seen as an unpleasant experience, given that it determines processes of loss, regardless of the length of stay in hospital and age group, and may have consequences for the development of children, such as relationship difficulties, feelings of fragility, fear of separation, particularly during their growth process, requiring serious adjustment to the various changes that take place in their everyday lives.[8] In this scenario, the main process is the family separation, featured by changes such as loss of power over the children, thus affecting the intimacy of the relationship between the children and family members. The admission to the PICU consolidates this separation, which temporarily subtracts the children from their families and social life and causes insecurity, due to the possibility of this separation becoming permanent.[9] The presence of one family member supporting a child in serious conditions promotes and maintains the inter-relation of this child with the family, neutralizes the effects resulting from the separation and helps with holistic care to the child, improving adaptation to hospital and favoring acceptance of treatment, thus supporting the formation of a bond between the child and the multi-professional team. Another aspect to be considered is the education of mothers concerning aspects of care to be performed at home. The strengthening of the relationship in these aspects provides the children with feelings of security, trust, joy, love, protection, and establishes internal resources to cope with the disease and hospitalization.[3,4,10,11]

Given this context, in this study, the intention is to describe the opinion of family members of the children admitted to the Pediatric Intensive Care Unit about the bond rupture caused by the child's separation from the family and, by understanding this context, to provide holistic and humanized care in this hostile environment.

Methodology

This is a descriptive, cross sectional and prospective study, based on a quantitative research and literature review. This study was developed in the Pediatric Intensive Care Unit of the Hospital das Clinicas at Botucatu Medical School of the Universidade Estadual Paulista "Julio de Mesquita Filho" – UNESP. The unit has seven hospitalization beds, with an average stay of 4.15 days. There are three visiting periods during the day, with a duration of two hours each, and three visitors are allowed during each visiting period.

The study population was composed of families of the children who were hospitalized in the period between 1 July and 30 September 2010. Inclusion and exclusion criteria were established for participation in the study. The inclusion criteria were to be family members of the children with minimum hospitalization period of two days in the PICU who were in the unit during visiting hours, as well as to have signed an Informed Consent Form. Concerning the exclusion criteria, these were to be family members of children with length of stay in the PICU under two days or who were not in the unit during visiting hours, as well as not having signed an Informed Consent Form.

Data collection was carried out by the researcher through structured interviews, involving family members of all the children who met the inclusion criteria. The data were statistically dealt with and analyzed according to statistical testability. The study received approval from the Research Ethics Committee of Botucatu School of Medicine, under registration number 188/2010 – CEP. All participants were informed about the research and, after acceptance, signed Informed Consent Forms.

Results

During the period of data collection, 53 children were admitted to the PICU. From these, 20 family members were interviewed. There were difficulties interviewing the remaining family members, due to the fact that they did not meet the inclusion criteria and also, in some cases, because family members were under age and the same child was hospitalized several times.

Table 1 shows the general characteristics of the 20 family members of the children in the PICU. Of the family members interviewed, 80% were the mothers of the hospitalized children. The age group percentage of the interviewed family members was: 40% between 36 and 45 years old, 30% between 26 and 35 years old, 20% over 46 and 10% between 18 and 25 years old. The level of education of the family members was mainly low, being that 70% had completed Elementary School. In relation to marital status, most of them were married (70%).

As for the aspect of the children being admitted to the PICU for the first time or not, 60% of the interviewed family members reported that this was their first time. The reasons why the children were admitted to the PICU were: 40% post-operative, 25% pneumonia, 10% multiple trauma, 10% meningitis and 5% hypoxic crisis, renal failure and neuropathy, respectively.

Another result shown in the research was related to the change in the children's behavior during their stay in the PICU while the family members were present in the unit, with 80% of agreement among the family members. Fourteen (70%) of these family members reported believing, however, that the expression of feelings, either positive or not, directly or indirectly affect the children's recovery. In any event, they then preferred not to show their feelings as a protective/preventive measure. In contrast, the other 10% reported not believing in the relationship between feelings and recovery.

Regarding family members being present during the procedures being performed in the PICU, 55% stated that they would like to. Most of the interviewed family members (60%) feel capable of continuing the care of the children at home, considering that they would do anything to have their family member at home. But others are still not certain about how to take care of the children when they are released from hospital. Most participants (85%) consider the length of visiting hours to the hospitalized children sufficient, taking into consideration the intensive care environment. Only 15% find it insufficient and would like to spend more time with the children.

As for the breastfeeding process, only one child was being breastfed before hospitalization and was unable to continue it due to their condition. Among other participants, none of the children were being breastfed. Of the participants, 16 (80%) reported knowing what is happening with their family member in the ICU, are aware of their diagnosis, how they spent their day, what treatment is being used and prognosis, through information provided by the team. But four of them stated that they are still not clear about the disease or about the children's condition.All of the participants reported being generally satisfied with the care provided to their family member and also reported to be free to express their thoughts, asking questions or criticizing. In these particular circumstances of admission to the PICU, the expression of various feelings, positive or negative, emerges without any predominance. Half of the participants mentioned fear as the most frequent feeling, though, followed by guilt, anguish and

anxiety. As positive feelings, there are hope, relief, gratitude, and even the expectation of hospital release. All family members consider their presence important for the children's recovery and believe they always have to be with the patients.

The staff of the unit supports the families during their children's hospitalization. Family members reported to have received support from all the team (35%), from the nursing team (30%), from the doctor (25%), from the cleaning assistance (5%), while 5% reported not having received support from anyone. Only 10% of the family members reported having communication problems with the professionals, mentioning they did not have time to talk or that they had disagreed with some of them.

Of the 20 participants, 70% needed and were provided with accommodation during their children's hospitalization, staying at the ward of origin. Twenty-five percent did not need support with accommodation due to the fact that they lived in Botucatu or had family living in the town. Only one (5%) person did not have support for the accommodation needed, because this was needed for more than one person, due to another member of the family also staying in the hospital.

Most family members (60%) did not alternate with other people in the visits. After the children's admission to the PICU, most family members reported a greater bond within the family (85%), for the following reasons: "the family was always close" (35%), "they had more contact with one another (29%), "always help each other" (12%), 6% listed "the severity of the disease", "missing home", "going back to church" or "reconciliation with the family". As reasons for separation, the participants reported previous problems within the family (33%), change in the close relationship (33%), and that the long hospitalization period causes the separation of other members of the family (33%).

Family members were asked if they developed any bond of friendship or affection in the waiting room of the PICU and 16 (80%) participants answered that they did develop a bond in the waiting room, 15 stating that it was with the families of other children who were hospitalized, taking the opportunity to exchange experiences and comfort. One family member reported to have developed a bond with the cleaning assistant, who provided comfort when needed. Part of the family members (35%) do not present any concern with the ICU environment, due to the trust they have in the team and because they know that it is a facility with continuous monitoring. But others reported being frightened by some aspects of the environment, such as the noise made by the equipment and monitors, the technical language used in the team, and others.

The results presented in Table 1 showed this concern.
When asked about the concern with their personal lives, 65% were concerned about having to be separated from their other children who were at home, from their partners or their work, but 30% were not concerned with this aspect because they believed that their children come first and that the rest could wait, while 5% were concerned about their financial situation.

Discussion

As noted in the present study, the reason for admission to the PICU is related to the immediate post-operative period, which occurs in most units, followed by respiratory diseases. According to the literature, respiratory diseases are the main causes of admission to the PICU throughout Brazil, due to climate change, temperature inversions and inappropriate actions of the population regarding fires and pollution.[2,4,12]

The hospitalization of children is a difficult situation for themselves and also for the mothers and/or legal guardians. Mothers are subject to unexpected and often unpleasant feelings, such as fear, insecurity and guilt, in conjunction with hope, trust and faith. Studies report this multiplicity of feelings because they feel unable to avoid the suffering of their children during the procedures performed in the unit; also, they feel guilty for not being able to prevent the illness and hospitalization of the children.[6,8,13]

Table 1. General features of 20 interviewed families

Features	Number	%
Relationship with the children		
Mothers	16	80
Fathers	2	10
Grandmothers	2	10
Age group in years		
18 to 25	2	10
26 to 35	6	30
36 to 45	8	40
[3]46	4	20
Level of education		
Elementary school	14	70
High school	6	30
Marital status		
Married	14	70
Single	3	15
Divorced	2	10
Widows/Widowers	1	5
Have noted a change in the children's behavior in their presence	16	80
Would like to be present during the procedures being performed in the PICU	11	55
Believe that their feelings affect the children's condition	14	70
Consider the length of visiting hours sufficient	17	85
Know what is happening with their family member	16	80
Feel capable of continuing the care at home	12	60
Are satisfied with the care provided to their family member	20	100
Currently predominant negative feelings		
Fear	10	50
Insecurity	4	20
Guilt	2	10
Anxiety	1	5
None	3	15
Currently predominant positive feelings		
Hope	10	50
Expectation of hospital discharge	5	25
Gratitude	2	10
Trust	1	5
Optimism	1	5
Faith	1	5
The most supporting professional		
Nursing team	7	35

Table 1. General features of 20 interviewed families (Cont.)

Features	Number	%
Doctor	5	25
Cleaning assistant	1	5
All the team	7	35
Have communication problems with the professional	2	10
Receive support with accommodation	14	70
Someone in the family alternates with visiting		
Mother/father	4	20
Father/mother/sister	3	15
Other	1	5
Does not alternate	12	60
Feel that the family became closer	17	85
Have developed bonds in the waiting room	16	80
What is their biggest concern in the PICU environment		
No concern	7	35
Equipment/Noise	5	25
Technical language	2	10
Visiting restrictions	2	10
Change in the appearance of the family member	4	20
What is their biggest concern personally		
No concern	6	30
Separation from their other child/children	13	65
Financial situation	1	5

Concerning the feeling experienced by the children during hospitalization, it was observed in this study that the hospitalized children's behavior changed while family members were present in the unit. Several studies have shown that the hospitalized children feel more secure, confident and protected in the presence of their families. A study reports that parents considered their presence with their children essential, but understood that their stay should be limited as a result of the features of the environment that require isolation, due to the severity of patients' conditions.[2] Another study reported that parents stated to subject themselves to any situation in order to be close to their children, in order to be able to be present and participate in the care, thus cooperating towards adherence and trust in the treatment and in the team.[3] Children and their family members can minimize the traumatizing effects of hospitalization through the inclusion of families in the care planning and the performance of the team, thus ensuring the success of medical actions.[4] In cases of sedation or intubation of children, some family members do not believe that their presence can affect behavior. Others, however, believe that the children can change their behaviors in a negative way, based on the negative feelings experienced and transmitted by the parents or supporting people.[3]

Several authors have found that the experiences of family members of patients admitted to the PICU generate negative feelings, such as fear, anxiety and insecurity, mainly due to the constant and intense noises caused by alarms and equipment, the instability and severity of patients, the rules

and routines established by the unit, which replace the daily lives of families, or even due to previous traumas, given that many children have recurrent admissions.[1-3,9] These feelings prevail due to the fear of separation and death of their children.[5,6] When the children progress positively, that is, present stability or improvement in their clinical conditions, families start to participate in the routine of the PICU and, therefore, express positive feelings, such as faith, hope, relief and expectation of hospital release.[3] The participation in the care generates joy, pleasure and security, as a confirmation that the doubts have been clarified, the challenges overcome and the obstacles removed.[4]

In this and another study, parents consensually considered their presence decisive in the recovery of the hospitalized children, narrowing the family ties, allowing family participation during hospitalization and the reduction of the guilt caused by the illness.[3,11] Authors highlight that this strategy improves everyone's emotional conditions, reduces intra-hospital infections, stimulates lactation, reduces the time and expenses of patients' hospitalization, improves the efficiency of healthcare services, improves human resources, favors a closer and intense relationship between patients and the multidisciplinary teams and prevents accidents.[5] In a study undertaken about the humanization of care of hospitalized children, it was verified that reading children's stories promotes the integration between mothers and children, bringing benefits to both and strengthening affection ties.[14] The literature, however, presents various opinions about the benefits of being present during the procedures performed with the children. Some authors stated that many family members wish to perform basic care with the hospitalized children and that this action helps to minimize the suffering caused by hospitalization.[3] Authors emphasized that this division of tasks between teams and families may cause problems because the family support is sporadic and superficial and results in the withdrawal of the professionals, since they delegate most tasks to the families, rather than working together with them.[11] The positive side is that family members start gaining autonomy and manual practice, reducing the anxiety and anguish caused by hospitalization and preparing for hospital release. There are family members who feel insecure and anxious about participating in the care though, due to the physical and emotional pain resulting from the environment, which makes it hard to deal with hospitalization.

The events generated by hospitalization of the children can either unite family members, as pointed out in this study, or cause their separation. The awareness about the permanent rupture of the family unit gives rise to a number of reflections and actions aimed at preservation, thus promoting the union in the home.[9] During this period, strength and hope emerge to overcome the uncertainties in a joint effort of mutual support, in order to avoid the collapse. Another study revealed that mothers become closer to their partners, who offer financial and emotional support, love, respect, good relationship, strength and help, making their relationship stronger.[3] Family members can also change the way they relate among themselves or with their social circle, joining them to their families in order to meet other demands.[9] Taking into consideration the presence of siblings of the children, the hospitalization of a family member in the PICU disrupts the household because the other children will stay at home and there will certainly be changes to their daily lives, leading to the re-adjustment of duties among the family members.[1,3] During this period, however, the re-adjustments in the family relationships become essential for the preservation of the family unit, since hospitalization and recovery of the children are the priorities. Over time, the financial and emotional resources start running out and the family members return to their activities and other members tend to take on certain tasks and promoting the continuity of the duty.[3,6]

In this study, a large part of the participants developed some kind of bond in the waiting room through the exchange of experience with other families. The families learnt to deal with other historical, cultural, ethical and religious standards, which cause them to reflect about their experience and reinforce their strength and

hope.[6] The family members reported to have trust in the care provided to the children, through the assistance with their needs in a careful, attentive and loving manner, together with technical-scientific knowledge. Another aspect is related to the harmonic relationship and quality care, which prevent the disorganization in the unit.[5] The family members feel grateful for the care and recovery of the children who often do not feel they have the right to demand improvements to their accommodation.[4]

As in this study, others showed a consensus in relation to the positive aspect of holistic care, not experienced in other units.[2] Most family members reported being concerned with the installed technology, as it causes movement and communication restrictions, leading to anguish and sadness.[2] The PICU environment is strange for most visitors, due to the noise, high technology, uninterrupted activity of professionals, technical languages, visiting restrictions and changes to patients' appearance, which can cause a psychological conflict and accentuate the risk of death.[3]

Final considerations

Through this research, it was possible to visualize the conflicts and changes that occur with the families of the children admitted to a Pediatric ICU. A variety of feelings are involved, which are related to different situations and need to be rationally resolved. Families are satisfied with the care provided to one of their members in its entirety. What mostly bothers them is the inability to stay full time with their children. They try to understand it, but all participants also believe that their presence is decisive in the children's recovery, witnessing the changes occurred in their behavior.

It is necessary that healthcare professionals pay more attention to the families and include them in the care planning, so that teams and families, essential to the children's recovery, are able to have a harmonic relationship. Families are prepared to do everything in order to have their family members back at home and this is a period of opportunity to enable them to care for the children, given that children in the PICU always require extra care.

Families are tied to the PICU routine and visiting hours and, due to the fact that most of them do not live close to the hospital facilities, they have to leave their personal responsibilities aside. However, they believe that everything is worth it for the children and that the rest can wait. Most times, they suffer because they have other children at home who need their attention and care. It is necessary to invest in family care as family members are excluded from the care, given that the team naturally handles the unit's routines, which causes them extreme concern. It is necessary to improve the knowledge related to this issue, so that healthcare teams and families can work together for the recovery of the children.

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