

# The family's perception of its presence at the pediatric and neonatal intensive care unit

A PERCEÇÃO DA FAMÍLIA SOBRE SUA PRESENÇA EM UMA UNIDADE DE TERAPIA INTENSIVA PEDIÁTRICA E NEONATAL

LA PERCEPCIÓN DE LA FAMILIA SOBRE SU PRESENCIA EN UNA UNIDAD DE TERAPIA INTENSIVA PEDIÁTRICA Y NEONATAL

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## ABSTRACT

This qualitative-based study aimed to understand how families perceive their own presence at the Pediatric and Neonatal Intensive Care Unit, as well as the acceptance of their presence by healthcare workers. Data was collected through semi-structured interviews with 14 parents of children admitted to the pediatric and neonatal ICU at two hospitals in northwestern Paraná State, Brazil. Content analysis was chosen to interpret the data. The results revealed the suffering experienced by parents, the alteration of family dynamics resulting from the child's hospitalization, and the perception of the benefits of remaining close to the child in terms of welcoming and quality of care. It was concluded that parents value the professionals' respect and attention towards the child, thus creating bonds of affection, trust and gratitude for the care received.

## KEY WORDS

Child hospitalized.  
Intensive Care Units.  
Professional-family relations.  
User embracement.

## RESUMO

O estudo, de abordagem qualitativa, teve por objetivo compreender como as famílias percebem a própria presença na unidade de terapia intensiva pediátrica e neonatal, e a aceitação dessa presença por parte dos profissionais de saúde. Os dados foram coletados por meio de entrevista semiestruturada a 14 pais de crianças internadas na UTI pediátrica e neonatal de dois hospitais na Região Noroeste do Paraná. Para a interpretação dos dados, optou-se pela análise de conteúdo. Os resultados revelaram o sofrimento vivenciado pelos pais, as alterações que ocorreram na dinâmica familiar em face da hospitalização do filho, e a percepção dos benefícios da sua permanência junto à criança, do acolhimento e dos cuidados recebidos. Concluiu-se que os pais valorizam o fato de os profissionais demonstrarem respeito e atenção para com eles e a criança, criando elos de afetividade e confiança, além de gratidão pelo cuidado.

## DESCRITORES

Criança hospitalizada.  
Unidades de Terapia Intensiva.  
Relações profissional-família.  
Acolhimento.

## RESUMEN

Este estudio, de abordaje cualitativo, tuvo por objetivo comprender como las familias perciben su propia presencia en la unidad de terapia intensiva pediátrica y neonatal, y la aceptación de esa presencia por parte de los profesionales de la salud. Los datos fueron recolectados por medio de entrevista semiestructurada a 14 padres de niños internados en la UTI pediátrica y neonatal de dos hospitales en la Región Noroeste de Paraná. Para la interpretación de los datos se optó por el análisis de contenido. Los resultados revelaron el sufrimiento experimentado por los padres, las alteraciones que ocurrieron en la dinámica familiar frente a la hospitalización del hijo y la percepción de los beneficios de su permanencia junto al niño, del acogimiento y del cuidado recibidos. Se concluyó que los padres valorizan el hecho de los profesionales demostrar respeto y atención para con ellos y el niño, creando vínculos de afecto y confianza, además de gratitud por el cuidado.

## DESCRIPTORES

Niño hospitalizado.  
Unidades de Terapia Intensiva.  
Relaciones profesional-familia.  
Acogimiento.

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## INTRODUCTION

Family life is inevitably affected by crisis. Sickness is a crisis-generating factor that may cause family life to alternate between stability and instability for some time. The best way to address these situations depends on many different factors: the stage of family life, the role the sick individual plays in the family, the impact of sickness on each element of the family, and the way the family is organized during the sickness among other factors<sup>(1)</sup>.

The hospitalization of a child may be considered a catastrophe in family life. Apart from the suffering caused by the disease itself, hospitalization is tiring and the generates alterations in most aspects of family life, including the separation from the parents and other members of the family<sup>(2)</sup>, especially when the family lives in another city and one of the parents needs to be absent indefinitely to take care of the child<sup>(3)</sup>. Thus, feelings of fear, worry and loneliness affect the balance of each one's roles, risking rupture of the family structure<sup>(3-4)</sup>.

Hospitalized children are exposed to many unpleasant situations as their health condition becomes more severe. They may require new exams and sophisticated apparatus, making them insecure and anxious. Fear and anxiety are also experienced by the family as the sickness becomes more severe. In addition, they feel guilty since they may be responsible for the disease etiology<sup>(1)</sup>.

Therefore, when the family learns that the child's condition requires the intensive care unit (ICU), it generally experiences a feeling of strangeness and helplessness due to stress, anxiety and fear from the child and the parents. The family not only immediately associates the ICU with death, but also finds the temporary separation from the child quite painful. Family members' emotional unbalance and instability are, therefore, apparent<sup>(5)</sup>.

Neonatal intensive care therapy units (pediatric – PICU and neonatal – NICU) were developed with a view to saving children under life-threatening risks. Medical science development, through more and more complex procedures, frequently invasive, allied to the use of even more potent technologies, have managed to save and prolong the life of patients of all age ranges; however, the cold and hostile environment of these units irreversibly traumatizes children and their families, especially when the right of the family to be close to the child is denied<sup>(6)</sup>.

The implementation of the Adolescent and Child Statute by Law # 8069 of 1990 regulates this situation in the country. Article 12 of this Statute establishes that hospitals must "provide for the full-time stay of one of the parents or a responsible party when a child or adolescent is hospitalized"<sup>(7)</sup>. However, this procedure is not yet followed fully

in many Brazilian institutions and states, despite the fact that the presence of the mother is the most efficient method to minimize a child's psychological trauma from hospitalization<sup>(8)</sup>.

Fortunately, this situation is changing. A change in professional behavior is underway in hospital institutions, mainly in Pediatric and Neonatal ICUs, where child and family-centered care has been adopted<sup>(9)</sup>. Basic principles of family-centered care comprise permission for the unrestricted presence of a family member in the Neonatal Intensive Care Unit, the family's participation in the care for the child, and open communication between parents and professionals<sup>(10)</sup>.

The presence of a family member usually maintains the relationship between the child and the family, neutralizing the effects of separation. The family is allowed to collaborate in the full-time care for the child, to improve their acquaintance with the hospital, and their acceptance of the treatment is facilitated, promoting a positive therapeutic response and diminishing stressful factors of the disease, procedures and hospitalization<sup>(1)</sup>. In addition, allowing the presence of the mother in ICU while the child is hospitalized is a strategy that promotes reduction in emotional stress both for the child and for the family, as it contributes for decreasing hospital time<sup>(3,11)</sup>.

During ICU hospitalization, parents experience periods of concern, sadness, insecurity, anxiety, and fear of death; however, since they can be with their child in these units, they feel more secure and thankful<sup>(1)</sup>.

On the opposite, the insertion of a companion and his/her involvement in the therapeutic process makes understanding the dynamics of relations between with care agents crucial, since poorly defined issues around care for the hospitalized child emerge, frequently interfering with the acceptance of the family in the pediatric units<sup>(9)</sup>.

The aim of this study was to better understand how the families perceive their own presence in the ICU and the acceptance of their presence by health professionals.

## METHOD

This study used a qualitative approach to investigate and describe the discourse of the family members interviewed. The chosen methodology is justified because it can deepen understanding of phenomena and facts as well as the understanding of private and specific processes related to the complexity of restricted groups that are susceptible to such intense research<sup>(12)</sup>.

The study was conducted in the NICU and PICU of the Regional University Hospital of Maringá (HURM) and in the

Hospitalization is tiring and the generates alterations in most aspects of family life, including the separation from the parents and other members of the family.

NICU of the *Santa Casa de Paranavaí*, both cities located in the Northwestern Region of Paraná. HURM is a public, medium-sized teaching hospital with 120 beds. It is regarded as reference for the city of Maringá and 28 other cities comprising the 15<sup>th</sup> Health Region. Its NICU was opened in February of 1998. It provides six beds for the care of newborns; the PICU was opened five years later with six beds for the care for children between 29 days and 14 years old.

*Santa Casa de Paranavaí* is a medium-sized hospital with 110 beds providing service to users of the Single Health System, many health insurance companies and private care. It is regarded as a reference center for Paranavaí and other cities of the 14<sup>th</sup> Health Region. Its NICU was opened in November of 2005 providing six beds for the care for newborns.

Although the number of beds is the same, the working systems of these units are different. The PICU of HURM and the NICU of *Santa Casa* are strict regarding visiting hours: both provide two visiting hours of one hour each, one in the afternoon and the other at night.

In PICU parents and one other visitor can enter, at visiting hours, in a rotation system. In some situations, after the evaluation of the team, a companion can stay with the child, preferably one of the parents. Yet in the NICU of *Santa Casa de Paranavaí*, parents can enter together or in rotation, depending on the number of children. According to the child's pathology, the mother is encouraged to hold the newborn.

In the NICU of the HURM, parents can enter anytime from 8 a.m. to 10 p.m. Also, they can stay with the newborn during this period. Skin-to-skin contact is encouraged as a way to offer warmth, security, affection and care. For the rest of the newborn's family members, a one-hour visit in one single period is provided.

Fourteen mothers/fathers were the informants in this study, where six had children in the NICU and six in the PICU of the HURM and two in the NICU of *Santa Casa de Paranavaí*. Only one case included the interview of both parents of the same child, because at least one of the parents was in the unit most of the time. The data collection instrument was developed by the researchers based on the study objective. It comprised a mixed script with 24 questions, capturing, in addition to the sample characteristics, the life of the child in the hospitalization process and the interaction with the environment and the NICU and PICU teams.

Data were collected throughout the period of October 5 through November 5 of 2006, through semi-structured interviews performed in private locations within the hospital, where ten questions regard the identification and participants' characteristics, and the others regard the way the family sees the ICU environment and their presence with their child; their perception regarding the professionals' acceptance about this presence; and the quality of care offered to their child by the professionals in the unit. The

interviews, if the authorization of participants was provided, were recorded and lasted on average 30 minutes. Data analysis and interpretation were performed using theme-based<sup>(12)</sup> content analysis, in three stages: pre-analysis, material exploration, and handling results and interpretation. The interviews were initially fully transcribed and data generated from these reports were read many times in order to attain a complete idea of the set. They were coded, cut and grouped by similarity. Each group was then analyzed separately and categories emerged. It's worth noting that these categories emerged spontaneously from the coded information. In other words, they expressed the elements contained in the grouped data under a generic title.

Finally, literature was searched for supporting information and the final text was written.

For presentation of the results, subjects' discourses were identified by the names of flowers. This format ensured, among other things, the preservation of their anonymity. Their participation followed the 196/96 Resolution of the National Health Council regarding research on human subjects. The project was approved by the Ethics on Research Committee of the State University of Maringá (Statement n# 288/2006).

## RESULTS AND DISCUSSION

Of the 14 parents participating in this study, most were part of a nuclear family, were females, were between 17 and 50 years old with an average age of 30 years old, and kept a stable relationship with a spouse. The number of children ranged between one and four and most parents were aided by their respective spouses in taking care of them. As for education level, five had not finished junior high school, four had finished junior high school, four had not finished high school, and one of the mothers had a college degree. Of all parents, eight were housewives, two mothers were registered housekeepers, two fathers were agriculture workers, one mother was a receptionist, and one a teacher. Most had their own house, lived outside the city of Maringá and had family income between one and six minimum wages.

### *Family: Source of base and support*

Although the family may exist in diverse forms, in this study the nuclear family was predominant. The nuclear family is understood to consist of the father, mother and children, functioning as the base for people's social living. It prepares human beings to face the world by inserting them in a community in which they will interact and form new families with the responsibility of taking care of the health of its members<sup>(5)</sup>.

The father, the mother gather, take care of the child, the house, of what belongs to them and live a calm life; it is a successful family, I believe in that and fight to live this life, to

be part of this system. If you have your children and you don't take care of them, they are then abandoned (Carnation).

Family relations present a multiplicity of formats determined by ties that unite its members; proximity and influences absorbed from the internal and external world, revealing the particular way that the family members relates to one another and to the world<sup>(13)</sup>.

From their discourse, we observed that parents, apart from considering the nuclear family, also consider it to be their role to take care of children and plan the family environment, envisioning a family life that provides quality of life to its members. Therefore, the family, even with its particularities, acts as a care unit within society, promoting the individual's well-being throughout the different stages of life<sup>(5)</sup>.

In the process of living, the family builds a world of symbols, meanings, values, knowledge and practices generated from their original family and from the influence of the socio-cultural environment. This fact directly influences the care for its members. Under this perspective, the family acts as a health unit for its members, holding its own frame of reference for understanding different health and sickness situations in the family unit and how to act upon them<sup>(13)</sup>.

The family not only comprises of a group of people – although it is frequently represented that way – but is also defined by the relations and ties between the family members. We observed from family members' discourse that there is a strengthening of this unit during crisis situations, and this strength is essential to the family members in order to satisfy their individual needs and for family group to become solid.

A very important thing is: the one who has a family, has more strength to live (Rose).

A strong bond was revealed between the mothers and other family members, especially with the spouse who supports, loves, and respects them and provides strength, which builds a good relationship. They feel that the experience of having a child in the hospital, at least initially, has made their relationship stronger and closer<sup>(5,14)</sup>:

Family is love, right, union, that's it (Daisy);

It is love and you don't feel lonely (Chrysanthemum);

It is the base of everything, husband, son... (Orchid);

family is everything, especially in these situations (Violet).

The family is an important space where survival, development and full protection for the children and other family members are ensured, regardless of the family layout or the way it is structured. Therefore, to feel part of a family, as well as being taken care of by one, is not only essential for the development of a child, but is also necessary for the other family members, at every stage of life. It is in the family environment that a person receives all the necessary psy-

chological, and emotional support and learns human and ethical values, in addition to other tools needed for its full physical and mental development<sup>(5,13)</sup>.

We observed in the mothers' discourse the importance of the family in their lives, especially at this crucial moment. Affection, love and the partnership in living as a family are perceived as fundamental aspects for facing the situation.

The study demonstrated that, when facing actual suffering and uncertainties imposed by the experience, strategies are elaborated and guided not only to preserve the family structure, but also to maintain relationships that will allow the family to stay together. In addition, being united ensures that the family can recharge its strengths in order to achieve its objective of preserving the family unit<sup>(15)</sup>.

### **About parents' experience in the Intensive Care Unit**

Of the 14 participants of the study, 11 were experiencing hospitalization of one child in the ICU for the first time, and the other three had been through the experience previously. Most demonstrated that they had been living a moment of much tension and distress since hospitalization in these units is usually related to a life-threatening situation [or, fear of death].

It is the first time, and in God's name, the last (Chrysanthemum).

I had never seen it, I thought it was much more dangerous, but when I got here, seeing it, observing it, understanding it, we can see that it is totally different from what we think. Sometimes the idea is that here is the end, but no, here, it is a new beginning. I thought that we came here to die or get well for good or that from here we wouldn't get out... (Carnation).

At first it was a shock, because I never thought my little girl would need to go to the ICU, because she never had anything. It was difficult for me, mostly because of the trauma I have been through with my other daughter. Even knowing that she is ok, recovering well, it is a great trauma (Primrose).

The ICU environment is strange to most parents, since they are frequently noisy and filled with advanced technology. In addition, the non-stop professional activity, technical language, visitors restrictions and changes in the patients' appearance, observed by family members in their first visit, comprise elements that can contribute to emergent feelings of isolation, fear, and possibly mental disorder<sup>(14,16)</sup>, which emphasizes even more the idea of the risk of death to the loved one.

The hospitalization of a child collapses the structure of the whole family, especially when the child is transferred to the ICU. In these cases, parents leave their usual activities, alter their professional routine and postpone their plans and appointments to stay with their child.

I should have been taking some exams this week, but I couldn't go because of my daughter's hospitalization (Primrose).



We must abandon work in these times, because it becomes insignificant, because the child, the wife and the family we are building are primordial (Carnation).

The value of the child was observed to overlap the meaning and value of work, leading to prioritizing the care for the sick child, especially in the first days of ICU. Afterwards, as time goes by, the family starts to reorganize itself. Some members take on certain tasks, so that a specific member, usually the mother, can assume the companion role and the care for the sick child.

### **Family contribution on children's recovery**

All parents agreed that their presence in the ICU contributed to children's recovery, opening opportunities for tightening family ties and allowing for the family to participate in the whole hospitalization process. In their view, this is a crucial factor for the improvement of the clinical state and recovery of the child.

With the family alongside them, children feel safe, taken care of, cheerful, comfortable, invigorated, more confident, happy, loved, and protected. This gives them strength to face sickness and hospitalization.

The presence is greatly valued, since it strengthens the patient, he feels better. For instance, their eyes glow when the family arrives (Carnation);

Important for the child's recovery. They feel safer with the father or mother or someone they like that there by their side; it really helps in the recovery (Primrose);

...the patient feels safe, feels well, the family comes to visit and makes him happy (Carnation).

We see that some patients that have their family with them recover faster, they do not have to worry about being unsafe, scared. Wondering if their father or mother will come back, if they will forget them here; because children think that way: *is my mother coming back, is she picking me up, maybe not...* and it is really important for the mother and the father to be with the child (Violet).

This perception from parents seems appropriate, since many studies have already emphasized that the absence of the mother causes a series of difficulties in children during hospitalization and for that reason, they highlight the importance of a companion with the patient throughout the whole process of recovery from the sickness<sup>(1)</sup>.

Also, it was demonstrated that, in the parents' perception, the presence of the family in the ICU, in addition to providing welfare for children, is also a safety factor for them. Because, this way they can follow and participate in the care for the child throughout hospitalization, allowing them to see that all that is possible and is best for the child is being done. It also minimizes the guilt they feel about their child getting sick.

...Well, because he is well provided for, the team is taking care of him. I think when people work well, they do it with or without the family around (Rose).

...when a nurse is working and just by observing them working we see that there is a point where the child's safety is greater. The father, when he sees that, as long as he can behave, he sees the work, and knows that everything that was possible was done. And if by some chance the child is taken by God, he knows that everything was done within standard procedures and everything that was possible that could have been done by man was done regarding their health. If it didn't work, it was God's work. The child is quiet with the presence of the father, the father is quiet because he saw that everything that could have been done was done (Carnation).

Most international pediatric guidelines favor the presence of parents with the child during hospitalization, including emergency situations, such as cardio-respiratory resuscitation, because This way, parents can follow events through the whole care procedure, consequently accepting events related to his/her health<sup>(11)</sup>.

However, in some cases and/or some moments, parents believe that staying with the child in the ICU can be harmful, because if they are not emotionally well balanced, they may show fear and insecurity, negatively interfering with the child's recovery.

Ah..When we cry, looking at the equipment..Looking at them...I think that they pay attention to that... (Azaleas).

I think that when we feel a little nervous, the children can feel it. Crying close to the child is not good because he will feel worse, he feels: *Darn, I think I look bad, because if my mom is crying it's because I am in bad shape.* So I think that is not positive (Primrose).

...I was so insecure there, very frightened, that my daughter felt it, she even felt really bad. So she had improved but then had a severe regression, but I think it was because of the insecurity I had, because when I felt more positive she recovered much better; but it is very interesting that the family stays with the child and knowing everything that is going on, good or bad, at least we are there with them (Violet).

Most psychological alterations present in people who have a family member in the hospital are negative, intensely marked by uncertainty, fear and concern related to the fact that the patient may die<sup>(14)</sup>; however, if the family is able to get over these problems, its presence is a benefit that favors the treatment. As days go by, as the child shows a positive improvement in his or her condition, showing signs of stabilization or improvement in symptoms, and as the family learns about, adjusts to and participates in the ICU routine, fear fades away.

I feel fine. On the first day I didn't feel right, I felt really bad, frightened. Afterwards, on the other days I felt more at ease (Rose);

Oh, Today I feel ok, as if I was at home; I feel as well as if I was at home, I felt safe, I felt that I had to work, it's important, the work of health is important... (Carnation).

The family is usually desperate by the time the child is hospitalized, and this is exaggerated in the first hours, due

to the undefined diagnosis and treatment deficiencies; but as days go by, they acquire experience and understand how the dynamics within the hospital work; therefore they become more tolerant to these situations<sup>(1)</sup>.

Previous experiences with diseases and hospital stay can positively or negatively influence the way a family faces a new experience and adjusts to the ICU environment<sup>(17)</sup>. For instance, three parents reported having negative previous experiences, marked by the hospital denying them the right to stay with the child and the lack of information and effective communication between professionals and the family, in addition to the child's suffering. Even as days went by, they affirmed that they did not feel well in the ICU environment, since these parents had difficulties adjusting and perceived the environment differently.

To tell you the truth, all my days there, I felt bad, I didn't... because my son was in bad shape, right... so, I didn't feel right in there... (Pansy);

I don't feel well. It's such a quiet place... I've been through a very difficult experience (Tulip).

Due to trauma, I feel a little... I don't feel ok [...] I don't feel ok because of the trauma I've been through, it was very difficult, traumatizing, I needed psychological help for a year and a half. That's a trauma I can't forget... (Primrose).

Therefore it is understood that these parents had negative experiences with this hospitalization due to previous traumas. This fact can generate great distress, and feelings of sadness and melancholy can be exaggerated when facing as conflicted and stressful situation as the hospitalization of a child. In addition, it is important to consider that even some parents that positively evaluate the care that their children are receiving during the hospital stay, refer to issues related to communication, since they were not well informed about the health conditions of their children<sup>(18)</sup>.

### ***The liberation of staying in with the son/daughter***

It has been proven that the presence of the family in the ICU unit brings benefits to the child; but, unfortunately, the liberation of parents to stay in with their children while hospital stay is not a reality in many Brazilian institutions, mainly in ICUs, which are considered as complex units<sup>(7)</sup>. In this study we observed that parents point to positive aspects of the liberation to stay in the ICU with the child.

The whole day and for everyone, it'll become a mess, the way it is, it's OK (Rose);

The time they let us in is good, it's good the way it is now (African daisy).

However, parents that experience the situation of not being able to be with their children during the process, express great sadness, distress and desire to be with them in order to ease the pain related to hospitalization.

The father and the mother should be able to stay longer (Orchid);

I think it's too little time, for so many people (Daisy);

it should be freer, it would be better, right? (Lily).

When I left she cried a lot, I had to say that I was going downstairs to buy some cookies for her, because she was scared, so that I could go, or say that I was going to sleep in the bedroom next door, if she needed me I would be right there, which wasn't true, right? Then in the night, she would wake up and cry a lot, had nervous crises, the loneliness of not seeing either me or her father there... She suffered a lot when I left, and when I arrived at 10 in the morning, I could hear her from the ICU door screaming for her mother and father. And she would wake up without the presence of her father or mother (Primrose).

From this mother's report about her daughter's suffering when she or her husband had to leave the ICU, it is clear that her daughter's suffering comprises her own. The way she expressed her pain and her daughter's go beyond the physical aspect, and in trying to minimize the child's suffering, she lies, even while knowing that it is perhaps not the best solution.

Some neonatal intensive care units offer social work services, religious chaplains and support groups. They believe that the families that have a child in the ICU lack support from the other family members and their friends<sup>(19)</sup>.

### ***Professionals welcoming the families***

The ICU is a place where technology has been constantly improving, making it a cold environment lacking affection. Professionals from this sector have the challenge to overcome barriers and allow for emotional expression within the family-child-professional relationship through humanized care, to strengthen these ties.

From most parents' discourse, they clearly felt welcomed in the ICU by all professionals that had a relationship with them. Disregarding the work period or the role they executed.

I thought that they were all excellent, from the cleaning clerk, nurses, doctors, all from the health sector, I thought they were excellent... (Carnation);

I noticed that they all welcomed me well... (Rose);

[...] they seem like a family, the nurses seem like a family. I like it, I feel at ease, as if we were all one family, all of us... (Daisy).

...in here they are friends, understanding, they talk, start a conversation, mostly to distract us, we can see that, so they are nice, understand? It seems that they work, that they like what they do. The ICU must have people that like what they do, cheerful, they are always playing, talking, laughing... (Violet).

The relationship with the hospital team can evolve to strengthen the ties if the family feels understood and that its needs are provided for<sup>(17)</sup>.

The health professional's interaction with parents must promote parents' greater understanding of the ICU world. It contributes to the success of the treatment and to overcoming the crisis during the child's hospitalization.

As they see the child in the ICU every day with their families, health professionals have the opportunity to exchange the sickness-centered perspective for a family-child-centered approach and they become more present, interested and concerned about the family.

In addition to being welcomed by the team, parents mentioned that the professionals presented gentle, happy, caring, respectful behavior, with friendship and interest for the well-being of the child and the family.

...we see that they show...a little of their feelings, right?... They share... a very close relationship... the kind of friendship that seems as if you know them for ages (Chrysanthemum).

Daily interactions make the family known to the nursing team, allowing for multiple dimensions of their needs to be also known and perhaps, in the near future, considered in the care plan.

### ***The family perceiving the care***

In ICU daily routine, professionals see themselves caught between knowing the technology well and the importance of humanized care to the children in it. Therefore, the exercise of valuing the being experiencing the sickness more than the body that carries it must be daily.

As they experience their child's sickness, families show themselves as whole, observing everything around them, and when trying to ensure that everything possible is being done for their child, they observe and evaluate how professionals take care of their children.

All parents interviewed, as they described the care for their children, affirmed that they were being well taken care of in the ICUs. They could see that care in the ICU consisted not only of executing techniques and procedures, but also encompassed feelings and attitudes, such as care, attention, cheerfulness, smiles and others.

...the treatment comes at the right time, the cleaning too... when we see them working, everyone happy, with a smile in their eyes, we feel well when they come to perform their work, medication... (Carnation).

Nurses are always where the children are, always checking the fever, blood pressure, heart beats, and they don't forget the time for medication (Violet).

Taking good care is the attention they show. They are always here, checking the temperature, they know every complaint they make... (Primrose).

We can also observe that parents perceive their child's hospitalization through the interaction with the health team members and the care provided for their son or daughter.

They value the technology and professionals' dedication, but above all, they value their respectful attitudes and consideration, considering them important for their interpersonal relationship.

A study of mothers of children in hospital due to acute diseases demonstrated that nurses were regarded as memorable when their care took into account the little things as gestures and attitudes. They provided support and helped the parents to face their children's hospital stay, making it more tolerable<sup>(20)</sup>.

The little things are defined as concern from the professional in treating them as individuals, calling children by their names, approaching the family as friends, showing love for the children, using the touch and caress and a smooth tone of voice, and setting an affectionate dialogue, as brief as it might be, as well as using the eye to transmit an infinite variety of messages. These *little things* do not depend on technology and pharmaceutical research, however they make a difference for the children and mothers in the hospital<sup>(20)</sup>, because they are the humanization that will most likely not be forgotten by the patient and by their families<sup>(4)</sup>.

### **FINAL CONSIDERATIONS**

Parents' statements reveal the intensity of the suffering they experience facing their children's hospital stay in the ICU. They become emotionally fragile and need to alter family dynamics in order to adjust to the new situation.

Apprehension and fear felt by the parents are understandable, since the hospitalization of a child alters their family structure, especially when ICU is needed, because this unit, for most laymen, is a synonym of death. However, it is also observed that as days go by and parents perceive a positive evolution in the child's prognosis, fear slowly fades away and is replaced by hope and trust.

We noticed that parents feel quieter if they can stay with their child, since they see their presence, support and care as essential for the child's recovery. For that reason, even if uncomfortable due to the lack of structure, what they want is to stay with their child and observe, follow and participate in the care, a fact that brings trust to the treatment and the team.

We also were able to demonstrate that the parents in this study felt welcomed by the team when professionals demonstrated respectful, caring, understanding and attentive attitudes; that care, in their point of view, goes beyond performing techniques and procedures and the close contact with the team creates bonds of affection, friendship and trust, in addition to developing feelings of gratitude for the care and attention provided for their child.

Therefore, it is important to make professionals aware of the importance of the family in the life of the child, es-

pecially when going through a crisis such as hospitalization. This is the first step towards a change of behavior and an improvement in the acceptance of the family into these units, not as imposed by law, but as a need felt from reviewing concepts, values and attitudes.

There is a need for new studies of the family and the child during the hospital stay, with a view towards valuing the family's expectations and opinions regarding the opportunity of being able to stay with their child, providing new resources for the reflection and rebuilding of care practices in pediatric and neonatal units.

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