

Benefits of mothers' permanence and participation in the care for their hospitalized child*

BENEFÍCIOS DA PERMANÊNCIA DE PARTICIPAÇÃO DA MÃE NO CUIDADO AO FILHO HOSPITALIZADO

BENEFICIOS DE LA PERMANENCIA DE PARTICIPACIÓN DE LA MADRE EN EL CUIDADO AL HIJO HOSPITALIZADO

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ABSTRACT

The purpose of the present study was to identify, according to the mothers' perspective, the benefits related to her permanence and participation in the care for her child hospitalized at a Pediatric Intensive Care Unit (PICU). The theoretical framework was Cross-cultural Nursing Theory, and the methodological framework was the assistant convergent research approach. Data was collected from six mothers of children hospitalized at a PICU of a University Hospital, in the period from January to May 2007, through interviews and active observation. Analysis was conducted following four generic processes: collection, synthesis, theorization and application. The results evidenced that the mothers' presence and care increased the attachment between mother and child, increased mothers' confidence, and made the child calmer. This produced positive feelings such as joy and satisfaction for being able to care for their child. Nurses should review their behavior toward the mothers accompanying their child at the hospital, and adopt attitudes that support her participation in the care for her hospitalized child.

KEY WORDS

Child, hospitalized.
Mother-child relations.
Intensive Care Units, Pediatric.

RESUMO

Este estudo objetivou levantar, na perspectiva das mães, os benefícios relacionados à sua permanência e participação no cuidado ao filho internado na UTIP. Utilizamos como referencial teórico a Teoria Transcultural do Cuidado e como referencial metodológico a Pesquisa Convergente-Assistencial. Os dados foram coletados junto a seis mães de crianças internadas na UTIP de um hospital universitário, no período de janeiro a maio de 2007, por meio de entrevistas e observação participante. Na análise dos dados seguimos quatro processos genéricos: apreensão, síntese, teorização e transferência. Os resultados evidenciaram que a presença e o cuidado da mãe estreitaram seu vínculo afetivo com o filho, trouxe segurança para a mãe e tranquilidade para a criança, suscitando o aparecimento de sentimentos positivos como alegria e satisfação por poder cuidar do filho. É preciso que os enfermeiros repensem seu comportamento quanto à mãe acompanhante e adotem atitudes que favoreçam sua participação no cuidado ao filho hospitalizado.

DESCRIPTORES

Criança hospitalizada.
Relação mãe-filho.
Unidades de Terapia Intensiva Pediátrica.

RESUMEN

Este estudio tuvo por objetivo conocer, bajo la perspectiva de las madres, los beneficios relacionados con su permanencia y participación en el cuidado del hijo internado en la UTIP. Utilizamos como marco teórico la Teoría Transcultural del Cuidado y como marco metodológico la Investigación Convergente-Assistencial. Los datos fueron recolectados junto a seis madres de niños internados en la UTIP de un hospital universitario, en el período de enero a mayo de 2007, por medio de entrevistas y observación participativa. En el análisis de los datos seguimos cuatro procesos genéricos: aprensión, síntesis, teorización y transferencia. Los resultados colocaron en evidencia que la presencia y el cuidado de la madre estrecharon el vínculo afectivo con el hijo, trajo seguridad para la madre y tranquilidad para el niño, suscitando la aparición de sentimientos positivos como alegría y satisfacción por el poder cuidar del hijo. Es preciso que los enfermeros repiensen su comportamiento en lo que se refiere a la madre acompañante y adopten actitudes que favorezcan su participación en el cuidado del hijo hospitalizado.

DESCRIPTORES

Niño hospitalizado.
Relaciones madre-hijo.
Unidades de Cuidado Intensivo Pediátrico.

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INTRODUCTION

Disease and hospitalization of children affects all family members and alters the whole family dynamics because, when a family experiences the disease of a child, it is inserted in a new world – the hospital world, whose organization, dynamics and logic are very different from their daily routine. This results in a high level of stress and anxiety, especially when the child needs intensive care. Therefore, the intensity of this suffering may vary according to the disease, clinical evolution and prognosis⁽¹⁻²⁾.

Having a child become sick is very painful and grieving for the relatives, as the child has a very important role in the family world, representing the future and the concretization of the parents' dreams and desires, who see the possibilities of the child as their own. The child's disease ruptures all these meanings and projects for the future, causing immense pain and family stress⁽¹⁾.

Nowadays, the importance of allowing the parents to remain in the hospital and their involvement in the child's health-disease-care process is well-known. Such consideration is based on psychological studies, evidencing the problems related to the separation of the binomial during the hospitalization period. In this context, the children tend to feel distressed when separated from the parents, whose absence causes feelings of grief. Such feelings lead to great and deep suffering, which is only overcome when the parents are allowed to stay with the hospitalized child all the time⁽³⁾.

The presence of an accompanying relative is a source of protection, support and security for the child, resulting in a set of enjoyable stimuli and making the pediatric intensive care unit (PICU) less aggressive. Besides, the situations experienced together contribute to strengthen emotional bonds, comprehension, love and care⁽⁴⁾.

Hence, allowing the mother to stay at the PICU during the hospitalization of the child is a strategy that makes it possible to strengthen the emotional bonds, reduce the emotional stress of both the child and the family, consequently contributing to a shorter time of hospitalization⁽⁵⁾.

In the daily routine of the hospital, it is often observed that the mother is the one who stays with her child during the whole period of hospitalization, or comes to visit the child more frequently. When it becomes possible to strengthen the relationship with these mothers, they are seen to harbor an intense desire to provide care to their child during the process of hospitalization, as a way to convey all their love, increase the mother-child bond and minimize the *feeling of guilt*, which is often present due to the disease of the child.

Strategies to encourage the mother to take part in care for her hospitalized child have frequently been discussed, but Brazilian healthcare practices in most institutions have not systematically incorporated the mother or the legal guardian in this care, due to the lack of preparation of the healthcare team, who is still resistant to accept the presence of the child's family. When the mother is inserted in the healthcare routine, it often happens inadequately, as the professionals only allow the mother to perform simple tasks, or otherwise complex ones, but without adequate orientation and supervision. The intention of this action is restricted to simply having tasks assigned^(3,5).

Therefore, although such care routines are part of the daily routine at the hospital and comprise the set of professional skills of the staff, every type of procedure represents something that is very new and abstract for the lay population, which most users of the healthcare system are part of. Besides, it needs to be considered that the moment of weakness of the mother/caregiver usually intensifies her comprehension difficulties⁽⁶⁾.

OBJETIVE

Observing the perceived necessity to insert the mother in the care provided to the child admitted in the pediatric intensive care unit (PICU), we decided to execute the present study, whose goal was to identify, according to the perspective of the mothers, the benefits related to their permanence and participation in the care provided to their hospitalized children.

METHOD

This is a descriptive convergent care study (CCS) with a qualitative approach⁽⁷⁾. The CCS is a field study that maintains a strict relationship with the healthcare practice during the whole process, with the aim of finding alternatives to solve or minimize problems, make changes and introduce practical innovations. Therefore, this type of research is directly committed to improving the social context studied.

Six mothers participated in the study, who had had their children hospitalized at the PICU and met the following inclusion criteria: a) being the mother of a child and his or her main caregiver; b) being available and wanting to provide care to the child during his or her permanence at the PICU; and c) the time of hospitalization of the child was longer than five days.

The theoretical reference was Trans-Cultural Care Theory⁽⁸⁾. We decided to use this reference because, in our work at the PICU, it was usual to see mothers who delivered informal care to their children in a singular way. We observed that their beliefs and cultural values were present

in their way of providing care and, as such, they had to be understood and respected. This would result in an approximation and establish mutual bonds of trust, as well as partnerships when providing care to the child.

The study was developed at the Pediatric Intensive Care Unit (PICU) of Hospital Universitário Regional Maringá (HURM), in the city of Maringá, located in the Northwest of the state of Paraná.

Data collection occurred from January to May 2007, in three phases, during the insertion process of the mother in the care provided to the child. Two semi-structured interviews were held with the mothers, one before and one after the process of insertion in the healthcare routine. A script with mixed questions was used for this purpose, elaborated by the researcher herself, based on the goals of the study and evaluated for clarity by two faculty members with a Ph.D. degree at the Nursing Department of Universidade Estadual de Maringá – one working in the family area and the other in pediatrics.

The mother was inserted in either the simple or complex care routines, according to the gravity and prognosis for the child, slowly and gradually, always monitored by the researcher. During the process of inserting the mother in the healthcare routine, all interactions between the mother and the researcher were observed and used in data collection, becoming informal interviews. This is the most appropriate type of interview in convergent care research, as it happens repeatedly over time, with the participation of all those involved in the process ⁽⁷⁾. In this stage of the study, in addition to the informal interview, we provided participative orientation followed by participative observation, being mindful of the mother's assimilation and comprehension of the healthcare actions provided to the hospitalized child.

After the conclusion of the mother's insertion process in the healthcare routines, near the moment of discharge to the pediatric wing or the hospital of origin, the mother was approached again, with the purpose of identifying the difficult and easy aspects she met during the whole process of insertion in the care routines for her child (formal assessment). This was done in order to work on the difficulties and clear the doubts of the mothers, so that they could be adequately prepared for discharge. This procedure was done with four mothers only, as the children of the other two had died during the study period.

On average, seven meetings were held with each mother. The problems or difficulties were identified at each meeting, considering both the execution of techniques or procedures and the formation or strengthening of bonds, which had to be solved or clarified in the next meeting. Therefore, daily planning was made, systematized according to the observations. However, at times, the planned

activities were not the ones the mother desired that day. In this case, the planning was re-elaborated and executed according to the mother's needs at that time, returning to the original plan as soon as possible.

Since the insertion of the mother in the healthcare routines was not usual at the unit, the person responsible for collecting the data would come to the sector outside her work shift to perform the activities related to the research, including the insertion of the mother in the care routine. It was not possible to detach her role of researcher from her position as a unit nurse, but she tried to avoid interfering in the development of routine service as much as possible.

The four generic processes of qualitative analysis ⁽⁷⁾ were followed to interpret the data collected in all meetings: apprehension, synthesis, theorization and transference. In apprehension, the whole set of information obtained during the process of inserting the mother in the care routine was considered, starting with the first interview. In the synthesis, the associations and variations of the information were subjectively assessed, considering the most significant data of the study. In theorization, we attempted to interpret the acquired data in association with the adopted theory and, in transference, we attributed meanings to the result and contextualized them, being careful to avoid generalizations.

In the presentation of results, the mothers and their children are identified by names of flowers (in Portuguese). This format was used to guarantee the preservation of the subjects' identities, among other aspects. Their participation complied with the determinations of Regulation 196/96 of the National Health Council, which covers research involving human beings. The project was approved by the Review Board of Universidade Estadual de Maringá (file # 389/2006). When the mothers were contacted to take part in the study, they were informed of all the procedures to be adopted during the research, and all of them signed two copies of the term of consent.

RESULTS AND DISCUSSION

Chart 1 presents some of the characteristics of the children and their mothers. It can be observed that the six mothers who took part in the study were relatively young, with four of them being married; their average age was 27 years, and they had between 1 and 5 children. Four families were of the nuclear type, and their income was between one and two times the minimum wage. Among the children, only 10-year-old Kalachuê and 17-month-old Girassol had acute conditions. The others experienced a chronic condition. Two of them were up to six months and had lived at the ICU since they were born, and two were around one and a half year old and had been hospitalized several times.

Chart 1 – Characteristics of the mothers and children, subjects of the study – Maringá – 2008

Child	Age	Diagnosis	Mother	Mother's Age	Education	Marital Status	# of Children
Violeta	1 ½ year	Werdnig Hoffmann's syndrome	Tulipa	34 years	High school	Married	3
Angélica	4 months	Bronchodysplasia	Hortência	24 years	College	Married	1
Amor-Perfeito	4 months	Edwards' syndrome	Amarilis	25 years	High school (unfinished)	Married	3
Girassol	1 year, 5 months	Seizures, pulmonary bronchoaspiration and acute respiratory insufficiency	Orquídea	26 years	High school	Married	2
Kalachuê	10 years	Septic shock and respiratory insufficiency (due to a wounded foot)	Rosa	37 years	Elementary school	Divorced	5
Chuva de Prata	1 year, 5 months	acute respiratory insufficiency, bronchopneumonia, bronchospasm and grave dehydration	Primavera	16 years	Elementary school (unfinished)	Single	1

Importance of the presence of the mother

According to most of the participating mothers, the PICU was a cold, aggressive environment, in addition to being restricted to professionals, which would cause her children to stay alone during the hospitalization. However, when presented with the information that they could stay with their child full time, they became aware of the possibility to offer maternal care to the child, represented by their company/presence throughout the hospitalization, as a way to express all their feelings of love and affection.

The hospitalization of their children at the PICU was a new experience for most mothers. However, those women were intuitively aware of the importance of their presence with the child during the process of hospitalization. For Orquídea, for example, her presence made her child feel comfortable and at ease.

[...] the presence of the mother, the contact, they're important. He knows I'm there, that his father is there. I'm sure, if he can hear my voice, he's going to feel more at ease (Orquídea).

It is known that the children's stress during the period of hospitalization at the PICU is unavoidable, involving several factors. These include fear, pain, long periods of sleeplessness, changes in the environment and absence of the extended family⁽⁹⁾. In this context, full of stressing stimuli, the family, represented by the mother, works as a mediator and facilitator of the child's adaptation to the hospital environment, in addition to being a source of affection and security. Therefore, when mothers remain together with

their children during hospitalization, they act to minimize the suffering of the children, bringing in a pacifier, staying close, comforting them after a stressful situation, preventing the execution of procedures, and/or insisting in mentioning certain pieces of information about the children⁽¹⁰⁾. When such a situation occurs, the children cry less, they feel more at ease, their health improves faster and they feel protected, since the mothers know what their children like^(3,10).

Primavera believed that her daughter felt her presence and was thus stronger to overcome her disease.

[...] she's seeing [...] I think that this goes through her head: *Oh, my mother is helping there, I'll struggle to stay with her* (Primavera).

Orquídea believed that her presence, in addition to conveying calm and affection, could help her son to recover.

[...] I'm sure I can help him recover. Being together, especially now that he wants to wake up [...] (Orquídea).

Some authors⁽¹¹⁻¹²⁾ say that the presence of the mother with her hospitalized child can minimize the traumatizing and stressful effects of hospitalization, and that the inclusion of the family in the plans of the hospital team entails success for any therapeutic actions in care for the hospitalized child, conferring a *new meaning to the family and care delivery*⁽¹⁰⁾.

Primavera reported noticing that her daughter could feel her presence, both at the PICU and in the neonatal ICU, when she was only a baby.

[...] Often, at the neonatal ICU, in Campo Mourão, I would hold her hand and I felt her squeezing my hand. Here she's sedated, but I feel that she squeezes my hand, I feel that she can feel I'm by her side, making her stronger. I talk to her, I feel that she pays attention to my talking, she feels that I'm there holding on her hand [...] (Primavera).

For Hortência, the bond between mother and daughter was only formed after she established a closer presence with the child, by stroking her while in her arms, and the general intimate contact between both:

[...] At that time I felt more like a mother, when I held her in my arms. When we hold the baby in our arms, we feel a closer bond with the child, just like yesterday; I felt closer to her. I think she felt more at ease. It was good for her and for me too [...] (Hortência).

The presence of the mother eases the mental distress of the child, produces emotional conditions that are more satisfactory for the pair, reduces intra-hospital infections, encourages lactation, shortens the patient's hospitalization, improves the efficiency of healthcare services, optimizes human resources, favors a closer and more intense relationship between the patient and the multidisciplinary team and prevents accidents. In addition to being a direct source of information about the evolution of the disease, it also favors the qualification of the mother to perform basic and complex care routines, which will often have to be performed at home, thus reducing the anxiety and grief caused by the hospitalization⁽¹²⁾.

However, not all mothers felt comfortable being with their children. Rosa, for example, even knowing that her presence near her son was important, would come to the hospital for the daily visits but she stayed there for a short time, unable to witness the suffering of her child.

[...] it's really sad to see my son like that, I can't stand it [...] (Rosa).

Although they accept the hospitalization of their children, some mothers saw the hospital as a strange place, one that they did not trust yet. This new environment would cause them physical and emotional suffering, making them feel tired and unwilling to provide care, as they felt that their needs were ignored, making their experience with the hospitalization more difficult⁽¹³⁾.

As time went by and the child's health improved, Rosa spontaneously decided to stay with her son for more time. She would stay at the PICU at night, since she had to take care of her other children and her house during the day. This routine lasted for over two months, causing physical and emotional distress to the mother.

[...] I can't stay with him all the time, it's difficult. I have so many things to worry about [...] I come here feeling exhausted, I don't know if I can take it [...] (Rosa).

The difficulties of the daily routine at the hospital cause ambivalent feelings, which are overcome or tolerated by

the family in favor of the child's well-being. However, at the same time as they do everything they can to stay with the child, the mothers feel tired and suffer⁽³⁾.

Although the mothers were granted the right to stay with their children full time, Tulipa was the only mother to stay at the PICU 24 hours a day. She would rarely leave the hospital for long periods and, when it happened, her husband would come to take her place.

For many women, care is conceived as a solitary action, centered on the mother figure. When there is aid, it is usually provided by the husband or partner⁽⁶⁾. However, staying with Violeta all the time was not easy for Tulipa because, in addition to missing her home, the accommodations were not good. She would sleep in a reclining chair, eat her meals on an improvised place and wash herself in the restroom located in the pediatric ward (about 200 meters away from the PICU). The lack of adequate physical structure caused discomfort for the mother. She wanted to remain by her daughter, but the suffering of being confined to the PICU was evident.

[...] Some people don't have the willpower, they can't stand being here, they can't take it, their emotional self can't take it. Then people say: *That mother over there has no heart!* It's not like that. It's difficult, we have to be really strong to stay here, confined, as they say (Tulipa).

In many healthcare institutions in Brazil and abroad, the physical area is organized uniquely to receive the child. The lack or insufficiency of physical space and adequate accommodations for the accompanying parents increase the suffering caused by the hospitalization, and the reason for the hospitalization is usually a lesser source of concern than the consequences of the confinement⁽¹⁴⁻¹⁶⁾. Nevertheless, even though they see joint permanence as a prison due to poor accommodations, lack of privacy and family isolation, studies show that most mothers feel so grateful and satisfied with the opportunity of taking part in the care provided to their children that they do not feel that they are entitled to making any other demands⁽¹²⁾.

A strategy that could minimize maternal suffering caused by the confinement is to allow the mothers to take on certain responsibilities for their children, such as hygiene, changing diapers and feeding, always under the orientation and supervision of a nursing professional. This helps them to realize that their perception of being prisoners in the institutional context is wrong, thus discarding idleness and replacing it by the feeling of being useful when they take part in the care provided to their children⁽¹⁷⁾.

However, actions performed with the purpose of providing care to the mother and/or the family are usually done in a very rigid way, unnaturally, centered on the judgment of the multidisciplinary team about what is good and what is not, instead of judging what would be necessary for that family in particular⁽¹⁰⁾.

Benefits of the insertion process in healthcare as perceived by the mother

At the end of the study, four mothers were interviewed once again and reported that their presence with their children, as well as their participation in the care provided to their sons and daughters, brought feelings of happiness, pleasure, security and others. With the training they received, most of their doubts about care had been solved, challenges had been overcome, barriers had been broken, and the goal of learning about providing care to children with special needs in a strange environment was achieved.

After being trained, Tulipa felt much more secure to provide care to her daughter. She mentioned being able to learn both simple and complex care routines due to her great willpower, being aware of the importance of care and her responsibility towards the child. Moreover, she felt the urge to provide care to her daughter at home.

[...] I believe that you just have to want to get down to it, to be trained by specialized professionals but, most of all, you have to do it with love, in everything, you have to practice and learn [...] I was really well-oriented. When I had doubts, I always tried to ask questions, so I would know what to do in a certain situation... Now I can aspirate her without many problems at home, after getting training. This gives us security. It's very rewarding to know that we can be close to our children and provide them with the security they need... [...] (Tulipa).

The mother's overburden as the main caregiver of the sick child sometimes forces her to develop strategies to cope with the new contexts and the new demands of life. This represents a stimulus for her to feel more capable and willing to learn new things⁽⁶⁾.

Orquídea felt more secure and at ease to provide care to her son in the pediatric ward because she had the opportunity to provide care to her child at the PICU. With her participation in the care routines, she was able to satisfy her curiosity about the nursing care provided to the child during her absence, and the functions and usage of the materials and devices connected to the child:

It's better to stay together there (PICU), because, otherwise, we tend to think: are they administering the medication? What care is he receiving in there? What is the exchange like? These things stick, and mothers, like me, are curious about them. What is it like when I'm not around? [...] I had many doubts [...] the instructions were good [...] (Orquídea).

The maternal presence at the ICU, in addition to increase the children's wellbeing, is a factor of security for the parents. They follow and take part in the care provided to their children throughout the hospitalization period, feeling reassured that the professionals are doing their best for the children, in addition to minimizing the feeling of guilt for the disease of the child⁽⁹⁾.

Providing care to a sick child during his permanence at the PICU was pleasurable for Orquídea, especially when she had intimate contact with the child:

[...] I never felt it was difficult to bathe him; I even got to like it. I think he felt more at ease. I don't know if it's because of the touch, he was there, still, and we were touching him all over, he was calmer [...] (Orquídea).

In most Brazilian families, the mother is the main caregiver for the children, being the person who identifies problems in their health situation and seeks solutions for the identified problems⁽¹⁸⁾. Therefore, it is common for them to have difficulties in sharing this care, as if they were the only ones with this task. Providing care during the hospitalization of their children minimizes a possible feeling of guilt in mothers, which may be latent in their thoughts. This may also bring tranquility for the mother and the child, resulting in feelings of closeness, security, pleasure and wholeness for both⁽¹⁾.

For some of the mothers, the fact of having taken part in the care provided to the child helped them to feel more at ease, although more attentive and careful.

[...] You do get more careful once you've gone through it. I'm pretty careful with my children, but it feels like it doubles up. You pay more attention [...] I feel safer and calmer after leaving that place (PICU) [...] I already knew that he was flabby, like a newborn baby. If I hadn't had contact with him in there (PICU), I'd see him here (pediatric ward) like this, and then, what would I do with my son like this, the size he is now, and in that situation [...] he'd barely open his eyes, how was I supposed to take care of him? [...] (Orquídea).

Also, there seems to be an exacerbation of the responsibility for the child, especially with the occurrence of certain physiological alterations.

[...] I know that my daughter is now under my direct care [...] (Tulipa).

[...] Now I know, whatever happens, I know how to control it [...] If someone ever has to help her, it will be me, because everybody is out at work, I stay with her at home [...] (Primavera).

When the mother takes part in providing care to her child during the hospitalization period, she incorporates the responsibility for some care routines, and they are assimilated as her duties. This happens because it is common for mothers to take responsibility for providing basic care to their children within the hospitals. Usually, nobody asks or observes if she is performing adequate care routines like as hygiene and feeding, among others, as the nurses simply assume that she is. The positive aspect of this is that mothers acquire autonomy and manual dexterity as they provide care to their children⁽³⁾.

Providing care to their children at the neonatal ICU brought more facilities than difficulties to Amarilis and

Primavera, who experienced the provision of care to their children at the PICU and the pediatric ward.

[...] I was afraid of doing or forgetting about any thing, but I left there (neonatal ICU) feeling more secure. For me he was doing great just for leaving that place (PICU); I thought the rest was easy, providing care, because I knew how to do it [...] (Amarilis).

[...] It was easy for me, because I had provided care at the neonatal ICU. If she were a newborn I wouldn't know how to do it. Here (PICU) I learned to change a bandage, something I had never done, and bathing. It was better for me to learn it, better for me to provide care to her in the pediatric ward and at home [...] (Primavera).

Parents who already had the experience of accompanying a son or daughter in a situation of hospitalization, due to either a new disease or relapse, or because the child had a chronic disease that implied frequent hospitalizations, usually feel more at ease when in the hospital environment, and have fewer difficulties in providing care to the child⁽³⁾.

As days went by, Amarilis became more familiar with the PICU environment, with the way care was provided to the child and the materials and equipment used in the techniques and procedures. She adapted to the routine of this new context, and this experience made her feel more at ease regarding the provision of care to her child at the pediatric ward. However, she knew she was going to face many new situations, as the child had a chronic condition:

[...] Really easy. We hold the child more steadily, we know there's no risk [...] Every day I came over to stay with him I thought it was easier, and I felt better when I was providing care to him. I thought bathing was easy, changing diapers, that's normal. Except for the aspiration [...] Nowadays I feel more reassured, because I learned it, and now it's easier for me to take care of him; I know how to pick him up and give care [...] As he is a special child, everything is new, even the pneumonia is new to me [...] (Amarilis).

In addition, she knew that it would be more difficult to provide complex care at home, as she would not have the professional support available at the hospital.

[...] It'll be more difficult at home. There's always someone here at the hospital to help us out: 'you can do this, you can't do that', I'll be alone at home [...] (Amarilis).

Usually, mothers of children with chronic diseases leave the hospital with a child who needs complex care in their arms, and new tasks upon their shoulders, which will trigger great changes in personal and family habits. Although their time in hospital provides them with a wide range of knowledge and experience, they still have many doubts and fears regarding their competence to deal with all of it⁽⁶⁾.

In this perspective, the insertion and active participation of the mother in the care provided to the child is necessary in the hospitalization period, even before discharge has been programmed, as this is the only way for us, healthcare pro-

fessionals, to be able to support these women in the exercise of their citizenship and in the development of competences and skills as caregivers for their children. As such, we will also enable these women to provide care in a practical and efficient way, which may be an effective factor in preventing frequent re-hospitalizations of these children, a fact that results in both emotional and financial damage⁽⁶⁾.

FINAL CONSIDERATIONS

This study attempted to comprehend, according to the mothers' perspective, the benefits their permanence with their children entailed for the binomial at the PICU throughout the process of hospitalization and their active participation in care. The findings were very favorable, revealing that it is possible to adopt such practice in PICUs, making a difference in pediatric nursing care. However, it is worth noting that both the resistance of the multidisciplinary team at the beginning of the study and the fear of the mothers regarding the manipulation of materials and equipment, as well as their possible lack of motivation, are limiting aspects that should be considered in future initiatives.

We observed that, upon receiving the news that they would be allowed to stay with their children and to take part in the care, the joy and hope of being able to satisfy their maternal desire of providing care to the child were reborn in most of the studied women, as a way of continuously providing care and love to the child.

These women were able to express the benefits brought to the binomial due to their presence and permanence with the child during the whole process of care, through gestures or words. Even though they lacked the scientific knowledge, they intuitively knew that their presence was a source of affection and love for the child, tranquility and security for the family. Besides, it also helped the child to recover or to stabilize.

However, even though some of the mothers were aware that their presence would be beneficial for the children, they felt unprepared to remain with the child full time, as both the suffering of the children and the stressful environment of the PICU caused them intense mental suffering, preventing them from staying with their children for long.

Each mother experienced the process of being inserted into the care routines in a singular way, since some of them had already experienced the hospitalization of the child in an ICU and had taken part, small as it was, in providing care to the child. The encounters were programmed and the actions were planned beforehand, according to the perceived needs; however, the mother was the one who directed the plan of action, since it was established according to the implied or explicit limit of what and how much she was prepared to learn. The intention was not to have it become an imposed model, but achieving spontaneous maternal participation. For that to happen, it was necessary to respect the needs and desires of the mother.

We believe that it was very important to respect this limit, since it is common to see the mother being forced to take part in care for the child, where the nursing professionals, believing and acting as powerful beings, delegate care routines to the mother without even asking her if she is prepared or willing to provide care to her child. Therefore, when the mother lacked the desire to provide care to her child or felt discouraged, we did not insist on it – instead, we tried to show her the benefits that maternal care could bring for the child and for her, and we attempted to understand the negative factors that interfered in the maternal desire to deliver care to the child.

Most of the studied mothers perceived the need to learn how to perform simple and complex care routines for the child as soon as possible. With the exception of Orquídea, whose son was hospitalized due to acute problems and had a quick recovery, without sequels, all others would take a child with special needs home, care routines that had not been necessary in the daily routine of the child and the family.

Inserting the mother in care is not a simple process, as we stumble on the resistance of the multidisciplinary team and lack of preparation in some professionals to perform the teaching-learning process, which demands time and patience, thus becoming a gradual process. The fear the mother felt to deliver care to her child due to the equipment and materials connected to the child and the fear of causing pain, discomfort and damage in the child are also important obstacles in the execution of the insertion process.

It was necessary to use all our knowledge as PICU nurses in order to have this process occur smoothly and provide parents with the necessary orientations. We would often let the feelings and acquired experiences guide the orientation offered to the mother, always with the purpose of facilitating the comprehension of these women – either beginners or experienced in the care process. As such, we believe that we were able to promote a more active and effective participation of the mothers in the care routines involving their hospitalized children, and that we made a difference in the life of some mothers, as we respected their desires and limits when providing care to their children in different situations and occasions. Therefore, we realized that each of these mothers, in her own way and intensity, provided care to the child, and this was a unique experience in their lives.

Furthermore, in order to insert the mother in the care routines, it is necessary for the nurse to be concerned with comprehending the expectations, anxieties and fears experienced by each of these women during this process of learning, which is very specific. This should happen before the nurses attempt to seek theoretical and technical-scientific qualifications.

This study may help professionals working in pediatric units to re-think their attitudes and behaviors regarding both the care provided to the child and the family and the importance of the process of inserting the mother in the care routines before hospital discharge, in professional practice and in family healthcare research.

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