

Existential experience of mothers of hospitalized children in Intensive Pediatric Care Unit*

EXPERIÊNCIA EXISTENCIAL DE MÃES DE CRIANÇAS HOSPITALIZADAS EM UNIDADE DE TERAPIA INTENSIVA PEDIÁTRICA

EXPERIENCIA EXISTENCIAL DE MADRES DE NIÑOS HOSPITALIZADOS EN UNIDADES DE TERAPIA INTENSIVA PEDIÁTRICA

Gilvânia Smith da Nóbrega Morais¹, Solange Fátima Geraldo da Costa²

ABSTRACT

This study has the objective of understanding the existential experience of mothers of children hospitalized in an Intensive Pediatric Care Unit (IPCU). It is a qualitative-based research grounded on the humanistic nursing theory. The investigation scenario was the IPCU of a public hospital. Five mothers of children who were hospitalized in the referred unit participated in the investigation. Data were analyzed from the standpoint of the five phases of the phenomenological nursing. The following issues emerged from the collected statements: the relationship between mothers and nursing professionals at the moment of admission and throughout the child's hospitalization period in the IPCU; and mothers who experience fear, despair and loneliness in face of the child's disease. The present study highlights the complexity of a mother-centered approach and subsidizes a new look at the field of the care, teaching and nursing research.

KEY WORDS

Mothers.
Child, hospitalized.
Intensive Care Units, Pediatric.
Professional-family relations.
Nursing theory.

RESUMO

Este estudo tem como objetivo compreender a experiência existencial de mães de crianças hospitalizadas em Unidade de Terapia Intensiva Pediátrica (UTIP). Trata-se de uma pesquisa de natureza qualitativa, consubstanciada na Teoria Humanística de Enfermagem. O cenário da investigação foi uma UTIP de um hospital público. Participaram do trabalho cinco mães de crianças hospitalizadas na referida unidade. Os dados foram analisados com base nas cinco fases da Enfermagem Fenomenológica. A partir dos discursos expressos durante a coleta de dados, emergiram as seguintes temáticas: a relação vivenciada entre as mães e os profissionais de enfermagem no momento da admissão e ao longo da hospitalização da criança na UTIP; e mães vivenciando sentimentos de medo, desespero e solidão diante do adoecimento do filho. O presente estudo ressalta a complexidade de que se reveste uma abordagem centrada nas genitoras e subsidia um novo olhar no âmbito da assistência, do ensino e da pesquisa em enfermagem.

DESCRIPTORIOS

Mães.
Criança hospitalizada.
Unidades de Terapia Intensiva Pediátrica.
Relações profissional-família.
Teoria de enfermagem.

RESUMEN

Este estudio tiene como objetivo comprender la experiencia existencial de madres de niños hospitalizados en Unidades de Terapia Intensiva Pediátrica (UTIP). Se trata de una investigación de naturaleza cualitativa basada en la Teoría Humanística de Enfermería. El escenario de la investigación fue una UTIP de un hospital público. Participaron del trabajo cinco madres de niños hospitalizados en la referida unidad. Los datos fueron analizados con base en las cinco fases de la Enfermería Fenomenológica. A partir de los discursos expresados durante la recolección de datos emergieron las siguientes temáticas: la relación experimentada entre las madres y los profesionales de enfermería en el momento de la admisión y a lo largo de la hospitalización del niño en la UTIP; madres experimentando sentimientos de miedo, desesperación y soledad delante de la enfermedad del hijo. El presente estudio resalta la complejidad de que se reviste un abordaje centrado en las genitoras y muestra una nueva perspectiva en el ámbito de la asistencia, de la enseñanza y de la investigación en enfermería.

DESCRIPTORES

Madres.
Niño hospitalizado.
Unidades de Cuidado Intensivo Pediátrico.
Relaciones profesional-familia.
Teoría de enfermería.

* Extract from the thesis "Relação dialógica entre profissionais de enfermagem e mães de crianças hospitalizadas em Unidade de Terapia Intensiva Pediátrica", Graduate Nursing Program at Federal University of Paraíba, 2007. ¹RN, MSc. in Nursing. Undergraduate Nursing Faculty at Faculdade de Enfermagem Nova Esperança. João Pessoa, PB, Brazil. ga_anjim@hotmail.com ²RN, Ph.D. in Nursing. Undergraduate and Graduate Nursing Faculty at Federal University of Paraíba. João Pessoa, PB, Brazil. solangefgc@gmail.com

INTRODUCTION

Hospitalizations are unpleasant experiences because they involve loss processes, regardless of the duration of the hospitalization and the age of the patient. However, children are especially vulnerable because this situation directly affects their development. The various changes that affect their daily lives require major adjustments.

The need to be admitted into a hospital almost always generates a double trauma in children. After being separated from the nurturing and protective family environment, they are taken to a cold, impersonal and hostile hospital environment. Hence, the presence of the family, and especially the mother, is imperative during the hospital stay. It contributes to their ability to deal with the situation, making them more capable of overcoming suffering and anxiety⁽¹⁾.

It is important to note that hospitalizations not only affect children's own lives, but also alter the dynamic of the whole family. This generates ambiguous feelings resulting from the family's loss of functional control, insecurities regarding the ability to regain balance, and doubts regarding the experience.

Therefore, families of children admitted into a hospital need

[...] support, guidance and permanent care from highly committed professionals, so that both the child and the family can be benefited⁽²⁾.

Families' characteristics and private needs, represented by mothers, must be observed.

When children are admitted into a Pediatric Intensive Care Unit (PICU), parents, and especially mothers, since they are the ones most often present, should be included in the perspective of care of nursing professionals. This attitude helps mothers adjust to the situation, since they are usually in distress, experience loss and feel that they are not in control.

In this perspective, it is important that nursing professionals establish an empathic and inter-subjective relationship with mothers of children admitted into an intensive care unit that will facilitate their participation in care. By using a family-care perspective in child care, nurses are able to reduce emotional stress, help the family deal with the situation and relieve the suffering of patients and their mothers.

As a student in the Nursing Graduation Course of the Federal University of Paraíba (UFPB), I had the experience of following up mothers and their children admitted to a hospital, and have been in the position of nurturing a mother facing the distress of having her only daughter in an intensive care unit. These experiences alerted me to the need to rethink the practices of nurses and nursing assistants' care regarding motherhood in the PICU context by emphasizing humanized care.

The necessity to humanize nursing care for mothers and their children admitted into a PICU gave rise to studies involving a dialogue relationship with subjects in the care context. Because of these studies, I became interested in performing work guided by the Nursing Humanistic Theory. I became involved with the Humanistic Theory when I was developing my Course Term Project that dealt with humanized nursing for children admitted into hospitals, and I read several books that reported the value of dialogue with mothers regarding nursing care using a humanistic perspective.

As I started my Undergraduate Program in Nursing at UFPB, I had the opportunity to study some courses that contributed via discussion and reflection to the development of research that would encourage new understanding of the experienced by mothers in the PICU.

With these considerations in view, this study aims to understand the existential experience of mothers of children admitted into the PICU within the framework of Nursing Humanistic Theory.

REVIEWING LITERATURE

The Intensive Care Unit enables a critically ill patient to survive. At the same time, it places the patient in an environment of isolation and anxiety, where he or she is exposed to stress and sensory overstimulation. Individuality and identity are suppressed as daily routine and the complex service provided by the unit *make nursing team members, frequently, forget to touch, talk and listen to the human being in front of them*⁽³⁾.

Children are subject to these aspects of hospitalization in an Intensive Care Unit. These conditions also affect the family and even the health professional team, generating distance, stress and suffering by harshly breaking the daily routine of children and affecting their family dynamics and identity⁽⁴⁾.

Having a son admitted into a hospital, in a passive state due to his condition, breaks down the family routine, adding to the responsibilities of other family members and placing the child in a more limited relationship to the family. These difficulties arise from the situation of the family and from the conditions imposed by the hospital or even the child's pathology⁽⁵⁾.

Negative experiences and meanings attributed to the disease and hospitalization of children cause emotional experiences in mothers that

emerge through feelings, actions and thoughts that reflect the difficulty in dealing with the situation, such as nervousness, constant crying, continuous walking around the hospital, lack of appetite and other behavioral alterations in its members⁽⁵⁾.

A child's hospitalization in intensive care units causes much pain and disquiet to the family, generating complex

care situations. Currently, care requires a *full care-aimed approach to the child-family binomial; this careful attention includes emotional support for the family*⁽⁶⁾.

Thus, when a child is admitted to a hospital, it is necessary to affirm the child-family bond and to clarify, guide and help family members and especially mothers to deal with problems, conflicts, fears and new responsibilities resulting from the child's hospitalization.

When mothers enter the restricted and foreign PICU environment, nursing professionals must support their actions when caring for children. Nursing professionals must consider mothers as potential clients, starting with a significant and authentic conversational meeting. Mothers must be seen as active participants in the process of taking care of their children; however, they frequently need to be assisted with autonomy, choice and responsibility issues in order to fully experience the situation they are dealing with⁽⁷⁾.

According to this perspective, nursing professionals acting in the pediatric intensive care environment must improve their practices. They must realize that it is crucial to provide humanized care to mothers by responding to their concerns and understanding their special needs, so that they are better equipped to deal with their children's experiences of hospitalization.

THE NURSING HUMANISTIC THEORY OF PATERSON AND ZDERAD

Paterson and Zderad developed the Nursing Humanistic Theory as a method of humanistic nursing practice. The theory arose from the nurses' own existential experiences and their descriptions and concepts of these experiences.

In developing this theory, the authors were influenced by humanist thinkers, phenomenologists and existentialists who *focus on the genuine presence of an authentic dialogue between people* as a way to perceive, detail and appreciate the facts of individual human existence⁽⁸⁾.

The Humanistic Theory is rooted in the holistic model of being and creating health. It attaches great importance to human interests, values and dignity, in contrast to the biomedical Cartesian model that favors the technique, or the do-with⁽⁹⁾.

The Nursing Humanistic Theory points out the relevance of being-with for care practice. It conceptualizes Nursing as an existential experience, a live dialogue emerging from inter-subjective relationships with each unique participant⁽¹⁰⁾.

Humanistic Nursing is guided by the essential aspects of nursing, affirming the phenomena of daily experience wherever they occur. It approaches each and every nursing situation as an instance of private human dialogue in the existential sense.

The Humanistic Theory deals with inter-human events where nurses and patients can consider themselves and the

others as objects, subjects, or anywhere in between. These interactions can be described in terms of the relationship categories and dimensions described by Martin Buber. In the subject-object (I-This) relationship as defined by Buber, one considers the other person as an object – in other words, as a thing possessing a single function or even a clinical case or clinical type. He contrasts this relationship with the subject-subject (I-You) relationship. In a subject-subject relationship, nurses and patients meet as human beings in an intuitive dialogue, maintaining their single identities that are common due to an authentic presence⁽¹⁰⁾.

The importance of the Nursing Humanistic Theory lies in the fact that it can be used to improve and guide practice through a care existentially guided by nurses' authentic commitment. Phenomenological Nursing has a methodological approach based on the dialogue and meeting between those who care and those who are cared for. This approach has no requirements except for the interactive/relational process that defines it.

Phenomenological Nursing conceptualizes the existential appreciation of nursing practice as occurring in five phases (the nurse understanding preparation to achieve knowledge; the nurse intuitively knows the other; the nurse scientifically knows the other; the nurse completely synthesizes known realities; replacing the paradox unit by a multiplicity of meanings as an internal process of nurses)⁽¹⁰⁾. These phases are described by the theories of the Nursing Humanistic Theory and are presented consecutively, although in this study they appear intertwined, as each phase may appear at any stage of the nursing process.

METHOD

This present study is a qualitative research study based on the Nursing Humanistic Theory of Paterson and Zderad. The setting for the investigation was a Pediatric Intensive Care Unit (PICU) of a public hospital in the city of João Pessoa – PB. This setting is used as a reference health structure that combines clinical services in different specialties.

The research was carried out with five mothers of children admitted into this unit. They were chosen for the study because they showed interest in participating. The availability of the mothers was also a selection criterion. Furthermore, it was necessary for their children to be hospitalized for a minimum of one week, so that they could adequately describe the existential experience of being a companion mother. There were no sample criteria that would indicate a specific number of participants. In qualitative research, the sample is selected by criteria *more connected to meaning and to the ability that the sources have to provide reliable and relevant information on the researched theme*⁽¹¹⁾.

Data collection was initiated after the approval of the dissertation project by the Research Ethics Committee, Protocol 0010/07 for the Federal University of Paraíba. The re-

search was evaluated with respect to ethical and legal issues regarding research on human subjects, according to Resolution # 196/96 of the National Council of Health.

Data collection occurred during May, June and July of 2007 in the same location where the child was admitted. This collection occurred in a consistent and amiable environment, allowing an informal dialogue that spontaneously generated the outlines of the participants' report on the proposed questions.

Interviews were recorded electronically. We took care to preserve the mothers' anonymity. The researcher explained the stages of existential experience by analogy with five Holy Spirit gifts.

The empirical data obtained from mothers were qualitatively analyzed within the framework of Humanistic Nursing. The data were interpreted in terms of the five phases of Phenomenological Nursing as applied to the dialogue between the researcher nurse and the mothers of children admitted into intensive care units. These phases are described as follows:

- *The researcher prepares to attain knowledge:* In order to gain access to the subjective experiences of the companion mother, and thus enable unique experiences shared through a live dialogue, the researcher initially sought to recover her own experiences, and tried to acknowledge herself in her uniqueness by reflecting about literary works that describe human nature and different ways of perceiving and relating to the world.

- *The researcher intuitively knows the other:* In this stage of Phenomenological Nursing, the researcher experienced the I-YOU relationship with the companion mother that began with her participation in the study. Initially the researcher listened to mothers talk about various day-to-day subjects, whether or not they were pertinent to nursing practice. Mothers could also be guided to personal and family topics, which are greatly influenced by the health-sickness process.

- *The researcher scientifically knows the other:* In order to enable scientific data collection about mothers and their existential experience as companion mothers, an interview was conducted. It was extended as far as was productive, based on a semi-structured script with questions that led the mothers toward phenomenology.

- *The researcher synthesizes the known realities:* With a view to better analyzing the interviewees' reports, each report and statement was looked at in detail. Thus, a view of the interview compilation as a whole was possible through successive and focused readings of each statement. The following categories of experience were identified for investigation: the relationship experienced between mothers and nursing professionals from the moment of admittance and throughout children's hospitalization into PICU; and mothers experiencing fear, despair and loneliness towards their sickened children.

- *A multiple succession for a paradox unit as the researcher's internal process:* This phase evolved from the description of phenomena experienced by mothers of children admitted into PICU. At this point, the researcher, through reflection upon multiple views, carried out a comprehensive review and expanded her own perceptions by comparing them to the pertinent literature.

DATA PRESENTATION AND ANALYSIS UNDER THE HUMANISTIC THEORY SCOPE

The researcher aimed to identify existential experience in the mothers of children hospitalized at the PICU, emphasizing the mothers' statements. They were considered in terms of the two aforementioned theme categories.

The relationship experienced between mothers and nursing professionals at the moment of admittance and throughout the child's hospitalization into PICU

As children are admitted into the hospital, the companion mothers are also affected by changes and disruptions of their routine⁽¹²⁾. Therefore, an approach that engages mothers in an authentic I-YOU relationship must initiate as from the moment children are admitted into the pediatric intensive care unit.

When describing their interactions with nursing professionals throughout their children's hospitalization, the interviewees appear satisfied. They based their opinion on the way they were treated by the nursing team and the absence of complaints from this team during their difficult stay as the companion of their hospitalized child. Some relevant excerpts are as follows:

They've treated me well [...]. Up till now, they've treated me right. They have no complaints (Advice).

I was very well welcomed! Up till now, I like everything, the treatment. Everything! They are very nice, really nice. They take good care of her (Understanding).

[...] I have no complaints. [...] Here they have the right medication, they have everything. Everything he needs they have here, thank God. The hospital has more possibilities for his treatment; so I felt better. In here he is confident, I am confident that he is being well treated (Mercy).

Mothers clearly report that when they believe their children are being well taken care of, they also consider their own needs to be well provided for. In view of the child's fragile condition, the mothers are concerned with their child's needs, *searching for means that could favor their recovery and survival. [...] In this context, parents [...] set them as a life priority*⁽¹³⁾.

The pediatric hospitalization process mobilizes mothers in favor of the children. They tend to provide for their child's needs at the expense of their own. The nursing team is then required to assume the task of providing for the mother's needs, as described in the previous statements⁽¹²⁾.

The participants in this research also indicated that the care provided for the children must not only be well performed with attention, care and helpfulness, but also must be associated with technical-scientific knowledge. The interviewees describe this by stating that medication was given at the correct time and that there were resources available for the diagnosis and treatment of the children. These aspects, all together, contribute to a quality experience. Mothers' satisfaction is promoted, encouraging them to deal with the hospitalization process in a positive way.

Although participants' statements reveal approval of their relationship with nursing professionals in the pediatric intensive care unit environment, one statement focused our attention on the full exercise of motherhood in the experience of having a child admitted into the PICU. This is reflected in the mother's implicit concern about being a *good girl* during the child's stay in the intensive care services in order to ensure a harmonious relationship that translates into appropriate care.

It is important to emphasize that mothers often feel the need to unburden themselves. They need to share their thoughts about their child's hospitalization experience. However, they prefer not to talk about it, because they fear the nursing team will see them as difficult and annoying mothers⁽¹⁴⁾.

This situation tends to distance the mothers of children admitted into PICU from nursing professionals working in the unit. Mothers worry that they might be seen as a disorganizing factor that could interfere in their child's care, disturbing the treatment; consequently, they feel they must behave appropriately.

A relationship must be established between nursing professionals and the mothers of children admitted into PICU. Based on their interpretation of the experience of having a child admitted to a hospital, this relationship involves being with the other through a lively dialogue that shares understanding of their needs, as stated in the Nursing Humanistic Theory.

Hence, in the PICU scenario, nursing professionals need to be available and accessible to the phenomenon existentially experienced by mothers. They need to understand this intuitively.

Mothers experiencing fear, despair and loneliness while their child's sickness

Having a child admitted to a pediatric intensive care unit is described by mothers as a highly difficult situation; loneliness, despair, and fear are some of the feelings reported by participating mothers.

In the hospital scenario, especially in the pediatric intensive care unit, intense suffering is common and is a recurring issue. Mothers pointed to this fact as they experienced the reality of being a companion mother while their children were being treated in the PICU.

Since they feel responsible for their children's well-being and integrity, they experience guilt for not being able to save their children from the stress resulting from sickness and hospitalization⁽¹⁵⁾.

The following statement demonstrates this suffering as it was experienced by one mother participating in this research.

Oh, I felt really bad. Really bad, it seemed as my world had ended [...]. I even came here, saw the suffering, how difficult it was to get her sedated, and the part that mostly affected me was when the doctor called me and said that her problem was very serious, that in the future, she could have brain death due to convulsion time, that really swept me away (Strength).

As they follow their child's sickness and hospitalization, mothers suffer from the severity of their child's medical profile that requires the child to stay in the PICU. Death is a constant presence that generates feelings of loss. Also, invasive interventions to monitor, diagnose and treat the vulnerable children affect the mothers, imposing passiveness on mothers as they patiently watch their children's clinical course.

On the other hand, as the sickness and hospitalization process is shared between mothers and children, parents, mostly mothers, observe invasive procedures that their children are subjected to, generating fear, distress and anxiety, *instead of getting involved in a suffering that is different from reality*⁽¹⁶⁾. Despite the feelings mothers experience while following their child's suffering in the hospital, being-with the child allows them to appreciate the experience.

Mothers' concern about their children's sickness also encompasses the unknown hospital and intensive care unit universe, where strict rules and routines override their once shared family routine. Inability to be with their children in the PICU generates even more fear, a feeling strongly present in the intensive care environment.

One factor emerging broadly from the participants' statements is grief over their children's sickness and therefore fear of death. Although death is our only certainty, we do not accept it since it takes our the loved ones away, and in the case of a child, mothers regard death as a premature and unacceptable reality⁽¹⁷⁾. The following statements report this observation.

[...] I felt a huge despair, very huge [...]. I felt as if I was dying too. So, as if I was to lose her and also..., it's really bad. It is a very sad experience; this was the first time I've been through this, and, in God's name, I don't want to go through it again, never [...] (Understanding).

I was scared when they told me he was coming to the ICU. I was afraid to leave him here alone. [...] I was desperate when I heard he had hemorrhagic 'dengue'. [...] We expect this to happen to anyone, but not with us, when it happens... I felt so down, I was desperate (Mercy).

In addition, the mothers' stay within the limits of the PICU represents an enclosure. They experience feelings of isolation, being restricted not only by the rupture of social

and family living, but also by the physical and functional structure of the PICU, where they lack resources that would normally help them deal with this life crisis situation. The following statements illustrate this:

Well, I don't really like it because I feel imprisoned, but I have to stay because of him. Oh, if only I had TV to watch a movie, you know. Something to entertain, not only to be closed in here. [...] I'm always looking at the walls, when not at the walls, I'm looking at the boy. I feel agony. Like, oh my God, I'm leaving, I'll leave him here [...] Then I regret that and I say: *I won't leave him alone in here; he needs to be fed* [...] I come back, I go out a little bit. (Advice).

[...] Some days, after such a long time in the hospital, you feel like talking, sometimes like crying [...]. (Wisdom).

In this context, the emerging feelings of loneliness are not only related to the limited freedom due to having a sick child that requires special care, but also to the distress of being in a unknown place, torn harshly away from their normal way of life, with their independence restricted, and having to live with strangers.

As described by one of the mothers, under some circumstances, feelings of anxiety give rise to a desire in mothers to abandon the child in the health service. Another triggering issue is the absence of social support networks that can help the mothers deal with the difficulties of the child's sickness and the hospitalization process.

As companions to their children in the hospital, mothers are exposed to situations that promote fear, distress, insecurity, hopelessness, loneliness and a feeling of uselessness. They suffer from uncertainty over what will happen to their children, from worries about the disease and the treatment and from the possibility that something that might go wrong or even that the child's condition might worsen and that they might lose the child⁽¹²⁾.

Therefore, mothers are exposed to a series of stressing issues that generate intense anxiety that may be transferred to their children. This constitutes a communication barrier since

anxious mothers are incapable of appropriately perceiving and providing for their hospitalized children's needs. A fact that damages their relationship, requiring nurses' intervention⁽¹⁸⁾.

The following excerpt illustrates the anxiety experienced by one of the mothers while in the PICU.

[...] Some days you wake up, I say, not well, upset, sometimes with agony, you walk back and forth and find no solution [...] (Wisdom).

In order to relieve the mothers' anxiety, the nursing team must not only know the causes and manifestations, but must also adopt measures to minimize the consequences of this anxiety to the mothers' relationship with nursing professionals⁽¹⁸⁾. Among the measures suggested by the author that can be adopted in the PICU environment

to help minimize the mothers' suffering, the following are worthy of mention:

Accept parents anxiety and their causes; explain procedures and treatments; inform about the health conditions of the child; explain about the disease's causes; teach and encourage mothers to take care of the children; make parents acquainted with the hospital environment; give parents the opportunity to discuss their feelings about hospitalization and their children⁽¹⁸⁾.

In order to care for the family, especially the mothers, we must understand it as a whole, reaching beyond externally revealed experience. To care for the family, the nursing team must capture the internal experiences that reveal the meaning the family attributes to such events⁽¹²⁾. Hence, the nursing team must be aware not only of the mothers' needs regarding their role as mothers, but also of those that emerge in the family arena due to the hospitalization and disease process of their children in the PICU.

FINAL CONSIDERATIONS

Hospitalization is an unpleasant experience. For children, the effects of hospitalization are obvious and harmful. These special beings have few mechanisms to deal with and overcome the stressful experience of being separated from parents and siblings, loss of control related to restrictions and limitations in their motor abilities and body injury due to invasive and painful procedures and exams.

Therefore, sickness and hospitalization constitute a crisis in the life of a child, especially in the pediatric intensive care unit, a restricted, mysterious, and frightening environment, where the presence of the mother is crucial, because mothers are the primary source of security for children.

However, PICU affects not only the sick children, but also alters family routine, especially for mothers, since they are usually the ones that share the health-sickness process experienced by children.

The fact that hospitalization of a child mobilizes so much pain and anxiety in the family, generating complex situations, makes it imperative for healthcare to prioritize both the children and the companions. This care must be humanized care where health professionals, especially nurses, can guide their practice towards coping and resolutions, using a broad approach to address the needs of the mothers who are dealing with a child's suffering.

Genuine, child-mother-centered care is based on the Nursing Humanistic Theory, which enables the professional to acknowledge the phenomenon and to understand the true meaning of the existence of each mother as a companion, and serves as a guideline for nursing care practice for these special individuals.

Scientific knowledge from statements of mothers of children admitted into PICU helps to understand the value

of dialogue between nursing professionals and these special individuals to help the nurse understand the mothers' experience. In other words, the richness in each statement can be observed, acknowledging and revealing the existential experience of each companion mother in this study.

The mothers' statements emphasize their satisfaction with their experience with nursing professionals relating especially to the way their children are treated in the pediatric intensive care environment.

In their statements, mothers have revealed their feelings of loneliness, despair and fear towards the sickness and hospitalization of their children. They refer to the severity of sickness, and the hostile environment of the ICU, with strong associations with suffering and death. Therefore, a mother-centered approach to practice, based on the revelation of an authentic I-YOU relationship, must be initiated at the moment of admittance. Tacit care and understanding that takes into account the mothers' existential

experience must be established, and must continue throughout the hospitalization process.

Subjective knowledge of the emerging phenomenon from the statements of the mothers in this study makes new horizons possible. Humanized nursing care for the companion mothers of their children in PICU must be viewed using a holistic perspective. This perspective contributes to providing care based on the respect for the uniqueness of these women experiencing moments full of suffering over the possibility of losing a beloved child, the uncertainty of returning home, being separated from children no longer under their care, dealing with an unknown environment, and social contact with professionals who see them only as companion mothers of children admitted into the PICU.

This research encourages a new look not only at the patient care field, but also at the scope of nursing research and education to promote humanized relationships between nursing professionals and companion mothers.

REFERENCES

- Litchteneker K, Ferrari RAP. Internação conjunta: opinião da equipe de enfermagem. *Rev Eletrônica Enferm* [periódico na Internet]. 2005 [citado 2006 jul. 3];7(1):[cerca de 10 p.]. Disponível em: http://www.fen.ufg.br/revista/revista7_1/pdf/ORIGINAL_02.pdf
- Santos MEM. A criança e o câncer: desafios de uma prática em psico-oncologia. Recife: A.G. Botelho; 2002.
- Vila VSC, Rossi LA. O significado cultural do cuidado humanizado em Unidade de Terapia Intensiva: "muito falado e pouco vivido". *Rev Lat Am Enferm*. 2002;10(2):137-44.
- Nascimento ER, Trentini M. O cuidado de enfermagem na Unidade de Terapia Intensiva (UTI): teoria humanística de Paterson e Zderad. *Rev Lat Am Enferm*. 2004;12(2): 250-7.
- Pinto JP, Ribeiro CA, Silva CV. Procurando manter o equilíbrio para atender suas demandas e cuidar da criança hospitalizada: a experiência da família. *Rev Lat Am Enferm*. 2005; 13(6):974-81.
- Valle ERM. Dor psíquica: significados do cuidar de um filho com câncer. In: Angerami-Camon VA, editor. *Psicossomática e a psicologia da dor*. São Paulo: Pioneira; 2001. p. 53-61.
- Barbosa ECV, Rodrigues BMD. Humanização nas relações com a família: um desafio para a enfermagem em UTI pediátrica. *Acta Scient Health Scienc*. 2004;26(1):205-12.
- Rolim KMC, Pagliuca LMF, Cardoso MVLM. Análise da teoria humanística e a relação interpessoal do enfermeiro no cuidado ao recém-nascido. *Rev Lat Am Enferm*. 2005;13(3): 432-40.
- Schaurich D, Padoin SMM. Experienciando um marco conceitual para o cuidado em enfermagem ao ser-familiar e/ou cuidador e ao ser-criança. *Cogitare Enferm* [periódico na Internet]. 2003 [citado 2006 jul. 3];8(2):[cerca de 10 p.]. Disponível em: <http://calvados.c3sl.ufpr.br/ojs2/index.php/cogitare/issue/view/192>.
- Paterson JG, Zderad LT. *Enfermería humanística*. México: Editorial Limusa; 1979.
- Duarte J. Entrevista em profundidade. In: Duarte J, Barros A. *Métodos e técnicas de pesquisa em comunicação*. São Paulo: Atlas; 2006. p. 62-83.
- Oliveira I, Angelo M. Vivenciando com o filho uma passagem difícil e reveladora: a experiência da mãe acompanhante. *Rev Esc Enferm USP*. 2000;34(2):202-8.
- Caetano LC, Scochi CGS, Ângelo M. Vivendo no método canguru a tríade mãe-filho-família. *Rev Lat Am Enferm*. 2005;13(4):562-8.
- Bouso RS, Angelo M. Buscando preservar a integridade da unidade familiar: a família vivendo a experiência de ter um filho na UTI. *Rev Esc Enferm USP*. 2001;35(2):172-9.
- Rodrigues AS, Jorge MSB, Morais APP. Eu e meu filho hospitalizado: concepção de mães. *Rev RENE*. 2005;6(3):87-94.
- Souza ABGS, Angelo M. Buscando uma chance para o filho vir a ser: a experiência do pai na UTI. *Rev Esc Enferm USP*. 1999;33(3):255-64.
- Pettengill MAM, Angelo M. Identificação da vulnerabilidade da família na prática clínica. *Rev Esc Enferm USP*. 2006;40(2):280-5.
- Borba RIH. Participação dos pais na assistência à criança hospitalizada. In: Chaud MN, Peterlini MAS, Harada MJCS, Pereira SR, editoras. *O cotidiano da prática de enfermagem em pediatria*. São Paulo: Atheneu; 1999. p.11-4.