Esc Anna Nery 2014;18(1):60-67

Importance attributed to the social support network by mothers with children in an intensive care unit

Importância atribuida à rede de suporte social por mães com filhos em unidade intensiva

Importancia atribuida a la red de soporte social por madres con hijos en unidad intensiva

Rosemeire Cristina Moretto Molina[1]
Ieda Harumi Higarashi[1]
Sonia Silva Marcon[1]

1. Universidade estadual de Maringá. Maringá - PR, Brazil.

Abstract

This qualitative descriptive study was carried out with six mothers of children hospitalized in a Pediatric Intensive Care Unit (PICU), with the aim of identifying the role of the social network for them. The data was collected through observation and semi-structured interviews. Two categories emerged from the analysis of the data. First, the sharing of experiences as a mechanism of coping with pain and suffering, and second the support of the family in the hospitalization of the child. The results demonstrate the importance of the social support network, with emphasis on the family support and the network formed by the mothers of the hospitalized children. It was concluded that the encouragement of support groups consisting of mothers/caregivers of children hospitalized in the PICU is an essential strategy to cope with this difficult period in life. This is all the more important when these women cannot count on a social support network outside the hospital.

Keywords: Social Support; Intensive Care Unit; Family; Child Health.

Resumo

Pesquisa descritiva de natureza qualitativa, realizada com seis mães de crianças internadas em Unidade de Terapia Intensiva Pediátrica (UTIP), objetivando apreender a importância da rede social para elas. Os dados foram coletados por meio de observação participante e entrevistas semiestruturadas. Da análise dos dados emergiram duas categorias: O compartilhar de experiências como mecanismo de enfrentamento da dor e do sofrimento e o Opoio da família nuclear, extensa e de outras pessoas durante a hospitalização da criança. Os resultados demonstraram a importância da rede social de apoio, com ênfase ao apoio familiar e à rede formada entre as mães das crianças internadas. Conclui-se que estimular a formação de grupos de apoio entre mães/cuidadoras de crianças internadas em UTIP, incluindo seus familiares, constitui estratégia essencial ao enfrentamento deste momento difícil da vida, especialmente nos casos em que estas mulheres não podem contar com uma rede social de apoio fora do hospital.

Palavras-chave: Apoio social; Unidades de terapia intensiva; Família; Saúde da criança.

Resumen

Investigación descriptiva de naturaleza cualitativa, realizada junto a seis madres de niños internados en una Unidad de Cuidados Intensivos Pediátrica (UCIP), para identificar la importancia de la rede social para ellas. Los datos fueron recolectados por medio de observación participante y entrevistas semiestructuradas. De su análisis, emergieron dos categorías: el compartir de experiencias como herramienta de enfrentamiento del dolor y del sufrimiento; y el apoyo de la familia en la hospitalización del niño. Los resultados demostraron la importancia de la red social de apoyo, con énfasis al apoyo familiar y a la red formada entre las madres de los niños internados. Se concluye que estimular la formación de grupos de apoyo entre madres/cuidadoras de niños internados en UCIP se constituye como estrategia esencial al enfrentamiento de este momento difícil, especialmente en los casos en que estas mujeres no pueden contar con una red social de apoyo fuera del hospital.

Palabras-clave: Apoyo Social; Unidad de Cuidados Intensivos; Familia; Salud del Niño.

Corresponding Author:
Rosemeire Cristina Moretto Molina.
E-mail: rcmmolina@uem.br

Submitted on 06/20/2012.
Resubmitted on 10/18/2012.
Accepted on 06/20/2013.

DOI: 10.5935/1414-8145.20140009

INTRODUCTION

Hospitalization is both a critical and delicate situation in everyone's life and even more so when it is a child. The family routine is affected and in particular that of the mother, who is generally the main caregiver of the child[1].

This unique situation in the life of the mother and child is characterized by doubt and uncertainty. It can often also cause psychological distress to the woman, who frequently enters the hospital world and has to deal with the child's hospitalization alone.

By prioritizing their presence with the hospitalized child, it is common for the mothers to distance themselves from their other duties. These include being a woman, partner, worker, daughter, and mother to other children and they become, almost exclusively, the mother of a sick child that requires hospital care. This situation is one of conflict, characterized by moments of suffering and loneliness for the mother. Accordingly, given the demands of staying in the hospital environment, the mother has to deal with a new routine and try to find ways of coping and adapting to the new situation. As a result they often establish bonds with other mothers who are going through similar experiences[2].

The behavior and feelings of internal conflict that the mother develops commonly emerge in response to the trial of going through a particularly difficult time in her life. In these cases the support of close and caring people, who understand her, can give her the courage and hope to cope throughout the process of illness and hospitalization of the child. In other words, this relationship is established by different social agents who, in some way, offer support to the family and the individual, in order to minimize their suffering, thus contributing to the improvement in their quality of life[3].

The support received by a person, in order to overcome difficult situations that life creates can be of different types: a) instrumental, which consists of both symbolic and material help; b) emotional which includes affection and admiration; c) affirmation that consists of certain behavior, perceptions and values); and d) information and guidance support[3].

At some point in life and in some way people seek some type of support to help them to overcome their personal difficulties. One such example would be the experience of having a child admitted to hospital, especially when the child is in a critical state of health and requires treatment in an ICU[4].

The Pediatric Intensive Care Units (PICUs) are sectors created to offer complex care to children at imminent risk of death. Despite its importance, the cold and hostile environment that characterizes such units is commonly associated with irreparable trauma for the child and their entire family. This is due to the culturally constructed idea of the association between the ICU and the concepts of death, pain and suffering. For the majority of people who enter these units for the first time, the feelings of fear and anguish are only averted through the support found within their social support networks, whether pre-existing or constructed during the experience of hospitalization[4].

A social support network is understood as the sum of all the relationships that an individual perceives as significant or different from the rest of society. It is considered as a type of third field of kinship, friendship, and social class. It is a social circle that consists of traces of affinity, and forms a network that brings people together[4]. Many of these support networks are formed within the hospital, as members of families come to share the same environment, as well as experiences and suffering related to the disease process. This is a way of maintaining their dignity[4].

With these support networks consisting of diverse people, amongst them are the mothers of the hospitalized children and the healthcare professionals who interact and unite in order to support the family in dealing the illness of the child. Nursing professionals are therefore part of the support network constructed in the hospital environment and can contribute positively to this unique experience in the life of the children and their parents, seeking ways of helping them and/or making it possible for them to benefit from their own support network[5].

In order to reveal some aspects of this theme, the aim of the study was to understand the importance that mothers, accompanying the hospitalization of their children in the PICU, attach to the social support networks formed inside and outside the hospital, and how these support networks help the mothers overcome their difficulties during the hospitalization of the child.

METHOD

This descriptive study has a qualitative approach and incorporates a Master's dissertation in Nursing. It was developed in order to understand the feelings, difficulties and ease experienced by mothers of children admitted to the PICU, as well as the process of their integration into the care of the hospitalized child.

The methodological framework used in the implementation of the proposal was that of Convergent Care Research[6]. Convergent Care Research is a type of field study that maintains a close relationship with the care practice throughout the process and aims to find alternatives to solve or minimize problems and to make changes and introduce innovations in the practice. Thus, this type of research is committed to directly improving the social context studied[6]. The theoretical framework used in the interpretation of the results was the Transcultural Care Theory of Madeleine Leininger[7]. This was due to the need to better understand the beliefs and cultural values of the mothers in order to foster the development of a relationship based on respect, comprehension and mutual trust.

The study was conducted in the PICU of the University Hospital of Maringá-Paraná (HUM), with six mothers who had children that were admitted to this unit and met the following

inclusion criteria: to be a mother and primary caregiver of a child that had been hospitalized for at least five days, and to be available and interested in participating in the study. Data collection took place from January to May 2007 through two semi-structured interviews. One interview was performed at the beginning and the other at the end of introduction of the mother into the care environment. For this purpose, a script with a variety of questions was prepared by the researcher based on the aims of the study. It was evaluated for content and clarity by two professors in the family and child health area. The interview questions sought to identify both the difficulties and ease encountered by mothers throughout the process of their introduction to the care plan. This will support the nurse in dealing with difficulties and answering questions from the mother, with the aim of adequately preparing them for discharge. Within this approach, the mothers were asked about the aspects that were helping or hindering them during this very difficult time. They were also asked about how these events occurred, in order to demonstrate the makeup of their social support networks. In addition, participant observation was used throughout the whole process. On average seven meetings with each mother took place, in which they were encouraged to speak freely about various topics. The recording of observational data, as well as the researcher's reflections, were made in a field diary shortly after the end of each meeting.

Thematic content analysis[8] was used to achieve an understanding of how a mother who has a child admitted to the PICU perceives the role and importance of their social support network. The implementation is by means of encoding the text and breaking it down into parts. This is followed by analogically grouping the extracts to form thematic categories that express the results according to the proposed inquiry. The findings, the statements of the subjects and the daily records were analyzed to identify the more common and frequently used meanings, as well as the singular discourses with high relevance. In the presentation of the results, the mothers and their children are identified using names of flowers. This format ensures, among other things, that the identities of the research subjects are preserved and that their participation met the requirements of Res196/96-CNS, for research involving humans. It should be noted that the project of the study was approved by the Human Research Ethics Committee of the State University of Maringá (Protocol Nº 389/2006). Clarification of the way the study was to be conducted was sent to the mothers with the invitation to participate. The mothers signed two copies of the terms of free prior informed consent.

RESULTS AND DISCUSSION

The six mothers in the study were relatively young. Their ages ranged between 16 and 37 years and they had between one and five children. Four of them were married and five were housewives. All were from low income families (family income between one and two minimum wages) that consisted of between three and seven people. There were four nuclear families (parents and children). Among the children, only Kalanchoe, ten years of age, and Sunflower, one year and five months, presented acute conditions. All the others were experiencing chronic conditions. Two of the children were less than six months of age and had been in the ICU since birth, and two, who were approximately one and a half years of age, had been previously admitted to the hospital on various occasions. From the data analysis two main themes emerged that will be discussed in depth: a) The sharing of experiences as a coping mechanism for pain and suffering, and b) the participation of the family during the hospitalization of the child.

The Sharing of experiences: a mechanism for coping with pain and suffering

During a long hospital stay, mothers create different strategies to overcome the suffering caused by the illness of the child. They begin to make contact with other mothers and almost instinctively create bonds of friendship and solidarity. Through this solidarity they begin to sympathize with one another, while at the same time seeking to comfort each other. This way, the mothers construct a common support network so they can get through this painful period of hospitalization of their children together. This process of mutual support and comfort, which is very evident in the group of mothers who accompany their children in the unit, also extends to the mothers of children newly admitted to the unit.

This situation can be illustrated by the behavior of Tulip who has been with her child in the PICU for a long time. She was always receptive and willing to talk to the parents of children newly admitted to the unit to order to ease their anxiety.

> *The parents that arrive with their children in the ICU are terrified, so I say to them: Calm down, what is wrong with your child? I say something like that and it calms them down a little and that shows them it is not as serious as we think. Then they are a little calmer. To say something is one thing, but in practice it is different (Tulip).*

Other studies confirm that this habitual behavior of solidarity and support shown to the newly arrived families or those who have been in hospital for less time is a means of facilitating adaptation, and encouraging them to deal with the situation through the sharing of common experiences and suffering[5]. As the following statement reveals:

> *[...] I realized that it wasn't only me that had this problem and that in the hospital they were many mothers going through the same thing as me. We hear a lot of stories. A baby weighing very little was born but left the hospital, went home and started to put on weight. This reassures*

us and gives us hope that our child is going to start to get better (Hydrangea).

Mutual support is a strategy that can consequently lead to the development of new expectations, and reinforce hope in difficult situations[2]. The offer of support can also be configured as a useful space for the transfer of important information and for sharing knowledge from the experiences in the ICU.

There could be another child with the same problem. If the mother is nearby, I say to her: Don´t do that because it isn't good. I share what I have learnt with the other mothers. I want to tell them about everything I have learnt. Share what I know. Because I can see my daughter suffer and I don't want to see other children suffering the same as Christmas flower or other mothers suffering the same as me (Primrose, the mother of Christmas flower).

The communal suffering of the mothers in this environment appears as the main driving force for constructing a network of solidarity and good relationships that are strengthened through the adversity and needs that punctuate the histories of these families. Throughout the period of hospitalization of their children in the PICU and the pediatric ward, Primrose and Amaryllis supported each other as they spent a lot of time together. With the readmission of her child to the PICU, Amaryllis asked the nursing staff about Primrose, as the following extract from the field diary reveals:

Have you seen Primrose? I miss her. We arranged to go to each other's houses, but Pansy had to be hospitalized. Does she know that my son has been hospitalized again? (Amaryllis, mother of Pansy).

It can be observed that even during long periods of hospitalization in the ICU, and faced with the inherent difficulties of such a situation, bonds of friendship are created between the mothers. This is due to the fact that they tend to look after each other, sharing positive experiences in order to strengthen their hope each day. In these cases, the solidarity is striking, reinforcing affections and experiences for the rest of the life[2,9].

Almost all the mothers made friends with each other in the PICU and had meals together, leaving the PICU to relax and chat. Rose, however, could not establish such a relationship during the hospitalization of her son. Instead, she was always sad and depressed, appeared very tired, and would only talk and play with her child. The team encouraged her to get to know the other mothers, however, the attempts were in vain. She remained lonely and introspective, wrapped up in the severity of the illness of her child.

Some women experience the suffering of their child intensely and are unable to give anything else their attention. In these cases the commitment to the child is of such magnitude that the mother even ignores her own necessities. Basic routines such as eating, sleeping and resting are interrupted by the task of looking after the child. This exclusive dedication inevitably ends up creating constant tension. As a result greater psychological distress is caused which is characterized by intense feelings of sadness, despair, anxiety and nervousness[10].

Living with these feelings on a daily basis can affect the mother's comprehension of the treatment measures employed by the healthcare team for the child that is in a critical state. This increases maternal emotional distress, making the job of monitoring the child in the ICU even more difficult[11].

Providing information to the family about the health-disease process of the child is a task that must be incorporated into the care practice quotidian. Nurses need to develop the necessary skills to perform this activity, in order to encourage and assist families in acquiring an appropriate level of autonomy and control of the situation. It is well known that when communication between the nursing team and family is efficient it is possible to reduce the anxiety that is associated with the hospital stay. This contributes to the acceptance and involvement of the parents in the care of the child, both at home and in the hospital. In turn this contributes to the adherence to the treatment, favoring the process of coping with the illness and its inherent necessities, as well as improving the overall development of both the sick child and the family. By giving the family information about the health-disease process of their child, the mother is effectively included in the care together with the hospitalized child. Autonomy is given to her to carry out simple and gradually more complex tasks, which encourages and motivates her to stay with her child. These actions should be incorporated in the care practice quotidian.

The nursing team needs to comprehend that the family of a hospitalized child is also heavily affected by events and that they also need to receive individualized care. However, it is essential for the nurses to develop skills and abilities that allow them to identify the real needs of the family before they make any necessary interventions. Continuous and effective communication has to be established in order to encourage and assist the family to acquire appropriate levels of autonomy, allowing them to make choices and informed decisions, and to participate more actively in the care process.

Effective communication between healthcare professionals and the family can reduce the anxiety that comes with the hospitalization of a child. This favors the process of coping with the illness and its inherent necessities and increases the acceptance and involvement of the parents in the care to their child, both in the hospital and at home. Factors, such as the permanence of the nursing team in the PICU, the practice of these professionals in the direct care to the hospitalized pediatric patients, and the educative-care profile of the practice of the

nursing professional, make the nursing team the most qualified for the role of protagonist in the provision of humanized care to the child and family. Therefore, these are the most qualified professionals for recognizing and strengthening the family support networks of families in these situations. This could be by encouraging the participation of other members of the immediate and extended family in the therapeutic process, or by forming groups of parents and families in order to share experiences and to carry out activities of specific guidance and health education.

The support of the immediate and extended family and other people during the hospitalization of the child

All of the mothers in the study reported the existence of family support, which was provided on different levels outside of the hospital environment. For these mothers, the family constituted an important space within the social support network. It was with their family that they were able to renew their energy in the fight for the lives of their children. Tulip, for example, revealed that the support she received from Carnation, her husband, was extremely important. It was he who looked after the children that remained at home by feeding them and taking care of the domestic tasks. He also took it in turns with his wife to accompany the child in the ICU. Moreover, Carnation was the sole provider of the family. Tulip, in turn, offered emotional support to him in moments of sadness and discouragement knowing that the burden of the hospitalization of their daughter and the disruption to the family routine would become too heavy for both of them. The mutual support between the partners in this couple was crucial for both of them to cope with the burden imposed by the illness and hospitalization of their daughter.

The comprehension, affection, esteem, companionship, advice, practical help, emotional support and solidarity in the relationship between family members, especially between spouses, acts as a revitalizing source for the mothers and can be understood as a way of helping them to learn and prioritize the care of their child[11]. Other support cited by the families was the maternal extended family, mainly represented by the figure of the grandmother:

> *My mother helped me a lot: While I'm at the hospital my mother looks after my daughters. She keeps me going. (Amaryllis)*

For some women, their mothers represented the family support, and perhaps there are no better people in the world to provide any kind of help in different situations, especially those related to family life, even more so when comes to the care of children[12]. In addition to their own mothers, sisters provided very important support for the participants in this study:

> *[...] My mother and sister helped me a lot. They understand me and know that I'm suffering. (Hydrangea, mother of Angelica)*

Despite the reports of family support and comprehension, the contexts of each family and how the various members relate to each other and with the extended family forcefully influence the quality of the support in crisis situations. Thus, not all the women who experienced the hospitalization of the child in the PICU received the desired support of their friends and/or their extended family:

> *[...] My husband is supporting me now. In the beginning he wasn´t supporting me at all and we just fought. Now he is supporting me but in the beginning it was my mother-in-law who supported me. I think it was her advice that we shouldn´t fight and that we had to stay together during this time. (Primrose)*

It is interesting to observe how the illness generally constitutes an external element that enters the family, promoting a change in its dynamics and interpersonal relationships. This is because the whole family is affected by the illness, and the pain and sadness generated by the suffering can distance people as much as bring them closer together[13].

When conflict already exists in a marriage the emergence of an illness in the family can require even greater adjustment from the couple. This is because, in the majority of cases, the father tends to be more distant and, while he contributes with economic support (instrumental), he does not communicate with the nursing team and finds it difficult to express his support to the mother. This is explained by the capacity that an event of this nature can have in triggering an emotional imbalance. All members of a household can be affected however, it is the parents in particular who suffer the most when the patient is a child[14].

Added to this is the fact that, with the distancing from the family, the woman can feel cut off from her relationships with her other children and partner, which makes her even more sensitive and fragile during the hospitalization of the child[2].

Another obstacle faced by the family accompanying the hospitalization of a child in the ICU is the distancing between them and other family members. Such behavior may reflect in a specific difficulty for people in the extended family in coping with the feelings of fear or abnormality of the new situation. This may be associated with the view held by the majority of the population that the ICU is a place of suffering and loss[4].

The following statement corroborates this idea:

> *[...] To be honest, my family doesn't help me out in general. My mother just asks, but doesn't come and visit. She only wants to hear the news. (Primrose)*

Despite the pain that this type of behavior can cause parents of hospitalized children and the sense of abandonment experienced, it must be noted that this type of behavior is not always related to the lack of interest of the extended family. By

taking this into consideration, ways of working through these coping difficulties, with appropriate professional support to all involved, must be considered. By doing so, these situations are transformed into opportunities for learning and incorporating new skills to deal with the situation.

As well as being synonymous with death, for some people the ICU is an inappropriate place to visit, as they may believe that their presence there could be harmful to the child, due to the emotional imbalance they are experiencing[4].

These people need to understand that a hospital visit can represent a time or ability to provide new stimuli for the hospitalized child, as well as an expression of solidarity and support for the parents. In fact, in this moment of exacerbated weakness, the support received is something very striking and representative for the mother, especially when their family members demonstrate their ability to perceive her material, physical and emotional needs and are willing to ease the maternal suffering with constant support.

> *[...] Daffodil's family helps me a lot, they come to visit the baby, help us to get here, give us money, ask how Christmas flower is, they all want to know, so I think they are more concerned [...] (Primrose).*

During the most difficult times, the presence of a family member means the anxieties related to the hospitalization and care of the child can be shared[15].

The concept of family can vary greatly from person to person. This differentiation can also be influenced by the moment and the difficulties experienced by each individual. It is when family bonds, are in fact put to the test. However, for Rose, a quiet and reserved mother, the family concept was different. After several meetings it became clear her contact was restricted to her children. This mother talked of living an isolated and solitary life with little contact with her extended family, due to having a difficult relationship with her father. However, she said that she had sometimes received instrumental and emotional support from her mother, with whom she had a good relationship:

> *[...] I have a lot of resentment of my father. My mother is nice. She helps me with money. Sometimes I talk with her to get things off my chest. My mother and sister are looking after my other children because I am here with Kalachoe. This is, however against my father's will. To be honest, my family is just me and my children (Rose).*

Some mothers can feel a conflict of emotions as they stay with their child in the hospital. It is not uncommon for them to feel torn between looking after the hospitalized child and the rest of the family. This situation can be exacerbated when there is no support and comprehension from the immediate and extended family. Due to their different perceptions of the situation they are unable to recognize the need the mother has to remain at the hospital with the sick child[2].

The professional nurse must be aware of both the intra and extra relationships to fully understand and care for the family. This is because a serious illness that a child suffers can weaken bonds that have previously been established. This can generate feelings and situations in which the entire family interaction network is destabilized[16].

From this perspective, the professional should always be attentive to the multiple configurations of the family members and the other people within the social circle of the mothers of children admitted to the ICU. This knowledge of any particularities, strengths and weaknesses in the relationships will assist in the choice of the best approach and the possibilities of individualizing the support to be offered by the multidisciplinary team, especially the nurse, to each child and family:

> *[...] I love my younger sister. She is my half sister on my mother's side, but we get along really well, actually my family is very affectionate. My grandmother, mother, uncle, all have great affection for one another. My sister is caring for my son for me. She is very responsible... When my bosses found out that my son was in the PICU they told me to go and stay with him. They have been nice but I don't know if I will return to work... My husband stays with him in the ward so I can rest because I am here the whole day [...] Orchid.*

The previous statement consolidates the observation that there are various people who offer support to the family and the individual throughout their life, especially in times of crisis, such as in cases of illness, hospitalization or death. These people can be highlighted as blood and close relatives or old friends, as well as work colleagues, neighbors and healthcare professionals, among the people without family ties. This collective group of individuals who form the core of the family relationships can help in several ways: They can provide material or financial support, perform the household chores, take care of the children who stay at home, and give information or offer emotional support. This all helps to alleviate the family suffering and improve the quality of life of the child[3].

There are still situations in which the nursing staff can constitute the main source of support to the family. They can fill the void with emotional support, information, comfort, and security[15].

However, due to the actual demands of humanized and integral care for pediatric patients, the key role of the acceptance of the child and the family must be taken into

account, with actions aimed towards the recovery and strengthening of the family, recognizing in this group, the human group whose original premise is the protection and maintenance of life of its members, their psychic development and the learning of the social interaction[17].

It can therefore be comprehended that the family still constitutes the primary social support network for mothers seeking support during the hospitalization of their child in the ICU[18]. It can be a source of revitalization for the mother and a place where she seeks psychic, emotional, material, spiritual and instrumental energy that helps her to continue the fight for the survival of the critically ill child. Furthermore, the importance of the support network outside the family cannot be ignored, which provides support not only for the mother but for other family members allowing them to act more effectively.

In times of crisis, such as the onset of an illness, the family can generally count on an external support network, which may consist of friends, neighbors, co-workers, family members of other sick children, and members of the healthcare institutions and religious communities. The support provided by this network is highly significant and can make the difference in how the family deals with the illness of the child[14]. This is because it provides support not only to the mother but also to other family members, allowing them to act more effectively together with the mothers.

FINAL CONSIDERATIONS

The hospitalization of a child in an intensive care unit is a situation that causes distress, anxiety and stress, which affects both the child and the parents as they are faced with the prospect of losing the most precious thing they have.

Parents who have experienced the trauma of the hospitalization of a child can provide essential support to other parents who are entering this world for the first time. They can help others to cope with the fears that are very much part of this experience.

This study illustrates the importance of the support that mothers of children hospitalized in the PICU can offer to the mothers of newly hospitalized children, who are often frightened and inconsolable due to their child's illness. The sharing of these experiences in coping with situations of psychological distress, through mutual support, leads to a strengthening of affection and friendship bonds. This is particularly important in cases where, due to distance or absence, the mothers-carers cannot count on the support of their families.

It is a fact that the responses of the mothers to the various support strategies offered are different, as are the various family and social support network configurations for the hospitalized children. The behavior of the mothers faced with the illness and hospitalization process of their children, whether seeking isolation and exclusively dedicating themselves to the care of the child, or seeking sources of support within or outside the hospital, should be the basis for the action of the healthcare professionals, paying attention to the different realities that surround the everyday experience of these families. Accordingly, the present study provides evidence of the multiplicity of different realities of the families of hospitalized children. In addition it demonstrates the key role played by the spouse, by the extended families, and by the social support networks in providing emotional, operational and material support for coping with the situation.

It is nurses who have the important role of encouraging the formation and strengthening of social support networks between mothers and/or caregivers within the PICU. It is these mechanisms that help the women to overcome these difficult times in their lives with more confidence and serenity, transforming the care spaces into spaces of humanity and of the construction of practices based on solidarity.

REFERENCES

1. Faquiello P, Higarashi IH, Marcon SS. O atendimento humanizado em unidade pediátrica: percepção do acompanhante da criança hospitalizada. Texto & contexto enferm. 2007 out/dez;16(4):609-16.
2. Ditty ES, Mota JAC, Sena RR. O cotidiano no alojamento materno, das mães de crianças internadas em uma unidade de terapia intensiva neonatal. Rev. bras. saude mater. infant. 2008 jan/mar;8(1):75-81.
3. Hayakawa LY, Marcon SS, Higarashi IH, Waidman MAP. Rede social de apoio à família de crianças internadas em uma unidade de terapia intensiva pediátrica. Rev. bras. enferm. 2010 mai/jun;63(3):440-5.
4. Molina RCM, Fonseca EL, Waidman MAP, Marcon SS. A percepção da família sobre sua presença em uma unidade de terapia intensiva pediátrica e neonatal. Rev. Esc. Enferm. USP. 2009 set;43(3):627-34.
5. Gomes GC, Pintanel AC, Strasburg AC, Erdmann AL. O apoio social ao familiar cuidador durante a internação hospitalar da criança. Rev. enferm. UERJ. 2011 jan/mar;19(1):64-9.
6. Trentini M, Paim L. Pesquisa convergente assistencial: um desenho que une o fazer e o pensar na prática assistencial em Saúde-Enfermagem. 2ª ed. Florianópolis(SC): Insular; 2004.
7. Leininger M. Transcultural nursing: concepts, theories, research and practice. New York (USA): John Wiley; 1978.
8. Bardin L. Análise de conteúdo. Trad. Luis Antero Reto e Augusto Pinheiro. Lisboa (POR): Edições 70; 2010.
9. Araújo de BBM, Rodrigues BMRD. Vivências e perspectivas maternas na internação do filho prematuro em unidade de tratamento intensivo neonatal. Rev. Esc. Enferm. USP. 2010 dez;44(4):865-72.
10. Milanesi K Collet N. Sofrimento psíquico da família de crianças hospitalizadas. Rev. bras. enferm. 2006 nov/dez;59(6):769-74.
11. Costa JB, Mombelli MA, Marcon SS. Avaliação do sofrimento psíquico da mãe acompanhante em alojamento conjunto pediátrico. Estud. psicol. 2009 jul/set;26(3):317-25.
12. Jussani NC, Serafim D, Marcon SS. Rede social durante a expansão da família. Rev. bras. enferm. 2007 mar/abr;60(2):184-9.
13. Sanchez KOL, Ferreira NMLA, Dupas G, Costa DB. Apoio social à família do paciente com câncer: identificando caminhos e direções. Rev. bras. enferm. 2010 mar/abr;63(2):290-9.

14. Araújo YB de, Reichert APS, Oliveira BRG de, Collet N. Rede e apoio social de famílias de crianças com doença crônica:revisão integrativa. Cienc. cuid. saude. 2011 out/dez;10(4):853-60.
15. Strasbug AC, Pintanel AC, Gomes GC, Mota MS. Cuidado de enfermagem a crianças hospitalizadas: percepções de mães acompanhantes. Rev. enferm. UERJ. 2011 abr/jun;19(2): 262-7.
16. Di Primio AO, Schwartz E, Bielemann VLM, Burille A, Zillmer JGV, Feijó AM. Rede social e vínculos apoiadores das famílias de crianças com câncer. Texto & contexto enferm. 2010 abr/jun;19(2):234-42.
17. Schaurich D, Padoin SMM, Paula CC, Motta MGC. Utilização da teoria humanística de Peterson e Zderad como possibilidade de prática em enfermagem pediátrica. Esc. Anna Nery. 2005 ago;9(2):265-70.
18. Morais GSN, Costa SFG. Experiência existencial de mães de crianças hospitalizadas em unidade de terapia intensiva pediátrica. Rev. Esc. Enferm. USP. 2009 jul/set;43(3):639-46.