

Support systems in the pediatric intensive therapy unit: family perspective

Sistemas de apoio na unidade de terapia intensiva pediátrica: perspectiva dos familiares
Sistemas de apoyo en la unidad de cuidados intensivos pediátrica: perspectiva de los familiares

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ABSTRACT

Objective: to identify and to analyze the support systems used by family members for the adaptation process to the child's hospitalization in the intensive care unit. **Method:** qualitative research, conducted in a hospital located in the Southern Brazil. Data were collected between June and July 2017, through semi-structured interviews with family members of hospitalized children. The adaptation model and thematic analysis were used for data processing. **Results:** four themes emerged: family and friends as a support system; the family members of other hospitalized children as a support system; spirituality as a support system; health team as a support system. **Final considerations:** identifying the support systems used in the process of family adaptation and their manifestations of interdependence was possible. The need of the nurses to intensify the listening to strengthen the support system of the family members of the children hospitalized in the unit studied.

Descriptors: Intensive Care Units, Pediatric; Family; Hospitalization; Psychosocial Support Systems; Pediatric Nursing.

RESUMO

Objetivo: identificar e analisar os sistemas de apoio utilizados pelos familiares para o processo de adaptação à internação da criança na unidade de terapia intensiva. **Métodos:** pesquisa qualitativa, realizada em um hospital localizado na região Sul do Brasil. Coletaram-se os dados entre junho e julho de 2017, por meio de entrevista semiestruturada com familiares de crianças internadas. Para tratamento dos dados utilizou-se o modelo de adaptação e análise temática. **Resultados:** emergiram quatro temas: a família e os amigos como sistema de apoio; os componentes familiares de outras crianças internadas como sistema de apoio; a espiritualidade como sistema de apoio; a equipe de saúde como sistema de apoio. **Considerações finais:** foi possível identificar os sistemas de apoio utilizados no processo de adaptação familiar e suas manifestações de interdependência. Evidenciou-se a necessidade de os enfermeiros intensificarem a escuta visando fortalecer o sistema de apoio dos familiares das crianças internadas na unidade estudada.

Descritores: Unidade de Terapia Intensiva Pediátrica; Família; Hospitalização; Sistemas de Apoio Psicossocial; Enfermagem Pediátrica.

RESUMEN

Objetivo: identificar y evaluar los sistemas de apoyo utilizados por los familiares en el proceso de adaptación a la hospitalización del niño en la unidad de cuidados intensivos. **Métodos:** investigación cualitativa, realizada en un hospital ubicado en la región Sur de Brasil. Se recogieron los datos entre junio y julio de 2017, mediante entrevista semiestructurada aplicada a familiares de niños hospitalizados. En el análisis de datos se utilizó el modelo de adaptación y análisis temático. **Resultados:** surgieron cuatro temas: la familia y los amigos como sistema de apoyo; los componentes familiares de otros niños hospitalizados como sistema de apoyo; la espiritualidad como sistema de apoyo; y el personal de salud como sistema de apoyo. **Consideraciones finales:** se pudo identificar los sistemas de apoyo utilizados en el proceso de adaptación familiar y sus manifestaciones de interdependencia. Se destaca la necesidad que tienen los enfermeros de intensificar la escucha con el fin de fortalecer el sistema de apoyo de los familiares de niños hospitalizados en la unidad estudiada.

Descriptor: Unidades de Cuidado Intensivo Pediátrico; Familia; Hospitalización; Sistemas de Apoyo Psicossocial; Enfermería Pediátrica.

INTRODUCTION

The hospitalization of a child in the Pediatric Intensive Care Unit (PICU) causes family members a strong impact on daily life, because all dreams are forgotten at that moment and what remains of life is transformed into fear, considering the serious condition of the child⁽¹⁾. In this context, to help in the family member's adaptation to the hospitalization of the child in a PICU, building a support system is necessary. This system can minimize the effects of the hospitalization process so that family members do not feel alone, but supported, and may also express their support to other people who experience the same situation⁽²⁾.

The support system is understood as the sum of all the relationships that the individual perceives as significant within society, being considered a third field of kinship, friendship, social class – a social circle consisting of affinity traces, forming an invisible web that unites people⁽³⁾. The support systems involve the will and the ability to love, respect and value people. Thus, by accepting and responding to the love, respect, and value attributed by others, the person who has a comfortable interdependence balance feels adequate and confident, being able to offer reciprocal support to other components⁽²⁾.

One considers that, during the hospitalization of a child, the families feel supported when building a support system – not only with their own family, their friends, and the professionals, but also with the relatives of other children admitted to the same place. Thus, they share the same space, experiences and sufferings related to the health-disease process of their children, and support themselves so that they can recover their human dignity together⁽³⁾.

According to the Roy adaptation model, the person is a holistic and adaptable system, whose input activates regulatory and cognitive mechanisms through stimuli aimed at maintaining adaptation; and the output, as systems, are their responses, that is, their behaviors, which in turn become a feedback to the person and the environment and are categorized as adaptive responses⁽⁴⁾.

When considering that the same stimulus causes different behaviors in individuals for being related to intrinsic coping factors, the theory by Callista Roy allows recognizing that people who undergo some aggravation can trigger responses that are adaptive or not when receiving stimuli. Therefore, nursing aims to help the person, group or community to adapt through the adaptive modes of the Roy adaptation model, thus contributing to the health of the individuals as a whole⁽⁵⁾.

Considering that, the leading question of this study was: what are the support systems used by family members in the adaptation process to the child's hospitalization in a pediatric intensive care unit?

OBJECTIVE

To identify and to analyze the support systems used by family members for the adaptation process to the child's hospitalization in the intensive care unit.

METHOD

Ethical aspects

For the conduction of the investigation, the ethical procedures required by the resolution No. 466/12 of the Brazilian National Health

Council of the Ministry of Health, on research projects involving human beings, were respected⁽⁶⁾. The interviews were conducted by the researcher in a private room at the Pediatrics Unit. To preserve the respondents' anonymity, they were identified by the letter "F", corresponding to "family", and by consecutive numbers, according to the sequence of the interviews (F1, F2...). This study was approved by the Research Ethics Committee of the School of Nursing from the Universidade Federal de Pelotas (CAEE 69933617.7.0000.5316).

Theoretical-methodological framework and type of study

This is a descriptive and exploratory study, with qualitative approach. Qualitative research requires the researcher's creativity, sensibility, and hard work, because it is not conducted linearly, but in a complex and challenging way. A semi-structured interview was the technique chosen for data collection⁽⁷⁾.

The nursing theory used was the adaptation model by Callista Roy. In this model, people are understood to trigger effective or ineffective adaptive responses when faced with some aggravation receiving stimuli⁽²⁾.

Type of study

As this is a qualitative study, its conduction sought to follow the checklist of recommendations of the Consolidated Criteria for Reporting Qualitative Studies (COREQ)⁽⁸⁾.

Study scenario

This study was carried out at the Pediatrics Unit, after the child's discharge from the PICU of a large hospital with eight beds for the Unified Health System and two for health plans, one multidisciplinary team, and 24h monitoring services, located in the Southern Rio Grande do Sul, Brazil.

Data source

Thirteen family members (guardians) of children who were admitted to the PICU during the data collection period participated in the investigation. For the selection of participants, the following inclusion criterion was defined: to be family member of children in the PICU during the data collection period. Family members of children who progressed to death; of children in palliative care; under 18 years of age; and who refused to sign the informed consent form were excluded.

Data collection and organization

The data were collected between June and July 2017, through a socioeconomic questionnaire and an individual semi-structured interview in a private place, which lasted about 30 minutes and was recorded using an electronic device. The family member interviewed, the child, and the interviewer were present in the place during data collection.

In the context of qualitative research, the semi-structured interview makes the appropriate adjustments to the individual context, since it allows bringing information from different perspectives to the fore, both on the context and on the phenomenon

investigated, and enables a better understanding and completeness of data in the analysis process⁽⁹⁾. The question used for this article was: where did you seek support to adaptation to the hospitalization process?

Data analysis

The information from the interviews were interpreted using the thematic analysis by Braun and Clarke⁽¹⁰⁾, which is a method to spot, analyze, and report patterns (themes) within the data, organizing and describing all the data set in detail, in addition to interpreting aspects of the research topic. At stage one, data were transcribed, read, and reread, and initial ideas were pointed out. At stage two, the systematic coding of the entire data set was initiated. Such coding was performed using colors, by identifying common ideas among the testimonies. Stage three began with the grouping of the codes into potential topics. Then, at stage four, the themes were reviewed, generating a thematic analysis map. At stage five, the names of the themes were pointed; and at stage six, the final analysis of the extracts selected was performed, producing an academic analysis report⁽¹⁰⁾.

Also, the information was interpreted using the Roy adaptation model, which is conceptualized as the support system defined by people, groups, or animals contributing to the satisfaction of the needs of human interdependence. The interdependence, which is considered the basis for the support system, consists of the closest relationships of people, aiming at helping in the effective adaptation to the process to be experienced. Thus, the receptive behavior (of those who receive support) and the contributive behavior (of those who contribute to the support system) are applied in receiving and giving, respectively, love, respect, and value to interdependence⁽²⁾.

From the thematic analysis of the interviews, the following themes were developed: family and friends as a support system; family members of other hospitalized children as a support system; spirituality as a support system; and health team as a support system.

RESULTS

The study included 13 family members; 12 mothers and 1 father, aged between 18 and 39 years. Five participants were married, and eight declared themselves as single. In addition, four participants declared themselves as Catholic, two as atheists, one as evangelical, and six said they had no belief in any religion, but believed in God. Four participants experienced the hospitalization process for the first time, and nine were experiencing a readmission.

Family and friends as a support system

When talking to the family members of children who were hospitalized at the PICU, one identified that they seek to build a support system with their own family and friends. The participants describe the development of mutual feelings of support among family members, with display of affection at a moment of their lives that is considered to be critical, thus developing

copied mechanisms when faced with the child's disease. In this sense, the family members unite and show emotional reciprocity.

My mother gave me the most support. She said, "You can't give up, she's your daughter, you have to be strong". I was really down in the dumps at times, I thought I would not be able to be here by her side [the child] right now, my mother was always helping me, but it was always her. (F3)

I had a lot of family support, they helped me a lot, my family and friends helped me [...]. People with whom we kind of had a friendship, but with whom we did not use to be in touch became very closer to me and my husband. (F4)

The importance of the family is also realized even if it is not physically present, offering distance support.

My family is very important. Even not being here, they come here every once in awhile, not every day, because we don't live near here, their access becomes difficult, but this is very important. You know that you can count on that person, you know he/she will come if you call him/her. The person is not here, but he/she is here symbolically. Of course, even not [...] standing here by your side, as the person calls you, he/she is worried about it. (F5)

Family support is shared as a element to help in coping with the child's hospitalization in the PICU.

My family gave me support by being here with me. When I needed everybody the most, they all came here [...]. Everything was quite difficult. Everyone came here, the phone calls, the prayers, everybody was moved [...], and that's what made me stronger. (F6)

My husband was always by my side, he was always there. Most of my relatives lives far from here, so they helped one another, they held the fort for one another. (F8)

Without my family, I wouldn't have been able to go through everything we've been through. You get nervous, you don't know what to do. (F9)

The support provided by family members is important because it helps in the process of adapting to the child's hospitalization. It occurs regardless of being provided personally or remotely, because the mere fact that the family members accompanying the child are aware of the concern and support from the other relatives reduces the effects of the hospitalization, resulting in the relief for knowing that there is a system on which they can count at that moment of their lives.

Family members of other hospitalized children as a support system

The support system can also consist of bonds made with the family of other hospitalized children. In this study, mutual support was identified among the family members of the children when faced with the situation experienced in the PICU.

When your kid is in the PICU, everyone helps one another, a mother always helps the other. (F2)

We talk a lot, the parents who are there talk a lot. Everyone starts talking a little bit about what's going on. (F7)

The sharing of experiences among the family members of other children hospitalized generates compassion among them, forming a friendship beyond the PICU hospitalization.

We made a lot of friends here. There at the door of the PICU, while we are waiting, we make a lot of friends. [...] People have already left the PICU, but they used to stay here [PICU waiting room], as their treatment in the PICU took last time than mine [...], and until today they call us to have news about him, [...] they became kind of a family. (F4)

The experience of having a child admitted to the PICU involves a long waiting time related to the treatment. During this waiting time, talking to the other children's family members helps to pass the time and reduces the pressure felt by the parents:

Some mothers talk to one another. They talk a lot, speak a lot and feel relief. We start making friends. Then it seems like the pressure we feel is reduced, because we feel a lot of pressure [...]. You are there and time goes slowly [the waiting room] if you have a person to talk to [...] time at least passes faster. I do nothing but that, I can only sit and wait, there's nothing else to do to calm me down but talk to the other family members. (F12)

Corroborating this testimony, F5 highlights the friendships established in this environment are what help parents in their adaptation to the context experienced in the PICU.

Do you know what helps us in the adaptation? The friendships we make, because when we arrive here, we feel exactly as the saying goes: "a fish out of water". So you are faced with this situation, you feel sad for being incapable of doing anything, but the friendships you make are what helps you in the adaptation and reduces this feeling. When you see them, you feel better. Then you talk, and when you enter [the PICU] [...] you already feel more relaxed, calmer, because we all talk about our problems. It is kind of a therapy, [...] Then when you enter the room, you're not shocked anymore, you're not feeling lonely for being incapable of doing anything for that person anymore, it's okay, you feel better. (F5)

The participant F5 reports the importance of the support among the family members of the different children hospitalized in the PICU, which helps in reducing the feeling of shock when faced with hospitalization, as well as the feeling of loneliness.

Health team as a support system

The support system is also present in the health team. The respondents recognize the role of the nurses in the family members' adaptation to the experiences at the PICU while their children are hospitalized.

The nurses were awesome, the proof of this is that they come here [at the Pediatrics unit] to see her [the child], all of them do it. I don't know how it works there, each of them has a patient; those who cared for her came here to see her in their work shift. So they help a lot, and she [the child] liked them very much. (F2)

As the professionals and family members spend much of their time together, they constantly exchange experiences with one another through dialogue, and an open communication between professional and family is clearly a coping mechanism for adaptation to the situation experienced.

Dialogue is very important nowadays, everything, with the nurse, with any other person, everything is dialogue. If you can talk, you can deal with that problem; if you don't talk, you can't go through the situation, you think everybody is against you [...]. Talking is the best solution [...], it relieves you of the situation, of that tension you feel. (F5)

Many nurses used to calm us down, to tell us similar cases, to reassure us despite everything that was going on. (F10)

From this perspective of the professional support system, another professional admired due to the bonds formed is the psychologist. Psychology contributed to the humanization process during the experience.

I always needed to vent and I had no one to talk to. So I met the psychologist, and I got all the feelings off: the fear, the anger, the anguish. (F1)

Because they try to give you hope when you don't have it anymore. Sometimes you lose all your hope, you can't believe this happened. It should have happened to me instead [...], then they appear and give you a word of affection, of faith, saying that everything will be better, that you have to have faith in God and such [...]. So we start to be more hopeful. (F8)

In the testimonies of F1 and F8, one observes the support offered by psychologists to the family members of the children in the PICU. This support favors the understanding of the child's condition. F8 also emphasized the difficulty in accepting, as a mother, the situation her child is going through, expressing that she wanted to be in his shoes. In turn, F4 realizes that psychologists, besides assisting the family members, also care for the children:

The psychologists were there both for me and for him [the child]. She, the girl who cared for him, truly provided him and me with care. One of them was good. They used to be around us, for a while; they were our support. (F4)

Based on these statements, the family members are perceived to feel comfortable to talk/vent with health professionals, building an important support system for the adaptation process. In addition to listening to them, the professionals conduct dialogue so as to family members can understand what is happening and accept the reasons for hospitalization and the treatment objectives.

Spirituality as a support system

During the period in the PICU, spirituality was shown to be an important support system for families. Faith in improvement and healing and the belief that everything would be okay in the end were essential to the family. The family members used religion, positive energies and, especially, God as their basis.

In my religion, I trust the positive, I trust that everything will be okay and come out well. I think it's a little bit of that. (F1)

I prayed a lot, I've never prayed that much in my life. (F8)

You have to have faith, hope and believe that angels exist. (F11)

Faith plays an important role in the family members' coping process when faced with the hospitalization of their child in a PICU.

I believe in God, that God will help, not in other things. The doctors are there, we believe that God is helping the doctors; If the doctors aren't there, God wouldn't do anything alone, He can't heal her alone, He needs the doctors, He needs the nurses. (F2)

I think I spent almost 3 hours there in the cathedral. [There is one] who puts Angels on our path, [...] Angels, good people who can help [...] those who are sick, ill, help us [...] to go away home in a shorter period, but we can't handle it without these people [...]. You have to believe, if you don't have faith in something, how can you get over it? [...] You have to believe in someone and move on. (F5)

A pastor came here, prayed to my son, it was very good, it made us feel safer, it seems that there is a major force that protects us, that protects him. (F13)

With the hospitalization of a child in the PICU, the family members create a support system with spirituality, developing confidence in any sign of hope within their reach. They mention that faith brings peace, tranquility and strength to overcome and adapt to everything they are living.

DISCUSSION

The family performs actions to cope with the difficulties, relying on the support system, from their family members or friends, from family members of other children admitted to the PICU, from the health team professionals and/or from spirituality. Faced with the hospitalization of a child, the relationship between the family members undergo a transformation. In many situations, the family member becomes closer to sustain the family bonds and to support those who need support the most at the moment, albeit physically distant⁽¹¹⁾. By strengthening the consanguineous bonds, the family members develop a behavior derived from their adaptation process, because it is defined by internal and external actions, and reactions produced to contribute to the strengthening of their support system⁽²⁾.

The presence and participation of the family in the support to the children and their parents during hospitalization is very important. The building of a support system is independent of the type of kinship with the family member (a spouse, wife, uncle, aunt, mother, father, among others): what really matters is the attention given, the availability of support, and the bond that becomes stronger, making the relationship of interdependence strengthened and indestructible⁽¹²⁾.

The hospitalization of a child in the PICU is an event of life in which the family seeks to remain even more united, because joining forces in favor of the health and well-being of the patient hospitalized is necessary. From this perspective, people begin to

rely on family members not only in moments of celebration, but also in those in which they are immersed in worries, anguish and fear, thus revealing the support system⁽¹³⁾.

A survey shows the need for the support system is mentioned by the family members when they report missing their family and being with it by their side. The contact with the family means having support to cope with the situation. In this sense, the presence and participation of the extended family is shown to be a necessary element in supporting the child and family members during the hospitalization period⁽¹²⁾.

The support system is based on the interdependence mode, which shows affective needs are satisfied with those who are closer to the person. In supportive families, the members feel more loved and assisted by one another, mutually comforting themselves in the difficult moments, such as in the hospitalization of a child⁽²⁾.

Interdependence is notorious among family members who experience hospitalization in the PICU, being revealed through the emotional, spiritual, and even financial support provided and being an important support to cope with the unfavorable situations that hospitalization causes⁽¹⁴⁾. Thus, mutual support is a way to focus on the interrelations linked to giving and receiving love and respect through the relationships with significant people, who are within the support system. The interdependence mode is associated with the effective adaptation and is directly related to the feeling of security⁽²⁾.

Thus, the interdependence mode is what is related to the effective adaptation, which involves contact with and affection for others, which are necessary in people as social beings; when this is expressed, adaptation to all situations also occurs⁽²⁾. From this perspective, the family is the main social support system of its members, because the possibility of family participation during the therapeutic process and the hospitalization of the child reduces the stress and suffering of the family and the child⁽¹²⁾.

As the person is an adaptive system, the family member is described as a whole comprising several parts, functioning as a unit for the sake of a goal. In this case, the bonds strengthening his/her support system are considered his/her parts – for example, his/her own family members. Through a unit that includes feelings of cooperation, empathy, and love, they seek to reach the objective of supporting themselves in the system together for adaptation to the moment lived⁽²⁾.

During their long stay in the hospital, the family members develop strategies to overcome the suffering caused by the illness of the child. Thus, they begin to relate to other family members, create bonds of friendship, become supportive and, in this exercise of solidarity, start to suffer from the suffering of others, while they seek to comfort one another⁽³⁾.

The permanence in the PICU and the continuous interaction with other family members who face the same situation favor the building of help relationships through the support and sharing of experiences⁽¹²⁾. The sharing allows strengthening the support system, causing those involved to realize that they are not alone at this difficult moment in their lives.

The relationship of interdependence between family members comforts, shelters, supports, confronts insecurity and raises the expectation of improvement of the children⁽²⁾, leveraging the

family members' adaptation to the experience in the PICU. In addition, the families go from strangers to friends who share the same system, building a friendship based on the hope of hospital discharge and on the overcoming of all the difficulties they faced together.

For newly admitted family members who are still being acquainted with the intensive hospital environment, the beginning of the building of the support system with family members of other children is essential, considering the sharing of experiences, the complacency, and the affection displayed between them. The family members feel comforted and, with all the reports and people around them, the feeling of loneliness is minimized.

The relationships of help in coping with the disease and the hospitalization of the child are basis and support for the family members, who, for not being in the same situation, have many desires and feelings in common, such as the recovery of the child, the desire to return home, and the fact that they miss their family. By sharing the same experience, the family members are understood in a mutual way, showing the need to be heard and to understand one another⁽¹²⁾. This broad movement of empathy leads us to recognize the people and the subjective dimensions of human experience as a central point for knowledge and valuation of the adaptation process, a movement called humanism⁽²⁾.

The suffering shared by the family members in the environment of a PICU appears as the main propellant for the formation of a solidarity network and of good relationships, which are strengthened in the face of the adversities and the needs that mark the trajectory of these families. During the entire period of hospitalization of the children in the PICU, the family members mutually support themselves, since they divide the same environment in full period⁽³⁾.

The support system can also be built by the health team professionals, who shelter the family in the care environment and become active actors in the care and in the dialogue about the best treatment approaches to be developed. The emotional experiences need to occur essentially in this period and to be explored, reducing the family's stress and suffering⁽¹⁵⁾.

The building of the support system with health professionals is undeniably important to family members, as it helps them in coping with and adapting to the child's disease, reducing the symptoms of stress and fear of finitude. When the reception and clarification of doubts are made according to the understanding of the family members, bonds of trust are created with the team, minimizing the negative feelings experienced with the hospitalization in the PICU, as well as with the treatment being made available to the child in critical condition.

The effective communication between health professionals and family builds a support system and can reduce anxiety when faced with the disease and the hospitalization of the child, favoring the process of dealing with the needs inherent in it and optimizing the parents' acceptance and involvement in the child's care. From this perspective, factors such as the constant permanence of the nursing team in the PICU, the direct care for the pediatric patient, and the educational and assistance profile of the professional nurse qualify their protagonism in the humanized care for the child and his/her family⁽³⁾. The nursing team aims to promote the family member's adaptation to the PICU, thus contributing to their health and quality of life⁽²⁾.

Health professionals who seek, recognize and strengthen the support systems of families in these scenarios encourage the participation of other members of the family nucleus and of the extended family in the therapeutic process, the formation of groups of parents and family members for the sharing of experiences, and the provision of specific orientation activities and health education⁽³⁾.

In this study, the support system is notorious in the relationship of interdependence with health professionals, and the nursing team is mentioned by the family members during the period experienced. The relationship built is so intense and important that, even after the discharge from the PICU, when the children go to the pediatric unit, the visits and the follow-up of the PICU professionals still continue to show the bonds built are strong and boosted the adaptation of the family member to the situation.

Thus, the promotion of relief for the family through the support system with professionals should be considered a goal in the care provided by the nursing team. Understanding this construct and its dimensions requires understanding the family universe and the different processes inherent in it throughout the hospitalization period⁽¹⁶⁾. The health professionals contribute to adaptive responses to its process, defined as promoting integrality in terms of the objectives of the human system⁽²⁾.

One study shows family members feel the need for professional support and follow-up to deal with emotional changes derived from the child's health-disease process. One can understand that the therapeutic action in the PICU involves, in most cases, only important technical and scientific aspects for the control and cure of the diseases that affect the child, without considering the threatening aspect arising from the environment of the PICU and the physical and emotional distress in the family members accompanying the hospitalized children⁽¹²⁾.

The nurse and his/her team should therefore create strategies to allow the family to trust in the care provided, transforming their negative feelings into hope of recovery and enabling them to comfort the child and show stability, making him/her more collaborative and facilitating the work of the team⁽¹⁷⁾.

The psychologist was also pointed out by the participants as important in the support system, being considered essential, for he/she helps in minimizing the grief of family members, as well as the suffering and anguish caused by the hospitalization. During the process of hospitalization in the PICU, the entire family nucleus and its daily life are affected. In most cases, their routine needs to be changed to live with the disease, and such change causes an enormous emotional impact on the whole family. In this context, a psychologist is important to help them in coping with the situation and to give them support⁽¹⁸⁾.

The respondents report that the psychologist plays a fundamental role when the support does not come from the closest family members, because he/she enables the parents to talk about the difficult moments they are experiencing, leading their thoughts to a process of adaptation and acceptance of everything that is to come. The psychological care in a PICU seeks emotional relief for the patient and his/her family, seeking to investigate the experience of both the sick child and the family member and intervening through an engaging, empathic, and flexible relationship. Thus, the care provided by this professional is focused on

psychic and physical pain, seeking to understand this moment that is difficult for the sick and their family⁽¹⁹⁾.

Thus, psychology contributes to the adaptation process and humanization of the hospital environment, and family members wish to be heard and welcomed at this very delicate moment of their lives. The children, their family members and the health team have feelings that need to be expressed, and the psychologist is the one who defines bonds in favor of the creation of the support system, focusing on feelings and emotions necessary for the welfare and for a quicker recovery both of the family member and of the patient⁽²⁰⁾. In this sense, considering the level of adaptation a turning point, which represents the ability of the person to respond positively in a given situation, the psychologists are understood to be directly associated with the reach of this adaptive level⁽²⁾.

Another support system mentioned by the participants is spirituality, since belief gives meaning to what is happening and is a human dimension that favors coping with adversities⁽²¹⁾. Spiritual care consists of encouraging the expression of feelings, fostering the attribution of meaning to the unavoidable suffering; as well as offering support, guiding the coping of the situation, and encouraging the search for meaning, tragic optimism, and responsible action⁽²¹⁾.

The hospital environment is exceptional in the families' lives. They undergo a period of adaptation to a new reality and to a different moment in their lives. In this context, spirituality is part of the support system, representing comfort, support, and hope.

Religious beliefs are mediators in the coping with issues related to the health-disease process, because they promote increased confidence, favoring the attribution of meaning to stress episodes⁽²²⁾. Spirituality is seen as a striking factor in the experience of families of children hospitalized, for it supports them and allows the establishment of spiritual connections to cope with obstacles.

Considering that health is a state and a process of being and becoming a total and integrated person⁽²⁾, when it is affected, especially in the case of a child, it causes family members to suffer; hence the need for spiritual help. Faced with sadness, family members consider themselves lacking strength to fight and seem to lose hope, thus needing help to restore their faith⁽²²⁾. Thus, faith and religiosity are supports for the family member when coping with the disease and play an important role in the maintenance and recovery of the child's health. Family members seek, through faith, the hope of healing or ways of dealing with the situation with less suffering⁽¹²⁾.

Faith in God is expressed as a force, a relief when dealing with the situation imposed on the family. It is a motivation not to surrender to the situation and to fight for the child's life. Then their hope that God will act, heal the child and remove them from that suffering arises⁽²³⁾. The family, when facing a difficult situation or disease, tries to seek answers to understand everything that is happening, in the context in which it lives. In most of the time, God is the One who is by their sides and helps the family understand the situations lived⁽¹²⁾. When family members rely on spirituality, trusting that God will guide the decisions of the health team, the burden of the disease is relieved, reducing suffering and favoring a faster and less stressful adaptation process.

Limitations of the study

Among the limitations of this study, one highlights the fact that it represents a specific reality, because it investigated only one health service. However, as this study has a qualitative approach, it avoids generalizations, focusing on the knowledge of reality so that formulating specific strategies to cope with the experience of the hospitalization of a child of the family in the PICU becomes possible, aimed at more effective adaptation processes.

Contributions to the field of nursing, health or public policy

This study allows reflecting on the professional actions related to the families, pointing strategies that can be adopted to favor more welcoming and less traumatic experiences. It shows the importance of therapeutic listening and of the clarification of information about the treatment and the clinical conditions of the child to strengthen the process of family adaptation. Therefore, the hospitalization period can be used for constructing positive interactions with the families, allowing them to be creative, to assign meanings to their experiences and to acquire new knowledge, thus promoting family health and, mainly, the child's health.

FINAL CONSIDERATIONS

The support system, coming from the family itself, from family members of other children admitted, from the health team or from the spirituality, plays an important role in adapting the family member to the child hospitalization. The family receives support from their family members, who contribute even when they are not physically present. This occurs by telephone, when relatives are in contact and are available to meet the needs of reorganization and adaptation the family accompanying the hospitalized child has. In this context, the family members of other children hospitalized become close to them for being experiencing the same moment of coping with a disease, building a great support system, sharing their experiences, and relieving their suffering during the process.

The health team, through the therapeutic listening, shows its role in the building of a support system in which nurses and physicians, by providing more detailed information about the hospitalization and about how the treatment will be provided, minimize the family's feelings of anxiety and fear. When the family members are aware of the therapeutic situation of their children and the quality of the care provided for the latter in the best possible place at that time, they feel safer.

In the context of hospitalization of the child, the results of this study point to the primordially of the health teams being attentive to the needs of each family, because many of them need people who listen to them; others feel a lack of clearer and more objective information regarding the child's disease. One believes that a well-oriented family, with an active support system, experiences child hospitalization with more ease and confidence and with positive thinking focused on better days. An attentive listening to what families facing child hospitalization express needs to be present in the daily routine of the pediatric health team.

The recommendation is to carry out studies that address, separately, families that experience the hospitalization in the PICU for the first

time and those that have already experienced this process of hospitalization previously, which will enable a more detailed comparison between the mechanisms of adaptation of the two conditions. The

study on how the nursing team can contribute to the use of the support systems when necessary, to broaden the knowledge and to help the family members in the adaptation process.

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