

# Needs of Parents in Caring for Their Children in a Pediatric Intensive Care Unit

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## Needs of parents in caring for their children in a Pediatric Intensive Care Unit

**Objective.** This work sought to describe the needs of parents to participate in caring for their children hospitalized in a pediatric intensive care unit (PICU).

**Methods.** This is a qualitative study based on the ethno-nursing research method proposed by Leininger. For data collection and analysis, in-depth open interviews were used, along with field notes and enabler guidelines proposed by Leininger: stranger-friend, observation, participation, reflexion, and the Sunrise model. Parents of children hospitalized in a PICU in the city of Tunja (Boyacá, Colombia) participated between February 2012 and October 2013. **Results.** The needs of parents to care for their children were described in the following themes: clear and timely communication, familiarization with technology, the value of the family, favoring the parent-children interaction during visits, and valuing and respecting generic (folk) knowledge.

**Conclusion.** The study provides knowledge, from the cultural perspective of parents with children hospitalized in PICU, as input to plan and develop care actions with them, according to their own needs.

**Key words:** intensive care units, pediatric; nursing theory; parent-child relations; qualitative research.

## Necesidades de los padres para cuidar a sus hijos en una Unidad de Cuidados Intensivos Pediátrica

**Objetivo.** Describir las necesidades de padres para participar del cuidado de sus hijos hospitalizados en la Unidad de Cuidado Intensivo Pediátrico (UCIP).

**Métodos.** Investigación cualitativa basada en el método de la etnoenfermería propuesto por Leininger. Para la recolección y análisis de la información se utilizaron la entrevista abierta a profundidad, las notas de campo y guías facilitadoras propuestas por Leininger: Extraño amigo, Observación, Participación Reflexión y el modelo del sol naciente. Participaron los padres de niños hospitalizados en una UCIP de Tunja (Boyacá, Colombia) entre febrero de 2012 y Octubre de 2013. **Resultados.** Se describen las necesidades de los padres para cuidar a sus hijos en los siguientes temas: Comunicación clara y oportuna, Familiarización con la Tecnología, El valor de la familia, Favorecer la

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interacción de padres-hijos durante la visita y Valorar y respetar el conocimiento genérico. **Conclusión.** Se describieron las necesidades de los padres en el cuidado de sus hijos internados en una UCIP. La enfermera debe tener en cuenta el conocimiento genérico de las personas y respetar las creencias que ellas tengan, con el fin de fortalecer su desempeño como profesional mediante la aplicación de teorías en enfermería.

**Palabras clave:** unidades de cuidado intensivo pediátrico; teoría de enfermería; relaciones padre-hijo; investigación cualitativa.

### **Necessidades dos pais para cuidar aos seus filhos numa Unidade de Tratamento Intensivos Pediátrica**

**Objetivo.** Descrever as necessidades de pais para participar do cuidado dos seus filhos hospitalizados na Unidade de Tratamento Intensivo Pediátrico (UTIP). **Métodos.** Investigação qualitativa baseada no método da etnoenfermagem proposto por Leininger. Para

a recolecção e análise da informação se utilizaram a entrevista aberta a profundidade, as notas de campo e guias facilitadoras propostas por Leininger: Estranho amigo, Observação, Participação Reflexão e o modelo do sol nascente. Participaram os pais de crianças hospitalizadas numa UTIP de Tunja (Boyacá, Colômbia) entre fevereiro de 2012 e Outubro de 2013. **Resultados.** Se descrevem as necessidades dos pais para cuidar aos seus filhos nos seguintes assuntos: Comunicação clara e oportuna, Familiarização com a Tecnologia, O valor da família, Favorecer a interação de pais-filhos durante a visita e Valorar e respeitar o conhecimento genérico. **Conclusão.** Se descreveram as necessidades dos pais no cuidado dos seus filhos internados numa UTIP. A enfermeira deve ter em conta o conhecimento genérico das personas e respeitar as crenças que elas tenham, com o fim de fortalecer seu desempenho como profissional mediante a aplicação de teorías em enfermagem.

**Palavras chave:** unidades de terapia intensiva pediátrica; teoria de enfermagem; relações pais-filho; pesquisa qualitativa.

## **Introduction**

According to the literature review, parents need to know and understand the situation their children are undergoing in the pediatric intensive care unit (PICU) and acquire knowledge and clear and timely information on their health status,<sup>1</sup> given that they show feelings of helplessness and become vulnerable when they ignore what is happening with their children.<sup>2</sup> Additionally, they must participate in caring and require indications on the tasks they can carry out, such as helping with feeding, lubrication of the skin and mucous membranes, prevention of ulcers, and rubdowns and define roles to conduct.<sup>3,4</sup> Likewise, the information provided must be adjusted to the language and sociocultural level of the parents for it to be clearly understood.<sup>5</sup> Literature indicates that the hospitalization of a child is an unexpected event for the parents, but their presence is essential to participate in caring and cooperating with the children's treatment.<sup>6</sup> In turn, when timely education is given, parents diminish

negative feelings, which impacts upon the quick recovery of their children.<sup>6</sup> The study reviewed research related to communication among children, parents, and healthcare personnel in the pediatric intensive care unit (PICU), where it was concluded that a hierarchical physician-patient relationship is established in which children and parents are not kept in mind to participate in the care and have little possibility of interrelating with the professionals.

Also, physicians and nurses have difficulties communicating amongst themselves.<sup>7</sup> It was found that it is important to motivate the parents so they can provide information on the care to their children.<sup>8</sup> Regarding care needs, it is mentioned that the care contributed by the parents carries meanings from the very culture, which nurses must bear in mind to establish a relationship among them,<sup>9</sup> thereby, granting a leading role to the parents to keep in mind their knowledge and practices, making them active subjects to participate in the care.<sup>10</sup> Hence, it is

recommended for nurses to receive education to offer care according to the culture, using terms the parents can understand and inquiring on what they expect and need to provide care.<sup>11</sup> Likewise, it was found that sometimes parents express scarce comprehensible information on the state of health of their children,<sup>7</sup> the language is often not clear, medical information is received in technical and structured manner once a day during visiting hours, while nurses communicate less formally several times per day.<sup>12</sup> With the aforementioned, it became necessary to inquire on the needs of parents belonging to the culture in Boyacá to participate in caring for their children, recognizing that the sociocultural characteristics of individuals guide the decisions related to healthcare.

Leininger's theory of universality and cultural diversity was used, which holds that culture was the broadest, most comprehensive, holistic, and universal aspect of human beings and predicted that care was embedded in culture.<sup>13</sup> One of the constructs of this theory is care, conceptualized as experiences or ideas of care, support, and facilitation toward others with evident or anticipated needs to improve human conditions or life styles; this construct includes traditional and professional care. Leininger denominates as *emic* the human being's local cultural knowledge and vision, which leads to generic care; the *etic* refers to the outside vision, from professionals, and institutional knowledge that leads to professional practices. Another construct is the culture, defined as "values, beliefs, norms, and life styles learnt, shared, and transmitted from one particular culture, which guide thoughts, decisions, and actions".<sup>14</sup>

The Sunrise model serves as graphic representation of the theory; it is the universe nurses must consider to value care from the cultural. This model kept in mind cultural values, beliefs, religious factors, technological factors, the family, practices, and generic care, according to the areas of interest in the research. The parent's environmental context was explored, along with feeding resources, routines, and ways of promoting and maintaining their wellbeing. The model served to guide and

carry out cultural care actions with favorable effects upon the health status of individuals.<sup>15</sup> By applying this theory, nursing professionals manage to identify the needs of parents, bearing in mind their beliefs, values, and practices accessing the discovery of care required by them in the culture of Boyacá. The aim of this study was to discover the needs of parents belonging to the culture of Boyacá to participate in caring for their children hospitalized in an intensive care unit.

## Methods

This was a qualitative research, ethnographic type, based on the Ethno-nursing research method.<sup>15</sup> The work was approved by the ethics committee of the research sub-commission at Universidad de La Sabana in Colombia. The sampling was carried out through pertinence, adequacy convenience, opportunity, and availability.<sup>16</sup> These criteria were applied by gathering the parents of children hospitalized in PICU, who were the key participants. The parents were interested and willing to intervene in the study, through prior informed signed consent and authorization from the institution (Hospital San Rafael de Tunja, tier III level of care); only one mother was kept from participating because she did not have the mental disposition at the moment, which was respected. The general participants were nursing professionals who worked in the PICU, who had general ideas of the research domain and were in contact with the parents, and shared appreciations with respect to the themes derived from the research. Participation was secured from 10 parents of children with a hospital stay of at least seven days.

The general participants were four nurses who worked in the PICU, who were approached individually during one of the monthly meetings of the service, discussing with them themes that emerged from the research. The principal researcher involved the key participants in various sessions; information from the general participants served to reflect upon the similarities and differences of ideas with respect to the key participants.

The principal researcher approached the field by reporting on the aim of the study; simultaneously, observing the context; interactions the parents had with their children during visits, and established an open and spontaneous dialogue, conducted a first interview exercise to approach the parents, thus, generating trust to obtain the information required for the study. Information analysis was performed with the work's director. Guidelines proposed by Leininger were used: the stranger-friend enabler going from strangers to assume a role of friends to discover nursing phenomena; the observation, participation, reflexion enabler, which was used throughout the whole collection and analysis process. The Sunrise model was also used, as previously stated, and the results are represented in graphical manner.<sup>15</sup> The principal author used the in-depth interview<sup>16</sup> that refers to various extensive, detailed sessions with one person, starting from a question, and according to the response, new questions were generated; there was no list prepared.

Three to five interviews were conducted per parent, and one with the nurses, to achieve data saturation; the interviews took place during various moments, lasting on average for two hours; the participants needed to have the time and mental availability to take part. The interviews with the key participants and the general participants were recorded and transcribed textually, agreeing on an appointment in a designated place in the hospital, where only the participant and the principal researcher were present, thereby, guaranteeing privacy without interference. The transcriptions were reviewed and analyzed by the principal researcher, as Master's student, and the thesis director. Thereafter, these were returned to the participants for their respective feedback and to accept comments and clarifications.

Data coding was accomplished between the principal researcher and the director of the research work. Similar categories were grouped as recurrent patterns and the themes were then identified. To organize the information, the following numerical reference was used: P1E3P2, where P corresponded to a key

participant, 1, 2, 3... E to interview, 1, 2, 3... and the last P to the paragraph corresponding to the interview transcribed. The descriptors were each of the testimonies from the key participants and the codes were created for the purpose of identifying units of meaning to finally generate the themes, each with its respective patterns; this whole process was carried out by the principal researcher with support from the work's director. The field notes<sup>17</sup> were used from the beginning to the end of the research; these consigned complete observations, bearing in mind factors of the social and cultural structure and the information related to generic knowledge and served to understand the behaviors and attitudes of parents during such difficult moments and advance toward needs from the cultural to participate in the care. The notes were registered in the field diary, processed in the computer, and then encoded for analysis with the director of the research work. These notes also registered the personal feelings and appreciations of the principal researcher, when making the interviews and observations. The research began in February 2012 and ended in October 2013.

## Results

In the sociodemographic characteristics of the parents it was found that they came from the department of Boyacá, 80% from the rural area, the mother – almost always present during the visit – was dedicated to the home, the father came on weekends and worked in agriculture, livestock, and in land transport as drivers. During visits, they complied with established norms and prayed in front of the altar of the image of the Mystic Rose, mother patron of the ill, which was at the entrance to the PICU. The ages of the parents ranged between 17 and 36 years; ages of the children ranged from one month of life to 15 years.

The first theme was denominated *Need for clear and timely communication* in the PICU, where the study took place; information on the state of health was exclusively in the hands of the medical staff; nurses are not authorized to speak with the

parents, they only apply the admission norms and indicate personal hygiene elements the children must have. In this regard, some parents agree with these rules, others stated wanting to be informed by the nursing staff as long as the information were clear, timely, and true. The following patterns emerged from this theme:

**Communication between parents and healthcare providers.** *Sometimes I do not understand them and sometimes I do because I haven't like studying, but lately I have had to understand the doctors; before I did not understand probably due lack of being used to this, but now I get what they tell me, but every day you get different information (P1E1Y2P27); sometimes I have had questions, but at the moment you just listen and believe everything is clear, but questions remain and then you start thinking to assimilate all that information they give you and that is where more questions emerge, so I have called the doctors and they have cleared the doubts I have or which I may have at that moment (P6E2P24); sometimes there are words one does not understand, doubt remains (P10E2P23)*

**Communication between parents and children.** *Now that she is more aware we talk to her because through dialogue the doctor told us she would evolve more, I talk to her; it is the only instant I have to be with her and I have to take advantage as much as possible (P3E2P16); well, he was more awake, he looked at me and would start crying; I talked to him a lot and he would stare at me, but he would really get very restless when he recognized me, but it seems important for him to listen to me and realize I am here (P5E2P22).*

**Communication among parents and nurses.** *Well, I would probably want to receive information from the nurses (P8E2P26); the nurses do not give us information when we ask them, they only say they have no authorization to provide information because all inquiries must be made to the doctor. They just do their work (P4E2P20); for example, I would like the nurse to tell me how my child is, how he has evolved, if any change*

*has taken place or if there is any novelty; one should be able to ask and they should answer because they are here all the time (P9E2P17).*

The second theme was denominated: *Need to become familiar with technology.* Parents from Boyacá feel “overwhelmed” in the PICU; it makes them fearful to see their children connected to so all the apparatuses, but trust science and believe their children are well cared for and will improve. Thus, the patterns mentioned ahead are derived:

**Technology as a means to administer treatments.** *The equipment my daughter has are mechanism that helps the organism to be stable; also, used with all the medications, they help so she does not have to be injected all the time; rather, all the medication can enter through one single part (P9E1P12).*

**Technology to prolong life.** *My son has had lots of equipment, but these are what have kept him alive and which will make him better day to day and have served for his recovery (P2E1Y2P14).*

**Technology as scientific progress.** *Well, you can't say this is another god, but it is scientific progress that helps quite a lot, although I say that because of God my daughter is alive but if science didn't exist and had she not been helped with that apparatus, my daughter would not have been able to breathe. We are very grateful to science and to God (P8E1P18); at least in that monitor you can see the saturation, you also see when she is breathing by himself without the aid of the ventilator; you can check the pressure, it registers everything, given that he cannot breathe on his own, the equipment has helped much (P2E1Y2P14).*

**Technology as a blessing from God.** *The equipment my son has is equipment God has provided the hospital for my son to be stimulated daily; God will provide. P1E2P21*

The third theme was denominated: *The need to value the family,* considered as cultural construct, with social, religious, political values,

and traditions. The following presents some testimonies: *My family means everything, it is the best God has given me, it is everything; my family is my reason for living. They have given me lots of courage (P1E1Y2); and for me they are a great support; they have been with me through good and bad (P4E1P4).*

The fourth theme refers to the *Need to favor parent-child interaction* during visits. To this effect, some mothers expressed wanting to spend more time with their children to show love and maintain the affective bond; they also wanted to learn how to care for the children, help feed them, or with rubdowns. Some of the testimonies to support the description are: *perhaps change his diaper, give him rubdowns because he has been in bed for a long time and must be tired. A doctor told me I could play music for him, so here in the hospital he was given a tape recorder and when I come to visit I turn it on, he opens his eyes, but nothing more (P1E1Y2P32); I would want the visit to last all day, but you know that it is for their good not to be here all the time because they are, nonetheless, very weak. Every day I wait for visiting hours to start, but I accept that it is such short time for their good. If they were to let me stay one more hour, it would be nice (P8E1P19); I would like to be taught how to change his diaper, move him, and be with him all the time because I miss him too much. I would also like to know about the therapies he gets; how to take care of him (P2E1Y2P16); I would like to learn how to apply ointments, change her diapers, clean her, comb her, but I fear causing damage and hurting her; in truth, I don't dare, I would have to be very careful, but I would like to learn (P4E1Y2P16).*

The last theme was denominated as *Need to value and respect generic knowledge*. Parents in Boyacá have different beliefs on the cause of their children's illness, which they attribute to a test from God, a punishment, as destiny, and due to bad care. The following presents some of the testimonies that support the description: *I think it is a small test God has given me, of many things that perhaps took place in the past (P1E1P1);*

*well, I believe these are things of destiny or things that have to happen, so I say... could it be that God has those things destined for him (mother). I say: whatever it is we have to accept it as sent by God and continue ahead (father) (P10E1P1); I think it all happened because the people who saw my son did not care for him on time, he has to get seriously ill for them to pay attention. For me, this has been a hard situation and I don't understand why it happened if I took so much care of my son and from one moment to another he got sick; it is not easy seeing him the way he is, knowing that – as the doctors say – he might get better or he might not, but it is very hard (P2E1Y2P1). What I wanted was for them to take better care of my son because if they had not let him convulse, he would not be as bad as he is now; he would be well and they would have controlled the meningitis he got, but they did not take good care, when they saw how serious his condition was and didn't know what to do, that is when they decided to send him here to the hospital. Here in the hospital it has all been different because they have all the equipment and medications the child needs (P2E1P22).*

In the PICU, some parents manifested belief in a superior being, which generates trust and hope to endure the situation; they see religion as a form of support during difficult situations and within an unknown setting. Besides, they believe that the disease is a test from God and caused by some cultural practices: *I always pray to the Virgin of Miracles to help me and for the child to get better. I also pray to God and to the Divine Child. I believe these prayers have helped me a lot because I have faith in that everything will be alright for and he will come back home with us (P2E1P13).*

## Discussion

On the theme referring to the *Need for clear and timely communication*, some parents agreed with the information provided by the medical staff on the current status and treatment of the children. These results are similar to those proposed by

Gómez and Pérez (2012), given that parents fully trust the information delivered by the physicians, seeing them as people with knowledge who can care for their children against any complication, and who will always be available to save the children's lives.<sup>10</sup> Mitchell and Chaboyer<sup>17</sup> mention that nurses provide excellent communication and that it is essential to satisfy the needs of parents in this sense, in a way that they understand what is happening to their children. However, Ruiz del Bosque,<sup>18</sup> states that nurses sometimes have difficulties when reporting because they do not have communication skills or because this is not part of their habitual work. It was clear, according to testimonies, that some key participants did not understand the information provided by the physician because the time to receive such was quite limited, merely minutes, and the parents often do not clearly understand and their doubts are not solved in timely manner. Upon reviewing the literature, it was found that parents express the need to know about their children's illness, but are sometimes given difficult to understand information.<sup>10</sup> Some parents stated the need to receive information from the nursing staff; this coincides with Gómez and Pérez<sup>10</sup> where they conclude that nurses generate peacefulness and comment in detail on the child's state of health, feeding aspects, and are willing to answer questions from parents. It should be highlighted that communication is an essential part of health professionals, thus, they need to consciously play the role of emitter to achieve adequate performance, which also implies receiving messages, understand them, interpret them, and act for them, in such a way that parents are considered active perceivers capable of making decisions and acting consequently.<sup>19</sup> From the analysis of this theme, new studies would emerge to inquire if the information offered to parents in healthcare institutions agrees with their sociocultural condition and has been clearly understood, expressed by McKiernan and McCarthy<sup>8</sup> as the need to know if true and comprehensible information has been received on the status of the children.

On the theme: *Need to become familiar with technology*, scientific progress has permitted

medicine to evolve to improve the quality of life of many children; however, technology influences upon the fears of the parents. Seeing so many cables, drainage tubes, and strange apparatuses creates in them the need to know what they are for.<sup>5,19</sup> Parents from Boyacá are impacted by the technology in the PICU and need to know about the equipment their children have, especially those with long stays feel familiarized with the technology and are aware when they hear a different noise or see an image that strikes their attention; at the moment, they become anxious and call the nursing staff. Many parents are curious and ask what the equipment is for; they associate the amount of equipment with the seriousness of their children's health and believe that it is what keeps them alive. In addition, technology generates negative feelings like fear, anxiety, and insecurity due to the constant noise from the warning alarms and equipment,<sup>5</sup> which is why the PICU environment becomes strange for the parents and a need emerges in them for an explanation in said respect.

On the theme of *The need to value the family*, some studies state that when the health of any of the family members is altered, especially if it is a child, the whole family's health is also threatened, depending on the degree of illness, as well as prior negative or positive experiences may also affect the family.<sup>20-22</sup> Frequently, these changes produce crisis within the family group, given that the child's hospitalization requires adaptation to a new environment, which produces stress due to the change of environment and the separation from the parents and the family.<sup>23-25</sup> Likewise, a distortion emerges in the family dynamics due to the change of roles in the family members.<sup>23</sup> The aforementioned agrees with research results, given that the disease and hospitalization of a child represents crisis for the whole family, but union and support makes the process more bearable.

On the theme related to the *Need to favor the parent-children interaction*, some mothers wish to spend more time with their children and learn to care for them, for example, they would

like to feed them and give them rubdowns. Literature mentions that nurses must favor parent participation in the child's treatment and provide indications on the tasks they can perform. Thus, this will contribute to defining the roles of parents, especially during visiting hours.<sup>15</sup> Additionally, the mother's participation in the care is a support that favors the child's recovery.<sup>20</sup> Martins *et al.*,<sup>6</sup> indicate that parents consider their presence fundamental to participate in the care and cooperate with adherence to the treatment of the children and that said participation brings them joy, pleasure, security and helps them to clear doubts and overcome obstacles.

Regarding the theme *Need to value and respect generic knowledge*, parents interpret that their children's illnesses have supernatural causes; through tests from God, of faith, and as God's punishment. Another cause is attributed to destiny, but also to bad care from the healthcare service. The aforementioned contributes to form diverse emotional responses in the parents, like guilt and helplessness that coincide with the study by Ruiz del Bosque,<sup>18</sup> which supposes emotional chaos associated to factors like the separation from the child and disturbance of the parental role, among others, which increases the idea of suffering and risk of imminent death present in PICU. Also, parents have ideas, beliefs, myths, and traditions from their past and social etiology with respect to their children's illness, which conform attitudes related to the serious disease, but – in general – feel overwhelmed when the child is admitted to PICU and it is difficult for them to understand that situation. Terms like health, illness, and disease are seen as cultural constructions, these terms may be attributed to agents like God's punishment.<sup>18</sup> In turn, many parents believe the presence of a supreme being is vital for their children to recover, hence, they cling to religious images, the Virgin, the Bible and go to the oratory. This coincides with results found in research, given that people from Boyacá believe in God and the Virgin, in this sense, knowledge of cultural values, beliefs, and life styles of human beings within their life experiences is important to open a source of new knowledge for Nursing and health practices.<sup>18</sup>

In conclusion, this study contributes knowledge, from the cultural perspective of parents with children hospitalized in PICU, as the input to plan and develop care actions with them; according to their own needs, it is necessary to value and respect their generic knowledge, establish clear and timely communication from healthcare providers, parents and children and between parents and nurses; facilitate familiarization with technology, bearing in mind that it is accepted by the parents, in spite of the fear it causes in them due to their lack of knowledge; heed the call to wanting to wanting to spend more time with their children and to learn basic activities to participate in their care; which leads to the nurses deciding what can be taught to the parents for their participation in caring for their children. Within this context, it is also true that the value they give to the family becomes a support to assume the situation they are experiencing.

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