

# FAMILY PARTICIPATION IN THE CARE OF CHILDREN HOSPITALIZED IN AN INTENSIVE CARE UNIT

*A participação da família no cuidado às crianças internadas em unidade de terapia intensiva*

*La participación de la familia en el cuidado de niños ingresados en la unidad de cuidados intensivos*

Original Article

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## ABSTRACT

**Objective:** To understand family involvement in child care in a Neonatal and Pediatric Intensive Care Unit (NPICU). **Methods:** Qualitative exploratory and descriptive study. The study was conducted in a university hospital in Northern Minas Gerais, Brazil, with parents of children in NPICU. Data were collected through semi-structured interviews and later underwent content analysis, which yielded two categories: experiencing the care for the child in the Intensive Care Unit and factors hindering and facilitating care. **Results:** It was clear that the family is not fully inserted in the care of hospitalized children. This happens due to parents' feelings of fear and insecurity, restrictions caused by the complexity of the technology and equipment used in health care, family members' unavailability because they need to perform other activities and live in other municipalities. The support from the staff in the sector was singled out by respondents as a factor that facilitates care. **Conclusion:** The study contributes to reflection on the importance of parental involvement in the care of children who need intensive care and highlights that family involvement is a necessity that must be taken into account by healthcare professionals in the comprehensive care process of pediatric patients.

**Descriptors:** Intensive Care; Hospitalized Children; Child Care.

## RESUMO

**Objetivo:** Compreender a participação da família no cuidado à criança internada em uma Unidade de Terapia Intensiva Neonatal e Pediátrica (UTINP). **Métodos:** Pesquisa exploratória, descritiva, de natureza qualitativa. O estudo foi realizado em um hospital universitário do norte de Minas Gerais, Brasil, e teve como participantes oito pais de crianças internadas na UTINP. Os dados foram coletados por meio de entrevistas semiestruturadas, os quais, posteriormente, foram submetidos à análise de conteúdo, originando duas categorias: vivenciando o cuidado com o filho na Unidade de Terapia Intensiva, e fatores dificultadores e facilitadores do cuidado. **Resultados:** Evidenciou-se que a família não está totalmente inserida no cuidado à criança hospitalizada. Isso acontece devido a sentimentos de medo e insegurança dos pais, restrição pela complexidade e tecnologia dos aparelhos utilizados na assistência, indisponibilidade de tempo dos familiares por precisarem realizar outras funções e por residirem em outros municípios. O apoio da equipe atuante no setor foi enfatizado pelos entrevistados como fator facilitador do cuidado. **Conclusão:** O estudo subsidia a reflexão sobre a importância da participação dos pais no cuidado à criança que requer terapia intensiva e destaca que o envolvimento da família é uma necessidade que precisa ser considerada pelos profissionais de saúde no processo de assistência integral ao cliente pediátrico.

**Descritores:** Cuidados Intensivos; Criança Hospitalizada; Cuidado da Criança.

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Daniele Zuba Ramos<sup>(1)</sup>  
Cássio de Almeida Lima<sup>(2)</sup>  
André Luiz Ramos Leal<sup>(2)</sup>  
Patrícia Fernandes do Prado<sup>(1)</sup>  
Valdira Vieira de Oliveira<sup>(1)</sup>  
Ana Augusta Maciel de Souza<sup>(1)</sup>  
Mirela Lopes de Figueiredo<sup>(1)</sup>  
Maisa Tavares de Souza Leite<sup>(1)</sup>

1) State University of Montes Claros  
(Universidade Estadual de Montes Claros  
- UNIMONTES) - Montes Claros (MG) -  
Brazil

2) Federal University of Jequitinhonha and  
Mucuri Valleys (Universidade Federal dos  
Vales do Jequitinhonha e Mucuri - UFVJM)  
- Diamantina (MG) - Brazil

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## RESUMEN

**Objetivo:** Comprender la participación de la familia en el cuidado al niño ingresado en una Unidad de Cuidados Intensivos Neonatal y Pediátrico (UCINP). **Métodos:** Investigación exploratoria, descriptiva y de naturaleza cualitativa. El estudio se realizó en un hospital universitario del norte de Minas Gerais, Brasil, con la participación de ocho padres de niños ingresados en la UCINP. Se recogieron los datos a través de entrevistas semiestructuradas las cuales, a posteriori, fueron sometidas al análisis de contenido, generando dos categorías: vivencia del cuidado con el hijo en la Unidad de Cuidados Intensivos y factores que facilitan y dificultan el cuidado. **Resultados:** Se evidenció que la familia no está totalmente involucrada con el cuidado del niño ingresado. Eso se da por los sentimientos de miedo e inseguridad de los padres, la restricción de la complejidad y tecnología de los aparatos utilizados en la asistencia, la indisponibilidad de tiempo de los familiares por dedicarse a otras funciones y por el hecho de vivir en otros municipios. El apoyo del equipo del sector fue identificado por los entrevistados como un factor que facilita el cuidado. **Conclusión:** El estudio refleja sobre la importancia de la participación de los padres en el cuidado del niño que está con cuidados intensivos y destaca que el involucramiento de la familia es una necesidad que debe ser considerada por los profesionales sanitarios en el proceso de la asistencia integral al cliente pediátrico.

**Descriptores:** Cuidados Críticos; Niño Hospitalizado; Cuidado del Niño.

## INTRODUCTION

The family is a group of individuals that is considered the main unit of development of the child as it is endowed with symbols, perspectives and skills to take on roles. As the first unit of care, it represents a social space in which its members interact and exchange information in addition to relying on each other and seeking solutions when health-related problems are identified. Most often, it is the emotional reference for its members. Each member now relies on the others when they need help, and parents should take on the responsibility for their young children<sup>(1-3)</sup>.

Since birth, the child starts a continuous process of growth and development in which s/he gains experience, abilities and skills. It is expected that s/he can go through all stages of life fully healthy and reach adulthood aware of the references of health promotion and quality of life; however, the child population does not always evolve this way. Hospitalization, when necessary, makes the child and family go through a period where they need to adjust to a new reality and a different moment in their lives. The

hospital world is something strange and extraordinary in their existential and experimentation trajectory<sup>(4)</sup>.

The child's admission to an Intensive Care Unit (ICU) is almost always considered a fatality in family life and often consolidates the detachment from the child and the sense of loss, leading parents to a sense of mourning as it is common to relate hospitalization in this scenario to the proximity of death<sup>(5,6)</sup>.

In the ICU, children live with aggressive, stressful and painful therapies resulting from technological advances in health care which produce physiological and behavioral disorganization and have a negative impact on their care. For parents, it is an environment of hope and fear. The hope is because they know that it is a place that is better prepared to serve their child and increase the chances of survival. The fear is because they know the risks inherent to patients admitted to such environment; in addition, there also feelings of frustration because they are not generally prepared for this separation<sup>(7,8)</sup>.

Studies point out the importance of family presence as an effective method to minimize the negative effects of hospitalization, mitigate disease and procedures stressors, as well as contribute to the treatment and recovery of children<sup>(9)</sup>. Given the knowledge of the benefits of maintaining family ties to the child's emotional health, the Statute of the Child and Adolescent (*Estatuto da Criança e do Adolescente – ECA*, Law No. 8069) ensures the presence of a companion during a child's hospitalization since 1990 with a view to a more humanized care<sup>(10)</sup>.

In the last thirty years, major changes have been implemented in ICU environments, following, in a certain way, a worldwide trend. The incorporation of new technologies, the increasing inflow of different professional categories in these services, the increasingly frequent presence of parents in sectors that were once very restricted, the practice of family support groups, the encouragement of parents' participation in the care of their child and in decision-making of treatment are already part of a reality that requires different attitudes of the healthcare team professionals<sup>(11,12)</sup>.

In this context, the health professionals who work in these units should now adopt a care model centered on the child and family based on a philosophy of modern care<sup>(7)</sup>. Changing the traditional perspective of care focused on the disease for an approach focused on the child and family in the ICU may not be something easy but it is a necessary task in the process of comprehensive and humanized health care considering the singularity of each core, member and family dynamics. The professional should promote the

companion's awareness of the reality experienced in the hospital and the preservation of the family-child bond<sup>(3,5)</sup>.

Considering that the inclusion of the family in the care of the child who requires intensive care is a necessity that needs to be considered by health workers in daily clinical practice<sup>(13)</sup>, the present study seeks to answer the following question: how has the family participated in the care of the child who experiences hospitalization in an ICU?

Thus, it is expected that the present study may provide contributions to the knowledge and care of the child in the ICU context to identify aspects that can contribute to a greater involvement of the family in the care process during the child's hospital stay, favoring the recovery and aiming at improving the care of the pediatric client.

Thus, the present study aimed to understand the family involvement in child care in a Neonatal and Pediatric Intensive Care Unit (NPICU).

## METHODS

This is a qualitative exploratory and descriptive research conducted in the Neonatal and Pediatric Intensive Care Unit (NPICU) of the Clemente de Faria University Hospital (*Hospital Universitário Clemente de Faria*). This hospital, which is located in the municipality of Montes Claros, Minas Gerais, Brazil, provides free and universal care through fully public services. The institution has 186 beds, 20 of which are in the NPICU, which serves children from birth to 12 years of age: ten beds are intended for intensive care and the other 10 are intended for intermediate care - nursery.

The research population was composed of eight parents of children admitted to the NPICU. Inclusion criteria were: participants should be at least eighteen years old and should have been accompanying their children for at least six days during the period of data collection - during this period, the family would have already experienced the routine of the hospital unit, allowing greater contact between the child and the health team.

Data were collected in February 2014 by one of the researchers of this study through individual semi-structured interviews consisting of the following guiding questions: *How have you participated in the care of your child in the ICU? What difficulties and facilities have you found in such care?*

The interviews took place in a private place in order to maintain the privacy of informants lasted, on average, 20 minutes. The statements were recorded using a digital recorder and then were transcribed. The interruption of data

collection occurred when there was saturation of the themes investigated. In the collection of qualitative data, the appropriate number of interviews should be understood as the one capable of reflecting the totality of its dimensions<sup>(14)</sup>.

The organization and analysis of information were performed on the basis of thematic content analysis, which consists of three phases: pre-analysis, exploration of data, treatment of results and interpretation. In the pre-analysis, the interviews were fully transcribed and read through several times in order to obtain maximum information. Then, statements were mapped and the key points were highlighted in order to facilitate the visualization of the material as a whole. In the next phase, the codes were identified and the necessary refinements were performed.

Finally, researchers sought to capture the information contained in the statements to establish the categorical units of the study<sup>(15)</sup>. The analysis of the statements identified two thematic categories: *“Experiencing the care for the child in the Intensive Care Unit”* and *“Factors hindering and facilitating care”*, which were discussed based on studies on the subject.

The research project was approved by the Research Ethics Committee of the State University of Montes Claros (*Universidade Estadual de Montes Claros – UNIMONTES*) – Opinion No. 473.488/2013, complying with the ethical principles established by Resolution 466/12 of the National Health Council/Ministry of Health<sup>(16)</sup>. All the participants read and signed the free informed consent form in duplicate. To ensure the anonymity, the study participants were identified by codes (I1 to I8) representing the order of the interviews.

## RESULTS AND DISCUSSION

This section presents the data related to the results of the study and the thematic categories that emerged from it.

Participants were seven mothers and one father whose age ranged 18-36 years. The length of stay of their children at the time of the interview ranged from seven days to five months.

### Experiencing the care for the child in the intensive care unit

This category covers the experience with the care for the child in the Intensive Care Unit. Parents reported that they accompany their children every day, with no visiting hours restrictions in the ICU. Procedures such as breastfeeding, diapering, affective contact and medication monitoring were mentioned by some respondents as forms

of participation in the care of their children, which become evident in the following statements:

*“[...] It has been two days since I started breastfeeding and handling, having real physical contact, cuddling him.” (I1)*

*“[...] I stay close to her, I can touch her, I hold her [...]. I keep watching, paying attention [...] to what they are doing, to the medication they are giving.” (I5)*

These statements corroborate a study whose results showed that the warmth, intimacy and constant relationship with the mother – or another person who replaces her on a permanent basis – are considered essential to the mental health of the hospitalized child, making it possible to establish an affective bond through tactile (touching and caressing) and auditory (talking and singing) stimuli<sup>(9)</sup>.

Study shows that according to health professionals working in an Intensive Care Unit, parental participation in the care, in addition to promoting the establishment of a bond, also contributes to reduce the child's hospital stay and favors the continuity of care at home<sup>(17)</sup>.

It should be noted that the family is the main source of safety and support and the defender of the child. Studies highlight the importance of family involvement in health care as a way to favor the psychosocial development of the hospitalized child<sup>(7,18)</sup>.

For the mother, participating in the care of the child is a chance to contribute to her/his cure, minimizing the feeling of guilt due to the child's illness. The authors describe that when caring for the hospitalized child, the mother recovers what is hers and regains her autonomy, leaving behind a background role and taking a lead role in the care of sick child<sup>(13)</sup>.

However, there are times when the mother's affective state becomes a factor that can inhibit their participation in the child's care; they do not recognize themselves as capable of providing maternal care, which is manifested as feelings of fear and insecurity and becomes evident in the following statement:

*“[...] I think she is still very fragile. I am afraid to hold her, you know, and hurt her.” (I2)*

This verbalization is in line with a study that aimed to know the experience of parents who had their children admitted to ICUs since birth. Research has demonstrated that having a child in such environment represents great uncertainty for parents due to the child's fragility and the possibility no survival. The emergence of these feelings represents an emotional response to situations requiring adaptation<sup>(6,19)</sup>.

Embracing parents is significantly important so that the experiences that may occur during this period are well accepted and the suffering is minimized. The focus on the family requests, their expectations and feelings requires actions that should be carried out by the nursing team, which strengthens the bond and favors the physical and mental development of the child through humanized care<sup>(20,21)</sup>.

Another aspect that interferes with parental participation in the care, as reported by one interviewee and described below, indicates that sometimes there are restrictions regarding family presence during procedures carried out by the health team.

*“[...] Sometimes we have to wait a little bit because they are medicating, doing something, an x-ray, something that we are not allowed to enter.” (I8)*

Most international pediatric guidelines allow the presence of parents accompanying their children during hospitalization – even in emergencies – as they understand that is a way parents can accompany the whole care and thus accept more easily the health-related events. In this sense, keeping the family away from medical and nursing procedures carried out with the sick child exacerbates parents' helplessness in relation to the child's situation<sup>(7,22)</sup>.

Carrying out invasive procedures and separating parents from the child are the main factors causing fear and anxiety in the child during hospitalization; therefore, according to the author, the permanence of the parents during the procedures should be encouraged<sup>(23)</sup>.

In the present study, the following statements show that there are times when family members accompany their children as spectators in a non-participatory manner and are not allowed to be involved in the child's care.

*“[...] So far, I have had physical contact with him for two days, but I was just watching.” (I1)*

*“[...] In the ICU I could not hold her because I was not allowed to do so there. And here in the nursery I arrived and she was still sleeping, but as soon as she wakes up I will hold her and breastfeed her.” (I2)*

*“[...] We wish we could cuddle, flatter, but we can not, right? We have to conform with it.” (I8)*

Some studies show that parental involvement is a complex subject that is addressed in a fragmented manner and there is still a lack of clear indicators of how such participation could be facilitated and supported in an institution. Family integration in the care context of the Intensive Care Unit is a necessity that needs to be considered and reconsidered by health workers as empirical evidence on the impact of the child hospitalization process

on the family dynamics is enough for the implementation of a family-centered care in the daily clinical practice<sup>(9,13)</sup>.

The mother's participation in the child's care in the ICU is not fully explored because the care is provided based on the professional's understanding of how the mother can participate – and not based on a mutual construction. In this sense, the team should know how parents would like to participate in the child's care, identifying, together, the best way to do so<sup>(24)</sup>.

### Factors hindering and facilitating the care for the child

In this category, the participants revealed the main difficulties and facilities experienced during the child's hospitalization process.

One factor regarded as hindering parental participation in the care is the fact that they cannot stay with the child as long as they want because they need to perform other duties, including activities with other family members, and because they live in other municipalities.

*"[...] I am not from Montes Claros, I am from Brasília de Minas and it is very difficult to come here to be with her." (12)*

*"[...] I do not have time, because I really want to stay. During this short time I have I also have to accompany my wife in the ICU [...]. Because we live far away, there is no way to come every day, stay longer. We only stay as long as we know we can stay." (16)*

*"[...] Lately I have been staying longer. Some days I stay only twenty minutes because it is very difficult. Because I also need to accompany my father who was in hospital and is now undergoing radiation therapy [...], but when I can I stay longer." (17)*

The lack of financial resources and operational and material difficulties were pointed out by mothers in a study as major factors that prevented them from accompanying their children admitted to an ICU. The lack of accommodation for families in the unit also hinders the contact between parents and children in the hospital<sup>(6,22)</sup>.

The study locale guarantees the right to full-time presence one of the child's parents and offers a recliner for the companion's accommodation and meals: breakfast, lunch and afternoon snack. Considering that the institution has a policy for serving the users of Brazil's National Health System (*Sistema Único de Saúde – SUS*) and receives, therefore, children from different places, it is necessary to develop strategies to meet the specific needs of families based on the justification of the need for parents to stay together with their children.

The family should be encouraged by the health team to participate in the care of the child during the time they are at the hospital, even if they spend a short time. This is because when parents participate in the care they can maintain the emotional bond with the child, feel active and participate in the treatment and, above all, share the responsibility over the hospitalization and care of the sick child<sup>(13)</sup>.

Some statements show that parental participation in the care is often limited and restricted due to the complexity and technology of the equipment used in the care of their children within the unit, which is expressed in the following statements:

*"[...] He is in the incubator; he has already been released to be put in the crib [...]. I am waiting on them to do this for me (sic) so I can have a closer contact with my son. So I would not need to be asking them to handle him, I could be holding him on my own, changing diapers and having more contact, right? Be closer." (11)*

*"[...] I have participated very little in the care for him, because I still cannot cuddle him. He still needs oxygen and cannot be moved from the crib." (17)*

It is clear in these statements that during hospitalization the family is faced with a new scenario that generates apprehension and anxiety due to the procedures that may be necessary. Many devices such as monitors, ventilators and infusion pumps are used in the care of the severe child in the ICU, and the use of these technologies leads family members to feel uncomfortable to participate in the child's care, increasing, therefore, the professional's power over the care provided<sup>(23)</sup>.

The statements of another participant show that the lack clear information provided by the health team to the family is another factor interfering with care.

*"[...] All the care that she needs she gets, but sometimes we do not have knowledge of the subject. And they say a more difficult word, some formula they say [...], a more difficult technical term. But clear, accurate information given to parents would be good. It is a matter of information, saying what it is [...], more clarity in information." (15)*

The information given to the family about the care of the child is like a strategy that ensures the mother's right to information and contributes both to their involvement in the care of her child and to the proximity to the team. The effective communication between parents/family members and the healthcare team was identified as an important factor for solving and minimizing conflicts and may be crucial for parents to feel safe in an environment alien to

them given their weakness and their feelings regarding the hospitalization of the child<sup>(17)</sup>.

Information must be given in a delicate and gradual manner according to the family's understanding. According to the authors, the family is often ashamed to ask questions to the team, feeling insecure and having unfounded beliefs about the child's situation. Therefore, it is important that the health team talks to the family, explains the technical procedures, clarifies the doubts and keeps it informed about the child's health without forgetting the physical, cultural, emotional and socioeconomic contexts of such family<sup>(23,25)</sup>.

With regard to the aspects facilitating the child's hospitalization process in the ICU, the statements described below point out that the interaction and support from the healthcare team are essential to face this process. Parents value the dedication of the team and report that professionals are attentive and clarify all their doubts.

*"[...] The team is very attentive to us and to the child too. They clarify all the doubts we have." (I2)*

*"[...] I really like it here, everyone is so attentive, everything they can do for us they do." (I8)*

It should be noted that the dialogue between mothers and health professionals was the factor identified in a study that showed the visibility of the possibilities of maternal participation in the care and the mutual creation of alternatives to implement them<sup>(24)</sup>.

In this perspective, the multiprofessional care becomes fundamental to the strengthening of interpersonal relationships with family. Given that, it is necessary that the team is aware of the importance of its intervention and its role in relation to potential difficulties that may arise during the family's stay in the unit. Health professionals should value emotional aspects, identifying vulnerabilities, and also the interaction with the family in order to provide security, affectivity and qualified care<sup>(17)</sup>.

However, religiosity appears as a cornerstone as parents rely on God to improve their child's health through their prayers.

*"[...] Being patient, praying, asking God and Our Lady to bless the hands of physicians and nurses and asking for good health for him. Good health, long life." (I8)*

Religious beliefs are mediators in addressing issues related to the health-disease process as they increase confidence and favor the attribution of meaning to stress episodes. For the authors, spirituality emerges as a remarkable factor in the experience of families who have a loved one who is hospitalized. Thus, it is up to the team to respect and support this religiosity, allowing the family to

establish spiritual connections to overcome the obstacles of such experience<sup>(6)</sup>.

## FINAL CONSIDERATIONS

The present research showed that parents are not fully inserted in the care of the child admitted to an NPICU. This is due to feelings of fear and insecurity in the family, restrictions posed by the complexity and technology of the equipment used in the health care, unavailability of time of family members who need to perform other duties and who live in other municipalities. Furthermore, there are restrictions regarding parental participation in the child's care procedures and also regarding the use of essentially technical language by professionals, which hinders the relationship between the healthcare team and the family.

The interaction with parents and the support from the healthcare team were key factors to face the child's hospitalization. Therefore, it is essential that health workers can identify the needs of each family and recognize them as an integral part of the care of hospitalized children. Thus, parents should be encouraged to participate in the care of the hospitalized child, even for a short period of time. By participating in the care, they can preserve the emotional bond with the child, feel active and contribute to a faster and better quality recovery. It is expected, therefore, that the present study may foster reflections to strengthen existing practices and to help build new alternatives for family participation in the care for children in ICU.

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**First author's address:**

Daniele Zuba Ramos  
Universidade Estadual de Montes Claros - UNIMONTES  
Campus Universitário Professor Darcy Ribeiro  
Avenida Dr. Ruy Braga, S/N  
Bairro: Vila Mauriceia  
CEP: 39401-089 - Montes Claros - MG - Brasil  
E-mail: danielezuba@yahoo.com.br

**Mailing address:**

Cássio de Almeida Lima  
Rua Dom João Pimenta, 781 apt 02  
Bairro: Centro  
CEP: 39400 003 - Montes Claros - MG - Brasil  
E-mail: cassioenf2014@gmail.com