The family’s adaptation process to their child’s hospitalization in an Intensive Care Unit

O processo de adaptação familiar à hospitalização infantil em Unidade de Terapia Intensiva

El proceso de adaptación familiar a la hospitalización infantil en una Unidad de Cuidados Intensivos

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ABSTRACT
Objective: To learn about the adaptation process of family members when experiencing their child's hospitalization in an Intensive Care Unit. Method: A qualitative, descriptive and exploratory study conducted at the Pediatrics Unit with family members of children from the Pediatric Intensive Care Unit. The thematic analysis technique was used. Results: Thirteen (13) family members, 12 mothers and one father participated. The following categories emerged from the results: Family impact on children's hospitalization in a Pediatric Intensive Care Unit and Mechanisms for adapting family members to hospitalization in a Pediatric Intensive Care Unit. Conclusion: The mechanisms adopted by the family in the process of adapting the child to admission to the Pediatric Intensive Care Unit were: positive thinking, understanding the treatment and the operation of the unit. Health professionals can offer strategies to the family in order to make hospitalization less traumatic, making it possible to share experiences and expand the knowledge of those involved.

DESCRIPTORS
Child, Hospitalized; Family; Caregivers; Intensive Care Units, Pediatric; Pediatric Nursing; Professional-Family Relations.
INTRODUCTION

The family is the child's first place of psychological, moral, social and spiritual formation\(^1\). A child's illness process is a situation which changes and impacts family dynamics, being permeated by doubts and uncertainties which cause psychological distress for the family and the sick child\(^2\). If hospitalization in itself is a distressing event generating stress and insecurity due to the vulnerable condition of the child's health, coping with this situation is even more difficult.

Families have anguish, feel fear and insecurity upon receiving the news of the need for their child's hospitalization in a Pediatric Intensive Care Unit (PICU), initiating a state of continuous surveillance motivated by concern, especially when they experience hospitalization for the first time. At this moment it appears that families begin an adaptation process to cope with the situation\(^3\).

The situation is nuanced to a greater extent when hospitalization takes place in the PICU. For relatives of the hospitalized child, the disease is a sudden event that the family does not expect. Thus, when they experience the phenomenon of falling ill, they become vulnerable due to the impact and uncertainties generated by the illness\(^4\) and the hospitalization. Although it can be explained in technical terms, it is difficult for family members to understand and emotionally accept the facts.

The PICU environment can constitute a threat to the family as it is an unknown location, and there may be a rupture in the affective interdependence among its members. Interdependence can be understood as the relationships in which love, respect and values are exchanged between individuals, favoring a feeling of security in a given context\(^5\). The impact regarding children's hospitalization needs to be worked with family members in order to minimize stress and suffering, providing a more comfortable environment for adaptation in relation to the situation to be experienced\(^5\).

In being faced with hospitalization, families can show themselves as adapting to the situation through adaptive responses, meaning those which are capable of promoting the comprehensiveness of the person in terms of survival, growth, reproduction and dominance. Adaptation also occurs due to ineffective adaptive responses, considered those which do not promote comprehensiveness and do not contribute to the objectives of adaptation, and which can threaten the person's survival, growth, reproduction and dominance; these still constitute an adaptive response even in these conditions. Thus, it is necessary to look at individual behavior according to the general objectives of adaptation in order to assess the process\(^5\). The way the process takes place will trigger adaptation mechanisms which will imply in how to cope with the hospitalization process.

Based on the above, the starting point of this study was to elaborate the guiding question: How does the adaptation process of family members occur when experiencing a child's hospitalization in a Pediatric Intensive Care Unit? In order to answer this question, this study aimed to understand the adaptation process of family members who experience their child's hospitalization in a Pediatric Intensive Care Unit.

METHOD

STUDY DESIGN

A qualitative, descriptive and exploratory study.

SCENARIO

The study was carried out in a large general hospital located in the South Region of Rio Grande do Sul state, Brazil. The hospital has mixed public and private general care, thus the PICU has eight beds for the care of the Unified Health System, and two beds for private health insurance plans. Data collection took place during the months of June and July 2017.

POPULATION

The inclusion criteria for the participants were family caregivers of children who accompanied their admission to the PICU and whose children were discharged during the data collection period, regardless of the number of hospitalizations the child already had experienced in their history. The exclusion criteria were family members of children who died; relatives of children in palliative care, and relatives of children under 18 years of age.

DATA COLLECTION

One opted for the semi-structured interview as the data production technique, as the data is obtained directly from statements through reports of experiences, feelings and perceptions around a specific subject. The invitation to participate was carried out face-to-face by the interviewer, a nurse and a Master's degree student with experience in qualitative research and who had not previously known any of the participants. All the family members agreed to participate, with no refusal at any time during and after the interview. At the time of the invitation, a Free and Informed Consent Form was presented in two copies, read, any questions were clarified, and then the form was signed by the participant. One copy was delivered to the participant and the other remained with the researcher. The choice of participants was intentional, from each admission to the Pediatric Unit after discharge from the PICU.

The interviews were conducted using a semi-structured questionnaire with closed questions tracing the profile of the interviewees, and the following open question for the analysis of this article: Talk about what it was like to experience your child's hospitalization in the PICU and what you did to adapt to the situation.

Each interview was conducted in the room in the Pediatrics unit according to the choice of the participants, with the family member to be interviewed, the child and the researcher. The interviews had an average duration of 30 minutes and were recorded individually in audio with an MP4 device. Thirteen (13) family members of children who were discharged from the PICU participated in the study, being 12 mothers and one father. The number of interviews was interrupted when there was data saturation\(^6\).
The interviewees were identified as F1, F2, respectively, with the letter “F” corresponding to “Family” and followed by a sequential number according to the order of the interviews.

**DATA ANALYSIS AND PROCESSING**

Thematic analysis by Braun and Clarke was used for data interpretation, which consists of six phases: 1st phase: familiarization with the data; 2nd phase: generating initial codes; 3rd phase: searching for themes; 4th phase: reviewing the themes; 5th phase: defining and naming themes; 6th phase: producing the report. The results were discussed in the light of Nurse Callista Roy’s Theory of Adaptation.

According to the Callista Roy model, the person is an adaptable system in which the input via stimuli, whether focal, contextual or residual, activates regulatory and cognitive mechanisms with the objective of promoting adaptation; on the other hand, the outputs are their responses, meaning their behavior will derive from adaptive or ineffective adaptive responses. Stimuli cause different behaviors in individuals, as they are related to intrinsic coping factors. Thus, the goal of nursing is to promote the adaptation of the person, group or community based on adaptive modes and to contribute to the health promotion of individuals.

**ETHICAL ASPECTS**

This study was developed respecting the ethical precepts of Resolution 466/12 of the National Health Council, which deals with research involving human beings. The project was approved by the Ethics Committee of the Faculty of Nursing of the Universidade Federal de Pelotas under Opinion no. 2.197.011/17.

**RESULTS**

Thirteen family members of children who were discharged from the PICU participated in the study, of which 12 were mothers and one father, aged between 18 years and 39 years. Regarding marital status, five participants were married and eight were single. Four participants experienced the hospitalization process for the first time and nine experienced rehospitalization. Four participants declared themselves to be Catholics, two were atheists, one evangelical and five said they had no religion, but reported that they believed in God. The following categories emerged after analyzing the data: “The family’s impact in facing a child hospitalized in the PICU” and “Mechanisms for adapting family members to PICU hospitalization”.

**THE FAMILY’S IMPACT IN FACING A CHILD HOSPITALIZED IN THE PICU**

The family’s experience in facing a child’s hospitalization in the PICU has an impact, which at first generates feelings of anguish for the child not waking up due to sedation, in addition to the presence of different devices previously unknown by family members. In this sense, the family suffers for not being able to help and fears for the child’s life.

*The first time I saw it, I felt an impact, it wasn’t easy, then you want that person to wake up and he doesn’t wake up (F1).*

Very badly, because it’s bad to see, sedated and with everything connected to her [devices], you talk to her, I knew she was sedated, but she didn’t react, it’s complicated! (F3).

Horrible, I suffered a lot (…) I had to be very strong (F6).

It’s horrible, the feeling that you see, inside, those children connected to those devices (F7).

It wasn’t very easy, we despair in seeing a child in that situation, I was very down, very nervous, but I had to be strong because be only depended on me inside (F9).

In this context, the family perceives its vulnerability as a human being, an unstable being who at any time may need support to face the situation in which they find themselves.

It’s difficult, first because, look, this is where you see [perceive] how sensitive you are, vulnerable, depending on everyone, but you can’t interact with him very much, even if you know that he is sedated (F5).

Imagine, I never thought of one day having to experience all this here, we are groundless, waiting for better days (F12).

The experience of hospitalization in the PICU is described by family members as the worst moment of their lives, as shown by the statements below.

*The worst thing I’ve ever been through, for a mother to see a child like that, it’s very difficult! [Crying] (F2).*

*The worst thing in the world, something that never seems to end, constant suffering (F13).*

On the other hand, the hospitalization process brings positive feelings to the families, which are related to the safety offered by the environment, the materials and the hospital staff.

*I felt very safe with the situation he was in, it was the only place he was bad, in there [ICU] he was monitored, [with] doctors there 24 hours a day, and so I was calm, even though we are distressed because we don’t have him suddenly improve, because we want him to get there and get better, but even so he got better very fast. I thought that there he had a real improvement, you looked and saw his improvement (F5).*

*When he went to the ICU, we saw that he started to improve, we felt safer (F8).*

*I thought it was much safer for him to be there [in the ICU], I felt safer, more protected with him there (…) than [with] him out there (F10).*

Thus, it can be observed that the family member starts an adaptation process already at the moment of hospitalization, since they receive focal and contextual stimuli when they experience an impact from the PICU environment with all the devices connected to the child, with the severity of the clinical condition, generating feelings of anguish and psychological suffering. However, when family members understand what is happening and how their child will be treated, they begin to show adaptive behavior, feeling safe because their child is in a place with so many technological resources.
MECHANISMS FOR ADAPTING FAMILY MEMBERS TO ADMISSION TO A PICU

After the first impacts of the child’s hospitalization, family members demonstrate behaviors which show adaptation to the new environment. Such a reaction makes them able to stay longer with the child, even in confronting feelings such as anguish and fear.

The first time it was more, I was scared because [she] was very tiny, it was very difficult. I went in and I couldn’t even stay inside to see her, after two days I managed to get in and stay longer, then I was getting used to it (F3).

It’s all very difficult, but the days go by and you understand how everything works, and everything improves, you feel more comfortable with the environment with the whole situation, however distressing it may be (F13).

Family members report that the initial impact is managed and then changed, and after some time you ‘get used to it’, and the impacting look on technological devices transforms, as shown in the excerpts below.

It’s horrible, it’s a feeling which is like something very bad is going to happen, it’s that feeling that we have when you see it, then it passes, then you get used to it, it’s only the first impact, but it passes. It’s something that every time you come and look, it’s only first [moment], then it passes, (...) then you already see it as normal, as if it were clothes [cardiac monitoring], this is how we see it (F5).

We have to experience it one day at a time, you know. The first days were horrible, then you get used to it inside (F7).

I had to adapt (...) I had no other choice, I had to face it and be strong (F6).

On the other hand, F12 presents other strategies which help in coping with the situation in search for adaptation:

We learn if we don’t always think positive, if we don’t think, if I don’t think my son will get better, if my family doesn’t send positive energy to me, my friends, they know too, we lose strength, I’m here alone (F12).

In observing the dynamics of the unit and getting to know the experience of other families as the days go by, family members comfort themselves and start adapting. They get used to the situations they experience.

I found it very, very, very tense, but then I got used to it, getting used to it and over time we get used to it (...) with the climate here, that children will arrive, that there is a child who is pretty bad in the room [PICU] that he was in. In the part there, there was a little girl who was very bad, all the time doing a procedure, it was very bad (...) I see that my son isn’t so bad. I won’t say that I got used to it, but I already knew how to deal with me (F4).

DISCUSSION

Family members are confronted based on focal, contextual or residual stimuli during the period experienced at the PICU in relating the impact of hospitalization to the adaptation level.

The focal stimulus, internal or external, is the one which most immediately confronts the family member; it is the event which attracts the person’s attention, in this case a view of the child in a PICU bed being severely affected by a disease, connected to devices and with death imminent.

The contextual stimulus in this case is related to all stimuli present in the situation; for example, environmental factors which directly influence how the family member will deal with the focal stimulus. The term adaptable means that the human system has the ability to effectively adjust to changes in the environment, and in turn affects the environment(13).

From this, the family member is confronted with various stimuli within the hospital environment which generate impacts and consequently elaborates an adaptation, with its change point focused on the ability to understand what is happening, and the absorption of what is to come regarding their child’s treatment(8). Many feelings can emerge in view of the moment experienced by family members when they come into contact with the transformations derived from treatment and with the possibility of death, for example, fear, insecurity, anguish and loneliness, disorganizing the family members(8). Thus, they project their expectations for the future for an adaptive process inherent to the hospitalization period when suffering a stimulus.

In its adaptive process, the family receives a focal stimulus as input, which confronts them with the moment of admission to the PICU through a perception of the severity of their child’s condition, and being linked to technological and invasive devices. Thus, they go into momentary suffering, disorganizing everything they have idealized about a healthy and full childhood.

Being a family member of a baby or child who has been placed in intensive care is a very difficult experience(8); it is critical, delicate and carries a great deal of psychological stress and emotional disparity, which has cumulative effects with long periods of hospitalization due to peculiarities of the hospital environment, leading to feelings such as sadness and anxiety(9), as family members need to understand the diagnosis, surgery and imposed treatment in a short period of time, which leads them to comprehend the health-disease process and learn to emotionally deal with the changes which occur(11).

An international study reaffirmed that the members of a family form a system, they usually experience psychological symptoms which can consequently result in stress disorders, depression and anxiety arising from the hospitalization process, which may persist after discharge, as well as within the wards and even after hospital discharge(10).

A study reports that the family suffers from the absence of the sick member and begins to learn to live with the momentary interruption in the family routine. Thus, the family, especially the mother, begins to dedicate their days to caring for the sick child, changing her daily life in facing the affliction which permeates the situation, in addition to the constant fear of the child’s death. This stressful event also correlates with the fact that the family is not prepared for all the changes which come from the sudden hospitalization and the entire hospital course(13).
Performing care establishes that those who do it have a disruption in their way of life which was previously lived before the disease. Thus, in order to accompany an inpatient, it is essential to rework their individuality, as the family caregiver gives up their leisure activities and gives up work to be at the service of the patient, in addition to the anguish and fears arising from the moment experienced.

Faced with changes, the focal stimulus is also exemplified when the family enters the PICU for the first time. Family members deal with several sensations at that moment, with the vision of an unhealthy child surrounded by devices. This situation is defined by family members as painful. Still, they report breaking up, needing to be strong to confront the hospitalization process.

When a child is admitted to a PICU, the child’s first reactions within the process generate negative feelings in the family, including fear, sadness, despair, nervousness, uncertainty and insecurity. From this point of view, the feeling of sadness installs itself when seeing the child in a situation never before experienced, being submitted to procedures and a newly defined treatment, impacting the families in such a way that the uncertainty and insecurity becomes something paramount which reaches everyone. Moreover, anxiety is felt by family members when participating in the physical and emotional suffering generated by the critical environment, making it difficult for family members to adapt during hospitalization.

In agreement, it is noteworthy that family dysfunction due to a child’s hospitalization in the PICU can be intensified by uncertainties and anxieties generated by the critical and emerging changes in the child’s health. Thus, it is stated that the sources of stress for family members include: insecurity related to the PICU environment, the child’s health condition and changes caused by the disease and even the proximity to death.

The contextual stimulus is correlated with the family member’s idea that the PICU is related to a symbol of death, plus the perception of a sad and desolate environment, and the child’s separation. Then, reactions arise which will directly resonate with the way they will deal with such a situation. The family member finds themself enveloped in a totally new context in this environment, in which stress, fear, and sometimes not accepting the child’s condition are constantly experienced.

The PICU environment is full of technological equipment, which can trigger the fear of the unknown in both the companion and the child. Thus, the family member may present an adaptation process with ineffective responses, hindering the natural process, impairing its comprehensiveness and the family’s well-being in the imposed circumstances.

In this context, it is understood that “the child’s hospitalization in the PICU is highly stressful, and affects all family members in various ways, as they feel vulnerable and sensitive due to the treatment offered to the child, without being able to help in the process. Thus, when families are faced with the complicated hospital world, they create ways of coping, with a view to healing and restoring the patient and family dynamics.”

A study reveals that family members feel overwhelmed within the PICU, afraid to see their children connected to all the devices, referring to the need to become familiar with technology as they trust science and believe that their children are being well taken care of and will improve.

Human vulnerability is revealed through suffering and constitutes a reality which accompanies the family’s life in all its trajectories, different ways and forms. It is understood that families identify their deep sensitivity in their suffering, in a totally unknown world, in which the health team is in charge of all the decisions which permeate the process.

From this perspective, family members receive contextual stimulus which is present in the environment, linking the hospitalization moment and their vulnerability in the process as the worst moment of their lives. The moment constitutes something that they had never experienced, which brings suffering, associating the unknown environment with the fear of treatment, death and the nuances which accompany hospitalization in the Intensive Care Unit.

In this context, it is believed that family members feel unstructured, at the mercy of the diagnosis to be informed by the health team, stripped of all the control they were used to. They often relate feelings of guilt and anguish for the child’s health status, being impacted by devices and sedatives within the intense treatment of critical patients.

Thus, it turns out that family members, at a first glance, understand hospitalization in a PICU as ‘something horrible’, later evolving to the thought that the child is in the best place they could be, receiving the appropriate treatment for their condition, going from ineffective adaptation behavior to one of adaptation. “The family tries to effectively adapt to the changes generated by the disease and the child’s hospitalization by finding positive meanings which favor the coping process and the adaptation to the demands added to their daily life.” Therefore, in considering the focal and contextual stimuli and the situations which confront family members during child hospitalization, they tend to adapt during the hospitalization, which is the best form of coping, making them stronger and united.

Family members demonstrate adaptation mechanisms to reach a level of adaptation, generating ‘positive feelings such as the hope of improving the health of the hospitalized child and the confidence that in the end everything will be OK’. Thus, family members point to the feeling of hope when they see that their child is in the best place, provided with resources and intensive care and 24-hour monitoring, and this constitutes as an adaptation mechanism.

Families reveal that their suffering is lessened during the child’s hospitalization when, for example, they accompany an improvement in the health status of their child and the other children hospitalized in the unit; they participate in care and see the commitment of health professionals during hospitalization. When the family member is allowed to take care of the child, their role as primary caregiver is reinforced, the one who takes care of the child’s development from the beginning of life, thus elevating the mode of self-concept regarding their psychological needs, realizing that they are useful for treating the child.
In this context, family members say they feel safe and protected due to intensive treatment, looking towards the comprehensive treatment their children will receive and with hope of improvement from a definition of the diagnosis and the beginning of treatment. Thus, it is evident that despite the severity of the child’s clinical condition, the fact that the child is being monitored 24 hours a day by a multidisciplinary team trained to care for the critical patient raises a feeling of safety and protection of family members, and consequently decreases psychological distress in facing the impact of their child’s hospitalization, revealing itself as an adaptation mechanism.

“The human being is a biopsychosociocultural–spiritual being, and any change in one of these dimensions has repercussions on the others; the disease and hospitalization process generates adaptations, changes and mobilization of subjective contents”(22). When referring to a child admitted to the PICU, the family members’ emotions may be more intense(22), with negative feelings arising from the impact of the hospitalization emerging in these family members. However, over time they demonstrate attempts to overcome adversity, which indicates an adaptation pattern to the circumstances to be faced.

Although the ICU represents an unknown and stigmatized environment, family members, when faced with the reality of illness and hospitalization as the days go by, begin to recognize it and adapt to it as a safe environment due to the technical and scientific support, which allows complex and necessary interventions to recover the child’s health(22). Allied with the search for the best form of coping, family members demonstrate a level of adaptation in this phase with positive thinking about their child’s recovery; this is defined as a point of change, which represents the person's ability to respond positively in a situation. This point of change is influenced by the demands of the situation and internal resources, including capacities, hopes, dreams, motivations and everything which makes the person move constantly towards the domain of the adaptation process(23).

Adaptation mechanisms are also demonstrated when family members compare the clinical status of other children to that of their children, and it is possible to see the evolution of each child, linking positive thinking to each day lived within the PICU. In this way, family members gain experience and win day after day of hospitalization, developing their own adaptation mechanisms in facing what they consider to be the ‘worst phase of their lives’. Thus, it is clear that the development of adaptation is essential for family members to be able to cope adequately with their children's hospitalization in the PICU, regardless of what resources they use to do so. Adaptation is developed by family members as the days go by, while anguish and suffering are minimized when they realize that their children are receiving the best and the most appropriate treatment for their condition, with hope and comfort emerging.

Regarding the whole perspective presented, it is up to nursing to carry out actions which reduce anguish, the feeling of fear, anxiety and other determinants in the child and in the family, as this is essential for the care to be performed comprehensively(23). Therefore, the importance of carrying out actions aimed at listening, affinity, creating a bond, solidarity, and providing information support is emphasized, as these are tools which will facilitate the family's effective adaptive process, helping them to feel safer in facing their child's hospitalization.

In this perspective, knowing the mechanisms used for adaptation can contribute so that nursing can plan qualified care for the family and the hospitalized child, taking into account all its particularities regarding the moment lived and therefore be able to perform holistic, comprehensive and singular care.

It is important to note that this study had limitations, evidencing the fact that it represents a specific reality due to having been conducted in only one health service. Therefore, it does not enable generalizations because it has a qualitative approach, but rather the knowledge of the family member's experience so that it is possible to elaborate specific strategies to cope with the child's hospitalization in the PICU by the family members, thus favoring more effective adaptation processes.

CONCLUSION

The adaptation process experienced by the family when the child is admitted to the Pediatric Intensive Care Unit has different phases. The adaptation process begins from the moment the family perceives the child in the PICU bed in a severe clinical condition, and the mechanisms which lead the family member to an effective adaptation begin.

As a contribution of this work, the importance of health professionals together with families during the hospitalization period to build positive interactions stands out, allowing them to be creative and express their emotions. In addition, meaning should be attributed to their experiences, enabling them to acquire new knowledge, thus promoting family and child health.

RESUMO

Objetivo: Conhecer o processo de adaptação de familiares ao vivenciar a internação da criança em uma Unidade de Terapia Intensiva. Método: Pesquisa qualitativa, descritiva e exploratória, realizada na Unidade de Pediatria, com familiares de crianças provenientes da Unidade de Terapia Intensiva Pediátrica. Utilizou-se a análise temática. Resultados: Participaram 13 familiares, 12 mães e um pai. Dos resultados emergiram as categorias: Impacto da família frente à internação infantil em Unidade de Terapia Intensiva Pediátrica e Mecanismos de adaptação de familiares à internação em uma Unidade de Terapia Intensiva Pediátrica. Conclusão: Os mecanismos adotados pela família no processo de adaptação da criança a internação na Unidade de Terapia Intensiva Pediátrica foram: pensamento positivo, entendimento do tratamento e de função da unidade. Os profissionais de saúde podem oferecer estratégias à família a fim de tornar a internação menos traumática, possibilitando o compartilhamento das experiências e a ampliação do conhecimento dos envolvidos.
RESUMEN
Objetivo: Conocer el proceso de adaptación de familiares que vivencian el internamiento del niño en una Unidad de Terapia Intensiva. 
Método: Investigación cualitativa, descriptiva y exploratoria, realizada en la Unidad de Pediatría, con familiares de los niños provenientes de la Unidad de Terapia Intensiva Pediátrica. Utilizó se el análisis temático. Resultados: Participaron 13 familiares, 12 madres y 1 padre. De los resultados emergieran las categorías: Impacto de la familia frente al internamiento infantil en una Unidad de Terapia Intensiva Pediátrica y Mecanismos de adaptación de los familiares al internamiento en una Unidad de Terapia Intensiva Pediátrica. Conclusión: Los mecanismos adoptados por la familia en el proceso de adaptación del niño en la Unidad de Terapia Intensiva Pediátrica fueran: pensamiento positivo, entendimiento del tratamiento y del funcionamiento de la unidad. Los profesionales de la salud pueden ofrecer estrategias a la familia para tornar el internamiento menos traumático, posibilitando el compartiendo de las experiencias y la ampliación de lo conocimiento de los participantes envueltos.

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