



FAMILY PERCEPTIONS ABOUT PAIN AND DISCOMFORT IN HOSPITALIZED CHILDREN

PERCEPÇÕES FAMILIARES SOBRE A DOR E O DESCONFORTO NA CRIANÇA HOSPITALIZADA

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ABSTRACT: The objective of this study was to understand family members' perceptions regarding pain and discomfort experienced by children during hospitalization. This was a descriptive and exploratory study conducted with 28 family members of children hospitalized in the pediatric sector of a public hospital in northwestern Paraná, Brazil, with data collected between September and November 2021 through semi-structured interviews and analyzed using thematic content analysis. The analysis allowed the identification of two categories: family experiences regarding pediatric hospitalization and perceptions of the care provided to the child, showing that hospitalization is a critical period marked by suffering and challenges inherent to the hospital environment; however, humanized care, including non-pharmacological therapies, welcoming attitudes, and effective communication by the healthcare team, was perceived as capable of alleviating suffering and providing greater safety for both children and their families, and it was also noted that family members recognize pediatric hospitalization as a time of intense distress for both children and caregivers, particularly in relation to invasive procedures.

KEYWORDS: Comfort; Child Hospitalized; Pain; Family Relations.

RESUMO: O objetivo foi apreender as percepções familiares acerca da dor e dos desconfortos vivenciados pela criança durante o período de internação. Trata-se de estudo descritivo exploratório realizado com 28 familiares de crianças hospitalizadas no setor pediátrico de um hospital público no noroeste do Paraná. Os dados foram coletados entre setembro e novembro de 2021 por meio de entrevistas semiestruturadas e submetidas à técnica de análise de conteúdo, modalidade temática. A análise dos dados permitiu a identificação de duas categorias: experiências familiares sobre a hospitalização na pediatria e, percepção sobre a assistência prestada à criança. Estas mostram que o período de internação é um momento crítico, marcado por sofrimento e desafios ao ambiente hospitalar. No entanto, o cuidado humanizado, com terapias não farmacológicas, acolhimento e comunicação eficaz por parte da equipe de saúde, demonstra atenuar o sofrimento e trazer segurança tanto para as crianças quanto para os familiares. Nota-se que os familiares reconhecem a hospitalização pediátrica como um momento de grande sofrimento, tanto para as crianças quanto para os cuidadores, especialmente em relação a procedimentos invasivos.

PALAVRAS-CHAVE: Conforto. Criança hospitalizada. Dor. Relações familiares.

INTRODUCTION

Hospitalization for children abruptly changes their and their families' routines. Hospitalization can compromise well-being and is considered a milestone in distancing the child from childhood activities. In this context, the harmony of living together is lost; this is usually a costly period marked by pain and discomfort¹. Nevertheless, the families of these children are surrounded by feelings of fear, uncertainty, anxiety, and helplessness, which further increases this cycle of worries².

In Brazil, comprehensive child protection is legally provided for in the Child and Adolescent Statute (ECA, in Portuguese)—Law No. 8,069 of July 13, 1990—which advocates the right to life and health of children and adolescents. The duties to do so extend from family members to other institutions, including the Brazilian Unified Health System (SUS), responsible for promoting, preventing, and recovering health³.

Implementing strategies such as play promotion can promote health and minimize the negative impacts of children's hospitalization. This approach can become a valuable tool in tackling issues related to comprehensive care, adherence to treatment, and guaranteeing the rights already established for children. In addition, playing favors the creation of communication channels between the child and the health professional, facilitating mutual understanding⁴.

Considering that pain is a vital sign commonly present in hospitalization, the existence of a multi-professional team is essential to deal with suffering in the hospital context, considering emotional, economic and cultural aspects when planning care, following regulatory requirements and internal regulations, which give health professionals the responsibility for relieving pain and promoting comfort⁵. Furthermore, in this context of rights and duties, there is a child and their family, and the sensitive impact of hospitalization⁶.

Therefore, it is essential to reinforce informational and emotional support to parents, recognize the family as a critical component of pediatric care, and value them cordially, especially during the stressful period of hospitalization⁷.

The perception of the family members of pediatric patients is sensitive and capable of evaluating the comfort offered or neglected, directly influencing the child's behavior and feelings. This reinforces the importance of the parental role in minimizing the damage caused by hospitalization, which requires an effective partnership in providing care⁸. In the hospital context, family members can either favor and facilitate the work and actions of professionals or limit the implementation of clinical practices and care for the child. This duality is sometimes based on the relationship of trust between family and professionals⁹.

The worsening of a pediatric patient's health condition can intensify their painful experience and worsen their prognosis, so the less time they spend in hospital, the better for their physical and mental health¹⁰.

The family's perception of the pain and discomfort experienced by pediatric patients helps health professionals. In addition to the family companion being by the child's side all the time (which professionals cannot do/be), the family knows their loved one so well that they can perceive minimal changes in behavior and even voice. This, therefore, can encourage discussions about the quality of care and bring about reflections on the subject, which in turn is easily misrepresented under the floorboards of biomedical care¹¹.

In addition, pain management and the quality of nursing care influence parental satisfaction. A study in Mexico analyzed the satisfaction of 127 mothers with their children's hospitalization, highlighting that maternal satisfaction was not related to the child's age, previous hospitalizations, or perception of health status, but instead to nursing care and the hospital structure¹².

Considering the above, this study aimed to understand family perceptions of the pain and discomfort the child experienced during hospitalization.

METHODS

This is a descriptive-exploratory study with a qualitative approach, carried out with family members of children hospitalized in the pediatric ward of a public hospital in the northwest of Paraná. The previously defined inclusion criteria were being 18 years old or older and being the primary family caregiver of a child hospitalized for at least 12 hours, regardless of diagnosis. In turn, family members were not included if they reported having no time for the interview or if they had any communication difficulties that made it impossible to conduct the interview.

The data were collected between September and November 2021 through semi-structured face-to-face interviews. To facilitate communication and maintain greater methodological rigor in the study, all the interviews were audio-recorded after consent and carried out by the same person, a final-year nursing student duly trained in qualitative data collection—who had no relationship with the potential participants.

During the interview, the researchers used an instrument based on the objectives of the study, which is made up of two parts: the first addresses questions relating to the socio-demographic characteristics of the participant (gender, age, marital status, education, profession, income, city of origin and number of children). The second part was guided by support questions that sought to trace the family's history and experience since the start of hospital care.

For analysis, the characterization data was entered into a Microsoft Excel spreadsheet. At the same time, the audio-recorded interviews were transcribed in full, preferably on the same day they were conducted, and recorded in Microsoft Word. The interviews were subjected to thematic content analysis, following the pre-established stages: pre-analysis, material exploration, and data treatment¹³.

Pre-analysis involved organizing the material, defining the objectives, selecting the corpus and floating reading to familiarize and identify relevant aspects, and planning the categorization. When the material was explored, it was coded by segmenting it into recording units - relevant words, phrases, or passages - which were grouped into thematic categories using an objective classification system. Finally, in the results processing stage, the results were analyzed and interpreted, relating them to the study's objectives and the theoretical framework. This allowed for formulating inferences and interpretations based on the findings to understand the phenomenon studied broadly and rigorously.

With this approach, methodological rigor was ensured by recording the interviews, training the interviewer, systematic data analysis, and triangulation of sources, guaranteeing the results' reliability.

The study was carried out following Resolution no. 510/2016 guidelines of the National Health Council, assessed and approved by the Permanent Committee for Ethics in Research involving Human Beings (COPEP) of the signatory institution (Opinion no. 4.819.283). All the participants agreed to participate in the study by signing the Free and Informed Consent Form (FICF) in two copies. To guarantee their anonymity, in presenting the results, the fragments of their statements are identified generically with the name "Maria", the degree of kinship with the child followed by the child's sex and age.

RESULTS

The study involved 28 family members responsible for 28 hospitalized children, all female, aged between 20 and 49 (12 were between 20 and 29, another 12 between 30 and 39, and the rest between 40 and 49). Regarding marital status, 24 had partners, eight were married, and four were single. Concerning education, 14 had completed high school, 8 had incomplete high school, three had completed or incomplete elementary school, and three had completed or incomplete higher education.

The average monthly family income was R\$2.596,00, while the minimum wage was R\$1.100,00¹⁴ during the research period. Of the 28 families, 14 had an income of between one and three minimum wages; eight had only one minimum wage; and six had an income of between four and five. Regarding where they lived, only seven children lived in Maringá; the rest came from neighboring municipalities. In addition, only six children were only children; the others had one to three siblings.

Seven of the 28 children hospitalized were under one year old, four were between one and three years old, nine were between four and seven, and the other eight were between eight and 14 years old. Eight of the 28 children who were hospitalized underwent surgical treatment. Of the 20 admitted for clinical treatment, nine had chronic conditions. The length of the stay at the time of the interview ranged from 2 to 60 days.

After reading the interviews in detail, two categories were identified based on the need to understand the subject of this study, which will be described below.

SUFFERING AND COPING: THE FAMILY EXPERIENCE OF PEDIATRIC HOSPITALIZATION

Family members recognized pediatric hospitalization as a critical moment, as each procedure significantly impacts the patient and their family. In addition, it is possible to identify that the provision of qualified care and the practical relationship between the health professional and the patient/family reflects on the user's satisfaction of the Brazilian public health service.

"It was only on the day we arrived that she took medicine into her vein and complained of pain all day(...) The nurses always explained to her what they would do and that it would hurt. It was always very calm; they would talk to her, say, "It's over now, hang on a bit longer." It was very calm. I liked the service; she said she was going to miss it. I'd never been hospitalized with her before, and people say many bad things about the SUS, but I thought it was great; it was very peaceful." [Maria, mother of a girl, 8 years old].

"She suffers from an illness and had to have surgery, so she suffered a bit, right? She'd never been through this procedure; the mother and daughter suffer." [Maria, mother of a girl, 7 years old].

Invasive procedures such as rectal lavage and the insertion of a delayed bladder catheter were highlighted by family members as the most traumatic situations during hospitalization. On the other hand, after the family members identified the benefit that the procedure had brought to the child, they felt more comforted and understood why it was necessary.

"The most painful were the first washes that were being done on him and that weren't working, it hurt me too much, seeing him do it, all the difficulty, all the discomfort, he became so agitated that I even had to sedate him, and I finished the procedure and there was no response. So that was difficult for me, as I did not see a solution initially. And, of course, I know

they were doing this to avoid cutting and putting in the colostomy bag, so the whole procedure was done to try to avoid this. It was harrowing. It became easier as soon as you could see the belly getting smaller and see him in less pain." [Maria, mother of a boy, 5 years old].

"The worst thing was the tube; she suffered, I suffered, I even saw that they suffer. But it was certainly the worst, poor thing. It was horrible; it was already hurting, but she needed it after she discovered the urinary infection." [Maria, mother of girl, 10 months].

However, family members demonstrated knowledge of the children's common behavioral characteristics, monitoring significant changes during hospitalization and periods of clinical deterioration. They identified clear signs of pain and discomfort, facial expressions of suffering, sleep disturbances, extreme tiredness, and loss of appetite. Among children under three, crying and restlessness were the most common signs.

"When he doesn't stop crying, even when he's been fed, changed, he doesn't stop crying and gets very restless, with his little legs moving and expressing himself. He gets more irritable, more agitated. I've noticed that he feeds less; he's less hungry. I think he focuses more on crying." [Maria, mother of boy, 11 days old].

"The crying, the restlessness, but more the crying. He doesn't eat, he gets more sly, more demanding of your lap, just like that." [Maria, mother of a boy, 2 years old].

The signs changed in patients aged 4 to seven and 8 to 14 due to neurodevelopmental characteristics and family interaction. Thus, family members emphasized physical prostration, seclusion, and/or concealment of symptoms, triggering the need for family members to investigate the patient.

"Her expression, she tries to hide it, but we see that she's not well," I ask her again, and she says: 'No mom, I don't have anything'. I say, daughter, you must tell the truth because if you're really in pain, you must go there and ask her to give you some medicine. Then she says: 'Oh mom, it's hurting here, it's hurting there'." [Maria, mother of a girl, 10 years old].

"Most of the time, he's quiet, he starts to stand in corners, he may know something is bothering him, he tends to hide it, he tries not to show us that he's in pain, but we notice him getting more nervous, some habits he wasn't having he starts to do, like biting his nails." [Maria, mother of a boy, 5 years old].

"Uncomfortable, right? She was uncomfortable; she moaned and tried to hide it, but I could see she was in a lot of pain. I could see by the look on her face that she wasn't well. She spent most days with her face closed, sadder, and only got better when a doctor came and played with her." [Maria, mother of a girl, 7 years old].

THE DUALITY OF ASSISTANCE: HUMANIZED CARE AND COMMUNICATION DIFFICULTIES

Family members highlighted the care provided by the healthcare team, evaluating it as good and efficient. They pointed to the agility of the professionals, the attentive look, and the care and cordiality in dealing with the children. The explanations of the procedures to be carried out, the non-pharmacological

practices, such as bathing, massages, administering oils, friendly language, games, and good humor. These are measures that ease the difficulties during hospitalization.

"Some nurses tried to massage his belly; I thought it was super different, and you feel that what the person is doing is out of love, right? It's not mechanical, you know. So you notice it in people, when the person is there feeling it, it feels like they're with you at that moment, and that's important even for the mother, not just the child. If the child realizes the mother is desperate too, that's it." [Maria, mother of a boy, 5 years old]

"They're very attentive, taking great care of my son; they're always around. I can only thank them for their service. The reassurance they gave him, always explaining what would happen, is perfect treatment." [Maria, mother of boy, 3 years old].

"I think the team assessed everything very well; everything was perfect, and they always treated him well. What's more, he's still being monitored, people call, ask how he's doing, I have nothing to complain about" [Mother of boy, 13 years old].

Family members highlighted comfort from different perspectives, especially kindness with non-pharmacological therapies, which simultaneously promotes the patient's well-being and comfort. In addition, some points, such as worry and noise, were highlighted as stressful factors for family members who find themselves with sick children in the hospital environment.

"They drew pictures for him, I think it made a big difference, we started putting together that panel of pictures, people would come and ask him, he would choose himself, they left the child free to choose, I thought it was really cool!" [Mother of boy, 5 years old].

"The little cigar! I'm not saying it to please her, but it does help. The way you talk to her, the way you talk to her, the way you look at her, catches my eye." [Maria, mother of a girl, 23 days old].

"It involves a cycle, because he's not well, automatically I'm not going to be well, I'm not going to sleep well, I'm going to be worried, and this can even cause a decrease in milk, I complain here to those at home... those at home are worried, so it's a multitude of problems caused by a problem that could be solved more easily, which is to reduce the noise. It's something that even the hospital could do; they could have a sign saying "keep quiet in an environment where there's a child/NR" [Maria, mother of a boy, 11 days old].

The interviewees saw the relationship between health professionals and family members as prestigious, while the professional's presence provided security and sometimes reassurance.

"The doctor looked at him (the patient) and said, "You can see he's in pain; he's in pain!" I called my sisters and said, "they've given me a lot of peace". Then the doctor said he was going to call the doctor who was in the operating room, and then he came to look at him" [Maria, mother of a boy, 10 years old].

"When they come to play, we feel good, grateful, even happier, even more comfortable, because we're here anxiously for those 10 days, but then there's that good part, the nurses and doctors who come and play with our children, even with us, so we feel even more comfortable, more relieved." [Maria, mother of a boy, 11 days old].

Caregivers saw children's hospitalization as a time of many expectations, and sometimes, the experience of hospitalization brought with it fear and insecurity. In this delicate situation, the health team acts precisely, contributing to the patient's evolution and to the family's experience within the service.

"(...) it was very distressing to see our daughter like this, going to work worried, very nervous. I was very grateful for the service. I liked the care they take with my daughter. I liked the activities, so she's less stressed. She's sitting and talking now, and when she arrived, she didn't do any of that." [Maria, mother of a girl, 5 years old].

"I was scared, how am I going to deal with this situation, I've never looked after anyone in this situation, with a tracheostomy, with a soft skull. I thought, my God, is it going to hurt? Will it not? So, all these doubts I used to ask the doctors here before I left, I learned a lot." [Maria, mother of a boy, 6 years old].

On the other hand, communication problems were mentioned, such as rude, harsh, and impolite treatment and particular situations of negligence during the service.

"There are some people who can be more empathetic. Of course, we understand that the nurse and the doctor are here working hard for 12 hours with several patients, but I'm here sleeping in a chair all sore. This relationship between the employee here working hard and the patient, it's not the patient who is more physically and psychologically fragile." [Maria, mother of a 10-month-old girl].

"I had a problem with a doctor, in the situation she said she wasn't joking and that she had no pity for me, that day I felt like crap, and she was still with all the students, so, I felt terrible, terrible as a mother. So, for medical professionals, nursing professionals, anyone, I recommend that when you have to say something, come and say it in private because occasionally, it ends up embarrassing." [Maria, mother of 11-day-old boy].

Family members also pointed out that there are exceptions, so there are reports of positive and negative situations experienced by the same family member. Forming a parallel between joy at good work and dissatisfaction with the mistakes made by some professionals, this contrast is visible in the reports of the same mother at different times.

"When I arrived, the staff hugged and carried me; they saw how shocked and terrified I was; it was all rapid for me. So, I had everything I needed, the treatment for him in the first place, and the human support, everyone talked to each other, doctors, nurses, the other day a psychologist even came to talk to me at six o'clock in the morning."

"I needed help, and she (the professional) didn't know how to help me. I had to run... I got very nervous; I thought, if she can't help me in the hospital, Jesus! At home, I won't be able to cope (shaky voice). I felt helpless that night; it was an early morning shift, and early morning is harder."

"But I'll tell you, I know how to separate a situation from a hospitalization, I have the experience of having paid for health insurance for many years, and I've had more care here in the public hospital than in the private one, I wouldn't change the care."

[Maria, mother of boy, 4 years old].

DISCUSSION

Performing invasive procedures on children is permeated by various feelings. For the child, as well as fear, the experience can be accompanied by pain, sometimes leading to a significant increase in crying. For family members, the situation is also challenging, as it generates a complete feeling of helplessness in the face of the sick child.

Considering this, a study carried out in a pediatric ward of a public hospital in the municipality of Cuiabá-MT found that hospitalization causes several stressors for children, especially regarding exposure to invasive procedures. On the other hand, children who have chronic conditions in which hospitalization is recurrent also frequently experience exposure to invasive procedures, so over time, they learn to cope better with the situation, experiencing it more calmly¹⁵.

Crying is the most frequent sign family members observe in situations of discomfort. Crying is a warning sign to parents. By paying attention to this sign, the healthcare team can manage the patient's pain, solve physiological needs, and distinguish, together with the caregivers, the right time to apply pharmacological or non-pharmacological interventions¹⁰.

Pain is often inherent in health procedures. However, this reality is different in the pediatric sector since health actions must be based on playfulness. It is, therefore, appropriate for the team to use stimuli for the imagination and even distractions that involve the child now of care, giving the child autonomy¹⁶. In addition, there are situations in which other more invasive and potentially traumatic health measures are necessary, depending on the patient's clinical condition. Thus, professionals who use clear language and explain in advance how each procedure will be carried out cooperate significantly with the child's well-being and, consequently, that of their family¹⁷.

The pediatric patient is inserted into an unfamiliar environment with very different routines from those the child experiences on a daily basis¹⁸. For this reason, accommodation, structural problems, and the organization of care directly interfere with the concept of the family and the patient. The limitations of the environment are compounded by the treatment and language adopted, potentiating distancing reactions. Pediatric care is complex and meticulous, which justifies the importance of differentiated behavior on the part of health professionals when the patient is a child¹⁹.

Comfort measures, especially those carried out by the nursing team, promote pain relief and favor interaction between professionals, children, and their caregivers, thus creating a more pleasant environment⁶. The bond of trust is gradually formed during care, and a harmonious relationship favors the recovery of pediatric patients⁹.

In addition to its structural conditions, the environment also has more detailed issues related to the needs of the hospitalized child, which can arouse the child's interest through social and cognitive development¹⁶. The importance of drawings, colorful walls, interactive panels, recreational environments, and others is highlighted.

The companion plays a central role in health care, especially in pediatric care, where they become the essential link between the nursing team and the patient. This interaction goes beyond emotional support, involving an active contribution to the child's recovery process. Establishing a respectful and cordial relationship between the team, the patient, and their family is fundamental, as it promotes an emotional bond that enhances the quality of care²⁰. An example of this is the situation described above, in which the same mother reports being welcomed and supported by the team but in another circumstance felt utterly helpless and unassisted during a health complication with her child, thus creating duality, even in the same service.

Pain and discomfort during hospitalization are varied and sometimes unavoidable. Still, it is precisely in this hospital environment that children and their families expect quality care, with committed professionals who can be sensitive to the real needs of each family.

The findings of this study highlight important practical implications for the work of health professionals, especially the nursing team. Firstly, it is essential that this professional communicates the procedures they are going to carry out, explains why they are going to carry them out and how they will do it, and promotes a welcoming environment that allows them to clarify any doubts. This will help to reduce the anxiety of the child and their family.

In addition, the continuous assessment of children's pain and discomfort should be carried out personalized. Paying attention to the observations of family members who are closer to the child and know them better than anyone allows them to perceive nuances that are sometimes invisible to professionals. Finally, the results of this study may contribute to developing more effective protocols for managing pain and discomfort, as well as underpinning public policies aimed at promoting and recovering health in children.

Possible limitations of the study are related to the fact that it was carried out in just one institution, which has its characteristics, including the clientele it serves - primarily people from lower socioeconomic backgrounds. Thus, family perceptions of the pain and discomfort experienced by the child may vary according to the characteristics of the context. This includes the family member's education and socioeconomic level, the child's age, the type of illness that led to the hospitalization, the child's clinical condition, and the care and local culture.

FINAL CONSIDERATIONS

Family members recognize pediatric hospitalization as a time of great suffering, not only for the child but also for themselves, especially with invasive procedures. However, the qualified and humanized interaction of health professionals, through clear and attentive communication and the adoption of non-pharmacological practices, contributes significantly to pain relief and comfort for children.

Given this study's findings, the importance of health promotion in children's hospitalization is reinforced. The study recommends that health professionals adopt educational actions to train caregivers, promoting continuity of care and reducing emotional overload. Public policies should guarantee support beyond the hospital environment, strengthening health promotion and disease prevention. Therefore, investing in practices that empower individuals and communities is essential to ensure comprehensive, humanized, and efficient care.

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