

## MOTHERS'/CAREGIVERS' EXPERIENCE FACING REGARDING THE PAIN OF THE CHILDREN WITH CEREBRAL PALSY

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### ABSTRACT

This study aimed to understand the experience of mothers/caregivers regarding pain in the child with cerebral palsy. This was a qualitative study conducted at the Center for Treatment and Early Stimulation with 21 mothers/caregivers of children with spastic quadriplegia cerebral palsy in November 2010. The Humanistic Nursing Theory was used, following Paterson and Zderad's phases of phenomenological nursing. Four categories emerged: reactions of children in pain with spastic quadriplegia cerebral palsy: the call for help; the uniqueness of the dialogue of children with spastic quadriplegia cerebral palsy with their mothers/caregivers; reactions of mothers to the pain of the children with spastic quadriplegia cerebral palsy; and, absence of pain in children with spastic quadriplegia cerebral palsy: perception of mothers/caregivers. The experiences of mothers/caregivers are established through continuous interaction between the caregiver-child dyad, when the identification of behavioral reactions and vocalizations occurs, characterizing the communication, and performance of non pharmacological and pharmacological relief measures, surrounded by mothers'/caregivers' feelings of concern, fear, anxiety and guilt.

**Keywords:** Child. Cerebral Palsy. Nursing. Caregivers. Nursing Theory.

### INTRODUCTION

Pain is common in children with cerebral palsy (CP) and it is likely that the CP-associated neurological damage changes the neurological system and, consequently, the ability to understand and communicate pain<sup>(1)</sup>. Children with cognitive and/or behavioral and/or neuromuscular disabilities have significantly restricted autonomy and possibilities of perception, expression and relationship<sup>(2)</sup>.

The experience of mothers/caregivers regarding pain in children with CP should be valued by health professionals, considering that they are familiar with the children's behavioral changes, especially when they have mild to severe cognitive and communication disabilities<sup>(1)</sup>.

The experience of mothers/caregivers can serve as a proxy for the identification of pain in these children, since they recognize the behavioral changes presented by children with CP during painful sensations, because they are directly involved in their demand for special care.

In this process, the view of nursing must go beyond technical and scientific knowledge and be involved by means of an existential and

human attitude, understanding this relationship of the meanings pain as a tool to direct care with the family. Humanization of healthcare permeates respect for the person's individuality, simultaneously raising a holistic perception of this human being, extrapolating the biological understanding of the disease and considering the psychological, social and spiritual aspects that directly or indirectly influence the health-disease process<sup>(3)</sup>.

Given this existential approach, according to Paterson and Zderad's Humanistic Theory, nursing implies a particular kind of encounter among human beings, which arises in response to a perceived need, related to a quality of health-disease that is characteristic of the human condition. This relationship emerges from the dialogue between the nurse and the person involved in care, in which communication should not be limited to the act of sending or receiving verbal and/or nonverbal messages, emphasizing dialogue in terms of call and response, showing that the caller requests help and the responder promotes support<sup>(4)</sup>.

Understanding how the mother/caregiver of the child with spastic quadriplegic CP - considered the most serious type when there is equal and symmetrical involvement of the four

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limbs<sup>(5)</sup> - experiences the pain of her child, grandchild and/or nephew/niece may assist nursing in managing the pain of those children, and also value their presence regarding therapeutic decisions for the treatment of pain.

Supported by the humanistic theory and seeking to understand the experiences of mothers/caregivers regarding children with CP, the question arises: What is the experience of the pain of children with CP for the mother/caregiver? Therefore, this study aims to understand the experiences of mothers/caregivers regarding pain in children with CP.

## METHODOLOGY

This was a descriptive, qualitative study, performed at the Center for Treatment and Early Stimulation (NUTEP), Hospital Complex at *Universidade Federal do Ceará* (Federal University of Ceará-UFC). The subjects consisted of 21 mothers/caregivers of children diagnosed with spastic quadriplegic CP, who were identified with names of Indian spices.

For this study, we followed the five phases of phenomenological nursing<sup>(4)</sup>: nurse preparation for coming to know; nurse's intuitive knowledge about the other; nurse's scientific knowledge about the other; nurse's supplementary synthesis about the realities she/he knows; and, finally, nurse inner succession from many to a paradoxal one.

In the first phase, we studied Paterson and Zderad's Humanistic Theory through analytical readings, followed by reflective readings, sources of knowledge about phenomenology, existentialism, humanistic care, nursing theories, communication, interpersonal relationships, among others.

In the second phase, data collection, we sought to intuitively know the other. Nurses related with caregivers among equals<sup>(4)</sup>. At this moment, the I-YOU relationship was established through dialogue, and participant observation and the interview were performed. This phase was performed in November of 2010.

Participant observation with the mother/caregiver was performed before and after the interview, with daily recording in a field diary. On these occasions, we observed expressions, attitudes, posture, interaction with others in the waiting and consultations rooms, and sometimes beside the child in the neuro-sensory stimulation room at NUTEP.

The recording of the characteristics of the subjects was completed before the interview, with the following data: identification of the mother/caregiver by a nickname, age, education, nationality, occupation and marital status. The guiding questions for the interview were: Do you realize that your child feels pain? How is the pain? How is it for you to experience the moment when your child feels pain? How do you realize that your child is in pain? How does he react to pain? At the moment he is in pain, how do you react? What do you do when he is in pain? What is the meaning of this moment for you? During the interview, a tape recorder was used, so that no omissions or loss occurred during the collection of information.

Afterwards, the dialogues were transcribed for the completion of data analysis and interpretation, following the last three phases of humanistic nursing. In the third phase, *nurse knowing the other scientifically*, it was necessary to deviate from the scenario and the study subjects to reflect and analyze the lived relations, in order to synthesize themes and concepts and thus symbolically interpret the reality experienced in the past, tracing a particular view of the object of study<sup>(4)</sup>.

In this case, the *I-YOU relationship* from the past had to be glimpsed from a scientific look, transposing it to *I-IT*, seeing the experience of mothers/caregivers as the object that should be reflected, analyzed, classified, compared, contrasted, related, interpreted and categorized<sup>(6)</sup>. After the initial analysis, intuitive and scientific knowledge was merged, when the lived realities were compared and understood as an object (IT) to be analyzed.

In the fourth phase, we performed the comparison and synthesis of multiple known realities, presenting an expanded view on the

experience of the mother/caregiver regarding pain in children with CP, through the categories. In the fifth phase, *nurse inner succession from many to a paradoxal one*, the multiple points of view of the subjects, after synthesizing, were merged, resulting in a conception on the experience of mothers/caregivers regarding pain of their child, grandchild and/or nephew/niece with CP.

The project was submitted and approved by the UFC Research Ethics Committee (COMPE), under protocol n.258/10.

## RESULTS AND DISCUSSION

Of the 21 mothers/caregivers, four were not the biological mother; two were grandmothers, one was an aunt and one was an adoptive mother. The ages ranged from 17 to 47 years, most (11) were married, including one who lived in a consensual union. Regarding education, nine had completed secondary education, seven had incomplete elementary education, three had finished elementary school, only one was illiterate and one had higher education. Eight were single and two were divorced; ten caregivers were without partners. As for the 21 children, most were female, ages ranging from seven months to eight years, with 18 aged between 28 months and ten years.

The following results and discussion resulted in four categories called: reactions of children in pain with spastic quadriplegia CP: the call for help; the uniqueness of the dialogue of children with spastic quadriplegia CP with their mothers/caregivers; reactions of mothers to the pain of the children with spastic quadriplegia CP; and, absence of pain in children with spastic quadriplegia CP: perception of mothers/caregivers. Based on 21 interviews with mothers/caregivers of children with CP, most (16) reported that the child felt pain, and they described the reactions of the child at that moment:

She cries a lot, cries, cries quite a lot, and when it is a stomachache, she shrinks, covers it with her little hand [...] She stretches, she shrinks [...] (Basil) [...] he starts crying, angry, when I touch him here [shows the location] it is when he

screams more. Then he gets very angry, just crying, because he is very calm, except when he's crying. (Sesame) [...] even the expression of his face, I realize he frowns, I realize it is pain. (Caraway)

The main reactions to the pain of children with CP were related to behavior, evidenced by reports of irritation, agitation, crying, frowning, changes in movement and muscle tone. We note that behavioral changes were not individually assessed, that is, the global and simultaneous reactions that occur at the time of pain were described and they were not considered in isolation.

One of the behavioral changes, identified by mothers/caregivers, was mood. They explain that the child exhibited an expected pattern of humor when performing the activities of daily living. Changes in this routine could indicate that the child felt pain:

When she is crying a lot, she is not a crying girl, so when she is in pain, I know right away, she starts getting sick and cries a lot [...] when she is in pain; she cries right away, she cries a lot. (Fennel) Because, you know, he is not a crying child, so when he is mad, crying, I know it's some kind of pain [...]. (Nutmeg)

Changes in the behavioral pattern, specifically the child's mood, were pain signals that were part of the daily lives of mothers/caregivers of children with CP or with severe cognitive impairment. Comparisons of behavior were identified as the possible presence of pain in children.

Crying appeared to be a typical manifestation of pain. However, when it expressed pain, it was different from other crying related to situations that involved changes in mood.

[...] She keeps crying, angry, she turns around, stretches a lot, stretches arms and legs, keeps inconsolably crying, unlike other crying, she cries... a cry not even I can cherish. (Clover) Because she moans, cries, gets agitated, then I realize she's feeling some kind of pain, then I'll touch her here [shows the location], touch her ear. Because she cries, then I realize she feels pain, so, I put my hand on her tummy. She gets irritated and impatient. (Chili Pepper) I recognize that his crying is different, it is more of a suffering cry [...] than when he is angry, when he yells, he flounders, I think it's different; usually I realize it's a painful cry, a long cry, a lot of suffering [...]. (Caraway)

Crying is part of the communication process of pain in children with CP, as well as in children who cannot verbalize it. Associated with other vocalizations, it helps identify whether the child is really in pain or not. Therefore, characteristics such as high or low, long or quick sounds, associated with moans and crying may suggest that the child feels pain.

The behaviors indicated by the mothers/caregivers were the same present in the scales for the assessment of pain in children with CP, the most frequently observed being facial expressions (91.6%), crying (90.7%), vocalizations, such as moans and whimpers (90.6%), irritability (82.2%) and changes in muscle tone (76.6%)<sup>(7)</sup>.

The most commonly cited behavioral patterns of pain were: crying, inactivity, seeking comfort, moaning, restlessness, agitation, irritability, being uncooperative, stiff, spastic and tense, sleep deprivation, difficulty satisfying and comforting, and moving parts of the body<sup>(8)</sup>.

In newborns and infants, the pain tended to manifest through crying and certain body movements, facial expressions, or even apathy. In children between one and three years of age, crying may arise accompanied by verbalizations or localized gestures in the focus area of pain, as well as by certain restless, violent or tantrum-like movements<sup>(9)</sup>.

### **The uniqueness of the dialogue of children with spastic quadriplegia CP with the mothers/caregivers**

In the perspective of verbal communication, the absence of speech prevailed in most children, because only one mother/caregiver reported that her child communicated verbally, which, as reported, hindered the process of communicating with the child.

Well, I don't know what she has, she doesn't speak [...] It is very difficult, because she can't talk, right? I'm worried right away. (Cinnamon) I'm worried, [...] my son doesn't know things right, can't speak or express. (Rosemary) When he feels some pain, I can't understand if he is suddenly feeling pain, but if he's in trouble, like now, he has a dislocation [...] He can't speak, can't tell or show me, really just by crying, so I get very sad. (Sesame)

Mothers/caregivers expressed concern and sadness because their children were unable to communicate verbally. They added that it was very difficult to understand what was really happening at the moment of pain or if pain was present at the time. Verbal language could help the child communicate the pain, so its absence interfered with the communication of pain, delaying its identification.

The statements indicated that synchrony established from the daily and constant interaction between caregiver and child favored communication of wellbeing or better-being of the child. Knowledge of the child's reactions to pain by mothers/caregivers could assist health.

From this perspective, the nurse's role is to assist human beings' better-being and overcoming. The effort of humanistic nursing is directed at enhancing the ability to make responsible decisions<sup>(4)</sup>. It is recognized that the intersubjective relationship that involves mother/caregiver and child in situations of pain consists of a humanistic attitude in order to enhance the participation and experience acquired during long periods of care for the child with CP.

Regarding the lack of verbal communication, it is common that most children with CP have difficulty in the development of functional speech. Anarthria can be present as a symptom, characterized by inability or articulatory dysarthria, which is defined as a speech disorder, manifested as spasticity or hypotonia<sup>(10)</sup>.

Valuing of the oral communication of the child by the mothers/caregivers can be justified by the ease and speed with which we share information, sensations and feelings. Speech is the most functional and rapid human element that allows effective communication<sup>(10)</sup>.

The uniqueness of symptoms of pain in children with CP was reflected in nonverbal messages. The mother/caregiver and the nurse should be alert and motivated to recognize the request for help through the behavior and expressions of the child with CP.

The dialogue established requires a humanized view from the mother/caregiver

and professional multidisciplinary team in order to have an effective response to the pain of children. The humanistic act, at this moment, is to put oneself in another's shoes and subjectively understand behavioral changes and expressions that may signal the presence of pain.

We found that the reactions of mothers/caregivers converged in order to identify the presence and location of the pain, using strategies that alleviated the pain and expressed their feelings.

The identification of pain in children by the mother/caregiver may be one of the measures to be adopted by the multidisciplinary team for assessment of pain in children with CP. We noticed that one of the reactions expressed by mothers/caregivers was trying to verify the presence of pain, as well as its origin:

So I put my hand on her little head and it is hot, that is my opinion [...] so touching her tummy to know where the pain is. (Cinnamon) Then I go and observe where the pain is, if earache, cramps. I just grip (shows how) her little ear, because they say it hurts when you press it, but she mostly feels cramps. (Fennel) I watch his ways, his face [...] (Oregano) I go trying to figure out where it is, then, when I identify it, I move to trying to stop it [...] (Sesame)

Mothers/caregivers reacted by identifying whether the pain was actually present, as well as looking for its location. To do so, they performed observation, touched, assessed behavioral changes, changes in facial expressions, and asked the child where the source of pain was, in case the child could indicate or communicate verbally.

A study in Texas indicated that searching for the source of pain through touch and observation was one of the ways used by parents to identify pain in children with CP<sup>(8,11)</sup>. In a qualitative research study conducted in Switzerland, the parents explained that in the first years of a child's life, identification of pain reactions was considered difficult, emphasizing that both parents and children developed a silent dialogue to express pain, and most emphasized that it took years to be able to distinguish and interpret pain in children with CP<sup>(11)</sup>.

The subtle changes in the pattern of child behavior suggested an alert to the mother/caregiver who, according to reports, initiated the assessment, then promotion of its relief.

If I have some pain medication, I give it to her and she starts calming down [...] I get her, put her on my lap, then she starts calming down, calming down, go touching her tummy [...] I go to the doctor right away. (Cinnamon) I keep her in my arms, cherish her, sooth her. (Ginger) I cherish her, stay there with her, then she stops crying, right? I cherish her, she goes to my arms, then she stops crying. (Black Pepper) I lie in the hammock and rock her [...] massage her belly and that helps her calm down. (Clover)

Mothers/caregivers associated pharmacological and non-pharmacological measures in order to relieve the pain in children with CP. The offered medicines, promoted massage, provided comfort, care and contact and when they did not observe improvement in pain, they sought medical help and opinion.

An experimental study with participation of ten children, aged four to 16 years, with a cancer diagnosis and a painful condition found that the pain level of children decreased after the application of music ( $p < 0.05$ )<sup>(12)</sup>.

A qualitative study about the experience of mothers in a nursing intervention through touch and conversation, showed that most mothers felt that the child suffered less during the painful procedure and, moreover, were satisfied by being able to help and participate in care<sup>(13)</sup>.

Therefore, we reflect on the need for a protocol of measures that could be implemented to relieve pain, especially when there is the possibility of conducting painful procedures. The protocol should be incorporated as an aid to pharmacological and non-pharmacological measures, yet the individuality and uniqueness of each child must be considered, so that the patterns do not restrict the existential and subjective view of the nurse who deals daily with people's pain<sup>(14)</sup>.

Regarding the pain of their children, grandchildren and/or nephews/nieces,

mothers/caregivers reacted, revealing their feelings:

I get desperate right away, I call my friends, call my sister-in-law and they say: 'Woman, settle down'. Because I don't know what she has, she can't speak [...]. (Cinnamon), I get mad, start crying, get nervous, I do everything for that pain to go away [...] I get very worried [...] I'm afraid, very afraid of, you know, this pain not stopping, I am so afraid of that happening [...]. (Fennel)

Mothers/caregivers expressed a desire to cry, get worried, sad, anguished, desperate, nervous and generally described the moment when the child was in pain as awful, one of the worst situations experienced while taking care of them.

The child's age, related to their time together, did not influence feelings, because the feelings of mothers/caretakers of children aged three, six and seven years, like Chili Pepper, Red Pepper and Caraway, respectively, were similar to the feelings of mothers/caregivers of young children, such as Clover (10 months) and Rosemary (10 months). Other reactions revealed feelings of guilt and helplessness:

If it was any mistake of mine, that I have made, having given some vitamin to her that she did not like, that caused her that pain, I feel guilty. (Basil) It is one of the worst moments for me, that agony of hers, I don't know, and sometimes we can't do anything. (Ginger) We get sad, right? Nobody can do anything without knowing what he is feeling, I feel a little agony [...] It's sad, because I wish he did not feel at all. (Oregano)

Pain in children signals that something is not right, serving as a warning of a possible problem or disease. Therefore, in most cases, mothers/caregivers demonstrated feelings of concern. These feelings appeared due to the difficulty of recognizing the characteristics of pain experienced by children with CP, because although they identified the presence of pain, they could not extract more accurate information about intensity, location and quality of the pain.

The reaction of mothers/caregivers converged with the feelings experienced by mothers of children who did not have any disabilities, especially when we consider that pain is an organic alert. Therefore, concern and other feelings related to the risk of a disease are expected and even justified,

because the illness of the child is very painful and distressing for the family, because it plays a very important role in the family's world <sup>(15)</sup>.

The burden of care of the mother/caregiver due to dependency and lack of mobility of the child causes stress, feelings of anguish and fear, leading to damage to his mental and physical health <sup>(16)</sup>. Thereby, we find that the feelings experienced by mothers/caregivers regarding the pain of their children are influenced by the condition of dependence and the need for ongoing care of the child with CP.

Mothers/caregivers and family try to adapt to what the complexity of the child care demands, which can increase feelings of guilt and/or helplessness, and stress for the family <sup>(17)</sup>.

#### **Absence of pain in children with spastic quadriplegia CP: perception of mothers/caregivers.**

The experience of parents and the bond established with the child may sometimes be insufficient for assessing specific pain in this special population, and thus does not result in perception of the pain in children by mothers/caregivers:

He never complains. Usually, when a child feels pain, he gets irritated, but he is calm, doesn't complain even when he's hungry, he's not a crier. (Saffron) She is always well, smiling, never crying, always good about life. (Mustard) He can't speak and there's no way of knowing if he is in pain. (Turmeric) I think she doesn't feel so much pain. (Dill) He doesn't. Because when you're in pain, you cry, and to this day he has no pain. (Tamarind)

Lack of manifestations, such as crying and irritation, determines the absence of pain. Although the evidence presented above in this study indicates that there is presence of pain in children with CP, we must consider their opinion to understand the reasons for these relations.

The limitations of expressions themselves, perceptions and sensations inherent to CP, may be related to the difficulty in recognizing the typical signs of pain. In this situation, it would be pertinent to conduct a follow-up of the child with his mother/caregiver and family

for a broader investigation in order to understand what determines their perception.

Another possibility may be related to lack of knowledge about pain and ways to assess it, in these children in particular. Mothers/caregivers need guidance and support to understand that children with CP feel pain, that some signs presented are peculiar and that his limited expression of pain may occur through atypical signs that do not clearly show the painful sensation.

Considering the subjectivity of expressing pain, it is noteworthy that the Humanistic Theory proposes that people who care develop an intersubjective relationship, considering the individuality of the reactions to the diseases and problems experienced. In the inter-human relationship, it is important that each one becomes aware of the other, considering their partner in a proper event<sup>(18-19)</sup>.

Thus, we suggest that nurses use such information to aggregate nursing care, redirecting their approach to interpersonal relationship with the mother/caregiver of the child, without judging their opinion.

Understanding the principles of health education should go beyond the field of information, redirecting the look to the significance of the subject as a being involved in his intellectual, emotional and cultural processes, which will influence the search for new practices to obtain a better quality of life<sup>(20)</sup>.

In the fifth phase, nurse inner succession from many to a paradoxal one, resulting in a concept: *The experience of mothers/caregivers regarding pain in children with spastic quadriplegic CP* is established through

continuous interaction between the dyad caregiver-child, when there is identification of behavioral reactions and vocalizations, characterizing communication, and implementation of measures of pharmacological and non-pharmacological relief, involved in feelings of mother/caregiver that pervades concern, fear, anxiety and guilt.

## FINAL CONSIDERATIONS

We believe that professionals who deal with this public need to develop educational strategies in order to empower caregivers to assist in the pain of children with CP, through measures focused on the management of pain in children aimed to motivate appropriate assessment, recording and follow-up, as well as working together with the team responsible for disability rehabilitation.

Due to paucity of research on pain in children with CP in our country, the discussion was restricted to studies originated in other countries, specifically in the area of physiotherapy and medicine. Moreover, given the aim of the present study, we restricted the subject for mothers/caregivers of children with CP. However, we understand the need to expand the investigation to nurses, regarding their perceptions of pain in children with CP and their actions.

With the present proposal, we believe we provide support for the search for well-being of children with CP through pain relief. Therefore, it is appropriate to conduct further studies related to this issue, especially in the area of Brazilian nursing.

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## VIVÊNCIA DAS MÃES/CUIDADORAS FRENTE À DOR DA CRIANÇA COM PARALISIA CEREBRAL

### RESUMO

Objetivou-se compreender a vivência dos cuidadores frente à dor da criança com paralisia cerebral. Estudo qualitativo realizado no Núcleo de Tratamento e Estimulação Precoce com 21 mães/cuidadoras de crianças com paralisia cerebral tetraparética espástica, em novembro de 2010. Utilizou-se a Teoria de Enfermagem Humanística, seguindo as fases da enfermagem fenomenológica de Paterson e Zderad. Emergiram quatro categorias: Reações da criança com paralisia cerebral tetraparética espástica à dor: o chamado de ajuda; A singularidade do diálogo da criança com paralisia cerebral tetraparética espástica com as mães/cuidadoras; Reações das mães/cuidadoras à dor da criança com paralisia cerebral espástica, e Ausência de dor na criança com paralisia cerebral tetraparética espástica: percepção das mães/cuidadoras. A vivência das mães/cuidadoras se estabelece por meio da interação contínua entre a díade cuidadora-criança, quando ocorre identificação das reações comportamentais e vocalizações, caracterizando a comunicação, e a realização de medidas de alívio

farmacológicas e não farmacológicas, envolvidas por sentimentos das mães/cuidadoras como preocupação, medo, angústia e culpa.

**Palavras-chave:** Criança. Paralisia cerebral. Enfermagem. Cuidadores. Teoria de enfermagem.

## EXPERIENCIA DE LAS MADRES/CUIDADORAS FRENTE AL DOLOR DEL NIÑO CON PARÁLISIS CEREBRAL

### RESUMEN

Este estudio tuvo como objetivo comprender la experiencia de los cuidadores frente al dolor del niño con parálisis cerebral. Estudio cualitativo realizado en el Centro de Tratamiento y Estimulación Precoz con 21 madres/cuidadoras de niños con parálisis cerebral con tetraplejia espástica, en noviembre de 2010. Se utilizó la Teoría de Enfermería Humanística, siguiendo las fases de enfermería fenomenológica de Paterson y Zderad. Surgieron cuatro categorías: Reacciones del niño con parálisis cerebral con tetraplejia espástica al dolor: el llamado de ayuda; La singularidad del diálogo del niño con parálisis cerebral con tetraplejia espástica con las madres/cuidadoras; Reacciones de las madres/cuidadoras al dolor del niño con parálisis cerebral espástica; y Ausencia del dolor en niños con parálisis cerebral con tetraplejia espástica: percepciones de las madres/cuidadoras. La experiencia de las madres/cuidadoras se establece a través de la interacción continua entre la diada cuidadora-niño, cuando ocurre la identificación de las reacciones de comportamientos y vocalizaciones, caracterizando la comunicación, y la realización de medidas de alivio farmacológicas y no farmacológicas, involucradas por los sentimientos de las madres/cuidadoras como la preocupación, el miedo, la ansiedad y la culpa.

**Palabras clave:** Niño. Parálisis cerebral. Enfermería. Cuidadores. Teoría de enfermería.

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