

## THE FAMILY OF CHILDREN WITH CEREBRAL PALSY: PERCEPTION ABOUT HEALTH TEAM ORIENTATIONS<sup>1</sup>

*Viviane Marten Milbrath<sup>2</sup>, Hedi Crecencia Heckler de Siqueira<sup>3</sup>, Maria da Graça Corso da Motta<sup>4</sup>, Simone Coelho Amestoy<sup>5</sup>*

<sup>1</sup> Paper taken from the thesis - Care delivery to families of children with cerebral palsy in the first three life years, presented to the Graduate Nursing Program at Universidade Federal do Rio Grande (FURG), 2008.

<sup>2</sup> Ph.D. candidate, Graduate Nursing Program at Universidade Federal do Rio Grande do Sul (UFRGS). Assistant Professor, School of Nursing, Universidade Federal de Pelotas. Rio Grande do Sul, Brazil. E-mail: vivimarten@ig.com.br

<sup>3</sup> Ph.D. in Nursing. Faculty, Graduate Nursing Program, FURG. Rio Grande do Sul, Brazil. E-mail: hedih@terra.com.br

<sup>4</sup> Ph.D. in Nursing Philosophy. Adjunct Professor, Maternal-Infant Nursing Department, School of Nursing, UFRGS. Rio Grande do Sul, Brazil. E-mail: mottinha@enf.ufrgs.br

<sup>5</sup> Ph.D. candidate, Graduate Nursing Program, Universidade Federal de Santa Catarina. CNPq grantee. Santa Catarina, Brazil. E-mail: samestoy@terra.com.br

**ABSTRACT:** Becoming the family of a child with cerebral palsy is a complex process, demanding professional preparation from the health team, besides the ethical and esthetical aspects of these families' care process. In this context, the aim was to get to know how families of children with cerebral palsy perceive the health team's information transmission for care delivery to children with cerebral palsy. The study was based on the perspective of Heidegger and Gadamer. A qualitative, exploratory and descriptive study was developed in Rio Grande-RS, Brazil, involving six families, with a total of nine subjects. Semi-structured interviews were used to collect data, later analyzed according to Thematic Analysis. When interpreting the information, incongruities were found between the health team's orientations and the families' demands for appropriate care delivery to children with special needs. It is relevant for health teams to be well equipped for holistic care delivery, focusing on the needs of these children and their families.

**DESCRIPTORS:** Care. Disabled children. Family. Cerebral palsy. Nursing.

## FAMÍLIA DA CRIANÇA COM PARALISIA CEREBRAL: PERCEPÇÃO SOBRE AS ORIENTAÇÕES DA EQUIPE DE SAÚDE

**RESUMO:** O tornar-se família de uma criança com paralisia cerebral é um processo complexo. Exige da equipe de saúde, preparo profissional, além dos aspectos éticos e estéticos do processo de cuidar dessa família. Sob este prisma, objetivou-se conhecer como a família de crianças com paralisia cerebral percebe a transmissão das orientações da equipe de saúde para o cuidado à criança com a paralisia cerebral. O estudo foi fundamentado com base na perspectiva de Heidegger e Gadamer. Consiste em um estudo qualitativo, exploratório-descritivo, realizado na cidade do Rio Grande-RS, tendo como participantes seis famílias, totalizando nove sujeitos. Utilizou-se entrevistas semiestruturadas para a coleta das informações, as quais foram analisadas segundo Análise Temática. Na interpretação das informações foram encontradas incongruências entre as orientações proferidas pela equipe de saúde e as demandas apresentadas pelas famílias para prestar o cuidado à criança com necessidades especiais. Constatou-se a relevância de uma equipe de saúde instrumentalizada para o cuidado integral, focado nas necessidades dessas crianças e suas famílias.

**DESCRIPTORIOS:** Cuidado. Crianças com deficiências. Família. Paralisia cerebral. Enfermagem.

## FAMILIA DEL NIÑO CON PARÁLISIS CEREBRAL: PERCEPCIÓN SOBRE DE LAS ORIENTACIONES DEL EQUIPO DE SALUD

**RESUMEN:** Tornarse familia de un niño con parálisis cerebral es un proceso complejo, exige del equipo de salud, preparo profesional, aspectos éticos y estéticos del proceso de cuidar de esa familia. Desde este punto, se objetiva conocer cómo la familia de niños con parálisis cerebral percibe la transmisión de las orientaciones del equipo de salud para el cuidado con estos. El estudio se basó en la perspectiva de Heidegger y Gadamer. Se trata de un estudio cualitativo, exploratorio-descriptivo, realizado en la ciudad de Rio Grande-RS, Brasil, participaron seis familias, total de nueve sujetos, se utilizó entrevistas semiestruturadas para la colecta de informaciones, analizadas segundo el Análisis Temático. En la interpretación de informaciones fueron encontradas incongruencias entre las orientaciones dadas por el equipo de salud y las demandas presentadas por las familias al prestar cuidado a los niños con necesidades especiales. Se constata la relevancia de un equipo de salud instrumentalizado para el cuidado integral, focalizando en las necesidades de esos niños y sus familias.

**DESCRIPTORIOS:** Cuidado. Niños con discapacidad. Familia. Parálisis cerebral. Enfermería.

## INTRODUCTION

Perinatal hypoxic-ischemic encephalopathy is the term used to designate clinical and neuropathological findings in newborns submitted to a significant episode of perinatal asphyxia and represents the most common cause of non-progressive neurological deficit in childhood. These deficits include a range of abnormalities called Cerebral Palsy (CP).<sup>1</sup>

The technology available today is unable to provide therapy that is capable of reducing the area compromised by the neurological injuries that were caused by the neonatal asphyxia and that triggered a CP. Therefore, the aim of treatment is to promote the child's independency to the maximum. Treatment needs to start early as, the earlier the central nervous system is stimulated, the better its response will be.<sup>2-3</sup>

In that sense, the revelation of the diagnosis and prognosis to the family is a moment that needs to be considered with caution and preparation, focusing on the human, emotional and professional dimensions of the health team members who will provide treatment. The family's lack of understanding, or in some cases even denial of the special needs deriving from CP can lead to the postponed start of treatment and to an increase in the family's difficulties to deliver care to children with special needs,<sup>4</sup> as well as to the loss of precious time for the child's physical and cognitive stimulation.

Studies<sup>5-7</sup> have demonstrated that children with special needs, especially with mild and moderate degrees, are being forwarded to stimulation programs in a late phase, which impairs their growth and development process.

The prognosis of children with CP can be more or less reserved, according to the location and size of the neurological injury. Indifferently from their CP level, however, their development is strongly linked with the accomplishment of physical and cognitive stimulation and with the care received from their families, as the main care network, allowing these children to overcome their own limitations and, at the same time, enhance their quality of life.

Becoming the family of a child with CP is a delicate and complex process though, which demands a redimensioning of its way of being-in-the-world. The way this family adapts to new situations depends on each member's preliminary experiences, beliefs and values, besides the influence, the space they occupy and the roles they

play.<sup>7-8</sup> The reorganization of the family's existential project and the adoption of authentic existence are fundamental for the child's development as, this way, the family can take care and attend to the child's needs. The child is a being-in-the-world under construction, in the biological as well as symbolic sense, and needs love and care in order to fully manifest itself as such.<sup>9-10</sup>

In this perspective, the importance of relations among human beings is perceived. In this study, more specifically, the issue of care delivery by the Neonatal Intensive Care Unit and the Pediatric Unit health team to the families of children with CP is perceived since the neonatal period. In view of the above, it should be highlighted that children with CP need family care with a view to reaching their maximum potential. The families, however, also need care from the health team in order to be able to resize their way of being-in-the-world and take care of the child. Thus, there is an urgent need for nurses and other team members to prioritize care planning, based on the needs of each child and family.

In view of the peculiarities of care delivery to children with CP and the parallel need to take care of the family, so that it can develop its role as caregiver for the child, questions emerged about the orientations the health team offers to the families responsible for taking care of the children and about their perceived efficacy in daily care for the children. The intent was to transform concerns into frameworks for the construction of this study, based on Heidegger and Gadamer's perspective, aiming to turn it into an instrument to improve the quality of life of children living with CP.

Therefore, the aim was to get to know how the families of children with cerebral palsy perceive the transmission of the health team's orientations for care delivery to children with cerebral palsy.

## METHODOLOGICAL TRAJECTORY

In this research, developed in Rio Grande, an interior city in the State of Rio Grande do Sul, the descriptive-exploratory method was used, in the light of the qualitative approach. It is qualitative as it attempts to incorporate the senses and meanings the families of children with cerebral palsy attribute to the orientations they receive from the health team to take care of these children. Hence, it works with the meanings, motives, aspirations, beliefs, values and attitudes, in constant transformation.<sup>12</sup>

The study received approval from the Research Ethics Committee of the *Associação de Caridade Santa Casa do Rio Grande*, under number 002/2008.

Study participants were six families, consisting of six mothers, two maternal grandmothers and one maternal grandfather, as these were considered the children's caregivers. Participants were identified as follows: F1Mother, F1Grandmother, F2Mother, F2Grandmother, F2Grandfather, up to F6Mother, respectively, in the order of the interview and according to the degree of parenthood with the child.

It should be informed that the study participants were all families of children born with a fifth-minute APGAR score of three or less and diagnosed with severe perinatal asphyxia in Rio Grande-RS, in 2005, 2006 and 2007, and who were alive at the time of data collection. The medical records of women who gave birth at two hospitals in the city were consulted to identify potential participants.

All participants invited for the study were contacted at their homes, accepted to take part in the research and signed the Informed Consent Term. Their privacy was preserved, respecting the ethical aspects of their anonymity and information secrecy.

Information was collected through semi-structured interviews, which were recorded and later transcribed. The intent was to address questions that involved the health team's orientations to these families in order to take care of the children with CP.

To interpret the collected information, thematic analysis was chosen, which comprises three phases: pre-analysis, data exploration, treatment of the obtained results and interpretation.<sup>12</sup> In the pre-analysis, the collected data were fully transcribed. Then, readings and floating re-readings took place with a view to exhaustive contact with the collected information. Then, the transcribed data were organized by looking at each interview separately, highlighting relevant aspects. After this phase, the interview statements were mapped, marking the key points, for the sake of an easier visualization of the entire material. In the data exploration phase, everything that was significant was underlined, i.e. words, phrases, paragraphs with the same thematic contents, identifying the units of significance and excerpts needed. New readings took place in the attempt to apprehend the manifest and/or hidden meaning of the ob-

servations and information in the reports, which were then subject to further reflections.

## RESULTS AND DISCUSSION

The dialogue/voice given to the families of children who were victims of severe perinatal asphyxia about their perception of the health team's orientations for care delivery to children with CP permitted the identification of incongruences between the health team's orientations and the families' demands with a view to care delivery to children with special needs. Based on the interpretation of the study participants' information, the following thematic units were constructed: Orientations the health team offered to the families for care delivery to children with CP and Dialogue: a need to orient care.

### **Orientations the health team offered to the family for care delivery to children with CP**

Care delivery to children with special needs, brought about by a CP, and their families goes beyond care from a mere biological perspective, adding much more than the anatomic-physiological aspects of CP. Thus, it is defended that taking care of children with CP and their families implies understanding the senses and meanings they attribute to each situation experienced throughout their existence. It also implies the joint use of available technological equipment with a view to reaching practical success, that is, the combination between the technologies of scientific knowledge and the meaning these care beings attribute to each existential moment.

Getting to know the families' perception about the orientations they received from the health team for health care to children with CP permitted identifying that the care orientations are incipient in view of the needs and complexity of being-a-child with CP and being-a-family. The voice given to the families revealed a limitation in the care the team delivers with regard to the orientations provided about how to take care of children with CP.

*Nobody gave any special care. They just told me to watch him, but did not give me any special care [...] they just told me to watch, I think if he ate well, slept well, I don't know really what I was to watch (F1Mother); [...] they did not tell me anything. Even when he left [the hospital] I was together with the girl [F1Mother] and everything, but they [professionals] did not talk about special care, they just said he was*



*fine* (F1Grandmother); [...] *no, they did not tell me anything* (F2Grandmother); [...] *no, they didn't say anything, like, about care* (F2Grandfather).

The statements reveal that these families received little clarification on how to take care of the child. F1Mother mentions that she was oriented to watch her son but, when asked about what she should observe, she faced difficulties to answer. Orienting the mother to observe some characteristics in the child's diet, growth and development is essential. It is fundamental, however, for the mother, or whoever the caregiver-observer may be, to know what to observe. Without this, the recommendation is not valid, that is, the caregiver would neither know how nor for whom to observe.

Growth and development monitoring is an essential action that gains broader nuances when the child was a victim of severe perinatal asphyxia and therefore developed CP. This special need is predominantly characterized by sensory-motor dysfunction, involving muscle tone, posture and involuntary movement disorders, manifested through a lack of control over one's movements, adaptive muscle length modifications and, in some cases, end up resulting in bone deformities.<sup>6</sup> Other associated disorders exist though, with different frequency levels, including: mental deficit; epilepsy; visual and language alterations; eating difficulties; intestinal constipation; behavioral disorders.<sup>2-3,13-14</sup> These situations strengthen the relevance of observing and monitoring these children.

F1Mother did not understand the relevance of observing her son though, nor did she knew what was actually important to observe. This situation reinforces the need to reconsider the relation/communication between the health team and the family. It should also be kept in mind that, in many cases, the relation between health professional and family is still mediated by an unequal relation, in which only one party is considered the "knowledge provider". Another study<sup>15</sup> developed to understand the meaning of educative practice in bonding among users, the pediatric team and health services, disclosed as an important result that health education remains centered on professional knowledge.

The relation that needs to exist between the health professional and the family should be mediated in a subject-subject perspective, and not a subject-object perspective.<sup>16-17</sup> Both are authentic human beings (professionals and relatives) with knowledge and important information, coming from different knowledge origins, but which can be complementary.

It should be highlighted that nurses play a fundamental role to explain/orient families about the care they need to take with the child, using a clear and understandable language and avoiding technical terms, and need to provide feedback, with a view to proving that the orientations offered to the family were understood.

In this perspective, the action/act of being able to establish a dialogue between caregivers and the being receiving care permits the construction of one's own rationality, which will emerge as a the product of these two authentic beings' dialogic and caregiving encounter.<sup>16</sup> If health professionals impose their scientific knowledge when acting, this can cause a distance between the professionals and the persons they want to take care of.

### **Dialogue: a need to orient care**

When established as a form of care, dialogue permits the construction of a particular rationality, that is, it is a product that emerges from the dialogic and caregiving encounter between two authentic human beings, with their own experiences and knowledge, knowledge in different but equally important perspectives, which are valued in the context of the encounter.<sup>16,17</sup> The family expresses its perspective, its observations in the child's daily life, and the professional uses them when evaluating the child. The family, in turn, uses the professional's orientations/information to improve care for the child. This results in the exchange and joint construction of knowledge, which will benefit the child.

In a dialogue, the issuer and receiver should speak the same "language". Both parties need to understand the expressions, the words used;<sup>16-18</sup> if not, the receiver turns into an information deposit. He receives a range of contents he is unable to absorb, and the information received is not put in practice.<sup>18</sup> If the mother does not know how and what to observe, she will not be able to put this action in practice. No matter how small the adaptation that takes place in the family routine to take care of the child with CP, the results can be significant, for the child's growth and development as well as for the minimization of family stress.<sup>19</sup>

*Ah, they just said that he had to drink formula, but the price is threefold! [...] (F2Mother).*

*A doctor, I had not seen him the whole time [...], the day I came home he told me some things I had to do, like take care when giving a bath, [...] to take her for the heel lance [...]. Then he gave me the prescription,*

they even gave me a medicine in there, the head nurse was a very good friend and she gave me the medicine he prescribed, everything in detail with the size of the syringe (F3Mother).

Ah, once a girl wanted me to give her a bath inside the ICU, but I said that I don't feel ready, I was afraid. Then, when she went to pediatrics they gave me a bathtub and do it with what you've got, oh, the water is there in the shower, take it care and give the bath, kind of the kid's yours, do what you can [...]. Do you think they told me something? No. Here's the bathtub and do it with what you've got, [...], nobody told me anything [...] (F4Mother).

[...] so, the doctor told me that he's a child, like, who needs various kinds of care. Like, catching a chill for example [...], and taking care with green vomit. [...] she told me not to use perfume, not to use talcum powder, perfume, talcum, smell, strong things [...] (F6Mother).

The statements demonstrate that these families received orientations about some care, but no specific care regarding the child's special needs.

F2Mother mentions she was oriented to give her child formula, but says that it is very expensive, making it unfeasible to buy it. Professionals should also consider financial issues when transmitting care orientations. It is important to know whether the person will be mentally, economically and socially able to follow the orientations. They may often feel constrained to request other alternatives that could also be used. Hence, nurses need to be sensitive to the importance of presenting alternatives that are applicable to each individual context.

F4Mother talks about the difficulty she faced to bathe her daughter. It should be highlighted that bathing should be a moment of pleasure, when the bond between mother and child can be strengthened and the child's motor and cognitive skills can be stimulated.<sup>19</sup> When she was stimulated to bathe her child at the Neonatal Intensive Care Unit (NICU), she felt insecure to do it at that time but, at the Pediatric Unit, she felt obliged to bathe her daughter alone. The action of bathing may seem simple, but F4Mother did not feel secure to do it. The child had just left the semi-intensive unit, so that the Mother still thought she was very fragile, perfectly explaining the maternal fear.

A similar situation was found in one study<sup>20</sup> in which difficulties were identified in the dialogue between professionals and mothers about how to take care of the child. The authors concluded that, when becoming a mother, the woman has to know and perform certain actions, like giving a bath. In F4Mother's situation, the health professionals

could have minimized this fear through a simple attitude, like accompanying her during the first bath for example.

Some parents tend to find the child's weakness frightening. In many cases, they perceive it as a piece of Chinese porcelain, arousing an exaggerated fear of making mistakes and insecurity.<sup>21</sup>

You know, I used to say, like, to my mother, I won't be able to take care of him, and she said like, how come you won't, you've already had one [...]. I got home, [...] and his father [name] asked how you should hold him? I don't know [...]. Because when he came here he was like a mouse [...] (F5Mother).

In the above excerpt, F5Mother is able to express the difficulty and fear she and F5Father felt to take care of their son, as they felt insecure in view of the fragility of such a small infant who had just been discharged from hospital.

Returning home with a baby with special needs, who was hospitalized at an NICU after birth, and being responsible for it is an obstacle to be overcome. The hospital often represents a safe place, where specialized professionals can cope with any difficulties that may emerge, while going home can represent the loss of this protection and the feeling of fear, anxiety and hesitance about how care for the infant will take place.<sup>4</sup> Therefore, it is fundamental for parents to be prepared to take care of the child since prenatal care and that, after discharge from hospital, they be referred to a health unit that can offer the support needed to facilitate the child's growth and development.

If discharge is an event the team should pay attention to in cases of infants without any problems, it comes with an aggravating factor when the child suffers from CP or was a victim of neonatal asphyxia, whose consequences have not been defined yet, considering the multiple specific care it will need. In this process, the nurse and the entire team should elaborate action strategies that involve the family, with a view to preparing them to take care of the child.

Taking care of the child also means taking care of the family. Supporting the mother, father or other members enables the family to enhance its skills, reduce its fears, clarify its phantasies, helping to perceive the child as an actual being, decreasing the stereotype of a frail and "un-manipulable/untouchable" figure that was transmitted to the parents during NICU hospitalization.

When the diagnosis of a child's chronic condition is received, an entire family is dis-

rupted. This situation demands the construction of new ways of seeing the surrounding world, of mobilizing often-unknown individual, family and social resources. In general, the children's limitations represent limitations for the parents themselves, evidencing their doubts, anguish and lack of knowledge.

After gaining different kinds of resources and care-related knowledge, however, after seeking to understand the situation they are going through, it is perceived that the parents move beyond and engage in the struggle for the child's quality of life, reflected in the extent and quality of care delivery.

The families' care action triggers the feeling of security when they perceive that they are not alone in the responsibility for the child's care. "The responsibility towards the other is an attitude that reinforces the bonds in the relations of being-in-the-world, it is authentic existence".<sup>10:159</sup> Being-in-the-world grants the being conditions of "becoming", as "it is in the relation with the other and through the other that the being starts to assume his human existence, gets to know himself and acknowledges this existence as a unique being, manifesting his own way of being".<sup>10:160</sup> In this perspective, health professionals and particularly nurses should use all opportunities to talk, exchange experiences with the parents, mediating conditions for the child's care.<sup>15</sup>

Among the conditions needed to develop the care process, availability, respect, intentionality, trust are fundamental, consequently promoting the growth of both: the caregiving being and the being receiving care.<sup>11</sup> The moments should be valued and treated as singular, in the parents' training/preparation process for hospital discharge and mainly to take care of the child at home. This situation is highlighted in the following excerpt:

*[...] well, I think like, that they should have told me, [...] that they should have talked to me, [...] about her having this problem, [...] I could have taken her early for treatment. 'Look, take her mom, take her to APAE'. I don't know where, but start doing something, of course she'd definitively have something [sequel], she wouldn't get rid of all sequelae, after everything she's gone through. [...] I know they didn't know about the extent of the sequel. But if they imagine that there's going to be something [sequel], then why not start the stimulation early? It wouldn't cost anything, right? (F4Mother).*

In the above testimony, F4Mother describes the lack of forwarding for early stimulation,

criticizing the lack of referral to a specialized care service for her daughter. The absence of an effective dialogue between the health team and the mother led to an unnecessary postponement of the start of treatment, a fact that was also found in other studies.<sup>4,15,21</sup>

In this situation, when discharged, the children should be forwarded to an early stimulation service, with a view to starting treatment as early as possible and reaching their maximum range of potentials, indifferently of their special needs.

The alterations the CP imposes will significantly vary according to the stimuli that are offered. When injured, despite current technology, the central nervous system remains unable to reconstitute itself, but should be stimulated early and intensively because, the more it is stimulated, the better its response will be, as discussed earlier. Early stimulation can considerably reduce developmental deficits.<sup>2</sup> Hence, the ability to be-able-to-be of children with CP is directly related to what they are offered.

In this perspective, it is based on the family's daily life that professionals who aim to take care of these children and their families seek to construct health, prioritizing protection, self-care promotion, solidary exchange, in the attempt to get away from the biomedical, dependent and disease-centered model.<sup>22</sup> The authors highlight that, thus, the philosophy that permeates care is more than a simple extension of the services, as it aims for a practice that permits criticism, changes and knowledge construction.<sup>22</sup>

## FINAL CONSIDERATIONS

The interpretation of the information evidences incongruences between the orientations provided and the families' actual needs to take care of the children.

In their testimonies, the family members expressed how valid it would be to use referral to a specialized service, that is, to have a support network in order to feel more secure to deliver care to the child. This arouses the need to reconsider how interactions among services are occurring, at all care levels.

The information the team provides to the family was often mediated by an ineffective communication process, in which receiver and issuer were not on a horizontal line, which in some cases led to the non understanding of the care orientations, delaying the start of the child's treatment, as evidenced in some studies mentioned above.



In view of this result, the need is identified to sensitize health professionals to the establishment of authentic dialogical relations with family members, which value these subjects' autonomy and co-accountability in care delivery to children with CP. Therefore, it is relevant to encourage permanent education projects for workers, in order to enable them to put in practice health education actions. In addition, they should be trained for forwarding in the network and offer information about these children's rights, with a view to preserving their citizenship.

It is highlighted that the health team and particularly the nurse could use some principles from Heidegger and Gadamer's philosophy, like their ideas about care and dialogue, in order to improve care delivery to users, that is, to the human beings who need care. As these authors value care as a way of being, going beyond the mere instrumental perspective, the care technique, dialogue takes place through a relation between authentic subjects. Therefore, for dialogue to occur in this perspective, professionals need to perceive users as authentic human beings with opinions and experiences they need to be respect and valued. Understanding these concepts allows professionals to (re)consider their way of being and acting towards the other (care being); reformulate their way of being a professional, of being a caregiver.

When one understands care and dialogue in this sense, one can (re)think the guiding principles of care practice and understand the need to go beyond the mere perspective of technical success, reaching the practical success of care actions. Thus, the human being one intends to take care of is value and the relation between professional and users is established.

In the context of the encounter mediated by care, health professional and users can understand the senses and meanings both attribute to certain situations. In this perspective, techno-scientific equipment can be made available to reach the desired practical success or, what is more, the happiness projects of these beings in their singularity.

Putting in practice this caregiving dialogue is our main challenge though, as it is not simple. The search for the caregiving encounter mediated by dialogue itself is an art, instead of a power to put in practice. This exercise is needed in our daily praxis as health professionals and, why not, as human beings. It is a continuous exercise to seek the adequate word to use with the other,

the appropriate gesture, the respect for my being as a historical individual and for the other as an authentic being, as a being-in-the-world in the most literal and complex sense of the expression.

The authors hope this research will indicate routes for further study, with a view to supporting care delivery to children with CP and their families, respecting them as authentic beings. It is highlighted that the study found gaps in the dialogue established between health team and family, making it difficult to put care for the child in practice. Thus, there is an urgent need to reconsider the relation established between professionals and relatives with a view to guaranteeing better care delivery to the children and, consequently, a better quality of life, allowing them to develop their potentials to the maximum.

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