

SOCIAL REPRESENTATIONS OF MOTHERS AND FATHERS ON CHILDREN WITH CEREBRAL PALSY

REPRESENTAÇÕES SOCIAIS DE MÃES E PAIS SOBRE CRIANÇAS COM PARALISIA CEREBRAL

REPRESENTACIONES SOCIALES DE MADRES Y PADRES SOBRE LOS NIÑOS CON PARÁLISIS CEREBRAL

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ABSTRACT

Objectives: the diagnosis and prognosis of cerebral palsy arouses intense feelings in the family, due to the fact that they have to deal with a special child, which makes this confrontation a delicate and difficult period. The present work aimed to understand the representations of mothers and fathers about the child with cerebral palsy. **Materials and Methods:** it is a qualitative research based on the procedural approach of the theory of social representations. Were used: the technique of drawing-story with theme; the focus group; and the semi-structured interview, with 19 participants. **Results:** the data were processed using the technique of thematic content analysis and analysis of the graphics of the drawings, with subsequent triangulation of the data. The image categories of the special child emerged; learning and practices of mothers and fathers; identity function of the recognition of the group of belonging. **Conclusion:** mothers and fathers of the researched social group materialize their representations about children with cerebral palsy in the care they provide, in the different modes of communication between the family and the child, which becomes a facilitator so that mothers and fathers can both learn and attend your child's needs. It was possible to perceive the manifestations of care, of learning in the support networks that are formed, of belonging to the studied social group.

Keywords: Cerebral Palsy; Mothers; Fathers; Child; Family.

RESUMO

Objetivos: o diagnóstico e prognóstico da paralisia cerebral desperta sentimentos intensos na família, pelo fato de esta ter que lidar com uma criança especial, o que torna esse enfrentamento um período delicado e difícil. O presente trabalho se propôs a compreender as representações de mães e pais sobre o filho com paralisia cerebral. **Materiais e Métodos:** trata-se de pesquisa qualitativa fundamentada na abordagem processual da teoria das representações sociais. Foram utilizadas: a técnica do desenho-estória com tema; o grupo focal; e a entrevista semiestruturada, com 19 participantes. **Resultados:** os dados foram processados pela técnica da análise de conteúdo temática e análise do grafismo dos desenhos, com posterior triangulação dos dados. Emergiram as categorias imagem da criança especial; aprendizado e práticas de mães e pais; função identitária do reconhecimento do grupo de pertença. **Conclusão:** mães e pais do grupo social pesquisado materializam suas representações sobre os filhos com paralisia cerebral no cuidado prestado eles, nos diferentes modos de comunicação da família com a criança, o que se torna um facilitador para que mães e pais possam tanto apreender e atender às necessidades de sua criança. Foi possível perceber as manifestações de cuidado, de aprendizado nas redes de apoio que se formam, de pertencimento ao grupo social estudado.

Palavras-chave: Paralisia Cerebral; Mães; Pais; Criança; Família.

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RESUMEN

Objetivos: el diagnóstico y el pronóstico de la parálisis cerebral despierta sentimientos intensos en la familia, pues se trata de convivir con un niño especial, lo cual hace que esta confrontación sea un período difícil y delicado. El presente trabajo tuvo como objetivo comprender las representaciones de madres y padres sobre el niño con parálisis cerebral. **Materiales y métodos:** investigación cualitativa basada en el enfoque procesual de la teoría de las representaciones sociales. Se utilizaron la técnica del dibujo-cuento con tema, el grupo focal y la entrevista semiestructurada con 19 participantes. **Resultados:** los datos se procesaron utilizando la técnica de análisis de contenido temático y análisis de los grafismos de los dibujos, con posterior triangulación de datos. Surgieron las siguientes categorías: imagen del niño especial, aprendizaje y prácticas de madres y padres, función identitaria del reconocimiento del grupo de pertenencia. **Conclusión:** las madres y padres del grupo social investigado concretan sus representaciones sobre los niños con parálisis cerebral en los cuidados que les brindan, en las distintas maneras de comunicación entre la familia y el niño, lo cual se convierte en facilitador para aprender y atender las necesidades del hijo. Se observaron manifestaciones de cuidado y aprendizaje en las redes de apoyo que se establecen, de pertenecimiento al grupo social estudiado.

Palabras clave: Parálisis Cerebral; Madres; Padre; Niño; Familia.

INTRODUCTION

Cerebral palsy (CP) is a set of abnormalities, the most common cause of disability in childhood, with motor disorders that compromise their growth and development, and the prognosis of children with CP may be more or less reserved, according to the location and size of the neurological lesion.¹

The diagnosis and prognosis of CP generally arouses intense feelings in the family, since the latter now has to deal with a special child.² The diagnosis of CP involves retardation or delay in motor development, persistence of primitive reflexes, abnormal reflexes and the failure of the development of protective reflexes, such as parachute response. And its classification is based on the analysis of the quality of muscle tone, motor expression pattern, region of cerebral impairment and severity.³

For concepts already internalized, parents act with their children according to their beliefs and values. Thus, culturally, the family expects their child to be born and be healthy, as well as a series of expectations is related to the future of that child, thus constituting the image of an "ideal child". The arrival of a disabled child, for many parents, represents exactly the "loss" of that idealized child.⁴ It is the moment for the family to live with a new reality, which influences the formation processes of the social representations that these individuals have about children with CP,

giving them cultural values specific to the environment in which they are inserted.

The theory of social representations is a "modality of knowledge socially elaborated and shared, with the practical objective that contributes to the construction of a reality common to a social group".⁵ It is a set of concepts, propositions and explanations created in everyday life, in the course of interindividual communication, with the main function of making the unfamiliar familiar.⁶

In the family formation phase, the couple highlights marital love and children as important values, prioritizing them in their routine and in family projects in which the very decision to have a child is part of the projects of these couples.⁷ It usually happens to be this is the family moment of knowledge of the diagnosis and prognosis of CP, which is usually marked by intense feelings of the family in relation, mainly, to the fact of having to deal with a special child.²

Many mothers and fathers may experience a denial of the diagnosis at this time, which can lead to a postponement in the start of treatment for these children.¹ These families face, from the diagnosis of CP, discrimination in view of people seeing their children as incapable or unwanted, even among the extended members of their own family, often hindering and restricting the acceptance of these children. Thus, it is noticed that there are many changes in the lives of fathers and mothers of children with CP, in professional, social and emotional life.³

CP, until then, was unknown to the family, until she starts to perceive on a daily basis that this child's behavior is different from what is expected for a healthy child. It is at this point, then, that parents seek to understand their child's reality. With the establishment of the diagnosis, the family starts to receive fragmented information from different professionals from different areas and through the interaction with mothers and fathers who already experience this reality.⁴

Thus, fathers and mothers, due to awakened emotional factors, face a delicate and difficult period and the family impact can be variable. Some families live this moment with crisis and disagreements, disharmony between the couple, culminating in marital separation, while others find strength in the diagnosis of CP to unite and dedicate themselves to share the commitments, responsibilities and care for the child diagnosed with CP.³ Thus, knowing how mothers and fathers of children with cerebral palsy share the same social reality becomes relevant, so that interventions are directed to the reality of these children. Therefore, what are the representations of mothers and fathers about their child with CP? Hence, this study aims to understand the representations of mothers and fathers about the child with cerebral palsy.

MATERIAL AND METHODS

This is a qualitative research based on the procedural approach of the theory of social representations.⁶ Carried out

in the municipality of *Jequié*, *Bahia*, Brazil, at the Association of Parents and Friends of the Exceptional (*Associação de Pais e Amigos dos Excepcionais* -APAE) and at the Physiotherapy School Clinic (*Clínica Escola de Fisioterapia* - CEF) of the *Universidade Estadual do Sudoeste da Bahia* (UESB).

The research participants consisted of 12 mothers and seven fathers of children diagnosed with CP, aged between four and 10 years old, with the following inclusion criteria established: being over or equal to 18 years old; being a mother or father of a child diagnosed with CP who was routinely monitored by APAE and/or CEF; and residing in the municipality of *Jequié*. And as exclusion criteria, mothers and fathers who were not found after three consecutive visits or who did not participate in all of the research data collection procedures.

Data collection was composed of three techniques: a) drawing-story with theme; b) focus group; c) semi-structured interview. The projective technique of drawing-story with theme was carried out individually, with the participating mothers and fathers. The semi-structured interview was conducted only with the fathers and the focus group with only the mothers and took place at three different times, weekly and previously scheduled with the participating mothers.

The material produced by the projective technique of drawing-story with theme was analyzed, according to the steps: a) systematic observation of the drawings; b) selection of drawings by graphic similarities and/or approximation of themes; c) floating reading of the thematic units of the stories; d) clipping and categorization; e) analysis and interpretation of thematic content grouped by categories; f) analysis and interpretation of drawings using graphics.⁸

For the analysis of semi-structured interviews and focus group meetings, the thematic content analysis technique was used. Finally, all data were triangulated, enabling the "combination and crossing of multiple points of view".^{9,10} To preserve the confidentiality of the participants' identities, they were designated by flower names chosen by their meanings according to the main adjectives expressed by the participants during data collection.

Resolution Nr. 466/2012 of the National Health Council, which regulates research procedures involving human beings, was complied with in all stages of the study. Thus, the research project was submitted to the Research Ethics Committee of the *Universidade Estadual do Sudoeste da Bahia* (CEP/UESB), and data collection was approved, through Opinion Report Nr. 961.459 and CAAE: 38942414.1.0000.0055.

RESULTS

After processing the data, the meanings of children with CP, mothers and fathers participating in the study emerged, through the categories: image of the special child; learning and practices of mothers and fathers; and recognition of the membership group.

One hundred and twenty-eight analysis' units (AU) were isolated, which constituted the corpus of the present research. Of these, 77 AUs (60.1%) constituted the image category of the special child; 29 AUs (22.7%) were in the category of learning and practices of mothers and fathers; and, finally, 22 AUs (17.2%) instituted the category identity function of the recognition of the group of belonging.

The first category, image of the special child, shows that the experience of caring for a child diagnosed with CP makes mothers and fathers represent them as a "special" being, which goes beyond the vision of being someone with different needs, both for your care and for the maintenance of your quality of life. But the word "special" is used as a different connotation, which transcends its meaning.

Some statements turn to the divine figure, "God", attributing to Him the fact that He sent or presented these participants with a special, exclusive child, as if He had a mission to fulfill in that family. Even in this feeling of being special, it was also noticed that these participants have mixed feelings about the child with CP, as shown in the AUs below.

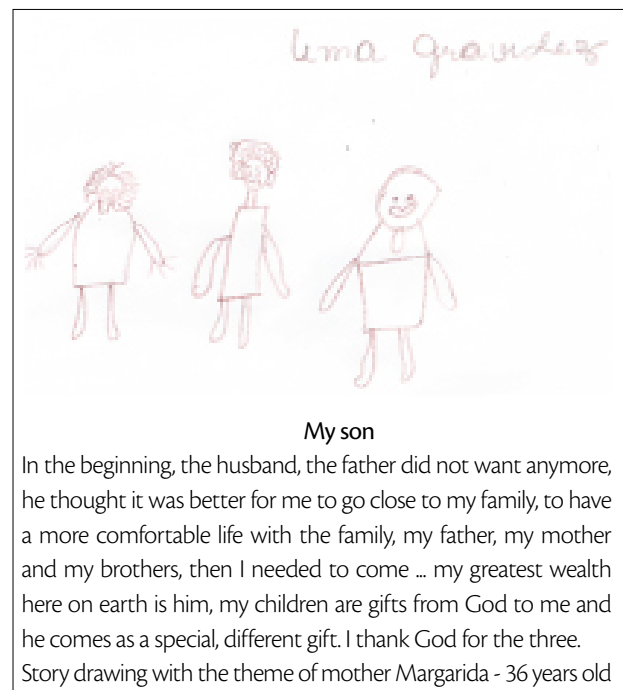


Figure 1 - Drawing-story with theme 1- My son. *Jequié*, BA, Brazil
Source: research corpus.

My son only brings me joy, I am proud of my special son
(Mother Cravina rosa).

I glorify the Lord; I say that it was a miracle in my life that he is my special son (Mother Íris).

Special child, each special son has a disability, but all are special children (Mother Gérbera).

God sent me a special one because He knew I needed him like that (Mother Hibiscus) [Focus group speeches].

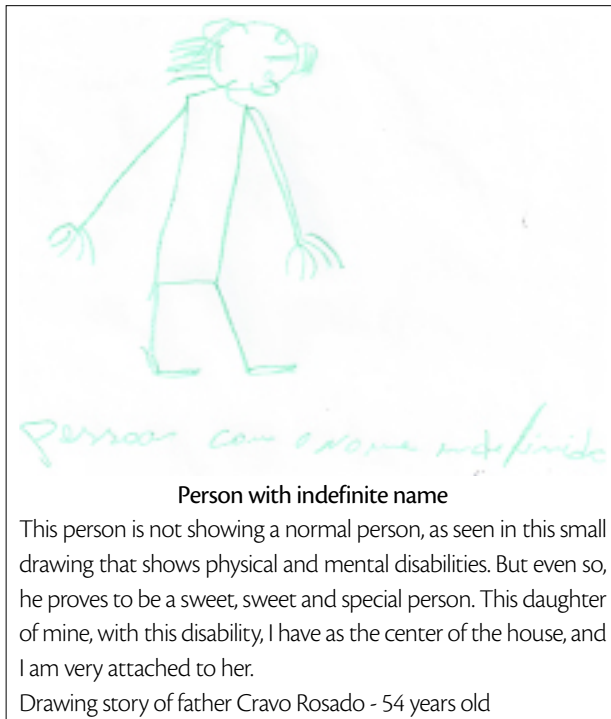


Figure 2 - Drawing-story with theme 2 - Person with an indefinite name. Jequié, BA, Brazil
Source: research corpus.

It was noticed in the speech of some mothers that since pregnancy it seemed that there was something different with that pregnancy, an observation that came mainly from those mothers who had already had other pregnancies before the arrival of the child with CP.

It was a pregnancy like this, different, the child did not move (Mother Gérbera) [Speech by the focus group].

[...] at the beginning, the father didn't want anymore, I left and I felt very sad, I didn't want to go out, take a bath [...]
(Mother Margarida) [fragment of the story].

In the second category, learning and practices of mothers and fathers, it is perceived that the representation about the child with CP is influenced by the learning process, from the new experiences, daily relationships and communicative interactions that these mothers and fathers experience, for exercising routinely take care of their children. This learning goes through the spheres, technical and

scientific, with the professionals who participate in this care, such as the professional support network of these parents. There is also learning from the spheres, emotional and spiritual.

You will be learning, because today I am a woman
(Mother Bromélia).

I learned, in faith, in patience, in love (Mother Dália amarela).

Teaches the family, relatives to value people (Mother Gérbera) [Focus group statements].

The wisdom to experience receiving her in my life. I learned to be very patient (Mother Dália amarela).

It taught us and teaches us all the time that life [...] (Father Cravo branco).

It is a blessing, so he has taught us a lot (Father Flor de amendoeira) [Fragments of stories].

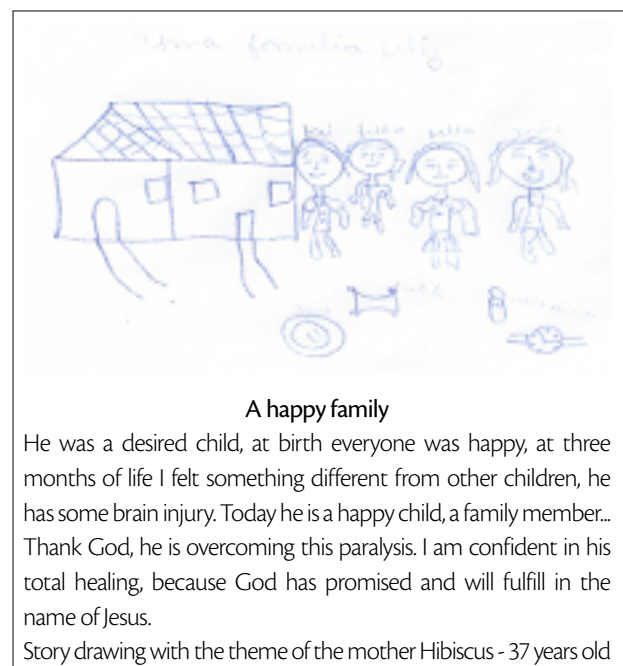


Figure 3 - Drawing-story with theme 3 - A happy family. Jequié, BA, Brazil
Source: research corpus.

The third category, the identity function of recognizing the group of belonging, demonstrates that the phenomena that permeate the acceptance of the diagnosis of CP - moment of sentimental confusion in relation to the ideation of the child and formation of the child's image, participants of the research in contact with other parents who experience

the same reality and the communication established between this social group - in some way they represent encouragement and help in the care and coexistence process, forming a social support network.

I saw other children, other mothers, gave me strength, knowledge and acceptance (Mother Dália amarela).

I got to know the mothers of special children, one goes on informing the other of the problems, medical guidance, talks about the routine... (Mother Tulipa) [Fragments of stories].

I met several mothers with each story different from each other and each mother learns more each day (Mother Cravina rosa).

I have already made and lost many friends on this journey, it is that many friends of mine who had a special child their children have already died (Mother Gérbera) [Speech by the focus group].

It is noticed that the categories mentioned anchor the representations of the parents about the formation process of social representations about the child with cerebral palsy, which is objectified from the selected AUs, that is, through the formation and materialization of the image about the represented object.

From the analysis of the graphics, it was found that the research participants showed a tendency to draw their children with CP highlighted among family members from a facial expression, size and/or position. Such graphic formations can express the feelings and care towards this special child, which corroborates the participants' statements. Still, regarding the structural aspects of the graphic images produced by the research participants, drawings were found whose characters assume deformed, primitive or phantasmatic configurations.

Regarding the bonds of affection analyzed from the graphic configurations, it was observed that only a few drawings had their members connected or linked together, suggesting the level of social adaptation or interrelation between the social individuals that make up the family. Still, in relation to the structuring of the environment in the drawing, there were few drawings that presented a base (floor), and in many, loose, disconnected and floating houses were observed.

The image of a future in which their children can walk and maintain a life enjoying all functions, motor, cognitive and social, appeared in some drawings, expressing the dreams that motivate mothers and fathers to invest and bet in the treatment of their children, as shown in Figures 4 and 5.

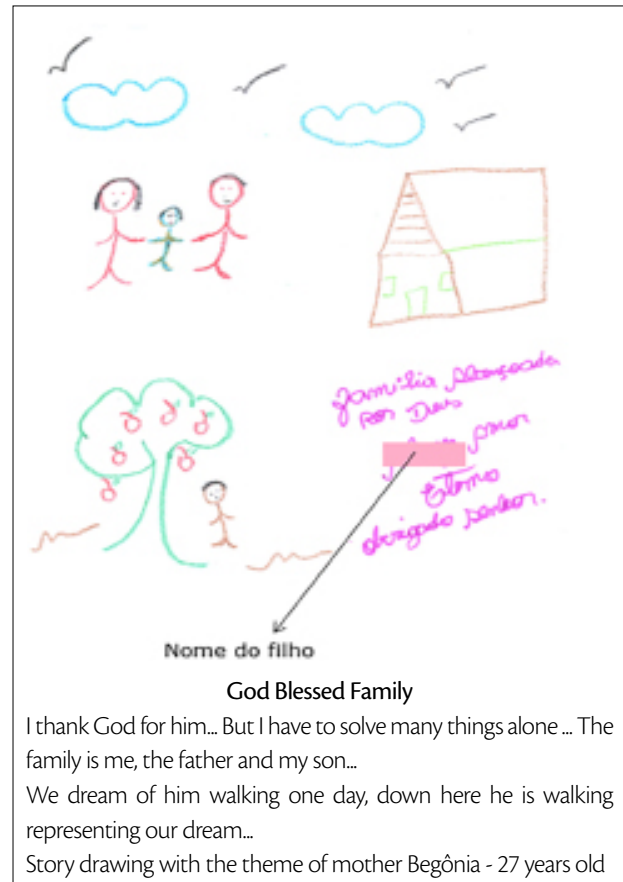


Figure 4 - Drawing-story with theme 4 - Family blessed by God. Jequié, BA, Brazil
Source: research corpus.

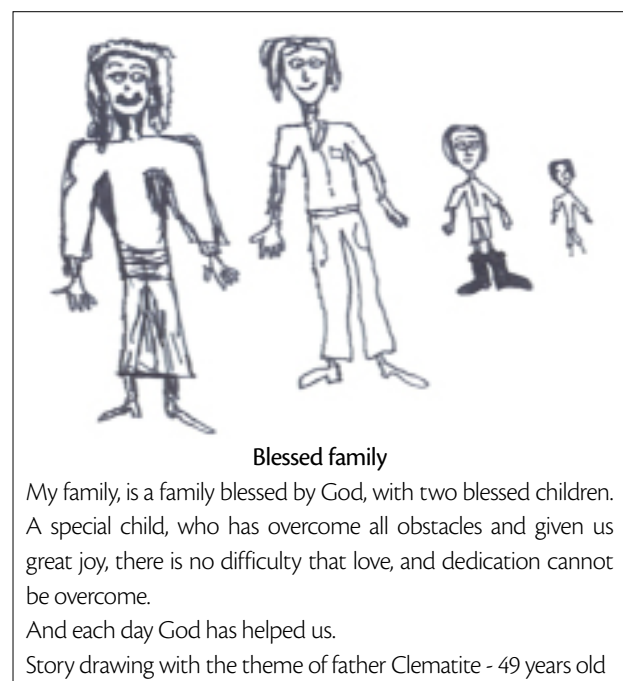


Figure 5 - Drawing-story with theme 5 - Blessed family. Jequié, BA, Brazil
Source: research corpus.

DISCUSSION

Social representations are immersed in everyday communications, circulate in speeches, ideas and images, materializing in conduct.¹¹ Mothers and fathers of the researched social group materialize their representations about children with CP in the care provided to them. Different modes of communication between the family and the child are being constructed in the care process, a look, a gesture, an act, becoming a facilitator so that mothers and fathers can both apprehend and meet the needs of the child with CP.³

This communicative process establishes codes, symbols and its own language capable of identifying bonds in the social group and generates positive effects among its members. In this way, these families discover the best way to interact with their special child to understand their needs.³ This process reaches a degree of identification and interaction between the subjects that these fathers and mothers call "special", as well as the whole family becomes "special", but in favor of caring for a single member, the child with CP, which was observed in the data produced by this research.

Representations are complex phenomena, always active and acting in social life, in the wealth of diverse elements, informative, cognitive, ideological, normative, beliefs, values, attitudes, opinions, image, etc. These elements are always organized as a kind of knowledge. In the diagnosis, prognosis and care for a child with CP, a conceptual universe, with its signs and symbols, is forming and interacting with those who are already part of the individuals.¹²

The impact of the diagnosis makes mothers and fathers create coping resources, and faith and hope in God influence the way they react and adapt to the new situation.³ Transcendence and spirituality appear in the representations that this group carries about their children with CP and serve as an incentive and motivating agent to continue fighting and believing in the recovery of their children. Likewise, in the formation of the image of these children, from the perspective of their parents, the special being is seen as a divine gift, full of meanings that are sources of lessons and teachings. It is part of this universe to reach the day when your children will be fully recovered. Especially with that parent who has the most contact and who most accompanies this child, this is usually a role played by the mother, both because of the values that are already in force in society, leaving the parents the role of providers of their families.¹³

Thus, in addition to consanguineous bonds, the bonds of friendship, companionship, solidarity and love are the ones that most predominate and strengthen the culture, values and beliefs of these families, in addition to reinforcing coexistence relationships.² The mother-child bond is a relationship established even in the intrauterine environment. Today it is believed that there is a maternal influence on the physical and emotional development of the fetus. Thus, maternal emotions and feelings during pregnancy may be able to interfere in this development.¹³ Some mothers

participating in the study expressed about their negative feelings during pregnancy and related them to the reality of their children's CP, thus demonstrating a sense of guilt.

In Winnicott's view, the mother-child relationship is primitive and central to the knowledge of the human being development, being in this relationship that the child has its needs supported and constitutes a self, the "I", from the maternal "I", able to overcome the obstacles inherent in living.¹⁴ In the relationship between mother and child with CP, the complicity of this bond seems to be linked to the child's responses in daily interactions with his family and the environment around him. The more positive these responses are, the more mothers feel encouraged by the act of caring.

Even with the difficulties of researching the universe of fatherhood, due to the difficulties of access to the social group of these parents, it is clear that in this situation they tend to participate more actively in family life and exercise their role of affection with their special children. This function differs from that of the mother, however, it also has a direct relationship with the child's development.¹⁵ Likewise, it is observed, even in smaller numbers, that the paternal universe represents their children with CP, with affection and concern, supplanting their role as material provider.

Caring occupies considerable prominence in the lives of parents, often decreasing and interfering in family interaction.² This may explain the fact that, in the drawings, many of the family characters are disconnected, expressing this difficulty in family interaction. In addition, in the graphic elaboration they revealed a very stereotyped, primitive representation, with ghost-like figures (story-designs with theme, 2 and 5), which can demonstrate a negative self-perception, with a feeling of worthlessness, inferiority and contempt. Phantom representations can express suffering that the individual cannot demonstrate, express verbally, his expression remaining only at the graphic level, originating from the unconscious.¹⁶

It was also found that some drawings were well produced, colorful, with ornaments. In a study¹⁶ carried out on the representation of depression in childhood, youth and the elderly, the drawings in this style were correlated as a probable defense or desire to get rid of the suffering that little by little affects them. For adults, the author emphasizes that, when they realize the danger that surrounds them, they withdraw the strength that remains to take care of their appearance and get out of the suffering that consumes them so much.

The family can go through a painful phase when they know that their child has CP, dealing with feelings of shock, denial, sadness and detachment, that is, it is the need to adapt to the arrival of a child with their own needs and care. But the parents restructure themselves and the family unites, moved by feelings such as love and affection, to then take care of their child.³

The support of an extensive family member is often reported by this social group, both in coping with the diagnosis moment,

and in coping with the daily difficulties. In addition, professional support also plays an influential role for mothers and fathers in the construction of representation about these children.^{2,3} In this sense, the communication elements of this social group are discussed again, through the identification process reported by the participants. As the theory of social representations predicts, one can observe the manifestations of adherence to the forms of thought of the class, the environment or the group of belonging, due to solidarity and social affiliation¹², which can explain the learning reported by mothers and fathers.

This interaction happens mainly when mothers in contact with each other in the institutions they attend for the treatment of their children exchange information, tell their stories, report their experiences and share the same reality. Thus, in these daily relationships and interactions, conceptual universes are created, particular to social reality that are formed and gaining consistency, in which the simple opinion becomes part of these subjects, in theory of common sense, guiding the conduct of the individual in the world society, its social values and aspirations.¹⁷

This interaction process in the studied social group can serve as a basis for the construction process of the representations and behaviors of other maternal groups of children with CP, however it is believed that this research has limitations regarding the number of participants and institutions involved, due to the characteristics of the researched region. Thus, it is recommended that future research involve multi-centers and interventionist actions with multicomponent characteristics that meet the needs of this social group.

CONCLUSION

Understanding the representations of mothers and fathers about the child with cerebral palsy was a challenging process, due to the complexity of the social manifestations that surround such representation. In addition, it is clear that the family institution influences the formation of representation about the object studied, through its values, ideas, opinions and the representations already crystallized in society, which permeate family institutions in each generation. From these manifestations, representations about the child with cerebral palsy are emancipated, based on the communicative interaction and daily relationships of this group, whether through contact with the concepts of the scientific world that is used in common sense or by the communicative movement within group, making the unfamiliar a family member.

Thus, the representations studied were classified or named based on the categories that emerged, which materialize the represented object, by the images that the social group composes, guiding their conduct, especially those related to the care of their children. The experience of using multi-methods in the production of data and its triangulation were valuable,

especially because they allow the deepening of this knowledge, without the intention of exhausting it, considering that these representations are in motion, they are not static and, therefore, can be modified.

From this study it is possible to reflect on the reality of these participants and on the role of the institutions that offer treatment for children with CP, in order to realize that these institutions play an important role in the interaction and reality of these families. Thus, it was possible to subsidize the survey of the needs of these families and, consequently, the necessary actions so that the concept of health, in its broadest sense, is exercised by these participants. The creation of a self-help group for these participants proved to be a perceived imposition and manifested by the participating mothers during the focus group meetings.

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