

PERCEPTIONS OF MOTHERS OF CHILDREN WITH CEREBRAL PALSY: A LOOK AT THE PAST AND THE FUTURE

Percepções de mães de crianças com paralisia cerebral: um olhar sobre o passado e o futuro

Percepciones de madre de niños con parálisis cerebral: una mirada sobre el pasado y el futuro

Funding agency: CAPES

Part of the doctoral dissertation entitled: Care practices, support networks and social satisfaction of primary caregivers of children with cerebral palsy (2016). Postgraduate Program in Behavior Theory and Research - PPGTPC Federal University of Pará - UFPA.

Tatiana Afonso¹, Simone Souza da Costa e Silva², Fernando Augusto Ramos Pontes³

How to cite this article:

Afonso T, Silva SSC, Pontes FAR. Percepções de mães de crianças com paralisia cerebral: um olhar sobre o passado e o futuro. Rev Fun Care Online. 2020 jan/dez; 12:138-145. DOI: <http://dx.doi.org/10.9789/2175-5361.rpcfo.v12.7146>.

ABSTRACT

Objective: this study aimed to understand the perceptions of mothers of children with cerebral palsy about the care and learning they have experienced since this diagnosis. **Method:** sociodemographic Inventory, Gross Motor Function Classification System and Interview were used. Participants: 13 mothers of children between 0 and 12 years old with diagnosis of cerebral palsy attended at a specialized referral center in the areas of growth and child development in Belém- Pará. **Results:** The mothers reported the importance of acquired learning, the maturation process, the suffering experienced, the perceptions about happiness and the challenges to be overcome. **Conclusion:** it was observed that despite the difficulties, the mothers perceived themselves accomplished with the construction of intense learning about the care required in cerebral palsy.

Descriptors: Cerebral palsy; Maternal perceptions; Child care; Grounded theory.

RESUMO

Objetivo: compreender as percepções de mães de crianças com paralisia cerebral acerca dos cuidados realizados e aprendizados vividos a partir desse diagnóstico. **Método:** utilizou-se Inventário Sociodemográfico, Sistema de Classificação da Função Motora Grossa e Roteiro de Entrevista. Participaram 13 mães de crianças entre 0 e 12 anos com diagnóstico de paralisia cerebral atendidas em um centro de referência

- 1 Psychology Graduate by the *Universidade Estadual Paulista (UNESP)*, MSc and PhD in Psychology by the Theory and Behavioral Research Postgraduate Program from the *UFPA*, Member of the *Laboratório de Ecologia do Desenvolvimento (LEDH)*.
- 2 Psychology Graduate by the *UFPA*, MSc in Psychology by the *UFPA*, PhD in Psychology by the *Universidade de Brasília (UNB)*, Postdoc in Rehabilitation Sciences by the *Technischen Universität Dortmund* – Germany, Coordinator of the LEDH, Professor at *UFPA*.
- 3 Psychology Graduate by the *UFPA*, MSc in Theory and Behavioral Research by the *UFPA*, PhD in Psychology by the *Universidade de São Paulo (USP)*, Postdoc by the *UNB* and the *Technischen Universität Dortmund* – Germany, Coordinator of the LEDH, Full Professor at *UFPA*.

especializado nas áreas de crescimento e desenvolvimento infantil da capital Belém-PA. **Resultados:** as mães relataram a importância dos aprendizados adquiridos, o processo de amadurecimento, os sofrimentos experimentados, as percepções acerca da felicidade e os desafios a serem vencidos. **Conclusão:** constatou-se que apesar das dificuldades, as mães percebiam-se realizadas com a construção dos intensos aprendizados acerca dos cuidados exigidos na paralisia cerebral.

Descritores: Paralisia cerebral; Percepções maternas; Cuidado à criança; Teoria fundamentada.

RESUMÉN

Objetivo: comprender las percepciones de madres de niños con parálisis cerebral acerca de los cuidados realizados y aprendidos vividos a partir de ese diagnóstico. **Método:** se utilizó Inventario Sociodemográfico, Sistema de Clasificación de la Función Motora Grossa y Ruta de Entrevista. Participaron 13 madres de niños entre 0 y 12 años con diagnóstico de parálisis cerebral atendidas en un centro de referencia especializado en las áreas de crecimiento y desarrollo infantil de la capital Belém-PA. **Resultados:** las madres relataron la importancia de los aprendizajes adquiridos, el proceso de maduración, los sufrimientos experimentados, las percepciones acerca de la felicidad y los desafíos a ser vencidos. **Conclusión:** se constató que a pesar de las dificultades, las madres se percibían realizadas con la construcción de los intensos aprendizajes acerca de los cuidados exigidos en la parálisis cerebral.

Descriptores: parálisis cerebral; Percepciones maternas; Cuidado al niño; Teoría fundamentada.

INTRODUCTION

Cerebral Palsy (CP), named non-progressive chronic encephalopathy of childhood, is caused by a lesion that occurs in the pre, peri or postnatal period and affects the central nervous system in the phase of structural and functional maturation. It is a predominantly sensorimotor dysfunction involving disorders of muscle tone, posture, and voluntary movement.^{1,2}

Sensory, cognitive, and language impairments appear in addition to learning difficulties and behavior problems. Commitments such as spasticity, muscle weakness, and postural instability result in walking difficulties in 90% of children with CP. In addition to the above-mentioned commitments, some children may also have complex mobility and self-care limitations, such as food, clothing, and hygiene.^{3,4}

The treatment is performed with the objective of promoting the highest degree of independence possible for the child, and it must be started early, in association with the care of a caregiver.⁵⁻⁷ The family adaptation of a child with CP is a delicate and complex process, so the way the family will adapt to the new situations will depend on the previous experiences and the beliefs and values of each one of its members.⁶

In relation to the different impacts arising from the children's compromises in family functioning, it is observed that the parents of children with greater difficulties reported poorer quality of life, experiencing greater suffering due to greater overload.⁸ A study of 200 parents from Jordan in assessing the degree of suffering of parents of children with CP indicated that more than 60% felt nervous and stressed at some point and that severe deficiency in children was associated with high psychic suffering.⁹

In addition to the severe impairment of the condition presented by the child, the incomprehension, or even, in some cases, the denial of the special needs due to cerebral palsy, demonstrates aggravating the condition of the mothers, leading to a postponement of the beginning of the treatment, which evidences the unpreparedness of these families to provide care to the child.^{8,10,11} So, it is observed that an expressive number of mothers report knowing little about cerebral palsy due to the lack of orientation of the medical teams.¹²

Cerebral palsy fragments perceptions of the capacity and reliability of primary caregivers, causing a slow and profound wound that leads the family to face a situation in which ambiguous feelings of satisfaction and concern arise.⁸ Caring for a child with a CP transcends care in a mere biologic perspective, adding much more than the physiological issues of the CP, understanding the meanings given to each situation lived throughout existence.⁶

Maternal experiences linked to the expectations and learning experiences that mark the onset of motherhood differ from those coming after diagnosis and treatment. Therefore, when taking into consideration the experiences lived in the past, mothers retrieve important stories of learning. Primarily, about the diagnosis, followed by the period in which adjustment adjustments were made and unusual situations when they often tested their resources and the daily operation of routines.¹³

On the other hand, looking to the future can underline different expectations, marked by concerns about health, safety, and special care when mothers are absent. Considering the aforesaid, learning is only possible because mothers, as temporal beings, have the capacity to attribute meanings to the experiences of cerebral palsy over time.¹⁴ Then, the time addresses significant differences from transitions that only make sense when understood chronologically.

Bearing in mind the expectations about the future of children, studies indicate that there are common demands on families, regardless of the type of child's disability, such as the need for guidance, information and services; and others that seem to be specific and related to the difficulties of children and the stage of child development in which they are.¹⁵⁻⁶ Accordingly, care experiences are understood as a function of the child's developmental stage and the transitions by which families pass and are influenced.

Considering the families of children bearing CP, the degree of impairment of motor capacity is directly related to the parents' expectations. Thus, expectations about the learning possibilities of those who can walk without limitations differ qualitatively from those with limited mobility and wheelchair users.

Objectives

Given the importance of the experiences reported by the mothers of children bearing CP, from the differentiation of meanings attributed to the experiences of cerebral palsy over time, the present work intends to understand and discuss the maternal insights about past experiences and future expectations arising from this condition.

METHODS

Participants

A total of 13 mothers of children within the age group from 0 to 12 years old and with diagnosis of cerebral palsy, who were assisted at a specialized referral center in the growth and child development areas in *Belém* city, *Pará* State. **Table 1** presents some of the social characteristics of mothers. In order to preserve the identity of the participants, the names adopted are fictitious.

Table 1 - About the mothers.

Mother	Age	Marital status	Schooling	Occupation	Child gender	Child age	GMFCS
Ana	22	Common-law marriage	Complete elementary school	Housewife	Female	4	3
Andressa	24	Married	Incomplete college	Student	Female	4	1
Fátima	51	Married	Incomplete high school	Housewife	Male	10	2
Janaína	34	Common-law marriage	Complete high school	Housewife	Female	12	5
Josileide	26	Single	Complete high school	Housekeeper	Male	3	2
Lidia	29	Single	Complete elementary school	Housekeeper	Female	12	5
Lucia	29	Single	Incomplete high school	Housekeeper	Male	4	5
Maria Cecília	50	Married	Incomplete high school	Housewife	Female	7	1
Márcia	30	Single	Complete high school	Housekeeper	Male	6	2
Marília	34	Single	Complete high school	Housekeeper	Male	2	3
Patrícia	35	Common-law marriage	Complete high school	Teacher	Female	8	5
Silvia	28	Common-law marriage	Complete high school	Housewife	Female	1	5
Talita	25	Common-law marriage	Incomplete high school	Student	Male	5	2

Source: Laboratório de Ecologia do Desenvolvimento (LED) – UFPA.

Participants' selection

A total of 13 mothers attending a university hospital attended a visit to children with CP. The mothers were invited to participate while awaiting the care of the children. After the registration of those living in the metropolitan area of *Belém*, they were contacted via telephone to schedule the interviews in their own homes. The exclusion criterion was three telephone contact attempts on consecutive days and at different times. If the contact was not established, the participant was excluded and attempts were initiated with other mothers.

Collection procedure

After reading and approving the participation through the Informed Consent Form (ICF), the following sequence of instruments was applied: SDI, GMFCS, and interview.

Instruments:

Sociodemographic Inventory (SDI): presents questions related to sociodemographic data; characterization of the family system and data related to the child with cerebral palsy.

GMFCS - Gross Motor Function Classification System is part of the Gross Motor Function Measure (GMFM)¹⁷ that is a scale of measurement of the gross motor function of children bearing Cerebral Palsy (CP), which evaluates the child in five levels (I, II, III, IV and V) according to age

considering what it can accomplish in terms of gross motor function. Level I: showing no limitation to walk. Level II: showing limitations to walk. Level III: can walk with the help of walkers or crutches, have difficulty walking outside the home and in the community. Level IV: limited mobility, requires a wheelchair to walk away from home and in the community. Level V: severely limited mobility, carried in a manual wheelchair.

Interview script:

The interview was structured in an open manner with the following general themes: life after the child's diagnosis, daily care and assistance in daily tasks, division of care tasks, time of care and perceived overload, need for greater support and ideal support. The questions functioned as possible themes of reports and reflections, and thus, the other themes brought by the participants, such as silences, cries, and outbursts, were respected. The elaboration of open and non-evaluative questions was necessary in order to stimulate the emergence of unforeseen and significant stories, in which the researcher sought to focus attention.

Ethical procedures

The project was submitted to the ethics committee of the Health Sciences Institute from the *Universidade Federal do Pará*, with a favorable Legal Opinion No. 473.140.

The participation of caregivers occurred through the signing of the ICF with which the purposes of the research were presented, as provided for in the Resolution No. 510 on April 7th, 2016, from the National Health Council/Brazilian Ministry of Health, which provides on research standards involving human beings. Hence, the participants have assured the confidentiality of the information and the right to access the results.

Data analysis

The data analysis was performed according to the Grounded Theory. The researcher transcribed, organized and problematized the speeches of the participants, entitled the phase of coding the data.¹⁸⁻⁹ Two coding phases were performed, as follows: in the first, named line-by-line, the transcripts of the interviews were divided into lines and the researcher rigorously studied the data presented from the lines; in the second, coding of the codes, the most relevant sense nuclei were selected from the registered material to be grouped with larger data.

In the comparison between the emergent data, in the line-by-line phase, codes that have appeared significant and provisional have emerged, such codes have received titles that preferentially use gerunds in order to detect processes and fix them to the data. The codes remained open, close to the data (in the same lines), precise, short, conserving actions and allowing the comparison between the data.¹⁹

The analyzes were carried out by comparing the statements within the same interview and, later, by comparing different interview statements, avoiding preconceived psychological concepts in codification.

The second coding phase comprised the analysis of more targeted, selective and conceptual codes than those previously generated by the word-by-word, line-by-line.¹⁹ In this phase, the previous codes were used which were more frequent and significant for large amounts of data. Generating, thus, an explanatory final structure. The explanatory model occurred from the constant analysis of the prepared memos.

The memos consisted of extensive notes made throughout the research process, comparing data and exploring ideas about the codes. They occurred from the initial phase of coding line-by-line, therefore, arranged next to the generated codes of the corresponding lines. Furthermore, they were used for the analysis of the most significant codes in the second phase of coding. By reviewing the memos, the categories emerged from the data, being chosen those that proved to be reliable to the maternal reports and to the proposed analyzes.

RESULTS AND DISCUSSION

The maternal reports were divided into two important analytical categories: **the past of learning and the future of challenges**. Two major categories were chosen to distinguish between discourses those that refer to the past and those that are primarily linked to the future, both of which emerge from the most significant codes of analysis. From these large categories, minor subcategories were listed with a view to qualitatively organizing the main findings, namely: **Maturing; Learning about happiness**, related to **The past**

of learning and Difficulties to be overcome, related to the **Future of challenges**.

The past of learning

Being a mother was a unique learning experience considering the intensity involved and the fact that they were not prepared for the difficulties of disability. For Josileide (mother of a 3-year-old boy, GMFCS 2), the specifics of the son's development were configured as an unforeseen maternity, although he was already the mother of a child. This issue is revealed in the following speech by the participant: "*I learned to be a mother literally*" (Josileide).

Not only the learning, but the maternal strategies for the search of information were relevant. The waiting room has become, therefore, a privileged place to exchange experiences about the diagnosis. When they talked about the process of child development, they weaved comparisons and built up knowledge. Then, the rooms were local conducive to learning about the development of children, reflecting the different conditions.

In this regard, it was observed that the levels of commitment of the children favored or limited the process of independence of the child and the mother. In the case of Andressa (mother of a 4-year-old girl, GMFCS 1), the daughter was already able to successfully carry out self-care, which was seen as favorable to the independence process of both. Nevertheless, she did not fail to notice how much more costly it was to other children:

Because the case of Ana Clara is different from other moms who cannot work... because it is one thing to have mild cerebral palsy, affecting a part of the body... the child is more independent... in some things she needs help, but not much (Andressa).

Andressa's reports highlighted lived experiences that were able to alter perceptions about one's own life, as well as moral judgments and prejudices as can be seen below:

That changes everything in our lives, right? The values, for instance, the question of helping others, right? Always be available and that changes our character, about tolerance, in the matter of prejudice, all this, right...? Well, the issue of disability only living really, because from the outside, we look, but you do not live that, so it is very different, the person who is left out looking, judging, right? (Andressa).

Being in or out of the care experience of a child with CP was a recurring metaphor among mothers, marking experiences different from those experienced by most mothers of typical children. In this regard, they often felt like "another world", neglected by the majority, highlighting the prejudice suffered:

I knew another world, right? We just see it... we talk about prejudice, but it's because people do not know, they have no idea, right? Then they are curious, before she wore a boot, when I got on the bus, everyone would take a look...

it's another world, it's different... I've come to know other people, other things... (Sílvia)

From the experience with this previously unknown reality, mothers gradually established important learning about cerebral palsy, as Fátima (the mother of a 10-year-old boy, GMFCS 2) pointed out: *"I learned a lot! Because I did not even know what cerebral palsy was, I did not know... I saw these children... and I wondered what those children had."* Marília (mother of a 2-year-old boy, GMFCS 3), emphasizes that she did not know that a child could be born with some type of disability, nor did he ever imagine that one day he would take care of a child with such characteristics: *"For me, the child would be born with good health... for me it was like this... I never imagined taking care of such a child..."* (Marília).

It can be said that, faced with the diagnosis, mothers were faced with a total lack of knowledge: *"Oh, I learned a lot! I did not know how to shower, give him food; I did not know how to go after a doctor! So... I learned a lot!"* (Patricia the mother of an 8-year-old girl, GMFCS 5). Another aspect that highlights maternal learning refers to responsibility for the life of the children. Mothers take responsibility from feeding to follow-up with all the professionals involved in rehabilitation: *"Responsibility, right? I learned to take responsibility!"* (Márcia, mother of a 6-year-old boy, GMFCS 2)

Therefore, being a mother, understanding the diagnosis, recognizing the peculiarities of the child's development, exchanging experiences, overcoming prejudices, assuming responsibility and promoting children's learning, they all together made up the main aspects involved in the learning process of mothers. The specifics were understood in a procedural way, as Marília (the mother of a 2-year-old boy, GMFCS 3) pointed out: *"I've been learning..."*

The phrase, although short, demonstrates how incomplete the learning process about the child is, gradually building up since the special characteristics of the development required time and sensitivity to the necessary adjustments. This corresponds to the mothers' very maturation process.

Maturing

Among other things, the mothers ripening process it is marked by learning about tolerance and patience, as pointed Ana (mother of a 4-year-old girl, GMFCS 3), Janaína (mother of a 12-year-old girl, GMFCS 5) and Lucia (mother of a 4-year-old boy, GMFCS 5). For Ana, the difficulties presented led to costly learning, characterized by lack of time for herself, causing moments of sadness and fear.

The participant pointed out that even though she felt very tired, she could not propose any kind of change in her nursing routine due to her daughter's aggressive behavior, learning how to tolerate and wait for her: *"I learned to have the patience that I did not have. I told her father: I learned to have patience with Vitória."* (Ana). Given the aforementioned, patience was so much in waiting for the improvements of the daughter's development, presented as slower, as by tolerance for aggressive behavior: *"I learned to be a mother even though*

my other daughter was so independent of me... so I learned to be a mother myself, right, daughter?" (Ana).

For Janaína (mother of a 12-year-old girl, GMFCS 5), patience proved to be the main learning of her life, she explained that diagnosis, recurring sadness, fear of seizures and separation of the father of the child taught her to wait and not to despair. Thus, as appropriated by the diagnosis, the learning is no longer so costly as in episodes of seizures that gradually began to be handled more adequately: *"I am stressed, I have learned to be more patient, I have learned a lot to be patient, I learned a lot, especially humbleness"* (Janaína).

In contrast, Lucia (the mother of a 4-year-old boy, GMFCS 5) understood from the beginning that she should learn to be an extremely tolerant and patient mother in view of her son's fragility:

Because he's special. Then I have a lot of patience with him, there're mothers who slap their kids, I've never, I've learned to have more affection, I've always been very nice to him. I learned to have a lot of patience. More affection, more patience. Everyone says I have a lot of love, a lot of patience. (Lucia)

The learning process revealed in the maturation of the mothers emphasized the acceptance of the diagnosis, the tolerance with the adversities and the experienced responsibility. For some mothers, this process was marked by conflicts and difficulties that occurred when they effectively assumed special maternity. Even so, in most cases, learning has proven to be extremely positive.

Learning about happiness

The emotional apprenticeship, exemplified by Maria Cecília (mother of a 7-year-old girl, GMFCS 1), cannot be forgotten, as she relates with emotion that her daughter taught her to be happy because she filled the void she had previously felt in personal life: *"I learned to be happy! (crying and choking voice) I think I was not happy... and Vitória... sorry, I cry too much... Vitória she came... how shall I say... she came to add a lot in my life... I do not know if it's that word"* (Maria Cecília).

Likewise, Silvia (mother of a 1-year-old girl, GMFCS 5) shared her personal learning in an emotional manner: *"I usually say that my life was a watershed before and after Giovana, there are people who come to us like that. It's like a fight, is not it? I do not think it's a fight... for me it's a happiness!"* (Silvia).

In fact, mothers tended to reinforce the lessons learned from a more positive perspective on special motherhood. The participant Andressa (mother of a 4-year-old girl, GMFCS 1), represented, from her life history, the main characteristic of this category: satisfaction with motherhood. Andressa's perceptions underscored the end of a phase of more intense care for the daughter with CP who corresponded to early childhood and the resumption of her career:

Things are very quiet... I will start working soon: I have a law degree and I have been approved by the Brazilian Bar Association recently, do you understand? Then when I get my portfolio I'll have the opportunity to be autonomous or work in an office. Then I'll have to leave the house, so the family will have to take care of Ana Clara for me (Andressa).

The feeling of achievement was also present in relation to the rights of special motherhood, as Lucia (the mother of a 4-year-old boy, GMFCS 5) points out, by attributing the gain of her own home to the fact that her son is special: *"This is Luigi's apartment that he won from the Brazilian program 'My house, my Life'... I always went after my rights, as well as his benefit..." (Lucia).*

Motherhood proved to be a source of learning, achievements and, in particular, knowledge about the development of the children, a process that required personal commitment to, finally, achieve developmental advances. In recognizing such advances, mothers began to show strong satisfaction, thrilled as they resumed their memories of the process.

For Ana (mother of a 4-year-old girl, GMFCS 3), the advances made by her daughter, such as babbling and walking, characteristics of a child who interacted and had a will of her own, proved to be important achievements. *"Nowadays, she is already talking 'da', 'mom', 'give'... Then I say: we will leave Vitória and she says yes. She does not have the 'ddy' is still 'da', everything is 'da'" (Ana).* Realizing, therefore, that advances such as sitting, walking, and cognitive performance themselves occurred slowly, but they did happen:

First, the doctor said that she was not going to walk and today she is walking. She sits down. Only... for me... she's like a 1-year-old. Now that she's learning things, now she's... kind of stuffing things into her little head. It's all slower (...) I talk to her like she's my oldest daughter, and she stares, paying attention, understanding what I'm saying to her. (Ana)

As well as the perceptions of Talita (mother of a 5-year-old boy GMFCS 2): *"He walks! He just walked on his knees, he just crawled like a snake. He was not agile, he lived... do you know those very sick kids? I lived in his corner..." (Talita).* A similar report is also presented by Fátima (the mother of a 10-year-old boy, GMFCS 2) in describing the advances of her son, who was increasingly able to understand what was going on around him, interacting more and performing activities than before he could not: *"Now he understands more... he is another child! At first, he did nothing, but now he does! He is already there!" (Fátima).*

In addition to the developmental gains, the learning and changes arose from the adequacy of the routines, as Márcia (mother of a 6-year-old boy, GMFCS 2) pointed out: *"Yes! It's so much better! We even go less to see the doctor... He talks a lot! Plays!" (Márcia).*

Nevertheless, learning has not always been sufficient. As a result of the traumatic experiences, some statements were strongly linked to future expectations. These expectations reflected the challenges to be overcome.

The future of challenges

The lack of a formal job has been the main concern about the future: *"It makes me very stressed to stay in the house... There are people who do not understand, you know? Oh, why are you stressed? He's not doing anything in the house... it's difficult" Josileide (mother of a 3-year-old boy, GMFCS 2).* The younger mothers who gave up their studies and their career with the birth of their child with a CP generally emphasized the desire to change their lives when they reflected on the future: *"Last week I even looked for a lawyer to know if I could work, right? Because of the benefit... I need to see if I do anything to help more, the benefit does not cover everything..." (Josileide)*

At this point, the affliction experienced was present in a forceful way: *"I thought, nowadays I do not even think anymore because I look at all these difficulties... I prefer to leave it still, I prefer... I do not dream much..."* The irreparable losses and disappointments were then evidenced by the impossibility of making plans, concluding, therefore, that it would not be worth *"dreaming much"*.

The future had in many cases been related to the desire for the resumption of their lives, in view of the "lost" period devoted to caring. Nonetheless, for an expressive number of mothers, looking to the future indicated, as a priority, the desire for the improvement and independence of the children.

Difficulties to be overcome

The main focus of the mothers' expectations was the developmental achievements of their children. For Márcia (the mother of a 6-year-old boy, GMFCS 2), the desire for the child's learning had as the main focus the school: *"I think the best for him... I want him to know how to read... that he will learn, right? The best thing for him is school! (...) the teacher says he's great! He is very intelligent!" (Márcia).*

Not only the school, but the rehabilitation institutions were important, as Ana (mother of a 4-year-old girl, GMFCS 3) pointed out: *"As long as I have the strength to walk, to stay with her close by, if I need to go to China after a doctor, I'll go!" (Ana).*

Better treatments and school life were presented as important resources in order to remedy the difficulties of children. Regarding the search for these resources, Márcia pointed out: *"(...) because the mother does not give up, right? That's why I ask God to give me strength as long as I can!" (Márcia).*

Others, however, in spite of identifying the difficulties of the children, restricted their actions to the domestic environment and to the ordinary care, giving up the search for new services and opposing school life. In these cases, the behavioral problems presented themselves as the main impediments: *"Even if she hits me, biting me, mom is always close to her! Right!?" (Ana).* *"When she gets very eager the seizure always comes... She cannot shake or get very excited, hence she always convulses, even taking that lot of pills" (Janaína).*

By organizing the maternal insights in regards to both past and future, it is observed that the past was associated with learning, achievements, and satisfaction with the results

obtained, thus showing itself to be positive. On the other hand, the future was marked by anxiety and dissatisfaction, either due to the loss of the career and the stagnation of the studies, or in the great difficulties and challenges to be experienced as children present greater commitments and behavioral deviations. Therefore, it can be said that talking about the past was associated with experiences of pleasure and satisfaction, however, when the future was glimpsed, the mothers did it with fear and concern about their personal difficulties and their children.

About the past...

The creation of the “mother” identity of a “special” child was presented as the main perception highlighted by the interviewees. In assuming this identity, they experienced a set of experiences that were not supported by any of the normative social experiences. In regards to this aspect, research indicates that mothers of children with disabilities share common aspects both in the level of care provided and in the way they deal in a more or less adaptive way in the face of difficulties, integrating experiences.¹¹

Therefore, there are perceptions about “being inside” or “being outside” the universe of shared learning with mothers in the same condition. Such perceptions are revealing of what they think and feel and are at the basis of every process of adaptation lived.⁶ “Being inside” emphasizes the search for information in specific contexts, usually medical centers and therapeutic treatments in order to remedy misunderstandings about cerebral palsy, the risks involved in this condition, and what to expect from the development of children.¹² “Being outside” reflects perceptions about evaluation and social judgment, an aspect that emphasizes emotional wounds linked to prejudices and lack of sensitivity of those who do not live and do not understand such condition.⁸

The set of learning experiences related to childcare leads to a unique maturation process in which aspects such as tolerance and patience are evident, which are considered by many theorists as adaptive.¹¹ Such perceptual aspects can be highlighted in disability coping strategies and are embedded in the positive stories of achievement and satisfaction.

Regarding the adaptive perceptions, the authors explain that they consist of: preserving the emotional balance to deal with feelings/emotions arising from the illness (revolt, anxiety, isolation); maintain satisfactory self-image; take care of the relationship between family and friends, often subject to changes resulting from the physical separations that disability implies, and, ultimately, prepare the family for an uncertain future in which the threat of a significant loss looms, while simultaneously hope of presence. So, the adaptive aspects depend on the characteristics of the person, the disability involved and the existing resources.¹¹

When the adaptive capacities are not able to sustain the actions of care in a positive way given conditions of the severity of the CP, the mothers are faced with a worrying future. Concerns may be due to uncertainties about the future of the child, or of social origin in association with

the characteristics of the mothers themselves. In fact, as time passes and developmental milestones, such as sitting, walking, talking, eating alone, do not occur, increase, and much, concern about what to do and what to expect.^{6,8,11}

About the future...

Concerning the future, research indicates that the feelings of the parents would be related to the perception of the children’s lack of adaptive competence.^{6,8,11} Hence, the satisfaction that would be present in front of the advances of the children ceased to happen, while, on the other hand, perceptions of concern and regret remained.

When the learning experiences were tough and the commitments severe, conjecture about the future presented itself as a process of pain, given the risks that remain in the face of the commitments and the ways to be taken in response to the suffering itself. Hence, the “special mother” identity presents itself as a burden in view of the long process of challenges facing the child’s difficulties, thus prolonging the psychological state of affliction about health and its development.

CONCLUSIONS

Cerebral palsy is a condition that goes beyond the physical commitment of the child, involving risks inherent in the process of family adaptation and the child’s own inclusion. So, they need a wide network of care, not only to the child but also to the parents as well. Faced with this reality, it is observed that measures have been taken vis-à-vis the services provided to this population. Nonetheless, much is still to be achieved in terms of mapping the needs of families.

Bearing in mind this perspective and with the intention of accessing the perceptions and emotions of the mothers, the main caregivers, the qualitative research was chosen, since the quantitative works are not sensitive to many of the psychological aspects involved. Remarking that only listening to the reports, their recording and reliable analysis are presented as the most adequate ways to understand how they think and problematize the difficulties involved in caring for their children.

It is important to underline the low comprehensiveness of the findings in populational standings. Therefore, it is suggested expanding the studies that aim to compare populations, especially the typical ones, having the families of CP bearing children.

REFERENCES

1. Lima CLA, Fonseca LF. Paralisia cerebral: neurologia, ortopedia, reabilitação. Rio de Janeiro: Guanabara Koogan, 2004.
2. Vasconcelos VM, Frota MA, Pinheiro AKB, Gonçalves MLC. Percepção de mães acerca da qualidade de vida de crianças com paralisia cerebral. *Cogitare Enferm.* 2010; 15(2): 238-244.
3. Raina P, O’Donnell M, Rosenbaum P, Brehaut J, Walter SD, Russell D, Swinton M, Zhu B, Wood E. The health and well-being of caregivers of children with cerebral palsy. *Pediatrics*, 2005; 115: 626-636.
4. Rocha AP, Afonso DRV, Morais RL de S. Relação entre desempenho funcional de crianças com paralisia cerebral e qualidade de vida relacionada à saúde de seus cuidadores. *Fisioter Pesq.* 2008; 15(3): 292-297.

5. Mancini MC, Alves ACM, Schaper C, Figueiredo EM, Sampaio RF, Coelho ZAC et al. Gravidade da paralisia cerebral e desempenho funcional. *Rev Bras Fisioter.* 2004; 8(3):253-260.
6. Milbrath VM, Siqueira HCH, Motta MGC, Amestoy SC. Família da criança com paralisia cerebral: percepção sobre as orientações da equipe de saúde. *Texto Contexto Enferm Florianópolis*, 2012; 21(4):921-928.
7. Rotta NT. Paralisia cerebral: novas perspectivas terapêuticas. *J Pediatr (Rio J)* 2002; 78(Suppl 1):48-54.
8. Milbrath VM, Cecagno D, Soares DC, Amestoy SC, Siqueira HCH. Ser mulher mãe de uma criança portadora de paralisia cerebral. *Acta Paul Enferm.* 2008; 21(3):427-431.
9. Al-gamal E, Longo T. Psychological distress and perceived support among Jordanian parents living with a child with cerebral palsy: A cross-sectional study. *Scand J Caring Sci.* 2013; 27, 624-631.
10. Dagenais L, Hall N, Majnemer A, Birnbaum R, Dumas F, Gosselin J et al. Communicating a diagnosis of cerebral palsy: caregiver satisfaction and stress. *Pediatr Neurol.* 2006; 35(6): 408-414.
11. Monteiro M, Matos A P, Coelho R. A adaptação psicológica de mães cujos filhos apresentam Paralisia Cerebral: Revisão da literatura. *Revista Portuguesa de Psicossomática*, 2002; 4 (2):149-178.
12. Gração DC, Santos MGM. A percepção materna sobre a paralisia cerebral no cenário da orientação familiar. *Fisioter Mov.* 2008; 21 (2):107-113.
13. Guillamón N, Nieto R, Pousada M, Redolar D, Muñoz E, Hernandez E et al. Quality of life and mental health among parents of children with cerebral palsy: the influence of self-efficacy and coping strategies. *J Clin Nurs.* 2013; 22: 1579-1590.
14. Huang YP, Kellett UM, St John W. Cerebral palsy: experiences of mothers after learning their child's diagnosis. *J. Ad Nurs.* 2010; 66(6):1213-1221.
15. Hiratuka E, Matsukura TS, Pfeifer LI. Adaptação transcultural para o Brasil do sistema de classificação da função motora grossa (GMFCS). *Rev Bras Fisioter.* 2010; 14(6):537-544.
16. Oliveira AKC, Matsukura TS. Estresse e apoio social em cuidadores de crianças com paralisia cerebral. *Cad Ter Ocup UFSCar.* 2013; 21 (3): 493-503. Palisano R, Rosenbaum P, Walter S, Russell D, Wood E, Galuppi B. Development and validation of a gross motor function classification system for children with cerebral palsy. *Dev Med Child Neurol.* 1997; 39: 214-223.
17. Russell D, Rosenbaum PL, Avery LM, Lane M. Medida da Função Motora Grossa GMFM-66 & GMFM-88 Manual do Usuário. São Paulo: Memnon, 2011.
18. Glaser BG, Strauss AL. *The Discovery of Grounded Theory: Strategies for Qualitative Research.* Chicago: Aldine Publishing Company, 1967.
19. Charmaz K. *A Construção da Teoria Fundamentada: guia prático para análise qualitativa.* Tradução de Joice Elias Costa. Porto Alegre (PA): Artmed, 2009.

Received in: 15/01/2018

Required revisions: 12/04/2018

Approved in: 02/07/2018

Published in: 10/01/2020

Corresponding author

Tatiana Afonso

Address: Rua Alegre, 156, Bairro Santa Paula

São Paulo, Brazil

Zip code: 09.550-250

E-mail address: afonso_tatiana@hotmail.com

Telephone number: +55 (11) 99572-9503

Disclose: The authors claim to have no conflict of interest.