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TAKING CARE OF A CHILD DIAGNOSED WITH CEREBRAL PALSY: FEELINGS AND EXPECTATIONS

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ABSTRACT. This study aimed at understanding the maternity experience for women who are mothers of a child diagnosed with cerebral palsy. Twenty-six mothers answered a semi-structured interview. The qualitative textual analysis of the interview resulted in the following categories: “the diagnosis moment”; “the perception of motherhood”; “worries, difficulties and aspirations” and “expectations for the future”. The interviewed mothers attributed the cause of Cerebral Palsy to medical error or to the negligence of health professionals during the pre-labor and labor phases, to the precariousness of resources in the hospital, or to their own fault. Among the concerns, the fear of becoming sick and dying, the lack of qualified health professionals, the worry that their child will suffer some kind of exclusion at school, and the need to promote the maximum autonomy possible. As for the difficulties, they mentioned public transportation for their children’s locomotion, the situations in which their child is not well accepted or suffers with prejudice, the criticisms towards the way that they care for their children and the lack of respect from some people on the streets. Concerning the future expectations, the mothers revealed that they would like to be able to work, to go back to school, to invest in their personal care, and to be able to have leisure time. The results indicate that motherhood requires constant adaptation to the needs of the child with cerebral palsy and highlight the importance of family support and the advising that mothers receive from health professionals.

Keywords: Cerebral palsy; motherhood; child care.

CUIDANDO DE UM FILHO COM DIAGNÓSTICO DE PARALISIA CEREBRAL: SENTIMENTOS E EXPECTATIVAS

RESUMO. Este estudo objetivou compreender a experiência da maternidade em mulheres que são mães de um filho com diagnóstico de Paralisia Cerebral. Participaram 26 mães, que responderam a uma entrevista semiestruturada. A Análise Textual Qualitativa da entrevista resultou nas categorias: “o momento do diagnóstico”; “a percepção em relação à maternidade”; “preocupações, dificuldades e desejos” e “expectativas para o futuro”. Elas atribuíram a causa da Paralisia Cerebral ao erro médico ou à negligência dos profissionais da saúde durante o pré-parto e o parto, à precariedade de recursos do hospital ou à própria responsabilidade. Entre as preocupações, estão o temor de adoecer e morrer, a falta de capacitação de profissionais da saúde, o receio de que o filho sofra algum tipo de exclusão na escola e a necessidade de promover o máximo de autonomia. Quanto às dificuldades, elas apontaram que o transporte público para locomoção dos seus filhos, as situações em que o filho não é bem aceito ou sofre preconceitos, as críticas recebidas em relação ao cuidado exercido e a falta de respeito por parte das pessoas nas ruas. Quanto às expectativas sobre o futuro, as mães salientaram a aspiração de poder trabalhar, voltar a estudar, investir no cuidado pessoal e dispor de momentos de lazer. O exercício da maternidade requer constante adaptação às necessidades de cuidado do filho com paralisia cerebral, é explícita a importância do apoio familiar e da orientação que as mães recebem dos profissionais da saúde.

Palavras-chave: Paralisia cerebral; maternidade; comportamento de cuidado da criança.

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CUIDAR A UN NIÑO CON DIAGNÓSTICO DE PARÁLISIS CEREBRAL: SENTIMIENTOS Y EXPECTATIVAS

RESUMEN. Este estudio tuvo como objetivo comprender la experiencia de la maternidad en las mujeres que son madres de un niño diagnosticado con parálisis cerebral. Se recolectaron los datos por intermedio de la aplicación de entrevista semiestructurada y la evaluación de la función motora gruesa. Participaron 26 madres que respondieron a una entrevista semiestructurada. Un análisis textual de la entrevista cualitativa resultó en las categorías: "El momento del diagnóstico"; "La percepción de la maternidad"; "Las preocupaciones, problemas y deseos" y "las expectativas para el futuro". Ellos atribuyeron la causa de la parálisis cerebral a un error o negligencia médica de los profesionales de la salud durante el preparto y el trabajo de parto, la precariedad de los recursos hospitalarios o de poseer responsabilidad. Entre las preocupaciones son el miedo a la enfermedad y la muerte, la falta de formación de los profesionales de la salud, el temor de que el niño sufre algún tipo de exclusión de la escuela y la necesidad de promover la máxima independencia. En cuanto a las dificultades, señalaron que el transporte público para el transporte de sus hijos, las situaciones en las que el niño no es bien aceptado o perjudicado, críticas recibidas en relación con el cuidado ejercido y la falta de respeto por parte de la gente en las calles. Lo que les gustaría hacer y no pueden por falta de tiempo, las madres destacaron la aspiración a trabajar, volver a la escuela, invertir en el cuidado personal y tener tiempo de ocio. Los resultados indican que el ejercicio de la maternidad requiere una adaptación constante a las necesidades de cuidado infantil, y explican la importancia del apoyo familiar y orientación que las madres reciben de los profesionales de la salud.

Palabras-clave: Parálisis cerebral; la maternidad; conducta de cuidado del niño.

Introduction

Cerebral Pasly (CP) comprises a set of permanent disorders in posture and movement, caused by non-progressive disorders that affect the immature brain (Bax, Goldstein, Rosebaum, Leviton, & Paneth, 2005). It is the most common cause of severe physical disability in childhood (O'Shea, 2008), and it is estimated that its incidence in developing countries is of seven children for 1,000 born alive (Fonseca, 2011).

The clinical manifestations of an individual with CP include muscle tone abnormalities, balance and coordination losses, strength decrease and lack of control of selective movements (Papavasiliou, 2008). Such primary deficit may reflect on the late manifestation, or even on the non-manifestation of some mature motor standards. Sensorial, cognitive, communication, perception and behavior alterations may also be present (Bax, Goldstein, Rosebaum, Leviton, & Paneth, 2005).

Therefore, the sensory-motor impairment in those people may limit the performance of functional activities and cause a huge impact in their quality of life, as well as in their family's (Tarsuslu & Livanelioglu, 2010). In fact, because of being a disorder with disabling character, the child with CP needs partial or total assistance to perform daily activities, such as eating, bathing and moving, which exposes their caregivers to physical (Sharan, Ajeesh, Rameshkumar, & Manjula, 2012) and psychological (Gondim & Carvalho, 2012) overload. Culturally, despite of the contemporary transformations, the basic care of a child is mainly executed their mother. When a child is sick or has some disability, the necessity of care and protection is magnified, and the mother has the function to provide daily special attention to her child. Researches on families with children with CP point out that the mothers are the main responsible for the care (Gondim, Pinheiro, & Carvalho, 2009; Sandor, Marcon, Ferreira, & Dupas, 2014; Miura & Petean, 2012).

Considering that the literature describes an intense mother's involvement with the situation of having a disabled child, one can imagine that, when a son or daughter has CP, the routine difficulties are enlarged by the disorder, at a smaller or a larger rate, depending on the intensity of the damage caused by the lesion. In view of this, and considering the responsibility overload regarding the care, those mothers would be more susceptible to emotional issues, and it justifies the importance of investigating the phenomenon. In this investigation, it was aimed to provide voice to the mothers intending to know more their reality of taking care of the child, by means of the perspective of the maternal view. This study aimed at understanding the maternity experience for mothers who have a child with CP diagnosis.

Method

Delineation

This is a transversal qualitative research, of descriptive and exploratory type.

Participants

A number of 26 mothers of sons or daughters (children, adolescents or adults) diagnosed with CP. The inclusion criterion was the fact of having a child with CP, at any age. The presence of other diagnosis was considered as an exclusion criterion.

Instruments

- Semi-structured interview script, at which the following themes were approached: the child's birth, the confirmation of the diagnosis, the routine with the child, the feelings stemming form the caring experience, current worries and expectations for the future;
- Classification scale of the gross motor function: Gross Motor Function Classification System-GMFCS (Palisano et al, 1997), which is used to evaluate the gross motor function in individuals with CP by means of activities that include sitting down, getting around and marching, besides running and jumping. GMFCS contains five levels and divisions at the following age groups: 0-2 years old, 2-4 years old, 4-6 years old, 6-12 years old and 12-18 years old. At level I, the individual presents the highest independence level, and, at level V, the highest level of motor disorder.

Procedures and data analysis

After the research was approves by an ethics committee, the mothers were invited to participate of the study when they were at the place where their children have treatment on Physiotherapy, in most cases, in school-clinics and at *Associações de Pais e Amigos dos Excepcionais* (Brazilian Association of Parents and Friends of Impaired People - APAEs). Some of them were indicated by other mothers who had previously taken part of the study. The data collection was carried out by undergraduates of Psychology and Physiotherapy courses, scholarship students and volunteer students, at places chosen by the mothers – the therapy place, while they waited for their kids, or their own home.

The mothers answered a semi-structured interview script between June 2013 and October 2014. The material collected from the interviews was audio-recorded and transcribed. It is important to mention that the data collected are originally in Brazilian Portuguese language, the participants' mother tongue. After the present paper was ready, it was entirely translated into English language, including the participant's speeches, for a better reader's understanding.

The transcribed data was subjected to Qualitative Text Analysis, a self-organized method; by means of it, new meanings are constructed in relation to the objects studied. This type of content analysis aims at deepening the understanding of the phenomena studied, allowing, then, the emergence of new meanings on the topic (Moraes, 2003). The first analysis step was unitarizing the corpus. The material was examined in a very detailed way; then it was fragmented, so that the constituent unities could be found. From the disassembling of the reports, it was possible to notice various basic unities, which, being related to each other, could be separated into subcategories. After that, the relation among those elements was established, which resulted in the following categories: a) the diagnosis moment; b) perceptions of maternity: worries, difficulties and aspirations and c) expectations for the future.

The Physiotherapy undergraduates evaluated the children of the mothers interviewed by means of GMFCS (Gross Motor Function Classification System). As GMFCS only evaluates people up to the age of 18, the ones who were older were not evaluated by this instrument. The children who were in hospital or with their mothers involved in traveling or moving homes were not evaluated, either. The scale was used, in this study, to characterize the sample as for the level of motor dependence of the participants' children.

Ethical Considerations

The research Project was approved by the research Ethics Committee of Centro Universitário Franciscano, according to CAEE 15887913.6.0000.5306 and opinion document nº 351.313. This research met the resolution 466/ 2012 of Conselho Nacional de Saúde (Brazilian National Health Council) on research with human beings.

In order to keep the secrecy of the participants, in this article, the mothers are named by the first letter of the word “mother”, followed by a number, according to the sequence in which the interviews were carried out. For the children with CP, fictional names were chosen.

Results and discussion

A number of 26 mothers of children, adolescents or adults with CP diagnosis participated of this study. As for the sociodemographic data, mothers’ ages varied from 25 to 65 years old, and the age of their children with CP varied form 02 to 28 years old. The family income varied from one to four minimum wages. The participants of this study have restricted financial resources, reality that can interfere with the situation severity and with the child’s development (Assis-Madeira, Carvalho, & Blascovi-Assis, 2013).

The characterization of the sample studied is presented in Table 1. The categories found from the analysis of the interviews are presented as follows: a) the diagnosis moment; b) the perception of motherhood: worries, difficulties and aspirations and c) expectations for the future.

The diagnosis moment

When receiving the CP diagnosis, among many ambivalent feelings, it is expected that many questions come up, such as: Why is this happening to me? What have I done wrong? Whose fault is it? Those questions are part of the initial phase of the news elaboration. In a study about this subject, mothers with children with CP evidenced, when they discovered their children’s diagnosis, four different experiences: a) the feeling of not holding the control, feeling impotent; b) mistrust in the health professionals; c) relief for finally being able to understand what happened to the child and, d) the feeling of guilt (Huang, Kellett, & St John, 2010).

In this study, many mothers attributed the cause of their children’s CP to medical error or to the negligence of health professional during the pre-labor and labor phases. In those cases, their reports indicate that the tie with the health professional team may be weakened since the baby is born, for they connect the diagnosis to the inefficiency of the attendance that they had during pregnancy and during labor. The clinical condition, in CP, demands health treatment, which occurs since the diagnosis moment and lasts for all the person’s life. Despite of the necessity of a close relationship with the health professionals, studies point out that the care for the caregiving mothers and/or family members needs to be improved, mainly concerning support, advising and communication of the diagnosis (Gondim et al., 2009; Miura, 2012; Dantas, Collet, Moura, & Torquato, 2010; Baltor, Borges & Dupas, 2014). There are relevant failures in the dialogue between the health team and the families of children with CP; those failures hamper the care execution (Milbrath, Siqueira, Motta, & Amestoy, 2012).

Some interviewed mothers feel responsible for the diagnosis and demonstrate guilty for not having had proper prenatal check-ups or not having cared better for their newborns. In another situation, mother 22 affirms that the cause of the CP were the precarious resources of the hospital where her child was born.

Table 1

Data with the characterization of the study's participants

Mother	Age	Job	School level	Married Status	Child /CP - Age	Other children's age	Mini-mum wages	GMFCS
M1	46	Cleaner	Unfinished Secondary School	Married	Aline -13	21	2	Not carried out
M2	35	Housewife	Primary School	Married	João-15	13	2	III
M3	45	Housewife	Unfinished Primary School	Widower	Vitor-28	-	1	V
M4	29	Nursing technician	Graduated	Married	Bruna -3	5 and 1	3 to 4	II
M5	36	Housewife	Finished Secondary School	Married	César -5	-	2	V
M6	31	Housewife	Finished Secondary School	Married	Júlio -4	-	3	V
M7	54	Farmer	Unfinished Elementary School	Single	Arthur -20	31,26,15	1	Not carried out
M8	41	Hairdresser	Finished Secondary School	Married	André -22	15,8	3 to 4	Not carried out
M9	28	Student	Finished Secondary School	Married	Caio -11	1month	2	I
M10	44	Housewife	Primary School	Married	Filipe -12	13	1	V
M11	48	Housewife	Unfinished Elementary School	Married	Sérgio-27	13	1	V
M12	52	Housewife	Unfinished Elementary School	Separated	Lucas -15	32, 25	3	V
M13	45	Housewife	Finished Secondary School	Married	Livia-19	26,19,14	3 to 4	V
M14	44	Stock person	Unfinished Secondary School	Married	Alberto -8	19	2	V
M15	47	Housewife	Primary School	Married	Leandro-11	27, 21, 9	3	V
M16	30	Housewife	Unfinished Elementary School	Married	Marcia-15	15, 12	1	Not carried out
M17	52	Housewife	Unfinished Elementary School	Married	Marina-18	26, 31	3	IV
M18	40	Housewife	Unfinished Elementary School	Separated	Diego-14	20, 22	3	III
M19	28	Cashier	Finished Secondary School	Separated	Vanessa-6	2	1	V
M20	39	Public servant	Graduated	Married	Carlos -8	8	3 to 4	III
M21	49	Housewife	Unfinished Secondary School	Married	Cecília -15	19	3 to 4	V
M22	43	Helath worker	Unfinished Secondary School	Married	Débora -27	25	3	Not carried out
M23	65	Housewife	Unfinished Elementary School	Separated	Larissa -9	38, 35, 18	3 to 4	V
M24	25	Housewife	Unfinished Elementary School	Married	Murilo -8	-	2	V
M25	48	Housewife	Primary School	Married	Lara - 9	-	2	V
M26	51	Housewife	Unfinished Elementary School	Separated	Heitor -14	-	2	I

The impact of the diagnosis was referred to by the participants as an initial shock, a difficult, sad, complicated, horrible moment, one that caused a lot of insecurity and fear. Some mothers used the expression *"I felt like the floor was falling out from under me"* to explain the uncertainty and the insecurity felt when the diagnosis was revealed. The period becomes even worse when the male parent does not accept the child's diagnosis (Milbrath, Soares, Amestoy, Cecagno, & Siqueira, 2009). Some mothers, after revealing the feeling they had at the moment that they heard the news from the doctor, realized the necessity to conform: *"What are you gonna do? Abandon the child? No, let's take care of him..."* (M12)

The mothers also reported the feeling of losing the idealized child; it corroborates with findings in which the mothers experiment with the loss of an "ideal" child with the arrival of a baby with CP. They also have to deal with the loss of a "normal" maternity and, consequently, the end of a social mission of generating a child and bringing up a healthy person, which is lost (Huang et al., 2010). In this study, mother 5 remembers the moment when she had the news about the diagnosis: *"You can see, but you don't want to accept. Then it was complicated... Those words... She killed César there for me. A César died there, and another César was born."* The mourning feeling is also related to the idea that the situation is not transitory, as mother 10 reports: *" ...so when you discover that there is a life-lasting problem, it's kind of shocking, until you get adapted it's very complicated."* Mother 14 understands that, from the delivery, she started to understand the world divided into two groups, one composed of normal people and another composed of the impaired. Thus, this mother's report expresses the try to live in two worlds, balancing the specificities of CP and the life in society, where people with typical development are predominant.

Among the complex experiences referred to by the mothers, mother 14's report can be highlighted: *"And mine doesn't suffer anything, but at the same time doesn't… isn't it, he vegetates, I think they vegetate if you don't make them live, understand? My son doesn't have a physical problem, in his body, but he doesn't live. And the children I know suffer, you know? They suffer with surgeries, but he is here, isn't it, his head is ok. And the brain is the only organ that can't be transplanted, isn't it!"*.

The mother's understanding is that she is her son's life; she does not see him as another being who is able to have wishes. Therefore, it can be noticed that there is a permanent grief for the son that she does not have, superimposed to the dream of changing reality by means of a transplant, and, after that, having the opportunity to bring the idealized healthy child back.

Perception of maternity: worries, difficulties and aspirations

In relation to the worries that were mentioned by some participants of this study, the worry about the future can be highlighted, especially regarding the fear they have of dying. Considering that they are the main caregivers of their child with CP, their death may mean their children's' destitution: "*I worry about the future because I don't have a family. I'm afraid of dying one day and what's gonna be of André. This is my worry"* (M18). "*The biggest mother's worry is about death! Who's gonna take care of them when we pass away. I think this is what I worry about, because nobody is gonna take care of them like we did."* (M8).

Besides the fear of dying, there is a constant fear of getting sick, which could mean losing the necessary skills to care for the child and keep their routine, as mother 12 exemplifies: "*I worry about not being able to, someday, may God not want that, help him, because how many things for him depend on me, everything practically. Eating, going to the toilet, I take him to school..."Oh, it's so many things, sometimes I think what if I'm not here, we think, how is his life gonna be?"*. For mother 18, getting sick and needing the help of other people is something really hard to cope with: *"My biggest difficulty now is getting sick and finding people who accept my son the way he is, for he needs help. One of the biggest difficulties is getting sick and needing help of others"*.

As can be observed from the transcribed reports, the worry about their own death and about what will happen to their children are issues that cause anxiety and uncertainties regarding the future, and this, inevitably, affects the living of the present time. Parents of children with CP are more frequently anxious in relation to their children's physical and psychological health, besides not having time to take care of themselves. Even though they cannot care for their health, they recognize that it is affected by the especial needs of their children. That is because taking care of the child daily requires overcoming the tiredness, having physical strength to help them move and having a routine that, many times, includes bathing, dressing, feeding, medicating, taking to physiotherapy sessions, among other functions (Svedberg, Englund, Markern, & Stener-Victorin, 2010).

The physical overload of the mothers is related to the level of motor disorder; 14 children, out of the 26, were classified, according to GMFCS, as being level V. It means that there is not independence, not even to control basic anti-gravitational postures. In those cases, going from one place to another by themselves is only possible when there is the capacity to handle a motorized wheelchair. According to Ribeiro, Porto and Vandenberghe (2013), the high investment in the care of the child with CP determines physical and psychic suffering and elevates stress levels. Frequently, this suffering is not recognized, for the care focus is on the treatment techniques; however, it can reverberate in a negative way on the dynamics of family relations and, as a consequence, provoke high costs to the health system

Among the concerns of the participants of this study, there were also references to the lack of health professionals' proper training, the fear of the child suffering with some kind of exclusion, or rejection at school, the necessity to provide as much autonomy as possible, for some evolution on the clinical situation, especially regarding the movement that involves the ability of walking. Mother 2 talks about the importance for her son to move without being helped: *"I prioritize physiotherapy. I prioritize it for him to move as much as he can. It's my priority today, that he can walk the way he can, but that he can do it somehow, to be more independent from me."* Mother 11 has the same preoccupation: *"I think about doing many things, he can walk, get firm…"*. In an especial way, mothers who have a child at pre-adolescence, also referred to aspects involving sexuality, menarche and the first interests in dating. According to the report of mother 9: *"For now, he is in that adolescent phase, now he says 'I'm not a child anymore', so he's starting the mystery of dating. The girls take his hand, talk about dating, write letters to him. Then I start thinking: 'my God, how can I deal with this situation?...'"* There is uncertainty as for the future, because, during childhood, it is difficult to predict how the child will develop in the following phases; besides that, each new phase demands new abilities from the mothers, which also occurs in relation to children under typical development.

In accordance with the literature, (Gondim & Carvalho, 2012; Silva, Brito, Sátiro, & França, 2010; Pereira, Matsue, Vieira, & Pereira, 2014), the mothers of this study also referred to an overload sensation, excess of responsibility and of tiredness, especially in the case of more disabled children, according to GMFCS, which make them more dependent on the maternal care. A research points out that caregivers who spent more time caring for children with CP had more fragile health than the ones who spent less time (Byrne, Hurley, Daly, & Cunningham, 2010). Moreover, in this study, the mothers revealed a strong connection with their children with CP; in their relationship, mother and child seem to be fused, as if they were only one person *"He doesn't walk, talk, or eat by himself, he uses diapers, he doesn't do like we do, uh? He doesn't go to the toilet, he uses a wheelchair. He depends on me, to be honest, he depends on me for everything! To eat, to dress, to wash, everything, everything on me! I'm his arms, I'm his legs, I'm his everything"* (M24).

It seems that the time living together and the feelings of guilt and mourning for the diagnosis produce, in time, a reciprocal dependence relation, in which those mothers do not recognize themselves as women, but only as mothers and caregivers. They cannot notice the meaning of their lives besides caring for their child. Within this context, mother 26 says: "*I want him to study, to find a job. My future is his life, until he exists."* Mother 19 highlights that her life is connected to her daughter's: *"I'm her and she's me; like I always say to everybody: I'm completely dependent on her."* According to the literature, mothers who have the total responsibility for taking care of the child with CP start to feel indispensable in their lives and hardly ever can leave them under the care of another person, for there is the fear that mistreatment may occur and the certainty that no one will care for them as well as they do (Silva et al., 2010).

> *If you go out, leave him, you always get worried, uh? Even when I carried him, if I went out without him, there was something missing, I had to have that weight with me. I did what I had to do very fast and went home, because it was wrong, it wasn't complete, uh? without him on my arms* (M10).

As time passes, in accordance with this kind of report, they leave their own life and start living in function of taking care of the child, neglecting their personal needs, including their physical and psychic health, to provide the welfare of their impaired child. Authors highlight that the continuous exposition to the overload related to the act of taking care, in addition to the lack of leisure and a restricted social life can mean a risk to those women's health, especially when the support network is weak (Costa, Pinto, Fiúza, & Pereira, 2013). Therefore, it should be noticed that this condition is not their conscious choice, but something constructed, because, in some cases, the support to share the workload is very limited or does not exist.

Besides that, the report of the mothers reveals a routine full of difficulties. When they were asked about what was the biggest difficulty, some of them referred to the public transport to take their children to different places in the city. They affirm that, many times, the driver does not stop the bus for them to enter with the wheelchair, saying that the bus lift is broken. Another aspect related to transportation was mentioned by mother 5, who claimed that, many times, when trying to take a taxi, the driver refuses to take the passenger because he will have to help to close the wheelchair and put it in the trunk, and, when they arrive, he will have to help to take the chair out from the trunk and put the child with CP on it, which requires more time and more effort from the driver. This result corroborates the findings of other researchers, who found out, in their investigations, that transportation is one of the main difficulties faced by the mother of a child with CP (Simões, Silva, Santos, Misko, & Bousso, 2013). In the study presented in this work, the dependence of public transportation is also related to the low family income, which impedes them to use their own transportation.

The mothers usually have a routine that includes taking their children to specialized health assistance, such as physiotherapy, occupational therapy, speech therapy, among others. The transport turns into a challenge or even a hindrance, considering that, in the city where the study was carried out, there is not a center for the integrated care to offer all the services necessary to people with CP in the same place. Mother 2 reports her experience: "*More inside home than out, the sidewalks, the buses, everything is difficult. The places where I go with the wheelchair are not accessible, the sidewalks are horrible... You have to take them everywhere, there isn't a place with physio, speech therapy, everything together."*

The difficulty to take a bus or a taxi is added to the lack of accessibility in the city's streets and sidewalks. According to some mothers, this situation impedes more social experiences to happen, restricting the child to the environment of their homes. It may contribute to isolation, which, in its turn, can lead to depression symptoms. According to mother 3: *"It's difficult to deal with the chair on the street. I think all of this, every person has the same answer, it's horrible, the streets, downtown… For children, the sidewalks are horrible. It stimulates us to stay home, because it's horrible."*

The low quality of the adapted public transportation is an obstacle for a life with more quality; despite of that, another relevant factor seen as a difficulty is the necessity to move the child. This task requires physical strength and causes body to hurt, especially when the children grow and become heavier, as mother 10 reports: *"Now it's getting difficult, lifting him, change chairs, bathing, things like that... it's what is more... Because of his weight, just because of this." Mother 3: It's very difficult, it's not easy... The most difficult thing for me is bathing. I'm losing the strength to carry him, and I don't have anyone to help me. No one has time to help the others".*

The transcribed speeches show a feeling of being powerless because of the physical limitations/lack of strength, besides a feeling of abandonment, for they do not find anyone to help them. In those cases, the social support from family, neighbors and friends is fundamental to minimize the negative repercussion of the care on the physical and psychological health of the mother. As the children grow, the need for instrumental support increases, and it is related to the physical aid to carry the children and the dedication of time. However, even though, in some situations, in the group of participants, their older children and their husbands/boyfriends provide some help, it can be concluded that the supporting network is weak and needs to be enlarged.

Another aspect that must be considered is the school inclusion, for it is a process that requires mothers' dedication and emotional investment. When the interviews were carried out, 15 of the 26 children were studying at regular schools. Despite the fact that Brazilian legislation assures the accessibility and the specialized assistance at school (MEC, 2008), there are obstacles for those children to stay in the public regular education network. Among them, the mobility by means of public transportation, as well as the city's streets and sidewalks. The *Estatuto da Pessoa com Deficiência* (Brazilian By-Law for Impaired People - Law nº 13.146, 2015) assures accessibility, but, in the reality of the mothers of this study, it is a barrier to go to school and to other places for socialization.

The difficulties mentioned by the mothers in this study are diverse. Among them, there is the worry about the child's health problems and the awareness that this situation is not transitory, i.e., that CP is irreversible, which implies the care for the child for all his/her live. Therefore, the dream and projects for the future are limited to the reality demands. Mother 8's speech illustrates that: *"To sum up: everything! Everything is very difficult. Like that! Everything, because it's a baby who never grows up, uses diapers, everything, everything... It's difficult, everything is difficult, but the biggest difficulty is that they don't change, they will always be like that."*

Besides what has been exposed, experiences in which the child is not accepted or suffers with prejudice, the criticism from other people in relation to the care that the mother provides and the lack of respect from people on the streets are pointed out as difficult aspects of maternal living. Mother 25, however, thinks differently: "*I don't see any difficulty. I think there aren't any.*". Mother 5, in her turn, denies the difficulty, but reveals a speech based upon her religious faith: "*There isn't something I find difficult; I think everything is simple, so easy… God gives me strength; I know I'll be strong enough to carry him.*" The belief/faith appear in researches as an important factor for those mothers' support, for it works as a spiritual aid, helps in consolation and search for answers to questions on the reasons why they are living the maternity of an impaired child (Sandor et al., 2014; Dantas et al.,2010).

Some researches highlight the repercussions of the difficulties to conciliate a remunerated job and the care for the child. According to them, having a job could contribute significantly to improve the family income, but, frequently, the opposite occurs, i.e., the outcome increases with the expenses with the child and the income reduces, for the mother has to stop working out of home. As a consequence, the relationship network becomes more restricted and the exclusive dedication to the child takes place. It contributes to the increase of the physical and psychic overload, as well as to stress and depression (Gondim & Carvalho, 2012; Pereira et al., 2014). This reality is in accordance with the findings of this study, which verified the predominance of mothers who had to stop working or studying to meet the child with CP's needs. Among the 26 mothers involved in this research, only five of them have a professional occupation and one is able to keep studying. Nevertheless, it is possible to infer that working out of home could offer a healthier balance in their lives, considering that the professional life may be a source of pleasure, causing improvement to the self-esteem, enlarge interpersonal relationships and increase the family income. Moreover, having an activity out of home could provide some hours far from the child, and this would allow developing the capacity to believe that the child can be looked after by another person, without her presence.

In spite of the benefits of a job, many interviewed mothers cannot return to their professional activities, which can be related to their low education, determining also a low salary, maybe insufficient to pay for a caregiver for their children. Therefore, the mothers organize their routines by prioritizing their children's welfare, with unconditional dedication, which can contribute to tiredness, overload and a feeling of being fused with their children, as already mentioned. Moreover, it contributes to a more restricted social living and lower possibilities for personal satisfaction out of the domestic environment. Those factors may affect those women's mental health quality.

The necessity of taking care of their children is considered essential to the mothers participating of this study. Nevertheless, when they were questioned about what they would like to do, if they had more time, the most frequent answers concerned the wish of having a job. Mother 10 says it is an impossible dream: *"I've worked before, I worked as a housekeeper, I even worked and had a good salary. So it was difficult, for I had been working since I was 17, and when I was 31 I had him."* Mother 17 also regrets: *"Oh! It would be so good if I could work, but there is no way, I have to think about her".* Not having a job is a fact that ends up turning into frustration, once the family income is unlikely to increase, and, with a very limited family income, there are few possibilities to dream of a more comfortable life.

In second place, after having a job, when mothers were asked about what they would like to do but do not, for their lack of time, appeared the mention of being able to go back to school. In third place, the wish to invest more in their self-care and in leisure activities, such as working out, going for a walk, taking a sauna, ball dancing, watching TV and having sex. However, three participants could not even think of the interest of doing something not linked to the care of their child. Mother 14 claims: *"I don't even know! Because we're so used to this routine, that maybe going out of it makes us feel lost".* Finally, three mothers say that they can do whatever they would like to, despite of the dedication that involves this especial maternity.

The aspects revealed by the mothers participating of this study, mainly the overload, the difficulties to transport the child, and the physical manifestations such as pain, may be associated to the level of severity of their children's disorder, once most of them is older than 10 years old and were classified as a level V on GMFCS, i.e., they present severe limitations and a lack of functional abilities necessary in daily life. In the research carried out by Öhrvall, Eliasson, Löwing, Ödman, Krumlinde-Sundholm (2010), the individuals with CP with more severe functional limitations, i.e., at levels IV and V who were older present none or only few functional abilities. As the child grows, the daily life activities tend to become more difficult, especially due to the worsening of their clinical conditions (Dantas, Pontes, Assis & Collet, 2012).

Future expectations

When asked about their expectations for the future, the mothers mention, one more time, the fear of dying, of getting sick and of not being able to take care of their child. Therefore, most of them, despite of the economic and transporting difficulties, seek for the greatest development for their children, in relation to the motor aspect as well as to cognition. Under the expectation to provide the children's autonomy, they look for assistance for their son or daughter by means of various treatments, such as physiotherapy, speech therapy, occupational therapy, equine therapy, hydrotherapy, among others.

This way, they can react to the feeling of impotence, before the certainty about their death and the reality, in which the child depends on much permanent basic care to survive. Mother 18 reveals: *"I'm afraid one day I'll die, and what is gonna be of Diego, this is my worry...".* Mother 5 presents a similar worry: *"Fear. Fear of the future. Fear of him growing up and me not being able to take care of him, I'll have to find strength somewhere. I'm afraid of dying and nobody will take care of him, because I have no one to stay with him, uh?"*

Mother 13, possibly as a strategy to deal with the anguish of probably dying before the daughter with CP, wishes that her neuro-typical daughter graduates on the health area to take care of her sister with CP. In this case, the mother's expectation is that, in the future, the sister will take the caregiver place that is currently occupied by her.

Besides their own death, mothers fear experiencing with their child's death. The mothers highlight an unfavorable medical prognosis, due to complications stemming from CP. However, for some mothers of this study, frequently in the cases in which the child is younger and is in a less severe clinical situation, the expectations are connected to the possibility for the son to reach new development phases, such as keeping the head firm, walking, talking and studying.

Among the participants, mothers 18 and 24 referred to expectations to save some money to assure more comfort to their child and meet their future financial needs. Only mother 22, after revealing the fear of losing her daughter, mentioned an expectation for herself: *"I think I want to be a good professional, because of that, I want to study, it's been my dream for a long time, and I stopped when I got pregnant of Débora."* What this mother says is the opposite of the others' perception, for all of them have their expectations linked to their child with CP, like the speeches of mothers 3 and 26 exemplify, respectively*: "Because I know he isn't going to get better, uh? My future? I don't know, I think about him. My future is while he is here, after he isn't here anymore, there is nothing. He is my life, if it's not he, it's nothing else" and "I want him to study, find a job. My future is his life, while he exists."*

The future, in the reports transcribed, is connected to the child's life development and, because of it, their future is characterized by uncertainty of an unpredictable future, for the impairment modifies the family expected vital cycle. It is necessary an adaptation to the specifics of an atypical development. Because of that, it is difficult for the mothers to imagine the next life steps. According to the literature, feelings of disbelief, rejection, self-guilt and sadness are worsened by the future uncertainty of the child with CP (Huang et al., 2010).

Final considerations

The results of this research point out that the maternity experience for the participating mothers causes the necessity to re-organize the personal life routine to meet the necessities of the care with a child with CP, especially because the mothers of this study have a low income, which hampers the hiring of a caregiver who can work as physical and affective support. After the diagnosis, the mothers' lives start being organized by the obligations with the care to meet those demands, and then they give up on their aspirations. Besides that, they suffer with worries, physical symptoms such as pain and tiredness, and a variety of difficulties to conciliate maternity with other personal and social demands. In the case of this study, besides limited financial resources, a worsening of difficulties was the severe situation of most children with CP and, many times, the lack of involvement of the biological father.

It must be mentioned that the fulfillment of public policies, like the ones that refer to the high-quality adapted transportation and accessibility, including pavements that allow the movement of wheelchair, could improve a lot the routine of those mothers, improving then the social life of people with CP, such as school life. Another aspect understood as a possible facilitating tool is the concentration of therapies on the same place, which would allow the establishment of a connection with the mothers with the professionals involved in the treatment, and, concomitantly, the mother could take part of projects to benefit them, including therapies such as massage, stretching, muscle strengthening, support groups and psychological care.

The mothers involved in the study are always adapting themselves to the care necessities of their children. For that, they find it important to have advising and support from health care professionals, even though they have some assistance from undergraduates during their academic internship. Thus, there is a constant change of the therapists responsible for the care of their children, hampering the construction of a strong and lasting connection. It can be concluded that, despite of the CP severity and of the diagnosis irreversible condition, there are several actions that can be taken to minimize the daily adversities faced by those women. Systematic review studies on this theme and the collection of support material to the caregivers are only a few possibilities.

References

Assis-Madeira,E. A., Carvalho,S. G., & Blascovi-Assis, S. M. (2013). Desempenho funcional de crianças com paralisia cerebral de níveis socioeconômicos alto e baixo. *Revista Paulista de Pediatria, 31*(1), 51-7.

Baltor, M. R. R., Borges, A. A.; Dupas, G. (2014). Interação com a criança com PC: comunicação e estigma. *Escola Anna Nery, 18*(1), 47-53.

Bax, M., Goldstein, P., Rosenbaum, P., Leviton, A., & Paneth, N. (2005). Proposed definition and classification of cerebral palsy. *Developmental Medicine & Child Neurology, 47*, 571-576.

Byrne, M. B., Hurley, D. A., Daly, L., & Cunningham, C. G.(2010). Health status of caregivers of children with CP. *Child Care Health and Development Journal*, 36(5), 696-702.

Costa, A., Pinto, N., Fiúza, A., & Pereira, E.(2013). Paralisia Cerebral e cuidado: o que muda na vida de quem cuida? *Oikos: Revista Brasileira de Economia Doméstica, 24*(1), 237-65.

Dantas, M. S. A., Pontes, J. F., Assis, W. D., & Collet, N. (2012). Facilidades e dificuldades da família no cuidado à criança com paralisia cerebral. *Revista Gaúcha de Enfermagem*, *33*(3),73-80.

Dantas, M. S. A., Collet, N., & Moura, F. M. (2010). Torquato IMB. Impacto do diagnóstico de PC para a família. *Revista de Enfermagem*, *19*(2), 229-37.

Fonseca, L. F. (2011). Encefalopatia crônica (paralisia cerebral). In L. F. Fonseca, C. C. Xavier, & G. Pianetti G. *Compêndio de neurologia infantil* (pp. 93-133). Rio de Janeiro: Medbook.

Gondim, K. M. & Carvalho, F. M. Z. (2012). Sentimentos das mães de crianças com paralisia cerebral à luz da teoria de Mishel. *Escola Anna Nery, 16*(1), 11-16.

Gondim, K., Pinheiro, P., & Carvalho, Z. (2009). Participação das mães no tratamento dos filhos com Paralisia Cerebral. *Revista da Rede de Enfermagem do Nordeste, 10*(4), 136-44.

Huang, Y. P., Kellett, U. M., & St John, W. (2010).Cerebral palsy: experiences of mothers after learning their child's diagnosis. *Journal of Advanced Nursing, 66*(6), 1213-21.

Lei *n 13.146/15 de 6 de julho de 2015*. (2015, 6 de julho). Instiui a Lei Brasileira da Inclusão da Pessoa com Deficiência (Estatuto da Pessoa com Deficiência). Brasília, DF: Presidência da República. Casa Civil. Subchefia para Assuntos Jurídicos. Recuperado em 25 de abril, 2017, de http://www.planalto.gov.br/ccivil_03/_ato2015-2018/2015/lei/l13146.htm

Ministério da Educação [MEC]. Secretaria de Educação Especial. (2008). Política nacional de educação especial na perspectiva da educação inclusiva. Recuperado em 25 abril, 2017, de http://portal.mec.gov.br/seesp/arquivos/pdf/politica.pdf

Milbrath, V. M., Soares, D. C., Amestoy, S. C., Cecagno,D., & Siqueira, H. C. H. (2009). Mães vivenciando o diagnóstico da PC em seus filhos. *Revista Gaúcha de Enfermagem*, *30*(3), 437-44.

Milbrath, V. M., Siqueira, H. C. H., Motta, M.G.C., & Amestoy, S. C.(2012). Família da criança com Paralisia Cerebral: percepção sobre as orientações da equipe de saúde. *Texto Contexto Enfermagem,21(4),* 921-8.

Miura, R. T. & Petean, E. B. L. (2012). Paralisia cerebral grave: o impacto na qualidade de vida de mães cuidadoras. *Mudanças – Psicologia da Saúde*, *20*(1-2),7-12.

Moraes, R. (2003). Uma tempestade de luz: a compreensão possibilitada pela análise textual qualitativa. *Ciência & Educação (Bauru),9*(2),191-211.

Öhrvall, A. M., Eliasson, A. C., Löwing, K., Ödman, P., & Krumlinde-Sundholm, L. (2010). Self-care and mobility skills in children with cerebral palsy, related to their manual ability and gross motor function classifications. *Developmental Medicine & Child Neurology, 52*(11), 1048-55.

O'Shea, T. M. (2008). Diagnosis, treatment, and prevention of cerebral palsy. *Clinical Obstetrics and Gynecology, 51*(4), 816-28.

Palisano, R. Rosenbaum, P. Walter, S., Russell, D., Wood, E., & Galuppi, B. (1997). Development and reliability of a system to classify gross motor function in children with cerebral palsy. *Developmental Medicine & Child Neurology , 39*(4), 214-23.

Papavasiliou, A. S. (2008). Management of motor problems in cerebral palsy: A critical update for the clinician. *European Journal of Paediatric Neurology,13*(5),387-96.

Pereira, A. R. P. F., Matsue, R. Y., Vieira, L. J. E. S., & Pereira, R. V. S. (2014). Análise do cuidado a partir das experiências das mães de crianças com paralisia cerebral. *Revista Saúde e Sociedade, 23*(2), 616-25.

Ribeiro, M. F. M., Porto, C. C., & Vandenberghe, L.(2013). Estresse parental em famílias de crianças com paralisia cerebral: revisão integrativa. *Ciência & Saúde Coletiva*, *18*(6),1705-1715.

Sandor, E. R. S., Marcon, S. S., Ferreira, N. M. L. A., & Dupas, G.(2014). Demanda de apoio social pela família da criança com paralisia cerebral. *Revista Eletrônica de Enfermagem, 16*(2), 417-25.

Sharan, D., Ajeesh, P. S., Rameshkumar, R., & Manjula, M. (2012).Musculoskeletal disorders in caregivers of children with CP following a multilevel surgery.*Work, 4,*1891-95.

Silva, C. X., Brito, E. D., Sátiro, F. S., & França. (2010). Criança com Paralisia Cerebral: Qual o impacto na vida do cuidador? *Revista da Rede de Enfermagem do Nordeste, 11*(número especial), 204-14.

Simões, C. C., Silva, L., Santos, M. R., Misko, M. D., & Bousso, R. S. (2013). A experiência dos pais no cuidado dos filhos com paralisia cerebral. *Revista Eletrônica de Enfermagem, 15(1),*138-45.

Svedberg, L. E., Englund, E., Marker, H., & Stener-Victorin, E. (2010). Comparison of impact on mood, health, and daily living experiences of primary caregivers of walking and non-walking children with CP and provided community services support. *European Journal of Paediatric Neurology*, *14*(3), 239-46.

Tarsuslu, T. & Livanelioglu, A. (2010). Relationship between quality of life and functional status of young adults with cerebral palsy. *Disability and Rehabilitation,32*(20),1658-65.

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