

Cerebral Palsy: how the child's age and severity of impairment affect the mother's stress and coping strategies

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Abstract *The aim of the study was to comprehend how the age group and the severity of the motor impairment of children with cerebral palsy modify the mothers' experiences of stress and to understand the coping strategies they use. A qualitative approach was used, with the method framed on Grounded Theory Analysis. Nineteen mothers of children and adolescents with different degrees of motor impairment participated in individual semi-structured interviews. A lack of support and increased time and effort invested in parenting, at the cost of other areas of life threaten participants' physical and emotional health. Mothers of children with mild impairment suffer more from the challenge of dealing with their children's emotional problems, aggression and learning difficulties. For mothers whose children have severe impairment, the major difficulties relate to coping with health complications and functional limitations. Mothers of younger children report diverse sources of stress and scarcity of resources; while mothers of adolescents have greater experience and are able to take up their life projects again. Experience, knowledge and support received are critical for adaptation.*

Key words Cerebral palsy, Mother, Child, Adolescent, Stress

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Introduction

Cerebral palsy is a neuro-developmental disorder that is the main cause of physical disability in children and occurs in 2 to 2.5 cases per 1,000 live births¹. The main characteristics are disorders related to muscle tone, posture and movement and secondary muscular-skeletal problems. Cerebral palsy is a heterogeneous condition with several causes, multiple neuropathological patterns in brain images, different clinical types and a number of associated developmental pathologies including autism, mental disability, alterations in perception, communication and behavior, epilepsy and visual deficiencies^{2,3}. Given the heterogeneous and etiologically complex nature of the condition, sometimes with multiple disorders, the clinical condition and levels of motor disability are extremely varied.

Much effort has been put into seeking to standardize and classify cerebral palsy and to facilitate communication between researchers and clinical teams. The Gross Motor Function Classification System (GMFCS) classifies the seriousness of the condition in five levels: patients classified with levels I and II present mild motor impairment and are able to walk; at level III the impairment is moderate and aids are required for walking; patients with levels IV and V present major motor impairment and require a wheelchair for moving^{2,4}. The associated pathologies are more frequent in individuals with greater motor impairment⁵⁻⁷.

People with cerebral palsy require high levels of care over a long period of time. Since the clinical manifestations and life contexts of patients are highly diverse, it is mothers – who generally assume the main responsibility for looking after the child – who are most exposed to the high levels of demands and who can be over-burdened^{8,9}. Support in daily activities and in the needs of general caregiving, schooling and socializing for their children must change over the years, based on the functional conditions and health of the child, the mother's expectations and the socio-cultural context.

These different challenges can be a continued source of stress, but can also serve as a spur to create adjustment and/or adaptation strategies. Vulnerability to stress resulting from different general life situations is influenced by the mother's and child's characteristics, by aspects of relationships and by family, economic, social and cultural context^{10,11}. The stress incurred on the relationship between parents and children is referred to as pa-

rental stress. The factors that can affect this stress include: characteristics of the parents and their children, family functioning, the ties between the parents and the child, access to formal care, employability and the socio-economic and cultural context¹². Of note is that more than half of those parents manage to deal with the stress and overcome the related challenges. The multiple coping strategies also have multiple determinants: the personalities of the parents, for example, have an influence on the behavior and attitudes that arise in adverse circumstances¹³.

Taking care of children with cerebral palsy affects the (physical and emotional) health¹⁴ and freedom of the parents and the financial stability of the family¹⁵. The condition has an impact on quality of life and means that adaptations to daily living are required¹⁶⁻¹⁸. The stress that mothers and carers suffer and their coping strategies have already been described in quantitative studies^{10,17,19}. However, there is a gap in the literature involving a shortage of knowledge about experiences of caring for children with different levels of motor impairment and how these experiences are described in the different life phases of the children. This knowledge will certainly be useful for health professionals to help these women to deal with the specific needs of their children and with the most challenging situations.

Thus, the objective of this study is to understand if the age range and seriousness of the motor impairment of children has an effect on the meaning that women who are mothers to children with cerebral palsy attribute to their stress, and to understand the coping strategies that they use.

Methods

This is an exploratory and descriptive study that applies a qualitative methodology and uses Grounded Theory Analysis. The research method was based on the construction of a conceptual model by means of data analysis and that seeks to understand the important elements of people's lived experience and to explain the causes and conditions through which these processes arise and change²⁰.

The study was approved by the research ethics committee at the Federal University of Goiás, respecting the ethical precepts of research with humans. In order to identify participants, intentional sampling and theoretical saturation criteria were used. The sample was made up of 19 mothers who complied with the inclusion crite-

ria: be the main caretaker; be the mother of the baby or child aged under two; be the mother of the child (aged three to nine); be the mother of the adolescent (aged between 10 and 19); be the mother of a child with mild to moderate motor impairment (levels I, II and III of the GMFCS); and be the mother of a child with serious impairment (levels IV and V of the GMFCS). Mothers with more than one child with cerebral palsy or whose children had another clinical condition that was associated with cerebral palsy were excluded.

The mothers were recruited in four rehabilitation institutions that provide free care to low income populations in the city of Goiania, the capital of Goiás State in Brazil. Data were collected between August and December 2013. Recruitment occurred based on the following steps: first contact with the institution where data was to be collected; contact with professionals from the rehabilitation team (in order to identify eligible mothers) and direct contact with mothers who were waiting for their children to be treated. After a first meeting, the mothers were invited to a room that provided privacy, where they received information about the study and were invited to participate. Those who agreed signed terms of free and informed consent.

There was no predetermined sequence, by age or level of child impairment, to select the sample. The mother was chosen based on the inclusion criteria, her availability to participate in the study (to be interviewed) and based on the simultaneous analysis of the interviews that had already been carried out (whereby the need to further explore a specific subject that arose in a prior interview was evaluated). After 19 interviews, theoretical saturation was obtained, in other words the data that had been collected and analyzed were considered to be appropriate in terms of relevance, repetition, consistency, density and representativity of the elements related to stress factors and to coping strategies used by the mothers. It was also considered sufficient as the basis for constructing a theoretical model that represents this population.

The data collection was carried out in the institution at the time that most suited the mother, by means of an individual semi-structured interview. The interviews, which on average lasted for an hour, were recorded and were guided by certain questions/requests: "How is to be the mother of a baby/child/adolescent with cerebral palsy?", "Tell me a bit about your experiences and how they have changed over the years", "Can you

speak about the positive aspects and those that are challenging (difficult)?", "What are your expectations?" Based on the answers that were obtained, other questions were made with a view to further exploring their knowledge about the theme.

Anonymity was guaranteed for all mothers. To identify them, the letter "M" was used, followed by a different number for each one of them, the phase in the child's life and their degree of impairment. The children's names, where used here, have been changed.

The interviews were transcribed and analyzed using as a reference Grounded Theory Analysis.

The trajectory leading up to the final write-up of the text was not linear; the entire process was simultaneously cyclical and analytical, including: collection, transcription of the interviews, representation of data segments using codes, analysis and code comparisons, re-reading of the interviews, redefinition of codes, writing-up of memoranda, construction of categories, identification of how the categories related to one another, identification of decisive events and moments that led to changes in the mothers' reports, definition of central categories and construction of the theoretical model. Various diagrams were constructed and changed a number of times in an attempt to achieve a design that best represented the theoretical model. The repeated analysis and the continuous comparison meant that it was possible to construct concepts that drew on reading of the material that was gathered (through the interviews) and produced (codes, categories, memoranda and diagrams).

Results

Nineteen women participated in the study, including six mothers of babies, six mothers of children and seven mothers of adolescents. Ten had children whose motor impairment was moderate or mild, and nine had children with serious impairment. The age of participants ranged from 19 to 51. Most of the mothers had low family incomes, were not in paid employment and had low levels of education.

The theoretical model that was constructed on the basis of the data collected has been summarized in Figure 1 and is represented by two central categories, labelled sources of stress and coping strategies. The sources of stress include the participants' suffering, challenges and concerns; the coping strategies include the daily ac-

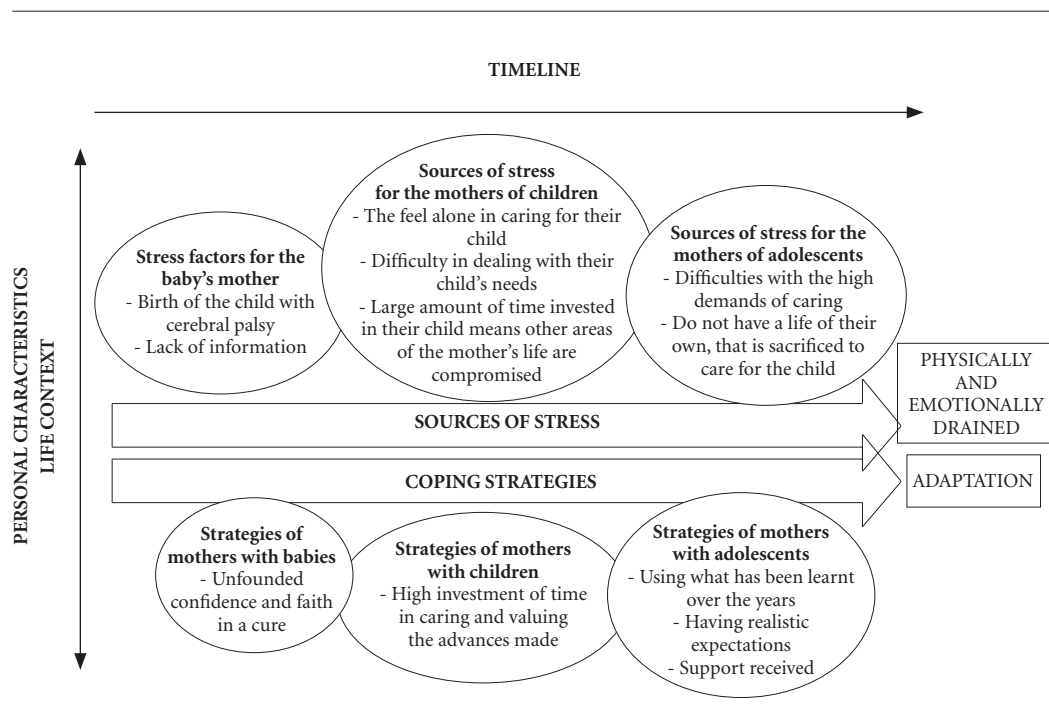


Figure 1. Theoretical mode of the sources of stress and coping strategies used by women who are mothers of children with cerebral palsy.

Source: author.

tivities and behaviors adopted by the women in order to adjust to the different conditions of their child's disability and to the different demands of caring for them. It is also necessary to consider the individual characteristics of the woman and her child, as well as the contextual factors that have an on-going impact on the degree to which they affect the individual's ability to engage and deal with certain situations.

The birth of the child is an important marker that determines the path that the woman will take in her life, with a significant increase in the amount of time and energy invested in being a mother, to the detriment of other areas of her life.

The mothers' experiences are related to and influenced by stress factors and coping strategies – marked by time, by their child's levels of impairment, spaces, relationships and life events – and are altered as the children grow up. However, the age range of their children does not provide reliable markers. Difficulties and challenges that were greater during certain periods of their lives may return to a greater or lesser degree depending on the moment in their lives.

Women whose children suffer from mild impairments report challenges related to the difficulties in dealing with emotional problems, with aggression and with their child's learning difficulties. For women who have children with serious impairments, the most difficult challenge is to deal with frequent health complications and with the child's dependence on them for mobility and for basic needs, which becomes more acute as the child grows and becomes heavier.

Mothers of babies reported fewer strategies for dealing with difficulties and mothers of children described a greater number of stress factors. They described how they began to adopt more coping strategies as their children grow. When their children are in adolescence, the mothers have already acquired more experience and are more secure in carrying out daily care tasks.

To successfully adapt to the challenges the woman needs access to information, and to resort to physical, emotional, family, social and financial resources or manage to develop efficient strategies for dealing with the specific demands. On the other hand, those women who do not have

access to such resources or who do not develop efficient coping strategies report being physically and emotionally drained or ill. When the networks of relationships that provide emotional and practical support are limited or inexistent, these participants report being in need of help and fear leaving their child without support after their death. However, faith, love of their children, knowledge acquired, support from their husband/partner and from other family members, the guidance received in the rehabilitation institutions and the experiences acquired over the years were all highlighted by the women as fundamental in adapting and allowing for a reorganization of their lives.

The categories below represent the main stress factors and coping strategies that were described by the participants.

Sources of stress

The *birth of a child with cerebral palsy* destabilizes a woman's life and the women themselves feel unsupported and overcome by contradictory feelings. Deception, sadness and revolt are interspersed with the feeling of happiness for having had a child. They stressed the lack of time for pleasurable activities and the need to give up professional activities, leading to having fewer financial resources. *It gives [me] real pain to see other babies of the same age sitting and playing. He is difficult; he cries a lot and gives me a lot of work. I don't know what to do... I don't do anything else, I just look after him* (M7, level V child from the GMFCS, baby). *It is difficult, a real disappointment! A mixture of rejection, pain, sadness, anger, mixed with the happiness of seeing him alive* (M5, level I child from the GMFCS, baby). *For a long time I have not had any time for my husband... I haven't looked after him nice, and also, there is no money. Before this, I worked!* (M19, level V child from the GMFCS, baby).

The participants complained of a *lack of information* provided by physicians, and of guidance on how to deal with the baby. They also criticized the inability of these professionals to communicate with them. The diagnosis and the prognosis were not clearly established. *The doctors are inhuman; I feel anger at the way they speak! They don't explain anything properly. They don't tell anything!* (M7, level V child, baby). *They don't explain anything well, whether [my daughter] will be able to walk, to speak, how long it will last. We end up not knowing what to do or what to think* (M5, level I daughter, baby).

As the children grow older, the participants continue without essential information, highlighting a serious failing of the health teams involved in the rehabilitation process. Without the appropriate guidance, they remain insecure; which leads to chaos in their lives as a result of a treatment that they believe will be brief. *I thought we would enter here [the institution], stay for a couple of months and that he would get better. But as time went by, I saw that in reality things were not like that! Things don't change overnight, so much so that I have been here now for 17 years. I thought that my son would soon be able to walk, to speak, to go to another school. But it's not really like that!* (M14, level V son, adolescent).

The women feel that they are on their own to deal with their child and report that they feel tied to a child that is dependent, while the people who could help them, including the child's father, are working and taking care of their lives. *On my own, I look after him on my own. Because not even his father helps me, everyone is working. On my own I do everything and more* (M6, level V son, child). *I wanted to relax a bit, to have a bit of quiet time* (M3, level III son, child). *I thought everything would soon be alright, I didn't realize it would be like this* (M9, level V son, child).

The *difficulty in dealing with the special needs of their child* were described by the participants as follows: women whose children have a greater motor impairment complain about the demands of caregiving, principally the overload brought about by health problems, frequent hospitalizations and the need to take care of their child's hygiene, feeding and mobility. The mothers of children with lower levels of impairment complained of learning difficulties, crying, sulking and aggression on the part of their children. *He coughs, so I go there and help him belch and clean him. It's all the time! Then I clean and give him a bath. Some days I wake up two or three times in the night to clear his tubes... We are overburdened* (M6, level V son, child). *There is no end to it. He requires looking after when he is out of the house, drawing attention to himself, not obeying me. I get very upset, and ashamed. I don't know what to do! I need help, guidance* (M3, level III son, child).

The interviewees also complained about social prejudices. They feel that people blame them for their child's disability and bad behavior. Stepping outside, taking the bus, going to a party are all major challenges. *Prejudice at school, because she doesn't learn. At the bus stop, everyone is staring. It makes me feel ashamed and angry. They think it's my fault* (M11, level II daughter, child).

The *high investment in taking care of their child compromises their lives*. The participants complained of social isolation, of a lack of financial resources, a lack of time for their husbands and other children and feeling like they have been put aside. They are disappointed that they have not managed to take care of their physical appearance and of their health and they have no time for leisure. They said they wanted to go back to having a paid job and thus help with the family finances. *We even stop looking after ourselves. I think I have a stomach problem. I never went to the doctor. I don't have time for my husband. My daughter keeps telling me that I don't like her, that I only like Tiago. Sometimes I have money and buy lunch for myself, sometimes when I get there [the institution] and there is left over from the children's food, the cook gives me lunch* (M6, level V son, child). *My entire life is dedicated to him. Before he was born I worked as a hairdresser in a salon. I would like to go back to work* (M3, level III son, child).

When the children grow up, *the difficulties can increase with the greater demands of caregiving*, particularly for those with serious motor limitations, due to their weight. The need for support to carry out basic activities, including getting about, washing and help with feeding overburdens the mothers. Mothers whose children can walk complain of the difficulty of dealing with aggression, with sexual coming of age, menstruation and behavioral and learning problems that are not adapted to the standards imposed by society. *He is 19 but has never learnt to read, to write, nothing. He can walk, but washing or getting dressed has to be done by me* (M17, level II son, adolescent). *He is already bigger than me! Because he does not control his weight, he has doubled in size. Since his private parts have now developed, no one else can help* (M15, level V son, adolescent).

The women make so many sacrifices over the years that they end up *giving up their own lives to take care of their child*. They report on the birth of their child with cerebral palsy as an important marker that determined the path their lives took. They recall with sadness the moment the doctor first told them of their child's condition, and when they do so, they reexperience the pain. The participants emphasized that in spite of all these challenges, the tiredness and physical and emotional pain, they care for their children. They find strength through faith in God and in the love that they feel. *I did everything! What you could, what you couldn't, breaking myself here, falling over myself there. And that's how it goes on till today*

(M10, level II son, adolescent). There are days when I put him on my lap and cry with pain, but I never give up. I speak a lot with God: I am tired, I am in pain, but if the child's father doesn't want to help, he can leave him here and I will look after him (M15, level V son, adolescent).

All the mothers of adolescents described, with great pain, emotion and concern, their fears of dying and leaving their child with no support. For them, caring for their child has become their meaning in life. They believe that only they are able to care for the child and that no one else, not even the father, would give up their work and life plans to dedicate time for their child. *If I die, there isn't going to be anyone to take care of him. I suffer for this every day.* (M15, level V son, adolescent). *I am terrified! I call on God to show mercy, that I don't die before him* (M17, level II son, adolescent).

Coping strategies

The mothers showed a *naive belief and faith that their child would be cured*. Believing that the treatment would be brief and that it was just a scare that would soon be over was a strategy that people use to face difficulties. The mothers want their children to grow and to develop normally and the focus on positive feelings and optimism as a way of heading off their fear. *I hope that he will just get better, thank God! That he can grow well, study, be intelligent, everything. That he will grow up to be a normal child. I think it was just a scare* (M2, level I son, baby). *I want to see him walking, talking, getting married. I just want the best for him. Then I will be able to work and to carry on with my life* (M7, level V son, baby). *I hope to see him well, cured! Any doubts, I hide at the back of my mind. Without the hope of seeing him recover, I would sink, stop, not be able to do anything* (M9, level V son, child).

The participants make an effort to imagine their child recovered and make a *massive investment of their time in caring and valuing the advances* gained through treatment; they place the children in rehabilitation activities in one, or more commonly, in several institutions. Going out of the house to leave their children with professional caretakers and having contact with other women is seen as positive, since it makes it possible to form friendships, to relax and to escape the problems at home. *I leave my house every day [to go to] the physiotherapist, speech-therapist, stimulation, group work, doctors' appointments. The more, the better! Better than staying at home.*

At least that way, I stay calm. If he isn't well, at least I have done my bit! (M9, level V son, child). I only live for him. I leave home every day and only return at night. I think it's good! (M3, level III son, child).

The interviewees highlighted the importance of institutions, of health professionals and of teachers in the evolution of their children. What they most wish for is to see their child walking, talking and studying. *This is priceless. To see Lucas walking! Everything is on the right track! I'm going to leave home [in the city of Pernambuco] carrying a trophy, him walking* (M4, level II son, baby). *When I entered here [the institution] they fixed him. Before I wanted to die, I was all cut up... After a week there, his behavior began to change. Now he is a real sweetheart!* (M17, level II son, adolescent).

Reverting to what had been learnt over the years was fundamental for the mothers' adaptation to the high demands placed upon them. The words and terms "calm" (tranquilo), "no work" (trabalho nenhum) and "used to it" (acostuma) were used repeatedly by the mothers of adolescents to show how they felt that they had adapted. You keep trying until you have worked everything out. When you learn more and begin the treatments, it becomes easier, doesn't it (M10, level II son, adolescent). *Now it's normal, now I'm calmer!... before, I thought he would be cured, but it's not really like that, is it! Now I just think about today!* (M14, level V son, adolescent).

When the women learn more about the disability and the condition of their children they are able to have *more realistic expectations*, to adapt, to return to their life projects and to reorganize their time. Their knowledge and accumulated experience are decisive when it comes to adapting. *When I came from [the state of] Maranhão, I came with hope. I thought I would be there for a year, that he would do physiotherapy, learn to walk and that we'd then go back. I guess I was a bit fresh faced, hey! I had no idea that it was a problem! Back then, I had massive expectations! Not now!* (M13, level IV daughter, adolescent). *I thought we would enter here [the institution], stay for a couple of months and that he would get better. But as time went by, I saw that in reality things were different! Things don't change overnight, so much so that I have now been here 17 years* (M14, level V son, adolescent).

The *support received* enables the women to restructure their lives. Where they are able to count on family support, to find new love, to have the chance to return to work, to invest their time

in leisure and personal activities, then they are able to restructure their lives and look after their child more serenely. The passing of time and the gaining of experience means that the mother can more calmly face difficult situations. The difficulties are no longer considered a burden and do not limit the mother's happiness. *When he was little, I stayed at home, but when his sisters grew older, they began to help and now I can work... wow! We go out a lot, he loves going out, holy moly!* (M12, level IV son, adolescent). *I've now been married for six years and my husband helps a lot. We have time for each other, I go out, I travel. Thank goodness I have a family that helps a lot! We always make plans that involve everyone* (M13, level IV daughter, adolescent).

Discussion

The women interviewed face a number of sources of stress when their child is young, and the development of a greater variety of coping strategies is a gradual process that culminates in a much broader repertory by the time their offspring are adolescents. Since the women feel that they receive little support when it comes to sharing responsibilities and receiving the information and guidance from doctors and other health professionals about the prognosis and needed coping strategies, they mainly rely on their own experiences.

Another important finding of this research is that the time and attention that the mothers dedicate to the special needs of their children with cerebral palsy a lot of responsibilities, in detriment of other areas of their lives.

Studies about the care provided to people with disability in Brazil have pointed to the need to discuss gender inequalities²¹⁻²³. Care is traditionally provided by women and in families, one of the responsibilities attributed to women is to look after the children while the father is seen to be responsible for providing financial support, thereby reinforcing some of the many social inequalities between women and men that have proliferated throughout history²¹. When the child has some kind of disability, the need for intensive support and specialized treatment means that there are high demands for care. The women must relinquish several daily activities, and many give up their studies or work, in order to meet their children's needs. They feel desolate as there is a lack of emotional and practical support, and public policies do not guarantee them basic social rights^{22,23}.

The literature also points to a lack of information for caregivers of children with disabilities and criticizes the way in which such information is disseminated. In the literature, the negative aspects of disabilities are considered to be over-emphasized in such information and the lack of preparation among professionals for dealing with the family is also highlighted. The parents' sparse knowledge about the diagnosis and its repercussions in the child's life is a factor that hinders their contribution to treatment, education and care²⁴. The lack of knowledge and information contributes to coping strategies that are ineffective such as naively hoping for a cure, fleeing, denial or harboring unrealistic expectations.

Fathers and mothers report similar impacts resulting from caring for their children. The negative impact on their quality of life is greater soon after the birth of the child and during transition periods such as entering school or starting adolescence¹⁵. The men and women who are responsible for caregiving describe more differences than similarities in the adaptation process. Both feel guilty. But the women express such guilt as intense and immediate and they feel it with regard to the relationship with their child, while the men express it more gradually, in a more concealed way, and at a personal level, as a failure of their own. Researchers report that both fathers and mothers may come to see the condition of their children as something positive that can strengthen their relationship and allows for growth¹⁶.

That women who have children with cerebral palsy dedicate more time to caring than those with children whose development is normal, is linked to more psychological problems and depressive symptoms among the mothers. The problems are the same whether their children can walk or not, and the severity of the child's disability is not a good predictor of maternal health. On the other hand, unemployment also has a negative impact on the mental health of mothers²⁵.

The problems become clearer as the children grow older: the children start school and are faced with prejudices. This period contains a lot of uncertainties. The women invest a lot of time and effort in trying to find appropriate treatment or even a cure for their children and become overburdened. On the other hand, by the time their children have reached adolescence, the mothers learn to deal with these demands, and make use of what they have learnt in the past from caring for an educating their children and they involve themselves in activities that give them pleasure.

A study of 223 mothers of children and adolescents concluded that levels of stress were greater among those with children, and less among those with adolescents²⁶.

Women whose children have mild motor impairment suffer more from the challenge of dealing with emotional problems, with aggression and with their child's learning difficulties. For those women whose children have serious impairment, the hardest thing is to deal with a child who is frequently ill, and that is particularly challenging when the child is older, heavier and entirely dependent on their mother. Research that was carried out with mothers of adolescents and adult children with cerebral palsy reported that, as their children grow older, their mothers become more confident in their ability to care and more proactive in looking after the health needs and education of their children⁸. Parents of adolescents and those whose children face less impairment manage to resolve the problems related to their child's diagnosis and to adapt better²⁷. However, the perception that some expectations were not met and uncertainty about the future can give rise to anxiety⁸.

Caring for children with cerebral palsy who have mild or serious motor impairment is a challenge and overburdens parents. Emotional problems are twice as likely in children with cerebral palsy, they are responsible for increasing their parents' levels of stress and their caretakers are found to have worse physical and psychological health²⁸. The high demands of caring are related to worse physical health¹⁰.

Looking after children who do not walk and have serious functional limitations is difficult. Professionals are already familiar with the technical strategies for dealing with such problems. However, little research has been done on the emotional and / or behavioral problems linked to this condition. In this respect, parents and professionals do not always know what to do. This point is worthy of attention since the mothers reported how these conflicts leave them and their children vulnerable to social prejudice which causes severe suffering. They require professional help to resolve these issues which are particularly difficult to manage as the children grow older.

The main resources that women use to deal with the challenges and reduce stress when performing their roles as mothers include: support received, the redefining of personal and family priorities and managing emotions^{8,17}; paid employment and leisure activities²³; good family relationships, support from the partner and love for

their children^{19,28}. Women report that the father uses the excuse of going to work to avoid getting involved with the children¹⁶. This choice may help to deal with difficult situations; however, it may lead to family dysfunction and be seen as a form of avoidance. It is also ineffective in the long term and can give rise to anxiety, irritability and stress¹³.

One point that is worth highlighting in the process of adaptation is the moment when the mothers are formally informed, or come to understand from their own experience, about the actual clinical condition and prognosis of their child. This is an important marker, since it means the mother can go ahead psychologically. In addition to knowledge, experience, support received and the availability of other resources, acceptance, proactive behavior, love for their children and optimism are factors that help mothers to construct realistic expectations, restructure their lives and to establish a positive outlook, finding benefits and meaning in adversity.

Conclusion

Stress and coping strategies change in the light of the moment through which mothers are passing, but generally, their physical and emotional health can be compromised when there are high demands and a lack of support. Mothers of chil-

dren with mild impairment describe challenges relating to difficulties in dealing with emotional problems, with aggression and with the learning difficulties of their offspring. For mothers whose children have severe impairment, the hardest thing is to deal with the frequent health problems and with their child's dependency on them for moving and carrying out basic activities, with these challenges becoming all the more acute as the child grows and becomes heavier.

Thankfully, the range of coping strategies reported by the mothers grows as the child grows up and the mothers become more secure in taking care for their children and returning to their life projects. Love for their child, acceptance, knowledge, emotional and practical support, the availability of resources and experience are all fundamental for adapting.

Families need to be provided with support, information, guidance and specialist and intensive medical interventions soon after the birth of a child with cerebral palsy. Specific interventions are necessary to help the family to deal with different challenges. This needs to be added to the implementation of public policies that guarantee gender equality and social rights, so that women do not need to give up their studies or their work and other activities that provide them with pleasure and with income, in order to look after their children.

Collaborations

MFM Ribeiro planned the study, along with L Vandenberghe, and implemented the data collection, made the first contact with the participating institutions, recruited the mothers, carried out the interviews, transcribed and codified the transcriptions, prepared a first version of the categories, drew up the analytical diagrams and wrote the final text. COM Prudente worked as the analytical sounding-board, evaluating the process as it was under way, discussing the construction of emerging categories and preparing analytical diagrams and the construction of the text. COM Prudente and VSC Vila reviewed the definition of the central categories, subcategories and the theoretical model. CC Porto provided overall guidance and participated in the entire process.

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