


Mothers of a Child with Cerebral Palsy: Perception on the Diagnosis Moment and the Child's General and Oral Health

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ABSTRACT

Objective: To analyze the perception of mothers of children with Cerebral Palsy (CP) on the diagnosis moment and the child's health. **Material and Methods:** Research with a qualitative approach, carried out with 19 mothers of children with CP, in a public higher education institution, in the state of Minas Gerais, Brazil. For data collection, the interview was used and for data interpretation, content analysis. **Results:** Mothers reported that the diagnosis of a child with CP resulted in major changes in the family's daily life, increasing their responsibility and demands. After the diagnosis, mothers revealed oscillating feelings, with progressively replaced by her motherly ability to take care, reestablishing the psychic balance. The health associated with the absence of disease and curative practices was frequently observed. Mothers reported a great concern with oral hygiene habits and frequent visits to the dentist. **Conclusion:** The diagnosis of a child with CP led to changes in the family's priorities and routine. After the moment of anguish, uncertainty and fear, the mothers accepted the reality. The biomedical principle significantly influenced the mother's perception of health, being health perceived as the absence of disease and curative practices. In relation to oral health, practices widely spread and recommended by the media and health services, such as correct tooth brushing, showed an orientation of patients to maintain oral health.

Keywords: Cerebral Palsy; Oral Health; Qualitative Research; Health Services for Persons with Disabilities.

Introduction

When a mother knows that she is pregnant, expectations, plans and hopes that the child is healthy are created. However, when receiving the diagnosis of a baby with Cerebral Palsy (CP), either before, during or after birth, a conflict for the child not corresponding to the expected standards is established [1-4].

The birth of a child with a disability intervenes in the whole family structure, as parents need to adapt to the new and sometimes stressing conditions. They come across with the child's limitations, fragility, and required demand for care. The demands and care of a child with a disability may turn into a challenge for the family [4-6]. The existence of family support and appropriate professional care is a point that needs to be highlighted. This support will help the family in creating coping strategies in face of a new life reality [1,3,7,8].

CP is one of the most common childhood disabilities [9,10]. It is characterized by a group of muscle tone, posture and/or permanent movement disorders, with limitations in the individual's functionality profile [9-11].

Individuals with CP usually need a multidisciplinary health care due to the great variation in the severity and the clinical outcomes of the disease [6,10-12]. On top of that, family involvement in the management of disabled children is remarkable, especially for mothers. The literature states that, in most cases, mothers are considered the main caregiver, the one who takes over the responsibility for the whole dynamics of raising and caring for a child with special needs [1,4,5,7,8].

Besides systemic conditions, individuals with CP may also have impaired oral health. This can be due to restricted or absent motor control of oral muscles, mouth breathing habit, and soft or liquid diet, often highly cariogenic. In addition, the inability for self-cleaning and the caregivers' difficulties to carry through oral hygiene makes individuals with CP more prone to develop oral diseases like dental caries, periodontal diseases, and malocclusion [13-15].

Therefore, this study aimed to analyze the mothers' perception of children with CP on the diagnosis moment and the child's health.

Material and Methods

Ethical Clearance

The study was approved by the Research Ethics Committee of Universidade Federal de Minas Gerais (Approval Letter No. ETIC 0457.0.203.000-09). Mothers who agreed to participate in the interview signed a Consent Form.

Study Design and Data Collection

This is a qualitative study of exploratory nature. The number of participants in the survey was defined by information saturation. Therefore, the sample closure was due to theoretical saturation [7,16]. Theoretical saturation is operationally defined as the suspension of inclusion of new participants when the data obtained starts to present a certain redundancy or repetition in the researcher's assessment, and it is not considered relevant to persist in data collection [17].

Thus, the sample was composed of 19 mothers of 3 to 12-year-old children with CP who seek dental assistance at Faculty of Dentistry of the Federal University of Minas Gerais in Belo Horizonte, southeast of Brazil. Mothers were interviewed in a private room, using a script addressing the core questions involving the study problem. The questioning aimed at guiding the mothers on the key points of the study and also allowed

them to discourse freely about the key points (Figure 1). The interviews lasted around 25 minutes, having been audio-recorded and transcribed literally. Aiming to improve the understanding of the interviewees' accounts, minor grammatical revisions were made.

1. Can you tell me a little bit about yourself so I can get to know you better (your life, your history ...).
2. What does it mean for you to have a child with special needs, such as Cerebral Palsy?
3. In your opinion, is your child healthy? Why?
4. In your opinion, does your child have a good oral health? Why?
5. What do you consider important for your child to develop an oral health? Why?
6. In your opinion, may your child's teeth condition interfere in his life and general health?
7. Would you like to report any other issue related to your child?
8. What is your opinion about this research that you and your child participated? Why?

Figure 1. Interview guide.

Qualitative research has its own criteria of scientific rigor that ensure the legitimacy and quality of the data generated in its use. The problematization of the criteria of reliability and validity in qualitative studies refers to establishing systematic and reliable mechanisms for apprehending social dynamics [18,19]. Thus, at first, some questions were asked and discussed among the researchers involved with the research. In a second step, a pilot study was carried out to verify if the interview script could extract the necessary information from the interviewees. The interview was able to answer the questions investigated in the research. Therefore, there was no need for adjustments to the questions.

Data Analysis

The study topic was explored by content analysis, performed manually by a researcher [19]. After organizing the data, exploring the material and processing the data, four thematic categories emerged: "Moment of the diagnosis", "Have a child with disability", "General health", and "Oral health" of a child with CP.

Results and Discussion

Moment of the Diagnosis

Mother's report has emphasized the great impact caused on the whole family after the diagnosis of CP in the child. It was observed a certain difficulty in accepting the initial diagnosis, expressed as incredulity and unawareness of the symptoms or consequences in the health of the child.

"I was a little stunned, sure! With family members, like this... Will it be because you think that cerebral palsy will affect a lot, like all the senses of the child? ... you don't think it's one thing only"
(Mother – 12 or more years of schooling, boy – 6 years old).

It is evidenced in the literature that the diagnosis of a child with CP has a great impact on the family, the acceptance of the child with a disability, and the adherence to the treatment [1,3,5,8,20]. Usually, at the moment of the diagnosis, the mother and family start seeking explanations regarding the reason why the child has that disability. After questioning, the mother starts to establish positive emotions and feelings when facing the possibilities the child may have.

The most common result among the interviewees was the acceptance of having a child with CP, as they consider him/her a grace of God.

“When God sends the child, it’s because He knows that you’ll take care of that child. He knows that you will make the effort, right? That you are going to make the possible and the impossible to take care of that child!” “I’ll do whatever I can for him the whole time! If there is anything to do, like in case he’s sick.” (Mother – 4 to 7 years of school; boy – 4 years old)

The reports showed a relationship between faith and acceptance. According to some authors, faith is a component that, associated with spirituality and believing, provides a new sense of life to face their children's condition. Faith reestablishes the feeling of happiness for the arrival of the child. Spirituality and faith have a strong influence in the parents' phase of acceptance and confrontation. The mother finds in that a path of strength and confidence in the child's recovery [2-4,21].

The acceptance process can be easier utilizing an appropriate approach from the involved health care providers when the diagnosis is conveyed to the parents. The lack of preparation and sensitivity of some professionals regarding the moment to inform the diagnosis to the family, as well as the use of technical terms, can lead to a lack of understanding of the real condition presented by the child. This can generate more anguish and fear, making the moment of the news despairing [3-6]. As a result, feelings of joy, expectation, anxiety and happiness may be replaced, at the moment of the diagnosis, for sadness, fear, shock, dismay, pity and hopelessness [1-3,5,15].

Parents have different ways to deal with the diagnosis of a disability, and their reactions may be associated with the perception of the child's lack of skills to adapt, concern for the uncertain future, and the way to deal with CP [3,4,8]. In many cases, they assign to themselves the reason for the child's disability and create guilt feelings. They assign it to their genetics or what they did or did not do during the pregnancy [3,5,6].

Have a Child with Disability

After the diagnosis, mothers can disclose oscillating feelings – sometimes rejection, other times welcoming, either happiness or sadness – while they gradually run the acceptance process.

The guilt previously felt by the mother is progressively replaced by her motherly ability to take care, reestablishing the psychic balance [4,5,8]. Through the reports, a feeling of motivation and responsibility at each new conquest of the child was observed.

“On the other hand, I’m happy! Happy for being her mother, happy for seeing something new in.... I say that being a mother is a gift of God! And being the mother of a child with special needs is a double gift. I’m quite happy and proud for being her mother!” (Mother – 8 to 11 years of schooling; girl – 3 years old)

“It means that we need to have a lot of responsibility. Much attention, affection, patience and perseverance.” (Mother – 12 or more years of schooling, boy – 6 years old)

Usually, the mother is considered the main caregiver, being exposed to high levels of stress. The demands and responsibilities to provide a better quality of life for the child can lead to fatigue, overload and changes in the caregiver's life. Consequently, the mother does not play her social roles anymore and, sometimes, becomes isolated [3-5,12,22,23].

However, this succession of feelings is not recurrent in all mothers. It is commonly observed that many of them stay in the rejection and shock phase. The dynamic of this process is due to several factors of the

mother's context of life [4,6,12,15]. Parents of special needs children usually report that daily life is extremely tiring and all their forces are consumed by the countless care demanded by the child [3,4,12].

It is also important to highlight the impact that a child with disability causes in his/her family's daily routine. The acceptance of the CP diagnosis allows the family to develop mechanisms to cope with future problems. Through mothers' report, distinct results were observed on the acceptance of the child by the family. Some mothers claimed that some family members accepted him/her with relative serenity and support.

"... my husband's family... they support us until today, they accept him. His grandmother used to pamper him, she was very affectionate, right?" (Mother – 4 to 7 years of schooling; boy – 4 years old)

However, other family members had different reactions concerning the birth of a child with special needs.

"My sister didn't accept. We don't even speak until today because she said that my son is crippled" (Mother – 4 to 7 years of schooling; boy – 4 years old)

Initially, family members pass through a process of feeling unstructured and frustrated. Gradually, the process of overcoming and acceptance happens. It can last for days, months or even years, in accordance with the characteristics of the family nucleus. Finally, strategies of reorganization and resources to cope with the new reality are created [2,3,6,7].

Families, particularly mothers, highlight the importance of being supported by health care providers, family members, friends and neighbors. The presence of these people plays an important role in the adaptation and acceptance phase [1,2,5,12].

Social support, either from friends, neighbors and/or other mothers who also face the same experience, can help positively to cope with the problems and the daily situations that may take place along the years and the development of the child with CP. Dantas et al. [20] and Almeida et al. [6] showed that the exchange of information, knowledge and reports about lived experiences correspond to a mutual contribution between these mothers. Together, they reassure and strengthen each other.

General Health and Oral Health of a Child with CP

General Health

When asked if their child is healthy, the mothers were unanimous in replying positively.

"Yes, [he is healthy]! Because he is joyful, you know..." (Mother – 8 to 11 years of schooling; boy – 4 years old)

"She's healthy. Comparing her with another child, with my other daughter, who is not a child with special needs, she hardly has a flu, a viral infection. There are also more cases, she has little pals who are quite weak. Not her, she has her own antibodies. She hardly sneezes." (Mother – 8 to 11 years of schooling; girl – 3 years old)

The general health of children with CP involves comorbidities, in a greater or lesser level of severity, in accordance with the impairment of the motor function. The literature shows that children with disabilities are usually more prone to infections, underweight, developing parafunctional habits, and other alterations. In this context, their quality of life can also be affected [8,13,15,24].

Through the reports, it is observed a clear comparison with other children, contrasting the severity of the problem, not its existence.

“At least according to what the doctors tell me, right? Her problem is not that serious, thus. In view of what I see with other children... Oh! I think she is healthy.” (Mother – 4 to 7 years of schooling; girl – 9 years old)

The biomedical concept of health was frequently noted in the interviews. This concept is known as the absence of disease, in which health is related to the fact of not falling ill. It opposes the bio-psycho-social model, which considers the quality of life as a multidimensional factor, of interaction of the child with the environment, the psychic, emotional state, social bonds, not only the presence or absence of disease [7,8].

The social and family environment has a great influence on the CP child's general health. Mothers of children with CP associate health with a loving and happy family environment; with the availability of basic social conditions, like having a home, access to education, healthy foods; with the conviviality with friends, the introduction in the society and also the practice of activities that offer health and fun. However, some mothers assign health with the financial aspect since they depend on resources for the treatment of the child with CP [7,25].

A bio-psycho-social view of mothers on the health-disease process makes them more prone to deal with the adversities caused by the child's disability and to keep healthy social and family interactions [6,12,13].

Oral Health

Neuromuscular problems inherited to the CP, alterations in the orofacial region, the development of parafunctional habits, feeding problems, difficulties in carrying through oral hygiene, and barriers of access to dental treatment can affect oral health and the quality of life significantly [8,13-15,24].

For most mothers, oral health was considered the absence of dental caries, gum problems, and halitosis.

“He has, he has no decayed tooth, he has no gum problem.” (Mother – 8 to 11 years of schooling; boy – 3 years old).

When considering children's oral health with CP, mothers demonstrated a great concern with oral hygiene habits and frequent visits to the dentist. Thus, the cultural factor involving feeding and hygiene may have influenced the oral health status of these children, not being the CP itself a factor of predisposition to dental caries and periodontal diseases [13,15].

The mothers are identified as the main responsible for the healthy development of their children's teeth.

“I always brush his teeth, whenever I have time.” (Mother – 12 or more years of schooling, boy – 6 years old)

“... it is to brush the teeth of the child every day, three times a day. After breakfast, lunch, and dinner, right? And to keep them brushed. And also, sometimes, take my child to the dentist to check how the teeth are.” (Mother – 4 to 7 years of schooling; girl – 4 years old)

Children with psychomotor impairment depend on their mothers/caregivers to have their teeth brushed. However, not all mothers have enough knowledge concerning the importance of good oral hygiene, either their children's or their own [7,14]. Moreover, the caregivers' socioeconomic status and level of education takes influence on the child's oral condition. Besides not having appropriate knowledge, many caregivers of children with CP present difficulty in carrying through the oral cleaning due to the characteristic hypertonia of these individuals [13,14].

A condition often pointed by the mothers was the difficulty to access dental assistance.

“And I don't have a dentist here. And it's difficult to find a dentist who takes care of a child like this, right?” (Mother – 12 or more years of school, boy – 4 years old)

Quite often, the parents consider medical and social care a main concern when compared to oral health care. And when they search for dental care, they are disappointed for not finding easily skilled dentists to treat children with disabilities [7,13,14,26].

“It's important for us to know how to do a lot of things: knowing what he had; what he has in the tooth; knowing that he is fine... Because we cannot go to the dentist all the time.” (Mother – 8 to 11 years of schooling; boy – 3 years old)

Several mothers highlighted oral health as something important for the general health of a child with CP. It was also evident the great importance given by the interviewees for the appearance of the teeth.

“Yes, if he is orally healthy, he can eat, today he has a bad breath that is ugly, it bothers.” (Mother – 4 to 7 years of schooling; boy – 4 years old)

“Because the person smiles. The person looks immediately to your teeth. Thus, if you are in front of a person with good hygiene, good feeding... you see by the teeth, then it's like a postcard of your arrival’. (Mother – 12 or more years of schooling, girl – 3 years old)

Some others claimed that there is no relation between oral and general health.

“I don't think there is [any relation].” (Mother – 4 to 7 years of schooling; girl – 9 years old)

Some interviewees stated that they only acquired knowledge regarding the relationship between oral health/general health after attend presentations performed by the health team.

“Because when I attended the presentation, she explained that we think it's not, but the tooth influences the whole body, right?” (Mother – 12 years or more years of schooling, boy – 6 years old)

Dental preventive approach is considered the most appropriate care for children with neuro-psycho-motor deficiency. In some cases, if any kind of intervention is required, a hospital environment and general anesthesia are needed, which may impose some risks to this group. The promotion of educational actions for the caregivers and an efficient preventive program can provide a better quality of life for these children [7,13,15,26].

Qualitative research has limitations that must be considered. The first is that the results found cannot be generalized; it is not possible to say that an entire population or most of its individuals think in a certain way based on the answers offered. In addition, because it is an exploratory study, it does not allow testing hypotheses and, through it, it is impossible to define the amplitude or quantity of a phenomenon.







Conclusion

The diagnosis of a child with CP caused alterations in priorities and routine of the family nucleus. Following the moment of anguish, uncertainty, and fear for the unknown, the mothers accepted the reality. The bonds between mother and child tend to be strengthened. The love feeling surpasses the painful experience of the diagnosis.

The biomedical principle exerted a significant influence on mother's perception of health, being health perceived as the absence of disease and curative practices. Regarding oral health, practices quite disseminated

and advocated by the media and the health services, like the correct and properly frequent tooth brushing, evidenced an instruction of the patients for maintenance of oral health.

Authors' Contributions

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All authors declare that they contributed to critical review of intellectual content and approval of the final version to be published.

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Conflict of Interest

The authors declare no conflicts of interest.

Data Availability

The data used to support the findings of this study can be made available upon request to the corresponding author.

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