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# Experience of mothers in the care of children and adolescents with special health needs

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**ABSTRACT.** To describe the family's experience in home care for children and adolescents with special health needs. Qualitative research supported by the theoretical framework of Patient- and Family-Centered Care, carried out in an Association that serves Children and Adolescents who need special health care in a municipality in the southern region of Brazil. Data were collected through semi-structured interviews with eight mothers of children and adolescents with special health care needs, which were recorded and transcribed verbatim, and subjected to content analysis in the thematic modality. Two categories were identified: Family reorganization to care for children with special health care needs at home; and Invisibility of the woman/mother. Caring for CSHCN at home imposes on families the need to reorganize themselves, so that the mother can dedicate herself, almost entirely, to this function, including neglecting health care. Despite this dedication, mothers do not recognize activities developed as difficult; however they make self-care invisible in relation to child care.

**Keywords:** chronic disease; caregivers; family nursing.

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## Introduction

The advancement of technology in recent years has benefited and favored the survival of children, who for various causes, such as traumas, congenital malformations, chronic diseases, prematurity, among others, need technologies to maintain life and care developed by a multidisciplinary team and by the family, what differentiates them from other children (Ramos, Moraes, Silva, & Goes, 2015). Thus, they constitute a group of children named in Brazil as Children and Adolescents with Special Health Care Needs (CSHCN) (Dias et al., 2019).

Because they have special health needs, these children generate demands for care that in Brazil were classified into six groups: developmental care, which includes the measures for children with muscular neuromotor dysfunction, functional and disabling limitations; technological care, in the case of children using life-sustaining devices (gastrostomy, tracheostomy, etc.); medication care, for children making continuous use of drugs (anticonvulsants, cardiotonics, etc.); habitual modified care, for children who need adaptive technologies in daily care and activities of daily living (moving around, dressing, etc.); mixed care, corresponding to the combination of one or more demands, except for the technological one; and, finally, clinically complex care, which involves the combination of all the previous ones including the management of life support technology (Góes & Cabral, 2017).

The last IBGE population census revealed that CSHCN represent almost a quarter of the Brazilian population of children, and the incidence of children under 14 years of age with at least one type of disability was 21.68% (Cabral & Moraes, 2016).

Due to the complexity of their health, CSHCN have limitations in their basic activities of daily living and require the management of technological devices and differentiated access to health services when compared to children without health impairment (Dias et al., 2019).

The main responsible for caring and performing home care are family members. For this reason, the whole family needs to organize its dynamics and routine to provide care for the child (Dias, Arruda, & Marcon, 2017).

The family is a permanent social institution with a complex network of relationships, interactions and emotions, which has the capacity to change and adapt to the situations experienced, as the birth of a member with a disability (Marcheti & Mandetta, 2016).

In the family environment, the interactions and demand for care by the CSHCN, due to their complex condition, has the potential to generate stress in the family, in view of the chronic character of the condition. This may compromise psychological, emotional, social and even functional aspects of the family units, requiring a constant process of adaptation of family dynamics (Araújo et al., 2018).

In their homes, CSHCN need medication, follow-up by rehabilitation services, monitoring of growth and development, changes in the family's routine and care provision, besides adaption to the use of technologies (Ramos et al., 2015).

Because of this, home care presents challenges related to changing the context of care that was previously hospital-based and now is home-based, under the responsibility of the family. The family now carries a high burden of demands and constant vigilance in daily care activities (Severo, Santos, Neves, & Ribeiro, 2019).

For health managers, the challenge is to guarantee effective public policies that promote the inclusion of CSHCN in society, as this clientele has been increasing in several countries (Ramos, et al., 2015).

In view of the diagnostic complexity of CSHCN that require differentiated care, recurrent and prolonged hospitalizations and a demand for care to be developed by the family at home, it is extremely important to reflect on the care process and the family's coping with the repercussions that this condition imposes in the family context.

Therefore, the realization of the present study is justified by the complexity and continuity of care provided to CSHCN at home by their families. Therefore, the objective of the study is to describe the family's experience in home care for CSHCN.

## Methodology

This is a qualitative research, supported by the theoretical framework of Patient- and Family-Centered Care (PFCC) and carried out in an Association that serves children and adolescents who need special health care in a municipality in the southern region of Brazil.

The Association is a non-profit, philanthropic institution that offers care in the educational and rehabilitation fields in the areas of: physical therapy, speech therapy, psychology, occupational therapy and social work.

The inclusion criteria used in the study were: being a family member, aged 18 years or older, who remained in the Association during the activities of the children/adolescents. In turn, the exclusion criteria were: family members who did not have a bond and were unaware of the care routine of children/adolescents at home because they were not the main caregivers.

Four visits to the Association were made in order to know the place and the research participants. All visits were previously scheduled with the social worker who contributed significantly to the researcher's approach to family members.

In the first meeting, the objective of the research was explained to the social worker and the family members present. Once this was done, the invitation to participate in the study was formalized and, later, the next meetings were scheduled for the interviews.

The interviews were conducted by the first author, in August 2019. They lasted an average of 20 minutes, were audio-recorded, and later transcribed verbatim. A semi-structured script prepared by the author was used during the interview. The script had questions to characterize family members, such as sex, age, religion, level of education and occupation, in addition to open questions related to the experience with the home care of the CSHCN and in relation to the moment of the diagnosis, changes in family relationships, daily care activities and practices.

The data were submitted to content analysis, in the thematic modality, which covers three distinct stages. The first is the pre-analysis and corresponds to the ordering of the data after full transcription of the interviews and organization of the material so as to determine the units of records and the form categorization. The second stage addresses the exploration of the material for the coding procedure. And finally, in the third stage, the treatment of results and interpretation is carried out, according to the philosophical framework of the study (Bardin, 2016).

The study was developed in accordance with the ethical and legal precepts regulated by Resolution nº 466/12 of the National Health Council and its project was approved by the Permanent Ethics Committee on Research with Human Beings of the State University of Maringá (Opinion 3,541,055). All participants signed the Informed Consent Form (ICF) and to guarantee anonymity, excerpts of their reports are identified by the letter M, followed by the number indicating the order of the interviews.

## Results

Eight mothers of CSHCN participated in the study. Their ages ranged from 34 to 57 years; four of them had incomplete high school, three had incomplete elementary school, and one had completed high school. Six of them were Catholic and two evangelical. All were married and five had other children.

All the mothers were the main caregivers of the CSHCN and, as a result, did not perform work activities outside the home. The average income of the families was one to two minimum wages, with emphasis on the aid of the Continuous Cash Benefit, received by the families due to the health situation of the children.

Five CSHCN lived in neighboring municipalities, five were female, and the average age was 11 years. Among the diagnoses, five presented Cerebral Palsy and the others, Cerebral Palsy associated with other conditions such as: West Syndrome, unspecified syndrome, and Gaucher Syndrome. Regarding the classification of predicted care demands, seven presented demands for technological, habitual and medication care, and one for technological and habitual care.

The analysis of the content of the interviews allowed identifying two categories, which will be described below.

### Family reorganization to care for children with special health care needs at home

The speeches showed that, when the special health need is diagnosed, families experience feelings of pain, sadness, shock and frustration.

In most cases, the diagnosis occurred shortly after birth. Some mothers could notice it immediately, and others only realized the chronic condition after a while.

> It was very sad, it was very sad because of the way the neurologist talked to me, I left there devastated; then, the despair started, right. (M-1)

> I was in a state of shock, I said it is not possible, then I asked people why the other [babies] walked so fast and my baby didn't, then after that I started to realize there was a problem, then I talked to the mothers here at school and I knew that my son was special, it was in this moment I got it; that's how I found out, after a long time. (M-5)

> We feel shocked, I was shocked when I first came here [association], I am human, and you don't expect that, I would never imagine that he would be like this. (M-6)

It was possible to identify that mothers behave as resigned before their child's diagnosis, and they also seek support in their spiritual beliefs to face the challenges experienced on a daily basis, believing that faith contributes positively to the ability to care.

> Learning about the diagnosis was a little painful, but if that was how God wanted, he knows that I have the capacity to take care of the child, right? (M-2)

> To say that I don't cry... I do all of that, but I'm not going to get stuck there. As I say, these are things that only I will go through, I have my moments that I cry, that I get desperate, but I think I know how to face the situation well. (M-6)

> He was a blessing, but he came up with something very difficult in my life, everything changed. (M-5)

> All this that happened to her is a gift from God, a gift from God, because when she got sick, an evangelical lady told me never to face what happened to her as a problem, told me to accept it, that it was a gift from God and that He chooses people who are capable of having such a child, and if you analyze it, it is true. (M-7)

As a result of the chronic condition, CSHCN generally need full-time care and attention at home. They are usually totally dependent on a caregiver for normal activities of daily living, regardless of age. However, some mothers reported that they did not receive guidance from health professionals about the care that should be given at home; they learned to do it over time.

> I never received guidance, I know I have to bathe, I know I have to clean, today my girl is 17 years old, but I know I have to do everything, but I didn't have that guidance, and I believe that other mothers don't either. (M-1)

> Some things, yes, but a person coming to tell me what I had to do, no, I found out by myself. (M-4)

> Not that I remember... I learned with the day to day. (M-8)

In this study, in all cases the main caregiver was the mother. In the speeches it was possible to perceive certain insecurity in delegating the care of the children, and also the lack of support from the family. However, although they found the routine of care with the CSHCN and with domestic chores hectic, they did not evaluate this task as difficult, indicating that there was an adaptation of the family to the usual care.

> [...] Just me and God, no one else. (M-2)

> No family support... Better leave it alone, it's just me and her and my husband. (M-2)

> Normal, I don't care... oh because I have to take care, right? She needs me I have to take care of her, right? It was automatic, carrying on, everything; it was automatic. (M-1)

> It's very hectic. But I won't tell you that it is something difficult, that causes trouble. I prepared myself mentally and decided that I was going to do everything. (M-2)

> Then I do everything... [sighs] he depends on me in everything, eating, changing, getting him out of bed, as if he were a baby. (M-3)

> Look... [sighs and becomes thoughtful] it's me, I have to take him to the bathroom, change and treat him. (M-5)

The intense care routine associated with the fact that they have to dedicate themselves full time to their children was the main reason for mothers to quit their jobs. It was observed in some reports that not being able to have a paid job generated frustration, sadness and feeling of worthlessness.

> Now I don't work, but during all my life I worked, today I have no one to leave her with, I'm staying at home. (M-1)

> I work at home with my daughter [laughs]. There's no way to go to work and leave her. (M-2)

> Today it is not possible for me to work because I have to bring her here, take her to physical therapy; there is nothing to do about it. (M-4)

> I don't work, I mean... I work twice as hard with him, you know? When he was born I quit work, because he was all the time hospitalized in these things, so I had to stop, there was no way out. (M-6)

When asked about help from the family to carry out care, they said that when there is help, it is sporadic or related to domestic chores. Some reports made it clear that the figure of the father is related to the provider of the household and not to the care of the child.

> They help me more with domestic chores, because I feel insecure about leaving him [son] with other people. (M-3)

> My husband works and arrives tired... poor thing. But also, he doesn't know how to give the medicine, he doesn't know how to give food, he doesn't know anything." (M-2)

> My husband helps me with some things in the house and with him [teenager] but it's mostly me. (M-3)

### The invisibility of the woman/mother

The speeches showed that when mothers dedicate entirely to the care of their children, they often end up renouncing themselves and isolating from social life and that, in some cases, they spontaneously leave friends.

> I don't want any more friends... I used to do a lot for them not to stay away, because I wanted him [son] to be close to other children, but I knew he was despised, so I saw that it is not worthwhile, today I don't I want it, he's my best friend. (M-5)

> The friends got away, you know, it's more the family and the girls here [the Association]. (M-7)

> Just by mentioning about going out, the girl [daughter] already starts with something, I can't believe it, then I get stressed out, then I don't go out for anything else, just to school and the doctor. (M-8)

Another important aspect to be considered is that being a mother of CSHCN with disabilities negatively impacts the women's self-care, who often have no time for life and are stressed due to the intense demand for care.

> I basically don't have time for me, right?... after we become a mother, that's how it is, especially when the child is like that. (M-2)

> I live for him; I take care of the house and him, that's all I do. (M-3)
>
> Now I have to take care of him and of the house, now it's over, we have to forget about life out there, now I live for him. You can see that I don't dress up like before, no way, I don't feel like it anymore. They [family members] think that I am that superwoman, but I get tired, get stressed... I need care, but I have no one to take care of me. (M-5)
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> When you have a special child you don't have time to think you're leaving everything behind, that you won't live, you don't have time for that. The care measures are so many, so intense, so much, that you don't have time for you, I have time for nothing. He [teenager] needs me. (M-6)
>
> I have no more life, it's just for her. But I do everything for her, everything for her, around her. (M-8)

## Discussion

With the analysis of the speeches, it was possible to identify that when the mothers received the diagnosis of the child's chronic condition, they experienced various feelings such as pain, shock and frustrations. Such feelings have already been described in other study that reported emotions such as fear, doubt, disappointment, guilt and impotence, called 'initial crisis reactions', as they are emotions experienced by parents as a way of coping with the moment considered (Oliveira & Poletto, 2015).

In the event of a disease in which the child presents special care needs, the family context also undergoes changes in its structural organization and in its daily life, since everyone needs to learn to deal with the limitations imposed by the child's condition, with his needs and with routine home care (Teles, Resegue, & Puccini, 2016).

Thus, the high demand for care that CSHCN present, in addition to usual care measures for their age, makes the family undergo an adaptation in relation to the home care process. Because of this, it is important that health professionals help the family to cope and adapt to their care, and also help them recognize their weak and strong points, including recognizing when it is needed to ask for help in the family environment and in health institutions (Dias et al., 2019).

However, the mothers expressed in their speeches that they did not receive significant guidance from health professionals regarding the care they should perform at home. They said that soon after the diagnosis, not only the performance of care was difficult, but mainly the lack of guidance on the part of professionals and lack of support from the family and society in general. It is noteworthy that qualified listening and dialogue could minimize this feeling.

They stressed that they were learning to deal with the children's limitations and the difficulties surrounding their care. Furthermore, they showed that, over time, contact with other mothers who experienced similar situations and the daily performance of activities made them acquire skills necessary for the performance of care, so that nowadays they do not even consider it difficult. It is noteworthy that the difficulties referred by the mothers in the study corroborate with the difficulties identified in a study carried out in Minas Gerais with a family of CSHCN (Reis, Alves, Barbosa, Lomba, & Braga, 2017).

The fact that the families report that most of the time they did not receive guidance in relation to care for the CSHCN at home indicates that this may not be recognized by health professionals as a unit of care. However, in order to change this practice, it is essential to use an approach that prioritizes the family as a foundation for professional practice. In this sense, the use of the assumptions of Patient and Family Centered Care (PFCC), guiding the assistance to these children/adolescents and their families, would make it more appropriate and consistent with the needs presented (Dias et al., 2019).

The high complexity and frequency of care, associated with the fact that this care is almost always performed by a single person, constitutes a triggering factor of the caregiver's overload and neglect with self-care, giving rise to feelings of worthlessness. These aspects were identified in an integrative review that described the impact that children with special health needs have on their families (Simonasse & Moraes, 2015)

It was also interesting to perceive low self-esteem in the speeches, as many mothers reported not having time to take care of themselves and that the focus was entirely on the children's well-being, thus neglecting their basic needs and their health. A similar result was noted in a study of 15 women/mothers of people with disabilities in a municipality in Brazil (Tomaz, Santos, Avó, Germano, & Melo, 2017).

As the routine of care is intense and the time is all spent with the CSHCN, it was observed that all mothers left work activities to dedicate entirely to the care of their children. This, however, caused negative repercussions on their psychological health, as the paid and out-of-home work represents the opportunity for social interaction, self-assertion and appreciation. On the other hand, being away from work can contribute to the development of feelings of isolation, incompleteness and low self-esteem (Tomaz, Santos, Avó, Germano, & Melo, 2017).

In this scenario, it was observed that, while seeking to face daily limitations, the mothers sought support in spirituality, believing that the child's situation was a divine blessing, and this in a way gives them strength to face the daily challenges. A study carried out in the southeastern region of Brazil about the impact of disability in cases of chronic diseases identified that the family has in religion and faith an important coping and overcoming strategy (Tomaz, Santos, Avó, Germano, & Melo, 2017).

## Conclusion

The results of this study showed that upon receiving the diagnosis of a chronic condition of the child, the mother experienced feelings of pain, shock and frustration, but over time they accepted the fact with resignation, what they understood to be a divine ordeal. They also showed that mothers considered that, after hospital discharge, they were not instructed by health professionals about the care of their children at home.

It is believed that the guidelines, to a lesser or greater extent, were given. However, it is possible that this happened in a moment that was not appropriate and/or in a non-contextualized way, causing an overload of information. In any case, we should not fail to appreciate the mothers' perspective, because in their view, the impression that remained is that guidelines were not provided.

It is noteworthy that these mothers felt alone in their arduous task of taking care of CSHCN, and that they often neglected and continue to neglect their own needs for self-care. Although the care for the CSHCN was already integrated into their routine of life, such care continues to represent an overload. The perception of not being counseled and guided needs to be considered by health professionals, so that their actions can somehow minimize the effects of this situation.

Through this study, it is expected to contribute to the knowledge of the family as a unit of care and in its empowerment, something still little discussed in public policies. The study highlights the importance of providing services, projects and programs involving families and that effectively consider their demands.

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