



The psychosocial impacts to caregiver of pediatric patient without possibility of disease-modifying treatment

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Abstract

Introduction: The caregiver of a child diagnosed with cerebral palsy incorporates a role for which he was not prepared. **Objectives:** To show the influence of this new situation of the caregiver in direct contact with the health system. **Methods:** Descriptive, qualitative paper, with 12 semi-structured interviews, with content analysis. **Results and Discussion:** When given a new role, the caregiver must deal with new contexts and prejudice; he is submitted to stressors and different burdens than those with children without complex health conditions. There is a change in the personal and family routine and an adaptation period to the new conditions. **Conclusion:** The psychosocial well-being of the caregiver has an influence on the child's evolution and outcomes, for which the family centered care is fundamental when dealing with a child with these conditions.

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INTRODUCTION

Waiting for a new member in the family causes great anticipation. The moment to tell the siblings or the feeling related to the arrival of the first child, the cleaning of the room, the organization of clothes are situations that generate several moments of uncertainty and also of happiness. Most of the time, everything goes as expected, but this is not the reality for some families¹. Intercurrences during pregnancy, childbirth, chronic conditions, accidents are some of the situations that can lead a family to face a child with cerebral palsy (CP).

The changes that a diagnosis brings permeate the child and affect the entire family emotionally and socially, requiring constant care and adaptation². The individual is required to re-signify his existence, adapting to limitations, frustrations and losses. In the case of patients with neurological impairment, there is still a need to re-signify family life³.

In this context, family members become the main agents in the management of their child's condition, which does not respond with the expected development, and presents multiple demands⁴. In pediatrics, children with CP are the ones that present more limiting functional alterations in the long term⁵. Caring for these children without adequate support can become an overload, with changes in the physical and mental health of their main caregiver⁶.

The management of these children is a complex public health problem, making it essential to search for improvements in diagnosis, estimation of burden on the family, social perception and well-being of caregivers⁷. It has been observed that these children require frequent visits to health institutions, with specialized and multidisciplinary care to deal with their conditions. However, the multiple clinical demands of these children cannot be the only focus of care. One must always keep in mind the importance of allowing a childhood, within its limitations.

The family is a complex system, formed by affective, emotional, physical, social and economic bonds that are constantly changing, which requires strategies to maintain the balance of the system. When the child needs frequent or prolonged hospitalizations, the burden on the family dynamics increases, especially in the case of an individual with no possibility of disease-modifying treatment^{2,8}.

The context in which the family is inserted is often represented by conflicts and dilemmas, and its knowledge is important for the definition of the patient's scenario and the adequate planning of health actions that promote their well-being⁸. Friction between the family can deconstruct the entire ongoing process^{9,10}. Consideration should also be given to reducing interventions that cause more stress than they add to the child's quality of life.

In developing countries, it is not customary to hire professional caregivers to deal with children with special needs, especially when it comes to low-income families, such as the subjects of this study. The informal caregiver is defined

as someone who does not have specific and paid training to assume the primary care role. Therefore, the mother, father or a close family member becomes the main caregiver⁷ who will be called caregiver in the text that follows.

Current literature shows that the mother becomes the caregiver in most cases, being the person who needs to meet the patient's demands, when in a home environment. Thus, it is usually necessary to quit the job, which causes a reduction in the family budget, at a time when it is necessary to increase expenses due to new drugs and costs². This mother is subjected to an unattainable agenda and her life is no longer important.

She becomes the protagonist of the child's rehabilitation process, having to deal with behavioral changes, communication difficulties, functional impairments, in addition to disability and social stigma. In this way, she deals with the double burden: the role of mother and caregiver of an individual who needs full-time care⁷, usually annulling herself as a woman, which leaves her fragile and vulnerable.

The disease-centered biomedical model increases the demands on family members and enhances the responsibility of smaller family units to provide care demands⁶. The fragmentation of care, excessive hospitalizations and medications are factors that generate expectations for parents, increase costs and demand a lot from children, in addition to reducing their precious time to enjoy childhood.

During prolonged hospitalizations and frequent routine consultations, the mother distances herself from other family members, generating expectations and frustrations and another stress factor for family dynamics². At this moment, the intervention of the health team is beneficial, as it implements actions that seek the biological, psychological and social balance of patients and family members³ and provide this mother with subsidies to proceed with care within her support network.

Family-centered care is of fundamental importance, as it elevates these caregivers and the family nucleus to the role of protagonists in the patient's therapy^{2,11}, thus avoiding excesses and seeking the rehabilitation of the child so that he has a good quality of life, life within its limitations, without the parents being burdened with it. It is still essential to assess the health status of caregivers, as they are an invaluable resource for the rehabilitation of the child considering long-term disabilities⁵. The purpose of this care is to promote the well-being of individuals and families and restore their control and dignity. The actions encompass not only the biological body, but also emotional, social, spiritual and developmental support¹¹.

Stress outcomes arise from the imbalance between physical well-being and mental health and the caregiver's ability to sustain their social roles. Its origin lies in the intersection between the demands imposed by patient care and the care capacity. Are associated with parental stress: behavior, temperament, severity of disability⁶. The caregiver of these children, often, understands their conditions better than the accompanying team, and it is of fundamental importance to consider their observations and accept their wishes.

Better social support is related to more efficient care management^{6,8}. Specific strategies for stress are associated with better caregiver health. The perception of how difficult it is to care for a child with disabilities may be related to depressive feelings⁶. A child who has an appointment schedule that does not allow for gaps, with excessive medication and at times that are difficult to maintain, lead to worse health conditions for the caregiver.

Support groups reduce parental stress and increase psychosocial well-being in domains such as hope, happiness, and self-esteem. It was also shown that caregivers with more knowledge meet care needs better, and actions can be taken to train these parents to care for their children, so that their expectations and fears are allayed¹².

Thus, the need to improve the quality of life and well-being of these caregivers becomes imperative, aiming at a better outcome for our children and a better quality of life for their families. It is up to the health team to identify the demands of the patient's family, in addition to their own, mobilizing possible support networks², training, qualification and guidance of these caregivers.

GOALS

Identify the demands of the caregiver of patients with special needs in relation to the health service provided.

From there, help the health professionals responsible for the assistance, in relation to the specific care that should be directed to these patients and their caregivers, focusing on the difficulties faced and on how to welcome and minimize them.

METHODS

Descriptive, cross-sectional, qualitative study, with a semi-structured interview; having as subjects the main caregiver of a child with cerebral palsy. Its relationship with the support offered to it during hospitalization of the child under its care was studied.

The interviews were recorded, in a document only with voice, after signing the term of image and sound by the subject. The identification of the caregiver in the interviews was made only by the initials of the name, so that there is no repetition of data or exposure of caregivers and patients.

As it is a qualitative research, the definition of the sample size was made by saturation of the data obtained in the interview. Data analysis was performed using the content analysis method, popularized by Bardin¹³, after transcribing the individual semi-structured interviews.

Questions addressed: How was the discovery that your child would be a special child? How did that change your life? How do you feel about the care he needs? How do you understand the picture he presents?

How do you divide your time today between this child, the other children and yourself, and between you and your

partner? What is your relationship with the health professionals who accompany your child? And how could this be different?

Inclusion criteria: 1) primary caregiver of a patient with cerebral palsy; 2) caregiver who worked at the Pediatrics Unit of the Hospital Regional do Distrito Federal.

Exclusion criteria: 1) caregiver who did not accept to sign the Free and Clarified Term of Clarification (ICF).

Twelve semi-structured interviews were carried out with a grandmother, a father and ten mothers who accompanied the child's hospitalization.

The project was submitted for approval by the Research Ethics Committee of FEPECS/SES/DF, with opinion number 3,076,491.

RESULTS AND DISCUSSION

Initial reactions related to the child's condition

"(...) and only I know what I went through at the time of [birth] and the suffering I went through. And to this day 'it's' being revolting, which 'is' happening, because he was supposed to be born with nothing, but that's how it is" (E3).

When faced with the discovery of a disabling chronic condition, the family is surrounded by doubt, uncertainty, guilt, anger and despair, seeking explanations to understand the situation and solutions that minimize the possible effects³. The news that the child will be a special child leads the family to a grieving process, with concrete and symbolic losses¹⁴.

"People never wait. (...) no one touches the belly saying they want a special baby" (E7). "A special child is not a disease. Sometimes, we are looked at with discrimination, with prejudice and this is such a natural thing. We learn so much from these children" (E6).

People with disabilities still face today, in a world of easy access to information and technology, prejudices regarding their conditions that are felt by these caregivers and that must be minimized within the health service.

Changes in personal and family routine

In most hospitalizations, as evidenced in the interviews, and even in home care, the mother is the protagonist of the care of the child with CP. This condition leads to changes in this woman's personal routine and in the family routine, creating a new family dynamics, which must take into account the fact that the mother spends more time in hospitals than at home with other children or with her spouse.

"I even got to know other mothers, so we were exchanging ideas, experiences and one was giving strength to the other" (E1).

These caregivers find in the hospital a support network that is formed from the need to exchange experiences with other mothers who go through similar situations. Some of them emphasize that they count on the help of the family, especially when they are in a home environment, but we realize that intra-hospital care has the caregiver as an agent. In the biopsychosocial model, this network of mothers, created from support groups, encourages health professionals to be moderators.

Studies show that the physical, mental and spiritual well-being of parents who have children in need of special care are different when compared to parents of children without comorbidities^{5,8,15}. The family of a child with CP has a greater financial demand, with increased expenses, at the same time that the caregiver is removed from the job market¹⁵.

Aggregate feelings

The caregiver and their personal characteristics, as well as the history shared with their care subject, social, economic and cultural contexts combine in an infinite variety of circumstances that can be factors in the generation or management of stress^{5,6}. Long-term care leads to psychological, emotional, social and financial burdens⁵.

"I try to take it the best way possible, so I don't weigh so much, because if I'm going to take care of them imagining the prognosis, I can't, so I try the best I can" (E9).

For others, the picture explained by the health team does not seem to represent the reality of the child.

"I think he can surprise, do many things that the doctors say he won't do" (E3).

There is evidence that an adequate understanding of the child's condition helps in the process of involvement with care and leads to better outcomes¹².

"Thank God, because if He gave her to us in this way, it is because we were 'prepared' to receive 'her'" (E8).

realized the importance of spirituality for adapting to this new routine, a greater sense of control in relation to events, as they influence the meaning and coping with the disease¹⁵. especially in the first moments after the discovery that the child had CP.

"We notice when she's 'fine', when 'she's' smiling, 'she's' active and everything. Sometimes she is not 'okay', she gets 'soft', starts to feel pain, these things that we notice in her" (E2).

Caring for a child with CP, who sometimes does not have verbal language, still requires understanding through non-verbal language, becoming the essential caregiver for the assessment of the child's follow-up by the health team.

The new social role

Becoming the caregiver of a child with CP introduces a new social role to this person, requiring the rearrangement of priorities and energy redirection, which can generate personal tensions and maximize reactions, usually negative⁶. There is evidence that the health of the caregiver, when impaired, is associated with worse outcomes in the child¹².

They are already mothers, wives, women and now they will also be full-time caregivers. Motherhood is in itself a time of change in routine and lifestyle, but comprehensive care demands even more from that woman.

"I myself have been let down, 'right', because then I prefer to take care of them than myself" (E9).

When asked about their comfort and well-being, the most common answer was the lack of time to take care of themselves. Many reported having to leave the job that supplemented the family income. They showed concern about the child's health only, even though their well-being was also related to the child's improvement.

Interaction with the health service

Children with CP have a higher risk of clinical comorbidities, especially those with more impairment, being more susceptible to hospitalizations and higher morbidity and mortality. They present with respiratory infections more frequently due to the characteristics of the condition, as well as gastroesophageal reflux disease and hip dislocations¹⁶.

Within the service where the interviews were carried out, we did not have, until the date they took place, an interdisciplinary team, a ward with adequate care for chronic patients, and outpatient follow-up adequate to the needs of families and children. However, when asked about the service in which they were inserted, the caregivers mentioned gratitude and a good personal relationship, reporting that there was no shortage for the children.

The approach to the relationship of these caregivers with the health professionals may have been biased when conducting the interview during hospitalization in a secondary service, but we had responses that demonstrated the need to welcome these mothers and children. However, we see with alarm the resignation of these caregivers in accepting what is offered, probably due to a lack of knowledge of what can be made available for the comprehensive care of their child, which is reinforced by the biomedical model.

Caring for a child with CP affects the mental and physical health of their primary caregivers. These are more subject to depression, anxiety, stress, muscle pain, greater financial

burden. An impaired health of the caregiver leads to a worsening of the health of the child under their care^{5,6,12}. When we change our way of looking at these children, we realize the need to offer comfort to their caregivers and their future.

CONCLUSION

The news of a chronic condition in a child, especially when it comes to the need for a full-time caregiver, leads to a re-signification of the existence of this caregiver, in addition to changes in family dynamics. This is a stressor factor that requires the health team to identify the family context, in order to guide the health care of the whole family. This caregiver is required to adapt to a new social role, for which he is not qualified, having to get rid of jobs, spend more time in hospitals for the health care of others and move away from family life for a long time. The psychosocial well-being of these caregivers is also of interest to the child's health care by improving evolution, outcomes and allowing comprehensive care.

Family-centered care makes family members the protagonists of this care, with the necessary tools to meet the demands and maintain themselves in good physical, mental, and spiritual health. It is in the interest of the health system to care for children with these conditions, considering the significant increase in the number of patients in special care.

We must always remember that the child does not stop having childhood when he has a chronic condition, becoming as important as physical health care, life outside the health service. It is necessary to improve the quality of life of the child and the family and also allow others to have coexistence and acceptance of those who are different from them.

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