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Family experiences in the care of adolescents with cerebral palsy

Vivências de famílias no cuidado de adolescentes com paralisia cerebral

Vivencias de familias en el cuidado de adolescentes con paralisia cerebral

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Abstract: Objective: To understand the experiences of families in the care of adolescents with cerebral palsy. **Method**: A qualitative, phenomenological research in the homes of five families in the Midwest region of Minas Gerais, from April to August 2017. After the approval of the research ethics committee, data was collected through semi-structured interviews and submitted to a comprehensive phenomenological analysis. **Results**: It was learned that the daily life of these families is impregnated with suffering and anguish to offer the adolescent with cerebral palsy a better quality of life. Health care is fragmented, which prevents progress in comprehensive care for this public. **Conclusion**: Adolescents with CP are considered to be poorly attended multi-professionally, and it is up to the nurse to create care strategies that can empower and support families in the search for resources available for integrality.

Descriptors: Adolescent; Cerebral Palsy; Family

Resumo: Objetivo: compreender as vivências das famílias no cuidado de adolescentes com paralisia cerebral. **Método:** pesquisa qualitativa, fenomenológica, realizada no domicílio de cinco famílias situadas na região centro-oeste de Minas Gerais, de abril a agosto de 2017. Após a aprovação do comitê de ética em pesquisa, os dados foram coletados por meio de entrevistas semiestruturadas com os familiares de adolescentes com Paralisia Cerebral (PC) e submetidos à análise compreensiva fenomenológica. **Resultados:** apreendeu-se que o cotidiano dessas famílias é permeado por sofrimento e angústia para oferecer, ao adolescente com PC, uma melhor qualidade de vida. A assistência em saúde é fragmentada impedindo avanços na integralidade do cuidado para esse público. **Conclusão:** considera-se que os adolescentes com PC estão sendo pouco assistidos multiprofissionalmente cabendo, ao enfermeiro, o desafio de criar estratégias de cuidado que possam empoderar e subsidiar as famílias na busca de recursos disponíveis visando à integralidade.

Descritores: Adolescente; Paralisia Cerebral; Família

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Resumen: Objetivo: comprender las experiencias de las familias en el cuidado de adolescentes con parálisis cerebral. **Método:** investigación cualitativa y fenomenológica realizada en los hogares de cinco familias en la región del medio oeste de Minas Gerais, de abril a agosto de 2017. Después de la aprobación del comité de ética en investigación, los datos se recopilaron mediante entrevistas semiestructuradas y se sometieron a un análisis fenomenológico integral. **Resultados:** se descubrió que la vida cotidiana de estas familias está impregnada de sufrimiento y angustia para ofrecer al adolescente con parálisis cerebral una mejor calidad de vida. El cuidado de la salud está fragmentado, lo que impide avances en la atención integral de este público. **Conclusión:** se considera que los adolescentes con PC no son bien atendidos multiprofesionalmente, y la enfermera tiene la responsabilidad de crear estrategias de atención que puedan empoderar y apoyar a las familias en la búsqueda de recursos disponibles para la integralidad.

Descriptores: Adolescente; Parálisis cerebral; Familia

Introduction

Cerebral Palsy (CP) is a set of permanent diseases that involve movement and posture causing limitation of motor activity. This is due to non-progressive disorders that occur in the fetal or infant brain during its development. Consequently, the motor disorders of cerebral palsy are often accompanied by changes in sensation, perception, cognition, communication and behavior.[1]

CP is classified according to the clinical manifestations presented in the child's first year of life categorized as: spastic, dyskinetic and ataxic.[2] In the spastic form, there is a lesion in the pyramidal system characterized by the presence of high tone (increased myotactic reflexes, clonus, cutaneous-plantar reflex in extension – Babinski's sign). This type is the most commonly identified in pre-term babies.[2] In the dyskinetic form, there is an extrapyramidal lesion, mainly in the nuclei of the cerebral base, characterized by more obvious atypical movements when the patient initiates a voluntary movement producing atypical movements and postures. It encompasses dystonia (very variable muscle tone triggered by movement) and choreoathetosis (unstable tone, with involuntary movements and associated movement). In ataxia, its occurrence is associated with cerebellar dysfunction and is characterized by a disruption of movement coordination due to dyssynergia, usually presenting a gait with increased support base and intentional tremor.[1]

The incidence of CP affects about two children per 1,000 live births worldwide, being the most common cause of severe physical disability in childhood.[3] In Brazil, according to the Department of Informatics of the Unified Health System (*Departamento de Informática do Sistema Único de Saúde*, DATASUS), the number of hospital morbidity registered by the Unified Health System (*Sistema Único de Saúde*, SUS), resulting from CP and other paralytic syndromes identified by place of hospitalization and in the range of 10 to 19 years old, it corresponds to 412,944.9 individuals. By region, incidence is broken down as follows: North, with 328.34 cases; Northeast, with 47,965.5; Southeast, with 277,311.6; South, with 33,769.53 and Midwest, with 53,569.88 individuals.[3]

However, these Brazilian data may be incomplete due to fragility in the health information system.[3] This has a direct impact on the studies on the prevalence and incidence of CP. However, these data indicate the extent of the injury, coinciding with the findings in developing countries.[3-6]

Given the above, despite the incidence of CP in the corresponding age group between 10 and 19 years old and the scarcity of studies in this area, there was a need to investigate this theme. In addition, Brazilian studies[7] involving the theme on adolescent health are concerned with reproductive issues and with the use of psychoactive substances,[6] which justifies conducting studies with adolescents facing other health problems such as CP.

In the dimension of care for adolescents with CP, it is important to consider the role of the family as the first care link. The family that has an adolescent child with CP experiences peculiar moments in their daily lives needing support and multi-professional assistance for coping and adjusting family dynamics.[8-9]

In this sense, although adolescents are accompanied since childhood in specialized centers, such as institutions for the care of children and adolescents with special health needs, it is up to the family to seek continuity of care, which can lead to intense physical and emotional overload.[9] This reality meets the international findings,[10-11] revealing that in the transition from child to adolescent care, health care naturally changes. However, there is a drastic decrease in terms of rehabilitation and follow-up in different occupational segments, showing that adolescents with CP and their family experience difficulties in accessing certain health services.

Given the above, the following research question arose: how is the experience of caring for these families in daily life? In order to understand this phenomenon, this work is justified so as to raise subsidies that may guide health actions for the professionals who work in this context, including Nursing professionals, due to their role of excellence in care. Thus, the objective of the study was to understand the experiences of the families in the care of adolescents with cerebral palsy.

Method

This is a research with a qualitative approach, which investigates problems that cannot be quantified or verified empirically through hypotheses.[12] The qualitative research emphasizes the socially constructed nature of reality seeking to study the intimate relationships of human beings and the solutions to questions arising from the lived experiences. For this, it seeks to understand the meanings attributed by the subjects about a certain issue and it interprets them.[12]

Thus, seeking to understand the family experiences about caring for adolescents with CP, the study had the phenomenology of Heidegger as theoretical framework, a philosophical current that seeks to understand the meaning of the discourse of the real experiences from attentive, directed, subjective listening, which reveals the phenomenon as it manifests itself, seeking the truth contained in the speech of the participants.[12]

The research was conducted in the Midwest region of the State of Minas Gerais from the registration data of families that have adolescents with CP and who attend an institution for children and adolescents with special health needs located in a municipality of this macroregion. This institution is a non-profit philanthropic entity, founded in 1970 to meet the demands of individuals with intellectual and multiple disabilities. Child care is multi-professional but, for adolescents, care is limited to two professional categories: physical therapy and nutrition. In the same physical space, the entity also has a school, where children and adolescents with CP are enrolled.[13]

The families identified in the register provided by that institution were the first ones invited by telephone contact. In the first contact, the mother or the primary caregiver of the adolescent was sought, when the study and its objectives were explained. In addition, the primary caregiver was asked to extend the invitation to the other family members to participate in the study, which may be the father, grandparents, uncles and/or other caregiver members of the adolescent.

For the convenience and privacy of the participants, data collection was performed at the families' homes and occurred after the approval of the Research Ethics Committee, under protocol No. 1,994,949, and after signing the Free and Informed Consent Form.

Five families of adolescents with cerebral palsy participated in the study, including those who had one or more children aged 10-19 years old, according to the World Health Organization classification, and regardless of the cause and time of CP. Families with outdated addresses and/or phones were excluded, which prevented contact for the invitation to participate in the study.

For data collection, semi-structured interviews were conducted with closed questions to identify and characterize the interviewed family members, followed by open-ended questions about the family member's experience with the adolescent from the diagnosis to the present day, questions that built a family's timeline with the adolescent, as well as the therapeutic itinerary. All families were interviewed in the home setting and the interview was a way of access between the researcher and the participants, thus allowing to internally understanding the dilemmas and questions of their experiences as subjects in a given situation.[14]

Two interviews were conducted with each family, totaling ten interviews. The time interval between the first and second interviews was one month. This period was stipulated so that the recorded interviews were fully transcribed after their completion; and also so that the family had time to organize according to their availability for the second moment of the research.

Data was initially analyzed by a floating reading of the material produced. Then, the exhaustive rereading of the collected product was performed, with the data grouped into categories based on the similar responses that met the study objectives, guided by the comprehensive phenomenological analysis.[12,14]

To ensure the anonymity of the families and adolescents, the participants were identified according to the label F1: FAMILY 1 and so on. The adolescents were mentioned according to the initial letter of their names.

The following table shows the characterization of the sample.

Family label	Family member interviewed	Initials of the adolescents' names	Age of the teenagers	PC cause
F1	Mother	L	15	Prematurity
F2	Grandfather	K	13	Pulmonary obstruction
F3	Mother	J	19	Meningitis
F4	Mother	T	15	Convulsive state
F5	Mother	C	18	Fetal distress

Chart 1: Characterization of the sample. Divinópolis, MG, Brazil,2017.

For involving human beings, this research met the criteria of Resolution No. 466/2012 of the National Health Council, and the project was approved by the Research Ethics Committee of the Federal University of São João del Rei-Midwest Campus under opinion No. 1,994,949, on April 1st, 2017.

Results and discussion

After identifying and analyzing the reality lived by these families through the speeches, it was possible to reach the understanding of the phenomenon in its subjective constitution, listing units of meaning. Thus, the first unit was built: the daily life of families and the challenges of the therapeutic itinerary, unveiled in the following speeches.

When discussing their experiences during the care of their teenage children, the families reported lack of material resources and of adequate professionals to ensure the quality of life of the family nucleus. They reported on the importance of an appropriate place for the care of adolescents with CP and of a qualified multidisciplinary team that is able to continue the treatment of the adolescent in these conditions and not only in the phase of their childhood.

> *What I say, they* [teenagers] *need care at the institution* [specific location], *I think from my point of view that* [the care] *would need to go beyond physical therapy, she* [the teenager] *would need to have an* [Occupational Therapist] *to have a little of this sensitivity, there are movements that she can't do, would need a speech therapist, the nutritionist they provided me, I don't go anymore because I have gone since she was born, so I have all the information and I follow up with the endocrinologist, that's why I don't go.* (F1. Mother)

Families believe that childhood treatment was more effective because their children were more stimulated and could count on multi-professional care. At this moment, adolescents have access to physiotherapy sessions conferring uniprofessionality in care, fragmenting care and its continuity.

> *It's just physical therapy, I think L deserved more, just like she has a need to talk, you guys realize that.* [...] *But then there it is, after they get moving and they start doing more, I think they could demand a little more, not lessen the service as they did. When he is a child, he has more specialty, more physical therapy. Ah, L. can already do it, walk, she can dance, but she could do more. She can conquer other moves she still doesn't make* [...] *So, I think teenagers are left a little aside.* (F1. Mother)

> *He came in with five months* [at the institution]*, he did the physiotherapies. Yes, we came two to three times a week* [...] *I come all the same, there was the occupational therapist, the speech therapist, the other things and everything.* (F2. Grandfather)

> *I'm not coming with him because he can't afford it. Where I live, I take almost an hour by van from here to there and almost another hour to get back. So to come here and stay 25 minutes and you know ay what times? I have to be here seven o'clock in the morning.* (F2. Grandfather)

> *She was having there from* [institution]*, as J. studies in the morning, she was going to continue treatment with physical therapy, but it was in the afternoon and for me to go in the afternoon for her to do physical therapy because there is half an hour, then, for me, it is not possible, by bus* [break]*, let's suppose they make an appointment with us, so, okay, then, at one thirty she'll be released, then there's no way I can go home, then I'll have to stay there from one thirty to five o'clock.* (F3. Mother)

In all families, the children attend the entity, which provides physical therapy for adolescents. However, they complain about the duration and the frequencies, as the sessions are offered to the user every fortnight, lasting 30 minutes. This reality becomes a challenge for families who need to move from other municipalities or distant neighborhoods for care, which takes time and financial resources to perform the therapeutic itinerary.

The physical therapy treatment aims to encourage children or adolescents with CP to take control of their movements by modifying or adapting them. However, family members need to be monitored to perform stimuli based on their abilities and the earlier the physical therapy intervention is started, the better the response and motor acquisition.[15] But the continuity of comprehensive care for adolescents with CP is not limited to this professional, it requires multidisciplinary care with access to medical consultation, Nursing consultation and procedures, care with therapists and speech therapists, and continuous monitoring of primary care, home visits, appointments and referrals to other professionals prevailing, at different levels of health care, according to their biopsychosocial needs.[16]

Internationally, several studies[10-11] reveal that adolescents with CP suffer limitations in primary health care and that the available financial resources are insufficient, impacting on the routine of those families who need to seek informal services to subsidize treatment. However, access to specialized Brazilian services is also limited due to the lack of human and material resources for care which, according to the National Health Policy of the person with a disability,[6] defines that care should be guaranteed, ranging from disease prevention to health protection supporting their rehabilitation and contributing to the promotion of quality of life.

The families point out that there are no activities aimed at adolescents with CP and other disabilities in the scenario of this study. They request the participation of other professionals who work in the entity to continue the treatment of their adolescents with CP, but there is no effectiveness as specified in the statements.

> *L. does physical therapy half an hour every 15 days, I think she would need more physical therapy, occupational therapy. I think demanding a little more from my daughter would give her a better return, she would grow more as a person, grow more as a teenager. I think there is a little something missing of [institution] there, to make an agreement with physiotherapy, speech therapy, occupational therapy, nutrition* [...] *So it may be more accompanied, it may be better.* (F1. Mother)

Another note made by the families refers to the drug treatment provided by the SUS. All the families use the popular pharmacy. Some of these drugs are lacking for the treatment of adolescents, and the caregivers deploy to acquire the drugs in the private network, which goes against the right established by the Child and Adolescent Statute (*Estatuto da Criança e do Adolescente*, ECA), Law No. 13,257, of March 8th, 2016,[17] which ensures specialized care for adolescents with disabilities, and the government is responsible for providing medications, prostheses and other resources related to the treatment.

> *Yeah lately* [it is] *missing everything because even the medication is missing. We have to buy the medication because we are not having it.* (F2. Grandfather)

Another relevant fact was the lack of accessibility of the basic health units, something commented with feelings of anger because, when taking their wheelchair-dependent child to the medical appointments, the family members are faced with a series of stairs. Not only has this been reported, but also the poor pavement conditions leading to the difficulty of driving the chair to the unit. The families also report with sadness that they seek alternatives for treatment and assistance in other places, due to these difficulties of physical structure and human resources.

Regarding the geographical accessibility of the units, the difficulty for accessing the services is observed, mainly due to the inadequate distribution of the Family Health Strategies (FHSs) within the territory, with a large distance between the users' residence and the health services, as well as the presence of hills and staircases. When units are far from the users' homes and they cannot afford public transportation, it becomes a hindrance to follow the recommended treatment causing the problem to be unresolved,[18] according to the following statements:

> *The problem is the street* [...]*. The problem there is the street that gets hard to climb the chair.* (F4. Mother)
>
> *But to the pediatrician proper I never took there because* [...] *How are you going to take a wheelchair in a health center with the doctor's room upstairs and it doesn't have a ramp, there are only stairs?* (F2. Grandfather)

From the reports of the interviewed families, it is clear that there is an overload of the main caregiver. All interviewees are the main caregivers and the other family members perform secondary activities such as feeding aids and helping to take them to the bath. These family members do not actively participate in the care of adolescents with CP. In this sense, most caregivers refer to the need for extreme dedication to the care of their adolescents, requiring the abdication of free time, daily activities and, in most cases, the abandonment of professional activities.

> *And, I'm not* [I am] *realizing I can shower him more in the shower every day because not every day my brother can help me.* [...] *I take care, I feed him, he takes pediasuremilk, which is that of soy, and I give fruit vitamin, I give* [...] *vegetable soup with vegetables, rice, I try to plant the vegetables in my house.* (F2. Grandfather)
>
> *He* [dad] *takes care of her there, but here at home, bathing, changing these things is just me.* (F3. Mother)
>
> *For me, as I've been used to for many years, I find it easy, very easy to take care of him. But, so, there is my husband who helps me, but it is very little. Not because you don't want to, but because of the service, you have to work. And my daughter, who always gives me strength, but most of the time I take care of myself.* (F5. Mother)

Little is known about the functionality of families in relation to the overload and the division of the routine activities. It is evident that a person with a disability entails non-existent demands in the typical family context, but the research studies do not reveal what is actually done in these families as activities and distribution of functions.[19-20]

Faced with the demands in the care attributed by CP, perceived throughout the growth and development of the child to the adolescence phase, the families undergo a transformation and their members dedicate themselves more intensely to care.[21]

In light of the phenomenological framework,[12,14] this study points out that the truth revealed by the interviewees - their experiences - reflects a scenario of families providing care to adolescents with CP, vulnerable to the fragility of the health care network that should subsidize and support them in their demands. Consequently, the burden of the main caregiver is observed, which becomes adequate in a daily life marked by uncertainties.[22] They become responsible for the main care, being responsible for the disease, and leave their social lives to perform the care.

The Heideggerian analysis allowed to infer that families feel helpless before the needs of adolescents dependent on special care. The family-being experiences what it is to take care of another person, depriving themselves of their own life, having to be with the other responsible for the continuity of health care at home. Thus, questions arise about the condition of having a child with CP who needs primary health services, constituting here the second meaning unit: primary health care *versus* integrality of care.

CP is a chronic disease such as diabetes mellitus and hypertension. Therefore, you need some special health and treatment services. Thus, the chronic disease interferes with the development and growth of the child and adolescent, who requires family and professional assistance.[19]

According to Law 8,080/90, the SUS guarantees health for all and is governed by the following doctrinal principles: equity, universality and completeness.[23] In this context, one of its public policies is primary care known as the "gateway" of users into the health systems, that is, the initial care aims to guide the prevention and promotion of diseases, solve the possible cases, and refer the most severe ones to higher levels of care in complexity.[23] The families with chronically ill members require a qualified care offered by primary care professionals, who assist as a supportive care network in order to address the demands for a comprehensive care.[24]

The adolescents with CP need a care network properly articulated in the perspective of sharing care between the health teams and the family and in the best strategies for the development of a quality therapeutic project involving all aspects of their health.[3]

When discussing their experiences during the treatment of their children, the interviewed families mentioned the failures in the assistance of the primary health care units, such as the lack and delays in the specialized medical consultations, the support of the Family Health Care Center, which offers physiotherapy professionals, a physical educator, a psychologist, a speech therapist and a nutritionist, as well as Nursing consultation and assessment and visits by Community Health Agents. Children and adolescents with chronic disease, such as CP, need a demand of professionals who integrate continuous and effective care to improve quality of life.[24]

The international study[11] conducted with caregivers of CP patients revealed that, for effective care and in the perception of parents, the health professionals need to have a good communication with the family, devoting more time to information and clarification of doubts that arise during the management with the adolescent in special health conditions.

In this sense, the families report that their children with special health needs are not adequately assisted by the FHSs in their coverage territories and only attend these network spaces to be vaccinated and obtain some material resources for the care of the adolescent child with CP. Thus, they emphasize that:

> *Nothing in the station, only when you need the vaccine, see only the same child, so when I took her, have a long time.* (F3. Mother)

> [They are] *the vaccines and the materials I use on him and I take him there. It's little gauze, probe, the syringe to give the diet.* (F2. Grandfather)

In addition, it is important to highlight the need for home care, which can be performed by any member of the multidisciplinary team and which is an important assistance to the individuals unable to travel to the unit. According to the interviewees' reports, it was noticed that there is a lack of home care in the studied scenario, as they informed that they never received visits and orientations in their homes even in the face of the condition of CP, which prevents the displacement to the service due to their motor impairment presented by changes in movement, posture and balance making it difficult to walk, which configures a disregard for this population, fragmenting care.

> *This issue of having a nurse, many people ask me this: "Does the nurse go to your house?" Never came a nurse to say: "We know you have a child and we came to assist." No! Never came no!* (F3. Mother)

The statements reveal the distancing of an individualized care for these families:

> *I had these things* [wound] *but when I asked* [home visit] *it was already like that, even bigger! Because I was taking care of myself at home.* (F4. Mother)

> *I requested* [home visit]*, but they only came once and never again, until I will demand.* (F5. Mother)

The phenomenological understanding[12] from the experience of these families allowed to identify that adolescents with CP present many challenges. In addition to their dependence in different levels, there are family problems to be faced such as: family routine and their functions in the organization of home care, as well as the need to rely on the organization of the services that serve them. These findings were also found in a study conducted in England,[25] which reinforces that the complexity of these adolescents' needs has to be underpinned by more effective services that can reduce major complications resulting from cerebral palsy.

Another study[20] pointed out that there is lack of continuity in primary, secondary and tertiary care in the care of children and adolescents with CP; there is a gap in primary health care causing discontinuous and fragmented care, supporting the data found in this research. There is a great need for an intense follow-up, valuing the singularities of each adolescent in the family context, establishing a strong relationship between the family and health services that favors a shared and integral care process.[10]

Final considerations

In this study, it is considered that adolescents with CP are not being adequately assisted due to the lack of articulation of the health care network with the focus on adolescent care with this profile. This reality brings a movement of care centered only on the families, overloading them. The families get lost in this process of care and feel helpless in care believing that primary care is only for the realization of vaccines and for the search of material resources for timely and non-integral home care.

In addition, secondary care, offered by the institution in the municipality studied, is limited and inarticulate with primary care focusing on care in early and second childhood and neutralizing care in the figure of some professionals who provide isolated monitoring to adolescents with CP, which generates dissatisfaction among the families. It is noteworthy that fragmented and discontinuous care is present, profoundly marking the experiences of these families, who have a daily life altered by the chronic disease of their adolescents and who need an effective support network that can fully attend both the teenager and their family.

It is worth stressing the importance of multi-professional care in the health care network for this public and how nurses can act in their practice scenarios, with significant implications through personalized actions for these adolescents and their families, through strategies of care that can empower and support the search for resources available by right in order to provide a better quality of life for their children with CP. Therefore, this study suggests new research studies on the theme that can leverage reflections and actions to achieve integrality in the care for the adolescent with CP.

The limitation of this study is related to not allowing the generalization of results in view of the limitation of the sample group and the non-diversity of the interviewed family members.

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