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Self-care and quality of life of mothers or informal caregivers of children and adolescents with Cerebral Palsy

Self-Care and Quality of Life of Mothers or Informal Caregivers of Children and Adolescents with Cerebral Palsy

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Summary

This study aimed to investigate the relationship between mothers or informal caregivers of children and adolescents with Cerebral Palsy and their self-care practices, seeking to understand how the care routine influences their physical, emotional, and social health. This is a cross-sectional, descriptive field study conducted with 21 caregivers of children and adolescents with Cerebral Palsy treated at a medical clinic linked to the Unified Health System (SUS) in the city of Marília (SP). Data collection was carried out using a structured questionnaire composed of 33 questions, organized into sociodemographic, physical, social, and emotional categories. The results indicated that most participants dedicate themselves full-time to the care of the dependent and do not have paid employment. A high frequency of body aches, sleep deprivation, and feelings of tiredness or discouragement were observed. In the social and emotional sphere, it was found that most caregivers do not have regular rest periods and do not receive psychotherapeutic support, although a large proportion showed interest in accessing this type of support. The findings highlight the burden experienced by these women and the difficulty in incorporating self-care practices into their routine. It is concluded that it is essential to expand attention to the health of caregivers within the context of health services, recognizing them as an essential part of the care process and promoting support strategies that favor their physical and emotional well-being.

Keywords: Self-care; Cerebral Palsy; Informal caregivers.

Abstract

This study aimed to investigate the relationship between mothers or informal caregivers of children and adolescents with Cerebral Palsy and their self-care practices, seeking to understand how caregiving routines influence their physical, emotional, and social health. This is a cross-sectional field study with a descriptive approach, conducted with 21 caregivers of children and adolescents with Cerebral Palsy treated at a medical outpatient clinic linked to the Brazilian Unified Health System (SUS) in the city of Marília, São Paulo. Data collection was carried out using a structured questionnaire consisting of 33 questions organized into four categories: sociodemographic, physical, social, and emotional aspects. The results indicated that most participants dedicate themselves to caregiving on a full-time basis and do not engage in paid work. A high frequency of physical pain, sleep deprivation, and feelings of fatigue or discouragement was observed. In the social and emotional domains, most caregivers reported not having regular moments of rest and not attending psychotherapy, although many expressed interest in receiving psychological support. The findings highlight the burden experienced by these women and the difficulty of incorporating self-care

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practices into their daily routines. It is concluded that expanding health care attention to informal caregivers is essential, recognizing them as a fundamental part of the care process and promoting support strategies that contribute to their physical and emotional well-being.

Keywords: Self-care; Cerebral palsy; Informal caregivers.

1. Introduction

The aim of this study is to investigate the relationship between women responsible for Care for children and adolescents with cerebral palsy and their self-care practices. A The motivation for this research arose from my experience during a hospital psychology internship. conducted at an institution that works in the diagnosis and treatment of children and young people with Paralysis. Cerebral.

During the internship, it was possible to observe and support mothers and other female caregivers (such as Grandmothers, stepmothers, and aunts) who accompany these patients in their daily care routine, assuming They often play the role of informal caregivers. In moments of listening and support, these Caregivers frequently reported situations of overload, body aches, and lack of... Moments dedicated to self-care in their routine.

Given this context, the need to investigate how these [actions] became evident. Women engage in self-care practices, seeking to better understand their routines and... Demands associated with the ongoing care of children and adolescents with Cerebral Palsy. Analyzing these experiences allows for a broader understanding of the physical and emotional impacts. and social experiences lived by these caregivers. In this sense, the present study has the general objective of... To investigate the relationship between mothers and female caregivers of children and adolescents with Paralysis. Cerebral self-care practices, seeking to understand how these practices can influence your physical and mental health.

2. Theoretical Framework / Results

2.1 Cerebral Palsy: risk factors, diagnosis and rights of people with disabilities

Cerebral palsy (CP) is a disability usually identified before the first few years of life. eighteen months of the child, characterized by permanent neurological changes that affect the Motor development and, often, cognitive development are affected. These changes involve difficulties. related to movement, body posture, and dysfunctions in the central nervous system. Children People with cerebral palsy may present with early clinical manifestations, such as motor and postural difficulties. different from what is expected for the developmental stage between three and five months of age (Ministry Ministry of Health, 2014).

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The condition can result from brain injuries that occurred during the prenatal, perinatal, or in early childhood — a phase of brain development — potentially leading to neuromotor deficits. and/or mental (Petean; Murata, 2000). According to Rotta (2002), risk factors in the prenatal period These include infections and parasitic diseases, exposure to radiation, trauma, and maternal factors, such as Chronic diseases, severe anemia, malnutrition, and advanced maternal age.

In the perinatal period, chronic asphyxia stands out, which occurs during gestation and can result brain damage can occur even when the newborn has good vital signs. (Rotta, 2002). In the postnatal period, triggering factors include traumatic injuries to brain damage during childbirth and brain infections (Leite; Prado, 2004). Assis-Madeira and Carvalho (2009) They emphasize that, in addition to biological factors, social and environmental factors also exert influence. in the development of the condition.

US statistics indicate an incidence of one case of Cerebral Palsy every every 5,000 live births (Fonseca; Lima, 2008). In developing countries, however, the incidence The rate tends to be higher, which is attributed to poor prenatal care and treatment conditions. to pregnant women (Ministry of Health, 2014). In Brazil, the estimated incidence is... approximately 7 cases per 1,000 live births (Santos; Farias; Neves, 2023).

Cerebral palsy can be classified according to the type and location of the impairment. motor impairment, which may be spastic (quadriplegic, hemiplegic or diplegic), dyskinetic, ataxic, hypotonic or mixed (Fonseca; Lima, 2008). In addition to motor impairments, people with CP may presenting associated deficiencies in the mental, auditory, and visual areas, in addition to difficulties related to communication, learning and social interaction (Petean; Murata, 2000).

It is estimated that around 88% of children with Cerebral Palsy have difficulties with communication. Among other observed symptoms are postural difficulties, muscle contractions involuntary movements of the facial muscles, changes in muscle tone (hypotonia or hypertonia), delay significant motor impairment and difficulties in motor coordination (Pereira, 2018).

In the context of social rights, the Statute of Persons with Disabilities guarantees to people with disability — including those with Cerebral Palsy — fundamental rights such as Accessibility, assistive technology, accessible communication, housing, school support, services. priority, equality and non-discrimination, as well as access to health, habilitation and rehabilitation and to a inclusive education system (Federal Senate, 2019).

Access to the Continuous Benefit Payment (BPC-LOAS) is also guaranteed, as provided for in the law. Article 20 of Law No. 8.742/1993 guarantees a monthly minimum wage to people with disabilities. or to an elderly person who proves that they do not have the means to provide for their own maintenance nor have it provided by your family (Chamber of Deputies, 2013).

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2.2 The impact of the diagnosis: challenges and expectations of caregivers

The moment of communicating the diagnosis is often a delicate one for families. Many Sometimes parents are not prepared to receive this news, and healthcare professionals may use technical language that is difficult to understand, which hinders the comprehension process and sensitivity to the suffering caused (Silva; Ramos, 2014).

The revelation of a diagnosis of Cerebral Palsy represents more than just information. It's not a medical event, but an event that redefines family expectations and alters the dynamics of their lives. responsible. This moment often generates insecurity and fear, especially for the mother, who She usually assumes the role of primary caregiver. In this context, the meaning of life for many Mothers begin to organize themselves around the care of their child (Smeha et al., 2017).

By understanding the diagnosis, the family—especially the mother—can experience a The symbolic mourning process for the loss of the idealized child (Oliveira; Matsukura, 2013). This mourning This refers to the disruption between previously established expectations about the child's future and the... reality presented by the diagnosis.

Another frequent challenge relates to the absence of other people who can share the Care. Thus, the role of caregiver often emerges as an obligation, and not as a... life choice. The emotional charge present in the relationship between mother and child directly influences this. function, which can oscillate between feelings of obligation and gratitude (Braz; Ciosak, 2009).

This reality can generate high levels of stress in caregivers, who frequently They face physical and emotional overload, highlighting the need for institutional support. family and professional support to ensure both the quality of life of the person with a disability and emotional health of the caregiver.

2.3 The dynamics of care: caregivers and the reality of care in Cerebral Palsy

Family members often feel fear and insecurity in the face of the fragility of a child with Cerebral palsy, which requires time to adapt to the demands of care. In this process, the Support from family and healthcare professionals becomes essential to assist caregivers in... to face the challenges imposed by disability in family dynamics (Dantas et al., 2010).

Cultural expectations related to gender roles also influence the The distribution of caregiving leads to women predominantly assuming this role. Many caregivers dedicate themselves intensely to the care of their children, often exceeding their own limits. their own physical and emotional limits for the benefit of the child and the family (Souza et al., 2007).

This overload can result in health problems, such as fatigue, irritability, and

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Feelings of guilt. For this reason, it becomes essential that the healthcare team and support network... Women should develop strategies that promote quality of life and the maintenance of health. of these caregivers.

Furthermore, many mothers face situations of social and family prejudice, as well as feelings of self-blame related to the socially constructed idea of motherhood and normality. The new reality imposed by disability requires emotional, structural and... significant financial burdens, falling primarily on the mother caregiver (Ribeiro et al., 2016).

Studies indicate that mothers of people with disabilities often give up aspects of their lives. She gave up her personal and social life to dedicate herself to caring for her son, adopting a new way of life. in light of this reality (Fernández-Alcántara et al., 2013).

Research also indicates that these mothers face significant changes in their lives. professional and financial demands, in addition to having reduced free time due to caregiving requirements. Consequently, there is a reduction in access to culture and a decrease in social interactions (Viera). et al., 2008).

According to the World Health Organization, self-care involves the ability of individuals, families, and communities to promote their own health, prevent disease, and cope with health conditions or disability, with or without the support of health professionals (WHO, 2021).

3. Materials and Methods

This research is characterized as a cross-sectional field study, with an approach... descriptive study, conducted with caregivers of children and adolescents with Cerebral Palsy treated at Medical clinic affiliated with the Unified Health System in the city of Marília-SP, offering Multidisciplinary care, encompassing the areas of medicine, physiotherapy, nutrition, psychology, Dentistry and physical education.

As a theoretical support step for the development of the data collection instrument and for the To interpret the results, a literature review was conducted on the topics of motherhood, Care, Cerebral Palsy and self-care. This survey was conducted in the databases. Google Scholar and SciELO, as well as guidelines and technical notes from health organizations, considering Publications in Portuguese, Spanish, and English.

For the purpose of conducting the field research, a data collection instrument was defined as... A structured questionnaire, composed of closed-ended questions with pre-defined answer options. totaling thirty-three questions. The questionnaire was designed to address the relationship of caregivers with the ability to care for themselves, considering that this practice is related to the concept of self-care (Girondoli; Soares, 2023).

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For the purposes of organizing and descriptively analyzing the collected information, the questionnaire was... divided into four categories: sociodemographic data, physical aspects, social aspects, and aspects emotional.

The selection of the categories that make up the questionnaire took into consideration what the The Ministry of Health (2021) points to the World Health Organization's definition of health. (WHO), understood not only as the absence of disease, but as a state of complete physical, mental, and social well-being. Therefore, the questions aimed to provide an overview of The presence of self-care in the routines of these caregivers, considering different dimensions of their lives. lives and the time commitment required to care for a person with Cerebral Palsy.

The questionnaire was sent to three female professors at the University of Marília with the following qualifications: Masters or PhD holders, with the aim of evaluating the clarity of the questions and identifying possible biases. that could influence the participants' responses. After this review, the questionnaire, Along with the Informed Consent Form, it was submitted to the Research Ethics Committee (CEP) by Plataforma Brasil and approved for the research to be carried out under the opinion number 6,726,397.

The invitation to participate in the research was made in a welcoming and non-invasive way to the caregivers of children and adolescents with Cerebral Palsy. At that moment, the participants were informed regarding the objectives of the study, the content of the questionnaire questions, and the possibility of withdrawing. they could participate at any time, should they wish, in addition to reading and signing the Informed Consent Form (ICF). In cases involving illiterate women, the ICF was read aloud by the researchers. In all cases, the questionnaire questions were asked by the students and the answers recorded. by the researchers, with the aim of standardizing the application of the instrument and ensuring participation. of women with different levels of education. The questionnaire was answered by a total of twenty-one caregivers.

Because this was a cross-sectional study, the data were collected at a single point in time with the participants, allowing them to describe aspects related to the self-care of caregivers in context investigated.

The data obtained through the questionnaire were organized in a descriptive manner and presented in tables, allowing visualization of the distribution of responses among the participants. For the presentation of the results, among the four categories of the questionnaire were The questions considered most representative of the investigated phenomenon were selected, being 06 questions regarding sociodemographic aspects, 4 related to physical aspects, 2 about the social aspect and 3 relating to the emotional aspect.

The complete questionnaire consisted of 33 questions; after the analytical selection, the following remained. 15 questions, the results of which will be presented and discussed. The selection of these questions sought to

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highlight the most relevant data to understand the relationship between the care provided by participants and the self-care practices in their routines.

The interpretation and discussion of the results were carried out in light of the scientific literature on the subject. Motherhood, caregiving, cerebral palsy, and self-care, based on studies. identified in the literature review previously described.

4. Results and Discussion

Table 1 presents the respondents' answers to the sociodemographic category questions. from the questionnaire. The responses to the question "What is your age?" show that 03 (14%) of Those responsible are between 20 and 29 years old, 6 (29%) are in the 30 to 39 age range, and 9 (43%) are between 40 and 29 years old. and 49 years old and 03 (14%) are between 50 and 59 years old, with no participants who opted for the “60” option. "years onward."

Regarding the question "What is your marital status?", 6 (29%) of the participants declared themselves single, 10 (48%) married, 2 (9%) divorced, 3 (14%) chose "other" and none The participant selected the option "widow".

Regarding the question "How many people are you responsible for caring for in order to carry out..." activities of daily living?”, 03 (14%) of the women chose the answer “Only my child’s” with Cerebral Palsy”, 04 (19%) stated “02 people”, 06 (29%) answered “03 people”, 08 (38%) indicated “04 or more” and no participant chose the response “I am not responsible” "for care."

When asked about “How many hours a day do you dedicate to caring for this child/adolescent?”, 02 (10%) of the interviewees stated that they dedicate an “Average of 5 to 6 hours daily”, while 19 caregivers (90%) reported dedicating themselves full-time. None The participant chose either the answer "Up to 4 hours" or "Average of 7 to 8 hours per day".

Regarding the question "Are the treatments performed in the same city where you live?", There were 13 responses (62%) indicating "No", while 8 (38%) stated that the treatments They occur in the same city of residence.

Finally, regarding the question "Do you engage in any for-profit activity?", 14 (67%) responded “I do not practice”, 4 (19%) answered “Yes, independently” and 3 (14%) stated they practice. Paid activity that is formally registered.

The sociodemographic data collected reveal a significant profile of the caregivers, highlighting the predominance of women between 40 and 49 years old (43% of the sample) and the burden of responsibilities, evidenced by the fact that 90% of the caregivers interviewed stated that they dedicating full-time care to a child or adolescent with Cerebral Palsy, which may

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to indicate high physical and emotional demands associated with caregiving.

Furthermore, the absence of profitable activities for 67% of those responsible is a number significant, which may be related to the high level of care required in their daily lives. women. This data is relevant, since, as pointed out by Vieira et al. (2008), the diagnosis Having a child can imply significant financial and professional changes for mothers of young children. with Cerebral Palsy.

The fact that 62% of caregivers need to travel to other cities to perform Treatment of their dependents highlights another facet of accessibility challenges, which can involving difficulties related to transportation offered by municipalities, such as availability of vans adapted for wheelchair users, in addition to travel time and distance traveled for access to health services.

In summary, the analysis of sociodemographic data points to a complex life scenario. of caregivers of children with Cerebral Palsy, marked by multiple responsibilities and demands. These findings suggest the importance of health professionals and policymakers Public policies should take these characteristics into account when developing support and intervention strategies. aiming to improve both the care provided to the children and the well-being of the caregivers themselves.

Table 2 presents the data relating to the physical category of the participants. For the question "Do you do physical activity?", 4 (19%) reported "Yes, more than once a week", 2 (9%) They said "Yes, once a week", 1 (5%) responded "Yes, fortnightly", while 14 Participants (67%) stated that they did not engage in physical activity.

In response to the question "Do you feel pain or discomfort in your body?", 12 (57%) answered "Yes, very frequently in the last month", 4 (19%) reported "Yes, with average frequency in last month", 3 (14%) reported "Yes, with low frequency in the last month", and 2 (10%) said "No".

Regarding the question "Have you been feeling discouraged, down or lacking energy?", 14 (67%) reported "Yes, frequently", 4 (19%) reported "Yes, rarely" and 3 (14%) of the participants They said "No".

Finally, the question "How many hours of sleep do you get per night?" was asked, in which 8 (38%) of those who responded "Up to 4 hours", 9 (43%) said "An average of 5 to 6 hours" and 4 (19%) reported "An average "7 to 8 hours."

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Table 01 - Sociodemographic Aspects

Área Sociodemográfica						
Variáveis	**Categoria e frequência (n)**					
Idade	Opções de Resposta:	20 a 29 anos	30 a 39 anos	40 a 49 anos	50 a 59 anos	60 anos em diante
	Nº total: 21	3	6	9	3	0
Estado Civil	Opções de Resposta:	Solteira	Casada	Viúva	Divorciada	Outro
	Nº total: 21	6	10	0	2	3
Responsável pelo cuidado de quantas pessoas para realizar atividades	Opções de Resposta:	Não se responsabiliza	Somente da pessoa com PC	02 pessoas	03 pessoas	04 ou mais pessoas
	Nº total: 21	0	3	4	6	8
Horas por dia você dedicadas ao cuidados da criança ou adolescente com PC	Opções de Resposta:	Até 04 horas	05 a 06 horas diárias	07 a 08 horas diárias	Tempo integral	
	Nº total: 21	0	2	0	19	
Tratamentos são realizados na cidade em que reside	Opções de Resposta:	Sim	Não			
	Nº total: 21	8	13			
Atividade lucrativa	Opções de Resposta:	Sim, de forma autônoma	Sim, de forma registrada	Não exerço		
	Nº total: 21	4	3	14		

The data presented in Table 2 reveal relevant information about the physical health of responsible. When analyzing the question "Do you do physical activity?", it is observed that only 33% of the participants reported engaging in some type of physical activity, while the majority stated they did not. to carry out such practices. This data is relevant because the absence of physical activity can have an impact negatively impacting health, especially in contexts of high levels of responsibility.

According to Manoel et al. (2013), care-related burden can act as an important physical and emotional stress factor.

From a physical standpoint, the intense caregiving schedule can make self-care more difficult. incorporated into the routine, often leading to an awareness of the importance of exercising, even though the Daily circumstances make it difficult to carry out this practice.

When asked about the frequency of pain or discomfort in their body, 57% of Caregivers reported experiencing pain very frequently. This high incidence may be associated with demanding care routine, in which many of them assume a large part of the responsibilities. related to the care of the dependent person.

These challenges also appear to have repercussions on emotional well-being, considering that 86% Those in charge reported feeling discouraged, downcast, or lacking energy at some point. Therefore, a possible relationship can be observed between physical overload, the presence of body aches and Emotional exhaustion can make self-care practices even more difficult.

Furthermore, the quality of sleep in these women is reduced, since a large Some of the participants reported sleeping only a few hours per night. Sleep deprivation can contribute to Symptoms such as irritability, fatigue, and difficulty concentrating negatively impact both Both physical and emotional health.

Given this scenario, it becomes pertinent to reflect on attention strategies also aimed at...

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to caregivers, considering that they play a central role in the daily care of their dependents.

In this sense, health services could consider creating welcoming spaces and guidance for caregivers, especially during times when children and adolescents are in customer service. Such initiatives could include active listening, guidance sessions, or even Psychoeducational activities, contributing to a broader understanding of self-care and health.

Table 02 - Physical Aspects

Área Física					
Variáveis	**Categoria e frequência (n)**				
Atividade Física	Opções de Resposta:	Mais de uma vez na semana	Uma vez na semana	Sim, quinzenal mente	Não
	Nº total: 21	4	2	1	0
Dores e desconfortos corporais	Opções de Resposta:	Com muita frequência no último mês	Frequência média no último mês	Baixa frequência no último mês	Não
	Nº total: 21	12	4	3	2
Desânimo ou baixa energia	Opções de Resposta:	Sim, com frequência	Sim, poucas vezes	Não	
	Nº total: 21	14	4	3	
Horas de sono por noite	Opções de Resposta:	Até 04 horas	05 a 06 horas	Média de 07 a 08 horas	
	Nº total: 21	8	9	4	

Table 3 presents the data on the social category of the participants. For the question "You Do you usually have practices in your routine that involve taking care of your appearance? (Like getting a haircut, going out) to the beauty salon, to get their nails done, to buy an accessory), only 01 (5%) of the responsible of the following responded “Yes, daily”, 7 (33%) said “Yes, weekly”, 6 (29%) chose the option “Yes, monthly” and 07 (33%) answered “No or very rarely”.

Next, the question was asked, "Do you have a network of close people who help you?" in the responsibilities of your child?”. Among the interviewees, 7 (33%) said “No, I am the responsible for my child's needs”, 12 (57%) responded “Yes, however I am the responsible for most of my child's needs” and 02 (10%) responded “Yes, we share "My child's needs."

The data presented in Table 3 reveal important aspects about social life and the

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Self-care practices of caregivers of children with Cerebral Palsy. The question about routine. A survey of appearance care shows that only 5% of participants claim to incorporate these practices. daily self-care routines, which suggests that this type of personal care does not occupy a central place in routine of most of the interviewees.

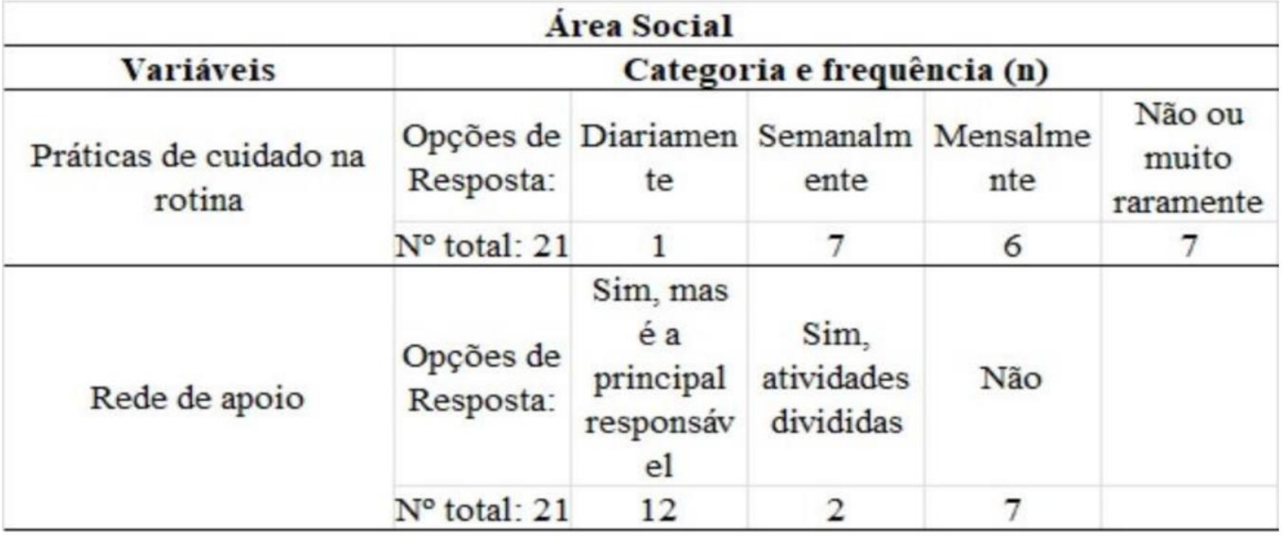
Based on this data, it is possible to reflect again on the term presented by Ayes et al. (2020), called “Caregiver Syndrome”, in which the overload of responsibilities can make causing the caregiver to stop dedicating time to their own self-care, due to the overload of Care. This concept seems to resonate with the findings of the present study, since, at the same time At a time when only 5% of caregivers reported having daily self-care practices, Table 1 shows that 90% of them dedicate themselves full-time to childcare or Teenager with Cerebral Palsy.

Taking care of one's appearance, although often socially interpreted as something Secondary well-being can represent an important aspect of self-esteem and subjective well-being. Thus, The absence or reduction of these practices may indicate limitations of time, energy, or resources. resulting from the intense care routine.

Regarding the support network, the majority of participants (57%) report having someone who helps them. in terms of responsibilities, but still considers herself primarily responsible for the needs of son. This data suggests that, although some level of support exists, most of the responsibilities It remains focused on the figure of the primary caregiver, usually the mother.

Only 10% of caregivers stated that responsibilities are effectively divided. This highlights the concentration of care on a single person in most cases. Furthermore... Of these, 33% of the participants stated that they did not have any support network. The absence of support social services can intensify the burden experienced by these women, as they limit access to It lacks emotional and practical resources and makes it difficult to find moments of rest or self-care.

Table 03 - Social Aspects



Área Social					
Variáveis	**Categoria e frequência (n)**				
Práticas de cuidado na rotina	Opções de Resposta:	Diariamente	Semanalmente	Mensalmente	Não ou muito raramente
	Nº total: 21	1	7	6	7
Rede de apoio	Opções de Resposta:	Sim, mas é a principal responsável	Sim, atividades divididas	Não	
	Nº total: 21	12	2	7	

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Table 4 presents the data for the emotional category of the questionnaire. For the question "You Do you have moments of rest away from your child in your routine?", none (0%) of the caregivers chose the option "Yes", 4 (19%) answered "Sometimes" and 17 participants (81%) answered "No".

Regarding the question "Do you undergo psychotherapy?", none (0%) of the respondents answered. answered "Yes", while 21 participants (100%) stated that they do not conduct follow-up. psychotherapeutic.

Finally, the question "If not, would you like to do it?" was asked, in which 6 (29%) of the caregivers responded. 15 participants (71%) responded "No", while 15 participants stated that they would like to carry out psychotherapy.

When observing the data from the emotional category, the question about rest periods reveals 81% of participants reported that they were unable to step away from their responsibilities to moments of rest, which may indicate a significant emotional overload. According As pointed out by Smeha et al. (2017), the overload of responsibilities associated with caregiving can This makes mothers more susceptible to emotional difficulties, reinforcing the importance of paying attention to this. phenomenon..

Furthermore, all participants in the study (100%) stated that they did not undergo psychotherapy. which may indicate difficulties in accessing mental health services or limitations related to time available to seek this type of support. At the same time, it is observed that 71% Of the caregivers, some expressed interest in undergoing psychotherapy, suggesting the existence of a potential demand for this type of support.

Given this, one can discuss the importance of considering integrated care services. especially considering that 90% of those responsible stated that they dedicate themselves full-time to care for their dependents. One possibility would be offering psychological support to them. caregivers in the very locations where the children or adolescents receive their treatments, allowing the caregiver to access care while the dependent receives it. psychological support. This strategy could reduce difficulties related to displacement and need to leave the dependent person under the responsibility of another person during the session, promoting access to mental health care.

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Table 04 - Mental/Emotional Aspects

Área Mental/Emocional				
Variáveis	**Categoria e frequência (n)**			
Momentos de descanso longe do filho	Opções de Resposta:	Sim	Às vezes	Não
	Nº total: 21	0	4	17
Faz psicoterapia	Opções de Resposta:	Sim	Não	
	Nº total: 21	0	21	
Interesse em psicoterapia	Opções de Resposta:	Sim, mas é a principal responsável	Sim, atividades divididas	
	Nº total: 21	15	6	

Final Considerations

The present study aimed to investigate the relationship between mothers or informal caregivers. of children and adolescents with Cerebral Palsy and their self-care practices, seeking To understand how your care routine influences your physical, emotional, and social health.

The results showed that most participants dedicate themselves full-time to... caring for a child or adolescent, often also accumulating other responsibilities. This scenario was associated with the absence of paid work for a large part of the family. of the caregivers, in addition to difficulties related to performing self-care practices. It was observed- If you still experience frequent body aches, sleep deprivation, and feelings of tiredness, or discouragement, aspects that may indicate significant impacts on the physical and emotional health of these women.

In the social and emotional realm, the data also revealed significant limitations in possibility of rest and self-care. Most participants reported not having moments like this. taking a break from their routine, as well as not undergoing psychotherapeutic follow-up, although a large part express interest in accessing this type of support. These findings are consistent with studies that They point out that the care of people with disabilities often falls primarily on the... women, resulting in physical, emotional and social overload (Souza et al., 2007; Fernández-Alcántara et al., 2013).

In this context, it becomes important to recognize that care directed towards children and

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Adolescents with cerebral palsy cannot be understood in isolation; it is necessary Consider also the living and health conditions of the caregivers. The literature indicates that self-care It constitutes a fundamental element for promoting health and addressing conditions. of illness or disability (WHO, 2021). However, when care demands are Intense and concentrated on a single person, the incorporation of these practices becomes more difficult in daily life.

Therefore, the results of this study reinforce the importance of health services and Public policies should also consider the needs of informal caregivers, recognizing them. as a fundamental part of the care process. Strategies such as offering listening spaces, Psychological support and guidance during child care appointments can represent... possibilities for expanding healthcare.

Limitations of this study include the small number of participants and the fact that... The research was conducted in a single healthcare facility, which does not allow for broad generalizations. of the results. Even so, the findings contribute to a broader understanding of reality. experienced by caregivers of children with Cerebral Palsy, indicating the need for new studies that delve deeper into this topic in different contexts.

Finally, reflecting on the self-care of these women implies recognizing that care does not It is sustained not only by individual dedication, but also by social, institutional and... affective factors that make it possible. Thus, caring for the caregiver proves to be an essential dimension for promoting health and building more humane and sustainable care practices.

References

AYES, Claudia Cancio Bello; RUIZ, Alexis Lorenzo; ESTÉVES, Guadalupe Alarcó. **Self-care: a theoretical approach to the concept.** Psychological Reports, ISSN-e 2422-3271, ISSN 2145-3535, Vol. 20, No. 2, 2020 (Ejemplar dedicated to: Jul-Dec), pages. 119-138.

ASSIS-MADEIRA, Elisângela. CARVALHO, Sueli. **Cerebral Palsy and Risk Factors for Motor Development: A Theoretical Review.** Cadernos de Pós-Graduação em Distúrbios do Desenvolvimento, São Paulo, v.9, n.1, p.142-163, 2009.

BRAZ, Elizabeth; CIOZAK, Suely Itsuko. **Becoming a caregiver in senescence.** 2009; 13(2):372-7.

Chamber of Deputies. **Organic Law of Social Assistance (LOAS).** 2013. Brasília - DF. Chamber Editions.

DANTAS, Meryeli Santos de Araújo; COLLET, Neusa; MOURA, Flávia Moura; TORQUATO, Isolda Maria Barros. **Impact of Cerebral Palsy Diagnosis on the Family.** 2010; 19(2):229-37.

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Year VI, v.1 2026 | Submission: 03/20/2026 | Accepted: 03/22/2026 | Publication: 03/24/2026

FERNÁNDEZ, Alcántara, M.; GARCÍA, Caro MP; BERROCAL, Castellano M., Benítez, A., Robles-Vizcaíno, C., & Laynez-Rubio, C. (2013). **Experiences and changes in parents of children with infantile cerebral palsy: a qualitative study.** *Annals of the Navarre Health System,* 36(1), 9-20.

FONSECA, Luis Fernando; LIMA, Cesar Luiz Andrade. **Cerebral Palsy.** Neurology, orthopedics and rehabilitation. 2nd ed, 2008. Medbook - Editora Científica Ltda. Rio de Janeiro, RJ.

GIRONDOLI, Yassana Marvila. SOARES, Mirian Cardoso de Rezende. **Self-care and Quality of Life.** Coordination of Attention to the Health of the Server (CASS). 2023. Accessed on 09/05/2024. Available at: https://prodi.ifes.edu.br/images/stories/Autocuidado_e_Qualidade_de_Vida.pdf.

VIEIRA, Naiana Gonçalves de Bittencourt; MENDES, Natália Carvalho; FROTA, Lêda Maria da Costa Pinheiro; FROTA, Mirna Albuquerque. **The daily lives of mothers with children with Cerebral Palsy.** Fortaleza-Ceará. Brazilian Journal of Health Promotion vol. 21, no. 1, 2008, pp. 55-60.

HEIDEGGER, M. (2012). **Being and Time** (1st ed., Fausto Castilho, trans.). Campinas, SP: Vozes. Campinas, RJ: Vozes.

LEITE, Jaqueline. PRADO, Gilmar. **Cerebral Palsy. Physiotherapeutic and clinical aspects. Neuroscience Journal.** Vol. 12, No. 1, pp. 41–45, 2004. DOI: 10.4181/RNC.2004.12.41. Available at: https://periodicos.unifesp.br/index.php/neurociencias/article/view/8886. Accessed on: March 7, 2024.

MANOEL, Maria Fernanda; TESTON, Elen Ferraz; WAIDMAN, Maria Angélica Pagliarini; DECESARO, Maria das Neves; MARCON, Sonia Silva. **Family relationships and the level of burden on the family caregiver.** 2013; 17(2):346-53.

Ministry of Health. **Self-care in health: and health literacy in the context of promotion, prevention and care of people with chronic conditions.** 2023.

Ministry of Health. **Guidelines for the care of people with Cerebral Palsy.** 2nd ed. Brasília: Ministry of Health, 2014.

Ministry of Health. **What does it mean to be healthy?** 2021. Available at: https://www.gov.br/saude/pt-br/assuntos/saude-brasil/eu-quero-meexercitar/noticias/2021/o-que-significa-ter-saude .

OLIVEIRA, Alyne Kalyane Câmara; Matsukura, Thelma Simões. (2013). **Stress and social support in caregivers of children with Cerebral Palsy.** *Cadernos de Terapia Ocupacional da UFSCar,* 21(3), 493-503.

PEREIRA, Heloisa. **Cerebral Palsy.** Pediatric Residency Journal. Vol. 8, No. 1. 2018. State University of Rio de Janeiro, Department of Pediatrics - Rio de Janeiro, RJ, Brazil. p. 49-55. DOI: , 10.25060/residpediatr-2018.v8s1-09.

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PETEAN, Eucia Beatriz Lopes; MURATA, Maria Ferreira. **Cerebral palsy: mothers' knowledge about the diagnosis and its impact on family dynamics.** Rev Paidéia. 2000; 10(19):40-6.

RIBEIRO, Maysa Ferreira Martins; VANDENBERGH, Luc; PRUDENTE, Cejane Oliveira Martins; VILA, Vanessa da Silva Carvalho; PORTO, Celmo Celeno. **Cerebral palsy: how the child's age and severity of impairment affect the mother's stress and coping strategies (2016).** *Ciência & Saúde Coletiva,* 21(10), 3203-3212.

ROTTA, Newra. **Cerebral palsy, new therapeutic perspectives.** Journal of Pediatrics - Vol. 78, Suppl. 1, 2002.

SANTOS, Quezia Paz; FARIAS, Luara Gabrielle; NEVES, Marcele Florêncio das. **Epidemiological profile of cerebral palsy in Brazil and its regions between 2018 and 2023.** XXVII Latin American Meeting of Scientific Initiation, XXIII Latin American Meeting of Postgraduate Studies and XIII Meeting of Initiation to Teaching - University of Vale do Paraíba – 2023. DOI: https://dx.doi.org/10.18066/inic1073.23.

Federal Senate. **Statute of Persons with Disabilities.** 2019, 3rd ed. Brasília-DF. Technical Publications Coordination.

SILVA, CCB, & Ramos, LZ (2014). **Family reactions to the discovery of their children's disability.** *Cadernos de Terapia Ocupacional da UFSCar,* 22(1), 15-23.

SMEHA, LN, Abaid, JLW, Martins, JS, Weber, AS, Fontoura, NM, Castagna, L. (2017). **Caring for a child diagnosed with Cerebral Palsy: feelings and expectations.** *Psychology in Study,* 22(2), 231-242.

SOUZA, Laura Vilela; SANTOS, Manoel Antonio. **The family and eating disorders.** Medicine. 2006; 39(3):403-9.

SOUZA, Luccas Melo de; WEGNER, Wiliam; GORINI, Maria Isabel Pinto Coelho. **Health education: a care strategy for lay caregivers.** 2007; 15(2):337-43.

World Health Organization. **Putting people first in managing their health: new WHO guideline on self-care interventions.** Geneva: WHO, 2021.

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