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ORIGINAL ARTICLE

Activity and participation of children and adolescents with Cerebral Palsy attended at an Outpatient Clinic in the Interior of Amazonas

Atividade e participação de crianças e adolescentes com Paralisia Cerebral atendidas em Ambulatório no Interior do Amazonas

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Abstract

Introduction: Cerebral Palsy is defined as a non-progressive set of neurodevelopmental disorders. Currently, there is a lack of information on the functionality of Brazilian children and adolescents with Cerebral Palsy. *Objective:* This study described the activity levels and participation of children and adolescents with Cerebral Palsy at a university's Physiotherapy Outpatient Clinic in the interior of Amazonas. *Methods:* A cross-sectional, retrospective study based on medical records of pediatric patients with Cerebral Palsy up to 18 years old from a university physiotherapy outpatient clinic in the interior of Amazonas, evaluated in 2022 and 2023. Sociodemographic characteristics and health conditions were observed, as well as activity aspects: mobility, self-care, and communication; and participation aspects: in preschool, school life and related activities, involvement in play, community life, social interactions, and recreation or leisure. A total of 17 participants were included. Descriptive analyses were conducted using percentages and frequencies. *Results:* Most participants were male (64,3%, n= 11), aged between 1 and 4 years old (52,9%, n=9). A total of 47,1% (n=8) had bilateral spastic Cerebral Palsy, and 41,2% (n=7) were quadriplegic. Regarding activities classified by the

Gross Motor Function Classification System, 47.1% (n=8) were at level V. Based on the Manual Ability Classification System, 29,4% (n=5) were at level I and 29,4% (n=5) at level IV. In terms of participation, most (64,7%, n=11) did not attend school activities, and 76,5% (n=13) had little or no involvement in play with friends. *Conclusion:* Limitations in gross motor function, functional mobility, and self-care activities, as well as restrictions in school participation, highlighted the need for multidisciplinary healthcare services and inclusive opportunities for this population.
Keywords: International Classification of Functioning, Disability and Health; Motor Activity; Activities of Daily Living; Cerebral Palsy; Child; Adolescent.

Resumo

Introdução: A Paralisia Cerebral é definida como um conjunto de desordens do neurodesenvolvimento, não progressiva. Atualmente, observa-se uma escassez de informações sobre a funcionalidade de crianças e adolescentes brasileiros com Paralisia Cerebral. *Objetivo:* Descreveu-se o nível de atividade e a participação de crianças e adolescentes com Paralisia Cerebral de um Ambulatório de Fisioterapia de uma Universidade no interior do Amazonas. *Metódos:* Estudo transversal, retrospectivo, baseado em prontuários de pacientes pediátricos com Paralisia Cerebral de um Ambulatório universitário de fisioterapia no interior do Amazonas, avaliadas nos anos 2022 e 2023. Descreveu-se características sociodemográficas e condições de saúde; atividades: mobilidade, autocuidado e comunicação; participação: na vida pré-escolar, escolar e atividade relacionadas, envolvimento em brincadeiras, vida comunitária, social e recreação ou lazer. Foram incluídos 17 participantes. Análises descritivas foram realizadas por meio de porcentagem e frequência. *Resultados:* A maioria dos participantes era do sexo masculino (64,3%, n=11) com idade entre 1 e 4 anos (52,9%, n=9). Cerca de 47,1% (n=8) apresentavam paralisia cerebral espástica bilateral e 41,2% (n=7) eram quadriplégicos. Em atividades, classificadas pelo Sistema de Classificação da Função Motora Grossa, 47,1% (n=8) estavam no nível V e no Sistema de Classificação da Habilidade Manual, 29,4% (n=5) estavam nos nível I e 29,4% no nível IV. Na participação, a maioria (64,7%, n=11) não frequentava atividades escolares e 76,5% (n=13) apresentavam pouco ou nenhum envolvimento em brincadeiras com amigos. *Conclusão:* As limitações em atividades que envolvem a função motora grossa, mobilidade funcional e autocuidado, assim como a restrição na participação escolar revelaram a necessidade de serviços de saúde multidisciplinar e oportunidades inclusivas para esta população.
Palavras-chave: Classificação Internacional de Funcionalidade, Incapacidade e Saúde; Atividade Motora; Atividade Cotidiana; Paralisia Cerebral; Criança; Adolescente.

Introduction

Cerebral Palsy (CP) is defined as a group of non-progressive neurodevelopmental disorders manifested by impairments in movement and posture, as well as sensory, perceptual, cognitive, behavioral, and communication alterations [1].

Understanding the functionality of individuals with cerebral palsy remains limited, particularly regarding performance in daily activities and engagement in meaningful social contexts [2]. In this regard, the use of the International Classification of Functioning, Disability and Health (ICF) is essential [3].

The International Classification of Functioning, Disability and Health (ICF), developed by the World Health Organization (WHO), recommends a biopsychosocial approach to assessment, considering activities and participation as equally important as impairments in body functions and structures. In the ICF framework, activity is defined as the execution of a task or action by an individual, while participation refers to involvement in life situations, which, for children and adolescents, may include engagement in household, school, and community activities [3].

Children with CP present various impairments, but in Brazil, interventions primarily focus on body structure and function, followed by activities. The most commonly used outcome measures emphasize the Gross Motor Function Measure – GMFM [2]. However, there is limited documentation on other daily activity limitations, including functional mobility, manual skills, feeding, communication, dressing, and hygiene, as well as on participation, related interventions, and outcome measures concerning home, school, and social life [2,4].

Disabilities related to activities, participation and body structure and function result from the interaction between the individual's intrinsic characteristics and their physical and social environment [2,5].

There is a scarcity of information on the child's functionality and disabilities of Brazilian children and adolescents with CP [2,6], particularly in the Northern region of the country [7]. This lack of data impacts the understanding of the physical-functional characteristics of this population. Although research on this topic has increased in recent years, there is still a gap in studies addressing activity and participation in different contexts of Brazil, especially in remote areas [6,7,8]. It is essential for physiotherapists to understand the ICF and assess children and adolescents with CP by considering both their motor abilities in tasks and their engagement in life situations. This approach enables the development of effective treatment strategies that maximize their developmental potential [9].

Given the need to understand the functionalities and disabilities related activity and participation in individuals with CP, especially those living in remote areas of Brazil, such as the interior regions of Amazonas, this study aimed to characterize the activity levels and participation of children and adolescents with CP attending a University Physiotherapy Outpatient Clinic in the Interior of Amazonas, based on the ICF framework.

Methods

This is a cross-sectional, descriptive study based on a retrospective analysis of medical records of patients with Cerebral Palsy (CP) from the Physiotherapy Outpatient Clinic at the Institute of Health and Biotechnology (ISB) of the Federal University of Amazonas (UFAM) in Coari, Amazonas. This research is part of a larger study approved by the University's Research Ethics Committee under protocol number 78536624.3.0000.5020. Data collection complied with the ethical principles established by Resolutions n° 466/2012 and n° 510/2016 of the Brazilian National Health Council.

The sample was selected conveniently, including physical medical records of children and adolescents aged 0 to 18 years old diagnosed with CP, who were monitored by the clinic. Only records with complete and legible data on Activities and Participation were included, provided they were the first patient record for the year 2022 or the first semester of 2023. Incomplete records regarding CP characterization in activity and participation and subsequent evaluation records of the same patient were excluded. As a result, seven records were removed.

The observed variables were related to sociodemographic aspects; health conditions; activities: mobility; self-care and communication; and participation: pre-school life, school and related activities, involvement in play, community and social life, recreation, and leisure.

Activity classifications were based on standardized assessment tools for CP patients, including:

1. Gross Motor Function Classification System (GMFCS) – classifies gross motor function in children and adolescents, focusing on sitting, transfers, and mobility, organizing them into five levels [10].
2. Manual Ability Classification System (MACS) – describes how children and adolescents with CP use their hands to manipulate objects in daily activities, categorizing them into five levels [11].
3. Communication Function Classification System (CFCS) – classifies daily communication performance in individuals with CP into five levels [12].
4. Functional Mobility Scale (FMS) – assesses functional mobility, considering the variety of assistive devices a child may use at three different distances [13].

Data collection was conducted between June and August 2024, adhering to the ethical principles established by Resolution 466/2012 of the National Health Council.

Initially, the data were tabulated using Microsoft Office Excel 2010 (Microsoft, Washington, United States), and subsequently analyzed using the Jamovi software, version 1.6.23.0 for Windows. Categorical variables were presented as absolute and relative frequencies.

Results

The study included 17 medical records of children and adolescents with CP. Among the sociodemographic characteristics, 64.7% (n=11) were male and 35.3% (n=6) were female, with ages ranging from 1 to 13 years old. The most prevalent age group was 1 to 4 years old, comprising 52.9% (n=9). 41.2% (n=7) were identified as mixed race. Regarding family structure, 58.8% (n=10) were only children. The predominant family income ranged between 1 and 2 minimum wages, 47.1% (n=8). In terms of occupation, 58.7% (n=10) of the mothers were housewives, while 41.1% (n=7) of the fathers worked informally.

The characteristics of the children and adolescents, including health conditions, types of CP, and topography, are described in Table 1.

Table 1 - *Characterization of Children and Adolescents with Cerebral Palsy (Health Condition, Type of CP, and Topography)*

Health Conditions and Functionality		N	(%)
Medical Diagnosis	Cerebral Palsy	9	52,9
	Cerebral Palsy and Other Conditions	8	47,1
Types of Cerebral Palsy	Bilateral Spastic	8	47,1
	Unilateral Spastic	5	29,4
	Ataxic	2	11,7
	Dyskinetic Dystonic	1	5,9
	Not Informed	1	5,9
Topography	Quadriplegia	7	41,2
	Hemiplegia	5	29,4
	Diplegia	4	23,5
	Not Informed	1	5,9

Data compiled by the author, N = absolute number % percentage.

Activity limitations were observed related to Gross Motor Function, Communication, and Manual Abilities, as shown in Table 2, as well as Functional Mobility and Self-care described in Table 3.

Table 2 - *Characteristics of Mobility, Communication, and Manual Skills*

System Activity Classification	Level/Performance	N	(%)
GMFCS	Level V	8	47,1
	Level II	3	17,6
	Level IV	3	17,6
	Level I	2	11,8
	Level III	1	5,9
MACS	Level I	5	29,4
	Level IV	5	29,4
	Level V	4	23,5
	Level II	2	11,8
	Level III	1	5,9
CFCS	Level V	5	29,4
	Level I	4	23,5
	Level II	4	23,5
	Level IV	3	17,6
	Level III	1	5,9

GMFCS = Gross Motor Function Classification System; Level I = walks without limitations; Level II = walks with limitations; Level III = walks using a manual mobility device; Level IV = self-mobility with limitations, may use motorized mobility; Level V = transported in a manual wheelchair [10]. MACS = Manual Ability Classification System; Level I = includes children with minor limitations, who manipulate objects easily and successfully; Level II = manipulates most objects, but with slightly reduced quality and/or speed; Level III = manipulates objects with difficulty, requires help to prepare and/or modify activities; Level IV = manipulates a limited variety of easily manageable objects in adapted situations; Level V = does not manipulate objects and has severely limited ability to perform even simple actions [11]. CFCS = Communication Function Classification System; Level I = effective sender and receiver with both unknown and known partners; Level II = effective sender or receiver, but slower with unknown or known partners; Level III = effective sender and receiver with known partners; Level IV = inconsistent sender and/or receiver with known partners; Level V = rarely effective sender and receiver, even with known partners [12]. Source: Data compiled by the author, N = absolute number % percentage;

Table 3 - *Characteristics of Functional Mobility and Self-Care*

Activity Performance			N	(%)
FMS	5m	Does not complete the distance	7	41,1
		Crawls at home	3	17,6
		Independent walking on level surfaces	2	11,8
		Independent walking	2	11,8
		Wheelchair	1	5,9
		Walking with the use of crutches	1	5,9
		Use of mobility aid	1	5,9
	50m	Does not complete the distance	9	52,8
		Independent walking	2	5,9
		Independent walking on level surfaces	2	11,8
		Crawls at home	2	11,8
		Use of mobility aid	1	5,9
		Wheelchair	1	5,9
	500m	Does not complete the distance	11	64,6
		Independent walking on level surfaces	2	11,8
		Wheelchair	2	11,8
		Independent walking	1	5,9
		Use of mobility aid	1	5,9
Self-care		Dependent	12	70,5
		Moderate dependency	2	11,8
		Independent	1	5,9
		Ignored	2	11,8

FMS = Functional Mobility Scale; 5m = (home march); 50m = (school march); 500m = (community march)[13]. Source: Data compiled by the author, N = absolute number % percentage.

The characteristics of Participation in Daycare/School and the Community are presented in Table 4, showing various participation restrictions. It was not possible to characterize participation at home.

Table 4 - *Characteristics of Participation in Daycare/School and Community*

Participation	Involvement	(n)	(%)
Daycare/School	Not Involved	11	64,7
	Involved	6	35,3
Church	Involved	4	23,5
	Not Involved	13	76,5
Playing with Friends	Slightly Involved	7	41,2
	Involved	4	23,5
	Not Involved	6	35,3
Other Recreation or Leisure Activities	Involved	8	47,1
	Slightly Involved	3	17,6
	Not Involved	6	35,3

Data compiled by the author, n = absolute number % percentage.

Discussion

The levels of activity and participation of children and adolescents with CP were characterized from a Physical Therapy Clinic at a University in the Interior of Amazonas.

The predominance of males, the age group between 1 to 4 years old, the bilateral spastic CP type, and quadriplegia found in this study are similar to those in previous studies [14,15,16].

The predominant family income of one to two minimum wages was similar to that observed in another study [14]. The most common occupation reported by the mothers was that of housewife, reflecting their role as the primary caregivers of their children. This finding is consistent with another study, which highlights the mother as the primary caregiver of children with CP, and this can be attributed to social expectations and traditional roles [17,18].

Evidence shows that the incidence of severe developmental disabilities is more prevalent in poorer families with lower educational levels and those residing in countries with a lower Human Development Index - HDI. These aspects define socioeconomic status and have consequences for caregiving [18].

Important limitations were observed in activities related to gross motor function in this study. Most of the participants were classified at level V of the GMFCS, meaning they needed to be transported in a wheelchair. This was consistent with the findings in functional mobility, where the majority could not complete distances of 50m and 500m, indicating a high dependency for locomotion. Additionally, there was a dependency in self-care activities, such as feeding, dressing, brushing teeth, and bathing independently. The percentage at level V in the GMFCS was consistent with the proportion of individuals with quadriplegia. In terms of manual skills using the MACS, levels I and IV were more prevalent, and in communication, nearly one-third were at level V of the CFCS.

Level V in the GMFCS was also predominant in previous studies, indicating the need for extensive assistive technology, in addition to physical assistance for the mobility of children and adolescents [7,8,14]. The literature shows that lower levels of the GMFCS are associated with better performance in mobility and daily activities, while higher levels require costly resources to ensure mobility [19].

In functional mobility as assessed by the FMS, up to two-thirds of individuals showed difficulties in moving distances of 5m, 50m, and 500m, which aligns with the number of individuals classified at levels IV and V in the GMFCS. Studies have also demonstrated a relationship between the FMS and GMFCS and stated that walking performance in children with CP is directly related to the amount of gross motor activity the child engages in [20,21].

Regarding manual skills, participants in this study were mostly classified at levels I and IV in the MACS. Similar results were found in previous studies [22]. Authors point out that gross motor function and manual skills often show discrepancies in children with CP [23].

Communication was more prevalent at level V in this study, meaning communication is rarely effective, even with familiar partners. This aligns with another study that determined GMFCS levels are highly correlated with CFCS levels [24].

Regarding self-care, most participants were dependent, similar to previous studies that identified both children and adolescents with CP as having deficits in functional skills and therefore being more dependent on caregivers [25,26].

The activity-related disabilities reported in this study reveal a critical issue faced by this population. The findings highlight the lack of assistive technology and the demand for modern and specialized multidisciplinary rehabilitation centers. The presence of mobility, manual skill, and communication impairments, combined with the financial constraints of these families, underscores the need for interventions and support from public health systems and policies.

The participation of children and adolescents with CP proved to be a challenge in this study. Most of them did not attend daycare or school, which can be attributed to environmental barriers. In contrast, research in other states of the country, such as Minas Gerais and Pará, identified more frequent school participation, with at least half of the participants attending school. These studies emphasized that despite various decrees created in Brazil and around the world to ensure the educational inclusion of people with disabilities, the necessary conditions for access are not provided due to the lack of specialized

professionals, absence of appropriate assistive technologies, architectural structure, and attitudes [8,14]. In this study, the children in the school environment were participating in the Pestalozzi Association.

Participation in church activities was also reported by nearly one-third of the participants. A study conducted in 2009 observed that a large portion of children with CP attended some religious institution, which facilitated their social interaction [27].

Around 76.5% of the children and adolescents reported little to no involvement in play with friends. Evidence suggests that play is a significant factor in social involvement [9,27]. Interaction with friends is essential for the social and emotional development of children with CP, and the lack of it can have negative impacts [28]. Participation in leisure activities was reported as an engagement by less than half of the participants. Among the mentioned activities were going to the park and visiting natural water environments with family. In other studies, participation in the community was also considerably restricted [7,14,27].

Authors state that the attitude of peers and social support are critical factors that influence participation in social and community activities [29]. Furthermore, the physical structure and accessibility of community activity locations also play an important role [30].

It was observed that children and adolescents with CP face significant restrictions in school and social participation, which limits their learning opportunities, social interaction, and consequently, their potential development. The lack of information about participation in home activities hinders the understanding in this context for these individuals.

This study has limitations, such as the sample size (n=17), which prevents generalization of the results, as a larger sample could provide a broader and more representative view of the characteristics related to activities and participation of children and adolescents with CP in this context, as well as the use of secondary data, which could lead to information biases. Nevertheless, it is hoped that the study will contribute information about this population located in a remote area of the country, in the interior of the Amazon, due to the lack of information on the characteristics of this population in this context.

It is hoped that this study will highlight the need to deepen the understanding of the functionality and disability of individuals living far from large urban centers and in remote areas, and raise awareness of the needs of this population, which lacks specialized health, educational, and social assistance services, currently hindered by the justification of geographical barriers imposed as obstacles to significant progress in these sectors.

Conclusion

This study, conducted with children and adolescents with CP attending a Physical Therapy Clinic in the interior of Amazonas, revealed significant activity limitations and participation restrictions that highlight the need for multidisciplinary rehabilitation health services, assistive technologies and inclusive opportunities.

Academic Affliation

This article represents the undergraduate thesis of Renata Maila da Silva Costa, supervised by Professor Alessandra Araújo da Silva, under the title *Activity and Participation of Children and Adolescents with Cerebral Palsy Attended by the Pediatric Physical Therapy Service of a University in the Interior of Amazonas*, at the Institute of Health and Biotechnology of the Federal University of Amazonas.

Conflicts of interest

The authors declare no conflicts of interest of any nature.

Author contributions

Study conception and design: Costa RMS, Sousa EFC, Silva AA; Data collection: Costa RMS, Silva OMS, Silva JRG; Data analysis and interpretation: Costa RMS, Sousa EFC, Silva AA; Statistical analysis: Costa RMS, Sousa EFC; Manuscript writing: Costa RMS, Silva OMS, Silva JRG, Silva AA; Critical revision of the manuscript for important intellectual content: Silva AA.

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