

ORIGINAL ARTICLE

Environmental factors of children and adolescents with Cerebral Palsy attended at an outpatient clinic in the Interior of Amazonas from the perspective of the International Classification of Functioning, Disability and Health

Fatores ambientais de crianças e adolescentes com Paralisia Cerebral atendidas em ambulatório no Interior do Amazonas sob a perspectiva da Classificação Internacional de Funcionalidade, Incapacidade e Saúde

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Received: April 11, 2025; Accepted: April 16, 2025.

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How to cite

Silva OMS, Costa RMS, Silva JRG, Sousa EFC, Silva AA. Environmental factors of children and Adolescents with Cerebral Palsy attended at an outpatient clinic in the Interior of Amazonas from the Perspective of the International Classification of Functioning, Disability and Health. Fisioter Bras. 2025;26(2):2075-2088. doi:[10.62827/fb.v26i2.1051](https://doi.org/10.62827/fb.v26i2.1051)

Abstract

Introduction: Cerebral palsy refers to a group of motor and postural disorders resulting from a non-progressive lesion in the developing central nervous system. Environmental factors may act as either barriers or facilitators to development. **Objective:** The environmental factors of children and adolescents with Cerebral Palsy receiving care at a University Outpatient Clinic in the interior of Amazonas were characterized. **Methods:** A cross-sectional, retrospective study. A total of 17 medical records of children and adolescents with Cerebral Palsy, aged 0 to 18 years, from a university physiotherapy outpatient clinic, evaluated in 2022 and 2023. The characteristics of personal factors were described - factors sociodemographic; characteristics clinical and functional; and characteristics of environmental factors: family, housing conditions, use of products and technology, social support and access to services were assessed. Descriptive analysis was performed using mean, standard deviation, percentage,

and frequency. *Results:* Most patients were male (64,3%, n= 11), and 47,1% (n= 8) had bilateral spastic Cerebral Palsy, classified as Level V on the Gross Motor Function Classification System. Levels I and IV were the most frequent in the Manual Ability Classification System (both with 29,4%, n=5). Numerous environmental barriers have been identified as lack of walking and mobility assistive devices up to 70,6% (n= 12), difficulty accessing pediatricians and neurologists 70,6% (n=12), lack of access to school or daycare (64,7%, n= 11), were low family income (47,1%, n= 8) and not receiving social assistance and/or benefits (52.9%, n=9). *Conclusion:* There are numerous environmental barriers to health services, educational, and social services, as well as in the consumption and use of personal products and technologies that affect the functionality and development of these children and adolescents.

Keywords: International Classification of Functioning, Disability and Health; Social Environment; Rehabilitation Services; Cerebral Palsy; Children; Adolescent.

Resumo

Introdução: Paralisia Cerebral refere-se ao conjunto de distúrbios motores e posturais decorrentes de uma lesão não evolutiva no sistema nervoso central em desenvolvimento. Fatores ambientais podem desempenhar o papel de barreiras ou facilitadores ao desenvolvimento. *Objetivo:* Caracterizou-se os fatores ambientais de crianças e adolescentes com Paralisia Cerebral atendidas em um Ambulatório Universitário no interior do Amazonas. *Métodos:* Estudo transversal, retrospectivo. Foram avaliados 17 prontuários de crianças e adolescentes com Paralisia Cerebral de zero a 18 anos de um Ambulatório universitário de fisioterapia, avaliadas no ano de 2022 e 2023. Descreveu-se as características de fatores pessoais – sociodemográficas; características clínica e funcional; e características de fatores ambientais: familiar, condições de moradia, uso de produtos e tecnologia, suporte social e acesso a serviços. Análises descritivas foram realizadas por meio da média, desvio-padrão, porcentagem e frequência. *Resultados:* A maioria dos pacientes era do sexo masculino (64,3%, n= 11) e 47,1% (n= 8) tinham Paralisia Cerebral espástica bilateral e eram nível V no Sistema de Classificação da Função Motora Grossa. Os níveis I e IV foram os mais frequentes no Sistema de Classificação de Habilidade Manual (ambos com 29,4%, n=5). Inúmeras barreiras ambientais foram identificadas como a falta de dispositivos auxiliares de marcha e de mobilidade para até 70,6% (n= 12), dificuldade de acesso aos médicos pediatra e neurologista para até 70,6% (n=12), falta de acesso à escola ou creche (64,7%, n= 11), baixa renda familiar (47,1%, n= 8) e o não recebimento de auxílios e/ou benefícios sociais (52,9%, n= 9). *Conclusão:* Há inúmeras barreiras ambientais de serviços de saúde, educacionais e assistenciais, bem como no consumo e uso de produtos e tecnologias para uso pessoal que impactam na funcionalidade e desenvolvimento dessas crianças e adolescentes.

Palavras-chave: Classificação Internacional de Funcionalidade, Incapacidade e Saúde; Paralisia Cerebral; Meio Social; Serviços de Reabilitação; Criança; Adolescente.

Introduction

Cerebral Palsy (CP) is a term used to refer to a group of motor and postural disorders resulting from a non-progressive injury to the developing central nervous system [1]. In about 30% of cases, the etiology of CP is unknown, and the risk factor has not been identified [2].

Worldwide, 2 out of every 1000 live births have CP, making the condition a determining factor for severe childhood physical disability [3]. A systematic review stated that in low and middle-income countries, the prevalence may be even higher, reaching up to 3.4 per 1000 live births. However, the estimate is inconsistent due to the lack of adequate records [4]. There are several changes presented in children with CP, ranging from musculoskeletal, sensory, cognitive, functional mobility, and postural alterations [1]. These changes result in functional impairments, limiting the performance of daily activities such as eating, dressing, hygiene, mobility, and even absence from school and social life [5].

The International Classification of Functioning, Disability, and Health (ICF) states that environmental and social factors can play the role of barriers or facilitators to development. Thus, impairments in body structures and functions, activity limitations, and participation restrictions are the result of the

interaction between individual conditions and the physical and social environment in which the person is inserted. Among the contextual factors, one can cite environmental factors such as the physical, social, and cultural environment, as well as personal characteristics such as sex, age, and lifestyle, which influence quality of life [6,7].

The Amazon represents a complex and diverse socio-environmental scenario. This context results in significant social, economic, and health disparities, with high income concentration and living conditions that are largely unfavorable for the majority of the population. In parallel, there is a lack of basic infrastructure and insufficient essential services, especially in healthcare, which intensifies inequalities and weakens the quality of life in the region [8].

Given the lack of information and the importance of environmental factors for individuals with CP, especially those far from large urban centers, where specialized and technological resources are located, the environmental factors of children and adolescents with CP treated at the Physiotherapy Clinic of a University in the interior of Amazonas were characterized.

Methods

This is a cross-sectional, descriptive, retrospective study on the analysis of medical records of patients with CP from the the Physiotherapy Clinic of the Institute of Health and Biotechnology – ISB of the Federal University of Amazonas – UFAM, in Coari, Amazonas. This study is part of a larger project approved by the Research

Ethics Committee of the University under number 78536624.3.0000.5020. Data collection followed the ethical principles outlined in Resolutions n° 466/2012 and n° 510/2016 of the Brazilian National Health Council.

The sample was obtained by convenience, and physical records of children and adolescents aged

0 to 18 years old with a diagnosis of CP monitored by the outpatient clinic were eligible, provided they contained complete and legible data on the type of CP and environmental factors and were the patient's first record between 2022 to the first half of 2023. Records with incomplete information on the characterization of CP and environmental factors, as well as records from subsequent evaluations of the same patient, were excluded. In total, seven records were excluded.

Data were collected between June and August 2024, after approval of the project by the Research Ethics Committee, and the evaluated variables were organized into the following specified dimensions:

A - Characterization of personal factors:

sociodemographic (sex, age range, ethnicity, and income).

B - Clinical and functional characterization:

medical diagnosis, types of cerebral palsy, topography, Gross Motor Function Classification System (GMFCS)⁹, and Manual Ability Classification System (MACS).¹⁰

C - Characterization of environmental fac-

tors: family (number of children, parents' occupation/profession, parents' marital status, parents' education level, parents' support), housing (number of residents, type of dwelling, type of flooring, electricity, plumbing, water treatment, presence of a bathroom, and number of rooms), use of products and technology (medications, orthotics, wheelchair, and walking aids), social support, and access to services (support from family, friends, access to health and educational services). The characterization of environmental factors in this study was based on some categories from the environmental factors of the CIF.

Descriptive analysis was performed using Microsoft Excel 2010 (Microsoft - Washington, United States), and data were subsequently evaluated using Jamovi software, version 1.6.23.0. Continuous variables were presented as mean and standard deviation, and categorical variables as absolute and relative frequencies.

Results

Personal Characterization – Sociodemographic

Seventeen patient records of children and adolescents with CP, aged between 1 and 13 years old, were included. The characteristics of personal factors are presented in Table 1.

Table 1 – Sociodemographic Personal Factors Characteristics

Personal Factors	N	(%)
Sex		
Female	6	35.3
Male	11	64.7
Race/ Ethnicity		
White	4	23.5
Mixed race	7	41.2
Not reported	6	35.3
Age group		
0 to 4 years	9	52.9
5 to 8 years	6	35.3
9 to 12 years	1	5.9
13 to 18 years	1	5.9
Family income		
Not reported	4	23,5
< 1 minimum wages	4	23,5
1 and 2 minimum wages	8	47,1
> 3 minimum wages	1	5,9

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

Clinical and Functional Characterization

The characteristics related to medical diagnosis, type of cerebral palsy, topography, and the classifications of gross motor function and manual ability are presented in Table 2.

Table 2 - Types and Topography of Cerebral Palsy

Health Condition and Functionality		N	%
Medical Diagnosis	Cerebral palsy	9	52,9
	Cerebral palsy and other conditions	8	47,1
Type of Paralysis	Bilateral spastic	8	47,1
	Unilateral spastic	5	29,4
	Ataxic	2	11,7
	Dystonic dyskinetic	1	5,9
	Not reported	1	5,9
Topography	Quadriplegia	7	41,2
	Hemiplegia	5	29,4
	Diplegia	4	23,5
	Not reported	1	5,9
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

Source: Data compiled by the author, n = absolute number % percentage GMFCS - Level I = walks without limitations Level II = walks with limitations Level III = walks with a handheld device Level IV = self-mobility with limitations/may use powered mobility Level V = transported in a manual wheelchair MACS – Level I = handles objects easily and successfully Level II = handles most objects but with slightly reduced quality and/or speed Level III = handles objects with difficulty requiring help to prepare or modify activities Level IV = handles a limited variety of easily manipulable objects in adapted situations Level V = does not handle objects and has severely limited ability even for simple actions.10

Environmental Factors - Family Characterization

Among the participants, most were only children (58.8%, n=10). Most mothers were housewives (58.8%, n=10), and 41.1% (n=7) of the fathers worked informally. 35.3% (n=6) of the subjects had married parents, and the same proportion was in stable unions. Regarding education, 77% (n=13) of the mothers and 29.5% (n=5) of the fathers had completed high school. Half of the subjects received support from their fathers (52.9%, n=9), and all received support from their mothers, who were the primary caregivers.

Environmental Factors - Housing Conditions

The average number of household members was 4.52 ± 1.69. It was observed that most participants' homes were made of masonry (64.7%,

n=11), followed by wooden structures (29.4%). The predominant floor type was ceramic (58.8%, n=10), with 35.3% (n=6) having wooden floors. Most households had electricity (94.1%), and all had running water. Only half treated the water they consumed (52.9%), and almost all (94.1%) had an indoor bathroom. The average number of rooms per household was 4.94 ± 1.63.

Environmental factors - Use of Products and Technology

The use of essential products and biomechanical alignment and mobility devices is presented in Table 3, highlighting significant barriers within the context of these patients.

Table 3 - Environmental factors of consumption and use of products and technologies for personal use

Use of Products and Technologies	N	%
Anticonvulsant medication		
Does not use	13	76,5
Uses	4	23,5
Botulinum toxin for spasticity		
Does not use	13	100
Orthoses		
Does not use	15	88,2
Uses	2	11,8
Wheelchair		
Does not use	11	64,7
Not applicable	4	23,5
Uses	2	11,8
Walking assistive devices		
Does not use	12	70,6
Not applicable	3	17,6
Uses	2	11,8

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

Environmental factors - Social Support and Access to Services

Only 35.3% (n=6) received support from other family members, and most did not receive support from friends (n=14).

Regarding support from healthcare professionals, and the use of educational and social systems and policies, numerous barriers were identified, as presented in Table 4.

Table 4 - Environmental factors of services, systems, and policies

Support from Professionals/Systems/Policies	N	%
Nursing		
No	16	94,1
Yes	1	5,9
Physical Therapy		
Yes	17	100
Speech Therapist		
No	15	88,2
Yes	2	11,8
Pediatrician		
No	11	64,7
Yes	6	35,3
Neurologist		
No	12	70,6
Yes	5	29,4
Access to school/daycare		
No	11	64,7
Yes	6	35,3
Receipt of social security benefits/social assistance		
No	9	52,9
Yes	6	35,3
Not informed	2	11,8

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

Discussion

The contextual factors of children and adolescents with CP in a university outpatient clinic in the interior of Amazonas were characterized.

Few factors appeared to facilitate the context of these children and adolescents, with access to physical therapy and maternal support standing out. However, several barriers were identified, such as the absence of social benefits and assistance, low socioeconomic status, lack of access to daycare or schools, inadequate use of medications, insufficient medical follow-up, lack of rehabilitative intervention, and the absence of assistive products and technology such as orthotics, wheelchairs, and walking aids.

In this study, the predominant sociodemographic and functional characteristics, such as age group, gender, and type of CP in this study were similar to those found in studies by Peixoto *et al.* [11] and Teixeira *et al.* [12].

Regarding family characteristics, the fact that most children and adolescents were the only child can be considered a facilitator for better family support. However, the socioeconomic condition of the subjects in this study, with family income predominantly between one and two minimum wages, along with the informal employment of parents, low parental education, and lack of paternal support, represented some barriers. The economic condition found in our study was similar to the findings of Alves *et al.* [13]. Poletto and Koller [14] state that risk situations such as low education levels, low social status, and lack of social and emotional support networks can negatively impact the development of children and adolescents. In our findings, all participants had maternal support as an environmental facilitator, but only half reported having paternal support.

Most of the individuals in this study reside in masonry houses; however, there is no information about the existence of adaptations that facilitate care and mobility within the home. Access to basic services is essential for the health and well-being of children. The availability of services and support systems is a priority environmental factor that affects the quality of life of individuals with CP [15,16].

Our results pointed out environmental barriers related to the lack of botulinum toxin use for managing spasticity, despite it being the most common type of CP among the participants, and the low number of children/adolescents using anticonvulsant medications, which are important for controlling epilepsy. Previous research revealed a slightly different situation [13]. The use of medications can be a relevant factor in managing symptoms and improving the quality of life for people with CP. However, the low usage rate may indicate a lack of access to healthcare professionals or medication, as well as a lack of information about the importance of medications in CP treatment [17,18].

The vast majority of participants do not use orthoses, which constitutes a significant environmental barrier in preventing deformities. Unlike studies from other regions of the country, the use of orthoses was identified as a facilitator [13,19]. The low use of orthoses is an environmental barrier influenced by unfavorable family income, lack of access to specialized healthcare services, and negative attitudes toward the use of assistive devices [20,21]. The perceptions of parents and caregivers regarding the effectiveness of orthoses, along with the lack of financial resources, can also influence their use [18].

The lack of walking aids was an important environmental barrier for most individuals in this study. The low usage of these devices can be attributed to environmental barriers, such as the lack of adequate infrastructure, and social barriers, such as the lack of support and encouragement for using these devices [22]. Additionally, the lack of financial resources for acquisition. Individuals with CP need assistive technologies to reduce difficulties and improve performance in daily activities [23].

These findings reinforce the alignment of public policies that ensure access to these products and devices, especially for those living in remote areas, as they are essential for the rehabilitation and improvement of functionality in children and adolescents with disabilities.

The lack of support from other family members and friends are challenges found in the context of families of children/adolescents with CP, similar to what was found in another study, which demonstrated that family members were more present as an instrumental support network than friends [24]. Authors state that other family members are the primary providers of emotional support and emphasize that such support is essential to prevent the breakdown of relationships within families of people with CP. Family members such as uncles, grandparents, and parents, in addition to providing emotional support, can also provide instrumental or material support, such as financial assistance [24].

Barriers related to access to services, systems, and policies, including healthcare services such as medical follow-up, education, social security benefits, and social aids, are present in the context of most individuals in this study. Most participants did not have medical follow-up with pediatricians, neurologists, or other healthcare

professionals such as nurses and speech therapists. The lack of follow-up by these healthcare professionals can be attributed to various barriers in accessing multidisciplinary health services and may point to failures in the public healthcare system [25].

Physiotherapy interventions were present for all children and adolescents in this study, which may indicate a prioritization of this type of service, possibly due to its importance or the availability of services that are accessible. Despite the presence of physiotherapy, the facility offering the services is located far from large urban centers, in the interior of Amazonas, and lacks modern resources and equipment to stimulate the full potential of these individuals.

Evidence shows that factors such as financial constraints, geographic inaccessibility, and inadequate healthcare resources are barriers to accessing and using healthcare services for children, especially in low- and middle-income countries [26].

Only one-third of the participants in this study attended daycare or school. A previous study in Minas Gerais also identified a significant number of children with CP without access to regular schools or daycare. The authors indicated that several environmental factors could be related to low school attendance, including the lack of appropriate assistive technologies to ensure greater mobility, architectural and attitudinal barriers, and non-adapted environments [13].

Evidence suggests that children from families with lower socio-economic status face more barriers in accessing healthcare and education services. Furthermore, only a small portion of children receive social security benefits or social aids, which may indicate a need for more inclusive policies to support these families [27].

The investigation of environmental barriers and facilitators is crucial to ensuring the participation of children and adolescents with CP in home, school, and community environments. The findings of this study highlight barriers that need to be minimized in order to secure the rights of these individuals and promote their health, well-being, inclusion, and functionality.

This study presents some limitations that should be considered, such as the sample size (n=17), which limits the generalization of the findings to larger populations regarding environmental factors related to children and adolescents with CP in this context, as well as the use of medical records that may be subject to biases related to

completeness and standardization of the recorded information. However, there are no records regarding the environmental barriers faced by people with disabilities in the Amazonian context, particularly those with CP. This study stands out as the first to address this aspect and provide information on challenges that have not been documented in the region. The results obtained allow us to demonstrate and highlight the existence of numerous environmental barriers faced by some children and adolescents with CP in a region like the Amazon, specifically in the state of Amazonas, where geographical particularities are often imposed as challenges for the provision of services and access to modern and technological resources.

Conclusion

This study presented results that revealed significant environmental barriers that can affect the functionality of children and adolescents with CP treated at an outpatient clinic in the interior of

Amazonas. These findings can contribute to discussions and the development of public policies for this population that needs better health services and assistance from a biopsychosocial perspective.

Academic affiliation

This article is the undergraduate thesis of Olívia Maria dos Santos Silva, supervised by Professor Alessandra Araújo da Silva, entitled Environmental Factors of Children and Adolescents with Cerebral Palsy Attended by the Pediatric Physiotherapy Service of a University in the Interior of the 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 kind.

Funding

This study received no financial support.

Author contributions

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

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