








Oral Health Care of Children and Adolescents with Different Impairments of Cerebral Palsy: Barriers and Challenges

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ABSTRACT

Objective: To evaluate the barriers to access and oral health care faced by children and adolescents with Cerebral Palsy (CP) according to their motor impairment through the perception of caregivers. **Material and Methods:** A case series study was carried out at three health institutions in Pernambuco, Brazil. The study sample consisted of 94 caregivers of 5-to-18-year-old patients with CP, according to GMFCS (The Gross Motor Function Classification System). Data were collected using a semi-structured form to evaluate the barriers to access and analyzed statistically by the chi-square and Fisher exact tests, adopting a 5% level of significance. In addition, binary logistic regression was performed to determine the weight of the variables in explaining the outcome variable. **Results:** There were major difficulties involving transportation ($p=0.04$) and structural accessibility to dental services ($p<0.01$) among children and adolescents with severe CP. In addition, the more severe the CP, the greater the difficulty of accessibility ($OR=4.09$), and the lower the income ($OR=8.80$), the greater the motor impairment. **Conclusion:** Despite the availability of access to dental services, low-income families have more severe CP patients, contributing to the daily difficulties already faced by them in oral health care.

Keywords: Cerebral Palsy; Dental Care for Disabled; Epidemiology.

Introduction

Cerebral palsy (CP) is a non-progressive disorder of posture and movement caused by an injury to the central nervous system during the early stages of life and represents the most common form of neuromotor impairment among children [1]. The global prevalence of CP is 2.11 for every 1000 live births, which may be higher according to the decrease in the socioeconomic status of a country [2,3]. Clinical manifestations vary depending on the extent of the lesion and the neurological area involved and are often accompanied by cognitive, sensory, communication and behavioral changes and seizures [4-6].

Individuals with CP have difficulties in carrying out and memorizing activities of daily living such as eating, walking, bathing, dressing, talking, and brushing their teeth [6-8]. Their oral health condition has been investigated and identified in national and international studies [3,6,7,9,10], confirming that no intraoral changes are characteristic of people with CP. However, these individuals are at high risk of developing dental problems such as malocclusion due to abnormal forces in the oral motor muscles, dental trauma, and bruxism. Furthermore, eating problems such as difficulty in swallowing (dysphagia) have been reported, in addition to sialorrhea and difficulties in maintaining adequate oral care due to motor difficulties [6,7,10].

Impaired oral self-care can lead to a greater need for dental treatment, which can increase with the child's age and vary with the severity of CP due to motor changes [3-5]. However, in addition to oral hygiene difficulties, there are obstacles related to the use of dental services by individuals with CP. The reasons cited for disparities in access are related to the availability, proximity, and access to dental services, in addition to the attitudes of caregivers and dental professionals towards CP patients [11,12].

It is known that the current concept of access to dental treatment exceeds by far its traditional meaning and involves patient self-centered factors such as the perception of the need for care and cultural and language differences, among others [13,14]. Besides these factors, the reduced knowledge of caregivers regarding the importance of oral health care, as well as the options to access it, are cited as hindering factors [12,15,16].

The difficulty in performing adequate oral care and the low access to dental services aggravate the oral health situation of this population, considering that these individuals are at higher risk of developing dental caries, periodontal disease, malocclusion, bruxism, and larger amounts of dental biofilm [4,6,9,10]. The susceptibility to caries and periodontal disease is directly linked to inadequate oral hygiene, consistency of the diet, and prolonged retention of food residues in the oral cavity. Another aggravating factor is the continued use of anticonvulsants since some of these medications when associated with the presence of bacterial plaque, can promote gingival hyperplasia, favoring the occurrence of periodontal problems and hindering daily oral hygiene [4,6].

Individuals who do not perform daily oral hygiene correctly, especially people with disabilities, are included in the highest risk category for oral diseases and require more frequent and intensive preventive services, despite the difficulties in obtaining them [8,10,17]. This demonstrates the importance of dental care performed daily by the caregiver, as well as access to dental services for people with CP.

Thus, this study aimed to assess the barriers to access and oral health care faced by children and adolescents with CP according to their motor impairment through caregivers' perception.

Material and Methods

Study Design

An observational case series study was carried out at three health services of different capacities that provide comprehensive continued assistance to children and adolescents with CP. The study was carried out from January to August 2017 in the cities of Recife and Jaboatão dos Guararapes, Pernambuco, Brazil.

Participants and Data Collection

The research participants were all the caregivers of children and adolescents with CP attending the services, which met the eligibility criteria, i.e., being the caregiver of 5- to 18-year-old children or adolescents diagnosed with CP and presenting mild, moderate, or severe motor impairment according to the Gross Motor Function Classification System (GMFCS). The GMFCS level of each child was collected through the institution's motor physiotherapy evaluation form. Caregivers of children and adolescents with pathologies other than CP - assessed based on the diagnosis contained in the patient's medical record - were excluded from the study. The GMFCS [18] is an instrument widely used to classify the degree of motor impairment in children and adolescents with CP according to five ordinal levels (I-II: mild; III: moderate; IV-V: severe) of mobility difficulties and the level of assistance needed by each individual.

Caregivers were contacted as they took their children and adolescents with CP to the health services and gave written informed consent to participate in the research and to permit the publication of the results. They were interviewed individually in the presence of only the researcher in a reserved room of the service, with the data obtained being kept confidential.

A semi-structured form was applied, which contained questions related to the study variables, including the assessment of the socioeconomic and demographic profile of the participants, the diagnosis of motor impairment, use of anticonvulsants, eating habits and oral hygiene of the children/adolescents, their type of access to dental care and the opinion of caregivers about the oral health of the child/adolescent.

Statistical Analysis

Data were analyzed statistically by descriptive analysis, calculating absolute and relative frequencies. The chi-square and Fisher exact tests were used to determine the association between family socioeconomic and demographic conditions, oral hygiene habits, and dental care according to the severity of CP. The severity of CP was divided into two categories: mild/moderate (levels I, II, and III) and severe (levels IV and V). A p-value <0.05 was adopted as statistically significant. In addition, binary logistic regression was performed to identify possible confounding and explanatory variables.

Ethical Clearance

The study was approved by the Ethics Committee on Research Involving Humans of the Federal University of Pernambuco (CEP/UFPE; Protocol 1.979.046) and was conducted in full agreement with the ethical principles of the Declaration of Helsinki, as revised in 2002.

Results

The study included 94 caregivers of 5-to-18-year-old children and adolescents diagnosed with CP. The main caregivers were most frequently represented by the mothers (87.2%), with a slight predominance in the age group of 40 years or more (38.2%); about two thirds (63.8%) had nine years or more of schooling and their monthly income was up to two minimum wages (77.7%).

Assessment of the degree of motor impairment of children and adolescents by the GMFCS revealed that 67% had severe impairment. The age range of the total sample was 5 to 9 years (67%), 64.9% of the subjects were males, and 66% were from the capital and metropolitan region of the State of Pernambuco. Regarding dental care, 8.5% of all participants reported never having visited a dentist, and among those who did, the first visit occurred between 1 and 5 years of age (82.6%).

Table 1 shows the socioeconomic and demographic characteristics of the caregivers and the clinical and dietary variables of the children/adolescents according to the degree of motor impairment. There was a significantly higher percentage of children with severe CP belonging to a low-income group, more frequently living in the capital and metropolitan region of the State of Pernambuco ($p < 0.01$). However, this prevalence is statistically lower than the number of residents of the capital or metropolitan region in the group of patients with moderate and low CP (87.1%).

In addition, younger mother/caregiver was seen to be the person mainly responsible for their oral hygiene ($p < 0.01$), and the group with severe CP was treated with anticonvulsants and received liquid/pasty foods through oral feeding ($p < 0.01$). However, this prevalence of oral feeding is statistically lower than in the group of patients with medium and low levels of CP, in which 96.8% are oral feeding.

Table 1. Characteristics of mothers/caregivers and children/adolescents with cerebral palsy according to the degree of motor impairment.

Variables	Cerebral Palsy			p-value
	Mild/Moderate N (%)	Severe N (%)	Total N (%)	
Mother/Caregiver				
Monthly Family Income [†]				
≤ 2	17 (54.8)	56 (88.9)	73 (77.7)	<0.01*
>2	14 (45.2)	7 (11.1)	21 (22.3)	
Receive Benefit				
Yes	19 (61.3)	59 (93.7)	78 (83.0)	<0.01*
No	12 (38.7)	4 (6.3)	16 (17.0)	
Place of Birth				
Capital and MA [‡]	27 (87.1)	35 (55.6)	62 (66.0)	<0.01*
Countryside	4 (12.9)	28 (44.4)	32 (34.0)	
Age (Years)				
20-29	4 (12.9)	25 (39.6)	29 (30.9)	0.01*
30-39	10 (32.3)	19 (30.2)	29 (30.9)	
≥40	17 (54.8)	19 (30.2)	36 (38.2)	
Education (Years of Study)				
≤ 8	10 (32.3)	24 (38.1)	34 (36.2)	0.74*
≥9	21 (67.7)	39 (61.9)	60 (63.8)	
Child/Adolescent				
Age (Years)				
5-9	17 (54.8)	46 (73.0)	63 (67.0)	0.12*
10-18	14 (45.2)	17 (27.0)	31 (33.0)	
Sex				
Male	20 (64.5)	41 (65.1)	61 (64.9)	0.86*
Female	11 (35.5)	22 (34.9)	33 (35.1)	
Use of Anticonvulsant				
Yes	11 (35.5)	53 (84.1)	64 (68.1)	<0.01*
No	20 (64.5)	10 (15.9)	30 (31.9)	
In affirmative case, what is the daily frequency of use? (n=64)				
1-2 times	2 (18.2)	8 (15.1)	10 (15.6)	0.55**
3 times	9 (81.8)	45 (84.9)	54 (84.4)	
If yes. What is the usage time (years)(n=64)				
≤ 2	9 (81.8)	42 (79.2)	51 (79.7)	0.61**

>2	2 (18.2)	11 (20.8)	13 (20.3)	
Feeding Pathway				
Oral	30 (96.8)	39 (61.9)	69 (73.4)	<0.01*
Tube/Gastrostomy	1 (3.2)	24 (38.1)	25 (26.6)	
Food Consistency				
Liquid/Pasty	6 (19.4)	44 (69.8)	50 (53.2)	<0.01*
Solid	1 (3.2)	2 (3.2)	3 (3.2)	
All	24 (77.4)	17 (27.0)	41 (43.6)	

*Chi-square test; **Fisher's exact test; † = Minimum wage (equivalent to USD 297.79); ‡ = Recife metropolitan area.

The caregivers' report on dental access at any time in the child/adolescent's life or in the last 12 months is shown in Table 2. Access was obtained based on the frequency of going to the dentist, age of the first dental appointment, in addition to means of transport used and if any professional refused to attend to the child. There were no significant differences in oral health care between the two groups studied.

Table 2. Dental access of children and adolescents with cerebral palsy according to the degree of motor impairment.

Variables	Cerebral Palsy			p-value
	Mild/Moderate N (%)	Severe N (%)	Total N (%)	
Have any dentists ever refused assistance?				
Yes	6 (19.4)	24 (38.1)	30 (31.9)	0.11**
No	25 (80.6)	39 (61.9)	64 (68.1)	
Did you ever go to the dentist?				
Yes	28 (90.3)	58 (92.1)	86 (91.5)	0.52**
No	3 (9.7)	5 (7.9)	8 (8.5)	
If yes				
Age of first visit to the dentist (years)				
01 - 05	21 (75.0)	50 (86.2)	71 (82.6)	0.16**
06 - 12	7 (25.0)	8 (13.8)	15 (17.4)	
Transport used				
Car	11 (39.3)	13 (22.4)	24 (27.9)	0.22*
Bus	13 (46.4)	31 (53.5)	44 (51.2)	
By foot	4 (14.3)	14 (24.1)	18 (20.9)	
Last 12 Months				
Visit to the dental office				
None	7 (22.6)	19 (30.2)	26 (27.7)	0.59*
≥1	24 (77.4)	44 (69.8)	68 (72.3)	
If you visited				
Type of service				
Private	10 (55.6)	14 (28.0)	24 (35.3)	0.07*
Public	8 (44.4)	36 (72.0)	44 (64.7)	
Reason for attendance				
Revision	15 (62.5)	21 (47.7)	36 (52.9)	0.30**
Urgency/Treatment	9 (37.5)	23 (52.3)	32 (47.1)	
Difficulties during dental care				
Yes	8 (33.3)	19 (43.2)	27 (39.7)	0.59*
No	16 (66.7)	25 (56.8)	41 (60.3)	

*Chi-square test; **Fisher's exact test.

Table 3 shows the difficulties reported by mothers/caregivers regarding access to dental care. The difficulties involved in not finding a dental service that attends to the disabled child, in addition to difficulties with transport, child collaboration during dental care, low dentists supply, dentist humanization and lack of structural accessibility that allows access to the service. There was a significantly higher proportion of mothers/caregivers who reported difficulties with transportation (p = 0.04) and accessibility to dental services (p<0.01) among children/adolescents with severe CP.

Table 3. Barriers to access to dental care for children and adolescents with cerebral palsy according to the degree of motor impairment.

Variables	Cerebral Palsy			p-value
	Mild/Moderate N (%)	Severe N (%)	Total N (%)	
Faced physical/social barriers				
Yes	24 (77.4)	50 (79.4)	74 (78.7)	0.95*
No	7 (22.6)	13 (20.6)	20 (21.3)	
If yes. What barriers? (n=74)				
Did not find the service				
Yes	16 (66.7)	36 (72.0)	52 (70.3)	0.84*
No	8 (33.3)	14 (28.0)	22 (29.7)	
Difficulty with transportation				
Yes	8 (33.3)	30 (60.0)	38 (51.4)	0.04*
No	16 (66.7)	20 (40.0)	36 (48.6)	
Difficulty with distance				
Yes	8 (33.3)	28 (56.0)	36 (48.6)	0.11*
No	16 (66.7)	22 (44.0)	38 (51.4)	
Child does not collaborate				
Yes	12 (50.0)	32 (64.0)	44 (59.5)	0.37*
No	12 (50.0)	18 (36.0)	30 (40.5)	
Low dentist supply				
Yes	23 (95.8)	47 (94.0)	70 (94.6)	0.61**
No	1 (4.2)	3 (6.0)	4 (5.4)	
Lack of humanization of the dentist				
Yes	13 (54.2)	37 (74.0)	50 (67.6)	0.14*
No	11 (45.8)	13 (26.0)	24 (32.4)	
Lack of accessibility (structural / architectural)				
Yes	14 (58.3)	44 (88.0)	58 (78.4)	<0.01*
No	10 (41.7)	6 (12.0)	16 (21.6)	

*Chi-square test; **Fisher's exact test.

The binary logistic regression shown in Table 4 revealed that the more severe the CP, the greater the difficulty of accessibility (OR=4.09) and the lower the income (OR=8.804). In addition, the parenteral route had a protective role (OR=0.028) for individuals with severe CP.

Table 4. Binary logistic regression according to the degree of CP motor impairment.

Variables	B	S.E.	Wald	df	Sig.	OR	95% CI for OR	
							Lower	Upper
Feeding Pathway	3.569	1.184	9.087	1	0.003	0.028	0.003	0.287
Accessibility Difficulty	1.409	0.562	6.275	1	0.012	4.090	1.359	12.312
Monthly Family Income	2.175	0.664	10.737	1	0.001	8.804	2.397	32.339
Constant	2.246	0.721	9.703	1	0.002	0.106		

Discussion

Among the main findings of the present study was a larger number of patients with severe CP belonging to families with less favored socioeconomic conditions, with significantly higher percentages coming from the outside of the metropolitan region of the state of Pernambuco, with greater difficulties in transportation and with lack of accessibility to dental services. These findings agree with studies reporting a significant association between people with disabilities and unfavorable socioeconomic factors, especially in the presence of severe disabilities [5].

It is known that about 45.6 million Brazilians have some disability. Of these, more than 13.2 million have motor disabilities, and the majority (71.9%) have a monthly household income of up to two minimum

wages. In Pernambuco, over 80% of people with motor disabilities belong to this low-income group, as assessed by IBGE - Brazilian Institute of Geography and Statistics - 2010 Population Census. The present study found that the chance of a child/adolescent with CP having a greater motor impairment was eight times greater for the group of lower socioeconomic condition (income below two minimum wages) due to the difficulties regarding the care offered compared to the group with mild/moderate CP. Indeed, it is already known that caring for a child with a disability increases the demand for resources, with the expenses being three times higher than those for the care of neurotypical children [11,12].

In this study, most participants also stated that they received a benefit, which allows the access of people with disabilities to the minimum conditions of a dignified life [19]. However, even so, the expenses for the care of these children/adolescents with CP are high, especially for the most serious cases, underscoring the importance of better economic conditions that would permit better oral and general health care, minimizing risk factors for these individuals [4,20].

The caregivers reported greater dependence on daily oral health care for children and adolescents with severe motor impairment. Similar studies have demonstrated that individuals with disabilities are highly dependent on a caregiver for activities of daily living, including oral hygiene [14,19]. This poses a burden on caregivers, with the consequent postponement or forgetting of oral hygiene practices, which should not be neglected [15,20-23].

The literature also clearly reports the interference of systemic and motor conditions of patients with disabilities, especially those with CP, with oral hygiene practices [4-7]. In addition, there is an effect of the type of food administered - predominantly liquid/pasty consistency - and of the frequent use of anticonvulsant medications, which often have high sucrose content and can cause xerostomia [4,6,16]. In this study, individuals with severe CP had significantly higher percentages of food received through the tube/gastrostomy, with the ingestion of food of pasty/liquid consistency and the continuous use of anticonvulsants, showing that this group has a higher risk to develop oral diseases such as caries and periodontal disease, as previously reported in the literature [3,6,7,9,10]. Thus, it is worth highlighting the importance of parent and caregiver counseling by dental surgeons about the oral hygiene of these individuals in particular - including those who receive parenteral nutrition - since the difficulty in oral health care is also a barrier that needs to be overcome as soon as possible.

Although the daily life of children and adolescents with CP involves many types of treatment, it is worth noting that dental care should be started as early as possible to avoid oral diseases in this population. Dental care - whether provided by a specialist or a generalist - should involve prevention with guidance on the care to be provided by the caregiver at home and regular office visits to promote oral health. Instructions on brushing should also be included, as well as clarifications about the importance of a non-cariogenic diet and the execution of the necessary dental procedures [11,19,20].

Public dental care for these individuals includes Basic Health Units for primary care and Centers of Dental Specialties for secondary care. These Specialty Centers created according to the National Oral Health Policy (PNSB) of 2002 seek to reduce inequities in access to specialized dental services - including care for people with special needs - and thus contribute to reducing oral health-related morbidity. Therefore, they represent a social achievement regarding the universal right to oral health through reducing barriers to access for these individuals [24].

The data of the present study regarding the caregivers' report on dental access at any time in the life of the child/adolescent or during the last 12 months are important for dental clinical practice because they

demonstrate the search for access to dental services. In addition, they underscore the importance of early care and the establishment of healthy oral practices to avoid oral diseases that can arise in patients with CP [6,10,16].

Most participants reported having access to dental services for their children/adolescents, most of whom used public oral health services, had an early first visit to the dentist (between one and five years of age) and used these services more than once in the previous 12 months. The positive findings of these results may be related to initiatives directed at the structuring of the Care Network for People with Disabilities, the aim of which is to expand access and improve the quality of care for disabled individuals in the Brazilian public healthcare system and the Smiling Brazil Program, which includes comprehensive care for patients with special needs [25].

However, the oral health status of the children/adolescents with severe CP reported by the participants and the most prevalent reason for visiting a dentist (treatment/urgent care) suggest problems in the effectiveness of health promotion strategies and prevention measures for controlling oral problems in this population. These aspects also reveal frailties in offering comprehensive oral health care by public dental services accessed by the population with CP [25,26].

The data from the present study referring to caregivers' reports on dental access at any time in the child/adolescent's life or in the last 12 months are important for the clinical dental practice, as they demonstrate the search for access to dental services. In addition, they emphasize the importance of early care and the establishment of healthy oral practices to avoid oral diseases that can arise in patients with CP [6,10,16].

Most participants reported having access to dental services for their children/adolescents, most of whom used public oral health services, had a first dental appointment (between one and five years of age) and used these services more than once in the previous twelve months. The positive findings of these results may be related to initiatives aimed at structuring the Care Network for People with Disabilities, whose objective is to expand access and improve the quality of care for people with disabilities in the Brazilian public health system, and the Smiling Brazil Program, which includes comprehensive care for patients with special needs [25].

However, the oral health status of children/adolescents with severe CP reported by the participants and the most prevalent reason for dental appointments (treatment/urgency) suggest problems in the effectiveness of health promotion strategies and prevention measures to control the problems in this population. These aspects also reveal weaknesses in providing comprehensive oral health care through public dental services accessed by the population with CP [25,26].

Other issues reported by the participants should be considered in this discussion, such as the low availability of dentists and the low level of humanization of dentists in caring for children/adolescents with CP. The low availability of dentists for patients with special needs remains a problem in Brazil, although it is one of the few countries that offer registered dental specialties to treat such patients [26,27]. In addition, professional barriers involved in dental care for patients with special needs are identified, such as technical and emotional difficulties, gaps in educational background and lack of professional training [28].

Then, the low degree of humanization in dental care may be related to these barriers, demonstrating possible problems regarding educational policies and professional qualifications for the care of this population to achieve broad and comprehensive oral health care, humanized through actions in primary care [28].

Among the barriers to dental care mentioned, the difficulty of transportation and the lack of structural/architectural accessibility were significantly higher among individuals with severe CP. A state initiative, the “Pernambuco Conducts - paths to accessibility” (PE Conduz) program, offers adapted quality transport and accessibility to health services to people with a high level of disability but does not include dental services. It covers the metropolitan area of Recife, in addition to some hubs in the hinterland of the state. However, the present data show that not all children and adolescents with severe CP in the studied sample are covered by this program in terms of access to dental services; hence, more initiatives of this type are needed to expand access to these services.

The present data are similar to those reported in previous studies showing lower access to dental services by children and adolescents with more severe motor or intellectual impairment, in addition to problems related to the use of these services, such as the lack of transportation and structural/architectural accessibility [29,30]. This reality must also be analyzed considering socioeconomic disparities that can hinder the access to and use of oral health services by children and adolescents belonging to less financially favored families [11].

Children and/or adolescents with severe CP were found to be four times more likely to have difficulties with structural/architectural accessibility in their daily lives. Considering these aspects, such findings demonstrate difficulties in complying with intersectoral public policies that include accessibility and adapted quality transport, which would facilitate the routine of mothers/caregivers and improve the quality of access of people with CP to health services, e.g., regarding a visit to the dental surgeon. In addition, these results corroborate other studies in which structural/architectural accessibility and transportation to dental services were reported to be the main difficulties experienced by mothers of a child with CP [20,29].









The GMFCS in this study was of great value because it allowed the assessment of children and adolescents with CP according to the level of motor impairment severity [18], helping to understand the difficulties of daily life, including oral health care and access to dental services.

It is important to highlight that the results of this research cannot be extrapolated to the entire population of patients with CP due to the nature of the case series design of the study. However, this study demonstrated the occurrence of greater challenges in daily oral health care for subjects with severe CP in addition to access barriers to dental services, with the assistance of these families being extremely important to meet their economic and social demands and to guide the attitude towards the provision of dental care to this population.

Conclusion

Despite the perceived availability of access to dental services on the part of caregivers, access barriers still exist, such as the lack of accessibility and transportation for the population of children and adolescents with severe CP from lower-income families, contributing to the daily difficulties already faced by them in oral health care.

Authors' Contributions

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All authors declare that they contributed to critical review of intellectual content and approval of the final version to be published.

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Conflict of Interest

The authors declare no conflicts of interest.

Data Availability

The data used to support the findings of this study can be made available upon request to the corresponding author.

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