# Oral health care for children and adolescents with cerebral palsy: perceptions of parents and caregivers

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**Abstract** The aim was to evaluate the oral health care of children/adolescents with Cerebral Palsy (CP) according to severity through the perceptions of parents/caregivers. A case series study was conducted at health services in the state of Pernambuco, Brazil with 94 mothers/caregivers of subjects with CP from 5 and 18 years old. Sociodemographic factors, oral health care and use of dental services (DS) were evaluated. The Gross Motor Function Classification System showed 67% with severe motor impairment. Subjects with severe CP had significantly higher frequencies of belonging to families with lower income (89%, p < 0.001), living in the interior (44%, p < 0.005), having transportation difficulties (60%, p = 0.04), difficulty regarding access to DS (88%, p = 0.009) and a greater need for oral hygiene (67%, p = 0.008), which was performed exclusively by the caregiver (94%, p < 0.001). Despite identified access barriers, dental care was facilitated for those with severe CP, early DS use, but low availability of dentists and low degree of humanization were cited as major problems. These results reveal problems related to daily oral health care, family living context, institutional support and quality of DS that should be addressed in comprehensive, inclusive, equitable social and economic public policies. Key words Cerebral palsy, Child, Adolescent, Dental care for disabled, Social conditions

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#### Introduction

Cerebral palsy (CP) is a non-progressive posture and movement disorder caused by damage to the central nervous system and is the most common neuromotor disorder in children. The clinical manifestations of the disorder vary depending on the extent of the damage and the affected neurological area1.

Both national and international studies have characterized the oral health status of individuals with CP<sup>2-6</sup>, with reports of greater frequencies of caries experience, periodontal disease, malocclusion and bruxism as well as a greater quantity of dental biofilm<sup>2</sup> in this population with special needs<sup>7,8</sup>, which can increase with the age of the child and vary depending on the severity of the disorder. 4,9 The vulnerability to caries is associated with the greater exposure to sociodemographic, family, clinical and behavioral risk factors in this population.<sup>6,10</sup> Studies report that children with CP submitted to social deprivation are those with a greater occurrence of caries. 4,10,11 Proximal risk factors include difficulty regarding activities of self-care in daily living, such as eating, walking, bathing, dressing, talking and brushing one's teeth<sup>2-4</sup>. Moreover, the types of foods consumed<sup>4,7</sup> and abnormal movements of the facial muscles favor the prolonged retention of foods in the oral cavity<sup>6,7</sup>.

Despite the recognition of the oral health needs of patients with CP<sup>5,6</sup>, which require specific public policies<sup>12</sup>, there are reports of barriers to the use of dental services<sup>5,13-15</sup>. Such barriers involve not only the availability, proximity and accessibility of dental services, but also the attitudes and beliefs of caregivers, dentists and individuals with disabilities 13,14,16.

In Brazil, although the implementation of the National Oral Health Policy in 2004 enabled advances in the structuring of oral health care on all levels and included the unprecedented assurance of comprehensive care for patients with special needs, difficulties persist in the access to and offer of comprehensive, resolutive care<sup>12,17,18</sup>. Children and adolescents with special needs repeatedly encounter problems, such as the low availability of trained dentists, scheduling delays and the need for general anesthesia<sup>5</sup>. Moreover, the fragile communication among levels of care compromises the comprehensiveness and intersectoral nature of actions necessary for oral health promotion in these patients, which constitutes another barrier regarding access to care<sup>10,17</sup>.

Despite the growing production of studies addressing the need for oral health care on the part of patients with special needs<sup>6,19</sup>, such production remains insufficient<sup>6,20,21</sup>. There is a gap in knowledge regarding the perceptions of parents and caregivers regarding the oral health care that should be offered to children and adolescents with CP5,6,20 on the different levels of health care that provide services for this population.

Therefore, the aim of the present study was to evaluate the oral health care of children and adolescents with cerebral palsy who use services specialized in the treatment of patients with special needs through the perceptions of mothers and caregivers.

#### Methods

An observational, case series study was conducted at three healthcare services of different sizes that offer care to children and adolescents with CP. This study was conducted in the city of Recife (capital of the state of Pernambuco, Brazil) at the pediatric gastroenterology and rehabilitation (physical therapy, speech therapy and occupational therapy) services of the hospital affiliated with the Federal University of Pernambuco, the physical therapy sector of the Pepita Duran Multiservice Clinic and the physical therapy sector of the Perrone Foundation in the neighboring city of Jaboatão dos Guararapes. All parents/caregivers of children and adolescents with CP who utilized these services between January and August 2017 were invited to participate in the study.

The inclusion criteria were being a parent/ caregiver of a child or adolescent with a clinical diagnosis of CP between five and 18 years of age with mild to severe motor impairment based on the Gross Motor Function Classification System (GMFCS). Parents/caregivers of children and adolescents with CP who had a congenital malformation not related to a chromosome disease, those with severe hearing or vision impairment and those with cognitive deficit were excluded from the study. After the application of these eligibility criteria, the sample was composed of 94 individuals.

The GMFCS is widely used to classify the degree of motor impairment in children and adolescents with CP on five levels (I-II: mild; III: moderate; and IV-V: severe) based on the child's/ adolescent's disabilities and level of dependence<sup>22</sup>.

Data collection involved interviews with the parents/caregivers using a questionnaire designed by the researcher and tested previously. The majority of questions were closed-ended and pre-coded. Some questions were open-ended and addressed the perceptions of parents/caregivers with regards to the oral health care of the child or adolescent.

The parents/caregivers were contacted upon bringing their children and adolescents with CP to the aforementioned services. Those who agreed to participate signed a statement of informed consent. The interviews were held in a reserved space at the service with only the parent/caregiver and researcher present to ensure the confidentiality of the data.

Data were collected on socioeconomic and demographic characteristics of the participant, the diagnosis of motor impairment, the use of anticonvulsants, eating habits, oral hygiene habits, child's/adolescent's history of access to dental care and the participant's opinion regarding her/his own oral health and the oral health of the child or adolescent.

Descriptive analysis (absolute and relative frequencies) was performed. Either the chisquare test with the Yates correction for binary tables or Fisher's exact test (when appropriate) was employed to test associations between CP severity and socioeconomic/demographic characteristics of the family, oral hygiene habits and dental care. For this analysis, CP severity was dichotomized as mild/moderate (levels I, II and II) or severe (levels IV and V). A p-value < 0.05 was considered indicative of statistical significance.

This study received approval from the Human Research Ethics Committee of the Center for Health Sciences of the Federal University of Pernambuco. Children/adolescents with treatment needs were sent to the special needs dental clinic of the Department of General and Preventive Dentistry of the university.

### Results

Ninety-four parents/caregivers of children and adolescents with CP participated in the present study. The main caregiver was predominantly the mother (87.2%), with a slight predomination of the age group 40 years or older (38.2%). Approximately two-thirds had nine or more years of schooling (63.8%) and 77.7% received up to two times the Brazilian monthly minimum wage. Regarding the degree of motor impairment among the children/adolescents evaluated using the GMFCS, 31 (33%) had mild impairment (levels I, II and III) and 63 (67%) had severe impairment (levels IV and V). The majority (67%) was between five and nine years of age; 64.9% were

boys and 66% were residents of the city of Recife and the metropolitan region. Regarding dental care, 8.5% had never been to the dentist. Among those that had been to a dentist, the first visit occurred between one and five years of age. Among the children/adolescents with severe CP, significantly higher percentages were found of a low income, residence outside metropolitan Recife, a younger mother/caregiver, the use of an anticonvulsant and feeding through a tube/gastrostomy with liquids and pasty foods (Table 1).

Table 2 displays the oral hygiene characteristics of the sample. Oral hygiene was performed significantly more often by the caregiver alone, who experienced difficulty due to the non-cooperation of the child/biting on the toothbrush. The use of moistened gauze/cloth to clean the teeth and the non-use of dental floss were frequent (Table 2).

Table 3 displays the perceptions of the parents/caregivers regarding their own oral health and the oral health of the child/adolescent. Significantly higher percentages of parents/caregivers perceived a greater need for oral health care for the child/adolescent. The majority (94.6%) stated that oral problems could have consequences, with significantly higher proportions of parents/caregivers of children/adolescents with severe CP citing toothache (p=0.03) as well as a negative impact on dental esthetics (p=0.01) and the behavior of the child/adolescent (p=0.008).

Table 4 displays the reports of the parents/ caregivers regarding access to dental care at some time in the life of the child/adolescent and in the past 12 months. No significant differences were found between the two groups studied (mild/severe motor impairment).

Table 5 displays the difficulties regarding access to oral health care. A significantly larger proportion of parents/caregivers of children/adolescents with severe CP reported difficulties in terms of transportation and access to dental services (p = 0.04 and p = 0.009, respectively).

#### Discussion

The present study was conducted to investigate the views of mothers and caregivers regarding oral health care for 94 children and adolescents with CP who utilized services directed at patients with special needs as well as identify associations between the severity of CP and socioeconomic/demographic, family and oral health care characteristics.

Table 1. Characteristics of mothers/caregivers and children/adolescents with cerebral palsy according to degree of motor impairment, Recife, 2017.

		_		
Variables	Total	Total Mild/Moderate		_ p
	N = 94 (%)	n (%)	n (%)	
Mother/caregiver				
Family income				
$\leq 2 \times BMMW$	73 (77.7)	17 (54.8)	56 (88.9)	< 0.001
$> 2 \times BMMW$	21 (22.3)	14 (45.2)	7 (11.1)	
Receives benefits				
Yes	78 (83.0)	19 (61.3)	59 (93.7)	< 0.001
No	16 (17.0)	12 (38.7)	4 (6.3)	
Place of residence				
Recife and metropolitan region	62 (66.0)	27 (87.1)	35 (55.6)	0.005
Other region of state	32 (34.0)	4 (12.9)	28 (44.4)	
Age (years)				
20-29	29 (30.9)	4 (12.9)	25 (39.6)	0.01
30-39	29 (30.9)	10 (32.3)	19 (30.2)	
≥ 40	36 (38.2)	17 (54.8)	19 (30.2)	
Schooling (years of study)				
≤8	34 (36.2)	10 (32.3)	24 (38.1)	0.74
≥9	60 (63.8)	21 (67.7)	39 (61.9)	
Child/Adolescent				
Age (years)				
5-9	63 (67.0)	17 (54.8)	46 (73.0)	0.12
10-18	31 (33.0)	14 (45.2)	17 (27.0)	
Sex	(1111)	( /	( ,	
Male	61 (64.9)	20 (64.5)	41 (65.1)	0.86
Female	33 (35.1)	11 (35.5)	22 (34.9)	0.00
Use of anticonvulsant	()	()	(= )	
Yes	64 (68.1)	11 (35.5)	53 (84.1)	< 0.001
No	30 (31.9)	20 (64.5)	10 (15.9)	( 0.001
If yes,	20 (31.5)	20 (01.0)	10 (10.7)	
Daily frequency (n = 64)				
1-2 times	10 (15.6)	2 (18.2)	8 (15.1)	0.55*
3 times	54 (84.4)	9 (81.8)	45 (84.9)	
If yes,	(0 1.1)	. (32.0)	(52.7)	
Duration of use $(n = 64)$				
≤2 years	51 (79.7)	9 (81.8)	42 (79.2)	0.61*
> 2 years	13 (20.3)	2 (18.2)	11 (20.8)	
Feeding route	(20.0)	= (10 <b>.2</b> )	(20.0)	
Oral	69 (73.4)	30 (96.8)	39 (61.9)	< 0.001
Tube/gastrostomy	25 (26.6)	1 (3.2)	24 (38.1)	. 0.001
Food consistency	25 (20.0)	1 (3.2)	21 (30.1)	
Liquid/pasty	50 (53.2)	6 (19.4)	44 (69.8)	< 0.001
Solid	3 (3.2)	1 (3.2)	2 (3.2)	\ 0.001
All	41 (43.6)	24 (77.4)	17 (27.0)	

<sup>\*</sup> Fisher's exact test; BMMW = Brazilian monthly minimum wage.

Among the main findings, a significantly larger number of individuals with severe CP were from families with a less privileged socioeconomic status, resided outside the metropolitan region of the state capital and had no access to dental services. These results are in agreement

**Table 2.** Oral hygiene habits of children/adolescents with cerebral palsy according to degree of motor impairment, Recife, 2017.

Variables	Total	Mild/Moderate	Severe	_ p
	N = 94 (%)	n (%)	n (%)	
Who performs hygiene				
Child with/without caregiver	25 (26.6)	21 (67.7)	4 (6.3)	< 0.001
Caregiver alone	69 (73.4)	10 (32.3)	59 (93.7)	
Daily frequency				
1-2 times	46 (48.9)	15 (48.4)	31 (49.2)	0.88
≥ 3 times	48 (51.1)	16 (51.6)	32 (50.8)	
Time spent on daily oral care (min)				
1-10	82 (87.2)	28 (90.3)	54 (85.7)	0.39*
11-20	12 (12.8)	3 (9.7)	9 (14.3)	
Difficulty performing hygiene				
Yes	69 (73.4)	19 (61.3)	50 (79.4)	0.10
No	25 (26.6)	12 (38.7)	13 (20.6)	
If yes,				
Bites brush/does not cooperate $(n = 69)$				
Yes	62 (89.9)	14 (73.7)	48 (96.0)	0.01*
No	7 (10.1)	5 (26.3)	2 (4.0)	
Use of toothbrush				
Yes	92 (97.9)	31 (100.0)	61 (96.8)	0.45*
No	2 (2.1)	0 (0.0)	2 (3.2)	
Use of moistened gauze/cloth				
Yes	46 (48.9)	5 (16.1)	41 (65.1)	< 0.001
No	48 (51.1)	26 (83,9)	22 (34.9)	
Use of dental floss				
Yes	16 (17.0)	12 (38,7)	4 (6.3)	< 0.001
No	78 (83.0)	19 (61.3)	59 (93.7)	

<sup>\*</sup> Fisher's exact test.

with data described in previous studies, which reported associations between disabilities and an unfavorable socioeconomic status, especially among individuals with more severe forms of disability<sup>23,24</sup>.

According to a study conducted by the Brazilian Institute of Geography and Statistics using data collected in 2010, 45.6 million Brazilians have at least one disability. Among those aged 10 years or older, 46.4% earn only up to the Brazilian monthly minimum wage. In the state of Pernambuco, this number is more than 50 thousand individuals with motor disability living in a low-income situation. The study also reveals that most individuals with disability have lower levels of schooling and academic performance<sup>25</sup>.

Caring for a child with a disability increases the demand for resources, as expenses are three times higher compared to those for children with typical development<sup>16,23</sup>. In the present study, most participants reported receiving benefits, which given individuals with disability a minimum capacity to lead a decent life<sup>26,27</sup>. However, the mothers of disabled children/adolescents belonging to lower social strata often leave their jobs to perform the daily care of their children<sup>17,20,24</sup>. Thus, the precarious living conditions seen among mothers/caregivers of the children/adolescents, especially those with more severe CP, can exert a strong negative impact on the oral health care of these children/adolescents as well as the quality of life<sup>28</sup> of both the caregiver and child/adolescent, as perceived by the participants of the present study.

The mothers/caregivers reported dependence regarding daily oral health care as well as a greater need for oral hygiene, especially among the children/adolescents with more severe motor impairment. Previous studies report that individuals with special needs are highly dependent

Table 3. Perception of mothers/caregivers regarding own oral health and oral health of children/adolescents with cerebral palsy according to degree of motor impairment.

	Cerebral Palsy				
Variables	Total	Mild/Moderate	Severe	_ р	
	N = 94 (%)	n (%)	n (%)	_	
Mother's/caregiver's self-rated oral health		-			
Satisfactory (good or fair)	67 (71.3)	23 (74.2)	44 (69.8)	0.84	
Needs improvement (poor)	27 (28.7)	8 (25.8)	19 (30.2)		
Access to dentist					
Yes	62 (66.0)	21 (67.7)	41 (65.1)	0.98	
No	32 (34.0)	10 (32.3)	22 (34.9)		
If yes,					
Type of service $(n = 62)$					
Private	32 (51.6)	13 (61.9)	19 (46.3)	0.37	
Public	30 (48.4)	8 (38.1)	22 (53.7)		
Child's/adolescent's need for oral hygiene					
Greater need for care	53(56.4)	11 (35.5)	42 (66.7)	0.008	
Same as other children/adolescents	41 (43.6)	20 (64.5)	21 (33.3)		
Child/adolescent currently has oral health					
problem?					
Yes	74 (78.7)	23 (74.2)	51 (81.0)	0.62*	
No	20 (21.3)	8 (25.8)	12 (19.0)		
If yes,					
Problems have consequences? $(n = 74)$					
Yes	70 (94.6)	22 (95.7)	48 (94.1)	0.63*	
No	4 (5.4)	1 (4.3)	3 (5.9)		
If yes,					
what consequences? $(n = 70)$					
Cause toothache					
Yes	65 (92.9)	18 (81.8)	47 (97.9)	0.03*	
No	5 (7.1)	4 (18.2)	1 (2.1)		
Cause stress					
Yes	62 (88.6)	18 (81.8)	44 (91.7)	0.20*	
No	8 (11.4)	4 (18.2)	4 (8.3)		
Affect eating					
Yes	54 (77.1)	18 (81.8)	36 (75.0)	0.74	
No	16 (22.9)	4 (18.2)	12 (25.0)		
Affect behavior					
Yes	66 (94.3)	18 (81.8)	48 (100.0)	0.008*	
No	4 (5.7)	4 (18.2)	0 (0.0)		
Affect dental esthetics					
Yes	64 (91.4)	17 (77.3)	47 (97.9)	0.01*	
No	6 (8.6)	5 (22.7)	1 (2.1)		

<sup>\*</sup> Fisher's exact test.

upon a caregiver for the performance of activities of daily living, including oral hygiene<sup>29,30</sup>, which places a burden on caregivers and, consequently, the postponement or forgetting of oral hygiene practices<sup>6,29</sup>. Moreover, caregivers face a set of problems on a daily basis, such as fatigue, sleep disorders, weight loss, hypertension, lower social/

emotional wellbeing, isolation, social exclusion, depression, a negative impact on relationships and the loss of life prospects<sup>20,28</sup>.

These problems can exert a negative impact on the quality of care offered to disabled individuals, affecting the general and oral health of both the care recipient and provider<sup>6,28</sup>. There are also

**Table 4.** Reports of mothers/caregivers regarding access to dental care by children/adolescents with cerebral palsy according to degree of motor impairment, Recife, 2017.

		Cerebral	Palsy	
Variables	Total	Mild/Moderate	Severe n (%)	_ p
	N = 94 (%)	n (%)		
Has any dentist ever refused to provide care?				
Yes	30 (31.9)	6 (19.4)	24 (38.1)	0.11*
No	64 (68.1)	25 (80.6)	39 (61.9)	
Ever visited a dentist?				
Yes	86 (91.5)	28 (90.3)	58 (92.1)	0.52*
No	8 (8.5)	3 (9.7)	5 (7.9)	
If yes,				
Age at first visit to dentist (years)				
1-5	71 (82.6)	21 (75.0)	50 (86.2)	0.16*
6-12	15 (17.4)	7 (25.0)	8 (13.8)	
Transportation used				
Car	24 (27.9)	11 (39.3)	13 (22.4)	0.22
Bus	44 (51.2)	13 (46.4)	31 (53.5)	
Walking	18 (20.9)	4 (14.3)	14 (24.1)	
Last 12 months				
Visit to dentist				
None	26 (27.7)	7 (22.6)	19 (30.2)	0.59
≥1	68 (72.3)	24 (77.4)	44 (69.8)	
If visited,				
Type of service				
Private	24 (35.3)	10 (55.6)	14 (28.0)	0.07
Public	44 (64.7)	8 (44.4)	36 (72.0)	
Reason for visit				
Checkup	36 (52.9)	15 (62.5)	21 (47.7)	0.30*
Urgent care/Treatment	32 (47.1)	9 (37.5)	23 (52.3)	
Difficulty during dental care				
Yes	27 (39.7)	8 (33.3)	19 (43.2)	0.59
No	41 (60.3)	16 (66.7)	25 (56.8)	

<sup>\*</sup> Fisher's exact test.

problems related to institutional support, which should be primarily directed at family caregivers in situations of social vulnerability<sup>19,26</sup>, who require basic health educational interventions as well as psychosocial counseling and social assistance<sup>17,26,27</sup>.

Based on the perceptions of the participants, most children/adolescents with severe CP have oral health problems that may be related to the occurrence and severity of caries, although the majority of caregivers reported being the person responsible for the oral hygiene of these subjects, performing it three times a day and being concerned regarding the oral hygiene of this population. The participants reported toothache, compromised esthetics and a change in the child's behavior as the consequences of dental caries.

These results are in agreement with findings described in previous studies reporting that higher levels of caries are concentrated in children/adolescents with CP, who are both biologically and socially vulnerable<sup>4,10,11</sup>.

Factors on the proximal level involved in the manifestation and severity of caries should be considered in this population. The literature reports the influence of systemic and motor conditions found in patients with special needs, especially those with CP¹, on oral hygiene practices²-6.9, such as the type of food (predominantly of a liquid and pasty consistency)⁴,7 and frequent use of anticonvulsant medications with a high sucrose content⁶.8.

In agreement with these findings, aspects reported by the parents/caregivers in the present

**Table 5.** Difficulties reported by mothers/caregivers who faced barriers regarding access to dental care for children/adolescents with cerebral palsy according to degree of motor impairment, Recife, 2017.

	Cerebral Palsy			
Variables	Total	Mild/Moderate	Severe n (%)	p
	N = 94 (%)	n (%)		
Experienced physical/social barriers				
Yes	74 (78.7)	24 (77.4)	50 (79.4)	0.95
No	20 (21.3)	7 (22.6)	13 (20.6)	
If yes, which? $(n = 74)$				
Did not find service				
Yes	52 (70.3)	16 (66.7)	36 (72.0)	0.84
No	22 (29.7)	8 (33.3)	14 (28.0)	
Transportation difficulty				
Yes	38 (51.4)	8 (33.3)	30 (60.0)	0.04
No	36 (48.6)	16 (66.7)	20 (40.0)	
Difficulty with distance				
Yes	36 (48.6)	8 (33.3)	28 (56.0)	0.11
No	38 (51.4)	16 (66.7)	22 (44.0)	
Child uncooperative				
Yes	44 (59.5)	12 (50.0)	32 (64.0)	0.37
No	30 (40.5)	12 (50.0)	18 (36.0)	
Low availability of dentist				
Yes	70 (94.6)	23 (95.8)	47 (94.0)	0.61*
No	4 (5.4)	1 (4.2)	3 (6.0)	
Lack of humanization from dentist				
Yes	50 (67.6)	13 (54.2)	37 (74.0)	0.14
No	24 (32.4)	11 (45.8)	13 (26.0)	
Lack of accessibility (structural/architectonic)				
Yes	58 (78.4)	14 (58.3)	44 (88.0)	0.009
No	16 (21.6)	10 (41.7)	6 (12.0)	

<sup>\*</sup> Fisher's exact test.

study, such as a low level of cooperation on the part of the children/adolescents to achieve effective oral hygiene, the prevalence of liquids and pasty foods and the greater use of anticonvulsants by those with severe CP, can increase the risk of caries by favoring the retention of food substrates on dental surfaces<sup>4,7,11</sup>. The greater frequencies of toothache perceived in the group with severe CP lend support to these suppositions and may be interpreted as evidence of the accumulation of risk in different domains<sup>31</sup>, with the consequent synergism of risk factors in areas of social vulnerability<sup>31</sup>, which affect children/adolescents at earlier ages from birth onwards.

Despite the need for dental care tailored to their conditions<sup>30</sup>, the lower access to dental services for children and adolescents with physical and mental disabilities and problems related to the use of these services remain barriers<sup>5,13,16,32</sup>. These aspects should be analyzed considering disparities of a social and economic order found in both Brazil<sup>15,33,34</sup> and other countries<sup>13,14,23</sup> that hinder access to and the use of oral health services by children and adolescents belonging to less privileged social strata.

Among the barriers regarding access to dental care cited in the present investigation, those referring to transportation difficulties and a lack of accessibility were more frequent in the reports of caregivers of children and adolescents with more severe CP, although this population has the right to adapted transportation of quality and accessibility and lives in places where the state initiative "Pernambuco Conducts – paths to accessibility"

has been implemented, which consists of special, free-of-charge services to facilitate the mobility of individuals with higher levels of disability<sup>35</sup>.

The present findings suggest the occurrence of difficulties in fulfilling intersectoral public policies on adapted transportation of quality and accessibility that would facilitate the routine of parents/caregivers and improve the access of individuals with CP to healthcare services, such as going to the dentist. These results are also in agreement with findings described in previous studies reporting that transportation and accessibility to oral health services are the main difficulties faced by mothers of children with CP5,16,24. However, the majority of participants reported having access to dental services for themselves and 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. These results are in agreement with data reported in previous studies conducted in primary care, which identified improvements in the access of special needs patients to dental care<sup>36,37</sup>. However, problems that exert an negative influence on the effectiveness of dental care for this population were also found<sup>36</sup>.

The positive findings 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 needs12,17,18. 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 the offer of comprehensive oral health care by public dental services accessed by the population with  $CP^{36}$ .

Other issues perceived by the participants should be considered in this discussion, such as the low availability of dentists and the low level of humanization of dentists when providing care for the children/adolescents. The low availability of dentists for patients with special needs continues to be a problem in Brazil, even though it is one of the few countries that offer registered dental specialties for such patients<sup>38</sup> and is where the expansion of the offer of dental services and

healthcare units intensified beginning in 2004 with the National Oral Health Policy<sup>18,31,39</sup>.

National studies point out a set of professional barriers involved in dental care for patients with special needs, such as difficulties of a technical and emotional nature, gaps in the educational background<sup>17,37,40</sup> and a lack of professional training<sup>12,40</sup>. The perception of the participants regarding the low degree of humanization in dental care may be related to these barriers, demonstrating possible problems regarding educational policies and professional training for providing care to this population<sup>12</sup> to achieve broad, humanized oral health care through actions on the primary care level<sup>12,17,37,39,41</sup>. Such professional difficulties related to the offer and humanization of health care are limiting factors with regards to ensuring quality care for the population with special needs, affecting the motivation and establishment of a bond between dentists in the public sector and the patients who use these services. This is one of the challenges to be addressed in oral health care policies to ensure access to comprehensive quality care to which this population has a right.

The major limitation of the present study was the use of a convenience sample (case series), which confers low external validity to the findings. The major strength of this study was the methodological care taken during the data collection so that the results indeed expressed the opinions of the participants, minimizing information bias.

This study demonstrated the occurrence of greater difficulties regarding daily oral health care of children/adolescents with severe CP. Despite the barriers regarding access to public dental services, the majority of parents/caregivers perceived facilitated access, with the early use of these services, but with problems related to the quality of the care offered.

## Final considerations

Based on the present findings, the problems perceived by mothers/caregivers of children/adolescents with CP need to be addressed by integral, inclusive, equitable, socioeconomic and health policies that result in an improvement in quality of life as well as comprehensive, humanized oral health care to which the population with special needs has a right. Moreover, professional barriers related to access to oral health care require greater investments in training through continued education. Such investments should be founded on

the precepts of expanded access to treatment and the national policy of the humanization of health care, with greater involvement and commitment in the occurrence of the social disadvantages and oral health needs of children and adolescents with CP, especially those with severe motor impairment.

#### Collaborations

ELMS Silva and MC Lima participated in all phases of the study and writing of the manuscript. PSA Góes, MMVB Vasconcelos, SR Jamelli, SH Eickmann and MMDC Melo contributed to the interpretation of the data as well as the writing and revision of the manuscript.

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