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Functioning profile and related impairments of children and adolescents with cerebral palsy - PartiCipa Brazil preliminary results

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Abstract

Background Limited information is available about functioning and related impairments of children and adolescents with Cerebral Palsy (CP) in low- and middle-income countries (LMIC) like Brazil. The aim of this study is to describe the characteristics, functioning, and impairments of Brazilian children and adolescents with CP.

Methods Cross-sectional preliminary study as part of the PartiCipa Brazil multicentered cohort study. Families of children and adolescents with CP from Brazil, 4 months to 15 years, were enrolled. They responded to an online survey with questions about their child's health condition, impairments, contextual factors, and functioning according to the Gross Motor Function Classification System (GMFCS) and the Manual Ability Classification System (MACS). Data were described as frequencies, percentages, means, and standard deviations, according to age bands.

Results Of the 404 participants (6.5±3.6 years) enrolled in this preliminary analysis, 54.7% are male, 90.4% under 12 years of age, 77.7% have bilateral CP, 49% in GMFCS levels IV and V, and 50.7% in MACS levels II and V. Most participants are from Southeast (63.4%) and Centre-west (19.5%) of Brazil. Regarding the impairments and functioning limitations: 1 in 2 did not talk; 1 in 2 has epilepsy; 2 of 5 reports pain, 1 of 4 has visual impairments, 3 out of 5 did not feed themselves, 1 out of 20 has a hearing impairment and 1 of 4 did not go to school.

Conclusion This first preliminar Brazilian study shows a high prevalence of children at MACS levels II and V and GMFCS levels IV and V, representing almost half of the group, indicating more impairments and limitations than children/adolescents from high-income countries. This study provides a preliminary deeper understanding of the key impairments and limitations in activities among children and adolescents with CP from various Brazilian regions.

Keywords Cerebral palsy, Functioning, Neurodevelopmental disorders, Low- and Middle-income countries

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Background

Cerebral palsy (CP) is the most common physical disability in childhood [1]. It is well known that CP describes a group of permanent disorders of the development of movement and posture, causing activity limitation and participation restriction [2]. The motor dysfunctions of CP are often accompanied by disturbances of sensation, perception, cognition, communication, behavior, epilepsy, and secondary musculoskeletal problems [2]. Although brain injury in CP is nonprogressive, the co-occurring impairments and limitations might change over time, potentially decreasing functioning and quality of life [3]. Additionally, the contextual factors related to where these children live can impact positively or negatively their functioning in different settings [4, 5].

A systematic review summarized the evidence of related impairments in children with cerebral palsy in high-income countries (HIC: Europe, United Kingdom, North America, and Australia based on CP register population data) and found, with high-grade evidence, that: 1 in 3 could not walk; 1 in 4 could not talk; 1 in 4 had epilepsy; and 1 in 25 were deaf [1]. Furthermore, there is moderate-quality evidence that 3 in 4 experienced pain; 1 in 2 had an intellectual disability; 1 in 3 had a hip displacement; 1 in 4 had a behavior disorder; 1 in 4 had bladder control problems; 1 in 5 dribbled; 1 in 10 were blind; 1 in 15 were tube-fed [1]. Taken together, it's important to highlight that the related impairments of children and adolescents with CP has been a topic of interest around the globe, motivating the development of more systematic reviews [6–11].

It has been reported that children and adults with CP who are unable to walk are more likely to experience these related impairments, however the risk for pain and behavioral problems occurs equally at all levels of the Gross Motor Function Classification System (GMFCS) [1]. Additionally, a study based on European population CP registries demonstrated that among children GMFCS levels IV and V, 75% had an associated severe intellectual impairment, 58% active epilepsy, and 25% severe visual impairment [12]. The authors stated that the burden of the condition was strongly dependent on CP subtype and the presence of related impairments [12]. Studies on co-occurring impairments in children from low-income (LICs) and low- and middle-income countries (LMICs) are scarce [13, 14].

On the other hand, research interest in CP epidemiology across countries has grown during the past 10 years, even in LMICs. Population-based data are also now emerging from regions of LICs and LMICs where higher rates of CP have been reported, especially in Africa, Bangladesh, and Uganda [15–17]. However, the CP etiologies and care in these countries differ from HICs, potentially being negatively influenced by contextual factors such as housing, health care, access to assistive devices, early diagnosis, and referral for therapy [4, 5, 16]. McIntyre et al. [18], found that the prevalence of CP in LMICs ranged from 3.3 to 3.7/1000 born children, while in the HIC the prevalence dropped to 1.6/1000 [18]. In HIC, there are significant and sustained declines in the birth prevalence of CP [18–22]. These findings have been attributed to clinical improvements in public health, maternal, and perinatal care [23, 24]. Because most births worldwide occur in LICs and LMICs, it is important that updates on the prevalence of CP and co-occurring impairments include data from these regions. The Bangladesh Cerebral Palsy Registry reported that only 50% of children with CP had access to rehabilitation [25]. Additionally, late referrals and higher levels of GMFCS are also more prevalent than in HIC [25, 26]. In Vietnam, only 2.6% of children who would have benefitted from assistive technology had wheelchairs [14].

In contrast, data from Brazil are scarce. A study performed in one of the Brazilian Northeast states (Sergipe), including 240 children and adolescents with CP, reported that the most common co-occurring impairments were epilepsy (48.3%), and intellectual disability (33.7%) [27]. The children were mainly male (56.3%), had black or brown skin (67.5%), and bilateral spastic CP (42.4%) [27]. Another study conducted in the Northeast of the country (Maceio), showed a prevalence of CP 140.4% higher than the highest prevalence found in HIC countries [28]. However, there is a lack of data from most Brazilian regions. Neither study conducted in Brazil reported data related to functioning [27, 28]. It has been hypothesized that the CP developmental trajectories in LMICs, like Brazil, might be more adverse, depending on access to healthcare and assistive technology [25]. It has been stated that people in Brazil usually depend on the public health system for health care and access to technology, which can be scarce in some parts of the country. However, to date there are no Brazilian studies investigating these outcomes.

Taken together, the scarcity of epidemiological and functioning information makes it difficult to manage and treat children with CP in LMIC countries. Given that most of the etiological factors of CP that make this health condition so prevalent in LMIC are modifiable and preventable, it is essential to have information on the extent of disability and functioning limitations of people with CP. This information can allow health professionals and managers to allocate the necessary resources for intervention, while also enabling parents to actively participate in the process, share decisions, and select the most suitable services for their children's needs. This a novel preliminary study aimed to describe the characteristics, functioning profile and related impairments of Brazilian children and adolescents with CP across the country.

Methods

This cross-sectional study is part of a multicentered cohort study entitled PartiCipa Brazil, which aims to create longitudinal curves of the functioning of children and adolescents with CP [5]. Families of children and adolescents with CP from 0 to 15 years throughout Brazil were invited to participate. The children were recruited mainly from public university rehabilitation centers in five large regions of the country (Southeast, Northeast, Central-West, North, and South), other general rehabilitation centers, referrals from researchers, and social networks. The family could respond to the questionnaire using their electronic devices or with the help of a researcher at the rehabilitation center. The recruitment of the study began on January 21st, 2021, during the COVID-19 pandemic, and this manuscript reports the preliminary data from the participants enrolled for the first evaluation, until 30th of September of 2023. Ethical approval was obtained (CAAE: 28540620.6.1001.5133) and all caregivers (i.e. parents or guardians of the children and adolescents that composed the sample of the study) were provided information of all the stages of the study, and those who agreed to participate signed an online informed consent term (i.e. the data collection started during the COVID-19 pandemic) and received a copy of the consent term.

The inclusion criteria were children and adolescents diagnosed with CP, born after 2007. Participants with clinical neuromotor characteristics and/or history consistent with CP, such as spasticity or mobility impairments, were included in the study if, in the judgment of the health professionals providing their therapies, these children 'look like' they have CP, even if no formal diagnosis had been given [5, 29]. Children under 2 years of age should have a confirmed diagnosis of CP to be included. The exclusion criteria were children and adolescents with other recognized neuromotor health conditions such as myelomeningocele, Down syndrome, or muscle dystrophies.

The sample size calculation was considered the formula for a finite population [30]. According to data from the Brazilian Demographic Census of 2021, the size of the population of children and adolescents in Brazil was assumed to be 41,051,100 million (19% of the population) [31, 32]. The prevalence for the occurrence of an unknown outcome (i.e., having a child with CP) was 70%, with a 95% confidence level and a sampling error of 6% points, resulting in a minimum of 224 participants to be included in this study.

Instruments and procedures

The main caregiver responded to an online survey with questions (supplementary material) about their child's health condition, related impairments (i.e., presence of eating and communication functions, epilepsy, hearing and visual functions, intellectual capacity, pain), information related to possible cause(s) of CP and diagnosis, contextual factors, and functioning based on the GMFCS (for gross motor), and Manual Ability Classification System (MACS) (for manual abilities).

Information on Health conditions and related impairments

The children and adolescents were described according to type of CP, such as unilateral or bilateral; type of muscle tone impairment – spastic, dyskinetic or ataxic, according to the parents' knowledge. The primary caregiver completed the information about contextual factors, including personal child factors (e.g., age, gender, educational level, CP etiology, age of CP diagnosis) and environmental factors (e.g., the Brazilian state of residence, and family income related to number of current minimum wages received; one minimum wage – for a working person with a registered job, in Brazil is approximately 250 dollars). Also, information on co-occurring health conditions and impairments in sensory, motor, and communication areas was completed in the questionnaire.

Functioning level

Participants' mobility was classified by the valid and reliable GMFCS [33]. GMFCS uses a five-level ordinal scale to describe the level of independence in postural control and mobility of children and adolescents with CP, stratified by age bands: < 2 years, 2 to <4 years, 4 to <6 years, 6 to <12 years, and 12 to 18 years of age [33]. Level I describe the most functional children, who walk independently and go up and down stairs without assistance. In contrast, level V represents children with lesst function, being full-time wheelchair users, with limited head and trunk control [33]. Caregivers filled the GMFCS family report, according to the respective age of the child/adolescent [34, 35].

The manual abilities of children and adolescents with CP from 4 to 18 years of age were classified using the MACS [36]. Children below 4 years of age were not classified. MACS uses a GMFCS-type five-level ordinal scale to describe the level of independence in using the hands for daily activities. Level I describes the most functional children, who use their hands without any assistance and have appropriate performance, whereas level V represents children with less function, who cannot use their hands even in the simplest activities [36]. Caregivers were provided with a description of the MACS, according to the MACS level identification chart and instructions for completing the scale, to identify the level that best represents their child's performance [37].

The literature reports the GMFCS and MACS are reliable to be reported by families of children and adolescents with CP [38–40]. Studies conducted in various

countries, including Canada, the United Kingdom, Sweden, Australia, and South Korea, have demonstrated high levels of reliability between parents and therapists for both the GMFCS and the MACS (ICC≥0.9) [33, 34, 36, 38–43]. In addition, Imms et al. demonstrated that there was stability in the caregivers' responses to both classifications over a 12-month period (ICC ⩾0.92) [37]. In Brazil, studies have also been conducted that have shown moderate to high reliability for the GMFCS (ICC=0.59–0.83 and k⩾0.7) and reasonable reliability for the MACS (ICC=0.79 and k⩾0.36) [38–40].

Data analysis

A descriptive analysis was performed of the characterization data of individuals, estimating the mean for numerical variables and frequency measures for categorical variables. The analyses were done according to age bands and GMFCS levels. All data were organized and analyzed in Microsoft Excel tables.

Results

In total, 404 Brazilian children and adolescents with CP, with ages ranging from 4 months to 15 years (6.5±3.6 years), were included in this preliminary study. Table 1 reports the descriptive characteristics of the participants. They were 54.7% male, 90.4% under 12 years of age, 77.7% presented bilateral involvement, 52.2% had spastic CP, and 41.1% of the caregivers did not know what type of CP their child had. GMFCS levels IV and V summed up to almost half of the sample (48.8%), and the GMFCS III was the least prevalent (11.6%). Of the participants classified by MACS (n=268), 35 (8.7%) caregivers of children over 4y didn't respond and 101 (24.8%) were younger than 4y of age. Of those that responded, 28.3% were MACS II and 22.4% were MACS V. The most prevalent conditions reported as the cause of CP were problems during gestation (27.7%) and hypoxia during labor (22%), with 64.6% being diagnosed before the first year of age. Half of the participants from the whole sample attended regular public schools (49%), 10.6% attended special school, and 108 (26.7% − 1 out of 4) did not attend school.

Regarding the family and environmental factors, 93.6% of the respondents were mothers; the majority didn't have paid work; and 61.4% had family income of less than 500 dollars/month. The majority depended on the Public Health System (57.3%) and did not receive the government benefit (52.5%). Participants are residents of all regions of Brazil, but mostly in the Southeast (57.5%) and Centre-west (16.6%). Table 2 presents the main family and environmental characteristics of the participants.

Table 3 presents the related impairments of the children and adolescents. In the total sample of participants: 48.8% did not walk (i.e., according to the GMFCS levels IV and V); 45.7% had epilepsy; 24.2% had a visual deficiency, 4.7% had a hearing impairment, 41.7% of parents reported their child experienced pain; 48.6% had communication limitations; 58.0% were fed by someone or had a G-tube; and 17.6% had medications for sleep disorders. Figure 1 summarizes the main results.

Discussion

To our knowledge, this is the first Brazilian study to describe the functioning profile and impairments of children and adolescents with CP across the country. This study was able to enroll 404 participants with CP and their families. In summary, the participants were mainly male, under 12 years, with bilateral involvement, spastic CP and, MACS II and V. GMFCS levels IV and V summed up to almost half of the group. The higher representation of males in our study aligns with the prevailing gender distribution observed in CP cases worldwide [22]. Additionally, we observed a predominance of bilateral and spastic CP, which is consistent with findings from various CP registries conducted internationally [18, 22, 44, 45]. The main causes of CP reported by respondents were related to pre- and peri-natal factors. Our findings indicate that the prevalence of most impairments is higher in this context than in HIC. Furthermore, one in four children with CP does not attend school. Additionally, families reported having limited resources to care for their children, with the majority depending on the Brazilian Public Health System.

Regarding impairments, it is known that the more associated impairments, poorer the functioning [2, 12]. In our study, related impairments were part of the child's health condition in 72.3% of children. A country with a similar monthly income (less than 500 USD) to the sample in this study, Bangladesh, has a similarly high proportion (81%) of children with cerebral palsy (CP) with at least one associated impairment and a higher prevalence of severe motor involvement (71%) [46]. In that country, being classified in GMFCS levels III-V significantly increased the odds of different types of associated impairments in those children [46].

Almost 50% of the children and adolescents that participated in this study were classified in GMFCS levels IV and V. This result contrasts with the prevalence reported in updates from Europe and Australia [22], where more than 52% of children were classified in levels I and II. Our findings align with a study from India where 57.7% of children were classified as level V [47]. These results are likely attributable to the contextual factors of LICs, LMICs and upper-middle-income countries (UMICs). Despite differences in classifications according to the World Bank, due to the varying gross domestic products (GDPs) per capita of each country, families in these regions face situations of social inequality and challenges in accessing health services and adequate prenatal care.

Table 1 Personal characteristics of the Brazilian children and adolescents with cerebral palsy, according to the total number of participants and per GMFCS levels

	Total ***N* (%)**	**GMFCS I** ***N* (%)**	**GMFCS II** ***N* (%)**	**GMFCS III** ***N* (%)**	**GMFCS IV** ***N* (%)**	**GMFCS V** ***N* (%)**	**No GMFCS (< 2 years)** ***N* (%)**
Participants	404 (100)	52 (12.9)	84 (20.8)	47 (11.6)	59 (14.6)	138 (34.2)	24 (5.9)
Age (Mean - SD)	6.5 (3.6)	7.7 (3.6)	7.6 (2.9)	6.4 (3.6)	7.3 (3.73)	6.0 (3.5)	1.3 (0.8)
Age bands							
< 1 y	8 (2.0)	0 (0)	1 (1.2)	0 (0)	0 (0)	0 (0)	7 (29.2)
1-1.99 y	39 (9.7)	1 (1.9)	2 (2.4)	11 (23.4)	7 (11.9)	2 (1.4)	16 (66.6)
2-5.99 y	163 (40.1)	17 (32.7)	29 (34.5)	14 (29.7)	21 (35.5)	81 (58.7)	1 (4.2)
6-11.99 y	156 (38.6)	23 (44.3)	46 (54.7)	18 (38.3)	23 (39)	46 (33.3)	0 (0)
> 12 y	39 (9.7)	11 (21.1)	6 (7.2)	4 (8.6)	8 (13.6)	10 (7.2)	0 (0)
Sex							
Female	183 (45.3)	21 (40.4)	44 (52.4)	15 (31.9)	18 (30.5)	72 (52.2)	13 (54.2)
Male	221 (54.7)	31 (59.6)	40 (47.6)	32 (68.1)	41 (69.5)	66 (47.8)	11 (45.8)
MACS							**MACS% without those that didn't respond**
MACS I	58 (14.6)	18 (34.6)	23 (27.4)	10 (21.3)	6 (10.2)	1 (0.7)	58 (21.7)
MACS II	76 (18.8)	19 (36.5)	31 (36.9)	10 (21.3)	12 (20.3)	4 (2.9)	76 (28.3)
MACS III	40 (9.9)	3 (5.8)	10 (11.9)	6 (12.8)	10 (17)	11 (8.0)	40 (14.9)
MACS IV	34 (8.4)	2 (3.8)	5 (6.0)	1 (2.1)	9 (15.3)	17 (12.3)	34 (12.7)
MACS V	60 (14.8)	3 (5.8)	3 (3.6)	1 (2.1)	2 (3.4)	51 (36.9)	60 (22.4)
Didn't inform	35 (8.7)	2 (3.8)	8 (9.5)	6 (12.8)	10 (16.9)	9 (6.5)	
No MACS (< 4 y)	101 (24.8)						
Type of CP							
Spastic	211 (52.2)	27 (51.9)	41 (48.8)	30 (63.8)	27 (45.8)	79 (57.2)	7 (29.2)
Dyskinetic	18 (4.5)	0 (0)	4 (4.8)	0 (0)	1 (1.7)	11 (8.0)	2 (8.3)
Ataxic	9 (2.2)	2 (3.8)	1 (1.2)	1 (2.1)	4 (6.8)	1 (0.7)	0 (0)
Doesn't know	166 (41.1)	23 (44.2)	38 (45.2)	16 (34)	27 (45.8)	47 (34.1)	15 (62.5)
Topography							
Bilateral	314 (77.7)	2 (3.8)	47 (56)	44 (93.6)	59 (100)	138 (100)	24 (100)
Unilateral	90 (22.3)	50 (96.2)	37 (44)	3 (6.4)	0 (0)	0 (0)	0 (0)
Causes							
Problems during gestation	112 (27.7)	20 (38.6)	26 (31)	14 (29.8)	20 (33.8)	30 (21.7)	2 (8.3)
Hypoxia during labor	89 (22.0)	7 (13.4)	21 (25)	13 (27.6)	8 (13.6)	29 (21.0)	12 (50.0)
Problems after birth	53 (13.1)	5 (9.6)	11 (13)	5 (10.6)	5 (8.5)	23 (16.7)	4 (16.8)
Prematurity	29 (7.2)	2 (3.8)	5 (6)	2 (4.2)	7 (11.9)	12 (8.7)	1 (4.1)
Other diseases*	28 (6.9)	4 (7.7)	6 (7)	2 (4.2)	2 (3.4)	12 (8.7)	2 (8.3)
Genetic	18 (4.5)	0(0)	0 (0)	3 (6.3)	4 (6.8)	10 (7.2)	1 (4.1)
Accidents	6 (1.5)	1 (1.9)	1 (1.2)	0 (0)	0 (0)	4 (2.9)	0 (0)
Doesn't know	11 (2.7)	3(5.9)	1(1.2)	2(4.3)	1(1.7)	2(1.4)	2(8.3)
Diagnostic age							
< 1 y	262 (64.6)	28 (53.8)	45 (53.6)	25 (53.2)	35 (59.3)	108 (78.3)	21 (87.5)
1–2 y	88 (21.8)	15 (28.8)	20 (23.8)	16 (34.0)	15 (25.4)	21 (15.2)	1 (4.2)
> 2 y	43 (10.6)	6 (11.5)	18 (21.4)	4 (8.5)	8 (13.6)	7 (5.1)	0 (0)
Doesn't know	11 (2.7)	3 (5.9)	1 (1.2)	2 (4.3)	1 (1.7)	2 (1.4)	2 (8.3)
Schooling							
Regular public school	198 (49.0)	30 (57.7)	54 (64.3)	29 (61.7)	34 (57.6)	49 (35.5)	2 (8.3)
Special public school	43 (10.6)	5 (9.6)	6 (7.1)	6 (12.8)	2 (3.4)	22 (15.9)	2 (8.3)
Private school	55 (13.6)	10 (19.2)	19 (22.6)	6 (12.8)	14 (23.4)	6 (4.3)	0 (0)
Doesn't go to school - total	108 (26.7)	7 (13.5)	6 (12.8)	6 (12.8)	9 (15.3)	61 (44.2)	
Doesn't go to school – >4y	35 (8.7)	3 (5.8)	4 (4.8)	0 (0)	4 (6.8)	24 (17.4)	

Legend GMFCS: Gross Motor Function Classification System; MACS: Manual Abilities Classification System; SD: standard deviation; N: number of participants; y: years. *e.g.: meningitis

Table 2 Family and environmental characteristics of the responders of the study

Respondents of the questionnaires	***N*** **= 404 (100)**
Relationship with the child	
Mom	378 (93.6)
Dad	16 (4.0)
Grandmother or Grandfather	7 (1.7)
Legal guardian	1 (0.2)
Another	2 (0.5)
School Years	
Kindergarten	15 (3.7)
Elementary school incomplete	41 (10.1)
Elementary school complete	18 (4.5)
High school incomplete	26 (6.4)
High school complete	125 (30.9)
College/University incomplete	47 (11.6)
College/University complete	113 (28.0)
Master or Doctor Degree	8 (2.0)
Never studied	11 (2.7)
Occupation	
Housewife	138 (34.2)
Paid job	3 (23.0)
Autonomous	81 (20.0)
Unemployed	73 (18.1)
Retired	7 (1.7)
Volunteer	7 (1.7)
Student	5 (1.2)
Family Income (minimum wage < U$ 250,00)	
< 1 minimum wage	19 (4.7)
1–2 minimum wage	229 (56.7)
> 2 minimum wage	156 (38.6)
Receives income from the government	
Yes	192 (47.5)
No	212 (52.5)
Main Health Service	
Public Health System (SUS)	232 (57.3)
Health Plan System (insurance)	142 (35.1)
Private Health System	31 (7.6)
Brazil Region	
North	1 (0.2)
Northeast	59 (14.6)
Centre-west	67 (16.6)
Southeast	232 (57.5)
South	45 (11.1)

Legend N: number of participants; SUS: Sistema Único de Saúde/ Public Health System

Furthermore, a notable lack of knowledge about CP exists among populations in these countries, which can influence the quality of care provided [25, 48]. Similarly, reports from other LICs (including Uganda), LMICs (such as Bangladesh, Nepal, Ghana, and Vietnam), and UMICs countries (such as Indonesia), have demonstrated a higher prevalence of severe forms of CP associated with low socioeconomic status, poor rehabilitation status, and poor access to assistive technology [14, 25, 44, 46, 49–51]. It is important to highlight that GMFCS level III was the least prevalent, probably due to the lack of access to adequate mobility equipment [52].

Regarding the manual skills, our study revealed a relatively balanced representation of children across levels, with a slightly higher prevalence of level II. This finding suggests that, despite the more important involvement in gross motor function, in many children manual abilities are relatively preserved, corroborating with other studies (from South Korea and Italy) [53, 54].

The presence of epilepsy in our study was twice as frequent as in HIC, which can be related to the high prevalence of this disorder in those with more significant involvement [55]. Our rate is also higher than the epilepsy rate found in Bangladesh (33%) [46], and in China (17.9%) [56]. This high rate of epilepsy and medication use (50.5%) reported by parents may partly reflect some children having had a seizure in the neonatal period who do not later develop epilepsy. The fact that we didn't have access to the medical files of the participants of this study, adds a limitation to the interpretation of this data.

The presence of pain and sleep disorders in children with CP are both associated with poorer quality of life and has been a subject of attention in scientific studies and clinical practice [57]. Our participants presented a lower pain rate than the rate found in other studies [1, 58]. Despite our numbers being lower, in clinical practice we know that children more severely compromised usually have more difficulties to report pain than those with milder disabilities. Furthermore, a small portion of participants receive pain medication, demonstrating that this condition is most likely not being assessed by professionals and therefore not treated. A study in Denmark using questionnaires for parents of 120 children with cerebral palsy aged between 2 and 19 years found that half of children with cerebral palsy suffered from chronic pain. Among these children, three-quarters did not receive sufficient treatment for their pain [59]. The low medication in relation to the proportion of pain reports may be related to many factors, such as (1) parents may be reluctant to give more medications to their child; (2) families have difficulties to access the medications or (3) the use of other non-pharmacological strategies such as physiotherapy, massages, swimming exercise, and assistive devices [60].

The same difficulty may also happen to diagnose communication and intellectual impairments in our participants, as many probably are not assessed with proper standardized cognitive and language assessments. Our study and the previous Brazilian study [27] demonstrated a rate of intellectual disability of 27.9% and 33%, respectively, while the rate is 50% in HIC [1], 50% in India [58], and 58% in China [56]. As noted, this variation may

Table 3 Associated impairments, presence of pain, forms of communication, eating and drinking, and medication in use of the participants of the study, according to the total number of participants and per GMFCS levels

	Total *N* (%)	GMFCS I *N* (%)	GMFCS II *N* (%)	GMFCS III *N* (%)	GMFCS IV *N* (%)	GMFCS V *N* (%)	No GMFCS (< 2 years) *N* (%)
Participants	404 (100)	52 (12.9)	84 (20.8)	47 (11.6)	59 (14.6)	138 (34.2)	24 (5.9)
Associated impairments							
Epilepsy	184 (45.7)	13 (25.0)	29 (34.5)	15 (31.9)	21 (35.6)	90 (65.5)	16 (66.7)
Intellectual disability	113 (27.9)	8 (15.4)	30 (35.7)	10 (21.3)	11 (18.6)	54 (38.8)	0 (0)
Visual impairment	98 (24.2)	5 (9.6)	18 (21.4)	9 (19.1)	13 (22.0)	46 (33.1)	7 (29.2)
Respiratory disease	56 (13.8)	5 (9.6)	12 (14.3)	9 (19.1)	5 (8.5)	23 (16.5)	2 (8.3)
Hearing impairment	19 (4.7)	2 (3.8)	3 (3.6)	3 (6.4)	1 (1.7)	9 (6.5)	1 (4.2)
Cardiac disease	7 (1.7)	1 (1.9)	2 (2.4)	1 (2.1)	1 (1.7)	2 (1.4)	0 (0)
Others	48 (11.9)	4 (7.7)	10 (11.9)	3 (6.4)	7 (11.9)	22 (15.8)	2 (8.3)
Does not present other health condition	112 (27.7)	26 (50.0)	20 (23.8)	17 (36.2)	23 (39.0)	21 (15.1)	7 (29.2)
Presence of pain							
Yes	169 (41.7)	25 (48.1)	45 (53.6)	17 (36.2)	28 (47.8)	50 (36.2)	4 (16.7)
No	201 (49.9)	26 (50.0)	35 (41.7)	25 (53.2)	28 (47.8)	73 (52.9)	14 (58.3)
Can't refer pain	34 (8.4)	1 (1.9)	4 (4.8)	5 (10.6)	3 (5.1)	15 (10.9)	6 (25.0)
Communication							
Verbal	197 (48.7)	45 (86.5)	66 (78.6)	30 (63.8)	34 (57.6)	18 (13)	4 (16.6)
Some impairment	117 (29)	6 (11.5)	18 (21.4)	15 (31.9)	14 (23.7)	57 (41.3)	7 (29.2)
Nonverbal	84 (20.8)	1 (1.9)	0 (0)	1 (2.1)	10 ()	59 (42.7)	13 (54.2)
Alternative and augmentative communication*	6 (1.5)	0 (0)	0 (0)	1 (2.1)	1 (1.7)	4 (2.9)	0 (0)
Eating and Drinking							
Dependent for feeding or drinking	189 (46.8)	7 (13.5)	19 (22.6)	20 (42.6)	34 (57.6)	92 (66.6)	17 (70.8)
Independent for feeding or drinking	170 (42.1)	45 (86.5)	63 (75.0)	27 (57.4)	25 (42.4)	9 (6.5)	1 (4.2)
Tube-fed	45 (11.1)	0 (0)	2 (2.4)	0 (0)	0 (0)	37 (26.9)	6 (25.0)
Medications in use							
For seizures	204 (50.5)	13 (25.0)	30 (35.7)	14 (29.8)	25 (42.4)	102 (73.9)	20 (83.3)
For sleep	71 (17.6)	7 (13.5)	10 (11.9)	9 (19.1)	7 (11.9)	34 (24.6)	4 (16.7)
For spasticity/hypertonia	71 (17.6)	1 (1.9)	4 (4.8)	8 (17.0)	9 (15.3)	40 (29)	9 (37.5)
For respiratory problems	33 (8.2)	4 (7.7)	4 (4.8)	2 (4.3)	5 (8.0)	17 (12.3)	1 (4.2)
For pain	14 (3.5)	0 (0)	3 (3.6)	1 (2.1)	2 (3.4)	7 (5.1)	1 (4.2)
For cardiac problems	2 (0.5)	1 (1.9)	1 (1.2)	0 (0)	0 (0)	0 (0)	0 (0)
Others	38 (9.4)	3 (5.8)	14 (16.7)	5 (10.6)	2 (3.0)	11 (8.0)	3 (12.5)
Doesn't use medications	135 (33.4)	30 (57.7)	34 (40.5)	21 (44.7)	25 (42.0)	23 (16.7)	2 (8.3)

*Tablet, computer, communication board

Legend GMFCS: Gross Motor Function Classification System; n: number of participants

reflect ascertainment bias (relatively low levels of available assessment resources). Another important hypothesis to think, is that the participants of this study, had a mean age of 7 years, making it even harder to diagnose the intellectual capacity as a disability or developmental learning disability.

Our results demonstrated that half of the Brazilian children with CP that participated in this study doesn't talk, which is high compared to a 25% prevalence in HIC [1]. Of the 51.3% of the participants that didn't use their voices to speak, 18% had some impairment in communication, 1.5% used alternative communication devices, and 20.8% (84 children) were non-verbal. Of the latter, only 13 children were under 2 years of age, expected not to be talking yet. Of the non-verbal, 69 children were classified as levels IV and V of the GMFCS. These findings corroborate with the results from India and China, which also showed a rate of 50% and 48%, respectively, of children who do not talk [56, 58]. Despite this result, communication devices are used by only 1.5% of children in our group; this possibly means that many of those who would benefit from these resources may not have access to them.

Another significant aspect of this study is that 1 out of 4 children do not go to school, and specifically, 44.2% of those functioning at GMFCS level V do not attend school. In Brazil, compulsory education begins at age four [61]. Our findings indicate that 8.7% of children

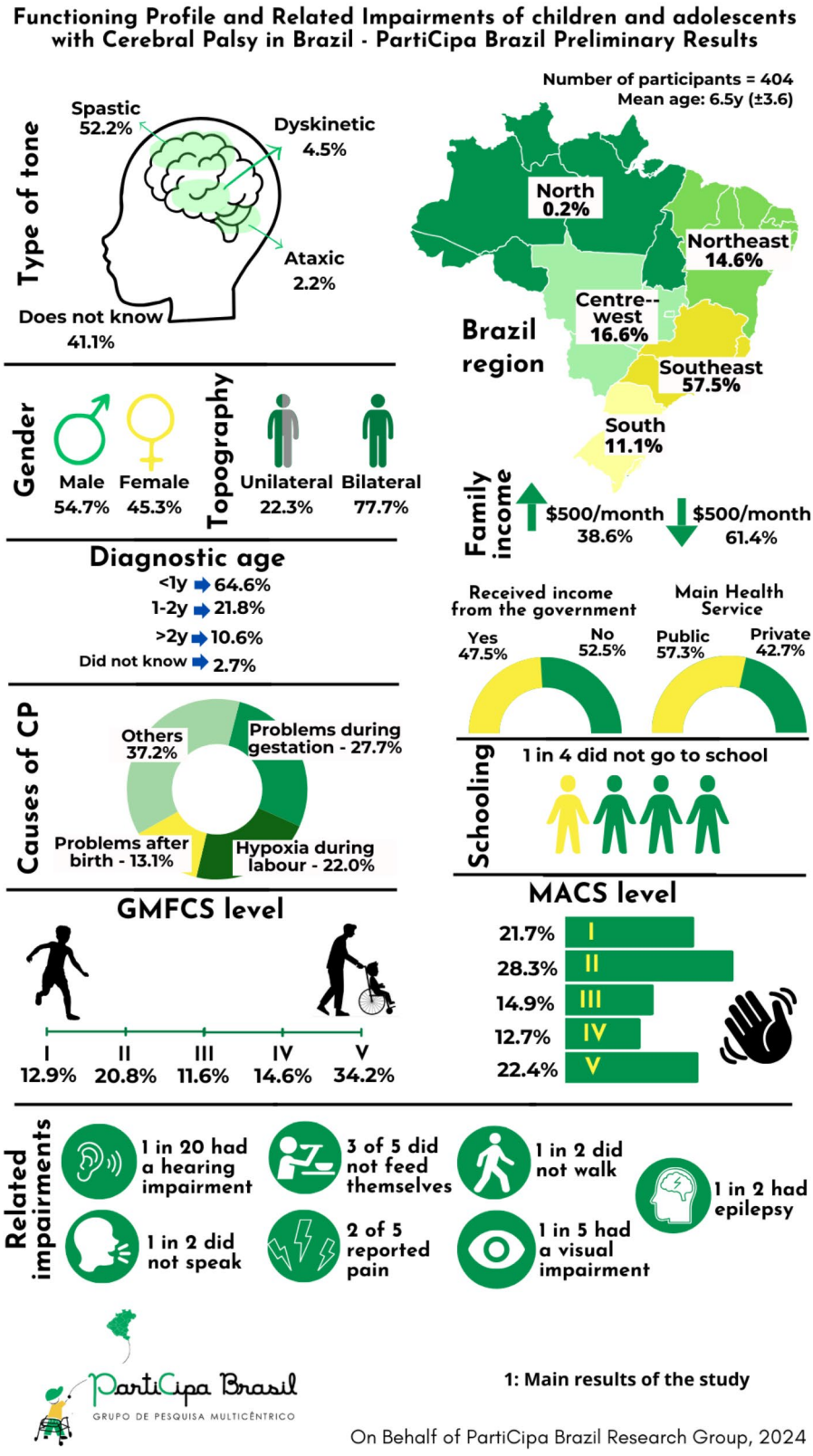

Fig. 1 Main results of the study. Legend: GMFCS: Gross Motor Function Classification System; MACS: Manual Abilities Classification System; N: number of participants; y: years

over this age were not attending school and 17.4% of these children were classified as level V on the GMFCS. These numbers are even higher in other LMIC studies [44, 62]. Even in HIC, school participation for children/adolescents with CP is a challenge, with reports of substantially lower school achievement compared with a general population [63]. These results can be attributed to intellectual and communication impairments; however, not all children with CP with severe motor or communication impairment have intellectual disabilities [63]. In Brazil, even though children with disabilities have the right to receive additional educational support, including a teaching assistant, they possibly face other challenges, such as environmental barriers that include lack of transportation, inadequate school shifts, and lack of preparation and resources to meet the needs of these children. Also, the lack of assistive technology can limit better integration and communication of the child in the school environment.

A noteworthy result is that 41% of families in our study were unaware of the specific CP type of their child. This finding highlights a significant communication gap between healthcare services and families and emphasizes the importance of having empathic and respectful conversations with families of children/adolescents with CP [64]. When families are aware of the characteristics of their child's condition, health status and prognosis, they can become more involved in rehabilitative and preventative interventions, such as preventing hip dislocation [65].

In this study, the main causes of CP were problems during gestation and hypoxia during labor, and the children were mostly diagnosed before the first year of age, which may be correlated to almost half of our sample being classified at GMFCS levels IV and V. These results are consistent with the literature that shows that, despite the advances in prenatal and perinatal care, disturbances caused by possible modifiable and preventable factors in these periods are still the main cause of CP [23, 66]. Advances in the methods for the detection of CP are also changing the referrals to therapy worldwide [67, 68]. Similar to our results, a study from Northeastern Brazil showed that CP diagnosis was predominantly obtained during the first sixth months of life [69]. Despite these findings, in the present study 35% of children still receive a diagnosis after the age of 1 year, which suggests challenges for on-time access to specialized services such as medical interventions, rehabilitation professionals, education, and social support [25, 69].

Brazilian families with children and adolescents with CP were primarily represented by mothers as the main respondents, of which a small proportion have a paid work. Women in their role as mother of a child with CP generally bear a disproportionate share of the childcare. Their childcare duties make it difficult for them to focus on their careers or jobs [70]. Additionally, most depended on the public health system and the income levels were approximately 500 dollars per month/per family (mean of 3.75 individuals/house), which falls below the national average (325 dollars/per person/month) [31]. Despite the low socioeconomic status, a significant portion of the families did not receive disability benefits from the government, which probably results in financial challenges in providing adequate care for their children when they are technically not 'needy enough'. In Brazil, only families with a monthly income lower than a minimum wage (i.e., around 250 dollars) are entitled to financial benefits from the government, unlike some HIC, where all children with disabilities receive a benefit, regardless of family income. Other LMIC studies report even lower family income, with potential for increased challenges in guaranteeing the necessary treatment [25, 26, 44].

Strengths and limitations

This study reports the functioning and related impairments in children and adolescents with CP in Brazil. Despite the present study including children and adolescents with CP from all the Brazilian regions and performing an online data collection in order to capture the sample size required, this study also has some limitation, as follows: (1) Despite parents being the best experts on the child and the ones who know the most about their conditions and limitations, it is important to consider that our data was generated through parent reports, using an online survey. Parent reports may have a bias of memory and understanding of the questions. (2) Most of our participants included were children under the age of 12, which limits the generalizability of our results to adolescents and the transition to adulthood. (3) The data represent preliminary data from a multicenter study and one important point to highlight is related to the Brazilian states' representation, which was more concentrated in the Southeast and Centre-West regions. Although the Southeast is the area with the largest population in Brazil, and the percentage attained in this area and the Centre-west passed the estimated rate of the population/area, the results cannot be generalized for the entire country, especially when considering that the North and Northeast have more limited resources compared to other regions [71]. (4) Due to the COVID-19 pandemic, all the data had to be collected by online-surveys, which might have limited the participants with low access to internet. Further research is needed, including a more representative sample from all regions of Brazil.

Clinical implications and action needed

The data from this study increases knowledge about CP functioning and impairments in children and adolescents

in Brazil. These data might support all the stakeholders (i.e., health professionals, families, and service providers) to implement strategies to monitor this population across life span. From this perspective, we highlight below several actions needed to prevent secondary impairments, promote early diagnosis and functioning in the CP population, as well as strategies to increased best scientific evidence in short and long term follow up:

(1) To promote awareness regarding tools and assessments to foster very early diagnosis of children with CP or at risk of CP. Currently, there are several sensitive tools, such as the Hammersmith Infant Neurological Examination, a tool with low cost that can be used by LMICs [44].
(2) To disseminate the importance of pre-natal care to minimize or mitigate preventable causes of CP, such as CP caused by infections and trauma. It is well stablished that these vectors are strongly related to socioeconomical inequalities. Thus, it is urgent to increase the government's actions to address these contextual modified factors [72].
(3) To promote the establishment of new CP registries in other LMICs, such as Brazil (www.registropc.br), from the initiative of the Global LMIC CP register (GLM-CPR) and Latin America Cerebral Palsy Register (LATAM-CPR) [73].
(4) To create awareness regarding the importance of enable multi- and inter-disciplinary teams to manage properly the impairments described in this study. Furthermore, as most of the people use the public health system and are families of children who are unable to walk, it is very important to foster the importance of assistive technologies, in order to accommodate the impairments and promote functioning [52].

Conclusion

Children and adolescents with CP from this preliminary Brazilian study are predominantly classified in GMFCS levels IV and V, MACS II and V and have a high frequency of related impairments. Although the majority depend on the Public Health System, mostly families do not receive adequate government benefits. Families face challenges accessing resources and education, which warrants contextual interventions. This study provides a deeper understanding of the key impairments and limitations in activities among children and adolescents with CP from various Brazilian regions.

Supplementary Information

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Supplementary Material 1

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Author contributions
PSCC, KMAA, AMT, ACRC, EL, RLSM, HRL, ACC and RSM have made substantial contributions to the conception, to the design of the work, interpretation of data, drafted the work and substantively revised. ACSFR, ALOL, DEF, EDDM, JMMS, MLFA, RFLM have made substantial contributions to the design of the work, interpretation of data, the acquisition and analysis of the data. PR and RJP have made substantial contributions to the conception, drafted the work and substantively revised. ALL AUTHORS have approved the submitted version, AND have agreed both to be personally accountable for the author's own contributions and to ensure that questions related to the accuracy or integrity of any part of the work, even ones in which the author was not personally involved, are appropriately investigated, resolved, and the resolution documented in the literature.

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Data availability
No datasets were generated or analysed during the current study.

Declarations

Ethics approval and consent to participate
Ethical approval was obtained at the Ethics Committee of the University Hospital of Universidade Federal de Juiz de Fora (CAAE: 28540620.6.1001.5133) and all caregivers (i.e. parents or guardians of the children and adolescents that composed the sample of the study) signed online the informed consent term (i.e. the data collection started during the COVID-19 pandemic) and received a copy of the consent term.

Consent for publication
Not applicable.

Competing interests
The authors declare no competing interests.

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