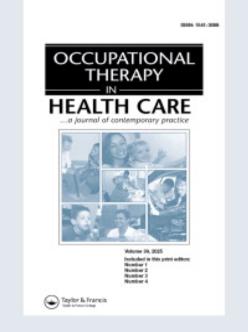

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Family Perspectives on Functional Priorities for Brazilian Children and Adolescents with Cerebral Palsy

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ABSTRACT

This study aimed to identify the functional priorities of parents/guardians of Brazilian children and adolescents with cerebral palsy (CP) and to examine possible variations in priorities concerning different age groups and functional classifications. This cross-sectional study included 171 children with CP (mean age: 7.68 ± 3.32 years). The Canadian Occupational Performance Measure was administered to the families to identify functional priorities. Among the 740 functional priorities identified, activities of daily living (ADLs) were the most frequent, followed by priorities related to body functions, motor skills, and play. The functional priorities were similar across different functional levels and age groups.

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KEYWORDS
Adolescents; cerebral palsy; children; functional priorities

Introduction

The term cerebral palsy (CP) describes a group of movement, tone, and posture disorders caused by permanent damage to the developing brain (Rosenbaum et al., 2007). CP is the most frequent cause of physical disability in childhood, resulting in activity limitations (Rosenbaum et al., 2007; Schiariti et al., 2014) and participation restrictions (Beckung & Hagberg, 2002; Cans et al., 2008). Children with CP may exhibit poor postural control (Donker, 2008), decreased dexterity and manual ability (Arnould et al., 2007), limitations in personal care, and reduced school participation (Parkes et al., 2010). The clinical presentation of CP is variable and can affect different domains of functionality, as classified by the International Classification of Functioning, Disability, and Health (ICF; dos Santos et al., 2012). The heterogeneity of CP means that different

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children and families have distinct priorities, requiring specific approaches from rehabilitation professionals. Therefore, interventions should ideally be tailored to each child, making it crucial to listen to families in order to incorporate their goals into the interventions.

Ample evidence in pediatric rehabilitation highlights the necessity of including parent/guardian throughout the intervention process, from defining priorities to implementing and executing the therapeutic plan (An, 2017; Chiarello et al., 2010; King et al., 2004; Novak et al., 2021). The family-centered approach integrates the family by working collaboratively with the professional, ensuring that the priorities and involvement of parents/guardians are respected (An et al., 2019; King et al., 2004). This practice is aimed at meeting the individual needs and specific characteristics of each family in defining meaningful priorities (An et al., 2019; King & Chiarello, 2014), allowing for goal-centered interventions, aligned with the real demands of the child and their family (Chiarello et al., 2010). When considering the context in which the child lives, as well as the family's functional goals, this practice increases adherence, motivation, and engagement in treatment, resulting in more successful interventions (King et al., 2004; Lammi & Law, 2003).

One approach which is widely recommended for incorporating parents' perspectives in defining functional priorities is the use of the Canadian Occupational Performance Measure (COPM; Law et al., 1990, 1998). Developed for use in client/family-centered practice, the COPM is an individualized measure that assists the therapist and family in setting intervention priorities (Law et al., 1998). Through the COPM, the family can identify activities that the child/adolescent wants, needs, or is expected to perform (Eyssen et al., 2005).

Some studies have investigated the functional priorities of parents of children/adolescents with CP through the COPM (Brandão et al., 2014; Chiarello et al., 2010; Jalili et al., 2019; Maggs et al., 2011; Torkan et al., 2023). Parental priorities vary among studies, with the most frequent being self-care (Brandão et al., 2014; Chiarello et al., 2010; Gimeno et al., 2013), functional mobility (Chiarello et al., 2010; Ostensjø et al., 2008), and physical recreation (Chiarello et al., 2010). The results of the scoping review by Morovat et al. (2023) included 12 studies and indicated that activities of daily living (ADLs) were the most frequent priorities for parents of children with CP. Brandão et al. (2014) analyzed 75 medical records of children with CP treated in a Brazilian rehabilitation service and found that the main parental priorities were self-care. Other demands, such as playing and functional mobility were also frequently reported parental priorities in the study by Brandão et al. (2014).

Most of the available literature regarding the functional priorities of parents/guardians of children/adolescents with CP comes from research in developed and high-income countries (e.g. the United States, the United Kingdom, Canada, and the Netherlands; Morovat et al., 2023; Verkerk et al., 2006). Research investigating the priorities of parents/guardians of children and adolescents with CP in low- and middle-income countries is scarce, and in this context, the scoping review by Morovat et al. (2023), found only studies conducted in Brazil and Iran. To the best of our knowledge, since the publication of Brandão et al. (2014), there has been little investigation regarding the functional priorities of Brazilian parents/guardians of children/adolescents with CP.

The implementation of the ICF in 2001 brought substantial advances in research (Leite et al., 2022). In the current scientific context, the relevance of promoting functioning through increased activity and participation and the prevention of secondary impairments is emphasized (Leite et al., 2022). From this perspective, by sharing their priorities, parents/guardians of Brazilian children/adolescents with CP can offer unique and valuable contributions to the development and implementation of interventions. Thus, the aim of this study was to identify the main functional priorities of families of Brazilian children and adolescents with CP. Additionally, it sought to investigate possible variations in the profile of these functional priorities according to the age group and functional classification of the children and adolescents.

Methods

This study is a cross-sectional segment of a longitudinal research project. All research protocols received approval from the Human Research Ethics Committee of the College of Medical Sciences of Minas Gerais (registration number: 72360923.9.0000.5134). Written consent was obtained from the parents/guardians of all children and adolescents before the evaluation.

Participants

Participants were conveniently selected from rehabilitation clinics across all regions of Brazil that are part of the TREINI program (from Portuguese Treinamento em Reabilitação Neurológica Intensiva or Intensive Neurological Rehabilitation Training). The TREINI program is designed for the neurological reeducation and rehabilitation of children and adolescents with neuropsychomotor developmental delays, attending them three to five times a week for 3–4 h per day, according to the functional priorities established with the family through the COPM. The program is intensive and includes two main components: a therapeutic garment, the TREINI Exoflex, and a naturalistic environment, the City of Tomorrow

(Loffi et al., 2024). The choice of the TREINI program is justified as this intervention follows the principles of collaborative practice and utilizes the COPM for selecting functional demands. In the TREINI program, 3–5 therapeutic priorities are collaboratively defined with the family through the COPM.

Parents or guardians of children and adolescents aged between 4 months and 18 years, of both sexes, diagnosed with CP were invited to participate in the study. The exclusion criteria were the same as those adopted by the TREINI program (presence of deformities in the lower limbs or trunk, epilepsy or poorly controlled seizures, cardiac or respiratory instability). A total of 171 children/adolescents with CP, along with their families, consented to participate in the study. The sample came from 40 clinics across all regions of Brazil, as presented in Figure 1. There was a predominance of participants from the Southeast region, with 129 children/adolescents (75.4% of the sample). The age of the participants ranged from 1.5 to 16.4 years, with 54.4% being male. The clinical and sociodemographic characteristics of the participants are presented in Table 1.

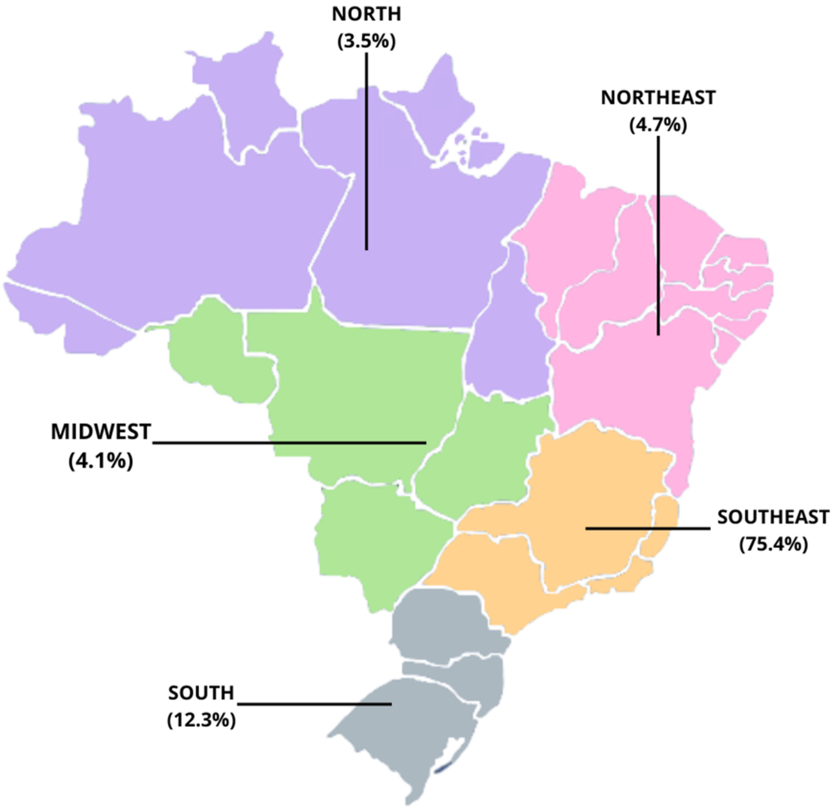

Figure 1. Distribution of participants by regions of Brazil.

Table 1. Characterization of the participants.

	Mean (SD)
	7.68 (3.32)
Patient age in years	*n* (%)
Age	
0–5.11 years	59 (34.5)
6–11.11 years	91 (53.2)
12–18.11 years	21 (12.3)
Sex	
Female	78 (45.6)
Male	93 (54.4)
GMFCS	
Level I	10 (5.8)
Level II	28 (16.4)
Level III	18 (10.5)
Level IV	36 (21.1)
Level V	76 (46.2)
MACS	
Level I	11 (6.4)
Level II	36 (21.1)
Level III	39 (22.8)
Level IV	44 (25.7)
Level V	41 (24.0)
Who responded to COPM	
Mother	148 (86.5)
Father	15 (8.8)
Others	8 (4.8)
Education of those who answered the COPM	
Complete fundamental I or incomplete fundamental II	4 (2.5)
Complete elementary school or incomplete high school	5 (3.1)
Complete secondary education or incomplete higher education	85 (53.8)
Complete higher education	63 (39.6)
Maternal occupation	
Household care	97 (56.7)
Part-time work	36 (21.1)
Full-time work	38 (22.2)
Paternal occupation	
Household care	7 (4.1)
Part-time work	24 (14.0)
Full-time work	138 (80.7)
Informal work	2 (1.2)

GMFCS: gross motor function classification system; MACS: manual ability classification system; COPM: Canadian occupational performance measure; SD: standard deviation.

Measurement instruments

To characterize the sample, a form developed by the authors was used to collect information such as age, sex, functional classification, and parents' education level and occupation, among other factors. The form was completed by each evaluator together with the families of the children and adolescents.

The COPM outcome measure was used (Law et al., 2009, 2014). The COPM investigates the individual's and/or their family's perception of occupational performance in the areas of self-care, productivity, and leisure. It is used in joint decision-making between the therapist and the family, where families are encouraged to define therapeutic priorities, through assessing their importance subjectively (An, 2017). The process involves five steps aligned with a focus on identifying activities within each performance domain. During the semi-structured interview conducted by an occupational therapist, all parents/guardians who agreed to participate in the study identified functional priorities for their children and assigned subjective importance scores from 1 to 10. The questionnaire was administered in an average time of 30 min, and no financial incentive was provided. To apply the COPM, parents/guardians are instructed to define up to five key priorities and then assess their child's current performance and their satisfaction regarding these priorities on a scale of 1–10 (higher scores indicate higher performance and satisfaction). The functional priorities identified by the parents/guardians constitute therapeutic priorities that guide interventions in pediatric practice (McColl et al., 2000). The COPM is client-centered, has been translated for the Brazilian population, and is widely used in pediatric practice (Law et al., 2009). All measurement properties of the COPM have already been evaluated. It demonstrated adequate validity (with Cronbach's alpha = 0.89), good test–retest reliability (0.87 and 0.84 for satisfaction and performance, respectively), and established minimal detectable change scores (Berardi et al., 2019; Carswell et al., 2004).

In addition to the COPM, the Gross Motor Function Classification System (GMFCS; Palisano et al., 1997) and the Manual Ability Classification System (MACS; Eliasson et al., 2006) were used to classify the gross motor function and manual ability of the participants, respectively. The GMFCS categorizes the gross motor function of children and adolescents with CP into five levels, based on functional limitations, the need for mobility devices such as wheelchairs, and the quality of movement. Lower levels (I and II) indicate better motor capacity. The MACS classifies the manual ability of children and adolescents with CP in daily contexts. It is also divided into five levels and evaluates how these individuals use their hands to manipulate objects in everyday activities. Lower levels on the MACS (I and II) indicate better manual ability. These functional classifications were performed by physiotherapy or occupational therapy professionals with experience in using the tools.

Procedures

The data collection for this study took place between August and October 2023. Participants who agreed to take part in the study signed the necessary informed consent form and were then invited to complete the sample characterization form and respond to the COPM to identify up to five functional priorities. The COPM assessment was applied by occupational therapists experienced in administering this questionnaire. To standardize the COPM application procedures, all occupational therapy professionals underwent training provided by the researchers of this study. Participants were assessed at the clinic where they already receive treatment through the TREINI program.

Statistical analysis

The Occupational Therapy Practice Framework: Domain and Process (4th ed.; AOTA, 2020) was used to categorize the functional priorities of participants. This document, from the American Occupational Therapy Association (AOTA), describes different categories of occupation-related activities in which individuals, groups, or populations engage, including ADLs, instrumental ADLs (IADLs), rest and sleep, education, work, play, leisure, and social participation. Each of these categories includes different types of activities (or subcategories of activities). Within the ADL category, for example, activities such as feeding, dressing, personal hygiene, functional mobility, and bathing are included, among others. All functional priorities established by the families were categorized within these AOTA categories or subcategories, resulting in a total of 24 specific activities (see Supplementary material 1). Two examples of how the functional priorities were classified within the AOTA categories are given as follows: 1) the priority "I would like my child to fit toy pieces functionally" was coded as "Exploratory play"; 2) the priority "I hope my child can climb a six-step staircase" was coded as "Functional mobility." The categorization of the families' functional priorities within the AOTA categories was carried out by two independent researchers (DOS and GSO), with discrepancies resolved by a third researcher (TKFC).

To examine the association between gross motor function, as classified by the GMFCS, and functional priorities, participants were divided into two distinct groups: one group composed of levels I, II, and III, and another formed by levels IV and V. This same division methodology was applied to investigate the relationship between functional priorities and the level of manual ability, using the MACS. Additionally, participants were organized into three age categories (0–6, 7–12, and 13–18 years) with the aim of analyzing the association between functional priorities and age.

After categorizing the goals, both the absolute number and the percentages of goals in each category were calculated. For statistical analysis using the chi-square test, the actual data counts were used to identify differences in functional priorities among age groups and different functional levels. The Statistical Package for the Social Sciences (SPSS Inc., Chicago, IL) Windows version 26.0® was used for data analysis. Descriptive statistics were adopted to describe the demographic characteristics of the participants.

Results

A total of 740 Functional Priorities were identified through the COPM by parents/guardians of the 171 participants. The most frequent functional priorities were related to ADLs (49.8%), body functions (14.0%), motor skills (10.0%), and playing (9.7%). The most frequent ADLs were feeding (12.3%), functional mobility (12.3%), and dressing (7.8%). Communication management appeared in 5.9% of the priorities, while priorities related to social participation (0.4%), rest and sleep (0.3%), and leisure (0.3%) were the least frequent. Figure 2 presents an overview of the functional priorities identified by parents/guardians of children/adolescents with CP.

Table 2 presents the functional priorities of parents/guardians of children and adolescents with CP according to age group. A total of 261 functional priorities were established by the families of children aged 0–6 years, 390 functional priorities by parents/guardians of children aged 7–12 years, and 89 functional priorities by the families of adolescents aged 13–18 years. ADL-related priorities were cited most frequently in all three age groups. Significant differences between age groups were observed only for demands related to toileting and personal hygiene; bathing and showering; and playing ($\chi^2 = 78.721$; $p < 0.002$). Toileting and personal hygiene demands were more frequent for adolescents than for children ($p < 0.05$). Similarly, bathing and showering demands were more frequent for adolescents than for children ($p < 0.05$), while play-related priorities were significantly more frequent in children aged 0–6 years ($p < 0.05$).

Table 3 presents the priorities of parents/guardians of children and adolescents with CP according to GMFCS levels. In total, 56 children and adolescents were classified in GMFCS levels I–III (242 priorities), and 115 in GMFCS levels IV–V (498 priorities). Dressing (13.6%) and feeding (13.6%) were the most frequent priorities for parents/guardians of children/adolescents in GMFCS levels I–III. For families of children/adolescents in

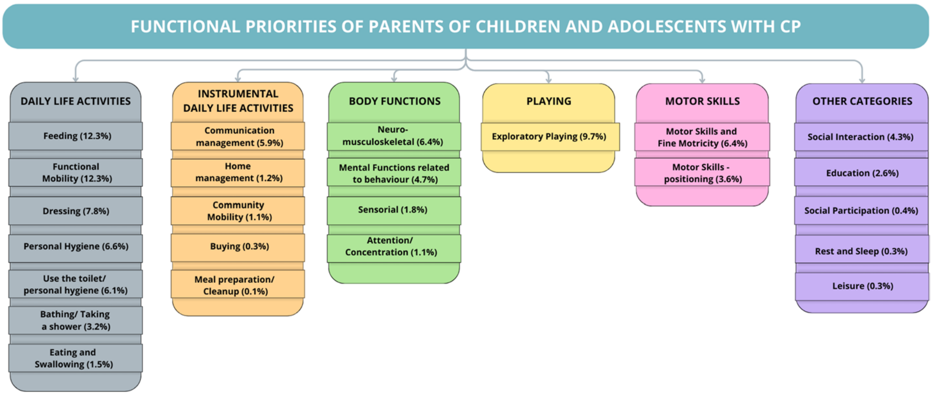

Figure 2. Functional priorities of families of children and adolescents with CP.

Table 2. Functional goals of families of children and adolescents with CP by age group.

AOTA categories	AOTA subcategories	0–6 years (n = 261) n (%)	7–12 years (n = 390) n (%)	13–18 years (n = 89) n (%)
Daily life activities	Feeding	33 (12.6)	47 (12.1)*	11 (12.4)
	Functional mobility	39 (14.9)	41 (10.5)	11 (12.4)
	To wear	17 (6.5)	33 (8.5)	8 (9.0)
	Personal hygiene	10 (3.8)	31 (7.9)	8 (9.0)
	Use the toilet and perform personal hygiene	9 (3.4)	25 (6.4)	11 (12.4)*
	Bathing and taking a shower	5 (1.9)	11 (2.8)	8 (9.0)
	Eating and swallowing	4 (1.5)	7 (1.8)	0
Instrumental daily life activities	Communication management	14 (5.4)	24 (6.2)	6 (6.7)
	Home management	1 (0.4)	7 (1.8)	1 (1.1)
	Community mobility	3 (1.1)	4 (1.0)	1 (1.1)
	Shopping	0	1 (0.3)	1 (1.1)
	Meal preparation and cleaning up	0	1 (0.3)	0
Body functions	Neuromusculoskeletal functions	19 (7.3)	24 (6.2)	4 (4.5)
	Mental functions related to behavior	8 (3.1)	20 (5.1)	7 (7.9)
	Body functions (Sensory)	7 (2.7)	6 (1.5)	0
	Attention and concentration functions	2 (0.8)	6 (1.5)	0
Playing	Exploratory playing	42 (16.1)*	29 (7.4)	1 (1.1)
Social interaction	Social interaction with peers and family	15 (5.7)	13 (3.3)	4 (4.5)
Motor skills	Manual and fine motor skills	18 (6.9)	26 (6.7)	3 (3.4)
	Motor skills (positioning)	8 (3.1)	15 (3.8)	4 (4.5)
Education	Formal education participation	4 (1.5)	15 (3.8)	0
Resting and sleeping	Resting and sleeping	1 (0.4)	1 (0.3)	0
Social participation	Community and familiar participation	2 (0.8)	1 (0.3)	0
Leisure	Exploratory leisure	0	2 (0.5)	0

CP: cerebral palsy; AOTA: American Occupational Therapy Association.
*$p < 0.05$.

Table 3. Functional goals of parents of children and adolescents with CP by GMFCS level.

		Levels I–III	Levels IV and V
AOTA categories	AOTA subcategories	n (%)	n (%)
Daily life activities	Getting dressed	33 (13.6)	25 (5.0)*
	Personal hygiene	16 (6.6)	33 (6.6)
	Feeding	33 (13.6)	58 (11.6)
	Use the toilet and perform personal hygiene	22 (9.1)	23 (4.6)*
	Bathing and taking a shower	7 (2.9)	17 (3.4)
	Functional mobility	32 (13.2)	59 (11.8)
	Eating and swallowing	1 (0.4)	10 (2.0)
Instrumental daily life activities	Communication management	9 (3.7)	35 (7.0)
	Home management	5 (2.1)	4 (0.8)
	Community mobility	4 (1.7)	4 0.8)
	Shopping	1 (0.4)	1 (0.2)
	Meal preparation and cleaning up	0	1 (0.2)
Body functions	Mental functions related to behavior	13 (5.4)	22 (4.4)
	Neuromusculoskeletal functions	4 (1.7)	43 (8.6)*
	Sensory functions	1 (0.4)	12 (2.4)
	Attention and concentration functions	3 (1.2)	5 (1.0)
Playing	Exploratory playing	17 (7.0)	55 (11.0)
Social interaction	Social interaction with peers and family	12 (5.0)	20 (4.0)
Motor skills	Manual and fine motor skills	17 (7.0)	30 (6.0)
	Motor skills (positioning)	2 (0.8)	25 (5.0)*
Education	Formal education participation	10 (4.1)	9 (1.8)
Rest and sleeping	Resting and sleeping	0	2 (0.4)
Social participation	Community and familiar participation	0	3 (0.6)
Leisure	Exploratory leisure	0	2 (0.4)

CP: cerebral palsy; AOTA: American Occupational Therapy Association.
*$p < 0.05$.

Table 4. Functional goals of parents of children and adolescents with CP by MACS level.

		Levels I–III	Levels IV and V
AOTA categories	AOTA subcategories	*n* (%)	*n* (%)
Daily life activities	Getting dressed	47 (12.5)	11 (3.0)*
	Personal hygiene	32 (8.5)	17 (4.7)*
	Feeding	49 (13.0)	42 (11.6)
	Use the toilet and perform personal hygiene	31 (8.2)	14 (3.9)*
	Bathing and taking a shower	11 (2.9)	13 (3.6)
	Functional mobility	54 (14.3)	37 (10.2)
	Eating and swallowing	1 (0.3)	10 (2.8)*
Instrumental daily life activities	Communication management	13 (3.4)	31 (8.5)*
	Home management	6 (16)	3 (0.8)
	Community mobility	4 (1.1)	4 (1.1)
	Shopping	2 (0.5)	0
	Meal preparation and cleaning up	0	1 (0.3)
Body functions	Mental functions related to behavior	20 (5.3)	15 (4.1)
	Neuromusculoskeletal functions	11 (2.9)	36 (9.9)*
	Sensory functions	1 (0.3)	12 (3.3)*
	Attention and concentration functions	8 (2.1)	0*
To play	Exploratory playing	19 (5.0)	53 (14.6)*
Social interaction	Social interaction with peers and family	17 (4.5)	15 (4.1)
Motor skills	Manual and fine motor skills	27 (7.2)	20 (5.5)
	Motor skills (positioning)	9 (2.4)	18 (5.0)
Education	Formal education participation	14 (3.7)	5 (1.4)*
Rest and sleeping	Resting and sleeping	0	2 (0.6)
Social participation	Community and familiar participation	0	3 (0.8)
Leisure	Exploratory leisure	1 (0.3)	1 (0.3)

CP: cerebral palsy; DLAs: daily life activities; IDLAs: instrumental daily life activities; AOTA: American Occupational Therapy Association.
*$p < 0.05$.

GMFCS levels IV–V, the most frequent priorities were related to functional mobility (11.8%), feeding (11.6%), and playing (11%). Significant differences between age groups were observed only for demands related to toileting and personal hygiene; bathing and showering; and playing ($\chi^2 = 78.721$; $p < 0.002$). Toileting and personal hygiene demands were more frequent for adolescents than for children ($p < 0.05$). Similarly, bathing and showering demands were more frequent for adolescents than for children ($p < 0.05$), while play-related priorities were significantly more frequent in children aged 0–6 years ($p < 0.05$).

Table 4 presents the functional priorities identified by parents/guardians, stratified by MACS levels; 86 children and adolescents were classified in the group of MACS levels I–III (377 priorities), and 85 participants in MACS levels IV–V (363 priorities). In MACS levels I–III, functional mobility (14.3%) and feeding (13.0%) were the most frequent priorities, whereas playing (14.6%) and feeding (11.6%) were the most frequent in levels IV–V. Significant differences between MACS levels were observed in 10 out of 24 functional priorities ($\chi^2 = 116.550$; $p < 0.001$). Priorities related to toileting and performing intimate hygiene, dressing, personal hygiene, attention and concentration functions, and education were more frequent in levels I–III ($p < 0.05$), and priorities related to swallowing, communication management, neuromusculoskeletal functions, sensory functions, and playing were more frequent in levels IV–V ($p < 0.05$).

Discussion

This study aimed to identify the functional priorities that constitute therapeutic priorities for parents/guardians of Brazilian children and adolescents with CP. Additionally, we aimed to investigate potential differences in functional priorities among GMFCS levels, MACS levels, and participant age groups. The results show that ADLs, playing, musculoskeletal functions, and motor skills are among the main priorities for parents/guardians. Education, social participation, rest and sleep, and leisure were not frequent priorities. Overall, the profiles of functional priorities were similar across age groups and GMFCS and MACS levels, although some differences were observed. Playing was a frequent priority for children aged 0– 6 years ($p < 0.05$) and for children and adolescents in GMFCS and MACS levels IV–V. These findings will be discussed further below.

The results of this study show that ADLs are the main functional priorities for families of Brazilian children/adolescents with CP. This finding is supported by previous studies in different countries. In the scoping review of Morovat et al. (2023), parents/guardians of children/adolescents with CP identified ADLs as the most frequent priorities, regardless of age group and GMFCS levels. Among the 12 studies included in that review (2024), only one involved Brazilian children/adolescents (Brandão et al., 2014), while four were from the USA, two from Canada, three from Europe, and two from Iran. This finding suggests that despite cultural differences, the identification of priorities for children/adolescents with CP is similar across different countries. The high demand for ADLs found in the current and previous studies is justified by the reduced motor ability of children/adolescents with CP (James et al., 2014; Van Zelst et al., 2006). Approximately 62% of the participants in this study were classified in GMFCS levels IV–V, indicating a greater need for parental assistance in performing ADLs. It is possible that parents/guardians prioritize ADLs so that their children achieve greater autonomy and efficiency in performing these activities, thereby reducing the parental burden and stress.

Although ADLs were identified as priorities, the categories of activities varied across studies. In this study, for instance, feeding and functional mobility were the most frequent priorities, whereas Feeding and Dressing were the ADLs prioritized in Brandão et al. (2014). Other ADLs related to self-care, such as bathing, personal hygiene, and toileting, were frequent in both studies. It is known that self-care skills in children are crucial for achieving independence and represent a major challenge for parents/guardians of children with CP (Jalili et al., 2019). According to Wiart et al. (2010), the performance of self-care activities depends on the child's mobility levels; thus, self-care and mobility are interdependent skills. However, mobility was the second most frequent functional priority among parents/

guardians in this study, comprising 12.3% of the total priorities. Therefore, healthcare professionals can play an important role in developing and implementing intervention strategies that promote gains in these areas.

Among the ADLs prioritized by families, swallowing/eating was the least frequently mentioned (11/870 priorities). This finding is surprising considering the high prevalence of dysphagia observed in children with CP (Abd-Elmonem et al., 2021; Calis et al., 2008; Speyer et al., 2019). Evidence suggests that up to 85% of children with CP may experience moderate to severe dysphagia (Abd-Elmonem et al., 2021). Dysphagia is closely related to gross motor function in children with CP. Kim et al. (2013) demonstrated that swallowing-related issues were significantly more common in children in GMFCS levels IV–V. Given that 62% of children/adolescents in this study were classified in GMFCS levels IV–V, a higher demand from parents/guardians regarding swallowing issues was expected. However, one factor that may contribute to the underreporting of swallowing-related concerns is parents' gradual adaptation to their children's challenges. As these parents/guardians cope daily with the difficulties associated with CP, they may end up normalizing certain symptoms or considering them less urgent compared to other more immediate health issues (Serel-Arslan et al., 2023).

Engagement in recreational or leisure activities is fundamental for children's development (Yoo et al., 2022). However, despite the evident benefits of leisure, the results of this study indicate that participation in leisure activities is not a priority for parents/guardians. Out of a total of 870 priorities, only 2 were related to leisure. A recent study that assessed leisure participation patterns among Brazilian children with CP showed that, on average, children participate twice every 4 months (Souto et al., 2023).

There are several reasons why parents/guardians may not prioritize participation in these activities. Parents/guardians of children with disabilities face a range of responsibilities and burdens with their children's general care, medical appointments, and therapies (Ribeiro et al., 2016). These demands not only create emotional and physical burdens, but also consume time and energy (Ribeiro et al., 2016). As a result, the time available to plan and organize leisure activities is limited or even nonexistent. Additionally, parents/guardians may prioritize other needs they consider more urgent or important for their children, such as ADLs. This hypothesis is supported by the high frequency of ADL-related priorities found in this study, as well as by psychological theories, which suggest that individuals first seek to satisfy their basic daily needs before considering leisure (Maslow, 2013).

Financial conditions can also be another obstacle to participating in leisure activities (Mihaylov et al., 2004). Some families face financial difficulties or limitations in accessing resources and facilities that offer leisure activities (Mihaylov et al., 2004). Furthermore, parents/guardians may not be aware of the benefits associated with leisure activities for their children (Yoo et al., 2022). Recognizing and overcoming all these barriers is crucial to promoting access to leisure participation opportunities (Souto et al., 2024). Creating adapted programs, educating parents about the benefits of these activities, and providing adequate support and resources to facilitate leisure participation are measures that can be considered by healthcare professionals and public authorities.

One of the most frequent priorities identified by parents/guardians in this study was related to Playing. Furthermore, playing was significantly more frequently identified as a priority for children aged 0–6 years and for children/adolescents with more severe conditions (levels IV–V of GMFCS and MACS). Similar results were reported by Brandão et al. (2014). Playing can be influenced by children's physical functioning difficulties and manual skills (Bult et al., 2011), which justifies the higher frequency of these priorities for children/adolescents in GMFCS and MACS levels IV–V. The high demand for playing by parents/guardians may be justified by the fact that children with CP demonstrate less playfulness than their typically developing peers (Okimoto et al., 2000). The ICF-Children and Youth (CY) version emphasizes the relevance of playing in children's lives, recognizing it as an essential occupation and a central activity in children's daily routines (WHO, 2007). Since playing is the primary occupation of all children and enhances their development, it is an essential concept to be explored by healthcare professionals, especially occupational therapists and physiotherapists (Case-Smith, 2013). The results of this study suggest that playing is an important functional goal for therapeutic intervention. It is also important for these professionals to guide parents/guardians on how to understand and facilitate their children's play activities.

In this study, only 2.6% of parents/guardians priorities were focused on education, suggesting that the academic life of their children is not a priority. This scenario is supported by recent data, revealing that only 58.8% of Brazilian children/adolescents with CP attend regular schools (Alves et al., 2024). Furthermore, a population-based study involving 819 children with CP showed that only 33% had education beyond lower secondary level (i.e. after age 15–16), compared to 77% of typical controls (Michelsen et al., 2005). These findings are concerning considering the importance of school participation for the development of children/adolescents. The Brazilian educational system has adopted inclusion policies, such as the National Policy on Special Education from the Perspective of Inclusive Education (Brasil Ministério da Educação. Secretaria de Educação Especial, 2008), aiming to ensure access and retention of students with disabilities in regular schools. However, significant challenges remain, including an inadequate infrastructure, insufficient teacher training to address specific needs, and limitations in adapted pedagogical resources.

These factors contribute to the low priority that parents/guardians place on the education of their children with disabilities, which is reflected in the concerning statistics presented.

Braccialli et al. (2016) examined how school participation affects the quality of life of Brazilian children and adolescents with CP. The authors found that those attending school achieve better outcomes in functionality, participation, physical health, and emotional well-being compared to those who do not attend. Challenges faced by parents/guardians regarding inclusion and accessibility may be related to low school attendance. According to Alves et al. (2024), 58% of parents/guardians reported accessibility difficulties in schools, and, as well as architectural barriers, attitudinal barriers toward school inclusion are likely significant obstacles to school participation (Mantilla et al., 2024). These findings support the hypothesis that the low interest of families in educational demands found in this study may be partially attributed to the children/adolescents being out of school. However, these are only assumptions, we did not investigate the school attendance of participants, which is a limitation to be addressed in future studies.

When analyzing the functional priorities established by families, it was observed that none were directly related to employability or concerns about the future. Two considerations can be made in this regard. First, since approximately 80% of the sample consists of children, it is possible that parents/guardians are not yet concerned about these aspects, which will only be addressed during adolescence and early adulthood. Second, prioritizing ADLs ensures satisfaction of basic needs and promotes independence in the home environment (Barrett & Kielhofner, 2002). Therefore, success in these activities facilitates the experience of independence and the development of skills for participation in other areas, such as education, leisure, and work. However, considering the low employability of people with CP (Michelsen et al., 2005), early consideration of the different aspects that can contribute to their integration into the labor market is important. A previous study involving Danish children showed that only 5% of people with CP are employed compared to 82% of typical controls (Michelsen et al., 2005). Similar results are reported in the Brazilian population, where only 4.5% are employed (Margre et al., 2010). These data underscore the need for education and healthcare professionals to focus on the future and adopt a life-span perspective when working with children/adolescents with CP.

Limitations

This study presents several limitations. The sample selection was convenience-based, and parental participation was entirely voluntary. It is important to consider that the families who chose not to participate may have different priorities. Additionally, these results cannot be extrapolated to the population relying exclusively on public health services, as participants in this study use private healthcare systems. There was non-homogeneous representation across age groups, with the majority of participants being children, and only 12% being adolescents. Similar discrepancies were observed regarding GMFCS and MACS levels and participants' demographic regions. The majority of the sample in this study was recruited from the Southeast region. Finally, this study used the COPM to identify family priorities for children and adolescents with CP. Future studies should investigate functional priorities from the perspective of children and adolescents. Giving voice to children and adolescents and recognizing their own priorities and desires is crucial, as children may be more motivated to work on priorities they find relevant. Future studies addressing all these limitations may be necessary.

Conclusion

Identifying the functional priorities of parents/guardians of children and adolescents with CP is essential for developing effective interventions. This study demonstrated that ADLs constitute the primary treatment priorities for families of Brazilian children and adolescents with CP. It is crucial for therapists to involve families in defining treatment priorities, in order to ensure that these priorities are understood and addressed. Therapists should be attentive to the families' priority needs and provide support for ADLs, while also encouraging participation in areas that may not be prioritized but that are important, such as participation, education, and leisure. The findings of this study are valuable and should be utilized by professionals and policymakers to develop intervention strategies that meet these needs. Future studies are required that involve samples assisted by the public health system and that investigate the priorities of children and adolescents with CP.

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The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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