

Perception of parents of children and young people who use wheelchairs about participation and the environment: a cross-sectional study

Percepção de pais de crianças e jovens que usam cadeiras de rodas sobre a participação e o ambiente: um estudo transversal

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ABSTRACT | INTRODUCTION: The wheelchair is often indicated to improve the participation of children/young people with disabilities. However, the literature is scarce regarding this effect, and the environment can be a barrier. **OBJECTIVE:** To know the perception of parents of children and young people who use wheelchairs about participation and the environment. **METHODS:** Cross-sectional study with parents/guardians of children/young people who use wheelchairs, aged between 5 and 17, who were treated at two rehabilitation centers in the capital of a Brazilian state. A sociodemographic questionnaire and the PEM-CY were administered. **RESULTS:** The survey obtained 43 participants, showing a perception of greater participation at home, mainly in being with other people (6.9 ± 0.2) and watching TV (6.6 ± 1.5). In the community, attendance was low for all activities and 79.1% wished that participation in organized physical activities were greater. At school, they participated more in classroom activities (5.7 ± 2.5). Home was perceived as an environment with the most facilitators (72.5%), the fewest barriers (17.0%) and the highest scores for kindness, resources and general support from the environment (88.1%; 80.3% and 84.9% respectively). **CONCLUSIONS:** According to parents' perceptions, participation is higher at home, as the environment is more supportive. At school, they are more restricted to classroom activities and being with peers, with fewer facilitators. There is little participation in the community, more often in passive activities, as there are more barriers and fewer resources available.

KEYWORDS: Wheelchairs. Adolescent. Children with Disability. Social Participation. Social Environment.

RESUMO | INTRODUÇÃO: A cadeira de rodas frequentemente é indicada para melhorar a participação de crianças/jovens com deficiência. Entretanto, a literatura é escassa quanto a esse efeito e o ambiente pode ser uma barreira. **OBJETIVO:** Conhecer a percepção dos pais de crianças e jovens que usam cadeiras de rodas sobre a participação e o ambiente. **MÉTODOS:** Estudo transversal com pais/responsáveis de crianças/jovens que usam cadeiras de rodas de 5 a 17 anos, atendidas em dois centros de reabilitação na capital de um estado do Brasil. Foi aplicado questionário sociodemográfico e a PEM-CY. **RESULTADOS:** A pesquisa obteve 43 participantes, demonstrando percepção de maior participação em casa, principalmente em estar com outras pessoas ($6,9 \pm 0,2$) e ver TV ($6,6 \pm 1,5$). Na comunidade, a frequência foi baixa para todas as atividades e 79,1% desejaram que a participação em atividades físicas organizadas fosse maior. Na escola participavam mais de atividades em sala de aula ($5,7 \pm 2,5$). A casa foi percebida como o ambiente com mais facilitadores (72,5%), menos barreiras (17,0%) e maiores escores de gentileza, recursos e apoio geral do ambiente (88,1%; 80,3% e 84,9% respectivamente). **CONCLUSÕES:** A participação, de acordo com a percepção dos pais, é maior em casa, sendo o ambiente mais favorável. Na escola, estão mais restritos a atividades em sala de aula e estar com colegas, possuindo menos facilitadores. Na comunidade há pouca participação, com maior frequência em atividades passivas, pois possui mais barreiras e menos recursos disponíveis.

PALAVRAS-CHAVE: Cadeira de Rodas. Adolescente. Criança com Deficiência. Participação Social. Meio Social.

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1. Introduction

As a representation of the social perspective of functionality, participation is defined by the International Classification of Functioning, Disability and Health (ICF) as "involvement in a life situation"¹. It is made up of two key elements: (I) attendance, measured by the frequency and/or diversity of activities that the person takes part in; and (II) involvement, which refers to the subjective feeling of participation during attendance, including aspects of motivation, social connection and level of affection². In addition, participation is greatly influenced by environmental factors¹.

For children and young people with disabilities, participation plays an important role in their quality of life; however, when compared to their peers with typical development, they have lower levels of participation³. It is estimated that in Brazil 8.9% of the population has a disability, in the Northeast this rate is 10.3%, and in Bahia 10.4%. Still on national data, among children and young people aged 2 to 9 and 10 to 19, 3.2% and 3.3% of the population, respectively, have a disability⁴. For those with limited mobility, the acquisition of wheelchairs is often indicated as a strategy to encourage participation. However, this depends on a series of environmental variables⁴ and there is still little evidence on parents' perceptions of wheelchair use.

The family is the main agent of primary socialization, in which relationships of care are produced between members, through protection, welcoming, respect for individuality and empowerment of others⁵. In addition, the family plays a fundamental role in providing life experiences in which children actively engage with the physical and social environment, promoting development⁶. In the context of the presence of a child with a disability, families need to reorganize and face situations related to: social restriction, financial instability, strain on family relationships, distressing feelings, changes in family dynamics and stress on health and well-being⁶.

In this way, the family's perception of participation is complementary to that of the child, considering concerns about safety, well-being and environmental influences². Studies evaluating the social participation and environment of children/young people who use wheelchairs in Brazil are scarce. And, given the importance of this topic, it is understood that knowledge about the participation and environmental issues of this public, from the perspective of parents and in coherence with the ICF¹, is essential. Therefore, the aim of this study was to know how parents of children and young people who use wheelchairs perceive participation and the environment.

2. Materials and method

This is a descriptive cross-sectional study carried out with parents/guardians of children and young people who use wheelchairs and are treated at two rehabilitation centers for people with disabilities in the city of Salvador. Parents or guardians whose children are between 5 and 17 years old and who used manual or motorized wheelchairs were included, composing an accessible sample.

Participants were recruited and data collected from July to August 2022, using primary and secondary data. Initially, patients were screened, using institutional medical records, for inclusion criteria and means of contact so that they could be invited to take part in the research. The invitation was made by telephone, during which the time and format of the interview were agreed upon, after signing the Free and Informed Consent Form. Data on the clinical diagnosis and cognitive function of the children/young people was also collected from the medical records. The primary data was obtained by interview, and the instruments were filled in virtually, using Google Forms and a telephone call, or in person, conducted by the researcher in charge, at the rehabilitation center.

The research instruments included a sociodemographic questionnaire produced by the researchers and the Participation and Environment Measure - Children and Youth (PEM-CY), validated and cross-culturally adapted for Brazil⁷ and created based on the ICF constructs^{2,8}. The PEM-CY has good to excellent internal consistency and moderate to good test-retest reliability (0.58 and above) measured within 1 to 4 weeks⁸. The concession for use was obtained from the CanChild Institute, McMaster University, Hamilton, Canada.

The PEM-CY assessed life situations in the home, school and community environment, the level of involvement of children/young people, barriers and limitations to participation, and the availability/adequacy of resources to facilitate participation. The participation items are grouped into three sub-scales: frequency, parental involvement and parents' desire for change; and the environment items into two others: barriers and facilitators. Frequency is graded on an eight-point scale (0-7), where 0 corresponds to "never" and 7 to "daily". For involvement, there is a five-point scale (1-5), with 1 being "not very involved" and 5 being "very involved". As for the desire for change, if parents said they had one ("yes" answer), they could refer to the frequency, level of involvement or variety of that type of activity⁷.

The numerical quantitative variables were described as means and standard deviations and the categorical variables as proportions, using the SPSS Statistics software® 22. As for the PEM-CY variables, individual scores were calculated by environment and by

activity, as recommended in the instrument itself, expressed as means and proportions, and these generated scores by group.

The participants signed a Free and Informed Consent Form to be included in the study, which was conducted in accordance with Resolução nº 466/2012 of the Conselho Nacional de Saúde and Orientações para Procedimentos em Pesquisas com Qualquer Etapa em Ambiente Virtual (Ofício Circular nº 2/2021/CONEP/SECNS/MS). The study was approved by the CEP/CONEP System under CAAE number 53808321.2.3001.0052.

3. Results

The survey was carried out with 43 parents/guardians of children and young people who use wheelchairs. However, some data was lost due to problems with the internet network when filling in the questionnaire, as well as the unavailability of the interviewees to complete the survey, and the corresponding sample number in these cases is described in the tables. The participants had a median age of 38 (interquartile range 33.5 - 43.5) years, the majority were female (40; 93.0%), living in municipalities other than Salvador (23; 53.5%) and in urban areas (35; 81.4%), self-declared black/brown (40; 93.0%) and had a partner (26; 60.5%). The majority had a high school education, 64.3%, and the degree of relationship with the child was predominantly that of the mother (37; 86.0%). The average number of residents in the household was 3.8 ± 1.0 people, and the monthly family income for 62.8% (27) was between 1 and 3 minimum wages (Table 1).

Table 1. Sociodemographic characteristics of parents/guardians of children and young people who use wheelchairs, Salvador-BA, 2022. (n=43)

Variables	Mean $\pm$ SD	n (%)
Age	38.2 $\pm$ 7.9	
Sex		
Male		3 (7.0)
Female		40 (93.0)
Skin Color		
Black / brown		40 (93.0)
White		1 (2.3)
Yellow		2 (4.7)
Town of residence		
Salvador		20 (46.5)
Other municipalities		23 (53.5)
Type of community		
Urban		35 (81.4)
Rural		8 (18.6)
Marital status		
With a partner		26 (60.5)
No partner		17 (39.5)
No. of people living in the house	3.8 $\pm$ 1.0	
Level of education*		
Low		11 (26.2)
Average		27 (64.3)
High		3 (9.5)
Relationship with child/youth		
Mother		37 (86.0)
Father		3 (7.0)
Others		3 (7.0)
Family income per month		
Up to 1 minimum wage		16 (37.2)
From 1 to 3 minimum wages		27 (62.8)

Source: the authors (2022).

SD - Standard Deviation; N° - number; *This data corresponds to 42 participants.

As for the children and young people who use wheelchairs, they were characterized as having a median age of 8 (6 - 10.2) years, the majority were male (28; 65.1%) and skin color black/brown (37; 86.1%). The most frequent clinical diagnosis was cerebral palsy (CP) (35; 81.4%) and 44.2% (19) had comorbidities, the most common being convulsion (8; 42.1%). While 42.9% (18) had no or mild cognitive impairment, the same proportion had moderate impairment. Thirty-five (81.4%) children/young people attended school, with an average time of 4.2 $\pm$ 3.5 years. All of them used a manual wheelchair (43; 100.0%), with an average time of use of 3.9 $\pm$ 2.4 years, and 58.1% (25) had received training in its use (Table 2).

Table 2. Sociodemographic and clinical characteristics of children and young people who use wheelchairs, Salvador-BA, 2022. (n=32)

Variables	Mean $\pm$ SD	n (%)
Age	8.1 $\pm$ 3.0	
Sex		
Male		28 (65.1)
Female		15 (34.9)
Skin Color		
Black / brown		37 (86.1)
White		5 (11.6)
Yellow		1 (2.3)
Clinical diagnosis		
Cerebral palsy		35 (81.4)
Duchenne muscular dystrophy		1 (2.3)
Spina bifida		2 (4.7)
Other		5 (11.6)
Presence of comorbidities		
Yes		19 (44.2)
No		24 (55.8)
Comorbidities		
Convulsion		8 (42.1)
Other		6 (57.9)
Cognitive impairment*		
None or light		18 (42.9)
Moderate		18 (42.9)
Grave		6 (14.2)
School		
Attend		35 (81.4)
Does not attend		8 (18.6)
Time at school (years)	4.2 $\pm$ 3.5	
Type of wheelchair		
Manual		43 (100.0)
Time spent using a wheelchair (years)	3.9 $\pm$ 2.4	
Wheelchair training		
Yes		25 (58.1)
No		18 (41.9)

Source: the authors (2022).

SD- Standard Deviation; *This data corresponds to 42 participants.

Participation in the home environment had the highest mean frequencies in the activities of being with other people (6.9 ± 0.2) and watching TV (6.6 ± 1.5). The lowest frequencies of participation were in preparing for school (1.9 ± 3.0) and in household chores (2.0 ± 2.9), although they were among the highest levels of involvement (4.6 ± 1.0 ; 4.6 ± 0.7 , respectively) among the children/young people who participated. The average level of involvement in this environment had little variation between activities but was slightly lower in homework (4.0 ± 1.3). The activity in which parents most often reported no desire to change was being with other people (74.4%). They wished for more participation in preparing for school (72.1%) and in household chores (58.1%); and less participation in watching TV, videos and DVDs (25.6%) (Table 3).

Table 3. Participation of children and young people who use wheelchairs and parents' desire to change: home environment, Salvador-BA, 2022. (n=43)

Living situation at home		Freq (0-7)	Env (1-5)	Parents' desire to change (%)					
		Mean ± SD	Mean ± SD	NM	+Freq	- Freq	+Env	-Env	Div
1.	Computer and video games	2.6 ± 3.3	4.4 ± 1.0	25.6	44.2	20.9	7.0	2.3	-
2.	Indoors games and play	6.0 ± 2.0	4.4 ± 1.1	39.5	30.2	2.3	23.3	-	27.9
3.	Arts, crafts, music and hobbies	5.9 ± 2.2	4.3 ± 1.1	55.8	16.3	7.0	18.6	2.3	7.0
4.	Watching TV, videos and DVDs	6.6 ± 1.5	4.6 ± 0.9	53.5	9.3	25.6	7.0	-	11.6
5.	Getting together with other people	6.9 ± 0.2	4.7 ± 0.7	74.4	14.0	-	14.0	2.3	2.3
6.	Socializing using technology	4.9 ± 2.7	4.5 ± 0.9	62.8	30.2	2.3	7.0	-	-
7.	Household chores	2.0 ± 2.9	4.6 ± 0.7	39.5	58.1	-	2.3	-	-
8.	Personal care management	5.1 ± 3.0	4.2 ± 1.3	30.2	46.5	-	23.3	-	23.3
9.	School preparation	1.9 ± 3.0	4.6 ± 1.0	25.6	72.1	-	4.7	-	2.3
10.	Homework	4.3 ± 3.2	4.0 ± 1.3	20.9	51.2	-	30.2	4.7	2.3

Source: the authors (2022).

SD - Standard deviation; Freq - Frequency; Env - Involvement; NM - No change desired; +Freq - Higher frequency desired;

-Freq - Lower frequency desired; +Env - Higher involvement desired; - Env - Lower involvement desired;

Div - Higher diversity desired.

In terms of school participation, there was a higher mean frequency in classroom activities (5.7 ± 2.5) and being with classmates outside the classroom (5.2 ± 3.0). They participated less in outings and school events (0.2 ± 0.6), but this was the activity with the highest mean level of involvement (5.0 ± 0.0), followed by being with classmates outside the classroom (4.6 ± 1.1). Thus, the activity in which most parents reported no desire to change was being with classmates outside of class (46.5%), wanting to be more involved in outings and events (62.8%), playing specific roles (58.1%) and joining teams, clubs and organizations prepared by the school (51.2%) (Table 4).

Table 4. Participation of children and young people who use wheelchairs and parents' desire for change: school environment, Salvador-BA, 2022. (n=35)

Life situations at school	Freq (1-7)	Env (1-5)	Parents' desire to change (%) *			
	Mean $\pm$ SD	Mean $\pm$ SD	NM	+Freq	+Env	Div
1. Classroom activities	5.7 $\pm$ 2.5	4.4 $\pm$ 0.9	32.6	20.9	25.6	2.3
2. Field trips and school events	0.2 $\pm$ 0.6	5.0 $\pm$ 0.0	11.6	62.8	-	-
3. School-sponsored teams, clubs and organizations	0.5 $\pm$ 1.6	3.7 $\pm$ 1.9	20.9†	51.2‡	2.3‡	-
4. Getting together with peers outside of class	5.2 $\pm$ 3.0 †	4.6 $\pm$ 1.1 †	46.5‡	20.9‡	11.6‡	-
5. Special roles at school	0.5 $\pm$ 1.3 †	3.6 $\pm$ 1.7 †	14.0‡	58.1‡	-	-

Source: the authors (2022).

SD - standard deviation; Freq - Frequency; Env - Involvement; NM - Do not want change; +Freq - Want more frequency;

+Env - Want more involvement; Div - Want more diversity; *This data corresponds to 32 participants;

†This data corresponds to 34 participants; ‡This data corresponds to 31 participants.

As for the community environment, the mean frequency of participation was low for all activities, being higher for walks in the neighborhood (3.9 ± 2.6) and lower for classes and courses (0.1 ± 0.8). Parents perceived children to be more involved in free physical activities (4.8 ± 0.6), being with other children (4.7 ± 0.9) and outings in the neighborhood (4.6 ± 1.0). The least involvement was for community events (3.0 ± 2.3). They most often reported not wanting to change when it came to trips or visits where they spent the night out (67.4%) and going for walks in the neighbourhood (62.8%), while they wanted to be more involved in organized physical activities (79.1%) and classes and lessons (74.4%) (Table 5).

Table 5. Participation of children and young people who use wheelchairs and parents' desire to change: community environment, Salvador-BA, 2022. (n=42)

Life situations in the community	Freq (0-7)	Env (1-5)	Parents' desire to change (%)				
	Mean $\pm$ SD	Mean $\pm$ SD	NM	+Freq	- Freq	+Env	Div
1. Neighborhood outings	3.9 ± 2.6	4.6 ± 1.0	62.8	30.2	-	2.3	4.7
2. Community events	0.8 ± 1.7	3.0 ± 2.3	55.8	41.9	-	-	-
3. Organized physical activities	0.8 ± 1.9	4.3 ± 1.6	18.6	79.1	-	-	-
4. Unstructured physical activity	3.2 ± 2.9	4.8 ± 0.6	39.5	55.8	-	4.7	9.3
5. Classes and lessons	0.1 ± 0.8	4.0 ± 0.0	23.3	74.4	-	-	-
6. Organizations, groups, clubs and voluntary or leadership activities	0.5 ± 1.5	4.2 ± 0.9	44.2	51.2	-	-	2.3
7. Religious or spiritual gatherings and activities	3.1 ± 2.6	3.8 ± 1.6	51.2	32.6	-	14.0	-
8. Getting together with children in the community	2.2 ± 2.3	4.7 ± 0.9	48.8	44.2	2.3	2.3	2.3
9. Overnight visits or trips	1.9 ± 1.7	4.4 ± 1.0	67.4	25.6	-	4.7	-

Source: the authors (2022).

SD - standard deviation; Freq - Frequency; Env - Involvement; NM - No change desired; +Freq - Higher frequency desired;

-Freq - Lower frequency desired; +Env - Higher involvement desired; - Env - Lower involvement desired;

Div - Higher diversity desired.

In the assessment of environmental factors, the home was the environment with the highest perception of facilitators of participation (72.5%) and the lowest in terms of barriers (17.0%). Similarly, it was the environment with the highest scores for kindness, resources and general support (88.1%, 80.3% and 84.9% respectively). Although the school had the lowest score for facilitators (61.7%), the community had the highest score for barriers (55.3%), and the lowest scores for helpfulness (64.1%), resources (41.8%) and overall environmental support (44.6%) (Table 6).

Table 6. Parents' perception of the environmental factors of children and young people who use wheelchairs, Salvador-BA, 2022. (n=43)

Environmental factors	Score
Facilitators (%)	
Home	72.5
School*	61.7
Community †	71.1
Barriers (%)	
Home	17.0
School*	21.4
Community †	55.3
Environmental Helpfulness	
Home	88.1
School‡	81.6
Community †	64.1
Environmental Resources	
Home	80.3
School*	69.2
Community †	41.8
Overall Environmental Support	
Home	84.9
School‡	63.6
Community †	44.6

Source: the authors (2022).

SD - standard deviation; *This data corresponds to 33 participants; † This data corresponds to 42 participants;

‡ This data corresponds to 32 participants.

4. Discussion

The participation of children and young people who use wheelchairs was highest at home, which was identified as the most favorable environment. Being with other people and watching TV, videos and DVDs were the most frequent activities. At school, the most frequent activities were in the classroom and being with peers outside the classroom, and they participated less in outings and school events. In the community, participation was infrequent for many activities and going for a walk in the neighborhood was the most common activity. As for environmental factors, the school was the environment with the fewest facilitators, and the community presented the greatest barriers, was less useful and had the fewest resources available, providing less support for the participation of the population studied.

Wheelchairs have the potential to provide benefits in terms of communication, independence, participation, self-care and social interaction⁹. However, the successful use of this assistive technology for independent mobility and greater participation depends on a series of environmental variables, and its role in the participation of children with disabilities is not well established in the literature³. However, the Gross Motor Function Classification System (GMFCS) can provide an idea of the differences in the participation of children with greater or lesser mobility restrictions and the possible use of locomotion aids in children with CP¹⁰.

The finding that watching TV, videos and DVDs is one of the most frequent and most involved activities is consistent with the greater sedentary behavior of children with disabilities, which is more evident in those who do not walk¹¹. However, in a study of young people with CP, there was no statistically significant association between the level of impairment of gross motor function and screen time¹². In the present study, some parents wanted their children/teens to do less of this activity, which raises the hypothesis that they may be aware of the possible damage associated with high levels of exposure to screens, which has been widely discussed in the literature¹³. In addition, it is known that the COVID-19 pandemic has mainly affected the child population with significant increases in sedentary activity time, with 46.8% of this period corresponding to screen time¹⁴.

The lowest attendance was for household chores, despite this being the activity with the highest level of involvement and the second item most parents wanted them to do more often. This result is confirmed by previous studies in which children with disabilities did less of this type of activity as their level of impairment increased, according to the GMFCS. This low frequency is worrying, as doing household chores at this stage can help build greater independence and autonomy in adult life¹⁵, which are already disadvantaged characteristics for people with greater self-mobility impairment¹⁶. It also enables the development of essential skills for living in the community, within an informal learning process in the family nucleus, making the child feel like a contributor and belonging¹⁷.

For the population in this study, organized physical activities were among the least frequent activities and the ones parents most wanted to change, in the community environment. In line with this, previous studies have shown that children and young people with CP are less physically active the greater their motor impairment^{12,18}. Sedentary behavior is influenced by social, economic and environmental barriers and predisposes to physical deconditioning and the onset of new diseases, which can lead to greater dependence on wheelchairs, further reducing daily energy expenditure. One way of reducing this risk is to provide greater access to and a larger variety of physical activities aimed at people with disabilities¹⁹.

In the present study, the results indicated a perception of limited social participation, since being with other people and playing games at home were among the activities that children/young people did most, and getting together with other children in the community was infrequent. It is known that participation can be influenced by the social support available, which includes that offered by friends¹, and that taking part in social activities is very important for the development of children and young people²⁰. Accordingly, previous findings have shown that the population of children with CP and spina bifida had little participation in social activities and few relationships with friends outside of school¹⁵, which was lower for those with greater motor impairment (GMFCS level V)¹⁰. However, qualitative analyses have suggested that the use of motorized wheelchairs has a positive impact on social interaction in the community²¹, being perceived by parents as a factor that facilitates daily routine, but which socially exposes their child's disability²².

As for environmental factors, in a study in Brazil, researchers found that children with CP who used wheelchairs or baby carriages had fewer barriers reported by their parents than those who walked²³. It has been discussed that there could be a relationship with the environments that the different groups accessed, since children who did not walk were generally more restricted to the home and those with a lower degree of disability may have experienced difficulties when expanding their experiences to the community. To complement this hypothesis, it was found that the need for environmental resources was significantly higher for children and adolescents with CP who did not walk compared to those who did²⁴. Thus, some authors have shown that children with lower levels of environmental resources were at greater risk of reduced participation in the community²⁵. However, children with CP at levels IV and V of the GMFCS had a frequency of activities outside the home equivalent to those at level I, which may be the result of the family support network's efforts to overcome existing barriers²⁰. In view of this, the results of the present study are consistent, showing that the most favorable environments had a higher participation rate and that in the less favorable ones the frequency was limited.

The main strength of this study was that it was a pioneer in understanding parents' perspectives on the participation and environment of children and young people who use wheelchairs in a large municipality in the Northeast region of Brazil. The use of an instrument that has been validated and cross-culturally adapted for the Brazilian population, and which can be applied via the web, are other benefits. In addition to reducing barriers related to the availability/viability of face-to-face meetings, the mixed collection ensured adequate understanding of the interviewees. Other advantages lie in the investigation of the family perspective, which is fundamental for pediatric health care, and in the partnership with professionals from rehabilitation centers.

Its limitations include: (1) not having carried out a sample calculation; (2) being an accessible sample of participants from rehabilitation services and users of manual wheelchairs, not allowing the results to be extrapolated to those who did not participate or to those who use motorized wheelchairs; (3) not having blinded the evaluators; (4) investigating only the family's view, which may differ from the child's/young person's self-perception of their participation; (5) not including information on the level of mobility and functionality of children and young people; (6) the time needed to answer the PEM- CY was a barrier to collection; and (7) the influence of the context of the end of the COVID-19 pandemic, which, due to the various social restriction measures adopted, possibly interfered with the possibility of participation by this population. It is also important to note that the data refers to parents and guardians of children who are treated at a state reference center, which may not reflect the results of other states or regions of the country, as well as other countries.

5. Conclusion

It is hoped that this research will contribute to comprehensive, family-centered care for children and young people who use wheelchairs. Furthermore, it can provide a basis for intervention strategies and health planning, including at the level of public policies and government actions. The results of this study suggest that the participation of children

and young people who use wheelchairs is greater at home, as it is the most favorable environment, participating more in passive activities related to screen time; that at school they are more restricted to classroom activities and to being with their peers outside the classroom, with fewer facilitators; that they have a low frequency of participation in the community, which has more barriers, is less useful and has fewer resources available. The need to educate and encourage families to participate in physical activities, household chores and social activities is emphasized. It is necessary to propose options that suit the context of each family, intervening to overcome barriers and insert facilitators. Furthermore, there is a clear need for further work to confirm these hypotheses.

Author contributions

The authors declared that they have made substantial contributions to the work in terms of the conception or design of the research; the acquisition, analysis or interpretation of data for the work; and the writing or critical review for relevant intellectual content. All authors approved the final version to be published and agreed to take public responsibility for all aspects of the study.

Competing interests

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