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Physiotherapy access for children and adolescents with physical disabilities in public institutions

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Abstract *This study aims to identify the factors that hinder physically disabled children and adolescent's access to physiotherapy in establishments accredited by the Unified Health System in Curitiba, Paraná, Brazil. This is a cross-sectional study that interviewed managers, physiotherapists, parents or guardians of children with physical disabilities. The perception of difficulties of each interviewed group was compared through descriptive statistics, considering the following realms: availability, purchasing power, information and acceptability. Considering the realm of availability, we identified the following hindrances: distance between the physiotherapy location and user's residence, inadequate supply of services and waiting list. Regarding the purchasing power, we observed the lack of financial resources among parents. Regarding information and acceptability, the lack of information about diagnosis and denial were reported by participants. We can conclude that the physiotherapy service has not been timely assured to children's motor development, so it is necessary to review the organization and distribution of services, and effective policies are required to ensure their use.*

Key words *Access to health services, People with disability, Children with disability, Public health, Physiotherapy*

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Introduction

Disability is an evolving concept, defined as body functions or structures issues and a significant loss or deviation[1]. One of its several forms is physical disability, which refers to the partial or complete modification of one or more human body segments, causing impairment of the physical function, that is, of the possibilities of bodily movement, maintenance of motor coordination and balance to perform daily tasks[2,3].

It is estimated that over one billion people worldwide have some disability, accounting for about 15% of the world's population[4]. According to the latest Brazilian Demographic Census conducted in 2010, more than 45 million people had some impairment[5]. The data also revealed that physical disability was the second most prevalent type in the country, found in 7% of the resident population[5]. Moreover, according to the World Health Organization (WHO), people with disabilities face barriers to access health services, education, employment, transportation and information[4]. Thus, the literature describes that people with physical disabilities are more likely to find difficulties in accessing services than those with other disabilities[6,7].

Access to health is a multidimensional concept that expresses a set of characteristics of the supply that increase or decrease the capacity of individuals to use health services[8]. It is a concept that varies over time due to the societal evolution and emergence of new needs[9]. Currently, it can be evaluated through four realms, which measure its equity or inequality, namely, availability, purchasing power, information and acceptability[9]. Availability includes, briefly, the geographical relationship between services and the individual, such as distance and transportation options, as well as the relationship between type, coverage, quality and quantity of health services provided[9]. In turn, purchasing power refers to the relationship between the cost of using health services and the individual's capacity to pay for them[9]. The information reflects the level of inequality between the knowledge of patients and that of health professionals[9], while acceptability is linked to the nature of the services provided and the perception of services by individuals and communities, and this realm is less tangible and, consequently, more difficult to detect because it varies according to cultural and educational aspects[9].

While access to health in Brazil is constitutionally guaranteed to all through the Unified Health System (SUS), people with disabilities still face hardships[10-14], even with support from different policies. Also, there are limitations in the investigation of the access of children and adolescents with disabilities to rehabilitation services[15,16], which do not allow us to know the fragilities that restrict full access to health. This study aims to identify the factors that hinder physically disabled children and adolescents' access to physiotherapy in establishments accredited by the SUS, located in the city of Curitiba, Paraná, Brazil, from the perspective of health care facility managers, physiotherapists and parents or guardians.

Material and Methods

This is a cross-sectional study[17] performed in physiotherapy establishments accredited by the SUS between June and September 2016, in the city of Curitiba, Paraná, Brazil, and submitted and approved by the Research Ethics Committee of the Pontifical Catholic University of Paraná. Thus, all ethical aspects were respected, according to CNS Resolution Nº 466/2012.

The research involved managers, physiotherapists and parents or those responsible for children and adolescents with physical disabilities who attended physiotherapy establishments accredited by the SUS. The criterion of inclusion defined to outpatient physiotherapy establishments, managers and physiotherapists was to provide care to this public for a period equal to or greater than two years. This temporal window was set as sufficient time to establish a bond between the parties, allowing managers and physiotherapists to be able to report on the difficulties faced by children and adolescents. The inclusion criterion for the parents or caregivers was the respective child or adolescent to be in physiotherapeutic treatment for at least two weeks. Physiotherapists assisted in the identification and indication of parents or guardians of children and adolescents with physical disabilities.

The sampling strategy considered the approximate number of children and adolescents with physical disabilities in physiotherapeutic treatment in establishments identified at the Municipal Health Secretariat (455 subjects), as well as the number of physiotherapists who provided care to this public (24 professionals). The fixed values $P = 0.5$ and $Q = 0.5$ were adopted to calculate the sample. In the absence of information about P, we assumed P and $Q = 0.5$, which leads to a larger sample size[18]. The approximate population of children and adolescents with physical disabilities receiving care in the six institutions was 455, using a 95% confidence level and a maximum sample error of 7% (E = 0.0677); the sample size calculated for parents or guardians was 144; and the total number of physiotherapists in the identified institutions that met the inclusion criteria was 24, assuming a 95% confidence level and a maximum sample error of 12% (E = 0.12). Therefore, the sample size arrived at 18.

Data collection occurred in four of eight establishments registered with the Municipal Health Secretariat since only these had children and adolescents with physical disabilities under care at the time of the research. We decided to include two special schools that provided physiotherapy services via the SUS to increase the number of subjects investigated, totaling a sample of six establishments.

The research was conducted through structured questionnaires proposed by the researchers, geared to managers (15 questions), physiotherapists (22 questions) and parents or guardians (46 questions). The questions prioritized the identification of factors that could hinder access to physiotherapy services, considering the four realms: availability, purchasing power, information and acceptability[9], with the exception of parents or guardians, whose questions were focused on the realms availability, purchasing power and information, besides the fact that the form also included sociodemographic and economic questions. Furthermore, questions related to the waiting list to receive the physiotherapeutic service, the number of therapies during the week, the child's diagnosis age, the age at which physiotherapy started, the place were therapy was performed, the neighborhood of residence, the type of transportation used, travel time and the level of difficulty to take the child to receive care, as well as the level of difficulty perceived to have access to the physiotherapy treatment.

Following identification and indication of the managers and physiotherapists of the possible subjects of research, we proceeded with the approach by convenience of individuals in the identified establishments. Data was collected from the managers and physiotherapists through the completion of the questionnaires, whose average duration was 20 minutes; together with the parents, this process was performed through individual interviews conducted by three previously trained researchers. The average duration of individual interviews was approximately 40 minutes.

Data were analyzed in the IBM SPSS Statistics software, through descriptive statistics, considering the four realms of access. The perception of the managers, physiotherapists, parents or responsible for the difficulties of access was compared through the chi-square test (χ^2). Non-respondents were excluded, and the level of significance was set at $p < 0.005$.

The mean and standard deviation (sd) of the variables related to the availability access realm were evaluated, namely: 1) age of diagnosis in months; 2) waiting list to receive the physiotherapeutic treatment; 3) age at which the child or adolescent initiated the physiotherapy treatment, by cause of physical disability; 4) number of visits during the week; 5) travel time in minutes, by type of transport. These variables were used to identify the existence of an association between individuals who reported access difficulties through Mann-Whitney U (two groups) and Kruskal-Wallis (more than two groups) since they referred to non-parametric data. The level of significance was $p < 0.005$.

Data referring to the distribution of the services, neighborhood or municipality of residence of the individuals were represented through georeferencing, generated by Google Earth.

Results

A total of 168 individuals participated, namely six managers, 18 physiotherapists and 144 parents or guardians, of which 123 represented children (85.4%) and 21 adolescents (14.6%).

The access hardships identified by the participants were structured by realm of access, namely, availability, purchasing power, information and acceptability and presented by thematic axis: parents or guardians, physiotherapists and managers (Table 1).

Perception of parents or guardians

Table 2 shows the perceptions of difficulties of access reported by the parents or those responsible for the availability indicators obtained through the interviews.

In this table, the association between the perception of distance and the time of travel in minutes is evidenced ($p < 0.005$). It was also emphasized that the time of travel was significantly lower for those who went by car (31.72 minutes, sd = 12.72 minutes) when compared to individuals traveling by collective transportation (70.89 minutes, sd = 27.23 minutes, $p = 0.000$), ambulance or municipal vehicles (93.75 minutes; sd = 89.43 minutes, $p = 0.011$).

Figure 1 shows the regional administration office of residence of children and adolescents, and the georeferenced establishments, where the majority resides far from the places where they receive physiotherapeutic care.

Regarding the perception of the lack of services, it was observed that the average number of physiotherapy sessions during the week was significantly lower among the group of parents or caregivers who reported the difficulty (Table 2).

Table 1. Difficulties of access to physiotherapy services accredited by the SUS reported by the research participants, by realm of access.

Difficulty of access	Parents or guardians		Physiotherapists		Managers		P[a]	% Total
	N	%	N	%	N	%		
Realm: Availability								
Distance between the establishment and the home of the child or adolescent							0.003	54.8
Yes	72	50.0	15	83.3	5	100.0		
No	72	50.0	3	16.7	0	0.0		
Waiting list to get treatment							0.144	41.1
Yes	57	39.6	11	61.1	1	20.0		
No	87	60.4	7	38.9	4	80.0		
Inadequate provision of services accredited by the SUS							0.651	39.3
Yes	58	40.6	7	38.9	1	20.0		
No	85	59.4	11	61.1	4	80.0		
Lack of physiotherapists							0.617	29.8
Yes	42	29.2	7	38.9	1	20.0		
No	102	70.8	11	61.1	4	80.0		
Lack of transport							0.001	28.6
Yes	34	23.8	12	66.7	2	40.0		
No	109	76.2	6	33.3	3	60.0		
High demand of attendances[b]							0.239	54.2
Yes	-	-	11	61.1	2	33.3		
No	-	-	7	38.9	4	66.7		
Delayed diagnosis[c]								22.9
Yes	33	22.9	-	-	-	-		
No	111	77.1	-	-	-	-		
Lack of specialized professionals[c]								15.3
Yes	22	15.3	-	-	-	-		
No	122	84.7	-	-	-	-		
Realm: purchasing power								
Lack of household's financial resources							0.000	33.3
Yes	40	28.0	13	72.2	3	60.0		
No	103	72.0	5	27.8	2	40.0		
Realm: information								
Lack of information of parents or guardians[b]							0.142	66.7
Yes	-	-	14	77.8	2	40.0		
No	-	-	4	22.2	3	60.0		
Realm: acceptability								
Denial of disability. Syndrome or injury[b]							0.673	58.3
Yes	-	-	11	61.1	3	60.0		
No	-	-	7	38.9	2	40.0		

[a] Analysis performed using $\chi 2$ to compare proportions or Fisher's test; [b] Question asked to professionals only; [c] Question asked to parents or guardians only.

Table 2. Difficulties of access, according to the perception of parents or guardians, versus indicators related to the realm of availability of access.

Difficulties reported by parents or guardians versus research indicators	N	Mean (μ) and Standard deviation (sd)	P-value
Distance hinders access physiotherapy versus walking time in minutes			
Yes	72	70.90 (40.66)	0.000*
No	72	39.17 (22.82)	
Total	144	55.03 (36.51)	
Poor supply of services versus number of physiotherapy attendances per week			
Yes	58	1.62 (0.74)	0.003*
No	85	1.98 (0.97)	
Total	143	1.84 (0.91)	
The waiting list hindered access physiotherapy versus waiting list time in days			
Yes	54	174.56 (226.72)	0.000*
No	87	21.06 (58.33)	
Could not inform waiting time	3	-	
Total	144	79.84 (164.80)	
Delayed diagnosis of the child or adolescent versus child's age of diagnosis in months			
Yes	32	19.84 (29.03)	0.196*
No	85	20.09 (37.07)	
Could not inform age of diagnosis	9	-	
Pregnancy	18	-	
Total	144		
Waiting time in days according to facility characteristics			
School clinic	41	23.24 (79.71)	0.000*
Clinic	100	103.01 (184.32)	
Could not inform	3	-	
Total	144	-	

*Mann-Whitney's U test.

It is also worth noting that the group of children, when compared to the group of adolescents, had a significantly higher average weekly attendance ($p = 0.002$; children = 1.9 weekly attendances versus adolescents = 1.3 weekly attendances).

The average waiting time for physiotherapy in days was significantly higher among parents or guardians who reported having faced it (Table 2). Regarding the characteristics of the establishment, it was identified that the waiting list was significantly lower in schools when compared to clinics ($p < 0.005$) (Table 2).

The lack of transportation was reported by 23.8% of parents or guardians. Of this total, 44.5% used collective transportation and 29.4%, own car, but no statistically significant association was identified between the type of transport and their lack thereof.

Regarding the perception of delayed in diagnosis, no association was identified between its mention and the age at which children and adolescents were diagnosed ($p = 0.196$) (Table 2). However, as shown in Table 3, the mean age of children at diagnosis by cause of physical disability varied. It was also observed that the mean time between the diagnosis and the onset of the physiotherapeutic treatment was 8.72 months, with variations depending on the cause of the physical disability.

Regarding the purchasing power realm, 28.0% of the parents or guardians reported having experienced at some point lack of financial resources for the treatment, either because of the inability to pay for the rehabilitation service or because of the lack of funds to pay for the transportation to the service (Table 1). Among those who reported this difficulty, 10% ($n = 4$) had a monthly household income below one minimum wage, 57.5% ($n = 23$) had income between one and two minimum wages, 20% ($n = 8$) had income between two and three minimum wages, 7.5% ($n = 3$) earned more than three minimum wages and

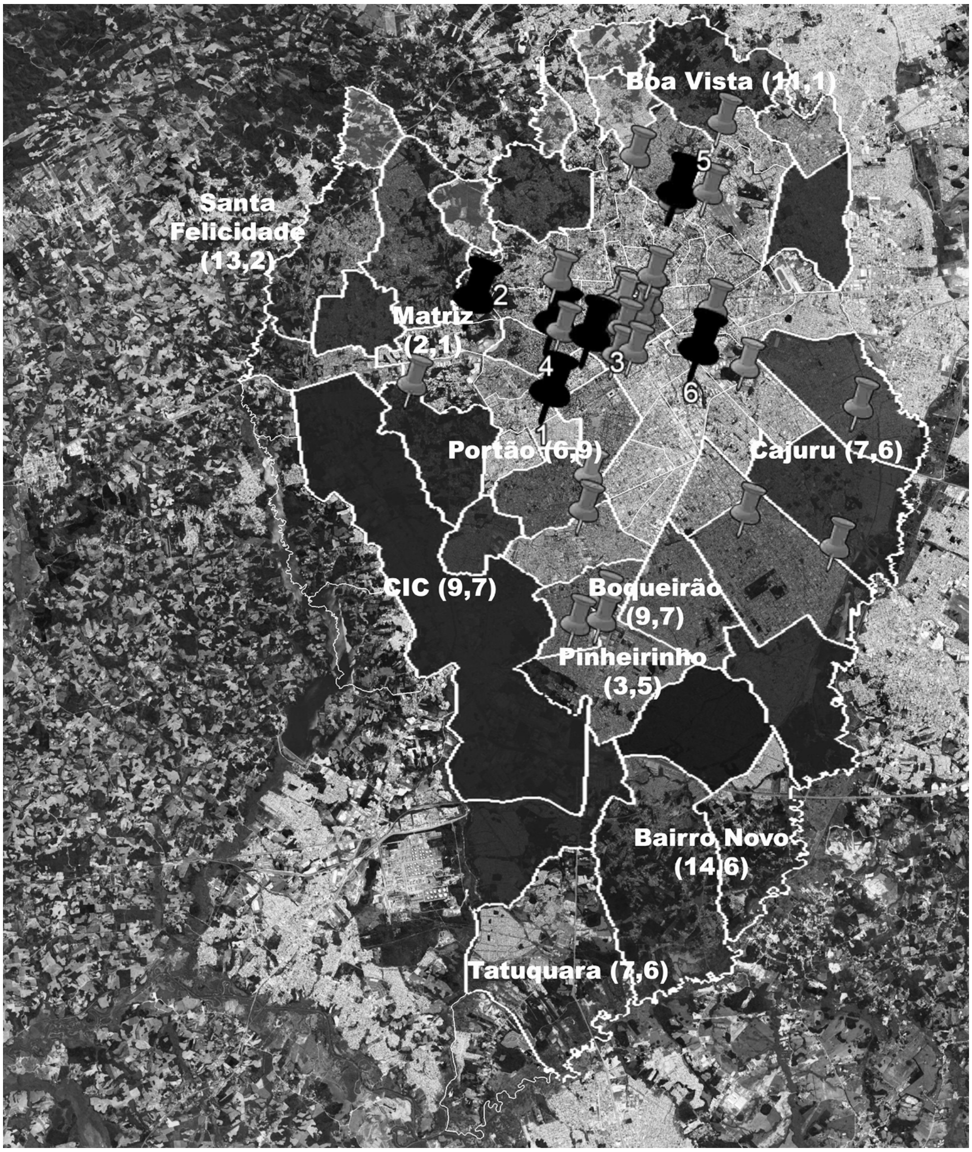

Figure 1. Percentage distribution of children and adolescents with physical disabilities, by regional administrative office of origin.

Note: Gray markers denote the physiotherapy establishments linked to the SUS and, in black, establishments that attended children and adolescents with physical disabilities.

two did not know how to answer (5.0%). There was no association between the lack of financial resources and monthly household income (p = 0.554). There was also no significant association between the age at which the child or adolescent began physiotherapy treatment and the monthly household income (p = 0,439). However, a statistically significant association was found between reference to the lack of financial resources and the waiting time to obtain the physiotherapeutic treatment (149.26 days; sd = 264.24 *versus* 50.06 days; sd = 89.06; p = 0.004).

In the information realm, 15.3% of the parents or guardians had an incomplete elementary education, 12.5% had a full elementary school, 11.8% did not finish secondary school, 40.3%

Table 3. Mean and standard deviation of the age at diagnosis, age at onset of treatment and waiting time between diagnosis and onset of physiotherapy in months, by cause of physical disability.

Cause of physical disability	n (%)	Age at diagnosis in months μ and sd	Age at onset of physiotherapy in months μ and sd	Time between diagnosis and onset of treatment in months μ and sd
Cerebral palsy and motor retardation	49 (42.2%)	11.73 (15.70)	18.06 (25.87)	6.33 (19.77)
Down Syndrome	26 (22.4)	0.46 (1.27)	3.12 (2.48)	2.65 (1.27)
Neuromuscular diseases	18 (15.5%)	67.33 (35.73)	84.83 (52.62)	17.50 (35.44)
Diseases of the central and peripheral nervous system	10 (8.6%)	34.40 (60.66)	53.30 (65.72)	18.90 (36.80)
Rare syndromes	7 (6.0%)	7.00 (8.81)	13.57 (15.49)	6.57 (19.85)
Congenital malformations of the lower limbs	4 (3.4%)	36.00 (72.00)	51.00 (78.00)	15.00 (11.16)
Myelomeningocele	2 (1.7%)	3.50 (4.95)	15.00 (4.24)	11.5 (0.70)
Total	116	20.20 (35.03)	28.92 (44.48)	8.72 (22.66)

finished their secondary school, and 20.1% had or attended higher education. No association was found between the parents/guardians' schooling and the age at which the children or adolescents began treatment (p = 0.051), and there was no relationship between the parents/guardians' schooling and the age at which the child or adolescent was diagnosed (p = 0.125).

Perception of physiotherapists

In the availability realm, the distance between the establishment and the home of the child or adolescent was reported by 83.3% of physiotherapists, followed by lack of transportation (66.7%). As a result, the waiting time to reach service and the high demand of attendances arrived at 61.1%. Similarly, the lack of physiotherapists and the low supply of services accredited to SUS were cited by 38.9% (Table 1). In the purchasing power realm, 72.2% of physiotherapists reported the household's lack of financial resources. In the information realm, the lack of information from parents or guardians was identified as a barrier to access to treatment (77.8%). Among the physiotherapists who stated this difficulty, 50% (n = 7) disagreed that parents or guardians understood the diagnosis of children and adolescents, and 35.7% (n = 5) agreed. Finally, in the acceptability realm, 61.1% of the professionals mentioned denial of disability, syndrome or injury as a difficulty of access (Table 1).

Perception of establishment managers

In the access availability realm, managers reported distance as the greatest difficulty of access, followed by lack of transportation (40.0%) and high demand for service (33.3%). The waiting list to get care, the low supply of services accredited by the SUS and the lack of physiotherapists were cited by only 20.0% of the managers. In the purchasing power realm, the lack of family resources was indicated by 60.0% of professionals. On the other hand, in the realm information, the lack of information of the parents or guardians was mentioned by 40.0% of the managers, while in the acceptability realm, denial of disability, syndrome or injury was reported by 60.0% of them (Table 1).

Discussion

The discussion is shown here considering the order of tangibility of the access realms[9], as well as the similarity of the perceptions of the actors involved.

In the availability realm, the distance between the service and the residence of the children or adolescents was the hardship widely mentioned by the actors of this research, and there was also a statistically significant association between the distance and the time of travel to the establishment. These findings corroborate the results of a study conducted in Fortaleza with people with disabilities[19], who identified as difficulties aspects related to geographical accessibility, such as the time to reach the establishment and distance, according to their perception and that of dentists.

At the same time, in this study, the georeferencing allowed to show that the services were allocated in the central regions, although users resided predominantly in remote regions. This remoteness can maximize the difficulties of access to services, and other studies have reported problems such as inadequate transportation, dependence on ambulances, which do not always meet the demands of the entire population, and lack of resources to pay for transportation and travel when in rural areas[12,13,20]. Although it is well known that the remoteness of establishments is due to the hierarchical and regionalized supply of services, so that the more specialized, the more distant are the services of the population[21], Travassos and Martins[22] state that the geographical accessibility is an essential factor for the effective use of the health services, and can attenuate or increase the difficulties of access. Travassos[23] still points out that the spatial distribution of health services must be coherent in order to be appropriately used.

Regarding the scarce supply of physiotherapy services accredited by the SUS, which showed a significant association between the reported difficulty and the number of weekly therapies, it is worth mentioning that perceptions of the high demand for care and the lack of physiotherapists emerged together. These factors suggest an imbalance between the demand and supply of services and are similar to the results of a study conducted in São Paulo, in which the reduced number of attendances and the lack of professionals to meet the full demand in the rehabilitation services[24] were observed. Another difficulty that may be linked to the provision of services is the waiting list, which evidenced a waiting time of approximately six months to achieve access to physiotherapy among the group of parents who reported having faced it. It is also worth noting that this waiting period was confirmed from Table 3, which highlights the existence of lapse in the system for access to medium complexity. Although these findings are not exclusive to this research, given that national and international studies have described similar situations in the services used by people with disabilities[6,14,20,25,26], overcoming these hardships is a challenge to public health, since it expresses the system's failure in assuring the right to health comprehensively, reiterated by the National Policy for the Health of People with Disabilities and the Statute of the Child and Adolescent[27,28].

Regarding the delay in diagnosis, there was a divergence between the perceptions of delay or not in obtaining the diagnosis, since the mean in months was higher among parents or guardians who denied this difficulty, which was not elucidated in this study. The age of the diagnosis varied with the causes of physical disability; in the case of cerebral palsy, for example, it was evidenced that the consolidation of the diagnosis occurred around the 12 months, corroborating the literature, since the child's motor development retardation becomes known during the months after the birth[29]. However, for the cases related to myelomeningocele, neuromuscular diseases and congenital malformations, the literature describes that the diagnoses can be obtained quicker than the means found in this research[30,31]. These findings suggest poor access to diagnostic services, which, in turn, culminate in late access to physiotherapy found in this study, in which it was observed that, except for children with Down syndrome, the others obtained the physiotherapy service after the first year of life, that is, in a time unfavorable to maximum motor development, since the child is more likely to develop motor capacity when stimulated until 12 months of age[32].

Regarding the perception of difficulties among the interviewed groups, we observed that managers reported less frequently the existence of problems related to the availability of services, such as a waiting list and a small supply of services, a finding that indicates possible bias, since it is a matter of organizational aspects that could or should not be linked to the governability of this stakeholder. Studies related to the perception of health managers have confronted these findings, pointing to the recognition of various weaknesses of the health system at different levels of care[33,34]. Thus, it is believed that the optimistic view of the managers in this research was due to the attempt to dilute the organizational difficulties of the services.

The lack of financial resources was identified in the realm of purchasing power, which can be attributed to the low income of the participants. It was noted that this hardship was significantly associated with a longer waiting list to access physiotherapy. Given this finding, it is believed that the lack of resources has delayed the search for service after obtaining the diagnosis, suggesting that the existence of public service, by itself, does not warrant its use. International studies have shown that financial factors affect the use of services[7,35], but the impact of the lack of financial resources on the use of the physiotherapy service was not investigated, given the cross-sectional nature of the study. Therefore, it is suggested to investigate the implication of financial factors in the use of public services in order to propose solutions that enable effective access.

In the information realm, it was found that parents' schooling had no influence on the age at which diagnosis was obtained and physiotherapy began, differing from some authors, who described the influence of schooling on access and use of services[36,37]. According to Barata[38], the use of services is influenced by the level of schooling, but with the creation of the SUS, access to them was extended to a vast majority of the Brazilian population, to minimize the differences arising from it.

Still in this realm, according to the professionals interviewed, there was a lack of information from parents or guardians and understanding the diagnosis, indicating poor communication between the health system and individuals[9]. Studies have pointed out the lack of information provided by health professionals to families with children and adolescents with chronic diseases[39,40]. There is, therefore, a need to sensitize health professionals about the development of educational actions, ensuring access to adequate and accessible information for the disabled and their families[41].

Regarding the denial, the difficulty related to the acceptability realm reported by professionals, which is characterized by non-acceptance of what happened to the child, the literature reveals that it can postpone the treatment and increase difficulties experienced by the family to provide care[41]. Considering that revealing the diagnosis and prognosis is a moment that requires adequate support from the team that will perform it, since it involves a difficult time for the family, who needs support to face this new situation[42], the professionals involved in this process should be sensitized to participate actively, in order to provide the necessary clarifications to parents or guardians.

One of the limitations of the study is that it was carried out in health care facilities, which may be biased, depending on whether the professional is financially dependent on the institution, and the parents or caregivers need it to ensure the treatment of the children, even considering that all the actors were informed that the research had no linkage with the establishment. It is also indicated the non-investigation of the real use of the services after being inserted in the system, something that does not allow to identify the impact of these difficulties in the received treatment.

Conclusions

This study aimed to identify the factors that hinder access of physically disabled children and adolescents to physiotherapeutic treatment in establishments accredited by the SUS, in the city of Curitiba, Paraná, Brazil. Although no generalizations can be made, the results show that the main hardships related to the availability realm are distance between the establishment and the residence of the children or adolescents, waiting list to obtain treatment, inadequate provision of services accredited by the SUS, delay in obtaining diagnosis and starting treatment after 12 months of age, with the exception of children diagnosed with Down syndrome. In the purchasing power realm, it was evidenced that the lack of financial resources is associated with a longer waiting list to obtain the treatment. Regarding information and acceptability, the lack of information and understanding of the clinical diagnosis of children or adolescents, as well as denial of disability, syndrome or injury were identified.

The findings suggest that children have not had access to the physiotherapy service in a time favorable for maximum motor development, which reduces their probability of developing their motor capacity. Although these difficulties are not exclusive to the municipality investigated, it is salutary to create strategies that ensure full access to the health of children and adolescents with absolute priority, as guaranteed by legislation in force.

Collaborations

VA Silva, DR Carvalho, ADL Moser and APC Loureiro idealized the study design, analyzed and interpreted the data, elaborated and critically reviewed the article, as well as approved the final version to be submitted. VA Silva, ARR Busnello and RC Cavassin performed the data collection during the field research, analyzed and interpreted the data, as well as participated in the writing of the article and approved the final version.

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