

Environmental barriers to social participation of children with cerebral palsy in Tehran

Zahra Nobakht, Mehdi Rassafiani*

Pediatric Neurorehabilitation Research Center

University of Social Welfare and Rehabilitation Sciences, Tehran, Iran

Pouria Rezasoltani

University of Social Welfare and Rehabilitation Sciences, Tehran, Iran

Robab Sahaf

Iranian Research Center on Aging

University of social welfare and rehabilitation sciences, Tehran, Iran

Farzaneh Yazdani

Oxford Brookes University, Oxford, England

Objectives: Cerebral palsy is the most common type of permanent movement and posture disorder in children leading to activity limitations. Children's participation is influenced by their functional ability, skills, interests, and environmental factors. The objective of the study was to describe parent perception of environmental barriers to participation of children with cerebral palsy.

Method: Secondary data analysis of the study of psychometric properties of the Persian version of the Craig Hospital Inventory of Environmental Factors for use with children with cerebral palsy. The questionnaire was administered to a sample of convenience of 75 parents of children with cerebral palsy aged between 5 and 12 years.

Results: Barriers to participation most commonly reported by parents were in the services and assistance subscale and the policies subscale of the measure. Also, parents reported the greatest barriers encountered by their children were availability of transportation and availability of education and training.

Discussion: Findings from this study indicate the presence of multiple environmental barriers to participation of children with cerebral palsy. Enhancing participation of children with cerebral palsy by altering barriers and increasing facilitators requires further research concerning these factors. This study suggested that people with lower function in gross motor, manual ability, as well as cognition require further support to participate in social activities

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Introduction

Cerebral palsy (CP) is a group of permanent disorders due to brain damage leading to abnormal movement and posture, contractures, deformities, and activity limitations (1,2). These limitations influence the participation of children with CP in various contexts such as at home and in school. It is known that children with disabilities tend to participate in fewer activities. Participation is essential in promoting child health, development, and well-being (3,4). The World Health Organization's (WHO) "International Classification of Functioning, Disability and Health (ICF)"(5) defines

participation as "involvement in a life situation" and also offers two qualifiers: "capacity" and "performance". According to this classification contextual factors cause inconsistencies between a child's capacity (what a child can do in an ideal environment) and performance (what a child actually does in the environment in which s/he lives). Contextual factors consist of personal and environmental factors. Personal factors are not classified in the ICF and include aspects such as sex, age, lifestyle, habits, coping style, and other such factors. Environmental factors are classified as (a)

*All Correspondences to: Mehdi Rassafiani Email: <mrassafiani@yahoo.com>

products and technology; (b) natural environment and human-made changes to environment; (c) support and relationships; (d) attitudes; and (e) service systems and policies (6).

Mostly encountered barriers in a newly conducted systematic review consisted of personal factors including: child's lack of knowledge and skills, preferences, fear and environmental barriers including: attitudes to disability, inadequate facilities, lack of transport, programmes (7). Diversity and intensity of participation of children with cerebral palsy is less than typically developing peers. It is also true about Iranian children. But there is no significant difference between the participation enjoyment of children with cerebral palsy and typically developing peers. It is clear that these children with less participation enjoy more. It was well established that differences between countries such as supportive system influence the patterns of children's participation. However, some similarities in participation patterns in different countries were found. These similarities were broadly linked to the functional level of children. As a case in point, children with lowest level of function had the lowest level in participation (8, 9). Also, the intensity of children's participation was influenced by the physical, social, and attitudinal environments. Higher participation in daily activities was significantly associated with a better physical environment (10).

Social supports, physical accessibility, attitudes, policies and the lack of support from staff and service providers are reported commonly as environmental factors influencing participation (11). Law et al (12) and Vogtset et al (13), by using the Craig Hospital Inventory of Environmental Factors (CHIEF) (14), found school and work environment, and natural and built environment were the most important source of barriers which a child with disabilities encountered. Although, Law found the least encountered barriers included attitudes and support environment, some studies reported social attitudes as an important barrier (13,15,16). The cultural aspect of environment also influences participation (17,18). In other words, the context in which a child with CP lives influences environmental barriers to participation (17,19). Therefore, the main purpose of this study was to determine the most frequently encountered environmental barriers these children experience in their daily activities in the context in which they live. The findings of this study help clinicians and policy makers to enhance their interventions and processes of care.

Methods

Participants and procedure - A convenience sample of 75 caregivers of children with CP aged between 5 and 12 years old who had lived in Tehran for at least a year completed the Persian version of the CHIEF long form and a personal characteristics questionnaire in clinic. The study was carried out at two outpatient clinics in Tehran (Valiasr Rehabilitation Center and Tavanyab). All participants signed an informed consent form approved by the Ethics Committee at the University of Social Welfare and Rehabilitation Sciences.

Instruments - The CHIEF questionnaire has two forms including a long form and short form consisting of 25 and 12 items respectively assessing environmental barriers to participation. These items are categorized into five subscales: policies, physical and structural, work and school, attitudes and support, and services and assistance. For each item, the participant is first asked to rate the frequency with which their child encounters barriers (daily=4, weekly=3, monthly=2, less than monthly=1, or never=0). Then, if the participant indicates that their child encounters environmental barriers at any frequency other than never, they are asked whether their child considers the barrier to be a big problem=2 or a little problem=1. Scoring of each item is the product of the frequency score and the magnitude of impact score and therefore ranges between zero and eight. A score of each subscale is calculated as the mean of frequency-magnitude product score across items of subscale and a total score is calculated as the mean of frequency-magnitude product score across all items (14).

The CHIEF has good test-retest reliability and internal consistency. It also has evidence of construct validity for children with physical disabilities (14, 20, 21). The CHIEF was translated from English into Persian based on the International Quality of Life Assessment (IQOLA) approach. This approach has three main stages consisting of forward translation, examination of forward translation and backward translation. The Persian version of the CHIEF has acceptable levels of face validity, construct validity, item discriminant validity, test-retest reliability, and internal consistency for use with children with cerebral palsy (22). In this study we used the CHIEF long form questionnaire.

The gross motor function and the manual ability of all children were determined according to the Gross Motor Function Classification System (GMFCS) (23) and the Manual Ability Classification System (MACS) (24). These two validated classification

systems are based on self-initiated movement and manual ability respectively. The GMFCS classifies the severity of motor impairment of children with CP into five levels. Children in level one have the most independent motor function while children in level five have the least. The MACS also classifies children with CP according to their manual abilities when handling objects in their daily activities. Children in level one have minor limitations, while children in level five have major limitations in handling the objects compared to typically developing children. The GMFCS and MACS levels of children were determined by the same occupational therapist with the help of caregivers and observation of the child if needed (25). The cognitive levels of the children were classified into three categories according to a form developed by the SPARCLE project: >70, 50-70, and <50, based on the responses of parents (25, 26).

Statistical analysis - Descriptive statistics (frequencies and descriptive) were used to determine environmental barriers to children's participation. To analyze data statistically, we performed a linear regression analysis. Linear regression estimates the coefficients of the linear equation, involving one or more independent variable that best predicts the value of the dependent variable.

Results

Seventy five children, 36 female and 39 male, who were 8.09 (± 2.07) years of age, participated in this study. Most of the children were classified as either level two or four of the MACS (26.7% and 21.3%, respectively) and the least as level three (16%). Most of the children were classified as either level two or four of the GMFCS (25.3%) and the least as level three (10.7%). About 81% of these children were classified as having the spastic type of CP (bilateral and unilateral) (table 1).

Table 1. Mean \pm SD for the CHIEF subscales and total score also grouped by sex and age

Item	Sex			Age			
	mean \pm SD	Female	male	5-7	7-9	9-11	11-13
policies	3.34 \pm 2.67	3.01 \pm 2.83	3.64 \pm 2.52	2.94 \pm 2.50	3.96 \pm 2.78	3.23 \pm 2.99	3.10 \pm 2.41
physical and structural work and school *	2.72 \pm 1.91	2.55 \pm 1.87	2.88 \pm 1.96	2.35 \pm 1.82	2.76 \pm 1.81	3 \pm 2.14	3.19 \pm 2.09
attitudes and support	2.73 \pm 2.24	2.47 \pm 2.09	3.03 \pm 2.43	2.36 \pm 2.33	2.92 \pm 2.43	2.51 \pm 2.04	3.33 \pm 2.44
services and assistance	2.71 \pm 2.18	2.56 \pm 2.24	2.85 \pm 2.14	2.68 \pm 2.02	2.90 \pm 2.37	2.37 \pm 2.29	2.98 \pm 2.18
Total	3.53 \pm 2.1	3.27 \pm 2.15	3.78 \pm 2.06	3.24 \pm 1.99	3.46 \pm 2.08	3.52 \pm 2.40	4.56 \pm 1.92
Total	3.09 \pm 1.69	2.85 \pm 1.78	3.32 \pm 1.60	2.82 \pm 1.66	2.24 \pm 1.67	3.04 \pm 1.93	3.60 \pm 1.43

*some children attended school (n=44)

The data from the CHIEF instrument were summarized as means \pm SD Table(1) and were displayed according to the frequency and magnitude of each item Table (2). In descending order, parents reported environmental barriers their children encountered as: the services and assistance (3.53 \pm 2.1), policies (3.34 \pm 2.67), work and school (2.73 \pm 2.24), physical and structural (2.72 \pm 1.91),

attitudes and support (2.71 \pm 2.18) subscales. Also, parents reported the greatest barriers encountered by their children were availability of transportation (81.33%) and availability of education and training (81.33%). In contrast, the least encountered barriers were lack of computer technology (33%) and experiencing discrimination (44%).

Table 2. Frequency and magnitude of the barriers

Items	N affected (%)	Frequency					missing	Magnitude		missing
		daily	Weekly	monthly	Less than monthly	never		Big problem	Little problem	
policies										
services in community	(78.67)59	21	15	12	11	16	0	44	15	0
policies of businesses	(58.67)44	22	6	6	10	30	1	38	6	1
policies of education*	(59.09)26	9	6	8	3	18	0	16	10	0
policies of government	(53.33)40	19	4	7	10	33	2	28	12	2
physical and structural										
design of home	(61.33)46	28	3	3	11	29	1	28	18	0
design of school*	(52.27)23	15	2	2	4	21	0	15	8	0
design of community	(70.67)53	17	11	8	15	22	2	35	18	0
natural environment	(53.33)40	11	8	5	16	34	1	17	23	1
surroundings	(72)54	26	10	8	10	21	0	35	19	0
technology	(32)24	7	2	8	7	51	0	9	15	0

Items	N affected (%)	Frequency					missing	Magnitude		
		daily	Weekly	monthly	Less than monthly	never		Big problem	Little problem	missing
work and school										
help at school*	(70.45)31	19	6	2	4	13	0	19	12	0
attitudes at school*	(50)22	7	6	2	7	22	0	10	12	0
support at school*	(54.55)24	7	6	5	6	20	0	12	12	0
attitudes and support										
attitudes at home	(58.67)44	23	4	4	13	31	0	29	15	0
attitudes in community	(74.67)56	26	10	8	12	19	0	42	13	1
support at home	(50.67)38	16	5	6	11	37	0	16	22	0
support in community	(49.33)37	6	9	7	15	38	0	18	19	0
discrimination	(44)33	15	12	9	7	32	0	30	12	1
services and assistance										
transportation	(81.33)61	27	19	8	7	14	0	46	15	0
information	(57.33)43	6	11	10	16	32	0	16	26	1
education/training	(81.33)61	23	12	11	14	14	1	43	18	0
medical care	(76)57	13	10	14	20	18	0	42	15	0
personal equipment	(58.67)44	17	5	8	14	31	0	28	16	0
help at home	(78.67)59	33	8	7	11	16	0	42	17	0
help in community	(61.33)46	26	9	5	6	28	1	38	8	1

*some children attended school (n=44)

We also examined the association between encountering barriers and the child's age, sex, cognitive levels, manual ability, and gross motor function. As demonstrated in Table (3), level four of the MACS and cognitive level 50-70 were significantly associated with the CHIEF total score and have the most important role in association with encountering

barriers. The results showed an increase from level two to level four of the MACS. Also, there is an increase from level two to level five of the GMFCS and there is an increase from cognitive level < 50 to cognitive level 50-70. No significant relationship existed between the CHIEF total score and the child's age and sex.

Table 3. Linear regression between CHIEF total score and the child's age, sex, gross motor function, manual ability, and cognitive level

Model	Unstandardized Coefficients		Standardized Coefficients	T	Sig.
	B	Std. Error	Beta		
(Constant)	0.639	1.061		0.602	0.549
MACS_2	0.244	0.526	0.064	0.464	0.644
MACS_3	1.042	0.643	0.227	1.620	0.110
MACS_4	2.075	0.697	0.506	2.976	0.004
MACS_5	1.243	1.009	0.288	1.232	0.222
GFMCS_2	-0.053	0.554	-0.014	-0.096	0.923
1 GFMCS_3	0.575	0.730	0.106	0.788	0.434
GFMCS_4	0.154	0.629	0.040	0.245	0.807
GFMCS_5	0.442	0.900	0.110	0.491	0.625
Cognitive <50	-0.490	0.691	-0.085	-0.709	0.481
Cognitive 50-70	1.212	0.441	0.314	2.747	0.008
sex.ch	-0.037	0.345	-0.011	-0.107	0.915
age.ch	0.012	0.007	0.175	1.656	0.103

a. Dependent Variable: mean of q1-q25

Conclusion

The purpose of this study was to determine the most encountered environmental barriers to participation of children with CP. Our results showed that these barriers were most encountered in the services and assistance subscale and the policies subscale.

However, Law et al. (12) and Vogtset al. (13) found the school and work subscale and the natural and built subscale to be the two highest scoring subscales. The decrease in the score of the school and work subscale in comparison with the services and assistance subscale and the policies subscale

may be related to the children's physical functioning. According to Law et al. (12) and Colver et al. (15), fewer environmental barriers were reported in children with a better level of functioning. The work and school subscale was scored for the children who went to school. Furthermore, the majority of these children were classified as either level one or two of the MACS and GMFCS. Parents reported these children encountered fewer barriers when they participated in the school environment.

Our results showed few differences between the means of the work and school, physical and structural, and attitudes and support subscales. Also, the results showed an increase of all means in comparison with those of Law et al. (12) and Vogts et al. (13). These increases may be due to the differences in the actual environment. The data indicated that the attitudes and support subscale includes the least encountered barriers which supports the findings of Law.

According to the frequency of the problematic items, the most daily reported barriers were availability of transportation and availability of education and training in agreement with Vogts et al. (13). According to the magnitude of the problematic items, the greatest was availability of transportation. Another purpose of the study was to examine the relationship between the CHIEF total score and the child's age, sex, gross motor function, manual ability, and cognitive level. Our results showed that the most important factors affecting children encountering barriers were level four of the MACS and cognitive level 50-70. According to the results of the study, children who were classified as either level four or five of the MACS and GMFCS encountered greater barriers than children who were classified as either level one or two of the MACS and GMFCS. The results are in agreement with those of Law et al. (12) and Colver et al. (15), that is children with lower functional abilities encountered more problems when attempting social activities.

Our results showed no significant relationship between the child's age and their experience of barriers. This contradicts the findings in Law et al.'s study (12) in that they found children in the group aged between 12 and 14 encountered more barriers than children aged between six and eight as well as the group aged between 9 and 11. Similarly, in a study by Hemmingson and Borell (27), older students were found to have experienced significantly more barriers than younger ones. Such variation could be explained by the increase in

children's level of participation when they become adolescents. We can conclude that there are no differences but this issue should be studied in a larger sample.

The data indicate no significant differences by the child's sex which supports Law et al.'s study (12). However, the results do not support Colver et al.'s study (15); they found in comparison with girls, boys experienced less favorable attitudes from family and friends.

According to the ICF, the gap between a child's capacity and performance was due to contextual factors. As for the personal aspects of these factors, except for a child's functional abilities including manual ability, gross motor function, and cognitive level, other factors did not importantly influence to what extent they encountered environmental barriers. Enhancing participation needs to decrease such barriers and increase facilitators.

The results showed that most barriers were encountered in the services and assistance subscale and the policies subscale. These two subscales are related to providing facilities and services, and the legislation and administration of policies for children with disabilities. It indicated that the availability of facilities and administration of policies were not sufficient to meet the needs of children with disabilities. According to the frequency and magnitude data, the most important barriers were availability of transportation and availability of education and training, and the most daily encountered barrier was home design. These barriers were the most important ones and need more attention by the relevant organizations.

This study suggested that people with lower function in gross motor, manual ability, as well as cognition require further support to participate in social activities. In other words, policy makers and responsible organizations need to develop their policy to integrate children with CP into society. According to the contextual differences between this study and others, it appears that contextual factors influence the types of barriers to participation children experience. Therefore, another qualitative study is required to identify these factors.

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