ORIGNAL ARTICLE

To Evaluate the Life Participation of Cerebral Palsy Children with their Environment

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ABSTRACT

Background: Cerebral palsy is a common disorder of the children with motor disabilities affecting the quality of life.
Aim: To determine how the cerebral palsy child participate with their environment.
Methodology: A Cross sectional study was conducted in Children Hospital Lahore from July to December 2019. Study population was the parents of cerebral palsy child. The sample size was 200 parents.
Result: A total of 200 parents and young child were included in this study and only 162 parents and young child responded. Parents were asked about different items related to physical environment at home, school, community and transport. When they were asked about that their child have adapted toilets at home almost 102(63%) responded that toilets were available. They were inquired about different items in home such as enlarged rooms, modified kitchens, walking aids, hoist and communication aids at home. About 69(42.6%) respondents respond that communication aids are available at their schools. When they were inquired about lifts for your child at public places almost 85(52.5%) responded that these facilities are available. Almost 72(44.4%) respondents said that they have accessible buses for their child.
Conclusion: Current study highlighted the participation of cerebral palsy child with their environment. The parents of cerebral palsy child were providing the facilities they needed for life participation. The physical environment, social support, attitude of teachers, therapist, family and classmates were found +ve toward cerebral palsy child.
Keywords: Cerebral palsy child, environment, parents and young child, facilities

INTRODUCTION

Cerebral palsy is most common disorder of the children that affect the muscle movements and coordination[1]. Its most common manifestation includes the motor disabilities. It occurs in early life and affects the quality of life. A child with cerebral palsy may experience postural disorders, sensory problems, balance problems and intellectual problems on their lifetime[2]. These symptoms limit the cerebral palsy children to participate in life. Many childrenhave difficulty in walking and performing activities of daily living and they are dependent for their self-care in others[3]. It may affect their quality of life as they are not able to perform their daily activities.Participation in activities is an important factor for all the children but the disabled children are not able to participate with their environment. Mei C et al, concluded in the study that despite the barriers experienced, children participated in a range of activities. Parents placed importance on communication and its influence on children's independence, behaviour and relationships. Barriers and facilitators identifiedand it highlighted aspects of the environment that could be modified through intervention to enhance communication and participation[4].

Another study was conducted in 2016 the aim of study was to investigate comprehensively the determinants of the quality of life (QOL) of caregivers of children with cerebral palsy (CP) based on the International Classification of Functioning, Disability and Health for Children and Youth (ICF-CY)[5].

In another study the effect of using the device was analyzed for spatio-temporal parameters, pelvic girdle angles and general gait cycle parameters. Among the eighteen initial parameters, seven presented a statistical significant difference when comparing stage 2 of the intervention with stages 1 and 3. Those changes showed the potential of the CPWalker to improve muscular strength and gait patterns of the patients with CP in the long term and to provide useful information for the designing of robotic devices of rehabilitation for future generations[6].

Previously this study was done in the different countries of Europe and they concluded a significant difference that how much facilities in the home affect the participation of the children. And in Pakistan no such study is conducted so we are conducting this study in Lahore to see either parents are providing the facilities to their children for their participation.If we provide the facilities to the children according to their environment then we promote the disabled children to participate in life with their environment. European child environmental questionnaire (ECEQ) was used to assess whether the families of cerebral palsy children were providing the facilities to their children or not.

The main objective of the study was to determine participation of children with cerebral palsy in life with their environment.

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MATERIALS AND METHODS

A Cross sectional study was conducted in children hospital Lahore from July to December 2019. In this study 200 parents of cerebral palsy child included. Convenient sampling technique was used. Data was collected by using the European Child Environment Questionnaires (ECEQ). Data was analyzed through SPSS version 23. Informed consents were taken from all the participants.

Parents of cerebral palsy diagnosed children of both genders with age ranging 6-15 years were included in the study. Children with other congenital musculoskeletal disorders like club foot, Torticollis, Developmental dysplasia of hip, spina bifida and with associated epilepsy or seizures were excluded.

RESULT

Parents were asked about different items related to physical environment at home, school, community and transport. When they were asked about that their childrenhad adapted toilet at home almost 102(63.0%) responded that toilet were available. They were also inquired about enlarged rooms, modified kitchens, walking aids, host and communication aids at home. About 69(42.6%) responded that communication aids were available at their schools. When they were inquired about lifts for children at public places almost 85(52.5%) responded that these facilities were available. Almost 72(44.4%) respondents said that they had accessible buses for their child.

Their responses varied to questions asked about social support from home and community. About 62(38.3%) responded that they didn't need any grant for home modifications while 76(46.9%) received grants for modifications and got practical physical help from the people in public places. They were inquired about the attitude of family, friends, teachers, therapists and classmates. Majority 110(67.9%) responded that they received emotional support from family and friends. 76(46.9%) respondents responded that they have special staff at their schools and 115(71%) said that their classmates had positive attitude toward their child (Table 1).

Table 1: Summary of Distribution of Responses to ECEQ Items

Questions	Response			
	Not needed%	Needed & available%	Needed& not available%	Total%
Does your child have suitably enlarged rooms or extensions at home?	98(60.5)	44(27.2)	20(12.3)	162(100.0)
Does your child have a suitably adapted toilet at home?	46(28.4)	102(63.0)	14(8.6)	162(100.0)
Does your child have a suitably modified kitchen at home (modified cupboards, work surfaces etc.)?	56(34.6)	51(31.5)	55(34.0)	162(100.0)
Are there ramps for your child to use in public places?	49(30.2)	88(54.3)	25(15.4)	162(100.0)
Are there suitably adapted toilets or toilet facilities for your child in public places?	69(42.6)	61(37.7)	32(19.8)	162(100.0)
Are there lifts for your child to use in public places?	52(32.1)	85(52.5)	25(15.4)	162(100.0)
Are there escalators for your child to use in public places?	63(38.9)	61(37.7)	38(23.5)	162(100.0)
Are doorways suitable for your child to use in public places?	60(70.0)	74(45.7)	28(17.3)	162(100.0)
Is there enough room in public places for your child to move around?	63(38.9)	65(40.1)	34(21.0)	162(100.0)
Are there smooth enough pavements in your town or village center for your child?	53(32.7)	75(46.3)	34(21.0)	162(100.0)
Does your family have an adequate vehicle for getting your child around?	60(37.0)	69(42.6)	33(20.4)	162(100.0)
Is there accessible car parking in public places?	60(37.0)	71(43.8)	31(19.1)	162(100.0)
Do you get an adequate bus service in your area?	62(38.3)	69(42.6)	31(19.1)	162(100.0)
Are there accessible buses for your child in your area?	55(34.0)	72(44.4)	35(21.6)	162(100.0)
Are there accessible train services in your area?	61(37.7)	68(42.0)	33(20.4)	162(100.0)
Are there accessible taxis for your child in your area?	58(35.8)	73(45.1)	31(19.1)	162(100.0)
Does your child have walking aids they need such as frames or splints?	63(38.9)	62(38.3)	37(22.8)	162(100.0)
Does your child have hoists at home?	55(34.0)	79(48.8)	28(17.3)	162(100.0)
Does your child have communication aids at home?	64(39.5)	61(37.7)	37(22.8)	162(100.0)
Do you receive grants for, or receive special equipment free of charge, such as wheelchairs, hoists, bathing aids etc.?	62(38.3)	69(42.6)	31(19.1)	162(100.0)
Does your family receive grants to pay for home modifications?	62(38.3)	67(41.4)	33(20.4)	162(100.0)
Does your family receive grants for holidays?	53(32.7)	76(46.9)	33(20.4)	162(100.0)
Did you receive information about financial benefits at the appropriate time?	63(38.9)	65(40.1)	34(21.0)	162(100.0)
Are the local leisure facilities suitable for your child?	0(0)	105(64.8)	57(35.2)	162(100.0)
Does your child receive emotional support from family members living in the home?	0(0)	94(58.0)	68(42.0)	162(100.0)
Does your child receive emotional support from wider family and friends?	0(0)	110(67.9)	52(32.1)	162(100.0)
Does your child receive practical physical help from family members living in the home?	59(36.4)	68(42.0)	35(21.6)	162(100.0)
Does your child receive practical physical help from wider family and friends?	51(31.5)	76(46.9)	35(21.6)	162(100.0)
Does your child receive practical physical help from people in public places?	66(40.7)	61(37.7)	35(21.6)	162(100.0)
Do teachers, therapists and doctors listen to your views as parents?	0(0)	103(63.6)	59(36.4)	162(100.0)
Is your child allowed extra time to encourage independence at home?	57(35.2)	68(42.0)	37(22.8)	162(100.0)
Does your child get specialized therapy services, such as Physiotherapy	61(37.7)	67(41.4)	34(21.0)	162(100.0)
Do doctors, therapists, nurses and other health service staff co-ordinate their work well to help your child?	0(0)	100(61.7)	62(38.3)	162(100.0)
Do social services such as personal helpers, holiday relief and day nurseries co-ordinate their work well to help your child?	61(37.7)	69(42.6)	32(19.8)	162(100.0)
Do you receive a service in which your child is looked after elsewhere for a few days including nights?	60(37.0)	67(41.4)	35(21.6)	162(100.0)
Does your child have a helper or assistant at home?	59(36.4)	70(43.2)	33(20.4)	162(100.0)
Do you have family or friends who regularly (about once a week) look after your child for a few hours?	61(37.7)	69(42.6)	32(19.8)	162(100.0)

Can you go to parent support groups in your area?	61(37.7)	67(41.4)	34(21.0)	162(100.0)
Is counselling available to you because you have a child with a disability?	58(35.8)	74(45.7)	30(18.5)	162(100.0)
Do family members living in the home have a positive attitude towards your child?	0(0)	104(64.2)	58(35.8)	162(100.0)
Do wider family and friends have a positive attitude towards your child?	0(0)	100(61.7)	62(38.3)	162(100.0)
Do people in public places have a positive attitude towards your child?	0(0)	98(60.5)	64(39.5)	162(100.0)
Does your child get encouragement to reach his/her potential from family members living in the home?	0(0)	107(66.0)	55(34.0)	162(100.0)
Does your child get encouragement to reach his/her potential from wider family and friends	0(0)	87(53.7)	75(46.3)	162(100.0)
Has your child got the wheelchair or modified buggy they need?	52(32.1)	77(47.5)	33(20.4)	162(100.0)
Has your child got the school placement he/she needs?	0(0)	85(52.5)	77(47.5)	162(100.0)
Are there ramps for your child to use at school?	53(32.7)	74(45.7)	35(21.6)	162(100.0)
Are there suitably adapted toilets for your child at school?	59(36.4)	72(44.4)	31(19.1)	162(100.0)
Are there lifts for your child to use at school?	47(29.0)	80(49.4)	35(21.6)	162(100.0)
Does your child have communication aids at school?	58(35.8)	69(42.6)	35(21.6)	162(100.0)
Are there special staff, therapists and helpers to help your child in school?	56(34.6)	76(46.9)	30(18.5)	162(100.0)
Is your child allowed extra time to encourage independence at school?	58(35.8)	76(46.9)	28(17.3)	162(100.0)
Does your child get encouragement to reach his/her potential from teachers, therapists and helpers at school?	0(0)	118(72.8)	44(27.2)	162(100.0)
Does your child get encouragement to reach his/her potential from classmates and similar age friends?	0(0)	107(66.0)	55(34.0)	162(100.0)
Does your child receive emotional support from teachers, therapists and helpers at school?	0(0)	113(69.8)	49(30.2)	162(100.0)
Does your child receive emotional support from classmates and similar age friends?	0(0)	117(72.2)	45(27.8)	162(100.0)
Does your child receive practical physical help from teachers, therapists and helpers at school?	62(38.3)	70(43.2)	30(18.5)	162(100.0)
Do teachers, therapists and helpers at school have a positive attitude towards your child?	0(0)	95(58.6)	67(41.4)	162(100.0)
Do classmates and similar age friends have a positive attitude towards your child?	0(0)	115(71.0)	47(29.0)	162(100.0)
Do teachers and helpers at school have sufficient understanding of your child's medical condition?	75(46.3)	70(43.2)	17(10.5)	162(100.0)

DISCUSSION

This study evaluated the life participation of cerebral palsy child with their environment. Results obtained by the study revealed the positive response by the parents and the young child. They were inquired about facilities related to physical environment, social support and attitude of community[7]. Majority of the respondents responded that facilities they needed were available and only small portion of respondents responded that the facilities that they needed were not available.Participation is an important health outcome for children with cerebral palsy and should be incorporated in routine clinical practice[8]. Physical, social, and attitudinal environment may restrict participation in children with cerebral palsy (CP). Defining and measuring potential environmental determinants of participation for children with CP needs further development; and here we propose how this might be done[9].

One study was conducted onchildren with cerebral palsy (CP) show difficulties in play and can also experience lower playfulness scores when compared to typically developing children. This paper analyses play and playfulness in children with CP using mainstream robotic toys with supporting adult play partners. They concluded that the role of the adult as play scaffolder has been important to mediate between the child with CP and the environment, toys included: the adult should be strongly aware of this role to better support the child in being in charge of the play situation. Further research is needed[10]. Questionnaire for cerebral palsy (LAQCP) provide the broadest description of what and how frequently children with cerebral palsy perform a range of activities and thereby indicate participation[11].

Another study showed that it was evident that mothers and siblings of pre-symbolic children with DS and with CP engaged them in reciprocal interaction. Findings on how mothers and siblings influence pre-symbolic children's communication suggest the need to involve them in assessment and intervention for these children[12]. One study was carried out to investigate gait characteristics in children with spastic cerebral palsy during inclined treadmill walking under a virtual reality environment and their result showed CP children showed similar adjustments for most gait parameters during uphill walking as TD children. With a lower walking speed, CP children could maintain similar dynamic balance as TD children. Uphill walking magnifies the existing abnormal gait patterns of the cerebral palsy children. We suggest that during a treadmill training with an inclination, the walking speed should be carefully controlled in the case of improving peak joint loading too much[13]. In our study parents were providing all the essential facilities to their child so that they can participate with their environment.

In 2008 one study was conducted on the participation of cerebral palsy child and they concluded that some factors most commonly identified as barriers to participation were social attitudes and the physical environment and they suggested a further study[14]. But the result of current study showed a supportive factor of social attitude and physical environment for participation.Higher levels of participation among children with CP are associated with residence in certain districts[15]. So that in our study we concluded that all the parents were providing the necessary facilities to their child to participate with environment.

CONCLUSION

Current study highlighted the participation of cerebral palsy child with their environment. So the parents of cerebral palsy child were providing the facilities they needed for life participation. The physical environment social support and attitude of teachers and therapist, family and friends, and classmates were positive toward the cerebral palsy child.

Recommendation and Limitations: This is a single center study. Only parents were involved and few parents were hesitant in providing informations. Multicentered study regarding this recommended with more sample size and teachers and other care givers to cerebral palsy child may be enrolled in study, to evaluate more about participation role and its effects on cerebral palsy child.

Declaration: It is declared that no funding was taken for this study and there was no ethical issue about this study and moreover participants data privacy secured throughout.

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