HAYDARPAŞA NUMUNE MEDICAL JOURNAL

DOI: 10.14744/hnhj.2020.55822 Haydarpasa Numune Med J 2023;63(1):33–39

ORIGINAL ARTICLE





Activity Preferences of School-Age Children with Cerebral Palsy: Comparison with Healthy Peers

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Abstract

Introduction: The aim of the study was to evaluate physically disabled children of 6–10 years of age with cerebral palsy (CP) with regard to functional independence levels and preferences of activity; and to compare these characteristics with those of their healthy peers, and also to highlight the relationship of the mothers' depression level with the preferences of activity. Methods: Eighty children with CP and 80 healthy ones were enrolled to the study together with their mothers. The main research group (Group A) consists of equal numbers of boys and girls in 6–8 and 9–10 years of age, a total of 80 children with CP, while Group C (control) is composed of equal numbers of age-and sex-matched healthy children. Sociodemographic data and Preferences for Activities of Children measures were collected from all children, whereas Pediatric Functional Independence Measurement were applied to children with CP, and their mothers were evaluated through Beck Depression Inventory.

Results: Among the children with CP, 47 were diplegic, 12 triplegic, 15 quadriplegic, one had total, and five had mixed type CP. Healthy children had higher levels of functional independence, and higher frequency of participation in the activities. Both groups of children mostly preferred to participate individual developmental activities and least in social-based activities. Mothers of children with CP had higher depression scores when compared to those of healthy children and depression scores of the mothers are inversely proportional to the total preference of participation in the activities in children with CP (p<0.05).

Discussion and Conclusion: Functional independence level and depression status of mothers of children with CP had a significant repressive effect on preferences of participation in activities.

Keywords: Activity; cerebral palsy; occupational therapy; participation; preference.

Cerebral palsy (CP) is recognized as a common developmental progressive disease of the early childhood with an estimated incidence rate of 2–2.5 /1000 in children^[1].

Children with CP suffer from neurological disorders such that spasticity, ataxia, dyskinesia, muscle weakness, epilepsy, hydrocephalus; emotional problems like hyperactivity and behavioral disorders; and disorders of cortical functions such that learning, visual, speech, and mental retardation and

sensory and perception disorders. Neurological disorders of the children restrict functional independence level by affecting gross and fine motor functions.

Disorders of emotional and cortical functions effect important functions such as problem solving, communication, and social behavior negatively. In addition, secondary problems affecting participation of the children with CP are environmental factors, health policies, etc^[2,3].

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Submitted Date (Başvuru Tarihi): 12.01.2020 Revised Date (Revize Tarihi): 10.09.2020 Accepted Date (Kabul Tarihi): 01.12.2020



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Children with CP may face increased risk for inadequate participation in social and leisure activities. Furthermore, abilities such as friendliness, well-being, and developing new habits may be impaired^[4-6]. A number of studies children with various disabilities can take part in much less activity compared with their peers and these activities are mostly home-based, less socialized, and less physical ones^[4,7,8].

To understand the complexity of participation in the activities in different age groups, one must comprehend factors that drive the child to participate and intervention methods to boost participation^[8]. Research showed that girls and boys differ in their participation in the activities; boys mostly preferred and enjoyed physical activities while girls participated and enjoyed skill-based, social, and individual developmental activities^[9-12]. Some reports cited that socializing is augmented and the rates of participation in recreational activities and scores of preferences respecting these decrease significantly with advancing age^[9,10,13,14].

Stress levels of mothers of children with CP were reportedly higher than those of children with developmental disorders^[15-17]. Some researches demonstrated that mothers caring disabled children suffer from significant anxiety and depressive disorder, leading to reduced life quality which, in turn, affects child's participation in and preferences of activities^[4,9,16,18,19].

The objective of the present study is to evaluate physically disabled children of 6–10 years of age with CP with regard to functional independence levels and preferences of activity; and to compare these characteristics with those of their healthy peers, and also to highlight the relationship of the mothers' depression level with the preferences of activity.

Materials and Methods

Our study is followed by Hacettepe University Medical, Surgery, and Pharmaceutical Research Ethics Committee with the registration number LUT 09/66. It was evaluated within the scope of the Declaration of Helsinki on July 02, 2009 and was found appropriate in terms of medical ethics.

Children with CP admitted in the pediatric ward of Ankara Physical Therapy and Rehabilitation Hospital within the study period were enrolled in this study. The hospital is located in the capital city of Ankara populated by more than 6 millions and serves a larger hinterland (around 20 millions of people). Clinical and sociodemographic characteristics of children with CP and their mothers presenting to

the hospital from many different parts of the country were compared with age and sex-matched healthy controls with similar socioeconomical status. Excluded from the study were uncooperative children, those who are unable to understand the test instructions and mentally retarded, who have serious hearing or visual impairment and those unable to walk even with aids.

Children between 6 and 10 years of age are in the era of distancing from the families and establishing ties with classmates, teachers and building new habits, self-confidence, self-achievements, and new skills. Therefore, this study focuses on how children with CP showed participation in activities and how this pattern changes with age, compared with the healthy children. Clinical and demographic data were obtained from all children and their mothers included in the study: Ages of the child and mother, gender, type of birth, subtype of CP, motor developmental type and level of CP, concomitant disorders, where the child lives, type of school, monthly income of the family, relative status between mother and father and their educational levels, how long the mother can accompany the child actively in a day. Children with CP were assessed with Pediatric Functional Independence Measurement (WeeFIM) and children in both groups were evaluated using Preferences for Activities of Children (PAC) scales, while the mothers were asked to respond Beck Depression Inventory (BDI).

WeeFIM can be used to evaluate all healthy children below 7 years of age and disabled children between 6 and 7 years of age. It comprises 18 items in six different fields. Scores range from 18 to 126^[20].

PAC scale is designed as an extension of the CAPE, but it can be used independently. PAC can be used as outcome measures to look at the nature of the participation (i.e., social vs. solitary, community-based vs. home based) and to assess the effectiveness of interventions designed to increase participation. The tool will help to document how children participate in everyday activities outside of the school mandate, over a 4-month period. It will measure a child's preferences of activities (through PAC). PAC reliability coefficient (alfa) for planned and unplanned activities is between 0.76 and 0.84^[14].

BDI can be used to evaluate all individuals older than 15 years of age. It is a 21-item and self-report rating inventory that measures characteristic attitudes and symptoms of depression. The BDI takes approximately 10 min to complete, and its reliability coefficient is calculated as 0.85, Spearman-Brown coefficient 0.86, and Guttman Split-Half coefficient as 0.82^[21].

Statistical Analysis

SPSS 15.0 for Windows software was used for statistical data analyses. Analysis results for descriptive statistics were given as number and percentage for categoric variables and mean, standard deviation, and range for numerical variables. Categorical comparisons were performed using Pearson's Chi-Square, Fisher's χ^2 , or Yates' χ^2 tests. Comparisons of numerical variables in two independent groups were performed using the Student's t-test when normal distribution conditions were established, using the Mann-Whitney U test when normal distribution was not established, and using one-way ANOVA and the Kruskal-Wallis test in more than two groups. Subgroup analyses of comparisons of more than two groups were performed with the Mann-Whitney U test and interpreted with Bonferroni correction. Relations between numerical variables were analyzed using Spearman correlation analysis since parametric test conditions were not established. Statistical significance was set at a level of p<0.05.

Results

Eighty children with CP and 80 healthy ones were included in the study together with their mothers. The main research group (Group A) consists of equal numbers of boys (n=40) and girls (n=40) in between 6 and 10 years of age, a total of 80 children with CP, while Group C (control) is composed of equal numbers of age- and sex-matched healthy children.

With special regard to CP, 47 children with CP (58.75%) were classified as diplegic, 12 (15%) triplegic, 15 (18.75%) quadriplegic, [8] one (1.25%) had total, and five (6.25%) had mixed type CP. All children with CP were found to have bipedal involvement respecting the motor development level. Healthy children were found to exhibit higher levels of functional independence in the daily life activities when compared to children with CP. Mean WeeFIM scores of the children with CP and healthy children were 98.65±18.13 versus 121.5±6.25, respectively (p<0.05).

Depression levels of the mothers of the children with CP as assessed through BDI were significantly higher than those of the mothers of the healthy children (18.1 \pm 12.1 vs. 9.8 \pm 7.2, respectively, p<0.05).

Both groups of children showed least participation preference in individual development activities (p=0.301) and most in social activities (p=0.057) (Table 1).

Healthy children preferred to participate all kinds of activities more frequently compared to children with CP (p=0.035). Data showed that both groups of children have participated most frequently social activities, followed by recreational, skill-based, physical, and least frequently individual development activities.

The difference between the two groups in terms of preferences of participation in planned (p=0.665) and unplanned activities (p=0.213) was not statistically significant. Social activities were the most preferred unplanned activity by both groups of children, while the least preferred was attending at the library which is an example of individual development activities (Table 2).

Healthy boys were not found to differ from those with CP regarding preferences of participation in activities, while boys with CP tended to prefer physical activities more than peer girls with the disease. The present findings also demonstrated that healthy girls preferred to participate in social and skill-based activities compared to healthy boys, whereas healthy girls preferred social and physical activities.

Girls with CP mostly preferred participation in social activities and least in physical activities, while boys with CP mostly participated in social activities and least in individual development activities. Healthy boys preferred to participate most in recreational activities and least in individual development activities.

When evaluated with special regard to age of the children, both groups of children showed preferences to participate in individual development activities more with advancing age. On the other hand, healthy children's preferences to

Table 1. Group comparisons of activity participation preferences via PAC

Activity preference	Group A (n=80)				Group C (n=80)				р
	Mean	SD	Min	Max	Mean	SD	Min	Max	
Recreational	2.58	0.33	1.3	3.0	2.62	0.29	1.8	3.1	0.335
Individual development	2.26	0.45	1.2	3.0	2.33	0.41	1.3	3.0	0.301
Social	2.66	0.28	1.9	3.6	2.75	0.27	1.8	3.0	0.057
Skill-based	2.52	0.43	1.4	3.9	2.58	0.43	1.1	3.0	0.339
Physical	2.47	0.41	1.4	3.0	2.56	0.37	1.4	3.0	0.152

Types of activity Social	Childre	n with CP	Healthy children			
	Most preferred	Least preferred	Most preferred	Least preferred		
	Walking around	Cooking	Having fun with friends/ next of kin	Cooking		
Recreational	Playing with toys	Playing with animals	Playing on PC	Puzzles		
Individual development	Shopping	Going to the library	Gardening	Going to the library		
Skill-based	Swimming	Stretching exercises	Dancing	Singing exercises		
Physical	Playing with ball outdoors	Individual physical activities	Playing with ball outdoors	Individual physical activities		

Table 2. Distribution of preferences of activity participation by healthy children and those with CP

participate in social, individual development, skill-based, and physical activities increased with advancing age, whereas preferences to participate in recreational activities remained the same.

With respect to age of the children, healthy children between 9 and 10 years of age preferred to participate in social and physical activities more than those with CP did.

Social activities were the most preferred ones by boys with CP between 9 and 10 years of age and all children with CP between 6 and 8 years of age, while physical activities were most preferred ones by girls with CP between 9 and 10 years of age.

Healthy boys between 6 and 8 years of age preferred physical activities significantly more than peer healthy girls, whereas healthy boys between 9 and 10 years of age preferred social, individual development, and skill-based activities significantly more than peer healthy girls.

Healthy children and those with CP between 9 and 10 years of age preferred to participate individual development activities more commonly compared to peer girls.

Social activities were the most preferred ones by all children in the sample except for girls between 9 and 10 years of age.

Discussion

Literature data postulated that economical and social factors have their impact on the patterns of participation of disabled children and their families. Families with disabled children are known to suffer from economical burden of the unaffordable health-care costs and difficulties in work life. Studies reported that participation types of disabled and healthy children are usually similar, and that insufficient participation of the children with CP results mostly from economical hardships and poor resources of the family rather than the child's disease^[12,13,20,22].

Although families with disabled children in this sample had

very limited economical resources, there were interesting exceptions in terms of participation, for example, a mother taking both of her children with CP to the municipal pool for swimming twice a week.

King et al.^[12] indicated that the time spent in unplanned activities is affected by economical resources of the family, preferences of participation, and support received from the child's classmates. For example, preferences of entertainment activities of the family can encompassathletic, social, educational practices, and comprise ways to enhance physical, cognitive, and communicative abilities of the child.

For instance, participation in school clubs can be seen as a planned social and physical activity but not a sportive one. Intra-school participation in chess games, story writing, photography, or scientific contests may improve communicative and social abilities of the child with CP without high costs. King et al.^[12] emphasized that participation frequencies of planned and unplanned activities were lower than expected and this finding warranted the need for investigation of the factors precluding children with CP from participation and also effective intervention methods to overcome these.

Despite the positive effects of the participation on all children, functional independence levels of children with CP in the daily life activities are found to be lower than healthy peers in the present study. This may have resulted from functional handicap due to neurological disorders such as spasticity, tremor and ataxia restricting the child's motor performance, timing difficulties in accomplishing the tasks, personal disabilities (social communication, motivation etc.), and environmental barriers. The physical abilities are known to affect activity preferences, whereas functional independence levels have their impact on participation patterns and variations^[23].

In the present study, healthy children participated in phys-

ical activities more commonly when compared to children with CP. This difference may have resulted from low functional independence levels of children with CP, because prerequisites of active physical performance are athletic physical functions, physical abilities and a harmony in the movements^[14].

The gender of the child has an impact on the selection of activities, frequency of participation, and enjoyment in the activity which, in turn, feed participation behavior again^[6,10-12,24-27].

A number of studies demonstrated that boys mostly preferred to participate physical and sportive activities, while girls tended to join skill-based ones, indicating an important role of gender in activity preferences^[10-12,24,26,27]. Both groups of children were found to participate most frequently in social (having fun with next of kin, visiting somewhere) and the least in individual development activities. In the present study, boys (both healthy and those with CP) preferred to join physical activities more frequently than girls.

Girls in both groups preferred to participate recreational, social, and individual development activities more commonly than boys. Healthy girls preferred participation in social and skill-based activities more commonly compared to healthy boys, and physical activities compared to girls with CP in the present study.

These findings are suggestive of sex and functional independence levels are among primary definitive factors of preference of activities which may stem from developmental differences between sexes. This information can be used in the field of ergotherapy providing opportunity for children dependent in their daily life activities to participate the activities they enjoy to enhance life satisfactions, functional abilities, and motivations and to evaluate improvements in participation in time for assessment of the efficacy of the treatment.

PAC is a tool used to determine preference of activities children and young individuals between 6 and 21 years of age. Information derived from this instrument may help planning future career and developmental contemplations of children including those with CP through identification of fields of interest.

Functional independence levels of the children with CP may not be sufficient to allow the performance of the activity preferred. We suppose that alternative activities should be kept in mind in such cases. In other words, other types of activities should be offered if the child fails to accomplish a certain activity. For example, we observed that a group

of children playing basketball on a wheelchair in Ankara School of Children with Orthopedical Impairment were not different in most sportive activities and motivations with the exception of the presence of scoliosis, kyphosis, and amputated lower extremities, and other problems which may affect upper extremity functionality.

Data derived from studies are suggestive of accessibility of the child to the activity (or bringing the activity to the child in some rural areas) may have important role in enhancement of the participation in the activities, which may be facilitated through institutions, schools, etc.

Literature data pointed out that the age of the child affected areas of interest, variations, and types of participation^[27]. The children tend to be more socialized and show less participation in recreational activities with advancing age – for example, time spent watching television reaches a peak in the school age and the nadir in adolescence^[9,27,28].

Law et al. [16] conducted a study on children with CP at ages 6–8, 9–11, and 12 and older than 12 years and reported that older children participated in recreational activities and enjoyed these activities much more than young children.

In a study by Palisona et al.,^[25] 277 boys and 223 girls with CP were enrolled and the authors put forth that participation in recreational activities were affected by age and preferences of activities, and some of these (puzzles, imagination plays, and toys) were preferred by school children more commonly than older children. Similar findings were noted in the present study; participation rates in individual development activities increased with advancing age in both groups of children.

Preferences of participation in individual development activities in school-age children with CP many factors are associated with augmented physical abilities and functions, acquisition of new skills, socializing, and increased self-confidence, whereas the same type of activities is increasingly preferred in healthy children with advancing age. This finding highlights the necessity of identification of factors precluding participation in physical activities by children with CP.

Children with physical disorders generally at risk of low participation in the activities and usually exhibit a passive attitude in the activities, for which they face social isolation and loneliness^[4,7,8,13,27,29,30]. Likewise, wellness status of the children with CP affects general health of the family proportionally^[19].

Mothers of children with CP are subject to significantly higher risk of depression, cognitive, speech, and social disorders when compared to others. Similarly, these mothers reportedly face higher levels of stress and emotional expectations than others, because of accompanying the child all the day. In accordance with these findings, these mothers are also exposed to high risk of somatoform disorders and anxiety disorders^[15-18,31]. In the present study, depression levels of the mothers of the children with CP were significantly worse than those of the mothers of the healthy children.

Weiss et al.^[31] claimed that single-parent families confront difficulties in activity development of the child, economical, and future concerns when compared to dual parent families whereas they can develop more adaptive behavior in response to stress and render responsibilities more flexible.

Majmener et al.^[17] pointed out that the child's rates of participation in recreational and individual development activities are closely bound up with family stress. Likewise, King et al.^[11] cited that certain family factors affected behavior style of the child negatively and restricted time spent in leisure and recreational activities. Family has a key role in planning the leisure activities of the child in the school age. In a study on 102 families with children with CP, Parker et al.^[26] found that low rates of participation in social activities were closely related to family stress, rather than physical and psychological well-being of the child.

Studies demonstrated that leisure activity participation by disabled children was lower than expected, and variation of activities is poor and these children mostly participated in social and recreational activities, [12,19,26] and interestingly, functional limitations and the severity of the disease had a mild impact on the activity level and enjoyment of the child^[4,9,19].

The present findings showed that barrier factors for children with CP are economical situation of the family, educational level and depression score of the mother, social support and services received by the family, and functional independence of the child in the daily life. Mothers of the children with CP were interviewed and indicated that most families especially those from the rural areas experienced import and difficulties to get access to high quality organized healthcare.

In addition, we have found that specialized institutions designed for training and care of the children with special needs are not adequate; therefore, children with physical disabilities are obliged to share classrooms with healthy peers, thereby experience delayed social development. Rehabilitation centers are of vital importance especially to render development of skill-based activities.

Ergotherapy units may host education and training of the mothers how to cope with stress, interventions to the children with special needs, and certain aspects of behavioral clues with the cooperation of the mother and the child. Social support services for economically deprived families should be enhanced to augment participation in certain types of activities.

A major limitation in this study is the lack of assessment of the impact of environmental and cultural factors on preferences of participation. Intervention strategies individualized for the child should be devised to provide an appropriate medium for them to grow up in accord with the personal interest and abilities. The future population-based studies can be designed with these objective.

Ethics Committee Approval: Our study is followed by Hacettepe University Medical, Surgery, and Pharmaceutical Research Ethics Committee with the registration number LUT 09/66. It was evaluated within the scope of the Declaration of Helsinki on July 02, 2009 and was found appropriate in terms of medical ethics.

Peer-review: Externally peer-reviewed.

Authorship Contributions: Concept: G.K.; Design: G.K.; Data Collection or Processing: G.K.; Analysis or Interpretation: M.U., G.K.; Literature Search: G.K.; Writing: G.K.

Conflict of Interest: None declared.

Financial Disclosure: The authors declared that this study received no financial support.

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