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Physical fitness, physical activity, psychosocial status and quality of life of adolescent siblings of neurologically disabled children

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Abstract

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Keywords

disabled child, adolescent, physical activity, physical fitness, psychology

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Authors' Contribution:

A Study Design
B Data Collection
C Statistical Analysis
D Data Interpretation
E Manuscript Preparation
F Literature Search
G Funds Collection

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INTRODUCTION

Family who has a disabled child comes across with a variety of problems. Each individual in the family tries to cope with these problems. Multiple issues like expenditure on the care and treatment of the child, financial limitations caused by additional expenditure, extra time spent on the child, and isolation from immediate surroundings, educational difficulties, and inadequate social support complicate the family life. It is stated that the quality of life level in a family who has a disabled child decreases [1, 2].

All individuals in the family should be examined in the studies assessing the effects of disabled children on their family. Problems like high anxiety, conflict with parents, and dedicating their life to the disabled child in their social life may be observed in the healthy siblings of a disabled child. It is emphasized that psychosocial features of the siblings of disabled children should be investigated and the services given to parents should also be presented to siblings [3].

Physical activity contributes to general, personal, motor, psychological, and social development of both children and adolescents [4]. Physical fitness means abilities to succeed in daily life activities without being over-fatigued and having a good physical, physiological, and psychological condition [5, 6].

People who are physically inactive have a lower level of physical fitness than physically active people [7]. Risk of developing chronic diseases in adulthood is also high in inactive children and adolescents [7, 8]. However, no information has been found about the effects of a disabled child on physical activity and physical fitness levels of their healthy siblings. Moreover, to our knowledge, there has been no study investigating how a disabled family member affects the physical fitness capacity of other members.

Physical activity, physical fitness, psychological adaptation and the quality of life of the siblings of disabled children were aimed to be measured in this study.

MATERIAL AND METHODS

50 adolescents, between 12 and 18 years of age, from among siblings of children who need physical therapy and rehabilitation were included in the study group by a simple randomized sample technique.

The control group included 50 adolescents who have healthy siblings and were between 12 and 18 years of age. Only one sibling was involved from each family. Consent forms were taken from the parents of all subjects.

Adolescents who have chronic lung and/or heart disease, rheumatic disease, oncologic diseases, endocrine disease, psychiatric diagnosis and who are incapable of adequate cooperation were excluded from the study.

Cases were found by the second author, whereas they were assessed by the first author who was unaware of the groups to make the study blind for elimination of bias.

Socio-demographic characteristics of all subjects and their families, their parents' education status, and their sibling's leisure activities were recorded.

Information regarding the disability of the sibling of the study group was also noted. Physical fitness level, physical activity level, psychosocial status and quality of life of the included adolescents were then assessed.

PHYSICAL FITNESS LEVEL

BMI was calculated as weight divided by height squared (kg/m^2) [9]. The Curl Up test was used to determine abdominal muscle strength and endurance. Strength and flexibility of trunk extension were assessed using the Trunk Lift test and the Vertical Jump test was used to assess the extensor strength of lower limb [9, 10]. The Modified Apley Test for the flexibility of the upper limb and the Sit and Reach test for the flexibility of hamstring and trunk muscles was used [10].

Grip strength of the dominant hand and fingers was measured using the Baseline Hydraulic Hand dynamometer (Baseline® measurements; Fabrication Enterprises Inc., Elmsford, NY, USA). The case was positioned with forearm support and elbow at 90 degree flexion. Grip values were firstly measured at neutral position, then at pronated and supinated positions. Every grip was measured three times and their average was taken.

PHYSICAL ACTIVITY LEVEL

The FELS Physical Activity Questionnaire which was developed for 7-19 year old children was used to assess the physical activity level. Its reliability and validity was performed [11].

PSYCHOSOCIAL STATUS

The adolescents' psychosocial status was assessed using the Depression Scale (CES-DC) which was developed by the Epidemiological Studies Centre. This scale was stated to be reliable and valid among children and adolescents aging 12-18 years old [12, 13].

QUALITY OF LIFE

The 87-item Child Health Questionnaire (CHQ), which was developed for children and adolescents who are older than 10 years, was used to assess the quality of life. It consists of 12 subscales including physical function, emotional role function, behavioural role function, physical role function, pain, global behaviour, mental health, self-confidence, global health perception, change in health, family activities and family cohesion [14].

ANALYSIS

Data was analysed using statistical package for social sciences (SPSS) 13.0 for Windows. Since data was not normally distributed, Chi square tests were also used to compare the categorical data. Mann-Whitney U and two tailed tests were used to determine differences between the arithmetic means of the groups. The difference at $p < 0.05$ level was considered to be statistically significant.

RESULTS

The study was completed with 50 adolescents of the study group who have a disabled sibling and 50 adolescents of the control group. The diagnoses of 50 children who were the physically disabled siblings of the study group were recorded. 38% of these children had cerebral palsy, 12% had autism, 10% had myopathy, and 8% had mental retardation.

The subjects' parents' working status was asked. There was no statistical difference in the mothers' working status ($p > 0.05$). 18% of the mothers of the study group worked, whereas 22% of the mothers of the control group worked. Similarly, no statistical difference was found in the fathers' working status between the groups ($p > 0.05$).

Except higher BMI results of the control group, the two groups were similar in their socio-demographic characteristics (Table 1).

According to the results, 25 (50%) of the adolescents who have disabled sibling have a health problem, in comparison to 9 (18%) of the adolescents who have healthy sibling. Headache (18%), abdominal pain (18%), idiopathic unrest and anxiety (14%), and feeling weak (12%) were the most commonly seen problems. There was a statistically significant difference in the number of health problems between the groups ($p < 0.05$) (Table 1).

Table 1. Sociodemographic characteristics of the children

	Study Group (n = 50)	Control Group (n = 50)	p-value
Age, X ±SD, years	14.6 ±2.3	14.8 ±1.9	0.582 [†]
BMI, X ±SD, kg/m ²	20.5 ±3.1	21.8 ±2.4	0.007 [†]
Sibling's age, X ±SD, years	9.87 ±3.48	9.94 ±3.69	0.653 [†]
Years of education, X ±SD, years	7.5 ±2.4	7.8 ±2.1	0.442 [†]
Number of persons at home, X ±SD	4.5 ±0.7	4.6 ±0.7	0.720 [†]
Number of siblings, X ±SD	2.3 ±0.6	2.3 ±0.5	0.757 [†]
Gender, n (%)			
Male	23 (46)	20 (40)	0.545 [‡]
Female	27 (54)	30 (60)	
Having any health problem (%)			
Available	25(50)	9(18)	0.001 [‡]
Not available	25(50)	41(82)	

Any health problem is based on the assessments of the Child Health Questionnaire

[†] – Mann-Whitney U test; [‡] – Chi-square test

Answers to an open-ended question "Which activities do you participate in in your leisure time?", which was asked to determine the leisure activities of the cases, were recorded. Since there was no limit for the answers, adolescents gave various responses. 68% adolescents of the study group stated that they watched TV or played games in their leisure time. 16% of this group answered the question as "I do sport in my leisure time". Computer use (82%) was the basic activity of the adolescents who had healthy sibling. 64% of this group answered the question as "I watch TV in my leisure time" and 14% said "I do sport in my leisure time".

The control group spent more time outside than the study group ($p < 0.05$). Adolescents in the control group met with their friends more frequently than the adolescents in the study group did, and the difference between them was statistically significant ($p < 0.05$) (Table 2). Looking at the frequency and duration of watching TV and doing sport regularly in Table 2, no statistical difference was shown between the groups ($p > 0.05$).

Table 2. Comparison of the mean of the frequency and duration of several daily activities between the study and control groups

	Study Group	Control Group	<i>p</i> -value [†]
Duration of spending time outside	7.8 ±2.6	8.8 ±1.7	0.022
Frequency of meeting with friends, X ±SD, (day/week)	6.8 ±0.8	7.0 ±0.0	0.042
Duration of watching TV, X ±SD, (hour/day)	2.6 ±0.9	2.4 ±0.9	0.167
Frequency of regular exercising, X ±SD, (day/week)	2.0 ±0.9	1.7 ±0.7	0.085
Duration of regular exercising, X ±SD, (hour/day)	1.7 ±0.8	1.5 ±0.5	0.294

† : Mann-Whitney U test; X: Mean; SD: Standard Deviation

The findings of the adolescents' physical fitness were presented in Table 3. The groups were similar in muscle strength, number of curl-ups and trunk lifts ($p > 0.05$). The mean of vertical jump height of the control group was statistically higher (39.7 ±5.6 cm) than of the study group (28.9 ±10.4 cm) ($p < 0.05$). The results of the Modified Apley Test, shoulder flexibility scores and the Sit and Reach test were similar ($p > 0.05$) (Table 3).

Table 3. Comparison of the mean of the physical fitness (PF) results between the study and control groups

	Study Group (n = 50)	Control Group (n = 50)	<i>p</i> -value [†]
Muscle strength of the upper limb, X ±SD, kg			
Wrist and forearm neutral	11.3 ±3.3	10.3 ±1.6	0.357
Supinated wrist	10.9 ±2.5	10.4 ±1.5	0.610
Pronated wrist	11.2 ±2.4	10.4 ±1.9	0.101
Number of curl-up repetitions, X ±SD	22.8 ±8.3	20.6 ±4.1	0.335
Trunk lift measurement, X ±SD, cm	22.6 ±5.9	22.5 ±3.8	0.617
Vertical jumping distance, X ±SD, cm	28.9 ±10.4	39.7 ±5.6	0.001
Modified Apley Test score, X ±SD			
Right arm	2.9 ±0.1	3.0 ±0.0	
Left arm	2.9 ±0.1	3.0 ±0.0	
Sit-and-reach test score, X ±SD	6.2 ±3.9	6.3 ±1.6	0.615
Shoulder flexibility score, X ±SD			
Right arm	1.0 ±0.2	1.1 ±0.2	0.648
Left arm	1.3 ±0.5	1.2 ±0.4	0.070

† : Mann-Whitney U test; X: Mean; SD: Standard Deviation

Table 4 indicates the scores of the FELS Physical Activity Questionnaire of the cases. The groups were similar in the sport index score ($p > 0.05$). The adolescents who had a disabled sibling had a statistically lower leisure score, occupation score and the total score than the adolescents who had a healthy sibling ($p < 0.05$) (Table 4).

Table 4. Comparison of the mean of the scores of the “FELS Physical Activity Questionnaire” subscales and its total scores between the study and control groups

	Study Group (n = 50)	Control Group (n = 50)	p-value [†]
Sports index score, X ±SD	2.7 ±0.9	2.8 ±0.6	0.294
Leisure index score, X ±SD	3.1 ±0.8	3.5 ±0.5	0.013
Occupation index score, X ±SD	2.6 ±0.7	2.8 ±0.5	0.037
Total score, X ±SD	8.4 ±1.6	9.1 ±1.1	0.009

[†] – Mann-Whitney U test; X – Mean; SD – Standard Deviation

Looking at the adolescents’ depression scores, which were determined by the Child Depression Questionnaire, the average depression score of the study group adolescents was statistically higher (15.8 ±1.1) than the average score of the control group adolescents (10.6 ±1.0) ($p = 0.001$).

No statistically significant difference was found in the quality of life between the groups, except the “family cohesion” subscale score ($p > 0.05$) (Table 5).

Table 5. Comparison of the mean of the scores of the Child Health Questionnaire (CHQ-PF87) subscales between the study and control groups

CHQ-PF87 subscales	Study group (n = 50)	Control group (n = 50)	p-value [†]
Global health	81.6 ±2.3	75.9 ±2.3	0.107
Physical function	91.9 ±1.4	88.7 ±1.4	0.129
Emotional role limitations	83.1±2.6	81.6 ±2.5	0.705
Behavioral role limitations	86.0 ±1.8	85.4 ±1.8	0.823
Physical role limitations	88.5 ±2.1	83.2 ±2.1	0.096
Bodily pain-discomfort	80.7 ±2.3	75.3 ±2.3	0.117
Behavior	86.1 ±1.7	81.9 ±1.7	0.096
Global Behavior	87.3 ±2.3	80.8 ±2.3	0.061
Mental health	72.7 ±1.9	69.5 ±1.9	0.269
Self esteem	70.3 ±2.2	74.0 ±2.2	0.264
Global health perception	65.8 ±1.9	63.4 ±1.9	0.396
Family activities	81.6 ±2.8	78.5 ±2.7	0.453
Family cohesion	80.9 ±2.4	71.2 ±2.4	0.009

[†] – Mann-Whitney U test; X – Mean; SD – Standard Deviation

DISCUSSION

Living with a disabled child as an experience which is shared by family members can affect the functions of family in all ways [15]. Disability brings essential responsibilities and problems for both the child and his family members [16]. Several adaptations of family members are required to supply the needs of the disabled child related to caring and treatment. Various programs which present support and education to parents are available, whereas there are very few attempts to support the disabled child’s siblings [17]. Although healthy siblings within family need psychological support, they can be in the background or in a smaller role in family due to the family concerns about the disabled child [18]. According to Atasoy, determination of the needs of healthy children about the effect of having a disabled sibling and their developmental needs is required to ensure their personal development, family interaction and support system [19].

Healthy adolescents who have a disabled sibling have more problems in the transition to different periods of development and show more painful duration to adapt to the change of their roles in the new developmental period [15, 20]. When healthy siblings enter the adolescent period, they wonder how having a disabled sibling will affect their own life. They can be angry due to the responsibilities for their disabled sibling, while they can also be worried about his/her future [21]. The study group had a higher level of idiopathic uneasiness and anxiety than the control group, so this finding supports the literature.

Subjects in the study group spent less time outside than those in the control group. Thus, healthy children tend to stay at home to help take care of their siblings. Similarly, previous studies indicated that healthy siblings supported activities like dressing and feeding the disabled child and they also undertook the roles of caring for their sibling as much as their parents [22, 23].

It was determined that both groups were similar in terms of leisure activities. The cases in both groups preferred to spend their leisure time by watching TV or using a computer instead of doing sport. Similarly to the current results, children and adolescents in developing countries watched TV or played computer games more often than they participated in physical activities [24, 25, 26].

The siblings in the control group of this study met with their friends more than the siblings in the study group. In addition, the study group spent less time outside their home than the control group although the cases in the study group had more activities which they needed to do outside. The findings indicated the effects of a disabled child on social and private life of a healthy sibling. Silver & Graham (2000) reported that sisters who had a younger disabled sibling experienced changes in their family roles and relationships, had more responsibilities for the home and had restrictions in their own daily activities [27]. In another study, adolescents who had a disabled sibling had more problems in their school and leisure functions and more limitations in their relations so they felt unhappy more often according to their peers who had a healthy sibling [28].

The groups were generally similar in terms of physical fitness in this study. However, extensor strength of the lower extremity of the siblings in the control group was higher than in the study group. Although physical fitness is a result of a physical activity habit, it can be affected by genetic factors [29]. Moreover, in some papers, it is remarked that variables like environmental factors, lifestyle, diets, family structure, socioeconomic status, and cultural differences affect physical fitness [30-32]. It is considered that muscular strength of the lower limb, which was found to be only difference between the groups, may be due to the subjects' physical features. Since social environment and athletic activities in schools of both groups were similar, the reason for similar levels of their physical fitness levels could be explained. However, as far as we know, no study investigated physical fitness of healthy siblings of disabled children. Therefore, due to lack of literature, the results related to physical fitness could not be discussed.

Assessing physical activity in children and adolescents is essential in order to prevent obesity, cardiovascular disease and diabetes, which are related to lack of physical activity [11]. In the current study, it was possible to specify the activity levels related to sport, leisure time, and studying in separate

subheadings by using the FELS questionnaire. According to the FELS, two groups were found to be similar in terms of sport related physical activity. However, siblings in the control group had a higher activity level related to leisure and studying. Sport-related questions of the FELS questionnaire include only school sport activities, while other two activity subheadings investigate leisure activity levels outside and at home. Therefore, it was determined that adolescents who had a disabled sibling were not adequately active outside school time. A low physical activity level outside school of the study group was an expected finding as the study group who did not spare time for themselves and had essential activities which could not be done. Similarly, in the study by Mactavish, it was indicated that family members who had a disabled child had less opportunities to do recreational activities outside of the family [33].

Adolescence is challenging due to the formation of personality. In this period, having a disabled sibling could cause negative effects on coping with stress and could complicate the adolescents' psychological cohesion [17, 34]. Well-being of healthy children can seriously be affected by a sibling in the family who has a chronic disease or disability [35, 36]. Adolescents who have disabled siblings were found to be more anxious and depressive than those who have healthy siblings in many studies. In addition, it was determined that children who have a disabled sibling experience more problems in social and bilateral relations and have more incidence of the development of a psychosomatic disease than the children who have a healthy sibling [37–39]. The most specific negative effect of having a disabled sibling was reported to be related to psychological functions, particularly depression [40]. In the study by Saban and Arıkan [41], people who had siblings with mental retardation were observed to be more anxious than the people who did not have. Similarly to previous reports, the healthy siblings of disabled children get higher depression points in the CES-DC Questionnaire than the control group peers. Since both groups were similar in socio-demographic variables, high depression points are considered to be related to disabled siblings.

Health related quality of life is accepted as a concept focusing on the assessment of physical health, mental health, and social functions [42, 43]. In a recent study, healthy siblings of children with chronic neurological impairments had a severe decrease in their quality of life [44]. In this paper, two groups of siblings had a similar level of the quality of life. More interestingly, the study group had significantly higher scores on the family cohesion subscale of the CHQ than the control group. It was specified that there was a correlation between the age of a disabled child and the parents' psychological stress. As the child is growing, the level of stress is increasing. According to the adaptation hypothesis explaining the related change in psychological status in literature, parents adapt to the child with whom they live, and their ability to cope with the disability increases [45–47]. The age of the disabled children and the children of the control group was averagely 10 years, which may play a role in finding similar levels of the quality of life in both groups.

When at least one of the parents had a permanent job, it was specified to be a protector factor against the effects of a disabled child on the psychosocial status of family members [47]. Since all of the parents of the study group worked and had a regular income, the level of their quality of life could be maintained.

Furthermore, living with a disabled sibling as an experience develops positive social behaviour like tolerance, thoughtfulness, and compassion [48]. Moreover,

it is reported that families who have a disabled child may increase family bonds and develop the opinions against each other [15]. Looking at other aspects of having a disabled child in a family, life with a disabled child may develop positive personal behaviour like maturing, taking responsibility, and being humane to family members [49]. In the study by Graff et al., which investigated adolescents who had siblings with Down syndrome, most of the adolescents stated that their disabled siblings contributed some good features like patience, tolerance, and compassion [50].

Types of children's disabilities not being homogenous was a limitation of this paper. Further papers may include siblings of homogenous and adequate in number disability groups and make comparisons between these disabilities. Moreover, laboratory tests could present more accurate results for muscular strength and flexibility.

CONCLUSIONS

Having a disabled child in the family may cause negative psychosocial effects on a healthy sibling.

Decrease in social life, tension and high depression levels seen in healthy child/adolescent were remarkable findings of this study.

It is considered that the siblings should also be assessed in addition to the parent while conducting the rehabilitation of a disabled child.

More extensive studies investigating children and adolescents who have disabled sibling will be beneficial.

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