JETR

JOURNAL OF
EXERCISE THERAPY
AND REHABILITATION

Journal of Exercise Therapy and Rehabilitation. 2021;8(3):245-253. DOI: 10.15437/jetr.840003

ORIGINAL ARTICLE

Participation in activity and quality of life in adolescents with Down Syndrome

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Purpose: The aim of this study was to evaluate the participation of adolescents with Down syndrome in activities together with their quality of life and to compare them with adolescents with normal development.
Methods: Thirty adolescents were included in the study. Of these, 15 cases with Down syndrome were included in the study group, and 15 cases with normal development were included in the control group. The Child and Adolescent Participation Scale was used to assess participation in activities, the Pediatric Quality of Life Inventory (13-18 years) to evaluate the quality of life, and the Gross Motor Function Scale-88 to evaluate gross motor functions.
Results: The gross motor functions of adolescents in the control group were more developed compared to adolescents in the study group ($p<0.05$). The quality of life of the adolescents in the control group was higher in physical and psychosocial aspects than the adolescents in the study group ($p<0.05$). Participation in the community and social life of the subjects in the study group was higher than the adolescents in the control group ($p<0.05$). On the other hand, participation at home of adolescents in the control group was higher ($p <0.05$).
Conclusion: Participation in the activities and quality of life of adolescents with Down Syndrome is generally lower than adolescents with normal development.
Keywords: Down Syndrome, Motor activity, Community participation, Quality of life.

Down sendromlu adölesanlarla aktiviteye katılım ve yaşam kalitesi

Amaç: Bu çalışmanın amacı, Down Sendromlu adölesanların aktivitelere katılımlarının yaşam kalitesiyle birlikte değerlendirilmesi ve normal gelişimli adölesanlarla karşılaştırılmasıdır.
Yöntem: Çalışmaya 30 adölesan dahil edildi. Bunlardan Down Sendromlu olan 15 olgu çalışma grubuna, normal gelişimli olan 15 olgu ise kontrol grubuna alındı. Aktivitelere katılımı değerlendirmek için Çocuk ve Ergen Katılım Ölçeği, yaşam kalitesini değerlendirmek için Çocuklar için Yaşam Kalitesi Ölçeği (13-18 yaş) ve kaba motor fonksiyonları değerlendirmek için Kaba Motor Fonksiyon Ölçeği-88 kullanıldı.
Bulgular: Kontrol grubundaki adölesanların kaba motor fonksiyonları, çalışma grubundaki adölesanlara kıyasla daha gelişmiş durumdaydı ($p<0,05$). Kontrol grubundaki adölesanların yaşam kalitesi fiziksel ve psikososyal yönden çalışma grubundaki olgulardan daha yüksekti ($p<0,05$). Çalışma grubundaki adölesanların toplumsal ve sosyal yaşama katılımları kontrol grubundaki adölesanlardan daha yüksekti ($p<0,05$). Kontrol grubundaki adölesanların ise ev içi katılımı daha yüksekti ($p<0,05$).
Sonuç: Down sendromlu adölesanların aktivitelere katılımı ve yaşam kalitesi, genel olarak normal gelişimli adölesanlara kıyasla daha düşüktür.
Anahtar kelimeler: Down sendromu, Motor aktivite, Toplumsal katılım, Yaşam kalitesi.

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Received: December 13, 2020. Accepted: February 16, 2021

In 1866, John Langdon Down described a group of children with mental retardation with distinct physical features, and about 100 years later, in 1959, Lejeune et al found that Trisomy 21 caused Down's Syndrome (DS).[1] The first information about DS being a chromosomal disorder was given by Waardenburg and Blayer in the 1930s. DS cases caused by the deterioration in the 21st chromosome constitute 95% of all DS cases. In addition to this situation, DS cases may be encountered due to other chromosomal reasons such as translocation and mosaic type. Trisomy 21 is seen once in 800-1000 births and is the most common non-fatal genetic anomaly.[1]

Quality of life according to the World Health Organization (available at www.who.int); it is how an individual perceives his life within the culture and value system he lives in; it is related to the aims, hopes, standards and concerns of the individual; It is the way people perceive their situation within the whole of their culture and value judgments in relation to their goals, expectations, standards, interests. With the increase in average life span, quality of life has become important in DS, too.

Due to the development of medicine and changes in society's attitudes, the increase in quality of life has led to the need to investigate issues related to well-being for DS individuals.[2] There is a special need to define the quality of life from the perspective of young adults with DS.[3] Quality of life is a subjective structure that includes the organization of the mental, physical, emotional and environmental states of the individual according to the importance of each state.[4] People with mental disability experience limitations in their daily life activities and instrumental activities.[5] The transition time from school to school emphasizes the experiences of young DS adults in major life areas such as employment, leisure time and interpersonal relationships.[6]

Activity is defined as the realization of a task or an action by the person according to the World Health Organization (available at www.who.int). Difficulties experienced while performing an activity are activity limitations. Participation, which is defined as the individual's being in life, represents the social dimension of functionality. Problems faced in living conditions are participation restrictions. Activity limitations often lead to participation restrictions, and both are related to disability.

There are many environmental and personal factors that can affect well-being for young adults with DS.[6] Environmental factors such as negative community attitudes affect the acceptance and participation of young DS adults in society.[7] These behavioral barriers affect employment opportunities, community life, and ultimately social interaction.[8] Young adults with DS are often constrained by parents' attitudes and safety concerns in their community participation; this may limit the transition to decision making and independence.[8] In addition, all contextual factors affect the friendships of young DS adults, including the time of parents to organize social meetings, parental mental health status, and access to community support.[9] Friendships can make the difference between community integration and isolation for young adults and therefore affect well-being.[10]

The aim of this study was to compare the quality of life and participation in the activity of adolescents with Down Syndrome (DS) and adolescents with normal development.

METHODS

The study was done in Pamukkale University School of Physical Therapy and Rehabilitation with permission. The study was approved ethically by the Medical Ethics Committee of Pamukkale University with the number of 60116787-020/2481 (date: 10.01.2018). Written informed consents were obtained from all the participant's parents and during the entire working process the Helsinki Declaration was followed.

Participants

Fifteen adolescents with DS who were attending a mentally disabled children's high school, aged 13-18 years, cooperative, walking independently without using any aid, and followed and treated by a special education and rehabilitation center were included in the study group of the study. Fifteen healthy adolescents with no diagnosis and aged 13-18 years were included in the control group of the study.

Measurements

Gross Motor Function Measure-88 (GMFM-88) was used to evaluate the gross motor skills;

Pediatric Quality of Life Inventory (PedsQL) 13-18 years for evaluating quality of life (parent form and adolescent form) and The Child and Adolescent Scale of Participation (CASP) for evaluating the participation in the activity of the adolescents.

Gross Motor Function Measure-88

GMFM-88 is a scale with 5 sub-dimensions which measures the activity completing levels in terms of sleeping, rolling (dimension A), sitting (dimension B), body control (dimension C), standing (dimension D) and walking and stair climbing activities (dimension E).[11]

The official website of GMFM-88 (www.canchild.ca) states that the measurement tool is free to use in academic studies. Despite the absence of Turkish validity and reliability, it is used for years in clinical research and theses as an assessment scale in Turkey.[12, 13]

Pediatric Quality of Life Inventory

The scale developed by Varni et al.[14] aims to measure the overall health-related quality of life in the 2-18 age group. For the 2-4, 5-7, 8-12 and 13-18 age group of the scale, there are four different forms arranged according to age group characteristics.

The official website of PedsQL (www.pedsql.org) states that the measurement tool is free to use in the not funded academic research. The reliability and validity of the Turkish version was performed by Memik et al. in 2003.[15]

The Child and Adolescent Scale of Participation

CASP measures the extent to which children participate in activities at home, at school and within the community compared to their peers, according to the parents' report. The scale is suitable for children over 5 years of age who have disability because of acquired brain damage or other reasons.

Subdivisions of the scale are 1- Participation in Home consists of 20 items and 4 sub-sections (2 items), 2- Participation in Community (4 items), 3- Participation in School (5 items) and 4 Social Life Activities (5 items). The total score is obtained by converting the sum of the points obtained from all items into a system of 100. The score is divided into 80 by the total number of items and then multiplied by 100 to give a total score of over 100. Total scores of subcategories can be used for more specific results. Here, the scores are converted into a system of 100 by the same method. A score of over 100 would be obtained.[16]

Statistical analysis

As a result of the power analysis, it was calculated that at least 14 cases (at least 7 cases for each group) could reach 90% power with 95% confidence. However, in order to make the statistics more efficient, at least 30 cases (at least 15 cases for each group) are planned to be included. Data were analyzed with SPSS package program. Continuous variables are given as mean ± standard deviation and categorical variables as number and percentage. Since the parametric test assumptions were not provided, Mann Whitney u test was used to compare the independent group differences.[17]

RESULTS

Findings of the study were collected in 4 groups: Demographic Data, Comparison of Gross Motor Functions, Comparison of Quality of Life, Comparison of Participation in the Activity.

Demographic Data

There were 15 (M=8, F=7) adolescents in the study group and 15 (M=7, F=8) adolescents in the control group. Table 1 presents the demographic data of the adolescents.

Table 1. Demographic data.

	Study Group	Control Group
	X±SD	X±SD
Age (yrs)	17.1±1.2	17.3±1.0
Height (cm)	157.5±9.5	170.5±7.7
Body weight (kg)	65.8±13.2	59.4±7.8
Body Mass Index (kg/m^2)	26.5±1.5	20.4±1.3

Comparison of Gross Motor Functions

Table 2 presents the comparison of the gross motor functions of the cases among healthy adolescents in the study group and healthy adolescents in the control group. All subjects received full score from the dimensions of bed, rolling (dimension A), sitting (dimension B), and above knee body control (dimension C), since there was independent walking criterion

without the use of walking aids in the inclusion criteria of the study. Therefore, no statistical analysis has been made on these dimensions.

According to Table 2, healthy adolescents were better about gross motor functions, walking and stair climbing activities and total points (p<0.05).

Comparison of Quality of Life

Adolescent Form

Table 3 shows the comparison of quality of life of patients according to their opinions.

According to Table 3, when the quality of life of the patients was evaluated based on their own opinions, healthy adolescents in the control group were physically better than adolescents with DS in the study group, but this was not statistically significant (p>0.05). From a psychosocial point of view, healthy adolescents in the study group were found to be better than the control group t (p<0.05). Healthy adolescents were better about the quality of life, but this was not statistically significant (p>0.05).

Parents Form

A comparison of quality of life of the patients according to the opinions of their parents is given in Table 4.

According to the parents' opinions, when the quality of life of the patients was compared, it was seen that healthy adolescents were in good condition compared to adolescents with DS (p<0.05). According to the opinions of the parents, when the quality of life of the patients was examined psychosocially, it was seen that healthy adolescents were better than adolescents with DS (p<0.05). When the total quality of life of the patients were examined according to parental views, it was seen that healthy adolescents were in good condition compared to adolescents with DS (p<0.05).

Comparing the Opinions of Adolescents with DS and Parents

Table 3 shows the comparison of quality of life of adolescents with DS according to their opinions and the parental opinions. Comparing to the parental opinions, adolescents with DS considered that their quality of life was better in both physical and psychosocial terms (p<0.05).

Comparing Participation in the Activity

Table 5 shows the participation in the activity of the groups.

Table 5 shows that participation in the activity of the study group was higher at home, but this was not statistically significant (p>0.05); Participation in the activity of the control group was higher in the society (p<0.05) and in the social life (p<0.05). Also, the participation in the activity of the control group was higher in total, but this was not statistically significant (p>0.05).

DISCUSSION

The aim of this study was to evaluate the participation in the activity and quality of life of adolescents with DS and healthy adolescents between the ages of 13 and 18, to find out the differences between them, to focus on this field by comparing the differences between adolescents and adolescents, and to contribute to the development of appropriate behavioral approaches. In addition, the aim of this study was to compare the views of parents of all groups in all fields with the views of adolescents and to contribute to the development of appropriate behavioral approaches for adolescents.

By the results of this study, according to the quality of life of adolescents and their parents, adolescents with DS have lower points than their healthy peers. However, contrary to expectations, the difference between the groups was not large, but the values were close. From this point of view, the quality of life should be evaluated within the population and even the individuals themselves; it can be concluded that the individual's perception of his/her own quality of life is related to his/her own activities and expectations of life. The fact that the quality of life of adolescents with DS was like their healthy peers is related to this result. Similarly, adolescents with DS were worse at the participation in activities in general, with little difference from their healthy peers.

Various musculoskeletal, cardiovascular and biological features of DS such as congenital heart disease, low muscle strength and cardiovascular endurance, growth retardation[18] and low running performance[19,20] may affect the number of activities that children can participate in and explain the difference between children with normal development. In current literature, there are studies showing that children with DS who have mental problems have reduced their participation in physical activities due to lack of cognitive, social

Table 2. Comparison of the gross motor functions within groups.

	Study Group	Control Group		
	X (SD)	X (SD)	z	p
Gross Motor Function Measure-88				
Standing	96.2±4.67	100±0	-3.198	0.001*
Walking, Running, and Jumping	88.6±7.56	100±0	-4.218	<0.001
Total	96.9±2.28	100±0	-4.480	<0.001

*p<0.05.

Table 3. Comparison of quality of life within groups.

	Study Group	Control Group		
Pediatric Quality of Life Inventory	X (SD)	X (SD)	z	p
Adolescent Form				
Physical	70.7±17.3	72.7±11.7	-0.333	0.739
Psychosocial	67.7±13.5	77.4±9.6	-2.701	0.007*
Total	68.3±13.8	75.7±10.1	-1.599	0.110
Parents Form				
Physical	53.9±12.2	88.0±12.8	-3.368	0.001*
Psychosocial	63.3±10.2	80.3±12.7	-3.518	<0.001
Total	60.1±10.8	82.9±11.6	-3.842	<0.001

*p<0.05.

Table 4. Comparison of Adolescent and Parents Form of Study Group.

	Study Group	Parents		
Pediatric Quality of Life Inventory	X (SD)	X (SD)	z	p
Physical	70.7±17.3	53.9±12.2	-2.305	0.021*
Psychosocial	67.7±13.5	63.3±10.2	-1.166	0.047*
Total	68.3±13.8	60.1±10.8	-1.413	0.046*

*p<0.05.

Table 5. Comparison of participation in the activity within groups.

	Study Group	Control Group		
Child and Adolescent Scale of Participation	X (SD)	X (SD)	z	p
Participation in Home	86.4±13.3	92.2±6.6	-1.058	0.290
Participation in Community	65.0±15.2	76.7±16.6	-1.944	0.049*
Participation in School	87.0±12.1	84.4±13.3	-0.567	0.037*
Social Life Activities	56.0±17.8	77.4±11.5	-3.097	0.002*
Total	73.6±11.4	82.6±7.3	-0.790	0.430

*p<0.05.

and behavioral skills.[21,22]

The health-related quality of life of children with DS was found to be lower in gross motor skills, autonomy, social and cognitive function compared to children with normal development[23]. These areas are the main subjects in the daily lives of children with DS. Remarkably, no significant difference was found between children with DS and healthy children in the field of physical complaints.[23] The results of our study were parallel with these results, and there was no difference between the healthy peers and physical quality of life according to adolescents with DS. However, parents of adolescents with DS think that their children are behind their healthy peers both physically and psychosocially.

While adolescents with DS see themselves in terms of their physical quality of life in a similar situation with their healthy peers, they see a worse condition in terms of psychosocial quality of life. When the parents of the adolescents in both groups were considered, the parents of adolescents with DS thought that their children were far behind their healthy peers in terms of both physical and psychosocial quality of life. In this regard, it is seen that adolescents with DS and their parents have different opinions. In terms of gross motor functions, while adolescents with DS are significantly lower than their healthy peers and feel themselves sufficient in terms of their physical quality of life and see themselves behind their peers in terms of psychosocial social aspects, when combined with their parents' perspective, one of the sources of the problems experienced by adolescents with DS in terms of quality of life. It is thought that their families are due to their possible protectionist attitude and hence their loss of self-esteem. Because adolescents with DS see themselves more physically than their healthy peers.

Social, environmental and familial factors may be effective in the participation of children with DS.[24] Factors that affect physical activity in children with normal development include activity preference, target orientation, physical competence, previous participation in physical activity and parent support.[25] These factors may pose a disadvantage in terms of children and children's ability to participate in physical activities. In the current literature, there are studies that show that parents of children with disabilities have encouraged children's participation in activities and that the role model becomes a part of the child's participation in activities.[26-28] It has also been shown that the excessive protectionism of parents restricts the participation of the DS child in activities.[29] The differences between the views of adolescents with DS and their parents in our study also support this conclusion.

Multivariate analysis of social life scores of children showed that both child and family factors were important. The high level of parental involvement of children with high levels of education and the encouragement of recreational activities in the family is evidence of the impact of parents' values and activities on children's social lives. The lack of factors related to the development of children in this equation also points to the importance of parental effects in determining the participation in the activities of children.[30]

When the participation in the activities at home and in society was examined, it was seen that the participation of adolescents with DS was less than their healthy peers. In contrast to this, it was understood that adolescents with DS are in better condition. From this point of view, it was understood that adolescents with DS are more active and are more active in their activities besides their peers who are designed according to themselves and who are mentally in the same situation.

Children with DS have difficulty in acquiring playmates[30]. The social interactions of school-age children are usually with children in the same school, both in and outside the school.[31] However, it has been shown that only 17% of children with DS spend time with their friends outside school, and this rate is even lower in children who attend their own schools[32] (e.g., school for the mentally disabled). Therefore, children with DS who attend the same school with children in their own situation may have more participants in activities within the school but may participate less in social life.

Adolescents with DS participate in social activities such as going to the cinema, going on vacation, playing sports games, going to parks/restaurants. This situation shows that these problems continue in the elderly people who have problems in society. Parents' overprotective attitudes towards the environment may also lead to a decrease in the

social participation of children with DS.

It has been shown that children with DS have decreased their participation in activities due to lack of social, cognitive and physical skills.[29] With the increasing importance given to social life and participation of disabled people in this life, the lower participation of children with disabilities in social life emerged and this situation was found to be alarming. According to Buckley and Sacks[33] and Shepperdson[34], it is necessary to identify and prevent the factors that may have an impact on social inclusion in order to prevent the decline in the relationships of the children with their peers with the risk of social isolation over time.

Adolescents with DS are also having retardations in participating in social life activities, such as preparing meals, doing laundry, shopping, planning daily tasks, using public transport and fulfilling school and business responsibilities. The DS cases, who have fallen behind their peers from an early age of social development, suffer from this problem in the adolescent period; they have difficulty in realizing their vital activities at home and in the community with their autonomy due to their possible protectionist approach and avoidance of giving responsibility. In a study conducted in this area, the quality of life of children with DS has been shown to decrease, especially in the area of autonomy and cognitive functions.[13] However, in this study, in the schools of mentally handicapped people who are given responsibility and approached in a suitable manner and allowed to create their own autonomy, the adolescents with DS participate in the activities better than their healthy peers.

Having an active lifestyle from an early age and training of parents in addressing problems related to the characteristics of DS has shown that children with DS increase their participation in activities.[29] In addition, it has been shown that the environmental conditions of the child affect their participation in activities.[35]

In the current literature, there are very few studies examining the quality of life of adolescents with DS in terms of their physical and psychosocial status compared to their healthy peers. At the same time, the number of studies examining the participation of adolescents with DS in the home, school, friends and community is also insufficient. Researchers should focus on new controlled studies in this area and should make population-based longitudinal cohort studies to obtain information on all aspects of social and social participation of adolescents with DS.

The strengths of this study were since the number of cases determined in the power analysis can be reached, the statistics have enough power to generalize the results of the study, there is a healthy control group where the data obtained from the study group can be compared, in order to generalize the results, it is the choice of a certain age group instead of all individuals with DS diagnosis.

Limitations

Limitations of this study were the fact that the questionnaires applied to the cases were based on the declaration basis and therefore the results of the survey were subjective, and the investigator was not blind to the study.

Conclusion

The quality of life and participation of adolescents with DS fall behind their healthy peers. The adolescents with DS see themselves in a similar situation with their healthy peers for physical quality of life but worse for psychosocial quality of life. Parents of adolescents with DS think that their children are far behind their healthy peers for both physical and psychosocial quality of life. One of the sources of problems experienced by adolescents with DS in terms of quality of life is their families' possible protectionist attitude and hence their loss of self-confidence. Participation in the activities of adolescents with DS at home and in the community are lower than the adolescents with normal development. In the schools where the cases continue their participation in the activities, the adolescents with DS are better. Adolescents with DS participate in social participation activities less than their healthy peers. This shows that these problems continue in the elderly people who have problems in society.

Acknowledgement: *None.*

Authors' Contributions: SST: Study design, literature search; **FT:** Providing subjects, writing.

Conflict of Interest: *None.*

Funding: *None.*

Ethical Approval: The protocol of the present study was approved by the Medical Ethics Committee of Pamukkale University (issue: 60116787-020/2481 date: 10.01.2018).

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