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Family functioning and child behavioral problems with Duchenne/Becker muscular dystrophy: A cross-sectional study

Duchenne/Becker musküler distrofi tanılı olgularda aile işlevselliği ve davranış problemleri: Kesitsel bir çalışma

Serkan Turan [1], Ayfer Ülgenalp [2], Hande Memiş [2], Uluç Yiş [3], Aynur Pekcanlar Akay [4]

[1] Ödemiş State Hospital, Department of Child and Adolescent Psychiatry, Izmir, Turkey
[2] Department of Medical Genetics, Dokuz Eylül University Medical Faculty, Izmir, Turkey
[3] Department of Pediatric Neurology, Dokuz Eylül University Medical Faculty, Izmir, Turkey
[4] Department of Child and Adolescent Psychiatry, Dokuz Eylül University Medical Faculty, Izmir, Turkey

ORCID ID of the author(s)

ST: 0000-0002-6548-0629
AÜ: 0000-0002-9969-203X
HM: 0000-0003-0323-2571
UY: 0000-0001-8355-141X
APA: 0000-0001-7535-1735

Corresponding author / Sorumlu yazar:
Serkan Turan
Address / Adres: Ödemiş Devlet Hastanesi, Çocuk ve Ergen Psikiyatrisi Anabilim Dalı, İzmir, Türkiye
e-Mail: drserkanturan@icloud.com

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Abstract

Aim: Duchenne/Becker muscular dystrophy (DBMD) in children is associated with emotional and behavioral problems and impairment at family functioning. The current study aimed to explicate family functioning and child behavioral problems with DBMD.

Methods: The study involved 28 child and adolescents with DBMD attending Dokuz Eylul University Medical Genetics and Child and Adolescent Psychiatry Outpatient Clinic from January 2019 to March 2019 and comprised 50 healthy control subjects. The participants who were evaluated with Kiddie-Sads-Present and Lifetime (K-SADS-PL) by blinded professionals completed a data form containing questions regarding sociodemographic and clinical features, Wechsler Intelligence Scale for Children-Revised (WISC-R) (for only DBMD cases), the Beck Depression Scale (BDS), State-Trait Anxiety Inventory (STAI), Parenteral Attitude Research Instrument (PARI), the Child Behavior Checklist (CBCL) and Family Assessment Device.

Results: Mothers of the children with DBMD demonstrated higher scores in Beck Depression Inventory and State-Trait Anxiety Inventory scales, which is associated with anxious and depressive states as compared with those from the control group but not statistically significant (P=0.888, P=0.584 and P=0.646, respectively). DBMD cases demonstrated significantly higher scores in most of the Child Behavior Checklist (activities, withdrawn/depressed, somatic complaints etc.), meaning that they have many problem areas affecting family functioning and the quality of life of the patient (P<0.001).

Conclusion: This study demonstrated that, for parents who have children with DBMD, DBMD had a negative effect on their lives, and their family relationships. However, further studies with larger sample sizes are required to reach stronger conclusions.

Keywords: Muscular dystrophy, Child behavioral problems, Family functioning

Öz

Amaç: Çocuklarda; Duchenne/Becker Musküler Distrofisi (DBMD) duygusal ve davranışsal problemlerle ve aile fonksiyonlarında ki bozulma ile ilişkilidir. Bu çalışma, aile işlevselliğini ve davranış sorunlarını, DBMD olan olgularda araştırmayı amaçlamaktadır.

Yöntemler: Çalışma; Ocak 2019 ve Mart 2019 tarihleri arasında Dokuz Eylül Üniversitesi Tıbbi Genetik ve Çocuk ve Ergen Psikiyatrisi Polikliniği'ne başvuran 28 DBMD tanılı çocuk ve ergen ile 50 sağlıklı kontrol olgusunu içermektedir. Duygulanım Bozuklukları ve Şizofreni Görüşme Çizelgesi-Şimdi ve Yaşam Boyu Şekli-Türkçe (K-SADS-PL) ile araştırmacılar tarafından değerlendirilen katılımcılara; sosyodemografik ve klinik özellikler ile ilgili sorular içeren veri formu, Wechsler Çocuklar İçin Zeka Ölçeği (WISC-R) (sadece DBMD vakaları), Beck Depresyon Ölçeği (BDI), Durum ve Süreklilik Kaygı Envanteri (STAI), Ebeveyn Tutum Değerlendirme Ölçeği (PARI), Çocuk Davranış Kontrol Listesi (CBCL) ve Aile Değerlendirme Ölçeği uygulanmıştır.

Bulgular: DBMD'li çocukların anneleri, Beck Depresyon Envanteri ve Durum-Sürekli Kaygı Envanteri ölçeklerinde, kontrol grubundakilere göre endişeli ve depresif durumlarla ilişkili daha yüksek ancak istatistiksel olarak anlamlı olmayan puanlar saptanmıştır (sırasıyla P=0.888, P=0.584 ve P=0.646). DBMD vakaları, Çocuk Davranışları Kontrol Listesinin çoğunda (aktiviteler, çekingen / depresif, somatik şikayetler, vb.) anlamlı olarak daha yüksek puanlar göstermiştir; bu, ailelerin işleyişini ve hastanın yaşam kalitesini etkileyen birçok problem alanına sahip oldukları anlamına gelmektedir (P<0.001).

Sonuç: Bu çalışma, DBMD'li çocukları olan ebeveynler için DBMD'nin yaşamları ve aile ilişkileri üzerinde olumsuz bir etkisi olduğunu göstermiştir. Bununla birlikte, daha güçlü sonuçlara ulaşmak için daha büyük örneklem büyüklüğünde daha fazla çalışma yapılması gerekmektedir.

Anahtar kelimeler: Kas distrofisi, Çocukluk çağı davranış problemleri, Aile işlevselliği

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Introduction

Duchenne muscular dystrophy (DMD) and Becker muscular dystrophy (BMD) are X-linked allelic diseases caused by mutations in the dystrophin gene [1]. These diseases, also called dystrophinopathy, are the most common neuromuscular diseases of childhood. Muscular dystrophies are hereditary, progressive, skeletal muscle diseases with muscular degeneration and characterized by loss of power. The beginning of the clinical symptoms varies from neonatal period to late adulthood [2].

In the treatment, it is aimed to provide new cells in order to repair the dystrophy needed to stop muscle degeneration or to preserve the regenerative capacity of the muscle. Nowadays, dystrophin-based treatment strategies as well as dystrophin-independent treatment methods are underway. Biological factors (lack of dystrophin and isoforms, effects on brain development and function), social and emotional factors and treatments which not specified to Duchenne/Becker muscular dystrophy (DMBD) patients constitute part of psychosocial health.

Some studies have explored psychosocial aspects and the effect of parenting for a child with DBMD. Their findings suggested that these parents accommodate some psychologic arrangements like facing loss, experiencing separation and also have shown higher stress and poorer health-related quality of life [3-5]. Nereo et al. [4] describes DMD like as a 'complex chronic condition' with impacts on the family similar to both chronic and terminal illnesses. Psychological and social consequences caused by the chronic condition affects both the child and the family. It is imperative to consider the common relationship between parents and children in the family view. On the one hand, the health status of the child depends on the psychological state of the parent and on the other hand the functioning and health of the parent affect the health of the child. Childhood chronic diseases like DMBD; symptoms, causes, treatment methods, course, daily activity limitation, long-term effect varies. However, there are common factors that cause stress response in children and families in all chronic diseases [6]. Research has identified large-scale parental stressors associated with increased economic burden of parents of children with chronic diseases, frequent hospitalization of parents of children, examination appointments, family roles that change with disease, and emotional adjustment [7]. According to the family systems model, it shows that families affect the well-being of children and that the health status of children affects the functioning of the family. Therefore, low-level problematic behaviors are observed in children with chronic diseases in high-functioning families. In this bi-directional interaction, behavioral problems and treatment course of children, especially in diseases such as DBMD; should not be examined independently of the social environment and family dynamics. This is an important issue in deciding on interventions for children's functionality.

When assessing the severity and course of problem behaviors in parents with chronic diseases from parental perspective, it is also important to consider parents' approach to disease and problem solving skills.

This study aimed to evaluate between behavioral problems, family functioning and psychopathology of DBMD and among healthy controls. A secondary aim of this study is to see the effects of long-term stress of parents with DBMD children; investigate the effects of neurological conditions, physical therapy and special education on parent attitude skills.

Materials and methods

The clinical sample of this study consisted of children with a history of 35 DBMD cases who admitted to Dokuz Eylul University Medical Genetics and Child and Adolescent Psychiatry Outpatient Clinic from January 2019 to March 2019 after the ethics committee approval was obtained. The Dokuz Eylul University Ethics Committee approved the study (Date: January 18th, 2019, Number: 2019/01-192). Priori power analysis demonstrated that a sample size of 42 participants per group was required based on an 80% power to detect the middle effect size (0.05) making use of an independent samples t-test with a 0.05 two-tailed significance level. Required number of patients could not be reached due to study schedule. Seven cases for whom missing or erroneous entries in the data collection instruments were found were excluded from the study. As a result, the data of a total of 28 children and adolescents with DBMD were subjected to statistical analysis.

The children who were admitted to our pediatrics outpatient clinic by parents for causes such as headache, acute infections but did not meet any diagnostic criteria constitutes healthy control group.

After the children and parents who were included in the study were informed about the purpose and method of the research, written consent was obtained from both groups. The participants who were evaluated with Kiddie-Sads-Present and Lifetime (K-SADS-PL) by blinded professionals completed a data form containing questions regarding sociodemographic and clinical features, Wechsler Intelligence Scale for Children-Revised (WISC-R) (for only DBMD cases), the Beck Depression Scale (BDS), State-Trait Anxiety Inventory (STAI), Parenteral Attitude Research Instrument (PARI), the Child Behavior Checklist (CBCL) and Family Assessment Device.

Sociodemographic data form

It is an information form filled by the researchers to obtain information about age, gender, education, family type, socioeconomic level, home conditions, status of parents, and background and family history.

Parental Attitude Research Instrument (PARI)

It was developed by Schaefer and Bell [8] (Total 115 items and 5 sub-dimensions). The adaptation of the scale to Turkish was performed by Küçük [9]. In the reliability study, the test-retest correlation coefficient was found to be 0.58-0.88.

Family assessment device

The McMaster Model of Family Functioning (MMFF), which aims to evaluate family problem areas and family functions according to the perception of family members, has been used clinically in families with Epstein et al. [10], in the United States by the Psychiatry and Human Behavior Department of the Medical Faculty of the Brown Hospital and the Butler Hospital in the framework of the Family Research Program developed by the family of the functions of the family to determine what matters or cannot meet the family is a

measurement tool that identifies the problem areas. The validity and reliability study of the scale was conducted by Bulut [11].

Beck Depression Scale (BDS)

It is a self-report based scale commonly used in the clinic [12]. BDS is a short, multi-lingual scale that has been developed for use in primary health care.

State-Trait Anxiety Inventory (STAI)

The State Trait Anxiety Inventory was developed by Spielberger et al. [13] in 1970, and adapted by Öner [14] and Le Compte to Turkish society in 1985 and it is a Likert type scale that measures state and trait anxiety levels separately with 20 questions. High scores indicate high levels of anxiety, and low scores indicate low anxiety levels. The Spielberger State and Trait Anxiety Inventory was filled with self-report to determine the parents' own anxiety levels.

Child Behavior Checklist (CBCL)

The 6-18 age group evaluates the problem behaviors of children and young people in terms of information obtained from their parents or caregivers [15]. The scale consists of 118 problem items. There are also 20 items related to social competence. The problems seen in the last 6 months are rated as 0, 1 and 2 according to the frequency of occurrence and the items are grouped into various subscales. Test-retest reliability of the scale was 0.84 in the total problem and 0.88 in the internal consistency [16].

Statistical analysis

Differences in all study variables were analyzed using the Statistical Package for the Social Sciences (IBM, NY), version 22 for Windows. Before the statistical analysis was performed, it was checked whether the data met the assumptions of the parametric tests and the normal distribution and homogeneity of variance by using the Shapiro–Wilk test. Variables that don't show normal distribution were evaluated by appropriate not show normal distribution were evaluated by appropriate analysis. In the interpretation of the variables, descriptive statistical techniques and quantitative data analysis were used. Chi-square analysis was used to compare categorical variables between groups. The Pearson Correlation Test was used to determine the direction and level of correlation between the variables, and the results were indicated by "r" (correlation coefficient) and "P" value (significance level). P < 0.05 was considered statistically significant.

Results

Table 1 summarizes those main features of the participants and the identification of the clinical characteristics between groups. A total of 78 children and adolescents were included in the study, 28 in the DBMD group and 50 in the healthy control group. The mean age of the patient group was 8.11 (2.76) and the mean age of the control group was 8.66 (2.71). There was no statistically significant difference between the groups in terms of the mean age (*P*=0.942). Also, no differences were detected on sex, parental education level and employment status between groups (Table 1).

When the Family Assessment Scale (FAD), which was filled by the parents in both groups, was evaluated, a statistically significant difference was found between the two groups in all subscale scores of the FAD, except problem solving, communication, roles. As the score from the all subscale scores of the FAD subscales increases, the function area in question is thought to be problematic.

Mothers of the children with DBMD demonstrated higher scores in BDI and STAI scales, which is associated with anxious and depressive states as compared with those from the control group but not statistically significant (*P*=0.888, *P*=0.584 and *P*=0.646, respectively). Mothers of the children with DBMD demonstrated significantly lower scores in PARI 1 and PARI 2 subscales, which is related to democratic attitude and attitude of over-parenting (evaluation of the mother's forced child intervention, the child's dependence on parents and measures encouraging conversations and sharing ratio with parents) as compared with those from the control group (*P*=0.051 and *P*=0.012, respectively). No significant difference was found in the other subscales in which the score increase in the scale reflects negative parental attitudes.

The comparisons of children behavioral problem areas between the DBMD and healthy groups using the CBCL subscales are presented in Table 3.

Table 1: Sociodemographic data of the DBMD patients and control groups

	DBMD n = 28	Controls n = 50	***P*-values**
Age* (mean (SD))	8.11 (2.76)	8.66 (2.71)	0.942
Gender n (%)	Male 28 (100%)	Male 50(100%)	
Mother's mean age (mean (SD))	34.06 (3.82)	36.41 (5.82)	0.382
Maternal education n (%)			
< 8 years	12 (42.85%)	22 (44%)	0.542
> 8 years	16 57.15(%)	28 (56%)	
Employment status n (%)			
Homemaker	20 (42.85%)	35 (42.85%)	0.235
Worker	8 (42.85%)	15 (42.85%)	

DBMD: Duchenne/Becker Muscular Dystrophy, SD: Standard deviation, * *P*<0.05, ** *P*<0.01

Table 2: Depression and Anxiety status, attitudes, and family functioning of mothers in the DBMD patients and control groups

	DBMD n=28 mean (SD)	Controls n=50 mean (SD)	***P*-values**
BDI	11.66 (8.66)	10.82 (7.03)	0.888
STAI-1	42.21 (14.76)	39.04 (9.77)	0.584
STAI-2	43.64 (10.47)	42.54 (7.52)	0.646
PARI 1- Attitude of over-parenting	38.14 (10.30)	42.44 (8.95)	0.051
PARI 2- Democratic Attitude	26.57 (3.63)	28.80 (3.88)	*0.012
PARI 3- Attitude of hostility and rejection	28.57 (8.10)	28.08 (8.53)	0.904
PARI 4- Marital Discordance	13.85 (3.54)	14.72 (4.54)	0.410
PARI 5- Authoritarian attitude	32.57 (7.97)	33.68 (9.20)	0.639
FAD 1- Problem Solving	1.78 (0.64)	1.98 (0.63)	0.229
FAD 2- Communication	1.66 (0.50)	1.83 (0.55)	0.192
FAD 3- Roles	2.00 (0.29)	1.96 (0.43)	0.929
FAD 4- Affective Responsiveness	1.55 (0.69)	1.83 (0.62)	*0.012
FAD 5- Affective Involvement	2.26 (0.53)	1.98 (0.47)	*0.011
FAD 6- Behaviour Control	2.01 (0.37)	1.75 (0.43)	*0.003
FAD 7- General Functioning	1.48 (0.46)	1.84 (0.57)	*0.011

DBMD: Duchenne/Becker Muscular Dystrophy, BDI: Beck Depression Inventory, STAI: State–Trait Anxiety Inventory, PARI: Parental Attitude Research Instrument, FAD: Family Assessment Device, SD: Standard deviation, * *P*<0.05, ** *P*<0.01

Table 3: Depression and Anxiety status, attitudes, and family functioning of mothers in the DBMD patients and control groups

	DBMD n=28 mean (SD)	Controls n=50 mean (SD)	***P*-values**
CBCL Activities	43.85 (9.51)	33.92 (12.15)	**< 0.001
CBCL Social	41.00 (8.09)	44.56 (7.83)	0.070
CBCL School	45.46 (6.45)	50.38 (4.12)	**< 0.001
CBCL Withdrawal/Depression	60.21 (5.34)	54.14 (4.07)	**< 0.001
CBCL Somatic Complaints	63.32 (6.76)	57.16 (6.01)	**< 0.001
CBCL Anxious/Depressed	57.03 (5.50)	56.70 (5.91)	0.590
CBCL Social Problems	59.92 (6.29)	54.98 (3.85)	**< 0.001
CBCL Thought Problems	60.32 (6.42)	55.98 (5.45)	*< 0.05
CBCL Attention Problems	57.10 (5.37)	54.68 (4.96)	*< 0.05
CBCL Rule-Breaking	55.75 (5.94)	53.64 (4.02)	0.143
CBCL Aggressive	56.03 (3.27)	54.24 (4.75)	0.116
CBCL Total Competence	41.57 (10.77)	37.18 (9.34)	0.128
CBCL Internalizing Problems	60.28 (5.68)	55.28 (6.05)	*< 0.05
CBCL Externalizing Problems	55.32 (4.62)	51.08 (6.14)	*< 0.05
CBCL Total Problems	58.96 (4.59)	53.22 (5.37)	**< 0.001

DBMD: Duchenne/Becker Muscular Dystrophy, CBCL: Child Behavioral Checklist, SD: Standard deviation, * *P*<0.05, ** *P*<0.01

Discussion

DBMD is a chronic disease with progressive proximal muscle weakness, mental impairment, hypertrophy in calves, and increased connective tissue in the muscle. In DBMD patients, the initial symptoms are usually frequent falls, running or stair climbing, and in many patients, the findings occur before the age of five years [2]. The main finding of our study is that behavioral problems and family functioning are worse than healthy controls in people with DMBD.

The results obtained in the studies investigating the psychosocial effects of DBMD differed due to the variables such as the clinical and demographic characteristics of the evaluated patient group and the nature of the measurement tools used. In terms of behavioral problems in our sample, we found that children and adolescents with DBMD had significantly higher CBCL scores on subscales of somatic complaints, withdrawal/depression, thought problems, social problems and attention problems, and had higher CBCL total problems scores, externalizing/internalizing problems than the healthy group. There were no statistically significant differences between the two groups in terms of aggressive behavior, anxiety/depression, rule breaking and total competence subscales. These findings are inconsistent with those of Sienko et al. [17], who found that children with DMD had no significant difference among the groups including internalizing and externalizing behaviors. The other hand, Colombo et al. [18] evaluated 47 children with DMD who were not differentiated from their intellectual abilities and found 23.4% internalized problems. Duchenne cases have mood and mood disorders and aggressive behaviors. In a study using a scale in which behavioral problems were evaluated, it was found that the families of DMD patients scored more than 32% of the cut-off point [19]. When all these results are evaluated together with the data of our study; disabilities of DBMD cases; it may be associated with behavior problems.

Mothers with children with DBMD compared to mothers with healthy children; depression and state-trait anxiety inventory scores were found to be significantly higher. DBMD mothers; Psychological, social, economic problems and the most struggling people to solve the daily life of children with disabilities, low self-esteem and depressive symptoms are defined [20]. The severity of the depressive symptom in mothers and the higher levels of anxiety; It may be related to loneliness, emotional-physical-economic difficulties caused by chronic disease. Also, the emotional commitment of the mother, the loss of hope for the future, and the deterioration in the quality of life of mothers may have contributed to this result. In a study evaluating the parents of DBMD; depressive symptoms at 40% [21], in some studies; the presence of increased levels of depression and anxiety in parents with a child with chronic disease is consistent with the results of our study [22,23].

Data from this study, it was found that mothers of children diagnosed with DBMD had difficulties in mental health and impaired family functioning. Consistent with previously reported studies, it is reported that depressive mothers exhibit a more negative parenting attitude. The roles and duties of the parents who cannot cope with the stress experienced in the family can be confused and disruptions in family functionality may occur. Some studies suggested that mothers who perceived life events outside their control and experienced extreme parental stress were more inadequate in motherhood, had no control over the events, and the sense of stress caused by the motherhood role led the mother to think about not responding to her child's negative behaviors [24,25].

When the FAD data were analyzed, it was found that the scores of DBMD group in “Affective Responsiveness”, "General Functioning", “Affective Involvement” and “Behavior Control” subscales were found to be statistically significant compared to the control group; “Problem Solving”, “Communication” and “Roles” subscales were not found any difference between the control group. Behavioral control includes assessment of the discipline applied by the parents. The control is asked to be flexible, solid, free or irregular. Parents of children diagnosed with DBMD think that behavior problems of their children will not change or may start to over react. Children with DBMD may not be able to adequately control their emotions and behaviors and may impose impulsivity on parents, so parents may have difficulty with appropriate Affective Involvement and Affective Responsiveness skills.

In our study, it was found that mothers of children with DBMD diagnosis had more difficulty in terms of mental health compared to controls; It is an important finding that should be kept in mind during the treatment process for the mothers of children. As a result of family intervention, it has been determined that the difficulties of the relatives of the patients have decreased in the care and that they can cope with the stress positively, there are positive changes in the family functions, the patient's compliance with the medication and control appointments increases, and the problem solving skills develop.

There are some limitations of our study. The fact that the health institution in which the patients were enrolled was the last step hospital, so that this was not a field study, the severity of physical illnesses were not measured, the sample size was small and the patients were more resistant to the treatment might have affected the research results.

Conclusions

When the results of our study are considered, it can be said that chronic muscle diseases constitute a burden which goes far beyond the medical dimension of the event both in practice and psychiatric terms for the family. Family functioning and severity of the child's disease may vary with the cognitive strengthening of maternal mothers who cannot cope with stress and the change in maternal behavior. In the treatment of children with muscle disease, it is important to include the family in the treatment process and family interventions are important and effective for caregivers.

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