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Brief Report / Kısa Araştırma

Quality of Life and Sleep in Children Diagnosed with Duchenne Muscular Dystrophy and Their Mothers' Level of Anxiety: a Case-Control Study

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ABSTRACT

Quality of life and sleep in children diagnosed with duchenne muscular dystrophy and their mothers' level of anxiety: a case-control study

Objective: Duchenne Muscular Dystrophy (DMD) is the most severe form among a variety of muscular dystrophies. While studies into the etiology and pathophysiology of DMD have progressed fast, there still is no therapy for the disease. The presence of a severe chronic disease such as DMD can seriously affect patients as well as caregivers. In this study, we planned to compare quality of life and sleep between cases diagnosed as DMD and healthy controls while at the same time assessing the levels of anxiety in the patients' mothers.

Method: In this study, 17 cases with a diagnosis of DMD and 20 healthy controls were enrolled. All the patients and controls were male. The social status of patients and controls was assessed with a sociodemographic data form. To evaluate the children's quality of life, the Pediatric Quality of Life Inventory (PedsQL) was completed by children and parents. The Pittsburgh Sleep Quality Index (PSQI) is a self-reported questionnaire used to evaluate the quality of sleep in children. We measured the mothers' anxiety with the State-Trait Anxiety Inventory (STAI) - state anxiety and trait anxiety forms. Mann-Whitney U test and chi square test were used for statistical analysis.

Results: A statistically significant difference was found in comparing both parents' and children's PedsQL forms between patients and controls. The quality of sleep also differed significantly between cases and controls. In the STAI state and trait anxiety forms, no significant difference was found between the anxiety levels of patients' mothers and the control persons' mothers.

Conclusion: As key result of our study, we found that there are more problems in the DMD patients' sleep, and the quality of life is lower than in the healthy controls. Problems in motor functionality may affect emotional and social functionality and possibly the quality of children's sleep.

Keywords: Anxiety, duchenne muscular dystrophy, quality of life, sleep

ÖZET

Duchenne muskuler distrofisi tanısı olan çocukların yaşam ve uyku kaliteleri ile annelerinin anksiyete düzeyi: Bir olgu kontrol çalışması

Amaç: Duchenne musküler distrofi (DMD) birçok musküler distrofi arasında en ciddi olanıdır. DMD'nin etyolojisi ve patofizyolojisi üzerine yapılan araştırmalardaki hızlı ilerleyişe rağmen, tedavisi henüz mümkün değildir. DMD gibi ciddi kronik bir hastalığın varlığı hem hastalar hem de bakımverenler üzerinde büyük etkilere sebep olabilir. Biz bu çalışmada DMD tanılı olgular ile sağlıklı kontrollerin yaşam ve uyku kalitesini karşılaştırmayı aynı zamanda olgu ve kontrollerin annelerinin de anksiyete düzeyini değerlendirmeyi planladık.

Yöntem: Çalışmaya 17 DMD tanılı olgu ile 20 sağlıklı kontrol dahil edilmiştir. Olgu ve kontrollerin hepsi erkektir. Olgu ve kontrollerin sosyal durumu sosyodemografik veri formu ile değerlendirilmiştir. Çocukların yaşam kalitelerini değerlendirmek için çocuklar ve ebeveynleri tarafından doldurulan Çocuklar için Yaşam Kalitesi Ölçeği (ÇİYKÖ) kullanılmıştır. Pittsburg Uyku Kalitesi İndeksi (PUKİ) çocukların uyku kalitesini değerlendirmek için kullanılan bir özbildirim ölçeğidir. Annelerin anksiyetesi Durumluk- Süreklilik Anksiyete Ölçeği (STAI)-durumluk ve süreklilik formları ile değerlendirilmiştir. Mann Whitney U ve kikare istatistiksel analiz olarak kullanılmıştır.

Bulgular:: Olgu ve kontrollerin hem ÇİYKÖ ebeveyn hem ÇİYKÖ çocuk formları kıyaslandığında istatistiksel anlamlı fark bulunmuştur. Olgu ve kontrollerin uyku kalitesi arasındaki fark da istatistiksel olarak anlamlı çıkmıştır. STAI durumluk ve süreklilik ölçeklerinde olgu ve kontrollerin annelerinin anksiyete düzeyleri arasında anlamlı fark bulunmamıştır.

Sonuç: Bizim çalışmamızın temel bulgusu DMD'li olguların uykuda daha fazla zorlukları olduğu ve yaşam kalitelerinin sağlıklı kontrollere göre daha düşük olduğudur. Motor işlevsellikteki zorlukların duygusal, sosyal işlevselliğe ve belki de çocukların uyku kalitesine etkileri olabilir.

Anahtar kelimeler: Anksiyete, duchenne muskuler distrofisi, yaşam kalitesi, uyku

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INTRODUCTION

Duchenne Muscular Dystrophy (DMD) is the second-most common genetic disease in the human population, being seen in 1 per 3,500 births in boys and around 1 per 50,000,000 births in girls (1,2). Among the clinical findings, weakness and atrophy of the muscles, beginning in the lower extremities and spreading to the upper extremities, pseudohypertrophy in some muscle groups, increased lordosis and effort difficulties are standing out (3). With therapeutic support, patients' life expectancy has increased from 14.4 years in the 1960s to 25.3 years in the 1990s (4). While a number of studies has been devoted to the etiology and pathophysiology of DMD, no effective treatment has so far been developed. In the second decade of their lives, many patients are wheelchair-bound and depend on others for their daily activities. Nowadays, some DMD patients live into the 4th decade of their lives, which is an important development in the history of DMD life expectancy (5).

In the general population, on average 10-20% of children are suffering from chronic diseases (6). In many countries of the world, the population of children with chronic diseases continues to grow, and chronic diseases are becoming a significant health problem (7). In relation to the chronic condition, the children's quality of life can also be negatively affected. While the presence of a serious chronic disease like DMD curtails physical activities, it also has an impact on the child's emotional and social world. Thus, in the assessment of the children's life quality, effects of the disease on the child's life has become more important (8). Health-related quality of life, encompassing physical, emotional, social, and cognitive aspects, changing over time, is a multidimensional concept gaining increasing importance in the field of health (9). Psychiatric findings about children and adolescents diagnosed with DMD and data about the effects of DMD on their quality of life in Turkey are limited.

Sleep, a fundamental and essential everyday-life activity affecting people's quality of life and health, is a concept with physiological, psychological, and social dimensions (10). Being one of the basic needs of humans, sleep is important for health and life quality at all ages (11). While there are numerous studies about the effect of chronic diseases on sleep, no studies into the impact of DMD on sleep were found in the literature (12,13).

A severe chronic disease such as DMD causes great effects on the patients as well as on the caregivers. The number of studies researching the impact of DMD on families is quite limited. Chronic diseases put emotional pressure on the lives of the child and all family members, increasing stress levels and negatively affecting quality of life. Chronic childhood diseases have a great impact on the child's life and on the entire family (14). A significant chronic disease with manifold clinical aspects like DMD can have numerous effects on the emotions and thoughts of the patient's parents and on family and social life. Considering that in chronic diseases, patients' mothers make the greatest efforts to solve the psychological, social, and economic problems, it is an important issue to research to what degree mothers are able to cope and how far they are experiencing worries (15). In the literature, there are only few studies dealing with this topic.

Aim of this study is to research the impact of DMD on the patients' quality of life and sleep. Another aim of our study is to assess the effect of DMD on the mothers' anxiety levels.

METHOD

This study has been carried out in the Child Neurology section of a medical faculty's Pediatric Department. Participants were patients regularly followed with a diagnosis of DMD and their mothers; both groups had given their consent.

If there was more than one child in the same family suffering from DMD, one of them was randomly selected to be enrolled in the study. A total of 17 children followed with a DMD diagnosis, aged 8-18 years, having no other known psychiatric or organic diseases, and their mothers were included in the study. The control group consisted of 20 healthy volunteers, matched with the study group according to age, sex,

level of education, and parents' education level, and their mothers. A sociodemographic data form recording general information was completed by the mothers in the presence of the doctor. All children and adolescents were administered the Pittsburgh Sleep Quality Index (PSQI) and the Pediatric Quality of Life Inventory (PedsQL) for children. The State-Trait Anxiety Inventory (STAI) and the PedsQL parent form were completed by the mothers. All participants of the study had received detailed information about the research and consented to take part; families signed the informed consent form. In case that patients or mothers did not understand certain questions in the information sheets, researchers provided them with detailed information. The study was approved by the medical faculty's ethics committee for non-invasive clinical research.

Sociodemographic Data Form: This form, prepared by the researchers, included questions about the patient's given name and surname, age, address, telephone number, educational level, number of siblings, peer relation and lesson status, as well as parents' education level, profession, income state, and presence of physical or mental diseases in the family.

Pediatric Quality of Life Inventory (PedsQL): A scale to assess the general quality of life for children and adolescents in the age group between two and eighteen years (16). For this scale, four separate forms have been elaborated, addressing the characteristics of different age groups, 2-4, 5-7, 8-12, and 13-18 years. The PedsQL consists of four subsections investigating physical, emotional, social, and school-related functioning. In evaluating the scale, emotional functioning score (EFS), social functioning score (SFS), school functioning score (SchFS), physical health summary score (PHS), psychosocial health summary score (PSHS), and total scale score (TSS) can be used.

The scale uses a five-point Likert-type indicator chart (0=never, 1=rarely, 2=sometimes, 3=often, 4=always). The points for the items are converted linearly into values between 0 and 100 (0=100, 1=75, 2=50, 3=25, 4=0). An increase of the score ranging from 0 to 100 indicates an increased quality of life (17). Validity and reliability of the PedsQL forms for the age groups 2-4 and 5-7 years in Turkish have been confirmed by Uneri et al. (18) , for the age groups 8-12 and 13-18 years by Memik et al. (19,20). For the present study, children's and parents' forms of the scale for the age groups 8-12 and 13-18 years have been used.

State-Trait Anxiety Inventory (STAI): Developed by Spielberger et al. (21) in 1970, the scale has been translated into Turkish by Oner and Le Compte (22) in 1977 and was used with adaptations to assess anxiety levels.

Pittsburgh Sleep Quality Index (PSQI): The PSQI was developed by Buysse et al. (23) and adapted to Turkish by Agargun et al. (24). It is a self-report scale with 19 items, assessing sleep quality and disturbances for the previous month. The 18 questions of the scale being scored consist of 7 components: subjective sleep quality, sleep latency, sleep duration, habitual sleep efficiency, sleep disturbances, use of sleeping medication, and daytime dysfunction. Each component is scored between 0 and 3 points. Total score of the 7 components yields the total score for the scale, ranging from 0 to 21 points.

RESULTS

Included in the study were 37 children of an age between 8 and 18 years, 17 in the patient group and 20 in the control group. Mean age in the patient group (n=17) was 9.59±4.21 years, in the control group (n=20) 9.80±3.27 years. The age difference between the two groups was statistically not significant (p=0.295). Mean age of the mothers filling in the scales was 37.68±8.00 in the patient group and 37.60±6.72 years in the control group. The age difference between the mothers in the two groups was also not statistically significant (p=0.618). Of the mothers in the patient group, 11 had completed primary school, 5 had a high school/university degree, and for one person, this information was not obtained. In the control group, 13

Table 1: Patients' and controls' quality of life and mothers' anxiety levels

Scale	Case group mean±SD	Control group mean±SD	p
STAI state	36.87±9.80	35.50±8.89	0.630
STAI trait	40.56±10.62	39.05±7.05	0.395
PedsQL PHS-children form	56.47±30.06	85.51±13.49	<0.001
PedsQL PSHS-children form	65.71±28.55	84.05±14.71	<0.01
PedsQL-total-children form	62.54±27.56	82.64±12.87	0.002
PedsQL PHS-parent form	60.83±29.10	78.78±25.71	0.003
PedsQL PSHS-parent form	61.41±23.25	79.34±20.24	0.002
PedsQL-total-parent form	60.97±23.67	79.10±21.32	<0.001

STAI: State-Trait Anxiety Inventory, PedsQL PHS: Pediatric Quality of Life Inventory Physical Health total score, PedsQL PSHS: Pediatric Quality of Life Inventory Psychosocial Health total score

Table 2: Sleep quality in patients and controls

PSQI	Patient	Control	p
Subjective sleep quality	0.85±0.93	0.58±0.61	0.179
Sleep latency	0.30±0.65	0	0.012
Sleep duration	0.45±0.88	0.05±0.24	0.018
Habitual sleep efficiency	0.20±0.41	0.64±1.00	0.311
Sleep disturbances	0.20±0.52	0	0.031
Use of sleeping medications	1.35±1.08	1.52±1.12	0.297
Daytime dysfunction	0.70±0.80	0.41±0.71	0.144
Total	4.05±3.06	3.23±2.04	0.031

PSQI: Pittsburgh Sleep Quality Index

of the mothers had completed primary education, 7 had a high school/university degree. No statistically significant difference was found between the mothers in the two groups regarding their educational status (p=0.25). Of the mothers in the patient group, 12 were housewives, the others were in employment. In the control group, 13 mothers were housewives and 7 in employment. Between the mothers in the two groups, no statistically significant difference was found in their employment status (p=0.136). In one family in the patient group a history of physical disease was established, no family had a history of mental disease. In the control group, in 6 families physical disease history was found but no history of mental disease. Regarding physical and mental disease, between the groups no statistically significant difference was found (not shown).

Anxiety in the mothers of the patient and control group, respectively, was compared using the STAI state-trait scores; no statistically significant difference was found.

Comparing patients and controls with regard to their quality of life, statistically significant differences were found in patients and mothers regarding physical and psychosocial aspects, with the DMD patients having a lower quality of life (Table 1). Sleep latency, sleep duration and total of PSQI in DMD patients was significantly worse than in control persons (Table 2).

DISCUSSION

DMD is a serious chronic disease with inevitable progression, leading to physical dependence. There are very few studies assessing the effect of DMD on patients and their families. Results of patients' self-report regarding DMD are important in assessment and treatment of the disease (25). Basic finding of our study is that quality of life and sleep in persons diagnosed with DMD is worse than in healthy controls.

Analyzing the effect of DMD on the quality of children's lives, Baiardini used the Children Health

Questionnaire and found that, compared to healthy controls, life quality of DMD patients and parents was lower. This result of Baiardini's work (26) is consistent with results for quality of life in our study. Uzark et al. (27) used PedsQL to assess the life quality of DMD patients and found, based on reports from the patients and their parents, that patients' physical and psychosocial quality of life was statistically significantly lower than that of the control group ($p<0.001$). This result is also consistent with our study.

Elsenbruch et al. (28) used the health-related quality of life scale to assess DMD patients' life quality, dividing the cases into children, adolescents, and adults. In the children group (8-12 years), psychosocial as well as physical quality of life were found to be lower than in patients with other chronic diseases; in the adolescent and adult groups, only the physical life quality was lower. Considering the mean age of participants in our study, finding both physical and psychosocial life quality to be lower than in the controls is consistent with the literature. The lower scores in physical life quality for patients and their mothers might be attributed to the progressive impairment of motor functions caused by DMD. Deteriorating motor functions may have a negative impact on psychosocial life quality and sleep.

Sleep is one of the most important needs for a healthy life. Right from birth, it is an important period for growth, development, learning, and rest, preparing the person in a healthy way for the following day (29). Being one of humans' basic requirements, sleep is important for all ages to maintain health and quality of life. Sleep is a basic element to strengthen physical growth and academic performance. It is known that children need sufficient sleep and rest for a successful realization of their developmental functions (30,31).

Sleep is very important for children and adolescents' learning, memory processes, and school performance. Studies have shown that poor sleep quality, increased interruption of sleep, as well as going to bed late and getting up early severely affect school performance and neurobehavioral functions (32). Sleep and life quality may also be affected as a result of the uncertainty in DMD. The day-to-day deterioration of patients' motor capacities can affect life quality as well as sleep quality, or the decreased quality of sleep in cases diagnosed with DMD may affect patients' quality of life. In the literature, we have not found any publication dealing with patients' quality of sleep. However, a study with patients attending hemodialysis due to chronic renal failure, another chronic condition, found that sleep quality in dialysis patients was poor (13). In a study with rheumatoid arthritis patients, too, patients' sleep quality was found to be lower than in controls (12).

We did not find a significant difference in the anxiety levels of patients' mothers compared to controls, which may be explained with patients' mothers' developing coping skills and adapting to the process. A study on coping skills in parents of DMD patients by Webb (33) found that parents after receiving the DMD diagnosis developed realistic and successful coping strategies, learned as much as possible about the disease, met with other patients' parents, reviewed their priorities, took on more active roles over time, became informed about disease progression, and learned how to support the patient. Beresford (34) showed in his study that working with parents concerned with coping skills had a great effect on understanding the disease effects and ways of help.

In addition to this data, the literature suggests that parents of children with DMD may experience feelings of uncertainty, tend towards denial, and may feel severe pain, anger, and rage, or develop fear, sorrow, confusion, lack of energy, or similar problems (35). In a study based on scales completed by the parents of 35 children with DMD aged 4-14 years, in 57% of parents a reduction in psychological adjustment was found. In addition, 50% of the parents showed depressive symptoms, and 31% symptoms of anxiety (36). A study in Turkey by Cakaloz et al. (37) found that the anxiety level in mothers of DMD patients was higher than in the mothers of the controls. It is known that the economic status of the family, parents' level of education, profession, marital status, severity of their children's disease, children's age, chronic disease state, amount of medical care needed, and similar factors affect the parents' stress status (38,39).

Even though in our study the anxiety levels in patients' and controls' mothers were similar, we could not comprehensively assess the mothers' mental state, beyond anxiety, nor the impact on their lives, given that we did not evaluate the mothers' depressive state nor the families' quality of life.

Our study is limited by the fact that the psychiatric state of children and mothers was not assessed by structured interview techniques and the number of participants being low.

Considering that a chronic disease like DMD can affect a family's quality of life or lead to depression in parents, measuring the families' quality of life and parents' depression level provides a contribution to the literature.

While our results can be seen as first results regarding the impact of DMD on children's quality of life and sleep, more studies with a larger sample and a longitudinal design are needed.

DMD is a serious chronic disease with inevitable progression, leading to physical dependence. Thus, one of the important therapeutic aims is to help the patients achieve the best possible quality of life and sleep.

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