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Evaluation of Quality of Life and Levels of Participation in Patients with Duchenne Muscular Dystrophy

Duchenne Musküler Distrofili Hastalarda Yaşam Kalitesi ve Katılım Seviyelerinin Değerlendirilmesi

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ABSTRACT

Introduction: The aim of this study was to investigate the quality of life and levels of participation levels in individuals with Duchenne muscular dystrophy (DMD) and assess the impact of preserved upper extremity muscle power and wrist functions on their quality of life and participation levels. The study was performed on 25 volunteers with DMD who were followed at Bakırköy Municipality, Atatürk Spor ve Yaşam Köyü from March to July 2015.
Methods: Quality of life was evaluated using the Short-Form-36 (SF-36), participation levels were assessed using the Craig Handicap Assessment and Rating Technique-Short Form (CHART-SF), upper extremity power was evaluated manual muscle test, and hand and wrist functions were assessed with the Duruöz Hand Index.
Results: SF-36 showed that Physical Health (34.31±5.32) and Mental Health (49.95±10.54) levels were fair to good. CHART-SF revealed that the patients demonstrated moderate to good levels in Physical Independence (61.12±14.22), Cognitive Independence (55.16±29.52), Mobility (64.64±17.87), and Social Integration (81.78±23.11), while the Work dimension was notably low (12.12±19.32). Patients exhibited moderate and low levels of muscle strength in the shoulder, elbow, and hand. Duruöz Hand Index indicated moderate to good hand function. It shows a relationship between shoulder flexion, shoulder extension, and shoulder abduction with the "Physical Health Component" of the SF-36 ($p<0.05$). It highlights a statistically significant and positive relationship between the "Work" dimension of the CHART-SF and the "Mental Health Component" of the SF-36 ($p<0.05$).
Conclusion: Patients with DMD revealed fair to good levels of Physical Independence, Cognitive Independence, Mobility, and Social Integration whereas Occupation level was low. It has been determined that impairment in upper extremity use and restriction in social participation affect physical and mental domains of quality of life.

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ÖZET

Giriş: Bu çalışmanın amacı, Duchenne kas distrofisi (DMD) olan bireylerin yaşam kalitesini ve katılım düzeylerini araştırmak ve korunmuş üst ekstremite ve el bileği fonksiyonlarının yaşam kalitesi ve katılım kısıtlamaları üzerindeki etkisini değerlendirmektir. Çalışma, Mart – Temmuz 2015 tarihleri arasında Bakırköy Belediyesi Atatürk Spor ve Yaşam Köyü'nde takip edilen 25 DMD gönüllüsü üzerinde gerçekleştirildi.
Yöntem: Yaşam kalitesi Short-Form-36 (SF-36) kullanılarak değerlendirilirken, katılım düzeyleri Craig Handicap Assessment and Rating Technique-Short Form (CHART-SF) ile değerlendirildi. Üst ekstremite gücü manuel kas testi ile değerlendirildi ve el ve el bileği fonksiyonları Duruöz El İndeksi ile değerlendirildi.
Bulgular: SF-36, Fiziksel Sağlık (34.31±5.32) ve Ruhsal Sağlık (49.95±10.54) seviyelerinin orta düzeyde olduğunu gösterdi. CHART-SF, Hastaların Fiziksel Bağımsızlık (61.12±14.22), Bilişsel Bağımsızlık (55.16±29.52), Hareketlilik (64.64±17.87) ve Sosyal Entegrasyon (81.78±23.11) açısından orta düzeyde olduğunu gösterdi, ancak Çalışma boyutunun belirgin bir şekilde düşük olduğunu (12.12±19.32) ortaya koydu. Hastalar, omuz, dirsek ve elde orta ve düşük düzeylerde kas gücü sergiledi. Duruöz El İndeksi, orta düzeyde el fonksiyonunu gösterdi.
SF-36'nın "Fiziksel Sağlık Bileşeni" ile omuz fleksiyonu, omuz ekstansiyonu ve omuz abduksiyonu arasında ilişki olduğunu göstermektedir ($p<0.05$). Ayrıca, CHART-SF'nin "Çalışma" boyutu ile SF-36'nın "Ruhsal Sağlık Bileşeni" arasında istatistiksel olarak anlamlı ve pozitif bir ilişki olduğunu vurgulamaktadır ($p<0.05$).
Sonuç: DMD'li hastalar, Fiziksel Bağımsızlık, Bilişsel Bağımsızlık, Hareketlilik ve Sosyal Entegrasyon konularında orta düzeyden iyiye kadar seviyeler gösterirken, İş seviyesi düşük olarak ortaya çıktı. Üst ekstremite kullanımındaki bozulma ve sosyal katılımdaki kısıtlamaların, yaşam kalitesinin fiziksel ve zihinsel alanlarını etkilediği belirlenmiştir.

1. Introduction

Duchenne Muscular Dystrophy (DMD) is the most common type of muscular dystrophy, although it is often found to be recessive due to the X chromosome, it may also show autosomal dominant transition. The incidence is 1/3500 in men. The disease manifests itself with weakness in the muscles due to the involvement of skeletal muscles (1). In the following periods, cardiac involvement is also added to the clinical picture. It has been revealed that the autonomic functions of the heart are impaired and the increase in the incidence of arrhythmia due to this has revealed that the cause of death in DMD is often due to respiratory and cardiac disorders (2). DMD is usually diagnosed before a child reaches the age of five. By the age of twelve, difficulty walking begins and they need auxiliary devices (wheelchair, scooter, lift, etc.) for ambulation. In their twenties, kyphoscoliosis and accompanying heart failure, lung infections, and joint contractures occur (3). In this disease, which cannot be prevented from progression, solving respiratory and cardiac orthopedic problems increases life expectancy (4).

DMD is the most common muscular disease in which skeletal muscles are affected (5). Dystrophin is needed for muscles to contract. The absence of dystrophin causes muscle degeneration and the transformation of muscle tissue into adipose tissue (6). It has been reported that patients with DMD have disruptions in walking functions from the age of 9.5 and continue until the age of 12.5 at most. It has been reported that they need help in their activities after the age of 12.5 (7). It is known that DMD can be diagnosed before the age of 4 in these patients, but families cannot observe this condition until the age of walking (8). The structure of the muscle sarcoplasm without dystrophin is irregular. This irregularity starts gradually with muscle inflammation and causes muscle injuries, necrosis, and fibrosis in the future. While the heart muscle and skeletal muscles are primarily affected, the first proximal muscles are affected (9).

DMD manifests itself with progressive weakness in the muscles due to the involvement of skeletal muscles (1). Up to the age of ten, complete dependence develops at the tip of the toe, duck-like walking, uprightness from the ground, difficulty climbing stairs, and ambulation over time. Today, although there is no treatment method that eliminates the disease, physical therapy and rehabilitation approaches including steroid use, exercise, and orthosis applications can prolong the walking and life span of children. In this way, their quality of life increases significantly. In the future, cardiac involvement will manifest itself in the clinic. The autonomic functions of the heart are impaired and the incidence of arrhythmia increases accordingly. In the twenties, kyphoscoliosis and accompanying heart failure, lung infections, and contractures occur. Respiratory and cardiac disorders are frequently the cause of death in DMD (10,11).

Quality of life is a multifaceted structure and generally includes 3 sections. These are; a) Physical Function, b) Psychological Function, and c) Social Function. Grootenhuis et al. showed a decrease in the health-related quality of life and social and emotional functions of children with muscular dystrophy between the ages of 8-11, including motor function and autonomy, compared to children in the healthy control group (12).

The aim of this study is to investigate the quality of life and participation levels in individuals with Duchenne muscular dystrophy (DMD) and evaluate the impact of preserved upper extremity and wrist functions on their quality of life and participation restrictions.

Hypotheses of the study:

H1: Upper extremity muscle strength has an effect on the quality of life in individuals with DMD.

H2: Upper extremity muscle strength has an effect on the level of participation in individuals with DMD.

2. Methods

The study included 25 adult DMD cases who agreed to participate in the study, which was followed up in Istanbul Province Bakırköy Municipality Atatürk Sports and Life Village Rehabilitation Unit between March and July 2015. Volunteers who were previously diagnosed with DMD had a mental level sufficient to express themselves, agreed to participate in the research, and gave verbal and written consent were included in the study. Patients with serious cardiac problems and chronic diseases, patients with low mental perception who could not comprehend the study, and patients who could not express themselves objectively were not included in the study.

2.1. Evaluations

The patient assessment form was completed to obtain sociodemographic information. The form included questions about age, age at diagnosis, gender, dependent level, personal care, the use of a wheelchair, and whether the patient had undergone any previous surgeries.

Upper Extremity Muscle Test: The manual muscle test was used to evaluate the upper extremity muscle strength of the participants. This test involves various conditions, including scenarios where the muscle moves the joint fully against gravity but collapses abruptly, where the muscle cannot hold the joint against resistance but moves

the joint fully against gravity, where the muscle moves the joint against gravity but not through the full range of motion, where the muscle moves the joint when gravity is eliminated, where a flicker of movement is seen or felt in the muscle, and where no movement is observed. The upper extremity muscles were assessed, including the shoulder flexors, shoulder abductors, shoulder extensors, elbow flexors, elbow extensors, wrist flexors, and wrist extensors. The scoring was performed on a scale from 0, indicating no movement, to 5, indicating normal strength. This test has been shown to be reliable in Duchenne muscular dystrophy (DMD) patients (13).

Hand Function: DHI was developed in 1996 to evaluate the limitations in the activities of daily living of patients with rheumatoid arthritis. It consists of a total of 5 categories consisting of culinary work, dressing, personal hygiene, workplace, and other activities. It consists of a total of 18 questions. A high score indicates that the limitation is high. The total application time of the scale is 3 minutes (14).

Quality of Life: Short Form-36 (SF-36) was used to assess quality of life (15). This form is collected in 2 special dimensions: physical health and mental health. Scored from zero (worst health) to 100 (best health).

Participation levels assessment: The Craig Handicap Assessment and Reporting Technique - Short Form (CHART-SF) was used to assess specific situations and daily activities related to individuals with disabilities. The scale was developed around the WHO concept of handicap (11). The scale includes assessing physical independence, mobility, occupation, social integration, and economic self-sufficiency (16).

2.2. Statistical analyses

The demographic characteristics of the groups were used in version 17.0 of the "SPSS (Statistical Package for Social Sciences) for Windows" statistical program in a computer environment. Descriptive statistics were used for the demographic and clinical characteristics of the sample and mean standard deviation (Mean±SD) values were given in the tables. Since the distribution in the sample was not normal, the relationship between the variables was evaluated with the Spearman test. The statistical significance level was accepted as $p<0.05$.

2.3. Ethical considerations

Ethical approval was obtained from the Halic University Non-Interventional Research Ethics Committee at the 5th meeting on May 16, 2015, decision number: 7. Permission for the research was granted by Bakırköy Municipality Atatürk Sports and Life Village. Voluntary informed consent forms were obtained from the participants.

3. Results

3.1. Primary Outcome

Table 1 shows the distribution of individual characteristics of the patients. All of the patients were male, with an average age of (16.8±3.22) years and an average age of diagnosis was (4.8±1.84) years. The majority of the patients were partially dependent 64% (n=16), and their care was provided by their families 96% (n=24). Most of the patients used a wheelchair 96% (n=24). Additionally, none of the patients had any habits, illnesses, or previous surgeries.

Table 1. Patient assessment (n=25)

	n	%
Age	16.8±3.22	(Min-Max: 10-24)
Age of Diagnosis	4.8±1.84	(Min-Max: 2-8)
Gender		
Male	25	100
Female	-	-
Dependent Level		
Full Dependent	8	32
Partially Dependent	16	64
Independent	1	4
Personal Care		
Self-care	1	4
Families	24	96
Wheelchair		
Yes	24	96
No	1	4
Habits/illnesses/ Previous surgeries		
None	25	100

Min.: Minimum, Max.: Maximum

Table 2 displays the mean scores for the upper extremity muscle test and the Duruöz Hand Index. Patients have moderate and low levels of shoulder elbow and hand muscle strength. Specifically, the individual demonstrated the ability to perform movements against gravity without any resistance in all directions for the shoulder and elbow. The Duruöz Hand Index (55.20±19.12) score indicated moderate to good hand function.

Table 2. Muscle test and hand function assessment

	Mean±SD	Min-Max
Upper Extremity Muscle Test		
Shoulder Flexion	2±0.76	1-3
Shoulder Extension	2.24±0.87	1-3
Shoulder Abduction	2±0.86	1-3
Elbow Flexion	1.96±0.84	0-3
Elbow Extension	2.2 ±0.76	0-3
Hand Wrist Flexion	2.4 ±0.71	1-4
Hand Extension	2.36 ±0.63	1-4
Duruöz Hand Index	55.20±19.12	9-79

Min.:Minimum, Max.: Maksimum, SD: Standard Deviation.

Table 3 displays the mean scores for the SF-36 scale and the CHART-SF, showing that the physical health component (34.31±5.32) and mental health component (49.95±10.54) were at

moderate to good levels. According to the CHART-SF values, physical independence (61.12±14.22), cognitive independence (55.16±29.52), mobility (64.64±17.87), and social integration (81.78±23.11) were at moderate to good levels, while the Work dimension (12.12±19.32) was at a low level.

Table 3. Patients SF-36 and CHART-SF scores

	Mean±SD	Min-Max
SF-36		
Physical Health Component	34.31±5.32	25.6-43.1
Mental Health Component	49.95±10.54	29.2-69.2
CHART -SF		
Physical Independence	61.12 ±14.22	36-88
Cognitive Independence	55.16 ±29.52	0-100
Mobility	64.64 ±17.87	30-100
Work	12.12 ±19.32	0-100
Social Integration	81.78 ±23.11	41-100

Min.:Minimum, Max.: Maksimum, SD: Standard Deviation.

Table 4 investigates the correlation between Upper Extremity Muscle Testing and the SF-36 Quality of Life Scale. It shows a relationship between shoulder flexion, shoulder extension, and shoulder abduction with the "Physical Health Component" of the SF-36 ($p<0.05$). A similar relationship was observed between shoulder extension and the "Mental Health Component" of the SF-36($p<0.05$). No correlation was found between hand-wrist flexion or hand-wrist extension and the SF-36 Quality of Life Scale dimensions ($p>0.05$). Examines the relationship between Upper Extremity Muscle Testing and the CHART-SF scales, revealing no statistically significant relationship between Upper Extremity Muscle Testing items and the total CHART-SF score ($p>0.05$). It shows the correlation between Duruöz Hand Index CHART-SF ($p<0.05$).

Table 4. Correlation between muscle test and hand function with SF-36 and CHART-SF

	SF-36 Physical Health Component		SF-36 Mental Health Component		CHART-SF	
Muscle Test	r^s	p	r^s	P	r^s	p
Shoulder Flexion	0.476	0.016	0.249	0.230	-0.156	0.457
Shoulder Extension	0.576	0.003	0.398	0.049	0.053	0.801
Shoulder Abduction	0.452	0.023	0.321	0.118	-0.092	0.663
Elbow Flexion	0.209	0.317	-0.209	0.316	-0.259	0.210
Elbow Extension	0.031	0.883	-0.093	0.658	-0.003	0.990
Hand Wrist Flexion	-0.107	0.611	-0.012	0.954	0.173	0.409
Hand Extension	-1.00	0.634	-0.036	0.864	0.076	0.717
Duruöz Hand Index	-0.130	0.535	-0.003	0.990	-0.517	0.008

r^s : Spearman Test, $p<0.05$

3.2. Secondary outcome

Table 5 analyzes the correlation between the CHART-SF dimensions and the SF-36 Quality of Life Scale. It highlights a statistically significant and positive relationship between the "Work" dimension of the CHART-SF and the "Mental Health Component" of the SF-36 ($p<0.05$). However, no statistically significant relationship was observed between Physical Independence, Cognitive Independence, Mobility, and Social Adaptation with the SF-36 Quality of Life Scale dimensions ($p>0.05$).

Table 5. Correlations between CHART and SF-36 scales

CHART-SF	SF-36 Physical Health Component		SF-36 Mental Health Component	
	r^s	p	r^s	p
Physical Independence	0.024	0.908	0.190	0.362
Cognitive Independence	-0.003	0.988	0.343	0.094
Mobility	-0.175	0.403	0.052	0.806
Work	0.306	0.137	0.414	0.040
Social Integration	-0.067	0.751	-0.036	0.865

r^s : Spearman Test, $p<0.05$

4. Discussion

The aim of the study was to investigate the quality of life and participation levels in individuals with Duchenne muscular dystrophy (DMD) and evaluate the impact of preserved upper extremity and wrist functions on their quality of life and participation restrictions. The study revealed that the quality of life of the DMD patients who participated was found to be at a good and moderate level. When evaluating the level of participation, it was observed that the "Work" dimension was at a low level. It was also found that upper extremity muscle strength affected mental health through shoulder movements. Additionally, the study identified the impact of hand functions on participation.

It was determined that the entire sample was male, the mean age was 16.8±3.22 years, and the mean age of diagnosis was 4.8±1.84 years. All of the patients in our study were male, and in the literature, DMD is defined as a recessive hereditary disease due to the X chromosome with a prevalence of approximately 1/3600-6000 live male births (10,17). The majority of cases are present in early childhood under the age of five. In this study, the mean age of diagnosis was 4.8±1.84 years. The mean age of death of the patients was stated as 19 years (10). According to some sources, death occurs in the second or third half of life (7).

Duchenne muscular dystrophy (DMD), primarily affects the lower extremities before the upper extremities. As individuals with DMD

age, this weakness gradually manifests in the upper extremities as well. Specifically, it is observed that the weight shifts towards the extremity where weight is transferred, particularly in the shoulders and head, and moves backward. In the advanced stages of the disease, the weakness progresses to the extent that it confines the individual to a wheelchair (18). Exercise interventions involving the upper extremities have been shown to have significant effects on the functions of individuals with Duchenne muscular dystrophy (DMD) from the early stages of the disease (19). According to the results of your study, the patients exhibited moderate and low levels of muscle strength in the shoulder, elbow, and hand. Specifically, the individual demonstrated the capability to perform movements against gravity without any resistance in all directions for the shoulder and elbow.

hand and upper extremity involvement represent a significant concern for both patients and clinicians in cases of Duchenne muscular dystrophy (DMD). Studies have reported that the hand functions of individuals with DMD can be observed from the early stages of the disease, in comparison to healthy individuals (20). According to the results of your study, the wrist functions of the patients were observed to be at a moderate and good level.

The World Health Organization defines quality of life as "how an individual perceives his/her life status in relation to his/her goals, expectations, standards and concerns within the culture and values system he/she lives in" (10). In the context of individuals with Duchenne muscular dystrophy (DMD), factors such as fatigue and wheelchair use have been identified as significant factors affecting health-related quality of life at a high level (21).

According to a study by Bothwell et al. (2002), it was determined that quality of life was more important than physical functions in families with a child with DMD (22). It has been determined that almost all health-related quality of life values are significantly impaired in children with DMD when compared to normal published data for children with other chronic diseases. On the other hand, although there were significant decreases in physical quality of life in adolescents and adults with DMD, it was determined that there was no significant difference in psychosocial terms when compared to published normal values. (23). According to the results of the survey conducted on DMD patients and their primary caregivers, it was determined that the majority of caregivers perceived their patients as happy or somewhat happy, but there was a decrease in the patient's quality of life values (10).

CHART-SF questionnaire is a participation levels assessment of physical independence, cognitive independence, mobility, social adaptation, work status, and economic independence. CHART allows assessing the extent to which people can fulfill different social roles based on measurable criteria rather than subjective interpretation. (24) . In our study, according to CHART-SF values, the "Physical Independence", "Cognitive Independence", "Mobility" and "Social Adaptation" dimensions of the patients were at medium and good levels. It was determined that the "Work" dimension had a low average. Studies have shown that the negative impact on the quality of life in neurological disability is often caused by the limitation of social participation. This situation reveals the importance of evaluating participation in the follow-up of patients with neurological disabilities. When children with DMD reach the age of 12, they cannot walk and are tied to a wheelchair (25). In our study, 80% of the participants used a wheelchair as an assistive device. Particularly, the fact that the "Mobility and work" dimensions appear to be at medium and low participation levels can be explained by the literature information given above. In light of the data obtained from our study, it was thought that the use of assistive devices may have reduced social participation.

4.1. Limitations

The limitations of this study included the need for a greater number of scales and tests, as well as a broader sample from different age groups, which could have expanded the scope of the study. Furthermore, the focus of the study on a specific geographic region could limit generalizability. Additionally, the period of the study could also be considered as a limitation. In progressive diseases like DMD, data obtained at a specific period may differ at various stages of the disease. Therefore, considering this, it is recommended to conduct a more extensive and long-term study..

5. Conclusion

The quality of life for individuals with DMD is generally considered to be good to moderate; however, low levels were observed in the "Work" dimension. To improve the quality of life for DMD patients, it is essential to provide programs and resources that support their functional independence. The strength of the upper extremities and wrist functions can significantly impact the level of participation. Early implementation of exercise programs is crucial to maintain and enhance upper extremity functions.

Conflict of Interest: There is no conflict of interest in this study.

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Ethics Committee Approval: Ethical approval was obtained from the Halic University Non-Interventional Research Ethics Committee at the 5th meeting on 16 May 2015, decision number: 7.

Authorship Contribution:

EBC : Conceptualization, writing.

MGY: Supervision, data analysis, conceptualization.

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