Title: Evaluation of the quality of life and sociodemographic features of patients with muscular dystrophies

Running Title: Quality of life in muscular dystrophies

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Abstract

Objective: Muscular dystrophies refers to a group of primary inherited myopathies that exhibit a chronic and unremitting progressive course. Quality of life is a concept, which mainly reflects individual responses given by a person to the physical, psychological, social and environmental impacts of the disease. In this study we aimed to evaluate quality of life and sociodemographic features of 146 patients who presented to the physical therapy and rehabilitation neuromuscular diseases outpatient clinic of our hospital.

Methods: Patients' sociodemographic data including gender, marital status and educational level were recorded and analyzed. WHOQOL-BREF survey was performed in order to determine quality of life in patients with muscular dystrophy. The scores obtained from the survey were transformed into WHOQOL 4-20 and WHOQOL 0-100 score ranges, and relationships between the sociodemographic data of the patients and WHOQOL-BRIEF survey results were evaluated.

Results: Eighty-five (58.2%) patients were male and 61 (41.8%) were female. No statistically significant difference was found between the male and female MD patients in terms of the physical, psychological, social relationships and environmental domains of WHOQOL-BREF scale (for all $p>0.05$). No significant difference was found between single, married, divorced and widowed patients (for all $p>0.05$). There were significant differences between educational levels of the patients in terms of the mean WHOQOL-BREF scores ($p<0.05$). The mean scores increased as educational levels increased.

Conclusion: Quality of life increases with the levels of education and does not differ according to gender and marital status in patients with muscular dystrophy. Patients with muscular dystrophy should be encouraged for education from the pediatric period.

Keywords: Myopathy, muscular dystrophy, quality of life, WHOQOL-BREF, education

What is already known?

- ✓ Muscular dystrophies are resulted from the interference of abnormal genes with normal protein production.
- ✓ All forms of muscular dystrophies negatively affect QOL of patients.
- ✓ Measurement of quality of life in patients with muscular dystrophies is important for an efficient rehabilitation and management of these patients.

What this article adds?

- ✓ Quality of life increases with the level of education in patients with muscular dystrophy.
- ✓ Quality of life does not differ according to gender and marital status in patients with muscular dystrophy.
- ✓ There is a need for studies comparing quality of life before and after rehabilitation and treatment programs in patients with muscular dystrophies.

Introduction

Genetic muscular dystrophies (MD) are primary muscle diseases that cause dystrophic changes in muscle biopsy by mutation of the gene. Dystrophies can be also classified as ion channel diseases, metabolic disorders and congenital myopathies. MDs are a hereditary group of chronic muscular disorders with prominent involvement of skeletal muscle and slowly progressing muscle loss, leading to weakening of the musculoskeletal system and primarily involve muscles (1). The incidence of MDs can not be exactly determined because of consanguineous marriages, different disease courses among persons and siblings with the same diagnosis and inability to identify those with a mild disease. MDs are resulted from the interference of abnormal genes with normal protein production (2). MDs that are in the groups of rare diseases have numerous subtypes with different features. These diseaases mostly begin in childhood and at young ages. The inheritance modes of those in this group differ according to the age of onset, clinical course and severity.

The most common forms of MD include Duchenne (DMD), Becker (BMD), Myotonic MD, Congenital MD, Limb Girdle MD, Facioscapulohumeral MD, Distal MD, Emery-Dreifuss MD, Inflammatory MD and Metabolic-Storage Myopathies. Knowing disease profile is very useful in the differential diagnosis of MDs. In Myotonic MD, difficulty in muscle relaxation, named “myotonia”, accompanied muscle weakness. It shows involvemet in more than one systems with affected smooth and striated muscles, while lifetime is not always affected (3). Congenital MD (CMD) is a muscle disease that occurs with the birth of the infant or in the early years of life. It has some features suggesting a dystrophic process such as congenital hypotonia, muscle weakness and articular contractures. CMDs are a heterogenous myopathy group due to their significant clinical and genetic heterogeneity and are characterized by muscle weakness involving muscles and pelvic girdles. Fasioscapulohumeral

muscular dystrophy (FSHD) is a genetic muscle disease characterized by weakness of muscles in the face, shoulders, and other areas of the body over time, abdominal and anterior leg muscles and progressive atrophy and can be seen both in children and adults. FSHD progresses slowly and quality of life is affected, but life expectancy is not affected much (4).

The pathogenesis of these dystrophy forms has been understood through the advancements in genetics. Today, it is known that most forms of MD are genetic while a few are acquired (5). These mutations usually occur in the genes encoding proteins of the dystrophin- associated glycoprotein (DAG) complex located at the sarcolemma and lead to partial or complete absence of DAG (6). MD leads to weakness and wasting of muscles, affects a specific skeletal muscle group such as proximal muscles of the lower and upper extremities and this suggests differences between muscles that make them prone to spesific pathologic etiologies. Each MD subgroup exhibits different specific involvements, while heart muscle and respiratory muscles may often be involved at different rates. In addition MD include eye involvement ocular involvement, partial hearing, metabolic hormonal and cognitive disorders, amyotrophy, cataract, endocrine disorders, and central nervous system findings of varying severity. In the adult form; behavioral disorders such as obsessive-compulsive disorder, schizotypal personality disorder, lack of empathy are seen. Distal myopathy, which is among the more commonly seen MD forms, is a heterogenous genetic disorder in which upper and lower extremities are disproportionately affected, while oculopharyngeal muscular dystrophy (OPMD) is a clinically late-onset, and slowly progressing rare hereditary muscle disorder characterized by bilateral ptosis, dysphagia, and proximal muscle weakness. Emery-Dreifuss muscular dystrophy (EDMD) is a rare form of muscular dystrophy charactrized by muscle weakness, premature contractures, cardiac conduction abnormalities, and cardiomyopathy. Inflammatory myopathies are non-genetic systemic connective tissue diseases characterized by symmetrical, proximal muscle weakness

and chronic inflammation of muscle tissue. Metabolic myopathies of the skeletal muscle are an infrequent and distinct group of diorders that prevents the normal function of the muscle due to specific defects in metabolism.

All these MDs have further subgroups, making their differential diagnosis challenging. Despite the developments in technologic tests, differential diagnosis, history and clinical evaluation remain important in the evaluation of these patients. In the diagnosis, elevated creatine kinase (CK) among the laboratory values is an important parameter. However, if muscle fiber necrosis is not diffuse or there is no membrane involvement, CK may not be high. Electromyographic (EMG) examination, biopsy and gene analysis are performed in cases compatible with the clinical picture (7, 8).

Quality of life (QOL) is a concept, which mainly affects personal satisfaction of an individual in adapting living conditions, and reflects individual responses given by a person to the physical, psychological and social impacts of the disease. All forms of MDs negatively affect QOL of patients. Measurement of QOL in patients with MDs is important for an efficient rehabilitation and treatment and management of these patients. The objective of this study was to evaluate sociodemographic factors affecting QOL in patients who presented to the physical therapy and rehabilitation neuromuscular diseases outpatient clinic of our hospital with primary diagnosis of MD using WHOQOL-BREF scale.

Material & Methods

Among patients who presented to the physical therapy and rehabilitation neuromuscular diseases outpatient clinics of our hospital between 2015 and 2020, 275 diagnosed with genetic-origin myopathy of primary involving muscles were followed-up. Of these, data of 146 patients with the definitive diagnosis of myopathy, who aged over 18 years and were illiterate for being able to respond to the survey by herself/himself were retrospectively evaluated in the study.

Data of the patients were obtained from the patient files. Some patients were admitted to our clinic with a diagnosis, while we diagnosed others who presented on suspicion or with referral. A detailed medical history was received, physical, neurologic exams and blood analysis were performed. During the examination; respiration, cardiac, urogenital, gastrointestinal, visual and hearing functions, cognitive disorders, mental retardation, psychological and musculoskeletal systems were evaluated. The head, neck, facial asymmetry and swallowing reflex was evaluated and a detailed posture assessment was performed during physical examination. In addition, sitting and walking balance, muscle strength, sensory-reflex, muscle atrophy and hypertrophy status, Gower's sign, myotonia and muscle cramps were examined within the scope of the muscular assessment.

Electromyography (EMG) scan was performed in patients without a definitive diagnosis, but with examination findings compatible with myopathy or those with a family history. Among these patients, gene analysis was ordered for definitive diagnosis in those with normal EMG findings, but who had findings supporting myopathy. The diagnosis of myopathy was confirmed according to the results of the gene analysis. Patients aged under 18 years, those who were not myopathic, patients with unconfirmed diagnosis of myopathy and those who rejected filling the survey forms were excluded from the study.

Patients' sociodemographic data including gender, marital status and educational level were recorded and analyzed. The patients were called for control visits with 3 to 6-month intervals based on the diagnosis, routine investigations were performed and the necessary rehabilitation and medical treatment were planned.

The WHOQOL-BREF survey was performed in order to determine QOL of the participants. The survey forms were filled by the patients themselves and filling of a form took approximately 30 minutes on average. The scores obtained from the survey were transformed into WHOQOL 4-20 and WHOQOL 0-100 score ranges, and relationships

between the sociodemographic data of the patients and WHOQOL-BRIEF survey results were evaluated.

WHOQOL-BREF Survey:

WHOQOL-BREF survey is a shortened form of WHOQOL-100 (10). It consists of 26 questions included in four domains including physical, psychological, social relationships and environment sections. Physical domain consists of questions about activities of daily living, energy and fatigue, mobility, pain and discomfort, dependence on medicinal substances and medical aids, work capacity and sleep and rest. Psychological domain includes items questioning negative and positive feelings, self-esteem, body appearance, personal belief / spirituality / religion, learning, thinking memory and concentration. Social relationships domain involves questions related to social support, personal relationship and sexual activity. Lastly, environmental domain questions financial resources, freedom, health and social care, physical safety and personal security, home environment, opportunities for acquiring new skills and knowledge, participation in recreation and leisure activities, physical environment (noise, traffic, climate etc) and transport.

Questions in WHOQOL-BREF are answered with a 5-Likert scale. WHOQOL-BREF scores were then transformed into two score ranges as WHOQOL-BREF 4-20 and WHOQOL-BREF 0-100 based on an algorithm considering the number of answered questions in each domain, and analyzed. Zero point indicates the worst possible health condition while 100 points represent the best possible QOL (10).

Ethics Considerations

Before the beginning of the study, the necessary approval was received from the local committee of our hospital with the 05/03/2021 dated and 688 numbered decision. The patients were informed about the objectives of the study in detail and gave written consent. The study was conducted in accordance with the ethical principles of the Declaration of Helsinki.

Statistical Analysis

Data obtained in this study were analyzed using SPSS 23.0 (SPSS IBM Inc., Statistical Package for Social Sciences, Chicago, IL, USA) statistical software. Normal distribution of the continuous variables was evaluated with Shapiro-Wilk test. Descriptive statistics (mean, standard deviation, median, minimum, maximum) were used to express continuous variables for comparison of various measurement results. Categorical variables were given as frequency (number) and percentage. $p<0.05$ values were considered statistically significant.

Results

A total of 146 patients who presented to the neurovascular outpatient clinic of our hospital and who were diagnosed with muscular dystrophy (MD) as a result of the examinations and investigations between 2015 and 2020 were enrolled in the study. Of all patients included in the study, 85 (58.2%) were male and 61 (41.8%) were female. When distribution of the patients according to MD forms was reviewed; the most common form of MD was Duchenne in 47 patients followed by myotonic MD in 27, congenital MD in 26, facioscapulohumeral MD in 24 and Limb Girdle in 22 patients. The rates of MD forms found in the patients are given in Figure 1.

The results of the WHOQOL-BREF survey applied in patients were transformed into 4-20 and 0-100 score ranges. Accordingly, when the results were evaluated according to WHOQOL-BREF 4-20 score range, the mean score was found as 10.19±2.510 (min-max: 4.00-24.00) for physical domain, 12.74±3.036 (min-max: 6.00-27.33) for psychological domain, 11.92±4.333 (min-max: 4.00-33.33) for social relationships domain and 11.48±2.660 (min-max: 4.44±17.33) for environmental domain. The mean WHOQOL-BREF 0-100 score was found as 38.69±15.68 (min-max: 0.00-125.00) for physical, 54.68±18.97 (min-max: 12.50-145.80) for psychological, 49.54±27.08 (min-max: 0.00-183.30) for social relationships and 46.78±16.62 (min-max: 2.78±83.33) for environmental domains of the scale.

There was no statistically significant difference between both genders in terms of the mean WHOQOL 4-29 and 0-100 scores received from the physical, psychological, social relationships and environmental domains of the scale (for all p>0.05). WHOQOL-BREF 4-20 and 0-100 according to genders are given in Table 1.

Table 1. Comparison of WHOQOL-BREF 4-20 and 0-100 scores between genders

DOMAIN	WHOQOL 4-20			WHOQOL 0-100		
	MALE (mean)	FEMALE (mean)	p value	MALE (mean)	FEMALE (mean)	p value
PHYSICAL	10.32	10.00	0.447	39.53	37.52	0.447
PSYCCHOLOGICAL	12.84	12.61	0.646	55.29	53.82	0.646
SOCIAL RELATIONSHIP	11.95	11.89	0.932	49.70	49.31	0.932
ENVIRONMENT	11.66	11.24	0.351	47.87	45.26	0.351

When marital status of the patients included in the study was examined; it was found that 95 participants were single, 47 were married, 3 were divorced and 2 were widows. Distribution of the marital status of the participants is given in Figure 2.

When WHOQOL-BREF 4-20 scores of the patients were evaluated according to marital status, no statistically significant difference was found between single, married, divorced and widowed MD patients in terms of the physical, psychological, social and environmental domains of the scale. Similarly, no statistically significant difference was found between single, married, divorced and widowed MD patients in terms of the physical, psychological,

social and environmental domains of the WHOQOL-BREF 0-100 scale. Results of the WHOQOL-BREF 0-20 and 0-100 score ranges based on marital status are given in Table 2.

247 **Table 2.** Comparison of WHOQOL-BREF 4-20 and 0-100 scores according to marital status

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DOMAIN	WHOQOL 4-20					WHOQOL 0-100				
	SINGLE (mean)	MARRIED (mean)	DIVORCED (mean)	WIDOW (mean)	p value	SINGLE (mean)	MARRIED (mean)	DIVORCED (mean)	WIDOW (mean)	p value
PHYSICAL	69.16	83.13	83.83	35.75	0.155	69.16	83.13	83.83	35.75	0.155
PSYCHOLOGICAL	69.97	80.36	107.33	27.25	0.100	69.97	80.36	107.33	27.25	0.100
SOCIAL RELATIONSHIP	73.45	74.87	89.00	20.50	0.304	73.45	74.87	89.00	20.50	0.304
ENVIRONMENT	70.75	79.77	73.17	56.00	0.620	70.75	79.77	73.17	56.00	0.620

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255 Education levels of the patients included in the study were also analyzed. Accordingly,
256 35 patients were literate, 41 were primary school graduates, 13 middle school graduates, 38
257 high school graduates and 19 college-university graduates. Distribution of MD patients
258 according to the educational levels is shown in Figure 3. WHOQOL-BREF 4-20 scores
259 according to the educational levels are given in Table 3. Accordingly, there were significant
260 differences in all domains of the scale between educational levels of the patients, and
261 WHOQOL-BREF 4-20 scores increased as the educational levels increased.

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263 **Table 3.** Comparison of WHOQOL-BREF 4-20 scores according to the educational levels

DOMAIN	EDUCATIONAL LEVEL					p value
	LITERATE (mean)	PRIMARY (mean)	MIDDLE (mean)	HIGH (mean)	COLLEGE (mean)	
PHYSICAL	63.09	65.52	63.58	86.66	90.37	0.026
PSYCHOLOGICAL	64.81	63.62	68.00	82.72	96.13	0.024
SOCIAL	63.90	61.60	57.88	91.82	90.92	0.002
ENVIRONMENT	65.96	64.26	59.62	92.01	79.82	0.016

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265 Finally, there were statistically significant differences between the groups in the
266 comparison of WHOQOL-BREF 0-100 scores between educational levels ($p<0.05$). There
267 was a statistically significant difference between the education groups in terms of the mean
268 scores obtained from the physical ($p<0.026$), psychological ($p=0.024$), social ($p=0.002$) and
269 environmental ($p=0.016$) domains of the scale.

In order to determine which education groups caused the difference, the patients were divided into literate, primary+middle and college+university groups. Accordingly, 35 patients (24%) were in the literate, 54 (37%) in the primary + middle school and 57 (39%) in the college + university group. The mean scores received by these groups from WHOQOL-BREF 0-100 scale are given in Table 4.

Table 4. Comparison of the mean WHOQOL-BREF 0-100 scores according to the education groups

DOMAIN	EDUCATION GROUPS			p value
	LITERATE	PRIMARY + MIDDLE	COLLEGE+ UNIVERSITY	
PHYSICAL	63.09	65.06	87.89	0.004
PSYCHOLOGICAL	64.81	64.68	87.19	0.007
SOCIAL	63.90	60.70	91.52	<0.001
ENVIRONMENT	65.96	63.14	87.95	0.004

In the physical domain, the mean score was statistically significantly higher in the college+university group compared to the literate (p=0.009) and primary+middle school graduates group (p=0.003). Similarly, the mean score received from the psychological domain of the scale was statistically significantly higher in the college+university group compared to the literate (p=0.014) and primary+middle school graduates group (p=0.005). In the social relationships domain of the scale, the mean score was statistically significantly higher in the college+university group compared to the literate (p=0.001) and primary+middle school graduates group (p<0.001), and the mean score obtained from the environmental domain was

statistically significantly higher in the college+university group compared to the primary+middle school graduates group (p=0.002).

Discussion:

Today, quality of life (QOL) is a major issue in the management of chronic diseases. QOL is defined as patients' assessment or perception of overall functioning in their daily life (11). QOL measurements provide useful information about the results of interventions made in patients. Muscular dystrophy (MD) diseases are eligible conditions for the measurement of QOL. By this way, it is possible to observe contributions of interventions and treatment administrations made in MD patients on QOL and progression of their functionality.

There are several studies in the literature investigating QOL in MD patients using various surveys and scales. The most commonly used QOL surveys/scales in the literature include WHOQOL and WHOQOL-BREF (12, 13, 14), 36-Item Short Form Health Survey (15, 16, 17), Pediatric Quality of Life Inventory (PedsQL) Duchenne MD Module (18), Quality of Life in Neurological Disorders (NeuroQOL) (19), Individualized Neuromuscular Quality of Life (INQoL) (16), Quality of Life Profile (19), Psychosocial Well-Being Questionnaire (20), TNO-AZL Questionnaire for Adult's Quality of Life (TAAQoL) (21) and EuroQol-5D (EQ-5D) (22). In the present study, we utilized WHOQOL-BREF survey to measure QOL in patients with various forms of MDs. However, widely recognized measurement tools with proven validity and reliability are still needed in order to evaluate the effects of MDs on QOL and to accurately measure the changes resulting from interventions, rehabilitation and treatment programs in QOL of MD. The existing scales do not measure all areas of QOL. In 2011, a meeting on priorities for MD research was held by the Centers for Disease Control and Prevention (CDC), and a significant gap was found in QOL scales since it was concluded that these scales do not adequately measure emotional aspect of the disease, personal meaningfulness sense, engagement in society and access to care (23). In addition, diversity of

QOL scales used in the evaluation of MD patients makes comparison between the studies and obtaining guiding information challenging.

In the current study, the factors affecting quality of life in patients with muscular dystrophy were investigated. In this context, the relationships between the gender, marital status and education level of MD patients were analyzed with the widely used WHOQOL-BREF survey. Above mentioned studies in the literature have predominantly investigated QOL in patients with Duchenne MD. Whereas, in our study WHOQOL-BREF survey was applied in patients with Duchenne, myotonic, congenital, facioscapulohumeral and Limb Girdle MDs. In the present study also Duchenne MD was the most common form of MDs by 32%. The main finding of our study was the significant differences found between educational levels in terms of the mean scores obtained from all domains of the WQOQOL-BRIEF survey. Accordingly, mean scores received from the physical, psychological, social and environmental domains of the survey increased as the level of education increased. We attributed this result to that MD patients with a higher educational level show a higher adherence to treatment plan and higher participation in social environment.

In the present study, no significant difference was observed between WHOQOL-BREF scores and genders. In addition, QOL scores received from the WHOQOL survey were similar between marital status groups of the patients (married, divorced, widow) in all domains (physical, psychological, social and environmental).

Marital status can mainly be classified as single, marriage problems (separation, divorcing etc) and married. In our study, marital status of MD patients was classified as single, married, divorced and widowed. Studies evaluating QOL according to marital status have reported lower QOL levels in married people due to marriage problems. In a study by Han et al., evaluating QOL according to the marital status in male and female participants using EQ-5D scale, QOL was reported as higher in single compared to married participants both in women

and men (24). In another study again by Han et al., QOL was investigated according to marital status among cancer patients, and it was found that QOL was lower in single cancer patients (25). In a study from Indonesia; gender, marital status and education level were evaluated as the predictors of QOL in elderly people using WHOQOL survey (26). Similar to our study, no significant difference was found between both genders in all four domains of WHOQOL. Marital status was grouped as married and divorced, and single persons were not included in that study. QOL was found to be higher among married individuals. Looking from the aspect of educatşonal level; QOL was found to be increased as educational level was increased, in parallel with our results.

Different results among studies might be resulted from the differences between the scales used and participants included. In fact, Han et al. investigated QOL in healthy persons and cancer patients, while Gondodiputro et al. evaluated QOL in elderly people (25, 26). In addition, economical, cultural and educational differences among countries may contribute to differences between studies on this issue (27).

Looking at the previous studies in the literature; in general the relationship between WHOQOL scale and functionality of MD patients has been examined. To our best knowledge, there is no study in the literature to investigate QOL and sociodemographic characteristics such as gender, marital status and educational level in patients with MDs. In this respect, our study is the first in the literature.

Study Limitations

This study has some limitations. First, the study was conducted in a single center with limited sociodemographic parameters. WHOQOL scores could be compared between more data groups (income level, comorbidities etc.). QUL measurements could be performed before and after interventions. Finally, WHOQOL scores could be compared between patients with different forms of MD. Nevertheless, being the first study in the literature to investigate QOL

and sociodemographic features of MD patients indicates a strength of our study. In this respect, we think that our study will be guiding for further comprehensive studies.

Conclusion

The results of this study indicate that quality of life increases with the level of education in patients with muscular dystrophy. On the other hand, quality of life does not differ according to gender and marital status in these patients. At this point, encouraging MD patients for education from the pediatric period can be recommended. Further multicenter and comprehensive studies with a larger number of parameters to be examined are needed. In addition, there is an urgent need in the literature for studies comparing quality of life before and after rehabilitation and treatment programs in patients with muscular dystrophies.

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Conflict of Interest: The authors declare no conflict of interest to disclose.

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Data Availability: Data used in this study can be obtained on demand.

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Figure Legends:

Figure 1. Distribution of MD forms found in patients

Figure 2. Distribution of the patients according to marital status

Figure 3. Distribution of the patients according to the educational levels