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COVID-19 and Patients with Muscular Dystrophy: How Did the Pandemic Affect Patients and Their Medical Care?

COVID-19 ve Kas Distrofili Hastalar: Pandemi Hastaları ve Tıbbi Bakımlarını Nasıl Etkiledi?

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Abstract

Objective: This study investigated the effects of Coronavirus disease-2019 (COVID-19) related lockdowns and the pandemic in patients with muscular dystrophy who require regular hospital admissions and follow-ups. Moreover, the effects of "fear of COVID-19" on these effects were also measured.

Methods: One hundred and five muscular dystrophy patients who were admitted to the neuromuscular diseases tertiary care clinic were evaluated. The patients' socio-demographic and clinical characteristics were recorded, and their fear of COVID-19 was assessed using the "fear of COVID-19 scale", and they were asked about the problems they encountered during the pandemic and lockdowns.

Results: We found that the patients had major restrictions in their access to healthcare, physical therapy/rehabilitation, and reduced physical and social activities. Moreover, they subjectively stated that their disease worsened with the pandemic. These restrictions were found to correlate with their fear of COVID-19 levels.

Conclusion: Patients with muscular dystrophy were found to have changes in their physical activity, participation in rehabilitation, problems with reaching healthcare services, and social problems. These problems were associated with their fear of COVID-19. As routine access to healthcare and therapies is crucial for these patients, both patients and health professionals should keep the potential harm of restrictions and fear in mind and strive for optimal solutions.

Keywords: Neuromuscular diseases, muscular dystrophy, COVID-19, medical care, rehabilitation

Öz

Amaç: Bu çalışma, düzenli hastaneye yatış ve takip gerektiren musküler distrofi hastalarında Koronavirüs hastalığı-2019 (COVID-19) ile ilgili sokağa çıkma kısıtlamalarının ve pandeminin etkilerini araştırmayı amaçladı. Ayrıca bu etkiler üzerinde "COVID-19 korkusu"nun etkisi de ölçüldü.

Yöntem: Nöromusküler hastalıklar üçüncü basamak kliniğine başvuran 105 musküler distrofi hastası değerlendirildi. Hastaların sosyo-demografik ve klinik özellikleri kayıt altına alınarak, "COVID-19 korku ölçeği" ile COVID-19 korkuları değerlendirildi, pandemi ve karantina sürecinde karşılaştıkları sorunlar sorgulandı.

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Öz

Bulgular: Hastaların sağlık hizmetlerine erişiminde, fizik tedavi/rehabilitasyonda önemli kısıtlamalar olduğu, fiziksel aktivite ve sosyal aktivitelerinde azalma olduğu saptandı. Üstelik pandeminin getirdiği değişikliklerle hastalıklarının kötüleştiğini sübjektif olarak belirtmişlerdir. Bu kısıtlamaların COVID-19 seviyelerinden duydukları korku ile ilişkili olduğu bulundu.

Sonuç: Musküler distrofili hastaların fiziksel aktivitelerinde değişiklik, rehabilitasyona katılım, sağlık hizmetlerine ulaşmada sorunlar ve sosyal sorunlar yaşadıkları saptanmıştır. Bu sorunların COVID-19 korkularıyla ilişkili olduğu tespit edildi. Bu hastalar için sağlık ve tedavilere rutin erişimleri çok önemli olduğundan, hem hastalar hem de sağlık çalışanları kısıtlamaların olası zararlarını ve korkularını akılda tutmalı ve optimal çözümler için çaba göstermelidir.

Anahtar Kelimeler: Nöromusküler hastalıklar, musküler distrofi, COVID-19, tıbbi bakım, rehabilitasyon

Introduction

Muscular dystrophies are a group of diseases that affect the structure of skeletal muscles and cause the muscles to break down over time[1]. This causes the patients to become weaker as the disease progresses, their movements and mobility are inhibited, and death may occur because of respiratory or other organ failures[2,3].

Most of these diseases are caused by genetic mutations in the structural proteins of the muscle, and a definitive diagnosis is made by genetic testing or biopsy[4]. Muscular dystrophies include Duchenne muscular dystrophy, Becker muscular dystrophy, facioscapulohumeral muscular dystrophy, limb-girdle muscular dystrophy, and myotonic dystrophy[1,2].

Although there is no definitive cure for muscular dystrophy, there are some therapeutic options for alleviating the symptoms. These options include physical therapy, bracing, or surgery to relieve symptoms and, in some cases, pharmacologic interventions[4]. Respiratory involvement may require the use of assisted ventilation. Pharmacological treatment options include steroids to slow muscle degeneration, anticonvulsants to control seizures and certain muscle activities, and immunosuppressants to delay muscle damage[5]. Physical therapy and rehabilitation are therapeutic options that should always be included, as maintaining mobility and functionality is crucial to both prognosis and quality of life. They help the patient maintain muscle strength and prevent complications due to inactivity and deformities that may occur over time[4,6].

The management of muscular dystrophies often involves more than one specialist in this field, namely neurologists, physical medicine specialists, surgeons, and therapists. Therefore, the follow-up of patients is essential for those who work for their management, to intervene at the right time and do their best.

The recent Coronavirus disease-2019 (COVID-19) pandemic has harmed not only those who are infected but also those who need medical care for other illnesses. While the hospitals' policy of accepting fewer patients than before puts a group of patients in distress, there were also patients who hesitated to seek medical help even when they needed it[7]. Hospital access was delayed for people with chronic neurodegenerative conditions, such as multiple sclerosis, movement disorders, or dementia, who are at a greater risk of serious consequences from infection[8]. Patients also received less service at the hospital, and it has been shown that admissions for stroke have decreased by 50%[9].

In parallel with these reports, we observed that the postponement or cancelation of routine follow-ups is increasing in patients with muscular dystrophy, and the excuse is fear of hospitalization after the pandemic. The patients seemed to avoid therapy because their illness made them more vulnerable and prone to complications from an infectious disease. However, no studies have demonstrated the existence of such a reservation or its possible causes in this population. Uncovering their problems with follow-up and rehabilitation can enable clinicians to offer possible solutions and increase the effectiveness of their treatments.

This study aimed to reveal whether patients with muscular dystrophy show fear and anxiety related to the pandemic that hinders their medical care. Another aim of the study was to reveal the possible causes of their fears and to offer solutions to the problem.

Materials and Methods

The participants with muscular dystrophy who had been followed up at the Neuromuscular Diseases Center of University of Health Sciences Turkey, İzmir Tepecik Education and Training Hospital, were included in this study. The study was approved by University of Health Sciences Turkey, İzmir Tepecik Education and Training Hospital (number: 2020/14-

36, date: 23.12.2020). Institutional Review Board for ethics. The questionnaires were administered from January 2021 to June 2021. All patients and their caregivers provided informed consent. The study was approved by an institutional review board before the initiation of the study. The inclusion and exclusion criteria were as follows:

Inclusion criteria:

1. Patients diagnosed with muscular dystrophy,

2. Those who can read and write Turkish.

Exclusion criteria:

1. Patients diagnosed with anxiety disorder,

2. Patients who lacked the mental capacity to participate.

After collecting demographic and clinical information, questionnaires were administered to the patients. Patients were given a questionnaire that included limitations in rehabilitation, limitations in physical activity and social life, and acceleration of clinical worsening. Patients were also asked about their symptoms, severity, and activities of daily living. The fear of the COVID-19 scale was also applied to the participants. If the participants were >12 years old, they answered the questions themselves, and if they were younger, their primary caregiver provided the answers.

Functional ambulation classification (FAC): FAC is an observational assessment that can be made by the investigator without requiring a device to evaluate mobilization. FAC is a scale that evaluates the physical support needed during walking (between 0 and 5) on 6 different scores[10].

Katz's activities of daily life index (ADL): ADL consists of six questions containing information about bathing, dressing, toilet use, movement, excretion, and feeding activities[11]. Depending on the independence of the activities mentioned, the subject receives a score ranging from 0 to 6, with higher scores indicating more independence.

Fear of the COVID-19 scale: The fear of the COVID-19 scale was developed by Ahorsu et al.[12] to assess patients' fears regarding the coronavirus pandemic. It consists of seven items. Using a 5-point Likert-type rating system (1: Strongly disagree and 5: Strongly agree). It was observed that the scale was self-consistent and that there was a positive and significant relationship between the total score of the scale and depression, anxiety, perceived contagiousness, and germ avoidance. The validity and reliability of the scale were made by Bakioğlu et al.[13].

Statistical Analysis

The data were analyzed using descriptive statistical methods. The groups were compared using the Mann-Whitney U test. Categorical variables were analyzed using chi-square tests, and Spearman's rank correlation test was used for correlation analysis. Statistical significance was set to $p<0.05$.

Results

One hundred and five participants were included in the study. The demographic and clinical characteristics of the patients are given in Table 1. Eighty percent of the patient population consisted of <20 years. Dystrophinopathies (Duchenne and Becker muscular dystrophy) formed the majority of the patients (54.3%), and as these pathologies are X-linked, 62.9% of the patients were male.

The inquiry about the changes in their participation in rehabilitation and their daily lives revealed that more than half of the patients had problems with their access to physical therapy, rehabilitation, and overall healthcare services. Moreover, more than half of the participants strongly agreed that their physical activity and social activities were reduced during the pandemic. Although not clear as these changes, 45.7% of the participants agreed or strongly agreed that their disease progression was faster during the pandemic. These results are presented in Table 2.

The results of the correlation analysis were performed to reveal whether the levels of fear of COVID-19 were associated with the issues that our participants stated. Fear of COVID-19 was found to be associated with restrictions in physical activity/exercise, social lives, access to physical therapy and rehabilitation, access to healthcare services, and more severe subjective disease progression ($p<0.01$) (Table 3). The correlation analysis between fear of COVID-19 and activities of daily life, and fear of COVID-19 and FAC were found to be insignificant ($R=-0.01$ and $p=0.84$, $R=-0.02$ and $p=0.79$, respectively). None of the patients stated a history of COVID-19 on the day they were referred.

Discussion

The results of this study have shown that the COVID-19 pandemic resulted in affected patients with muscular dystrophy with reductions in physical activity, social interactions, physical therapy/rehabilitation, and access to healthcare services. Moreover, patients stated that their conditions worsened during the pandemic even without contracting COVID-19. These reductions were associated with

Table 1. Socio-demographic and clinical characteristics of the patients [n% or mean (SD)]	
Age group (yrs)	
0-9	44 (41.9%)
10-19	40 (38.1%)
20-29	18 (17.1%)
30-39	3 (2.9%)
Gender	
Female	39 (37.1%)
Male	66 (62.9%)
Occupation	
None	43 (41%)
Worker	9 (8.6%)
Civil servant	18 (17.1%)
Student	35 (33.3)
Self-employed	6 (5.7%)
Education	
None	6 (5.7%)
Elemantary	37 (35.2%)
High-school	40 (38.1%)
College or higher	22 (21%)
Diagnosis	
Duchenne muscular dystrophy	22 (21%)
Becker muscular dystrophy	35 (33.3%)
Facioscapulohumeral muscular dystrophy	11 (10.5%)
Limb-girdle muscular dystrophy	22 (21%)
Myotonic dystrophy	15 (14.3%)
Therapies	
Pharmacologic therapy	51 (48.6%)
Physical therapy	81 (77.1%)
Surgical ıntervention	5 (4.7%)
Other	17 (16.2%)
FAC	
0	28 (26.7%)
1	12 (11.4%)
2	5 (4.8%)
3	39 (37.1%)
4	39 (37.1%)
5	18 (17.1%)
Orthoses and use of medical equipment	
AFO	32 (30.5%)
KAFO	3 (2.8%)
Wheelchair	28 (26.7%)
Spinal brace	2 (1.9%)
Activities of daily life index (Katz)	**4.26 (1.76)**
Pain	**49 (46.7%)**
Respiratory problems	**13 (12.4%)**
Cardiac problems	**19 (18.1%)**
Gastrointestinal problems	**34 (32.4%)**
Fear of COVID-19 scale	**15.4 (7.2)**
Activities of daily life index (Katz)	4.26 (1.75)

FAC: Functional ambulation classification, SD: Standard deviation, COVID-19: Coronavirus disease-2019

their fear of COVID-19, which may result in overprotective actions.

The coronavirus pandemic that spread throughout the world in the early months of 2020 resulted in a year like not other. Although the exact starting moments differed across countries, the first case of coronavirus in Turkey emerged in March 2020[14]. With the expanding numbers, the outbreak resulted in rapid measures quarantines, and lockdowns[15]. Either due to these regulations, fear of infection, or avoidance, the lifestyles of the people changed, which included decreased physical activity, social isolation, remote working, or postponing their needs or their desires[16].

Patients with neuromuscular disorders, including muscular dystrophies, were no exception. It was shown that in the earlier few months of the pandemic, the physical activity of patients with neuromuscular diseases was already significantly reduced[17]. Many experts and organizations have published plans or recommendations for the management of this population in the age of the pandemic[18]. Most of the opinions aimed to plan their management in a case of coronavirus infection, or how to prevent a possible infection. Still, some of them also focused on how to alleviate the effects of isolation, quarantines, and lockdowns, which may also potentially harm patients with neuromuscular disorders[19]. In parallel with these studies, patients reported delays, postponement, and even cancelation of their appointments, both due to regulations and fear. It is reasonable to protect these patients from a possible infection because it can be more threatening than the general population because they are susceptible to pneumonia with their impaired pulmonary clearance[20,21].

Still, there are also reports on the fact that COVID-19 may not be as severe as it is feared in children with neuromuscular diseases[22]. these patients benefit from physical therapy and

Table 2. The problems that the patients encountered during the pandemic (n%)	
I couldn't get physical therapy, I couldn't go to rehabilitation, or my visits decreased during the pandemic.	
Strongly disagree	14 (13.3%)
Disagree	8 (7.6%)
Undecided	10 (9.5%)
Agree	14 (13.3%)
Strongly agree	59 (56.2%)
Although I tried, I could not get healtcare service during the pandemic.	
Strongly disagree	11 (10.5%)
Disagree	10 (9.5%)
Undecided	12 (11.4%)
Agree	16 (15.2%)
Strongly agree	56 (53.3%)
During the pandemic, my physical activity and exercise frequency decreased.	
Strongly disagree	9 (8.6%)
Disagree	9 (8.6%)
Undecided	15 (14.3%)
Agree	11 (10.5%)
Strongly agree	61 (58.5%)
During the pandemic, my social activities were restricted, I was able to meet less people and do activities together.	
Strongly disagree	9 (8.6%)
Disagree	7 (6.7%)
Undecided	8 (7.6%)
Agree	15 (14.3%)
Strongly agree	66 (62.9%)
During the pandemic, I think that my disease progressed faster and that my condition is worse than before.	
Strongly disagree	23 (21.9%)
Disagree	14 (13.3%)
Undecided	20 (19%)
Agree	9 (8.6%)
Strongly agree	39 (37.1%)

rehabilitation, and a lifelong adherence to these programs and routine controls for this dynamic process is crucial for its effectiveness[4]. Although it differs among individuals, stages, and types of the disease, a home-based rehabilitation program is a viable option for an important fraction of patients. Even in home-based programs, most patients opt to get help from doctors and therapists on a routine basis, and some require more. Therefore, overprotective behavior from the fear of infection can also harm these patients, just as the risk of infection does.

The pandemic severely affected these patients' ability to receive rehabilitation care, potentially leading to disease progression, functional worsening, and psychological distress. furthermore, COVID-19 could significantly worsen functional outcomes in these patients in the context of several respiratory and musculoskeletal sequelae, including mild cases in home isolation[18]. A study that was conducted on Danish children found that the pandemic harmed biopsychosocial health and quality of life of children with neuromuscular diseases[23]. Similar to our population, there are reports from around the world that claim that home isolation resulted in restrictions on physical therapy, schooling, and access to healthcare during a pandemic in patients with neurological disabilities, including cerebral palsy[24]. A study from Turkey also focused on access to healthcare services and fear of COVID-19 during the pandemic in children with cerebral palsy and found severe limitations in attending their routine check-ups. The authors also claimed that telemedicine can be a viable option for such scenarios[25]. The results of our study support these reports and recent findings. Likewise, we found that patients with neuromuscular disorders also had difficulties in their hospital appointments, physical therapy, and social activities. Moreover, they stated that their physical activity also decreased during the pandemic. However, while excessive physical activity may deteriorate the functioning in neuromuscular diseases, a healthy dose of activity must remain functional and preserve the muscles.

We proposed that fear of COVID-19 may have affected the restrictions that our patients experienced. While

Table 3. The correlations between the fear of COVID-19 and the problems encountered during the pandemic						
		Reductions in physical therapy/ rehabilitation	**Reduction in visits to the healthcare centers**	**Reductions in exercises**	**Reductions in social activities**	**Percecption of disease/ physical limitations getting worse**
Fear of COVID	Rho	0.320**	0.352**	0.289**	0.360**	0.312**
	p	0.001	0.000	0.003	0.000	0.001
COVID: Coronavirus, COVID-19: Coronavirus disease-2019, **: Denotes statistical significance						

this population has never been a focus for the former studies, studies regarding healthcare and chronic patients proposed that a high fear of COVID-19 was present in these populations[13,26]. Moreover, this fear was associated with more problems in reaching the healthcare that they need.

Study Limitations

Our analyses also showed that increased fear of COVID-19 was associated with more severe limitations and troubles during the pandemic. Moreover, we also performed analyses to show whether disease severity and disability status affected this fear, as more severe disease or worse disability status may have had an effect, and found no correlations. These results show that fear of COVID-19 may be an important factor for these patients to avoid behavior and face restricting consequences. It is imperative to weigh the pros and cons of these restrictions and let the patients have the healthcare access, physical therapy, physical activity, and social activity they require while protecting them from the infection itself. Addressing the fear of COVID-19 and proper patient education can help with the solution of the problem, as well as telemedicine and telerehabilitation when in need, as proposed by Cankurtaran et al.[25].

This is the first study in Turkey to study the effects of the pandemic on patients with muscular dystrophy. With the inclusion of different types of these disorders and broad age groups, the results of this study may be generalized to this population. However, it has some limitations. Greater numbers of participants could provide more reliable results from a broader population. While we subjectively questioned their habits, such as physical activity, we could not use a validated and structured outcome measure, such as IPAQ. Moreover, we did not have such a measure before the pandemic, which was unexpected and resulted in a drastic change. However, there is a lack of outcome measures for physical activity for these patients, which differs from the healthy population. Because they have many items that require activities they are unable to perform, novel studies should aim to create or modify these measures for this special group of patients.

Conclusion

The pandemic of COVID-19 has resulted in major changes worldwide. Patients with muscular dystrophy were no exception, and it caused changes in their physical activity, participation in rehabilitation, problems with accessing healthcare services, and social problems. These problems were associated with their fear of COVID-19. Although protection of this sensitive population from infection is a must, both patients and health professionals should keep the potential harm of restrictions and fear in mind and strive for optimal solutions.

Ethics

Ethics Committee Approval: The study was approved by University of Health Sciences Turkey, İzmir Tepecik Education and Training Hospital (number: 2020/14-36, date: 23.12.2020).

Informed Consent: All patients and their caregivers provided informed consent.

Authorship Contributions

Surgical and Medical Practices: G.T., M.Y.K., B.T., F.B., Concept: G.T., F.M.S., Design: G.T., F.M.S., Data Collection or Processing: G.T., M.Y.K., B.T., F.B., Analysis or Interpretation: G.T., F.M.S., M.Y.K., B.T., F.B., Literature Search: G.T., F.M.S., Writing: G.T., F.M.S., M.Y.K., B.T., F.B.

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