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ORIGINAL ARTICLE

# The impact of COVID-19 pandemic on adult individuals with neuromuscular disease

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***ABSTRACT***

**Objectives:** The study aimed to examine the pandemic-related attitudes and behaviors of adult individuals with neuromuscular disease during the coronavirus disease 2019 (COVID-19) pandemic.

**Patients and methods:** A total of 87 individuals (55 males, 32 females; mean age: 39.7±14.5 years; range, 19 to 80 years) with neuromuscular disease were included in the cross-sectional study between July 2022 and December 2022. After obtaining the demographic information of the individuals, information about neuromuscular disease and COVID-19, vaccination status, and their situation during the pandemic were questioned with yes/no or open-ended questions.

**Results:** While the most prevalent neuromuscular disease was spinal muscular atrophy (n=30, 34.5%), 72 (82.8%) individuals had no comorbities. Twenty-nine (33.3%) individuals had COVID-19, and seven (24.1%) of these individuals had COVID-19 with high severity. Eighty-two (94.3%) individuals were vaccinated. Among the individuals who had COVID-19, 10 (34.5%) individuals stated that their physical condition was worse than before the pandemic. Among the whole participants, 40 (48.3%) individuals stated that it was worse and much worse. Only 15 (17.2%) individuals continued to participate in physical therapy practices during the pandemic period. Forty-three (49.4%) individuals said that their social life was worse and much worse than before the pandemic.

**Conclusion:** The course of COVID-19 in individuals with neuromuscular disorders may not be as severe as expected. Further studies are needed to generalize these findings to the broader neuromuscular disease population.

*Keywords:* COVID-19, neuromuscular disease, pandemic.

Since the end of December 2019, the severe acute respiratory syndrome virus 2 (SARS-CoV-2) pandemic has claimed the lives of more than 6,882,000 individuals worldwide.[1] Hence, this infection has been declared a public health emergency, and in many countries, people were asked to live in home confinement for several months, while hospitals have been forced to reduce their outpatient activities to cope with the high number of hospitalizations.[2,3] Symptomatic SARS-CoV-2 infection causes a wide spectrum of symptoms (referred to as coronavirus disease 2019; COVID-19), such as fever, dry cough, and fatigue in milder cases and systemic manifestations in severe disease courses. In parallel, SARS-CoV-2 infection poses a greater risk for old, oncologic, and immunosuppressed patients, which also include many individuals with hereditary and acquired neuromuscular disorders (NMD) that may already present increased risks due to the underlying disease.[4]

Individuals with NMD need an active physical activity through regular exercise practice

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to protect/improve their muscle strength and endurance and to prevent osteoarticular complications due to disuse.[5] They are considered to be the group that needs attention against severe complications of COVID-19 due to their frailty and cardiorespiratory deficiencies.[6] Individuals with NMDs, particularly those with reduced respiratory capacity, have been recognized as a vulnerable population since the onset of the pandemic.[4,7] Individuals with NMDs may experience more frequent and severe COVID-19-related complications compared to the general population.[8] For this population, COVID-19 also represents a factor that accelerates muscle wasting through inactivity-related deconditioning and a high risk of being confined to bed.

The aim of the study was to examine the profiles and pandemic-related attitudes and behaviors of adult individuals with NMD who were admitted to our neurological rehabilitation clinic during the COVID-19 pandemic.

## PATIENTS AND METHODS

This cross-sectional study was conducted with 87 participants (55 males, 32 females; mean age: 39.7±14.5 years; range, 19 to 80 years) between July 2022 and December 2022 at the Faculty of Medicine, Department of Physical Therapy and Rehabilitation, of the Hacettepe University. Inclusion criteria were as follows: *(i)* being diagnosed with NMD by a neurologist, *(ii)* Mini-Mental State Examination score ≥24, and *(iii)* being between 18 and 65 years old. Exclusion criteria were as follows: *(i)* having another neurological disease other than NMD and *(ii)* having an additional orthopedic problem that could affect physical activity performance. Among the individuals who were referred to the outpatient clinic from the Department of Neurology, Hacettepe University Hospitals, those who met the inclusion criteria were selected. The individuals who agreed to participate in the study were informed in detail about the study and gave written informed consent. The study protocol was approved by the Hacettepe University Non-Interventional Clinical Research Ethics Committee (Date: 22.10.2022, No: GO 22/601). The study was conducted in accordance with the principles of the Declaration of Helsinki.

After obtaining the demographic information of the individuals (age, sex, body mass index, and occupation), information about NMD and COVID-19, vaccination status, and their situation during the pandemic process were questioned with yes/no or open-ended questions. Disease name-type, duration, ambulation status, presence of concomitant disease were recorded.

Patients' COVID-19 positivity, the symptoms they had (fever, cough, diarrhea, runny nose, headache, nausea, vomiting, loss of sense of smell/taste, joint/muscle pain, shortness of breath, and sore throat), whether they had pneumonia, the severity of disease, the treatments they received, hospital or home stay during the disease duration, the effect of the disease on their physical condition, and their fear of having COVID-19 were questioned. Patients' vaccination status was questioned; if unvaccinated, they were questioned on their reasons for not receiving the vaccine. If vaccinated, the number of doses received and the type of vaccine were questioned.

Sustainability of physiotherapy practices during the pandemic, changes in disease-specific findings (e.g., muscle weakness, fatigue, joint contractures, muscle shortness, scoliosis, decreased walking distance, balance disorders, swallowing disorders, increase in fall frequency, malnutrition/weight change, respiratory problems, and sleep disorders), physical condition, the influence of the pandemic on social life, and compliance with pandemic rules (e.g., wearing mask, distance, and hygiene) were questioned.

### Statistical analysis

Statistical analyses were performed using IBM SPSS version 20.0 software (IBM Corp., Armonk, NY, USA). Numerical variables were expressed as mean ± standard deviation, while the qualitative data were expressed as frequency and percentage. The conformity of the variables to normal distribution was examined by visual methods (histogram and probability graphics) and the Kolmogorov-Smirnov test. Nonparametric tests were used because the data obtained were nonnormally distributed. The chi-square test was used to compare the quantitative data, and the Mann-Whitney test was used for the qualitative data. The level of statistical significance was set at $p<0.05$.

## RESULTS

The most prevalent NMDs were spinal muscular atrophy (n=30, 34.5%), followed by myopathy (n=13, 14.9%), motor neuron diseases (n=12, 13.8%), myotonic dystrophy (n=7, 8%) and muscular dystrophy (n=7, 8%), Becker muscular dystrophy (n=6, 6.9%), limb-girdle muscular dystrophy (n=6, 6.9%),

fascioscapulohumeral muscular dystrophy (n=5, 5.7%), and polyneuropathy (n=1, 1.1%). The mean disease duration was 171.5±221.8 months.

Seventy-two (82.8%) individuals had no comorbities. The most common comorbidities were hypertension (n=4, 4.6%) and heart failure (n=2, 2.3%). Other comorbities were rheumatic disease, diabetes, hearing loss, asthma, psychiatric illness, anemia, hyperlipidemia, lymphedema, and hypothyroidism (n=1, 1.1%). Ambulation status was categorized as walking with or without support (n=70, 80.5%) and inability to walk (n=17, 19.5%). The demographic characteristics and general health status of the participants are summarized in Table 1.

Twenty-nine (33.3%) individuals had COVID-19. Two (6.9%) individuals remained asymptomatic throughout the course of infection. Twelve (41.4%) individuals presented with some mild symptoms, and eight (27.6%) individuals had COVID-19 disease with moderate severity, and seven (24.1%) individuals had COVID-19 disease with high severity. Twelve (41.4%) individuals used drugs for COVID-19. Twenty-eight (96.6%) individuals were not hospitalized. The most common symptom of COVID-19 was arthralgia/myalgia (n=20, 69%). The other symptoms were fever and persistent cough (n=14, 48.3%), headache and anosmia/ageusia (n=12, 41.4%), nasal congestion and sore throat (n=9, 31%), nausea/vomiting and dyspnea (n=5, 17.2%), and diarrhea (n=3, 10.3%). Eighty-two (94.3%) individuals had been vaccinated. The most common vaccine was Biontech (n=40, 46%). Twenty-five (28.7%) individuals had been vaccinated with both Biontech and Sinovac. One individual had

**TABLE 1**
Demographic characteristics and general health status of the participants (n=87)

| | n | % | Mean±SD |
|---|---|---|---|
| Age (year) | | | 39.7±14.5 |
| Sex | | | |
| Male | 55 | 63.2 | |
| Female | 32 | 36.8 | |
| Body mass index (kg/m$^2$) | | | 23.8±4.3 |
| Diagnosis | | | |
| Myopathy | 13 | 14.9 | |
| Motor neuron diseases | 12 | 13.8 | |
| Myotonic dystrophy | 7 | 8.0 | |
| Becker muscular dystrophy | 6 | 6.9 | |
| Spinal muscular atrophy | 30 | 34.5 | |
| Limb girdle muscular dystrophy | 6 | 6.9 | |
| Muscular dystrophy | 7 | 8.0 | |
| Fascioscapulohumeral muscular dystrophy | 5 | 5.7 | |
| Polyneuropathy | 1 | 1.1 | |
| Disease duration (mo) | | | 171.5±221.8 |
| Comorbidities | | | |
| None | 72 | 82.8 | |
| Rheumatic disease | 1 | 1.1 | |
| Hypertension | 4 | 4.6 | |
| Diabetes | 1 | 1.1 | |
| Heart failure | 2 | 2.3 | |
| Hearing loss | 1 | 1.1 | |
| Asthma | 1 | 1.1 | |
| Psychiatric illness | 1 | 1.1 | |
| Anemia | 1 | 1.1 | |
| Hyperlipidemia | 1 | 1.1 | |
| Lymphedema | 1 | 1.1 | |
| Hypothyroidism | 1 | 1.1 | |
| Ambulation status | | | |
| Walk with/without support | 70 | 80.5 | |
| Cannot walk | 17 | 19.5 | |

SD: Standard deviation.

been vaccinated with Moderna. Thirty (34.5%) individuals were afraid of contracting COVID-19.

Among the individuals who had COVID-19, only one (3.4%) stated that his physical condition was better than before, 18 (62.1%) individuals stated that it was the same, and 10 (34.5%) individuals stated that it was worse. Characteristics of COVID-19 in adults with NMDs are summarized in Table 2.

**TABLE 2**
Characteristics of COVID-19 in adult individuals with NMDs

| | n | % |
|---|---|---|
| *Total* | 87 | |
| Who had COVID-19 | | |
| Yes | 29 | 33.3 |
| No | 58 | 66.7 |
| Who has vaccinated | | |
| Yes | 82 | 94.3 |
| No | 5 | 5.7 |
| Types of vaccine | | |
| Sinovac | 16 | 18.4 |
| Biontech | 40 | 46.0 |
| Both of Synovac and Biontech | 25 | 28.7 |
| Moderna | 1 | 1.1 |
| Afraid of getting COVID-19 | | |
| Yes | 30 | 34.5 |
| No | 57 | 65.5 |
| *Total* (who had COVID-19) | 29 | |
| Severity of COVID-19 | | |
| Asymptomatic | 2 | 6.9 |
| Low | 12 | 41.4 |
| Moderate | 8 | 27.6 |
| High | 7 | 24.1 |
| Very high | 0 | 0 |
| COVID treatment | | |
| None | 17 | 58.6 |
| Oxygen/increased need for respiratory support | 0 | 0 |
| Drugs for COVID-19 | 12 | 41.4 |
| Medical care | | |
| Home care | 28 | 96.6 |
| Medical unit | 1 | 3.4 |
| Intensive care unit | 0 | 0 |
| Clinical features | | |
| Fever | 14 | 48.3 |
| Cough | 14 | 48.3 |
| Diarrhea | 3 | 10.3 |
| Nasal congestion | 9 | 31.0 |
| Headache | 12 | 41.4 |
| Nausea/vomiting | 5 | 17.2 |
| Anosmia/ageusia | 12 | 41.4 |
| Arthralgia/myalgia | 20 | 69.0 |
| Dyspnea | 5 | 17.2 |
| Sore throat | 9 | 31.0 |
| Physical condition after COVID-19 | | |
| Better than before | 1 | 3.4 |
| Same as before | 18 | 62.1 |
| Worse than before | 10 | 34.5 |
| Much worse than before | 0 | 0 |

COVID-19: Coronavirus disease 2019; NMDs: Neuromuscular disorders.

Fifteen (17.2%) individuals continued to participate in physical therapy practices during the pandemic period. The most worsening symptoms were fatigue (n=49, 56.3%), muscle weakness (n=45, 51.7%), and decrease in walking distance (n=45, 51.7%) during the pandemic period. The other worsening symptoms were balance problems (n=30, 34.5%), nutritional disorder/weight gain (n=22, 25.3%), muscle shortness (n=18, 20.7%), increase in the frequency of falls (n=18, 20.7%), sleep dysfunction (n=17, 19.5%), contractures (n=13, 14.9%), swallowing dysfunction (n=9, 10.3%), respiratory dysfunction (n=9, 10.3%), and scoliosis (n=2, 2.3%).

Three (3.4%) individuals stated that their physical condition was better than before the pandemic, 42 (48.3%) individuals stated that it was the same, 40 (46%) individuals stated that it was worse, and two (2.3%) individuals stated that it was much worse. On the other hand, five (5.7%) individuals said that their social life was better than before the pandemic, 39 (44.8%) individuals said that it was the same, 38 (43.7%) individuals

**TABLE 3**
Pandemic profile in adult individuals with NMDs (n=87)

| | n | % |
|---|---|---|
| Participating in physical therapy practices | | |
| Yes | 15 | 17.2 |
| No | 72 | 82.8 |
| Worsening symptoms | | |
| Muscle weakness | 45 | 51.7 |
| Contractures | 13 | 14.9 |
| Muscle shortness | 18 | 20.7 |
| Scoliosis | 2 | 2.3 |
| Decrease in walking distance | 45 | 51.7 |
| Fatigue | 49 | 56.3 |
| Balance problems | 30 | 34.5 |
| Swallowing dysfunction | 9 | 10.3 |
| Increase in the frequency of falls | 18 | 20.7 |
| Nutritional disorder/weight gain | 22 | 25.3 |
| Respiratory dysfunction | 9 | 10.3 |
| Sleep dysfunction | 17 | 19.5 |
| Physical condition | | |
| Better than before | 3 | 3.4 |
| Same as before | 42 | 48.3 |
| Worse than before | 40 | 46.0 |
| Much worse than before | 2 | 2.3 |
| Social life | | |
| Better than before | 5 | 5.7 |
| Same as before | 39 | 44.8 |
| Worse than before | 38 | 43.7 |
| Much worse than before | 5 | 5.7 |

said that it was worse, and five (5.7%) individuals said that it was much worse. The pandemic profile in adults with NMDs are presented in Table 3.

## DISCUSSION

Based on published literature, our study is one of the few studies examining the impact of COVID-19 pandemic on adults with NMDs in Türkiye and globally. Adult individuals with NMDs, due to the nature of their disease and the additional health problems they experience, are considered an extremely vulnerable group and are at high risk of severe infection if they have COVID-19.[9]

Although adult individuals with NMDs are considered vulnerable, our study found that 33.3% of individuals had COVID-19; 6.9% of these individuals were asymptomatic, 41.4% had mild symptoms, 27.6% had moderate symptoms, and 24.1% had severe symptoms. It was found that 96.6% of the individuals who had COVID-19 experienced the disease at home and 58.6% did not receive any medical support. According to our results, it appears that the risk of having COVID-19 is low and those who do have COVID-19 have mild symptoms. This may also be attributed to the low comorbidity rates of the individuals participating in our study.

No comorbities was observed in 82.8% of the individuals in this study. Similarly, a study conducted on pediatric patients with NMDs showed that the impact of COVID-19 on this patient group, which was considered vulnerable, was not as severe as expected. This study also emphasized that although more than 40% of patients had severe respiratory involvement (use of noninvasive ventilation for at least eight months) before COVID-19, respiratory complications and extra ventilation support were not common during the COVID-19 process.[10] Similarly, another study showed that none of the individuals with Duchenne muscular distrophy with COVID-19 had moderate or severe symptoms, and although the individuals had been receiving corticosteroid treatment for many years, low-level respiratory failure and cardiomyopathy findings were revealed.[9] In the same study, the researchers emphasized that patients were not undergoing even the most basic cardiorespiratory assessments against the risk of contracting COVID-19 and expressed the hope that these results would provide some reassurance and encourage patients to fulfill their basic treatment requirements.[9]

The most common symptom in individuals with COVID-19 was found to be joint pain/muscle pain in 69% of cases. The underlying reasons for the high incidence of joint pain/muscle pain are; it can be interpreted that the complaints of muscle weakness and muscle pain that individuals experience most frequently due to the nature of NMDs increase with COVID-19.

According to the data from the Ministry of Health of Türkiye, 93.4% of the population is vaccinated with one dose against COVID-19, while 85.7% of the population over the age of 18 is vaccinated with two doses.[11] In our study, 94.3% and 89.7% of individuals with NMDs were vaccinated, respectively. The results of our study showed that patients were vaccinated at a very high rate. This result suggested that patients had a high perception of health and a high sensitivity to protect both themselves and the individuals they lived with from the effects of the pandemic.

In the present study, only 17.2% of the individuals continued to participate in physical therapy practices during pandemic. Guidon and Amato[10] stated that in the care of individuals with NMDs, outpatient care decreased in nonemergency situations and that physiotherapists contacted individuals by phone or online portals instead of face-to-face rehabilitation sessions during the pandemic.

Another study stated that some dramatic changes occurred in patients' physical therapy services during the pandemic, such as canceling face-to-face rehabilitation sessions and utilizing telehealth for clinical evaluations/rehabilitation sessions.[12] The results of our study are compatible with similar studies in the literature. It is thought that the reason for this may be that patients are afraid of contracting COVID-19 when they go to healthcare institutions.[13] Healthcare institutions are among the leading places for COVID-19 to be transmitted to patients. Therefore, we believe that strategies such as telemedicine and telerehabilitation will reduce the clinical impact of the pandemic on adults with NMD. In the literature, studies emphasized the importance of telerehabilitation applications.[4] It was stated that home-based rehabilitation programs helped maintain or improve respiratory muscle strength, endurance, and exercise tolerance by counteracting fatigue in neuromuscular patients after COVID-19.[8]

In the present study, the significant decrease in individuals' participation in physical therapy

practices can be interpreted as an increase in the time they spend at home, suggesting a significant reduction in their physical activity levels. A study showed that the physical activity levels of individuals with NMDs decreased during the pandemic period, and this negatively affected their quality of life.[2] It should not be forgotten that physical inactivity in individuals with NMDs causes a more significant loss of muscle mass compared to healthy individuals.[14]

In our study, the most frequently worsening symptoms of individuals during the pandemic were fatigue (56.3%), muscle weakness (51.7%), and decrease in walking distance (51.7%). Although it is expected that these symptoms will worsen over time due to the nature of NMDs, it is thought that the worsening of these symptoms compared to other symptoms is due to the decrease in physical activity levels. The quarantine period, above all, negatively affected walking activities in individuals with NMDs. The main explanation for this may relate to the fact that walking represents an easily accessible, low-intensity, aerobic activity for the entire population.[15] In our study, 80.5% of the individuals were ambulatory. Considering that these individuals were active individuals before the pandemic and actively used their muscles by walking with or without support, it is expected that muscle weakness will increase, fatigue will appear, and walking distances will decrease as this situation decreases during the pandemic period. We believe that the curfew restrictions implemented in Türkiye are also effective in this result. We think that our findings will also attract the attention of health policy developers as they show the negative consequences of patients being confined to their homes in similar pandemic situations that may occur in the future.

Considering both physical condition and social life during the pandemic, individuals generally stated that they felt the same (48.3% and 44.8%) or worse (46% and 43.7%) than before the pandemic. We believe that this situation is not only due to their abandonment of physiotherapy programs but also due to their decreased physical activity levels.

This study had some limitations. The number of individuals included in the study was relatively small, and the study was conducted at a single center. Although our method of collecting cases in our study was successful, it may be considered noncomprehensive and may not reflect all cases. The study had a cross-sectional design and was based on a subjective survey about the health status of adult individuals with NMDs during the pandemic. Questions were prepared by reviewing studies in the literature, as there are no reliable tools to assess the impact of COVID-19 or the pandemic on healthcare and health status of individuals with NMDs, which may have introduced bias.

In conclusion, although our results cannot be generalized to all adult individuals with NMDs, we believe that it is a positive situation that most individuals recovered from COVID-19 without significant complications. As risks remain, such as the emergence of different variants of COVID-19, and the rate of spread increasing from time to time, social distance and hygiene should still be the primary recommendation for all adults with NMDs and their primary caregivers to reduce the risk of contracting the virus.[10] In addition, telerehabilitation practices should be emphasized to ensure continuity in the evaluation and treatment processes of patients and to be ready for similar emergencies that could prevent individuals from presenting to health institutions. Finally, guidelines that include technological support, such as telerehabilitation/activity monitors, should be created to protect the activity levels of patients in groups such as NMDs, where physical activity restrictions will have negative effects under extraordinary circumstances such as the pandemic.

**Data Sharing Statement:** The data that support the findings of this study are available from the corresponding author upon reasonable request.

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