





# Neuromuscular diseases and social distance resulting from the COVID-19 pandemic

## *Doenças neuromusculares e o distanciamento social decorrente da pandemia COVID-19*

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### Abstract

**Background** Coronavirus 2 severe acute respiratory syndrome (SARS-CoV-2), generically called COVID-2019, classified as a pandemic by the World Health Organization, has made health practices around the world face unique challenges. Since then, physical distancing and measures such as confinement have been adopted by different governments to control human-to-human transmission. This distance affected the treatment of individuals with progressive diseases such as neuromuscular diseases (NMDs).

**Objective** To identify how patients with NMDs performed the therapeutic routine during social distancing and confinement resulting from the COVID-19 pandemic.

**Methods** Application of a questionnaire prepared in the Google forms application, whose link for access and participation was sent by email or WhatsApp for family members and/or individuals with DNMs to respond. The questionnaire consisted of multiple-choice questions, divided into the following sections: personal data, treatments performed before and during the pandemic, activities performed during confinement, and characterization of motor function in activities of daily living comprising the period between September and October 2020.

**Results** We observed a significant reduction in medical appointments for patients with NMDs. On the other hand, the results showed that most patients underwent motor and/or respiratory physiotherapy in person or by telemonitoring. The study participants reported spending more time playing indoors, and all pointed out motor changes during social distancing.

**Conclusion** There were changes in the therapeutic routine of patients with NMDs during the period of social distancing due to COVID-19.

### Keywords

- ▶ COVID-19
- ▶ Neuromuscular Diseases
- ▶ Physical Therapy Modalities
- ▶ Locomotion
- ▶ Drug Therapy

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## Resumo

**Antecedentes** A síndrome respiratória aguda grave por coronavírus 2 (SARS-CoV-2), genericamente chamada de COVID-2019, classificada como pandemia pela Organização Mundial da Saúde, tem feito as práticas de saúde em todo o mundo enfrentar desafios únicos. Desde então, o distanciamento físico e medidas como o confinamento foram adotadas por diferentes governos para controlar a transmissão inter-humana. Este distanciamento afetou o tratamento de indivíduos com doenças progressivas, como no caso das doenças neuromusculares (DNMs).

**Objetivo** Identificar como os pacientes com DNMs realizaram a rotina terapêutica durante o distanciamento social e confinamento decorrentes da pandemia de COVID-19.

**Métodos** Aplicação de um questionário elaborado no aplicativo Google forms, cujo link para acesso e participação foi enviado por e-mail ou WhatsApp para familiares e/ou indivíduos com DNMs responderem. O questionário consistiu em questões de múltipla escolha, dividido nas seguintes sessões: dados pessoais, tratamentos realizados antes e durante a pandemia, atividades realizadas durante o confinamento e caracterização das funções motoras nas atividades de vida diária, referente ao período de setembro a outubro de 2020.

**Resultados** Observamos uma redução significativa nas consultas médicas dos pacientes com DNMs. Por outro lado, os resultados demonstraram que a maior parte dos pacientes realizou fisioterapia motora e/ou respiratória de modo presencial ou por telemonitoramento. Os participantes do estudo relataram gastar mais tempo com atividades dentro de casa, além de todos terem apontado mudanças motoras durante o distanciamento social.

**Conclusão** Houve mudanças na rotina terapêutica de pacientes com DNM durante o período de distanciamento social da COVID-19.

## Palavras-chave

- ▶ COVID-19
- ▶ Doenças Neuromusculares
- ▶ Modalidades de Fisioterapia
- ▶ Locomoção
- ▶ Tratamento Farmacológico

## INTRODUCTION

Neuromuscular diseases (NMDs) are those that affect the upper and lower motor neurons, the peripheral nerves, the neuromuscular junction, and the muscles,<sup>1</sup> fitting into the vast group of different diagnoses of genetic, acquired, or autoimmune origin that affect children and adults with a degree of functional impairment that can vary widely from one individual to another, even among those affected with the same diagnosis of the specific disease.<sup>2</sup> Solé et al.<sup>3</sup> expose some examples of NMDs, including muscle diseases such as muscle dystrophies, congenital myopathies, metabolic myopathies, inflammatory myopathies, and muscle channelopathies; neuromuscular junction diseases such as acquired or congenital myasthenic syndromes and disorders of peripheral nerve; disarmed neuropathies, amyloid neuropathies, and Charcot-Marie-Tooth disease; and spinal muscular atrophies.<sup>4</sup> The World Muscle Society divides the genetic base into 16 categories and updates it regularly.<sup>1</sup>

Progressive and disabling, NMDs can be degenerative and lead to death, also affecting the quality of life of patients and their families.<sup>4</sup> In addition, the vast majority of NMDs has no cure, so the treatment consists of clinical therapy, physical therapy, speech therapy, and psychotherapeutic follow-up, among others, continuously, to alleviate symptoms or delay their onset.<sup>4</sup>

In Brazil, the line of care that provides care to people with these diseases is structured by Primary Care and Specialized Care, in accordance with the Health Care Network, and following the Guidelines for Comprehensive Care for People with Rare Diseases in the Brazilian Unified Health System (SUS, in the Portuguese acronym), such as carrying out actions and urgent and emergency services, rehabilitation services, specialized outpatient clinics and hospitals, supporting and complementing primary care services in a resolute and timely manner.<sup>3,4</sup>

However, severe acute respiratory syndrome by coronavirus 2 (SARS-CoV-2), generically called COVID-2019, classified as a pandemic by the World Health Organization (WHO), has made health practices around the world face unique challenges. Solé et al. (2020)<sup>3</sup> state that the current practice in the treatment of neuromuscular diseases, which are considered a risk group according to the Ministry of Health, has also significantly changed.

A significant number of these patients are severely disabled and may have cardiac and/or respiratory problems.<sup>3</sup> The magnitude of the impact of this public health emergency on the care of patients with NMDs is not clear,<sup>5</sup> despite certain changes in neuromuscular care systems and an unprecedented reorganization for rapid delivery of clinical care around the world has already occurred.<sup>2,6</sup>

**Table 1** Sample characterization

Neuromuscular disease	n	Sex (%)		Age (years old; mean $\pm$ SD)
		Male	Female	
DMD	36	100		13.8 $\pm$ 9.5
BMD	3	100		15.0 $\pm$ 7.2
LGMD	2		100	16.0 $\pm$ 19,7
SMA	9	77.8	22.2	18.2 $\pm$ 15.5

Abbreviations: BMD, Becker muscular dystrophy; DMD, Duchenne muscular dystrophy; DP, standard deviation; LGMD, limb girdle muscular dystrophy; n, number of participants; SMA, spinal muscular atrophy.

Therefore, considering the consequences that COVID-19 infection can bring to the treatment of people with NMDs, we proposed to identify how individuals with these diseases performed their therapeutic routine during confinement resulting from the pandemic.

## METHODS

The present study was approved by the Research Ethics Committee of the Universidade Federal de São Paulo (UNIFESP, in the Portuguese acronym), opinion 4,293,585 (No:1107/2020), according to the Normative Resolution 466/12 of the National Health Council.

The participants in the present research were the parents and/or caregivers of patients diagnosed with NMD, or patients with NMD who experienced the situation of social isolation and confinement due to the COVID-19 pandemic, and only those who consented and marked "agree" in the Informed Consent Form (FICF) and answered the online questionnaire were included. The participants of the present study were contacted from a private list of researchers constructed during the collection of data from pre-pandemic studies on COVID-19 performed at the Neuromuscular Disease Research Sector of the Department of Neurology and Neurosurgery at the UNIFESP.

The questionnaire contained questions about: (1) characteristics of individuals with NMDs; (2) therapeutic routines before and during the pandemic; (3) activities performed during confinement; and (4) characterization

of motor function in activities of daily living. The questions were prepared using the Google Forms tool, a search management application launched by Google. Users can use Google Forms to search and collect information about other people and can also be used for surveys and registration forms. The information collected and the results of the questionnaire were transmitted automatically. In addition, Google Forms also has multiuser collaboration and sharing capabilities.<sup>7</sup>

The participants were invited by email or WhatsApp, and responses were collected between September and October 2020. Responses stored in the tool were later transferred to a Microsoft Excel (Microsoft Corporation, Redmond, WA, USA), version 2206) file, being subsequently organized and analyzed.

## Data analysis

Descriptive analysis was performed: absolute and percentile frequency distribution for categorical variables and mean and standard deviation (SD) for continuous variables according to the diagnosis of NMD.

## RESULTS

► **Table 1** depicts the characterization of the 50 patients with NMD, most of them diagnosed with muscular dystrophy, with Duchenne muscular dystrophy (DMD) being the most frequent. Patients from all regions of the country were interviewed, with the Southeast region showing the highest frequency of 33 participants (64.7%), followed by the North region with 7 (13.7%) participants, the South region with 6 (11.8%), the Northeast region with 3 (5.9%) participants, and the Midwest region with 2 (3.9%) participants.

Twelve participants (23.5%) moved independently without any support device; the other participants are dependent for movement, with 1 (2%) of the interviewees needing the aid of a walker, 8 (15.7%) relying on a wheelchair to travel long distances. Most 30 (58,8%) participants used a wheelchair full-time.

► **Table 2** indicates that of the 36 respondents with DMD, most performed motor physical therapy before the pandemic, half performed respiratory physical therapy, and only 11

**Table 2** Characterization of physical therapy routine before the pandemic

Neuromuscular disease	Motor physiotherapy		Weekly frequency (Mean $\pm$ SD)	Respiratory physiotherapy		Weekly frequency (Mean $\pm$ SD)	Aquatic physiotherapy		Weekly frequency (Mean $\pm$ SD)
	n (%)			n (%)			n (%)		
	Yes	No	Yes	No	Yes	No			
DMD	32 (88.9)	4 (11.1)	1.61 $\pm$ 1.1	18 (50)	18 (50)	1.08 $\pm$ 1.6	11 (30.6)	25 (69.4)	0.42 $\pm$ 0.7
BMD	3 (100)		3.67 $\pm$ 3.7		3 (100)		1 (33.3)	2 (66.7)	0.33 $\pm$ 0.57
LGMD	1 (50)	1 (50)	1.0 $\pm$ 1.4	1 (50)	1 (50)	4.0 $\pm$ 5.6			
SMA	7 (77.8)	2 (22.2)	8.0 $\pm$ 0	7 (77.8)	2 (22.2)	3.22 $\pm$ 2.6		3 (100)	

Abbreviations: BMD, Becker muscular dystrophy; DMD, Duchenne muscular dystrophy; LGMD, limb girdle muscular dystrophy; n, number of participants; SD, standard deviation; SMA, spinal muscular atrophy.

**Table 3** Characterization of therapeutic routine during the pandemic period from April to September 2020

		Muscular disease			
		DMD	BMD	LGMD	SMA
Medical appointment <i>n</i> (%)	Yes	2 (5.6)			2 (22.2)
	No	33 (91.7)	3 (100)	2 (100)	7 (77.8)
Hospitalization <i>n</i> (%)	Yes	2 (5.6)		1 (50)	
	No	34 (94.4)	3 (100)	1 (50)	9 (100)
Motor physiotherapy <i>n</i> (%)	Presential	25 (69.4)	1 (33.3)	1 (50)	4 (44.4)
	Telemonitoring	9 (25)	2 (66.7%)	1 (50)	5 (55.6)
	Did not perform	2 (5.6)			
Respiratory physiotherapy <i>n</i> (%)	Presential	29 (80.6)	2 (66.7)	1 (50)	4 (44.4)
	Telemonitoring	1 (2.8)	1 (33.3)	1 (50)	5 (55.6)
	Did not perform	6 (16.7)			
Difficulty in telemonitored appointment (%)	Yes	14 (38.9)			2 (22.2)
	No	22 (61.1)	3 (100%)	2 (100%)	7 (77.8)

Abbreviations: BMD, Becker muscular dystrophy; DMD, Duchenne muscular dystrophy; LGMD, limb girdle muscular dystrophy; *n*, number of participants; SMA, spinal muscular atrophy.

performed aquatic physical therapy. Among the participants with Becker muscular dystrophy (DMB), all three performed motor physiotherapy; of these, one performed aquatic physiotherapy. We observed that of the participants diagnosed with limb-girdle muscular dystrophies (LGMDs), only one underwent motor and respiratory physiotherapy, with a higher frequency of respiratory physiotherapy per week. Among the participants with spinal muscular atrophy (SMA), two are SMA type 1 and were in home care; only 2 did not undergo any type of physical therapy treatment (► **Table 2**).

► **Table 3** characterizes the therapeutic routine of participants with NMDs during social distancing due to COVID-19, and reveals that out of the 50 participants, only 2 with DMD and 2 with EMS had a medical consultation during this period. Among the 33 participants with DMD, 3 with DMB and 2 with LGMD said they had not had any type of medical consultation. Only two patients with DMD and one with LGMD needed this service during this period of social distancing.

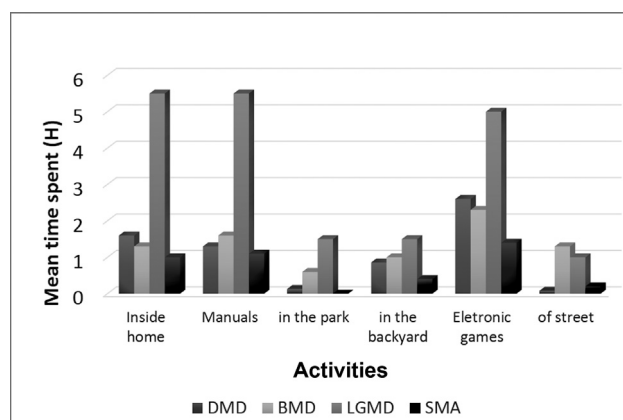
Regarding motor physiotherapy treatment, most participants with DMD underwent physical therapy in person, and only 5.6% did not undergo motor physical therapy during this period (► **Table 3**). Regarding the participants with DMB, most underwent motor physiotherapy by telemonitoring. Among the participants diagnosed with LGMD, one underwent on-site motor physiotherapy and the other by telemonitoring. Among the participants with EBF, 44.4% received physical therapy in person.

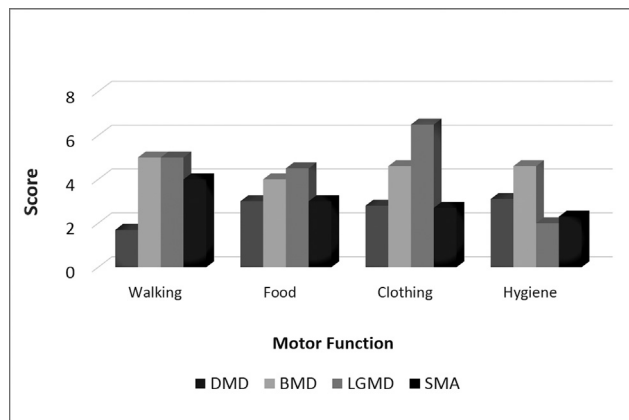
Regarding respiratory physiotherapy, most participants with DMD received this intervention in person, and only 2.8% via telemonitoring (► **Table 3**). A total of 66.7% of the three participants with DMB had face-to-face respiratory physiotherapy. Among the two participants with LGMD, one was attended in person and the other by telemonitoring. Regarding the participants with EBF, 44.4% had face-to-face respiratory physiotherapy care, while the other 5 only had telemonitoring (► **Table 3**).

Among the participants with DMD who underwent telemonitoring care, 38.9% reported having trouble in this type of care, and 2 (22.2%) of the participants with EBF also had difficulties. The participants with DMB and LGMD had no difficulties (► **Table 3**).

► **Figure 1** represents the average time, in hours, of each activity performed by the participants in games (leisure) during social distancing. Thus, it is noted that for indoor games, the participants with DMD spent ~ 1.6 hours involved with these activities; those with DMB spent ~ 1.3 hours, those with LGMD spent 5 hours, and the participants with SMA spent 1 hour. Regarding manual activities/plays, the time spent on average in these activities was 1.3 hours for DMD, 1.6 hours for DMB, 5.5 hours for LGMD, and 1.1 hours for EBF. Participants with LGMD spend more hours on these activities than the others.

The average time, in hours, for play in the park was low: 0.13 hour for DMD, 0.6 hour for DMB, 1.5 hours for LGMD, and participants with EBF did not perform activities/plays in the

**Figure 1** Characterization of leisure activity routines in hours per day during the period of social distancing/confinement.



**Figure 2** Characterization of motor function in points during the period of social distancing/confinement.

park. The performance of activities/plays performed in the backyard was 0.86 hour for DMD, 1 hour for DMB, 1.5 hours for LGMD, and 0.42 hour for SMA. For activities/plays in the street, participants with DMD spent 0.8 hour of their time, while participants with DMD spent 1.34 hours, those with LGMD spent 1 hour, and those with EBF spent 0.2 hour (►Figure 1).

For electronic games, the average time, in hours spent, was 2.6 hours for DMD, 2.3 hours for DMB, 5 hours for LGMD, and 1.4 hours for participants with EBF (►Figure 1).

►Figure 2 represents the assessment of the participant's motor function; scoring from 1 to 10, during social distancing caused by the pandemic. It is observed that in regarding walking, participants with DMD reported that during social distancing the average score was 1.7; for DMB and LGMD, it was 5 points; and for EBF, it was 4 points. Regarding feeding, the average score was 3 points for DMD, 4 points for DMB, 4.5 points for LGMD, and 3 points for SMA. The hygienic activity, on average, had a score of 3.1 points for DMD, 4.6 points for DMB, 2 points for LGMD, and 2.3 points for SMA. Regarding the clothing activity, the average score was 2.8 points for DMD, 4.6 points for DMB, 6.5 points for LGMD, and 2.7 points for SMA (►Figure 2). Participants with SMA were the ones who most reported changes in motor function during distancing, except for the clothing variable (►Figure 2).

## DISCUSSION

In the present study, we investigated the impact of social distancing/confinement resulting from the COVID-19 disease in the treatments of individuals with NMDs through the identification of their therapeutic routine during the period from September to October 2020.

The pandemic entailed a series of sudden changes in the lifestyles of individuals to contain the rapid spread of the SARS-Cov-19 virus. For patients with NMDs, the negative effects of social distancing can be even greater, as these patients need to be monitored regularly to minimize the consequences of the disease.<sup>8,9</sup>

Outpatient care, which used to be face-to-face, was significantly reduced to reduce exposure to patients, commu-

nities, and medical teams. Changes varied according to geographic location, local prevalence of COVID-19, and patient population.<sup>6</sup> This was reflected in our results, in which we observed that only 4 of the 50 participants, 2 with DMD and 2 with SMA, had a medical appointment during the period of social distancing.

Currently, the American Academy of Neuromuscular and Electrodiagnostic Medicine has published guidelines on clinic visits, electrodiagnostic testing, and telemedicine during the COVID-19 pandemic. In this regard, many institutions have adapted a triage system to allocate scheduled outpatients for face-to-face meetings, for telemedicine meetings, or to postpone the visit or procedure if clinically appropriate.<sup>6</sup> It is worth noting that the implementation of telehealth in neurology and particularly in the neuromuscular diseases sector was slow before the COVID-19 pandemic).<sup>10</sup> However, with the need to switch to online care, most outpatient encounters, due to the pandemic situation; made neurologists quickly discover the new tools and skills needed to assist this population, as well as the limitations of this type of care.<sup>6</sup>

It is important to remember that patients with NMD require strict monitoring, essential immunotherapies, muscle rehabilitation, and physical exercise.<sup>8,9,11</sup> Through the practice of regular exercise, which improve or maintain muscle strength, endurance capacity and prevention of osteoarticular complications due to disuse, the exercise must be performed under the supervision of a specialist such as physiotherapists in an integrated and individualized manner.<sup>6</sup> This radical change in daily life resulting from the pandemic can have negative effects on high-risk patients, who need to perform regular exercise to neutralize the negative consequences of certain diseases, such as NMDs.<sup>9</sup>

Our results showed that most participants underwent physical therapy in person or by telemonitoring, and only two participants with DMD did not undergo motor physical therapy in this period of social distancing/confinement. Regarding respiratory physiotherapy, 6 patients with DMD had no respiratory follow-up during this period.

Professional and personal challenges during the COVID-19 pandemic imposed limitations on formal neuromuscular treatment in homes or in different routine outpatient care. The COVID-19 pandemic has forced a rapid and unprecedented reorganization of clinical care delivery across the world.<sup>6</sup> Outpatient physiotherapists and occupational therapists have mainly communicated with patients via telephone and patient portal sessions (telemonitoring), often sending photos and exercise videos.<sup>6</sup>

In view of the distancing recommendations due to the COVID-19 pandemic, encouraging the population to maintain a physically active life routine as a preventive measure for health is essential during this period of fighting against the spread of the virus, and it is not different for patients with NMDs. Some examples of leisure activities performed during the social distancing phase were characterized in the present study, such as games adapted for this population indoors, manual games, games in the park and in the backyard, electronic games, and street games with the family only, as sedentary behaviors can have negative consequences for the health of the entire

population, and in particular for those with additional risk factors such as NMD. Therefore, since outdoor activities are not practicable due to confinement, it is essential to maintain an active lifestyle and to make exercise at home, both for healthy individuals and for NMD patients.<sup>12</sup>

Despite the relevant impact of the COVID-19 pandemic on the health of patients with NMDs, some studies have provided recommendations for the care of these patients.<sup>3,6,13</sup> Isolation at home can lead to poor nutrition, poor sleep quality, and reduced levels of physical activity.<sup>14-16</sup>

In the present study, participants assessed their motor functions (walking, eating, clothing, and hygiene), scoring them from 1 to 10 to indicate how much has changed in each situation compared with before the pandemic. All participants pointed out motor changes during distancing. Inactivity and sedentary lifestyle lead to musculoskeletal changes such as hypotrophy, for example. These physiological changes usually occur after a few weeks, but they can also be faster in older people or in patients with NMDs.<sup>16,17</sup>

The limitations resulting from the COVID-19 pandemic contributed to a significant change in the care of NMD patients due to the difficult access to medical and physical therapy treatments.<sup>6</sup> Therefore, it is important to highlight these unwanted consequences of social distancing to develop and provide practical and useful recommendations, since this can directly influence the quality of life of these patients.

In conclusion, the present study highlights the negative impact of distancing due to the COVID-19 pandemic and the changes in the therapeutic routine of patients with NMDs. A significant reduction in medical visits was reported by patients with NMDs. On the other hand, the present study has demonstrated that most participants underwent motor and/or respiratory physiotherapy in person or by telemonitoring.

Study participants also reported spending more time playing indoors, and all pointed out motor changes (walking, eating, clothing, and hygiene) during social distancing. Sedentary behavior can have negative health consequences for the entire population, especially for those with additional risk factors such as NMD.

Therefore, despite the current challenges, it is essential to maintain the treatment of NMD patients to prevent the progression of the disease, which can occur more quickly when not properly assisted, and thus, to maintain the quality of life of these patients.

We consider extremely important to continue these investigations to monitor the routine and new condition of the natural development of NMDs.

#### Authors' Contributions

All authors participated in the design, execution, and analysis of the paper, and all authors have reviewed and approved the present manuscript.

#### Conflict of Interest

The authors have no conflict of interests to declare.

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