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# A web-based questionnaire survey on the influence of coronavirus disease-19 on the care of patients with muscular dystrophy

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## Abstract

To clarify the influence of coronavirus disease-19 (COVID-19) on the care of muscular dystrophy patients, we performed a questionnaire survey that was posted on the internet on May 11, 2020. By the end of July 2020, 542 responses had been collected. Approximately 30% of patients postponed regular consultations, and one-quarter of patients who received consultation more than once a month used telephone consultations. Two of 84 patients with Duchenne muscular dystrophy had reduced their steroid doses. A shortage of ventilator accessories and infection protection equipment occurred following the onset of COVID-19, and this shortage had a serious impact on medical care and infection prevention measures. Reductions in rehabilitation and other services, and avoidance of outings, led to a decrease in exercise and an increase in caregiver burden. Inpatients were restricted from going out and visiting family members. More than 20% of patients reported physical or mental complaints; however, few required treatment. COVID-19 has seriously affected the activities and quality of life of patients with muscular dystrophy. We will continue this survey and analyze the longitudinal changes. © 2021 The Author(s). Published by Elsevier B.V.

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**Keywords:** Muscular dystrophy; Coronavirus disease-19; Respiratory care; Undersupply; Activities of daily living; Quality of life.

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## 1. Introduction

Since the beginning of 2020, coronavirus disease-19 (COVID-19), which is caused by severe acute respiratory syndrome coronavirus-2 (SARS-CoV-2), has become a worldwide pandemic. The pandemic has had a great impact on not only medical treatment, but also on society and the economy.

Patients with muscular dystrophy are at high risk of developing severe disease if they acquire COVID-19, and prevention is paramount. As a precaution against COVID-19, avoiding the so-called three-Cs, “closed space with poor ventilation,” “crowded places with many people nearby,” and “close conversation and vocalization at close range”, is important. However, in intractable neuromuscular diseases such as muscular dystrophy, many patients need assistance in their daily lives, and close contact with caregivers is unavoidable. For patients requiring medical care, the number of people required for support may be high, making a balance between infection control and daily life and medical care difficult. If infection prevention is prioritized too much by reducing daily care and services and limiting contact with others, the underlying disease is more likely to worsen, the care burden is likely to increase, and the patient’s quality of life will likely decrease.

The COVID-19 pandemic has had a significant impact on the procurement of medical devices and hygiene products. This shortage has had a severe impact on medical care and infection prevention measures. On the other hand, various public and private support services have been provided for these situations. The purpose of this study was to clarify how patients with muscular dystrophy are affected by the COVID-19 pandemic.

## 2. Materials and methods

The questionnaire was divided into a primary survey (Supplementary file 1) for all respondents and a secondary survey (Supplementary file 2) for patients and caregivers infected with COVID-19. The ethics board of the National Hospital Organization Toneyama Medical Center, which is a representative facility, approved this study (approval no. TNH-2,020,004). Consent was obtained by having participants check the consent questions in each survey. Because the infection status, infection control, and support for COVID-19 change over time, evaluating the longitudinal changes is important. Therefore, we allowed the same respondent to answer multiple times using a nickname. Results from the longitudinal study will be reported at a later time.

In the primary survey, we asked for background information (respondents/patients), impacts on medical care, home/facility services, daily life, personal and public support, health conditions, and infection with COVID-19 in both patients and caregivers. We also collected free answer comments (Supplementary file 1). The secondary survey investigated whether persons with COVID-19 were muscular dystrophy patients or caregivers, their age, the outcome of

Table 1  
Number of patients by walking ability and disease.

Disease	Ambulatory	Non-ambulatory
DMD	67	137
BMD/female dystrophinopathy	43	26
LGMD	10	9
CMD	9	31
DM	124	26
FSHD	20	8
Others	16	14

DMD: Duchenne muscular dystrophy, BMD: Becker muscular dystrophy, LGMD: Limb-Girdle muscular dystrophy, CMD: congenital muscular dystrophy, DM: Myotonic dystrophy, FSHD: facioscapulohumeral muscular dystrophy.

COVID-19, respiratory management treatment in the most severe cases, and drugs used (Supplementary file 2).

The subjects of this study were patients with muscular dystrophy and related diseases. In principle, surveys were answered on a website (<https://mdcst.jp/>), but mailing the completed survey was also possible. The study was announced on the research group’s website, patient registries (Remudy: Registry of muscular dystrophy), patient advocacy groups, and cooperating facilities. The survey started on 11 May 2020 and is still ongoing. In this paper, we analyzed the data obtained by 31 July 2020. For those who responded multiple times within this period, the initial registration data were used.

SPSS version 27 was used for statistical analysis, and the chi-squared test was used for comparisons between groups.

## 3. Results

### 3.1. Profiles of respondents

By the end of July 2020, 542 people from 45 of 47 Japanese prefectures had responded to the questionnaire. Table 1 shows the breakdown of 291 ambulatory patients and 251 non-ambulatory people by disease type. The respondents included 183 minors (under 20 years of age) and 359 adults. Regarding respiratory management, 377 patients did not require any mechanical ventilation, and 165 patients received mechanical ventilation. Regarding nutritional management, 441 patients consumed an ordinary diet, 64 patients consumed texture-modified food, 35 patients received tube feeding, and two patients did not answer the question. Regarding living conditions, 481 patients lived at home, and 61 did not (including 57 patients in long-term hospital/facilities).

### 3.2. Impact on medical care

Of the 481 responders resident at home, those with a high frequency of consultation for muscular dystrophy before the COVID-19 pandemic had a lower rate of maintaining conventional consultations (53.7%, 57.8%, 61.2%, 71.1%;  $p=0.175$ ) and a higher percentage of use of telephone consultations; the latter was statistically significant (25.0%, 15.2%, 2.4%, 2.2%;  $p < 0.001$ ). Around 30% of patients reduced hospital visits regardless of the frequency

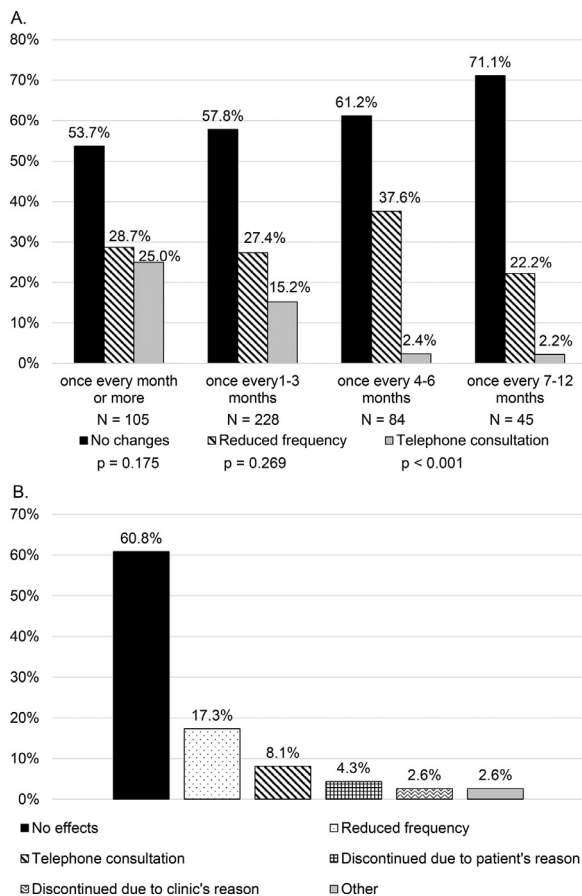


Fig. 1. Changes in medical consultations after the COVID-19 pandemic began. A. Medical consultation for muscular dystrophy. The subjects are 462 patients after excluding 19 of the total of 481 home residents who did not have regular consultation. Chi-squared tests were performed on the data of four groups. B. Visits to the doctor or house visits by the home doctor. The subjects are 348 patients, excluding inpatients and home residents without a home doctor.

of consultation (Fig. 1A). More than 60% maintained conventional care with home physician management, but some patients discontinued medical management by home physicians due to the patient’s (4.3%) or clinic’s (2.6%) reasons (Fig. 1B). Regarding treatment, of the 84 Duchenne muscular dystrophy patients taking steroids, two (2.4%) patients reported reducing their steroid dose. In addition, of the 147 patients taking myocardial protective medication, one patient halved the dosage and doubled the hospital visit interval because he was so afraid to be infected by visiting a hospital.

Of the 165 people receiving mechanical ventilation, 147 (89.1%) responded that “there was no influence on respiratory management.” However, 24 (14.5%) respondents answered that “there was a problem in obtaining ventilator-related items.” Four (2.4%) patients were compelled to change the ventilation mask or tracheal cannula. Five (3.0%) people could not receive a regular check of the respirator as planned. In addition, seven (4.2%) respondents answered that “We changed the ventilation of the patient’s room” (Supplementary Table 1).

Of the 79 patients using a mechanical cough assist device, 72 (91.1%) patients responded that they were “implementing the same method and frequency as before.” Seven (8.9%) patients changed the infection prevention method, and three (3.8%) patients changed the ventilation method. One (1.3%) patient discontinued the use of a cough assist device (Supplementary Table 2). Regarding sputum drainage and suction treatment, excluding the patients who responded “no need for sputum drainage and suction treatment,” 90 of 107 (84.1%) patients answered, “We kept the same method and frequency as before.” However, 12 (11.2%) patients changed the infection prevention method, and three (2.8%) patients restricted the number of caregivers who implement it (Supplementary Table 3).

Regarding respiratory physiotherapy, excluding the patients who responded “not receiving respiratory physiotherapy,” 99 of 168 (58.9%) patients answered “implementing the same method and frequency as before.” Twenty-eight (16.7%) patients reduced the frequency of implementation, and 30 (17.9%) patients discontinued respiratory physiotherapy by the therapist. In addition, 13 (7.7%) patients changed the infection prevention method (Supplementary Table 4). The reduction/discontinuation rate was higher in patients without a mechanical ventilator than in those requiring mechanical ventilation (37.9% vs 32.4%;  $p = 0.350$ ) (Fig. 2A). Regarding rehabilitation other than respiratory physiotherapy, excluding the patients who responded “not receiving rehabilitation,” 174 of 337 (51.6%) patients reported “implementing the same method and frequency as before.” Seventy-two (21.4%) patients reduced the frequency, and 77 (22.8%) patients stopped rehabilitation by the therapist. Thirty (8.9%) patients changed the infection prevention method (Supplementary Table 5). Reduction/discontinuation accounted for the majority of ambulatory patients (58.0% vs 35.3%;  $p < 0.001$ ) (Fig. 2B).

Regarding nutritional management, of 99 patients who consumed texture-modified food or received tube feeding, 93 (93.9%) patients reported “implementing the same content, method, and frequency as before,” but three (3.0%) patients changed the infection prevention method. Four (4.0%) patients restricted their caregivers, and two (2.0%) patients answered, “We sometimes couldn’t get the necessary food and nutrition” (Supplementary Table 6).

Regarding the securing of requisite materials for medical care, less than 60% of the 481 home residents were able to secure the items as usual except for diapers. In particular, despite the high usage rates of masks and disinfectants/cleaning agents, less than 40% could secure them as usual (Table 2).

### 3.3. Impact on service usage

The utilization rate of home visit services was high in patients with respiratory management, and the utilization rates of home visit nursing, home visit rehabilitation, and helpers were greater than 50%. Regarding outpatient services, daycare and short-term admissions were high in those requiring

Table 2  
Procurement of medical and daily care necessities.

	Masks	Gloves	Gowns	Eye guards	Disinfectants	Diapers
No. of users	375	93	20	21	168	74
Percent	78.0%	19.3%	4.2%	4.4%	34.9%	15.4%
Procurement with no problem	134	40	10	12	51	60
Procured the required quantity somehow	170	33	5	4	75	9
Not procured the required quantity and have managed to make ends meet	65	17	4	4	35	3
Major obstacle to medical and/or daily care due to a shortage of necessities	6	3	1	1	7	3

The number of users is the sum of the responders from “No problem” to “Severe obstacle.”.

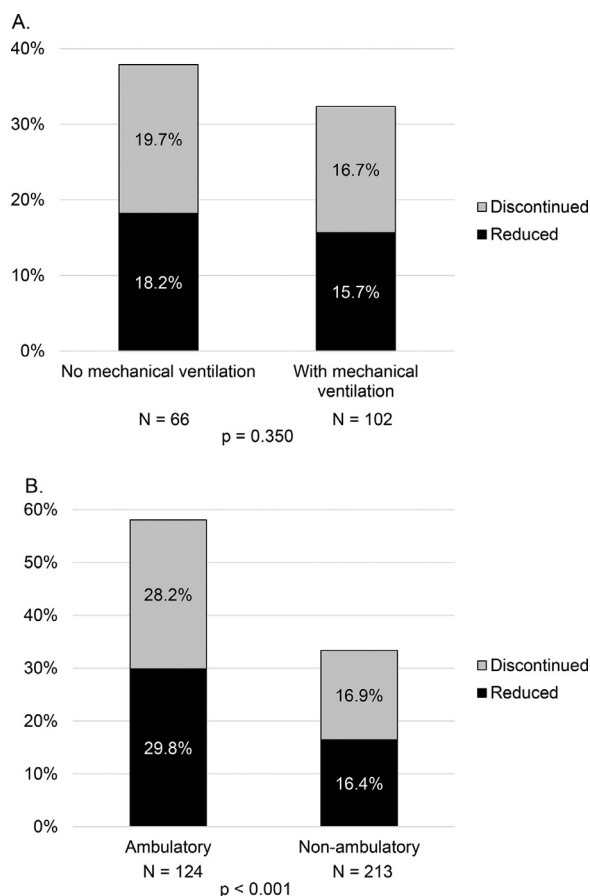


Fig. 2. Comparison of impacts on respiratory physiotherapy and rehabilitation according to the stage of illness. A. Comparison of the proportion of patients who reduced or discontinued respiratory physiotherapy according to breathing conditions. B. Comparison of the proportion of patients who reduced or discontinued rehabilitation other than respiratory physiotherapy according to walking ability. Chi-squared tests were performed on the total number of reductions and discontinuations.

respiratory management, but little difference was found in outpatient rehabilitation (Fig. 3). More than 60% of the home visit services were “no changes,” but the rate of reduced/discontinued due to the patient’s reasons was higher than the rate of reduced/discontinued due to the facility’s reasons. Outpatient services were unchanged in less than one-third of patients and were often changed or discontinued

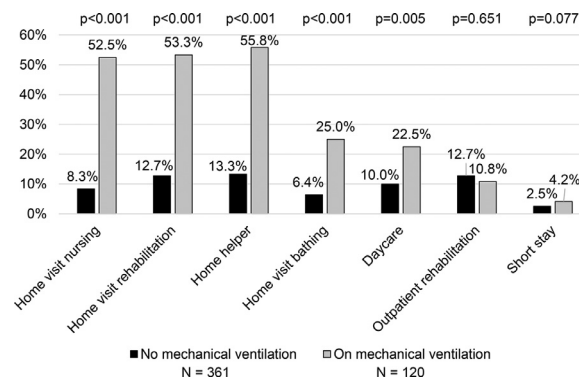


Fig. 3. Comparison of service usage according to breathing condition. Before the COVID-19 pandemic, patients on mechanical ventilation show a higher utilization rate of home visit and outpatient services than those not on mechanical ventilation, except for outpatient rehabilitation. In particular, home visit nursing, home visit rehabilitation, and helper use account for more than half. Chi-squared test was performed on the data of 2 groups.

for the facility’s reasons rather than the patient’s reasons (Table 3).

Regarding hospitalization/facility services, of the 57 inpatients, 50 (87.7%) were restricted regarding visits and going out. Thirteen (22.8%) patients had some changes in daily care. Only 15 (26.3%) patients were able to receive the same services as before.

### 3.4. Impacts on daily life

Regarding impacts on daily life, the percentage of home residents reporting impact was higher for all items, and more than 90% answered that they were refraining from going out or traveling (95.0% vs 70.5%; p < 0.001). “There was a change in schoolwork and employment” was reported by more than 70% of minors. “Decrease in physical activity” was reported by more than 50% of ambulatory patients (54.0% vs 32.7%; p < 0.001), and “increase in care burden” was more common among non-ambulatory patients (7.6% vs 29.9%; p < 0.001) (Fig. 4).

3.5. Impacts on health condition

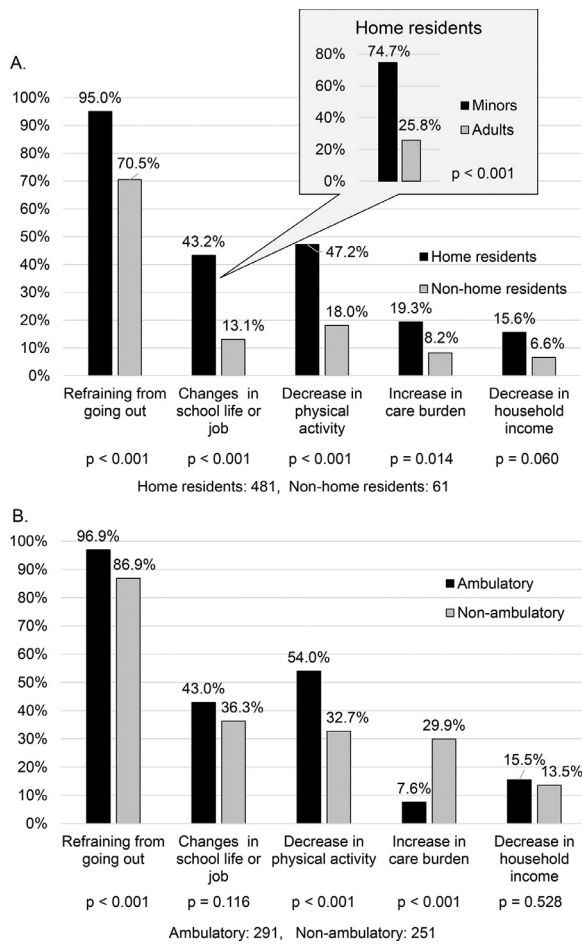


Fig. 4. Impact of the COVID-19 pandemic on daily life. A. Comparison according to living style (Box in the inset indicates the impacts on school life or job in outpatients who are minors or adults). B. Comparison according to walking ability. Chi-squared test was performed on the data of 2 groups.

Regarding the health condition, 415 people reported, “We have maintained the same physical condition as before the COVID-19 pandemic.” We observed a tendency for physical complaints to be high in in-home residents and non-mechanical ventilation users (21.0% vs 11.4%;  $p=0.112$ , 21.4% vs 16.3%;  $p=0.300$ , respectively). Many of them reported reduced strength and weight gain due to avoidance of outings and service usage. Some respondents said that the decrease in posture adjustment due to reduced service use caused exacerbation of pain and skin problems. Mental distress was high in patients with ventilators and non-home residents (18.9% vs 34.8%;  $p=0.002$ , 17.8% vs 27.9%;  $p=0.005$ , respectively). Patients also reported anxiety about infection, stress/irritability, lack of sleep, etc. in the free answer comments (Fig. 5). Most of the complaints were at non-treatment levels, but six hospitalizations for physical disorders and four for pneumonia were reported.

According to the responses, three caregivers and one patient had acquired COVID-19, and one caregiver between 70 and 80 years of age died. However, we were unable to confirm the existence of muscular dystrophy patients with COVID-19 in the reported prefecture of residence.

3.6. Public and private support (financial and non-financial)

Regarding support, 393 respondents answered, “We have not received any financial or non-financial support” (Supplementary Table 7). The rate of “no support” was lower in June (62.7%) and July (66.0%) when the flat-rate benefit for all citizens became more widespread than in May (77.7%). Regarding non-financial support, provision of care products such as masks, disinfectants, and water for humidifiers, shopping support, and food support were reported in the free answer comments.

Table 3  
Impacts on service usage.

	No. of users(percent)	No changes	Reduced or discontinued due to patient’s reason	Reduced or discontinued due to provider’s reason	Newly introduced
Home visiting service					
Home visit, nursing	96 (20.0%)	70	16	7	3
Home visit, rehabilitation	112 (23.3%)	84	22	4	2
Home helper	117 (24.3%)	71	31	13	2
Home visit, bathing	55 (11.4%)	36	13	4	2
Daycare service					
Daycare	66 (13.7%)	20	28	15	3
Outpatient rehabilitation	56 (11.6%)	14	17	22	3
Short stay	15 (3.1%)	5	3	6	1

The number of users is the sum of the responders from “No changes” to “Newly introduced”.

### 3.7. Free answer comments

Various answers were reported in the free answer comments. Examples were fear of getting COVID-19, anxiety about how to respond when a patient or caregiver became infected or came into close contact, anxiety about using services, concern about infection risk due to medical consultation, concern about infection risk due to steroids, concerns about healthcare collapse, lack of useful information for these patients, mental stress, difficulty in obtaining items needed for medical care and daily life, hope for widespread online consultation, expectations for the development of vaccines and treatment methods, and enhancement of the testing system.

## 4. Discussion

The first case of COVID-19 in Japan (a resident returning from Wuhan) was reported on 16 January 2020, and the number of patients increased in March, with the first wave peaking in mid-April. The number of cases subsided in May but began to increase again in late June, with the second wave peaking in early August. As a social countermeasure, schools were closed on 2 March 2020. A state of emergency was declared on 7 April 2020 (Supplementary Figure). We tried to start the survey as early as possible, but we required time to finalize the questionnaires and obtain ethics approval. We were finally able to start the survey at the end of the first wave of the pandemic. At that time, due to the global pandemic, a continuing shortage of masks and disinfectants was prevalent, and securing personal protection equipment and mechanical ventilator-associated items at hospitals was not easy. In the beginning, public support was provided mainly to businesses, such as leave allowance and business continuity benefits. In contrast, the special flat-rate benefit (100,000 Japanese yen (approximately 950 US\$)/person) for all citizens was paid from June to July.

As a result of publicity activities with the cooperation of patient registries (Remudy) and advocacy groups, we were able to obtain more than 500 responses from all over Japan in a short period of time. The survey revealed that patients with muscular dystrophy are affected by COVID-19 in various ways.

In terms of medical care, the percentage of patients who continued to see their doctor as before decreased among patients who were seen more frequently. Among these patients, the number of patients who received a telephone consultation increased. In the free answer comments, patients were concerned about contracting COVID-19 through visits to hospitals, and a desire for remote medical consultation was reported. Medical institutions implemented strict infection control measures. The risk of infection from medical consultations is considered low; however, considering the difficulty with transfer of the patient and the risks associated with the transfer, the combination of remote and in-person medical consultation may be an issue for the future. A

small number of patients had reduced their steroid and cardioprotective drugs. In principle, the treatment of muscular dystrophy should be continued even during the COVID-19 pandemic [1–3]. Information should be provided to prevent excessive concern about infection affecting the treatment of the primary disease.

For respiratory care, a surge in demand for respiratory treatment due to the COVID-19 pandemic, which increased the number of patients requiring ventilatory management, combined with undersupply due to reduced production capacity and difficulties in securing transportation, had a significant impact [4]. Changes to non-invasive ventilation masks and tracheal cannulae due to procurement disruptions directly impacted respiratory management. The inability to perform inspections on schedule posed a safety management problem. There were severe difficulties in obtaining masks, disinfectants, and cleaning agents for care products related to infection control. These procurement problems have improved over time but continue to persist. Non-invasive ventilation, cough assist, and suction pose a risk for aerosol production, and thus, better ventilation and infection control methods need to be devised [1–8]. In this survey, a few patients changed infection control methods and ventilation in terms of the usage of mechanical ventilation, cough assist device, and respiratory physiotherapy, indicating a high level of awareness of this issue. Nutritional management was less severely affected by COVID-19 than respiratory care, partly because nutrition requirements are less severely impacted by COVID-19.

The strong desire to avoid contact with others as much as possible to prevent infection affected various aspects of rehabilitation, service use, and lifestyle. Patients with mild disease stages reduced or discontinued respiratory physiotherapy and other forms of rehabilitation more frequently than advanced cases. Even if this was unavoidable in the short term, concerns persisted about the impact of prolonged periods on motor function maintenance and prevention of secondary disorders. Regarding the use of visiting services, which were frequently used in advanced cases, the continuation rate was high. Still, the rate of change or discontinuation of services for patients' reasons was high. The rate of continuation of daycare services was low, and the rate of change or discontinuation of services was high for institutional reasons. This may be due to infection control issues in transportation and limiting the number of users to avoid the three Cs. More than 80% of the inpatients had restrictions on visiting and going out of the hospital. Some patients were reluctant to be admitted to the hospital because of restrictions on escorting and visiting family members and helpers at the time of admission. Some concerns about stopping the use of services and medical checks were that the burden of care would increase and that patients would be less likely to notice changes in their physical condition. More than 90% of home residents said they refrained from going out and traveling. In addition, more than 70% of minor patients reported that their schoolwork was

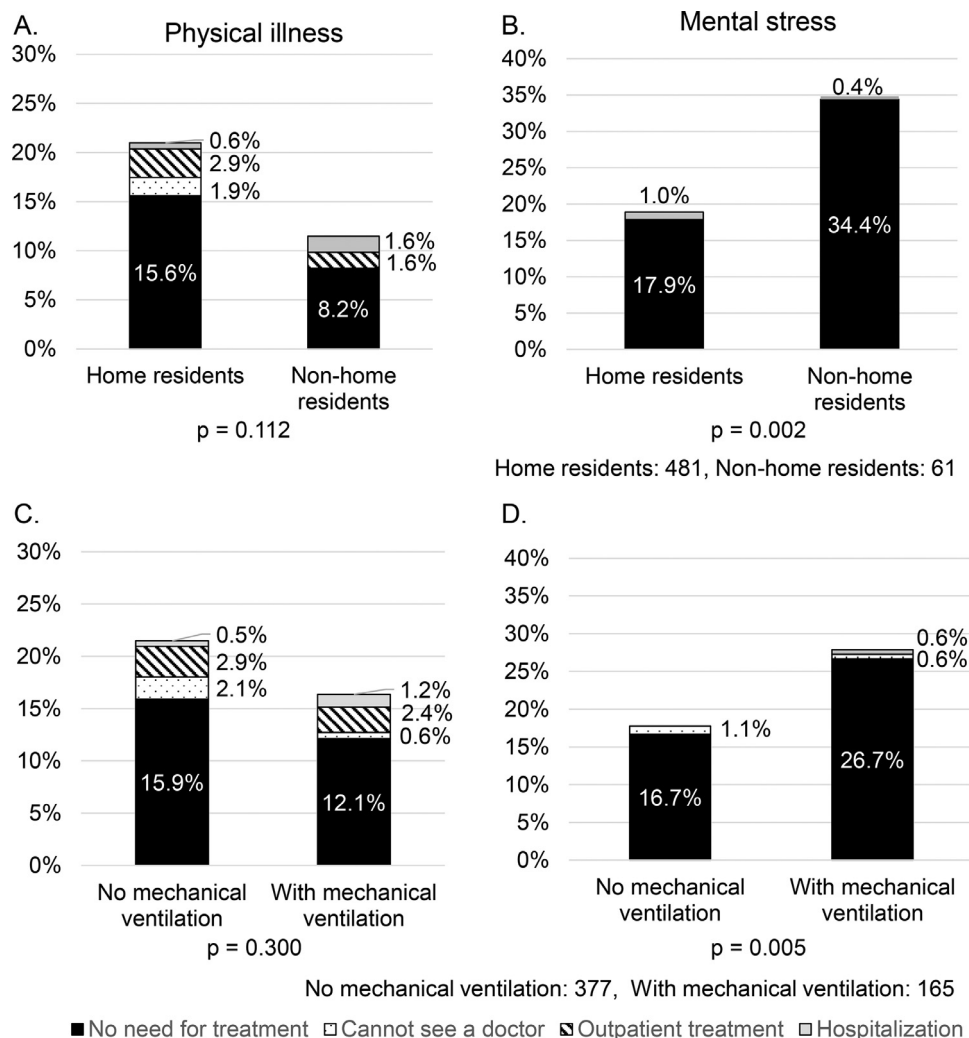


Fig. 5. Impacts of the COVID-19 pandemic on the health condition. A. Comparison of physical illness rates according to the living condition. B. Comparison of mental stress rates according to the living condition. C. Comparison of physical illness rates according to the breathing condition. D. Comparison of mental stress rates according to the breathing condition. Chi-squared tests were performed on the total number of patients who reported physical illness and mental stress.

affected due to school cancellation measures. These factors caused reduced motor function and increased stress and irritability.

Regarding health conditions, a higher percentage of patients in mild disease stages complained of decreased physical activity and physical discomfort. Complaints of mental health were more common among the advanced and non-home residents, reflecting concerns about the risk of aggravation of COVID-19 and stress due to restricted visiting. Most were at a level that did not require treatment, but six people were hospitalized for physical illness during the study period. Four of these patients had pneumonia. In addition, three caregivers and one patient reported having acquired COVID-19 disease, although we could not confirm this. When a patient with muscular dystrophy is suspected of having a fever and respiratory infection, an appropriate response at the medical facility will need to be devised. The ideal method of consultation will vary depending on the prevalence of COVID-19, but consulting with a health

care provider regarding consultation methods is always advisable.

This survey has several limitations. Because this survey was a web-based anonymous study, we cannot verify the correctness of the data. In particular, the credibility of the information on COVID-19 incidence is unknown. Because of the time required for questionnaire preparation and ethics review, the survey could not start until mid-May, after the peak of the first wave of infection in Japan. In terms of support, even in July, when the government’s distribution of special flat-rate benefits and masks was widespread, 66% of respondents said they had received no support. This suggests that support for the entire population may not have been perceived as support for muscular dystrophy. Despite these limitations, we believe that the fact that we could collect and analyze opinions directly from the patients is significant.

Many concerns exist about COVID-19. Because SARS-CoV-2 is a new type of virus, preventing the spread of the disease is difficult. Patients with muscular dystrophy



have the potential to become severely ill when they contract COVID-19. For this reason, most patients took measures to avoid contact with people as much as possible. As a result, many patients experienced a lack of exercise, worsened motor impairment, increased care burden, and increased mental stress. In a small number of cases, what appeared to be excessive measures were also taken, such as reducing or stopping medication, including steroids and cardioprotective drugs. The global pandemic's impact also caused severe disruptions in procurement, particularly of care products related to mechanical ventilation and infection protection. Unless an effective vaccine and treatment are developed, the COVID-19 pandemic is unlikely to be brought to an end in the short term. Maintaining a response in the early stages of the pandemic that places the highest priority on infection prevention for a long time will greatly impact the primary disease and quality of life. Establishing a proper response in the “with corona” era that balances infection control with daily life and medical care is necessary. To achieve this, enhancement of the testing system for COVID-19 is essential.

## 5. Conclusions

This survey revealed that patients with muscular dystrophy are affected by the COVID-19 pandemic in many ways, including their medical management, daily care, service use, lifestyle, and health conditions. This study will continue to analyze the impact of the COVID-19 pandemic and the effectiveness of support.

## Declaration of Competing Interest

The authors report no conflicts of interest regarding this study.

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## Supplementary materials

Supplementary material associated with this article can be found, in the online version, at doi:[10.1016/j.nmd.2021.04.008](https://doi.org/10.1016/j.nmd.2021.04.008).

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