

# Experience with telemedicine in neuromuscular clinic during COVID-19 pandemic

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**Objectives.** The aim of the present study was to evaluate the feasibility and acceptability of telehealth for the care of neuromuscular patients during the COVID-19 pandemic.

**Methods.** Neuromuscular patients or their caregivers, as well as health care providers (HCPs), who completed a televisit during the pandemic received an online survey, assessing satisfaction with the visit, quality of care, and experience with the televisit interference.

**Results.** Surveys from 46 neuromuscular patients (including 18 with motor neuron disease [MND])/caregivers and 7 HCPs were completed. Several aspects of televisits including good communication, adequate time to discuss concern, provision of equal care, and telemedicine interference were rated favorably among participants. Telehealth was strongly satisfactory in 30 (65.22%) and satisfactory in 15 (32.61%) neuromuscular patients/caregivers. In 18 MND patients, this was 10 (55.56%) and 7 (38.89%), respectively. Moreover, 24 (52.17%) neuromuscular patients/caregivers would strongly agree and 18 (39.13%) would agree to participate again in televisits. This was 10 (55.56%) and 4 (33.33%) for MND cases, respectively. Various medical issues were addressed during the televisits including medication management, ordering tests/referrals, discussion of goals of care, and research. The predictive stepwise logistic model found younger age as a predicting factor for higher satisfaction from, or participation again in, televisits in neuromuscular patients. Limb onset location was also a predicting factor for strong satisfaction from televisits in MND cases.

**Conclusions.** Telemedicine is feasible and highly effective at achieving personalized care that was rated satisfactory by the majority of neuromuscular patients/caregivers and HCPs during the COVID-19 pandemic.

**Key words:** telemedicine, televisit, neuromuscular clinic, amyotrophic lateral sclerosis (ALS), motor neuron disease (MND), COVID-19

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## Introduction

A worldwide unprecedented change in clinical care delivery has rapidly occurred since corona virus 2019 (COVID-19) pandemic. The volume of elective or nonurgent outpatient care was markedly decreased during the pandemic, mainly to limit exposure to patients and medical staff to COVID-19 infection. The American Academy of Neuromuscular and Electrodiagnostic Medicine (AANEM) published guidance regarding clinical visits, electrodiagnostic studies, and telemedicine during COVID-19 pandemic<sup>1</sup>. Accordingly, many institutions in the United States (US) have adopted systems to allocate many scheduled outpatients to telemedicine encounters or to delay the procedures if medically appropriate. Prior to the COVID-19 pandemic, implementation of telehealth services in neurology, and particularly in neuromuscular medicine, was limited<sup>2</sup>. This has been mainly due to the necessity of detailed neurologic examination in in-person neuromuscular encounters. Amyotrophic lateral sclerosis (ALS) clinics in few US institutions have already established telehealth services for patients with ALS and other motor neuron diseases (MNDs) prior to the COVID-19 pandemic<sup>3</sup>. Notably, within a few-week time period, many medical institutions in the US robustly implemented telemedicine in this pandemic era with less consideration of prior regulatory limitations<sup>4</sup>. With inevitable need to transition to telehealth service for most outpatient encounters, neurologists have been quickly discovering the strength and limitations of telemedicine in which new tools and skills are required<sup>5</sup>. Importantly, studies

on outcomes and resource utilization as well as patient and provider satisfaction with virtual visits seem necessary to inform what portions of this emergency telemedicine will endure beyond COVID-19.

There is currently limited data whether telehealth care leads to similar or better outcomes for neuromuscular patients and their caregivers compared with in-person care. This is an important consideration, as access to multidisciplinary neuromuscular clinics, especially for ALS patients, may be problematic because of long distance from the nearest clinic, cost of travel to the clinic, and most importantly, physical limitations<sup>6</sup>. Telemedicine has been tried in the care of ALS patients over the last few years prior to the COVID-19 pandemic, although the adoption of telemedicine to supplement multidisciplinary ALS care is only beginning to emerge<sup>7,8</sup>. Retrospective studies have shown the cost effectiveness of this approach compared to in-person clinics from both patient and institutional perspectives<sup>9</sup>.

In the present study, we conducted an online survey study on neuromuscular patients receiving telehealth visits as well as the related health care providers (HCPs) at the UMass Chan Medical School during the COVID-19 pandemic as part of their medical care to determine whether these visits are technically feasible and provide equivalent or improved satisfaction among patients, caregivers, and health care professionals. We also investigated the patients' demographic, disease characteristics, as well as frequency of addressed issues in televisits to explore potential factors that predict the higher levels of participations in and satisfaction from televisits.

## Methods

The use of human subjects as well as all study procedures for this clinical study were approved by the institutional review board at the UMass Chan Medical School (IRB# H00020488, date of approval: 06/26/2020).

### Participants

All study subjects were patients receiving care at the UMass Memorial Medical Center between July 2020 and January 2022. The inclusion criteria were: (i) adult patients (age  $\geq 18$  years, including pregnant women) who had televisits appointment for neuromuscular disease in either the neuromuscular or multidisciplinary ALS clinic at UMass Memorial Medical Center, (ii) available cell phone with application or other computer/laptop/iPad devices with hardware/internet connection to support either phone call or video conferencing during the televisits, (iii) ability and willingness of patients to provide informed online consent or have a legally authorized representative (LAR) who was able and willing to do so, and (iv) ability to communicate sufficiently to ensure completion of the evaluation. The exclusion criteria for online survey were: (i) patients or their caregivers not interested to participate or unavailable for televisits, and (ii) patients who spoke languages other than English, as the online survey was only provided in English language and not any other languages.

### Study method

During their neuromuscular telehealth visit, the patients or their LAR were informed about the survey on their telemedicine visit. If they

were interested in the participation, the link for survey which included online consent was sent to the patient or their caregiver who participated in the visit by an email or text message from the telehealth software/application used (*i.e.*, Zoom<sup>®</sup> health or Doximity<sup>®</sup> application). After approval of patients or their LAR through signing online consent, then the patients (or their caregivers) were able to fill out the online survey regarding their experience with and satisfaction from the telehealth encounter within one week. The HCP for the televisit had also access to a link for a similar online survey. Participating HCPs were members of the neuromuscular or multidisciplinary ALS clinical team who were willing to fill out the online survey. These surveys were delivered via email and were securely transmitted and stored using REDCap (Research Electronic Data Capture), a data capture for research studies<sup>10</sup>. Additional variables were collected, including patients' age, gender, education level, race (white or not), home distance from clinic (calculated by entering the patient's home address and zip code into Google Maps [<https://www.google.com/maps>]), ambulatory status, use of supportive equipment or sources at home (*i.e.*, non-invasive ventilation, gastrostomy tube, tracheostomy, and home hospice), type of neuromuscular disease, clinical issues addressed during televisits, as well as frequency of actions taken in follow-up to items discussed during televisits. Information about televisits including type of encounter (new versus follow-up visit), frequency of disconnections during televisit, televisit duration, type of televisit (phone call only versus video call visit) and type of software used for video calls (Zoom<sup>®</sup> health, Doximity<sup>®</sup>, or others) were also collected. In patients with MNDs, additional data including type of MNDs (ALS, progressive muscular atrophy [PMA], or primary lateral sclerosis [PLS]), disease duration (months), disease onset location, genetic testing status and results of performed genetic testing, time from previous in-person visit (weeks), as well as ALS Functional Rating Scale Revised (ALSF<sub>RS</sub>-R) and forced vital capacity (FVC) in the current and previous visit if available.

### Online surveys

The survey for both patients (or their caregivers) and HCPs had 2 parts (Appendix, supplementary material online):

- (i) **Quantitative Part.** It consisted of 9 questions with a five to five-point Likert-type scale (from strongly disagree to strongly agree with a neutral middle option). These consisted of 6 questions about telemedicine encounter and 3 questions about the experience with the telehealth software, with an additional question about number of disconnections during the televisit.
- (ii) **Qualitative Part.** It included open-labeled questions about what patients, caregivers, or HCPs like, dislike, and would change about the telemedicine visit.

### Statistical analysis

Continuous variables were reported as mean  $\pm$  S.D. or median (25th-75th quartile). Categorical variables were reported as proportions. Normality of data was examined using the Shapiro-Wilk test. A non-parametric Kruskal-Wallis test was used to compare survey responses in the quantitative part across responder groups. Bonferroni correction was used to compensate for multiple comparisons. Multivariate logistic regression was used for predictor of higher level

of satisfaction or participation again in the televisits. For the qualitative part of online survey, participant responses were overall reviewed separately by two authors (M.G. and K.M.D.) and categorized based on similarities. Individual responses in the same category expressed over multiple sessions were considered one response. The SAS® On-Demand for Academics software as well as GraphPad Prism (Version 6.07) were used for statistical analysis and preparation of figures. A  $P$  value  $< 0.05$  was considered significant.

## Results

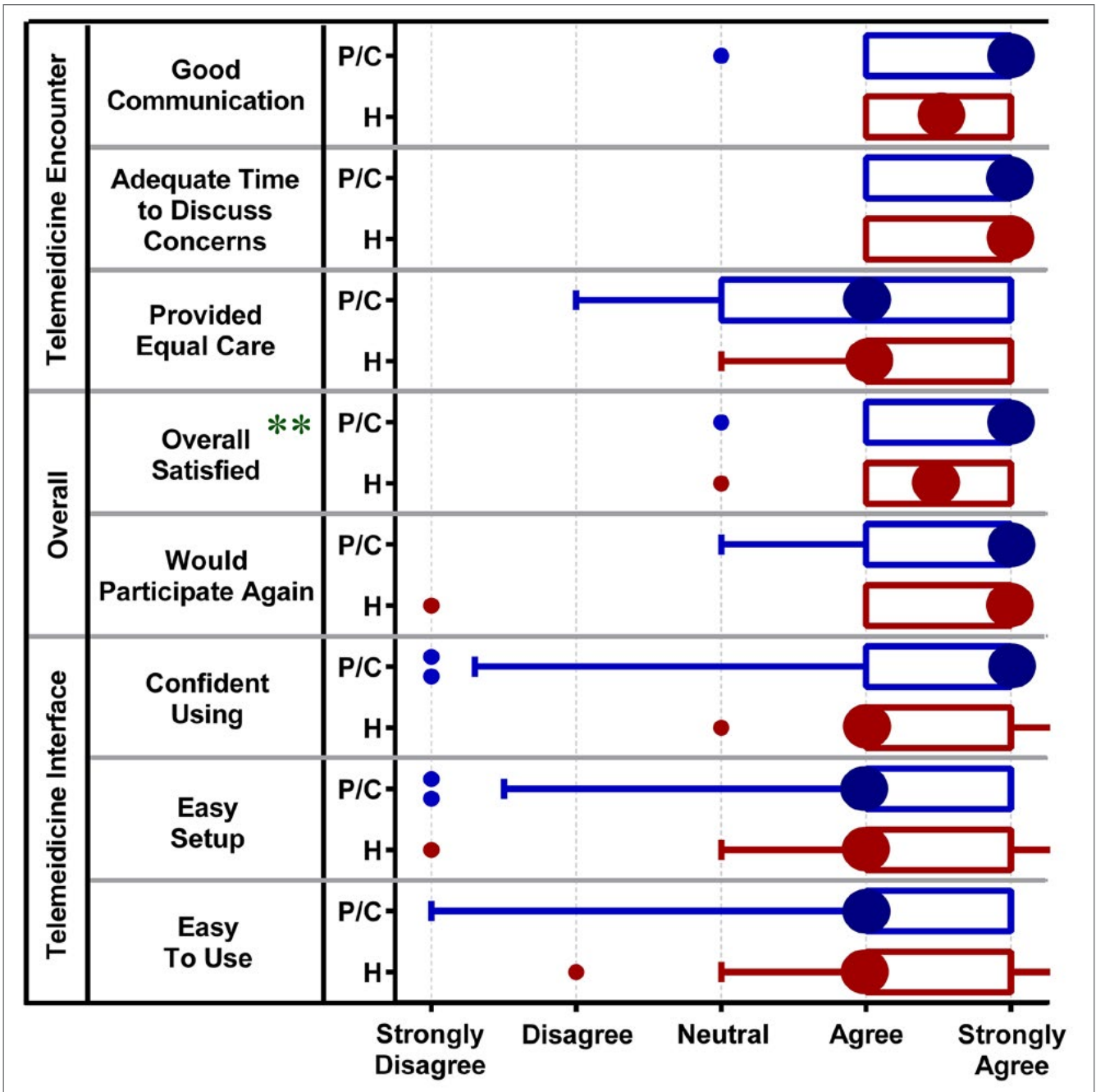
Out of 84 patients with neuromuscular diseases who received the online survey, 46 patients or caregivers (54.76%) completed the telehealth visits online survey. Moreover, seven HCPs participated in the online surveys for these 46 encounters which included 6 neuromuscular subspecialists and one nurse practitioner working in the ALS/Neuromuscular clinic. As shown in Table I, the mean age of patients was 60.91 years, and 27 patients (58.70%) were female. Forty three (97.73%) patients were white; and 14 (30.43%) and 12 (26.09) had college graduate and postgraduate education, respectively. Thirty (65.22%) patients were ambulatory without any assistance and 7 (15.22%) were using a supportive equipment including non-invasive ventilation or gastrostomy tube. The average home distance to the neuromuscular/ALS clinic was 34 miles. Overall, 18 (39.13%) patients had confirmed MND diagnosis, among which 16 patients had ALS, one with PLS, and one with PMA. Four (8.7%) televisits were new visits and all 46 (100%) televisits were as the whole visit without being as part of an in-person visit. In 17 televisits (36.96%), caregivers or families were present, and 41 (89.13%) televisits were video calls. The mean duration of televisits were 30.98 minutes. Forty (86.96%) televisits had no disconnections during the encounter.

The online survey final analysis on total 46 neuromuscular patients/caregivers and the related HCPs for these visits are shown in Figure 1. Telehealth was highly effective at achieving convenient and personalized care that overall was rated favorably and satisfactory by neuromuscular patients/caregivers and HCPs. Thirty (65.22%) patients/caregivers were strongly satisfied, and 15 (32.61%) were satisfied from televisits. Additionally, 24 (52.17%) patients/caregivers would strongly agree and 18 (39.13%) would agree with participation again in the future televisit encounters. For questions regarding telemedicine encounter (*i.e.*, communication perceptions, adequate time to discuss concerns, and equal care in quality compared to in-person visit) as well as telemedicine interference (*i.e.*, confidence in using, and easy setup and use of the system), there were no significant differences in mean responder ranks between patient/caregiver and HCP responders within each category. The mean ranks of the responses from all groups were different between the 9 questions ( $P < 0.001$ ). Post-hoc analysis revealed that patient/caregiver responder's overall satisfaction was significantly ( $P < 0.01$ ) higher than all other responses related to the televisit encounter, but not the telemedicine interference (Fig. 1).

Open-ended responses from all neuromuscular patients/caregiver and HCPs to questions to what they like, dislike, change in televisits are categorized in Tables SI and SII (the original responses are shown in Table SI). Overall, nineteen patients/caregivers and 5 HCPs

**Table I.** Demographics of neuromuscular patients and their televisit information.

Variables	Measures
<b>Patients Information</b>	
Age (mean $\pm$ S.D.)	60.91 $\pm$ 13.37
Gender (female, %)	27 (58.70)
Education level (N, %)	
High school	10 (21.74)
Some college	10 (21.74)
College graduate	14 (30.43)
Postgraduate	12 (26.09)
Race (white, %)	43 (97.73)
Home distance to clinic, miles (mean $\pm$ S.D.)	34 $\pm$ 27.05
Mobility level (N, %)	
Ambulatory without assistance	30 (65.22)
Ambulatory with assistance	14 (30.43)
Non-ambulatory (Wheelchair bound)	2 (4.35)
Supportive equipment or resources	
Non-invasive ventilation	3 (6.52)
Gastrostomy tube	4 (8.70)
Tracheostomy	0 (0)
Home hospice	0 (0)
Type of neuromuscular disease (N, %)	
Motor neuron disease (MND)	18 (39.13)
Peripheral neuropathy (acquired or hereditary)	12 (26.09)
Spinal cord disease/radiculopathy	9 (19.57)
Neuromuscular junction disorder	8 (17.39)
Muscular dystrophy or congenital myopathy	4 (8.70)
Myopathy	3 (6.52)
Myotonia (dystrophic or non-dystrophic) or periodic paralysis	0 (0)
Unspecified	2 (4.35)
<b>Televisit Information</b>	
Type of encounter (N, %)	
New Visit	4 (8.7)
Follow up visit	42 (91.3)
Televisit as (N, %)	
Whole visit	46 (100)
Part of an in-person visit	0 (0)
Number of televisits in which family/caregiver(s) present (N, %)	17 (36.96)
Type of televisits (N, %)	
Phone call	5 (10.87)
Video call	41 (89.13)
Software used for video televisits	
Doximity	9 (20.93)
Zoom health	32 (74.42)
Others	2 (4.65)
Duration of televisits, min (mean $\pm$ S.D.)	30.98 $\pm$ 10.36
Number of televisits with disconnections during encounter (N, %)	
0 (no disconnection)	40 (86.96)
1	3 (6.52)
2	2 (4.36)
3	1 (2.17)



**Figure 1.** Ratings of the telemedicine service by patients (P), caregivers (C), and HCPs (H) in all 35 televisit encounters. The median is marked by a large circle. Rectangles range from the first quartile (Q1) to the third quartile (Q3) of data. Thin lines extend to the furthest data point within 1.5 x (Q3-Q1) of Q1 or Q3. Individual markers outside this range are outliers. \*\* Indicates questions where the overall mean rank rating was different than others in telemedicine encounter category ( $P < 0.01$ ).

liked televisits as they are convenient. The major dislike from both patients/caregivers and HCPs were limitation in physical examination. Overall, patients/caregivers proposed no changes in the current televisits, and few mentioned no phone call only visits. The HCPs also suggested improvements in connection & waiting time for connection to video calls (Tab. SII).

Aspects of care addressed or discussed in televisits as well as medical action during or immediately following these visits in neuromus-

cular patients are demonstrated in Table SIII. The most addressed issues in televisits were medication management (73.91%), as well as discussion about ordering tests or referrals (47.83%), results of tests (47.83%), goals of care (30.43%), and research (26.09%). Acute health issues and home care team were less frequently discussed during these encounters. The most common medical action during or immediately following a televisit with neuromuscular patients was at least one medication adjustment/prescription (63.04%) followed

**Table II.** Demographics and televisit information based on overall satisfaction ranking in all neuromuscular patients (total 46).

Variables	Overall Satisfaction from Televisits			P Value
	Neutral (1)	Agree (15)	Strongly Agree (30)	
Age, years (mean ± S.D.)	55	67.40 ± 10.09	57.87 ± 13.98	0.313
Gender (female, %)	0 (0)	7 (46.67)	20 (66.67)	0.212
Education level (N, %)				0.486
High school	0 (0)	5 (33.33)	5 (16.67)	
Some college	0 (0)	4 (26.67)	6 (20)	
College graduate	0 (0)	3 (20)	11 (36.67)	
Postgraduate	1 (100)	3 (20)	18 (26.67)	
Race (white, %)	1 (100)	14 (93.33)	28 (93.33)	0.767
Home distance to clinic, miles (mean ± S.D.)	73.8	28.33 ± 26.93	35.5 ± 26.69	0.237
Type of neuromuscular disease, MND	1 (100)	7 (46.67)	10 (33.33)	0.311
Need any assistance/equipment at home (N, %): <i>e.g.</i> , for ambulation, non-invasive ventilation, gastrostomy tube, tracheostomy, home hospice	1 (100)	6 (40)	10 (33.33)	0.380
Visit duration, min (mean ± S.D.)	40	34 ± 9.10	29.17 ± 10.75	0.115
Televisit type				0.887
Video	1 (100)	13 (86.67)	27 (90)	
Phone	0 (0)	2 (13.33)	3 (10)	

by ordering tests/referrals (52.17%), home care team management (15.22%), new equipment prescription (8.70%) or other managements (8.70%) including physical/occupational therapy, assisted devices, and nutrition (Tab. SIII).

To find out possible factors that are associated with highest level of overall satisfaction from televisits with neuromuscular patients, we first presented these demographics and televisit data based on overall satisfaction ranking in all 46 neuromuscular patients which is depicted in Table II. Individual univariate analysis for each factor (*i.e.*, age, gender, education, race, home distance to clinic, type of neuromuscular disease [MND or not], need any assistance/equipment at home, televisit duration, or televisit type) did not show statistically significant difference between strongly satisfied, satisfied, and neutral groups. However, when we performed predictive stepwise logistic model (strongly satisfied versus the remaining groups) for factors predicting strongest level of satisfaction from televisits in neuromuscular patients, the only factor that was potentially predicting the highest level of satisfaction was younger age ( $P = 0.032$ ).

To find out possible factors that are associated with strongest tendency to participate again in future televisits in neuromuscular patients, we then presented these demographics and televisit data based on agreement ranking for participation again in televisits in all 46 neuromuscular patients (Tab. III). As shown in this Table, individual univariate analysis for each factor showed statistically significant difference between strongly agree, agree, and neutral groups for age ( $P = 0.010$ ) and televisit type ( $P = 0.046$ ). However, when we performed predictive stepwise logistic model (strongly agree versus the remaining groups) for factors associated with strong agreement for participation again in future televisits in neuromuscular patients, the only factor that was associated with strong agreement to participate again in future televisits was younger age ( $P = 0.007$ ).

### Subgroup analysis of patients with MND

The mean age of patients with MND was 58.94 years, and 11 patients (61.11%) were female (Tab. SIV). Fifteen (83.33%) patients were white and 10 (55.56%) had college graduate or postgraduate education. Sixteen (88.89%) patients had ALS, one (5.56%) PLS and one (5.56%) with PMA. Average disease duration was 33.06 months, and the onset location was limb, bulbar, and respiratory in 13 (72.22%), 4 (22.22%), and 1 (5.56%) patient, respectively. The average ALS functional rating scale-revised (ALSFRRS-R) score in previous and present visit were 36 and 34, respectively. The average time from previous visit was 13.5 weeks. The average forced vital capacity (FVC) was 68.92 and 66.37% predicted in previous and current visit, respectively. Seven (38.89%) patients with MND were ambulatory without any assistance and 6 (33.33%) patients were using supportive equipment including non-invasive ventilation or gastrostomy tube. The average home distance to the neuromuscular/ALS clinic was 43.79 miles for these patients. Only one (5.56%) televisit was a new visit and all 18 (100%) televisits were video calls (5 using Doximity® and 13 using Zoom® health software). In 15 televisits (83.33%), caregivers or families were present. The mean duration (S.D.) of televisits were 36.67 (10) min.

Again, the online survey analysis demonstrated that overall MND patients/caregivers and HCPs rated the telehealth visits favorably and satisfactory (Fig. 2). Ten (55.56%) patients/caregivers were strongly satisfied, and 7 (38.89%) were overall satisfied from televisits. Additionally, 10 (55.56%) patients/caregivers would strongly agree and 4 (33.33%) agree with participation again in future televisits. For questions regarding telemedicine encounter (*i.e.*, communication perceptions, adequate time to discuss concerns, and equal care in quality compared to in-person visit) as well as telemedicine interference (*i.e.*, confidence in using, and easy setup and use of the system), there were no significant differences in mean responder ranks

**Table III.** Demographics and televisit information based on overall tendency to participate again in televisit in all neuromuscular patients (total 46).

Variables	Would Participate Again in Televisit			P Value
	Neutral (4)	Agree (18)	Strongly Agree (24)	
Age, years (mean ± S.D.)	66.75 ± 16.01	67 ± 9.35	55.37 ± 13.59	<b>0.010</b>
Gender (female, %)	2 (50)	11 (61.11)	14 (58.33)	0.919
Education level (N, %)				0.310
High school	0 (0)	4 (22.22)	6 (25.0)	
Some college	2 (50)	2 (11.11)	6 (25.0)	
College graduate	0 (0)	8 (44.45)	6 (25.0)	
Postgraduate	2 (50)	4 (22.22)	6 (25.0)	
Race (white, %)	4 (100)	17 (94.44)	22 (91.67)	0.627
Home distance to clinic, miles (mean ± S.D.)	38.40 ± 29.71	39.49 ± 32.87	29.14 ± 21.61	0.454
Type of neuromuscular disease, MND	2 (50)	6 (33.33)	10 (41.67)	0.772
Need any assistance/equipment at home (N, %): e.g. for ambulation, non-invasive ventilation, gastrostomy tube, tracheostomy	2 (50)	7 (38.89)	8 (33.33)	0.796
Visit duration, min (mean ± S.D.)	32.5 ± 5	33.33 ± 11.50	28.96 ± 10	0.390
Televisit type				<b>0.046</b>
Video	3 (75)	14 (77.78)	24 (100)	
Phone	1 (25)	4 (22.22)	0 (0)	

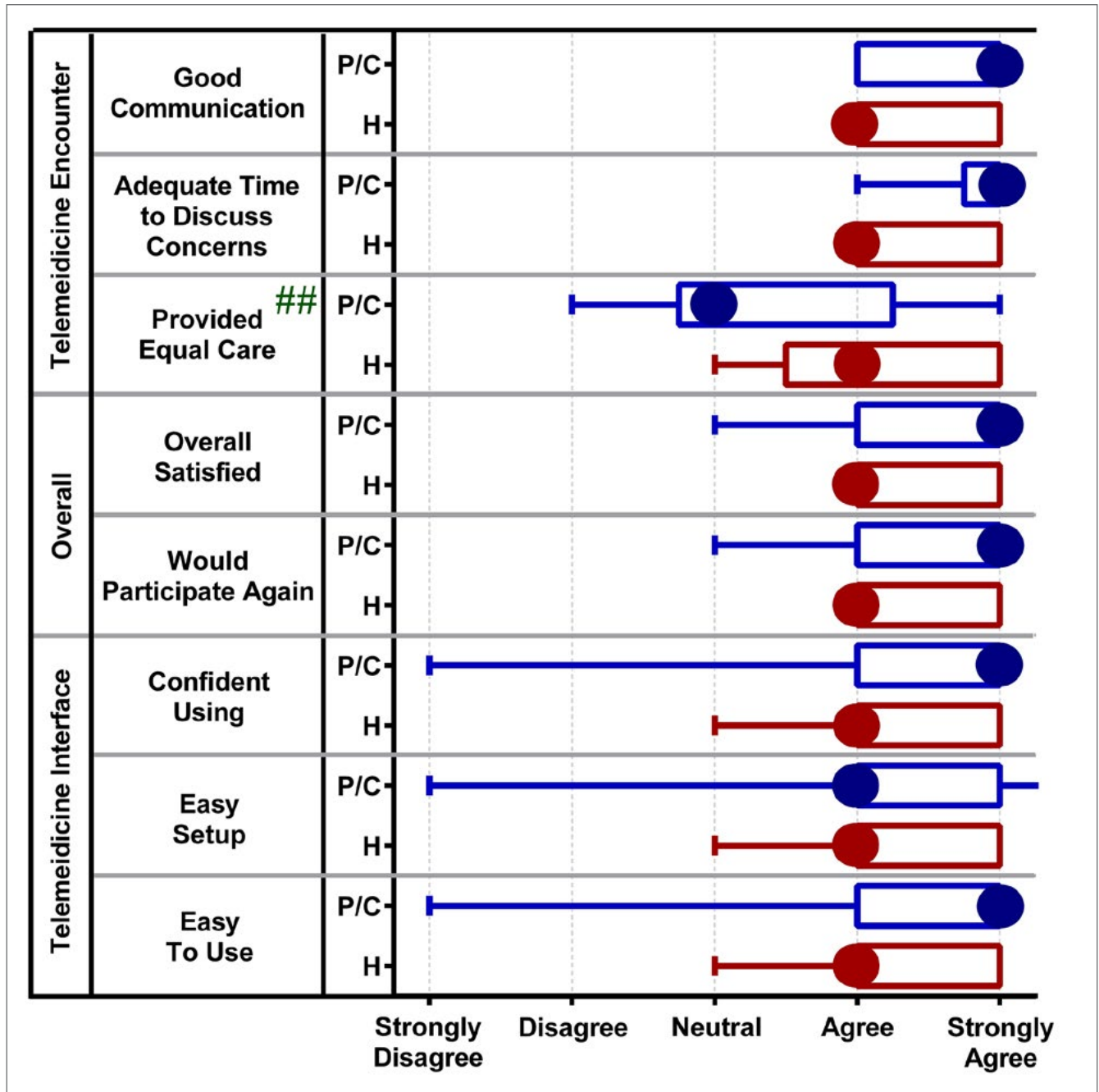
between patient/caregiver and HCP responders within each category. The mean ranks of the responses from all groups were overall different between the 9 questions ( $P = 0.0073$ ). However, post-hoc analysis did not reveal any significant differences in either patient/caregiver or HCPs responders with regards to overall satisfaction or tendency to participation again in televisits with other groups from telemedicine encounter or interference categories (Fig. 2).

Table SV also shows the responses of MND patients/caregivers and HCPs to questions to what they like, dislike, change in televisits. Seven patients and 2 HCPs liked televisits as they are convenient. No travel, good physician encounter, and staying at home were also mentioned by 4, 3, 2 patients/caregivers, respectively. The major dislike from patients/caregivers were limitation in physical examination. Four patients also responded that they preferred in-person visits. Overall, patients/caregivers proposed no changes in the current televisits, and only few mentioned no phone call only visits, improvement in holographic video experience, early access to televisit link, and audio/video. The HCPs also suggested improvements in connection and waiting time for connection to video calls as well as holographic video experience (Tab. SV).

The most addressed issues in televisits with MND patients were goals of care discussion (72.22%), medication management (55.56%), discussion about ordering tests or referrals (55.56%), research (50%), results of the tests (27.78%), and discussion of home care team management (22.22%). Other aspects such as acute health issues were less frequently discussed during these encounters (Tab. SVI). The most common medical action during or immediately following a televisit with MND patients was ordering tests/referrals (61.11%) and at least one medication adjustment/prescription (55.56%) followed by home care team change/management (38.89%), new equipment prescription (22.22%), or change in respiratory management (16.67%) (Tab. SVI).

To find out possible factors that are associated with highest level of overall satisfaction from televisits with MND patients, we presented the demographics and televisit data based on overall satisfaction ranking in these patients (total 18 patients) which is depicted in Table IV. Individual univariate analysis for each factor (*e.g.*, age, gender, education, race, home distance to clinic, type of MND, disease duration, onset location, ALSFRS-R, time interval from previous visit, need any assistance/equipment at home, televisit duration, and video software type) showed statistically significant difference between strongly satisfied, satisfied, and neutral groups in only two factors including type of MND ( $P < 0.001$ ) and disease onset location ( $P = 0.033$ ). However, when we performed predictive stepwise ordinal logistic model (strongly agree versus the remaining groups) for factors predicting highest level of overall satisfaction from televisits in these patients, the only factor that was potentially predicting the highest level of satisfaction was the onset (*i.e.*, limb) location ( $P = 0.005$ ).

To find out possible factors that are associated with strongest tendency to participate again in future televisits in MND patients, we then presented the demographics and televisit data based on overall agreement ranking to participate again in televisits all 18 patients with MND (Tab. SVII). Individual univariate analysis for each factor (*i.e.*, age, gender, education, race, home distance to clinic, type of MND, disease duration, onset location, ALSFRS-R, time interval from previous visit, need any assistance/equipment at home, televisit duration, and video software type) did not show statistically significant difference between strongly agree, agree, and neutral groups in any of the factors, although there was a tendency for the type of MND ( $P < 0.056$ ) (Tab. SVII). Moreover, when we performed predictive stepwise ordinal logistic model (strongly agree versus the remaining groups) for factors predicting strongest level of agreement for participation again in future televisits in MND pa-



**Figure 2.** Ratings of the telemedicine service by motor neuron disease (MND) patients (P)/caregivers (C), and HCPs (H). The median is marked by a large circle. Rectangles range from the first quartile (Q1) to the third quartile (Q3) of data. Thin lines extend to the furthest data point withing 1.5 X (Q3-Q1) of Q1 or Q3. Individual markers outside this range are outliers.

tients, no statistically significant factor was found to be potentially predicting the strongest level of agreement to participate again in future televisits in these patients.

## Discussion

Telemedicine is revolutionizing our clinical practice across medical specialties worldwide, and this has been accelerated since COVID-19 pandemic<sup>11-14</sup>. We found that telehealth service in our neuromuscu-

lar and multidisciplinary ALS clinic during the COVID-19 outbreak to be considerably satisfying, feasible, and effective in providing personalized care from both patient/caregiver and HCP perspectives. Over 90% of patients (either with neuromuscular diseases in general or with MND)/caregivers were either strongly or overall satisfied from the telemedicine encounters. A considerable number of responders to the open-ended questions also found these visits convenient with no need for travel to the clinic. Previous studies have also shown the positive convenience of telehealth in ALS clinics<sup>7,15</sup>. This is important,

**Table IV.** Demographics and televisit information based on overall satisfaction ranking in all motor neuron disease (MND) patients (total 18).

Variables	Overall Satisfaction from Televisits			P Value
	Neutral (1)	Agree (7)	Strongly Agree (10)	
Age, years (mean ± S.D.)	55	61.43 ± 6.02	57.6 ± 13.77	0.745
Gender (female, %)	0 (0)	4 (57.14)	7 (70)	0.377
Education level (N, %)				0.334
High school	0 (0)	4 (57.14)	2 (20)	
Some college	0 (0)	1 (14.29)	1 (10)	
College graduate	0 (0)	0 (0)	4 (40)	
Postgraduate	1 (100)	2 (28.57)	3 (30)	
Race (white, %)	1 (100)	7 (100)	9 (90)	0.655
Home distance to clinic, miles (mean ± S.D.)	73.8	37.63 ± 36.89	45.10 ± 22.80	0.516
Type of motor neuron disease (N, %)				<b>0.0009</b>
ALS	0 (0)	7 (100)	9 (90)	
PMA	0 (0)	0 (0)	1 (10)	
PLS	1 (100)	0 (0)	0 (0)	
Disease duration, months (mean ± S.D.)	65	26.57 ± 9.9	34.75 ± 16.66	0.063
Onset location (N, %)				<b>0.033</b>
Limb	0 (0)	3 (42.86)	10 (100)	
Bulbar	1 (100)	3 (42.86)	0 (0)	
Respiratory	0 (0)	1 (14.29)	0 (0)	
Time from previous visit, weeks (mean ± S.D.)	14	10.43 ± 3.41	15.6 ± 11.28	0.521
ALSFRS-R				
Current	26	35.57 ± 6.24	33.25 ± 11.32	0.565
Previous	26	35.60 ± 4.93	40 ± 5.57	0.138
Need any assistance/equipment at home (N, %): e.g. for ambulation, non-invasive ventilation, gastrostomy tube, tracheostomy	1 (100)	3 (42.86)	8 (80)	0.214
Visit duration, min (mean ± S.D.)	40	35.71 ± 9.32	37 ± 11.35	0.921
Software Type				0.814
Doximity	0 (0)	2 (28.57)	3 (30)	
Zoom health	1 (100)	5 (71.43)	6 (70)	

because 65.2% of neuromuscular patients in general and close to 40% of MND patients were even ambulatory without assistance at the time of their televisits and participation in our survey. The majority of patients who needed home assistance for ambulation/wheelchair, non-invasive ventilation, or gastrostomy tubes were MND patients, supporting the idea that televisits may facilitate continuity of care in these patients that need such home services or equipment<sup>16</sup>.

Moreover, telehealth visits seemed to be well suited for discussing/addressing various aspects of care, the most common of which were medication changes/prescription, ordering tests/referrals, and discussion about test results, goals of care, and research. Based on these discussions, HCPs were also able to take several follow-up actions in medical care of neuromuscular patients. Although medications change/prescription was the most comment issue addressed in neuromuscular patients in general, goals of care discussion followed by the medications change/prescription and tests/referral were the most common addressed issues in MND patients. This is an important consideration, because family members or caregivers were present in over one third (37%) of televisits in general and more than 80% of patients with MND. This indicates that patients, especially those

with MND, may feel comfortable at home and may be surrounded by a group of their family members and caregivers that makes televisits feasible for goals of care discussion. In our multidisciplinary ALS clinic, often time during our in-person clinic visits with patients with ALS we perform joint visits that include ALS specialist, palliative care team, patient, and their family/caregiver for discussion about goals of care. The current data from our televisit experience with MND patients, may suggest that future videoconference televisits, in which ALS HCPs, palliative care team, patients, and their family or caregiver that can join the meeting together, may provide equal or even better quality of goals of care discussion and social support compared to separate in-person visits by each subspecialty.

In our neuromuscular patients (including the subgroup of patients with MND), > 50% of patients/caregivers had strong tendency and more than 30% had overall tendency to participate again in the future televisits. In a recent telephone survey study on 520 neuromuscular patients, it was also found that approximately half of the patients (50.4%) preferred in-person visits compared to virtual visits during the COVID-19 pandemic<sup>17</sup>, which was influenced by the lack of physical examination in telehealth visits<sup>17</sup>. In another study on 753



patients with telehealth visits (53% video versus 47% phone visit) in a neurology clinic during the pandemic, 77% reported satisfaction with the virtual visit<sup>18</sup>. However, only 51% would consider a future virtual visit, and this was associated with the inability to complete neurologic examination<sup>18</sup>. Accordingly, in the open-ended responses from the participants in our survey, the major dislike from both patients/caregivers and HCPs were limitations in physical examination during the televisit. This may explain why only about > 50% of our neuromuscular patients would strongly agree to participate again in the future televisits.

Our data also showed that younger age can predict the strongest level of satisfaction from and participation again in the televisits among neuromuscular patients. One possible explanation for this result is that younger patients may feel more ease at utilizing technology and televisit software compared to older population. Accordingly, the changes that were mostly suggested by participants in the open-ended questions were to improve the connection, waiting time for connection to video call, and holographic video experience, as well as no phone call only visits. It is also noteworthy that except for the data from their neurological conditions, we did not collect information regarding other medical comorbidities (usually present more in elderly) that may also affect their ability to participate in the telehealth visits; and this warrants further investigation. Interestingly, in the subgroup of MND patients, the limb onset location was a predicting factor for strongly higher level of satisfaction from televisits. This may be because MND patients with bulbar symptoms may not feel comfortable to participate in the televisits due to difficulty communicating through videoconference and they may prefer in-person visits, where they have better physician encounter.

Although our study demonstrated an overall satisfaction from and acceptability of televisits by both patients/caregivers and HCPs, one cannot ignore the potential weaknesses or limitations of telehealth visits in the neuromuscular field. For example, our data from the open-ended responses from the participants (both patients/caregivers and HCPs) showed that the major dislike from these televisit encounters were limitations or lack of appropriate physical and neurological examination during the visits. This is an important issue especially for new patient visits, when physicians need a careful physical/neurological examination for appropriate diagnostic work up and management of patients. Therefore, a limited or lack of physical examination may considerably limit televisits to mainly follow-up visits and not the new encounters. Moreover, during or after the visits, diagnostic investigations such as blood/urine testing may be indicated. Patients usually undergo such testing after their in-person visits in our center. For this reason, some patients may not prefer televisit, as they have to come to the lab for such tests even after the televisits. Other weaknesses of televisits include their overall short duration compared to in-person visits, difficulty using computers or laptops at home for some patients/caregivers, as well as video/audio software or internet availability. These may affect such visits especially in rural regions where people have limited access to internet or equipment for video calls.

Our study has some limitations. Similar to many other survey studies, not all the patients received the online survey link participated in the survey. In our study, only 55% of patients participated in the sur-

vey. Therefore, a relatively small sample size remained for statistical analysis on predicting factors for higher level of satisfaction from or participation again in the televisits. This was especially true for the subgroup of patients with MNDs.

## Conclusions

In conclusion, telehealth visits were feasible, convenient, and highly effective at achieving personalized and multidisciplinary care that overall were rated favorably and satisfactory by various neuromuscular patients (including those with MND)/caregivers and related HCPs during the COVID-19 pandemic. This satisfactory experience with telemedicine during the viral outbreak can impact the current and future of care in patients with neuromuscular diseases, especially in the longitudinal follow up of such patients in the neuromuscular and/or multidisciplinary ALS clinic.

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## Conflict of interest statement

None of the authors has any conflict of interest to disclose.

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## Authors' contribution

MG: conceptualization, investigation, software, data curation, formal analysis, writing - original draft as well as its review & editing, funding acquisition, project administration; KP: conceptualization, methodology, data curation, writing - review & editing; KMD: conceptualization, methodology, investigation, supervision, writing - review & editing. BS: conceptualization, supervision, methodology, writing - review & editing.

## Ethical consideration

We confirm that we have read the Journal's position on issues involved in ethical publication and affirm that this report is consistent with those guidelines. The use of human subjects as well as all study procedures for this clinical study were approved by the institutional review board at the UMass Chan Medical School (IRB# H00020488, date of approval: 06/26/2020).

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Supplementary Tables at <https://www.actamyologica.it/article/view/245/189> and Supplementary Appendix at <https://www.actamyologica.it/article/view/245/190>