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## Use of Telemedicine Among People with Multiple Sclerosis Before and During the COVID-19 Pandemic

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### Abstract

**Introduction:** Multiple sclerosis (MS) is the most common progressive neurological condition with onset in young adulthood. Because people with MS (PwMS) are often separated from specialty care by distance or disability, telemedicine can help alleviate that burden by removing obstacles to accessing care.

**Methods:** We surveyed 762 PwMS in the iConquerMS research network about their use of in-person and telemedicine services pre-pandemic (January–February 2020) and during the coronavirus disease 2019 (COVID-19) pandemic (September–November 2020). The survey asked PwMS about their use of in-person and telemedicine services, technology access, perceptions and preferences of telemedicine, their most recent telemedicine encounter, and reasons for not using telemedicine.

**Results:** Pre-pandemic, the most cited reason for not using telemedicine was providers not offering remote visits. During the pandemic, there was a decrease in the use of in-person health care (100% to ~78%) and an increase in telemedicine utilization (25% to ~80%). Most participants had access to telemedicine-enabling technologies and a large portion indi-

cated a preference for using telemedicine for some or most/all of their MS health care (41–57%). Before the pandemic, telemedicine utilization was highest for primary care, while during the pandemic, utilization of telemedicine was greatest for general MS care. Mental health telemedicine encounters increased during the pandemic.

**Discussion:** The dramatic increase in telemedicine utilization during the COVID-19 pandemic has provided access for PwMS to multispecialty care. Maintaining the policy changes that enabled remote health care to expand during the pandemic will be critical for sustained access to MS specialty care for this vulnerable population.

**Keywords:** telemedicine, telehealth, multiple sclerosis, neurology, COVID-19 pandemic, survey

### Introduction

Multiple sclerosis (MS) is the most common progressive neurological disease with onset in young adulthood. Although less prevalent than other chronic diseases, people with MS (PwMS) have long lifespans and high outpatient and inpatient health care utilization.<sup>1,2</sup> Long travel times to specialized medical facilities and the variety of neurological deficits among PwMS can be major barriers to accessing appropriate health care. Telemedicine, defined as the use of technology to provide access to clinical care when distance separates patients and providers, is one approach that can help overcome these obstacles among PwMS. Several recent studies have demonstrated the feasibility and validity of using telemedicine for the remote neurological examination, including Expanded Disability Status Scale (EDSS) assessments.<sup>3–6</sup> A recent systematic review on telemedicine utilization among PwMS also showed that

remote clinical exams, medicine management, and rehabilitation were beneficial, cost-effective, and satisfactory for both patients and providers.<sup>2</sup>

The coronavirus disease 2019 (COVID-19) pandemic brought telemedicine to the forefront of many health care practices. The federal COVID-19 public health emergency declaration, a temporary measure allowing government health insurance reimbursement for telemedicine, made it easier to receive care remotely.<sup>7</sup> Changes in federal and state policies as a result of the emergency declaration meant providers could use secure televideo platforms for virtual visits to the home, and telemedicine encounters could in some cases be delivered across state lines.<sup>7,8</sup> Practitioners and patients had to quickly adjust to all aspects of remote clinical care.

We surveyed PwMS to assess the extent of their telemedicine utilization, to understand their unique experiences, and to identify the benefits and drawbacks of telemedicine from the patient perspective. Our study was initiated in January 2020, before the COVID-19 pandemic. After the pandemic reached the United States, we refiled the survey in the fall of 2020 to compare the use of telemedicine among PwMS pre-pandemic and during the pandemic. This report reviews our findings within the context of the ongoing pandemic.

## Methods

### IRB APPROVAL

This study, including participant consent obtained through web-based survey, was approved by the Institutional Review Boards for the iConquerMS cohort (the WIRB-Copernicus Group IRB, #420140400/1210591), and the Washington, DC Veteran's Health Administration Medical Center (#01885).

### SAMPLE SELECTION

iConquerMS is a research network composed of PwMS who contribute health data through an online platform.<sup>9</sup> On January 8, 2020, we invited all iConquerMS participants by email to take part in our telemedicine survey (Survey 1, pre-pandemic, 4,457 members contacted). Survey 1 remained open until February 25, 2020. Between September 2 and November 2, 2020, a second survey was fielded (Survey 2, during pandemic, 5,191 members contacted). For the purpose of calculating our response rate, we defined "active" members as those that had submitted at least one iConquerMS survey in the 2 years prior. There were 1,590 active participants when Survey 1 was administered, and 2,018 participants when Survey 2 was administered.

*Surveys.* Both surveys included questions on participant's demographic and disease characteristics, use of in-person health care services, use of telemedicine, technology access and use,

and perceptions of telemedicine. Among the subset of those who used telemedicine we asked about their most recent telemedicine experience, and among the subset of those who did not use telemedicine we asked about their reasons for not using telemedicine. In Survey 2, all questions from Survey 1 were included with a few additional pandemic-related questions or answer choices. Survey 1 was piloted with six PwMS in the Washington, DC area. Written and verbal feedback was obtained from these patients to optimize the wording of questions and possible answers.

### ANALYSIS

We grouped survey participants into three categories. Group A included participants who only took the survey once pre-pandemic. Group B included participants who only took the survey once during the pandemic. Group C took the survey twice, at Time point 1 (pre-pandemic) and Time point 2 (during the pandemic). We report results for each group separately. Our cross-sectional analysis compared results of Group A and Group B, and our longitudinal analysis compares Time point 1 and Time point 2 for Group C. In the data presented in the main text, we excluded missing, prefer not to answer, and do not know responses. These data are, however, included in Supplementary Data

### STATISTICS

We used "R" version 4.0.3<sup>10</sup> software and the R packages *dplyr*<sup>11</sup> and *DescTools*<sup>12</sup> to conduct statistical tests for this study. We compared Group A and Group B, and Time point 1 and Time point 2 for Group C participants. All tests used a *p*-value of 0.05 to establish significance. *p*-Values lower than 0.001 are designated as <0.001. When comparing Group A and Group B (cross-sectional analyses), we used Pearson's chi-square test, Fisher's exact test for count data, a two-sample *t* test of equal variance, or a two-sample test for equality of proportions with continuity correction. When comparing Time point 1 and Time point 2 for Group C (longitudinal analyses), we used McNemar's chi-square test with continuity correction, or the Stuart-Maxwell test. For both cross-sectional and longitudinal analyses in which a participant could select multiple responses and for which we analyzed each response individually, we used the Benjamini and Hochberg method, a multiple test correction.

## Results

We present, in this study, the sample characteristics and our findings on participants' use of, preferences for, and opinions about telemedicine. We then discuss the subset who had at least one telemedicine visit in the recall period, and the subset who did not use telemedicine.

### SAMPLE CHARACTERISTICS

There were a total of 762 respondents who fully or partially completed the survey: 260 in Group A, 240 in Group B, and 262 in Group C. The response rate, which we based on the number of active iConquerMS members at the time of each survey, was 33% for Survey 1 and 25% for Survey 2 (Fig. 1). The demographics of survey participants are noted (Table 1), with most being female, white, and non-Hispanic. Median ages were in the mid to late 50s. Most of the survey participants had relapsing remitting MS, and the mean duration since diagnosis was about 15 years. Most participants had some degree of disability; about half had gait disability or required a cane or bilateral support, although most did not require a caretaker. The majority were taking disease-modifying therapies (Table 2).

### IN-PERSON CARE AND TELEMEDICINE UTILIZATION

Before the pandemic, 25% of participants had at least one telemedicine health care visit in the previous year. During the pandemic, the percentage of participants who had a telemedicine visit since the pandemic began increased to about 80%. By contrast, the percentage of participants making in-person visits fell from almost 100% before the pandemic to about 78% during the pandemic ( $p < 0.001$ ) (Fig. 2). For many health care services, the percentages of participants who used telemedicine during the pandemic increased significantly while the percentages receiving them in-person declined significantly. For example, the proportion of PwMS who used telemedicine for exercise therapy or coaching, general MS

care, mental health services, physical therapy, primary care, urology, and other services during the pandemic was significantly greater (Supplementary Tables S3 and S4).

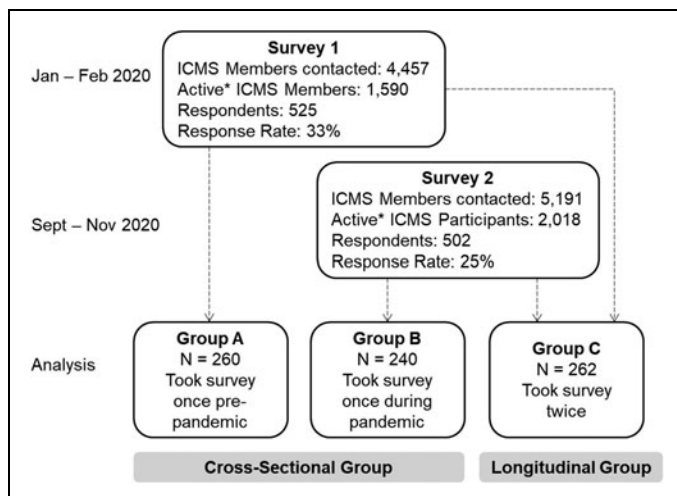
### TECHNOLOGY ACCESS AND USE

The switch to telemedicine was feasible for our participants because the majority had the necessary equipment and connectivity before and during the pandemic. Most PwMS in this online survey cohort had access to smartphones at both time points. More than 98% of participants had access to computers, tablets, or webcams; only four participants pre-pandemic and five during the pandemic did not have access to any of these items. About 50% of participants had access to a webcam pre-pandemic, which increased slightly during the pandemic to about 60%. More than half of participants had a smartphone with a data plan and had high-speed internet. Over 65% in all groups felt fairly comfortable or very comfortable with telecommunication equipment. In the longitudinal group, there was a statistically significant increase in the number of people who had smartphones with a data plan between the two time points ( $p = 0.01$ ). The longitudinal group also had a statistically significant shift in comfort level with telecommunication equipment ( $p < 0.01$ ), with more people reporting that they were very or fairly comfortable during the pandemic than pre-pandemic (Supplementary Table S5).

### PREFERENCES AND OPINIONS ABOUT TELEMEDICINE

When asked about preferences for using telemedicine for their MS care pre-pandemic, a substantial minority of the cross-sectional group preferred using telemedicine for some of their MS health care (41%), followed by using telemedicine occasionally (32%), using telemedicine for most or all MS care (12%), and preferring not to use telemedicine (12%). The responses were relatively similar among those in the cross-sectional group surveyed during the pandemic, with just a slight increase or decrease in the proportion of responses for each answer choice. The longitudinal group, however, had an increase in the number of people who preferred using telemedicine for some or most/all of their MS health care (30% to 38% and 11% to 19%), and a decrease in the number of those who would only consider using telemedicine occasionally (43% to 29%). The number who would not like to use telemedicine for their MS health care remained relatively steady at <11% of participants (Table 3).

During the pandemic, most PwMS indicated that protection against exposure to the coronavirus or another infection was an advantage of using telemedicine. The next most common advantages cited both before and during the pandemic



**Fig. 1.** Surveys, response rates, and analysis groups for the iConquerMS telemedicine survey. \*The response rates are calculated using the number of active ICMS participants as a denominator, where active members had participated in at least one survey in the 24 months before the telemedicine survey. ICMS, I conquer multiple sclerosis; MS, multiple sclerosis.

**Table 1. Demographics of Telemedicine Survey Participants**

|   | CROSS-SECTIONAL GROUPS |              | LONGITUDINAL GROUP |
|---|------------------------|--------------|--------------------|
|   | GROUP A                | GROUP B      | GROUP C            |
| Respondents <sup>a</sup>                  | 260                    | 240          | 262                |
|   | <i>N</i> (%)           | <i>N</i> (%) | <i>N</i> (%)       |
| Sex                                       |                        |              |                    |
| Female                                    | 195 (81.6%)            | 187 (83.1%)  | 199 (76.5%)        |
| Male                                      | 44 (18.4%)             | 38 (16.9%)   | 61 (23.5%)         |
| Age                                       |                        |              |                    |
| Mean (SD)                                 | 54.3 (11)              | 56.2 (11.4)  | 58 (11.2)          |
| Range (min-max)                           | (27-85)                | (28-81)      | (29-78)            |
| Ethnicity                                 |                        |              |                    |
| Hispanic or Latino                        | 7 (3%)                 | 7 (3.2%)     | 8 (3.2%)           |
| Not Hispanic or Latino                    | 230 (97%)              | 215 (96.8%)  | 242 (96.8%)        |
| Race                                      |                        |              |                    |
| Black or African American                 | 12 (5.2%)              | 6 (2.7%)     | 3 (1.2%)           |
| White                                     | 216 (92.7%)            | 212 (96.8%)  | 247 (98.4%)        |
| Other <sup>b</sup>                        | 6 (2.6%)               | 2 (0.9%)     | 5 (2%)             |
| Census region <sup>c</sup>                |                        |              |                    |
| Northeast                                 | 38 (17.8%)             | 53 (27%)     | 60 (26%)           |
| Midwest                                   | 54 (25.2%)             | 40 (20.4%)   | 52 (22.5%)         |
| South                                     | 69 (32.2%)             | 56 (28.6%)   | 63 (27.3%)         |
| West                                      | 52 (24.3%)             | 47 (24%)     | 56 (24.2%)         |
| U.S. territory                            | 1 (0.5%)               | 0 (0.0%)     | 0 (0.0%)           |
| Country <sup>d</sup>                      |                        |              |                    |
| U.S.                                      | 215 (90.0%)            | 198 (88.0%)  | 230 (90.6%)        |
| Outside U.S.                              | 24 (10.0%)             | 27 (12.0%)   | 24 (9.4%)          |
| Urban/rural                               |                        |              |                    |
| Urban                                     | 181 (87.4%)            | 175 (89.7%)  | 203 (89%)          |
| Rural                                     | 26 (12.6%)             | 20 (10.3%)   | 25 (11%)           |
| Household income                          |                        |              |                    |
| \$50,000 or less                          | 78 (38.6%)             | 69 (36.5%)   | 76 (35.7%)         |
| \$50,001-\$100,000                        | 60 (29.7%)             | 46 (24.3%)   | 69 (32.4%)         |
| \$100,001-\$150,000                       | 36 (17.8%)             | 32 (16.9%)   | 38 (17.8%)         |
| \$150,001 or more                         | 28 (13.9%)             | 42 (22.2%)   | 30 (14.1%)         |
| Health insurance                          |                        |              |                    |
| No health insurance                       | 10 (4.2%)              | 3 (1.3%)     | 7 (2.8%)           |
| Private, commercial, prepaid <sup>e</sup> | 158 (66.7%)            | 157 (70.1%)  | 176 (69.6%)        |
| Veterans affairs or CHAMPVA               | 8 (3.4%)               | 6 (2.7%)     | 4 (1.6%)           |
| Medicare                                  | 0 (0.0%)               | 0 (0.0%)     | 0 (0.0%)           |
| Medicaid                                  | 96 (40.5%)             | 92 (41.1%)   | 118 (46.6%)        |
| Other public <sup>f</sup>                 | 18 (7.6%)              | 12 (5.4%)    | 15 (5.9%)          |

continued →

**Table 1. Demographics of Telemedicine Survey Participants** *continued*

|                             | CROSS-SECTIONAL GROUPS |              | LONGITUDINAL GROUP |
|-----------------------------|------------------------|--------------|--------------------|
|                             | GROUP A                | GROUP B      | GROUP C            |
| Respondents <sup>a</sup>    | 260                    | 240          | 262                |
|                             | <i>N</i> (%)           | <i>N</i> (%) | <i>N</i> (%)       |
| Other                       | 18 (7.6%)              | 13 (5.8%)    | 10 (4%)            |
| Employment                  |                        |              |                    |
| Employed                    | 91 (38.7%)             | 78 (34.7%)   | 89 (35%)           |
| Homemaker                   | 9 (3.8%)               | 9 (4%)       | 6 (2.4%)           |
| Student                     | 1 (0.4%)               | 3 (1.3%)     | 2 (0.8%)           |
| Unemployed looking for work | 8 (3.4%)               | 7 (3.1%)     | 7 (2.8%)           |
| Unemployed                  | 6 (2.6%)               | 6 (2.7%)     | 6 (2.4%)           |
| Other <sup>g</sup>          | 120 (51.1%)            | 122 (54.2%)  | 144 (56.7%)        |

<sup>a</sup>Respondents include all PwMS who either partially or fully completed the survey. One person responded to the survey who replied that they had never been diagnosed with MS, and is excluded for all other survey questions.

Statistical tests comparing Group A versus Group B indicated that there was no significant difference between groups, with the exception of age. Age was significantly different when comparing age categories, but not when comparing means (*Supplementary Table S1*).

The percentage of missing, prefer not to answer, or do not know responses for individual questions (excluded from this table) ranged from 0% to 20.4%, and is provided in *Supplementary Table S1*.

<sup>b</sup>American Indian or Alaskan Native, Middle Eastern, South Asian, Other Asian.

<sup>c</sup>Applicable to only U.S. participants.

<sup>d</sup>Analysis did not stratify non-U.S. residents.

<sup>e</sup>For example, BlueCross BlueShield, WellPoint, UnitedHealth, Aetna, and other plans offered by your employer or purchased on your own.

<sup>f</sup>TRICARE, state health plan—U.S., national or non-U.S. government-sponsored health plan, or Other.

<sup>g</sup>Other is workers compensation, disabled, or retired but not disabled.

PwMS, people with multiple sclerosis; SD, standard deviation.

included greater convenience and better access to services or specialists that are not available in their local area. A significantly smaller proportion of people cited lower cost as an advantage during the pandemic compared with the prepandemic period. A small proportion (<8%) also cited that there were no advantages to telemedicine during the pandemic compared with before the pandemic.

The most frequently cited disadvantage of telemedicine for PwMS was that it is more difficult to receive a full examination. Between the two time points, there was a significant decrease in the proportion of participants who cited concerns about privacy and security, and in those who cited cost or health insurance coverage issues. Difficulty communicating with the health care provider due to technological issues was also a commonly cited disadvantage (*Table 3*).

We asked participants about their preferences to use telemedicine, have in-person visits, or to have a combination of the two for specific types of health care services (*Supple-*

*mentary Tables S8 and S9*). Participants provided clear and logical preferences for receiving health care. For example, in-person only was typically participants' choice for hands-on treatments such as chiropractic care, exercise therapy, physical therapy, and occupational therapy or procedural-based urology. Telemedicine only was the preference for services such as diet/nutrition. Finally, a mix of preferences between in-person or telemedicine was found for general MS care and primary care. The distribution of preferences for mental health services, social work services, and speech therapy were more evenly distributed between in-person, telemedicine, and a combination of both types of services.

#### THE MOST RECENT TELEMEDICINE EXPERIENCE, AMONG THE SUBSET OF TELEMEDICINE USERS

The subset of participants who use telemedicine were asked about their most recent telemedicine experience. Between the two study time points, the most frequent type of visit shifted

**Table 2. Disease Characteristics of Telemedicine Survey Participants**

|                                  | CROSS-SECTIONAL GROUPS |             | LONGITUDINAL GROUP |  |
|----------------------------------|------------------------|-------------|--------------------|--|
|                                  | GROUP A                | GROUP B     | GROUP C            |  |
| Respondents <sup>a</sup>         | 260                    | 240         | 262                |  |
|                                  | N (%)                  | N (%)       | N (%)              |  |
| Years Since Diagnosis            |                        |             |                    |  |
| Mean (SD)                        | 15.2 (9.6)             | 15.5 (10.6) | 15.9 (9.9)         |  |
| Range (min-max)                  | (1-56)                 | (1-51)      | (1-48)             |  |
| Form of MS                       |                        |             |                    |  |
| Clinically isolated syndrome     | 6 (2.4%)               | 4 (1.7%)    | 6 (2.3%)           |  |
| Relapsing-remitting              | 158 (62%)              | 150 (63%)   | 152 (58.2%)        |  |
| Secondary progressive            | 62 (24.3%)             | 56 (23.5%)  | 71 (27.2%)         |  |
| Primary progressive              | 29 (11.4%)             | 28 (11.8%)  | 32 (12.3%)         |  |
| Patient-determined disease steps |                        |             |                    |  |
| Normal                           | 47 (18.2%)             | 40 (16.7%)  | 36 (13.7%)         |  |
| Mild disability                  | 24 (9.3%)              | 34 (14.2%)  | 27 (10.3%)         |  |
| Moderate disability              | 43 (16.7%)             | 29 (12.1%)  | 27 (10.3%)         |  |
| Gait disability                  | 31 (12%)               | 27 (11.3%)  | 48 (18.3%)         |  |
| Early cane                       | 37 (14.3%)             | 45 (18.8%)  | 31 (11.8%)         |  |
| Late cane                        | 26 (10.1%)             | 23 (9.6%)   | 31 (11.8%)         |  |
| Bilateral support                | 33 (12.8%)             | 20 (8.4%)   | 39 (14.9%)         |  |
| Wheelchair/scooter               | 16 (6.2%)              | 21 (8.8%)   | 23 (8.8%)          |  |
| Bedridden                        | 1 (0.4%)               | 0 (0%)      | 0 (0%)             |  |
| Caregiver required               |                        |             |                    |  |
| Yes <sup>b</sup>                 | 91 (35.3%)             | 85 (35.6%)  | 95 (36.3%)         |  |
| Not required                     | 167 (64.7%)            | 154 (64.4%) | 167 (63.7%)        |  |
| Current DMT use                  |                        |             |                    |  |
| Yes                              | 230 (89.1%)            | 201 (84.1%) | 215 (82.4%)        |  |
| No                               | 28 (10.9%)             | 38 (15.9%)  | 46 (17.6%)         |  |

<sup>a</sup>Respondents include all PwMS who either partially or fully completed the survey.

Statistical tests comparing Group A versus Group B indicated that there was no significant difference between groups (*Supplementary Table S2*).

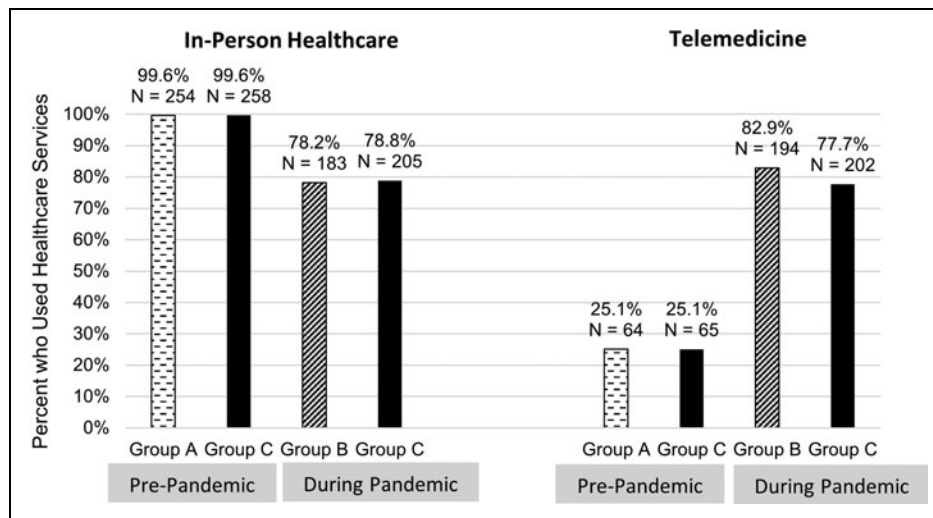
<sup>b</sup>Required for daily living, including personal care, household help, or transportation.

The percentage of missing, prefer not to answer, or do not know responses for individual questions (excluded from this table) ranged from 0% to 1.9%, and is provided in *Supplementary Table S2*.

DMT, disease-modifying therapy.

from primary care to MS care, and visits for mental health services increased. Although not statistically significant, a greater proportion of telemedicine visits were longer than 30 min during the pandemic compared with prepandemic suggesting these were virtual visits and not phone calls.

During the pandemic, a greater proportion of PwMS indicated that their insurance paid for the full cost or part of the cost for their most recent telemedicine visit (*Table 4*). Prepandemic, many telemedicine visits were scheduled *ad hoc* in response to an immediate need while during the pandemic most remote



**Fig. 2.** Use of in-person and telemedicine health care before and during the COVID-19 pandemic among people with MS. Group A are participants who only took the survey pre-pandemic. Group B are participants who only took the survey during the pandemic. Group C took the survey twice. In the pre-pandemic survey, participants were asked about service use within the last 12 months. In the survey during the pandemic, participants were asked about service use “since March.” The differences between Group A and Group B and between Group C Time point 1 and Time point 2 were statistically significant ( $p < 0.001$ , using either Pearson’s chi-square test or McNemar’s chi-square test with continuity correction.) Group A  $N = 255$ , Group B  $N = 234$ , and Group C  $N = 259$ . Participants with missing responses are excluded (*Supplementary Table S3 and S4*). COVID-19, coronavirus disease 2019.

visits were scheduled in advance. Pre-pandemic, a plurality cited “saving time spent traveling” as a primary reason for choosing telemedicine while during the pandemic, many people cited COVID-19-related reasons for choosing telemedicine. Most PwMS were satisfied with their visit and definitely or probably would like to continue using telemedicine (*Supplementary Table S6*).

#### REASONS FOR NOT USING TELEMEDICINE AMONG THE SUBSET OF NONUSERS

The proportion of participants who did not use telemedicine decreased from about 75% to about 20% between the two study time points. Before the pandemic 80 participants indicated that their health care providers did not offer telemedicine, while during the pandemic only 6 had the same response (sum of cross-sectional and longitudinal groups). Relatively few PwMS cited other reasons for not using telemedicine and only one participant indicated that they did not have the necessary phone or internet connection for telemedicine. During the pandemic, few PwMS responded to these questions, but among those who responded most believed that an in-person visit is better than a telemedicine visit, or cited other reasons for not using telemedicine, such as not needing a visit during the specified time frame (*Table 5*). During the pandemic, PwMS were also asked if they have canceled or

postponed visits because telemedicine was the only option—a total of 11 participants responded yes (*Supplementary Table S7*).

#### Discussion

Changes to in-person health care services have occurred in every patient population, including PwMS, as a result of the seclusion imposed by the pandemic. This survey has demonstrated that telemedicine is an important platform for care delivery for PwMS. For PwMS with neurological disability that impairs independent travel, telemedicine can help fill the gap for those living in a rural area or lacking transportation. We had the advantage of assessing responses before and during the COVID-19 pandemic. Pre-pandemic, saving time spent traveling was one of the most frequently cited advantages of telemedicine, followed by better access to specialists and greater convenience. As the pandemic progressed, we observed the same dramatic increase in the use of telemedicine that was seen in the general population<sup>13</sup> and participants cited protection against exposure to COVID-19 as the main advantage of remote visits.

Our data replicate the results of an Italian survey, which asked PwMS about their use and preferences for telemedicine.<sup>14</sup> When asked if they were open to using telemedicine for visits with their neurologists in an MS center, the



**Table 3. Telemedicine Survey Participant's Perceptions of Telemedicine**

| RESPONDENTS <sup>a</sup>  | CROSS-SECTIONAL GROUPS |              |                            | LONGITUDINAL GROUP |              |                              |
|---|------------------------|--------------|----------------------------|--------------------|--------------|------------------------------|
|   | GROUP A                | GROUP B      | A VS. B<br><i>p</i> -VALUE | GROUP C            |              |                              |
|   | 260                    | 240          |                            | 262                |              |                              |
|   | <i>N</i> (%)           | <i>N</i> (%) |                            | TIME POINT 1       | TIME POINT 2 | T1 VS. T2<br><i>p</i> -VALUE |
|   |                        |              | <i>N</i> (%)               | <i>N</i> (%)       |              |                              |
| Preference for telemedicine   |                        |              |                            |                    |              |                              |
| I would like to use telemedicine for most or all of my MS health care                             | 29 (11.9)              | 32 (14.2)    | 0.24 <sup>c</sup>          | 28 (11)            | 48 (18.8)    | 2.47E-11 <sup>e</sup>        |
| I would like to use telemedicine for some of my MS health care                                    | 99 (40.7)              | 88 (39.1)    |                            | 77 (30.2)          | 98 (38.3)    |                              |
| I would consider using telemedicine occasionally for my MS health care                            | 77 (31.7)              | 77 (34.2)    |                            | 110 (43.1)         | 74 (28.9)    |                              |
| I would not like to use telemedicine for any of my MS health care                                 | 28 (11.5)              | 26 (11.6)    |                            | 27 (10.6)          | 28 (10.9)    |                              |
| Not sure  | 10 (4.1)               | 2 (0.9)      |                            | 13 (5.1)           | 8 (3.1)      |                              |
| Advantages of telemedicine <sup>b</sup>   |                        |              |                            |                    |              |                              |
| Protection against being exposed to the coronavirus or another infection ( <i>Pandemic-Only</i> ) | N/A                    | 192 (86.1)   | N/A                        | N/A                | 219 (86.2)   | N/A                          |
| Better access to services and/or specialists that are currently not available in my local area    | 119 (51.5)             | 103 (46.2)   | 0.69 <sup>d</sup>          | 108 (44.6)         | 107 (42.1)   | 1 <sup>f</sup>               |
| Greater convenience for me  | 179 (77.5)             | 178 (79.8)   | 0.39 <sup>d</sup>          | 198 (81.8)         | 206 (81.1)   | 0.59 <sup>f</sup>            |
| Lower costs for me  | 109 (47.2)             | 69 (30.9)    | 0.01 <sup>d</sup>          | 119 (49.2)         | 79 (31.1)    | <0.001 <sup>f</sup>          |
| Better interactions with the health care provider   | 52 (22.5)              | 32 (14.3)    | 0.16 <sup>d</sup>          | 40 (16.5)          | 40 (15.7)    | 1 <sup>f</sup>               |
| Other   | 11 (4.8)               | 7 (3.1)      | 0.69 <sup>d</sup>          | 17 (7)             | 10 (3.9)     | 0.46 <sup>f</sup>            |
| I do not think telemedicine would provide any advantages for me                                   | 32 (13.9)              | 11 (4.9)     | 0.01 <sup>d</sup>          | 33 (13.6)          | 21 (8.3)     | 0.20 <sup>f</sup>            |
| Disadvantages of telemedicine <sup>b</sup>  |                        |              |                            |                    |              |                              |
| More difficult to communicate with my health care provider due to technological issues            | 51 (22)                | 51 (22.8)    | 0.91 <sup>d</sup>          | 68 (27.2)          | 60 (23.8)    | 0.63 <sup>f</sup>            |
| Concerns about privacy and security   | 52 (22.4)              | 28 (12.5)    | 0.03 <sup>d</sup>          | 56 (22.4)          | 34 (13.5)    | 0.01 <sup>f</sup>            |
| More difficult to receive a full examination using telemedicine                                   | 191 (82.3)             | 206 (92)     | <0.01 <sup>d</sup>         | 222 (88.8)         | 227 (90.1)   | 0.73 <sup>f</sup>            |
| Cost or health insurance coverage issues  | 60 (25.9)              | 31 (13.8)    | 0.02 <sup>d</sup>          | 65 (26)            | 24 (9.5)     | <0.001 <sup>f</sup>          |
| Other   | 7 (3)                  | 2 (0.9)      | 0.37 <sup>d</sup>          | 9 (3.6)            | 11 (4.4)     | 0.86 <sup>f</sup>            |
| I do not think telemedicine would present any disadvantages for me                                | 25 (10.8)              | 15 (6.7)     | 0.42 <sup>d</sup>          | 21 (8.4)           | 20 (7.9)     | 1 <sup>f</sup>               |

<sup>a</sup>Respondents include all PwMS who either partially or fully completed the survey.

<sup>b</sup>More than one choice could be selected by survey participants.

T1: Time point 1; T2: Time point 2

For more information see *Supplementary Table S8*.

Statistical tests: <sup>c</sup>Pearson's chi-squared test.

<sup>d</sup>Two-sample test for equality of proportions with continuity correction.

<sup>e</sup>Stuart-Maxwell test.

<sup>f</sup>McNemar's chi square test with continuity correction.



**Table 4. Services Received, Cost, Insurance Payment, and Length of Visit for Participant's Most Recent Telemedicine Encounter**

| RESPONDENTS <sup>a</sup>  | CROSS-SECTIONAL GROUPS |            |                    | LONGITUDINAL GROUP    |                       |                      |
|---|------------------------|------------|--------------------|-----------------------|-----------------------|----------------------|
|   | GROUP A                | GROUP B    |                    | GROUP C               |                       |                      |
|   | 64                     | 194        |                    | 65                    | 202                   |                      |
|   | N (%)                  | N (%)      | A VS. B<br>p-VALUE | TIME POINT 1<br>N (%) | TIME POINT 2<br>N (%) | T1 VS. T2<br>p-VALUE |
| Service received  |                        |            |                    |                       |                       |                      |
| Primary care  | 21 (34.4)              | 36 (19)    | 0.06               | 23 (35.9)             | 40 (20.2)             | 0.06                 |
| General MS care   | 15 (24.6)              | 84 (44.4)  | 0.02               | 18 (28.1)             | 81 (40.9)             | <0.001               |
| Physical therapy  | 0 (0)                  | 1 (0.5)    | NT                 | 1 (1.6)               | 4 (2)                 | 0.56                 |
| Exercise therapy/coaching   | 5 (8.2)                | 3 (1.6)    | 0.06               | 5 (7.8)               | 6 (3)                 | 1                    |
| Occupational therapy  | 0 (0)                  | 0 (0)      | NT                 | 0 (0)                 | 0 (0)                 | NT                   |
| Speech therapy  | 1 (1.6)                | 1 (0.5)    | NT                 | 1 (1.6)               | 1 (0.5)               | NT                   |
| Chiropractic therapy  | 0 (0)                  | 0 (0)      | NT                 | 0 (0)                 | 0 (0)                 | NT                   |
| Mental health services (psychiatrist, psychologist, other mental health professional) | 7 (11.5)               | 35 (18.5)  | 0.40               | 8 (12.5)              | 38 (19.2)             | <0.001               |
| Social work services  | 1 (1.6)                | 0 (0)      | NT                 | 1 (1.6)               | 1 (0.5)               | NT                   |
| Diet/nutrition services   | 3 (4.9)                | 7 (3.7)    | 0.89               | 2 (3.1)               | 2 (1)                 | 1                    |
| Urology   | 2 (3.3)                | 4 (2.1)    | 0.87               | 2 (3.1)               | 8 (4)                 | 0.21                 |
| Other <sup>b</sup>  | 6 (9.8)                | 18 (9.5)   | 1                  | 3 (4.7)               | 17 (8.6)              | 0.02                 |
| Length of visit   |                        |            |                    |                       |                       |                      |
| Less than 30 min  | 52 (85.2)              | 135 (71.8) | 0.07               | 52 (85.2)             | 137 (69.5)            | 0.07                 |
| More than 30 min  | 9 (14.8)               | 53 (28.2)  |                    | 9 (14.8)              | 60 (30.5)             |                      |
| Who paid  |                        |            |                    |                       |                       |                      |
| My insurance paid the full cost   | 25 (49)                | 124 (67.8) | 0.002              | 24 (45.3)             | 126 (64.9)            | 0.03                 |
| I paid the full cost  | 6 (11.8)               | 6 (3.3)    |                    | 9 (17)                | 12 (6.2)              |                      |
| My insurance paid part, and I paid part   | 7 (13.7)               | 37 (20.2)  |                    | 10 (18.9)             | 45 (23.2)             |                      |
| Other   | 13 (25.5)              | 16 (8.7)   |                    | 10 (18.9)             | 11 (5.7)              |                      |
| Cost of visit   |                        |            |                    |                       |                       |                      |
| Less than \$25  | 5 (45.5)               | 15 (36.6)  | 0.79               | 6 (33.3)              | 16 (30.2)             | 1                    |
| \$26-\$50   | 3 (27.3)               | 16 (39)    |                    | 9 (50)                | 24 (45.3)             |                      |
| \$51-\$100  | 2 (18.2)               | 4 (9.8)    |                    | 2 (11.1)              | 7 (13.2)              |                      |
| More than \$100   | 1 (9.1)                | 6 (14.6)   |                    | 1 (5.6)               | 6 (11.3)              |                      |

<sup>a</sup>Questions on the most recent telemedicine encounter were only asked of people who used telemedicine. The number of respondents in this table is the number who were asked these questions.

<sup>b</sup>Other responses included administrative needs, general wellness or check-ups, exercise/weight/nutrition, counseling or mental health, neurologic exams, and other miscellaneous visit types (previsit for colonoscopy, sleep, and medication management.)

T1: Time point 1; T2: Time point 2

The percentage of missing, prefer not to answer, or do not know responses for individual questions (excluded from this table) ranged from 1.5% to 79.7%, and is provided in *Supplementary Table S6*.

NT, not tested, too few observations.

**Table 5. Reasons for Not Using Telemedicine for People with Multiple Sclerosis that Did Not Receive Telemedicine Services in the Recent Past**

| RESPONDENTS <sup>a</sup>                                   | CROSS-SECTIONAL GROUPS |          |                    | LONGITUDINAL GROUP |              |                      |
|--|------------------------|----------|--------------------|--------------------|--------------|----------------------|
|  | GROUP A                | GROUP B  | A VS. B<br>p-VALUE | GROUP C            |              | T1 VS. T2<br>p-VALUE |
|  | 54                     | 12       |                    | 46                 | 20           |                      |
|  |                        |          |                    | TIME POINT 1       | TIME POINT 2 |                      |
| N (%)  | N (%)                  | N (%)    |                    | N (%)              |              |                      |
| None of my health care providers offer telemedicine visits | 40 (74.1)              | 1 (8.3)  | <0.001             | 40 (87.0)          | 5 (25.0)     | <0.001               |
| My insurance plan does not cover telemedicine              | 9 (16.7)               | 0 (0)    | 0.37               | 7 (15.2)           | 1 (5.0)      | 0.12                 |
| I believe an in-person visit is better                     | 5 (9.3)                | 5 (41.7) | 0.06               | 9 (19.6)           | 10 (50.0)    | 1                    |
| I do not have the necessary phone or internet connection   | 0 (0)                  | 0 (0)    | NT                 | 1 (2.2)            | 0 (0.0)      | NT                   |
| Other  | 10 (18.5)              | 6 (50)   | 0.14               | 5 (10.9)           | 7 (35.0)     | 0.88                 |

<sup>a</sup>Respondents for this table is the number of people who replied that they did not use telemedicine, and also responded to this particular question.

T1: Time point 1; T2: Time point 2

More than one reason could be selected by survey participants.

The percentage of missing, prefer not to answer, or do not know responses for individual questions (excluded from this table) ranged from 58.3% to 76.1%, and is provided in *Supplementary Table S7*.

Zero respondents selected the option "I do not have the necessary equipment."

majority of PwMS responded "yes" (54%). The remainder (46%) either responded "no" or "not sure." The advantages and disadvantages of telemedicine reported were also very similar to our study (although the Italian survey did not ask about COVID-19-related advantages and disadvantages). The main advantage cited was saving time, and main disadvantage cited was inability to measure neurological status. Other studies of telemedicine in PwMS have demonstrated the clinical utility of telerehabilitation<sup>15</sup> and teleneurology.<sup>5</sup> Telemedicine has also been shown to be effective and well received by patients with other neurological conditions, such as chronic migraines,<sup>16</sup> people with Parkinson's disease,<sup>17</sup> and those who require general neurological care.<sup>18</sup>

Both before and during the pandemic a large portion of our survey participants indicated a preference for using telemedicine for some, most, or all of their health care (41–57%). Prepandemic, however, the most common reason for not using telemedicine was that health care providers did not offer telemedicine visits. The policy shifts that occurred as a result of the COVID-19 pandemic emergency made telemedicine more accessible, and dramatically increased the proportion of survey participants who used telemedicine from 25% to nearly 80%. The types of telemedicine visits conducted also shifted

toward visits scheduled in advance and toward general MS care and showed an increase in mental health care. These shifts in the type of telemedicine visits likely reflect the increased availability of specialists using telemedicine during COVID-19, as well as the overall increased need for mental health services that has been widely observed both before and during the pandemic.<sup>19</sup>

Some types of health care services, like mental health care, are more obviously transferrable to telemedicine than others. However, a significant proportion of the patient population expressed a preference for using telemedicine for at least some of their health care for a range of different specialties, including diet/nutrition services, general MS care, mental health services, primary care, and social work services. It is also important to note that the most frequently cited disadvantage of telemedicine was that it is more difficult to receive a full examination, and patient preferences reflected this in the desire for continued in-person care for the more hands-on specialties. These results suggest the need for more training among providers to learn how to optimize the telemedicine exam, and a need to develop new technologies to improve the remote exam. That said, there will be a continued need for in-person visits for specific purposes such as an initial visit.

Our study has strengths and limitations. The iConquerMS cohort includes PwMS who participate in online surveys, and therefore likely have some level of comfort with technology. As such, comfort with and access to technology likely affects patients' experiences with telemedicine, and our findings. The survey period was also before the availability of COVID-19 vaccines in the United States. The availability of vaccines may have changed opinions or behaviors with respect to in-person health care and telemedicine. We also did not examine the relationship between disability and telehealth preferences, which would be a fruitful area for further study. Strengths of our study include the national representation of survey participants, the range of age and disability levels, and the longitudinal assessment of survey data.

## Conclusions

Our survey demonstrates the utility of telemedicine services among PwMS and demonstrates that there is a desire for these services and inherent improvements in access to care in this population. Providers, PwMS, and policy makers can use these results to promote the continued development and reimbursement for telemedicine services for the MS population.

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## Authors' Contributions

L.S. was responsible for the original draft and visualization (lead). All authors contributed to review and editing and validation of results (equal). M.W., H.S., S.M., R.M., and S.L. contributed to the conceptualization and survey methodology (equal). H.S. programed and conducted the survey (lead). N.F. (lead), L.S. (lead), and L.S.(supporting) designed and conducted the formal analysis. M.W. was responsible for overall supervision, project administration, and funding acquisition (lead).

## Data Access Statement

All compiled survey data are available in the online Supplement. Please contact the authors for any further information that may be required.

## Disclosure Statement

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## Supplementary Material

Supplementary Data

Supplementary Table S1

Supplementary Table S2

Supplementary Table S3

Supplementary Table S4

Supplementary Table S5

Supplementary Table S6

Supplementary Table S7

Supplementary Table S8

Supplementary Table S9

## REFERENCES

1. Yamabe K, DiBonaventura MD, Pashos CL. Health-related outcomes, health care resource utilization, and costs of multiple sclerosis in Japan compared with US and five EU countries. *Clinicoecon Outcomes Res* 2019;11: 61-71.
2. Yeroushalmi S, Maloni H, Costello K, et al. Telemedicine and multiple sclerosis: A comprehensive literature review. *J Telemed Telecare* 2020;26: 400-413.
3. Bove R, Bevan C, Crabtree E, et al. Toward a low-cost, in-home, telemedicine-enabled assessment of disability in multiple sclerosis. *Mult Scler* 2019;25: 1526-1534.
4. Wood J, Wallin M, Finkelstein J. Can a low-cost webcam be used for a remote neurological exam? *Stud Health Technol Inform* 2013;190: 30-32.
5. Kane RL, Bever CT, Ehrmantraut M, et al. Teleneurology in patients with multiple sclerosis: EDSS ratings derived remotely and from hands-on examination. *J Telemed Telecare* 2008;14:190-194.
6. Kurtzke JF. Rating neurologic impairment in multiple sclerosis: An Expanded Disability Status Scale (EDSS). *Neurology* 1983;33:1444-1452.
7. U.S. Health and Human Services. Public Health Emergency Declarations. Washington, DC; 2021. Available at <https://www.phe.gov/emergency/news/healthactions/phe/Pages/default.aspx> (last accessed October 12, 2021).
8. U.S. Health and Human Services. Telehealth: Policy changes during COVID-19. Washington, DC; 2021. Available at <https://telehealth.hhs.gov/providers/policy-changes-during-the-covid-19-public-health-emergency/> (last accessed October 12, 2021).
9. Accelerated Cure Project. iConquerMS. Waltham, MA; 2021. Available at <https://www.iconquerms.org/> (last accessed October 12, 2021).
10. R Core Team. *R: A Language and Environment for Statistical Computing*. Vienna, Austria: R Foundation for Statistical Computing, 2020.
11. Wickham H, François R, Henry L, et al. *dplyr: A Grammar of Data Manipulation. R Package*. Version 1.0.2. ed. 2020.
12. Signorell A, et al. DescTools: Tools for descriptive statistics. *R Package*. Version 0.99.41 ed. 2021.
13. Mann DM, Chen J, Chunara R, et al. COVID-19 transforms health care through telemedicine: Evidence from the field. *J Am Med Inform Assoc* 2020;27:1132-1135.

14. Landi D, Ponzano M, Nicoletti CG, et al. Patient's point of view on the use of telemedicine in multiple sclerosis: A web-based survey. *Neurol Sci* **2022**;43: 1197–1205.
15. Tarakci E, Tarakci D, Hajebrahimi F, et al. Supervised exercises versus telerehabilitation. Benefits for persons with multiple sclerosis. *Acta Neurol Scand* **2021**;144:303–311.
16. Chiang CC, Halker Singh R, Lalvani N, et al. Patient experience of telemedicine for headache care during the COVID-19 pandemic: An American Migraine Foundation survey study. *Headache* **2021**;61:734–739.
17. Chen YY, Guan BS, Li ZK, et al. Application of telehealth intervention in Parkinson's disease: A systematic review and meta-analysis. *J Telemed Telecare* **2020**;26:3–13.
18. Davis LE, Coleman J, Harnar J, et al. Teleneurology: Successful delivery of chronic neurologic care to 354 patients living remotely in a rural state. *Telemed J E Health* **2014**;20:473–477.
19. Rajkumar RP. COVID-19 and mental health: A review of the existing literature. *Asian J Psychiatr* **2020**;52:102066.

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