

The Impact of COVID-19 on the Lives of Individuals With Multiple Sclerosis: 1 Year Into the Pandemic

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CE INFORMATION

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TARGET AUDIENCE: The target audience for this activity is physicians, advanced practice clinicians, nursing professionals, mental health professionals, social workers, and other health care providers involved in the management of patients with multiple sclerosis (MS).

LEARNING OBJECTIVES:

1. Compare early-pandemic national and international research assessing the emotional, social, and economic status of patients with MS with the current study of a cohort of patients at the University of Kansas Medical Center MS Clinic 1 year into the COVID pandemic.
2. Characterize and describe the ways the COVID pandemic affected this cohort of patients with MS.

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ABSTRACT

BACKGROUND: The COVID-19 pandemic resulted in implementation of restrictive public health policies requiring people to limit or avoid interaction with others. These policies also had an economic impact. Individuals with multiple sclerosis (MS) already experience higher incidences of depression, anxiety, social isolation, and job loss, and the continuing pandemic may exacerbate these.

METHODS: Between November 2, 2020, and February 12, 2021, 233 individuals with MS completed the Hospital Anxiety and Depression Scale, the modified Medical Outcomes Study Social Support Survey, the Centers for Disease Control/National Institutes of Health Common Data Element Repository economic impact questions, and study team–designed questions about social and family relationships and adherence to public health policies.

RESULTS: Study participants reported high rates of mask wearing, good hand hygiene, and limited interactions with those outside their homes. They felt isolated from family they did not live with, friends, and coworkers. The frequency of conflicts with their spouses/partners increased “a little” among 20% of respondents, but overall relationships with housemates were “unchanged” or “a little better.” Ninety-one percent of participants reported experiencing no financial impact. On the Hospital Anxiety and Depression Scale, 16.0% of 218 respondents reported depressive symptoms and 26.8% of 216 reported symptoms of anxiety above the commonly accepted clinically significant cutoff points. Only 3.4% of participants reported contracting SARS-CoV-2.

CONCLUSIONS: During the first year of the pandemic, this study found no pronounced impact on the emotional, social, or economic stability of the individuals with MS it surveyed. It seems that these study participants adapted to the restrictions created by the pandemic and, by adhering to guidelines, protected themselves from contracting SARS-CoV-2.

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Little is known about the COVID-19 pandemic's impact on individuals with multiple sclerosis (MS). Before the pandemic, mental health difficulties were noted to be more common in individuals with MS than in the general population.^{1,2} Individuals with MS also experience more changes in physical and cognitive function, social isolation, job loss, and an overall reduced quality of life.^{3,4}

Other studies of the pandemic's impact on the mental health and quality of life of individuals with MS were conducted from mid-January through spring of 2020 in North America (Canada, United States),⁵ Europe (Belgium, Denmark, Italy, United Kingdom, Serbia, Spain and Turkey),⁵⁻⁹ China,⁹ and Iran.¹⁰ Comparisons of baseline depression scores gathered up to 1 year earlier revealed no change in 1 study.⁷ Three others^{5,6,8} reported an increase in depression symptoms, with only 1 found to be statistically significant.⁶ A similar pattern was noted for anxiety, with 2 studies reporting no change^{5,7} and 2 noting an increase,^{6,8} but only 1 of these was statistically significant.⁸ During a COVID-19 surge in Iran, a cross-sectional study found reports of moderate to severe anxiety in a cohort of 33 patients.¹⁰

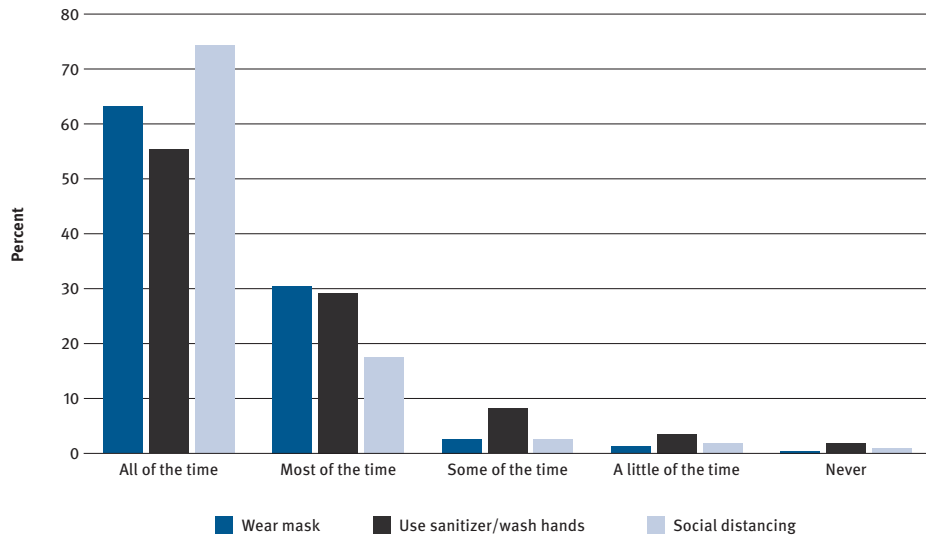
Some authors have speculated that individuals with MS might have some degree of resilience to the uncertainty that the pandemic created.⁷ Because they perceive that they are at greater risk if they contract SARS-CoV-2, patients with MS may be more rigorous when following public health policies. This may make them feel safer and reduce related anxiety and depression.⁵ Social interactions and ratings of support during lockdowns were higher than at baseline,^{5,7} contrary to what had been expected. It is possible that spending more time interacting with live-in family resulted in a perception of increased support.⁸ Furthermore, individuals with more severe forms of MS frequently experience limited social interaction. Consequently, the isolation induced by lockdowns might have been no different from their previous experiences.^{5,7}

Early in the pandemic, individuals with MS in Europe and North America reported little effect on their financial well-being.^{5,9} In contrast, 55% of individuals with MS surveyed in China reported that it had “a lot” or “quite a lot” of impact.⁹ The survey in China took place after lockdowns had been lifted,

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FIGURE 1. Adherence to Public Health Guidelines by Individuals With Multiple Sclerosis

whereas other surveys occurred during initial lockdowns. Those who had been experiencing the pandemic for a longer period may have experienced a greater economic impact.⁹

Although research indicates that the mental health and economic stability of individuals with MS remained relatively stable during the initial months of the pandemic, this could change during a prolonged pandemic. This study focused on the impact of the initial phase of the pandemic on the emotional, social, and economic stability of individuals with MS, including their adherence to guidelines to protect themselves from contracting the virus. Examination of a later pandemic period may help clinicians develop a better understanding of the differences between short- and long-term pandemic effects on individuals with MS.

METHODS

Participants/Procedures

Anonymous surveys were used to gather data from individuals with MS during their return appointments (face-to-face and virtual) at the University of Kansas Medical Center MS Clinic. Data were collected from November 2, 2020, to February 12, 2021. Patients received the survey or a link to it during their clinic appointment. Surveys were returned by mail or by using the link. Surveys asked participants to rate their experiences during the previous month. Inclusion criteria included the ability to read and write English fluently, a definite diagnosis of MS according to the 2017 McDonald criteria,¹¹ age 18 years or older, and the ability to complete the survey independently. This study was approved by the University of Kansas Medical Center institutional review board, and participants were provided with an anonymous survey consent letter.

Measures

Participants reported on their type of MS, MS medications, and disease duration. The Patient-Determined Disease Steps scale was used to self-report mobility.¹² Two items from the Centers for Disease Control/National Institutes of Health Common Data Element Registry addressing the economic impact of the pandemic¹³ were included. The Hospital Anxiety and Depression Scale^{14,15} and the modified Medical Outcomes Study Social Support Survey (mMOS-SSS)¹⁶ were also included.

The study team designed questions regarding the pandemic's impact on relationships and adherence to public health guidelines that were answered using a 5-point Likert scale. Participants rated changes in social and family relationships and degree of isolation that had been experienced with their spouse or partner, live-in family members, non-live-in family members, friends, and coworkers. Participants also rated their adherence to public health guidelines.

Data Analysis

Descriptive statistics were used to describe the sample characteristics and findings, including mean, median, and percentage of frequency reported. Denominators for percentages included only those who responded to the item or who reported having the relationship. Means, medians, and 95% CIs are reported for administered measures.

RESULTS

Of the 233 survey participants, 184 (79.0%) were women. Age was reported in 5-year intervals from 18 to 85 years, with 77.2% of participants aged 31 to 60 years. The median years of education was 16 (interquartile

TABLE 1. Basic Characteristics of the Participants With MS

Overall change in relationship with	Participants, %				
	A lot worse	A little worse	No change	A little better	A lot better
Spouse/partner	1.2	9.4	61.8	20.6	7.1
Live-in family	<0.1	<0.1	68.9	14.4	8.3
Non-live-in family	5.3	18.1	65.5	9.7	1.3
Friends	7.2	26.5	61.4	3.6	1.3
Coworkers	<0.1	12.8	79.5	<0.1	<0.1
Change in frequency of conflicts with	Participants, %				
	Never have conflicts	A lot less often	No change	A little more often	A lot more often
Spouse/partner	7.7	8.9	61.5	20.7	1.8
Live-in family	9.1	9.8	69.7	9.1	2.3
Non-live-in family	12.7	5.0	68.6	12.3	1.4
Friends	18.3	3.2	72.3	6.0	0.0
Coworkers	12.3	2.6	76.3	8.8	0.0
Feelings of isolation with	Participants, %				
	Don't feel isolated	A little isolated	More isolated	A lot more isolated	Feel completely isolated
Spouse/partner	87.5	9.5	1.8	1.2	0.0
Live-in family	83.8	11.1	3.4	1.7	2.6
Non-live-in family	31.7	29.9	21.4	15.6	4.0
Friends	25.2	30.7	25.2	12.8	6.0
Coworkers	55.9	22.0	13.8	5.5	2.6

range [IQR], 14–18). Subtypes of MS reported included relapsing-remitting (70.8%), primary progressive (12.4%), secondary progressive (7.3%), unknown (6.7%), and not reported (2.6%). The median disease duration was 13 years (IQR, 4–20 years). Seventy-seven participants (33.0%) were not taking disease-modifying therapies (DMTs); 62 (26.6%) were taking oral DMTs, 64 (27.5%) were taking platform injectables, 22 (9.4%) were receiving infusions, and 8 (3.4%) did not report their DMT use. Mobility self-ratings on the Patient-Determined Disease Steps scale were normal/mild disability, 50.0%; moderate/gait disability, 17.4%; early/late cane, 16.9%; and bilateral support/wheelchair/scooter, 15.6%.

Of all the participants, 8 (3.4%), all 60 years and younger, reported contracting SARS-CoV-2 per a positive test or diagnosis by a health care provider. **FIGURE 1** reports adherence to public health guidelines. Participants limited their social activities, reporting “never” or “less than 1/week” for attending in-person events (84.2%); eating out (81.5%); and socializing with those not in their bubble individually (70.2%) or in a group (85.4%). Sixty-four percent of participants ran errands “once a week” or “daily.”

The Hospital Anxiety and Depression Scale mean $\pm$ SD and median scores were 6.6 ± 4.1 and 6.0 (IQR, 4.0–9.0; CI, 6.0–7.0) for anxiety and 4.8 ± 3.5 and 4.0 (IQR, 2.0–7.0; CI, 3.5–5.0) for depression. Thirty-five of 218 participants (16.0%) scored above the cutoff value for depression and 58 of 216 (26.8%) scored above the cutoff value for anxiety.

The mMOS-SSS score means, standard deviations, and CIs for the 4 types of support (emotional/information, tangible, positive interaction, and affection) are reported compared with the mMOS-SSS¹⁷ scores standardized to percent of possible (0–100) in **TABLE S1** (published in the online version of this article at ijmsc.org).

Seventy-six percent of participants reported living with a spouse/partner and 63.1% with family members. Other relationships reported: 98.3% had friends; 98% had non-live-in family; and 59.1% had coworkers. See **TABLE 1** for changes in family and social relationships from March 2020 to the time of survey completion for those who reported having these relationships.

Employment was not affected for 55.8% of participants, 22.7% reported increased remote work, 11.2% reported working more than usual, and 11.2% worked with children in the house. Financial status was not affected for 91.0% of the participants. Only 7.3% had difficulty paying bills, and 0.90% lost their home or did not have a regular place to sleep/stay.

DISCUSSION

To our knowledge, this is the first study to describe the 1-year impact of the COVID-19 pandemic on the emotional, social, and economic stability of a group of individuals with MS, including the degree to which they protected themselves from contracting SARS-CoV-2.

Most participants followed public health guidelines, reporting that they wore a mask, completed hand hygiene, and practiced social distancing “all” or “most”

of the time. Participants also reduced their exposure risk by “never” or “rarely” attending in-person events, eating in restaurants, and gathering with others outside their bubble. Although they did run errands, doing so once a week or more, it is possible that they reduced their exposure risk by following public health guidelines. Only 8 study participants (3.4%) reported contracting the virus. On the day the study closed, the confirmed US infection rate was 8.26% of the population (25,454,589 infections¹⁸ vs a total population of 332,131,914¹⁹).

Because individuals with MS demonstrate a higher incidence of mental health difficulties than the general population,^{1,2} one might suspect that the uncertainty and health threats posed by the pandemic would worsen their mental health status. In the international studies surveyed, limited or no change in depression and anxiety was noted.⁵⁻⁸ In the present study sample, mean depression and anxiety scores fell below commonly accepted cutoff values, suggestive of generalized anxiety disorder and major depression.²⁰ Only 16.0% of 218 participants reported depression above these cutoff values, and 26.8% of 216 reported anxiety above these cutoff values. Because a recent study found the prevalence of depression in individuals with MS to be 30.5% and anxiety to be 22.1%,²¹ this sample's mental health seems to be consistent with or slightly better than that of the MS population before the pandemic with a slight increase in anxiety.

The individuals in the present study followed public health guidelines. This finding seems to support a premise presented early in the pandemic that individuals with MS felt safer by following these guidelines, and that choice supported their mental health.⁵ The mental health of the study participants, who attended clinic appointments, may be better than average and may not represent the experience of those not included in the survey. Those who could not/did not attend clinic appointments may have experienced greater social and mental health impacts.

Individuals with more severe MS frequently experience limited social interaction.^{3,4} Some concern was raised that individuals with MS might experience increased social isolation and reduced social support during the pandemic, but the present group seemed to improve over baseline, despite the fact that 50% of the sample rated their mobility between moderately disabled and requiring a wheelchair. Overall, study participants limited their activities outside the home and their participation in in-person events. Not surprisingly, they expressed feelings of isolation from those who were not a part of their household. However, relationships with housemates were the same or “a little” better 1 year after the pandemic began; just more than 20% reported an increase in the frequency of conflicts with spouses/partners. The mMOS-SSS scores were consistently above the normalized mean for all

PRACTICE POINTS

- » Most of the 233 individuals with multiple sclerosis (MS) seen for in-person or virtual follow-up in our MS clinic seemed to adapt to the restrictions put in place because of the COVID-19 pandemic.
- » Most of the 233 patients did not experience declines in their social relationships during the first year of the pandemic and that spending more time with those in their bubble may have improved their support systems.
- » Most of the 233 patients followed public health measures to reduce their risk of contracting the SARS-CoV-2 virus.

4 types of support. It seems that participants received adequate social and emotional support from those in their homes, which likely helped them maintain stable mental health. The present sample had a median disease duration of 13 years, so participants may have already experienced significant lifestyle changes. It is possible that already having experienced significant adversity, they were better able to adjust to lifestyle changes brought on by the pandemic.

Although the risk of contracting the virus in work and social settings resulted in business closures and reduced the workforce in many industries, 91.8% of this cohort reported no financial impact. This sample had an overall higher educational level, which may have contributed to their apparent economic stability, which then likely further supported their mental health.

There were several limitations to this study. The design did not allow for comparison with prepandemic status. The present population was predominantly female, younger, and had higher educational levels. This study examined only the impact of the public health restrictions and no other variables, such as the political climate or overall community reaction to public health guidelines. Furthermore, participants were English speakers recruited during onsite or virtual appointments, and the results may not represent the experience of non-English speakers or those who did not engage in clinic care. Future studies should include these groups and should also study the association between disease severity and the pandemic's socioeconomic effects.

In summary, 1 year into the pandemic, this sample of individuals with MS did not report a notable negative impact on their emotional, social, or economic stability. Based on findings early in the pandemic, it was proposed that the experience of living with an MS diagnosis may lead to a greater level of resilience than that found in the healthy population.⁷ These data seem to support this possibility. The present

study also found that individuals with MS followed public health measures and experienced a low level of SARS-CoV-2 infections overall. Although it may be difficult to measure resilience, it seems that the individuals with MS in this study found the means to adapt to the uncertainty that the pandemic created. They reported good social and emotional support from those within their bubbles and mental health and economic stability. □

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