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Exploring the impact of the COVID-19 pandemic on social isolation and mental health in people with MS



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ARTICLE INFO	A B S T R A C T	
Keywords: COVID Mental health Multiple sclerosis Mood Isolation	Background: People with multiple sclerosis (MS) may be disproportionally impacted by the coronavirus disease of 2019 (COVID-19) as various factors important to their functioning and quality of life are at-risk and/or compromised during the pandemic. In particular, the social distancing and quarantine practice during the pandemic maybe detrimental to MS patients' social and emotional health. Compared with the general population, MS patients may be under increased social strain and suffer worse health consequences from social isolation. To date, there has been no research examining the social consequences of the pandemic on MS patients' emotional and social health.	
	<i>Methods</i> : This is a retrospective longitudinal study of 266 adults with MS who were followed at a large academic medical center in the Midwest. Each participant completed monthly surveys including depression, anxiety, and social health variables.	
	<i>Results</i> : T-Tests shows worse anxiety (95% CI [-5.03, -3.05]; <i>p</i> -value < 0.001), worse depression (95% CI [-2.67, -1.03]; <i>p</i> -value < 0.001), and worse satisfaction with social roles (95% CI [2.37, 3.95]; <i>p</i> -value < 0.001) since the COVID-19 outbreak (March 2020). Social isolation is associated with worse anxiety (95% CI [-8.98, -4.58]; <i>p</i> -value < 0.001) and depression (95% CI [-6.88, -3.24]; <i>p</i> -value < 0.001). However, individuals who had in-person	
	visits before and after the outbreak did not experience any changes in anxiety, depression, or social health. <i>Conclusion</i> : MS patients' anxiety, depression, and social participation worsened during the COVID-19 pandemic. Social isolation is found to be associated with worse anxiety and depression. However, those who attended in- person visits for their MS treatment did not experience negative changes in their emotional or social health. This study highlights the importance of healthcare provider's alertness to MS patients' social health and the	
	interplay between social and emotional health during the COVID-19 pandemic.	

1. Introduction

People with Multiple Sclerosis (MS) may be disproportionally impacted by COVID-19 as various factors important to their functioning and quality of life are at-risk and/or compromised during a pandemic and endemic (Sastre-Garriga et al., 2020). In particular, the social distancing and quarantine practiced during the pandemic may carry psychological consequences for MS patients. It is well-established in the literature that social health facilitates overall well-being, and quality of life in people with disabilities (Skinner et al., 2000; Levasseur et al., 2004). In the case of MS, social health may be especially relevant as many common MS symptoms (e.g., physical immobility, fatigue, vision social health even without the pandemic. Indeed, Stenager et al. (1994) found that people with MS are under increased social strain – almost half of MS patients experienced reduced outgoing social contacts. In addition, management of MS symptoms typically requires regular

problems) interfere with one's social life and complicate MS patients'

In addition, management of MS symptoms typically requires regular and frequent assistance from others, which makes social support particularly essential for MS patients' emotional health. Stenager et al. (1994) found over half of MS patients were dependent on their families for help. Those who have strong social support report less anxiety and depression (Henry et al., 2019). During the pandemic, such support from families may not be accessible for MS patients. The combination of stress from the pandemic, in conjunction with reduced social support, indicate

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that the pandemic could represent a significant mental health challenge for MS patients. Indeed, studies from around the world clearly demonstrate a significant impact of the COVID-19 pandemic on the mental health of MS patients (e.g., 6, 7, 8, 9). Overall, MS patients reported significantly higher depression and anxiety, worse sleep quality, higher perceived fatigue, and reduced quality of life. However, most of these studies were cross-sectional studies conducted during the first wave of the pandemic, so the changes in MS patients' mental health before VS. after the pandemic is less clear.

Moreover, the pandemic has brought about unique challenges to people's social health. The Centers for Disease Control and Prevention identified limiting face-to-face contact with another person as the best way to reduce the spread of the virus. In compliance, multiple states issued stay-at-home orders, quarantine, and shelter-in-place orders to limit face-to-face contact. For many, particularly those who live alone, this has meant little to no human contact for months at a time. This level of social isolation presented unprecedented public health challenges because social isolation is associated with various psychological consequences, such as higher risk for suicidal ideation (Beutel et al., 2017) and poor psychological well-being (Cacioppo et al., 2015). While we do not yet know, and may not know for many years, the full extent of the social and emotional consequences of the pandemic, current evidence does suggest that social and emotional health is significantly impacted by the pandemic. A survey study of US adults found that depressive symptom prevalence was more than 3-fold higher during the COVID-19 pandemic than before (Ettman et al., 2020). At risk populations such as those with lower economic resources were particularly at risk for depressive symptoms. A preliminary survey done in June 2020 (University of Michigan National Poll on Healthy Aging, 2020) found 56% of people over the age of 50 reported feeling isolated from others - more than double the 27% who felt this way in 2018. Nearly half of them reported infrequent social contact (once a week or less) with family, friends, or neighbors. When comparing their feelings in June 2020 to before the pandemic, about half of the survey participants felt more isolated. Compared to the general population, MS patients' social health may be especially affected by the pandemic as they were already at risk for social isolation even predating the pandemic.

Our interest in this study is to expand on current literature and investigate the impact of the pandemic on mental health and social isolation in people with MS by (1) investigating changes in mental health and social participation during the COVID-19 pandemic in people with MS; (2) identifying the consequences of social isolation on mental health; (3) identifying the changes in mental health and social participation among MS patients who utilized in-person visits during the COVID-19 pandemic. Our hypotheses are: (1) anxiety, depression, and social participation worsened during the COVID-19 pandemic; (2) social isolation was associated with worse anxiety and depression since the beginning of the COVID-19 pandemic; (3) considering MS patients who utilized in-person visits may be able to engage in other social activities and experience less social isolation than those utilized virtual appointments, MS patients who utilized in-person visits would experience fewer changes in depression, anxiety, and social participation during the COVID-19 pandemic. We tested these hypotheses at a large tertiary referral center for MS located in Midwest United States where 266 adults with MS were recruited and asked to completed monthly surveys including depression, anxiety, and social health variables.

2. Materials and methods

2.1. Study design and population

This cross-sectional retrospective study recruited MS patients who are followed by a large tertiary referral center for MS. To be eligible, the participants must be an adult with a diagnosis of MS who is also a member of our large internal research database. All database participants complete standardized patient surveys (e.g., demographics, disease characteristics) on a tablet as part of their routine clinical care. Participants competed the survey instrument once a month. The survey was a closed survey that were only given to eligible patients. All participants gave consent to participate and share their de-identified data for research. Responses completed before March 1st, 2020 were categorized as pre-pandemic data, whereas responses completed after March 1st, 2020 were categorized as post-pandemic data. March 1st, 2020 was set as the cutoff date as it was immediately before early cases of COVID-19 were detected and state of emergency was declared in the state of Ohio. The study was approved by the Institutional Review Board of our institute. Deidentified survey data was stored in a secure HIPPA compliant web-based database. The design was described and results were reported following the CHERRIES statement (Eysenbach, 2004).

2.2. Demographics and disease characteristics

Demographics (age, sex, race, ethnicity, employment status, years of education, living situation, marital status), MS characteristics (MS type, years since MS diagnosis), and types of visits (in-person or virtual visits) for their MS care were collected using questionnaires as part of patients' routine clinical care.

2.3. Study outcome measures

The Depression Short form subscale and Anxiety Short form subscale of Quality of Life in Neurological Disorders were used to assess mental health. Quality of Life in Neurological Disorders is a self-report survey to measure health-related quality of life for adults with neurological disorders including MS (Cook et al., 2015). It uses 5-point Likert scale ranging from 1 (never) to 5 (always). The depression subscale measures one's experience of loss and feelings of hopelessness, negative mood, decrease in positive affect, information-processing deficits, negative views of the self and negative social cognition. The anxiety subscale measures unpleasant thoughts and/or feelings related to fear, helplessness, worry and hyperarousal. The raw scores of the two subscales were converted to a t-score (M = 50, SD = 10). Higher scores represent worse depression/anxiety.

To assess participants' social health, we utilized the Satisfaction with Social Roles and Activities subscale of Neuro-QoL. This subscale measures one's satisfaction with involvement in one's usual social roles, activities and responsibilities including work, family, friends and leisure. The raw scores of this subscale were also converted to a t-score. Higher scores represent better satisfaction with social roles and activities. In addition, to evaluate participants' sense of social isolation during the COVID-19, we included a single question in the survey: "Since the COVID-19 outbreak, do you feel more socially isolated?" The participants could either respond "yes," "no," or skip this question.

2.4. Statistical methods and data analysis

Descriptive statistics of continuous variables were reported as mean and standard deviation. Categorical factors were summarized with frequency (%). Differences between patients' depression, anxiety, and social health scores before and after March 2020 were assessed by Dependent T-Test. Differences of anxiety and depression among patients felt socially isolated and among those who did not since the pandemic were assessed by Student's T-Test. Demographic comparisons were done using Student's T-Test, Chi-Square Test or Fisher exact test as appropriate. Significance level was set at p < 0.05. Analyses were done using R Statistical Software (version 4.0.2). Normality of distribution was evaluated and ensured by qq plots. T-tests were chosen to analyze group differences because of the normal distribution, its appropriateness for our design, and simplicity for interpretation. A very low level of missing data was observed at the item level (e.g., 2 for anxiety subscale, 1 for depression, 0 for satisfaction with social roles and activities subscale).

3. Results

The demographic and clinical data are displayed in Table 1. A total of 266 patients were included in the survey analyses.

The study participants were predominantly female (74.4%), white (92.9%), and non-Hispanic (94.7%). The mean age of the participants was 51.5 (SD 12.4). As for employment status, over half of the participants were employed (53.8%), 24.4% identified as disabled/unemployed, 15.8% identified as retired, and 6.0% identified as other. The mean years of education is 15.7 (SD 2.34). The majority of the participants were married (71.1%) and living without assistance (91.4%). On average, participants have been living with MS for 17.6 years (SD 11.7). A total 68.8% of the participants has RRMS, 20.3% SPMS, 7.5% PPMS, and 3.4% PRMS.

To assess for survey response-bias, we compared our sample's demographics to our large internal MS patients database who did not fill out the survey. Database participants who enrolled between January 2019 and February 2020 were collected (n = 18,382). When compared with the internal database enrollees (N = 18,382), the COVID-19 survey sample significantly differed in race, ethnicity, employment status, years of education and living situation. The demographic differences are displayed in Table 2.

3.1. COVID19 pandemic's impact on mental health

Graph 1 displays the differences in participants' anxiety, depression, and satisfaction with social roles scores pre- and post- pandemic. After

Table 1

MS patient demographic and clinical data.

	Overall
	(N = 266)
Age	
Mean (SD)	51.5 (12.4)
Sex	
Female	198 (74.4%)
Male	68 (25.6%)
Race	
White	247 (92.9%)
Black	10 (3.8%)
Unknown	9 (3.4%)
Ethnicity	
Hispanic	6 (2.3%)
Not Hispanic	252 (94.7%)
Unknown	8 (3.0%)
Employ Status	
Disabled/Unemployed	65 (24.4%)
Employed	143 (53.8%)
Retired	42 (15.8%)
Other	16 (6.0%)
Years of Education	
Mean (SD)	15.7 (2.34)
Marital Status	
Married	189 (71.1%)
Divorced	26 (9.8%)
Single	50 (18.8%)
Other	1 (0.4%)
Living Situation	
Home With Assistance	22 (8.3%)
Home Without Assistance	243 (91.4%)
Unknown	1 (0.4%)
Years of MS	
Mean (SD)	17.6 (11.7)
MS Type	
RRMS	183 (68.8%)
SPMS	54 (20.3%)
PPMS	20 (7.5%)
PRMS	9 (3.4%)

Abbreviations: RRMS, relapsing-remitting MS; SPMS, secondary progressive MS; PPMS, primary progressive MS; PRMS, progressive-relapsing MS.

Tab	le 2		
MS 1	patient	demographic	differences

	MSPATH	COVID-19 Survey	<i>p</i> -value
	N = 18,382	N = 266	
Race:			< 0.001
White	10,176 (55.4%)	247 (92.9%)	
Black	1694 (9.22%)	10 (3.76%)	
Other	4661 (25.4%)	0 (0.00%)	
Unknown	1851 (10.1%)	9 (3.38%)	
Ethnicity:			< 0.001
Hispanic	628 (3.42%)	6 (2.26%)	
Not Hispanic	10,650 (57.9%)	252 (94.7%)	
Unknown	7104 (38.6%)	8 (3.01%)	
Employ Status:			< 0.001
Employed	6681 (40.3%)	143 (53.8%)	
Disabled/Unemployed	4474 (27.0%)	65 (24.4%)	
Retired	2428 (14.7%)	42 (15.8%)	
Other	2977 (18.0%)	16 (6.02%)	
Years of Education	14.2 (3.18)	15.7 (2.34)	< 0.001
Living Situation:			< 0.001
Home With Assistance	2761 (15.0%)	22 (8.27%)	
Home Without Assistance	13,473 (73.3%)	243 (91.4%)	
Unknown	2148 (11.7%)	1 (0.38%)	

the pandemic, MS participants experienced worse anxiety (mean difference: -4.03; 95% CI [-5.03, -3.05]; *p*-value < 0.001), worse depression (mean difference: -1.85; 95% CI [-2.67, -1.03]; *p*-value < 0.001), and less satisfaction with social roles and activities (mean difference: 3.16; 95% CI [2.37, 3.95]; *p*-value < 0.001).

3.2. COVID-19 pandemic's social implications

Social isolation was defined by answers to "Since the COVID-19 outbreak, do you feel more socially isolated?" in COVID-19 survey. 183 patients answered "yes", 80 answered "no", and 3 patients did not respond to this question. Graph 2 displays the differences in anxiety and depression between those who endorsed feeling more socially isolated and those who did not. For participants who endorsed feeling more socially isolated since the pandemic, their anxiety (mean difference: -6.78; 95% CI [-8.98, -4.58]; p-value < 0.001) and depression (mean difference: -5.06; 95% CI [-6.88, -3.24]; p-value < 0.001) are significantly worse than those who did not feel more socially isolated.

3.3. Changes in emotional health and social health among those who utilized in-person visits

Changes in emotional and social health among patients who utilized in-person visits was evaluated using the internal research database. We identified MS patients who utilized in-person visits pre- and post- the COVID-19 pandemic. Patients who completed their in-person visits between January 2019 and February 2020 were classified as prepandemic, whereas those completed their in-person visits afterwards were classified as post-pandemic. Group comparison pre- and post- the COVID-19 pandemic is shown in Table 3. No differences between the pre- and post- pandemic participants were found on the demographic or MS characteristic, (p > 0.05), meaning that there were no pre-existing group differences on those variables. Among MS patients who utilized in-person visits, their anxiety, depression, and satisfaction with social roles did not change significantly after the COVID-19 pandemic.

4. Discussion

This study yielded several important conclusions regarding the social implications of the COVID-19 pandemic among MS patients. First, we found evidence that some MS patients' depression, anxiety, and social health have declined during the COVID-19 pandemic. Interestingly, MS patients who utilized in-person visits for the routine care did not experience significant declines in their emotional and social health. In



Graph 1. Differences in participants' anxiety, depression, and satisfaction with social roles scores pre- and post- pandemic.



Graph 2. Differences in anxiety and depression between participants who endorsed feeling more socially isolated vs. those who did not.

addition, our findings indicated that poorer social health was associated with worse anxiety and depression among MS patients.

Our finding - that anxiety and depression worsened during the COVID-19 pandemic confirmed previous research (Motolese et al., 2020; Ramezani et al., 2021; Alirezaei et al., 2022; Zhang et al., 2021). These findings underlie the importance of checking in with MS patients about their emotional health. Previous literature has shown that following a serious natural disaster, the mental health consequences long outlast the physical ones (Bromet et al., 2011). This suggests the emotional health decline we found, will likely persist well beyond the pandemic. Before the COVID-19 pandemic, the MS patients were already at higher risk for depression and anxiety than the general population (Beutel et al., 2017). For example, a cohort study (Wood et al., 2013) shows anxiety (44.5%) and depression (18.5%) were extremely common among individuals with MS. Here our study shows that MS patients' depression and anxiety exacerbated during the pandemic. As a result, they may be at even higher risk of psychological illnesses for the foreseeable future. MS care providers should pay particular attention to the psychological impact of the pandemic.

Perhaps the most interesting finding of this study is that the patients who utilized in-person visits retained their emotional and social health throughout the pandemic. This could be because patients who were able to use in-person visits for their MS routine care chose to attend other social activities, which helped buffer against the emotional toll of the pandemic. This result further supports our findings that poorer social health is linked with worse anxiety and depression among MS patients. It also serves as an important reminder that while the use of telemedicine offers promising potential (Bokolo, 2021), in-person visits have their own merit by encouraging patients to leave their homes and engage with a care-provider in a safe environment. The pandemic has significantly changed how MS outpatient care is delivered in health care settings. To decrease the risk of transmitting the COVID virus to patients, providers converted a sizable number of in-person visits to telemedicine visits. In April 2020, overall telehealth utilization for office visits and outpatient care was 78 times higher than in February 2020 and has remained relatively stable since then (Bestsennyy et al., 2022). As the social distancing restrictions start to lift in the United States, MS care providers and policy makers face the important question of whether to continue encourage use of telehealth. Our finding regarding in-person visit's benefit may be relevant for clinicians and policy makers.

We observed that MS patients with poorer social health have poorer depression and anxiety. This confirms our hypothesis and is clinically relevant. Caregivers who work with MS patients should assess their patients' social well-being and provide support when needed. Some interventions that may enhance social health include support groups, enhancing one's natural networks, and one-on-one counseling. When warranted, a referral to health psychology may be beneficial to help the patient get connected with these interventions. In addition, while the psychiatric consequences of returning to work may be low among the general population (Tan et al., 2020), special populations such as MS patients (Zanghì et al., 2020) have been found to experience clinically significant post-traumatic stress disorder symptoms, anxiety, depression, and stress when they go back to work. As such, MS patients' psychological health may be exacerbated even further as they resume work. Clinicians should be mindful of this possibility and bring it up with their patients when appropriate and needed. Psychological interventions can also help MS patients deal with stress and thus mitigate possible psychiatric issues when they return to work.

Table 3

Participant demographics comparison pre- and post- the COVID-19 pandemic.

	Before <i>N</i> = 3818	After N = 325	P-value
Age	50.4 (12.6)	50.0 (12.1)	0.602
Sex:			0.097
Female	2789 (73.0%)	223 (68.6%)	
Male	1029 (27.0%)	102 (31.4%)	
Race:			0.251
White	3151 (82.5%)	261 (80.3%)	
Black	418 (10.9%)	35 (10.8%)	
Unknown	249 (6.52%)	29 (8.92%)	
Ethnicity:			0.427
Hispanic	112 (2.93%)	8 (2.46%)	
Not Hispanic	3579 (93.7%)	302 (92.9%)	
Unknown	127 (3.33%)	15 (4.62%)	
Employ Status:			0.614
Employed	1959 (51.3%)	172 (52.9%)	
Disabled/Unemployed	1192 (31.2%)	93 (28.6%)	
Other	667 (17.5%)	60 (18.5%)	
Years of Education	14.5 (2.50)	14.6 (2.50)	0.253
Marital Status:			0.861
Married	2418 (63.3%)	199 (61.2%)	
Divorced	399 (10.5%)	36 (11.1%)	
Single	958 (25.1%)	86 (26.5%)	
Other	43 (1.13%)	4 (1.23%)	
Living Situation:			0.288
Home With Assistance	673 (17.6%)	47 (14.5%)	
Home Without Assistance	3070 (80.4%)	273 (84.0%)	
Unknown	75 (1.96%)	5 (1.54%)	
Years of MS	16.9 (11.6)	16.2 (11.6)	0.263
MS Type:			0.349
RRMS	2192 (63.9%)	175 (60.6%)	
SPMS	644 (18.8%)	56 (19.4%)	
PPMS	304 (8.87%)	25 (8.65%)	
PRMS	289 (8.43%)	33 (11.4%)	
Depression t-score	46.1 (7.99)	46.5 (8.26)	0.553
Anxiety t-score	49.0 (9.62)	49.9 (9.37)	0.212
Satisfaction with social roles t-score	47.0 (7.89)	46.2 (7.91)	0.216

This study presents several limitations. First, due to the nature of the cross-sectional survey, the findings of this study are correlational in nature and should be interpreted with caution. Second, we recognize the potential for bias, particularly response bias, which could impact data quality. The fact that our survey solely relied on self-report measures may introduce response bias such as social-desirable responding (Holtgraves, 2004). Future research may benefit from including objective measures, a structured interview, or a measure of social desirability. In addition, while some evidence supports response equivalence between in-person survey and online survey (McMorris et al., 2009), the differences we found between participants who utilized in-person visits versus virtual visits may be influenced by different survey delivery modes. Third, the generalizability of the results may be limited as the sample is not representative of the general MS population. In particular, the COVID-19 survey participants were drawn from a convenient sample that required computer/smart device access. Compared with the MS PATHS participants, the survey sample participants were less racially diverse, more employed, more educated and required less assistance at home. As such, the survey sample likely represented higher functioning level when compared to the general MS population. Future research should gather a more diverse sample that includes participants with and without computer/smart device access.

5. Conclusion

This study marks a needed step forward in assessing the emotional and social impact of the COVID-19 pandemic. Indeed, a recent article in *Lancet* (Holmes et al., 2020) called for research that "ascertain the effects of lockdown and social isolation." Practitioners and policymakers can use our findings to inform their actions to alleviate the social and emotional consequences of the COVID-19 pandemic.

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Authors contribution

All listed authors (Drs Shu Ling, Brandon Moss, Amy Sullivan and Ms Zhini Wang) meet the criteria for authorship set forth by the International Committee of Medical Journal Editors and have significantly contributed to, seen, and approved the final submitted version of the manuscript. This manuscript has not been previously published and is not being considered for publication in another journal. No conflict of interest related to this paper was acknowledged. All authors are available to provide any data related to their own consulting, inventions and funding. Medical writing, editorial assistance, and submission were not funded.

Declarations of Competing Interest

No acknowledgements, no funding or competing interests related directly to this article. Dr. Moss and Dr. Sullivan both disclose relationship with industry in the past 2 years, that are not related to this article:

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