

RESEARCH ARTICLE

The Socioeconomic and Psychological Impact of the COVID-19 Pandemic on People with Multiple Sclerosis in Turkey

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ABSTRACT

Introduction: Various restrictions due to the coronavirus infection have affected working life globally. People with multiple sclerosis (pwMS) have several difficulties in social life, patient follow-up, and receiving treatments. In this study, we aimed to evaluate the experiences of pwMS during the COVID-19 pandemic.

Method: We developed a 50-question survey aiming to determine fears, anxieties, and the problems experienced by patients regarding their diseases and social lives during the COVID-19 pandemic. The questionnaire was released online via the Turkish MS Society website, local MS societies websites, and social media accounts. Only the answers of the patients who filled out the questionnaire completely were evaluated.

Results: In total, 6008 patients took the survey, and 3255 of them completed the questionnaire. Among all, 378 patients (11.6%) were

positive for COVID-19. The most common COVID-19-related symptom was fatigue (48.4%). The routine medical follow-up was interrupted in 61.4% and the medication was discontinued in 14% of the patients. Approximately 25% of the patients reported different symptoms related to relapse activity. The main concern of the patients related to the COVID-19 pandemic was the disruption of the health of the ones they loved. Among all the patients, 4.4% lost their jobs.

Conclusion: Our data showed that the COVID-19 pandemic strongly affected the working lives of pwMS. Also, the pandemic changed the attitudes of patients and neurologists. Therefore, the long-term effects of the COVID-19 pandemic on disease approach, patient follow-up, social conditions, and working life should be monitored.

Keywords: Multiple sclerosis; pandemic; psychological effects; socioeconomic effects

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INTRODUCTION

Multiple Sclerosis (MS) is an auto-immune, neurodegenerative disease affecting the central nervous system (1). The estimated number of people with MS (pwMS) is more than three million worldwide, including approximately 70,000 patients in Turkey (2,3). MS is the most common non-traumatic disability among young people around the world, and most of those young pwMS are active in working life. Therefore, it is crucial to continue treatment to prevent disability and proceed with working life (4).

Coronavirus (SARS-CoV-2) infection (coronavirus disease 19 [COVID-19]) may cause severe acute respiratory syndrome (5). The number of infected patients is nearly 470 million, and more than 6 million people are dead due to the COVID-19 pandemic (https://www.worldometers.info/coronavirus/). In Turkey, the first case was reported on March 10, 2020, and the first death was on March 17, 2020.

Due to respiratory transmission, various restrictions have been applied since the COVID-19 pandemic. Some of those are curfews, temporary closures of workplaces, travel restrictions between cities, or total lockdowns. As a result, many countries have been economically affected, leading to a decrease in the number of working people (6,7).

These restrictions also led to several difficulties in pwMS, such as getting fired, financial problems, lack of public transport to hospitals, cancelling physician consultations, and delays in receiving medications. In addition, many tertiary centers were converted into pandemic hospitals, and outpatient clinics cancelled appointments. Therefore, cornerstones of MS, such as patient follow-up, magnetic resonance imaging (MRI) monitoring, and treatment applications, were negatively affected (8).

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Highlights

- Routine medical examinations of MS patients were ineffective during the COVID-19 pandemic.
- More than one-third of the pwMS could not perform all the tests required for their MS relapse symptoms.
- MS patients' main concerns were COVID-19 diagnosis and MS relapses.
- The COVID-19 pandemic strongly affected the working lives of pwMS.

The COVID-19 pandemic has exposed the link between socioeconomic difficulties and health outcomes, especially in the area of chronic neurological diseases. For this reason, our study primarily aimed to examine working life, the consequences of delays in treatment, and the follow-up of pwMS in a national cohort during the pandemic conditions. We secondarily investigated attitudes towards the COVID-19 pandemic and the methods to cope with the current circumstances.

METHOD

Questionnaire

The questionnaire was developed by a professional team of experts, including MS physicians, psychologists, pwMS, and statisticians. A 50-question survey was developed, aiming to determine the problems experienced by patients regarding their diseases and social lives during the course of the pandemic. The questionnaire consisted of six parts, which took approximately 15 minutes to complete. All items of the survey were designed as follows:

The first section included sociodemographic data; the second section included MS diagnosis and comorbid disease; the third section included current MS treatments; the fourth section included the reasons for treatment discontinuation during the pandemic, the fifth section included relapse-related conditions; and the sixth section included data on fears and anxieties related to the pandemic. Pandemic-related concerns were evaluated by asking participants yes or no questions.

Participants

The study was designed as a web-based and cross-sectional study. The study link was released online via the Turkish MS Society website, local MS Society websites, and social media accounts, including Whatsapp, Facebook, and Instagram, between July 1st, 2020 and February 28th, 2021. The survey was accessed by 6008 pwMS from 7 regions of Turkey. The answers of 3255 MS patients who volunteered to participate in the questionnaire and answered all the questions were evaluated. The study was approved by the Republic of Turkey Ministry of Health and Acıbadem University Ethics Committee (approval number: 2020-12/23).

Statistical Analysis

The data were analyzed using IBM SPSS Statistics for Windows, version 24 (IBM Corp., Armonk, NY, USA). Kolmogorov-Smirnov and Shapiro-Wilk tests were used to test the normality of the data. Quantitative data were given as mean, standard deviation, and categorical data were given as frequency and percentages. For comparisons of the variables not distributed normally between the groups, the Mann-Whitney U test was used. A Wilcoxon signed-rank test was used for numerical data analysis for two dependent groups. The results were evaluated using a 95% confidence interval, and p<0.05 was considered statistically significant.

RESULTS

Study Population (patients' characteristics)

A total of 6008 pwMS accessed this study via the web. At the end, 2753 people were excluded from the study due to incomplete answers, and the questionnaires of 3255 pwMS were evaluated. Data was accumulated from every region of Turkey; but, most of the participants were from large cities.

Demographics and Clinical Characteristics

We presented the demographic data of 3255 pwMS in Table 1. The mean age of the participants was 37.8, and 72.4% of the patients were female. The clinical phenotype was predominantly relapsing-remitting MS (RRMS); however, most participants were not aware of their disease course type. Most of the pwMS (32.8%) treated frequently used injection treatments. In addition, 16.5% of the participants had no treatment, and 5.1% of them did not know the name of their medication. Another remarkable point was that one-third of the patients were smokers.

COVID-19 Status of the Patients

Of the 3255 patients, we observed that 631 patients (19.4%) had symptoms consistent with COVID-19 infection, and 495 of them (15.2%) were tested. Reverse Transcriptase-Polymerase Chain Reaction (RT-PCR) swab tests showed that 11.6% of the whole cohort and 59.6% of the suspected cases (378 patients) were positive for COVID-19. The most common symptom related to COVID-19 was fatigue (48.4%). The other common complaints were cough (43.9%), fever (40.2%), headache (27.5%), and myalgia (25.4%). Only 23 patients (0.007%) were hospitalized, and no patient was intubated or admitted to the Intensive Care Unit (Table 2).

Patient Follow-up During the Pandemic

In our survey, 61.4% of the participants reported that their follow-up was interrupted during the COVID-19 pandemic. The most common response was "I did not want to go to the hospital due to the pandemic" (73.85%). The second common answer was, "I did not go to the hospital because I thought the routine tests could not be performed anymore during the pandemic" (30.19%). In addition, participants stated hospital-related disruption reasons such as appointment cancellation (26.38%)

Table 1. Clinical and demographic data of the patients

Demographics	Patients (n=3255)
Age, mean ± SD (range)	37.78±9.37 (18-62)
Gender	
Female	2356 (72.4%)
Male	899 (27.6%)
Disease duration (years, mean ± SD, range)	8.85±6.93 (1-29)
Clinical Phenotype	
Relapsing-Remitting MS	28.1%
Secondary-Progressive MS	3.6%
Primary-Progressive MS	6.0%
"I do not know the clinical phenotype"	62.1%
Current treatment	
Interferon beta	20.1%
Glatiramer acetate	12.7%
Teriflunomide	9.4%
Dimethyl fumarate	12.7%
Natalizumab	4%
Ocrelizumab	15.2%
Alemtuzumab	0.4%
Other	3.8%
No treatment	16.6%
I do not know the treatment	5.1%

MS: Multiple sclerosis; SD: Standard deviation

Table 2. COVID-19 status in MS patients

	Patients (n=3255)
Suspected of having COVID-19	631 (19.4%)
Tested for COVID-19	495 (15.2%)
Positive RT-PCR swab test result for COVID-19	378 (11.6%)
Being in contact with COVID-19 positive people	683 (20.9%)
Relative or family member who had COVID-19 diagnosis	420 (12.9%)
Symptoms related to the COVID-19 (n=378)	
Fatigue	183 (48.4%)
Cough	166 (43.9%)
Fever	152 (40.2%)
Headache	104 (27.5%)
Myalgia	96 (25.4%)
Loss of smell	86 (22.7%)
Loss of taste	80 (21.2%)
Sore throat	78 (20.6%)
Bone joint	74 (19.5%)
Other	103 (27.2%)
Hospitalization	23 (6%)

Table 3. Patient follow-up throughout the COVID-19 pandemic

Has your routine patient follow-up been disrupted during the COVID-19 pandemic?	n=3255					
Yes	61.46%					
No	38.54%					
What was the reason for the disruption?						
I did not want to go to the hospital due to fear of getting the infection	73.85%					
I could not go to the hospital because I could not perform the tests	30.19%					
My appointment has been canceled	26.38%					
Travel restrictions	13.59%					
Age restriction	2.67%					
Conversion of the hospital into a pandemic unit	0.91%					
I could not get in touch with my doctor	0.79%					
I did not have any complaints	0.68%					
Personal reasons	0.4%					
I was too busy	0.34%					
I called my doctor via phone/online platforms	0.11%					
No answer	0.11%					
Did you discontinue your current treatment?						
No	2799 (86%)					
Yes	455 (14%)					

Table 4. The reasons for treatment discontinuation throughout the pandemic period

	Total (n=455)	Female	Male	р
Physician decision	32.52%	30.01%	40.05%	0.54
Patient decision	19.34%	19.61%	18.42%	0.78
Pregnancy or pregnancy planning	17.14%	22.52%	N/A	N/A
Drug side effect	11.85%	12.68%	9.21%	0.23
I postponed my treatment due to the pandemic; however, I consider to receive it at a proper time	8.80%	5.79%	20.26%	0.02
Drug inefficacy	6.59%	6.35%	7.36%	0.67
Difficulty in drug supply	2.89%	1.89%	4.70%	0.05
Physician decision due to the COVID-19 diagnosis	0.87%	1.15%	0%	<0.01

P values were calculated by the chi-square test. N/A: not applicable. Alpha value (<0.05 significant)

Table 5. Data of relapse-related conditions

Did you have any sign of relapse during the COVID-19 pandemic period?	Yes n=830	No n=2425	р		
Total (n=3255)	25.52%	74.48%			
Female (n=2356)	26.18%	73.82%			
Male (n=899)	23.91%	76.09%			
18-24 years	35.10%ª	64.90%	<0.01		
25-34 years	28.57%ª	71.43%	0.02		
35-44 years	23.68%	76.32%	0.67		
45-54 years	21.10%	78.90%	0.58		
55-64 years	19.46%	80.54%	0.52		
65+ years	21.74%	78.26%	0.59		
Employed	23.57%	76.43	0.67		
Unemployed	28.02% ^a	71.98%	0.02		
With comorbidity	30.31% ^a	69.69%	0.01		
Without comorbidity	24.47%	75.53%	0.69		
Did you perform all the tests required for your relapse symptoms in the hospital?					
None of them is done	10.	28%			
Partially done	24	24.9%			
Performed all	64.	82%			
Did you have physician consultation during relapse symptoms?					
Consultation achieved	8	83%			
Consultation did not achieved	1	17%			
Did you receive steroid?					
Received steroid	58	.1%			
Did not received steroid	41	41.9%			

 $^{^{\}rm a}\text{Statistically significant}$ according to study population ratio*

Table 6. Prominent concerns associated with the COVID-19

Patients (n=3255)	Female	Male	р
Disruption of the health of ones I love	19.78%	20.33%	0.45
Diagnosis of COVID-19	17.92%	18.14%	0.78
Worsening of my disease (MS)	15.53%	15.56%	0.67
Having a new relapse	11.58%	11.78%	0.55
Anxiety for the future of my child/children	10.54%	10.77%	0.33
Anxiety for my own future	8.36%	8.23%	0.39
Getting away from family and friends	6.45%	6.39%	0.87
Financial problems	4.95%	3.80%	0.01
Being unemployed	2.02%	3.99%	0.02
Interruption of education life	0.93%	0.94%	0.51
I do not want to answer	2.19%	1.65%	0.04

p: Alpha value (<0.05 significant)

Table 7. Working-life conditions during the COVID-19 pandemic

	Female	Male	р	RRMS	SPMS	PPMS	р	Secondary school and lower	High school	University and higher	р
Please describe your employment	status duri	ng the CO	VID-19 p	andemic?							
Home-office	28.4%	24.0%	0.86	32.8%	34.4%	28.1%	0.56	2.7%	10.9%	35.2%	<0.01
I continued to work full-time as before the pandemic	8.6%	17.0%	0.03	9.8%	3.3%	4.4%	0.02	11.4%	12.7%	10.7%	0.63
I switched to flexible working/ part-time working system	7.4%	16.3%	0.03	8.6%	6.6%	8.8%	0.59	9.8%	11.4%	9.8%	0.63
I was on official permission due to MS diagnosis	10.0%	13.3%	0.58	14.7%	11.5%	12.3%	0.61	2.7%	9.2%	12.6%	0.02
I had to quit my job	2.5%	2.9%	0.64	2.0%	1.6%	2.6%	0.65	7.6%	3.0%	1.8%	0.03
I changed my routine shift time	0.2%	0%	0.73	0.2%	0%	0%	0.73	0%	0%	0.2%	0.73
I got fired	1.6%	2.4%	0.52	1.0%	3.3%	0%	0.048	2.7%	2.5%	1.5%	0.58
Free permission	5.7%	6.6%	0.71	4.9%	1.6%	7.0%	0.04	11.4%	9.5%	4.1%	0.03
I was not working when the pandemic started	35.6%	17.6%	<0.01	26.0%	37.7%	36.8%	0.03	51.6%	40.8%	24.0%	0.02
Do you think multiple sclerosis pos	es an incre	ased risk	for conti	racting CO	VID-19 inf	ection?					
Yes	60.6%	53.9%	0.62	56.7%	49.4%	65.1%	0.04	69.1%	60.9%	56.4%	0.62
No	39.4%	46.1%	0.61	43.3%	50.6%	34.9%	0.03	30.9%	39.1%	43 6%	0.63

PPMS: Primary progressive multiple sclerosis; RRMS: Relapsing-remitting multiple sclerosis; SPMS: Secondary progressive multiple sclerosis; P values were calculated by chi-square test

by the hospital management. The others were the conversion of hospitals into pandemic clinics (0.91%) and communication difficulties with their physicians (0.79%). One of the most important issues was the discontinuation of the current MS treatment during the pandemic. We observed that 455 patients (14%) discontinued their therapy during the COVID-19 pandemic (Table 3). The most common cause for treatment discontinuation was physician decision (32.52%). This was followed by the patients' own decision (19.34%). The rate of pwMS who stopped treatment with physician decision due to the diagnosis of COVID-19 infection was only 0.87%. The other reasons are listed in Table 4.

Relapse Status During the Pandemic

Eight hundred thirty-one (25.52%) of pwMS reported different symptoms related to relapse activity during the COVID-19 pandemic. In addition, we observed that patients between 18 and 24 years old, unemployed, and people with comorbidities described more relapse-related symptoms than other groups. No patients had a severe COVID-19 infection due to corticosteroid therapy.

We evaluated the feasibility of the required tests for relapse symptoms in the hospital. Sixty-four percent of the patients described that all necessary tests were done. However, 35.18% indicated that they could not complete the required examinations. On the other hand, 17% of the patients reported that a physician did not evaluate them during relapse symptoms, and 58.1% received steroids due to the relapse activity (Table 5).

Concerns of the Patients Related to the COVID-19 Pandemic

In this part of the questionnaire, patients were asked to express their anxieties related to the pandemic. The most-reported situation was the disruption of the health of the ones they love. The other striking answers were the diagnosis of COVID-19, the worsening of MS, a new relapse, and future anxiety for their family. In addition, female patients were more anxious about financial problems, and male patients were concerned about being unemployed (Table 6).

Working-life Status During the Pandemic

We evaluated the working lives of our patients during the COVID-19 pandemic. Twenty-seven percent of the patients started working from home. This rate was 35.2% in highly educated patients (university degree); however, only 2.7% of patients with less than 12 years of education worked from home (p<0.01). Eleven percent of the pwMS continued to work full-time just like before the pandemic, and 10.2% of the patients switched to a flexible or part-time working system. Patients becoming

unemployed constituted 4.4% of the participants. Two-point six percent had to quit their current jobs, and 1.8% of the patients were fired. Another remarkable point was that approximately one-third of the patients were not already working before the pandemic.

Almost 59% of patients reported that MS puts them at a higher risk of contracting COVID-19 infection. This perception was similar even in highly educated patients (56.4%) (Table 7).

DISCUSSION

This study examined the effects of COVID-19 on pwMS and the data from the study belongs to the period of the first 2 waves of the pandemic. Our main aim was to evaluate the conditions, including patient follow-up, working life, and patient attitudes during the pandemic. Firstly, we observed that the routine visits of pwMS were mostly disrupted. A significant part of the patients did not go to the hospital out of their own accord or postponed their appointments because they thought they would not be able to perform the tests to evaluate the disease activity. Also, outpatient clinic appointments have been cancelled due to community-based restrictions or the transformation of tertiary centers into pandemic hospitals.

The second important point in patient follow-up was that pwMS have experienced various difficulties in receiving treatments at the early stages of the pandemic. It is known that approximately 70% of pwMS are still under treatment worldwide (9). In our study, we observed that 14% of our patients did not receive medication during this period. Treatments were delayed or postponed most frequently due to the decisions of the physicians. Also, we observed that the patients either stopped the treatments out of their own accord or postponed them to start again at the proper time. In the early stages of the pandemic, it was unknown whether MS treatments would have a negative impact on COVID-19. However, after some early data, it was recommended to delay anti-CD20 treatments in particular (10). After all, the treatments were started again and people receiving anti-CD20 treatments were warned about the strict sanitary rules and social distancing restrictions (11). In addition, our data showed that the treatment discontinuation rate due to COVID-19 was less than 1%. Still, the treatment approach in our country is to continue MS treatments unless a severe COVID-19 infection occurs.

Corticosteroids are the first-line treatment for MS relapses. In some studies (12), steroids were associated with a high rate of opportunistic infections. Moreover, other studies have shown an increased mortality risk with high-dose steroids in patients with COVID-19 infection (13,14). However, several studies showed no association between high-dose corticosteroids and the risk of COVID-19 infection (11). Due to these different opinions, there was no consensus on receiving steroids for MS relapses at the beginning of the pandemic. While some centers recommended limiting steroids, others showed a similar approach to the pre-pandemic period. In our study, we observed that one-quarter of the patients described symptoms related to relapse. In addition, patients with comorbidity and unemployed patients had more complaints related to relapse activity. More than one-third of the pwMS could not perform all the tests required for their relapse symptoms, and physician consultation was not obtained in 17% of the patients. In addition, over half of the patients received steroids due to the relapse activity during this period. Sormani et al. found increased risk for severe COVID-19 infection with recent methylprednisolone exposure, however, we found no association with the severity of infection and corticosteroid therapy (14).

Mental health concerns, such as fear of the disease worsening, psychological distress, anxiety, and despair, have become prominent concerns in pwMS during the COVID-19 pandemic. The fears and

anxieties related to health conditions, working life, and social factors affected patients and shaped their attitudes (15). In our study, we observed that the most prominent concern of pwMS is the worsening of the health of one they feel close to. During the pandemic, the diagnosis of COVID-19, the worsening of MS, and the fear of having a new relapse were the main concerns. In addition, we observed that financial and educational problems had less impact on pwMS with respect to family issues and disease conditions.

The concerns related to COVID-19 have also affected the working life of pwMS. Most patients with a higher education level worked from home. Male patients continued to work full-time as they did before the pandemic, compared to female patients. This association was similar to switching to a flexible or part-time working system. Although it was in a minority of the patients, a group of pwMS had to quit their jobs or get fired. Not only in pwMS, but many people lost their jobs during the pandemic in our country. The other remarkable point about working life was that approximately one-third of the patients were not working before the pandemic. While this rate was 25% in highly educated patients, half of the less educated patients did not participate in working life. Moreover, most of the pre-pandemic unemployed patients were women, and this rate was higher in progressive MS patients than in RRMS. Recent research shows that 90% to 96% of pwMS are employed before the diagnosis; however, with time, 40% to 80% of the patients become unemployed. The risk factors, including less education, higher EDSS, and female gender are similar to those in our study (16). Unfortunately, unemployment is still a critical problem for pwMS.

Mateen et al reported the impact of COVID-19 on neurologists' therapeutic approach to MS and the concerns of physicians about pandemic. Ninety-eight percent of the neurologists reported that they were worried about pwMS contracting the virus due to their auto-immune disease (17). In our study, 58.9% of the patients reported that MS has an increased risk factor for contracting the COVID-19 infection. This rate was similar between genders. However, we observed that this ratio was the highest among the least educated people.

As a limitation, this is a web-based study. Although online surveys are growing in popularity, they can introduce bias if the response rates are selective and low when compared to face-to-face studies. However, a web-based approach seemed the best method to reach patients during a pandemic, and every effort was made to avoid misleading results by MS experts in our study.

CONCLUSION

The COVID-19 pandemic has exposed the link between socioeconomic factors and health outcomes, especially in the area of chronic diseases. Our data showed that the COVID-19 strongly affected the working lives of pwMS. Also, the pandemic changed the attitudes of patients and neurologists. Therefore, the long-term consequences of the COVID-19 pandemic on disease approach, patient follow-up, social conditions, and working life should be monitored.

Ethics Committee Approval: Ethics Committee approval was obtained from Republic of Turkey Ministry of Health and Acıbadem University Ethics Committee (approval number: 2020-12/23).

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