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The Experience of Living with Multiple Sclerosis during the COVID-19 Pandemic

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Abstract

Background: Many studies have shown that psychological distress such as worries and anxiety is one of the causes of the development, recurrence, or exacerbation of multiple sclerosis (MS). This study aimed to explore the lived experiences of patients with MS during the COVID-19 pandemic.

Methods: This qualitative study was conducted using an interpretive phenomenological approach. The participants were selected from patients with MS in Tehran, Iran who were members of the Iranian MS Society in 2021. The research sample included 19 patients with MS who were selected using purposive sampling. The data were collected using semi-structured interviews until the data were saturated. The collected data were analyzed using Van Manen's phenomenological approach, and the validity and truthfulness of the data were confirmed using the four criteria proposed by Lincoln and Guba.

Results: Explication of the data revealed 22 subthemes and 5 main themes. The main themes identified were: Feeling of helplessness and fear of inadequacy in self-care, Economic concerns and financial problems, Ineffective interaction with family members, preoccupations and obsessions with the pandemic, and ambivalent and conflicting beliefs about others.

Conclusion: The experiences of those affected by the pandemic were linked to personal and familial concerns, health issues, feelings of inadequacy in self-care, and economic difficulties. Additionally, participants were preoccupied with the pandemic and the social problems they faced. Gaining an understanding of these experiences can offer valuable insights to medical professionals, families of patients, and relevant organizations regarding the lived experiences of individuals with MS.

Keywords: Multiple sclerosis, COVID-19 pandemic, Lived experience, Phenomenological approach

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Introduction

Multiple sclerosis (MS) is a chronic autoimmune and inflammatory neurological disease of the central nervous system. The disease attacks myelinated axons in the central nervous system and causes their destruction to varying degrees (1). The estimated number of people with MS worldwide by 2020 was about 2.8 million persons (2). The prevalence of MS in Iran is equal to 87 patients per 100 000 (3). Since the onset of the epidemic, stress, anxiety, and depression levels in the general population have increased significantly (4). Restrictions were also imposed by governments to prevent the spread of the coronavirus. However, neuroscientists have warned that long-term restrictions lead to a second pandemic that causes severe psychological problems (5).

Studies have shown that patients with MS experience high-level psychological distress such as anxiety, worry, and hopelessness in most cases. Some researchers believe that anxiety is one of the causes of development, recurrence, and exacerbation of MS (6-8). In addition, patients with MS are theoretically at risk of developing viral pandemics, so these patients are predicted to undergo higher levels of anxiety (9). Moreover, there is also a statistically significant difference between the levels of anxiety experienced by patients with MS before and after an epidemic (10). Thus, it is essential to address the fear and anxiety experiences of MS patients due to the very high symbiosis of anxiety with other psychological disorders (11) and its impact on the quality of life of these patients (12).

It should be noted that previous quantitative studies on the psychological distress of patients with MS during the COVID-19 outbreak have been conducted based on the researcher's subjectivity or using the data collected through questionnaires. Thus, no study to date has explored MS patients' experiences during the COVID-19 epidemic. In other words, our understanding of the psychological experiences of MS patients from previous studies merely reflects numbers that indicate the severity or correlation of psychological constructs explored in these studies. Furthermore, a quantitative look at this issue fails to provide enough information available to the intervening institutions. Thus, it is not clear to what individual, family, or social levels the factors underlying these problems are placed. Consequently, it is not possible to conduct interventions based on the degree of significance of these factors. However, since the data in this study were collected through semi-structured interviews and analyzed using a phenomenological approach, the findings of this study can provide more accurate and in-depth insights into patients with MS and their psychological problems. Moreover, an awareness of MS patients' lived experiences can help easily determine the type of interventions required because such awareness can reveal the nature of the experience and the context in which the experience is formed, as well as the factors influencing it. This study aimed to explore MS patients' lived experiences during the COVID-19 pandemic.

Methods

This study was conducted using Van Manen's phenomenological approach. The participants were selected using purposive sampling from the members of the Iranian MS Society in 2021. The data were saturated after 19 interviews with the participants. Examples of the questions asked in the interviews are as follows:

- Would you please share with us your daily life experiences as someone living with MS during the COVID-19 pandemic?
- We would like to hear about your experiences in various situations, such as at home, in the workplace, and during different events, with regard to the spread of the COVID-19 virus.

Since this study was a goal-directed research project, before starting the interviews, a short interview was conducted to assess the participants' willingness to participate in the main interview, the lack of physical and communication barriers to the transfer of experiences, the participants' willingness and cooperation to share their experiences, and arrangements needed to determine the time and place of the interviews. Each interview lasted 43 to 52 minutes (894 minutes in total). The interviewer was male. Four interviews were conducted via video calls and 15 interviews were conducted in person. After each interview, the audio files were converted to text, and after reaching theoretical saturation, the interviews were stopped. It should be noted that the interviews were scheduled weekly so that the interviews would not be canceled by the interviewer if the data were saturated. After transcribing the interviews, the text of the interview was given to the participants. A total of 14 participants stated that they had read the text of their interview and three stated that they realized they were very anxious and needed to see a specialist.

The collected data were analyzed using Van Manen's phenomenological method (13). To this end, the experiences reported by the participants were read many times so that the researcher had a deep and long-term involvement with the participants' experiences. The focus was then on the nature of the participants' experiences to provide a deep analysis of the participants' narrations. Afterward, statements and their clusters were analyzed to reveal the meanings hidden in the statements and shed light on the MS patients' lived experiences during the COVID-19 outbreak. This in-depth analysis revealed the themes related to the participants' experiences. The extracted themes were then merged in an interpretive way. Overall, the data analysis included six stages (13): 1- Reviewing and studying the experiences, 2- In-depth study of the experiences of the participants, 3- Reflecting on the essences of themes and concepts derived from it, 4- Writing and rewriting interpretation, 5- Maintaining a strong and continuous relationship with the phenomenon under investigation, and finally 6- Adapting the context of the study by considering the components and themes. At all stages of analysis, a strong relationship with the phenomenon in question was maintained. Finally, the results of the analysis were provided to the participants to receive their feedback and validate the findings.

To check the rigor and adequacy of the data, four criteria (14) including credibility, transferability, dependability, and confirmability were used. The credibility of the data was ensured through long-term involvement (14), peer checking (15), member checking (16,17), and triangulation (18). The duration of the participants' involvement with the epidemic confirmed the transferability of the findings. Semi-structured questions were also asked during the interviews as an audit trial tool (19) and specifically as an information promotion tool (20). The confirmability of the extracted themes was peer-checked by another researcher.

To comply with ethical considerations, the participants were selected voluntarily, informed consent was obtained from the participants for the audio recording of the interviews, the content of the participants' audio files was kept confidential, a code was used instead of each participant's name, the text of the interviews was given to the participants, and the results of data analysis were presented to the participants.

Results

Table 1 shows the participants' demographic characteristics.

As indicated earlier, the MS patients' lived experiences during the COVID-19 pandemic were categorized into 5 main themes and 22 subthemes (Table 2).

Feeling of helplessness and fear of inadequacy in self-care

The participants reported that they had no confidence in the stable functioning and health of the immune system.

Table 1. The participants' demographic data

Code	Gender	Age	Education	Marital status	Residential district in Tehran	Occupation	Duration of illness	Medication	Interview mode
1	Male	28	Master's degree	Single	4	Programmer	6	Actovex administered weekly	In-person
2	Female	25	Bachelor's degree	Single	5	Student	5	Actovex administered weekly	In-person
3	Female	31	Bachelor's degree	Divorced	5	Unemployed	9	Rituximab administered every 6 months	In-person
4	Female	25	Bachelor's degree	Single	10	Designer	1	Tebazio	In-person
5	Female	42	Master's degree	Divorced	2	Psychologist	4	Cinnovex administered weekly	In-person
6	Female	28	Bachelor's degree	Single	22	Accountant	8	Traditional medicine	Video call
7	Female	29	Bachelor's degree	Married	2	Nail specialist	5	Cinnovex administered weekly	Video call
8	Female	49	Middle school	Married	15	Housewife	18	Novantrone	In-person
9	Female	26	Bachelor's degree	Single	5	Unemployed	7	Copamer	Video call
10	Female	24	Bachelor's degree	Single	10	Inspector	2	Ziferon	Video call
11	Male	27	Master's degree	Single	3	Digital marketing assistant	4	Tebazio	In-person
12	Male		Ph.D.	Single	1	Industrial counselor	19	Fingolimod	In-person
13	Male	31	Master's degree	Single	5	Editor	4	Tebazio	In-person
14	Male	37	Bachelor's degree	Single	4	Marketer	5	Tysabri	In-person
15	Female	32	Bachelor's degree	Married	1	Housewife	7	Actovex administered weekly	In-person
16	Female	34	Bachelor's degree	Married	3	Accountant	9	Glatiramer acetate	In-person
17	Female	29	Bachelor's degree	Single	5	Secretary	8	Ziferon	In-person
18	Female	37	Diploma	Married	22	Hairdresser	13	Plegridy	In-person
19	Female	30	Bachelor's degree	Single	11	Chef	5	Novantrone	In-person

Accordingly, one of the participants stated, "*As an MS patient, I'm not sure of my immune system and afraid of the immune system not functioning properly*" (Participant 12).

Economic concerns and financial problems

One of the concerns reported by the participants was the negative financial and economic consequences. Sometimes, these concerns were so intense that some participants reported experiencing certain physical limitations that impose separate treatment costs on them. One of the participants stated, "*Well when there is no ceremony, how can I make money? What should I film? How to make a living and pay for my medicines, medical tests, etc.?*" (Participant 13).

Ineffective interaction with family members

The MS patients in this study reported that they experienced a kind of isolation at home, despite their inner desires, for fear of being infected with the coronaviruses and perceiving other family members as a risk factor. For example, one participant said, "*I did not leave my room as much as I could, so it was a bad feeling, I was worried that they would go out*" (Participant 3).

Preoccupations and obsessions with the pandemic

Unrealistic identification of the COVID-19 symptoms with normal physical pains and symptoms was a kind of concern reported by the patients with MS in this study. Accordingly, participants perceived some of their indications such as cough, muscle aches, and digestive problems as the COVID-19 symptoms. All of these conditions occur very mildly, such as sore throats or localized pain, some of which are caused by dry throat, persistent smoking, poor eating and sleeping behaviors, the physical symptoms of MS, and side effects of drugs. For example, one participant reported, "*I always had a fever those days because of the side effects of the ampoule, but I did not understand the fever was due to the ampoule or the coronavirus, and this made me anxious*" (Participant 2).

Ambivalent and conflicting beliefs about others

Surrounding people and members of the community are considered as different levels of social support that facilitate interpersonal interactions. However, the participants reported ambivalent and conflicting beliefs about those around them and the public during the COVID-19 outbreak. For instance, they perceived all members of society as carriers and feel threatened by

Table 2. Main themes and subthemes identified in the study

Main themes	Sub-themes
Feeling of helplessness and fear of inadequacy in self-care	Uncertainty about the stable functioning and health of the immune system
	Fear of the unknown future
	Decreased life expectancy
	Strict control of negative emotions for fear of developing MS
	Intensification of obsessive behaviors when perceiving danger
Economic concerns and financial problems	Negative financial and economic consequences
	Concern about the inability to adapt to the digital structure of jobs
Ineffective interaction with family members	Isolation at home
	Perception of physical need and dependence on parents or spouse
	Extreme family restrictions
	Concerns about the health of family members
Preoccupations and obsessions with the pandemic	Unrealistic identification of COVID-19 symptoms with normal physical pains and symptoms
	Negative emotions following the news of the worsening of COVID-19 symptoms
	Predictions before the event
	Trying to stop annoying thoughts
	Positive perception of restrictions controlling the disease
	Conspiracy theory about the origin of the coronavirus and population control through it
Ambivalent and conflicting beliefs about others	Perceiving all members of the community as disease carriers
	Wrath of non-compliance with health protocol and social myths
	Developing the disease as a factor for the public to understand the problems and pain suffered by MS patients
	Feelings of rejection and abandonment
	Limited access to useful information resources

them. One participant said, "*When I go out, I feel that everyone has been affected by COVID-19 and it drives me crazy*" (Participant 15).

Discussion

The five main themes identified in this study were feeling of helplessness and fear of inadequacy in self-care, economic concerns and financial problems, ineffective interaction with family members, preoccupations and obsessions with the pandemic, and ambivalent and conflicting beliefs about others.

The first main theme participants reported was one or more failure experiences or a belief in failure in self-care. For instance, some participants believed that their immune system was not functioning properly. Numerous studies have shown that the life expectancy rate in normal people has decreased in the last 2 years (21-24). Furthermore, life expectancy in patients with MS is lower by 6 to 7 years compared to healthy individuals (25), and thus their life expectancy was further reduced during the epidemic conditions. Fear is associated with the eruption of autonomous arousal for fight-or-flight responses, perceptions of imminent danger, and elusive behavior (26). The patients with MS were not only worried about their present conductions but also were concerned about their future. Feeling insecure about the future was also reported in other studies (27,28). Moreover, patients with MS may engage in religious behaviors as one of the clinical stress management strategies (29). Similarly, the MS patients in this study reported obsession in most of their religious behaviors.

The second theme extracted from the data in this study was the economic concerns and financial problems experienced by patients with MS. The patients reported that they were seriously concerned about financial problems and their consequences during the COVID-19 epidemic (28,30). The severity of the disease and the recurrence of MS attacks were associated with reduced quality of life in MS patients (10).

The third theme extracted in this study was the MS patients' ineffective relationships and interactions with family members. Accordingly, it can be argued that the greater the perceived severity of loneliness, the lower the level of mental health (31). The perception of the recurrence of attacks and infection with the COVID-19 virus can worsen this fear, leading to the perception of physical need and dependence on the parents or spouse experienced for the fear of getting the COVID-19 virus (11).

The fourth theme extracted from this study was preoccupations and obsessions mixed with anxiety experienced by patients with MS due to the risk of the COVID-19 pandemic. Previous studies have shown that a significant percentage of MS patients develop obsessive-compulsive disorder (27, 32,33). One of the signs of obsessive-compulsive disorder is trying to suppress disturbing thoughts as reported by MS patients and can also be seen in epidemic conditions (26-27). Apelian Soureshgani and Khodabakhshi-Koolaee analyzed obsessive-compulsive disorder experiences in patients with MS and identified three main themes including childhood and family member's experiences underlying obsessive-compulsive disorder, disturbing thoughts and emotions about the disease and its treatment, and experiences about an uncertain future (27). They also reported that these fears and obsessions increased with the outbreak of the coronavirus.

The fifth theme that was extracted from the interviews with the MS patients in this study was related to the ambivalent and conflicting beliefs that the patients experienced in relation to those around them and people in general. They perceived other people to be carriers of the COVID-19 virus and assumed that people do not comply with health protocols, and these perceptions led to pessimism and hatred towards people who were careless about the disease (28). The publication of lies and fake news or even unscientific therapies, as well as inconsistent statistics released in media and social networks, reduced the MS patients' trust in news agencies, and a sense of confusion was developed in the patients due to the release of publishing fake news and recommended treatments for COVID-19 (28). In their study, Costabile et al found that people with MS reported higher levels of depression than other groups during the COVID-19 epidemic (29). Pokryszko-Dragan et al also showed that patients with MS faced many family, health, and economic problems during the COVID-19 epidemic (30). A study conducted in Iran showed that the psychological well-being of MS patients during the COVID-19 epidemic was severely reduced and also the fear of recurrence of symptoms was another problem of MS patients during the epidemic (31). These crises were much more severe in developing countries where governments could not afford to provide household necessities and subsidies (28). Disappointment, uncertainty about the future, and stress are some of the psychological problems of patients with other neurological disorders (27,32). These symptoms were exacerbated by the COVID-19 epidemic (33). The MS patients had financial concerns and lack of access to medicine before the pandemic (34), and after the outbreak, the condition got harder.

Implementing educational, therapeutic, supportive, and physical activity (35) interventions for MS patients during the epidemic helps to care for them. In addition, the use of applications for information as well as Telehealth can help improve the health and self-care behaviors of people with MS (36-38).

Due to the COVID-19 outbreak at the time of this study, telephone follow-ups were conducted instead of face-to-face interviews for validation of the data. Besides, the observations made in qualitative studies are rooted in the cultural, psychological, economic, and social conditions of interviewees, and thus the findings of these studies cannot be generalized to other groups.

Conclusion

The lived experiences of patients with MS were categorized into five main themes including feeling of helplessness and fear of inadequacy in self-care, economic concerns and financial problems, ineffective interaction with family members, preoccupations and obsessions with the pandemic, and ambivalent and conflicting beliefs about others.

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Authors' Contribution

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Competing Interests

The authors reported no conflict of interest.

Ethical Approval

This research project was approved by the Ethics Committee of Shahid Beheshti University under the code IR.SBU.REC.1401.079.

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