



Qualitative Insights into the Diagnosis, Treatment, and Socioeconomic and Psychological Challenges of Patients with Multiple Sclerosis in a Turkish Public Hospital

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Abstract

Objective: Objective of the study is to qualitatively evaluate challenges multiple sclerosis (MS) patients faced during diagnosis, treatment, and social life.

Materials and Methods: Population of our qualitative study consisted MS patients with expanded disability status scale score ≤ 5 (19-50 years of age) who were admitted to a public university hospital neurology department. Semi-structured question guide were applied via in-depth face-to-face interviews. Interviews were audio-recorded after permission. Twelve participants agreed to participate voluntarily, the recordings were transcribed, thematic analysis was conducted.

Results: "Attitude of family members and social circle", "problems came across" and "worries and coping mechanisms" were the most significant themes. Participants had anxiety after diagnosis because of fear of death, probability of losing functions and having no clue about what MS will bring in the future. Their families started to act more sensitively and with understanding after the diagnosis. While this situation was welcomed by some of the participants, some perceived this situation negatively a triggering factor for their feeling of insufficiency. Participants were exposed to stigma. One participant narrated he faced stigmatization due to his gait. Their educational life adversely affected. Participants faced situations such as not being hired or termination of employment. Probability of attacks to occur at work could become an obstacle. Some participants stated it would be difficult to carry their responsibilities due to MS and start a family, so they would have difficulties in establishing romantic relationships. Some emphasized the disease would not cause a problem, but their partners' approach to MS was important. They were worried that their families would experience sadness and anxiety, that they would not be able to support their spouses and children if their disease progressed, they were also worried about risk of transmitting MS to their children. They developed coping strategies such as avoidance, religion, self-soothing.

Conclusion: Participants' knowledge about MS is limited. Families have a supportive attitude towards patients and takes steps to make participants' lives easier. Studies developing scales such as quantitatively measuring stigma or perceived empathy in MS patients can be recommended.

Keywords: Multiple sclerosis, challenges, qualitative study, social life, stigma

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Introduction

Multiple sclerosis (MS) is a chronic, autoimmune, demyelinating disease that frequently affects the central nervous system in young adults (1-5). The clinical signs and symptoms of MS include motor, sensory, autonomic, and cognitive impairments that vary according to the region of the central nervous system it affects (1). In epidemiological studies conducted in Turkey, the prevalence of MS was observed to be 0.4-1 in 1000 young adults. This is very similar to the global prevalence of MS (1-3). It is 2 times more common in women than in men (1). The average age of onset in Turkey is reportedly 30 years (1). In addition, several studies have revealed that the MS disease has a geographical distribution pattern (2,3). According to the studies, although various causes of the disease have been suggested, a definite cause has not been revealed (4,5). The general acceptance today is that there is a genetic predisposition in patients and that the disease occurs with the addition of environmental factors and other causes to this heredity (4,5).

MS patients are reported to come across several social, economic and psychological challenges both in Turkey and in the whole world (1,4-8). The loss of functionality caused by the progression of this disease leads to new problems and develops uncertainties and stress in the patient's self-perception, role performance, and expectations with their lives and relationships (6-8). According to a past study, since patients with MS deal with both the stress of daily life and the stress caused by the symptoms of the disease, stressful life events, and family problems occur more in these patients than in healthy individuals (6,7). Considering the lack of any definite treatment for this disease and accepting that a stress-free life is not possible with this condition, it has become important for patients to manage stressful situations that affect the disease course and to adapt to the disease by adopting effective coping mechanisms (6).

Considering the uncertainty related to this disease and its process, MS directly affects the quality of life of patients not only physically but also psychologically and socially (8). The treatment and postattack periods have a negative impact on the patient's work and social life as well as on their relatives (6,8). The psychological effects induced by MS can be classified as depression, stress, and anxiety, and from a social aspect, it includes problems such as family problems, job loss, stigmatization, the lack of access to social rights, and exclusion in social life (6-8). Although these problems are felt intensely from the first encounter with the disease until espousal, they reduce the quality of life by directly affecting the social functioning of the patients and their relationships with other people (7,8). Limitations caused by physical health problems of the patient, the increased dependence on others, the changing roles in the family, the loss of economic security, and the inability to attend or participate in social activities can affect the quality of

life, as well as the social relationship between the patients and relatives (8).

The objective of this study was to qualitatively evaluate the challenges patients with MS face in a Turkish Public Hospital during its diagnosis and treatment and the societal aspects.

Materials and Methods

The sample was selected with maximum diversity in accordance with the purposeful sampling approach from patients visiting the outpatient clinic. The population of the study consisted 12 patients with MS (5 male and 7 females) of ages 19-50 years who were diagnosed with MS according to the McDonald 2017 Criteria and expanded disability status scale (EDSS) <5.5 (mild to moderate disability) who had been admitted to a public university medical school training and research hospital neurology department in Istanbul, Turkey. While an EDSS score of 5.5 included ambulation without aid, a patient with an EDSS score >6 (severe disability) needed one-sided help to walk. Various studies indicated that the quality of life of patients with MS is adversely affected in patients with EDSS score >6 than in those with EDSS score <5.5. Excluding severe cases might limit our findings' generalizability, in other words we can be biased as if MS patients don't have severe social challenges in life. Patients with cooperation difficulties, psychotic diseases, those who had an MS attack in the last 30 days, those who had received steroid therapy, and those with an active lesion visible on MRI were excluded from the study.

A mini questionnaire and a semistructured question guide were used in the study. The min-questionnaire included questions about their sociodemographic information and clinical status, while the semistructured question guide inquired about problems encountered while coping with MS, particularly concerning social life. Data was collected via an in-depth face-to-face interview. The interviews were audio-recorded after obtaining oral and written consent from the participants. Each interview lasted 30-55 min. A private room was used in the interviews to ensure that the participants felt safe and comfortable. All participants had previously met with their physicians and discussed their illnesses in similar rooms at the same polyclinic.

The audio records were deleted the same day after transcription. Two researchers were involved in each interview. The first researcher who conducted the interview and asked the questions. In cases where voice recording was not permitted, the second researcher was included in the interview with the participant's permission to take notes and observe the participant's body language and interview atmosphere.

Statistical Analysis

Each transcript was analyzed separately by two different researchers. The interviews were stopped when data saturation

was reached by the researchers and no new information could be obtained based on the responses of the participants. Themes and subthemes were determined after marking the codes with the consensus of the research team. A process of thematic and open coding was used to extract the themes. A coding manual was created to ensure intercoder reliability and coding consistency. Memos were used to obtain evidence of the decisions made to develop codes, sub-themes, and themes and then compared by the researchers. This method was adopted to ensure consistency, intercoder agreement, and trustworthiness, and to ascertain themes. This approach was followed exhaustively until saturation was reached and no new themes surfaced. Reliability and consistency were examined regularly through frequent comparisons of the transcripts. Validity was tested through the creation of a coding manual to ensure intercoder reliability and coding consistency.

Atlas-ti was used as the software program in the data analysis. In data analysis, the stages of data preparation (bracketing), phenomenological reduction (bracketing and phenomenological reduction), creative variation (imaginary variation), and revealing the essence of the experience (synthesizing meaning and essences) were used.

Ethical Considerations

Verbal informed consent was obtained from the participants before the interview began, and patients who did not give consent were not included in the study. Voice recordings were made during the interviews with the permission of the participants. The interviews were continued by asking different questions in some cases by replacing some of the items in the questionnaire. The participants were assured of the confidentiality and anonymity of their information so that they

could respond freely. The participants were informed before the interview that they could not use their names and could use a nickname if they wished. The participant's data were protected in the voice recordings and analyses and not shared with any third party or institution. The data has been presented anonymously in this paper.

The study was approved by the Ethics Committee of Marmara University Faculty of Medicine (approval no: 09.2022-118,2, date: 10.10.2022) and complied with the principles of the Declaration of Helsinki. The participants were free to leave the study at any point of time and informed about the same before the start of the study.

Results

In this study, the experiences during the diagnosis and treatment periods and the burdens of the social life of 12 participants who were admitted to the neurology department of a public hospital in Istanbul, Turkey were investigated qualitatively. The sociodemographic features of the participants are listed in Table 1.

Of the 12 participants, 7 (58%) were females, and the age range of the participants was 19-50 years. One participant had no education, 1 had a postgraduate education (after a university degree), 1 was unemployed, 3 were housewives (not working), 9 were working, 1 was a student, and 6 (50%) had low income. No participants declared that they had a high income.

All participants, except one, had a core family, and all families lived in the urban area. While 6 participants had a history of febrile/rash illness, 1 had a relative with MS. In addition, 1 participant had essential thrombocytosis and another 1 had epilepsy.

Table 1. Distribution of participants according to their socio-demographic characteristics

	Sex	Age	Age of diagnosis	Educational status	Profession	Children	City they lived the longest	Marital status	Income
P1	Male	49	32	High school	Office worker	None	Mersin	Single	Low
P2	Female	48	35	Primary school	Housewife	3	Elazig	Married	Low
P3	Female	20	13	High school	Retail worker	None	Samsun	Single	Low
P4	Female	36	15	High school	Housewife	1	Bursa	Married	Middle
P5	Female	41	35	Middle school	Housewife	3	Istanbul	Married	Middle
P6	Female	19	17	High school	Student	None	Istanbul	Single	Low
P7	Male	46	34	Primary school	Unemployed	2	Istanbul	Widower	Middle
P8	Male	43	29	Undergraduate	Industrial worker-(packaging)	2	Istanbul	Married	Low
P9	Female	23	16	Associate degree	Nurse	None	Istanbul	Single	Middle
P10	Female	32	27	Postgraduate	Banker	None	Istanbul	Single	Middle
P11	Male	40	37	High school	Industrial worker-(chemical painting)	2	Kocaeli	Married	Middle

The themes and subthemes of the interview results are presented in Table 2.

THEME A: EXPERIENCES DURING THE DIAGNOSIS AND TREATMENT PERIOD

Sub-theme A1: First Reactions to Diagnosis

Some participants stated that they had felt anxious and fearful when they were first diagnosed with MS. They explained that the reasons why they had felt so were mainly due to their thoughts and feelings including the fear of death, the possibility of the loss of function, and having no clue about what their future with the disease.

"I felt weird because I didn't know what the disease was like, I was scared."

(Participant 6, F, 19)

"I searched online how people who have MS disease live and I was shocked by how difficult it seemed at the time. There were many bad examples then I thought to myself "Am I going to end up this way? (laughs)."'

(Participant 9, F, 23)

Sub-theme A2: Treatment

The participants admitted that the side effects and application methods of MS medication, which interfered with their daily functioning, made them hesitant to adhere to the treatment.

"...for example, I took my medication on the 17th of last month and will take it again this month on the same day but there will be some adjustments to my medication, so I am going to take it on the 25th this month. Obviously, it affects my social life when it is like this, affects my health, upsets me... (lost in tears)."'

(Participant 3, F, 20)

"There were times when I couldn't reach a nurse (to administer medication). Drugs themselves also cause dizziness; I sometimes feel like the ground is shaking when I'm traveling in a car. Although I have blurry vision sometimes, I can't convince my doctor about it. After that, I didn't want to attend the visits and hadn't attended for a year."

(Participant 4, F, 36)

THEME B: ATTITUDE OF FAMILY MEMBERS AND THE SOCIAL CIRCLE

Sub-theme B1: Attitudes of Family Members

The participants declared that after being diagnosed with MS, their family members approached them with more consideration and tactfulness and also started to act more sensitively and with compassion than before the diagnosis (Figure 1). While this situation was welcomed by some of the participants, considering it as a substantial indicator of the support extended by the family members, it was regarded unfavorably or perceived negatively by other participants, perceiving it as a trigger to the feeling of insufficiency and a sign of the family members' concerns (Figure 1).

"...They (parents) used to say 'It will clear up eventually, by God's will' as they had no idea about the extent of the disease and what it is. But still, they showed empathy toward me. They scold me when I want to work: 'It's not necessary, stay home! They don't want me to get tired because of MS."

(Participant 7, M, 46)

"... (After the diagnosis) Everybody got worried. A state of fear and panic among everybody... They got more delicate, you know... Just as if one acts toward a child. It spoils you, how wouldn't it? (Laughs) Attention surely spoils you!"'

(Participant 11, M, 40)

Table 2. Themes and sub-themes

Themes	Sub-themes (illustrative quotes)
A. Experiences during diagnosis and treatment period	A1- First reactions to diagnosis (<i>Am I going to end up this way?</i>) A2- Treatment (<i>Drugs themselves also cause dizziness</i>)
B. Attitude of family members and social circle	B1- Attitude of family members (<i>"They got more delicate... Attention surely spoils you!"</i>) B2- Attitude of social circle (<i>"the people brought me unsalted bread or unsalted olives while I was taking cortisone...!"</i>) B3- Stigmatization (<i>"...You should not stare at me with hostility!"</i>) B4- Thoughts about society's knowledge of the disease (<i>"...They just view you like an immobile patient who can do nothing, who's bedridden..."</i>)
C. Problems came across	C1- Problems came across in education (<i>"...my internship would go to waste!"</i>) C2- Problems came across in profession (<i>"...my movements were restricted (at work)...!"</i>) C3- Problems came across in social life (<i>"Zumba activity. I can't come to that, it's too energetic....It's affecting me badly!"</i>) C4- Problems came across in romantic relations (<i>"...when I tell a lady.... they turn away from me...!"</i>)
D. Worries and coping mechanisms	D1- Individual worries (<i>"... I thought that it (weakness on left side) would permanently stay with me all the time (Lost in tears)!"</i>) D2- Worries about family (<i>"...if there was a risk that our baby would inherit the same disease.... "</i>) D3- Religious coping, Self-soothing (<i>"... it is a test from my God....!"</i>) D 4-Affirmation, Avoidance (<i>"... it is tougher to be a cancer patient...."</i>)

Sub-theme B2: Attitude of the Social Circle

Most of the participants stated that they were not exposed to any kind of discrimination from their social circle and that they received extensive support, both materially and morally, after the diagnosis. Like the findings in Sub-theme 1, the participants diverged regarding their approach to the attitude shown to them, as it made some feel "backed up" and made some of them feel rather "insufficient." Certain participants abstained from sharing their feelings about their affliction related to

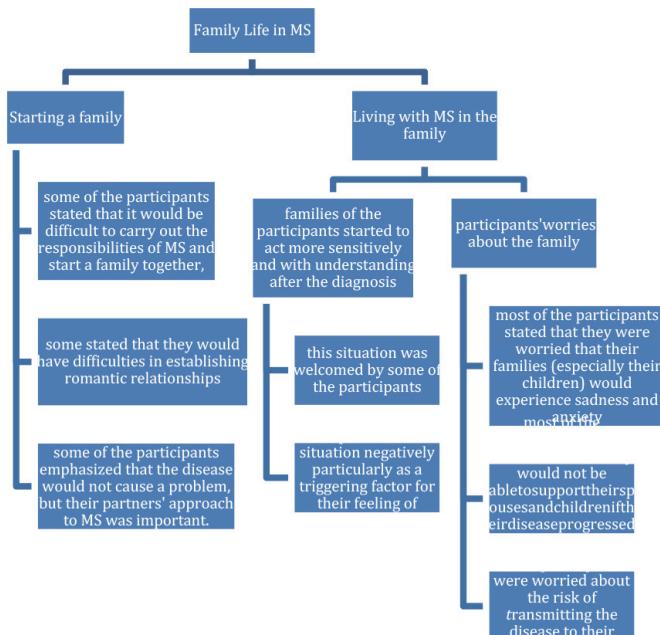


Figure 1. Figure summarizing the key findings of the study

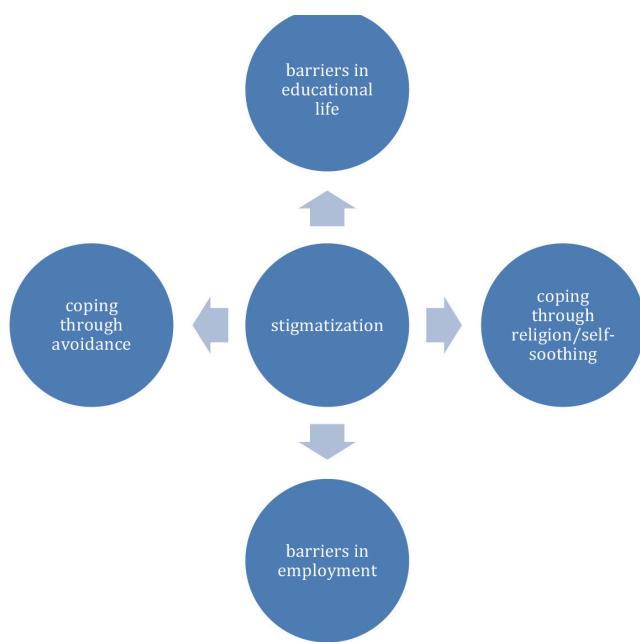


Figure 2. Family Life in MS

MS: Multiple sclerosis

MS from their social circle, but most showed no reluctance in expressing their problems, viewing it as a part of their support mechanism. Contrary to other participants, one participant expressed reproach when mentioning his social circle because of his feelings that no concern has been shown for him in his social circle.

"My boyfriend has a profound knowledge about MS, as his work is related to health insurance. I mean... He has supported me a lot. He has always stood by me, all the time after he came into my life."

(Participant 10, F, 32)

"I encountered more care and affection after the diagnosis. For instance, the people that brought me unsalted bread or unsalted olives while I was taking cortisone... (laughs) ... (My schoolmates) They were all amazing! All of them came to the hospital and did what they could to entertain me. (joyfully) They flew balloons in front of my window, I can never forget that."

(Participant 4, F, 36)

Sub-theme B3: Stigmatization

It is observed that participants are exposed to stigmatization due to MS (Figure 2). This includes cases such as colleagues viewing the treatment process and the probability of attacks to occur in the workplace might be becoming an obstacle, or their diagnosis being disbelieved altogether (Figure 3). For example some colleagues thought that the participant was pretending to be sick to have frequent leaves at work (Figure 3).

The participants considered being disallowed from doing chores/daily housework by their close ones at home as a form of stigmatization, despite knowing that the underlying intentions were good (Figure 1). One participant stated that he faced stigmatization due to his gait.

"...People around me and my relatives always say, "don't tell her anything", "don't interfere with her" as some kind of protection thing, including my husband. It didn't exist before."

(Participant 5, F, 41)

"...You should not stare at me with hostility as if I'm the bogeyman. I mean, God forbid, this is not like a contagious disease after all."

(Participant 2, F, 48)

Sub-theme B4: Thoughts About Society's Knowledge of the Disease

Most participants believed that society is not adequately informed about MS. They expect society to obtain more reliable information, enabling them to recognize MS and the conditions caused by it. The participants contemplate that stigmatization can be reduced with an increase in the knowledge and awareness in the community about MS.

"...As far as I've seen, they're not that aware of MS in my surroundings. If I conducted research before, I got it, I would be more conscious

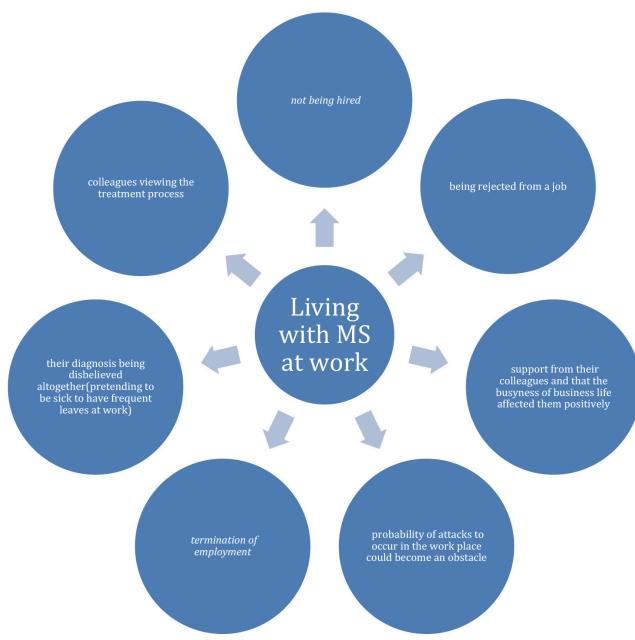


Figure 3. Living with MS at work

MS: Multiple sclerosis

about the disease. I would have taken care of myself more, but this all happened to me because I didn't know."

(Participant 2, F, 48)

"...I think they don't know at all. Because you explain it, and you see that they have no information by any means. They just view you like an immobile patient who can do nothing, who's bedridden..."

(Participant 9, F, 23)

THEME C: PROBLEMS CAME ACROSS

Sub-theme C1: Problems Encountered in Education

Participants whose education was continuing when they were diagnosed with MS indicated that the disease affected their educational life and that they struggled with keeping up with the school (Figure 2). Some participants said they could not proceed with their education or steer for the profession they desired.

"... Well, I was in high school during that time. I couldn't go to school for 3-4 months. Because the doctor said that I should rest after my discharge. I was also doing an internship at that time. My internship would go to waste... With that fear, my absence was more stressful. It (my education) got affected a little badly."

(Participant 9, F, 23)

"... for instance, I didn't want nursing school. Now I feel happy about my school but at the same time not really. Let me say I must feel content because of my illness. I wanted something related to aviation, to be honest. This is a disease that is not accepted in aviation, I feel bad about this for example."

(Participant 6, F, 19)

Sub-theme C2: Problems Encountered in the Profession

Most of the participants stated that MS had an adverse impact on their career, with many facing circumstances like rejection from a job and even employment termination (Figure 3); these concerns were negatively affected by this situation both financially and psychologically.

"... In fact, when the employers learned about this disease, they told me to get a medical report and do not come to work. I was also impressed by that. I didn't go to work for two or three months, and at one point they even considered firing me. Did they know MS better than me? They even said there was a disease that made him faint and fall down... Epilepsy???, So, I had financial difficulties; when you don't work, you don't get money at the beginning of the month." (Participant 8, M, 43)

"... I mean, of course, when my movements were restricted (at work), you don't feel good when you can't do the action you wanted to do. Then the situation starts to become psychological. No wonder you feel angry toward yourself. And there is a difference between me 10-15 years ago and now needless to say. You are more energetic, nimbler, and faster. Of course, your elbowroom narrows. Thus, having a psychological effect on you. There's nothing else." (Participant 1, M, 49)

On the other hand, some of the participants argued that they received extensive support from their colleagues and that the busyness of business life worked positively for them (Figure 3).

"... The company protected us since it is a big well-known one. My responsibilities have been taken away (reduced). Otherwise, if you asked me, I would have fired directly. Is this why I hired you... The factory looked out for me. The protection taught us some things: "Don't say what I am, say what I'll become."

(Participant 11, M, 40)

Sub-theme C3: Problems Encountered in Social Life

While most of the participants stated that they experienced a limitation in their social life due to the presentation of their symptoms, some said that they continued their normal lives as much as possible by adjusting their social plans such that they would not trigger attacks/relapses by trying to adapt to their illness.

"... Only the first two months were too hard. Other than that, I go to the cinema and wander around with my daughter. The only thing that bothers me is the three months of summer, for example, I cannot go out much because of the heat. My husband takes me out with the car in the evenings. For instance, going out for dinner or shopping, I can do them only in the evening. I can't do anything in the daytime. Heat is my only nuisance..."

(Participant 5, F, 41)

"I kept doing everything normally, so I did not encounter any difficulties. There is just a situation like this; For example, we have a

group. An activity will be done. I tell them this game is not suitable for me because I have such a disease. For example, what can I say about the Zumba activity. I can't come to that, it's too energetic." I don't need to raise my body temperature too much. It's affecting me badly. I say there is such a situation."

(Participant 10, F, 32)

Sub-theme C4: Problems That Came Across in Romantic Relations

Some of the participants stated that acknowledging the difficulty in carrying out the responsibilities of MS and starting a family together made it difficult to establish romantic relationships (Figure 1). However, some of the participants emphasized that the disease would not cause a problem, but their partners' approach to MS was important (Figure 1).

"...I mean it feels like if the other party had searched or knew (the disease) it might work; my wife is a primary school drop-out, she didn't know anything about the disease. "If I didn't tell her about my disease, then it would have caused problems in our marriage."

(Participant 8, M, 43)

"... Now, for example, I would not want to marry a woman with MS. Because the child will most likely be born with MS. Now, I don't want my child to go through what I went through. So, for example, when I tell a lady, I'm like this, they turn away from me..."

(Participant 1, M, 49)

THEME D: WORRIES AND COPING MECHANISMS

Sub-theme D1: Individual Worries

Participants admitted that they had been feeling anxious that their disease might progress in an unfavorable manner, ultimately resulting in the loss of function, causing them to be "in need of someone." They also mentioned that their anxieties tended to increase when they saw some other patients with MS with a more severe form of the disease.

"... (People had told me) 'I have a friend, relative with MS disease and they don't walk, hear... Had a disease attack now he/she cannot see, have troubles on his/her left side.' I also had a disease episode that affected mainly my left side and I kept remembering what they had been saying... I thought that it (weakness on left side) would permanently stay with me all the time (Lost in tears). When I have an appointment at the doctor's office, I usually prefer it early in the morning so it would not be likely for me to see elderly people with advanced diseases. I feel like I will end up like them too in the future when I see them."

(Participant 3, F, 20)

Sub-theme D2: Worries About Family

Most of the participants stated that they were worried that their families (especially their children) would experience sadness and anxiety and that they would not be able to

support their spouses and children if their disease progressed. In addition, they were worried about the risk of transmitting the disease to their children (Figure 1). A participant also mentioned that they worried about becoming a burden to their family.

"... I had not wanted to have a baby for 6 years... Later, we decided to have a baby. At that time, my husband told me that he was concerned if there was a risk that our baby would inherit the same disease, if anything bad would happen to him/her."

(Participant 4, F, 36)

"... I used to cry a lot... when I see my mother or my children. It used to affect my children a lot when I cried. I felt rebellious when I was diagnosed. I had a 1-year-old child, and I wished that I hadn't had a baby in the first place."

(Participant 2, F, 48)

Sub-theme D3: Religious Coping/Self-soothing

Many participants stated that they adopted religion and religious motives as their coping mechanism throughout their disease course (Figure 2). They explained that the use of this approach helped them comprehend the meaning of their disease and express their feelings. The participants thought that the situation in which they lived was too much for their essence and tried to accept the disease by glorifying the cause of the disease.

"It is what God has given... what can I do? I suppose He's testing me."

(Participant 1, M, 49)

"I comfort myself by thinking it is a test from my God. I wish for the best for myself."

(Participant 7, M, 46)

"...Coming from God... it has come to us too."

(Participant 12, M, 50)

Sub-theme D4: Affirmation and Avoidance

Affirmation: The participants tried to accept their disease by disregarding it and convincing themselves that it is not very severe in comparison with other diseases/medical conditions (Figure 2).

"... it is tougher to be a cancer patient. I mean, think about the worse diseases. The course of the disease could be worse."

(Participant 5, F, 41)

Avoidance: Some participants tried to cope with their situation by avoiding negative thoughts or neglecting the fact that they had a medical condition (Figure 2).

"I don't want to put myself in such a negative mood. When negative thoughts/feelings occur, I think to myself '... there's nothing bad,

you are over-thinking, don't mind it, let's do this/that (some activity)'

(Participant 3, F, 20)

... I went to work, if I stayed home I would be constantly thinking like 'What's going to happen next? Will it cause me harm? Will I have a disease attack?' whether I like it or not. While I was working, I wouldn't think about it, so I worked.'

(Participant 8, M, 43)

Discussion

This study investigated how individuals diagnosed with MS spent their diagnosis and treatment period what sort of socio-economic and psychological challenges they faced in their family life, social life, educational, and professional life during this period, and their coping mechanisms. In addition to the trust ensured by the clinical environment maintained during the interviews, the participant's trust in the doctors and clinical team, who have been following them up for years, provided the researchers with the ability to conduct in-depth interviews. Although the experiences of the participants varied based on the sociocultural structures of their families, social circles, and their perspectives, some common patterns were detected within the examined problems. In harmony with its purpose, the experiences of individuals diagnosed with MS regarding the diagnosis and treatment processes and the problems experienced in social life were examined in-depth by this study and approached in a multidimensional manner.

In connection with the limitation of the public's knowledge and awareness about MS, the participants were left alone with severe internal problems because they did not have any information about the disease at the time of their diagnosis. This could also have been raised from the impressions gained from the lives of patients with MS they had come across. The thoughts underlying the fears and anxieties felt as the initial reactions after the diagnosis were mostly related to the probable decline in functionality and quality of life, uncertainty about the future, the idea of approaching death and leaving family members behind. In a similar study conducted in Greece, most patients diagnosed with MS stated that the most common emotion they had was fear because of the uncertainty of what MS would bring to them in the future (9). In another similar study conducted in Turkey, the participants were asked, "How did you react after you learned the diagnosis?" (8) to which they mostly replied with "I cried," "I could not accept, I was very upset," "I was very surprised," and "I was afraid of what would happen," indicating fear, shock, and uncertainty (8).

In our study, all the participants lived in metropolitan cities during the diagnosis and treatment process and none reported any difficulties accessing the routine treatment. All participants were committed to their treatment. However, the drugs were required to be used continuously and the related

side-effects of these drugs were an important reason for the periodic disruption of treatments. In a study conducted in Iran (10), some of the participants stated that they stopped the drug treatment because they were tired of the long treatment process and wanted to continue with their normal lives; furthermore, some patients turned to herbal treatments and waited for complete recovery. In this past study, the families and social circles of the patients with MS seemed to exhibit supportive behavior and made efforts to ease the participants' lives (10). Although several participants agreed with this, they mentioned that behavior changes after the diagnosis may lead a person to feel insecure and incompetent. They also mentioned that feelings of anxiety displayed by family members were disturbing at times (10). In another study conducted in Norway, a similar distinction was noted among the participants' approach to their family members' actions (11). It was also found that pampering patients could lead them to inflict a discriminatory manner even when the intentions were good, which was recognized as a derivative of stigmatization (11).

In a similar study (12), patients wanted to learn more about the disease before taking any action as MS was a completely new disease for them at the time of their diagnosis, as verified by many participants stating misperceptions about the disease before the diagnosis. They stated that the reason for the misperceptions about MS was due to the lack of knowledge and negative attitudes of individuals in society toward patients with MS (12).

In the present study, the limited knowledge of patients, their relatives, and society about MS was striking. It is therefore evident that the level of knowledge shapes the manner of approach to patients by their social environment. Moreover, wrong and incomplete beliefs about the course and effects of the disease may cause experiences that are negatively evaluated by the participants, such as stigmatization and discrimination in the workplace (12,13). The process of obtaining information usually proceeds through the efforts of the patients themselves; however, this process may not always occur through reliable sources. For some of the participants, obtaining information about the disease course was perceived as anxiety-provoking, which undermined the process of obtaining information.

The participants thought that increased knowledge and awareness of the community about MS could prevent acts of stigmatization from occurring. Similar to that in previous studies, here, many participants stated that the community did not have sufficient knowledge about MS. The participants hoped that the community would learn and understand MS and related symptoms.

Similar to that in the literature, the present participants also faced various problems in their educational life (14). Physical and mental difficulties stemming from MS led to issues such

as absenteeism or a downfall in academic performance throughout patients' education, which affected their career choices. In a similar research (14), patients with childhood-onset MS had difficulty adapting to school life, and they exhibited a decline in their academic performance, which negatively affected their education.

Unemployment is an important drawback for people diagnosed with MS. Some researchers suggest that this issue stems from personal factors such as disability, tiredness, or a lack of education, while others have linked this issue to societal causes such as negative attitudes toward the patients or a lack of physical amenities (12-16).

In parallel with the literature reports, this research exhibited that participants faced disruptions in their occupational and educational lives due to the inability caused by MS and due to the process of treatment. Some participants who faced the threat of termination of employment due to MS or had encountered discrimination in the recruitment processes faced financial losses. On the contrary, the accounts of participants who had received support from their employers or co-workers constituted a crucial sample that displayed consideration of the disease burdens in the workplace, resulting in a positive impact on the patient's quality of life.

Another study demonstrated that social support could be highly beneficial for patients to develop skills regarding coping with health problems (15). A social circle that is aware of the social, physical, and mental problems of MS can help the patient get relief in terms of both apprehension and the burden of the disease.

According to a past study, the fear caused by the uncertainty of the prognosis was identified as a significant factor that could have a stronger negative impact on the quality of life than the disease itself (12). The anxiety levels of patients can be ameliorated by having adequate knowledge about the prognosis of MS. It is therefore speculated that informative sessions following outpatient controls can assist in this regard. Counseling services and therapeutic interventions offered by healthcare professionals can be beneficial in maintaining the patients' mental well-being.

It is remarkable that most participants described seeking information about MS and seeing other patients with worse clinical status as triggering factors for anxiety. The participants stated that these concerns affected their mood chronically. The probability of symptoms progressing raised concerns in the patients, built upon the thoughts of losing function and affecting the family members. It was concluded by a population-based study that people with MS scored significantly higher in anxiety and depression scales, on the grounds of the physical symptoms of MS and its effect on their families (16). It is therefore attested that MS can paradoxically exert both

negative and positive effects on family life based on emotional stress, separation, economic hardship, fear of abandonment, or familial relationships becoming more profound (17).

Participants described living with MS as a situation that created an emotional burden. The commonly used mechanisms to cope with this burden included perceiving the disease as a divine outcome, either ignoring the symptoms totally or underestimating its extent, making efforts to recuperate so as not to burden others, and engaging in distracting activities. Particularly, in the early stages of MS, avoidance was found to be often applied as a coping mechanism. Emotional support of the social circle and information about physical activity were identified as being crucial for orientating into a life with MS (18). Notably, coping mechanisms differed among patients in relation to their familial structures and sociocultural features (18,19). Another study identified "denial" as the most sighted coping mechanism (19).

Study Limitations

Considering the qualitative nature of this study, the results cannot be generalized to all populations. The participants were selected from patients with MS who were admitted to neurology outpatient clinics and were not in the attack period. Patients with an EDSS score <5.5 were included in this study. Therefore, the participants were mobile, could maintain their daily lives, and did not have permanent functional loss. The findings related to patients with severe functional loss were not included in our study. Excluding severe cases may have limited our findings' generalizability, in other words, it adds bias as if patients with MS do not have severe social challenges in life. The veracity that the study was conducted at a single center with patients who did not experience any limitations in access to treatment can be shown as a limitation.

Conclusion

The results indicated that participants may experience problems such as stigmatization, anxiety, and discrimination due to the insufficient level of knowledge about MS. Official sanctions applied against discrimination in schools and workplaces may prevent patients from losing their social rights and experiencing a downfall in their quality of life. Practical interventions, such as community education programs or patient-centered care models, should be developed and implemented.

Researchers believe that conducting population-based cross-sectional quantitative studies in larger samples and with variations in the loss of function may produce results that could be generalized to the population. Past studies including those on people with severe MS can be recommended. New quantitative studies developing scales such as quantitatively measuring stigma in patients with MS or perceived empathy in patients with MS can be recommended after our qualitative

study or conducting prospective longitudinal studies can also be recommended.

Further studies inquiring about implementations by health authorities for patients and their relatives might be needed. The development of better health education policies by health authorities with the aim of targeting the population is also recommended.

Ethics

Ethics Committee Approval: The study was approved by the Ethics Committee of Marmara University Faculty of Medicine (approval no: 09.2022 -1182, date: 10.10.2022).

Informed Consent: The participants were free to leave the study at any point of time and informed about the same before the start of the study.

Footnotes

Authorship Contributions

Surgical and Medical Practices: B.O.G., B.M.S., A.E.K., A.U., M.N.K., D.I.G., G.S., Concept: A.S.K., S.H., M.T.B., M.K., Design: A.S.K., S.H., M.T.B., M.K., K.A., Data Collection or Processing: B.O.G., B.M.S., A.E.K., A.U., M.N.K., Analysis or Interpretation: A.S.K., S.H., M.T.B., B.O.G., B.M.S., A.E.K., A.U., M.N.K., M.K., Literature Search: A.S.K., M.T.B., B.O.G., B.M.S., A.E.K., A.U., M.N.K., Writing: A.S.K., M.T.B., B.O.G., B.M.S., A.E.K., A.U., M.N.K., M.K.

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