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Explaining the burden of cultural factors on MS disease: a qualitative study of the experiences of women with multiple sclerosis

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Abstract

Background Multiple sclerosis (MS) is a debilitating, non-traumatic disease that is common among young adults. Cultural factors, as background factors, can affect how patients adapt and their quality of life. This study aimed to explain the burden of cultural factors on Multiple sclerosis.

Methods This study was conducted with a qualitative approach and conventional content analysis among women with Multiple sclerosis in Mashhad. The data were collected through semi-structured interviews with women with MS. Fifteen patients with Multiple sclerosis were selected using purposeful sampling. The Graneheim and Lundman method was used to analyze the collected data. The transferability of the study was evaluated using the Guba and Lincoln criteria. MAXQADA 10 software was used to manage and analyze the data.

Results In explanation of the cultural factors of patients with Multiple sclerosis, one category (cultural tensions) and five subcategories (forced communication with spouse's family, definition of women's role in society, people's behavior, social beliefs and isolation of the patient) were extracted.

Conclusion The results obtained in this study show that female MS patients face various concerns. Overcoming these challenges require a change in the attitude of people in the society towards women with MS, which is important in the context of formulating practical policies to create a suitable culture. Adopted policies should aim to internalize the culture of changing society's views of female MS patients. Therefore, the authors argue that there is a need for cultural policies, followed by the systems implementing these policies to consider the challenges mentioned in this study as a priority for MS patients.

Keywords Multiple sclerosis, Cultural factors, Qualitative study

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Background

Multiple sclerosis (MS) is a chronic inflammatory auto-immune disease of the central nervous system (CNS) [1]. Multiple sclerosis is usually diagnosed between the ages of 20 and 40 [2]. The prevalence and incidence of MS is expanding worldwide, and the prevalence of MS is estimated to be 35.9 persons per 100,000 population (2.8 million people) in 2020 [3]. The probability of MS in women is almost to 2–3 times higher than that in men [4, 5]. The prevalence of MS in women and men was estimated to be 44.8/ 100,000 and 16.5/ 100,000, respectively [6].

People suffering from this disease need to deal with and adapt to its everlasting challenges [7]. Cultural practices and beliefs of patients affect their coping style with challenges. Due to the abundance and complexity of a person's relationship with the society and its culture, the influence of cultural factors on human behavior cannot be ignored [8].

Every culture has certain views, behaviors and beliefs that not only affect people's way of life, roles and their worldviews, but also affect the health and the numerous illnesses that plagues the people in the society [9]. Cultural differences can influence the concepts of health and diseases of societies and each society creates ways to treat and manage illnesses based on its culture [10].

The word "culture" refers to systems of knowledge, concepts, rules and activities that are learnable and are passed down from one generation to another [11].

Culture influences the ways of describing and understanding patients' experiences and visible behavioral cues in clinical encounters, symptomatology, clinical manifestations, treatment expectations, adaptation to the disease, and treatment responses [12].

Psychosocial stressors and cultural characteristics may cause problems in communication and affect the diagnosis and treatment [13]. Sociocultural norms and beliefs lead people in society to have certain expectations based on specific gender roles for women [14].

For example, the irrational expectations of the spouse's family and their great influence on the spouse's decisions has become the basis for more worries in life [15]. Studies show that the main notions of the way of doing the housework have not changed much for men and women. They also show that housework and taking care of children are still considered the main duties of women [16].

On the other hand, the unequal distribution of power, resources and responsibilities between men and women has been institutionalized traditionally and has even taken root in women's own thoughts and has become a rule. In many societies, women are in charge of nutrition, immunization, cleaning, hygiene, management, organizing ceremonies and celebrations without receiving wages, and women must perform tasks such as cleaning, raising children, cooking, and taking care of their husband [17]. Having children is considered one of the main goals of marriage [18]. Therefore, social and cultural norms and beliefs impose significant pressure on women by imposing gender expectations on them [14].

Considering that MS is more common in women of reproductive age, it may have a significant and long-term effect on women and families who are affected by this condition [19]. One view about pregnancy and the birth of a baby from a mother with MS is that pregnancy is potentially dangerous for the mother and her baby [19].

Another common concern in MS patients is sexual dysfunction. Sexual dysfunction is a very common and devastating problem in people with MS [20]. Young women with MS face challenges in finding a partner, raising a family, and managing their sex lives [21]. Studies show that patients are very discouraged by the behavior of people around them and their seemingly sympathetic advice [22]. A major issue in MS employment research is the strong effect of disease status on occupational participation [23]. Studies show that MS affects the occupational status of patients in various ways. Discrimination in the workplace may result in wrongful termination or failure to provide reasonable accommodations [24–26].

A qualitative study conducted explained the psychosocial factors of the burden of illness and demonstrated that patients with multiple sclerosis experience stress, agitation, and stigmatization [27]. However, in addition to the psychosocial challenges, women with MS also experience other challenges. Some of these challenges can be related to beliefs, perceptions, and cultural barriers [28]. In the long term, insensitivity to cultural aspects can have adverse effects on health and thus perpetuates health inequalities [29].

Many studies have addressed one or two cultural factors affecting the occurrence or exacerbation of MS; however, due to the diversity and extent of cultural factors, none of them provided integrated classification of these factors and the true contribution of cultural factors on the health outcomes of MS patients is not understood. Since studies have not specifically focused on cultural factors affecting MS, in this study, an attempt was made to understand and classify cultural factors that are effective in exacerbating MS. Cultural beliefs are crucial for providing adequate care and support, and efforts to break cultural barriers also enable better care for people with MS. By addressing this research gap, we can help to develop effective cultural interventions. Which ultimately leads to improving the attitude and reducing the health disparity of MS patients.

Methods

This study employed a qualitative approach with conventional content analysis to examine women patients with multiple sclerosis (MS) in Mashhad, Iran, a major city located in the eastern part of the country, during the year 2022.

Participants and recruitment

In this research, the purposeful sampling method was used and the sampling continued until data saturation was reached.

Considering the maximum diversity in social situations in the city level (from different geographical, urban, and rural areas and different ages), the participants were selected from among 4600 patients admitted to the comprehensive MS center and the MS association. Age, duration of illness, level of education, marital status, and occupation were among the important underlying factors considered in this study.

With official permission, the researcher went to the Comprehensive MS Center and the MS association. She explained the purpose and importance of the research to the officials, and the necessary coordination was conducted with the officials of each department. Then, while communicating with the patient, the researcher explained the objectives, the importance of the research and the conditions of the research to the patients. Participants were allowed to bring their family or caregiver with them during the interview. However, all participants preferred to be interviewed alone. Finally, the patients who wanted to participate in the interview were selected and were interviewed after the necessary coordination.

Inclusion and exclusion criteria

Iranian patients with MS (according to the 2017 McDonald criteria) [30] and residents of Mashhad, can participate in this study after voluntarily completing and signing the consent form, if at least one year has passed since their MS was diagnosed by a physician. The exclusion criterion was the unwillingness of the participants to continue their cooperation at each stage of the research.

Ethical considerations

Before the interviews, the objectives and importance of the research were explained to the participants. The patients were assured that all information and interviews are only for research purposes and confidentiality and anonymization of information is respected in all stages. The participants' voices were recorded with their permission. All the stages of this study were conducted following the Helsinki Declaration.

Data collection and analysis

Face-to-face semi-structured interviews were conducted with MS patients to collect data. After twelve patients were interviewed, the data became saturated because no new concepts were obtained from the interviews, and the codes and concepts were repeated. It should be noted that three more interviews were conducted to ensure data saturation. Interviews were conducted by the first author (FP: who is a PhD student in health education and health promotion). The interviewer had experience and interest in conducting interviews on factors related to MS. No of the participants withdrew from the study. Two test interviews were conducted to assess the validity of the tool.

Quantitative and qualitative articles on the cultural factors affecting MS worldwide were reviewed to guide the related questions. The questions were then formulated and revised according to the experiences of the research team. The guide questions are provided in Supplementary File 1.

For example, in this study, questions were asked such as has this disease affected your relationships with others? If yes, how? Can MS affect others relationship with your? Explain it. What factors cause you worry? Explain it.

At the end of any interview, the researcher asked the participants to talk about any topic they wanted, which the researcher did not mention. The interviews were conducted in the MS Comprehensive Center that was suitable in terms of ventilation, light, and sound.

The interviews were conducted between July and September 2022. Depending on the participant's tolerance level and environmental factors, the duration of each interview varied from 30 to 63 min. In order for personal thoughts to not affect the process of data collection and analysis, the researcher wrote down her thoughts on paper to avoid emphasizing them.

During the study, the researcher carefully observed the participants' behaviors in terms of feelings, emotions, and reactions. The researcher then added notes collected during the observations to the interview margins. The researcher provided her contact information to the participants so that wherever the participants felt the need to provide more detailed information to the researcher, they could contact the researcher.

A qualitative data analysis was performed using the five-step approach proposed by Graneheim and Lundman. In the first stage, immediately after completing the interviews, the recorded interviews were written on paper to create the primary data. In the second step, the texts were read several times to obtain a general understanding of their content. In the third step, the textual content is divided to determine semantic units and basic codes. In the fourth step, to obtain more comprehensive categories, the primary codes were classified based

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on their similarities and differences. In the fifth stage, the main subject of each category was determined [31]. First, the voices of participants were voluntarily recorded using a mobile phone recorder. Data backup was ensured by using two voice recorders. After each interview, the recorded interviews were transcribed on paper and were read several times. In the next step, handwritten transcripts were typed in Word 2016 as the primary research data. Typed interviews were analyzed using MAXQDA version 10 software. In the next step, the important sentences and phrases were first determined, and then the words and sentences (semantic units) were coded by the researcher, and open codes were formed. After the initial codes were extracted, those that were semantically and conceptually similar or related were classified into a category and formed a subcategory of a single topic with a higher level of abstraction. After the formation of more comprehensive categories, the analysis process continued to create the main and subcategories. To check the created codes, an independent researcher also checked the codes, and if there was an unresolved difference between the first and second researchers, the third researcher entered to resolve the difference (Fig. 1).

Methodological considerations

Validity, verifiability, transferability, and reliability are the four standards of Lincoln and Guba that were considered to strengthen the data [32, 33]. To validate the data, interviews were conducted with various patients. The extracted codes and texts were shared with several interviewees. To review the transcribed interviews, several meetings were held with the team leader.

To ensure the correctness of data, some of the codes and free subsets were checked by experts. In addition, part of the interpretation of the participants was checked by the participants themselves and corrections were made wherever needed.

To assure the transferability of the data, a purposeful sampling method was used, and sampling was performed with maximum diversity and continued until data saturation. The researchers increased the transferability of the data by providing a detailed and step-by-step
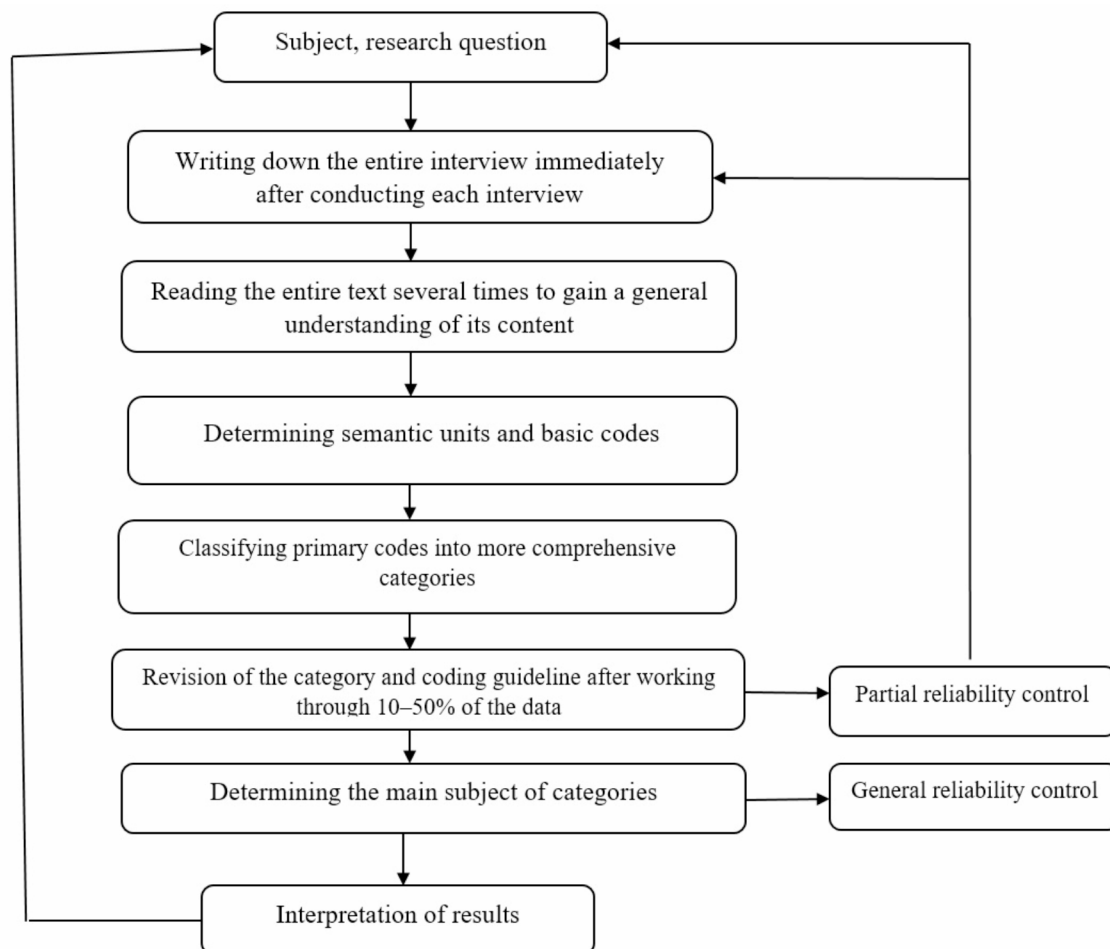
Fig. 1 Flowchart of methodological steps

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Table 1 Research participants' demographic characteristics

Variable	Category	N (%)
Marital status	Single	2(13.3)
	Married	9(60.0)
	Separated	4 (26.7)
Education level	Incomplete diploma	1 (6.7)
	Diplomas	6 (40.0)
	Bachelor's degrees	5 (33.3)
	Master degrees	1 (6.7)
	Doctorate	2 (13.3)
occupation	Housewife	9(60.0)
	Employed	5(33.3)
	Unemployed	1 (6.7)

Table 2 The view of multiple sclerosis patient women about cultural factors affecting the exacerbation of the disease

Maine category	Sub-category	Free codes
cultural tensions	Obligatory Communication with the Spouse's Family	unwanted participation in parties, tolerating snide comments and remarks for the sake of their spouse, keeping the spouse's family happy, recurring arguments, jealousy, turning their husband against them, and constant judgments
	Definition of Women's Role in Society	care of their husband and children, housekeeping, being an income generator, keeping up appearances, meeting the expectations of the family, and having adequate sexual activities
	People's Behavior	pitying the patient, changes in people's views, and backbiting the patient's family members
	Societal Beliefs	belief that the patient should not get married nor get pregnant, the patient being a burden, and not having a place in society
	Patient Isolation	reduced participation, ignoring the patient, and lack of trust in the patient

description of how to conduct the research process, and also described the characteristics of the studied population in order for other researchers to follow the research process. To check the reliability, the research team revised the process in two steps. In the first stage, partial reliability control was carried out and that the researchers checked the categories and coding instructions after working with 10–50% of the data. In the second step, the general reliability was examined by listing the final category at the end of the task (Fig. 1).

Results

Tis study was performed through semi-structured interviews with 15 patients with MS. Participants ranged in age from 27 to 52 years with a mean age of 37.13 years old and standard deviation (±7.49). Participant's duration of the disease ranged in from 3 to 22 years with a mean of 9.99 and standard deviation (±6.46). (Table 1).

Analysis of the 15 interviews resulted in 138 extracted codes, and after exclusion of the duplicate codes, a total of 22 main codes remained. These codes were classified into five sub-categories (Obligatory communication with the spouse's family, definition of women's role in society, people's behavior, societal beliefs and patient isolation) and one main categories (cultural tensions). More complete results can be seen in Table 2.

In the following, we will describe each of the categories.

Main category: cultural tensions
First subcategory: obligatory communication with the spouse's family
The participants reported that obligatory communication with the spouse's family such as unwanted participation in parties, tolerating snide comments and remarks for the sake of their spouse, keeping the spouse's family happy, recurring arguments, jealousy, turning their husband against them, and constant judgments were associated with worsening symptoms.

Participant No. 7 (Duration of illness 3 years): "… my husband doesn't know about my illness, I don't want him to know about my illness, because I'm afraid that my husband will tell his family, I haven't visited my husband's family for a long time, because communicating with them bothers me. Fortunately, now that I don't see them anymore I feel much better. That's why I'm calm. That's the only reason. When I look back, I ask myself why did I make such a mistake! I ask myself, when they create so many problems for me and my children, why did I go and see them in the first place? Why did I keep telling myself that no, you should go visit them for the sake of your husband?"

Participant No. 8 (Duration of illness 13 years): "… there are many people who get on my nerves, like in the beginning my mother-in-law used to tease me a lot. It's because of my mother-in-law's behavior that I'm not well and that I've reached this point. Whenever I went to their house I used to come back sad and crying. Now it's been forty days since the last time I went to their house. The last time, she said something to me again that made me very upset, my husband wanted us to go to his mother's house but I said I won't come to their house anymore, you go. There are some people whom you cannot break your relationship with. My mother-in-law disregards my illness, even though she knows that I am sick, she still speaks her mind."

Second subcategory: definition of women's role in society
In this context, the participants consider societal beliefs about women's roles such as taking care of their husband

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and children, housekeeping, being an income generator, keeping up appearances, meeting the expectations of the family, and having adequate sexual activities to be effective.

Participant No. 11 (Duration of illness 5 years): "… I have four children; I don't have time to exercise at all. All day long, I am doing housework, taking care of children and cooking. I told my husband: One of the patients is participating in training classes, exercise classes, flower-making classes and goes out of the house sometimes and her condition has improved a lot, but he said to me: If I were that woman's husband, I would definitely divorce her." my husband believes that the wife's job is doing housework."

Participant No. 3 (Duration of illness 3 years): "… I tried very hard to always have good and perfect marital life, because my husband cares a lot about sexual matters. Sometimes I am not physically and mentally ready to have sex, but I know that I am obligated to have sex with my husband. Because if I say that I don't want to have sex, my husband says: It's because of your MS that you have a lower sex drive."

Third subcategory: people's behavior

In this context, the participants consider people's behavior such as pitying the patient, changes in people's views, and backbiting the patient's family members to be effective.

Participant No. 4 (Duration of illness 9 years): "…we are like other people, we don't like being pitied by others and people changing their behavior because of our illness, we are just like them, we are people, we have a life, only our condition has become a little more difficult, that's all."

Participant No. 7 (Duration of illness 12 years): "… I don't have any expectations from the people around me, people are bad, if they find out that you have a problem, they take advantage of you.

Fourth subcategory: societal beliefs

In this context, the participants consider societal beliefs such as the belief that the patient should not get married nor get pregnant, the patient being a burden, and not having a place in society to be effective factors.

Participant No. 10 (Duration of illness 3 years): "…for now, my husband said: go and take the appropriate medicine and treatment, when your body reaches a stable state, then we will have a baby. It is not advisable to have a baby now. Of course, I'm also afraid, everyone also says it won't be too late to have a baby, you should wait for a while."

Participant No. 2 (Duration of illness 13 years): "… but one of the main reasons for choosing Cinnovex was that it was free, because I did not want my husband to pay for these issues. My husband does not say that he won't pay, but I would be very upset if I became a burden on my husband."

Participant No. 14 (Duration of illness 5 years): "… Everyone thinks of ideal things when getting married, and everyone wants to choose a beautiful, healthy, and rich girl for their son. I am very worried. If you say you are sick before marriage, they refuse to marry you."

Fifth subcategory: patient isolation

In this context, participants consider behaviors that lead to patient isolation such as reduced participation, ignoring the patient, and lack of trust in the patient, to be effective factors.

Participant No. 2 (Duration of illness 13 years): "…I didn't tell the company that I was sick. If a private company knows that you are sick, they won't hire you. Private companies are so conservative because of insurance issues, and most of the people there do not have a positive attitude and they aren't fun people to work with, everyone is looking for their own interests and they might even take advantage of your illness, for example, the moment something bad happens, they will say that this lady has a problem and she is not fit for working in this company."

Participant No. 7 (Duration of illness 12 years): "… I am his big sister, but without telling me anything, they went to propose for my brother, and they preferred not to include me. Then they said: We were afraid that something would be said during the proposal that would upset you. We didn't tell you anything, for your own sake. But it was pretty clear that they didn't want me, who is sick and stutters because of my MS, to go to the proposal with them. They thought to themselves that if the girl's family saw my condition, they wouldn't let their daughter marry my brother."

Participant No. 5 (Duration of illness 13 years): "… I was very stressed at work and my boss was very pushy about whether the work was done correctly or not. It was as if he did not trust my performance. Last time there was a fierce fight between us which made me leave the company, and again in the next company, there were still many challenges that were bothering me."

Discussion

This study aimed to explain the burden of cultural factors on Multiple sclerosis. Based on the results, one main category (cultural tensions) and five subcategories (obligatory communication with the spouse's family, definition of women's role in society, people's behavior, societal beliefs and patient isolation) were constructed.

The results of this study showed that female MS patients are often forced to communicate with their spouse's family in order to keep their spouse satisfied and prevent marital disputes. This obligatory communication

may impose a lot of psychological pressure on them, which can lead to the exacerbation of the disease.

The behaviors of the spouse's family, such as their interferences, jealousy, selfishness, gossips, vilification, insults, disrespect and their objections to the lack of sociability of the husband and wife cause consequences such as increasing worries, increasing tension between spouses, and the emergence and onset of depression symptoms [34, 35]. The results of Datta's study showed that conflict with the husband's family and especially the mother-in-law is a fundamental issue in the topic of marital conflicts [36]. A dissatisfying relationship with one's mother-in-law is an important risk factor for married women, which endangers their health [37].

The results of this study showed that female MS patients, due to the societal expectations of women's role, are often forcing themselves to act a certain way in order to keep their husbands happy and avoid marital disputes. This forced relationship may impose a lot of psychological pressure on them, which leads to the exacerbation of their disease.

The main views of men and women about how to do housework have not changed much, and housework and taking care of children are still considered the main duties of women [38].

The role of women has changed due to economic conditions and social demands, women have to endure tremendous pressure to get a job similar to their men counterparts, while having to maintain an active role in their personal life [39].

Work-life balance is a key issue in all types of jobs due to dual-career families becoming more common and stressful jobs with long hours becoming the norm. Work life integrated with personal life creates stress [40].

People with MS, considering the types of sexual dysfunction and its indirect effects on mental health, quality of life and intimate relationships, may see sexual dysfunction as the most negative feature of this disease [41].

The results of this study showed that female patients with MS often experience changes in the views and behaviors of those around them, and these behavioral changes are disturbing and lead to the exacerbation of their disease.

A study showed that being pitied by others is an uncomfortable situation that is characterized by a lack of understanding of the situation [42]. Another study showed that most patients notice a change in other people's opinions of them after the diagnosis [43].

The results of a study showed that the patients' families believed that because of the label of the disease, in addition to the patient themselves, the families are also treated differently. They felt that they were judged negatively and were simply ignored [44].

The results of a study showed that the support of the surrounding people should be such that it does not cause the patients to be dependent on them or create a feeling of being pitied in the patients, so that they can find the identity and purpose of their lives in post-illness conditions [45].

According to our study, the exposure of female MS patients to societal beliefs increases negative feelings, such as avoiding marriage and feeling like a burden, and these negative feelings are the basis for the exacerbation of the disease.

Women would avoid having children due to the false belief that it would worsen the overall course of the disease [46].

MS is diagnosed in adulthood and is more common in women. Therefore, many women with this disease are discouraged from starting a family when their disease is diagnosed [47].

Although pregnancy has been shown to have no effect on MS and MS to have no effect on pregnancy, some women may still be discouraged by some family members and health professionals [19].

Some patients expressed their discomfort with feeling like a burden and that their family is wasting a lot of time and money on them [48].

The importance of raising the awareness of family and community members about their possible negative influence on the MS patients and encouraging them to review their behaviors to prevent putting more pressure on the patients, should be emphasized [49].

Not considering a specific position for these people in society creates difficult and unfortunate conditions for them, especially those who had strong personalities and were influential members of society before contracting the disease [50].

Patients with physical disabilities believe that their functional limitations cause problems for their caregivers and significant others. Feeling like a burden may lead to distress and complicate the relationship with the caregiver [51, 52].

Considering that many women with MS are vulnerable to societal beliefs, it is necessary to formulate policies to change these beliefs so that society can take a step towards positive changes, and to reduce the frequency of these behaviors.

The results of this study showed that female MS patients are ignored by others during the disease, and the trust of others in their abilities decreases. This Distrust may impose a lot of psychological pressure on them, which leads to the exacerbation of their disease.

The results of studies show that many MS patients face a challenging work life. A higher proportion of people with MS report unemployment, part-time employment

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or reduced working hours, and lower income compared to the general population [23, 53].

MS is associated with work difficulties, reduced working hours or their involvement and participation in their workplace, being transferred to jobs or other departments that is below their skill or knowledge level due to their employers' impression that they are unable to handle the stress or the pressure of such works, and termination of voluntary and involuntary work or unemployment [54]. Greiton et al. found that the gender of women with MS was associated with their rate of unemployment [55].

Negative encounters such as discrimination and uncertainty from colleagues, managers or supervisors, and work organizations contribute to job transfer and termination, while positive support is associated with organizational embeddedness and job continuity [56, 57].

Women with disabilities have also historically faced double discrimination due to their physical disability and gender, and have been ignored in many parts of society [58]. Simmons et al.'s study showed that many MS sufferers have difficulty keeping jobs, even in good economic times [59].

Most of the participants were dissatisfied with the normalization of the disease for the doctors, followed by their superficial response to the patient and the lack of sufficient attention to the patient, and this issue had reduced their motivation to pursue treatment and follow medical recommendations [60, 61].

Research limitations

The results of this study are limited to explaining the burden of cultural factors on disease worsening in women with MS in the Iranian culture. Therefore, to benefit from the findings of this study, it is necessary to conduct similar investigations in other fields and cultures. Although the researcher tried his best to be neutral during the interviews. However, this important principle may not have been inadvertently observed. Finally, more research is needed to provide complete insight into the cultural factors associated with MS.

Conclusion

The results obtained in this study show that female MS patients face concerns. Overcoming these challenges require a change in the attitude of people in the society towards women with MS, which is important in the context of formulating practical policies to create a suitable culture. Adopted policies should aim to internalize the culture of changing society's views of female MS patients.

Therefore, the authors argue that there is a need for cultural policies, followed by the systems implementing these policies to consider the challenges mentioned in this study as a priority for MS patients.

Abbreviations
MS   Multiple sclerosis
CNS   Central Nervous System

Supplementary Information

The online version contains supplementary material available at https://doi.org/10.1186/s12905-024-03328-0.

Supplementary Material 1

Declarations

Ethics approval and consent to participate
The study was approved by the Ethics Committee of Mashhad University of Medical Sciences with the code of ethics IR.MUMS. FHMPM. REC.1400.024 (Cod: 992067). All participants signed informed consent to participate in the study. All procedures performed in this study were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Consent for publication
Not applicable.

Competing interests
The authors declare no competing interests.

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