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Social Barriers Faced by Women with Multiple Sclerosis in Tehran: A Qualitative Content Analysis

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Abstract

Background: Multiple sclerosis (MS) is a significant neurological disease primarily affecting young adults. The prevalence of this disease in women is about two to three times higher than in men. This study aimed to explore the challenges faced by women with MS using qualitative content analysis (QCA).

Methods: This qualitative study was conducted using a content analysis approach. A total of 23 patients with MS who visited the Iran MS Society were selected to participate in the study using a purposive sampling method until data saturation was reached. Data were collected through semi-structured interviews and analyzed using QCA.

Results: The social barriers identified as the main issues faced by patients with MS comprised nine subcategories including *insufficient financial support*, *lack of job opportunities*, *employers' inadequate information about the specific conditions of MS patients*, *loss of educational opportunities*, *decreased social cohesion and responsibility*, *lack of environmental adaptation appropriate for MS patients*, *social stigma*, *lack of public awareness about MS*, and *deficiencies in the public transport system*.

Conclusion: It is essential to enhance social support for patients with MS by raising public awareness, improving public transportation systems, and developing empathy among family members and the community.

Keywords: Multiple sclerosis, Qualitative research, Social support, Stigma

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Introduction

The increase in the burden of chronic diseases is one of the major challenges for healthcare systems worldwide in the 21st century (1). Chronic diseases are long-standing conditions that often do not a have definitive treatment, with available interventions merely aimed at reducing symptoms, preventing disease progression, and improving the overall health of affected individuals (2). Multiple sclerosis (MS), as a chronic illness, is the most common inflammatory neurological disease among young adults. The mean age at diagnosis is approximately 30 years (3). In 2016, there were more than two million MS patients globally, with substantial country-specific disparities in prevalence and incidence, and a clear predominance of females (4,5). According to the World Atlas of MS 2013, Iran was considered a medium-prevalence country with 20–60 MS patients per 100 000 (6). A systematic review reported the prevalence of MS in Iran as 29.3 per 100 000, significantly higher in women than in men (7). Recent studies have shown an increasing trend in MS incidence in Iran, particularly among young people aged 25 to 29 years (8).

The underlying cause of MS remains unknown, and the disease now affects even individuals under the age of 20 (9). The prevalence of MS in women is two to four times higher than in men. The most common age of onset of the disease is between 20 and 40 years, a period during which individuals often bear the most significant family and social responsibilities and are in their prime reproductive years (10).

Symptoms of MS include visual disturbances, stuttering, limb muscle cramps, sexual dysfunction, depression, dizziness, mood changes, fatigue, paralysis, cognitive problems, urinary incontinence, numbness and tingling, and impaired concentration (11). MS has a significant impact on patients, resulting in a wide range of complications. According to the International Classification of Functioning, Disability, and Health

(ICF) (12), MS affects three dimensions of patients' lives including body structures and functions (impairments), activity limitations (difficulties in daily tasks), and participation restrictions (problems in social situations and work). Physical restrictions associated with MS, including weakness, tremors, and problems with coordination, along with cognitive impairments (mostly in speech and memory) can limit one's activities (e.g., driving, managing finances, self-care) and social participation (e.g., work, social integration, and family roles) (13).

MS threatens one's independence and ability to participate effectively in family and community life, often leading to a sense of inadequacy and low self-confidence (14). Patients with MS experience a range of challenges, including the high cost of treatment, limited access to necessary medications, lack of empathy from healthcare providers, sexual dysfunction, unemployment, and family issues (15).

Social problems are among the most important challenges MS patients usually encounter. Studies have shown that limitations and weaknesses in social functioning are the most important problems faced by MS patients (16,17). The financial burden of treatment and rehabilitation has also been addressed in some studies (18). Notably, 75% of individuals with MS are women, with the disease predominantly manifesting in the mid-thirties. Given that MS impacts all facets of an individual's life, leading to disability and hindering their ability to fulfill various roles and responsibilities, women with disabilities have often faced dual discrimination due to both their physical impairments and gender. This dual discrimination has resulted in their marginalization in many sectors of society. Consequently, women were chosen as the focus group for this study (19).

So far, various quantitative and qualitative studies have investigated the challenges faced by women with MS both domestically and internationally. However, to the best of the researchers' knowledge, no study has specifically focused on the social problems faced by this group in Iran. Considering that women with chronic illnesses encounter numerous limitations and challenges due to the cultural and social fabric of the country, this study aims to answer the question of what social problems women with MS face.

Methods

This study was carried out using qualitative content analysis (QCA). Conventional content analysis is potentially one of the most important qualitative research techniques in social sciences that focuses on analyzing the content of data to achieve a deeper understanding (20). The QCA was designed and implemented as a systematic reduction of content, with a particular emphasis on the context in which data are created to identify themes and extract meaningful interpretations. Accordingly, the present study used the conventional content analysis, which is typically applied to describe a phenomenon (21), to explore the emotional experiences and reactions of patients.

The research population included female MS patients residing in Tehran, Iran. A total of 23 women with MS were selected to participate in the study. The inclusion criteria were being female, being diagnosed with MS for at least two years, having undergone treatment, having the ability to communicate verbally, and providing informed consent. The exclusion criteria included unwillingness to continue participation and instances of disease relapse.

Participants were selected using purposive sampling with maximum diversity (in terms of MS type and treatment method). Volunteers who met the inclusion criteria were selected from a list provided by the Iran MS Society, and invited to participate in the interviews. Initially, the first author explained the objective of the study, the interview procedures, and the participants' right to withdraw from the study. Subsequently, informed consent was obtained from all participants. Data were collected through in-depth semi-structured individual interviews (22).

Interviews were conducted by the first author, who was experienced in qualitative interviews and had conducted several workshops on qualitative research. The second author, a faculty member at the university, supervised the interviews carried out at the MS society and community support centers for patients with MS in Tehran, Iran.

The main interview questions were developed in consultation with the research team and through initial interviews with several patients. The interviews began with a broad question: "Could you describe your experience of participating in society with MS?" Follow-up questions were then asked to gather more detailed information and clarify participants' statements. The follow-up questions were guided and determined by the participants' responses. The interviews were recorded with the consent of the participants, and the recordings were transcribed promptly, along with field notes, first handwritten and then typed. The transcribed text was reviewed multiple times and broken down into constituent meaning units, and subsequently into the smallest meaningful units. The codes were then read multiple times to be organized into subcategories and main categories based on semantic similarity. Both the initial texts and final categories were re-read several times until the researchers and participants reached a shared understanding of the categories. Additionally, efforts were made to minimize the influence of the researchers' biases and assumptions on the data analysis process.

To ensure the validity of the data, the four criteria proposed by Lincoln and Guba including credibility, dependability, confirmability, and transferability were employed (23). The credibility of the data was established through continuous engagement with the research topic and data. Feedback from faculty members of the research team regarding the interview process, data analysis, and extracted data was also sought. The interview transcripts, extracted codes, and subcategories were shared with some participants and a neurologist with extensive experience in MS, and their feedback was incorporated. A combination of data collection methods (interviews and field notes) was used, and participants were selected with maximum diversity in terms of age, type of disease, treatment and medications used, economic status, and education level. To ensure the dependability of the data, the same integration method was utilized for data collection, and an external observer familiar with qualitative research reviewed the data, achieving consensus on the procedures and findings. For confirmability, all activities, including the research process and how the findings were obtained, were meticulously documented, and a report on the research process was provided. To increase the transferability of the data, the findings were shared with five female MS patients outside the study who had similar conditions to the participants, and their feedback confirmed the findings.

Ethical considerations in this study included maintaining the confidentiality of information, obtaining informed consent for interviews and recording conversations, and ensuring participants' right to withdraw from the study at any time. Ethical code 17,8,1 was adhered to throughout the research.

Results

A total of 23 women with MS who were under treatment participated in this study. The age of the participants ranged from 23 to 47 years, and their education level varied from lower than high school to postgraduate. The duration of illness ranged from 3 to 21 years. Regarding medication, 8 patients received Iranian injectable drugs, 14 received foreign injectable drugs, and only one patient received oral medications to prevent the recurrence of symptoms, along with corticosteroids in the event of an attack (Table 1).

Table 1. Demographic information of the participants

Demographic information	Number	Percent
Age		
23-30	7	30
31-38	4	4
39-46	9	39
46-53	3	14
Education level		
Middle School degree	1	4
High school diploma	13	57
Associate's degree	2	8
Bachelor's degree	6	27
Master's degree	1	4
Marital status		
Single	5	22
Married	8	35
Divorced	10	43

Rich and in-depth descriptions from the participants led to the identification of one main category: Social Problems. This category was further divided into nine subcategories, detailed as follows:

Insufficient financial support from government and society

Most participants expressed that MS was a costly disease, and they did not receive sufficient financial support from both the government and non-governmental organizations (NGOs) to cover treatment costs. Patients reported dissatisfaction regarding living costs, challenges in obtaining financial support from NGOs, and a lack of integrated community support. For example, one participant stated: "*I went to the MS Society for a loan because my husband does not pay the treatment costs. They asked for a guarantor to repay the loan. What would I do if I had someone to support me*?" (Participant 9, a 46-year-old housewife).

Lack of job opportunities

Most participants had job-related problems such as incompatibility between their jobs and medical conditions, unemployment due to illness and medication side effects, and loss of job opportunities because of disease symptoms including excessive fatigue and performance limitations. Participant 14 stated, "*I have loved working since childhood, but because of the fatigue caused by my MS and movement disorders, I had to decline the opportunity*" (a 30-year-old housewife with a bachelor's degree).

Employers' inadequate information about the specific conditions of MS patients

Most participants complained that employers were not aware of MS and its specific conditions. This led to ignoring patients' problems, capabilities, and potential barriers. In some cases, employers even imposed additional workload on MS patients. For example, participant 20 stated, "*Since my colleagues were informed of my illness, the school principal insisted that I should not teach but work in the archives, although I have been successful in teaching*" (A 47-year-old employee with a high school diploma).

Loss of educational opportunities

Most participants reported missed educational opportunities due to the adverse effects of the disease, treatment side effects, decreased concentration, and impaired cognition which would hinder learning new materials. For example, participant 17 said, "*I have* *difficulty concentrating due to MS, and I cannot focus on my lessons*" (23 years old, unemployed, associate's degree).

Decreased social cohesion and responsibility

Most participants were dissatisfied with issues such as decreased social solidarity, experiencing disrespectful behaviors from others because of their social problems, and reduced social responsibility towards patients. In this regard, Participant 2 mentioned, "*If you are standing with a cane on a bus or even have difficulty moving and standing, nobody would offer you a seat*", (A 35-year-old employee with a bachelor's degree).

Lack of environmental adaptation appropriate for MS patients

Most of the participants addressed issues such as walking difficulties due to uneven urban surfaces, inadequate space for walking in parks, insufficient pedestrian bridges, and inappropriate passages and corridors of offices and organizations. Moreover, they reported other problems like the lack of seats for patients to rest in public places, long waiting times for elevators, insufficient public toilets, and inadequate recreational facilities tailored to the needs of MS patients. Participant 18 stated, "*The streets are full of potholes, which make me lose my balance and fall*" (A 39-year-old housewife with a high school diploma).

Social stigma

Many participants reported experiencing perceived social stigma, including being labeled as beggars, drug addicts, and patients infected with HIV/AIDS or other contagious diseases. For example, participant 15 said, "*When a passenger in a taxi learned I have MS, he thought the disease was contagious and got off quickly*" (45 years old, unemployed, bachelor's degree).

Lack of public awareness about MS

Most participants complained about the general public's insufficient awareness of MS, noting that even educated individuals held misconceptions. For some, MS is an unknown condition, leading to misunderstandings like considering it a physical disability, asking irrelevant questions from the patient, and ignoring the capabilities of the patient. Accordingly, participant 7 stated, "*In the community, because of people's unawareness and my mobility problems, I have to say I have arthritis and my legs hurt, even when I use a chair to pray in the mosque*" (a 46-year-old housewife with a high school diploma).

Deficiencies in the public transport system

Most participants pointed to the difficulties in using public transportation, including subways and buses, due to overcrowding and inappropriate conditions, high costs of non-public transport options, and the risk of MS attacks on buses and subways because of overcrowding. They also complained about the lack of facilities for the well-being of patients, the absence of special seats for patients, tiredness due to standing, and the inability to maintain balance in subways and buses. Participant 11 noted, "*I become frustrated on crowded buses and subways, worrying about MS attacks*" (A 45-year-old employee with a high school diploma).

Discussion

This study was conducted using QCA to identify the social problems faced by female MS patients. The codes extracted based on the experiences of the participants led to the identification of nine social challenges including *insufficient financial support*, *lack of job opportunities*, *employers' inadequate information about the specific conditions of MS patients*, *loss of educational opportunities*, *decreased social cohesion and responsibility*, *lack of environmental adaptation appropriate for MS patients*, *social stigma*, *lack of public awareness about MS*, and *deficiencies in the public transport system*.

MS leads to limitations in social activities, the loss of independence, and a sustained decrease in one's quality of life (24). Social support, which affects individual health, is defined as information that fosters a belief in being loved, affirmed, and valued by family and peers. In broad terms, it conveys a sense of belonging to a network of relationships and interactions (25,26).

In the present study, participants complained of insufficient support from governmental and non-governmental organizations for service provision, particularly concerning the high costs of treatment. This finding aligns with research indicating that the high costs of treatment affect not only MS patients but also those with other specific diseases, such as cancer. Medication costs for patients with MS and cancer are high in both governmental and private sectors. Many patients have difficulty affording treatment costs, and government tariffs and subsidies have not significantly reduced these costs (27). Physical illnesses such as MS can impair the perception of receiving social support as patients may gradually withdraw from social contact and relationships with family members and friends (28).

Participants also complained about being ignored by employers and job loss. The results of a study showed that most MS patients lose their jobs five years after diagnosis (29) . Other studies in different parts of the world have also suggested disability and drug side effects contribute to workplace problems and increase the likelihood of job loss (30-32). It has been reported that 43% of people with MS have stopped working three years after diagnosis, and the corresponding value after 10 years is 70% (33). The study conducted by Kalantari et al., also indicated that some patients attempt to hide their disease to protect themselves from social isolation and exclusion from social services or job opportunities (34).

Participants believed that the public transport system has not been designed to meet their mobility and balance needs, and streets and highways lack the facilities to meet their requirements. Environmental adaptation or disabled individuals' easy accessibility to public places is crucial for ensuring equal opportunities to participate in social, economic, and political spheres. The absence of citizen participation in environmental planning is directly related to the physical disability of individuals and the inadequacies of urban spaces (30).

The lack of public awareness regarding MS emerged as a prominent concern for participants. In some cases, community members labeled patients with MS as drug addicts, prostitutes, or individuals infected with HIV/AIDS. To avoid social stigma, some patients chose mislabeling their condition as osteoarthritis rather than disclosing their true illness. Social stigma results from negative social attitudes and exacerbates the burden of the disease, leading to long-term disabilities (31,32). According to some studies, patients with MS experience a wide range of stigma, and social stigma is one of the most important factors that affect patients' quality of life (33). Another study demonstrated that patients with MS in Iran are labeled by some members of the community and have to hide their disease (35).

This study indicated patients with MS in Tehran, the capital of Iran, face many social problems. Given the concentration of medical, economic, and social facilities in Tehran compared to other provinces, patients in other parts of the country face similar problems. Findings from various studies conducted in different regions of the world also showed patients with MS experience problems such as job loss, social stigma, the financial burden of treatment, and a lack of support from authorities and the community to varying degrees (25-28,35).

This study focused on female MS patients in Tehran, and the findings reflect the experiences of this specific group. The research team did not have access to patients with MS who were not members of the Iran MS Society. One of the strengths of the present study was identifying the social problems faced by MS patients resulting in social isolation and reduced social participation. Future research is recommended to address these problems and develop appropriate strategies that facilitate their active participation in the community.

Conclusion

This study indicated that female MS patients encounter different problems such as insufficient financial support from government and society, lack of job opportunities, loss of educational opportunities, lack of environmental adaptation, social stigma, and deficiencies in the public transport system. These problems contribute to social isolation, stigmatization, and a pervasive sense of worthlessness in society. Thus, it is recommended to increase social support for patients with MS by raising public awareness, improving the public transport system, and developing empathy among patients' family members and the community.

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Authors' Contribution

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Competing Interests

The authors declare that they have no conflict of interest.

Ethical Approval

The study received ethical approval from the Ethics Committee of the University of Rehabilitation Sciences and Social Welfare in 2017 [code: USWR.REC.1393.168].

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