

Concerns of Women of Reproductive Age with Multiple Sclerosis: A Qualitative Study

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Abstract

Introduction: Psychological disorders are the leading cause of disabilities, social harms, and reduced quality of life in patients with Multiple Sclerosis (MS). This qualitative study was conducted to describe the concerns of females with MS.

Methods: In this qualitative study, 16 females with MS at the reproductive age with medical records at the MS Society of Tabriz were selected using the purposive sampling technique and underwent semi-structured in-depth individual interviews. All interviews were recorded, transcribed, and analyzed using conventional content analysis.

Results: In this study, 23 codes were identified from transcribed interviews and categorized to two sub-categories, fears and feelings. These two sub-categories formed the main category, named concerns.

Conclusions: Regarding concerns of these patients, their regular health monitoring by physicians and healthcare providers is recommended in an attempt to alleviate these concerns.

INTRODUCTION

Chronic or non-communicable diseases are long duration diseases with generally slow progression that lead to mortality and complications during middle age and old age [1]. Multiple Sclerosis (MS) is a chronic, disabling, neurodegenerative, autoimmune, and demyelinating disease of the central nervous system [2]. Therefore, MS often affects people at their productive phase of life, and results in these patients being worried about their family roles and responsibilities [3]. Multiple sclerosis affects approximately 400 000 people in the United States and about 2.5 million people worldwide [4]. Given that Iran's population in 2011 was 75600000, the prevalence rate of MS was calculated as 45/100 000 population. Seventy percent of these patients were between 20 and 40 years of age. The maximum prevalence rate (80 per 100 000 populations) was seen in Isfahan province, located

in central part of Iran [5]. Previously, Iran was considered a low prevalence area, yet recent investigations have shown that the prevalence of MS in Iran has increased significantly [6]. Multiple Sclerosis leaves dramatic physical, economic, psychological, and social effects on different issues concerning everyday lives of patients and their families [7]. In addition to physical effects such as fatigue, pain, walking disorders, intestinal and bladder dysfunction, sexual dysfunctions, and vision problems, there are visible changes in emotional and cognitive functions (such as information processing, attention, memory, and mood) in most people with MS [8]. Having chronic concerns is among characteristics of patients with MS [9]. They usually endure a greater amount of stress, pain, and depression [10]. Although there are a few studies about MS concerns, it seems that these concerns can provoke

anxiety and distress. Concern is a stable understanding characterized by recurrent thoughts about negative [life] events and attempts made to solve these problems subjectively [11]. Concerns risk health through increasing stress and its long-term effects on endocrine and immunity functions [12]. Although a low amount of concern is normal for patients with MS and is even useful for problem solving, heightened concerns may become problematic for them [13].

According to previous studies, normal concerns as well as concerns specific to patients with MS (treatment, disease-associated financial problems, and becoming a burden on the family) are very common among such patients [13-16]. Patients with MS often express a greater amount of concerns when compared to normal people. This difference is more significant in females with MS, specifically regarding health-related concerns when compared with general concerns [17-20]. It seems that qualitative studies provide a more complete and in-depth understanding of concerns among females with MS; however, there is limited knowledge of and a few studies on health-related concerns in patients with MS [21]. Identification of these concerns may contribute to proper planning of interventions and devising of effective plans to enhance life expectancy and improve quality of life of patients with MS; therefore, this study was conducted to explore the concerns of MS patients at their reproductive age.

Table 1: Socio-Demographic Characteristics of Participants	
Characteristics	N (%)*
Age (Year)	
20-29	3 (18.8)
30-39	8 (50.0)
40-49	5 (21.2)
Marital status	
Single	4 (25.0)
Married	10 (62.6)
Divorced	1 (6.2)
Widowed	1 (6.2)
Education of women	
Guidance school	3 (18.8)
Diploma	7 (43.8)
Bachelors	4 (25.0)
Master's Degree	1 (6.2)
PhD	1 (6.2)
Duration of disease	
< 10 years	3 (18.8)
10-20 years	12 (75.0)
20 years >	1 (6.2)

METHODS

Participant Selection and Data Collection

This qualitative study was conducted on Tabrizian females diagnosed with MS at least one year before the study, aged 20 to 49 years, living in Tabriz, and members of the MS Society

of Tabriz. The purposive sampling method was conducted to select the research samples. Sampling was done on eligible females with MS, considering the above criteria and maximum variation of marital status, educational attainment, and duration of disease. The researcher continued the sampling process until data saturation after 16 individual interviews. The data collection instrument included an interview guide with semi-structured questions. The interview time and place were set according to the participants' opinions. All interviews were recorded after obtaining an informed written consent of the patients, using a digital voice recorder. Field notes were also recorded, if needed, during the interview. Duration of interviews ranged between 30 and 45 minutes. Data analysis was conducted using conventional content analysis. Demographic characteristics of the participants are presented in Table 1.

Trustworthiness

To check data trustworthiness, acceptability (credibility), consistency (dependability), confirmability, and transferability of research data were evaluated. To check the acceptability of qualitative data, some coded interviews were returned to the participants to specify their agreement or disagreement with interpretations. Any disagreement or need for additional details were addressed and reconsidered. Establishing long-term relationships with participants and assigning adequate time for the study were among approaches to enhance acceptability. Peer check was based on additional comments of colleagues through separate coding of interviews by two individuals experienced in qualitative research at the same time. Participants were selected from different centers with maximum diversity to enhance data acceptability. Consistency of data was assessed through an external check. To this end, some parts of the transcribed interviews, along with associated codes and categories were delivered to a number of observers to check the accuracy of the conducted analysis. The research process was designed with a follow-up stage to ensure the verifiability of the research and unbiased research process. The researcher's interest in and long-term involvement with the subject, transcription of interviews, and attempts made to obtain additional and critical comments of participants, research team members, and other qualitative researchers were among factors ensuring verifiability of the study. Transferability in qualitative studies means generalizability of results to other similar groups and environments. In the current study, sampling with maximal diversity was used and methodological details were explained to approve transferability.

Data Analysis

Data management was done with the MAXQDA10 software. Data obtained from this qualitative study was analyzed using conventional content analysis. To this end, the recorded information was precisely reviewed by the researcher after each interview, in the shortest possible time. After transcribing interviews, transcriptions were read several times to come up with a general idea and look for desired subjects. The selection of units of analysis is an important decision in content analysis. Although the size of a unit of analysis can vary, the

Table 2: Example of the Analysis Process

Meaning unit	Code	Subcategory	Category
I think my life is good unless my illness becomes worse	Fear of the future	Fears	Concerns
I'm afraid of my mouth becoming deformed and they may laugh me	Hiding the disease due to fear of others		
Almost three months ago I had an abortion when I was six months pregnant, it was because of these pills. I didn't know I was pregnant. I took the pills for one month. They said that the fetus had abnormality because of the pills. So, I don't want to be [pregnant. I fear [of that	Fear of disease impact on outcome of future pregnancies		
I always thought that if my illness was exacerbated, I could no longer walk, I could no longer hold something by my hand	Fear of disability		
I always thought that if my illness was exacerbated, I could no longer walk, I could no longer hold something by my hand. I always had such thoughts. It always made me mad	Fear of exacerbation of disease in future		
I want to be alone. I don't want to see anyone. If somebody says something I will cry	Sensitiveness	Feelings	
I frequently become angry. I become very angry	Becoming easily tempered		
I don't have hope to live at all, I feel so bad	Hopelessness		
I become upset and begin crying	Crying		

recommended size is the entire text transcribed from an interview or observation. In other words, it should be large enough to be considered a whole and small enough to be used for specifying meaning units. In the current study, the whole text from each interview was considered to be the unit of analysis. Meaning units are words, statements or sentences that include different aspects of the main concept in their relevant text or context. In the current study, the meaning units in each text were specified after reading the transcribed texts several times. The meaning units were converted to codes after extraction and compression. The mechanism of content analysis, and extraction of codes, subcategories, and main category are presented in Table 2.

RESULTS

Twenty-three initial codes were extracted from 16 interviews. Initial categorization of the codes was initiated from the first interviews to form the category and subcategories. In the next interviews, the codes extracted from each interview were compared to codes from previous interviews to specify their similarities and differences. Then, they were assigned to specific classes based on the obtained similarities and differences. Due to their similarities, the following codes formed a specific group, called 'fears.'

Fear of loneliness or lack of support from others

Fear of the future

Fear because of the lack of knowledge of MS

Fear of being humiliated

Hiding the disease due to fear of others

Fear of being judged by others

Fear of disease impact on outcome of future pregnancies

Fear of pregnancy

Fear of disability

Fear of disease development in children

Fear of [associated] problems

Fear of relatives' reactions in the future

Fear of exacerbation of disease in the future

Fear of financial problems in the future

One of the participants expressed her fear of disability, 'I always thought that if my illness was exacerbated, I could no longer walk, I could no longer hold something in my hand. I always had such thoughts. It always made me mad'. [p.6]

According to another participant, 'I fear thinking about marriage and the future. Even if someone accepts my disease, I cannot think about pregnancy and kids...' [p. 10]

Another participant said, 'almost three months ago I had an abortion when I was six months pregnant, it was because of these pills. I didn't know I was pregnant. I took the pills for one month. They said that the fetus had abnormalities because of the pills. So, I don't want to be pregnant. I fear [of that]'. [p. 2]

Another participant added, 'my baby was very young, something like 5 months when I developed the disease, I was thinking about having someone else take care of my baby. I [always] thought about someone for looking after my baby. I said one time, the left side of my body was totally numb, no sensation, no movement neither in my hands nor in my legs and my eyes. My mouth drooped. I didn't know, they didn't show me, didn't tell me. I thought about someone for looking after my child. My child is 16 years old now'. [p. 1]

Another participant said, 'I thought my body would go numb, a part of my body would become totally paralyzed, I would not be able to move. I used a wheelchair. It came to my mind that I might no longer live, my family might not help me, or my children [might] think differently about me...' [p. 3]

Due to their similarities, the following codes formed a specific class, called 'feelings.'

Sensitiveness

Becoming easily tempered

Sense of confusion

Impatience

Sorrow

crying

Hopelessness

Helplessness

Sense of happiness despite the disease

According to a participant, 'well, I was tired of life'. [p. 8]

Another participant talked about frustration, 'I was totally frustrated. I felt that I would never recover'. [p. 1]

A participant said, 'I frequently become angry. I become very angry. My husband is dead and my daughter does not mess with me much, but I am sad. I become very sad. I become easily angry. Very soon, I turn sad [of my behavior] because they bear no guilt [over my problem]'. [p. 5]

Another participant said, 'my husband says that my MS is a gift from God. Now, the happiest couple among my family and my husband's family is us. We try more to understand each other' [p. 7]

DISCUSSION

In this study, 23 codes were extracted from the transcribed interviews and categorized to two sub-categories, namely fears and feelings. These two sub-categories formed the main category, namely concerns. Having chronic concerns is among characteristics of patients with MS. For example, a study conducted on 50 patients with MS and 45 healthy individuals (as control group) showed significantly higher number of concerns among the former group than the latter. These concerns were significantly correlated with their sense of fatigue, sleep disorders, problem-solving deficits, and [physical] disability [13]. One of the extracted sub-categories was fear of different issues, such as the lack of support by others, and future issues, such as the chance of pregnancy. Fear is among psychological symptoms in patients with MS, which could worsen their physical function [9]. These fears have also been reported by other studies. A qualitative study, with a phenomenological approach, was conducted on 27 adults with MS, aged 55 to 81 years, using in-depth interviews. The major concern of the participants was the fear of the future. This type of fear included unique concerns of participants over becoming paralyzed, greater dependence, and a burden on caregivers, and necessity of displacement to a nursing home [21]. Another qualitative study, with a phenomenological approach, conducted on mothers with MS in Italy showed that fear of stigma was among the most important experiences of participants that was perceived as sympathy by others; therefore, these patients were reluctant to expose their illness [22].

Fear of disease progression was reported by Ghoozadeh et al. Fear of MS could have harmful impacts on the patients. It seems that extending knowledge of MS and its treatments could ease fear of MS progression and thus enhance the chance of adaptation [23]. In the current study, fear of financial problems among the participants was due to their concerns over doctor visit costs, MS medication costs, and costs of transportation to gyms. In this regard, results from a qualitative study with semi-structured interviews on 18 females with MS showed that they had many concerns and problems about the costs of treatment services [24]. Another study on 405 patients with MS showed that their major concern was inability to afford healthcare costs. These concerns were directly and significantly correlated with depression, anxiety, fatigue, sleep disorders, pain interference, social function, and perceived cognitive function [25]. Another subcategory

of this study was the experience of feelings such as sensitivity, becoming easily tempered, impatience, sorrow, crying, hopelessness, helplessness, and sense of happiness despite the disease. Neuropsychiatric symptoms were very common among patients with MS. According to a qualitative study conducted with semi-structured interviews on 10 females with MS, the participants reported changes in their mental and psychological states, including anger. Frustration was among mental outcomes of chronic diseases. Chronic duration of MS, along with long duration of treatment and MS-associated physical disability caused frustration in patients [26].

Another qualitative study in Iran was conducted on 25 patients with MS, selected through purposive sampling. Results from unstructured interviews and content analysis showed that emotional reactions were among 4 major themes identified in the study. The sub-themes of emotional reaction included the concepts of denial, anger, fear and anxiety, consternation and confusion, and being demoralized. Many participants preferred to hide their disease due to social stigma attached to MS and to avoid sympathy by others. However, this act is less prevalent in other countries [27]. Another qualitative study was conducted on 25 patients, using unstructured interviews and content analysis, and identified seven main themes. Anger and sorrow were two sub-themes of emotional reactions (one of the seven main themes) [28]. Hopelessness was among feelings expressed by participants of this study. Feeling of hopelessness was common among patients with MS. A descriptive study conducted on 65 patients with MS showed moderate level of hopelessness and life satisfaction among patients [29]. Hopelessness has a significant role in human health and adaptation with chronic diseases. Hope helps a patient with MS to become more successful and stay independent for a longer time. It boosts self-esteem and enhances well-being, and can also have synergistic effects on conventional medical treatments. Therefore, raising hope should become an indispensable part of a multidisciplinary MS treatment [30]. Results from the above studies confirm the findings of the current study; however, participants in the current study expressed a greater number of concerns. As a result, it should be tried to eliminate their concerns through developing effective strategies and providing financial, information, and emotional support to enhance life expectancy and quality of life of patients with MS. Similar to other qualitative studies, findings of the current study had limited generalizability. This is because it was conducted on a limited number of females covered by the MS society of Tabriz. Moreover, this study was conducted on females at the reproductive age; therefore, it should be generalized cautiously to other age groups.

Regarding concerns of patients with MS, regular health monitoring by physicians and healthcare providers is recommended in an attempt to alleviate their concerns. It is also recommended to make interventions that enable patients with MS develop a greater sense of control over their disease. In addition, the provision of better and greater social supports to reduce their fears and emotional problems is recommended.

CONCLUSIONS

Regarding concerns of these patients, their regular health monitoring by

physicians and healthcare providers is recommended in an attempt to alleviate these concerns.

ETHICAL CONSIDERATIONS

This research was part of a PhD thesis that was funded and approved (Ethics code: SBMU2.REC.1394.142) by Shahid Beheshti University of Medical Sciences.

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CONFLICT OF INTEREST

There is no conflict of interests between Authors.

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AUTHOR CONTRIBUTIONS

Tajdar Alizadeh: researcher, Data gathering and analysis
Dr Zohreh Keshavarz, Supervisor, research design
Dr Mojghan Mirghafoorvand, Advisor, research design
Dr Zayeri: Advisor, Data analysis.

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