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“Life behind the mask”: Sexual life of Iranian women with multiple sclerosis

Nahid Dehghan-Nayeri ^a, Zohreh Khakbazan ^b, Faezeh Ghafoori ^{b,*}

^a Nursing Management Department, School of Nursing and Midwifery, Tehran University of Medical Sciences, Tehran, Iran

^b Reproductive Health Department, School of Nursing and Midwifery, Tehran University of Medical Sciences, Tehran, Iran

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ABSTRACT

Background: Multiple sclerosis (MS) is a debilitating and life-long disease that affects the sexual life of people. However, in Iran little attention has been paid to the sexual life of women with MS.

Objective: The aim of this study was to understand the sexual life and experiences of Iranian women with multiple sclerosis.

Methods: A qualitative study was designed, and face-to-face semi-structured interviews were conducted with twenty-five women with MS. The interviews were tape-recorded and transcribed verbatim. Data were analyzed using a content analysis approach and through MAXQDA.10 software.

Results: The main themes identified during the analysis were: (1) limited sexual activity, (2) sex life behind the mask, and (3) lack of sexual support during the rehabilitation process. In fact, the participants in this study expressed that their sexual activity was negatively affected by MS. They were trying to hide their sexual problems, and present themselves to their husbands differently from what they are, which can be considered as sex life behind the mask. Furthermore, Iranian women with MS received little sexual support from the rehabilitation team.

Conclusions: Hiding sexual problems from husbands is thought to be a common practice and behavior among Iranian women with MS. Understanding this insight and its consequences can assist the rehabilitation team in helping and solving sexual problems of women with MS. Moreover, sexual awareness and education should be extended, especially among the husbands of women with MS.

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Introduction

Multiple sclerosis (MS) can attack the nervous system and cause a wide range of symptoms.¹ It seems that, these symptoms along with the side effects of medication therapies can directly or indirectly affect the patients' sexual life.² Previous studies have shown that, 40%–80% of people with MS have complaints about their sexual life.^{3,4}

This disease is more likely to develop in women rather than men, especially women of reproductive age (20–40 years old), which is a critical period in terms of sexual activity in every woman's life.^{5–7} Therefore, these young women with a near-

normal lifespan will face MS-related sexual problems and challenges for many years.⁸

However, little is known about how women with MS understand sexual problems and remain sexual beings.^{9,10} In a study in Turkey that aimed to explore sexual experiences and perceptions, women with MS reported that they were very worried about their sexual life.¹¹ In another study conducted in the USA, women with MS stated that, despite their disability, they need to be recognized as sexual beings. They emphasized this need must be considered by their rehabilitation team.¹² Conversely, a study in Canada showed that participants with MS who had sexual problems had a tendency to downplay the importance of their sexual problems.⁹ Similarly, in another study in Australia, the majority of participants did not express any concern about their sexual dysfunctions. They accepted sexual dysfunction as a symptom of their disease and felt there is nothing that they can do about it and therefore have no expectations from their rehabilitation team.¹⁰

In Iran, a country with a conservative culture, sexual dysfunction of women with MS is often neglected.¹³ Despite a relatively high

* Corresponding author. Reproductive Health Department, School of Nursing and Midwifery, Tehran University of Medical Sciences, Western Nosrat St., Tohid Sq., Tehran, Iran.

E-mail addresses: faezeh.ghafoori@yahoo.com, f-ghafoori@razi.tums.ac.ir (F. Ghafoori).

prevalence of MS in Iran, especially among women, few studies have been done on the sexual life of Iranian women with MS.^{13,14} Based on our knowledge, no qualitative study has even been conducted in Iran on this subject. Qualitative study is a preferred method for exploring people's perceptions and experiences of health problems and understanding the context in which experiences are made.¹⁵

However, about the sexual experiences of Iranian women without chronic disease including MS, Hashemi et al. (2013) and Shirpak et al. (2008) showed that talking about sexual matters is seen as taboo among most Iranian women.^{16,17} Janghorban et al. (2015) also confirmed that Iranian women are in a shadow of silence and avoid discussions about sex.¹⁸ Therefore, the question that arises is, after having a chronic and lifelong illness such as MS, and faced with a lot of sexual problems, how will the sexual behaviors of Iranian women change? Do they continue to silence, break, or intensify it?

Thus, considering the effect of MS on young and sexually active women,¹⁹ and the context-bound nature of sexuality,²⁰ this qualitative study was conducted to understand the sexual life and experiences of women with MS in an Iranian cultural context.

Methods

Study design and participants

A qualitative study was conducted based on the conventional content analysis approach to understand the sexual experiences of Iranian women with MS. Content analysis is an appropriate method for studying context-bound subjects.¹⁵ It is commonly used to interpret meanings from the content of textual data.^{15,21} In conventional content analysis, codes and categories are directly resulted from the textual data without pre-assumptions from previous theories.²²

This study was conducted at Iran's MS society, a referral consultation and rehabilitation center for MS in Tehran, the capital of Iran, over a six-month period from August 2016 to January 2017.

Participation was limited to married women (due to socio-cultural barriers in sexual activity of Iranian single, divorced and widowed women), over 18 years of age with a heterosexual partnership for more than six months after definite diagnosis of MS (diagnosed by the neurologist). They were recruited in the study if they had no chronic illness except MS and were willing to share their sexual experiences.

In total, twenty-five Iranian women with MS were recruited based on purposeful sampling. Purposeful sampling was defined as selection of information-rich persons related to the interested phenomenon.²³ The maximum variation strategy was also considered, and participants with different characteristics in terms of age, education, occupation, duration of marriage, number of children, MS phenotypes, length of MS and disease modifying therapies (DMTs), and physical disability status (Expanded Disability Status Scale or EDSS showed the severity of physical disability with the score of 0–10 and was estimated by a neurologist) were enrolled in the study (Table 1).

Data collection

Qualitative data were collected through interviews, and researcher's field notes and memos. Interviews were individual, semi-structured and open ended. Interview is an effective data-collection method for gaining in-depth information. In this method, participants can express their experiences in their own words in an entirely open and flexible process.²⁴

In this study, interviews began with the general questions

including: "How is your sexual life?" "Are you experiencing any problems in your sexual relations?" "Please tell me your thoughts and feelings about your sexual life?" "How is your sexual life affected after MS?" "What happened in your sexual life after MS? What changes occurred?" These questions were followed by probing questions to elicit more detailed explanations, including: please explain more, describe what you mean by that? What do these explanations mean? In fact, we were focused on identifying and understanding the sexual aspect of their Post-MS Life. It must be mentioned that, an attempt was made not to use the words that could lead the participants during the interviews.

In total, 25 face-to-face semi-structured interviews were carried out with Iranian women with MS. Four interviews were performed in participants' homes because they had mobility restrictions and could not attend the MS Society. In addition, field notes were made during the interviews to remember the environment of the interviews, and nonverbal behaviors of the participants. Memos were used to design the next questions to be asked from the participants, and also helped in the process of data analysis.

Data analysis

All of the interviews were tape-recorded (duration of 35–90 min) and transcribed verbatim with the permission of the participants. Interview transcripts, field notes and memos were integrated and analyzed. The data analysis was performed concurrently with data collection, using a content analysis approach.^{21,22} Based on this approach, transcripts were coded and themes gradually emerged using constant comparison of the codes. Therefore, themes were developed inductively and directly extracted from the textual data. This content analysis was descriptive, not to generate theory. MAXQDA.10 software was used for code management.

Trustworthiness

Credibility, dependability, conformability, transferability were

Table 1
Socio-Demographic and clinical characteristics of the participants.

Variables	Participants (N = 25)
Age (mean ± SD)	31.7 ± 3.1
Education level (N. %)	
Elementary	3 (12)
Intermediary	7 (28)
University	15 (60)
Occupation (N. %)	
Housewife	18 (72)
Employed	7 (28)
Duration of marriage (mean ± SD)	10 ± 4.2
Number of children (mean ± SD)	1.4 ± 1.1
Contraception method	
Hormonal	8 (32)
Non-hormonal	12 (48)
Withdrawal	5 (20)
MS phenotypes (N. %)	
Relapsing-remitting MS	13 (52)
Secondary-progressive MS	8 (32)
Primary-progressive MS	4 (16)
Disease duration (mean ± SD)	6.8 ± 3.5
Onset age of disease (mean ± SD)	23.1 ± 7.3
Length of DMT use (mean ± SD)	4.6 ± 4.4
EDSS score (N. %)	
4.5 or lower	14 (56)
5 to 7	6 (24)
7.5 or greater	5 (20)

Abbreviations: DMT = Disease Modifying Therapy, EDSS = Expanded Disability Status Scale.

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