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## Sexual problems among women with Multiple Sclerosis

Effat Merghati-Khoei<sup>1,2</sup> [Assistant Professor], Kowsar Qaderi, MS.c<sup>3</sup>, Leila Amini<sup>4</sup> [Senior Lecturer], and Jeffrey E. Korte<sup>5</sup> [Assistant Professor]

<sup>1</sup>Tehran University of Medical Sciences, Tehran Iran

<sup>2</sup>Fellowship in Medical University of South Carolina SC, USA khoeie@musc.edu

<sup>3</sup>School of Nursing and Midwifery, Tehran University of Medical Sciences, Tehran Iran

<sup>4</sup>School of Nursing and Midwifery, Tehran University of Medical Sciences, Tehran Iran

<sup>5</sup>Department of Public Health Sciences, Medical University of South Carolina SC, USA Korte@musc.edu

### Abstract

**Background**—Sexual problems are prevalently experienced by women with multiple sclerosis (MS) and have investigated in several studies. The nature of sexual changes in MS is best defined as primary, secondary, and tertiary.

**Objectives**—The aim of this study was to investigate three levels of sexual problems (SP) in female patients with MS and to examine their relationship with various clinical and demographic variables.

**Methods**—132 women with MS completed two questionnaires; demographic and clinical history, and Multiple Sclerosis Intimacy and Sexuality Questionnaire-19 (MSISQ-19). Fatigue was evaluated by Fatigue (energy) sub-scale of Multiple Sclerosis Quality of Life-54 (MSQOL-54) questionnaire. General physical ability and frequency of sexual intercourse were also evaluated.

**Results**—115 patients (87.1%) reported primary SP. The most frequent symptoms of primary, secondary and tertiary sexual problems were delayed orgasm, spasticity and concern about partner's sexual satisfaction, respectively. The MSISQ-19 total score was correlated with age( $p=0.002$ ), disease duration( $p=0.010$ ), marriage duration( $p=0.001$ ), fatigue( $p<0.001$ ), number of children( $p=0.006$ ), physical ability( $p<0.001$ ), education( $p=0.006$ ), economic status( $p=0.002$ ), number of times having sexual intercourse( $p=0.007$ ) and number of times approached by spouse for intercourse( $p=0.012$ ) in the last 30 days.

**Conclusions**—Sexual problems were prevalent among our participants. Appropriate management of SP depends on understanding the disturbed level.

## Background & Objectives

The prevalence of sexual problems (SP) among women with MS is high worldwide. Sexual functioning is a complicated process related to the neurological, endocrine and vascular systems. In Multiple Sclerosis (MS), a chronic neurological disease, sexual problems that adversely affect quality of life are significant but are hardly discussed [1-3]. Studies on sexual dysfunction in patients with MS report a wide range of frequencies between 40%-80% in women and 50%-90% in men [4-7]. Almost half (47%) of American women [8] and 61% of Israeli women [9] had sexual dysfunction, while in Turkey, the majority of women (75-80.1%) reported sexual dysfunction [3,10].

The etiology of SP in MS is still a matter of discussion [11]. The ways MS influences sexuality have been identified by Foley and Iverson. They classified SP as primary, secondary, and tertiary [7,11]. Primary SP are caused by MS-related neurologic lesions in the central nervous system, and directly impair sexual responses or feelings. These problems include decreased genital sensation, decreased libido, problems with arousal and orgasm, decreased or lack of vaginal lubrication and difficulties with achieving or maintaining an erection. Secondary SP are composed of MS-related physical changes that indirectly impair sexual responses. These changes are caused by MS symptoms that are not related to the neural pathway of the genital system, and include fatigue, muscle weakness, spasticity, sphincter malfunction and difficulty with mobility. Tertiary SP are related to psychological, emotional, social and cultural aspects of MS that may interfere with sexual functioning such as altered self-image, lowered self-esteem, depression and anger [6,7,12].

Associations between sexual problems and various MS-related clinical and socio-demographic variables have been investigated [2-3,9,11,13-21]. To our knowledge, however, the sexuality of the Iranian MS population has not been directly investigated. In this paper, we report the results of a study aimed to investigate women's sexual problems in three levels, and to determine the associations between sexual problems and some clinical and socio-demographic variables among Iranian women referred to the Iranian MS Society.

## Methods

### Participants and Procedure

Women were recruited from the Iranian MS society by advertisement and were invited to participate in a 20 minute self-report questionnaire (clinical and socio-demographic questions and Multiple Sclerosis Intimacy and Sexuality Questionnaire-19: MSISQ-19). Married women (n=145) with clinically diagnosed MS completed the questionnaires between November 2010 and February 2011. Participants were excluded from the study if they had another chronic illness, psychological disorders, were pregnant, hospitalized due to severity of MS, and if they were not sexually active during the last six months. Following 4 months of data collection, 13 women were excluded, and the final sample consisted of 132 women.

Women were referred to the researcher (KQ), and directed to a private room. The interviewer first explained the study aims, and that the participant was going to be asked to

answer a series of questions related to her sexual behavior. The participants were reassured that responses and information would be kept confidential and anonymous; and that they could quit the study if they felt uncomfortable with the questions. After reading and signing the informed consent form, women were instructed to complete a battery of questionnaires: socio-demographic and clinical history information and MSISQ-19.

## Outcome Measures

**Our primary measures included**—Sexual problems: The Multiple Sclerosis Intimacy and Sexuality Questionnaire-19 (MSISQ-19) is a 19-item questionnaire that evaluates sexual problems. Each item is classified into one of three categories: primary problem (direct physical, 5Qs), secondary problem (indirect physical, 9Qs) and tertiary problem (psychosocial, 5Qs). The scale therefore provides an overall score as well as the three subscales for each patient. Each patient rates how various MS symptoms interfered with their sexual activity over the last 6 months, and the scoring is based on a scale ranging from 1 = “never” (never interfered with my sexual activity or satisfaction), 2 = “almost never,” 3 = “occasionally,” 4 = “almost always,” to 5 = “always” (always interfered with my sexual activity or satisfaction)[6]. Fatigue was evaluated by the fatigue (energy) sub-scale of Multiple Sclerosis Quality Of Life-54 (MSQOL-54) questionnaire. Scoring: 0-100 and higher values indicated lower fatigue [22].

Socio-demographic and clinical history information: we developed a 18-item survey to collect information regarding age, education, economic status, length of disease, onset age of MS, parity, contraception method, number of children, sex education, medications for MS and physical ability (an estimated score for performing everyday tasks; scoring:1-10). The number of sexual intercourse and the number of times approached by the spouse for sexual intercourse in the last 30 days were also asked from participants.

Statistical analysis was performed using the Statistical Package for the Social Sciences (SPSS), version 16.0. Pearson’s correlation coefficients as well as analysis of variance between groups (ANOVA) were used to examine the relationship between three levels of SP as well as the MSISQ-19 total score and clinical and socio-demographic variables. All P-values were based on two-tailed-test and a p-value of 0.05 was chosen to denote statistical significance. Ethical approval was obtained from the Ethics Committee of Tehran University of Medical Science and the Iranian MS Society.

## Results

### Sample characteristics and prevalence of sexual problems

In the present study, 115 (87.1%) of 132 women who completed the questionnaires, reported at least one of the primary SP items (score 3 in each item of primary SP). Delayed orgasm (75.7%) was the most frequent symptoms of primary SP. Of participants 65.9% had less intense or pleasurable orgasm, 60.6% had inadequate vaginal lubrication, 58.3% had decreased libido, and 34.8% had decreased genital sensation.

Participants were all in heterosexual marriages. Other demographic and clinical characteristics are shown in tables 1. The mean $\pm$ SD age of patients was 36.9 $\pm$ 8.3 year. Sexual and reproductive related information is presented in Table 2.

In our study the highest score of sexual problems was found in the primary level, while the lowest score was found in the tertiary level of SP (Table 3).

Meaningful correlations were found between the primary SP score and all socio-demographic and clinical variables except onset age of disease (Table 5). As shown in Table 4, of 5 primary SP items, decreased genital sensation was significantly associated with length of medication, fatigue and physical ability. Also, decreased libido showed a statistically significant relationship with fatigue, physical ability, spouse's age, length of marriage, number of acts of sexual intercourse and number of times approached by spouse for intercourse in the last 30 days (Table 4). Less intense or pleasurable orgasm and delayed orgasm showed significant associations with all socio-demographic and clinical variables except onset age of disease (Table 4). Inadequate vaginal lubrication was related to age, length of disease, spouse's age, length of marriage, length of medication, fatigue, physical ability, number of acts of sexual intercourse and number of times approached by the spouse for intercourse in the last 30 days (Table 4). Our results showed spasticity was the most frequent item of secondary sexual problems, and the secondary SP score was not significantly associated with the onset age of disease, length of disease and parity (Table 5). Between five items of tertiary sexual problems, concern about partner's sexual satisfaction was the most frequent item. Also, a statistically significant relationship was identified between tertiary SP score and physical ability and fatigue (Table 5). The mean of the MSISQ-19 total score was 48.1 and the mean score of three levels of SP is shown in Table 6.

As can be seen in table 5, the MSISQ-19 total score was correlated with age, length of disease, spouse's age, length of marriage, length of medication, fatigue, number of children, physical ability, number of sexual intercourse and number of times approached by the spouse for intercourse in the last 30 days. Furthermore, the MSISQ-19 total score showed significant associations with level of education ( $p=0.006$ ) and economic status ( $p=0.002$ ). No associations were found between the MSISQ-19 total score and parity, spouse's education, and onset age of disease.

Significant correlations were observed between MSISQ-19 total score and all 19 items of SP. Among the 5 items of primary SP, less intense or pleasurable orgasm had the strongest relation with MSISQ-19 total score ( $p<0.001$ ,  $r=0.771$ ). Among the 9 items of secondary SP, problems with the body moving during sexual activity ( $p<0.001$ ,  $r=0.727$ ) and among the 5 tertiary SP items, feeling less confident about sexuality ( $p<0.001$ ,  $r=0.679$ ) had the strongest association with MSISQ-19 total score.

## Discussion

The primary sexual problems were prevalent among Iranian women with MS (87.1%). This finding is consistent with several previous studies showing that SP are a prevalent sequel in

women with MS [3,10]. The total score of MSISQ-19 was 48.1, indicating a higher score than in the studies of Demirkiran et al, Celik et al and Yeliz et al [3,4,23]. Nevertheless, these studies were all performed in Turkey and with smaller numbers of patients (51, 89 and 59 respectively). Participants in these studies were both male and female. Cultural differences have to be kept in mind: for example, a lack of sexual counseling and education among MS patients in Iran may help to explain these results.

In the present study, delayed orgasm was the most common symptom women experienced. This finding is consistent with some studies performed previously in Norway and Australia [14,24], while in some other studies conducted in Turkey and Serbia, low sexual desire has been reported as the most common symptom of SP [3,11,23]. However 24 of patients in our study treated with antidepressants and 20 of them had delayed orgasm that may be caused by side effect of these drugs.

In MS patients, both genital sensation and orgasmic response can be diminished by MS plaques; in addition, orgasm can be inhibited by secondary symptoms, such as fatigue and cognitive problems, as well as tertiary problems like anxiety, depression, and loss of sexual self-confidence. Accordingly, the prevalence of orgasm problems is only partially attributable to genital sensation problems [7]. In our study only 34.8% of women reported genital sensation problems. This finding was comparable with others [3,23]. Treatment of orgasmic problem in MS depends on understanding the factors contributing to the problem [7].

Among secondary SP items, muscle tightness was the most common symptom. The evidence suggests that physical limitations and pain, especially in the pelvis and lower limbs, interfere with proper body positioning during intercourse, and that alternative sexual positions for intercourse and anti-spasticity medications can be helpful [7].

Among five tertiary SP symptoms, concern about the partner's sexual satisfaction was the most common. Even if the disease has only a limited neurological impact on sexual function, couples can experience anxiety and tertiary sexual problems, and they may experience reduced satisfaction from sexual interactions [14,25]. In previous studies performed using similar instruments (MSISQ-19), the results of secondary and tertiary SP were not mentioned.

In the present study, correlation analysis (Pearson and ANOVA) between demographic and clinical variables and the MSISQ-19 total scores showed a positive and significant association between sexual problems and age, which was consistent with various earlier studies [13,15,16] but in contrast to the Fraser et al study [17]. It seems that in the absence of MS, sexual problems increase with age, and that in the presence of a chronic debilitating disease like MS, the impact of age on sexual problems is exacerbated.

We found a direct significant relationship between duration of disease and sexual problems, which was consistent with some studies [11,15,18,19] but not with some others [13,16,17,20,21]. Due to the progressive nature of the disease, with increasing disease duration, physical disabilities and mental distresses increase and their role in sexual problems should be taken into consideration. Also, the total score of sexual problems had a

significant correlation with duration of medication. On average, a longer duration of medication will be associated with longer duration of disease. Analyses relating to duration of medication have not been reported in other studies [11,15,18,19].

The association between the total score of sexual problems and age at onset of disease was not significant; this finding is similar to Zivadinov et al findings [13], but contrary with McCabe's [14] results. Regardless of the disease onset age, may be sexual problems in three levels have a similar trend.

The total score of sexual problems was also inversely associated with the husband's age, and the length of the marriage. Based on our experience after years of working with these women, lower reporting of SP with long marriages may be partly due to perception changes and discounting of problems that exist as sexual frequency has declined over time.

We found that the number of acts of sexual intercourse, and the number of times approached by the spouse for sexual intercourse, had a weak but significant negative correlation with the total score of sexual problems. Undoubtedly the husband's role is important among women experiencing sexual problems. Conducting a joint interview with the MS patients and their well partners helps to gain a better understanding of the problem as it is experienced by both individuals [26].

In line with others [3,13] and in contrast with Redelman's study [16], our results showed lower SP in patients with higher education and higher economic status. Possible explanations for this association may include a greater awareness and orientation toward sexuality matters among educated and well-off patients, as well as better access to health care and related resources. An inverse association between husbands' level of education and the total score of sexual problems that we found has not been reported by others [2,11,13,15,17,20,23].

Similar to earlier studies [2,11,13,15,16,17,20,22,23], that sexual dysfunction had the association with disability (measured by EDSS<sup>6</sup>), in our study the total score of sexual problems had the strongest inverse correlation with the general physical ability score. Some previous studies, however, did not find this relationship [12,21,24]. With progression of MS, it is possible that increased rates of SP complaints are partially attributable to disability, depression, and partner frustration.

Sexual function, more than any other factors, is affected by physical impairments such as disability and fatigue. In some cases, sexual activity may not be a priority for the patients, especially in special circumstances such as MS acute attacks, or prolonged hospitalization. For example, after Betaferon injections, patients may experience pain, fatigue, and depressed mood. In such conditions the patient's sexual function will be reduced [29].

With one exception [21], other studies found associations between sexual problems and fatigue in patients with MS [2,3,11,15,17,27,28]. In this study, we also found a direct and significant relationship between sexual problems and fatigue. MS patients have less energy

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<sup>6</sup>Expanded Disability Status Scale



compared with healthy people, and their energy is particularly drained in the afternoon and night time, increasing the likelihood that they may avoid sexual activity. This is a rationale for advising MS patients to engage in sexual activity early in the morning to reduce the incidence of sexual problems due to fatigue [29].

In our study, several methodological limitations should be pointed out. We were not able to directly determine the direction of causality between our variables, in particular between SPs and MS symptoms. We collected data only from one center. Validation of our results requires repeating the analysis on data from multi-center and longitudinal trials to assess the stability of the correlations. We only recruited those patients who were referred to the Iranian MS society, and hospitalized patients were not recruited. Therefore, we must be cautious about generalizing the results to all Iranian individuals living with MS. In addition, we cannot exclude the possibility that our data are affected by reporting biases given the sensitive nature of the questions. Religion, culture, and society are influencing factors in forming our sexual thoughts, views, and expectations about sexuality. As an unspoken topic, obtaining sexual information from Iranians, whether healthy or ill, is relatively difficult. We could only include married women because sexual activity for single and widowed women not only is culturally unaccepted, but also legally forbidden.

In summary, our results do support that sexual problems are prevalent among MS patients. Appropriate management of the SP depends on finding the interfering factors that are contributing to the SP. If confirmed in further research, health professionals may want to consider including culturally appropriate interventions for sexual problems as part of the health care package for women presenting with MS symptoms so as to improve the quality of sexual life and avoid marital discord.

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**Table1**

Demographic and clinical information of 132 Iranian women with multiple sclerosis

Variables	N(%)	Mean±SD	Range
Age(years)		36.9±8.3	20-58
Economic status			
Satisfied	22(16.7)		
Intermediate	81(61.3)		
Dissatisfied	29(22)		
Occupation			
Housewife	103(78)		
Employee	25(19)		
Retired	4(3)		
Education level(years)			
Primary(1-8)	20(15.2)		
Secondary(9-12)	80(60.8)		
University(13+)	32(24)		
Disease duration(years)		6.8±5.3	1-27
Age at onset of disease(years)		30.1±7.3	15-50
Physical ability		6.5±2	2-10
Fatigue		47.2±21.2	0-100
Length of medication (years)		4.6±4.4	0-19
Medication			
No	12(9.1)		
Yes	120(90.9)		
Interferons	93(70.4)		
Psychiatric Drug(Sedatives and Antidepressants)	24(18.1)		
Other(Complementary, Herbal, Corticosteroids)	47(35.4)		

**Table2**

Sexual &amp; reproductive related information of 132 Iranian women with multiple sclerosis

Variables	N(%)	Mean±SD	Range
Length of marriage(years)		15±9.2	1-43
Age of husband(years)		41.9±9.5	25-65
Number of Pregnancy		1.7±1.3	1-7
Number of Children		1.4±1.1	1-6
Number of times approached by spouse for intercourse in the last 30 day		5.3±5	0-30
Number of sexual intercourses in the last 30 day			
3	63(47.7)		
4-5	38(28.8)		
6	31(23.5)		
Contraception method			
Withdrawal	47(35.6)		
Condom	30(22.7)		
Other	55(41.7)		
Training on sexual issues			
No	111(84.1)		
Yes	21(15.9)		
Book	10		
Health Care provider	4		
Internet	4		
Other	3		

**Table 3**

Distribution and mean score of primary, secondary and tertiary SP items

<b>Over the last six months, the following symptoms have interfered with patient's sexual activity or satisfaction:</b>	<b>Never (1)</b>	<b>Almost never (2)</b>	<b>Occasionally (3)</b>	<b>Almost always (4)</b>	<b>Always (5)</b>	<b>Mean score(1-5)</b>
Primary SP items	N (%)					
Less feeling or numbness in genital	65(49.6)	21(15.9)	25(18.9)	10(7.6)	11(8.3)	2.10
Lack of sexual interest or desire	31(23.5)	24(18.2)	21(15.9)	26(19.7)	30(22.7)	3.00
Less intense or pleasurable orgasms	25(18.9)	20(15.2)	17(12.9)	39(29.5)	31(23.5)	3.23
Delayed orgasm or climax	18(13.6)	14(10.6)	16(12.1)	42(31.8)	42(31.8)	<b>3.57</b>
Inadequate vaginal lubrication	36(27.3)	16(12.1)	21(15.9)	23(25)	26(19.7)	2.97
Secondary SP items						
Muscle tightness or spasms in body	23(17.4)	31(23.5)	35(26.6)	32(24.2)	11(8.3)	<b>2.82</b>
Bladder or urinary symptoms	45(34.1)	22(16.7)	32(24.2)	27(20.5)	6(4.5)	2.44
Bowel symptoms	39(29.5)	26(19.7)	35(26.6)	25(18.9)	7(5.3)	2.50
Feelings of dependency because of MS	49(37.1)	29(22)	29(22)	22(16.6)	3(2.3)	2.25
Tremors or shaking in hands or body	47(35.6)	30(22.7)	28(21.2)	24(18.2)	3(2.3)	2.28
Pain, burning, or discomfort in body	32(24.2)	19(14.4)	48(36.4)	28(21.2)	5(3.8)	2.65
Body-moving problems during sexual activity	49(37.1)	35(26.5)	18(13.6)	20(15.2)	10(7.6)	2.29
Problems with concentration or memory	22(16.7)	30(22.7)	45(34.1)	30(22.7)	5(3.8)	2.74
Exacerbation or significant worsening of MS	37(28)	37(28)	31(23.5)	24(18.2)	3(2.3)	2.38
Tertiary SP items						
Feeling that my body is less attractive	49(37.1)	36(27.3)	21(15.9)	18(13.6)	8(6.1)	2.24
Feeling less feminine due to MS	58(43.9)	37(28)	17(12.9)	15(11.4)	5(3.8)	2.03
Fear of being rejected sexually	56(42.4)	41(31.1)	15(11.4)	16(12.1)	4(3)	2.03
Worrying about partner's sexual satisfaction	50(37.9)	18(13.6)	36(27.3)	19(14.4)	9(6.8)	<b>2.38</b>
Feeling less confident about sexuality	50(37.9)	36(27.3)	21(15.9)	18(13.6)	7(5.3)	2.21

**Table 4**

Bivariate correlations (Pearson) between primary SP items and demographic and clinical variables

variables	Decreased genital sensation	Decreased libido	Less intense /pleasurable orgasm	Delayed orgasm	Decreased lubrication
Age			0.266(**)	0.293(**)	0.293(**)
Disease duration			0.272(**)	0.243(**)	0.406(**)
Onset age at of disease					
Length of marriage		0.221(*)	0.308(**)	0.322(**)	0.291(**)
Age of husband		0.173(*)	0.314(**)	0.307(**)	0.280(**)
Physical ability	-0.195(*)	-0.362(**)	-0.397(**)	-0.348(**)	-0.327(**)
Length of medication	0.175(*)		0.308(**)	0.324(**)	0.317(**)
Fatigue	-0.224(**)	-0.431(**)	-0.370(**)	-0.369(**)	-0.264(**)
Number of times approached by spouse for intercourse		-0.219(*)	-0.287(**)	-0.265(**)	-0.305(**)
Number of intercourses		-0.216(*)	-0.291(**)	-0.277(**)	-0.300(**)
Number of Pregnancy			0.188(*)	0.190(*)	
Number of Children			0.210(*)	0.205(*)	

\*\* Correlation is significant at the 0.01 level (2-tailed).

\* Correlation is significant at the 0.05 level (2-tailed).

**Table5**

Bivariate correlations (Pearson) between three levels of sexual problems as well as MSISQ-19 total scores and demographic and clinical variables

variables	Primary SP score	Secondary SP score	Tertiary SP score	MSISQ-19 total score
	r	r	r	r
Age	0.293(**)	0.238(**)		0.264(**)
Length of disease	0.297(**)			0.223(**)
Onset age of disease				
Length of marriage	0.304(**)	0.295(**)		0.285(**)
Age of husband	0.308(**)	0.232(**)		0.247(**)
Physical ability	-0.417(**)	-0.457(**)	-0.502(**)	-0.524(**)
Length of medication	0.320(**)	0.249(**)		0.263(**)
Fatigue	-0.424(**)	-0.466(**)	-0.446(**)	-0.513 (**)
Number of times approached by spouse for intercourse	-0.268(**)	-0.188(*)		-0.217(*)
Number of intercourses	-0.272(**)	-0.200(*)		-0.234(**)
Number of Pregnancy	0.186(*)			
Number of children	0.194(*)	0.193(*)		0.201(*)

\*\* Correlation is significant at the 0.01 level (2-tailed).

\* Correlation is significant at the 0.05 level (2-tailed).

**Table 6**

The mean $\pm$ SD of three levels of sexual problems and MSISQ-19 total scores

score	M $\pm$ SD
Primary SP	14.87 $\pm$ 5.6
Secondary SP	22.35 $\pm$ 6.8
Tertiary SP	10.89 $\pm$ 4.7
MSISQ-19 total score	48.11 $\pm$ 15.0