#### **ORIGINAL PAPER**



# The Effect of Sexual Health Promotion Package on Sexual Life in Women with Multiple Sclerosis: Designed Based on the Results of a Mixed Method Study

Vida Ghasemi, et al. [full author details at the end of the article]

Accepted: 9 May 2021 / Published online: 12 June 2021 © The Author(s), under exclusive licence to Springer Science+Business Media, LLC, part of Springer Nature 2021

#### Abstract

Sexual dysfunction (SD) is one of the most prevalent problems in patients with multiple sclerosis (MS) that can have a negative impact on their sexual quality of life. The aim of this study was to determine the effect of sexual health promotion package on SD and quality of sexual life in women with MS. This randomized clinical trial, was performed on 72 married women aged between 18 and 50-years-old with MS and SD presenting to the Iranian MS Society in Tehran. Participants were randomly divided into two groups of intervention (n=36) and control (n=36). The content of the sexual health promotion package was designed and prepared based on the results of an explanatory sequential mixed method study and review of literature and was performed in six sessions for the intervention group, while the control group received its routine care. For evaluating the effect of the intervention on SD and quality of sexual life, Multiple Sclerosis Intimacy and Sexuality Questionnaire19 (MSISQ-19) and Sexual Quality Of Life-Female (SQOL-F) were respectively completed before, immediately, one month and two months after the intervention. Based on the type of information, Mann-Whitney, Chi-square, independent t-test and repeated measures ANOVA test were performed using SPSS version 25. The results of repeated measures ANOVA test between the two groups during the four periods of time, showed that a significant decrease in the total MSISQ-19 score as well as primary, secondary and tertiary SD score and a significant increase in the quality of sexual life score in the intervention group (p < 0.001). By contrast, no significant difference was observed in the control group in terms of the total SD score (p=0.336), primary SD (P=0.058), secondary SD (P=0.075), tertiary SD (P=0.554) and quality of sexual life (P=0.105). The results of this study showed the effectiveness of a need-based and evidence-based sexual health promotion package designed based on the results of a mixed method study on SD and quality of sexual life of Iranian women with MS. Given the significant role of sexual life in MS patients, it is strongly recommended to consider and implement training and counseling sessions based on a comprehensive, complete and multidimensional content which includes all the factors affecting the sexual health of these patients.

**Keywords** Multiple Sclerosis · Sexual Dysfunction · Women · Sexual Quality of Life · Islamic Republic of Iran

# Introduction

Multiple sclerosis (MS) is a chronic progressive inflammatory disorder with central nervous system atrophy which affects 2.2 million people worldwide [1]. The prevalence of MS in Iran is 29.3 per 100,000, three times more likely to affect women, and symptom onset begins between the ages of 20 to 40. Therefore, women of reproductive age are the most vulnerable people to this disease [2–4]. One of the most prevalent problems in these women is sexual dysfunction (SD) and about 62% of Iranian women with MS suffer from this disorder [5].

The SD caused by MS has a multidimensional nature and is affected by several factors [6]. This disorder can be caused by the effect of MS-induced lesions on the nervous system (primary SD), which reduces sexual desire, impairs orgasm, vaginal lubrication, and reduces genital sensation. SD can also be due to the indirect effect of physical symptoms including fatigue, numbness, pain, burning sensation, muscle spasm and bladder and bowel dysfunction (secondary SD), or through psychological, social and cultural factors caused by the disease, including feeling less attractive, fear of spousal dissatisfaction, depression, stress, and so on (tertiary SD) [6, 7].

The onset of the disease usually occurs at the reproductive age when people are sexually active and at the peak of individual and family responsibilities. Therefore, for these patients sexual problems may be considered as a negative feature of the MS. These sexual problems have many negative effects on all aspects of their life [8, 9].

Although sexual health disorder is common in women with MS, it is often overlooked for a variety of reasons, especially in some countries such as Iran [10]. In a study, Iranian women with MS complained of the inadequate attention of the treatment team to the post-disease sexual issues and lack of adequate training and counseling in this area [11]. This lack of attention can be due to obstacles such as the physician's focus on neurological symptoms, the presence of family or friends during the visit, lack of knowledge about sexual issues, insufficient time for counseling and being embarrassed about expressing sexual problems [12].

Given the fact that most sexual disorders in MS patients are caused by uncomplicated and treatable factors, special attention to sexual health promotion programs is an essential factor to improve sexual function and quality of sexual life of these patients. Considering the effect of education and awareness in improving the sexual problems of MS patients, one of the best treatments for sexual problems of these patients is the design and implementation of educational sexual interventions. Owing to the multidimensional nature of sexual problems and different needs of these patients, training and counseling should be need-based and evidence-based [3, 13]. In fact, the patients should be allowed to express their problems and needs and, then, this information can be used in the design of training interventions.

Generally, in most interventions performed in Iran and other countries, the content of intervention is designed quantitatively based on a review of literature or common educational models which may not completely address the complex sexual problems of these women. Therefore, this study aimed to investigate the effect of a need-based and evidence-based sexual health promotion package, designed based on a mixed quantitative and qualitative study, on SD and quality of sexual life in MS women.

#### Study Design and Participants

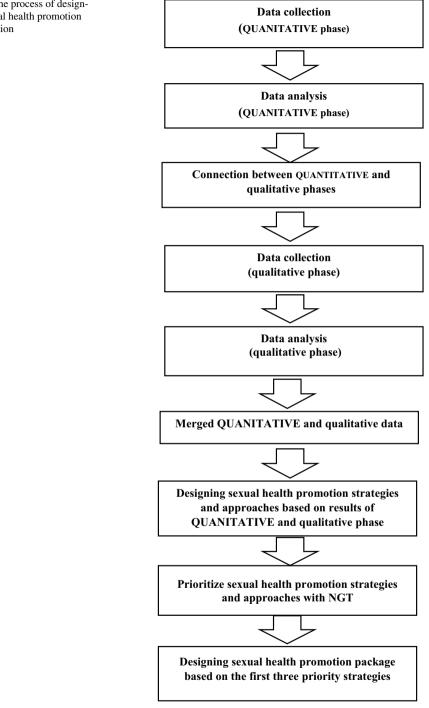
This interventional study was conducted as a randomized controlled clinical trial from November 2019 to February 2020 in order to determine the effect of sexual health promotion package on the SD and quality of sexual life of married women with MS referring to the Iranian MS Society in Tehran. Convenience sampling methods were used and all eligible MS-women were invited to participate in the study after obtaining informed consent and explaining the objectives of the study to them. Inclusion criteria were answering at least one question of the MSISQ-19 with the options of "often" or "always" for diagnosing SD, aged between 18 and 50 years, not being menopause, being married, definitive diagnosis of MS by a neurologist based on McDonald criteria (2010) [14], at least one year had passed since the diagnosis, having sexual activity in the last six months, not being pregnant or breastfeeding, (EDSS < 7), no severe fatigue (i.e. fatigue score should be less than 5.1 using the Fatigue Intensity Scale or FSS), no severe depression (depression score should be less than 29 using Beck Depression Inventory II or BDI-II), not being in the recurrence stage or non-recurrence of the disease in the last 30 days, and without other acute or chronic diseases or being treated for them. The exclusion criteria were recurrence of the disease in the study process, unwillingness to participate in the continuation of the sessions and migration from Tehran. Finally, based on the formula of sample size for comparison of means in paired data and 80% power, 72 eligible women with MS were invited to participate in the study. After obtaining informed consent and explaining the objectives of the research, the participants were randomly assigned into one of the control (n=36) and intervention (n=36) groups. Randomization of individuals was performed using random numbers in Excel software with the Rand function ().

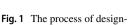
#### Intervention Design

The present interventional study is part of a comprehensive multi-stage study. At first, we conducted an explanatory sequential mixed method study to determine the problems and needs of sexual health promotion in women with MS and we used the results to design and prepare the content of this sexual health promotion package (Fig. 1). Explanatory sequential mixed method study consists of first collecting quantitative data and then collecting qualitative data to help explain the significant findings of quantitative phase [15]. In our study, explanatory sequential mixed method study also included quantitative (Cross-sectional) and qualitative phases, which was done as follows:

In the quantitative phase, in order to determine the predictor factors of SD in women with MS, a cross-sectional study was conducted in 260 married MS-women using valid and reliable standard questionnaires. Based on the results of this phase, the severity of disability, number of parities, duration of disease, duration of medication use, urgency urinary incontinence, anxiety, depression, sexual self-efficacy and fatigue were the final predictors of SD in these women [16].

In the second phase, a qualitative study was conducted to further explain the significant results of the quantitative phase and explain sexual life in MS-women and the perception and experience of these women with their sexual life. For this purpose, the





ing sexual health promotion intervention

significant results of the quantitative phase became the basis of data collection in the qualitative phase. In other word, quantitative and qualitative sections were connected by using the significant results of the quantitative phase to design the questions of the qualitative phase [17]. Eighteen subjects participating in the qualitative phase included 13 MS-women aged 18–50 years presenting to Iran MS Society and 5 key informants including neurologists, sexologists, reproductive health specialist, psychologist and a spouse with at least six months of living with a woman with MS. In this section, eligible MS-women were selected using purposive sampling with maximum variation from the participants of quantitative phase. Maximum variation was observed in terms of age, level of education, employment status, disease duration, married duration, type of MS and disability status score [18]. The data were collected by conducting in-depth semi-structured interviews until data saturation was achieved. The data were analyzed in MAXQDA10 using the conventional content analysis based on the approach proposed by Graneheim and Lundman [19].

The results of the qualitative phase led to the emergence of six themes, including: 1- the effect of physical-psychological factors of the disease on sexual health with the categories of psychological factors and physical problems caused by the disease and their treatment; 2- the decline in the quality and quantity of sexual relationships with the categories of poor sexual function of women, reduction in the frequency of the sex, fear of recurrence of negative sexual experiences; 3- sexual role impairment with the categories of low sexual self-efficacy and self-neglect in sexual relationships; 4- self-control in the disease and sexual health with the categories of self-management of disease and sexual problems, treatment finding and how to deal with the problem; 5- sexual skills and the lack of sexual skills in the couples with the categories of the incorrect performance of man in sexual relationship (for example not having the sexual skills to prepare a woman for sex and low sexual activity) and providing physical and psychological preparations for sexual intercourse; 6- sexual and non-sexual interaction of couples with the categories of verbal and non-verbal interaction of couples in sexual life and the role of interpersonal interaction pattern of couples in sexual performance.

Then, the results of the quantitative and qualitative phases were merged by Side-by-Side comparison of the results of these two phases [17]. According to the results, all the significant variables in the quantitative phase, which could be explained, were explained by the experiences of the participants in the qualitative phase. However, given the fact that in mixed research deductive and inductive thinking are combined with each other, this method will lead to a richer and more complete description of the subject than any of the quantitative phase not only covered the quantitative results, but also led to the emergence of new themes for understanding the sexual problems and needs in these patients. Therefore, given the fact that the results of the qualitative phase were considered as six strategies for the promotion of sexual health and the codes of these themes were considered as the needs of sexual health promotion. Then, sexual health promotion strategies were designed for these needs based on a review of literature (Table 1).

In the next stage, sexual health promotion strategies, which were extracted from the results of the quantitative and qualitative phases, were prioritized in a 1.5-h session with the presence of 10 experts including five reproductive health specialists, two sexologists, a psychologist with the experience of working in the field of sexual health of women with MS, a neurologist, and a PhD in medical education using the Nominal Group Technique (NGT). The priorities set in this session were used in the design of the training intervention.

Table 1         Priority strategies for designing a sexual health promotion intervention	romotion intervention	
	The needs extracted from the mixed study	Strategies
chological factors of the disease on sexual health	Depression Anxiety	Training the patient about having correct position during the sex despite muscle stiffness
	Stress Fear of death Muscle stiffness	Training progressive muscle relaxation techniques to control mood changes
	Pain Numbness and tingling in the limbs	Training the patient to take measures for improving and reducing muscle pain and muscle stiffness
	Urinating during the sexual intercourse. Urinating during the sexual intercourse. The negative effect of fatigue on sexual desire	Training the patient to take measures for reducing the impact of fatigue on sex
	Lack of enough energy to have sex	Training the patient to take measures for reducing the impact of urinary incontinence on sex
		Training problem-solving skills, communication skills and negotiation with spouse
Strategies for dealing with the declined quality and	The negative effect of the disease on sexual desire	Sensate focus exercises
quanuty of sexual relationships	Vaginal uryness Vaginal pain during intercourse	Training Kegel exercises to strengthen the pelvic floor muscles
	Protonged orgasm or lack of it in woman No experience of enjoyable orgasm experience Reduced times of sevial intercourse	Training the sexual response cycle and the impact of disease on sexual health
	Understanding the sexual dissatisfaction of the spouse	Correcting misconceptions and attitudes about sex Training the use of vasinal lubricants
		Education about the anatomy and physiology of the repro- ductive system
		Training how to enjoy all stages of sex, not just orgasm and penetration

Table 1 (continued)		
Strategies to improve self-control in disease and sexual life	Need to limit the impact of fatigue on sex Lack of knowledge about the use of lubricants to	Education about general energy conservation techniques such as having sex at the right time with more energy
	reduce vaginal dryness Lack of knowledge about one's ability and energy in sexual intercourse	Training the patient to use vaginal lubricants so that dry- ness does not affect sexual intercourse
	Need to plan for having sex at the right time with more energy Search in official and unofficial sources for treatment	Training the patient to seek treatment and search for infor- mation when necessary
	and information	Training to follow the physician's instructions
	Failure to follow the physician's instructions regularly Lack of self-confidence due to the impact of disease on a one's abilities	Training and counseling to strengthen the patient's self- confidence
	Feeling unable to solve the problems of the disease	Training the problem-solving skills to solve the problems which are caused by the disease and affect sexual health

Using the opinions of the research team and experts, the first three priorities of these strategies were decided to be used in the design of the training package. According to the results of this session, the strategy of coping with the effect of physical and psychological factors of the disease on sexual health, the strategy of coping with the decline in quality and quantity of sexual relationships, and the strategy of improving self-control in disease and sexual health were the first three priorities respectively (Table1).

Then, the required training content was prepared based on search in articles and sites, guidelines and valid books. The flowchart of the steps of doing the work is shown in Fig. 1. The training content of each session are shown in Table 2.

## Intervention

Before the intervention, the questionnaires of demographic information and disease history, Multiple Sclerosis Intimacy and Sexuality Questionnaire19 (MSISQ-19) and Sexual Quality Of Life-Female (SQOL-F) were completed by the participants. For the intervention group, six 60–90 min sessions in small groups of 5–7 MS-women were conducted for six weeks in the form of lectures, questions and answers and role-playing in the Iranian MS Society in Tehran. Three sessions were presented by the researcher who is a PhD student in reproductive and sexual health and three other sessions by a psychologist with the experience of working in the field of sexual life of MS patients (Table 2). During the intervention period, the control group received routine care and they were assured that they could participate in the counseling sessions after the end of the study. In order to determine the effectiveness of the intervention, the MSISQ-19 and SQOL-F questionnaires were completed by the samples immediately, one month and two months after the intervention.

## Data Collection Tools

In addition to the questionnaire related to the socio-demographic and disease information, the Expanded Disability Status Scale (EDSS) score was determined by a neurologist present at the Iranian MS Society with scoring between 0 (normal) and 10 (death). The EDSS scale examines the Functional Systems: Pyramidal (motor function), Cerebellar, Brainstem, Sensory, Bowel and Bladder, Visual and Cerebral or Mental [21].

The Multiple Sclerosis Intimacy and Sexuality Questionnaire (MSISQ-19) was used to assess SD. This 19-item questionnaire, designed and psychometrically examined in 2000 by Sanders et al., measures SD in patients with MS in the three areas of primary SD (questions 12 and 16–19), secondary SD (questions 1–6, 8, 10, 11), and tertiary SD (questions 7, 9 and 13–15) in a 5-point Likert scale (never=1, rarely=2, sometimes=3, often=4 and always=5). The sum of the scores is between 19 and 95 [22]. This tool is validated in an Iranian MS population with the Cronbach's alpha of 0.90 [23].

For the assessment of the quality of sexual life, SQOL-F was used. This questionnaire has 18 questions with a Likert scale of six options ranging from totally agree to totally disagree and was designed and psychometrically examined in 2005. The total score of the tool ranges from 18 to 108 and a higher score means a higher quality of sexual life [24]. This questionnaire was psychometrically examined in Iran and its reliability was confirmed with the Cronbach's alpha coefficient of 0.73 and intra-cluster correlation coefficient of 0.88 [25].

lable 2 Content of sexual nearth promotion sessions	eauti promotion sessions	
Number of session	Content	Trainer
First	Multiple sclerosis and its symptoms, sexual health, anatomy and physiology of the male and female reproductive systems, correction of sexual misconceptions and attitudes	PhD of Reproductive health
Second	The effect of MS on sexual health, psychological symptoms of the disease affecting sexual health and ways to deal Psychologist with them, such as progressive muscle relaxation, yoga, counseling to improve coping with negative thoughts and fear, etc	Psychologist
Third	Physical symptoms of the disease affecting sexual health such as fatigue, muscle cramps, urinary and fecal inconti- PhD of Reproductive health nence, and the ways of dealing with them such as exercises for reducing muscle stiffness, correct sexual position, Kegel exercise and so on	PhD of Reproductive health
Fourth	Sexual dysfunction caused by the disease and its effect on sexual health such as vaginal dryness and pain during intercourse, orgasmic disorders and decreased sexual desire and the ways of dealing with them such as sensory and non-sensory concentration techniques. Kegel exercises, bridge maneuvers, the use of lubricants, body map training, and identification of irritable points, etc	PhD of Reproductive health
Fifth	Training of techniques for strengthening sexual self-confidence and problem-solving skills	Psychologist
Sixth	Training of communication and negotiation skills with the spouse in relation to problems affecting sexual and public life	Psychologist

Table 2 Content of sexual health promotion sessions

🙆 Springer

The Fatigue Severity Scale (FSS) was used to assess the severity of fatigue which was designed and examined psychometrically by Krupp et al. [26]. This questionnaire has 9 items and each item score range is between 1 and7. Therefore, the total score for nine items is between 9 and 63. The mean score over the nine items is between 1 and 7 and higher than 5.1 indicated severe fatigue.

The Beck Depression Inventory (BDI) as a 21-item self-report questionnaire was used to assess the severity depression in this study. This questionnaire was designed by Beck et al. in 1988. All questions have 4-choice answers (0 to 3), the total score range from 0 to 63, and a score  $\geq$  29 is considered a sign of severe depression [27].

# Ethics

The present study was extracted from a Ph.D. thesis on reproductive health, and approved by Iran MS Society and the Ethics Committee of Shahid Beheshti University of Medical Sciences. In addition, the study was registered in the Iranian Registry of Clinical Trials (register number: IRCT20190721044292N1). The researcher explained the purpose and procedure of the study and ensured them of the confidentiality of their information and the voluntary type of participation. All of the participants provided their informed consent.

## Statistical Analysis

Based on the type of information, descriptive and analytical statistics such as Mann–Whitney, Chi-square, and independent t-test were used to compare demographic variables between the two groups. The repeated measures ANOVA test was also used to compare the mean of MSISQ-19 and SQOL score during the different times between the two groups. Data analysis was performed using SPSS version 25.

## Results

72 married women with MS participated in this study but in intervention group 4 peoples (2 because of recurrence of MS, 1 because of unwillingness and 1 because of Immigration from Tehran) and in control group 3 peoples (2 because of recurrence of MS and 1 because of unwillingness) drop out the study and finally 65 MS-women were assessed (Fig. 2). Before the intervention, there was no significant difference in demographic, clinical and obstetric information of the participants in the two groups (Table 3). The mean age of participants was  $35.71 \pm 7.44$  years in the intervention group and  $36 \pm 6.51$  years in the control group (p = 0.872). The mean duration of marriage was  $8.35 \pm 1.47$  years in the intervention group and  $8.16 \pm 1.42$  years in the control group (p = 0.828). The mean score of disability severity was  $1.81 \pm 1.37$  and  $1.93 \pm 1.47$  in the intervention and control group respectively (p = 0.722). Other characteristics are shown in Table 3.

In order to investigate the effect of the intervention on SD and quality of sexual life of women with MS, MSISQ-19 and SQOL questionnaires were completed by the samples before the intervention and immediately, one month and two months after the intervention, and the results were compared between the two groups. The results of independent t-test with Bonferroni correction showed that before the intervention the mean of MSISQ-19 was

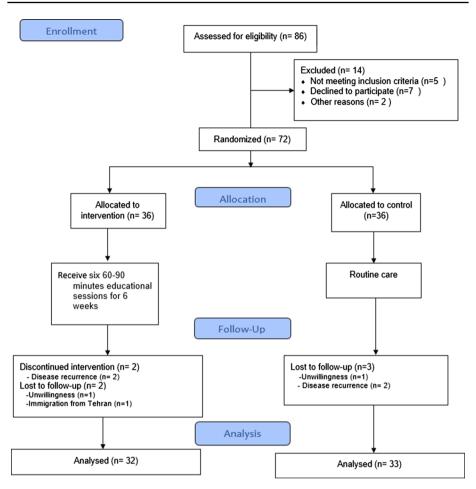


Fig. 2 Consolidated standards of reporting trial (CONSORT) flow chart of study

not significantly different between the two groups in terms of the total score (p=0.609), primary SD (p=0.074), secondary SD (p=0.570), tertiary SD (p=0.502) and also the mean score of sexual quality of life (p=0.591). However, these means included the mean of primary SD, secondary SD, tertiary SD and sexual quality of life were significantly different between the two groups at times immediately, one month and two months after the intervention (p < 0.001) (Table 4,5).

Measuring the effect of the intervention on SD and quality of sexual life, the results of repeated measures ANOVA showed that the interaction between time and group was significant (p < 0.001). This means that the trend of changes in the mean total score of MSISQ-19 and its dimensions included primary, secondary and tertiary SD and total score of quality of sexual life are not the same over time in the two groups. To determine and compare the nature of the difference in the trend of changes in the two groups, the changes in the mean total score of MSISQ-19 and its dimensions and total score of quality of sexual life through four stages of evaluation were examined separately in each of the two groups. In the intervention group, the mean total score

Variable	Intervention group $(n=32)$	Control group $(n=33)$	p value
	Mean (SD)/N (%)	Mean (SD)/N (%)	
Education level			
Primary	6 (18.8)	5 (15.2)	$0.643^{*}$
Secondary	8 (25)	7 (21.2)	
High school and diploma	8 (25)	10 (30.3)	
University	10 (31.3)	11 (33.3)	
Spousal education level			
Primary	7 (21.9)	6 (18.2)	$0.649^{*}$
Secondary	8 (25)	7 (21.2)	
High school and diploma	7 (21.9)	9 (27.3)	
University	10 (31.3)	11 (33.3)	
Economic status			
Satisfied	6 (18.8)	5 (15.2)	$0.724^{*}$
Intermediate	18 (56.3)	19 (57.6)	
Dissatisfied	8 (25)	9 (27.3)	
Employment status			
Housewife	23 (71.9)	21 (63.6)	$0.478^{**}$
Employee	9 (28.1)	12 (36.4)	
Contraceptive method			
Hormonal	8 (25)	10 (30.3)	$0.886^{**}$
Nonhormonal	15 (46.9)	14 (42.4)	
Others	9 (28.1)	9 (27.3)	
Number of Parity	$1.75 \pm 0.950$	$1.69 \pm 1.28$	0.851***
Number of sexual intercourses in the last month	$3.34 \pm 2.58$	$4.66 \pm 3.42$	0.084***
Disease duration(years)	$7.78 \pm 4.83$	$8.39 \pm 5.87$	$0.648^{***}$
Duration of DMT use (years)	$6.78 \pm 4.95$	$7.21 \pm 4.65$	$0.719^{***}$
Disease course			
Relapsing-remitting MS	21 (65.6)	20 (60.6)	$0.915^{**}$
Secondary-progressive MS	6 (18.8)	7 (21.2)	
Primary-progressive MS	5 (15.6)	6 (18.2)	
Fatigue Severity Scale (FSS)	$24.33 \pm 4.78$	$25.72 \pm 6.47$	0.332***
Depression severity (BDI)	$16.90 \pm 3.81$	$15.66 \pm 4.35$	$0.227^{***}$

Table 3 Comparison of socio-demographic, obstetrics, and disease characteristics of study groups

\* Mann-Whitney U Test, \*\* Chi-Square Test, \*\*\* Independent sample t-test

of MSISQ-19 and its dimensions and total score of quality of sexual life was significantly different during these four time periods (p < 0.001). However, in the control group, there was no significant difference during the follow-up period in terms of the total score (p = 0.336), primary SD (P = 0.058), secondary SD (P = 0.075), tertiary SD (P = 0.554) and total score of quality of sexual life (p = 0.105) (Table 4, 5).

	c			
noisenation of the second s	Group Time	Intervention (n=32) Mean±SD	Control (n = 33) Mean±SD t-test	l-lest
Total score	Before the intervention	57.56±11.55	$56.06 \pm 11.98$	0.609
	Immediately after intervention	$40.09 \pm 13.61$	$55.00 \pm 10.65$	P < 0.001
	1 months after intervention	$32.75 \pm 11.53$	$55.36 \pm 10.29$	P < 0.001
	2 months after intervention	$30.03 \pm 8.96$	$56.87 \pm 10.58$	P < 0.001
Repeated measures analysis		$P < 0.001^{a}$	$P = 0.336^{a}$	
		$P < 0.001^{\rm b}, F = 75.920$		
Primary SD score	Before the intervention	$18.28 \pm 3.43$	$16.78 \pm 3.17$	0.074
	Immediately after intervention	$11.34 \pm 4.20$	$16.81 \pm 3.17$	P < 0.001
	1 months after intervention	$10.06 \pm 4.03$	$17.21 \pm 3.12$	P < 0.001
	2 months after intervention	$9.40 \pm 3.36$	$17.54 \pm 3.27$	P < 0.001
Repeated measures analysis		$P < 0.001^{a}$	$P = 0.058^{a}$	
		$P < 0.001^{\rm b}, F = 91.757$		
Secondary SD score	Before the intervention	$23.59 \pm 7.26$	$22.60 \pm 6.68$	0.570
	Immediately after intervention	$18.62 \pm 6.92$	$22.33 \pm 6.08$	P < 0.025
	1 months after intervention	$14.15 \pm 4.81$	$22.42 \pm 6.10$	P < 0.001
	2 months after intervention	$13.15 \pm 3.86$	$23.30 \pm 5.99$	P < 0.001
Repeated measures analysis		$P < 0.001^{a}$	$P = 0.075^{a}$	
		$P < 0.001^{\text{b}}, F = 59.233$		
Tertiary SD score	Before the intervention	$15.68 \pm 4.20$	$16.66 \pm 7.09$	0.502
	Immediately after intervention	$10.12 \pm 4.17$	$15.84 \pm 4.32$	P < 0.001
	1 months after intervention	$8.53 \pm 4.59$	$15.72 \pm 3.58$	P < 0.001
	2 months after intervention	$7.46 \pm 3.65$	$16.03 \pm 3.95$	P < 0.001
Repeated measures analysis		$P < 0.001^{a}$	$P = 0.554^{a}$	
		$P < 0.001^{\text{b}}$ $F = 17.728$		

 Table 4
 Comparison of total score and each dimension score of MSISO-19 between intervention and control groups

<sup>a</sup> Each group during the 4 times. <sup>b</sup> Group \*Time

	Group			
Time	Intervention (n = 32) Mean $\pm$ SD	Control $(n=33)$ Mean $\pm$ SD	t-test	
Before the intervention	$59.46 \pm 14.59$	61.69±18.41	0.591	
Immediately after intervention	81.87±19.49	$60.81 \pm 16.82$	P<0.001	
1 months after intervention	88.93±18.87	$59.96 \pm 17.38$	P < 0.001	
2 months after intervention	$91.56 \pm 17.11$	$57.81 \pm 16.53$	P<0.001	
Repeated measures analysis	$P < 0.001^{a}$	$P = 0.105^{a}$		
	$P < 0.001^{\rm b}, F = 64.780$			

 Table 5
 Comparison of SQOL score between intervention and control groups

<sup>a</sup>Each group during the 4 times. <sup>b</sup> Group \*Time

# Discussion

The present study was conducted for the first time in Iran and the world with the aim of investigating the effect of evidence-based and need-based sexual health promotion package on SD and quality of sexual life in women with MS. Designing the evidence-based and need-based interventions should be considered in all educational areas, because by meeting the special needs of patients, it increases patients' self-efficacy to deal with the symptoms of the disease and thus improve their health [13, 28]

The present training package was designed as a comprehensive, complete, evidencebased and need-based package based on the three strategies extracted from the results of quantitative and qualitative phases, which, according to experts view, had the highest priority. The strategy of coping with the effect of physical and psychological factors of the disease on sexual health was the first priority. Physical and psychological problems caused by the disease or its treatment can negatively affect the health, activity and quality of sexual life of these patients which are classified by Foley et al. as the secondary and tertiary SD [3, 10, 13]. The second and third strategies were coping with the decline in the quality and quantity of sexual relationships and improving self-control in the disease and sexual health, respectively. According to recent studies [11, 29], MS and its symptoms have a great impact on the quality and quantity of sexual relationships of people with this disease. Evidence suggests that SD and decreased number of sexual intercourse are the first signs of change in post-MS sexual life [29, 30]. Additionally, for many MS patients, maintaining the high quality of life requires making informed decisions and using problem-solving resources and skills to manage unpredictable symptoms. Generally, successful self-control in disabling situations requires learning certain skills and employing them in performing certain tasks [31]. Therefore, the training content of the present study included strategies for educating the MS-women to improve their sexual health.

The results of the present study showed the positive effect of the intervention on the improvement of SD in women with MS in all three dimensions of primary SD, secondary SD and tertiary SD. The results of a study which conducted by Wright et al., showed that training can increase the knowledge and attitude of women with MS about their sexual problems and has a positive effect on improving sexual satisfaction and solving their sexual problems [32].

Consistent with the results of the present study, the results of the study conducted by Azari-Barzandig et al. in 2020 showed that one 60–90-min session counseling based on EX-PLISSIT model improved the total score as well as the primary and tertiary dimensions of MSISQ-19 in women with MS [33]. The results of this study were in line with the results of the present study in terms of improving the total scores and primary and tertiary SD. However, in this study, contrary to our study, the intervention had no effect on improving the secondary SD. This difference can be interpreted from two aspects. This may be due to the fact that secondary SD includes the effect of physical symptoms such as urinary and intestinal problems, muscle cramp, pain, burning and tremors on the sexual function of these patients, which require longer and more comprehensive intervention as well as medication and rehabilitation treatments. However, in the study of Azari-Barzandig et al., the intervention was held in only one session, which seems to be insufficient for solving the sexual problems of these women. Of course, it should be noted that the mean disability score of the participants in this study was higher than the participants of our study (6 vs. 2) which means that the problems of these people in the secondary SD are more severe. This reason can also affect the difference in results between the two studies [33].

In the study of Daneshfar et al., despite the fact that sexual counseling based on the EX-PLISSIT model showed a significant difference in the scores of all three primary, secondary and tertiary SD between the two groups, in the secondary dimension, the intervention had no significant effect on reducing the bladder and intestine problems, tremor, concentration and memory as well as the feeling of dependence on sexual function [2]. The reason for the difference between these results and the results of the present study can be due to the fact that in the present study, the content of the intervention was based on the evidence and the needs of MS-patients, and comprehensively included trainings and solutions for dealing with problems in all three dimensions included: primary SD (sexual dysfunction caused by nerve injury), secondary SD (indirect effects of physical symptoms of the disease on sexual function) and tertiary SD (the effect of psychosocial symptoms of the disease on sexual function).

In other words, the content of the present training package not only included strategies for improving sexual problems in these patients, but also comprehensively provided solutions for dealing with the physical, psychological and social symptoms of the disease. In general, sexual counseling and education, which includes specific strategies for symptoms affecting the sexual life of MS patients, has been introduced as an important method for solving the sexual problems of these patients [13].

In a study conducted in 2017 with the aim of evaluating the impact of sex therapy on the quality of life of women with MS, the educational content included 12 weekly sessions of sex therapy. To evaluate the effect of training, the Female Sexual Function Scale (FSFI) was completed at the beginning of the intervention and three months after the intervention. The results showed that the patients of the intervention group had improvements in various aspects of sexual function such as sexual desire, arousal, lubrication, orgasm, satisfaction and pain [34]. Although the results of this study are in line with the results of the present study, this study used FSFI questionnaire, which is a general scale for measuring sexual function and is not able to assess different areas of sexual function in MS patients. However, one of the strengths of our research is the use of an appropriate tool such as MSISQ-19, which is specifically used for MS patients and assesses their SD in three dimensions of primary SD, secondary SD and tertiary SD.

Based on the results of the present study, the intervention has a positive effect on the quality of sexual life of MS women. Generally, the quality of sexual life is a multidimensional structure and an important part of quality of life which is influenced by physical and

mental health, activities related to sexual and emotional relationships with the spouse, and sexual and marital satisfaction [25, 35, 36]. A study conducted in 2014 showed that sexual problems have a significant impact on the sexual quality of life in patients with MS. This may be due to the impact of sexual problems on sexual satisfaction and sexual self-confidence of these patients [37]. Therefore, it seems that training and counseling with the aim of improvement and promotion of the sexual health has a significant impact on improving the quality of sexual life.

In contrast with the present study, the results of another study showed that counseling based the extended PLISSIT model (Permission, Limited Information, Specific Suggestion, and Intensive Therapy), despite improving sexual function, had no effect on the quality of sexual life of married women with MS [33]. This may be due to the fact that in the present study, the SD of these people has been studied in a multidimensional way and the content of the intervention not only includes physical and sexual factors but also factors such as the improvement of sexual self-confidence, problem-solving, progressive muscle relaxation training, and the improvement of communication and negotiation skills.

#### Strengths and Weaknesses

The followings are some strengths of the present study. The content of the intervention was evidence-based, culture-based and based on the needs of the MS-patients. Moreover, the present sexual health promotion package as a multidisciplinary was designed with the cooperation of a team of reproductive health specialists (students and professors), a neurologist, an urologist and a psychologist and, then, was implemented in a multidisciplinary way with the cooperation of a PhD student of reproductive health and a psychologist.

Lack of education for the husbands of these women due to cultural and social barriers and refusal of the participating women to talk about sexual issues, because of cultural issues, were limitation of the present study.

# Conclusion

The results of our study demonstrated the effectiveness of a need-based, evidence-based, and culture-based training package on the improvement of SD in women with MS in all three dimensions of primary SD, secondary SD and tertiary SD and quality of sexual life in women with MS. Therefore, comprehensive and complete education can improve the sexual health of these patients. Given the significant role of sexual life in MS patients and as this issue has been ignored in the treatment process of these patients, it is strongly recommended to consider and implement training and counseling sessions based on a comprehensive, complete and multidimensional content which includes all the factors affecting the sexual health of these patients. It is also recommended to compare the sexual health of MS-women with women in the general population or women with other debilitating diseases such as spinal cord injuries, etc., and recognize the differences in their sexual health needs.

Acknowledgements This study was approved by the Ethics Committee of Shahid Beheshti University of Medical Sciences as a part of the Ph.D. thesis of Vida Ghasemi, Ph.D. candidate of reproductive health in Shahid Beheshti University of Medical Sciences. We are also grateful to Shahid Beheshti University of Medical Sciences for founding the research, all participants and personnel of the Iran MS Society and individuals who cooperate with us to conduct this study.

Funding This research was funded and supported by Shahid Beheshti University of Medical Sciences (Grant Number 15666).

#### Declarations

Conflict of interest The authors declare that they have no conflicts of interest.

## References

- Wallin, M.T., Culpepper, W.J., Nichols, E., Bhutta, Z.A., Gebrehiwot, T.T., Hay, S.I., Khalil, I.A., Krohn, K.J., Liang, X., Naghavi, M.: Global, regional, and national burden of multiple sclerosis 1990– 2016: a systematic analysis for the global burden of disease study 2016. The Lancet Neurol. 18(3), 269–285 (2019)
- Daneshfar, F., Behboodi-Moghadam, Z., Khakbazan, Z., Nabavi, S.M., Nayeri, N.D., Ghasemzadeh, S., Montazeri, A.: The influence of Ex-PLISSIT (extended permission, limited information, specific suggestions, intensive therapy) model on intimacy and sexuality of married women with multiple sclerosis. Sex. Disabil. 35(4), 399–414 (2017)
- Bronner, G., Elran, E., Golomb, J., Korczyn, A.: Female sexuality in multiple sclerosis: the multidimensional nature of the problem and the intervention. Acta Neurol. Scand. 121(5), 289–301 (2010)
- Azami, M., YektaKooshali, M.H., Shohani, M., Khorshidi, A., Mahmudi, L.: Epidemiology of multiple sclerosis in Iran: a systematic review and meta-analysis. PloS one 14(4), e0214738 (2019)
- Ghasemi, V., Simbar, M., Ozgoli, G., Nabavi, S.M., Alavi Majd, H., Mohammad Souri, B., Rashidi Fakari, F., Saei Ghareh Naz, M.: The prevalence of sexual dysfunction in iranian women with multiple sclerosis: a systematic review and meta-analysis. Shiraz E-Med. J. 20(6), e83490 (2019)
- Çelik, D.B., Poyraz, E.Ç., Bingöl, A., İdiman, E., Özakbaş, S., Kaya, D.: Sexual dysfunction in multiple sclerosis: gender differences. J. Neurol. Sci. 324(1–2), 17–20 (2013)
- Orasanu, B., Frasure, H., Wyman, A., Mahajan, S.T.: Sexual dysfunction in patients with multiple sclerosis. Mult. Scler. Relat. Disord. 2(2), 117–123 (2013)
- Schairer, L.C., Foley, F.W., Zemon, V., Tyry, T., Campagnolo, D., Marrie, R.A., Gromisch, E.S., Schairer, D.: The impact of sexual dysfunction on health-related quality of life in people with multiple sclerosis. Mult. Scler. J. 20(5), 610–616 (2014)
- Qaderi, K., Khoei, E.M.: Sexual problems and quality of life in women with multiple sclerosis. Sex. Disabil. 32(1), 35–43 (2014). https://doi.org/10.1007/s11195-013-9318-4
- Dehghan-Nayeri, N., Khakbazan, Z., Ghafoori, F., Nabavi, S.M.: Sexual dysfunction levels in iranian women suffering from multiple sclerosis. Mult. Scler. Relat. Disord. 12, 49–53 (2017)
- 11. Dehghan-Nayeri, N., Khakbazan, Z., Ghafoori, F.: "Life behind the mask": sexual life of Iranian women with multiple sclerosis. Disabil. Health J. **11**(2), 274–280 (2017)
- Tudor, K.I., Eames, S., Haslam, C., Chataway, J., Liechti, M., Panicker, J.: Identifying barriers to helpseeking for sexual dysfunction in multiple sclerosis. J. Neurol. 265(12), 2789–2802 (2018)
- Delaney, K.E., Donovan, J.: Multiple sclerosis and sexual dysfunction: a need for further education and interdisciplinary care. NeuroRehabilitation 41(2), 317–329 (2017)
- Polman, C.H., Reingold, S.C., Banwell, B., Clanet, M., Cohen, J.A., Filippi, M., Fujihara, K., Havrdova, E., Hutchinson, M., Kappos, L.: Diagnostic criteria for multiple sclerosis: 2010 revisions to the McDonald criteria. Ann. Neurol. 69(2), 292–302 (2011)
- Creswell, J.W., Clark, V.L.P.: Designing and conducting mixed methods research. Sage publications, (2017)
- Ghasemi, V., Simbar, M., Ozgoli, G., Nabavi, S.M., Majd, H.A.: Prevalence, dimensions, and predictor factors of sexual dysfunction in women of Iran Multiple Sclerosis Society: a cross-sectional study. Neurol. Sci. 41(5), 1105–13 (2020)
- Creswell, J.W., Plano Clark, V.: Choosing a mixed methods design. Des. Conduct. Mix. Methods Res. 2, 53–106 (2011)
- Ghasemi, V., Simbar, M., Ozgoli, G., Nabavi, S.M., Alavi Majd, H.: Sexual life under the shadow of multiple sclerosis in women: a qualitative study in Iran. Sex. Disabil. 38(4), 715–730 (2020)
- Graneheim, U.H., Lundman, B.: Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. Nurse Educ. Today 24(2), 105–112 (2004)
- Tashakkori, A., Teddlie, C.: Sage handbook of mixed methods in social and behavioral research. Sage, United States (2010)

- 21. Kurtzke, J.F.: On the origin of EDSS. Mult. Scler. Relat. Disord. 4(2), 95–103 (2015)
- Sanders, A.S., Foley, F.W., LaRocca, N.G., Zemon, V.: The multiple sclerosis intimacy and sexuality questionnaire-19 (MSISQ-19). Sex. Disabil. 18(1), 3–26 (2000)
- Mohammadi, K., Rahnama, P., Montazeri, A., Foley, F.W.: The multiple sclerosis intimacy and sexuality questionnaire-19: reliability, validity, and factor structure of the persian version. J. Sex. Med. 11(9), 2225–31 (2014)
- Symonds, T., Boolell, M., Quirk, F.: Development of a questionnaire on sexual quality of life in women. J. Sex. Marital Ther. 31(5), 385–397 (2005)
- Maasoumi, R., Lamyian, M., Montazeri, A., Azin, S.A., Aguilar-Vafaie, M.E., Hajizadeh, E.: The sexual quality of life-female (SQOL-F) questionnaire: translation and psychometric properties of the Iranian version. Reprod. Health 10(1), 25 (2013)
- Krupp, L.B., LaRocca, N.G., Muir-Nash, J., Steinberg, A.D.: The fatigue severity scale: application to patients with multiple sclerosis and systemic lupus erythematosus. Arch. Neurol. 46(10), 1121–1123 (1989)
- Beck, A.T., Steer, R.A., Garbin, M.G.: Psychometric properties of beck depression inventory, twenty five years of evaluation. Clin. Psychol. Rev. 8, 77–100 (1988)
- Ndosi, M., Johnson, D., Young, T., Hardware, B., Hill, J., Hale, C., Maxwell, J., Roussou, E., Adebajo, A.: Effects of needs-based patient education on self-efficacy and health outcomes in people with rheumatoid arthritis: a multicentre, single blind, randomised controlled trial. Ann. Rheum. Dis. 75(6), 1126–1132 (2016)
- McCABE, M.P., McKERN, S., McDONALD, E., Vowels, L.M.: Changes over time in sexual and relationship functioning of people with multiple sclerosis. J. Sex. Marital Ther. 29(4), 305–321 (2003)
- McCabe, M.P., McDonald, E., Deeks, A.A., Vowels, L.M., Cobain, M.J.: The impact of multiple sclerosis on sexuality and relationships. J. Sex Res. 33(3), 241–248 (1996)
- Plow, M.A., Finlayson, M., Rezac, M.: A scoping review of self-management interventions for adults with multiple sclerosis. PM and R 3(3), 251–262 (2011)
- Wright, D.E., Stepleman, L.M., Davis, K.N., Hughes, M.D.: Development of a group educational intervention for sexual functioning and intimacy concerns in patients with multiple sclerosis. Int. J. MS Care 11(3), 107–113 (2009)
- Azari-Barzandig, R., Sattarzadeh-Jahdi, N., Nourizadeh, R., Malakouti, J., Mousavi, S., Dokhtvasi, G.: The effect of counseling based on EX-PLISSIT model on sexual dysfunction and quality of sexual life of married women with multiple sclerosis: a randomized controlled clinical trial. Sex. Disabil. 38(2), 271–284 (2020)
- Zamani, M., Tavoli, A., Khasti, B.Y., Sedighimornani, N., Zafar, M.: Sexual therapy for women with multiple sclerosis and its impact on quality of life. Iran. J. Psychiatry 12(1), 58 (2017)
- Dogan, T., Tugut, N., Golbasi, Z.: The relationship between sexual quality of life, happiness, and satisfaction with life in married Turkish women. Sex. Disabil. 31(3), 239–247 (2013)
- Lai, Y.-H., Hsieh, S.-R., Ho, W.-C., Chiou, A.-F.: Factors associated with sexual quality of life in patients before and after coronary artery bypass grafting surgery. J. Cardiovasc. Nurs. 26(6), 487–496 (2011)
- Lew-Starowicz, M., Rola, R.: Sexual dysfunctions and sexual quality of life in men with multiple sclerosis. J. Sex. Med. 11(5), 1294–1301 (2014)

Publisher's Note Springer Nature remains neutral with regard to jurisdictional claims in published maps and institutional affiliations.

## Authors and Affiliations

Vida Ghasemi<sup>1</sup> · Seyed Massood Nabavi<sup>2,3</sup> · Masoumeh Simbar<sup>4</sup> · Giti Ozgoli<sup>4</sup> · Hamid Alavi Majd<sup>5</sup> · Maryam Sadat Mirshafaei<sup>6</sup> · Behzad Mohammadsoori<sup>7</sup> · Mojdeh Banaei<sup>8</sup>

Masoumeh Simbar msimbar@gmail.com

> Vida Ghasemi Vidaghasemi89@gmail.com

Seyed Massood Nabavi seyedmassoodnabavi@gmail.com

Giti Ozgoli g.ozgoli@gmail.com

Hamid Alavi Majd alavimajd@gmail.com

Maryam Sadat Mirshafaei Janan.shafaei@gmail.com

Behzad Mohammadsoori Drbehzadsoori@gmail.com

Mojdeh Banaei mojdeh.banaei@gmail.com

- <sup>1</sup> Student Research Committee, Department of Midwifery and Reproductive Health, School of Nursing and Midwifery, Shahid Beheshti University of Medical Sciences, Tehran, Iran
- <sup>2</sup> Regenerative Biomedicine Department, Neurology and MS Group, Royan Institute for Stem Cell Biology and Technology, ACECR, Tehran, Iran
- <sup>3</sup> Department of Brain and Cognitive Sciences, Royan Institute for Stem Cell Biology and Technology, ACECR, Tehran, Iran
- <sup>4</sup> Midwifery and Reproductive Health Research Center, Department of Midwifery and Reproductive Health, School of Nursing and Midwifery, Shahid Beheshti University of Medical Sciences, Tehran, Iran
- <sup>5</sup> Department of Biostatics, School of Paramedicine, Shahid Beheshti University of Medical Sciences, Tehran, Iran
- <sup>6</sup> Department of Psychometrics, Faculty of Psychology and Educational Sciences, Allameh Tabatabaei University Sciences, Tehran, Iran
- <sup>7</sup> Urology & Nephrology Research Center, Hamadan University of Medical Sciences, Hamadan, Iran
- <sup>8</sup> Mother and Child Welfare Research Center, Hormozgan University of Medical Sciences, Bandar Abbas, Iran