



Marital quality in the spouses of men with multiple sclerosis: A descriptive comparative study

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ABSTRACT

Multiple sclerosis (MS) is a chronic neurological disease that not only affects the patient but also has a considerable impact on marital relationships and the quality of life of spouses. This study investigated marital quality in the spouses of men with MS. This descriptive comparative study included 82 men registered with the MS Association of Shiraz, Iran, and their spouses; and 82 healthy men and their spouses. The participants were selected using the convenience sampling method. Data on marital quality were collected using the Perceived Relationship Quality Components inventory. The validity and reliability of this inventory has been previously confirmed in Iran. Data analysis was performed using SPSS software, version 21. The significance level was set at $p < 0.05$. The mean (\pm standard deviation) age of the men with MS was 35.9 ± 9.69 years and the mean duration of the relationship with their spouse was 14.24 ± 3.85 years. The total score for the Perceived Relationship Quality Components inventory and scores for the components satisfaction, passion, intimacy, and love were significantly lower in the spouses of men with MS compared with the spouses of healthy men ($p < 0.001$). For spouses of men with MS, the disease negatively impacts the marital relationship quality, particularly in terms of satisfaction, passion, intimacy, and love. Therefore, to improve the quality of life and marital relationships in MS patients and their spouses, it is important to include couple-based educational programs and marital therapy in rehabilitation programs for MS.

Keywords: Marital relationship quality, Multiple sclerosis, Spouse

INTRODUCTION

Multiple sclerosis (MS) is a chronic, progressive demyelinating disease of the central nervous system that typically affects young adults [1]. Worldwide; there are about 2.5 million people with MS, including 400,000 in the United States [2]. The prevalence of MS in Iran is 9 per 100,000 people [3]. The onset of MS typically occurs in the third or fourth decades of life, which correspond to the age of fertility, family development, and the establishment and strengthening of social and marital relationships [4,5]. For patients with MS, the disease threatens independence, effective participation in family and society, and influences all dimensions of daily life, leading to a feeling of incompetence and a lack of self-confidence [6]. Patients with MS often undergo difficult treatment regimes, and suffer from drug side effects, physical disability, and the physiological consequences of unpredictable disease symptoms. These challenges can limit the ability to achieve life goals, and can lead to occupational and economic problems, desperation in relationships, decreased leisure time, disruption to normal daily life, and reduced quality of life and satisfaction [7].

Chronic diseases are becoming more prevalent in the modern world, and in many cases, family and married life are negatively impacted [8]. Because MS is naturally unpredictable and progressive, patients and their families suffer considerable stress [8,9]. Many studies have shown that patients with MS have a low quality of life [7,8,10,11], and sexual dysfunction is an important contributor to this, with considerable impact on marital relationships [12]. Therefore, for chronic diseases like MS that are essentially incurable, the main purpose of treatment is to optimize quality of life for patients [13]. However, many debilitating chronic diseases such as MS not only affect patients but also present a serious threat to family relationships and marital life [14] by disrupting the day-to-day lifestyle of patients and their families [15]. When the marital relationship is already weakened, MS can contribute to the final breakdown of the marriage. This disease can be a pretext for many sexual, emotional, and relationship issues. Often the needs of spouses are overlooked, and the grief resulting from the husband or wife being diagnosed with MS tends to overshadow the effects of the possible loss of an effective sexual partner [16]. The challenge of adjusting to the disease, relationship-based problems, and disorders of sexual function are among the factors potentially threatening romantic relationships between couples [17]. A study carried out by Sahebalzamani *et al.* [3] in Iran showed that 95% of patients with MS expressed a need for education or guidance with respect to sexual issues and establishing emotional relationships with spouses.

Family members are the most obvious primary source of support for patients with MS, but the progressive nature of the disease places considerable pressure on family dynamics. In particular, when the patient is in need of care and the spouse has a caregiver role, the impact on family will be considerable [8]. Most adults expect to undertake the responsibility of care for children and the elderly during their life, but do not expect to undertake the responsibility of caring for their chronically ill spouse, especially at a time when they are focused on personal, professional, and family progress [18]. In turn, for the disease sufferer, increased dependency on their spouse according to the degree of disability and the disease duration, places great pressure on the relationship [19]. When the caregiver role of spouses is ongoing, it can be difficult for couples to return to the level of intimacy they enjoyed prior to the onset of MS [5], and the stress involved with the role of caregiver can result in decreased marital quality [17]. There is strong evidence to suggest that the negative influence of MS on marital relationships increases the likelihood of divorce [20]. For example, one study reported an increased probability of divorce when one partner contracted a chronic disease before 36 years of age and if the couple were childless [14].

Gender is one of the ten main factors influencing marital problems resulting from chronic disease in one partner. Men with MS are more likely to suffer from depression, decreased sexual desire, perceived lack of sexual attraction, and sexual dissatisfaction than women [11]. Furthermore, 92.1% of men with MS suffer from sexual dysfunction compared with 21.9% for other chronic diseases [21]. Therefore, it is probable that the spouses of men with MS experience more marital problems than the spouses of men with other chronic diseases. One qualitative study found that almost all women felt that their sexual relationship with their chronically ill husband had changed, but intimacy was still a priority [5]. The women reported that the lack of interest in sexual activity among their spouses and the decreased frequency of intercourse led to feelings of helplessness and disappointment [5]. In general, the negative influence of debilitating diseases impacts spouses more than other family members and women are affected more than men by chronic disease in their spouse [22].

Among chronic diseases, MS has a particularly broad impact on the dimensions of life. The disease places a burden not only on the patient but also on their spouse, and the quality of the relationship between the two is inevitably affected [23]. Constantly encountering the adjustment problems facing patients with MS greatly increases the level of anxiety among spouses [10]. This is a well-recognized phenomenon often referred to as the "contagion effect" [24]. Family system theory describes a triangle of disease, patient, and the healthy spouse, based on the concept of reciprocal influence in the patient-spouse relationship [25]. As part of this system, the influence of the disease on the patient destroys the stability of the relationship, and requires that both partners endeavor to adjust to the problems caused by the disease [10]. Therefore, in investigations of the marital relationship in patients affected by MS, it is important to consider the perspectives of spouses, and to understand the consequences of the psychological and physical adjustments they must face.

In many cultures, it is difficult or forbidden to talk openly about sexual matters and marital life. Particularly in patients with physical disability, such as those with MS, sexual and family matters are often completely overlooked or ignored [12]. One study revealed that 63% of patients with MS had not shared their sexual and marital problems with their physician [26]. Importantly, it is even less likely that spouses, especially women, would discuss such matters.

To date, most research has focused on the prevalence of and contributing factors to psychological and sexual problems in patients with MS. Furthermore, studies on sexual activity have primarily concentrated on physical–sexual dimensions such as sexual function and sexual intercourse [15]. However, the present study aimed to investigate the quality of the marital relationship in broader terms, with emphasis on the views of spouses of men with MS. We examined the influence of MS on the healthy wife, not only in terms of sexual contact but also in terms of other components of a complete marital life such as love, commitment, intimacy, satisfaction, and trust. In fact, some researchers believe that MS provides an opportunity for development and growth of the marital relationship, with a shared quest for making life meaningful, and a joint focus on the positive dimensions of life involved in facing the challenges of a chronic disease [27]. It is important that healthcare professionals understand diseases such as MS from the perspective of the married couple, so they can provide the couple with relevant support and interventions [5]. Improved knowledge of the impact of chronic disease such as MS on relationship dimensions, and awareness of the opportunities for enrichment of the marital relationship, will contribute to better marital quality and overall quality of life among the suffers of MS and their spouses.

MATERIALS AND METHODS

We conducted a descriptive comparative study to compare the quality of perceived marital relationship components between the spouses of men with MS and the spouses of healthy men. The two study groups included adult men with MS registered with the MS Association in Shiraz, Iran, in 2014, and their spouses; and healthy men and their spouses. The two groups were matched in terms of age, occupation, the duration of the relationship, level of education, socioeconomic status, and the number of children. The study inclusion criteria for the men with MS were the existence of definite disease and some degree of disability based on the Expanded Disability Status Scale. Other inclusion criteria included age of 21–49 years, no other acute or chronic physical or mental disorder that could affect the quality of the marital relationship, a minimum of one year since the diagnosis of MS, living with their wife at the time of the study, and no history of divorce, addiction, or severe family conflicts before the diagnosis of MS. Except for criteria relating directly to the disease, the inclusion criteria were the same for the healthy men in the control group.

Eighty two eligible men with MS and 82 eligible healthy men and their respective spouses were selected to enter the study for a total of 164 couples. The convenience sampling method was used to select the men with MS from among patients who were members of the Shiraz MS Association. The healthy men were selected using multistage and cluster sampling methods. Five regions with different populations were considered as the study categories. Clusters that were considered as blocks of each of the five regions were randomly selected from each category, and sampling was conducted within each block. The beginning point was selected randomly. At the earliest possible time after informed written consent was obtained from all eligible men and their spouses (on the same day or the following day), both men and women completed a demographic survey, and the women completed the questionnaire on marital quality.

Survey instruments

The instrument for data collection was a questionnaire consisting of two parts. The first part included demographic information such as age, disease duration, socioeconomic status, level of education degree, occupation, number of children, and the duration of the relationship. The second part included the Perceived Relationship Quality Components (PRQC) inventory designed and constructed by Fletcher *et al*, [28]. The PRQC inventory is an 18-item questionnaire addressing the quality of the marital relationship as a whole, and six components of the marital relationship, namely satisfaction, commitment, intimacy, trust, passion, and love. Each component is assessed based on three items. The participants respond using a 7-point Likert type scale from 1 (not at all) to 7 (completely). The minimum possible score is 18 and the maximum possible score is 126. Lower scores indicate poor quality of the marital relationship and higher scores indicate better quality [28]. The convergent validity, divergent validity, the confirmatory factor analysis, and reliability of the questionnaire for use in Iran have been confirmed based on internal consistency and stability of the instrument, as previously reported by Nilforoshan *et al*. [29].

Ethical considerations

The current study was approved in 2014 by the Research Ethical Committee of Islamic Azad University of Zahedan in Iran. Ethical considerations of the study included the methods and tools used, aim of study, obtaining informed consent, confidentiality of information, and participants' right to withdraw from the study at will. Written informed consent including consent for publication of data from all participants were obtained.

Data analysis

The data were analyzed using IBM SPSS (Statistical Package for the Social Sciences), Version 21.0 (IBM Corp., Armonk, NY, USA). All comparisons were two-tailed, and p-values <0.05 were considered significant. Descriptive statistics for the various variables such as percentages, means and standard deviations, were used to describe the sample. To compare variables between the control and intervention groups, independent t-test (for quantitative variables) and Chi-squared test (for qualitative variables) were used. Moreover, Pearson correlation coefficient was used to investigate the correlation between life quality score and the variables of age, disease duration and shared life duration.

RESULTS

The mean age (\pm standard deviation[SD]) of the men with MS was 35.9 ± 9.69 years (range, 21–49). The mean age at disease outset was 22.03 ± 2.02 years and the mean disease duration was 6.70 ± 3.89 years. More than half of the patients (55%) were unemployed or out of work but 45% percent were employed. In terms of education, 16% of the patients had primary education only, 57.3% had secondary education to lower than diploma level, and 26.7% had a diploma or higher qualification. More than 78% had a history of at least one disease attack; 62.1% percent had relapsing–remitting MS, 16.05% had progressive–relapsing MS, 15.85% had primary progressive MS, and 6% had secondary progressive MS.

The characteristics of the spouses of the men with MS and healthy men are presented in Table 1. The mean age (\pm SD) of the spouses of men with MS was 30.09 ± 6.54 years, and for the spouses of healthy men the mean age was 29.32 ± 6.39 years. The majority (61%) of the spouses of men with MS and of healthy men (69.5%) belonged to the middle socioeconomic group. The mean duration of the relationship was 14.24 ± 3.85 years for the spouses of men with MS patients and 15.54 ± 4.42 years for the spouses of healthy men. In terms of education, 28.05% of the spouses of men with MS had primary education only, 50% had secondary education to lower than diploma level, and 21.95% had a diploma or higher qualification. The respective results for the spouses of healthy men were 26.8%, 48.8%, and 24.4%, respectively. The majority of the spouses of men with MS (67.1%) and the spouses of healthy men (71.95%) were housewives. The mean (\pm SD) number of children for the spouses of men with MS and the spouses of healthy men was 1.88 ± 0.85 and 2.02 ± 1.0 , respectively. Results of independent t tests (used to compare age, duration of relationship, and number of children) and chi-squared tests (used to compare occupation, education level, and socioeconomic status) showed that there were no significant differences between the two groups in terms of demographic characteristics ($p > 0.05$).

The results of the PRQC inventory section of the questionnaire are presented in Table 2. The mean scores for satisfaction, intimacy, passion, and love, and the quality of the marital relationship as a whole were 12.37 ± 5.03 , 16.74 ± 3.08 , 9.67 ± 4.56 , 15.50 ± 2.59 , and 86.32 ± 10.71 , respectively, for the spouses of men with MS, and 18.92 ± 2.85 , 19.09 ± 2.70 , 17.0 ± 3.14 , 19.61 ± 1.36 and 101.68 ± 9.63 , respectively, for the spouses of healthy men. There was a significant difference between the two groups for these five variables (independent t tests, all $p < 0.05$). The scores for the spouses of men with MS indicated that feelings of satisfaction, intimacy, passion, and love, and the overall quality of the marital relationship were much lower compared with the spouses of healthy men.

However, there was no significant difference between the two groups for commitment and trust in the marital relationship. The scores were 19.13 ± 3.37 and 18.62 ± 2.73 , respectively, for spouses of men with MS, and 18.60 ± 2.35 and 18.67 ± 2.07 , respectively, for spouses of healthy men (independent t tests, both $p > 0.05$).

DISCUSSION

The results of this study clearly show that the quality of the marital relationship, as perceived by the spouses of men with MS, declines as a result of the disease. Previous studies have shown that extensive changes occur in different aspects of marital function after the onset of a serious mental or physical disease [30]. Spouses of men with MS sacrifice their individual and social needs for their husbands and often feel guilty if they cannot fulfill their role as caregiver [11]. This process results in moral tension and dissatisfaction in the relationship and other life dimensions. The findings of the present study agree with previous research that has show that quality of life and the quality of relationships between family caregivers and male patients with MS are lower compared with the general female population; such as Patti *et al.* 2007[31]; Rivera-Navarro *et al.* 2009[32]; Perrone *et al.* 2006[8]; Samios *et al.* 2015[10]; Glantz *et al.* 2009[33]; Simmons 2010[9]; Esmail *et al.* 2010[11]; McPheters & Sandberg 2010[34]. Many men with MS have psychological and sexual problems that have an impact on the marital relationship [11]. In many

parts of the world, including Iran, the spouses of men with MS are expected to act as the primary caregiver for their husband. Apart from the consequences of the chronic disease affecting their husbands, the role as caregiver further decreases the quality of life for these women, including the quality of the marital relationship [17]. Contrary to the present findings, Samios [10] found that, within one year of the diagnosis of MS in their husbands, women felt a higher degree of marital relationship satisfaction. Ackroyd *et al.* [27] also reported that providing care for disabled patients generated satisfaction. However, in most cases the quality of marital life in couples living with chronic disease is considerably lower than that in the healthy population [5]. A qualitative study carried out in Iran by Sadat *et al.* [15], showed that MS can destroy social relationships and disturb family relationships, including the marital relationship, because MS is a debilitating disease and a serious threat to the relationship between couples [14].

The perceived quality of satisfaction, intimacy, passion, and love in the marital relationship was clearly lower in the spouses of men with MS compared with the spouses of healthy men. These four components were more negatively influenced by the disease than the components commitment and trust, which were similar in the two groups. The quality of the sexual relationship in patients with MS from the perspective of both partners has been investigated in many studies. Similar to the present study, most have found that MS causes many sexual problems and sexual dissatisfaction. According to family system theory and the contagion effect, the rate of such problems in the spouses of patients with MS is high [25]. Given the nature of the sexual relationship, the passion in relationships decreases and many relationships fail. Many women report that MS in their partners has a negative influence on their sexual relationship and the frequency of intercourse because the men are no longer attractive to them. Often women will engage in sexual activity to reinforce sexual confidence in their male partner with MS. Moreover, the use of assistive devices by men often decreases sexual passion [11]. In contrast to the present research findings that sexual satisfaction decreases in the spouses of men with MS, Marita *et al.* [35] found that, although patients with MS and their spouses have more problems than healthy people, there was no significant difference between their satisfaction with life and sexual relationships. This result may reflect the high prevalence of sexual and relationship problems among the normal population.

The findings of Perrone *et al.* [8] were similar to the present results suggesting that, compared with the spouses of healthy men, the spouses of patients with MS have a lower quality marital relationship overall, and a lower level of satisfaction, especially in terms of physical intimacy. Hugging provides a strong basis for physical closeness and intimacy as a valuable part of the relationship between couples [11]. However, many men with MS have difficulty with physical closeness and intimacy such as hugging and patting because of physical restrictions, skeletomuscular weakness, pain, sensory problems, fatigue, and decreased energy [36]. In psychological terms, the spouses of men with MS often hide their feelings of dissatisfaction from their husbands, and surprisingly, many feel that their husbands also hide some of their feelings from them [11]. This situation reduces the feeling of intimacy within the couple, especially over time.

The adjustments to lifestyle associated with MS, relationship problems, and sexual dissatisfaction have negative effects on both the romantic and physical love relationships between couples [17]. Based on Sternberg's love theory, passion and intimacy are two elements of love [37]. Therefore, the deterioration of these two elements as part of the marital relationship in the spouses of men with MS in the present study indicates that the degree of love in these couples, as a function of these two variables, also deteriorated. Esmail *et al.* [5] also suggest that sexual problems are accompanied by decreased love, amour, and intimacy. Contrary to the present results, Perrone *et al.* [8] found that one of the positive effects of MS on the relationship between couples was an increased statement of love from wives towards their husbands.

Another finding reported by Perrone *et al.* [8] was that there was no significant difference in the dimensions of commitment and trust between the spouses of men with MS and the spouses of healthy men. Therefore, similar to the present study, the findings of that study indicated that the disease had no negative influence on commitment and trust, and furthermore, the mean score for commitment was a little higher for the spouses of men with MS than for the spouses of healthy men (19.13 ± 3.37 and 18.60 ± 2.35 , respectively). In contrast to the present findings, McCabe [38] reported that only one third of the patients in that study experienced failure in the marital relationship, one third felt that there was no change, and one third experienced an improvement in the marital relationship. As mentioned above, Perrone *et al.* [8] argued that MS could have both positive and negative effects on the relationship between couples, and some patients with MS and their spouses felt that their relationship improved over the year since diagnosis [35]. Indeed, some spouses of patients with MS have a positive experience in terms of their relationship. They redefine love and togetherness, and look for enjoyable activities and common interests. Despite

the existence of the problems related to the disease, they reinforce commitment and trust in the relationship [39–41]. Ackroyd et al. [27] believe that one of the advantages of MS is the deepening of relationships, increased understanding of the value of life, and increasing spiritual interests that can enhance commitment between couples. In many cases, the spouses of men with MS understand that, to maintain the marital relationship, they should accept the disease, and consider it as part of their existence; “this is our disease not his” [11]. This way of thinking is likely to improve marital commitment. In the present study, the duration of relationships among the couples affected by MS was long (14.24 ± 3.85 years). It is reasonable to expect that marital trust and commitment would have increased over time, and would not decrease as a result of disease in one partner. Moreover, in the present study, there was no significant relationship between the degree of physical disability and disease duration, and the quality of the marital relationship. However, McCabe et al. [19] found that the pressure on the relationship between couples did depend on the degree of disability and disease duration.

Strengths and limitations

Most previous studies on sexual disorders and quality of life in patients with MS have been carried out using instruments such as the health-related quality of life (HR-QOL) and short-form 36 (SF-36) surveys. These surveys address different dimensions of the quality of the marital relationship, and focus less on the perspectives of spouses. The investigation of multiple dimensions within the marital relationship, including from the perspective of the spouses of patients with MS, using a short and targeted survey instrument, is the strong point of the present study. The limitations include the small sample size, limited generalizability of the results, and the fact that only married couples, and not unmarried but well-established couples living together, were selected for the study.

Table 1 Demographic characteristic of MS spouses and healthy spouses

Variable	MS spouses Mean \pm SD	Healthy spouses Mean \pm SD	Test results
Age	30.09 \pm 6.54	29.32 \pm 6.39	P=0.09
Duration of marriage	14.24 \pm 3.85	15.54 \pm 4.24	P=0.41
Number of children	1.88 \pm 0.85	2.02 \pm 1.01	P=0.07
Occupation			
	Number(Percent)	Number (Percent)	P=0.26
Housekeeper	55(67.1)	59(71.95)	
Employee	21(25.6)	15(18.3)	
Others	6(7.3)	8(9.75)	
Total	82(100)	82(100)	
Education			
Primary	23(28.05)	22(26.8)	P=0.51
Lower than diploma	41(50)	40(48.8)	
Higher than diploma	18(21.95)	20(24.4)	
Total	82(100)	82(100)	
Socio-economical level			
Low	22(26.8)	16(19.5)	P=0.20
Moderate	50(61)	57(69.5)	
High	10(12.2)	9(11)	
Total	82(100)	82(100)	

Table 2 Comparison of mean and standard deviation (SD) of the perceived relationship quality components (PRQC) scores in MS spouses and healthy spouses

Variable	MS spouses Mean \pm SD	Healthy spouses Mean \pm SD	Independent t-test
Satisfaction	12.37 \pm 5.03	18.92 \pm 2.85	P=0.0001
Intimacy	16.74 \pm 3.08	19.09 \pm 2.70	P=0.001
Trust	18.62 \pm 2.73	18.67 \pm 2.07	P=0.86
Commitment	19.13 \pm 3.37	18.60 \pm 2.35	P=0.45
Love	15.50 \pm 2.56	17.00 \pm 3.14	P=0.01
Passion	9.67 \pm 4.56	19.61 \pm 1.36	P=0.0001
Total	86.32 \pm 10.71	101.68 \pm 9.36	P=0.0001

CONCLUSION

Apart from the limited positive effects mentioned in some studies, the results of the present study support previous research and suggest that MS in men, as perceived by their spouses, has undesirable influences on most components

of the marital relationship, in particular satisfaction, intimacy, love, and passion. Although these effects do not threaten the life of the patient with MS, they cannot be ignored because they have important negative impacts on quality of life, and the inability to control relationship-based stress can lead to exacerbation of the disease.

Despite the increasing research into MS and into the needs of patients suffering from the disease, some important issues have been largely overlooked. Marital problems among the spouses of patients with MS cause considerable distress, are not well recognized, are underreported, and patients and their healthy spouses rarely discuss these issues with their physician. Programs to address marital relationship problems should be included as essential therapy for patients with MS. In addition, supportive strategies should also be provided for the spouses of patients with MS. Educational programs, group couple therapy, and relationship enrichment as part of rehabilitation programs would improve the quality of the marital relationship in couples affected by MS, and in turn, improve the quality of life of MS patients and their spouses. Furthermore, a strong marital relationship and the support of a satisfied, and actively participating spouse could potentially minimize the risk and severity of disease attacks, reduce the burden on the caregiver, improve productivity, and facilitate acceptance of the disease. Future research will further increase the awareness of relationship issues in suffers of MS, particularly among physicians, nurses, psychologists, and MS support associations. Many women are especially sensitive and vulnerable to stress relating to caregiving and relationships. It is important to test the efficacy of educational, supportive, and consultative packages used to promote the quality of the marital relationship between patients and spouses because, as Patti [31] showed, female gender is a predictor of low quality of life among family caregivers.

Availability of data and material

Not applicable

Competing interests

The authors declare that they have no competing interests.

Authors' contributions

AN was the main investigator, designed and supervised the study and interpreted the data. MF performed statistical analysis of data and wrote the first draft. FA collected the data. All authors reviewed and edited the manuscript and approved the final draft.

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