

ORIGINAL PAPER

BASIC HUMAN NEEDS IN PATIENTS WITH MULTIPLE SCLEROSIS: INTIMACY AND SEXUALITY

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Abstract

Aim: To analyse the occurrence of sexual dysfunction in patients with multiple sclerosis. **Design:** A quantitative cross-sectional study. **Methods:** The study was conducted in cooperation with the Croatian Association of Patients with Multiple Sclerosis, in the form of a questionnaire. A total of 106 patients responded: 24 (23%) male and 82 (77%) female. All subjects were in the age group 21–63 years. Data were analysed using descriptive statistics and the Mann-Whitney test, Kruskal-Wallis test, ANOVA test, and Spearman's rank correlation coefficient. **Results:** Primary sexual dysfunction (lack of sexual interest and desire), Secondary sexual dysfunction (the occurrence of bladder or urinary symptoms), and Tertiary dysfunction (caused by emotional aspects of MS) were present in most patients. There were no statistically significant differences between subjects within individual categories. **Conclusion:** Sexual dysfunction is very common among patients suffering from multiple sclerosis, significantly impairing quality of life since sexual and intimate expression are basic human needs which persist in spite of disability or illness. However, patients are reluctant to talk about this highly sensitive issue.

Keywords: basic human needs, communication intimacy, multiple sclerosis, sexuality.

Introduction

Multiple Sclerosis (MS) predominantly affects young people, and in most patients, the symptoms occur between the ages of 20 and 45, and only rarely before the age of 15 and after the age of 55. Women are affected twice as often as men. The disease has a highly variable course, characterized by frequent deteriorations in the clinical picture of varying degrees, interchanged with sudden improvements. Clinical signs and symptoms that appear in patients include visual disorders, sensory disorders, motion and balance disorders, urinary and defecation disorders, intellectual function disorders, and sexual function disorders (Topić et al., 2004).

Sexual dysfunction (SD) symptoms are common in multiple sclerosis patients. Men experience impotence, loss of desire, genital sensory disturbance, ejaculation disorder, and inability to achieve or maintain erections. Women experience genital stiffness, decreased intensity of orgasm, decreased libido, unpleasant sensations during intercourse, and reduced vaginal secretion.

Foley divide sexual dysfunction in MS patients into three categories: primary, secondary, and tertiary (Kalb, 2018). Primary sexual dysfunction in patients is caused by nerve damage, due to which brain signals can no longer “travel” to parts of the body that are involved in sexual activity. A classic example of primary dysfunction is genital insensitivity. Examples of difficulties that lead to secondary dysfunction are urinary incontinence, diarrhea, constipation, spasticity, hand tremor: i.e. everything that indirectly complicates intimacy. Tertiary dysfunction is caused by emotional aspects of MS: i.e., psychosocial or cultural issues related to sexuality and intimacy that may have an impact on the feelings of a patient.

Sexuality is a set of feelings, behaviors, attitudes and values that are linked to sexual desire and identity. In other words, every human being is defined by their sex, gender and sexuality. As an integral part of human development throughout all stages of life, sexuality includes physical, psychological, and social components. An intimate relationship is a particularly close form of interpersonal relationship and can be defined by the following characteristics: recurring interaction, emotional attachment, and fulfilment of needs (Brehm et al., 2007; Stangor et al., 2014).

Sexuality is dynamic and changes over time, sometimes as a response to life experiences.

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Sexuality is a personal journey through life, and no matter how it changes, it is important for health and personal satisfaction. The World Health Organization states: “A central aspect of being human throughout life encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction. Sexuality is influenced by the interaction of biological, psychological, social, economic, political, cultural, legal, historical, religious, and spiritual factors” (WHO, 2002).

For most people, sexuality and sexual expression are natural and very important components of self-image, emotional well-being, and, above all, good quality of life.

Aim

The objective of the study was to make an epidemiological analysis of the occurrence of certain forms of sexual dysfunction in patients diagnosed with multiple sclerosis.

Patients were interviewed, with the additional aim of analyzing whether there was a difference in the occurrence of certain forms of sexual dysfunction in terms of age, sex of subjects, and the total duration of the disease.

Methods

Design

A quantitative cross-sectional study.

Sample

The survey was conducted in cooperation with the Croatian Association of Multiple Sclerosis Patients in the form of a questionnaire – The Multiple Sclerosis Intimacy and Sexuality Questionnaire-19 (MSISQ-19) (Sanders et al., 2000) translated into Croatian. The questionnaire was sent to 500 members of the association by e-mail.

Data collection

The questionnaire was composed of 19 questions to identify difficulties that directly or indirectly interfered with respondents' sexual satisfaction or activity over the six months prior to the survey. Subjects were asked to express their agreement with the 19 questions/assertions, using a Likert scale from 1–5.

The occurrence of primary sexual dysfunction was determined through responses to subscale items about the existence of desire for/interest in sexual intercourse, intensity of and time needed to achieve orgasm, problems with lubrication (women), and problems with erections and maintaining erections (men) – i.e., questions 12, 16, 17, 18 and 19.

Subscale items indicating secondary sexual dysfunction were questions 1, 2, 3, 4, 5, 6, 8, 10 and 11.

Subscale items indicating tertiary sexual dysfunction were questions 7, 9, 13, 14 and 15.

Data analysis

All data were explained descriptively and in tabular form. Nominal features were displayed in numbers and percentages. With respect to the small number of subjects, the Shapiro-Wilk test was used to test the distribution of the analyzed features. If features did not indicate normal distribution, they were compared with the non-parametric Mann-Whitney test and the Kruskal-Wallis test. One-way analysis of variance (ANOVA) was used for features for which normal distribution was recorded. Correlations between continuous features were determined by computing Spearman's rank correlation coefficient.

All statistical tests were performed at the level of statistical relevance of $p < 0.05$ with the use of the statistical software, Statsoft.Statistica (version 13.3).

Results

A total of 106 patients (21%) of the 500 subjects to whom the questionnaire was sent provided a response.

Of the 106 subjects, 24 (23%) were male and 82 (77%) female. The age of subjects ranged from 20 to 63 years. The majority of subjects, i.e., 70 (70%), were in the age group from 31 to 50 years. There were 15 (15%) subjects under the age of 30, and 14 subjects (15%) over the age of 50. The duration of the disease for subjects ranged from one to 32 years, with 62 subjects (62%) suffering from MS less than ten years, 24 subjects (24%) 11 to 20 years, and 13 subjects (13%) more than 20 years.

Out of the 106 returned questionnaires, some questions in the questionnaire were not scored, but the rest of the questionnaire entered the analysis, 99 in total.

Results of subjects' responses regarding symptoms of sexual dysfunction that directly or indirectly interfered with sexual satisfaction or activity over the six months prior to the survey are shown in Table 1.

The results of comparison of the occurrence of particular categories of sexual dysfunction in subjects are presented in Table 2.

There was no statistically significant difference in the occurrence of particular categories of sexual dysfunction in the study sample. The three categories of sexual dysfunction were represented evenly among all subjects.

Table 1 Overview of sexual dysfunction symptoms experienced by MS patients

MSISQ 19 (Sanders et al., 2000) Over the last 6 months, the following symptoms have interfered with my sexual activity or satisfaction:	% of subjects				
	never	rarely	occasionally	almost always	always
1. muscle tightness or spasms in arms, legs, or body	16	20	35	21	7
2. bladder or urinary symptoms	15	16	24	33	11
3. bowel symptoms	25	23	24	22	5
4. feelings of dependency because of ms	30	18	27	17	7
5. tremors or shaking in arms or body	18	25	27	21	8
6. pain, burning, or discomfort in body	23	21	18	19	8
7. feeling that own body is less attractive	32	17	23	14	13
8. problems moving body during sexual activity	17	13	28	23	18
9. feeling less masculine or feminine due to ms	34	16	24	14	11
10. problems with concentration, memory, or thinking	7	14	28	32	18
11. exacerbation or significant worsening of ms	26	31	20	18	4
12. less feeling or numbness in genitals	26	27	22	20	4
13. fear of being rejected sexually because of ms	36	16	20	11	16
14. worries about sexually satisfying to partner	26	19	23	12	19
15. feeling less confident about sexuality due to ms	23	22	12	28	14
16. lack of sexual interest or desire	20	16	28	21	14
17. less intense or pleasurable orgasms or climaxes	27	16	31	16	9
18. takes too long to orgasm or climax	15	21	23	18	20
19. inadequate vaginal wetness or lubrication (women)/difficulty getting or keeping a satisfactory erection (men)	20	20	29	16	14

Table 2 Comparison of the occurrence of a particular categories of sexual dysfunction in all subjects

Category of sexual dysfunction	primary	secondary	tertiary
primary		0.59	0.5
secondary	0.59		0.53
tertiary	0.5	0.53	

Due to abnormalities in the distribution in these three variables, Spearman's rank correlation coefficient was used.

Table 3 The comparison of differences between men and women in the occurrence of a particular categories of sexual dysfunction

Category of sexual dysfunction	RS W	RS M	U	Z	p
primary	3,882	1,068	792	0.68	0.5
secondary	4,047.5	902.5	626.5	2.05	0.04*
tertiary	3,722.5	1,227.5	796.5	-0.64	0.52

RS – rank sum; W – woman; M – men; U – U score; Z – Z score; p – p-value; *statistically significant difference established. Normal distribution was tested by the Shapiro-Wilk test and it was established that the data are not normally distributed. Therefore, the Mann-Whitney test was used.

Analysis of the differences in the occurrence of particular categories of dysfunction between male and female subjects is presented in Table 3.

There was a statistically significant difference between men and women in secondary sexual dysfunction, with women achieving significantly higher values ($p = 0.04$). There were no statistically significant differences between men and women in primary and tertiary sexual dysfunctions ($p > 0.05$).

Subjects who stated their age ($n = 99$) were divided into three age categories: A = up to 30 years; B = 31 to 50 years; C > 50 years. The results of comparison of the occurrence of particular categories of sexual dysfunction in the three age categories are presented in Table 4.

No statistically significant differences among the three age categories were found in any of the categories (primary, secondary, or tertiary dysfunction). During analysis of the occurrence of primary dysfunction, the highest values were recorded in age category B (31 to 50 years), although without statistical significance ($p = 0.24$). Age group A (up to 30 years) recorded the highest values for occurrence of secondary and tertiary dysfunctions.

All subjects who stated the duration of disease were divided into three groups: Group 1 = up to 10 years; Group 2 = 11 to 20 years; Group 3 > 20 years. The results of the comparison by disease duration are presented in Table 5.

Table 4 Differences between 3 age categories in the occurrence of particular categories of sexual dysfunction

Category of sexual dysfunction	A AS ± SD	B AS ± SD	C AS ± SD	F	p
primary	13.27 ± 5.5 A $\bar{R}\bar{R}$	14.41 ± 4.92 B $\bar{R}\bar{R}$	12.07 ± 4.48 C $\bar{R}\bar{R}$	1.45 H	0.24 p
secondary	54.3	50.46	43.1	1.16	0.56
tertiary	56.93	50.83	38.43	3.22	0.2

A – up to 30 years; B – 31 to 50 years; C – > 50 years; SD – standard deviation; AS – the mean sum of squares; F – F score; H – H score; p – p-value; $\bar{R}\bar{R}$ – middle value of ranks in the sample; Normal data distribution was recorded in the primary sexual dysfunction category, therefore the one-way variance analysis was used (ANOVA). There was an abnormal distribution of the data in the secondary and tertiary sexual dysfunction components. Therefore, the Kruskal-Wallis test was used.

Table 5 The occurrence of a particular categories of dysfunction by disease duration

Category of sexual dysfunction	1 AS ± SD	2 AS ± SD	3 AS ± SD	F	p
secondary	26.06 ± 7.63 1 $\bar{R}\bar{R}$	24.16 ± 6.71 2 $\bar{R}\bar{R}$	25.23 ± 8.37 3 $\bar{R}\bar{R}$	0.56 H	0.57 p
primary	52.22	43.88	50.73	1.48	0.48
tertiary	51.37	43.9	53	1.46	0.48

1 – up to 10 years, 2 – 11 to 20 years, 3 – > 20 years; AS – the mean sum of squares; F – F score; H – H score; p – p-value; $\bar{R}\bar{R}$ – middle value of ranks in the sample. Normal data distribution was recorded in the secondary sexual dysfunction category, therefore the one-way variance analysis was used (ANOVA). There was an abnormal distribution of data in the primary and tertiary sexual dysfunction components. Therefore, the Kruskal-Wallis test was used.

No statistically significant differences were found among these three groups in any of the categories (primary, secondary, or tertiary dysfunction). In the primary and secondary categories, the highest values were recorded in Group 1 (up to 10 years), whereas in the tertiary category, the highest value was recorded in Group 3 (> 20 years).

Discussion

In addition to the other problems related to the underlying disease that multiple sclerosis patients encounter daily, sexuality and intimacy are a special challenge, both for patients and for the healthcare system. Despite increases in therapeutic options, many patients with MS do not seek treatment for their SD complaints (Orasanu et al., 2013). In a project conducted by Orasanu et al. (2013) to determine the prevalence of various SD symptoms among MS sufferers, 17,883 surveys were sent to patients and 9,861 (55.1%) were returned, only 6,739 (68.3%) of which included responses to questions regarding sexuality, suggesting that patients are reluctant to talk openly about issues such as sexuality and intimacy.

To analyze the occurrence of sexual dysfunction in MS patients in Croatia, a questionnaire was sent to 500 members of the Croatian Multiple Sclerosis Association, only 106 (21%) of whom completed the questionnaire. The participation of such a small number of subjects in the study could mean that only a small number of MS patients, or only a small number of the members of the Association had sexual/intimate difficulties, or that the majority of the

patients (79%) did not wish to share their sexual/intimate difficulties (in support of this, it should be pointed out that this type of research had not been carried out in Croatia before).

The MSISQ-19 was used for the study. The value of the MSISQ-19 questionnaire has been verified in numerous studies. A study conducted in Iran representing a sample of 226 women (Mohammadi et al., 2013), and a US study conducted on a larger sample of 6,300 subjects of both sexes (Foley et al., 2013) demonstrated that the MSISQ-19 questionnaire was a reliable and valid indicator for sexual dysfunction measurement in all three dimensions, both in female and male respondents.

Sexual dysfunction symptoms are common in MS patients. Although research in this area is still limited, studies indicate a sexual dysfunction prevalence rate of 40 to 80% in women, and 50 to 90% in men (Zorzon et al., 2001). From the respondents' answers it can be concluded that sexual dysfunction is present in the majority. A very small number of respondents claimed not to have experienced any sexual problems, 21% claimed not to have had any problems indicating the existence of primary sexual dysfunction, 19% claimed not to have had problems regarding secondary dysfunction, and 28% claimed not to have had difficulties regarding tertiary sexual dysfunction. All other subjects had experienced some degree of sexual dysfunction. While a small number of respondents had experienced temporary difficulties, a large number had experienced prevalent problems, requiring medical attention.

MS symptoms can begin at any age between 10 and 80 years, although they usually start between 20 and 40 years, with a mean age of 32 years (Lew-Starowicz & Gianotten, 2015). The youngest subject to complete the questionnaire in our study was 20 years old, the oldest was 63 years old, and the majority of patients were in the age group between 31–50 years old.

Globally, multiple sclerosis is more prevalent in women than in men. Of the 106 participants in our survey, 77% were female. There are no known data on the proportion of women in the total population of MS patients in Croatia. Therefore, it is debatable whether these results can be interpreted as a greater readiness in women to talk about sexual difficulties (as in a study in Iran: Mohammadi et al., 2013) or whether this reflects the likely proportion of women to men with MS in Croatia.

Multiple sclerosis can affect sexuality in many ways. Dysfunction is not only related

to brain or spinal cord lesions within areas directly involved in sexual response but also to limited mobility, spasticity, fatigue, pain, bowel and bladder dysfunction, and psychological disturbances, cognitive dysfunction, and depression. It is hard to find definite correlations

between brain and spinal cord lesions and particular sexual dysfunctions that will explain the problem in the majority of patients. This may also be due to the multifactorial nature of the sexual response (Lew-Starowicz & Gianotten, 2015). In sexual dysfunction, organic and nonorganic factors may coexist.

No differences were found in the interviewed sample during the analysis of the occurrence of particular categories of sexual dysfunction. Difficulties arising from nerve path disruptions due to nerve damage caused by pathophysiological processes, difficulties related to the urinary system, spasticity, hand tremor, and anything else that can indirectly complicate the intimate and emotional life of patients (perception of one's own body, mood swings, self-esteem) were equally present ($p = 0.72$).

The results of studies on differences between men and women in primary, secondary, and tertiary categories of sexual dysfunction are highly controversial. Zorzon et al. (1999) found sexual dysfunction in 73% of patients, with difficulties in the primary category of sexual dysfunction being most common for both men and women, with similar results reported by Demirkiran et al. (2006). In contrast, Çelik et al. (2013) found that secondary sexual dysfunction was most common for both men and women, although women had more difficulties in this category. Our study indicated similar results,

with a significant difference between male and female subjects in the secondary sexual dysfunction category, for which female respondents recorded significantly higher scores. There were no statistically significant differences in the primary and tertiary categories.

When primary, secondary, and tertiary sexual dysfunction were analyzed in relation to age, no significant differences were found between the three age categories for any of the dysfunction categories. In the primary sexual dysfunction category, the highest values were recorded in the 31 to 50 years age group, whereas the highest values in the secondary and tertiary categories were observed in subjects up to 30 years of age.

A number of studies have found sexual dysfunction in MS patients to be associated with duration of disease (Demirkiran et al., 2006; Khan et al., 2011). However, it is not known whether the picture for each category of dysfunction changes over time. In our study, no significant difference was found between categories of sexual dysfunction with respect to the duration of MS. In the primary and secondary categories, the highest values were recorded in subjects with disease duration of up to ten years, while in the tertiary category the highest values were recorded in subjects with disease duration of more than 20 years.

Nowadays, a considerable amount of information is readily available regarding sex and sexuality, which might seem to imply that the topic is easy for all to discuss, and that sex is practiced by everyone without any difficulties or feelings of shame or guilt.

Changes induced by MS may affect sexual response by making sexual activity physically and emotionally more difficult. Common MS issues, such as fatigue, changes in muscle tone, lack of coordination and/or pain, can result in frustration related to sexual expression and lack of desire. Incontinence disorders, both urinary and bowel, can cause inhibitions and a sense of shame.

Of all the symptoms occurring in MS, cognitive changes are potentially among the most damaging to relationships and intimacy with others, as they may distort perceptions of the sufferer's personality.

Many of the symptoms of MS are not visible, while others are painfully present. All have a strong influence on quality of life and self-esteem. In a study of the impact of sexual dysfunction on the overall quality of life of a sample of 6,183 patients with multiple sclerosis, the authors concluded that sexual dysfunction, in comparison to physical dysfunction, has a much greater detrimental effect on the mental state of patients (Sanders et al., 2000).

For most people, sexuality and sexual expression are natural and very important components of self-image, emotional well-being, and, above all, good quality of life. Some individuals and couples affected by MS give little or no priority to intimacy and sexuality, since they are preoccupied by other issues related to the underlying disease. Regardless of whether a patient is in an intimate relationship or not, it is a great challenge to maintain their sexual identity and to take care of their sexual self-esteem while having to face a chronic disease like MS.

Today, numerous medications and aids are available to help MS patients overcome difficulties in the sphere of sexual function. Discussing intimacy and sexuality is very important, but can often be difficult for both MS patients and healthcare professionals. Often, conversations about this subject are avoided by healthcare professionals due to personal discomfort, lack of professional education on the subject of sexuality and intimacy, or fear of invading the privacy of the patient. On the other hand, intimacy and sexuality are also a difficult topic for MS patients, either due to a lack of information on problems related to the disease which might affect intimacy and sexuality, or due to discomfort, fear of condemnation, or cultural inhibitions.

Health and illness should not be seen in absolute terms: “How can we claim to provide holistic care if we are not assessing aspects of sexuality and intimacy?” (Maslow, 1954). If a person has multiple sclerosis, this does not mean that other needs, especially basic human needs such as sexuality, should be neglected.

Conclusion

The study indicated that all patients with MS experience sexual dysfunction to a certain degree, and that there is no difference between incidence of primary, secondary, and tertiary sexual dysfunction. Patients with MS find it very difficult to talk about intimacy and sexuality. Healthcare professionals should give every patient the opportunity to discuss their problems whenever they feel the need to talk about them.

Overcoming barriers successfully requires creativity, communication and patience. Healthcare professionals can assist MS patients in several ways:

- by initiating conversation on sensitive subjects;
- by explaining that sexuality and intimacy are part of everyday life;
- by informing them about useful sources of information;

- by assuring patients that they can contact a professional without hesitation whenever they feel the need to;
- by informing patients about medication and their possible impacts on intimate intercourse;
- by informing patients about aids that can help them during intimacy (sensory body maps, mechanical aids, visual stimulation, medication, lubricants, etc.);
- by recommending communication between the patient and their partner.

Multiple sclerosis patients should not have to suffer in silence. Healthcare professionals must listen to them without prejudice, with an open ear and mind, and create a secure and comfortable environment in which they will be able to discuss sensitive issues at their ease. If MS patients feel uncomfortable with such a conversation, they should be given the option of expressing their fears, questions, and experiences in writing and they should receive a written response.

An intimate relationship consists of much more than the simple interaction of body parts, and intimacy is far more than the sexual act itself. The foundation must be good communication, and trust in both healthcare professionals and their partner.

Ethical aspects and conflict of interest

The study was approved by the institutional review board of the University of Applied Science, Bjelovar (IRB 2103/01-21-01-17-01).

The survey was conducted in cooperation with the Croatian Association of Multiple Sclerosis Patients, and The City of Zagreb Multiple Sclerosis Society in the form of a questionnaire.

Consent for the survey was obtained from the president of the Society. Participants in the survey completed a questionnaire sent by email. Completion of the questionnaire was regarded as agreement to participate in the research, with the right to terminate further participation at any time.

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Author contributions

The concept and study design (DT, RM), data analysis and interpretations (DT, TB, RM), processing the draft of the manuscript (RM), critical revision of the manuscript (RM), article finalisation (DT, RM).

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