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Selected Determinants Affecting the Quality of Sexual Life of Women Diagnosed with Multiple Sclerosis

Wybrane determinanty wpływające na seksualną jakość życia kobiet ze zdiagnozowanym stwardnieniem rozsianym

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Abstract

Introduction. Multiple sclerosis is a chronic disease of the central nervous system, resulting from immune system dysfunction and characterized by demyelination and neurodegeneration. An essential aspect of therapy, besides improving overall quality of life, is also the quality of sexual life of patients with multiple sclerosis.
Aim. The aim of this study was to assess the quality of sexual life of female patients with multiple sclerosis.
Material and Methods. The study was conducted among 100 female patients diagnosed with multiple sclerosis in the Neurology Department. Research tools included a questionnaire regarding patients' demographic and clinical data, as well as the Sexual Quality of Life Questionnaire — Female (SQoL-F).
Results. The level of sexual quality of life among female patients with multiple sclerosis in the neurology department was associated with the following domains: psychosexual feelings, sexual satisfaction, relationship satisfaction, worthlessness, and sexual repression. 44% of women rated their relationship with their partner as poor. Sexual activity was rated as poor in 43% of cases, and 32% experienced a deterioration in their sexual life before and after the onset of multiple sclerosis. Factors such as demographic characteristics (place of residence, employment status, marital status) and clinical factors (obesity and diabetes) influenced the assessment of sexual quality of life.
Conclusions. The mean score for quality of life in the SQoL-F questionnaire was 69.02 with a standard deviation of SD=25.86 and a median of Me=75. Both socio-demographic and clinical factors influenced the assessment of the level of sexual quality of life among patients with multiple sclerosis. **(JNNN 2024;13(1):23–28)**
Key Words: multiple sclerosis, quality of life, sexual quality of life

Streszczenie

Wstęp. Stwardnienie rozsiane to przewlekła choroba układu nerwowego, wynikająca z dysfunkcji układu odpornościowego i charakteryzująca się demielinizacją i neurodegeneracją. Istotnym aspektem terapii, obok poprawy ogólnej jakości życia, jest również jakość życia seksualnego pacjentów ze stwardnieniem rozsianym.
Cel. Celem badania była ocena jakości życia seksualnego pacjentek ze stwardnieniem rozsianym.
Materiał i metody. Badanie przeprowadzono wśród 100 pacjentek chorujących na stwardnienie rozsiane, hospitalizowanych na Oddziale Neurologii. Narzędziem badawczym był Kwestionariusz Jakości Życia Seksualnego — Kobiety (SQoL-F) a dane socjodemograficzne i kliniczne pozyskano z dokumentacji medycznej pacjentek.
Wyniki. Poziom jakości życia seksualnego pacjentek ze stwardnieniem rozsianym na oddziale neurologii wiązał się z następującymi obszarami: uczucia psychoseksualne, satysfakcja seksualna, satysfakcja z relacji, bezwartościowość i represje seksualne. 44% kobiet oceniło swoją relację z partnerem jako słabą. Aktywność seksualna została oceniona jako słaba w 43% przypadków, a 32% doświadczyło pogorszenia się życia seksualnego przed i po wystąpieniu stwardnienia rozsianego. Czynniki takie jak cechy demograficzne (miejsce zamieszkania, status zatrudnienia, stan cywilny) oraz kliniczne (otyłość i cukrzyca) wpłynęły na ocenę jakości życia seksualnego.

Wnioski. Średni wynik jakości życia w kwestionariuszu SQoL-F wyniósł 69,02, ze standardowym odchyleniem SD=25,86 i medianą Me=75. Zarówno czynniki społeczno-demograficzne, jak i kliniczne wpłynęły na ocenę poziomu jakości życia seksualnego pacjentów ze stwardnieniem rozsianym. **(PNN 2024;13(1):23–28)**
Słowa kluczowe: stwardnienie rozsiane, jakość życia, jakość życia seksualnego

Introduction

The quality of life of patients diagnosed with multiple sclerosis is an interdisciplinary concept encompassing psychological, physical, and sexual aspects. Multiple sclerosis is a disease entity primarily leading to disability, resulting in loss of independence and significant deterioration in quality of life. Individuals with multiple sclerosis often face social consequences such as changes in life plans, job loss, relationship problems including rejection by partners, sexual activity issues, and the abandonment of personal passions. Multiple sclerosis typically manifests between the ages of 20 and 45, a period when building relationships, starting families, and planning for offspring become significant. Women are more prone to multiple sclerosis and tend to progress more towards the secondary progressive form, resulting in motor impairment and reduced sexual activity, pleasure, and perceived attractiveness as sexual partners. Women with multiple sclerosis experience a significant decrease in sexual satisfaction, leading to dissatisfaction, depression, and relationship breakdown. It is crucial for patients to receive support, particularly from their partners. Acceptance and coping with the situation, both by patients with diagnosed multiple sclerosis and their partners, play a crucial role in the treatment and rehabilitation process. Maintaining good relationships is a preventive factor that enhances sexual function and quality of life, irrespective of the degree of damage to the nervous system [1–3].

Material and Methods

The study was conducted among 100 female patients of the Neurological Department of the Silesian Hospital in Cieszyn diagnosed with multiple sclerosis from November 1, 2020, to February 28, 2021. The research was conducted after obtaining written consent from the director of the facility to conduct it. Participation in the study was voluntary and anonymous. Respondents were informed about the purpose of the study. The study was carried out using a proprietary questionnaire and the Sexual Quality Of Life Questionnaire-Female (SQoL-F). The proprietary questionnaire included questions about sociodemographic and clinical data. The Sexual Quality Of Life Questionnaire-Female (SQoL-F) is a questionnaire assessing the quality of sexual life in women. The SQoL-F questionnaire contains 18 items. In cases where items score from 1–6, the total scale score can range from 18 to 108 (or 0–90 if items score 0–5). To standardize this to a score of 0–100, the following algorithm was used: Standardized score=(unstandardized score — 18)×100/90. Thus, a score of 63 (halfway between 18 and 108) would be standardized as follows: (63–18)×100/90=50. If the items scored 0–5, subtracting 18 was omitted and simply multiplied by 100/90. The interpretation of the SQoL-F questionnaire is that the higher the score obtained, the higher the quality of life rating. The fewer points obtained in the questionnaire, the lower the quality of sexual life. The Sexual Quality Of Life — was used after obtaining written consent from the author (Symonds) [4,5]. Statistical calculations were carried out using the R-4.0.3 statistical package and Excel 2016 spreadsheet. Quantitative scale variables were characterized by mean arithmetic and standard deviation, while qualitative variables measured on a nominal scale were presented by frequency and percentage values. The significance of differences between two groups, i.e., the model of unrelated variables, was examined by the significance difference test, namely the Mann–Whitney U test. The dependence between two quantitative variables was examined using Kendall's tau correlation coefficient. The normal distribution of variables was tested using the Shapiro–Wilk test. A significance level of $p<0.05$ was adopted in all calculations.

Results

Detailed socio-demographic characteristics of the surveyed group are presented in Table 1.

Table 1. Socio-demographic characteristics of the studied group

Variable	N	%
1	2	3
Age		
>25 years old	18	18.0
25–40 years	52	52.0
<40 years old	30	30.0
Marital status		
Single	24	24.0
Married	70	70.0
Widow/Widower	6	6.0

Table 1. Continued

1	2	3
Education		
Primary	0	0.0
Vocational	8	8.0
Secondary	73	73.0
Higher	19	19.0
Occupational activity		
Yes	60	60.0
No	40	40.0
Place of residence		
Rural	52	52.0
Urban	48	48.0
Comorbidity*		
No	22	22.0
Yes, the size of the group:	78	78.0
Diabetes	21	21.0
Hipertension	36	36.0
Obesity	21	21.0
Aartherosclerosis	2	2.0
Asthma	9	9.0

* Multiple choice questions, answers are not cumulative; N — number of observations; % — percent

From the statistical analysis, it is evident that categories such as psychosexual feelings (M=25.64, SD=10.07), satisfaction with sex and relationship (M=18.98, SD=7.59), as well as worthlessness (M=11.79, SD=4.43), and sexual repression (M=12.61, SD=4.18) exhibit lower values. The mean score for quality of life in the SQoL-F questionnaire was 69.02 with a standard deviation of SD=25.86 and a median of Me=75.50. Table 2 presents the descriptive statistics of quality of life including mean, minimum, and maximum values.

Table 2. Descriptive statistics of quality of life

Variable	$\bar{x}$	SD	Min	Max	Me
Psychosexual feelings	25.64	10.07	7.00	41.00	29.00
Satisfaction with sex and relationships	18.98	7.59	5.00	30.00	20.00
Nihilism	11.79	4.43	3.00	18.00	13.00
Sexual repression	12.61	4.18	3.00	18.00	13.50
SQoL-F	69.02	25.86	20.00	107.00	75.50

$\bar{x}$ — mean; SD — standard deviation; Min — minimum value; Max — maximum value; Me — median

Differences in the level of sexual quality of life were examined based on marital status. Analysis of questionnaire data indicates that surveyed women who are single or widowed exhibit higher satisfaction with sex in terms of psychosexual feelings (31.70, SD=7.90) than women in relationships (23.00, SD=9.80). Similarly, in the categories of satisfaction with sex and relationships, worthlessness, and sexual repression, the level of sexual quality of life is higher among women not in relationships than those in relationships. The SQoL-F questionnaire revealed that women in relationships show a lower level of sexuality (62.50) than women not in relationships (84.30).

Statistical analysis demonstrated statistically significant differences in the level of sexual quality of life based on place of residence, with a significance level of p<0.005. Considering psychosexual feelings, women living in urban areas (28.50) exhibit a higher average compared to women in rural areas, where psychosexual feelings average 23.00, and satisfaction with sex and relationships average 17.10. Worthlessness (10.80) and sexual repression (11.60) among women in rural areas are lower than among women in urban areas, where worthlessness was 12.90 and sexual repression was 13.80. Women living in urban areas show a higher level of sexuality (M=76.10) than those living in rural areas (M=62.50).

Statistical analysis revealed statistically significant differences in the level of sexual quality of life based on occupational activity. Psychosexual feelings (30.30) and satisfaction with sex and relationships (22.40) among professionally active women are significantly higher than among non-professionally active women. The average satisfaction with sex and relationships among non-professionally active women was M=13.80, while psychosexual feelings averaged M=18.70. Worthlessness and sexual repression among non-professionally active women averaged M=8.90 and M=9.90, respectively, which did not significantly differ from professionally active women where worthlessness t was M=13.80, while sexual repression was M=14.40. Professionally active individuals show a higher level of sexuality with M=80.90 compared to non-professionally active individuals with M=51.20.

Table 3 presents a detailed clinical characterization of the examined group with Multiple Sclerosis.

The presence of comorbidities as a discriminating factor in the level of sexual quality of life was statistically analyzed. Considering women with comorbidities, their averages in categories such as psychosexual feelings (M=23.40, SD=9.80), satisfaction with sex and relationships (M=17.30, SD=7.50), as well as worthlessness (M=10.80, SD=4.30) and sexual repression (M=11.70, SD=4.10) indicate a lower level of sexual quality of life. Women diagnosed with multiple sclerosis (MS) and comorbidities exhibit a lower level of sexuality (M=63.20) compared to women with MS without comorbidities (M=89.82) at a significance level of (p<0.05).

Table 3. Clinical characteristics of the studied group

Variable	N	%
Having children		
No	24	24
Yes	76	76
Number of pregnancies		
0	23	23
1	22	22
2	29	29
3	19	19
4	6	6
5	1	1
Frequency of miscarriages		
Yes, the size of the group	17	17
1 Miscarriage	10	10
2 Miscarriages	7	7
No	83	83
The birth of a child after being diagnosed with Multiple Sclerosis		
Yes	45	45
No	55	55
Length of relationship with life partner		
Less than two years	13	13
5–10 years	47	47
Over 10 years	40	40
Assessment of the relationship		
Very good	1	1
Good	9	9
Average	21	21
Bad	44	44
Very bad	25	25
Assessment of sexual activity with life partner		
Good	15	15
Average	42	42
Bad	43	43
Sexual life before and after the onset of Multiple Sclerosis		
It has deteriorated	32	32
It remained at the same level	59	59
It has improved	9	9
Using a wheelchair		
Yes	31	31
No	69	69

N — number of observations; % — percent

Statistical analysis revealed statistically significant differences in the level of psychosexual feelings, sexual satisfaction, relationship satisfaction, and overall sexuality due to diabetes. The average score for women with diabetes concerning sexual feelings was 19.00, significantly lower than women without diabetes, where the average was M=25.00. Satisfaction with sex and relationships among women without diabetes as a comorbidity of MS is considerably higher (M=18.60) than women with diabetes (M=13.70). Individuals with diabetes show a lower level of sexuality in areas of sexual repression, worthlessness, satisfaction with sex, and sexual feelings than those without diabetes. The mean score obtained in the questionnaire for patients with diabetes was M=51.80 with a standard deviation of SD=24.60, while the average for patients without diabetes was M=67.40, SD=24.40, significantly higher than in women with diabetes.

Statistical analysis revealed statistically significant differences in psychosexual feelings and sexual repression due to obesity. Women with obesity (M=19.90) in psychosexual feelings exhibited a lower level of sexuality than women with obesity, where the average was M=24.40. Regarding sexual repression, a difference can also be observed between women with multiple sclerosis and obesity. They exhibit a lower level of sexuality than women without obesity (M=54.60), whereas those without obesity (M=66.30). In other dimensions, no significant differences were observed between women with MS and obesity and women with MS without obesity.

Discussion

The sexual aspect is a very important and one of the basic life functions of humans. It plays a key role in reproductive life. Sex integrates emotional, physical, psychological factors, and affects the quality of life [4]. The concept of sexual quality of life is subjective and is significantly associated with the current state of physical and mental health, social status, and education. It is undeniable that the occurrence of disease negatively affects the quality of life in general, and the sexual quality of life. Trojanowska [6] identifies sexuality with problems of the entire community with disabilities. This indicates that the perception of sexuality and disability in our environment is still largely conditioned by ingrained, established patterns of thinking and cultural-religious beliefs. It highlights the thinking and perception of multiple sclerosis and patients with this disease entity. She concludes that people with other ailments are viewed more favorably in society than those with multiple sclerosis. Society strives to portray the image of a person as an idealized, beautiful, young, full of vitality, healthy

individual without any disorders. Therefore, this image often causes people with multiple sclerosis to fall into depressive states, face identity issues, and experience sexual dysfunction, which consequently leads to a decrease in the level of sexual quality of life. In this study, the sexual quality of life was examined using the Sexual Quality of Life Questionnaire for Female Patients with Multiple Sclerosis (SQoL-F), which is a brief questionnaire assessing the relationship between female sexual dysfunction and quality of life. The study was conducted among 100 female neurological ward patients aged between 20 and 45 years, who were characterized by too low a level of sexual activity.

In the study conducted by Maasoumi et al. [4], which investigated the psychometric properties of the SQoL-F questionnaire for the Iranian version, it was found that women scored lowest on the sexual repression subscales. The study was carried out on 100 women, where the average age of respondents was 33 years. The average scores for women in the subscales were: psychosexual feelings averaged 28.2, satisfaction with sex and relationships averaged 24.3, worthlessness averaged 15.4, and sexual repression averaged 13.9. Meanwhile, the average overall assessment of sexual quality of life was 86.4. Our own studies also show divergent values in the subscales of psychosexual feelings, averaging 25.64, satisfaction with sex and relationships averaging 18.98, worthlessness averaging 11.79, and sexual repression, where the average was 12.61. Worthlessness and sexual repression were rated among the patients as some of the lowest subscales at an average of 12.61. The average level of sexual quality of life among the studied women in the neurology department was 69.02.

As the studies show, multiple sclerosis negatively affects sexuality and the quality of sexual life in women. In the study group, there were 52 women who declared that in 32% of cases their level of sexual quality of life had deteriorated after being diagnosed with the disease. More than half claim that the disease has not affected their sexual relations with their partner in any way, and only 9% report an improvement in the quality of sexual life.

Similar results are presented by Lew-Starowicz et al. [7]. They used the SFQ28 (The Female Sexual Function Questionnaire — a questionnaire on sexual activity and sexual life) and the SQoL-F questionnaire to study women with multiple sclerosis, where the average age was 50.7. The study group included 137 patients with multiple sclerosis. From his studies, it is evident that 41.4% of women stated that their sexual quality had worsened after the diagnosis of MS, more than half noticed no difference, and barely 3.1% of respondents declared an improvement in the quality of sexual life after receiving the diagnosis. The results regarding the deterioration or improvement of the quality of sexual life of women with MS are divergent. However, the data concerning the impact of multiple sclerosis on the sexual life of patients are consistent.

Białek and colleagues [8], studying women up to 18 months and 5 years after mastectomy, indicate that the disease slightly affected the level of sexual satisfaction with a partner in intimate contacts (M=54.24). They used the SQoL-F questionnaire to assess the quality of life of women in relation to sex. The study was conducted among 120 women between the ages of 22 and 65, where nearly half of the women did not notice changes in feeling sexual satisfaction. These results are consistent with our own, which indicate that in 59% of cases, the disease of multiple sclerosis did not affect the assessment of the quality of sexual life.

In this work, an attempt was made to assess the impact of sociodemographic and clinical factors on the quality of life. The sociodemographic factors studied include marital status, professional activity, and place of residence. Our calculations indicated that women, mostly aged between 20 and 45 years old, who were more professionally active and living in urban areas, showed better sexual quality of life. Calculations show that professionally active women had a higher level of sexuality (M=80.90) compared to those not professionally active (M=51.20). Stachowska et al. [9] also reached similar conclusions. In their research, they used the MSQoL-54 (Multiple Sclerosis Quality of Life Instrument) — a quality of life assessment questionnaire for people with MS. The study was conducted at the Multispecialty Neurology Department of the J. Strus City Hospital in Poznań and in the home environment of patients with multiple sclerosis in the city of Poznań, where the study group consisted of 55 women. It shows that working individuals demonstrate higher values in quality of life assessments, also in the area of sexual sphere (M=54.90). Non-working individuals more often fell into depressive states and rated their sexual quality of life as low. The results of our own research and those of Stachowska are consistent. Our own studies showed that women living in partnerships exhibit lower sexuality and quality of sexual life than women living independently. The average for women in relationships was M=62.50, while for women not in relationships, the average was 84.30.

Obesity and diabetes are disease entities that create many difficulties in everyday life. Considering multiple sclerosis, an incurable disease to date, along with diabetes, it can be said there are problems in the physical, psychological, and sexual spheres. Our research indicated that women with coexisting diseases (M=63.20) had a lowered level of sexual quality of life. It should also be added that such disease entities as diabetes (M=51.80) and obesity (M=54.60) significantly affected the assessment of sexual quality of life. Bąk et al. [10] in

their studies, which involved 163 female patients with diabetes and 115 women without diabetes in the premenopausal period, showed that sexual dysfunctions occur more frequently in women with diabetes. One of the tools used in the studies was the SQoL-F questionnaire. In addition to diabetes, menstrual cycle phases were considered, specifically the follicular and luteal phases. Patients with type 1 diabetes in the luteal phase showed lower values in the sexual sphere compared to the follicular phase ($p<0.001$). However, for type 2 diabetes, no differences were shown in these phases ($p<0.005$). The quality of sexual life among patients with type 2 diabetes tends to decrease, which is influenced by age and deteriorating mood. Our own studies also showed a downward trend in women with MS and diabetes as a coexisting disease.

Conclusions

The quality of life of women with multiple sclerosis in all domains: psychosexual feelings, satisfaction with sex and relationships, worthlessness, and sexual repression, was assessed as low. Demographic factors such as place of residence, occupational activity, and marital status influence the assessment of sexual quality of life. Clinical factors such as the presence of comorbidities like obesity and diabetes also affect the assessment of sexual quality of life.

Implications for Nursing Practice

Multiple sclerosis (MS) is a medical condition primarily leading to disability, resulting in loss of independence and significant deterioration in overall quality of life, including the sexual dimension. It is noteworthy that this topic is still rarely discussed by patients themselves, their partners, and medical personnel.

In the case of women with multiple sclerosis, satisfaction in the sexual domain significantly decreases, consequently leading to dissatisfaction, despondency, and depression. Acceptance and coping with the situation, both by patients diagnosed with multiple sclerosis and their partners, play a crucial role in the treatment and rehabilitation process. Maintaining good relationships in the partnership is a significant preventive factor that improves the sexual sphere and quality of life.

Effective education for patients and their partners should be a standard in the care of patients with multiple sclerosis, rather than a random conversation initiated by a doctor, nurse, or psychologist with a woman suffering from multiple sclerosis.

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A — Concept and design of research, B — Collection and/or compilation of data, C — Analysis and interpretation of data, D — Statistical analysis, E — Writing an article, F — Search of the literature, G — Critical article analysis, H — Approval of the final version of the article

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