

Validation and cross-cultural adaptation of sexual dysfunction modified scale in multiple sclerosis for Brazilian population

Validação e adaptação transcultural da escala modificada de disfunção sexual em esclerose múltipla na população brasileira

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ABSTRACT

Multiple sclerosis (MS) is a chronic inflammatory disease of the central nervous system (CNS). These patients suffer from various comorbidities, including sexual dysfunction (SD). The lesions of MS may affect regions of the CNS along the pathway of sexual response. The Multiple Sclerosis Intimacy and Sexuality Questionnaire-19 (MSISQ-19) is a scale that assesses sexual dysfunction. Objectives: Adapt and validate the MSISQ-19 to Brazilian patients with MS. 204 individuals were evaluated, 134 patients with MS and 70 healthy persons for the control group. It was determined reproducibility, validity, internal consistency and sensitivity of the MSISQ-19-BR. Among patients with MS, 54.3% of male and 71.7% of female presented some kind of SD. In the control group the results were 12.5% and 19.5%, respectively. The MSISQ-19-BR is reproducible, reliable and valid for the Brazilian population and may be used as a tool for assessing the impact of sexual dysfunction in patients with MS.

Keywords: sexual dysfunction, multiple sclerosis, questionnaires.

RESUMO

A esclerose múltipla (EM) é uma doença crônica inflamatória do sistema nervoso central (SNC). Esses pacientes sofrem de várias comorbidades, incluindo a disfunção sexual. As lesões da EM podem afetar várias regiões do SNC inclusive a via de resposta sexual. O *Multiple Sclerosis Intimacy and Sexuality Questionnaire-19 (MSISQ-19)* é uma escala de avaliação da disfunção sexual. Objetivo: Adaptar e validar o MSISQ-19 para os pacientes brasileiros com EM. 204 indivíduos foram avaliados, 134 pacientes com EM e 70 controles saudáveis. Foi determinado a reprodutibilidade, validade, consistência interna e a sensibilidade do MSISQ-19BR. Entre os pacientes com EM, 54,3% dos homens e 71,7% das mulheres apresentam algum tipo de DS. No grupo controle os resultados foram 12,5% e 19,5%, respectivamente. O MSISQ-19BR foi reprodutível, confiável e validade para a população brasileira e pode ser usado como uma ferramenta de avaliação do impacto da disfunção sexual nos pacientes com EM.

Palavras-chave: disfunção sexual, esclerose múltipla, questionários.

Multiple sclerosis (MS) is a chronic inflammatory disease of the central nervous system (CNS) in which demyelination and axonal loss occur in the brain and spinal cord. The disease affects 2.5 million people worldwide. Although the etiology of MS is unknown, there is evidence of genetic predisposition and that some environmental factors may induce an immune system alteration that leads to oligodendrocyte and myelin injury, thus impairing neurotransmission.

The disease course can be slow and progressive, with periods of remission and exacerbation of symptoms, which may include speech and visual disturbances, loss of

strength, fatigue, cognitive and emotional disorders, balance and coordination alterations, and also urinary, bowel and sexual problems.

There are four subtypes of MS according to the course of the disease: relapsing-remitting (RRMS), primary progressive (PPMS), secondary progressive (SPMS), and progressive with relapses (RPMS). The available treatments can change the progression of the disease, but special attention should be paid to the diversity of symptoms that may be present.

The quality of life of MS patients is a serious concern. The onset of MS symptoms occurs between 20 and 40 years of age;

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one of these symptoms, sexual dysfunction (SD), has a striking impact on the lives of patients with MS.

Sexuality is now recognized as one of the major determinants of quality of life in patients with chronic diseases. Sexual satisfaction is considered a relevant variable in assessing social, familial, and affective relations.

Lilius et al. found that SD affects 82%–91% of men and 59%–72% of women with MS compared to 13% in non-MS subjects¹. Szasz et al.² found that 50% of MS patients reported being “concerned” about their sexual life. Lundberg³ showed that sexual dysfunction is common even in mild and moderate cases. These percentages are extremely important and should be considered by health professionals when providing a multidimensional treatment.

Sexuality is hard to define. Furthermore, it is a private matter that raises many taboos and involves personal, cultural, and religious factors. In order to understand the effects of MS on sexual functioning, it should be noted that the pathways of sexuality control extend through certain brain centers that receive information from the sense organs and limbic regions and send stimuli to medullary centers that control the effector organs of sexual response. The presence of MS lesions can affect points along the sexual response pathway.

Sexual dysfunction in MS is described according to three basic generating factors: 1) primary, a direct result of neurological injuries involving the genital system itself; 2) secondary, a result of symptoms unrelated to the genital system, or 3) tertiary, a result of cultural and psychosocial issues related to the disease that in some way interfere with sexual function⁴. Despite this categorization, it is very common for patients to have more than one type of SD.

The most common primary dysfunctions in MS are reduction or loss of libido, decreased genital sensitivity, pain or a tingling sensation in the genitals, and difficulty in reaching orgasm. Among men, Vas⁵ highlights erectile dysfunction, which affects between 60% and 80% of patients.

The secondary dysfunctions include spasticity (especially in the lower extremities), fatigue, muscle weakness, urinary and/or fecal incontinence, pain and paresthesia, tremor, shuddering, impaired attention and concentration, and behavioral changes.

Tertiary dysfunctions are mainly related to the social impact of the disease on self-esteem, mood, and personal and professional life. Considering all the above-mentioned factors, it is important to develop an effective survey strategy to elucidate and measure the main impacting features of SD. In a review of sexual function in MS patients, Dupont⁶ determined that one of the biases in studies of sexuality is the limited use of standardized instruments.

The Multiple Sclerosis Intimacy and Sexuality Questionnaire-19 (MSISQ-19), a scale that assesses SD considering the three levels of compromise, was empirically developed as a specific scale to address the multidimensional nature of sexual issues in MS⁷. The MSISQ-19 was previously

used as a tool to evaluate SD in MS⁸; Foley has recently developed and validated a version with 15 items of the scale based on a large sample of North American patients⁹.

The questionnaire is self-completed and there is a risk that it might be interpreted differently across cultures and populations. Thus, it is recommended that these questionnaires be pre-tested and validated for each population. In this context, the aim of the present study was to adapt and validate the MSISQ-19 to be used as an assessment tool of the impact of sexual dysfunction on Brazilian patients with MS while maintaining the core characteristics of the original version.

The aim of this study was to develop a cross-cultural adaptation and validation of the MSISQ-19 so that it can be used as a tool to evaluate SD in Brazilian patients with MS.

METHOD

Instrument

The MSISQ -19 is composed of 19 self-report items measuring the influence of MS symptoms on sexual activity and satisfaction and how they have interfered with the patient's sexual life over the preceding six months. The instrument is divided into three subscales: SD1, for primary sexual dysfunction (items 12, 16, 17, 18, and 19); SD2, secondary (items 1, 2, 3, 4, 5, 6, 8, 10, and 11), and SD3, tertiary (items 7, 9, 13, 14, and 15). Each item is rated from 1–5 based on the Likert scale (1 = never; 2 = seldom; 3 = sometimes; 4 = often, and 5 = always); a final score is generated by the summation of the scores across items. The higher the score, the greater the impact of SD on patients' lives¹⁰.

The Expanded Disability Status Scale (EDSS) is a 10-point scale typically employed to assess the progression of MS-related disability. The scale has 20 levels of clinical impairment graded in 0.5 increments, with 0 (zero) being the best score (normal neurological examination) and 10 the worst (death from MS)¹¹.

Translation and cultural adaptation

The cross-cultural adaptation and validation protocols were followed according to specialized literature¹². Initially, the items of the English version were translated into Portuguese by two independent English teachers who were aware of the objective of the study. These two translations were compared and modifications were made until consensus was reached. The consensus translation was back-translated into English by a native English teacher who had not participated in the previous step. The back-translated English version and the original questionnaires were compared and no significant discrepancies were noted.

A pilot study was carried out for pre-test analysis of cultural equivalence. The scale was applied to a group of 11 MS patients without cognitive impairment selected randomly

at the Centre of Care and Treatment of Multiple Sclerosis (CATEM) at the *Santa Casa de Misericórdia de São Paulo*. The purpose of this procedure was to identify issues that were not understood by the population and therefore were deemed culturally inappropriate; however, no question fit those parameters. Thus, the final versions of the Portuguese language scale, named MSISQ-19-BR, were generated.

Subjects

In all, 134 patients with MS, including 99 women and 35 men, were selected. The control group comprised 70 non-MS subjects, with 46 females and 24 males. The patients with MS were randomly selected among those being treated at the CATEM.

The inclusion criteria was a confirmed diagnosis of MS according to the revised McDonald criteria 2010 and the absence of other pathological conditions that might lead to SD, such as psychological disorders, abnormal hormonal activity, vaginismus, previous erectile dysfunction, sexual arousal disorders and use of specific medication, among others. Participants were excluded if they were undergoing an MS outbreak. All subtypes of MS were included, trying to respect the prevalence proportion. The 70 non-MS subjects were randomly selected among accompanying of patients with MS at the CATEM and of other patients with other conditions being treated at the same hospital. The exclusion criteria for the control group were having MS or any other pathology that might cause SD.

All subjects were informed about the purpose of the study and provided written informed consent.

The MSISQ-19 questionnaire was administered in a quiet and private environment to minimize possible constraints. Data regarding gender, age, level of education, disease duration and MS subtype, neurological examination, and EDSS score were collected. After 30 days, the same researchers gave a retest with 48 patients to analyze the stability and reliability of the scale.

Statistical analysis

Descriptive analysis was done based on the frequency of categorical variables and measures of position and dispersion of continuous variables. A multivariate analysis of variance was performed for gender, age, level of education, disease duration, and EDSS score to identify extraneous variables. The results were analyzed and compared between the

control group and patients with MS in order to clarify the significance of the final score.

To validate the instrument, we followed the standards proposed by Instrument Review Criteria (SAC) and assessed reliability, validity, and sensitivity^{13,14}. The reliability of the questionnaire was assessed based on internal consistency and test-retest stability, obtained respectively by Cronbach's alpha and Pearson's correlation coefficients. The validity of the instrument was determined by comparing the results of the MSISQ-19-BR with the EDSS scores using Pearson's correlation coefficient. The sensitivity of the scale was established by comparing the results of four different groups: control group with and without SD; MS patients with and without SD. This subdivision allowed an evaluation of the ability of the scale to identify each of these four groups using the Mann-Whitney and Kruskal-Wallis tests¹⁵.

The level of significance was set at $p = 0.05$ for all statistical tests. The statistical analyses were conducted with the aid of the Statistical Package for Social Sciences (SPSS) version 17.0.

RESULTS

We evaluated 204 individuals: 70 in the control group and 134 patients with MS. The socio-demographic and clinical data are shown in Table 1. The multivariate analysis of variance showed that gender, age, and level of education did not affect the results of the test and retest nor the subsequent analysis.

Among the patients with MS, 54.3% of the male individuals and 71.7% of the female exhibited some degree of SD, defined as a score greater than 30 or any response 4 (often) or 5 (always). For the control group, the results were 12.5% and 19.5%, respectively. The means and standard deviations for the SD1, SD2 and SD3 subscales and the total score of the MS group were compared between male and female subjects (Table 2).

The internal consistency for the subscales (SD1, SD2 and SD3) and between the 19 questions in MSISQ-19-BR was assessed using Cronbach's alpha coefficient for all subjects and individually for each group. These results are shown in Table 3.

A high level of reproducibility was found, with 86.76% of concordance between the studied behaviors. The

Table 1. Socio-demographic and clinical data of the control group and the MS group.

Socio-demographic data	Control group (n = 70)	MS group (n = 134)
Gender F:M	41F : 29M	99F : 35M
Age	41.37 (14.59)	41.34 (11.88)
School index (% with high school)	77.1%	79.9%
Disease duration		6.54 (6..77)
EDSS		3.18 (2.18)

Data are presented as mean +/-SD. SD: standard deviation; F: female; M: male; MS: multiple sclerosis; EDSS: Expanded Disability Status Scale.

average scores for the test and retest were 35.15 and 35.40, respectively. The correlation between outcomes in the test and retest as assessed by Pearson's correlation coefficient showed a strong association, with a value of more than 0.90 and $p < 0.001$.

Validity was determined by an evaluation of the behavior domains of the MSISQ-19-BR depending on the extent of EDSS, also using Pearson's correlation. Although other studies have demonstrated an association between the EDSS score and SD¹⁶, no significant correlations were observed in our study, which is consistent with the results of the study by Tzortzis et al.¹⁷.

Sensitivity is a measure of the ability of a scale to distinguish groups with different characteristics. The study subjects were divided into four groups (control and MS, with or without SD) and the scores were compared using the Mann-Whitney and Kruskal-Wallis tests. The results are shown in Tables 4 and 5.

DISCUSSION

Sexual satisfaction is considered a relevant variable in quality of life assessments. Problems with sexual function are common in patients suffering from degenerative and disabling diseases.

Table 2. Parallel between women and men of the MS group.

Aspect	Women (n = 99)	Men (n = 35)
SD1	12.29 (6.42)	9.22 (4.83)
SD2	19.80 (9.02)	18.14 (8.27)
SD3	11.11 (6.17)	9.54 (5.72)
Total	43.21 (19.77)	36.91 (17.09)

SD1: Sexual Dysfunction Primary; SD2: Sexual Dysfunction Secondary; SD3: Sexual Dysfunction Tertiary; MS: multiple sclerosis.

Table 3. Internal consistency given by Cronbach's alpha coefficient.

Cronbach's alpha	For subscales (DS1, DS and DS3)	For questions (1 to 19)
All subjects	0.898	0.955
Control group	0.870	0.918
MS group	0.879	0.945

MS: Multiple Sclerosis; SD1: Sexual Dysfunction Primary; SD2: Sexual Dysfunction Secondary; SD3: Sexual Dysfunction Tertiary.

Table 4. Sensitivity analysis of MSISQ-19-BR and control groups MS, with and without SD.

Aspect	Control without SD (n = 58)	Control with SD (n = 12)	MS without SD (n = 44)	MS with SD (n = 90)	Significance (p)
SD1	5.46 (1.18)	11.58 (5.99)	6.40 (2.04)	13.97 (6.00)	$p < 0.0001$
SD2	9.60 (1.41)	15.91 (5.35)	11.18 (2.49)	23.37 (8.01)	$p < 0.0001$
SD3	5.17 (0.56)	8.00 (3.30)	5.50 (0.95)	13.24 (5.90)	$p < 0.0001$
Total	22.55 (7.80)	24.33 (9.50)	23.09 (3.38)	50.60 (17.22)	$p < 0.0001$

Data are presented as mean +/- SD. MSISQ-19: Multiple Sclerosis Intimacy and Sexuality Questionnaire-19; SD: standard deviation; MS: multiple sclerosis; SD1: Sexual Dysfunction Primary; SD2: Sexual Dysfunction Secondary; SD3: Sexual Dysfunction Tertiary.

Zorzon et al.¹⁸ reported that the incidence of SD in patients with MS (73%) is higher than in people with chronic diseases (39%) and in the general population (13%). The incidence of SD in our study was approximately 72% in women and 54% in men. Other studies have found incidence rates ranging from 50% to more than 70%. In a study by Lilius et al.¹, 64% of men and 39% of women described their sex life as "unsatisfactory". Sexual dysfunction seems to be affected by the level of disability and disease duration, but the impact of those factors remains unclear. Hulter and Lundberg noted that 90% of MS patients using wheelchairs have "big problems with sexual function"¹⁹, which need to be properly addressed.

Patients with MS have high levels of SD and their partners also show less satisfaction with their sex lives and relationships. How patients react to the perception of their disease by others impacts their sexual behavior.

If the patient with MS becomes unable to engage in sexual activity, the partner and the whole family dynamics can be affected. Sexual satisfaction is frequently associated with acceptance, trust, and communication. Therefore, SD should not be treated as a single somatic disorder; rather, it should also be seen in its cognitive and emotional aspects, thus helping patients to find a new path in their sex lives.

Most researchers suggest that MS has a negative impact on relationships and satisfaction with the romantic relationship is lower than in the general population^{20,21,22}. Health professionals should be aware of the high rates of SD and low levels of sexual satisfaction among individuals with MS. Nevertheless, it is estimated that 94% of MS patients have never been questioned about their sexuality²¹. Disorders related to sexuality are often pushed into low priority by health professionals, especially because of the difficulties in effectively approaching this subject and the lack of more specialized information. Patients often feel uncomfortable and

Table 5. Sensitivity analysis of MSISQ-19-BR and control groups MS.

Aspect	Mann-Whitney U	Significance (p)
SD1	2016.00	$p < 0.0001$
SD2	1431.50	$p < 0.0001$
SD3	1871.00	$p < 0.0001$
Total	1297.50	$p < 0.0001$

MSISQ-19: Multiple Sclerosis Intimacy and Sexuality Questionnaire-19; SD1: Sexual Dysfunction Primary; SD2: Sexual Dysfunction Secondary; SD3: Sexual Dysfunction Tertiary.

unable to speak about their sexuality, but most of them believe it to be appropriate to address sexual functioning in routine office visits²³.

Previous studies have demonstrated that sexual counseling is helpful²⁴; educational materials and conversations about sexual problems in MS also seemed beneficial²⁵. In providing care, it is important for the health professional to find a balance between distance and intimacy, allowing patients to address their sexual issues without judgment. First of all, the physician should perform a complete evaluation and determine what type of SD the patient manifests and whether it appeared before or after the onset of MS symptoms.

Treatment of any SD begins with information provided to patients; however, other factors should be considered, such as the etiology of the disorder, the patient's age, sexual experience, and whether the patient and partner are in a steady relationship. Bronner et al.²⁶ suggested some interventions that could minimize the impact of SD: hormone administration, treatment of underlying conditions (e.g., depression, urinary incontinence), and masturbation, among others.

Therapy starts when the physician shows concern about the patient's sex life. It is important to consider that, despite the high prevalence of SD in MS, other conditions should not be neglected, such as hypertension, diabetes, incontinence, psychiatric disorders, and side effects of drugs²⁷. Assessing the prevalence and cause of sexual problems that may require clinical intervention is essential.

Depression, for example, is highly prevalent in MS patients^{28,29}. The feeling of dependence related to depressive episodes can also cause decreased sexual drive. The fear of being rejected sexually, the feeling of being less attractive, communication difficulties, fear of isolation and abandonment, guilt, and the impact of the disease on the partner—especially when he or she becomes the caregiver—are some of the prominent issues.

In this context, some areas related to sexual behavior should be explored: responsiveness to sexual stimulation, motor difficulties, hygiene aspects, urinary and fecal incontinence, fertility, libido, communication with partners, and prospects for sex life. Considering all the aspects that have been discussed, the present study confirms the need to address sexuality in MS patients. The use of a standardized tool can facilitate the initial approach and introduce the topic in a non-threatening way in clinical practice.

In conclusion, the MSISQ-19-BR is a reproducible, reliable, and valid instrument for the Brazilian population. It also showed easy clinical applicability and can be used in the day-to-day care of patients with MS. The administration of a standardized instrument can facilitate the initial approach and introduce the theme of sexuality in regular physician office visits. Therefore, the MSISQ-19-BR is a valuable tool to help physicians and patients in addressing this sensitive subject and to enable a multidimensional treatment, thereby improving the quality of life of MS patients.

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ANNEX

Multiple Sclerosis Intimacy and Sexuality Questionnaire-19 [MSISQ-19]

Instructions

In order to better understand the impact of multiple sclerosis (MS) on intimacy and sexuality, this 19-item questionnaire asks you to rate how various MS symptoms have interfered with your sexual activity or satisfaction over the last six months. Questions may be answered by placing a check or any other mark in the square located next to the question and below the appropriate number. There are no right or wrong answers. If you are unsure how to answer a question, please choose the best answer you can.

Over the last six months, the following symptoms have interfered with my sexual activity or satisfaction:	Never	Almost Never	Occasionally	Almost Always	Always
	1	2	3	4	5
1. Muscle tightness or spasms in my arms, legs, or body					
2. Bladder or urinary symptoms					
3. Bowel symptoms					
4. Feelings of dependency because of MS					
5. Tremors or shaking in my hands or body					
6. Pain, burning, or discomfort in my body					
7. Feeling that my body is less attractive					
8. Problems moving my body the way I want during sexual activity					
9. Feeling less masculine or feminine due to MS					
10. Problems with concentration, memory, or thinking					
11. Exacerbation or significant worsening of my MS					
12. Less feeling or numbness in my genitals					
13. Fear of being rejected sexually because of MS					
14. Worries about sexually satisfying my partner					
15. Feeling less confident about my sexuality due to MS					
16. Lack of sexual interest or desire					
17. Less intense or pleasurable orgasms or climaxes					
18. Takes too long to orgasm or climax					
19. Inadequate vaginal wetness or lubrication (women)/ difficulty getting or keeping a satisfactory erection (men)					

Scoring:

Primary sexual dysfunction

items = 12, 16, 17, 18, 19

Secondary sexual dysfunction

items = 1, 2, 3, 4, 5, 6, 8, 10, 11

Tertiary sexual dysfunction

items = 7, 9, 13, 14, 15

Any item scoring "4" or "5" should be discussed with your MS health care provider.

Escala sobre intimidade e sexualidade na esclerose múltipla**Instruções**

Para melhor entender o impacto da esclerose múltipla (EM) na intimidade e sexualidade, este questionário com 19 itens pede para você classificar como os diversos sintomas da EM tem interferido na sua atividade sexual ou na sua satisfação sexual nos últimos seis meses. As questões podem ser respondidas através de uma marcação no quadrado localizado ao lado da questão e abaixo do número que correspondente a sua resposta. Não existe resposta certa ou errada. Caso você não tenha certeza de como responder a pergunta, por favor, escolha a melhor resposta que você puder.

Nos últimos seis meses, os sintomas abaixo têm interferido na minha atividade sexual e satisfação sexual:	Nunca	Quase nunca	Ocasionalmente	Quase sempre	Sempre
	1	2	3	4	5
1. Rigidez muscular nos meus braços, pernas ou corpo					
2. Sintomas de incontinência urinária					
3. Sintomas no intestino					
4. Sentimentos de dependência por causa da EM					
5. Tremores ou agitações em minhas mãos e corpo					
6. Dor, queimação ou desconforto em meu corpo					
7. Sentimento de que meu corpo é menos atrativo					
8. Problemas movendo meu corpo do jeito que eu quero durante a atividade sexual					
9. Sentindo-me menos masculino ou feminino devido a EM					
10. Problemas de concentração, memória ou pensamentos					
11. Exacerbação ou significativo agravamento da minha EM					
12. Menor sensibilidade ou entorpecimento das minhas genitais					
13. Medo de ser rejeitado sexualmente por causa da EM					
14. Preocupações a respeito da satisfação sexual do meu parceiro					
15. Sentindo-me menos confiante sobre minha sexualidade devido à EM					
16. Falta de desejo ou interesse sexual					
17. Orgasmo ou clímax menos intensos e/ou menos prazerosos					
18. Demora ao orgasmo ou clímax					
19. Lubrificação e umidade vaginal inadequada (mulher)/ dificuldade de obter ou manter ereção satisfatória (homem)					