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FACE, CONTENT, AND CULTURAL VALIDITY OF THE ARABIC VERSION OF THE MULTIPLE SCLEROSIS INTIMACY AND SEXUALITY QUESTIONNAIRE-15 (MSISQ-15)

by
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ABSTRACT
OF THE PROJECT OF

Aya Ahmad Azzam for Master of Science in Nursing
Major: Nursing – Adult Gerontology
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Title: Face, Content, and Cultural Validity of the Arabic Version of the Multiple Sclerosis Intimacy and Sexuality Questionnaire-15 (MSISQ-15)

Background: Multiple Sclerosis (MS) patients may experience sexual dysfunction, but they may not be adequately assessed for this issue in Lebanon. The Multiple Sclerosis Intimacy and Sexuality Questionnaire-15 (MSISQ-15) is used to assess the effects of symptoms of MS on the patient's sexual activity and satisfaction in both genders and has high validity and reliability. The short-term goals of this project were: 1) Conduct face, content, and cultural validity of the Arabic MSISQ-15 in patients with MS at an MS Center in Lebanon. 2) Encourage Lebanese healthcare professionals to screen for sexual dysfunction in patients with MS in Lebanon by providing them with a culturally valid tool. The long-term goal is to improve screening practices and treat sexual dysfunction in patients with MS in Lebanon.

Methods: An expert translator conducted the translation from English to Arabic, and one of the professors at AUB back translated into English without looking at the original questionnaire to check for the accuracy and equivalence of the translated materials. We followed the expert, pretest, and observations approaches to test the face validity and expert judgment to test the content validity. Cultural validity was also assessed by patients and experts' judgement. We sought IRB approval before initiating any contact with the participants. The sample was purposeful and followed the maximum variation technique whereby two registered nurses and three physicians (research fellows) working at the MS center at AUBMC and eleven patients with MS visiting the MS center at AUBMC were included.

Results: Sixty-three percent of the patients were females. Research fellows were all medical doctors who have been hired as research fellows in the MS center. The overall questionnaire was deemed credible to participants, and appeared adequate for the assessment of primary, secondary, and tertiary sexual dysfunction. Our project showed that the Scale-Content Validity Index (S-CVI) of the MSISQ-15 Arabic version was 0.987 and the Item-Content Validity Indices (I-CVIs) ranged between 0.8 to 1. Cultural validity indices raged from 0.8 to 1. The overall cultural validity of the scale was 0.973. All items were clear and understandable by the patients except the second and third questions; patients did not understand these two questions during the interview until examples were added to each, after which they found them appropriate.

Conclusion: The Arabic version of the MSISQ-15 has good face validity and adequate content and cultural validity in the Lebanese population for assessing the impact of MS symptoms on sexual activity and satisfaction.

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ABBREVIATIONS

MS: Multiple Sclerosis

MSISQ: Multiple Sclerosis Intimacy and Sexuality Questionnaire

AUBMC: American University of Beirut Medical Center

IRB: Institutional Review Board

SSFS: Szasz Sexual Functioning Scale

CVI: Content Validity Index

I-CVI: Item Content Validity Index

S-CVI: Scale Content Validity Index

HRQoL: Health-Related Quality of Life

SF-36: Short-Form-36

SEA-MS-F: Sexual Dysfunction Management and Expectations Assessment in Multiple sclerosis - Female

CHAPTER I

INTRODUCTION

A. Multiple Sclerosis

Multiple sclerosis (MS) is a chronic inflammatory and auto-immune disease which leads to demyelination in the central nervous system, resulting in progressive neurological dysfunction (Dighriri et al., 2023). There are four subtypes of MS: - Relapse-Remitting MS (RRMS) that is a period of relapse where new symptoms develop or current symptoms get worse, followed by a period of remission where symptoms completely or partially disappear. Secondary progressive MS (SPMS) that is when the disease might progress from RRMS to SPMS where there is progressive worsening of symptoms. Primary progressive MS (PPMS) is a progressive worsening of symptoms from the onset of the disease without a period of relapse and remission. Progressive-relapsing MS (PRMS) is similar to PPMS where there is progressive worsening of symptoms from the onset of the disease but with periods of relapses that involve intensified symptoms similar to RRMS. This subtype is the least common. Clinically isolated syndrome (CIS) is referred to as the first attack where symptoms last for at least 24 hours but does not meet the criteria of multiple sclerosis. CIS may or may not develop into MS (Guo et al., 2012). The exact cause of MS is unknown; MS is a multi-factorial disease that involves genetic and environmental influences (Dighriri et al., 2023). MS symptoms range from mild to severe ones, depending on the extent and location of nerve damage. These symptoms include visual damage, double vision, weakness of the extremities, altered sensation, unsteady gait, bladder and bowl problems such as retention, incontinence, or intermittency and sexual dysfunction (de Sa et al., 2011).

There are 2.8 million individuals living with MS worldwide (Multiple Sclerosis International Federation, 2020). There are at least twice the number of females affected by MS compared to males. In the Western Pacific and South-East Asia regions the skew towards females is even greater, where there are three times as many females to males (Multiple Sclerosis International Federation, 2020). A study conducted by Zeineddine et al (2021) showed that Lebanon is a moderate to high-risk area for MS, were in 2018 overall incidence rate of MS in Lebanon was 8.36 cases per 100,000 persons with a mean age at onset of 34.5 ± 12.5 year, and prevalence rate was 62.91 cases per 100,000 persons, 2248 individuals were identified with MS in Lebanon between the period of January 2018 and December 2018 were 67.1% were female (female: male ratio 2:1).

B. Sexual Dysfunction in Multiple Sclerosis

According to the World Health Organization sexual health is defined as “a state of physical, emotional, mental and social well-being in relation to sexuality; it is not merely the absence of disease, dysfunction or infirmity” (WHO, 2006a). According to the National Institute on Aging “Sexuality is the way we experience and express ourselves sexually. It involves feelings, desires, actions, and identity, and can include many different types of physical touch or stimulation” (Rheaume at al., 2008). Intimacy is defined as “feelings of closeness, connectedness, and bondedness in a close relationship” (Hook et al., 2003). Sexual dysfunction is defined as a problem in any phase of the sexual response cycle that prevents the person from having a satisfying sexual activity (Chen et al., 2013). Sexual response cycle consists of four phases that include: - excitement, plateau, orgasm, and resolution (Walton et al., 2017)

Sexual dysfunction is a common problem in MS (Gaviria- Carrillo et al., 2022). It can occur at any stage of the disease but is more prevalent as the disease progresses (Lew-Starowicz and Rola, 2013). It can be due to psychological and physiological factors (Domingo et al., 2018). Sexual dysfunction in patients with MS is classified into primary, secondary, and tertiary. The primary sexual dysfunction is due to the presence of lesions in the central nervous system, which can lead to a decrease or loss of sensation in the genital area, resulting in loss or decrease in libido, decrease in vaginal lubrication and dryness and anorgasmia in females, and loss or decrease ability of erection and ejaculation in males. Secondary sexual dysfunction is related to non-sexual causes such as fatigue, pain, poor bladder and bowl control, tremors or spasticity that could affect bending or changing position (Domingo et al., 2018). Secondary sexual dysfunction can also include side effects of medications, delayed or loss of orgasm is one of the side effects of antidepressant, around 30%-60% of the patients treated with selective serotonin reuptake inhibitors suffer from sexual dysfunction. As a result, this problem can be solved by lowering the dose or switching to another type of antidepressants with a low propensity to cause sexual dysfunction (Guo et al., 2012). Tertiary sexual dysfunction is due to psychological problems caused by MS such as depression and anxiety, changes in social roles, and/or demoralization, low self-esteem, feeling less feminine or masculine, changes in body image, and fear of rejection by one’s partner (Domingo et al., 2018). Exacerbation of MS can directly affect both primary and secondary factors leading to a negative impact on sexual function and satisfaction. This, in turn, contributes to the deterioration of patients’ psychological well-being, which represents a tertiary consequence (Gopal et al., 2021). Sexual dysfunction is directly related to the quality of life of patients with MS. The greater the sexual dysfunction, the worse is the quality of life (Esteve Ríos et al., 2023). The most reported forms of sexual dysfunction in men with MS are erectile dysfunction (50%-75%), orgasmic and/or ejaculatory dysfunction (50%), reduced libido (39%), anorgasmia (37%). The most reported forms of sexual dysfunction in females with MS are decrease in libido (31.4%), inability to reach orgasm (37.1%), decrease in sensation from the thighs to the genital area and vaginal dryness leading to dyspareunia (35.7%) (Guo et al., 2012). Men most commonly experience erectile and ejaculatory dysfunction while women experience decrease in vaginal lubrication, clitoral erection dysfunction and painful intercourse (Drulovic et al., 2020).

C. Significance

MS commonly occurs in young people (20-40 years) who are usually sexually active; thus, for these young patients, a healthy sex life may be of prime significance for the maintenance of their quality of life (Guo et al., 2012). Unfortunately, in MS, sexual dysfunction is highly prevalent, around 40% to 80% of women and around 50% to 90% of men with MS experience sexual dysfunction (Gaviria- Carrillo., 2022). Sexual dysfunction is more common in MS than any other neurological diseases and is often underdiagnosed, rarely screened by health care professionals, and often not addressed due to social taboos (Gaviria- Carrillo., 2022). Lack of questions regarding patients’ sex life can leads to sexual dysfunction remaining unnoticed; the latter may negatively impact the patients’ quality of life and may have psychological impact on the patients which include fear, anxiety, and stress (Sheng, 2021). In Lebanon it is still considered a taboo to discuss sexual issues; patients avoid discussing sexual problems with their health care providers (Azar et al., 2021). It is highly important to have a thorough sexual history to be able to assess and diagnose sexual dysfunction in patients (Hatzichristou et al., 2016). In the MS center in Lebanon, formal sexual health assessment may not be regular practice, probably due to the lack of questionnaires (for the assessment of sexual health in MS) in Arabic language. Thus, implementing a validated Arabic questionnaire to assess sexual dysfunction in the MS centers and other healthcare facilities in Lebanon would aid in evaluating sexual issues among MS patients. Moreover, validated questionnaires can help identify factors that can be directly or indirectly causing sexual dysfunction in patients with MS and help elucidate the effect of the MS symptoms and disabilities on sexual function (Gaviria Carrillo et al., 2023).

D. Project's goals

1. *Short-term goals*

- Conduct face, content, and cultural validity of the Arabic MSISQ-15 in patients with MS at an MS Center in Lebanon.
- Encourage Lebanese healthcare professionals to screen for sexual dysfunction in patients with MS in Lebanon by providing them with a culturally valid tool.

2. *Long-term goal*

- To improve screening practices and treat sexual dysfunction in patients with MS in Lebanon.

CHAPTER II

LITERATURE REVIEW

Sexual dysfunction is directly related to the quality of life of patients with MS. The greater is the sexual dysfunction, the worse is the quality of life (Esteve Ríos et al., 2023). A study explored the association between sexual dysfunction with health-related quality of life (HRQoL) in patients with MS stratified by disease duration where the HRQoL was measured using SF-36 Short Form Health Survey, showed that sexual dysfunction is linked to a notable decrease in HRQoL scores in individuals with MS, even if they have had MS for a relatively short time (Vitkova et al., 2014). Sexual dysfunction in MS is underdiagnosed, rarely screened by health care professionals, and often not addressed due to social taboos (Gaviria-Carrillo., 2022). A study conducted by Audrey et al., (2022) to evaluate expectations regarding treatment and information for sexual dysfunction in women with multiple sclerosis in France using the SEA-MS-F (Sexual Dysfunction Management and Expectations Assessment in Multiple sclerosis - Female) questionnaire showed that 59.8% of the participants reported sexual dysfunction and only 22.4% raised the issue with their health care providers. According to Lew-Starowicz and Rola (2013), where they evaluated the prevalence of sexual dysfunction among one hundred and thirty-seven women with MS in Poland, 97.8 % of the study subjects did not discuss their sexual health with their health care providers. Similarly, a study done by the North American Research committee on multiple sclerosis (NARCOMS) showed that only 20% of the patients were asked about their sexual dysfunction by their health care providers (Mahajan et al., 2014). In a study analyzing the search for care with regards to specific sexual problems conducted in 29 countries including Northern Europe: Austria, Belgium, Germany, Sweden and the UK; Southern Europe: France, Israel, Italy and Spain; non-European West: Australia, Canada, New Zealand, South Africa and the USA; Central/South America: Brazil and Mexico; Middle East: Algeria, Egypt, Morocco and Turkey; East Asia: China (including Hong Kong), Japan, Korea and Taiwan; South-east Asia: Indonesia, Malaysia, Philippines, Singapore and Thailand where the survey involved 27,500 men and women, only 9% of the interviewees were asked about their sexual function by their health care providers in the past three years; in fact, patients believe it is the healthcare providers role to inquire about their sexual health; they are grateful when asked about it (Moreira et al., 2005). A study conducted by Altmann et al (2021) that included ninety-three patients with MS and seventy-five neurologists treating MS in Austria showed that 84 % of the patients would be grateful to be asked about their sexuality by their neurologists, in contrast only 15% of the neurologists reported asking every patient about their sexuality. According to Gaviria- Carrillo et al (2022) where fifty Colombian neurologists answered a survey showed the main reasons for not talking about sexual dysfunction with patients with MS were: lack of knowledge (65.1%), presence of a companion (65.1%), lack of time (55.8%), discussing about sexual dysfunction generates anxiety and discomfort (14%) and not enough skill to manage those topics and therefore feels uncomfortable (16.3). A study conducted by Griswald et al (2003) surveyed a group of health-care professionals, members of the Consortium of Multiple Sclerosis Centers at Teaneck, New Jersey showed that the reasons why patients with MS are not evaluated for sexual dysfunction are: clinicians having limited time for patient encounters (44%), sexual health assessment perceived as being “outside of my role” (15.3%), patient discomfort

(12.5%), lack of training in addressing sexual health assessment (6.9%), other health priorities (5.6%), limited medical coverage (2.8%), the assessment perceived as being too intrusive for the patients (2.8%). According to a study conducted by Kisic-Tepavcevic et al (2015) where the study population was 93 patients (Females:66, Males:27) with MS who were assessed for sexual dysfunction at three points intervals (baseline, and at the 3- and 6-year follow-up) showed that the symptoms of sexual dysfunction were increasing in both genders during the period of observation. These symptoms include incomplete erections, erections not effective to penetrate, inability to ejaculate, premature ejaculation, and reduced libido in males and anorgasmia and difficulties in achieving orgasm, decreased vaginal lubrication, and reduced libido in females. Although there is literature looking into the "sentimental and sexual life" (in the context of assessment of the quality of life) of MS patients in Lebanon (Farran et al., 2020), there have not been studies assessing sexual dysfunction in patients with MS. However, there was a study in Lebanon involving obstetrics and gynecology physicians showed that only 31% of them almost always asked their patients about their sexual problems (El-Kak et al., 2004).

The first step in managing sexual dysfunction is to acknowledge that it is a significant problem that most patients with MS face during their lives. The second step is that patients need to talk with their health care providers about their sexual concerns. Management for sexual dysfunction can include consulting physical therapist who can provide pelvic floor muscle training and positioning techniques that can improve sexual comfort (Gopal et al., 2021), clinical psychologists play a huge role in supporting and counseling the patients and their partners about managing their specific sexual dysfunction, and providing interventions to improve self-esteem, treat anxiety and depression, and enhance their coping skills (Pöttgen et al., 2020).

A. Tools used for the Assessment of Sexual Dysfunction in patients with Multiple Sclerosis

The search was done using CINAHL, PubMed, AUB library and Google Schoolar. MESH words that were used during the search were “multiple sclerosis”, “sexual dysfunction”, “assessment tools”, “questionnaires”. Boolean operators like “AND” and “OR” were used. There are multiple tools that can be used to assess sexual dysfunction in patients with MS, but most are gender specific. These tools include Female Sexual Function Index, Sexual Dysfunction Management and Expectations Assessment in Multiple Sclerosis–Female that are specifically designed to assess sexual dysfunction in females with MS. On the other hand, International Index of Erectile Function is specifically used to assess sexual dysfunction in males with MS. There are also complementary tools that can help in assessing sexual dysfunction in patients with MS. These tools were developed for some other purpose, yet there is a section that addresses sexual dysfunction. These tools include Quality of Life Scales and Disability Scales such as Expanded Disability Status Scale, Patient Determined Disease Steps, Functional Independence Measure, and Guy’s Neurological Disability Scale (Gaviria Carrillo et al., 2023).

There are only two tools available that are designed to specifically assess sexual dysfunction in patients with MS that are not gender specific, Szasz Sexual Functioning Scale (SSFS) and Multiple Sclerosis Intimacy and Sexuality Questionnaire (MSISQ) 19 and 15 (Appendix I) (Foley et al., 2013; Gaviria Carrillo et al., 2023; Sanders et al., 2000; Szasz et al., 1984). The authors of the SSFS reported that, “the Sexual Function Scale, in itself, is insufficient to indicate the nature of sexual problem” (Audrey et al.,2000), thus, this tool is limited in its ability to assess the nature of sexual problem. MSISQ-19 is a valid tool; however, the study that was conducted to validate this tool had some limitations mainly the small sample size (155), the small percentage of men included (46 male participants), and the lack of cultural diversity of the sample (all participants were residents of New York) (Audrey et al.,2000). As a result, MSISQ-19 was revalidated with a bigger sample size, 6300 patients with MS were recruited from the North American Research Committee on Multiple Sclerosis (NARCOMS) registry where 1599 patients were males, and the scale was shortened to 15 items with a good validity and reliability, Cronbach’s alpha 0.923 (foley et al., 2013). A study was done by t Hoen et al., (2017) to systematically review which validated patient-reported outcome measures are available to evaluate sexual function in neurologic patients and to critically assess the quality of the validation studies showed that strong evidence was found only for MSISQ-19 and MSISQ-15 to evaluate sexual function in neurologic patients, MSISQ-15 had excellent internal consistency, content and structural validity while MSISQ-19 had good internal consistency and structural validity, and excellent content validity.

B. MSISQ-15

In the current project, we chose to use the MSISQ-15 because of its ability to assess sexual dysfunction in both genders and assess the effects of symptoms of MS on the patient’s sexual activity and satisfaction and due to its validity and reliability in previous studies on patients with MS (Appendix I). The MSISQ-15 has a high validity and reliability where

Cronbach’s alpha for the total scale is 0.92 and the subscales (primary, 0.87; secondary, 0.82; tertiary, 0.91). MSISQ-15 was translated to different languages with good validity and reliability. It was translated to Polish with Cronbach’s alpha coefficients of > 0.7 (Przydacz et al., 2021), Dutch with Cronbach's alpha of >0.8 (Noordhoff et al., 2018), French with Cronbach’s alpha of 0.90 (Lefebvre et al., 2023), Greek with Cronbach’s alpha >70 (Tzitzika et al., 2021), Croatian with Cronbach’s alpha of 0.93 (Uzarevic et al., 2021), Spanish with Cronbach’s alpha of 0.89 (Esteve Ríos et al., 2023), Italian with Cronbach’s alpha >0.7 (Monti et al., 2020) and Turkish with Cronbach's alpha coefficient > 0.80 (Dogan et al., 2022) . MSISQ-19 was translated to Arabic and used in a study to assess the pattern and magnitude of sexual dysfunction among patients with MS in Saudi Arabia, the translated Arabic version had good reliability with a Cronbach’s alpha of 0.81 that was assessed based on pilot sample of 20 patients. Correlation between scores of Arabic and original versions was done to assess content validity and it was found to be 0.93 (Alqahtani et al., 2020).

Intimacy and Sexuality Questionnaire-15 is a self-reporting questionnaire that assesses the impact of MS symptoms on sexual activity and satisfaction in the past 6 months (Appendix II). The questionnaire consists of 15 items that cover three domains primary, secondary, and tertiary sexual dysfunction. Primary sexual dysfunction subscale items: 8, 12, 13, 14, 15; secondary sexual dysfunction subscale items: 1, 2, 3, 4, 5; tertiary sexual dysfunction subscale items: 6, 7, 9, 10, 11. Each item is scored on a scale ranging from 1 (never interfered with my sexual activity or satisfaction) to 5 (always interfered with my sexual activity or satisfaction). The survey authors recommend that any question that is marked 4 or 5 be discussed with the healthcare providers. The questionnaire has a possible score of 15 to 75 (sum of the 15 items), where the higher the score the greater is the sexual dysfunction (Przydacz et al., 2021). This questionnaire will allow healthcare providers to address sexual dysfunction and treat them accordingly. Implementing this tool at the MS centers will help the healthcare providers to screen all patients with MS visiting the MS centers for sexual dysfunction as part of the regular screening.

CHAPTER III
METHODOLOGY

A. Project Design and Validity Definitions

This is a cross-sectional project for the assessment of face, content, and cultural validity of the Arabic MSISQ-15 in patients with MS at an MS Center in Lebanon.

"Face validity is an informal review of a questionnaire by non-experts, who assess its clarity, comprehensibility, and appropriateness for the target-group, whilst content validity involves a formal assessment by subject experts, to determine appropriateness of content and identify any misunderstandings or omissions" (Tanner, 2018). A test's face validity refers to how closely it appears to measure the concept or quality it is intended to. Face validity can be useful as a quick and easy way to assess a measure's apparent validity. However, it does not reliably indicate the test's actual validity. Face validity is essential because it affects a test's perceived credibility and acceptability. There are several ways to assess a test's face validity, including expert review, pretest, and observations. Expert review is where subject matter experts can review the test and provide their subjective judgment on whether it appears to be measuring what it's intended to. Pretest is where a small group of people can be asked to complete the test and provide feedback on whether the questions seem to be measuring the intended construct. The recommended sample size for pre-testing ranges between 15-30 subjects (Gunawan et al., 2021). Observations is where we can observe people completing the test and note any problems or difficulties they have when answering the questions (DeVellis, 2016).

Content validity is measured through expert judgment where experts in the field review the questions in the questionnaire and decide whether the questions cover the domain of interest. These experts provide feedback on whether the questionnaire items are relevant and appropriate for the desired domain of study (Creswell & Creswell, 2017). According to Gunawan et al., (2021) the recommended experts to test the content validity ranges between 2 to 20 experts. Another study (Zamanzadeh et al., 2015) recommended a minimum of 5 experts to check the instrument to ensure sufficient control over change agreement. Cultural validity is about how well a test or research method fits the cultural norms and values of the people being studied, ensuring accuracy without bias due to cultural differences (Kūkea Shultz & Englert, 2021).

B. Ethical Consideration

We sought IRB approval before initiating any contact with the participants. Approval from the Director of the MS center at AUBMC was sought as well. Consent from the participants was sought before approaching them by the research coordinator at the center and then we obtained their oral consent (Appendix IV).

C. Sampling

Purposeful sampling was conducted, and the maximum variation technique for the patients/ participants was used. Two registered nurses and three physicians (research fellows) working at the MS center at AUBMC and eleven patients with MS visiting the MS center at AUBMC were included. The maximum variation sampling technique was according to the following criteria: gender, marital status, religion, age, veiled and unveiled Muslim woman, has symptoms and asymptomatic. The inclusion criteria for the patients/ participants were having been diagnosed with multiple sclerosis, being older than18 years old, and being willing to participate in the project.

D. Data Collection

The MSISQ-15 was used in our project. We could not use the MSISQ-19 as translated into Arabic by Alqahtani et al (2020) research group since we were unable to obtain the Arabic translated version from the authors, thus we had an expert translator conduct the translation from English to Arabic, and one of the professors at AUB back-translated into English without looking at the original questionnaire to check for accuracy and equivalence of the translated materials (Lee et al., 2009). The health care providers were approached by the research coordinator at the center asking for their approval before we approached them. If they agreed to participate, they were invited to an interview that was planned according to their time and date preferences. The patients also were approached by the research coordinator at the center asking for their preliminary approval before we approached them, and then we obtained their oral consent (Appendix IV). To assess the face, content and cultural validity of the Arabic version, one-on-one interviews were conducted with the participants at the MS center at AUBMC in a quiet room. During the interview the participants were given an Arabic copy of the MSISQ-15 and asked to rate on a scale how well-understood and culturally appropriate and relevant the items are (Appendix III). Appropriateness is the extent to which the item is clear, unambiguous, and appropriate for the Lebanese population. Relevance is its fit with a concept pertinent to sexual dysfunction as a construct. The researcher observed the participants for any problems or difficulties when answering the questions. The time for each interview was around 30-40 minutes.

E. Data Analysis

Descriptive statistics (frequencies and percentages) will be presented. For the sake of this project, we followed the expert, pretest, and observations approaches to test the face validity and expert judgment to test the content validity. Cultural validity was assessed by evaluating the appropriateness of the questions within the Lebanese culture. The Arabic version of the MSISQ-15 was rated for appropriateness and relevance by all the participants using scoresheets provided in Appendix III.

Content validity index (CVI) for relevance was calculated both for item level (I-CVI) and scale level (S-CVI). Content validity index for relevance of each item I-CVI was calculated by dividing the number of those experts judging the item as relevant (“Extremely relevant” or Relevant but requiring minor modification”) by the total number of experts. S-CVI is the sum of all I-CVIs divided by the total number of items (Zamanzadeh et al., 2015). Cultural validity index was calculated by dividing the number of those experts judging the item as appropriate (“Appropriate” or “Slightly appropriate”) by the total number of experts. The whole scale cultural validity is the sum of the cultural validity indices divided by the total number of items.

CHAPTER IV

RESULTS

A. Healthcare Providers (Experts) Characteristics

There were five healthcare providers (experts) including three research fellows and two registered nurses working at the MS center at AUBMC. All the three research fellows were medical doctors who recently graduated from medical school and were hired as research fellows in the MS center. Registered nurses had several years of experience.

Table 1. Healthcare Providers (Experts) Characteristics

	Research Fellow 1	Research Fellow 2	Research Fellow 3	Registered Nurse 1	Registered Nurse 2
Gender	Male	Male	Male	Female	Female
Age	25	25	25	30	34
Years of experience (Years)	1	1	1	9	12
Married	No	No	No	Yes	Yes

B. Patients Characteristics

The sample included 11 patients with MS. Patients' age ranged from 27 to 69 years old, with a mean of 45.3. Majority of the sample were females (63.6%). There were 5 Muslim females where 4 of them were veiled. More than half of the sample had symptoms of MS (63.6%). Most of the sample were married (81.8%). As for the religion, 63.6% of the sample were Muslim, 27.3 were Christian and 9.1% was Druze. As for the education, 54.5% had college degree. Patients' year of diagnosis with MS ranged from 2008 to 2024 (Table 2).

Table 2. Patients Characteristics

	All patients (n/%) (Total N= 11)
Age Category:	
18-30 years	1
31-40 years	3
41-50 years	4
>51 years	3
Gender:	
Male	4 (36.4%)
Female	7 (63.6%)
Veiled Muslim female	4 (80%)
Unveiled Muslim female	1 (20%)
Symptomatic	7 (63.6%)
Asymptomatic	4 (36.4%)
Married	9 (81.8%)
Unmarried	2 (18.2%)
Religion:	
Muslim	7 (63.6%)
Christian	3 (27.3%)
Druze	1 (9.1%)
Education:	

School	5 (45.5%)
College/University	6 (54.5%)
Year of diagnosis with MS:	
2005-2010	2
2011-2020	6
2021-2024	3

C. Appropriateness and Relevance

As shown in Table 3, two research fellows and one registered nurse rated all items as “Appropriate”. One research fellow rated the second and the third questions as “Slightly inappropriate” in terms of language and noted that they will not be understood by the Lebanese population and suggested minor modification. He also suggested adding "تخدير" to the eighth question to improve clarity. One of the registered nurses rated the sixth and seventh questions as “Slightly appropriate” to be used within the Lebanese population. All items were rated as “Extremely relevant” by all experts except the third question, one research fellow rated it as “inability to assess relevance without revision” because he was unfamiliar with bowel symptoms affecting sexual function.

Table 3. Arabic MSISQ-15 Items Rating for Appropriateness and Relevance by Healthcare Providers (Experts).

Arabic MSISQ-15 questions	Number of experts	Appropriateness rating	Number of experts	Relevance Rating	Comments	Questions modified
تقلص العضلات أو تشنجات في ذراعي أو ساقي أو جسدي	5 (100%)	Appropriate	5 (100%)	Extremely relevant		
أعراض المثانة أو المسالك البولية	4 (80%) 1 (20%)	Appropriate Slightly inappropriate	5 (100%)	Extremely relevant	"المثانة might not be understood”	أعراض المثانة أو المسالك البولية مثل تبول لا ارادي او تكرار التبول او الحاجة الملحة للتبول
أعراض الأمعاء	4 (80%) 1 (20%)	Appropriate Slightly inappropriate	4 (80%) 1 (20%)	Extremely relevant Inability to assess relevance without revision	“Specify examples”	أعراض الأمعاء مثل الإمساك او خروج لا ارادي او الحاجة

						الملحة للخروج
ارتعاش أو رجفة في يدي أو جسدي	5 (100%)	Appropriate	5 (100%)	Extremely relevant		
الشعور بالألم أو الحرقان أو انزعاج في جسدي	5 (100%)	Appropriate	5 (100%)	Extremely relevant		
الشعور بأن جسدي أصبح أقل جاذبية	4 (80%) 1 (20%)	Appropriate Slightly appropriate	5 (100%)	Extremely relevant		
الشعور بقلة الرجولة أو الأنوثة بسبب مرض التصلب المتعدد	4 (80%) 1 (20%)	Appropriate Slightly appropriate	5 (100%)	Extremely relevant		
شعور أقل أو تنميل في أعضائي التناسلية	5 (100%)	Appropriate	5 (100%)	Extremely relevant	A research fellow preferred to add تخدير	شعور أقل أو تنميل او تخدير في أعضائي التناسلية
الخوف من التعرض للرفض الجنسي بسبب	5 (100%)	Appropriate	5 (100%)	Extremely relevant		

مرض التصلب المتعدد						
قلق بشأن إرضاء شريكي جنسيًا	5 (100%)	Appropriate	5 (100%)	Extremely relevant		
الشعور بثقة أقل بشأن حياتي الجنسية بسبب مرض التصلب المتعدد	5 (100%)	Appropriate	5 (100%)	Extremely relevant		
عدم وجود اهتمام جنسي أو رغبة جنسية	5 (100%)	Appropriate	5 (100%)	Extremely relevant		
النشوة أو الذروة أقل شدة أو متعة	5 (100%)	Appropriate	5 (100%)	Extremely relevant		
أستغرق وقتًا طويلا للوصول إلى النشوة أو الذروة	5 (100%)	Appropriate	5 (100%)	Extremely relevant		
رطوبة وإفرازات غير كافية في المهبل (لدى النساء),	5 (100%)	Appropriate	5 (100%)	Extremely relevant		

صعوبة الحصول على انتصاب مُرضٍ او الحفاظ عليه (لدى الرجال)						

As shown in Table 4, all items were clear and understandable by the patients except the second and third questions; patients did not understand these two questions during the interview until examples were added to each, after which they found them appropriate. A patient preferred adding "تخدير" to the eighth question. During the interview, a 69-year-old veiled Muslim patient initially felt that some of the questions were inappropriate to ask, expressing conservatism. However, after we explained the importance of asking these questions to assess sexual dysfunction in patients with MS, she reconsidered and rated all questions as “Appropriate”. One of the patients rated the fourth question as “Irrelevant”, as she believed the symptom does not lead to sexual dysfunction. Another patient rated the tenth and eleventh question as “Irrelevant”, this patient was recently diagnosed with MS, so she felt downhearted and saddened. She believed that worrying about sexually satisfying her partner and being confident about her sexuality is irrelevant and did not affect her sexual function. All items of the questionnaire were rated as “Extremely relevant” by most of the patients. Some items were rated as “Inability to assess relevance without revision” by some of the patients, this is because they had not experienced the symptoms inquired about, making it difficult for them to relate.

Table 4. Arabic MSISQ-15 Items Rating for Appropriateness and Relevance by Patients.

Arabic MSISQ-15 questions	Number of patients	Appropriateness rating	Number of patients	Relevance rating	Comments
تقلص العضلات أو تشنجات في ذراعي أو ساقي أو جسدي	11 (100%)	Appropriate	11 (100%)	Extremely relevant	
أعراض المثانة أو المسالك البولية	11 (100%)	Appropriate	10 (90.9%) 1 (9.1%)	Extremely relevant Inability to assess relevance without revision	
أعراض الأمعاء	11 (100%)	Appropriate	10 (90.9%) 1 (9.1%)	Extremely relevant Inability to assess relevance without revision	
ارتعاش أو رجفة في يدي أو جسدي	11 (100%)	Appropriate	8 (72.7%) 2 (18.2%)	Extremely relevant Inability to assess relevance	

			1 (9.1%)	without revision Irrelevant	
الشعور بالألم أو الحرقان أو انزعاج في جسدي	11 (100%)	Appropriate	11 (100%)	Extremely relevant	
الشعور بأن جسدي أصبح أقل جاذبية	11 (100%)	Appropriate	11 (100%)	Extremely relevant	
الشعور بقلة الرجولة أو الأنوثة بسبب مرض التصلب المتعدد	11 (100%)	Appropriate	11 (100%)	Extremely relevant	
شعور أقل أو تنميل في أعضائي التناسلية	11 (100%)	Appropriate	10 (90.9%) 1 (9.1%)	Extremely relevant Inability to assess relevance without revision	A Patient preferred to add تخدير
الخوف من التعرض للرفض الجنسي بسبب مرض التصلب المتعدد	11 (100%)	Appropriate	11 (100%)	Extremely relevant	

قلق بشأن إرضاء شريكي جنسيًا	11 (100%)	Appropriate	10 (90.9%) 1 (9.1%)	Extremely relevant Irrelevant	This patient was recently diagnosed with MS, so she felt downhearted and saddened
الشعور بثقة أقل بشأن حياتي الجنسية بسبب مرض التصلب المتعدد	11 (100%)	Appropriate	10 (90.9%) 1 (9.1%)	Extremely relevant Irrelevant	This is the same patient who was recently diagnosed, so she felt downhearted and saddened
عدم وجود اهتمام جنسي أو رغبة جنسية	11 (100%)	Appropriate	11 (100%)	Extremely relevant	
النشوة أو الذروة أقل شدة أو متعة	11 (100%)	Appropriate	11 (100%)	Extremely relevant	
أستغرق وقتًا طويلا للوصول إلى النشوة أو الذروة	11 (100%)	Appropriate	10 (90.9%) 1 (9.1%)	Extremely relevant Inability to assess relevance without revision	
رطوبة وإفرازات غير كافية في المهبل (لدى	11 (100%)	Appropriate	11 (100%)	Extremely relevant	

النساء), صعوبة الحصول على انتصاب مُرضٍ او الحفاظ عليه (لدى الرجال)					

Table 5. I-CVI and S-CVI for Relevance of the Arabic MSISQ-15.

Items of the Arabic MSISQ-15	I-CVI
Item- 1	1
Item- 2	1
Item- 3	0.8
Item- 4	1
Item- 5	1
Item- 6	1
Item- 7	1
Item- 8	1
Item- 9	1
Item- 10	1
Item- 11	1
Item- 12	1
Item- 13	1
Item- 14	1
Item- 15	1

S-CVI = 0.987

Table 6. Cultural Validity Indices of the Arabic MSISQ-15 Items.

Items of the Arabic MSISQ-15	Cultural Validity Index
Item- 1	1
Item- 2	0.8
Item- 3	0.8
Item- 4	1
Item- 5	1
Item- 6	1

Item- 7	1
Item- 8	1
Item- 9	1
Item- 10	1
Item- 11	1
Item- 12	1
Item- 13	1
Item- 14	1
Item- 15	1

Scale Cultural Validity = 0.973

Face validity was assessed based on experts' opinion and patients' rating for relevance and appropriateness of the questionnaire and based on our observation for any problems and misunderstanding of the questions during the interviews. Therefore, the questionnaire (after amendment of the second and third questions) was evaluated to have good face validity. The overall questionnaire was deemed credible to participants, and appeared adequate for the assessment of primary, secondary, and tertiary sexual dysfunction. They didn't have any negative comments toward the questionnaire. Our project showed that the S-CVI of the MSISQ-15 Arabic version was 0.987 and the I-CVIs ranged from 0.8 to 1 (Table 5). Cultural validity indices ranged from 0.8 to 1. The overall cultural validity of the scale was 0.973 (Table 6). After using the modified version of the second and third questions, all items were deemed appropriate for the cultural context by all the patients.

CHAPTER V
DISCUSSION

Our project was designed to test the face, content, and cultural validity of the MSISQ-15 Arabic version. Our project findings present a preliminary overview on the Arabic MSISQ-15 for use in MS patients in Lebanon. Researchers suggest that an ideal scale with excellent content validity should consist of I-CVIs of 0.78 or higher and S-CVI of 0.9 or higher (Shi et al., 2012). This shows that our project has excellent content validity. In the Polish (Przydacz et al., 2021), Dutch (Noordhoff et al., 2018) and French (Lefebvre et al., 2023) versions, patients found the translated questionnaire to be clear, understandable, and easy to complete during the pre-testing phase which indicate good face validity and had adequate content validity. Our project showed that most of the questions in the Arabic version were clear and understandable except the second and third questions that required some modifications. After adding examples to each (such as urinary incontinence for the second item and stool incontinence for the third item), they were deemed as understandable and clear by the patients.

Previously, the MSISQ-19 was translated to Arabic prior our project and used in a study to assess the pattern and magnitude of sexual dysfunction among patients with MS in Saudi Arabia, their translated Arabic version had good reliability with a Cronbach's alpha of 0.81 that was assessed based on pilot sample of 20 patients. Correlation between scores of their Arabic and original versions was done to assess content validity and it was found to be 0.93 (Alqahtani et al., 2020). We were unable to get the Arabic version from the authors. Our

Arabic MSISQ-15 had a high content validity of 0.987. The Arabic version of the questionnaire has not been used in any Arabic speaking country except in the research study conducted in Saudi-Arabia. The study conducted in Saudi-Arabia only tested the internal consistency and content validity of the questionnaire. Cultural validity was not tested in any Arabic speaking country. The Arabic MSISQ-15 seemed to be a culturally acceptable tool for assessing sexual dysfunction in patients with MS in Lebanon. Cultural differences can impact the result of cultural validity thus it should be considered. For example, in some cultures patients might have different perceptions regarding sexual dysfunction, some might believe that the discussions about sexuality are considered taboo, and that sexual dysfunction may be seen as a private matter not to be openly discussed while in others, they might believe that it is an important subject to be discussed with the healthcare providers. These cultural differences can affect the patient's perception towards the appropriateness of the items in the questionnaire. We recommend that for those who will be using the instrument in the future to use the following items based on the modifications we made:

- أعراض المثانة أو المسالك البولية مثل تبول لا ارادي او تكرار التبول او الحاجة الملحة للتبول 2
- أعراض الأمعاء مثل الإمساك او خروج لا ارادي او الحاجة الملحة للخروج 3

The above second and third items were modified based on expert feedback, as they were deemed slightly inappropriate due to lack of clarity. After modification, they were used during our interviews with the patients and were rated as appropriate. During the translation process, the word "Numbness" in the 8th item was translated as "تنميل" which doesn't exactly mean numbness, so it was suggested by an expert to add "تخدير” to the item to improve clarity but it wasn’t tested during the interviews with the patients. Similarly, in the Turkish version modifications to the translated items were done by experts (three physical therapists and a neurologist) and some terms in the questionnaire were replaced with culturally appropriate ones in terms of language. The items were modified according to experts’ suggestions before administering the questionnaire to the patients, after that further revision to the items were also made based on the patients’ suggestions (Dogan et al., 2022). On the other hand, in the Spanish version, there were 4 translators, 2 translated from English to Spanish and 2 back translated to English, and modifications were made according to the translators’ suggestions. The Spanish version was not assessed by experts, it was only assessed by patients where they found the questionnaire understandable (Esteve Ríos et al., 2023). Findings from this project helped in the refinement of the translated items of the assessment questionnaire to be better understood and interpreted in our cultural context. Thereafter, further testing will be warranted for validity and reliability in the Lebanese population, and for proposing any modification to the tool. After establishing its validity and reliability, this questionnaire will facilitate the assessment of the impact of MS symptoms on sexual activity and satisfaction in both clinical practice and research settings in the Lebanese population.

A. Strength

To the best of our knowledge, our project is the first to test the face, content, and cultural validity of an Arabic questionnaire that assesses the impact of MS symptoms on sexual activity and satisfaction in Lebanon. Our findings demonstrates that the Arabic MSISQ-15 has good face validity, adequate content, and cultural validity.

B. Limitation

One of the limitations is that we opted to only assess face, content, and cultural validity due to the limited timeframe available for project completion. We need to reassess validity after modifications that have been made. The sample was selected only from the MS center at AUBMC so our findings cannot be generalized.

C. Recommendations

Replicating the project with a larger sample size: The project's sample size was relatively small, which could limit the generalizability of the results. Therefore, it is recommended to conduct a similar project with a larger sample size from multiple settings to increase the power of the project. It will be important to conduct a study with the modifications that we made to the items, and examine construct validity, and reliability. It is recommended to conduct studies on sexual dysfunction in patients with MS in Lebanon including the prevalence and incidence.

D. Conclusion

As a preliminary overview, the Arabic version of the MSISQ-15 has good face validity and adequate content and cultural validity in the Lebanese population for assessing the impact of MS symptoms on sexual activity and satisfaction. Minor modifications may further improve cultural appropriateness. Importantly, the incidence and prevalence of sexual dysfunction in MS among the Lebanese are unclear due to the lack of epidemiological studies. The use of a valid and reliable Arabic tool can help better identify and treat MS patients with sexual dysfunction.

APPENDIX I

TOOLS THAT ARE NON-GENDER SPECIFIC TO ASSESS SEXUAL DYSFUNCTION IN PATIENTS WITH MS

Name of first Author and reference	Study name	Population	Tool name	Validity and Reliability
Tzitzika, M. (Tzitzikaet al., 2023)	Sexual Rehabilitation and Relational Satisfaction in People with Multiple Sclerosis and their Partners	120 participants with MS from Greece consisted of 60 couples with 51.75% being women and 48.3% men since two couples were same-sex	MSISQ-15	Reliability analysis yielded very satisfactory results for every assessment (baseline assessment: α = 0.867, 2nd assessment 10 weeks after: α = 0.870, six months later α = 0.877)
Tzitzika, M Tzitzika et al., 2020)	Prevalence of Sexual Dysfunction Among Greek MS Patients	866 patients with MS from Greece Women: n=576 Men: n=290 Age: 46.34 ± 10.37 years	MSISQ-15	α = 0.867
Carolyn A young (Young et al., 2017)	Sexual functioning in multiple sclerosis: Relationships with depression, fatigue and physical function	432 patients with MS from several UK centers Male: n=124 Female: n=308 Age: 18-58+ years	MSISQ-15	MSISQ-15-P: α=0.82 MSISQ-15-S: α:0.85 MSISQ-15-T: α=0.86
Tudor, Katarina Ivana (Tudor et al., 2015)	BARRIERS IN CLINIC TO DISCUSSING SEXUAL DYSFUNCTION DUE TO MULTIPLE SCLEROSIS	74 patients with MS in London/UK Male: n=20 Female: n=54 (Mean age 45,877±8,823 years))	MSISQ-15	Results are restricted

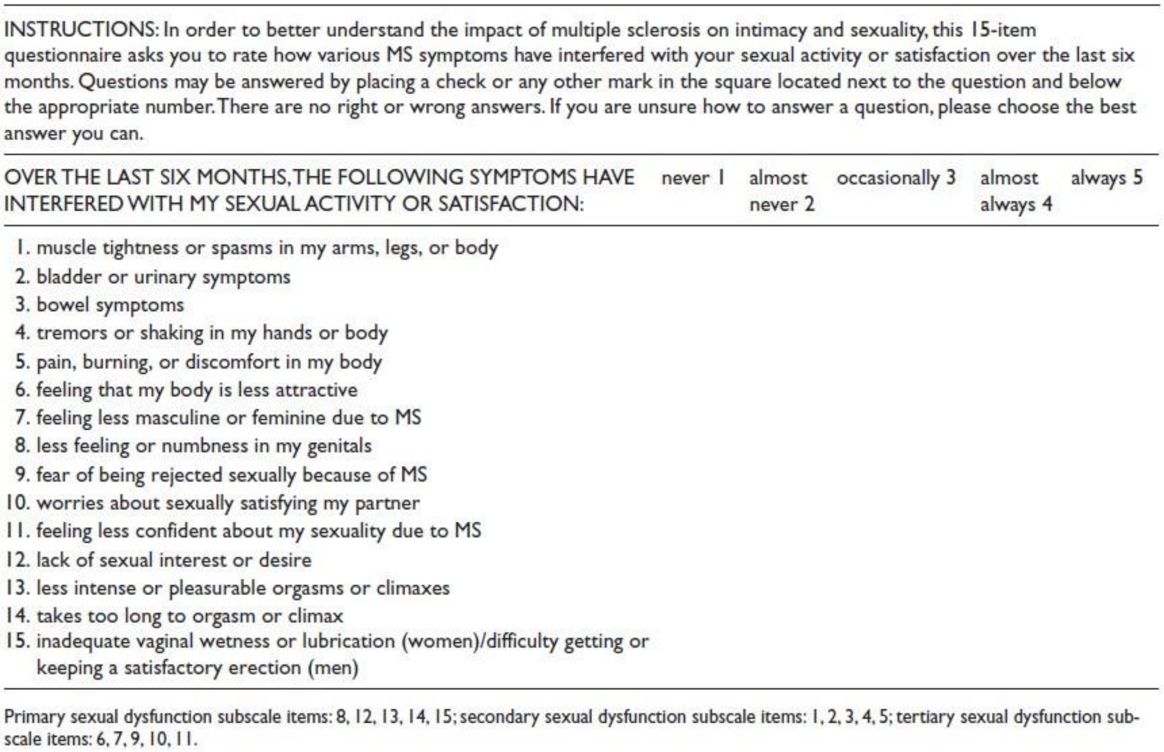
Katarina Ivana Tudor (Tudor et al., 2018)	Identifying barriers to help-seeking for sexual dysfunction in multiple sclerosis	74 patients with MS in UK Male: n=20 Female: n=54 42.4 ± 10.7 years (range 21–64)	MSISQ-15	” (MSISQ), a validated 15-item questionnaire (Reference)” Cronbach’s alpha for the total scale (0.92) and the subscales (primary, 0.87; secondary, 0.82; tertiary, 0.91) (Foley et al., 2013)
Hanna Pašiü (Pašić et al., 2019)	SEXUAL DYSFUNCTION AND DEPRESSION IN PATIENTS WITH MULTIPLE SCLEROSIS IN CROATIA	101 patients with MS from Croatia Male: n=26 Female: n=75 Age: mean age 42.09 (range 19-77) years	MSISQ-15	α =0.930
Kisic-Tepavcevic Darija (Darija et al., 2015)	Sexual dysfunction in multiple sclerosis: A 6-year follow-up study	93 participants with MS from Serbia 29% male and 71% female Age: 20-61 years	Szasz sexual functioning scale	The main drawback is that they have used Szasz sexual functioning scale, previously proposed in the study of Zorzon et al which has not been validated
DK Tepavcevic (Tepavcevic et al., 2008)	The impact of sexual dysfunction on the quality of life measured by MSQoL-54 in patients with multiple sclerosis	109 patients with MS from Serbia Male: n=31 Female: n=78 Age: 41.7 ± 8.7 years	Szasz sexual functioning scale	Validity and reliability of the tool were not mentioned
Franziska Di Pauli (Di Pauli et al., 2023)	Sexual dysfunction in female and male people with multiple sclerosis: disability, depression and	152 patients with MS from Austria Male: n=50 Female: n=102 Age: 44 (±11) years	MSISQ-19	Validity and reliability weren’t mentioned.

	hormonal status matter			
Nabavi, Seyed Massood (Nabavi et al., 2021)	Prevalence of Sexual Dysfunction and Related Risk Factors in Men with Multiple Sclerosis in Iran: A Multicenter Study.	320 participants with MS from Iran Only men Age: 17-72 years	MSISQ-19	"This questionnaire was validated and assessed for reliability by Mohammadi et al. [[28]] in Iran". MSISQ-19 (0.90) and for the primary (0.85), secondary (0.90) and tertiary (0.78) subscales (Mohammadi et al., 2014)
Khadijeh Mohammadi (Mohammadi et al., 2020)	sexuality among young women with multiple sclerosis	117 patients with MS from Iran Only women Age: ≤35 year	MSISQ-19	"Psychometric properties of the Iranian version of MSISQ-19 are well documented (Reference)". MSISQ-19 (0.90) and for the primary (0.85), secondary (0.90) and tertiary (0.78) subscales (Mohammadi et al., 2014)
Effat Merghati-Khoei (Merghati-Khoei et al., 2013)	Sexual problems among women with multiple sclerosis	132 patients with MS from Iran Only women Age: 20-58 years	MSISQ-19	Validity and reliability of the tool were not mentioned
Pawel Dobrakowski Dobrakowski et al., 2020	Sexual Satisfaction in Fully Ambulatory People with Multiple Sclerosis: Does Disability Matter?	76 patients with MS from Zabrze/Poland Male: n=30 Female: n=46 Age: 21-54 years	MSISQ-19	Cronbach's alpha: 0.82–0.87
Elham Manouchehri (Manouchehri et al., 2021)	Evaluation of sexual self-efficacy and sexual function in women with	260 patients with MS from Iran Women only Age: 18-53 years	MSISQ-19	Cronbach's alpha coefficient of the whole scale was 0.90 and of the primary, secondary, and tertiary subscales

	multiple sclerosis in Mashhad, Iran, in 2019: A cross-sectional study			was 0.85, 0.90, and 0.78, respectively.
Samantha Domingo (Domingo et al., 2018)	Factors Associated with Sexual Dysfunction in Individuals with Multiple Sclerosis Implications for Assessment and Treatment	162 patients with MS from Cleveland, OH/USA Female: n= 126 Male: n= 36 Age: 45.55 ± 9.52	MSISQ-19	“MSISQ-19 has been validated in the MS population (Reference)” Internal consistency for the whole scale (α =0 .91) and for the primary (α =0 .82), secondary (α=0 .85) and tertiary (α=0 .87) subscales (Sanders et al., 2000)
Zina Ali Alqahtani (Alqahtani et al., 2020)	Sexual dysfunction among married multiple sclerosis patients in Kingdom of Saudi Arabia 2020	303 patients with MS from Saudi Arabia Female: n= 157 Male: n=146	MSISQ-19	Cronbach’s alpha of 0.81

APPENDIX II

MSISQ-15 (ENGLISH AND ARABIC VERSION)



INSTRUCTIONS: In order to better understand the impact of multiple sclerosis on intimacy and sexuality, this 15-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 1	almost never 2	occasionally 3	almost always 4	always 5
1. muscle tightness or spasms in my arms, legs, or body					
2. bladder or urinary symptoms					
3. bowel symptoms					
4. tremors or shaking in my hands or body					
5. pain, burning, or discomfort in my body					
6. feeling that my body is less attractive					
7. feeling less masculine or feminine due to MS					
8. less feeling or numbness in my genitals					
9. fear of being rejected sexually because of MS					
10. worries about sexually satisfying my partner					
11. feeling less confident about my sexuality due to MS					
12. lack of sexual interest or desire					
13. less intense or pleasurable orgasms or climaxes					
14. takes too long to orgasm or climax					
15. inadequate vaginal wetness or lubrication (women)/difficulty getting or keeping a satisfactory erection (men)					

Primary sexual dysfunction subscale items: 8, 12, 13, 14, 15; secondary sexual dysfunction subscale items: 1, 2, 3, 4, 5; tertiary sexual dysfunction subscale items: 6, 7, 9, 10, 11.

مرض التصلب المتعدد وتأثيره على الحياة الجنسية والعلاقة الحميمة

استبيان رقم 15

التعليمات: من أجل فهم أفضل لتأثير مرض التصلب المتعدد على الحياة الجنسية والعلاقة الحميمة، الرجاء تعبئة هذا الاستبيان المؤلف من 15 عبارة تقييمية. يهدف هذا الاستبيان إلى تقييم مدى تأثير أعراض مرض التصلب المتعدد على النشاط الجنسي أو الرضا الجنسي خلال الأشهر الستَة الماضية. يُمكن الإجابة على الأسئلة عن طريق وضع علامة (√) أو أي علامة في المربع الموجود بجانب السؤال وأسفل الرقم المناسب. لا توجد إجابات صحيحة أو خاطئة. وإذا لم تكن متأكدا من كيفية الإجابة عن السؤال فيُرجى اختيار أفضل إجابة ممكنة.

على مدى الأشهر الستة الماضية، تداخلت الأعراض التالية مع نشاطي أو شعوري بالرضا الجنسي:	أبدًا 1	تقريبًا أبدًا 2	أحيانًا 3	تقريبا دائما 4	دائماً 5
1. تقلص العضلات أو تشنجات في ذراعي أو ساقي أو جسدي					

2. أعراض المتانة أو المسالك البولية					
3. أعراض الأمعاء					
4. ارتعاش أو رجفة في يدي أو جسدي					
5. الشعور بالألم أو الحرقان أو انزعاج في جسدي					
6. الشعور بأن جسدي أصبح أقل جاذبية					
7. الشعور بقلة الرجولة أو الأنوثة بسبب مرض التصلب المتعدَد					
8. شعور أقل أو تنميل في أعضائي التناسلية					
9. الخوف من التعرض للرفض الجنسي بسبب مرض التصلب المتعدَد					
10. قلق بشأن إرضاء شريكي جنسيًا					
11. الشعور بثقة أقل بشأن حياتي الجنسية بسبب مرض التصلب المتعدَد					
12. عدم وجود اهتمام جنسي أو رغبة جنسيَة					
13. النشوة أو الذروة أقل شدَة أو مُتعة					
14. أستغرق وقتًا طويلاً للوصول إلى النشوة أو الذروة					
15. رطوبة وإفرازات غير كافية في المهبل (لدى النساء)، صعوبة الحصول على انتصاب مُرضٍ أو الحفاظ عليه (لدى الرجال).					

العناصر الأساسية لخلل الوظيفة الجنسية 8 12، 13، 14، 15، العناصر الثانوية لخلل الوظيفة الجنسية: 1، 2، 3، 4، 5، العناصر الثالثية لخلل الوظيفة الجنسية: 6، 7، 9، 10، 11

APPENDIX III

TOOL APPROPRIATENESS AND RELEVANCE RATING SCALE

You are kindly asked to rate each of the fifteen items of the Arabic MSISQ-15 screening tool for cultural appropriateness and conceptual relevance.

Appropriateness is the extent to which the item is clear, unambiguous, and appropriate for the Lebanese population. The rating is on a 4-point scale using the following criteria: 1 = inappropriate, 2 = slightly inappropriate, 3 = slightly appropriate, and 4 = appropriate. Please use the table below to rate the items for appropriateness and note under "Comments" any changes in wording or other that you think are needed.

Item	Appropriateness Rating	Comments
1. تقلص العضلات أو تشنجات في ذراعي أو ساقي أو جسدي		
2. أعراض المثانة أو المسالك البولية		
3. أعراض الأمعاء		
4. ارتعاش أو رجفة في يدي أو جسدي		
5. الشعور بالألم أو الحرقان أو انزعاج في جسدي		
6. الشعور بأ ن جسدي أصبح أقل جاذبية		
7. الشعور بقلة الرجولة أو الأنوثة بسبب مرض التصلب المتعدد		
8. شعور أقل أو تنميل في أعضائي التناسلية		
9. الخوف من التعرض للرفض الجنسي بسبب مرض التصلب المتعدد		
10. قلق بشأن إرضاء شريكي جنسيًا		

11. الشعور بثقة أقل بشأن حياتي الجنسية بسبب مرض التصلب المتعدد		
12. عدم وجود اهتمام جنسي أو رغبة جنسية		
13. النشوة أو الذروة أقل شدة أو متعة		
14. أستغرق وقتًا طويلا للوصول إلى النشوة أو الذروة		
15. رطوبة وإفرازات غير كافية في المهبل (لدى النساء)، صعوبة الحصول على انتصاب مرضٍ أو الحفاظ عليه (لدى الرجال)		

The item's **relevance** is its fit with a concept pertinent to sexual dysfunction as a construct. Please rate each item for relevance from 1 to 4 using the following criteria: 1 = irrelevant; 2 = inability to assess relevance without revision; 3 = relevant but requiring minor modification; 4 = extremely relevant.

Item	**Relevance Rating**	**Comments**
1. تقلص العضلات أو تشنجات في ذراعي أو ساقي أو جسدي		
2. أعراض المثانة أو المسالك البولية		
3. أعراض الأمعاء		
4. ارتعاش أو رجفة في يدي أو جسدي		
5. الشعور بالألم أو الحرقان أو انزعاج في جسدي		
6. الشعور بأ ن جسدي أصبح أقل جاذبية		

7. الشعور بقلة الرجولة أو الأنوثة بسبب مرض التصلب المتعدد		
8. شعور أقل أو تنميل في أعضائي التناسلية		
9. الخوف من التعرض للرفض الجنسي بسبب مرض التصلب المتعدد		
10. قلق بشأن إرضاء شريكي جنسيًا		
11. الشعور بثقة أقل بشأن حياتي الجنسية بسبب مرض التصلب المتعدد		
12. عدم وجود اهتمام جنسي أو رغبة جنسية		
13. النشوة أو الذروة أقل شدة أو متعة		
14. أستغرق وقتًا طويلا للوصول إلى النشوة أو الذروة		
15. رطوبة وإفرازات غير كافية في المهبل (لدى النساء)، صعوبة الحصول على انتصاب مرضٍ أو الحفاظ عليه (لدى الرجال)		

APPENDIX IV

ORAL CONSENT

(Oral consent script) Hello. My name is Aya Azzam. I am a graduate student in the Hariri School of Nursing at AUB. This notice is for an AUB-IRB Approved Research project for Dr. Myrna Doumit principal investigator at AUB. I would like to invite you to participate in a research project about testing the face, cultural, and content validity of the Arabic version of the Multiple Sclerosis Intimacy and Sexuality Questionnaire-15, which is about asking you whether in your opinion the items in the questionnaire are appropriate and relevant. Before we begin, I would like to take a few minutes to explain why I am inviting you to participate, and what will be done with the information you provide. You will be asked to participate in a short interview. Please stop me at any time if you have questions about the project. I am doing this project as part of my studies at AUB. I will be interviewing around 16 person including patients with multiple sclerosis visiting the multiple sclerosis center and health care providers working at the multiple sclerosis center at AUBMC, asking them to read each question of the Arabic version of the questionnaire and rate on a scale how appropriate and relevant the questions are and will use the information as the basis for my project dissertation. I may also use this information in articles that might be published, as well as in academic presentations. Your individual privacy and confidentiality of the information you provide will be maintained in all published and written data analysis resulting from the project. Your name will not be disclosed, however with your permission your religion, marital status, gender, symptomatic or not, veiled or not, age, year of diagnosis and education will be shared with the project readers and with the audience during my project dissertation and might be published in articles as well. Your participation should take approximately 30-40 minutes. Please understand your participation is entirely on a voluntary basis and you have the right to withdraw your consent or discontinue participation at any time without penalty. During the interview the questions that will be asked are about sexual function and symptoms caused by multiple sclerosis that will affect the sexual function. The benefit which may reasonably be expected to result from this project is developing an appropriate and relevant Arabic version of the Multiple Sclerosis Intimacy and Sexuality Questionnaire-15. It is important to note that there will be no payment or compensation for participation. If at any time and for any reason, you would prefer not to answer any questions, please feel free to skip those questions. If at any time you would like to stop participating, please tell me. We can take a break, stop and continue at a late date, or stop altogether. You will not be penalized for deciding to stop participation at any time. In case you feel disturbed you have the full right to stop the interview and to ask for support from the research coordinator Ms. Lina Malaeb. Interrupting the interview will not interfere with our care at the center nor with our relationship with your physician. I would like to tape record this interview so as to make sure that I remember accurately all the information you provide, the recordings will be kept under a secure code that no one has access to it except me. These tapes will be deleted after the research project is completed. You can also participate without being taped and instead handwritten notes will be taken. If you have any questions, you are free to ask them now. If you have questions later, you may contact me at aaa264@mail.aub.edu. If you have concerns about the project or questions about your rights as a participant, you can contact the AUB IRB Office at irb@aub.edu.lb or 5445.

Participant agrees to participate. ☐

Participant agrees to be audio recorded. ☐

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