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Frequency of sexual dysfunction in women with rheumatic diseases

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ABSTRACT

Objective: To assess the prevalence of sexual dysfunction in women followed up at the Rheumatology Outpatient Clinic of the Hospital Universitário de Brasília and of the Hospital das Clínicas da Universidade de São Paulo with the following rheumatic diseases: systemic lupus erythematosus; rheumatoid arthritis; systemic sclerosis; antiphospholipid antibody syndrome; and fibromyalgia. **Methods:** The Female Sexual Function Index (FSFI), obtained by applying a 19-item questionnaire that assesses six domains (sexual desire, arousal, vaginal lubrication, orgasm, sexual satisfaction and pain), was used. **Results:** This study assessed 163 patients. The mean age was 40.4 years. The prevalence of sexual dysfunction was 18.4%, but 24.2% of the patients reported no sexual activity over the past 4 weeks. Patients with fibromyalgia and systemic sclerosis had the highest sexual dysfunction index (33%). Excluding patients with no sexual activity, the sexual dysfunction rate reaches 24.2%. **Conclusion:** The prevalence of sexual dysfunction found in this study was lower than that reported in the literature. However, 24.2% of the patients interviewed reported no sexual activity over the past 4 weeks, which might have contributed to the low sexual dysfunction index found.

Keywords: sexuality, sexual dysfunction, rheumatic diseases, quality of life, sexual behavior.

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INTRODUCTION

Sexuality is part of human life and of quality of life, accounting for individual well-being. It relates not only to sexual intercourse itself, but also to a whole spectrum that ranges from self-image and self-valuing to relationship with the 'Other'. Appropriate sexual activity comprises phases from sexual arousal to relaxation, with pleasure and satisfaction.¹

Sexual dysfunction is a change in a phase of the sexual activity that can culminate in frustration, pain, and a reduction

in the number of sexual intercourses.² Some studies have shown a prevalence of sexual dysfunction in the general female population of as much as 40%.³ Chronic diseases are known to influence the quality of sexual life, but their effect is little studied, and sexual dysfunction, little diagnosed.² This is due to two reasons: patients do not report their sexual dysfunctions because of shame or frustration, and physicians rarely ask their patients about those dysfunctions.^{3,4}

When asked, health professionals allege to have little time for consultation, lack of privacy in their medical offices, and lack of ability to discuss the issue. In addition, patients tend

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to avoid speaking about that subject. Recently, the *Association Nationale de Défense Contre l'Arthrite Rhumatoïde* (French Association for Rheumatoid Arthritis) has sent, via e-mail, a questionnaire about sexuality to their members. Only 38% responded, and 70% reported a negative impact of the disease on their sexual life. Seventy-two per cent reported never having spoken with their physicians about sexuality.⁴

Studies on the Brazilian population that could help to delineate the real impact of rheumatic diseases on sexual functioning still lack. Knowing the extension of the problem is necessary, so that therapeutic possibilities can be provided, because sexual dysfunction is one of the major determinants of reduced quality of life.

This study aimed at assessing the prevalence of sexual dysfunction in women followed up in the Rheumatology Outpatient Clinic of the Hospital Universitário de Brasília (HUB) and the Hospital das Clínicas of the Universidade de

São Paulo (HC-FMUSP), who have the following rheumatic diseases: systemic lupus erythematosus (SLE); rheumatoid arthritis (RA); systemic sclerosis (SSc); antiphospholipid antibody syndrome (APLS); and fibromyalgia (FM).

PATIENTS AND METHODS

This study assessed 163 women followed up at the Rheumatology Outpatient Clinic of the HUB and HC-FMUSP (patients with APLS). Those women had been diagnosed with RA, SLE, SSc, FM, and APLS.

The presence of sexual dysfunction was identified by use of the Female Sexual Function Index (FSFI), obtained by applying the questionnaire proposed by Rosen et al.,^{5,6} which is widely used in several countries and whose Portuguese version has been validated⁷ (Table 1). That questionnaire contains 19 items that assess the following six domains: sexual desire; arousal; vaginal

Table 1Female sexual function index (FSFI)

Instructions

This questionnaire asks about your sexual life over the past 4 weeks. Please answer the questions as honestly and clearly as possible.

Your answers will be kept secret. To answer the questions, use the following definitions:

Sexual activity: comprises caressing, foreplay, masturbation ("jerking off"/female masturbation) and sexual act.

Sexual act: penetration (insertion) of the penis into the vagina.

Sexual stimulus: includes situations such as fondling the partner, sexual auto-stimulation (masturbation) or sexual fantasy (thoughts).

Sexual desire or drive: includes the disposition to engage in sexual activity, to feel receptive to

the sexual initiative of a partner, and to think about or fantasize with sex.

Sexual excitement or arousal: sensation that includes physical and mental aspects. It might include sensations

such as genital heat or swelling, lubrication (feeling wet/"wet vagina") or muscle contractions.

PLEASE, JUST SELECT ONE ANSWER PER QUESTION.

Name:

Registry number:

QUESTIONS

1) Over the past 4 weeks, how often did you feel sexually aroused ("turned on") during sexual activity or intercourse?

- 1. No sexual activity.
- 2. Almost always or always.
- 3. Most times (more than half the time).
- 4. Sometimes (about half the time).
- 5. A few times (less than half the time).
- 6. Almost never or never.

2) Over the past 4 weeks, how would you rate your level of sexual arousal ("turn on") during sexual activity or intercourse?

- 1. No sexual activity.
- 2. Very high.
- 3. High.
- 4. Moderate.
- 5. Low.
- 6. Very low or none at all.

3) Over the past 4 weeks, how often did you feel sexual desire or interest?

- 1. Almost always or always.
- 2. Most times (more than half the time).
- 3. Sometimes (about half the time)
- 4. A few times (less than half the time).
- 5. Almost never or never.

- 4) Over the past 4 weeks, how would you rate your level (degree) of sexual desire or interest?
- 1. Very high.
- 2. High.
- 3. Moderate.
- 4. Low.
- 5. Very low or none at all.

5) Over the past 4 weeks, how confident were you about becoming sexually aroused during sexual activity or intercourse?

- 1. No sexual activity.
- 2. Very high confidence.
- 3. High confidence.
- 4. Moderate confidence.
- 5. Low confidence.
- 6. Very low or no confidence.

6) Over the past 4 weeks, how often have you been satisfied with your arousal (excitement) during sexual activity or intercourse?

- 1. No sexual activity.
- 2. Almost always or always.
- 3. Most times (more than half the time).
- 4. Sometimes (about half the time).
- 5. A few times (less than half the time).
- 6. Almost never or never.

Table 1 (continued)

Female sexual function index (FSFI)

7) Over the past 4 weeks, how often did you become lubricated ("wet") during sexual activity or intercourse?

- 1. No sexual activity
- 2. Almost always or always.
- 3. Most times (more than half the time).
- 4. Sometimes (about half the time).
- 5. A few times (less than half the time).
- 6. Almost never or never.

8) Over the past 4 weeks, how difficult was it to become lubricated ("wet") during sexual activity or intercourse?

- 1. No sexual activity.
- 2. Extremely difficult or impossible.
- 3. Very difficult.
- 4. Difficult.
- 5. Slightly difficult.
- 6. Not difficult.

9) Over the past 4 weeks, how often did you maintain your lubrication ("wetness") until completion of sexual activity or intercourse?

- 2. Almost always or always.
- 3. Most times (more than half the time).
- 4. Sometimes (about half the time).
- 5. A few times (less than half the time).
- 6. Almost never or never.

10) Over the past 4 weeks, how difficult was it to maintain your lubrication ("wetness") until completion of sexual activity or intercourse?

- 1. No sexual activity.
- 2. Extremely difficult or impossible.
- 3. Very difficult.
- 4. Difficult.
- 5. Slightly difficult.
- 6. Not difficult.

11) Over the past 4 weeks, when you had sexual stimulation or intercourse, how often did you reach orgasm (climax)?

- 1. No sexual activity.
- 2. Almost always or always.
- 3. Most times (more than half the time).
- 4. Sometimes (about half the time).
- 5. A few times (less than half the time).
- 6. Almost never or never.

12) Over the past 4 weeks, when you had sexual stimulation or intercourse, how difficult was it for you to reach orgasm (climax)?

- 1. No sexual activity.
- 2. Extremely difficult or impossible.
- 3. Very difficult.
- 4. Difficult.
- 5. Slightly difficult.
- 6. Not difficult.

13) Over the past 4 weeks, how satisfied were you with your ability to reach orgasm (climax) during sexual activity or intercourse?

- 1. No sexual activity.
- 2. Very satisfied.
- 3. Moderately satisfied.
- 4. About equally satisfied and dissatisfied.
- 5. Moderately dissatisfied.
- Very dissatisfied.

14) Over the past 4 weeks, how satisfied have you been with the amount of emotional closeness during sexual activity between you and your partner?

- 1. No sexual activity.
- 2. Very satisfied.
- 3. Moderately satisfied.
- 4. About equally satisfied and dissatisfied.
- 5. Moderately dissatisfied.
- 6. Very dissatisfied.

15) Over the past 4 weeks, how satisfied have you been with your sexual relationship with your partner?

- 1. No sexual activity.
- 2. Very satisfied.
- 3. Moderately satisfied.
- 4. About equally satisfied and dissatisfied.
- 5. Moderately dissatisfied.
- 6. Very dissatisfied.

16) Over the past 4 weeks, how satisfied have you been with your overall sexual life?

- 1. No sexual activity.
- 2. Very satisfied.
- 3. Moderately satisfied.
- 4. About equally satisfied and dissatisfied.
- Moderately dissatisfied.
- 6. Very dissatisfied.

17) Over the past 4 weeks, how often did you experience discomfort or pain during vaginal penetration?

- 1. No sexual activity.
- 2. Almost always or always.
- 3. Most times (more than half the time).
- 4. Sometimes (about half the time).
- 5. A few times (less than half the time).
- 6. Almost never or never.

18) Over the past 4 weeks, how often did you experience discomfort or pain following vaginal penetration?

- 1. No sexual activity
- 2. Almost always or always.
- 3. Most times (more than half the time).
- 4. Sometimes (about half the time).
- 5. A few times (less than half the time).
- 6. Almost never or never.

19) Over the past 4 weeks, how would you rate your level (degree) of discomfort or pain during or following vaginal penetration?

- 1. No sexual activity.
- 2. Very high.
- 3. High.
- 4. Moderate.
- 5. Low.
- 6. Very low or none at all.

SCORING SYSTEM Score Multiplication Minimum Maximum Domain Questions range factor score score Desire 1-5 0.6 1.2 1.2 6.0 Arousal 3, 4, 5, 6 0 - 50.3 0.0 6.0 0-5 6.0 Lubrication 7, 8, 9, 10 0.3 0.0 11, 12, 13 0-50.0 6.0 Orgasm 0.4 Satisfaction 14, 15, 16 0 (ou 1) -50.4 0.8 6.0 Pain 17, 18, 19 0-50.0 6.0

lubrication; orgasm; sexual satisfaction; and pain. Individual domain scores are obtained by adding the scores of the individual items that comprise the domain and multiplying the sum by the domain factor. The full scale score is obtained by adding the six domain scores. Values ≤ 26 indicate sexual dysfunction.

The study's inclusion criteria were as follows: 18–69-year-old women diagnosed with specific diseases (RA, SLE, SSc, FM, APLS) by a rheumatologist according to the American College of Rheumatology criteria and Sidney criteria for APLS,⁸⁻¹³ and who had had at least one sexual intercourse in life. Those who refused to participate in the study and those whose questionnaires were not fully completed were excluded.

The following demographic and clinical data of the participants were collected: diagnosis; disease duration; age; religion; educational level; marital status; medications used; date of the last period; and use of hormone replacement therapy. This study was approved by the Committee on Ethics and Research of the Universidade de Brasília.

Statistical analysis

Categorical variables were described as absolute frequency and percent relative frequency. Quantitative variables were described as mean \pm standard deviation, when their distribution was symmetrical, or as median and interquartile interval, when asymmetrical.

RESULTS

This study selected 181 patients, 18 of whom were excluded due to the following reasons: misunderstanding in

questionnaire completion (5); virginity (1); and incomplete questionnaire (items left unanswered) (12). The disease distribution of the 163 patients remaining in the study was as follows: SLE, 82 patients; RA, 24; FM, 15; SSc, 3; and APLS, 39 (all patients with primary APLS) (Table 2).

The mean age of the patients was 40.4 years. The characteristics of the participants according to their diseases are shown in Table 3. Regarding menstruation, 46% had regular cycles and 28.7% were in menopause. Only one patient was on hormone replacement therapy. Most patients (76%) had more than 7 years of schooling and only 1.2% were illiterate.

Table 2
Demographic data and menstrual cycle of all patients studied and drugs used

	Total number of patients
Sample	163 (100%)
Religion Catholic Evangelical Baptist Others or no religion	51.5% 23.75% 1.25% 32.7%
Marital status Long-term companionship Single Separated Widow	65.1% 21.73% 7.45% 5.6%
HRT	0.6%
Menstrual cycles	46.25%
Menopause	28.7%
Drugs	3.47

HRT = Hormone replacement therapy.

Table 3

Demographic data, disease duration, educational level (years of schooling) and frequency of sexual dysfunction in several rheumatic diseases studied

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	General	SLE	RA	FM	SSc	APLS		
Number of patients	163 (100%)	82 (50%)	24 (14.7%)	15 (9.2%)	3 (1.8%)	39 (24%)		
Mean	40.4	36.1	41.2	50.4	45	40.1		
Age (SD)	10.9	10.1	8.5	7.5	_	11.4		
Median	40	34	40	51	45	40		
Disease duration (years)	_	7.6	8.3	6.2	2.5	9.4		
Schooling Illiterate 1 to 7 years > 7 years	1.2% 22.6% 76%	1.2% 15.8% 83%	4.2% 25% 71%	0 60% 40%	0 100% 0	0 15% 85%		
Sexual dysfunction	18.4%	22%	8.3%	33.3%	33.3%	10.2%		
No sexual activity	24.2%	17%	17%	47%	0	36%		

SD: standard deviation; SLE: systemic lupus erythematosus; RA: rheumatoid arthritis; FM: fibromyalgia; SSc: systemic sclerosis; APLS: antiphospholipid syndrome.

The patients reported the following marital status: married, 51.5%; single, 21.7%; living with partner, 13.6%; separated, 7.4%; and widow, 5.6%. For the purpose of this study, those married and those living with their partners were gathered in one group, called the long-time companionship group, corresponding to 65.1% of the interviewees. Most participants reported being Catholic (41.2%).

The prevalence of sexual dysfunction was 18.4%, but 24.2% of the patients reported no sexual activity over the previous 4 weeks. The prevalence of sexual dysfunction according to the subgroups of disease was as follows: FM and SSc, 33.3% of the patients (the highest rate); SLE, 22% of the patients; RA, 8.3% of the patients; and APLS, 10.2% of the patients. Excluding the patients with no recent sexual activity, the prevalence of sexual dysfunction reaches 24.2%.

The mean number of medications per patient was 3.4. The most used drugs were fluoxetine and tricyclic antidepressants (18.7%). Both drugs were more often used by patients with FM (12 patients), followed by those with SLE (7), RA (3) and SSc (2). The mean FSFI score of patients on fluoxetine or tricyclic antidepressants was 30.4. Patients not on those drugs had a mean score of 19.51.

DISCUSSION

Rheumatic diseases can interfere with sexual function due to factors related to both the disease itself and its treatment.^{1,14} Pain, morning stiffness, joint edema and fatigue might both lead to a decrease in sexual drive and impair sexual intercourse. In addition, low self-esteem and negative body image, which usually affect individuals with rheumatic diseases, are relevant psychological factors. The drugs used to treat those diseases can also reduce libido.^{2,15,16}

A few studies have assessed the impact of rheumatic diseases on sexual function. A study conducted in Cleveland, USA, has shown a lower frequency of sexual activity and reduced vaginal lubrication in patients with SLE as compared with controls. ¹⁴ Patients with SLE have also reported an increase in vaginal discomfort or pain during intercourse; however, sexual drive, motivation, arousal and climaxing were similar to those in controls. ^{14,17}

The prevalence of sexual dysfunction found in this study was lower than that reported in the literature. Research with individuals with RA has shown a 50%–60% impact on their quality of sexual life. Abdel-Nasser et al. have studied 52 women with RA, 60% of whom had reported a decrease in their sexual drive and satisfaction, as well as in sexual performance.

Ayden et al.¹, using the FSFI questionnaire in patients with FM, have reported 54.2% of sexual dysfunction *versus* 15.8% in controls. However, Impens et al.¹⁹ have applied that same questionnaire to patients with SSc and have found a mean score of 24, but with a high sexual abstinence rate (40%).

An Egyptian study¹⁴ on RA has reported sexual dysfunction in 60% of the patients studied, with libido loss or decrease in 46% of them, and that correlated with disease activity parameters. Joint pain can restrict certain sexual positions, mainly in the presence of knee or hip joint impairment.¹⁸ Other studies have also shown a trend towards more sexual dysfunction in patients with RA.^{1,4,14} In this study, sexual dysfunction was found in 8.3% of the patients with RA, which is lower than that reported in other studies on the theme.

The few studies on SSc have shown a reduction in sexual activity due to psychological and physical factors, such as vaginal dryness and ulcerations. ^{19,20} In addition, skin thickness might lead to joint contractures, resulting in difficulties to sexual relationship. ²⁰ Our study assessed only 3 patients with SSc, which hinders other conclusions about the theme.

Regarding FM, depression seems to be the determinant factor for sexual dysfunction, ²¹ which, in those patients, manifests mainly as a reduction in sexual drive^{21,1} and in orgasm rate, in addition to pain during sexual intercourse. ²² In our study, the patients with FM had the highest sexual dysfunction rate (33%) and the highest percentage of sexual abstinence (47%), in accordance with reports in the literature. Depression is extremely common in FM, being associated with reduced libido and self-esteem, being, thus, an important factor in sexual dysfunction. ¹

In addition, the use of antidepressants worsens or contributes to worsen the quality of sexual life. As much as 60% of patients on serotonin uptake inhibitors have sexual dysfunction. Tricyclic antidepressants, serotonin uptake inhibitors and monoamine oxidase inhibitors are the antidepressants that most reduce libido. In this study, a considerable increase in the FSFI score of the patients on fluoxetine and tricyclic antidepressants was observed, as compared to those not using those drugs (30.4 *versus* 19.51).

Of the patients interviewed, 24.2% reported no sexual activity over the previous 4 weeks, which might have contributed to the low sexual dysfunction rate found in our study. Some of those patients might have some degree of sexual dissatisfaction or difficulty, which might lead to abstinence or a reduction in the frequency of sexual intercourses.

The educational level was high, with 76% of the participants having more than 7 years of schooling. Nevertheless, difficulty in understanding the questions might have occurred.

The questionnaire is a self-report tool (except in cases of illiteracy, when the doctor met the answers), but many patients asked about the meaning of certain items. In addition, 17 patients were excluded because of a misunderstanding in questionnaire completion or lack of answer to any item.

The quality of sexual life is still rarely assessed during medical consultations. Further studies are required to delineate the impact of disease on sexuality and to make rheumatologists aware of the importance of discussing those questions with their patients.

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