Sexual Function in Italian Women with Systemic Sclerosis Is Affected by Disease-related and Psychological Concerns

Susanna Maddali Bongi, Angela Del Rosso, Svetlana Mikhaylova, Marco Baccini, and Marco Matucci Cerinic

ABSTRACT. ***Objective.*** In patients with systemic sclerosis (SSc), sexual function is somewhat impaired. Our aim was to evaluate sexual function in women with SSc in comparison to controls, and to investigate the association with sociodemographic and disease characteristics, and physical and psychological variables.

Methods. Forty-six women with SSc and 46 healthy women were assessed for sociodemographic characteristics and gynecological development and administered the Female Sexual Function Index (FSFI), Medical Outcomes Study Short Form-36 (SF-36), Health Assessment Questionnaire (HAQ), Hospital Anxiety and Depression Scale (HADS), Rosenberg Self-Esteem Scale, Coping Orientation to Problems Experienced-New Italian Version, and Functional Assessment of Chronic Illness Therapy-Fatigue Scale. Patients were also assessed for disease duration and subset, Female Sexual Function in SSc, Hand Mobility in Scleroderma test (HAMIS), Cochin Hand Functional Disability Scale, Mouth Handicap in Systemic Sclerosis Scale (MHISS), Disability Sexual and Body Esteem Scale (PDSBE); and fist closure, hand opening, and mouth opening.

Results. In patients with SSc, only FSFI desire subscale score was significantly lower ($p = 0.035$) versus controls. Total FSFI score, similar to controls, was related with Medical Outcomes Study Short Form-36 mental component, HAQ ($p = 0.022$), MHISS ($p = 0.038$), and HAMIS ($p = 0.037$). In SSc, the main factors independently associated with sexual functioning were vaginal dryness [regression coefficient (B) = –0.72; $p < 0.001$], PDSBE (B = 0.42; $p = 0.001$), and HADS depression scale (B = –0.23; $p = 0.035$). Together, these variables explained 70% of the variance in the FSFI total score.

Conclusion. In SSc, sexual function, although not different from controls, is influenced by specific disease-related and psychological concerns. Thus it should be included in patient evaluations and assessed in daily clinical practice. (First Release Sept 1 2013; J Rheumatol 2013;40:1697–1705; doi:10.3899/ jrheum.121540)

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QUALITY OF LIFE

Systemic sclerosis (SSc) is a connective tissue disease characterized by microvascular alterations, perivascular inflammation, and excessive accumulation of collagen, causing fibrosis in skin and internal organs. The organ-based complications reduce both health-related quality of life (HRQOL) and overall survival[1].

Chronic rheumatic diseases may affect all aspects of life including normal sexual functioning, consisting of sexual activity with transition through the phases from arousal to relaxation, and with a feeling of pleasure, fulfillment, and satisfaction[2,3].

Various SSc-related features, such as mouth shrinking, skin tightening around vaginal introitus and breast, vaginal dryness, joint pain, muscle weakness, Raynaud phenomenon, reflux, vomiting, diarrhea, low self-esteem, as well as some drugs, can reduce desire and satisfaction in women and thereby diminish intercourse frequency[4,5,6,7].

Sexual function, although important for individuals with and without chronic disease, remains largely ignored in daily clinical practice and is seldom included in research studies in rheumatology. Research items evaluating sex are included in only 2 questionnaires assessing function (World Health Organization Disability Assessment Schedule II and International Classification of Functioning, Disability and Health core sets for rheumatoid arthritis), and instruments evaluating sexual function are rarely used[8,9,10].

Few studies have assessed sexual functioning in women with SSc[4,5,6,7,8,11,12], and the studies draw different conclu-

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sions. Bhadauria, *et al* reported a lower number and intensity of orgasms in women with SSc in comparison with women with rheumatoid arthritis (RA) or systemic lupus erythematosus, and decreased desire and sexual satisfaction in all 3 patient groups[7]. Patients with SSc reported skin tightness, heartburn, and muscle weakness as symptoms affecting their sexual relations[7]. In contrast, in the study by Schouffoer, *et al*[13], although sexual function was reduced in SSc, desire and satisfaction were not impaired, and no disease-specific variables were associated with sexual functioning. One study reported higher sexual impairment in women with diffuse cutaneous (dcSSc) than in those with limited cutaneous SSc (lcSSc)[8], while others found sexual dysfunction unrelated to disease subset[13,14]. Impens, *et al,* in multivariate analyses, studied sexual functioning and causes of sexual inactivity but did not include factors associated with sexual impairment[14].

To the best of our knowledge, only 2 studies had a design including controls[11,13]. However, none of the studies assessing sexual function in SSc examined hand and mouth disability, coping styles, self-esteem, and their potential association with sexual functioning[5,6,7,8,11,12].

Our objective was to evaluate sexual function in women with SSc compared with healthy women, the association of the disease with sociodemographic and disease characteristics, and with physical and psychological variables.

MATERIALS AND METHODS

The study had a cross-sectional design with a control group. Eighty-seven consecutive patients with SSc[15] classified as lcSSc or dcSSc[16] were enrolled from the outpatient clinic and day hospital of the Division of Rheumatology of Florence University.

A general practitioner (GP) invited 60 consecutive apparently healthy women aged more than 35 years to participate in the study as a control group. This population was composed of women without SSc, other rheumatic diseases, or chronic infections. They frequented the GP's office either to accompany chronic patients (mainly, their parents) for regular examinations, or because of periodic controls and/or prescription of occasional medications for themselves.

Of the 87 women with SSc who were invited to participate, 46 (53%) returned completed questionnaires. The 41 patients with SSc who did not return the questionnaires had the same clinical and laboratory characteristics as subjects who completed the survey [p = not significant (NS) for all the comparisons; data not shown].

Among controls, the final response rate was 77%: 46 out of 60 women, of whom 32 (69.56%) were caregivers of chronic patients regularly attending a GP clinic, and 14 (30.44%) were visiting a doctor's office for periodic appointments and/or prescription of occasional medications.

The percentage of responses, although higher in controls than in SSc, was not significantly different between groups (p = NS by chi-square test).

All participants gave their written informed consent to participate and the procedures followed were in accordance with the Helsinki Declaration of 1975/83. The study was approved by the local ethical committee.

Assessment. During a routine visit, all participants were assessed for sociodemographic data (age, marital status, level of education, occupation) and gynecological characteristics (menstrual status, dyspareunia, vaginal dryness). They were also given the Female Sexual Function index (FSFI), Medical Outcomes Study Short Form-36 (SF-36), Health Assessment Questionnaire (HAQ), Hospital Anxiety and Depression Scale (HADS), Rosenberg Self-esteem Scale (RSES), Coping Orientation to Problems Experienced-New Italian Version (COPE-NIV), and the Functional Assessment of Chronic Illness Therapy-Fatigue Scale (FACIT-F).

For the patients with SSc, assessment included the Female Sexual Function in SSc (FSFS) test, the Hand Mobility In Scleroderma Test (HAMIS), the Cochin Hand Functional Disability Scale (CHFDS), the Mouth Handicap in Systemic Sclerosis Scale (MHISS), Disability Sexual and Body Esteem Scale (PDSBE), and tests of fist closure and hand and mouth opening.

Patients and controls were instructed to return the completed questionnaires to the physicians who administered them at the following visit.

Patients with SSc were assessed by a rheumatologist for disease duration (years) and subset (lcSSc, dcSSc)[16]. Skin involvement was evaluated by the modified Rodnan Skin Thickness Score[17]; interstitial lung disease was examined by high-resolution computed tomography, respiratory functionality tests, and/or bronchoalveolar lavage; pulmonary arterial hypertension by color Doppler echocardiography and right heart catheterization; heart involvement was defined if pericarditis, arrhythmia, or left ventricular congestive heart failure were present; esophagus involvement was defined by the presence of hypomotility at barium radiography and/or manometry. Also the presence of hand ulcers was recorded. Hand involvement was defined by the finding of arthralgias, arthritis, flexion contractures, or hand ulcers. Positivity to antinuclear antibodies, anti-Scl 70, and anticentromere antibodies (ACA) was recorded.

Sexual function assessment. FSFS, administered only to patients with SSc, measures the effect of SSc on sexual function. Patients are asked if they were sexually active, and if not, for what reason; to list which SSc-related problems affect their sexual functioning; and to specify the 3 most critical ones in order of importance[14].

FSFI, administered both to patients with SSc and healthy controls, is a 19-item self-report measure of female sexual function measuring 6 domains (desire, arousal, lubrication, orgasm, satisfaction, pain). Higher FSFI subscale or total scores (range 2–36) indicate a better sexual function[18]. The cutoff score > 26.55 was used to discriminate between subjects with impaired and unimpaired sexual functioning[18].

Quality of life and fatigue assessment. The SF-36, assessing HRQOL, consists of 36 items organized into 8 domains measuring 8 health concepts: physical functioning (PF), role limitations due to physical problems (PP), bodily pain (BP), general health perceptions (GH), vitality (V), social functioning (SF), role limitations due to emotional problems (EP), and general mental health (MH), combined into a summary physical index (SPI) and a summary mental index (SMI), with higher scores corresponding to better HRQOL (range 0-100)[19].

Functional Assessment of Chronic Illness Therapy-Fatigue (FACIT-F) evaluates consequences of fatigue on daily activities. Total score range is 0–52, with high scores representing less fatigue[20].

Psychological and self-esteem assessment. The HADS identifies psychological distress by 2 subscales: HADS-A (anxiety) and HADS-D (depression). Each score ranges from 0 (no depression or anxiety) to 21 (maximal depression or anxiety)[21].

The Rosenberg Self-esteem Scale (RSES) is used to assess global self-esteem by 10 questions. In the scale (range 0-30), higher scores indicate higher self-esteem[22].

COPE-NIV is a 60-item questionnaire exploring 15 types of coping grouped into 5 dimensions: social support (SS), avoidance strategies (AS), positive attitude (PA), problem solving (PS), and transcendent orientation (TO)[23]. Higher scores indicate better ability to overcome stress.

Disability assessment in patients with SSc. HAQ[24] assesses global disability. It is organized into 20 items and divided into 8 domains of activities of daily living, rated from 0 (no difficulty) to 3 (unable to do).

HAMIS is a performance-based test evaluating hand function in SSc and composed of 9 items related to movements that are part of daily activities, with a total score of 27 for each hand; higher scores indicate greater disability[25,26].

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CHFDS measures hand ability in performing 18 hand tasks. Total score range is 0–90, with higher scores meaning higher disability[27,28].

MHISS assesses handicaps associated with SSc mouth disability. It consists of 12 items (with total score ranging 0-48) divided into 3 subscales: subscale 1 examines handicap related to reduced mouth opening; subscale 2 assesses handicap related to sicca syndrome; subscale 3 examines aesthetic concerns[29,30].

The PDSBE Scale is a 10-item questionnaire evaluating respondents' capacity to feel positive about their sexuality and body while living with a physical impairment. Total score range is 10-50, with higher values reflecting a more positive evaluation of disability and body esteem[31].

Range of motion measures in patients with SSc. Fist closure is valued as the distance between the fingertip of the third finger and the thenar eminence when making a fist, and hand opening as the distance between the fingertip of the third finger, when extended, and the table.

Maximal oral aperture is measured as the distance between the lower and upper lip vermilion border while the patient opens the mouth as widely as possible.

All measures were reported in cm and as the mean of 2 consecutive measurements.

Statistics. Continuous and binomial variables are presented as mean ± SD (median, range) and as numbers and percentages, respectively. To compare the clinical characteristics of groups, Fischer's exact test or the chi-square test were used to test for binomial variables, and the Student t test and Mann-Whitney test for continuous variables (as appropriate).

In patients with SSc and controls, bivariate association between sexual functioning, psychological, physical, and disease-associated variables were assessed by Spearman's correlation. Variables significantly correlated with sexual functioning were entered in hierarchical multiple regression models in which the FSFI score was the dependent variable.

For all tests, the significance was set at a p value < 0.05. All analyses were performed using SPSS version 20.0 for Windows.

Table 1. Sociodemographic characteristics of patients with systemic sclerosis (SSc) and healthy controls. Data are n (%) unless otherwise indicated.

Characteristics	SSc, n = 46	Control, n = 46	p
Age, yrs, mean ± SD	56.1 ± 12.4	52.0 ± 9.0	NS
Education level			
Primary school	10 (21.7)	4 (8.7)	NS
Middle school	19 (41.3)	16 (34.8)	NS
High school	14 (30.4)	21 (45.6)	NS
University	2 (4.4)	5 (10.9)	NS
Postgraduate education	1 (2.2)	0	NS
Work status			
Paid employment	11 (23.9)	24 (522)	0.009
Unemployed	5 (10.9)	3 (6.5)	NS
Housewife	9 (19.6)	10 (21.7)	NS
Pensioner	21 (45.6)	9 (19.6)	0.014
Marital status			
Single	2 (4.4)	3 (6.5)	NS
Engaged	3 (6.5)	4 (8.7)	NS
Married/living with a partner	35 (76.1)	33 (71.8)	NS
Widow	6 (13.0)	6 (13.0)	NS
Gynecological variables			
Menopause	35 (76.1)	25 (54.4)	0.029
Menopause age, yrs, mean ± SD	48.23 ± 3.9	50.64 ± 3.01	0.012
Dyspareunia	19 (41.3)	14 (30.4)	0.044
Vaginal dryness	19 (41.3)	14 (30.4)	0.044
Sexually active participants	33 (72)	41 (89)	0.036

NS: not significant.

RESULTS

There were no significant differences between patients and controls in age, education level, and marital status.

Compared to controls, fewer women with SSc had a paid profession (p = 0.009) and more of them were pensioners (p = 0.014). The patients with SSc more often reported dyspareunia (p = 0.044) and vaginal dryness (p = 0.044), and more of them were in menopause (p = 0.029; Table 1).

The clinical and laboratory characteristics of patients with SSc are shown in Table 2.

Sexual function assessment. Of the patients with SSc, 13/46 (28%) were no longer sexually active. Reasons for sexual inactivity were lack of a partner (n = 6; 46%), health status of the partner (n = 1; 8%), or personal choice (n = 6; 46%). No patient indicated SSc as the primary reason for sexual inactivity.

When asked about disease-related problems potentially affecting sexual functioning, the symptoms most often mentioned were vaginal dryness (52%), inability to use hands (48%), vaginal pain (45%), finger sores (45%), and hand pain (42%; Table 3).

Compared to controls, patients with SSc had a lower FSFI desire subscale score (p = 0.035). There were no significant differences in FSFI total score and all the other subscale scores (including arousal, lubrication, orgasm, satisfaction, and pain) between women with SSc and controls (Table 4).

With the application of the FSFI cutoff score of > 26.55[17], 31/46 (67%) of patients with SSc and 25/46 (54%) of controls (p = NS) may be considered to have an impaired sexual function.

FSFI scores according to sexual activity. When assessed for sexual activity, 5/46 (11%) of controls were not sexually active (p = NS vs patients with SSc), because of personal choice (n = 3; 60%) and lack of a partner (n = 2; 40%).

In patients with SSc and in healthy controls, sexually active women presented a higher FSFI total score than inactive subjects (24.24 ± 8.54 vs 2.00 ± 0.00; p < 0.001 and 23.46 ± 9.81 vs 2.00 ± 0.00; p < 0.001, respectively).

No significant difference was found in FSFI total score between sexually active patients with SSc and active healthy women (24.24 ± 8.54 vs 23.46 ± 9.81; p = NS) and between sexually inactive patients with SSc and inactive healthy women (2.00 ± 0.00 vs 2.00 ± 0.00; p = NS).

Thirty-eight out of 46 patients with SSc (83%) and 37/46 (80%) of healthy women have a partner (p = NS). Among subjects without a partner, a higher number of controls (8/10; 80%) than patients with SSc (1/8; 13%) reported to be sexually active (p = 0.015).

Patients with SSc who had a partner had higher FSFI total score than patients without a partner (21.37 ± 10.92 vs 2.13 ± 0.35; p < 0.001). Healthy women living with a partner presented higher FSFI total scores than

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Table 2. Clinical characteristics of patients with systemic sclerosis (SSc). Data are n (%) unless otherwise indicated.

Characteristics	SSc, 46 Patients	lcSSc, 29 Patients	dcSSc, 17 Patients	p (lcSSc vs dcSSc)
Age, yrs, mean ± SD	56.0 ± 12.47	57.10 ± 12.61	55.00 ± 12.6	NS
Disease duration, yrs, mean ± SD	9.85 ± 5.9	9.30 ± 5.3	10.71 ± 6.86	NS
Skin score, mean ± SD	9.89 ± 3.72	8.07 ± 2.15	13.19 ± 3.75	< 0.0001
Hand ulcers	16 (34.78)	8 (27.59)	8 (47.06)	NS
Clinical hand involvement	18 (39.13)	9 (31.03)	9 (52.94)	NS
Cardiac involvement	16 (34.78)	9 (31.03)	7 (41.18)	NS
Lung hypertension	15 (32.6)	10 (34.48)	5 (29.41)	NS
Interstitial lung disease	23 (50)	14 (48.27)	9 (52.94)	NS
Esophageal involvement	13 (28.3)	9 (31.03)	4 (23.53)	NS
ANA	44 (95.65)	28 (96.55)	16 (94.11)	NS
ACA	25 (54.35)	24 (82.75)	1 (5.88)	0.02
Scl-70	14 (30.44)	5 (17.24)	9 (52.94)	0.02

ANA: antinuclear antibodies; ACA: anticentromere antibodies; NS: not significant.

Table 3. Problems related to systemic sclerosis (SSc) that affect sexual functioning. Data are n (%).

SSc-related Problems	Sexually Active Participants, n = 33
Fatigue	13 (39)
Hand pain	14 (42)
Body pain	13 (39)
Shortness of breath	8 (24)
Heartburn	7 (21)
Abdominal pain	4 (12)
Finger sores	15 (45)
Inability to use hands	16 (48)
Vaginal dryness	17 (52)
Vaginal pain	15 (45)
Mouth dryness	6 (18)
Depression	8 (24)
Esthetic appearance	9 (27)
Raynaud phenomenon	11 (33)
Medications	5 (15)

those without a partner (23.89 ± 9.82 vs 11.20 ± 11.88; p = 0.001).

FSFI total score was not different between patients with SSc and controls with a partner (21.37 ± 10.92 vs 23.89 ± 9.82, p = NS), while controls without a partner had a significantly higher FSFI total score than patients with SSc who did not have a partner (11.20 ± 11.88 vs 2.13 ± 0.35; p = 0.039).

Quality of life and fatigue assessment (Table 4). SF-36 scores of SPI, PF, PP, BP, GH were lower in patients with SSc than in controls (p < 0.05 for all comparisons). No other differences were found in the other SF-36 domains and in SMI according to groups.

No difference in FACIT-F between patients with SSc and controls was shown (p = NS for all comparisons).

Psychological and self-esteem assessment (Table 4). Patients with SSc reported higher levels of self-esteem than controls on the RSES (p < 0.001).

No difference was shown in HADS-D and HADS-A between patients with SSc and controls (p = NS for all comparisons).

Compared to controls, patients with SSc presented lower values in COPE-NIV total score (p < 0.001), AS (p < 0.001), and PS subscale scores (p < 0.001).

Comparison between lcSSc and SSc. Patients with dcSSc (age and disease duration: 55.00 ± 12.60 and 10.71 ± 6.86 yrs, respectively) compared to patients with lcSSc (age and disease duration: 57.10 ± 12.61 and 9.30 ± 5.30 yrs, respectively) presented higher skin scores (p < 0.0001), higher positivity for Scl70 (p = 0.02), and lower positivity for ACA (p = 0.02; Table 2).

No significant differences according to subset were found in FSFI score and subscores or in HRQOL, fatigue, psychological and self-esteem variables, or scales and anthropometric measures assessing disability (p = NS for all comparisons; Table 5).

Correlations. In the women with SSc, total FSFI score was negatively correlated with age (p = 0.014), HADS-D (p < 0.001), total HADS (p = 0.002), FACIT-F (p = 0.044), and COPE-NIV AS subscale (p = 0.012).

Patients with SSc showed positive correlations of FSFI total score with PDSBE (p < 0.001) and these SF-36 domains: SMI (p = 0.006), GH (p = 0.029), EP (p = 0.011), and MH (p = 0.034).

Among disease-associated variables, patients with SSc showed negative correlations of FSFI total score with HAQ (p = 0.022), total MHISS (p = 0.038), and mean HAMIS (p = 0.037) scores (Table 6).

In the controls, FSFI total score was negatively correlated with age (p < 0.001), HADS-D, total HADS (p = 0.002 and p = 0.01), FACIT-F (p = 0.026), and COPE-NIV TO subscale (p = 0.034).

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Table 4. Sexual functioning and psychological and physical variables in patients with systemic sclerosis (SSc) and healthy controls. Values are mean ± SD.

Characteristics	SSc, n = 46	Control, n = 46	p
Age, yrs	56.0 ± 12.47	52.10 ± 9.02	NS
Disease duration, yrs	9.85 ± 5.90	—	NA
FSFI subscale 1 (Desire)	2.78 ± 1.56	3.48 ± 1.56	0.035
FSFI subscale 2 (Arousal)	2.89 ± 2.17	3.28 ± 2.10	NS
FSFI subscale 3 (Lubrication)	3.13 ± 2.48	3.65 ± 2.40	NS
FSFI subscale 4 (Orgasm)	3.15 ± 2.46	3.41 ± 2.32	NS
FSFI subscale 5 (Satisfaction)	3.37 ± 2.10	3.93 ± 1.92	NS
FSFI subscale 6 (Pain)	2.91 ± 2.44	3.61 ± 2.39	NS
FSFI total	18.02 ± 12.34	21.2 ± 11.45	NS
Rosenberg Self-esteem Scale	22.00 ± 3.92	15.57 ± 1.76	< 0.001
HADS anxiety	6.74 ± 4.10	6.98 ± 4.35	NS
HADS depression	6.07 ± 4.42	5.70 ± 3.58	NS
HADS total	12.86 ± 7.85	12.567 ± 7.20	NS
SF-36 Physical Functioning	69.78 ± 25.67	84.61 ± 15.00	0.001
SF-36 Physical Role Limitation	52.72 ± 37.17	76.10 ± 29.32	0.002
SF-36 Body Pain	55.37 ± 24.48	69.22 ± 20.26	0.004
SF-36 General Health Perception	38.96 ± 20.62	57.83 ± 16.01	< 0.001
SF-36 Vitality	55.00 ± 20.87	55.11 ± 15.29	NS
SF-36 Social Functioning	74.00 ± 24.63	70.76 ± 20.55	NS
SF-36 Emotional Role Difficulties	63.35 ± 43.02	71.57 ± 35.89	NS
SF-36 Mental Health	60.76 ± 20.90	63.13 ± 18.93	NS
SF-36 Summary Physical Index	39.17 ± 9.33	48.50 ± 6.96	< 0.001
SF-36 Summary Mental Index	45.39 ± 11.90	43.54 ± 11.36	NS
FACIT-F	13.98 ± 9.37	11.13 ± 6.39	NS
COPE NIV SS subscale	26.78 ± 7.34	29.61 ± 7.48	NS
COPE NIV AS subscale	22.58 ± 5.74	28.74 ± 6.13	< 0.001
COPE NIV PA subscale	31.24 ± 6.18	32.48 ± 4.59	NS
COPE NIV PS subscale	25.91 ± 5.33	31.13 ± 5.07	< 0.001
COPE NIV TO subscale	22.36 ± 5.00	21.00 ± 4.62	NS
COPE NIV total	128.87 ± 16.38	142.96 ± 11.56	< 0.001
PDSBE	33.11 ± 10.25	—	NA
HAQ	0.70 ± 0.71	—	NA
MHISS mouth opening	8.78 ± 6.52		NA
MHISS Sicca syndrome	6.06 ± 5.27		NA
MHISS aesthetic concerns	3.48 ± 3.14		NA
MHISS total	17.78 ± 10.98		NA
Maximal oral aperture	4.00 ± 1.12		NA
CHFDS	11.29 ± 12.71		NA
HAMIS right	4.28 ± 4.06		NA
HAMIS left	4.17 ± 3.94		NA
Hand opening right	3.50 ± 1.31		NA
Hand opening left	3.35 ± 1.37		NA
Fist closure right	0.77 ± 1.18		NA
Fist closure left	0.85 ± 1.35		NA

FSFI: Female Sexual Function Score Index; HADS: Hospital Anxiety and Depression Scale; SF-36: Medical Outcomes Study Short Form-36 health survey; FACIT-F: Functional Assessment of Chronic Illness Therapy-Fatigue Scale; COPE NIV: Coping Orientation to Problems Experienced-New Italian Version; SS: social support subscale; AS: avoidance strategies subscale; PA: positive attitude subscale; PS: problem solving subscale; TO: transcendent orientation subscale; PDSBE: Disability Sexual and Body Esteem Scale; HAQ: Health Assessment Questionnaire; MHISS: Mouth Handicap in Systemic Sclerosis Scale; CHFDS: Cochin Hand Functional Disability Scale; HAMIS: Hand Mobility in Scleroderma Test; NS: not significant; NA: not applicable.

Controls showed positive correlation of total FSFI with SF-36 domains PF ($p < 0.001$), PP ($p = 0.005$), GH ($p = 0.041$), and V ($p = 0.038$).

Total FSFI was positively correlated with COPE-NIV PA ($p = 0.007$) and PS ($p = 0.008$; Table 6).

Independent predictors of sexual functioning. In the hier-

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Table 5. Sexual functioning and psychological and physical variables in patients with diffuse cutaneous systemic sclerosis (dcSSc) and limited cutaneous SSc (lcSSc). Values are the mean ± SD. None of the items were different between subsets.

Characteristics	lcSSc, n = 29	dcSSc, n = 17
Age, yrs	57.10 ± 12.61	55.00 ± 12.60
Disease duration, yrs	9.30 ± 5.30	10.71 ± 6.86
FSFI subscale 1 (Desire)	3.03 ± 1.50	2.35 ± 1.62
FSFI subscale 2 (Arousal)	3.24 ± 2.10	2.29 ± 2.23
FSFI subscale 3 (Lubrication)	3.45 ± 2.47	2.59 ± 2.48
FSFI subscale 4 (Orgasm)	3.38 ± 2.35	2.76 ± 2.66
FSFI subscale 5 (Satisfaction)	3.59 ± 2.11	3.00 ± 2.09
FSFI subscale 6 (Pain)	3.24 ± 2.46	2.35 ± 2.37
FSFI total	19.62 ± 12.12	15.29 ± 12.61
Rosenberg Self-esteem Scale	21.97 ± 4.58	22.06 ± 2.54
HADS anxiety	6.79 ± 4.22	6.65 ± 4.01
HADS depression	5.97 ± 4.35	6.24 ± 4.67
HADS total	12.76 ± 7.90	12.88 ± 8.01
SF-36 Physical Functioning	70.00 ± 26.56	69.41 ± 24.87
SF-36 Physical Role Limitation	56.90 ± 39.47	45.59 ± 38.77
SF-36 Body Pain	57.59 ± 24.70	51.59 ± 24.25
SF-36 General Health Perception	42.72 ± 20.71	32.53 ± 19.38
SF-36 Vitality	58.10 ± 18.15	49.71 ± 24.52
SF-36 Social Functioning	74.41 ± 23.45	73.29 ± 27.25
SF-36 Emotional Role Difficulties	63.76 ± 42.34	62.65 ± 45.47
SF-36 Mental Health	62.72 ± 19.30	57.41 ± 23.62
SF-36 Summary Physical Index	40.00 ± 9.75	37.76 ± 8.67
SF-36 Summary Mental Index	46.17 ± 10.31	44.06 ± 14.48
FACIT-F	12.64 ± 8.53	16.18 ± 10.51
COPE NIV SS subscale	27.29 ± 7.05	25.94 ± 7.95
COPE NIV AS subscale	22.46 ± 5.57	22.76 ± 6.18
COPE NIV PA subscale	31.61 ± 5.59	30.65 ± 7.20
COPE NIV PS subscale	25.93 ± 4.88	25.88 ± 6.15
COPE NIV TO subscale	22.75 ± 4.90	21.71 ± 5.23
COPE NIV total	130.04 ± 15.35	126.94 ± 18.28
PDSBE	33.62 ± 10.25	32.19 ± 10.51
HAQ	0.72 ± 0.90	0.65 ± 0.61
MHISS mouth opening	7.72 ± 6.99	10.59 ± 5.34
MHISS Sicca syndrome	6.28 ± 4.65	5.71 ± 6.33
MHISS aesthetic concerns	3.07 ± 3.22	4.18 ± 2.96
MHISS total	16.21 ± 11.12	20.47 ± 10.51
Maximal oral aperture	4.31 ± 0.93	3.47 ± 1.18
CHFDS	10.61 ± 14.18	12.41 ± 10.12
HAMIS right	3.48 ± 3.67	5.65 ± 4.44
HAMIS left	3.31 ± 3.40	5.65 ± 4.43
Hand opening right	3.69 ± 1.51	3.18 ± 1.42
Hand opening left	3.55 ± 1.55	3.00 ± 1.22
Fist closure right	0.71 ± 1.18	0.88 ± 1.32
Fist closure left	0.76 ± 1.43	1.06 ± 1.34

FSFI: Female Sexual Function Score Index; HADS: Hospital Anxiety and Depression Scale; SF-36: Medical Outcomes Study Short Form-36 health survey; FACIT-F: Functional Assessment of Chronic Illness Therapy-Fatigue Scale; COPE NIV: Coping Orientation to Problems Experienced-New Italian Version; SS: social support subscale; AS: avoidance strategies subscale; PA: positive attitude subscale; PS: problem solving subscale; TO: transcendent orientation subscale; PDSBE: Disability Sexual and Body Esteem Scale; HAQ: Health Assessment Questionnaire; MHISS: Mouth Handicap in Systemic Sclerosis Scale; CHFDS: Cochin Hand Functional Disability Scale; HAMIS: Hand Mobility in Scleroderma Test.

Table 6. Correlation of total FSFI with clinimetric measures and clinical characteristics in patients with systemic sclerosis (SSc) and controls. Values are mean ± SD.

Characteristics	FSFI Total SSc		FSFI Total Controls	
	p	r	p	r
Age	0.014	–0.36	< 0.001	–0.50
Disease duration	NS	—	NA	—
Rosenberg Self-esteem Scale	NS	—	NS	—
PDSBE	< 0.001	0.62	NA	—
HADS Anxiety	NS	—	NS	—
HADS Depression	< 0.001	–0.53	0.002	–0.45
HADS Total	0.002	–0.45	0.01	–0.37
SF-36 Physical Functioning	NS	—	< 0.001	0.51
SF-36 Physical Role Limitation	NS	—	0.005	0.41
SF-36 Body Pain	NS	—	NS	—
SF-36 General Health Perception	0.029	0.32	0.041	0.30
SF-36 Vitality	NS	—	0.038	0.31
SF-36 Social Functioning	NS	—	NS	—
SF-36 Emotional Role Difficulties	0.011	0.37	NS	—
SF-36 Mental Health	0.034	0.31	NS	—
SF-36 Summary Physical Index	NS	—	NS	—
SF-36 Summary Mental Index	0.006	0.40	NS	—
FACIT-F	0.044	–0.30	0.026	–0.33
COPE NIV SS	NS	—	NS	—
COPE NIV AS	0.012	–0.37	NS	—
COPE NIV PA	NS	—	0.007	0.40
COPE NIV PS	NS	—	0.008	0.39
COPE NIV TO	NS	—	0.034	–0.31
COPE NIV total	NS	—	NS	—
HAQ	0.022	–0.34	NA	—
MHISS mouth opening	NS		NA	—
MHISS sicca syndrome	NS	—	NA	—
MHISS aesthetic concerns	NS	—	NA	—
MHISS total	0.038	–0.31	NA	—
Maximal oral aperture	NS	—	NA	—
CHFDS	NS	—	NA	—
HAMIS right	0.036	–0.31	NA	—
HAMIS left	0.05	–0.29	NA	—
HAMIS mean score	0.037	–0.31	NA	
Hand opening right	NS	—	NA	—
Hand opening left	NS	—	NA	—
Fist closure right	NS	—	NA	—
Fist closure left	NS	—	NA	—

FSFI: Female Sexual Function Score Index; HADS: Hospital Anxiety and Depression Scale; SF-36: Medical Outcomes Study Short Form-36 health survey; FACIT-F: Functional Assessment of Chronic Illness Therapy-Fatigue Scale; COPE NIV: Coping Orientation to Problems Experienced-New Italian Version; SS: social support subscale; AS: avoidance strategies subscale; PA: positive attitude subscale; PS: problem solving subscale; TO: transcendent orientation subscale; PDSBE: Disability Sexual and Body Esteem Scale; HAQ: Health Assessment Questionnaire; MHISS: Mouth Handicap in Systemic Sclerosis Scale; CHFDS: Cochin Hand Functional Disability Scale; HAMIS: Hand Mobility in Scleroderma Test; NS: not significant; NA: not applicable.

archical multiple linear regression models, FSFI total score of patients with SSc was significantly associated with vaginal dryness (B = –0.72; t = –5.56; p < 0.001), PDSBE (B = 0.42; t = 3.67; p = 0.001), and HADS-D (B = –0.23;

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t = –2.22; p = 0.035), which together accounted for 70% of the variance in the FSFI total score.

Healthy participants showed association of FSFI total score with age (B = –0.47; t = –3.52; p = 0.001), FACIT-F (B = –0.36; t = –2.91; p = 0.006), PP of SF-36 (B = 0.29; t = 2.42; p = 0.02), and COPE-NIV TO (B = –0.24; t = –2.15; p = 0.037), which together explained 44% of the variance in total FSFI.

DISCUSSION

In our study, only FSFI desire subscale score was significantly lower in patients with SSc in comparison with healthy controls. Similarly, Bhadauria, *et al*[7] reported a decrease of desire in 57% of women with SSc.

Other studies found impairment in arousal, lubrication, and frequency and intensity of orgasm as measured by FSFI[7,13] while, according to our data, scores in those domains were not significantly different in patients with SSc and controls.

The mean FSFI total scores that we found both in SSc patients (18.02) and controls (21.20) were lower than those reported in other studies[14,32]. However, in agreement with a previous study that used an FSFI cutoff score > 26.55[13], the prevalence of sexual dysfunction in our patients with SSc was 67%, a result not significantly different from the controls (54%). Previous studies reported sexual dysfunction in healthy women as ranging from 5% to 63%, varying widely according to countries and age groups[33,34,35]. Thus, locally validated and age-adapted FSFI cutoff scores should be useful to better understand FSFI results.

The lack of difference in sexual function according to disease subsets (lcSSc and dcSSc) confirmed previous data[7,32]. Differently from sexual functioning, HRQOL related to physical problems was lower in patients with SSc than in controls. SF-36 SPI, PF, PP, BP, and GH scores were significantly lower in patients with SSc than in controls.

Patients with SSc declaring sexual activity and having a partner had higher FSFI scores than those sexually inactive and without a partner. However, women with SSc who did not have a partner had lower FSFI scores than controls without a partner, and among the patients, subjects declaring sexual activity were fewer than among the controls. Thus, although no patient indicated SSc as the primary reason for sexual inactivity, it is evident that concerns related to the disease affect normal sexual functioning, defined as all the phases of sexual activity, not only as intercourse[2,3].

Among disease-specific problems potentially affecting HRQOL[36] and sexual functioning, our patients with SSc most often reported vaginal dryness, inability to use hands, vaginal pain, finger sores, and hand pain. The high prevalence of symptoms referring to hands may be related to the selection of patients, mostly enrolled from our day hospital, which is devoted to care for digital ulcers. These results are different from the data of Impens, *et al*, who found fatigue the most-reported concern affecting sexual activity in patients with SSc[14]. Further, in contrast with other studies[37,38,39,40], our patients with SSc did not present higher levels of fatigue compared to controls.

In the SSc group, menopausal age was lower than in age-matched controls. The number of participants in a menopausal state, as well as those reporting dyspareunia, was significantly higher in patients with SSc, as reported elsewhere[7,41,42].

Further, our study showed vaginal dryness as the main factor independently associated with sexual functioning in SSc. Vaginal dryness, chronic inflammation in the vaginal wall, chronic cervicitis, fibrosis, and vaginal ulcerations were already reported as the most important causes of dyspareunia in women with systemic autoimmune disease, especially at postmenopausal age[7,12,43].

Patients with SSc reported significantly higher levels of self-esteem than controls. In assessing global self-esteem, various dimensions (such as interpersonal relationships, ability to control the environment, emotional reactions, professional success, family life, and health) should be considered[44]. It has been demonstrated that self-esteem development across adult life increases during young and middle adulthood, reaching a peak at about 60 years (near to the mean age of our patients) and then declining in old age[45]. Thus, the unexpectedly higher level of self-esteem reported in our study by patients with SSc is in agreement with the results of Sandqvist, *et al*, showing how patients with SSc were able to reach a balance of activities in daily life by prioritizing meaningful activities such as work and private life, and adapting to their own resources and limitations[46]. Our data, showing that patients with SSc do not have an impaired sexual function compared to controls despite disease-related limitations, and the higher number of subjects in menopausal state, may lead to the hypothesis that such meaningful activities could also include sexual activities.

In the bivariate analyses, sexual functioning of patients and healthy participants was significantly correlated with age, depression, and level of fatigue, in accordance with previous studies[13,14,32].

Moreover, sexual functioning in our patients with SSc was associated with mouth and hand disability, as assessed by MHISS and HAMIS, and physical disability and sexual and body esteem, as evaluated by PDSBE.

Studies have reported that hand and mouth involvement can affect the sexuality of patients with SSc. Tightening of face skin and sclerosis and ulcers of the fingers can lead to difficulty in using hands and lips[4,7,47]. For these reasons, women may feel unattractive and avoid sexual contacts[47]. However, to date no studies have investigated whether mouth and hand disability and sexual and body esteem could be independently associated with sexual function in SSc.

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In our study, body esteem, assessed by PDSBE, was independently associated with decreased sexual function of patients with SSc, confirming that physical changes affect body image and sexuality in our female patients. Schoffeour, *et al*[13] found no correlation of FSFI with global disability, in contrast with our study. These results may be due to a longer disease duration (mean 9.9 vs 6.5 years) and to a different selection of our patients, who were derived both from an outpatient clinic and from a day hospital that treated subjects with more severe forms of disease.

We found that sexual functioning was correlated with SF-36 mental subscales in patients with SSc and with physical subscales in controls. This finding is similar to recent surveys, reporting in women with SSc a stronger association of sexual function with psychological than with physical features[13,14].

Patients using avoidance coping strategy, according to our data, were more likely to have an impaired sexual functioning. In patients with chronic pain, one of the most frequently used concepts of adaptation strategies differentiates active and passive coping, such as avoidance[48]. The use of passive coping in patients with RA and chronic pain was associated with higher levels of pain, depression, and functional disability[49,50], found to significantly affect sexual functioning[13,32,51].

Age, fatigue, physical role limitation of SF-36, and less active transcendent orientation coping were independently associated with decreased sexual activity in healthy participants. As demonstrated in other studies, age-related physical and psychological changes are included among the causes of female sexual dysfunction in the general population. Hormonal changes in menopause, thinning of the vaginal mucosa and reduced lubrication, cardiovascular disease, fatigue, and partner sexuality may affect sexual functioning[52,53].

As underlined by previous studies, sexual function surveys are rarely included in the assessment of patients with rheumatic diseases[8,38]. However, sexuality is influenced by specific disease-related concerns, as confirmed by our data, thus rheumatologists and GP should discuss sexual health with patients with SSc, paying attention to both psychological and physical problems and helping them to find strategies to adapt to a chronic disease, and referring them to specialists when appropriate.

The relatively low percentage of patients responding to our study (53%) is close to that (54%) obtained by Schouffoer, *et al*[13] who were the first to administer the FSFI to patients with SSc. This response rate underlines how the completion of a complex set of questionnaires including FSFI may be regarded as too demanding by patients who are not used to discussing sexuality with doctors; patients may find it difficult to comply because of the intimate contents of the FSFI itself.

A limitation of our study was the relatively small sample size of patients and controls, making it impossible to compare sexual functioning between sexually active and inactive participants. That comparison is needed, and research to confirm the relationship of psychological, physical, and disease-associated problems with sexual function impairment.

In SSc, sexual function, although not different from controls, is influenced by specific disease-related and psychological concerns, with vaginal dryness, physical disability, sexual and body esteem, and depression as independent predictors of sexual impairment. Also, mouth and hand disabilities, typical of the disease, are related to sexual impairment. Thus, evaluation of sexual function should be included in clinical assessment of patients with SSc, ultimately to help them to improve their HRQOL.

REFERENCES

1. Denton CP, Black CM, Abraham DJ. Mechanisms and consequences of fibrosis in systemic sclerosis. Nat Clin Pract Rheumatol 2006;2:134-44.
2. Prady J, Vale A, Hill J. Body image and sexuality. In: Hill J, ed. Rheumatology nursing: a creative approach. Edinburgh: Churchill Livingstone; 1998:109-24.
3. Wells D. Caring for sexuality in health and illness. Edinburgh: Churchill Livingstone; 2000.
4. Saad SC, Pietrzykowski JE, Lewis SS, Stepien AM, Latham VA, Messick S, et al. Vaginal lubrication in women with scleroderma and Sjogren's syndrome. Sex Disabil 1999;17:103-13.
5. Schover LR, Jensen SR. Sexuality and chronic illness: a comprehensive approach. New York: Guilford; 1988.
6. Trilpell LM, Nietern PJ, Brown AN, eds. Prevalence of female sexual dysfunction among women with systemic sclerosis. Boston: 9th International Workshop on Scleroderma Research; 2006.
7. Bhadauria S, Moser DK, Clements PJ, Singh RR, Lachenbruch PA, Pitkin RM, et al. Genital tract abnormalities and female sexual function impairment in systemic sclerosis. Am J Obstet Gynecol 1995;172:580-7.
8. Knafo R, Thombs BD, Jewett LR, Hudson M, Wigley F, Haythornthwaite J. (Not) talking about sex: a systematic comparison of sexual impairment in women with systemic sclerosis and other chronic disease samples. Rheumatology 2009;48:1300-3.
9. Hudson M, Steele R, Taillefer S, Baron M; Canadian Scleroderma Research. Quality of life in systemic sclerosis: psychometric properties of the World Health Organization Disability Assessment Schedule II. Arthritis Rheum 2008;59:270-8.
10. Stucki G, Cieza A, Geyh S, Battistella L, Lloyd J, Symmons D, et al. ICF Core Sets for rheumatoid arthritis. J Rehabil Med 2004;44 Suppl:87-93.
11. Levis B, Hudson M, Knafo R, Baron M, Nielson W, Hill M, et al. Sexual activity and impairment among women with systemic sclerosis. Arthritis Rheum 2011;63 Suppl 10:2489.
12. Tristano AG. The impact of rheumatic diseases on sexual function. Rheumatol Int 2009;29:853-60.
13. Schouffoer AA, van der Marel J, Ter Kuile MM, Weijenborg PT, Voskuyl A, Vliet Vlieland CW, et al. Impaired sexual function in women with systemic sclerosis: a cross-sectional study. Arthritis Rheum 2009;61:1601-8.
14. Impens AJ, Rothman J, Schiopu E, Cole JC, Dang J, Gendrano N, et al. Sexual activity and functioning in female scleroderma patients. Clin Exp Rheumatol 2009;3 Suppl 54:38-43.
15. Subcommittee for scleroderma criteria of the American Rheumatism Association Diagnostic and Therapeutic Criteria

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Committee. Preliminary criteria for the classification of systemic sclerosis (scleroderma). Arthritis Rheum 1980;23:581-90.
16. LeRoy EC, Black C, Fleischmajer R, Jablonska S, Krieg T, Medsger TA, et al. Scleroderma (systemic sclerosis): classification, subsets and pathogenesis. J Rheumatol 1988;15:202-5.
17. Clements P, Lachenbruch P, Seibold J, White B, Weiner S, Martin R, et al. Inter and intraobserver variability of total skin thickness score (modified Rodnan TSS) in systemic sclerosis. J Rheumatol 1995;22:1281-5.
18. Rosen R, Brown C, Heiman J, Leiblum S, Meston C, Shabsigh R, et al. The Female Sexual Function Index (FSFI): a multidimensional self-report instrument for the assessment of female sexual function. J Sex Marital Ther 2000;26:191-208.
19. Apolone G, Cifani S, Liberati MC, Mosconi P. Questionario sullo stato di salute SF-36. Traduzione e validazione della versione italiana: risultati del progetto IQOLA [Italian]. SF-36 questionnaire. Translation and validation of the Italian version. Metodologia e Didattica Clinica 1997;5:86-94.
20. Cella D, Yount S, Sorensen M, Chartash E, Sengupta N, Grober J. Validation of the Functional Assessment of Chronic Illness Therapy Fatigue Scale relative to other instrumentation in patients with rheumatoid arthritis. J Rheumatol 2005;32:811-9.
21. Zigmond AS, Snaith RP. The hospital anxiety and depression scale. Acta Psychiatr Scand 1983;67:361-70.
22. Gray-Little B, Williams VSL, Hancock TD. An item response theory analysis of the Rosenberg Self-Esteem Scale. Pers Soc Psychol Bull 1997;23:443-51.
23. Sica C, Novara C, Dorz S, Sanavio E. Coping orientations to problems experienced: traduzione e adattamento italiano [Italian]. Boll Psicol Applic 1997;223:25-34.
24. Ranza R, Marchesoni A, Calori G, Bianchi G, Braga M, Canazza S, et al. The Italian version of the Functional Disability Index of the Health Assessment Questionnaire. A reliable instrument for multicenter studies on rheumatoid arthritis. Clin Exp Rheumatol 1993;11:123-8.
25. Sandqvist G, Eklund M. Hand Mobility in Scleroderma (HAMIS) test: the reliability of a novel hand function test. Arthritis Care Res 2000;13:369-74.
26. Del Rosso A, Maddali-Bongi S, Sigismondi F, Miniati I, Bandinelli F, Matucci-Cerinic M. The Italian version of the Hand Mobility in Scleroderma (HAMIS) test: evidence for its validity and reliability. Clin Exp Rheumatol 2010;28:S42-7.
27. Brower LM, Polle JL. Reliability and validity of the Duruoz Hand Index in persons with systemic sclerosis (scleroderma). Arthritis Rheum 2004;51:805-9.
28. Ingegnoli F, Galbiati V, Boracchi P, Corni D, Gualtierotti R, Zeni S, et al. Reliability and validity of the Italian version of the hand functional disability scale in patients with systemic sclerosis. Clin Rheumatol 2008;27:743-9.
29. Mouthon L, Rannou F, Bérezné A, Pagnoux C, Arène JP, Foïs E, et al. Development and validation of a scale for mouth handicap in systemic sclerosis: the Mouth Handicap in Systemic Sclerosis scale. Ann Rheum Dis 2007;66:1651-5.
30. Maddali Bongi S, Del Rosso A, Miniati I, Galluccio F, Landi G, Tai G, et al. The Italian version of the Mouth Handicap in Systemic Sclerosis scale (MHISS) is valid, reliable and useful in assessing oral health-related quality of life (OHRQoL) in systemic sclerosis (SSc) patients. Rheumatol Int 2012;32:2785-90.
31. Taleporos G, McCabe MP. Development and validation of the physical disability sexual and body esteem scale. Sex Disabil 2002;20:159-76.
32. Guerriere JA, Rosen RC, Seibold JR. Quality of life and sexual function in women with systemic sclerosis (SSc) [abstract]. Arthritis Rheum 2001;44 Suppl:S328.
33. Wallwiener CW, Wallwiener H, Seeger H, Mueck AO, Bitzer J, Wallwiener M. Prevalence of sexual dysfunction and impact of contraception in female German medical students. J Sex Med 2010;7:2139-48.
34. Burri A, Spector T. Recent and lifelong sexual dysfunction in a female UK population sample: prevalence and risk factors. J Sex Med 2011;8:2420-30.
35. Chedraui P, Perez-Lopez FR, San Miguel G, Avila C. Assessment of sexuality among middle-aged women using the Female Sexual Function Index. Climacteric 2009;12:213-21.
36. Hudson M, Thombs BD, Steele R, Panopalis P, Newton E, Baron M, Canadian Scleroderma Research Group. Health-related quality of life in systemic sclerosis: a systematic review. Arthritis Rheum 2009 61:1112-20.
37. Kwan KS, Roberts LJ, Swalm DM. Sexual dysfunction and chronic pain: the role of psychological variables and impact on quality of life. Eur J Pain 2005;9:643-52.
38. Hill J, Bird H, Thorpe R. Effects of rheumatoid arthritis on sexual activity and relationships. Rheumatology 2003;42:280-6.
39. Kwakkenbos L, van Lankveld WG, Vonk MC, Becker ES, van den Hoogen FH, van den Ende CH. Disease-related and psychosocial factors associated with depressive symptoms in patients with systemic sclerosis, including fear of progression and appearance self-esteem. J Psychosom Res 2012;72:199-204.
40. Ibn Yacoub Y, Amine B, Bensabbah R, Hajjaj-Hassouni N. Assessment of fatigue and its relationships with disease-related parameters in patients with systemic sclerosis. Clin Rheumatol 2011;31:655-60.
41. LaMontagna G, Vatti M, Valentini G, Tirri G. Osteopenia in systemic sclerosis: evidence of a participating role of earlier menopause. Clin Rheumatol 1991;10:18-22.
42. Loucks J, Pope JE. Osteoporosis in scleroderma. Semin Arthritis Rheum 2005;34:678-82.
43. Maddali Bongi S, Del Rosso A, Orlandi M, Matucci Cerinic M. Gynecological symptoms and sexual disability in women with primary Sjögren's syndrome and sicca syndrome. Clin Exp Rheumatol 2013 May 27 [E-pub ahead of print].
44. Bracken BA. Multidimensional Self-Concern Scale – MSCS. Austin, Texas: Pro-Ed; 1992.
45. Orth U, Trzesniewski KH, Robins RW. Self-esteem development from young adulthood to old age: a cohort-sequential longitudinal study. J Pers Soc Psychol 2010;98:645-58.
46. Sandqvist G, Hesselstrand R, Scheja A, Håkansson C. Managing work life with systemic sclerosis. Rheumatology 2012;51:319-23.
47. Saad SC, Behrendt AE. Scleroderma and sexuality. J Sex Res 1996;33:215-20.
48. Brown GK, Nicassio PM. Development of a questionnaire for the assessment of active and passive coping strategies in chronic pain patients. Pain 1987;31:53-64.
49. Jensen MP, Turner JA, Romano JM, Karoly P. Coping with chronic pain: a critical review of the literature. Pain 1991;47:249-83.
50. Ramírez-Maestre C, Esteve R, López AE. Cognitive appraisal and coping in chronic pain patients. Eur J Pain 2008;12:749-56.
51. Haythornthwaite JA, Heinberg LJ, McGuire L. Psychological factors in scleroderma. Rheum Dis Clin North Am 2003;29:427-39.
52. Laumann EO, Paik A, Rosen RC. Sexual dysfunction in the United States: prevalence and predictors. JAMA 1999;281:537-44.
53. Phanjoo AL. Sexual dysfunction in old age. Adv Psychiatr Treat 2000;6:270-7.

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