

The Association of Body Image Dissatisfaction and Pain with Reduced Sexual Function in Women with Systemic Sclerosis: a Cross-Sectional Study

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Running Head: Body image, pain, and sexual impairment in SSc

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ABSTRACT

Objective: Pain and body image distress are common among women with systemic sclerosis (SSc), but their relative associations with reduced sexual function have not been assessed. The objective of this study was to assess the independent associations of pain and body image distress with reduced sexual function in women with SSc.

Methods: Female SSc patients completed measures of sexual function (Sexual Relationships subscale of the Psychosocial Adjustment to Illness Scale–Self-Report), body image dissatisfaction (Adapted Satisfaction With Appearance Scale), and pain (Visual Analog Scale). Multiple regression analysis was used to assess the associations of body image dissatisfaction and pain with reduced sexual function, controlling for sociodemographic and disease variables

Results: The sample included 117 female SSc patients (33 [28.2%] diffuse; mean age 51.4 ± 11.9 years; mean time since diagnosis 9.1 ± 8.5 years). Unadjusted analyses found that reduced sexual function was associated with pain ($r=0.44$, $p < 0.001$), body image dissatisfaction ($r = 0.35$, $p < 0.001$) and being unmarried ($r=0.34$, $p < 0.001$). In multivariate linear regression, disease duration ($\beta=0.17$, $p=0.046$), pain ($\beta=0.29$, $p=0.001$), and unmarried status ($\beta=0.23$, $p=0.006$) were independently associated with reduced sexual function. Dissatisfaction with appearance was not significantly associated with reduced sexual function ($\beta=0.16$, $p=0.067$).

Conclusion: Pain is an important indicator of sexual function among women with SSc. Body image dissatisfaction was not independently associated with sexual impairment and appears to be less important factor than pain in determining sexual function. Future research should focus on isolating specific sources of pain that may be amenable to intervention in order to improve sexual function.

Key words: Systemic sclerosis; sexual impairment; women's health; pain; body Image

Systemic sclerosis (SSc), or scleroderma, is a chronic autoimmune disease characterized by microvascular disease and abnormal fibrotic processes that can affect multiple organ systems, including the skin, the lungs, and the gastrointestinal and renal systems [1]. Approximately 80% of SSc patients are women, with age of onset highest between 30 and 60 years [2]. Consequences of the disease include extensive and disfiguring skin thickening, painful finger ulcers, joint contractures, pulmonary hypertension, renal failure, and early mortality [1-3]. Patients experience significantly impaired health related quality of life compared with general population samples (4), and often report problems with sexual function [5,6].

Impaired sexual function refers to problems such as reduced desire and enjoyment, impaired arousal, difficulty reaching orgasm, and painful sexual intercourse and has psychological and biological determinants [7]. More than half of women with SSc report some degree of sexual impairment [8]. Sexual impairment is significantly greater among women with SSc compared to healthy controls [9] and the general population [10]. A recent systematic review found that women with diffuse SSc experienced levels of sexual impairment similar to or higher than women with breast cancer, HIV, and gynaecological cancer [11]. Women with limited SSc experienced levels of impairment greater than women with breast cancer [11].

Psychological and physical consequences of SSc that may negatively impact sexual function for women include depression, fatigue, shrinking of the mouth and other distressing changes in appearance, skin tightening and discomfort, joint pain, Raynaud's phenomenon, gastrointestinal symptoms (e.g., chronic diarrhea), and vaginal tightness and dryness [6,8,12]. Saad et al. found that 45% of 65 women with SSc and Sjogren's syndrome reported vaginal dryness, which can make sexual intercourse uncomfortable [8]. Another study found that nearly one-third of 150 female SSc patients reported dyspareunia (painful sex) based on a single item

inquiry [13]. Other work [14] found that almost three quarters of 60 women with SSc experienced vaginal dryness, and nearly half reported dyspareunia and fewer or less intense orgasms, or both, after disease onset. A study by Impens et al. identified cosmetic appearance, fatigue, hand pain, dryness of the mouth, heartburn, Raynaud's phenomenon, and vaginal dryness and discomfort among some of the symptoms that may affect sexual functioning [10]. Other symptoms reported by patients with SSc that may affect sexual function include thickening of the skin around the lips, skin tightness, joint pain, and muscular weakness [13,14].

Body image and pain are important predictors of sexual function and impairment among many women with medical illness but have not been assessed in relation to sexual function in SSc. Body image is an important part of an individual's self-concept and includes dimensions such as satisfaction with appearance, investment or concern with appearance, and social comfort related to appearance [15,16]. One large study of 360 sexually active young women with early stage breast cancer, for instance, found that 55% of the women were embarrassed about their body at least some of the time and that their body image concerns were associated with sexual impairment, even after controlling for physical, psychosocial, and treatment related factors [17]. Pain has been similarly associated with low sexual satisfaction in arthritis [18,19] and other chronic pain patients [20,21]. In patients with chronic pain, both the pain itself and treatments for pain can negatively affect sexual function [22].

Significant levels of pain and body image distress related to disfigurement are common in SSc [23-26] and a recent consensus statement called for research on interrelated sources of distress for patients with SSc, including pain, body image, and sexual function [24]. No studies, however, have assessed the degree to which pain and body image distress may be independently

associated with reduced sexual function in SSc. Thus, the objective of this study was to investigate the associations of pain and body image with sexual function in women with SSc.

PATIENTS AND METHODS

Patients and Procedure

Study participants were patients receiving treatment for limited or diffuse SSc at the Johns Hopkins Scleroderma Center who were enrolled in a longitudinal study examining psychosocial adjustment to SSc that took place from 1998 to 2004 [25]. Patients who completed the Sexual Relationships subscale of the Psychosocial Adjustment to Illness Scale – Self-Report (PAIS-SR) [27], which was administered from March 2000 to March 2001, were included in the current study. Patients were diagnosed with SSc if they met American College of Rheumatology criteria, had three of the five features of the CREST syndrome or if they had definite Raynaud’s phenomenon (RP), typical scleroderma nailfold capillary changes and the presence of a scleroderma specific antibody. Patients were classified by their Scleroderma Center expert rheumatologist as having limited or diffuse SSc based on the classification of LeRoy et al. [28]. Patients completed the study questionnaire during their clinic visit or at home following the visit. Informed consent was obtained by a research assistant for participants surveyed in person, and a signed consent form was returned along with the survey by participants who completed the questionnaires by mail. All surveys and consent procedures were reviewed and approved by the Johns Hopkins University School of Medicine Internal Review Board.

Measures

Patients provided information on their age, ethnicity, and marital status. SSc disease duration was obtained by patient-reported duration since date of diagnosis.

Assessment of sexual function

Patients completed the Sexual Relationships subscale of the PAIS-SR [27]. The subscale assesses illness-related changes in the quality of sexual functioning and relationship (i.e., “sexual adjustment”) over the past 4 weeks. There are 6 self-report items that address the quality of sexual relationship, sexual satisfaction, sexual dysfunction, sexual interest, and the relative frequency of sexual activity (whether or not it has increased or decreased). This instrument does not assess whether patients were active versus inactive. Responses are rated on 4-point scales (e.g., 0-3, ‘no loss of interest’ to ‘significant loss of interest’). Total scores range from 0-18 and higher scores reflect poorer sexual function. The Sexual Relationships subscale has shown good internal reliability (Cronbach’s $\alpha = .83$) [27] in a sample of cardiac bypass patients. The PAIS-SR has been previously used to assess psychosocial adjustment in SSc ($\alpha = .78$) [32], and Cronbach’s $\alpha = .83$ in the present study. The actual PAIS-SR items are available in Derogatis & Lopez [27].

Assessment of body image

The Satisfaction with Appearance Scale (SWAP) [29] was originally designed to measure non-weight related body image dissatisfaction and the perceived social-behavioral impact of appearance in burn patients. A 15-item version of the SWAP, the Adapted Satisfaction With Appearance Scale (ASWAP) [30] has been validated for SSc and was used in this study. The ASWAP contains 14 items from the original SWAP and one additional item (“my appearance makes others uncomfortable”). Respondents rate the extent to which they agree with each item on a 7-point scale (‘strongly disagree’ to ‘strongly agree’; e.g., “I am satisfied with the appearance of my arms”). Total scores range from 15-105, and higher scores indicate greater body image dissatisfaction. The ASWAP had Cronbach’s $\alpha \geq 0.88$ at two time points among

patients from a longitudinal study that included patients from the current report [30]. ASWAP items can be found in Heinberg et al. [30].

Assessment of pain

Pain was assessed with the single-item Visual Analogue Scale (VAS) of the McGill Pain Questionnaire [31]. Patients place a mark on a 10 cm line at a point that corresponds with the intensity of their pain. The line is labeled ‘no pain’ on one end, and ‘worst possible pain’ on the other. Scores on the VAS are obtained by measuring the distance of the patient’s point from 0 in millimeters. Hence, total scores range from 0 to 100. The VAS has been used previously to assess pain in SSc [9,32] and has received high validation criteria ratings for face, content, criterion, discriminant, and construct validity by a panel of SSc assessment experts [33].

Data Analyses

Pearson correlations were used to assess the bivariate associations between sociodemographic variables, disease-related variables, body image dissatisfaction, and pain, with scores on the PAIS Sexual Relationships subscale. Multivariable associations of pain and body image dissatisfaction with reduced sexual function scores were assessed using multiple linear regression, controlling for sociodemographics and disease-related variables. The assumptions of homoscedasticity and normality of residuals were checked with residual plots and quantile-quantile plots. All tolerance values were between .83 and .95, and all bivariate correlations between variables included in the model were $\leq .34$, indicating that multicollinearity was not an issue. Analyses were conducted using PASW statistics version 18.0 (Chicago, IL), and all statistical tests were 2-sided with a $p < .05$ significance level.

RESULTS

Sample Characteristics

For the entire longitudinal study, 49 of 49 patients approached in the clinic agreed to participate, and 210 of 325 patients who were mailed questionnaires completed them, resulting in overall participation of 259 out of 374 patients (69.3%). However, the PAIS-SR and ASWAP were each administered for only a portion on the study period, and there were 117 women who completed the Sexual Relationships subscale, the ASWAP, and the VAS. The mean age and standard deviation were 51.4 ± 11.9 years; the mean time since SSc diagnosis was 9.1 ± 8.5 years; 71.8% had limited SSc; 83.8% were non-Hispanic White; and 76.1% were married. The mean Sexual Relationships score was 4.8 ± 4.2 ; the range was 0-18, and the interquartile range was 1.0-8.0; the mean ASWAP score was 46.3 ± 19.4 ; and the mean VAS score was 25.3 ± 26.3 (Table 1).

The Association of Body Image Distress and Pain with Sexual Function

Bivariate analyses found moderate positive correlations of poorer sexual function with pain ($r = 0.44$, $p < 0.001$), dissatisfaction with appearance ($r = 0.35$, $p < 0.001$), disease duration ($r = 0.25$, $p = 0.009$), and not being married or living as married ($r = 0.34$, $p < 0.001$).

Limited/diffuse status, age, and ethnicity were not significantly associated with sexual function (Table 1). As shown in Table 2, analyses with multiple linear regression found that being unmarried ($\beta = 0.23$, $p = 0.006$), disease duration ($\beta = 0.17$, $p = 0.046$), and pain ($\beta = 0.29$, $p = 0.001$) were independent predictors of reduced sexual function. Body image distress was not independently associated with reduced sexual function ($\beta = 0.16$, $p = 0.067$), and this result held even when only patients who were married or living as married ($n = 89$) were included in the model. Overall, variables in the model accounted for 34.2% of variance in sexual function.

DISCUSSION

This is the first study to investigate the relative associations of pain and body image with reduced sexual function in women with SSc. Pain was related to reduced sexual function in both bivariate and multivariate analyses. Body image dissatisfaction was significantly associated with reduced sexual function in the bivariate analysis, but, compared to pain, had a smaller and non-significant relationship with reduced sexual function in multivariate analysis. Longer disease duration and being unmarried were also significantly and independently associated with reduced sexual function.

The independent association of overall pain with reduced sexual function in SSc is consistent with results from studies of patients with arthritis and other chronic pain conditions [18-21]. It is also consistent with studies of patients with SSc that have identified specific sources of pain that have been associated with sexual impairment in bivariate analyses, including vaginal pain, joint pain, skin pain, gastrointestinal pain, and pain from Raynaud's phenomenon [9,10,14].

There are steps that patients with SSc can take that may allay symptom specific pain, and in doing so, may make sex and related activities more comfortable. Over the counter anti-inflammatory drugs can be used to treat joint pain [6] and paraffin wax treatment in combination with hand exercises may alleviate skin tightness which can be a source of pain [34]. If vaginal pain occurs during penetration, vaginal lubricants can be used to lessen vaginal dryness and reduce the occurrence of dyspareunia [6,8,14]. Concern about finding a comfortable position is common in patients with SSc [21], and this may be facilitated through discussion with the patient's partner. The Arthritis Society of Canada recently published an online manual to help patients with issues related to sex and intimacy, and the manual emphasizes open discussion of

sources of pain and exploring alternatives to traditional positions and sexual acts as a means of reducing physical discomfort [35].

Body image dissatisfaction was not independently associated with sexual function impairment and appears to be a less important factor than pain in determining sexual function. It is possible, however, that this finding is due to the small sample size of this study. Body image was associated with sexual impairment in bivariate analysis and had a potentially important, although not statistically significant, association in multiple linear regression. Disfigurement is common in SSc and is associated with psychological distress and appearance self-esteem [36]. SSc patients with more extensive skin disfigurement, particularly those with more significant hand involvement, report higher levels of body image dissatisfaction and low appearance self-esteem [25]. Lower body esteem, in turn, and distracting thoughts about one's appearance during sexual encounters have been shown to be associated with lower sexual satisfaction [37]. Additional research should attempt to better understand the nature of the relationship between disfigurement, body image dissatisfaction, and sexual function in SSc.

There are limitations that should be considered in interpreting the results of this study. The relatively small sample size may limit generalizability of the findings and did not allow investigation of interactions. Limited power may also explain the non-significant multivariate association of body image with reduced sexual function. In addition, information about medical problems common in SSc, such as gastrointestinal problems, which may interfere with normal sexual function, and skin tightening, which may affect body image, or on medications that may have affected sexual interest and function [21] was not available. Participants in this study were not asked if they were sexually active, thus no comparison of active versus inactive women was possible. There are no validated cut-off scores for the PAIS-SR that would have allowed us to

compare those with reduced sexual function problems to those without. Due to the small number of men enrolled in this study, our analyses only included women. The VAS pain measure is a measure of general pain. Future research should investigate the relationship between specific symptoms related to pain in SSc with sexual function impairment, using multivariate techniques, so that tailored treatments may be devised. Another limitation is that this study did not discuss depression or general distress, although the PAIS-SR does include a measure of overall distress. This is because in cross-sectional studies it is impossible to determine where depressive symptoms lie on the causal pathway of pain, body image, and reduced sexual function. Depressive symptoms could be a parallel outcome variable, could influence pain and body image, or it could be that pain and body image influence depressive symptoms, which in turn influence sexual function.

Data were not available regarding whether patients completed the study measures at home or in the clinic, so it could not be determined if there were any differences on key variables related to where they completed the measures. Since over 80% (210 out of 259) of patients in the overall study, however, completed the measures at home, it is unlikely that these differences would have affected overall results substantially. Symptom onset estimates, often used to determine disease duration, were also unavailable thus we do not know if this would have yielded different results compared to patient-reported date of diagnosis. We were also unable to report on the participation rate for the period of time when data for this analysis were collected. The overall participation rate was only available for the entire study period. Furthermore, information regarding non-responders was not collected thus it would be impossible to determine if there are group differences.

There have been cross-sectional studies that use standardized measures like the Female Sexual Function Index (FSFI) [9,38] to investigate sexual impairment in SSc. Large multicenter studies of patients with varied disease profiles are also needed to better grasp the prevalence of sexual impairment in women with SSc, to confirm the relationship between disease related pain and body image distress with reduced sexual function, and to discern SSc specific variables (e.g., joint pain, vaginal dryness) that are most important for sexual function.

In sum, reduced sexual function is a common problem among women with scleroderma. This study showed that pain plays an important role in sexual function. Body image distress, on the other hand, appears to have a less substantial role, although it may be an important factor for some women. Future research is needed to isolate specific factors that cause pain and alters normal sexual function.

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Table 1. Sociodemographic Variables, Medical Variables, and Correlations with Sexual Adjustment as Measured by the PAIS Sexual Relationships Subscale (N = 117)

Variables		Pearson Correlation with PAIS Sexual Relationships subscale	P
Sociodemographic Variables:			
Age (years), <i>mean ± standard deviation</i>	51.4 ± 11.9	0.01	0.949
Race/Ethnicity White, <i>n (%)</i>	98 (83.8)	0.15	0.109
Not Married or Living as Married, <i>n (%)</i>	89 (76.1)	0.34	< 0.001
Medical Variables:			
Time Since Diagnosis of Systemic Sclerosis (years), <i>mean ± standard deviation</i>	9.1 ± 8.5	0.24	0.009
Diffuse Systemic Sclerosis, <i>n (%)</i>	33 (28.2)	0.18	0.059
Visual Analog Scale (0-100)*, <i>mean ± standard deviation</i>	25.3 ± 26.3	0.44	< 0.001
Satisfaction With Appearance Scale (15-105)*, <i>mean ± standard deviation</i>	46.3 ± 19.4	0.35	< 0.001
PAIS Sexual Relations subscale (0-18)*, <i>mean ± standard deviation</i>	4.8 ± 4.2	-----	-----

*Higher scores indicate greater distress

Table 2. Multiple linear Regression of the Relationship between Sociodemographic Variables, Medical Variables, and Sexual Adjustment as Measured by the PAIS Sexual Relationships Subscale (N = 117)

Variables	B	SE B	β	P
Sociodemographic Variables:				
Age (years)	0.00	0.03	0.00	0.960
Race/Ethnicity White	1.46	0.91	0.13	0.110
Not Married or Living as Married	2.24	0.81	0.23	0.006
Medical Variables:				
Years Since Diagnosis of Systemic Sclerosis	0.09	0.04	0.17	0.046
Diffuse Systemic Sclerosis	1.16	0.76	0.12	0.129
Pain Visual Analog Scale (0-100)*	0.05	0.01	0.29	0.001
Satisfaction With Appearance Scale (15-105)*	0.03	0.02	0.16	0.067

*Higher scores indicate greater distress

KEY MESSAGES

Reduced sexual function is common in women with systemic sclerosis.

Pain is associated with reduced sexual function in systemic sclerosis.

Future research is needed to isolate factors that cause pain and alter normal sexual function.