Sexual activity and functioning in female scleroderma patients

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ABSTRACT

Objective. *Few studies exist on sexual activity and functioning in female patients with systemic sclerosis (SSc, scleroderma). We studied the patient-reported impact of SSc on sexual functioning among female patients.*

Methods. *101 SSc patients completed the Short Form-36 (SF-36), the Female Sexual Functioning Index (FSFI) and the Female Sexual Function in Scleroderma (FSFS) questionnaires.*

Results. *Sixty patients reported being sexually active (59.4%). Reasons for sexual inactivity included lack of a partner (36.6%), personal choice (31.7%), and health status of the respondent's partner (19.5%). Only 7 subjects (17%) listed scleroderma as the primary reason for sexual inactivity. The mean FSFI score in the sexually active population was 24.9 (SD=6.7, range = 4.5–34.8) which is significantly lower than the mean score of 30.5 reported for the general population. Sexual functioning was significantly correlated with the Mental Component Score of the SF-36 (r=0.54, p<0.001) but surprisingly not with the Physical Component Score of the SF-36, age, and disease classification or duration. Several scleroderma-related problems including fatigue, body pain, vaginal dryness, and vaginal discomfort were cited as contributing to sexual difficulties.*

Conclusion. *Women with scleroderma do remain sexually active overall in spite of several disease-related physical and psychological difficulties. Many of their problems are amenable to health interventions and should be addressed during health care visits.*

Introduction

Systemic sclerosis (SSc, scleroderma) is a complex disorder including varying degrees of vascular occlusion, tissue fibrosis and inflammation (1). Although around 80% of those diagnosed with SSc are women (1), most of the studies on the effect of SSc on sexual functioning have involved men (2-6). Male erectile dysfunction has been noted in as many as 80% of afflicted persons and is attributed to scleroderma vasculopathy although cavernosal fibrosis may play a role in some patients (2, 3). Little is known of the impact of scleroderma on female sexual functioning and on quality of female sex life. We conducted an investigation on the patient-reported impact on sexual functioning among female SSc patients.

Existing research suggests that physical changes associated with SSc can have a negative impact on female sexuality and sexual functioning. Skin tightening around the vaginal introitus, joint contractures, muscle weakness, changes in skin around the breasts and breast muscle, and joint pain are frequently mentioned as symptoms associated with lower levels of sexual functioning, desire, arousal, lubrication, and satisfaction in female SSc patients (2, 4, 6). Changes in the vaginal mucosal may lead to difficulties with lubrication. These symptoms can hinder sexual enjoyment for SSc patients as well as cause their sexual partners to be reluctant to engage in sexual activity due to the fear of causing pain or discomfort to the person with SSc.

There are many other issues that can also impact sexuality and sexual functioning among women with SSc. For instance, in cultures that place a high value on women's beauty, changes in appearance due to tightening of the skin on the face and other areas of the body can lead to feelings of unattractiveness and can impede scleroderma patients in attracting sexual partners or prevent women from exhibiting confidence (2). Moreover, many patients with SSc have significant limitations on exercise capacity with dyspnea, decreased stamina, and coughing that may interfere with certain sexual behaviours (2, 3). Finally, many

of the supportive medications used to treat the symptoms associated with SSc have also been known to impact sexual desire and sexual functioning including diuretics, vasoactive therapies, antidepressants (*e.g.* selective serotonin reuptake inhibitors) and others (7).

Missing from the research is a connection between these potentially inhibiting scleroderma-related symptoms and female patient reports of diminished sexual functioning. The current study sought to examine this relationship. We hypothesized that female SSc patients would remain sexually active regardless of their physical functioning, adapting to limitations and impacts SSc has had on their sexual functioning.

Methods

Subjects

Sequential female ambulatory SSc patients (n=78) were recruited over an 8-week period through the outpatient clinic of the Scleroderma Program at UMDNJ-Robert Wood Johnson Medical School (RWJMS), New Brunswick, New Jersey. Additional female scleroderma patients (n=85) were identified from the RWJMS outpatient clinic database and were contacted by mail. Response rate during clinic visit was 93.6% (n=73) compared to 30.3% (n=28) for the mail questionnaires. The final sample was comprised of 101 female SSc patients. The current study was approved by the UMDNJ-RWJMS Institutional Review Board. Informed consent was obtained from all study subjects.

Instruments

Three self-administered paper questionnaires were used to assess general quality of life (QoL), health status, sexual functioning, and the impact of scleroderma on sexual functioning.

SF-36. Health-related QoL (HRQoL) was measured in the current study using the Medical Outcomes Study Short Form Health Survey (SF-36). The SF-36 has a well-documented psychometric history as a psychometrically strong measure of HRQoL (8-12). Analyses in the current study used both SF-36 scales and composite summary measures. The eight scales of the SF-36 are: physical functioning, role physical, bodily pain, general health, vitality, social functioning, role emotional, and mental health. The scales are aggregated to comprise the physical component summary (PCS) and the mental component summary (MCS) measures. Standardized scores with a mean of 50 and a standard deviation (*SD*) of 10 in the general US population were used for all SF-36 scales and summary measures using norm-based methods; higher scores indicate better HRQoL (10, 11).

Female Sexual Function Index. Sexual functioning was measured using the Female Sexual Function Index (FSFI) questionnaire (13). The FSFI is a 19 question self-report survey which quantitatively assesses six domains of sexual functioning: desire, subjective arousal, lubrication, orgasm, pain, and satisfaction. The six domains are scaled yielding an overall score of sexual functioning; low scores indicate decreased functioning. Finally, internal consistency, test-retest reliability, discriminant validity, convergent validity, and divergent validity were all found to be appropriate on an appropriately large sample (14) of sufficient demographic variability (13). The FSFI is best adapted for use in a sexually active population therefore only data from those patients who reported sexual activity in the four weeks prior to completing the survey was used in the analyses regarding sexual dysfunction.

Female Sexual Function in Scleroderma. The impact of scleroderma on sexual function was assessed using a Female Sexual Function in Scleroderma (FSFI; 15) pilot questionnaire developed by the Robert Wood Johnson Scleroderma Program (Appendix 1). The FSFS was designed to qualitatively assess the impact of scleroderma-related physical problems on patient sexual functioning. Patients were asked to self-identify which scleroderma-related problems affected both their sexual functioning and quality of sexual life.

Additional data. Descriptive data were compiled from the medical charts regarding the extent and severity of scleroderma. Information collected included patient age, classification of disease including classification criteria of the American College of Rheumatology, (16), duration of disease as measured from onset of the first non-Raynaud's phenomenon symptom, and the presence or absence of major scleroderma visceral involvement (gastrointestinal, myocardial, pulmonary, renal, skeletal muscle).

Data analysis

As a measure of relative context, correlations between the FSFI and other measures were undertaken first. Specifically, the FSFI total score was correlated with the SF-36 scales as well as the two summary measures of PCS and MCS, age, and disease duration using Pearson product-moment correlations. Additionally, Differences on the FSFI total score were examined between diffuse and limited SSc patients using a *t*-test.

Next, symptoms noted by SSc patients on the FSFS were examined. Any symptoms in the FSFS with at least 10% response rate were flagged for examination. Specifically, mean differences on the FSFI were examined for any flagged FSFS symptom between those that indicated the symptom and those that did not. Analyses were conducted with *t* tests and effect sizes (Cohen's *d*) were also examined. Control for alpha was conducted using Tukey's (17) control for correlated outcomes with an unknown correlation, in order to provide appropriate control of Type I error. Please note that the Tukey process has been found to be more accurate in its control of alpha (18) than either Bonferroni (19) or Hochberg (20).

Results

A total of 101 sets of questionnaires were completed. Sixty patients indicated they were sexually active (59.4%) and 41 patients cited no sexual activity (40.6%). The sexually inactive population was substantially older with a mean age of 55.9 years compared to a mean age of 47.5 years for the sexually active group. Reasons for sexual inactivity included lack of a partner (n=15, 36.6%), personal choice (*n*=13, 31.7%), and health status of the respondent's partner (n=8, 19.5%). Of note only 7 subjects (17%) cited their scleroderma as the primary reason for sexual inactivity.

Table I. Correlations Between FSFI and SF-36 Scales.

Variable	r	*p*	Adjusted *p*
Physical Component Score (PCS)	0.194	0.137	0.372
Mental Component Score (MCS)	0.540	<0.001	0.003*
Physical Functioning (PF)	0.264	0.042	0.127
Physical Role Limitations (RP)	0.277	0.032	0.098
Body Pain (BP)	0.291	0.024	0.074
General Health Perception (GH)	0.397	0.002	0.006*
Vitality (VT)	0.393	0.002	0.006*
Social Functioning (SF)	0.578	<0.001	0.003*
Emotional Role Difficulties (RE)	0.473	<0.001	0.003*
Mental Health (MH)	0.540	<0.001	0.003*

Alpha adjustment based on correlated outcomes of unknown size for 10 outcomes results in an alpha .016. This alpha is compared to the recalculated *p* values in the last column, based on formula from Tukey *et al*. (19).
*statistically significant at alpha=adjusted level.

The FSFI is best adapted for use in a sexually active population therefore only data from those patients who reported sexual activity in the four weeks prior to completing the survey were used in the analyses regarding sexual dysfunction. The mean FSFI score in the sexually active population was 24.9 (*SD*=6.7, range=4.5-34.8). This is lower than the mean score of 30.5 (*SD*=5.29) reported in the FSFI validation study (21): the difference is statistically significant (t=7.14, p<0.001) with a large effect size (Cohen's d=1.01).

Regarding the SF-36, mean Physical Component Score (PCS) in the current sample was 39.6 (SD=10.9) and mean Mental Component Score (MCS) was 47.7 (SD=12.8).

For the first planned statistical analysis, FSFI scores were correlated with SF-36 scores, age, and disease duration in order to identify which aspects of health status were related to sexual function (see Table I). Sexual functioning was strongly and positively correlated with MCS (r=.54, p<.001) and the mental scales (MH, RE, SF, and VT). However, sexual functioning was relatively unrelated to PCS and the physical scales (PF, RP, GH, and P). Nonsignificant relationships were found between sexual functioning and age as well as between sexual functioning and disease duration. FSFI scores did not differ between patients with diffuse or limited scleroderma. This seems to confirm that physical health appears to be unrelated to sexual health in this study sample.

Although physical functioning (SF-36) was not correlated with sexual functioning, a number of scleroderma-related problems were identified by participants as contributing to sexual difficulties (Table II). Fatigue, body pain, vaginal dryness, and vaginal discomfort were cited most often. In order to identify how specific scleroderma problems affected sexual function, those symptoms reported by ten or more patients were analyzed by comparing mean FSFI scores of patients reporting the problem with those who did not (see Table III). The mean FSFI scores were significantly decreased for patients presenting with depression, Raynaud's phenomenon, vaginal dryness, or vaginal discomfort.

Table II. Scleroderma-related sexual problems.

Scleroderma-related problem	Sexually active participants citing difficulties
Abdominal pain	9 (15%)
Body pain	24 (40%)
Cosmetic appearance	10 (16.7%)
Depression	17 (28.3%)
Fatigue	36 (60%)
Finger sores	9 (15%)
Hand pain	13 (21.7%)
Heartburn	13 (21.7%)
Inability to use hands	8 (13.3%)
Medications	6 (10%)
Mouth size/dryness	14 (23.3%)
Raynaud's phenomenon	13 (21.7%)
Shortness of breath	16 (26.7%)
Vaginal discomfort	23 (38.3%)
Vaginal dryness	25 (41.7%)

Although not identified through the general quality of life SF-36, scleroderma-related physical problems appear to impact sexual functioning.

Conclusions

Sexual dysfunction is a common problem in both men and women in the general population (22). In a large cohort study included in the National Social Life Survey, Health, and Aging Project (NSHAP) the reported rate of sexual inactivity in the prior year was 13.6% (23). The rate of sexual inactivity among SSc patient in the current study was much higher at 40.6%. Importantly, our study asked about sexual activity in the prior four weeks. Similar to the cohort study, sexually inactive female scleroderma patients were more likely to be older, report emotional or stress-related problems, and were more likely to report dysfunction in several areas of sexual functioning. Our findings suggest that scleroderma patients are similar to women in the general population in that sexual dysfunction is common and is strongly associated with psychosocial health (23, 24). Similar findings have also been reported in studies on sexual function in other rheumatic diseases such as fibromyalgia where depression was the only covariate associated with sexual dysfunction in multivariate analysis (25).

Although our findings suggest that emotional health plays an important role in sexual functioning, we also observed that women with SSc have disease-specific physical symptoms which may further impair their sexual functioning. Previous studies in chronic diseases such as RA and diabetes indicated that women with these diseases often experience sexual dysfunction due to pain, fatigue, and mechanical difficulties (26, 27). Similarly, based on self assessment, scleroderma patients in this study identified common SSc physical symptoms which they believed adversely affected their sexual functioning. Raynaud's phenomenon, hand pain, vaginal dryness and discomfort, and fatigue, were physical findings that correlated with decreased sexual functioning. In addition to the emotional and psychological burden that SSc

places on female patients, there is an additional physical burden which may impact sexual functioning and further decrease quality of life.

One limitation of the subjective self-assessment of physical difficulties related to sexual functioning in this study is in the use of the FSFS. This is a pilot questionnaire which has not been fully validated. Assessment can be further complicated by the fact that many women may compensate for their physical difficulties. With the use of artificial lubricants, women may not experience as much vaginal discomfort or dryness thus symptoms may have been underreported. A previous study identified a high prevalence of vaginal dryness, pain, and ulceration in scleroderma patients (4). However, that study compared sexual impairment before and after onset of disease and relied on the recall of events occurring "several years ago and "selective recall" after disease onset" (4). Additionally, our study was conducted during the summer months. The patients may have had less frequent or less severe attacks of Raynaud's phenomenon and so its impact on sexual function may also have been underreported. Vaginal health and disease-related vasculopathy may have an even greater impact on sexual health than is identified in this study.

Sexual dysfunction is a problem that many women with scleroderma face. Mental health stands out as an important risk factor for decreased sexual functioning but physical difficulties in scleroderma appear to also impact sexual functioning. However, women with scleroderma remained sexually active overall (60%) in spite of a host of physical and psychological difficulties associated with their disease.

Our results suggest a need for enhanced focus on female specific health issues in the care of patients with scleroderma. A variety of problems identified by our population seem amenable to simple health interventions including assessment of and instruction in the use of vaginal lubricants; advice about sexual positioning that may minimize musculoskeletal and perineal discomfort; and general advice about relaxation techniques and energy conservation. Sensitive focused questioning and support can be enabling to the individual who is reticent about this universal domain of human activity. It seems reasonable to surmise that issues such as vaginal dryness and the influence of Raynaud's phenomenon might be amenable to pharmacologic interventions although such studies need to be performed. Finally, our data once again call attention to the role of psychological health in individuals with chronic physical disease such as scleroderma thus suggesting additional opportunities for interventions to enhance quality of life.

Table III. Comparison of FSFI scores in patients with a scleroderma-related problem and those without.

Scleroderma-related problem	Group	Mean FSFI	*p*	Adjusted *p*
Body pain	Present (n=24) Absent (n=36)	23.2 26.0	0.106	0.310
Cosmetic appearance	Present (n=10) Absent (n=50)	21.2 25.7	0.052	0.162
Depression	Present (n=17) Absent (n=43)	21.0 26.4	0.004	0.013*
Fatigue	Present (n=36) Absent (n=24)	23.7 26.8	0.079	0.239
Hand pain	Present (n=13) Absent (n=47)	21.7 26.0	0.019	0.062
Heartburn	Present (n=13) Absent (n=47)	25.9 24.6	0.530	0.918
Mouth size/dryness	Present (n=14) Absent (n=46)	22.7 25.6	0.154	0.426
Raynaud's phenomenon	Present (n=13) Absent (n=47)	20.1 26.2	0.003	0.010*
Shortness of breath	Present (n=16) Absent (n=44)	22.9 25.6	0.172	0.465
Vaginal discomfort	Present (n=23) Absent (n=37)	19.7 28.1	<0.001	0.003*
Vaginal dryness	Present (n=25) Absent (n=35)	20.3 28.2	<0.001	0.003*

Alpha adjustment based on correlated outcomes of unknown size for 11 outcomes results in an alpha .015. This alpha is compared to the recalculated *p*-values in the last column, based on formula from Tukey *et al*. (19).

*statistically significant at alpha = adjusted level.

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