

Concise Report

(Not) talking about sex: a systematic comparison of sexual impairment in women with systemic sclerosis and other chronic disease samples

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Objective. Sexual impairment in women with SSc has received little attention. The objective of this study was to compare levels of sexual impairment in women with SSc with samples of women with medical illnesses for which sexual impairment has been researched more extensively.

Methods. SSc patients completed the Sexual Relationships subscale of the Psychosocial Adjustment to Illness Scale—Self-Report (PAIS-SR). A systematic review was conducted to select comparison samples. Sexual Relationships subscale scores from SSc patients were compared with scores from comparison samples (breast or gynaecological cancer and HIV) using *t*-tests and Hedges's *g* to calculate effect sizes.

Results. Samples from 138 female SSc patients were analysed (28.3% diffuse; mean age 52.1 ± 12.3 years; mean time since diagnosis 9.0 ± 8.3 years). Women with dcSSc (6.1 ± 4.2) reported significantly greater sexual impairment ($P < 0.05$) than those with lcSSc (4.4 ± 4.2), three breast cancer samples (1.8 ± 0.1 , 3.4 ± 3.9 , 1.6 ± 0.6) and two samples of HIV-positive female patients (4.4 ± 3.8 , 4.5 ± 3.9). Scores in dcSSc were similar to one sample of HIV-positive women (5.8 ± 4.1) and gynaecological cancer patients (7.3 ± 4.3). Scores in lcSSc were significantly higher than two breast cancer samples, similar to one breast cancer sample and two HIV-positive samples, and significantly lower ($P < 0.05$) than in one HIV sample and gynaecological cancer.

Conclusion. Women with SSc, particularly those with dcSSc, have high levels of sexual impairment compared with women with other chronic diseases, where sexual function has received greater attention. Further research is needed on sexual function among women with SSc.

KEY WORDS: Systemic sclerosis, Sexual impairment, Women's health, Systematic comparison.

Introduction

SSc, or scleroderma, is a chronic auto-immune CTD characterized by the fibrosis of multiple organ systems. It affects four times as many women as men [1]. Pain, body image distress related to acquired disfigurement, depressive symptoms and impaired physical functioning are common [2].

Between 36 and 65% of the SSc patients have clinically significant symptoms of depression [3], and one study found that sexual dysfunction was more closely associated with symptoms of depression than any other functional domain [4]. Sexuality is important for individuals with and without chronic disease [5]. The ability to achieve healthy sexual function involves both physiological factors that affect the sexual response cycle (e.g. desire, arousal, plateau, orgasm and resolution) and interpersonal factors that influence intimate partner relationships [5]. For women with chronic illness, both physiological and psychosocial factors often result in impaired sexual function [5]. Clinical reviews [6, 7] and case studies [8] have documented the negative impact of SSc on sexual health. One study found that nearly three-quarters of 60 women with SSc experienced vaginal dryness, and roughly half reported dyspareunia (i.e. painful sex), fewer and less intense

orgasms, or both [9]. Another study reported that nearly 60% of the 83 women with SSc experienced sexual dysfunction based on a single-item inquiry [6].

Overall, however, female sexual function has been largely ignored in SSc. When health-care providers discuss sexual issues with women who have SSc, the focus is typically on fertility, pregnancy or contraception, whereas sexual function is usually not addressed [10]. No research studies have used a validated measurement tool to assess sexual function impairment among women with SSc. The Sexual Relationships subscale of the Psychosocial Adjustment to Illness Scale—Self-Report (PAIS-SR) [11] assesses the impact of illness on sexual function, and data from samples with a variety of chronic medical problems are available. The objective of this study was to compare impairment in sexual function among female SSc patients with impairment in female patients who have other medical conditions, where sexual function has received greater attention. We hypothesized that SSc patients would have similar levels of sexual impairment compared with women with other chronic illnesses.

Patients and methods

SSc patient data

Existing data from a study of patients treated for SSc at the Johns Hopkins University Scleroderma Center between March 2000 and March 2001 were analysed. Patients were included in this analysis if they completed the Sexual Relationships subscale of the PAIS-SR and if they had a diagnosis of limited or dcSSc based on ACR criteria. The PAIS-SR was administered over a 1-year period of a cohort study that was conducted between

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1998 and 2005. For the overall study, all 49 patients who were approached in the clinic agreed to participate and completed the study questionnaires. In addition, 210 of 325 patients who were mailed the questionnaires completed them (64.6%), for an overall participation rate of 69.3% (259 of 374 patients). Patients were not excluded if they reported other medical conditions. Detailed study procedures are documented elsewhere [12]. The study was approved by the Johns Hopkins University School of Medicine Internal Review Board, and all patients provided informed consent.

Comparative data article search strategy and study selection

The MEDLINE, CINAHL and PsycINFO databases were searched on 27 February 2009 for studies in any language that used the Sexual Relationships subscale of the PAIS-SR and reported original data with raw score of mean \pm s.d. for ≥ 30 women with chronic illness. At least 30 women were required for comparison samples to avoid very small samples that could produce unstable estimates of impairment. We used the search term (PAIS OR PAIS-SR OR 'Psychosocial Adjustment to Illness Scale') AND Sexual. Studies that reported data for men and women or patients with and without chronic illness were included only if data for women with chronic illness were reported separately. Two investigators independently reviewed studies for eligibility and extracted relevant study data. Discrepancies were resolved by consensus.

Assessment of sexual function

The Sexual Relationships subscale of the PAIS-SR [11] is a 6-item self-report measure that assesses illness-related changes in the quality of sexual functioning and relationship over the past month. Items address frequency of sexual activity, quality of sexual relationship, satisfaction, dysfunction and interest. Responses are rated on 4-point Likert scales (0–3; e.g. 'no loss of interest' to 'significant loss of interest'). Total scores range from 0 to 18, and higher scores indicate poorer adjustment. The Sexual Relationships subscale has shown good internal consistency reliability (Cronbach's $\alpha=0.83$) in a sample of cardiac bypass patients ($n=69$) [11]. Cronbach's $\alpha=0.83$ in the present study.

Assessment of symptoms of depression

The Beck Depression Inventory (BDI) [13] was included to assess depressive symptoms. The BDI is a widely used 21-item questionnaire and has been administered in studies of patients with chronic illness and was found to have good internal consistency reliability, including Cronbach's α of 0.90 in patients with scleroderma from this cohort [14].

Data analysis

In the table and text, data are presented as mean \pm s.d.. Sexual Relationships subscale scores for women with diffuse and lcSSc in our sample were compared separately with means from existing samples using two-tailed *t*-tests. Effect sizes for differences between women with limited and dcSSc and comparison samples were calculated using Hedges's *g*, the difference between two means divided by their pooled s.d. [15]. Effect sizes were interpreted based on Cohen's operational definitions (small = 0.2, medium = 0.5 and large = 0.8) [16].

Results

SSc sample characteristics

A total of 138 women completed the Sexual Relationships subscale. The mean age was 52.1 ± 12.3 years; mean time since SSc diagnosis was 9.0 ± 8.3 years; 28.3% had diffuse SSc; 81.0% were non-Hispanic white; 77.9% were married; 65.1% completed at least some college; and 25.0% reported that they were disabled and unable to work. The mean Sexual Relationships score was 4.8 ± 4.3 . Women with dcSSc, however, had significantly higher scores (more sexual problems) than women with lcSSc ($P=0.034$; Table 1). In a *post hoc* analysis, results did not differ substantively if adjusted for BDI scores ($P=0.017$).

Search results

The first step of the search process identified 192 unique abstracts. On review, 92 studies that potentially met inclusion criteria were identified for full article review. Two investigators independently reviewed each study and excluded 12 that did not use the Sexual Relationships subscale, 54 that did not present raw

TABLE 1. Summary of Sexual Relationships scores for scleroderma and comparison samples

Study	Sample characteristics	<i>n</i>	Mean age, years	PAIS-SR sexual relations	dcSSc		lcSSc	
					<i>P</i> -value	Hedges's <i>g</i>	<i>P</i> -value	Hedges's <i>g</i>
Present study	dcSSc, mean illness duration: 7.1 years lcSSc, mean illness duration: 9.6 years	39	51	6.1 \pm 4.2	–	–	0.034	0.40
Breast cancer		99	53	4.4 \pm 4.2			–	–
Arena <i>et al.</i> [17]	9% Stage 0, 59% Stage I, 32% Stage II breast cancer ^a 55% mastectomy, 33% lumpectomy, 24% reconstructive surgery ^a 46% radiotherapy, 44% chemotherapy ^a	56	49 ^a	1.8 \pm 0.1	<0.001	1.57	<0.001	0.74
Kreitler <i>et al.</i> [21]	59% Stage I, 41% Stage II breast cancer 31% surgery, 54% surgery + radiation or chemotherapy, 15% surgery + radiation + chemotherapy	96	53	3.4 \pm 3.9	<0.001	0.68	0.088	0.24
Petronis <i>et al.</i> [19]	5% Stage 0, 57% Stage I, 38% Stage II breast cancer ^b 41% mastectomy, 58% lumpectomy, 22% reconstructive surgery 60% radiotherapy (19% recent), 38% chemotherapy (13% recent)	142	54 ^b	1.6 \pm 0.6	<0.001	2.24	<0.001	1.01
HIV positive								
Karus <i>et al.</i> [18]	41% asymptomatic, 41% symptomatic, 19% AIDS ^c	139	35 ^c	4.4 \pm 3.8	0.019	0.43	0.924	–0.01
Siegel <i>et al.</i> [20]	10% asymptomatic, 43% symptomatic, 47% AIDS 1994–96 Mean 11.3 illness-related symptoms	73	36	4.5 \pm 3.9	0.043	0.40	0.887	–0.02
	2000–02 10% asymptomatic, 43% symptomatic, 47% AIDS Mean 11.4 illness-related symptoms	73	37	5.8 \pm 4.1	0.751	0.06	0.026	–0.35
Gynaecological cancer								
Molassiotis <i>et al.</i> [22]	57% ovarian, 32% cervical, 11% endometrial ^d Mean illness duration 4.4 years ^d	40	51 ^d	7.3 \pm 4.3	0.200	–0.29	<0.001	–0.69

^aSample characteristics and mean age based on 78 patients, only 56 of whom were administered the PAIS-SR. ^bSample characteristics and mean age based on 237 patients, only 142 of whom were administered the PAIS-SR. ^cSample characteristics and mean age based on 146 patients, only 139 of whom were administered the PAIS-SR. ^dSample characteristics and mean age based on 62 patients, only 40 of whom were administered the PAIS-SR.

score mean \pm s.d., 19 that combined results for male and female patients or patients and spouses, and 1 that included <30 female participants.

Characteristics of studies reviewed are summarized in Table 1. A total of six studies with seven patient samples published from 1997 to 2006 were reviewed, including four studies from the USA [17–20], one from Israel [21] and one from Hong Kong [22]. There were three studies on patients with breast cancer [17, 19, 21], two on patients with HIV [18, 20] and one on patients with gynaecological cancers [22]. One study on patients with HIV [20] reported data from two independent age- and disease-matched comparison samples.

Comparison of SSc patients with selected cohorts

Based on the Sexual Relationships subscale, 39 women with dcSSc reported significantly greater sexual function impairment than women with lcSSc (small–medium effect size), three samples of women with breast cancer (medium–large to large effect sizes) [17, 19, 21] and two of three samples of HIV-positive women (small–medium effect sizes) [18, 20]. Women with dcSSc reported similar levels of sexual impairment as one sample of HIV-positive women [20] and a sample of women with gynaecological cancers [22]. Ninety-nine women with lcSSc had significantly greater sexual function impairment than two breast cancer samples (small and medium–large effect sizes) [17, 19] and similar levels of impairment as one breast cancer sample [21] and two HIV-positive samples [18, 20]. Women with lcSSc had significantly lower impairment than one sample of HIV-positive women (small–medium effect size) [20] and women with gynaecological cancer (medium–large effect size) [22].

Discussion

This study is the first to report levels of sexual impairment among female SSc patients using a validated measure of sexual function. The results of this study show that women with SSc, particularly women with dcSSc, experience levels of sexual impairment comparable with or greater than women with conditions where this is a known and well-documented problem. Long-term sexual dysfunction has been documented in >50% of the women treated for breast or gynaecological cancer [23], and similarly high levels have been reported among HIV-positive women [24, 25]. Literature is increasing to help health-care providers address issues of sexual functioning and sexuality among both female cancer survivors and women with HIV [23, 25]. Sexual impairment in women with SSc, on the other hand, has been virtually ignored as a subject of scientific inquiry despite levels of dysfunction similar to or higher than women with gynaecological cancer, breast cancer and HIV, and despite clinical reports and patient testimonials that describe loss of sexual function as a common and important problem [6, 7]. These findings underscore the need for additional research to systematically investigate disease factors that may predict or contribute to sexual function impairment in SSc and to develop effective interventions. Notwithstanding, the high level of sexual impairment reported in this study emphasizes the need for clinicians to be able to address sexuality with women who have SSc.

Although there is little research on the topic, reports have documented that vaginal dryness and dyspareunia, gastrointestinal symptoms, RP, and skin and joint pain contribute to discomfort or pain during sexual activity for women with scleroderma [6]. In addition, women with SSc often experience shrinking of the mouth and tightening of facial skin, which can make intimate acts uncomfortable. Finger ulcers and calcium deposits that are painful to the touch can also impede sexual activity [6]. There are some steps that women with SSc can take to attempt to reduce discomfort during sexual activity (6). For example, women with SSc can use extra blankets and adjust the room temperature to

keep warm and reduce the likelihood of a Raynaud's episode. They may find it helpful to plan sexual activity so that they are rested and anti-inflammatory drugs are working. A warm bath may also help to relax stiff joints, and water-based lubricants may help with vaginal dryness or dyspareunia. Women with a range of motion deficits, such as limited hip mobility, may benefit from attempting alternative sexual positions. For example, standing positions supported by a piece of furniture or a side-by-side position may increase comfort [26]. Patients with serious gastrointestinal symptoms may find it useful to avoid eating right before sexual activity [6]. In addition, good communication during sexual activity is important so that patients can inform partners of activities that are painful and need to be avoided or altered [6].

Physicians and other health-care providers may avoid talking to female SSc patients about sexual health and sexual problems due to the sensitive nature of the topic and the concern that it could lead to embarrassment or discomfort [23, 24]. Health-care providers may also mistakenly assume that the disabled or chronically ill, including women with SSc, are not sexually interested or active [6]. Many health-care providers may not feel that they are properly trained or competent to address sexual issues adequately, and few discuss sexual problems with patients, even when they believe it is important [23, 24]. Clinicians often wait for patients to initiate the discussion of sexual problems [23, 24], whereas patients with sexual problems often feel uncomfortable broaching the topic with their physicians. These patients typically want information to understand the nature of their problem and possible solutions, as well as reassurance that their concerns are normal [24].

There are steps that can be taken to facilitate the provision of information to patients. For example, clinicians can have information readily available in non-threatening formats, such as pamphlets, that describe symptoms typically associated with scleroderma, including sexual problems. Such information would normalize the issue of sexual problems and send a message to patients that they can discuss their sexual health with health-care providers. Training in how to provide factual, non-judgemental information on sexuality can be offered to physicians, who may benefit from this support. In addition, it is often helpful for health-care providers who work with patients with SSc to have a referral network of trained specialists who can offer more focused counselling, when necessary.

There are limitations that should be considered when interpreting the results of this study. The small size of the dcSSc sample suggests caution in interpreting results and could influence generalizability. Replication with a larger sample is necessary. In addition, we had a small comparison group of seven samples of women with three other illnesses. We were not able to compare patients with SSc with patients on similar medications, for instance. Nonetheless, the consistent finding of similar or higher levels of sexual impairment in women with SSc compared with these groups emphasizes that this is a serious problem that merits increased attention. A limitation of the PAIS-SR Sexual Relationships subscale is that, whereas it covers aspects of sexuality, such as interest, frequency and pleasure, it does not address physiological aspects of sexual function. Other measures should be considered in future research with women with SSc. The Female Sexual Function Index (FSFI) [27], for instance, measures six domains of female sexual function, including desire, subjective arousal, lubrication, orgasm, satisfaction and pain.

In summary, our findings show that women with SSc, particularly those with dcSSc, experience high levels of impairment of sexual function, similar to or greater than women with breast cancer, HIV and gynaecological cancers. Health providers should be aware that sexual impairment is an important consequence of SSc, and should address sexual consequences of SSc with their female patients by providing information or referral to specialists when appropriate. Further research to identify

clinical correlates and predictors of sexual impairment in women with diffuse and lcSSc is essential to develop and empirically test potential interventions.

Rheumatology key messages

- Women with SSc experience significant sexual impairment.
- Sexual function is largely ignored in women with SSc.
- Health providers should offer information on sexual problems and referral to specialists when appropriate.

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References

- 1 Mayes MD, Reveille JD. Epidemiology, demographics, genetics. In: Clements PJ, Furst DE, eds. Systemic sclerosis. Philadelphia: Lippincott Williams & Wilkins, 2004:1–15.
- 2 Haythornthwaite JA, Heinberg LJ, McGuire L. Psychological factors in scleroderma. *Rheum Dis Clin North Am* 2003;29:427–39.
- 3 Thombs BD, Taillefer SS, Hudson M, Baron M. Depression in patients with systemic sclerosis: a systematic review of the evidence. *Arthritis Rheum* 2007;57:1089–97.
- 4 Roca RP, Wigley FM, White B. Depressive symptoms associated with scleroderma. *Arthritis Rheum* 1996;39:1035–40.
- 5 Nusbaum MRH, Hamilton C, Lenahan P. Chronic illness and sexual functioning. *Am Fam Physician* 2003;67:347–54.
- 6 Saad SC, Behrendt AE. Scleroderma and sexuality. *J Sex Res* 1996;33:215–20.
- 7 Mayes MD. The scleroderma book: a guide for patients and families, 2nd edn. New York: Oxford University Press, 2005.
- 8 Wilson D, Goerzen J, Fritzler MJ. Treatment of sexual dysfunction in a patient with systemic sclerosis. *J Rheumatol* 1993;20:1446–7.
- 9 Bhadauria S, Moser DK, Clements PJ *et al*. Genital tract abnormalities and female sexual function impairment in systemic sclerosis. *Am J Obstet Gynecol* 1995;172:580–7.
- 10 Saad SC, Pietrzykowski JE, Lewis SS *et al*. Vaginal lubrication in women with scleroderma and Sjogren's syndrome. *Sex Disabil* 1999;17:103–13.
- 11 Derogatis LR, Lopez M. Psychosocial adjustment to illness scale (PAIS & PAIS-SR) scoring, procedures, & administration manual – I. Baltimore: Clinical Psychometric Research, 1983.
- 12 Benrud-Larson LM, Haythornthwaite JA, Heinberg LJ *et al*. The impact of pain and symptoms of depression in scleroderma. *Pain* 2002;95:267–75.
- 13 Beck AT, Beamesderfer A. Assessment of depression: the depression inventory. *Mod Probl Pharmacopsychiatr* 1974;7:151–69.
- 14 Benrud-Larson LM, Heinberg LJ, Boling C *et al*. Body image dissatisfaction among women with scleroderma: extent and relationship to psychosocial function. *Health Psychol* 2003;22:130–9.
- 15 Hedges LV. Estimation of effect size from a series of independent experiments. *Psychol Bull* 1982;92:490–9.
- 16 Cohen J. Statistical power analysis for the behavioral sciences, 2nd edn. Hillsdale, NJ: Lawrence Earlbaum Associates, 1988.
- 17 Arena PL, Carver CS, Antoni MH, Weiss S, Ironson G, Durán RE. Psychosocial responses to treatment for breast cancer among lesbian and heterosexual women. *Women Health* 2006;44:81–102.
- 18 Karus D, Siegel K, Raveis VH. Psychosocial adjustment of women to living with HIV/AIDS. *AIDS Behav* 1999;3:277–87.
- 19 Petronis VM, Carver CS, Antoni MH, Weiss S. Investment in body image and psychosocial well-being among women treated for early stage breast cancer: partial replication and extension. *Psychol Health* 2003;18:1–13.
- 20 Siegel K, Karus D, Dean L. Psychosocial characteristics of New York city HIV-infected women before and after the advent of HAART. *Am J Public Health* 2004;94:1127–32.
- 21 Kreitler S, Kreitler H, Chaitchik S, Shaked S, Shaked T. Psychological and medical predictors of disease course in breast cancer: a prospective study. *Eur J Pers* 1997;11:383–400.
- 22 Molassiotis A, Chan CWH, Yam BMC, Chan SJ. Quality of life in Chinese women with gynaecological cancers. *Support Care Cancer* 2000;8:414–22.
- 23 Schover LR. Sexuality and fertility after cancer. *Hematology* 2005; 523–7.
- 24 Florence E, Schrooten W, Dreezen C *et al*. Prevalence and factors associated with sexual dysfunction among HIV-positive women in Europe. *AIDS Care* 2004;16:550–7.
- 25 Ortiz MR. HIV, AIDS, and sexuality. *Nurs Clin North Am* 2007;42:639–53.
- 26 Arthritis and sexuality. <http://www.arthritis.ca/tips%20for%20living/sexuality/default.asp?s=1> (17 June 2009, date last accessed).
- 27 Rosen R, Brown C, Heiman J *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.