African American race associated with body image dissatisfaction among patients with systemic sclerosis

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ABSTRACT

Objective. *Studies have shown a high degree of body image dissatisfaction among patients with systemic sclerosis (SSc). We aimed to identify demographic and phenotypic characteristics that correlate with body image dissatisfaction.*

Methods. *Ninety-eight patients with SSc were recruited from Georgetown University Medical Center 2003-2004. Anonymous surveys collected demographic information (age, race, gender, duration/type of SSc) and assessed degree of body image dissatisfaction on a scale of 0-3 in relation to phenotypic features of SSc (hand contractures, finger ulcers, pigmentation changes, lip wrinkling/thinning, telangiectasias). A composite total distress score was derived. Parametric and nonparametric T tests were used to compare groups.*

Results. *Of 98 patients, 86 were female and 12 male. The majority of patients were 30-60 years old. The sample was 62% Caucasian, 27% African American, and the rest identified as "other". Twenty-seven percent had limited SSc, 48% diffuse, and 25% "other". African American patients had greater total body image dissatisfaction (p=0.002), specifically with respect to digital ulcers, pruritus, and pigmentation changes, than Caucasian participants. Patients with diffuse SSc had greater body image dissatisfaction than those with limited disease (p=0.002).*

Conclusion. *Our results suggest that African American patients with SSc and those with diffuse subtype suffer a higher degree of body image dissatisfaction. Screening for and addressing this issue in SSc patients is prudent. Further study is needed to understand racial differences in body image dissatisfaction among patients with SSc.*

Introduction

Systemic sclerosis (SSc) is a multisystem connective tissue disease characterised by chronic inflammation, vascular insufficiency, and fibrosis resulting in skin thickening, ischaemic ulceration, and internal organ involvement (1). In the United States, systemic sclerosis is estimated to affect 24.2 per 100,000 people (2). Several surveys in the United States show that African-Americans have a higher age-specific incidence rate and experience more severe disease than whites (3). The phenotypic features of the disease are heterogeneous as the extent and course of the disease are quite variable. The skin and vascular manifestations of the disease frequently cause some form of disfigurement and associated pain and disability (1). Cutaneous manifestations of SSc include edema and sclerosis of the skin leading to a taut, shiny appearance sometimes with lip retraction, perioral furrows, and beaking of the nose. Telangiectasias, patches of dyspigmentation, and cutaneous ulcers may also contribute to disfigurement (4).

There has been a growing interest in the study of psychosocial factors affecting the quality of life of patients with chronic illness. In recent years, this interest has extended to patients living with SSc (5). Two reviews have demonstrated that individuals with SSc not only self-reported depressive symptoms at higher rates than the general population but also at higher rates than patients with other serious illnesses (6, 7). The psychosocial factors affecting quality of life extend beyond depression, and include sexual dysfunction and body image dissatisfaction. Frikha *et al*. found that the prevalence of sexual dysfunction among married women with SSc is higher than that of women in the general population (8). And, body image distress has repeatedly been raised as a mitigating factor affecting the quality of life of patients' living with SSc (9).

Prior to 2002, the vast majority of body image literature related to normal

weight women and women with eating disorders (10). The body image of medical populations has only gained attention in recent years, with the literature on disfigurement focusing mostly on sudden disfiguring injuries like burns. Fewer studies have examined the body image dissatisfaction of patients with progressively disfiguring illnesses (11). Given the disfiguring characteristics of SSc, there has long been the supposition that SSc patients also develop body image dissatisfaction. In 2002, Fauerbach *et al*. found that SSc patients reported greater body image dissatisfaction than patients with serious burn injuries requiring hospitalisation, and Jewett et al. reported similar findings in 2012 (13).

Body image dissatisfaction has been shown to be directly related to depressive symptoms which are associated with poorer psychosocial functioning. Individuals affected by disfigurement tend to focus more on their body and appearance than individuals without disfigurement. This has been attributed to disfigured individuals' awareness of others' reaction to them as well as awareness of the ways their disfigurement is disadvantageous in social interactions (11). Facial disfigurement, hand contracture, and telangectasias have been posited as the disfigurements most associated with body image distress. In a large Canadian sample, facial skin involvement and finger-to-palm distance were related to greater dissatisfaction with appearance, and facial skin involvement, upper body telangiectasias, and younger age were associated with greater social discomfort (14). Amin *et al*. found one third of SSc patients ranked their face as the area of greatest concern, followed by hands (27%) and lungs (23%) (15). Hyper and hypopigmentation are common early manifestations in Africans with SSc and may cause patients' distress (16).

Although location and extent of disfigurement have been shown to affect degree of body image dissatisfaction, investigators have also suggested that psychosocial and demographic factors may impact adjustment to disfigurement. Jewett *et al*. found that although age was not strongly correlated with dissatisfaction with appearance, it was strongly associated with feelings of social discomfort (13). This is consistent with prior research that shows that older age is generally associated with less distress related to body image.

Many prior studies on body image dissatisfaction in patients with SSc have included predominantly female cohorts and few have studied the effect of race on adjustment to disfigurement (11). Our study is unique in that it includes a sizable percentage of African American patients and includes male participants.

Methods

Study participants were recruited from the SSc Clinic at Georgetown University Medical Center from 2003 to 2004. Patients over 18 years of age with a SSc spectrum disorder in the Georgetown University SSc registry were invited to participate in this anonymous survey. As patients left the clinic, front desk personnel offered patients the anonymous survey enclosed in an addressed, stamped envelope for them to take home, complete, and return. One hundred fifty surveys were distributed and 98 were returned.

Measures

Participants completed an anonymous survey that inquired about age range, race, sex, and duration and type of SSc. All of these points were self-reported and not confirmed by the treating physician because of the anonymous nature of the survey. The survey used Likert scales to assess patients' degree of body image dissatisfaction in response to various phenotypic features of SSc: hand contracture, finger ulcers, changes in pigmentation, upper lip wrinkling and thinning, and telangiectasias. Zero signified no distress, 1 signified mild distress, 2 signified moderate distress, and 3 signified severe distress. A composite total distress score was derived by summing patients' distress scores for each feature. T tests and Mann Whitney U tests were used to identify which demographic factors and phenotypic aspects of disease significantly affected body image dissatisfaction. We were primarily interested in (a) the effect of various demographic markers, specifically race and sex, on body image dissatisfaction, and (b) which phenotypic aspects of SSc were most strongly associated with body image dissatisfaction and whether these varied by race.

Data analysis

Normality was assessed using the D'Agostino and Pearson omnibus normality test, Shapiro-Wilk normality test, and Kolmogorov-Smirnov normality test. For normally distributed data, we ran unpaired *t*-tests. For non-parametic data, Mann Whitney U-tests were used. An F test was used to compare variances. For all tests, the significance was set at a p-value <0.05. All analyses were performed using GraphPad Prism (GraphPad Software, La Jolla, CA, US).

Ethical approval

This study was approved by the Institutional Review Board of Georgetown University Medical Center.

Results

Baseline characteristics

The demographic and clinical characteristics of the 98 respondents are shown in Table I. Of 98 patients, the majority were female (88%) and were between 30 and 60 years old (77%). Although the majority of respondents were Caucasian (62%), a sizable percentage was African American (27%). The rest were Asian, Hispanic, or did not identify. More patients self-identified as having diffuse cutaneous SSc (48%) than limited cutaneous (27%), but an additional group identified as having "other" type of SSc (25%), possibly because they were not sure whether they had limited or diffuse cutaneous disease.

The association of disease features with body image dissatisfaction is shown in Table II.

Age and sex were not associated with any differences in body image dissatisfaction in our patients. Compared to Caucasians, African American patients had greater total body image dissatisfaction (14.77±7.6 *vs*. 9.74±6.6, p=0.002). African American patients had higher degrees of distress with re-

Table I. Demographic variables and body image dissatisfaction.

Variable	Total no. (%)	Mean total distress score (SD)	*p*-value
No. of patients	98	11.64 (7.4)	
Age, no. (%)			0.764
< 30 years	3 (3)	13.33 (5.8)	
30-60 years	75 (77)	11.73 (7.2)	
> 60 years	20 (20)	10.60 (8.5)	
Sex, no. (%)			0.612
Female	86 (88)	11.51 (7.3)	
Male	12 (12)	12.58 (8.5)	
Race, no. (%)			0.002
African American	26 (27)	14.77 (7.6)	
Caucasian	61 (62)	9.74 (6.6)	
Other	10 (10)	16.00 (8.1)	
Duration of disease, no. (%)			0.809
<1 year	7 (7)	9.57 (10.2)	
1-3 years	29 (30)	12.83 (6.0)	
3-6 years	30 (30)	11.00 (7.2)	
6-10 years	11 (11)	11.00 (8.5)	
>10 years	21 (21)	11.95 (8.3)	
Type of disease, no. (%)			0.002
Limited	26 (27)	7.85 (8.3)	
Diffuse	46 (48)	12.28 (6.8)	
Other	24 (25)	14.83 (8.9)	

Table II. Disease features and body image dissatisfaction, AA: African American.

Variable	African American % with none/ mild/mod/ Severe distress	African American mean distress (SD)	Caucasian % with none/ mild/mod/ Severe distress	Caucasian mean distress (SD)	*p*-value
Degree of skin thickening	24/44/8/24	1.32 (1.1)	34/33/16/16	1.15 (1.1)	0.494
Contractures of hands	28/12/20/40	1.72 (1.3)	33/26/11/30	1.38 (1.2)	0.287
Ulcers on fingers	35/15/8/42	1.58 (1.4)	61/13/10/16	0.82 (1.2)	0.011
Having to itch	12/28/32/28	1.76 (1.0)	48/21/18/13	0.97 (1.1)	0.002
Dark body pigment	16/32/36/16	1.52 (1.0)	61/23/8/8	0.64 (1.0)	<0.001
White body pigment	42/23/27/8	1.00 (1.0)	70/15/8/7	0.51 (0.9)	0.015
Facial changes	16/40/12/32	1.60 (1.1)	43/25/23/10	1.00 (1.0)	0.021
Darker facial pigment	28/20/16/36	1.60 (1.3)	72/16/10/2	0.41 (0.7)	<0.001
Facial white spots	54/15/15/15	0.92 (1.2)	90/7/3/0	0.13 (0.4)	<0.001
Wrinkles above lip	64/28/4/4	0.48 (0.8)	52/11/20/16	1.00 (1.2)	0.098
Thinning of upper lip	54/27/12/8	0.73 (1.0)	52/20/11/16	0.92 (1.1)	0.632
Telangiectasias	54/15/15/15	0.92 (1.2)	48/33/10/10	0.82 (1.0)	0.94
Total distress		14.77 (7.6)		9.7 (6.6)	0.002

spect to digital ulcers, pruritus, and skin pigment changes than Caucasian participants. Although not significant, the only feature which caused more distress in Caucasians' than African American's was wrinkles above the lip. All other disease features showed no difference between groups. Patients who reported diffuse SSc had greater distress in regard to appearance than those who reported limited disease (p=0.002), and patients who reported their disease subtype as "other" had still higher degrees of distress (p=0.002).

Discussion

The high rate of body image dissatisfaction among patients with SSc noted in our study is concordant with findings from other studies (11). In our study of 98 patients with SSc, African American patients with SSc and those with diffuse subtype suffered a higher degree of body image dissatisfaction than Caucasian patients and those with limited subtype. To the best of our knowledge, ours is the first study noting the racial differences in body image dissatisfaction among SSc patients. It is not known why African American patients may have greater body image dissatisfaction, especially with features like digital ulcers or pruritus which would likely be present in both African Americans and Caucasians. It is likely that the pigmentation changes associated with SSc may have a more obvious effect on appearance and may be more psychologically distressing for patients with darker skin tones. Physicians need to be aware of the effects of disfigurement on African American patients. Hyperpigmentation is a common early manifestation of SSc in African Americans, possibly related to typical inflammatory effects on melanin and post inflammatory hyperpigmentation. These differences warrant further study.

There are a number of important limitations to this study. First, the survey used was not a previously validated tool for the assessment of body image distress. Though Likert scales are widely used in scoring models to assess body image distress and quality of life, the particular questions used in this survey were not validated across multiple populations. In future studies, survey tools previously validated to assess body image dissatisfaction, like the SWAP or Brief SWAP, may be helpful (16). Although many prior studies have shown that younger age is associated with greater body image dissatisfaction in patients with chronic illness, our study found no significant differences in body image dissatisfaction based on age (11, 17). In patients with RA, for example, age has been shown to be a valuable predictor of body image concerns with younger patients demonstrating greater body image distress (17). The effects of age on body image dissatisfaction may have been underestimated in our study. Participants reported their ages in ranges to help protect anonymity, but this may have limited our sensitivity in detecting differences in body image dissatisfaction. Or, our study may have been underpowered to detect differences based on age.

Of note, our sample has a higher proportion of diffuse subtype patients than other scleroderma patient samples. This may be because all respondents were patients at a SSc specific clinic at

a tertiary care centre. It is unclear how this may have affected the results.

Another important limitation of our study was that all patients were asked about their level of distress in response to all phenotypic aspects of the disease, even if the patient didn't have all phenotypic features. There was no objective measurement of the presence or severity of these phenotypic features among the study's participants. Also, it is unclear what type of SSc patients who identified as "other" really had. Although these patients may have had an overlap form of SSc (*i.e.* lupus-SSc overlap), we suspect that they did not know their subtype of SSc. All participants were recruited from an academic tertiary care centre, so our results may not be generalisable to community settings.

Our findings demonstrate that body image is of significant concern to patients with SSc, especially in African American populations. This warrants a higher sensitivity among practitioners to screen SSc patients for body image dissatisfaction, and when suspected, refer for appropriate intervention. Further study is needed to understand racial differences in body image dissatisfaction among patients with SSc.

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