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# Examination of the association of sex and race/ethnicity with appearance concerns: a Scleroderma Patient-centered Intervention Network (SPIN) Cohort study

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## ABSTRACT

**Objective.** Appearance concerns are common in systemic sclerosis (SSc) and have been linked to younger age and more severe disease. No study has examined their association with sex or race/ethnicity.

**Methods.** SSc patients were sampled from the Scleroderma Patient-centered Intervention Network Cohort. Presence of appearance concerns was assessed with a single item, and medical and sociodemographic information were collected.

**Results.** Of 644 patients, appearance concerns were present in 72%, including 421 of 565 women (75%), 42 of 79 men (53%), 392 of 550 patients who identified as White (71%), 35 of 41 who identified as Black (85%), and 36 of 53 who identified as another race/ethnicity (68%). In multivariate analysis, women had significantly greater odds of reporting appearance concerns than men (odds ratio (OR)=2.97, 95% confidence interval (CI)=1.78-4.95,  $p<0.001$ ). Black patients had significantly greater odds of appearance concerns than White patients in unadjusted (OR=2.64, 95% CI=1.01-6.34,  $p=0.030$ ), but not multivariate analysis (OR=1.76, 95% CI=0.67-4.60,  $p=0.250$ ). Compared to a general population sample, appearance concerns were substantially more common in SSc, particularly for men across all age groups and for younger women. The most commonly reported features of concern were related to the face and head, followed by the hands and fingers; this did not differ by sex or race/ethnicity.

**Conclusion.** Appearance concerns were common in SSc. Women were substantially more likely than men to have

appearance concerns. Although non-significant in multivariate analysis, Black patients were more likely to have concerns than White patients, likely due to more severe changes in appearance.

## Introduction

Disfiguring appearance changes, including telangiectasia, hand contractures, skin pigmentation changes, digital ulcers, and altered facial features, are common in systemic sclerosis (SSc). These appearance changes often affect body parts that are highly visible and that play a central role in social interactions, such as the face, mouth, and hands (1-3). Treatments can lessen the impact of some SSc symptoms but do not alleviate manifestations of irreversible tissue damage that affect appearance.

Among individuals with visible differences due to medical illness or injury, there is a well-established relationship between the extent and severity of appearance changes and psychological outcomes (4, 5). Consistent with this, in SSc, the presence, severity, and perceived noticeability of appearance changes are associated with greater body image dissatisfaction and social discomfort, as well as poorer overall psychosocial and psychological functioning (6-12). The association of younger age and greater appearance concerns is also well-established, both among people with visible differences and in the general population (4, 13, 14). Among 2,100 randomly sampled members of the UK general population, 70% of women and 50% of men 30 years or younger reported at least one appearance concern compared to 33% of women and 21% of men 61 years or older (14). Younger patients

with SSc have also been found to experience greater social discomfort related to appearance than older patients (7). No published studies have investigated the degree to which sex and race/ethnicity may be associated with appearance concerns in SSc, likely due to the small numbers of men and non-White patients in most study samples. Among other groups of people with visible differences (*e.g.*, skin conditions, burn scarring, limb disfigurement), however, women experience more worry about their appearance and greater general distress, social anxiety, and social avoidance than men (15-20). Less is known about the association of race/ethnicity and appearance concerns due to visible differences. One survey of 458 adults with a variety of visible disfigurements found that people from non-White racial/ethnic backgrounds experienced significantly greater worry about their appearance and heightened concern that their condition was noticeable to others than White respondents (20). This may have been because people with darker skin tones are more vulnerable to visible changes in skin pigmentation and report greater psychosocial impact compared to individuals with lighter skin tones (21). In SSc, skin involvement and pigmentation changes are more common among Black patients than White patients, whereas White patients are more likely to have telangiectasia (22).

The objective of the present study was to examine the association of sex and race/ethnicity with the presence of appearance concerns, controlling for factors that are known to influence appearance concerns (*e.g.* age, disease severity) in a large, international cohort of SSc patients. We also compared the percentage of patients with SSc who reported the presence of appearance concerns to rates previously published from a UK general population sample, stratified by sex and age groups (14).

### Methods

The sample consisted of patients enrolled in the Scleroderma Patient-centered Intervention Network (SPIN) Cohort (23) who completed baseline

study questionnaires from April 2014 through August 2015. Patients were enrolled at 21 SPIN centres in Canada, the USA, and the UK. To be eligible for the SPIN Cohort, patients must have a confirmed diagnosis of SSc according to the 2013 American College of Rheumatology/European League Against Rheumatism classification criteria (24), be  $\geq 18$  years of age, have the ability to give informed consent, be fluent in English or French, and have access and the ability to respond to questionnaires via the Internet. The SPIN sample is a convenience sample. Eligible patients are invited by attending physicians or supervised nurse coordinators from SPIN centers to participate in the SPIN Cohort, and written informed consent is obtained. The local SPIN physician or nurse coordinator completes a medical data form that is submitted online to initiate patient registration. After completion of online registration, an automated welcoming email is sent to participants with instructions for activating their SPIN account and completing SPIN Cohort measures online. SPIN Cohort patients complete outcome measures via the Internet upon enrolment and subsequently every three months. Patients who had complete data at their baseline assessment for all variables necessary for the planned multivariate analysis were included. The SPIN Cohort study was approved by the Research Ethics Committee of the Jewish General Hospital, Montréal, Canada and by the research ethics committees of each participating center.

### Sociodemographic characteristics

Patients enrolled in the SPIN Cohort provided sociodemographic data, including sex, race/ethnicity, age, education level, marital status, and employment status. Response options for race/ethnicity differed slightly for patients from Canada, the USA, and the UK, consistent with how racial/ethnic status is typically characterised in each country. In the Canadian sample, patients could identify as White, Black, Aboriginal, Asian, Latin American, or Arab. In the USA sample, patients could identify as White (non-Hispan-

ic), African American or Black, Hispanic or Latino, Asian, American Indian/Alaska Native, Native Hawaiian/Other Pacific Islander, or Mixed-race. In the UK sample, patients could identify as White, African, or Asian. In the present study, racial/ethnic status was collapsed into three categories across Canadian, American, and UK samples, consisting of White, Black, or Other. Across countries, responses indicating White racial/ethnic status were combined to create one White race/ethnicity category; responses indicating Black, African American or Black, or African were combined to create one Black race/ethnicity category; and other responses were combined to create one Other race/ethnicity category.

### Disease-related and medical characteristics

SPIN physicians or nurse coordinators provided disease and medical information, including time since onset of the first non-Raynaud's symptom (disease duration); disease subtype (limited or diffuse); and presence of telangiectasia, skin pigmentation changes, hand contractures, skin thickening on the fingers of both hands, and body mass index (BMI). Limited SSc was defined as skin involvement distal to the elbows and knees only, whereas diffuse SSc was defined as skin involvement proximal to the elbows and knees, and/or the trunk (25). Telangiectasia was defined as the visible dilation of superficial cutaneous blood vessels that collapse upon pressure and fill slowly when pressure is released (24). Skin pigmentation changes included either hyper- or hypo-pigmentation of the skin. In the present study, telangiectasia and skin pigmentation changes were coded as present on the body and face, present on the body only, or none. Hand contractures, which entail limitations in the range of motion of a joint, secondary to tightening around the joint, were measured for small joints on the hands (*i.e.* proximal interphalangeal joints, metacarpals, and/or wrists) and categorised as None/Mild (0-25% limitation in range of motion), Moderate (25-50%), or Severe (>50%). Skin thickening on the fingers of both hands

was defined as skin thickening or hardening extending proximal to the metacarpophalangeal joints (22).

### Presence of appearance concerns

The Derriford Appearance Scale-24 (DAS-24) (26, 27) is a self-report measure of distress related to problems with appearance. It assesses social anxiety and avoidance related to self-consciousness due to appearance. The DAS-24 has an introductory item, not included in the scoring of the measure, that asks, "Is there any aspect of your appearance (however small) that concerns you at all?" (yes/no). This item was used as the primary outcome in the present study. Published prevalence of appearance concerns using this question is available for the UK general population (14), which we used for comparison. In addition, for patients who answer yes to the appearance concern question, the DAS-24 includes a further inquiry, "The aspect of my appearance about which I am most sensitive or self-conscious is ..." with space for open response. If patients reported more than one aspect of appearance concern, the first listed was used.

### Data analysis

Descriptive statistics were calculated for all sociodemographic and disease/medical variables, including means and standard deviations (SDs) for continuous variables. Chi-square tests were used for categorical variables, and a one-way Analysis of Variance was used for continuous variables to compare patients on sociodemographic and disease/medical characteristics across sex and race/ethnicity categories. For illustrative purposes, Bonferroni-corrected comparisons were done to assess statistical significance between pairs of racial/ethnic groups for variables with statistically significant overall tests. To maintain the family-wise error rate  $<0.05$ , the Bonferroni-corrected  $\alpha$  for each of the three subgroup comparisons for each variable was 0.0167.

The associations of sociodemographic variables (sex, race/ethnicity, age, marital status, education level), and disease/medical variables (telangiectasia, skin pigmentation changes, hand con-

tractures, skin thickening on fingers, disease subtype, BMI) with the presence of appearance concerns were assessed using binary logistic regression. All variables included in the regression analysis were selected a priori based on previous research indicating variables likely to relate to appearance concerns in SSc. Discrimination and calibration of the multivariate model were assessed with the c-index and Hosmer-Lemeshow goodness-of-fit test statistic, respectively (28). The c-index is the percentage of comparisons where patients with appearance concerns had a higher predicted probability of having appearance concerns than patients without appearance concerns for all possible pairs where patients were discrepant on outcome variable status. The Hosmer-Lemeshow goodness-of-fit statistic is a measure of the accuracy of the predicted number of cases of appearance concerns compared to the number of patients who actually reported appearance concerns across the spectrum of probabilities. A relatively large  $p$ -value indicates a reasonably good model fit (28). All analyses were conducted using SPSS (v. 22), and statistical tests were two-sided with  $\alpha < .05$ .

The percentage of women and men with SSc who reported appearance concerns was compared to levels of appearance concerns reported in a sample from the general UK population (14). The relative risk of reporting appearance concerns was calculated for women and men, separately, stratified by age groups. Race/ethnicity data were not provided for the UK population sample, thus comparisons for these groups separately could not be conducted.

### Results

In total, 757 SSc patients completed baseline assessments. There were 717 who answered the binary appearance concern item, of whom 644 had data for all variables included in the multivariate model and were included in analyses. Of these, 463 (72%) indicated that there was an aspect of their appearance that caused them concern. Rates were similar among the 73 patients excluded for missing data, with 57 (78%) indicating that there was an

aspect of their appearance that caused them concern.

Sociodemographic and disease/medical characteristics are displayed in Table I. Mean age in the total sample was 55.3 years (SD=12.1), and the majority of patients were White ( $n=550$ , 85%) and married or living as married ( $n=471$ , 73%). Mean time since onset of the first non-Raynaud's symptom was 11.5 (SD=8.7) years.

There were 565 (88%) women and 79 (12%) men included. There were no statistically significant differences between women and men for any sociodemographic or disease/medical variables (see Table I). There were 41 (6%) Black patients and 53 (8%) patients who identified as a member of another racial/ethnic group. As shown in Table I, White patients were older and more likely to be married than Black patients, but less likely to have skin thickening on the fingers and to have diffuse SSc (statistically significant,  $p < 0.0167$ ). There were also statistically significant differences between White and Black patients in presence of telangiectasia and skin pigmentation changes. White patients were older and less likely to have diffuse SSc than patients from other racial/ethnic groups (statistically significant,  $p < 0.0167$ ). There were also statistically significant differences in skin pigmentation changes between White patients and those from other racial/ethnic groups (see Table I).

Among women, 75% (421 of 565) reported appearance concerns, compared to 53% (42 of 79) of men ( $p < .001$ ). Across racial/ethnic groups, 85% (35 of 41) of Black patients reported appearance concerns, compared to 71% (392 of 550) of White patients and 68% (36 of 53) from other racial/ethnic groups ( $p = 0.122$ ).

Of the 463 patients who indicated that there was an aspect of their appearance that caused them concern, 444 listed the specific feature of greatest concern. As shown in Table II, the most common category was the face/neck/head/mouth (41%), followed by the hands/fingers (27%). Results were similar for female and male patients and patients classified as White, Black, or Other racial/ethnic status.

**Table I.** Sociodemographic and disease characteristics (n=644).

Variable	Total n=644	Race/Ethnicity			p-value	Sex		p-value
		White n=550	Black n=41	Other n=53		Female n=565	Male n=79	
Age (years), mean ± SD	55.3 ± 12.1	56.5 ± 11.5 <sup>a,b</sup>	47.7 ± 11.5 <sup>a</sup>	48.1 ± 14.1 <sup>b</sup>	<.001	55.1 ± 12.0	56.2 ± 12.8	.462
Education >12 years, n (%)	512 (79.5)	434 (78.9)	33 (80.5)	45 (84.9)	.579	451 (79.8)	61 (77.2)	.591
Currently employed (full or part-time), n (%)	268 (41.7) <sup>c</sup>	225 (41.0) <sup>d</sup>	21 (51.2)	22 (41.5)	.439	236 (41.8)	32 (41.0) <sup>e</sup>	.901
Married/living as married, n (%)	471 (73.1)	413 (75.1) <sup>a</sup>	21 (51.2) <sup>a</sup>	37 (69.8)	.003	412 (72.9)	59 (74.7)	.741
Time since onset of first non Raynaud's symptom (years), mean ± SD	11.5 ± 8.7 <sup>f</sup>	11.6 ± 8.9 <sup>g</sup>	8.9 ± 5.6 <sup>h</sup>	10.2 ± 7.8 <sup>i</sup>	.067	11.7 ± 8.8 <sup>j</sup>	10.4 ± 7.8 <sup>k</sup>	.227
BMI, mean ± SD	26.04 ± 6.1	26.14 ± 6.1	26.14 ± 6.8	24.97 ± 5.3	.413	26.0 ± 6.3	26.19 ± 5.0	.82
Patients with diffuse SSc, n (%)	258 (40.1)	200 (36.4) <sup>a,b</sup>	28 (68.3) <sup>a</sup>	30 (56.6) <sup>b</sup>	<.001	226 (40.0)	32 (40.5)	.971
Telangiectasia(s)					<.001			.058
None, n (%)	183 (28.4)	137 (24.9) <sup>a</sup>	26 (63.4) <sup>a</sup>	20 (37.7)		153 (27.1)	30 (38.0)	
Body and face, n (%)	298 (46.3)	273 (49.6) <sup>a</sup>	7 (17.1) <sup>a</sup>	18 (34.0)		262 (46.4)	36 (45.6)	
Body only, n (%)	163 (25.3)	140 (25.5) <sup>a</sup>	8 (19.5) <sup>a</sup>	15 (28.3)		150 (26.5)	13 (16.5)	
Pigmentation changes					<.001			.497
None, n (%)	438 (68.0)	396 (72.0) <sup>a,b</sup>	13 (31.7) <sup>a</sup>	29 (54.7) <sup>b</sup>		385 (68.1)	53 (67.1)	
Body and face, n (%)	105 (16.3)	71 (12.9) <sup>a,b</sup>	18 (43.9) <sup>a</sup>	16 (30.2) <sup>b</sup>		89 (15.8)	16 (20.3)	
Body only, n (%)	101 (15.7)	83 (15.1) <sup>a,b</sup>	10 (24.4) <sup>a</sup>	8 (15.1) <sup>b</sup>		91 (16.1)	10 (12.7)	
Hand contractures					.898			.988
No/mild (0-25%), n (%)	488 (75.8)	418 (76.0)	31 (75.6)	39 (73.6)		428 (75.8)	60 (75.9)	
Moderate (25-50%), n (%)	121 (18.8)	102 (18.5)	7 (17.1)	12 (22.6)		106 (18.8)	15 (19.0)	
Severe (>50%), n (%)	35 (5.4)	30 (5.5)	3 (7.3)	2 (3.8)		31 (5.5)	4 (5.1)	
Skin thickening on fingers, n (%)	360 (55.9)	293 (53.3) <sup>a</sup>	31 (75.6) <sup>a</sup>	36 (67.9)	.004	311 (55.0)	49 (62.0)	.242
Presence of appearance concerns, n (%)	463 (71.9)	392 (71.3)	35 (85.4)	36 (67.9)	.122	421 (74.5)	42 (53.2)	<.001

SD: standard deviation; BMI: body mass index. <sup>a</sup>White patients statistically significantly different from Black patients. <sup>b</sup>White patients statistically significantly different from patients from another racial/ethnic group. <sup>c</sup>Sample size based on n=643. <sup>d</sup>Sample size based on n=549. <sup>e</sup>Sample size based on n=78. <sup>f</sup>Sample size based on n=595. <sup>g</sup>Sample size based on n=510. <sup>h</sup>Sample size based on n=40. <sup>i</sup>Sample size based on n=45. <sup>j</sup>Sample size based on n=519. <sup>k</sup>Sample size based on n=76.

As shown in Table III, on an unadjusted basis, the odds of appearance concerns were greater for female patients compared to male patients odds ratio (OR)=2.70, 95% Confidence Interval (CI)=1.73-4.22,  $p<0.001$ ), and for Black patients vs. the reference group, White patients (OR=2.64, 95% CI=1.01-6.34,  $p=0.030$ ). Patients with another racial/ethnic status did not have significantly different odds compared to White patients (OR=0.92, 95% CI=0.52-1.65,  $p=0.788$ ). Other variables that were significantly associated with the presence of appearance concerns on an unadjusted basis included younger age, diffuse disease subtype, presence of moderate hand contractures, and presence of skin thickening on the fingers.

In the multivariate analysis, only sex, age, and presence of moderate hand contractures were significantly associated with appearance concerns, after controlling for covariates of race/eth-

nicity, BMI, education level, marital status, disease subtype, telangiectasia, pigmentation changes, and skin thickening on the fingers. The odds of appearance concerns were significantly greater than for male patients (OR=2.97, 95% CI=1.78-4.95,  $p<.001$ ). Older patients were also less likely to report appearance concerns than younger patients (OR=0.98 per year, 95% CI=0.96-0.99,  $p=0.007$ ), equivalent to a reduction of 18% in the OR for every 10-year increase in age. The odds of reporting appearance concerns did not differ significantly for Black versus White patients (OR=1.76, 95% CI=0.67-4.60,  $p=0.250$ ). The odds of reporting appearance concerns for patients with moderate hand contractures were almost twice those of patients with no or only mild hand contractures (OR=2.05, 95% CI=1.17-3.60,  $p=0.012$ ) (see Table III). Model fit for the 11 predictors included was less than

ideal based on the Hosmer-Lemeshow test ( $\chi^2(8, n=644)=10.65, p=0.022$ ), and the c-index statistic was 0.69.

As shown in Table IV, rates of appearance concerns were higher, across all age groups, for women and men with SSc, compared to women and men from the general UK population sample (14). The relative risk of reporting appearance concerns among SSc patients compared to the general population was greater for men than for women across age groups. For both women and men, the relative risk was substantially higher among older patients.

## Discussion

The main findings of this study were that women with SSc were substantially more likely than men to report appearance concerns, controlling for sociodemographic and disease/medical variables. Black racial/ethnic group membership was significantly associat-

**Table II.** Appearance concerns reported by SSc patients who specified feature of concern (n=444)

Feature	Total (n, %)	Race/Ethnicity			Sex	
		White (n, %)	Black (n, %)	Other (n, %)	Female (n, %)	Male (n, %)
<b>Body area-related</b>						
Face/mouth/head/neck	180 (40.5)	149 (40.5)	14 (40.0)	17 (41.5)	159 (41.2)	21 (36.2)
Hands/fingers	119 (26.8)	103 (28.0)	7 (20.0)	9 (22.0)	99 (25.6)	20 (34.5)
Arms	5 (1.1)	3 (0.8)	1 (2.9)	1 (2.4)	5 (1.3)	0
Chest/stomach	9 (2.0)	9 (2.4)	0	0	8 (2.1)	1 (1.7)
Legs/feet	13 (2.9)	12 (3.3)	1 (2.9)	0	12 (3.1)	1 (1.7)
<b>Skin-related</b>						
Telangiectasia(s) (any)	33 (7.4)	28 (7.6)	1 (2.9)	4 (9.8)	26 (6.7)	7 (12.1)
Skin pigmentation changes (any)	12 (2.7)	9 (2.4)	1 (2.9)	2 (4.9)	10 (2.6)	2 (3.4)
Skin tightening or hardening	7 (1.6)	5 (1.4)	1 (2.9)	1 (2.4)	5 (1.3)	2 (3.4)
Skin unspecified/other	20 (4.5)	16 (4.3)	1 (2.9)	3 (7.3)	17 (4.4)	3 (5.2)
<b>Weight-related</b>						
Loss	4 (0.9)	3 (0.8)	1 (2.9)	0	4 (1.0)	0
Gain/bloating/swelling	22 (5.0)	17 (4.6)	2 (5.7)	3 (7.3)	22 (5.7)	0
Unspecified	20 (4.5)	14 (3.8)	5 (14.3)	1 (2.4)	19 (4.9)	1 (1.7)
<b>Total</b>	<b>444 (100.0)</b>	<b>368 (100.0)</b>	<b>35 (100.0)</b>	<b>41 (100.0)</b>	<b>386 (100.0)</b>	<b>58 (100.0)</b>

ed with appearance concerns at the bivariate level; however, the association was not statistically significant after accounting for the influences of other sociodemographic and disease/medical variables. Consistent with findings from previous studies, older age was significantly associated with reduced odds of appearance concerns. Among disease variables, moderate hand contractures were significantly associated with greater odds of appearance concerns. Compared to data from a general population sample, both women and men with SSc were more likely to report appearance concerns, although the relative risk was higher for men with SSc compared to women. In addition, for both women and men, the relative risk was substantially higher, compared to the general population, among older patients than among younger patients. The most commonly reported features of concern were related to the face and head, followed by the hands and fingers; this did not differ by sex or race/ethnicity.

The finding that female SSc patients had greater odds of experiencing appearance concerns is consistent with previous research on the relationship between sex and visible differences, which has highlighted that women tend to experience greater distress, social anxiety, and difficulty adjusting to disfiguring appearance changes than

men (16-18). Although 85% of Black patients reported appearance concerns compared to 71% of White patients, race/ethnicity was not independently associated with appearance concerns in the multivariate analysis. It is possible that the small number of Black people in the study could explain the non-significant result. This finding may

also have occurred because Black patients tended to be younger, have diffuse disease, and have greater pigmentation changes and skin thickening on the fingers compared to White patients, as these are all factors associated with appearance concerns. Although men with SSc were less likely to report appearance concerns than

**Table III.** Unadjusted and adjusted comparisons of appearance concerns across sociodemographic and disease variables.

Variable	Unadjusted OR (95% CI)	p-value	Adjusted OR (95% CI) <sup>a</sup>	p-value
<b>Race/ethnicity (reference = White)</b>				
Black	2.64 (1.01-6.34)	.030	1.76 (0.67-4.60)	.250
Other	0.92 (0.52-1.65)	.788	0.59 (0.31-1.14)	.117
Age	0.97 (0.96-0.98)	<.001	0.98 (0.96-0.99)	.007
Female sex	2.70 (1.73-4.22)	<.001	2.97 (1.78-4.95)	<.001
Education ≤ 12 years	0.69 (0.47-1.02)	.063	0.74 (0.48-1.14)	.174
Not married/living as married	1.36 (0.92-2.00)	.121	1.05 (0.68-1.60)	.841
BMI	1.00 (0.92-1.10)	.951	1.01 (0.98-1.05)	.421
Diffuse disease subtype	1.76 (1.24-2.50)	.002	1.18 (0.76-1.83)	.456
<b>Telangiectasia (reference = none)</b>				
Body and face	0.81 (0.54-1.22)	.313	1.48 (0.89-2.47)	.136
Body only	0.70 (0.44-1.09)	.116	1.20 (0.77-1.86)	.420
<b>Pigmentation changes (reference = none)</b>				
Body and face	1.58 (0.96-2.58)	.071	0.91 (0.52-1.57)	.730
Body only	1.50 (0.92-2.47)	.108	1.02 (0.51-2.06)	.947
<b>Hand contractures (reference = none/mild)</b>				
Moderate	2.33 (1.41-3.86)	.001	2.05 (1.17-3.60)	.012
Severe	2.03 (0.88-4.70)	.099	1.96 (0.75-5.15)	.170
Skin thickening on hands	1.64 (1.18-2.28)	.003	1.48 (1.00-2.19)	.050

OR: odds ratio; CI: confidence interval; BMI: Body Mass Index.

<sup>a</sup>Adjusted for age, sex, race/ethnicity, education level, marital status, disease subtype, telangiectasia, pigmentation changes, hand contractures, and skin thickening on fingers.

women with the disease, men with SSc had a greater relative risk of appearance concerns compared to the general population sample than women. In both SSc and the general population, women are more likely than men to have appearance concerns, but the increase in appearance concerns is much greater for men with SSc. A similar phenomenon can be seen with respect to age. For both women and men in the general population, the proportion of people with appearance concerns drops substantially in older groups, particularly for people aged 61 and older. The proportion also diminishes across age groups for people with SSc, but much less dramatically, and in SSc, older people are more likely to report appearance concerns compared to the general population, where worries about appearance have mostly subsided among older adults.

The finding that the majority of patients across sexes and race/ethnicities listed the face and head body regions as the primary feature that caused them concern, followed by the hands and fingers, is consistent with previous research in SSc, which has reported that appearance changes to visible and socially relevant body regions are common and of the greatest distress to patients (2, 6, 7, 9, 12). While the categories of appearance concern in the present study were broad, results showed that the general types of appearance concerns reported by patients were fairly consistent across sex and racial/ethnic groups.

The present study has limitations that should be considered in interpreting results. First, the SPIN Cohort constitutes a convenience sample of SSc patients receiving treatment at SPIN recruiting centers, and patients at these centers may differ from those in other settings. SSc patients in the SPIN Cohort also complete questionnaires online, which may further limit the generalisability of findings. An additional limitation relates to the nature of disease characteristics included in the analyses. Specifically, the majority of the variables consisted of fairly crude indicators of either the presence or absence of a particular disease factor and did not pro-

**Table IV.** Proportion of women and men who reported appearance concerns based on age in general population and SPIN samples.

	General Population Sample (n, %) <sup>a</sup>	SPIN Sample (n, %)	Relative Risk SPIN / General Population (95% CI)
Women age bands (years)			
18-40	367/537 (68)	50/60 (83)	1.22 (1.07-1.38)
41-50	139/226 (62)	80/101 (79)	1.29 (1.12-1.49)
51-60	151/240 (63)	145/183 (79)	1.26 (1.11-1.42)
61+	58/174 (33)	146/221 (66)	1.98 (1.57-2.50)
Men age bands (years)			
18-40	152/341 (45)	5/9 (56)	1.25 (0.69-2.26)
41-50	69/170 (41)	8/11 (73)	1.79 (1.20-2.69)
51-60	49/202 (24)	12/22 (55)	2.25 (1.43-3.54)
61 +	45/218 (21)	17/37 (46)	2.23 (1.44-3.44)

<sup>a</sup>Based on values reported in Harris and Carr, 2001 (14). CI: confidence interval.

vide a measure of severity. This may have reduced the ability to identify any associations, if present, between the severity of visible differences from the disease and the presence of appearance concerns. An additional limitation is that the sample sizes of Black patients and those who self-identified as members of another racial/ethnic group were small. These limitations may have been reflected in the model fit statistics, which were less than ideal (28). It is also possible that the relatively limited information obtained from the predictive model was due to the dichotomous outcome variable. Most patients reported the presence of appearance concerns; however, measuring appearance concerns may not be something easily categorised as present or absent, and thus, the study results may differ if a more robust measure of appearance concerns were used. Additionally, the general population sample comparison was done with the only general population data that were currently available. While it was useful to contextualise patterns of appearance concerns among patients with SSc, the degree of actual differences may have been influenced by factors not considered in the present analysis. Another limitation is that the categories for reporting features of concern that were used in the present study were somewhat broad and non-specific, which did not allow for a detailed description of the features listed by patients. Nonetheless, they provided a general understanding of the common types of appearance concerns among

patients and underlined that those most important do not vary substantially across sex or racial/ethnic groups. Finally, we used self-reported race/ethnicity classifications. Race/ethnicity is a complex construct that may reflect sociocultural aspects of experience as much as biological aspects. Furthermore, the Other race/ethnicity category allowed us to separate out people who did not identify as White or Black, but its composition was heterogeneous and not necessarily informative in relation to the experience of any patient or group of patients classified in the Other group.

In sum, female SSc patients had significantly higher odds of reporting appearance concerns than male patients. Although Black SSc patients had higher odds of experiencing appearance concerns than White patients on an unadjusted basis, this result was not statistically significant when accounting for the influence of other sociodemographic and disease/medical characteristics. It may be the case that greater appearance concerns among Black patients reflect more significant appearance changes, such as skin involvement, including pigmentation changes. Both women and men with SSc were more likely to report appearance concerns than general population survey respondents. The difference in reporting of appearance concerns between SSc patients and the general population was greatest for men and for older patients. In both of these cases, rates in the general population were relatively

low for these groups, but much less so in SSc. Despite differences in overall rates, across groups defined by sex or race/ethnicity, the most commonly reported features of appearance concern related to the face and head regions, followed by the hands and fingers. Replications of the current study with larger samples of Black and other racial/ethnic groups are needed. In addition, future studies should include assessment of appearance concerns with a continuously measured outcome variable or one that explores multiple domains of appearance concerns, as well as include factors, such as disease duration and disease and serological subtype, to explore their potential impact on appearance concerns.

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