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ORIGINAL RESEARCH

Factors associated with satisfaction with social roles and activities among people with systemic sclerosis: a Scleroderma Patient-centered Intervention Network (SPIN) cohort cross-sectional study

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ABSTRACT

Objective The objectives were to (1) compare satisfaction with social roles and activities in a large multinational systemic sclerosis (SSc) cohort to general population normative data and (2) identify sociodemographic, lifestyle and SSc disease factors associated with satisfaction with social roles and activities.

Methods Participants in the Scleroderma Patient-centered Intervention Network Cohort completed the Patient Reported Outcomes Information System Version 2 satisfaction with social roles and activities domain questionnaire. Multivariable regression was used to assess associations with sociodemographic, lifestyle and disease factors.

Results Among 2385 participants, mean satisfaction with social roles and activities T-score (48.1, SD=9.9) was slightly lower than the US general population (mean=50, SD=10). Factors independently associated with satisfaction were years of education (0.54 per SD, 95% CI 0.14 to 0.93); non-White race or ethnicity (–1.13, 95% CI –2.18 to –0.08); living in Canada (–1.33, 95% CI –2.40 to –0.26 (reference USA)) or the UK (–2.49, 95% CI –3.92 to –1.06); body mass index (–1.08 per SD, 95% CI –1.47 to –0.69); gastrointestinal involvement (–3.16, 95% CI –4.27 to –2.05); digital ulcers (–1.90, 95% CI –3.05 to –0.76); moderate (–1.62, 95% CI –2.78 to –0.45) or severe (–2.26, 95% CI –3.99 to –0.52) small joint contractures; interstitial lung disease (–1.11, 95% CI –1.97 to –0.25); pulmonary arterial hypertension (–2.69, 95% CI –4.08 to –1.30); rheumatoid arthritis (–2.51, 95% CI –4.28 to –0.73); and Sjogren's syndrome (–2.42, 95% CI –3.96 to –0.88).

Conclusion Mean satisfaction with social roles and activities is slightly lower in SSc than the general population and associated with multiple sociodemographic and disease factors.

WHAT IS ALREADY KNOWN ON THIS TOPIC

⇒ Individuals with systemic sclerosis (SSc) face multiple challenges that can negatively affect their ability to fulfil social roles and participate in social activities.

WHAT THIS STUDY ADDS

⇒ On average, satisfaction was only minimally lower than the US general population.
⇒ Many factors are significantly associated with satisfaction with social roles and activities in SSc.

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

⇒ Our study suggests that many individuals with SSc may have learnt how to adapt and cope with their limited capacities leading to a minimal impact on their satisfaction with their social roles and activities.
⇒ More research is needed to better understand strategies that may be used to support coping.

INTRODUCTION

Systemic sclerosis (SSc, scleroderma) is a chronic autoimmune disease characterised by microvascular damage and fibrosis of the skin and multiple other organs including the lungs, gastrointestinal tract, kidneys and heart.[1] Associated challenges include pain, fatigue, disability and diminished physical function, dissatisfaction with appearance, social discomfort, fear of disease and symptom progression, and reduced mental health,[1–6] all of which may negatively influence the

ability to successfully fulfil social roles and participate in activities.[7]

There is limited data on how satisfied people with SSc are with their ability to successfully carry out social roles and participate in activities, but individuals with SSc may experience substantial impairment in social functioning, including limitations in the ability to work, complete personal and household responsibilities, and perform typical daily routines.[8–11] A 2018 systematic review[10] (7 studies; 795 people with SSc and 1154 healthy controls) found a mean difference in scores on the Short Form Survey-36 social functioning subscale, which measures limitations in social activities due to physical or emotional problems, between SSc patients and healthy controls of 13 points (95% CI 5 to 21 points),[10] an approximately 0.5 standardised mean difference.[12 13] Only relatively small studies with <300 participants have examined factors associated with satisfaction with social function or participation in social roles in SSc, and these studies have included only small numbers of general SSc disease characteristics as possible factors (eg, diffuse or limited subtype, disease duration) but not specific physician-assessed disease manifestations.[14 15]

A better understanding of satisfaction with social roles and activities among people with SSc and factors associated with satisfaction would support development of tools to improve social function and adjustment to changes in social functioning. The objectives of this study were to (1) compare satisfaction with social roles and activities in a large multinational SSc cohort to general population normative data, and (2) identify sociodemographic, lifestyle and SSc disease factors associated with satisfaction with social roles and activities.

METHODS

This was a cross-sectional study that evaluated baseline data from the Scleroderma Patient-centered Intervention Network (SPIN) cohort.[16–18] It was reported based on guidance in the Strengthening the Reporting of Observational Studies in Epidemiology statement.[19] Methods from studies that use data from the SPIN cohort are similar. Thus, we followed reporting guidance from the Text Recycling Research Project.[20]

Participants and procedures

The SPIN cohort is a convenience sample of participants from seven countries: Australia, Canada, France, Mexico, the UK, the USA and Spain.[16–18] Eligible participants are recruited by the attending physician or a nurse coordinator during regular physician visits. Participants included in the SPIN cohort must be ≥18 years of age; fluent in English, French or Spanish; and classified as having SSc based on the 2013 American College of Rheumatology/European League Against Rheumatism classification criteria for SSc[21] as verified by a SPIN site physician. After obtaining written informed consent from eligible participants, onsite staff submit an online medical data form and participants receive an automated email with instructions on how to activate their online SPIN account and complete their baseline measures. SPIN cohort participants are invited to complete subsequent online assessments every 3 months. This study used baseline assessment data from participants enrolled in the SPIN cohort from April 2014, the date of inception, until March 2023. SPIN cohort participants were included in this study if they completed all Patient Reported Outcomes Information System (PROMIS-29) version 2.0 domains at their baseline assessment.

Measures

SPIN cohort participants provided sociodemographic (race or ethnicity, education level, marital status) and lifestyle (eg, smoking status, alcohol consumption) information and completed patient-reported outcome measures. Physicians reported participants' age; sex; height; weight; years since initial onset of non-Raynaud phenomenon symptoms; SSc subtype (limited, diffuse, sine); modified Rodnan skin score (mRSS); presence of gastrointestinal symptoms (upper; lower; or no gastrointestinal involvement); presence of digital ulcers anywhere on the fingers; presence of tendon friction rubs (currently; in the past; never); presence of small or large joint contractures (none; mild (≤25% range of motion limitation); moderate to severe (>25%)); presence of pulmonary arterial hypertension; presence of interstitial lung disease; existing history of SSc renal crisis; presence of current or past overlap syndromes (systemic lupus erythematosus, rheumatoid arthritis, Sjogren's syndrome, autoimmune thyroid disease, idiopathic inflammatory myositis and primary biliary cirrhosis); and presence of SSc-related antibodies (antinuclear antibody, anticentromere, anti-topoisomerase I and anti-RNA polymerase III).

Satisfaction with social roles and activities

Satisfaction with social roles and activities was evaluated in the SPIN cohort using the 4a Short Form of the PROMIS-29 V.2.0 satisfaction with social roles and activities domain, which assesses patient-reported health status over the past 7 days.[22] This domain measures the level of satisfaction individuals have with their ability to perform different social roles and activities such as work inside and outside the home, personal and household responsibilities, and daily routines.[23] Satisfaction with social roles and activities is assessed with four items, each rated on a 5-point Likert scale. Item scores are summed to give a satisfaction with social roles and activities domain score that is converted into a T-score standardised to the US general population (mean=50, SD=10).[24] Normal levels of satisfaction with one's social roles and activities is represented by a T-score over 45.0, mild impairment by a T-score that ranges between 40.0 and 45.0, moderate impairment between 30.0 and 39.9 and severe impairment in satisfaction with social roles and activities by a T-score less than 30.0.[25] The PROMIS-29 V.2.0 has been validated within the SPIN cohort, with a satisfactory Cronbach's α ranging

from 0.86 to 0.96 for all PROMIS-29 V.2.0 domains and a good convergent validity.[26]

Pruritus

Pruritus severity was evaluated with a single item: 'In the past week, how severe was your itch?', with patients using an 11-point numeric rating scale (0=not severe at all to 11=unbearable). Similar numerical rating scales have been shown to be valid for assessing pruritus severity.[27]

Pain

Pain intensity in the last week was assessed with the PROMIS-29 V.2.0 using a single-item: 'In the past 7 days, how would you rate your pain on average?'.[28 29] This item is rated on a 10-point numerical rating scale (0=no pain to 10=worst imaginable pain). Single-level and multi-level item measurements of pain intensity have been shown to perform equivalently in individuals with SSc.[30] Pain interference in the last week was assessed with the PROMIS-29 V.2.0 using four items, each rated on a 5-point Likert scale (1='not at all' and 5='very much').

Statistical analysis

We computed descriptive statistics for all variables for the entire sample and separately for those with diffuse and limited SSc (including sine) and by sex. Unadjusted outcomes were generated with simple linear regressions used to assess bivariate associations of sociodemographic, lifestyle and disease-related variables with satisfaction with social roles and activities. Adjusted outcomes were generated via multivariable linear regression used to assess the independent association of each variable with satisfaction with social roles and activities. We identified items to be included in the model a priori based on factors associated with psychosocial outcomes in SSc[4 7 31–33] and based on the experience of research team members who either have or provide healthcare for individuals with SSc. We did not include psychosocial or functional variables that are outcomes of SSc (depression symptoms, anxiety symptoms, pain, fatigue, self-efficacy) as predictors in the main model as they are likely to have bidirectional causal associations with social functioning. We did this to avoid reverse causality where outcome variables may be causally associated to predictor variables, which can lead to (1) biased model coefficients, potentially masking important associations between disease variables and social functioning; (2) spuriously inflated goodness-of-fit estimates (R^2); and (3) inability to determine the relative causal influence between the variables for which reverse causation is likely.[34]

Variables included in the main analysis were age (years standardised); male sex (reference=female); years of education (years standardised); single, divorced or separated, or widowed (reference=married or living as married); non-White (reference=White); Canada, UK, France, other (Australia, Mexico, Spain) (reference=USA); body mass index (BMI) (standardised); years since first non-Raynaud's symptoms (years standardised); diffuse subtype (reference=limited or sine); gastrointestinal involvement (reference=no); digital ulcers (reference=no); current or past tendon friction rubs (reference=never); moderate or severe small joint contractures (reference=none or mild); moderate or severe large joint contractures (reference=none or mild); history of SSc renal crisis (reference=no); interstitial lung disease (reference=no); pulmonary arterial hypertension (reference=no); systemic lupus erythematosus (reference=no); rheumatoid arthritis (reference=no); Sjogren's syndrome (reference=no); autoimmune thyroid disease (reference=no); idiopathic inflammatory myositis (reference=no); primary biliary cirrhosis (reference=no). We did not include variables such as smoking status or alcohol consumption as social functioning may influence these. See online supplemental material 1 for variable specifications.

We accounted for missing data by using multiple imputations via chained equations, using the mice package in R.[35] We generated 20 imputed datasets, using 15 cycles per dataset. Variables included in the mice procedure included: all variables in the main regression model, all variables considered in sensitivity analyses, alcohol consumption and smoking status, and anxiety, depression, pain intensity and interference, fatigue, sleep, and physical function domain scores on the PROMIS-29 V.2.0.

We conducted four multivariable sensitivity analyses. We (1) conducted a complete case analysis of the main model; (2) added pruritus and pain to the main model; (3) replaced disease subtype with continuous mRSS; and (4) added SSc-related antibodies (antinuclear antibodies (reference=negative); anticentromere (reference=negative); antitopoisomerase I (Scl70) (reference=negative); and anti-RNA polymerase III (reference=negative)) to the main model. See online supplemental material 1.

We standardised continuous predictor variables after imputation and prior to entering them into the models. We reported unstandardised regression coefficients with 95% CIs and total explained variance for each model (adjusted R^2). All regression analyses were conducted in R (R V.3.6.3, RStudio V.1.2.5042).

Patient involvement

Patient members of the SPIN Steering Committee play a role in developing SPIN research priorities, including identifying the need for the present study. Five patient members of the Steering Committee reviewed and provided comments on the study protocol and manuscript and are coauthors.

RESULTS

Our sample consisted of 2385 participants from 53 sites with baseline SPIN cohort PROMIS-29 V.2.0 satisfaction with social roles and activities domain data. Participants were predominantly female (N=2079; 87%) and White (N=1970; 83%). Mean (SD) age was 54.9 (12.6) years, mean (SD) education was 15.0 (3.7) years and mean (SD)

BMI was 25.3 (5.6). Most participants were from the USA (N=813; 34%), France (N=713; 30%) or Canada (N=515; 22%). Mean (SD) years since onset of first non-Raynaud's symptoms was 10.9 (8.8), and 904 (38%) participants had diffuse SSc. Table 1 shows participant sociodemographic and disease characteristics, including the number with data for each variable, for the full sample and by disease subtype. See online supplemental material 2 for participant characteristics by sex.

As shown in table 2, the mean (SD) satisfaction with social roles and activities score in the full sample was 48.1 (9.9), which is slightly lower than the USA general population mean (SD) of 50.0 (10.0). Among all participants, 1307 (55%) had social functioning scores within normal limits; 590 (25%) reported mildly impaired scores, 387 (16%) reported moderately impaired scores; and 101 (4%) reported severe impairment. By country, mean (SD) scores ranged from 45.5 (10.2) among 241 participants from the UK to 50.7 (8.5) in 101 participants from Australia, Mexico or Spain. Participants with diffuse SSc reported a lower mean (SD) of satisfaction with social roles and activities 46.8 (9.8) than those with limited or sine SSc 49.0 (9.8). Scores were similar by sex.

In the main multivariable analysis (table 3), among sociodemographic variables, fewer years of education (−0.54 points per SD in years, 95% CI −0.93 to −0.14); self-reported race or ethnicity other than White (−1.13 points, 95% CI −2.18 to −0.08); and living in Canada (−1.33 points, 95% CI −2.40 to −0.26) or UK (−2.49 points, 95% CI −3.92 to −1.06) were associated with reduced satisfaction with social roles and activities. Higher BMI (−1.08 points per SD in BMI, 95% CI −1.47 to −0.69) was also significantly associated. Among disease variables, there were significant associations with gastrointestinal involvement (−3.16 points, 95% CI −4.27 to −2.05); digital ulcers (−1.90 points, 95% CI −3.05 to −0.76); moderate (−1.62 points, 95% CI −2.78 to −0.45) or severe (−2.26 points, 95% CI −3.99 to −0.52) small joint contractures; interstitial lung disease (−1.11 points, 95% CI −1.97 to −0.25); and pulmonary arterial hypertension (−2.69 points, 95% CI −4.08 to −1.30). Among overlap syndromes, rheumatoid arthritis (−2.51 points, 95% CI −4.28 to −0.73); and Sjogren's syndrome (−2.42 points, 95% CI −3.96 to −0.88) were significantly associated. Variables not significantly associated were age; sex; marital status; living in France, Australia, Mexico or Spain; years since first non-Raynaud's symptoms; disease subtype; presence of current or past tendon friction rubs; moderate or severe large joint contractures; history of SSc renal crisis; systemic lupus erythematosus; autoimmune thyroid disease; idiopathic inflammatory myositis; and primary biliary cirrhosis. Adjusted R^2 for the final model was 0.10.

Complete case analysis results, which included 1664 participants, were similar to those of the main analyses (see online supplemental material 3). When adding pruritus and pain intensity to the model in a sensitivity analysis, both pruritus (−0.83 points per SD in pruritus, 95% CI −1.20 to −0.47); and pain intensity (−5.33 points per SD in pain intensity, 95% CI −5.69 to −4.98) were associated with reduced satisfaction with social roles and activities. The sensitivity analysis replacing disease subtype with mRSS found that mRSS was significantly associated with satisfaction with social roles and activities (−0.69 points per SD in mRSS score, 95% CI −1.18 to −0.21). No antibodies had a significant association. See online supplemental materials 4–6.

DISCUSSION

Among 2385 participants with SSc from 7 countries, the mean T-score for satisfaction with social roles and activities was 48.1 (9.9), which is approximately 0.2 SD below the US general population mean. Over half (55%) of participants reported satisfaction with social roles and activities within normal limits. We found that disease variables associated with reduced satisfaction with social roles and activities included gastrointestinal involvement, digital ulcers, the presence of moderate or severe small joint contractures, interstitial lung disease, pulmonary arterial hypertension, mRSS, pruritus, pain intensity, and the presence of overlap syndromes including rheumatoid arthritis and Sjogren's syndrome. We also found that fewer years of education, self-reported race or ethnicity other than White, living in Canada or the UK, having a higher BMI, pruritus, pain intensity and mRSS were associated with greater impairment in satisfaction with one's social functioning. Among those with large associations, gastrointestinal involvement may reduce one's ability to carry out social roles due to symptoms such as nausea, abdominal pain or faecal incontinence[36]; pulmonary arterial hypertension can cause breathlessness, fatigue and dizziness, which can impact the ability to perform everyday tasks such as travelling to work or taking care of household chores[37 38]; hand and joint involvement can decrease one's the ability to carry out many tasks necessary for work or household roles[8]; overlap syndromes, including rheumatoid arthritis or Sjogren's syndrome, present their own challenges and can exacerbate other symptom-related barriers from SSc.

Our findings on satisfaction with ability to participate in social roles and activities are generally consistent with the next largest study of people with SSc and another large study of people with rheumatoid arthritis or systemic lupus erythematosus.[39 40] One study assessed 477 Australian patients with SSc and reported a mean (SD) on the PROMIS-29v1 social interaction domain of 46.5 (9.7).[39] The other study assessed 4346 participants with rheumatoid arthritis and 240 with systemic lupus erythematosus, and reported PROMIS-29 satisfaction with social role T-score means (SD) of 48.9 (9.7) for rheumatoid arthritis, and 49.2 (10.0) for systemic lupus erythematosus.[40]

Our findings on satisfaction with social roles and activities, which were close to the US general population mean, differed from our findings on physical function using data from the same participants from the SPIN

Table 1 Sample sociodemographic and disease characteristic

	Full sample (N=2385)		Limited SSc* (N=1456)		Diffuse SSc (N=904)	
	N†	Mean (SD) or N (%)	N	Mean (SD) or N (%)	N	Mean (SD) or N (%)
Age (years)	2381	54.9 (12.6)	1452	56.6 (12.4)	904	52.1 (12.4)
Sex	2385		1456		904	
Female		2079 (87%)		1299 (89%)		759 (84%)
Male		306 (13%)		157 (11%)		145 (16%)
Education (years)	2377	15.0 (3.7)	1450	14.9 (3.8)	902	15.1 (3.6)
Marital status	2381		1453		903	
Married or living as married		1661 (70%)		1035 (71%)		611 (68%)
Single, divorced/separated, widowed		720 (30%)		418 (29%)		292 (32%)
Race or ethnicity‡	2379		1453		901	
White		1970 (83%)		1268 (87%)		684 (76%)
Non-White		409 (17%)		185 (13%)		217 (24%)
Country	2383		1455		903	
USA		813 (34%)		436 (30%)		370 (41%)
France		713 (30%)		470 (32%)		241 (27%)
Canada		515 (22%)		332 (23%)		173 (19%)
UK		241 (10%)		143 (10%)		94 (10%)
Australia, Mexico, Spain		101 (4%)		74 (5%)		25 (3%)
Smoking status	2382		1454		903	
Smoker		177 (7%)		118 (8%)		55 (6%)
Non-smoker		2205 (93%)		1336 (92%)		848 (94%)
Alcohol consumption (drinks per week)	2379	2.0 (4.1)	1453	2.1 (4.3)	901	1.8 (3.5)
Body mass index	2385	25.3 (5.6)	1456	25.5 (5.6)	904	24.9 (5.7)
Years since first non-Raynaud's symptoms	2190	10.9 (8.8)	1325	12.1 (9.3)	843	8.9 (7.4)
Disease subtype	2360		1456		904	
Diffuse		904 (38%)		0 (0%)		904 (100%)
Limited or sine*		1456 (62%)		1456 (100%)		0 (0%)
mRSS	1983	7.7 (8.0)	1213	4.2 (4.2)	754	13.4 (9.4)
Gastrointestinal involvement	2,353		1442		891	
Yes		2016 (85%)		1225 (85%)		779 (87%)
No		337 (14%)		217 (15%)		112 (13%)
Digital ulcers	2287		1407		859	
Yes		365 (16%)		132 (9%)		228 (27%)
No		1922 (84%)		1275 (91%)		631 (73%)
Tendon friction rubs	2100		1308		775	
Current		232 (11%)		120 (9%)		110 (14%)
Past		221 (11%)		41 (3%)		178 (23%)
Never		1647 (78%)		1147 (88%)		487 (63%)
Small joint contractures	2255		1388		848	
None or mild		1663 (74%)		1176 (85%)		473 (56%)
Moderate		424 (19%)		161 (12%)		260 (31%)
Severe		168 (7%)		51 (4%)		115 (14%)
Large joint contractures	2211		1359		833	
None or mild		1937 (88%)		1263 (93%)		658 (79%)

Continued

Table 1 Continued

	Full sample (N=2385)		Limited SSc* (N=1456)		Diffuse SSc (N=904)	
	N†	Mean (SD) or N (%)	N	Mean (SD) or N (%)	N	Mean (SD) or N (%)
Moderate		200 (9%)		65 (5%)		134 (16%)
Severe		74 (3%)		31 (2%)		41 (5%)
History of SSc renal crisis	2351		1442		890	
Yes		101 (4%)		24 (2%)		77 (9%)
No		2250 (96%)		1418 (98%)		813 (91%)
Interstitial lung disease	2335		1431		883	
Yes		827 (35%)		390 (27%)		432 (49%)
No		1508 (65%)		1041 (73%)		451 (51%)
Pulmonary arterial hypertension	2271		1398		852	
Yes		207 (9%)		131 (9%)		74 (9%)
No		2064 (91%)		1267 (91%)		778 (91%)
Pruritus	2154	1.8 (2.6)	1300	1.6 (2.5)	831	2.1 (2.8)
Pain intensity	2385	3.6 (2.6)	1456	3.5 (2.6)	904	3.8 (2.6)
Pain interference	2384	55.5 (9.7)	1455	54.8 (9.6)	904	56.6 (9.7)
Systemic lupus erythematosus	2323		1428		876	
Yes		65 (3%)		44 (3%)		20 (2%)
No		2258 (97%)		1384 (97%)		856 (98%)
Rheumatoid arthritis	2322		1426		877	
Yes		125 (5%)		64 (4%)		59 (7%)
No		2197 (95%)		1362 (96%)		818 (93%)
Sjogren's syndrome	2285		1403		863	
Yes		176 (8%)		124 (9%)		52 (6%)
No		2109 (92%)		1279 (91%)		811 (94%)
Autoimmune thyroid disease	2277		1397		861	
Yes		143 (6%)		99 (7%)		44 (5%)
No		2134 (94%)		1298 (93%)		817 (95%)
Idiopathic inflammatory myositis	2322		1430		872	
Yes		121 (5%)		60 (4%)		59 (7%)
No		2201 (95%)		1370 (96%)		813 (93%)
Primary biliary cirrhosis	2301		1413		869	
Yes		44 (2%)		38 (3%)		5 (1%)
No		2257 (98%)		1375 (97%)		864 (99%)
Antinuclear antibodies	2194		1360		818	
Positive		2069 (94%)		1296 (95%)		757 (93%)
Negative		125 (6%)		64 (5%)		61 (7%)
Anticentromere	1861		1171		680	
Positive		665 (36%)		609 (52%)		54 (8%)
Negative		1196 (64%)		562 (48%)		626 (92%)
Antitopoisomerase I (Scl70)	2077		1267		799	
Positive		555 (27%)		243 (19%)		311 (39%)
Negative		1522 (73%)		1024 (81%)		488 (61%)
Anti-RNA polymerate III	1353		808		539	
Positive		245 (18%)		49 (6%)		195 (36%)

Continued

Table 1 Continued

	Full sample (N=2385)		Limited SSc* (N=1456)		Diffuse SSc (N=904)	
	N†	Mean (SD) or N (%)	N	Mean (SD) or N (%)	N	Mean (SD) or N (%)
Negative		1108 (82%)		759 (94%)		344 (64%)

*Includes 73 participants with sine SSc.
†N for some variables <2385 due to missing data.
‡Race or ethnicity data were self-reported in each country using standard categories used in that country. Therefore, categories differed between countries and could only be aggregated in the two categories reported.
mRSS, modified Rodnan skin score; SSc, systemic sclerosis.

cohort.[41] In that study, we found a mean T-score (SD) for the PROMIS-29 V.2.0 physical function domain of 43.7 (8.9), equivalent to approximately 2/3 of an SD below the US general population mean. The finding of substantially lower physical function but only minimally impaired satisfaction with social roles and activities may reflect the nature of each construct. The physical function domain is a relatively objective measure, though self-reported, of one's ability to complete concrete tasks, such as going up and down stairs, whereas the satisfaction with social roles and activities domain measures one's satisfaction with their ability to fulfil social roles and participate in activities. This is also seen in other chronic diseases, where people adapt their expectations and satisfaction with what they can do, despite objectively decreasing abilities. This phenomenon is known as a response shift[42] and suggests that people may be coping with the changes they are experiencing by adapting their expectations and, thus, their level of satisfaction with what they are able to do despite their adverse circumstances.[43 44] The degree to which people may be able to participate in social roles and activities may be reduced but their satisfaction with their ability to participate is not.

The adjusted R^2 for the main multivariable model was 0.10. Low R^2 measures are expected in samples of people with a chronic condition as all experience similar symptoms and side effects of the condition. High R^2 values are an important consideration in predictive modelling but are not as valuable when models are used for testing hypotheses about the possible effects of variables of interest. In such cases, including in the present study, having a large enough sample size to generate reasonably precise parameter estimates is a more important consideration.[34]

More studies of this nature are needed to better understand the course of satisfaction with social roles and activities in SSc. Future studies might focus on pinpointing characteristics of individuals who successfully cope and adapt and potential reasons as why differences occur. We found that a wide variety of factors may impact an

Table 2 Satisfaction with social roles and activities by country, disease subtype and sex

	T-score mean	Within normal limits (T-score>45)	Mild (T-score 40–45)	Moderate (T-score 30–39.9)	Severe (T-score<30)
Full sample (N=2385)	48.1 (9.9)	1307 (55%)	590 (25%)	387 (16%)	101 (4%)
Country					
USA (N=813)	48.8 (9.7)	466 (57%)	191 (24%)	136 (17%)	20 (3%)
France (N=713)	48.0 (9.9)	395 (55%)	177 (25%)	105 (15%)	36 (5%)
Canada (N=515)	47.8 (9.9)	274 (53%)	134 (26%)	81 (16%)	26 (5%)
UK (N=241)	45.5 (10.2)	101 (42%)	65 (27%)	57 (24%)	18 (8%)
Other* (N=101)	50.7 (8.5)	71 (70%)	21 (21%)	8 (8%)	1 (1%)
SSc subtype					
Limited or sine† (N=1456)	49.0 (9.8)	858 (59%)	343 (24%)	212 (15%)	43 (3%)
Diffuse (N=904)	46.8 (9.8)	440 (49%)	243 (27%)	167 (19%)	54 (6%)
Sex					
Female (N=2079)	48.0 (9.8)	1134 (55%)	518 (25%)	338 (16%)	89 (4%)
Male (N=306)	48.6 (10.1)	173 (57%)	72 (24%)	49 (16%)	12 (4%)

*Includes 40 participants in Australia, 21 in Mexico and 40 in Spain.
†Includes 73 participants with sine SSc.
SSc, systemic sclerosis.

Table 3 Linear regression analysis of sociodemographic and disease characteristic associations with satisfaction with social roles and activities

	Satisfaction with social roles and activities	
	Full Sample (N=2385)	
	Unadjusted regression coefficient (95% CI)*	Adjusted regression coefficient (95% CI)*
Sociodemographic variables and body mass index (BMI)		
Age (years standardised)	0.15 (–0.25 to 0.54)	0.08 (–0.34 to 0.49)
Male sex (reference=female)	0.55 (–0.63 to 1.74)	1.04 (–0.12 to 2.21)
Years of education (years standardised)	**0.70 (0.31 to 1.10)**	**0.54 (0.14 to 0.93)**
Single, divorced/separated or widowed (reference=married or living as married)	**–0.90 (–1.76 to –0.03)**	–0.53 (–1.37 to 0.31)
Non-White (reference=White)	**–1.45 (–2.50 to –0.40)**	**–1.13 (–2.18 to –0.08)**
Country (reference=USA)		
Canada	–0.99 (–2.08 to 0.09)	**–1.33 (–2.40 to –0.26)**
UK	**–3.33 (–4.74 to –1.92)**	**–2.49 (–3.92 to –1.06)**
France	–0.80 (–1.78 to 0.19)	–0.87 (–1.89 to 0.15)
Other (Australia, Mexico, Spain)	1.92 (–0.11 to 3.95)	1.53 (–0.45 to 3.51)
BMI (standardised)	**–0.89 (–1.28 to –0.49)**	**–1.08 (–1.47 to –0.69)**
Disease variables		
Years since first non-Raynaud's symptoms (years standardised)	0.13 (–0.28 to 0.55)	0.33 (–0.11 to 0.77)
Diffuse subtype (reference=limited or sine)	**–2.17 (–2.99 to -1.36)**	–0.60 (–1.54 to 0.35)
Gastrointestinal involvement (reference=no)	**–3.73 (–4.86 to –2.61)**	**–3.16 (–4.27 to –2.05)**
Digital ulcers (reference=no)	**–3.33 (–4.43 to –2.23)**	**–1.90 (–3.05 to –0.76)**
Tendon friction rubs (reference=never)		
Current	**–2.36 (–3.69 to –1.03)**	–0.26 (–1.64 to 1.12)
Past	**–2.04 (–3.41 to –0.67)**	–0.30 (–1.77 to 1.17)
Small joint contractures (reference=none or mild)		
Moderate	**–3.02 (–4.07 to –1.98)**	**–1.62 (–2.78 to –0.45)**
Severe	**–4.45 (–5.97 to –2.93)**	**–2.26 (–3.99 to –0.52)**
Large joint contractures (reference=none or mild)		
Moderate	**–4.01 (–5.44 to –2.57)**	–1.43 (–2.99 to 0.13)
Severe	**–3.03 (–5.28 to –0.77)**	–1.31 (–3.71 to 1.08)
History of SSc renal crisis (reference=no)	**–3.48 (–5.43 to –1.53)**	–1.40 (–3.34 to 0.55)
Interstitial lung disease (reference=no)	**–2.24 (–3.07 to –1.40)**	**–1.11 (–1.97 to –0.25)**
Pulmonary arterial hypertension (reference=no)	**–3.48 (–4.87 to –2.09)**	**–2.69 (–4.08 to –1.30)**
Overlap syndromes		
Systemic lupus erythematosus (reference=no)	–1.80 (–4.20 to 0.60)	–0.27 (–2.63 to 2.09)
Rheumatoid arthritis (reference=no)	**–3.98 (–5.74 to –2.21)**	**–2.51 (–4.28 to –0.73)**
Sjogren's syndrome (reference=no)	**–3.68 (–5.22 to –2.13)**	**–2.42 (–3.96 to –0.88)**
Autoimmune thyroid disease (reference=no)	–1.08 (–2.73 to 0.57)	–0.11 (–1.70 to 1.49)
Idiopathic inflammatory myositis (reference=no)	**–3.64 (–5.44 to –1.84)**	–1.67 (–3.46 to 0.11)
Primary biliary cirrhosis (reference=no)	–0.68 (–3.63 to 2.27)	–0.96 (–3.80 to 1.88)

*All regression coefficients are unstandardized. Standardised predictor variables calculated by subtracting raw scores from mean and dividing by SD. Bold results are statistically significant (p<0.05). Adjusted R^2=0.10.
SSc, systemic sclerosis.

individual's satisfaction with their social abilities, some of which are modifiable (eg, BMI), but some of which are not (eg, co-occurring diseases such as rheumatoid arthritis). Considering this, future studies are needed to help patients who are less satisfied with their social roles and activities cope with and accept the challenges related to living with SSc. One potential strategy may be acceptance and commitment therapy (ACT), which works on verbal behaviour to influence and change one's thoughts and feelings.[45] A 2016 systematic review (N=18 studies) on the use of ACT in chronic and long-term conditions concluded that evidence is promising, although limited.[46]

Strengths of our study include its large international sample with participants from 53 SPIN sites across seven countries, our analysis of a wide range of sociodemographic, lifestyle and physician-assessed disease-related factors, and the involvement of people with lived SSc experience in the project via leadership in SPIN and participation in the study. There are some limitations that also need to be considered. First, the SPIN cohort is a convenience sample. However, a comparison with the European Scleroderma Trials and Research and Canadian Scleroderma Research Group cohorts indicated broad comparability of participant characteristics, which supports generalisability in SSc.[17] Second, participants were required to answer questions via online questionnaires, which could potentially reduce generalisability of our results. Third, this was a cross-sectional study and we cannot infer causality based on our results. Fourth, our sample may have been older or differed in other ways compared with the US general population sample to which we compared levels of satisfaction with social roles. Fifth, we did not assess the number of organs involved or the presence of end of stage organ dysfunction.

To summarise, we assessed the association of several factors with satisfaction with social roles and activities in 2385 patients with SSc. We found many variables statistically significantly associated, including fewer years of education, self-reported race or ethnicity other than White, living in Canada or the UK, having a higher BMI, gastrointestinal involvement, presence of digital ulcers, moderate or severe small joint contractures, interstitial lung disease, pulmonary arterial hypertension, pruritus, pain intensity, mRSS, rheumatoid arthritis and Sjogren's syndrome. However, overall, there was only a minimal impairment in satisfaction with social roles and activities, despite evident physical limitations. This may suggest that many individuals with SSc have learnt how to adapt and cope with limited physical capacity. More research is needed to better understand strategies that may be used to support coping. For the time being, healthcare providers can work to help patients adapt and cope with their current symptoms, side effects, and levels of satisfaction with their social roles and activities.

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REFERENCES

1 Allanore Y, Simms R, Distler O, *et al*. Systemic sclerosis. *Nat Rev Dis Primers* 2015;1:15002.
2 Thombs BD, Hudson M, Taillefer SS, *et al*. Prevalence and clinical correlates of symptoms of depression in patients with systemic sclerosis. *Arthritis Rheum* 2008;59:504–9.
3 Thombs BD, Taillefer SS, Hudson M, *et al*. Depression in patients with systemic sclerosis: a systematic review of the evidence. *Arthritis Rheum* 2007;57:1089–97.
4 Kwakkenbos L, van Lankveld WGJM, Vonk MC, *et al*. Disease-related and psychosocial factors associated with depressive symptoms in patients with systemic sclerosis, including fear of progression and appearance self-esteem. *J Psychosom Res* 2012;72:199–204.
5 Bassel M, Hudson M, Taillefer SS, *et al*. Frequency and impact of symptoms experienced by patients with systemic sclerosis: results from a Canadian national survey. *Rheumatology (Oxford)* 2011;50:762–7.
6 Jewett LR, Hudson M, Malcarne VL, *et al*. Sociodemographic and disease correlates of body image distress among patients with systemic sclerosis. *PLoS One* 2012;7:e33281.
7 Kwakkenbos L, Delisle VC, Fox RS, *et al*. Psychosocial aspects of scleroderma. *Rheum Dis Clin North Am* 2015;41:519–28.

8 Galetti I, Nunzio S di, Brogelli L, *et al*. How do systemic sclerosis manifestations influence patients' lives? Results from a survey on patients and Caregivers. *Curr Med Res Opin* 2021;37:5–15.
9 Hudson M, Thombs BD, Steele R, *et al*. Quality of life in patients with systemic sclerosis compared to the general population and patients with other chronic conditions. *J Rheumatol* 2009;36:768–72.
10 Li L, Cui Y, Chen S, *et al*. The impact of systemic sclerosis on health-related quality of life assessed by SF-36: a systematic review and meta-analysis. *Int J Rheum Dis* 2018;21:1884–93.
11 Frantz C, Avouac J, Distler O, *et al*. Impaired quality of life in systemic sclerosis and patient perception of the disease: a large International survey. *Semin Arthritis Rheum* 2016;46:115–23.
12 Hays RD, Shapiro MF. An overview of generic health-related quality of life measures for HIV research. *Qual Life Res* 1992;1:91–7.
13 Stewart A, Ware J. Measuring functioning and well-being: the medical outcomes study approach. In: *Summary and discussion of MOS measures. Measuring functioning and well-being: the medical outcomes study approach*. Duke University Pres, 1992: 345–71.
14 Murphy SL, Kratz AL, Whibley D, *et al*. Fatigue and its association with social participation, functioning, and quality of life in systemic sclerosis. *Arthritis Care Res (Hoboken)* 2021;73:415–22.
15 Murphy SL, Whibley D, Kratz AL, *et al*. Fatigue predicts future reduced social participation, not reduced physical function or quality of life in people with systemic sclerosis. *J Scleroderma Relat Disord* 2021;6:187–93.
16 Dougherty DH, Kwakkenbos L, Carrier M-E, *et al*. The Scleroderma Patient-centered Intervention Network cohort: baseline clinical features and comparison with other large scleroderma cohorts. *Rheumatology (Oxford)* 2018;57:1623–31.
17 Kwakkenbos L, Jewett LR, Baron M, *et al*. The Scleroderma Patient-centered Intervention Network (SPIN) cohort: protocol for a cohort multiple randomized controlled trial (cmRCT) design to support trials of Psychosocial and rehabilitation interventions in a rare disease context. *BMJ Open* 2013;3:e003563.
18 The Scleroderma Patient-centered Intervention Network. Available: https://www.spinsclero.com/en/about [Accessed 21 Jan 2024].
19 Vandenbroucke JP, von Elm E, Altman DG, *et al*. Strengthening the reporting of observational studies in epidemiology (STROBE): explanation and elaboration. *Ann Intern Med* 2007;147:W163–94.
20 Text Recycling Research Project. Best practices for researchers. Available: https://textrecycling.org/resources/best-practices-for-researchers/ [Accessed 21 Jan 2024].
21 van den Hoogen F, Khanna D, Fransen J, *et al*. Classification criteria for systemic sclerosis: an American College of Rheumatology/European League against Rheumatism Collaborative Initiative. *Ann Rheum Dis* 2013;72:1747–55.
22 Hays RD, Spritzer KL, Schalet BD, *et al*. PROMIS(®)-29 V2.0 profile physical and mental health summary scores. *Qual Life Res* 2018;27:1885–91.
23 Patient-reported Outcomes Measurement Information System. Satisfaction with social roles and activities. A brief guide to the PROMIS satisfaction with social roles and activities instruments. Available: https://www.healthmeasures.net/images/promis/manuals/PROMIS_Satisfaction_with_Participation_in_Social_Roles_Scoring_Manual.pdf [Accessed 21 Jan 2024].
24 HealthMeasures. Intro to PROMIS. Available: https://www.healthmeasures.net/explore-measurement-systems/promis/intro-to-promis [Accessed 21 Jan 2024].
25 HealthMeasures. PROMIS score cut points. Available: https://www.healthmeasures.net/score-and-interpret/interpret-scores/promis/promis-score-cut-points [Accessed 21 Jan 2024].
26 Kwakkenbos L, Thombs BD, Khanna D, *et al*. Performance of the patient-reported outcomes measurement information System-29 in scleroderma: a Scleroderma Patient-centered Intervention Network cohort study. *Rheumatology (Oxford)* 2017;56:1302–11.
27 Phan N, Blome C, Fritz F, *et al*. Assessment of pruritus intensity: prospective study on validity and reliability of the visual analogue scale, numerical rating scale and verbal rating scale in 471 patients with chronic pruritus. *Acta Derm Venerol* 2012;92:502–7.
28 Salaffi F, Stancati A, Silvestri CA, *et al*. Minimal clinically important changes in chronic musculoskeletal pain intensity measured on a numerical rating scale. *Eur J Pain* 2004;8:283–91.
29 Woo A, Lechner B, Fu T, *et al*. Cut points for mild, moderate, and severe pain among cancer and non-cancer patients: a literature review. *Ann Palliat Med* 2015;4:176–83.
30 El-Baalbaki G, Lober J, Hudson M, *et al*. Measuring pain in systemic sclerosis: comparison of the short-form McGill pain questionnaire versus a single-item measure of pain. *J Rheumatol* 2011;38:2581–7.
31 Levis B, Kwakkenbos L, Hudson M, *et al*. The Association of Sociodemographic and objectively-assessed disease variables with fatigue in systemic sclerosis: an analysis of 785 Canadian scleroderma research group Registry patients. *Clin Rheumatol* 2017;36:373–9.
32 Thombs BD, Hudson M, Bassel M, *et al*. Sociodemographic, disease, and symptom correlates of fatigue in systemic sclerosis: evidence from a sample of 659 Canadian scleroderma research group registry patients. *Arthritis Rheum* 2009;61:966–73.
33 Schieir O, Thombs BD, Hudson M, *et al*. Prevalence, severity, and clinical correlates of pain in patients with systemic sclerosis. *Arthritis Care Res (Hoboken)* 2010;62:409–17.
34 Allison P. *Multiple regression: a primer*. Sage Publications, 1999.
35 van Buuren S, Groothuis-Oudshoorn K. Mice: multivariate imputation by chained equations in R. *J Stat Softw* 2011;45:1–67.
36 Nassar M, Ghernautan V, Nso N, *et al*. Gastrointestinal involvement in systemic sclerosis: an updated review. *Medicine (Baltimore)* 2022;101:e31780.
37 Rich S, Dantzker DR, Ayres SM, *et al*. Primary pulmonary hypertension. A national prospective study. *Ann Intern Med* 1987;107:216–23.
38 Aldrighetti R, Armstrong I, Ferrari P, *et al*. The impact of pulmonary arterial hypertension (PAH) on the lives of patients and carers: results from an international survey, Available: https://www.phaeurope.org/wp-content/uploads/PAH_Survey_FINAL.pdf [Accessed 21 Jan 2024].
39 Morrisroe K, Stevens W, Huq M, *et al*. Validity of the PROMIS-29 in a large Australian cohort of patients with systemic sclerosis. *Journal of Scleroderma and Related Disorders* 2017;2:188–95.
40 Katz P, Pedro S, Michaud K. Performance of the patient-reported outcomes measurement information system 29-item profile in rheumatoid arthritis, osteoarthritis, fibromyalgia, and systemic lupus erythematosus. *Arthritis Care Res (Hoboken)* 2017;69:1312–21.
41 Santo TD, Rice DB, Carrier M-E, *et al*. Factors associated with physical function among people with systemic sclerosis: a Scleroderma Patient-centered Intervention Network (SPIN) cohort cross-sectional study. *Rheumatology* [Preprint] 2023.
42 Sprangers MAG, Schwartz CE. Integrating response shift into health-related quality of life research: a theoretical model. *Soc Sci Med* 1999;48:1507–15.
43 Luthar SS, Cicchetti D. The construct of resilience: implications for interventions and social policies. *Dev Psychopathol* 2000;12:857–85.
44 Herrman H, Stewart DE, Diaz-Granados N, *et al*. What is resilience *Can J Psychiatry* 2011;56:258–65.
45 Hayes SC, Pierson H. Acceptance and commitment therapy. In: *Encyclopedia of cognitive behavior therapy*. New York: Springer, 2006: 1–4.
46 Graham CD, Gouick J, Krahé C, *et al*. A systematic review of the use of acceptance and commitment therapy (ACT) in chronic disease and long-term conditions. *Clin Psychol Rev* 2016;46:46–58.