

Effect of Coping Strategies on Patient and Physician Perceptions of Disease Severity and Disability in Systemic Sclerosis

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ABSTRACT. *Objective.* Systemic sclerosis (SSc) results in impaired function, disability, and reduced health-related quality of life. We investigated the effect of coping strategies on the patient global assessment of health (PtGA) and Health Assessment Questionnaire–Disability Index (HAQ-DI), after controlling for clinical characteristics and disease activity. We also explored the relationship between coping strategies and the correlation between the PtGA and physician global assessment (PGA) in SSc.

Methods. We undertook posthoc analyses using baseline data obtained from the Raynaud Symptom Study (RSS). The PtGA, Coping Strategies Questionnaire, Pain Catastrophizing Scale, and Scleroderma Health Assessment Questionnaire were collected alongside the PGA, clinical characteristics, and patient demographics. Multivariable linear regression models and correlations were used to evaluate the relationship between coping strategies with the PtGA, HAQ-DI, and PGA.

Results. Of the 107 patients with SSc enrolled in the RSS, there were sufficient data available for the analysis of 91 participants. The mean PtGA was 40/100 (SD 27) and the mean HAQ-DI was 0.87/3.0 (SD 0.73). After controlling for clinical and patient demographics, pain catastrophizing and maladaptive coping skills were significantly associated with the PtGA and HAQ-DI scores ($P < 0.05$ for both), but not the PGA.

Conclusion. The effect of coping strategies on PtGA and HAQ-DI (but not PGA in SSc) could influence the result of composite measures incorporating these outcome measures. Interventions to improve patient coping skills may support increased resilience and improve patient-perceived functional status and PtGA in SSc.

Key Indexing Terms: coping, disability, pain, quality of life, scleroderma, systemic sclerosis

Systemic sclerosis (SSc) is a complex rheumatic disease characterized by vascular dysfunction, immunologic derangements, and fibrosis.¹ SSc is associated with increased morbidity, including chronic pain, which has significant effects on both function and health-related quality of life (HRQOL).^{2,3} Previous analyses suggest that the patient global assessment of health (PtGA) is greatly influenced by the degree of pain, skin fibrosis (skin scores), and breathlessness.⁴ Further, surveys and longitudinal evaluations of patients with SSc suggest that perceptions of

physical health greatly affect HRQOL and pain trajectories over time.⁵ The PtGA, Health Assessment Questionnaire–Disability Index (HAQ-DI), and physician global assessment of health (PGA) are important components of the American College of Rheumatology Composite Response Index in diffuse cutaneous SSc (ACR CRIS).⁶ Previous reports have identified discordance between the PtGA and PGA in SSc (intraclass correlation coefficient [ICC] 0.377) but the reasons for this have yet to be elucidated.⁷ Similar discordance has been observed in other rheumatic disease populations such as rheumatoid arthritis (RA)⁸ and systemic lupus erythematosus.⁹

Coping is defined as a management strategy for distress that may be behavioral, affective, or cognitive in nature.¹⁰ In general, coping strategies include active approaches or behaviors used to control pain or function, and passive approaches or behaviors that involve withdrawing and surrendering control over pain. Active coping strategies include coping self-statements, diverting attention, ignoring pain sensations, increasing activity level, and reinterpreting pain sensations.¹¹ Passive coping strategies include praying/hoping and catastrophizing. Generally, active coping strategies have been associated with positive adaptation with respect to pain, including decreased depression and better psychological adjustment.¹² Passive coping strategies are typically characterized as maladaptive and associated with increased pain and negative emotion. Specifically, pain catastrophizing

DDD is supported by the Jerome L. Greene Foundation.

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The authors declare no conflicts of interest relevant to this article.

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Accepted for publication April 14, 2021.

is a cognitive response to pain that leads to magnification of pain sensations and has been associated with worse pain-related outcomes, including anxiety and depression.¹³ We sought to further evaluate the influence of coping strategies on the PtGA and HAQ-DI in SSc, having hypothesized that maladaptive coping strategies would be associated with worse ratings on the PtGA and HAQ-DI. We also explored the effect of coping strategies on the correlation between the PtGA and PGA, to better understand the influence of factors such as coping on the discordance between physician and patient assessments of global health severity in SSc.

METHODS

We undertook a posthoc analysis using baseline data from the previously reported Raynaud Symptom Study (RSS), a multicenter study designed to assess the features and determinants of Raynaud phenomenon (RP) symptoms in SSc. The RSS was an exploratory research study comprising a convenience sample of patients with SSc attending routine clinic reviews in 2 centers. Methods for data collection and survey have been described elsewhere.^{14,15} Briefly, patients fulfilling the 2013 American College of Rheumatology/European League Against Rheumatism classification criteria for SSc were enrolled at routine clinical care visits from specialty care clinics in Bath, UK, and Salt Lake City, USA, between April 2015 and January 2017. The study received ethical approval at each site (Bath REC 15/LO/1521 and Utah Institutional Review Board #80665) and participants provided informed written consent (including for posthoc data analyses). Patient demographics and clinical characteristics were collected including age, sex, ethnicity, disease duration based on time since first non-RP symptom, smoking history, clinical phenotype, SSc autoantibody status, gastroesophageal reflux disease symptoms, puffy fingers, sclerodactyly, digital ulcers (DU), digital pitting, telangiectasia, pulmonary arterial hypertension (PAH), and interstitial lung disease (ILD). Relevant patient comorbidities and medications were also collected, alongside local weather data (which may affect SSc symptoms).

Self-administered questionnaires. Clinicians completed a 100-mm visual analog scale (VAS) PGA of disease severity and RP severity ("In the past week, how would you rate this patient's overall health?"). Patients completed the Scleroderma Health Assessment Questionnaire ([SHAQ]; comprising the HAQ-DI and SSc-specific 150-mm VAS subscales), Coping Strategies Questionnaire (CSQ), Pain Catastrophizing Scale (PCS), and separate 100-mm VAS assessments for PtGA of disease severity ("In the past week, how would you rate your overall health?"). For all questionnaires, higher scores indicate worse global assessments.

The CSQ is scored using a 7-point numerical rating scale ([NRS]; 0–6, ranging from "never do" to "always do that") and evaluates the following domains: diverting attention, reinterpreting pain sensations, catastrophizing, ignoring sensations, praying and hoping (referred to as "prayer"), coping self-statements, and increasing behavioral activities.¹⁶

The PCS instrument is scored using a 5-point NRS (0–4, ranging from "not at all" to "all the time") and a composite score (0–52) is calculated.¹⁷ Higher scores indicate that the individual possesses or exhibits higher levels of catastrophizing. Subdomains of the PCS include rumination, magnification, and helplessness.

Statistical analysis. Descriptive statistics were calculated for demographic and SSc characteristics. Multivariable regression models were used to evaluate predictors of the PtGA, HAQ-DI, and PGA. Regressions were constructed separately for the PtGA and HAQ-DI using the best combination of patient characteristics and physician scores according to adjusted R².¹⁸ This criterion was used to balance the variability of PtGA and HAQ-DI explained prior to accounting for coping against model complexity; a predictor was included in the model only if it increased fit more than would be expected by chance.

The core model for the PtGA consisted of the following variables: age, sex, telangiectasia, and the physician global health VAS. The core model for the HAQ-DI consisted of the following variables: sex, clinical diagnosis (limited vs diffuse cutaneous involvement), disease duration, DUs, PAH, and the physician global health VAS. Patients were dichotomized for each domain according to low coping strategies (score 0–2) and high coping strategies (score 3–6); the PCS domains and composite score were each added to the core model one at a time to discern the effects on the PtGA and HAQ-DI, respectively, controlling for the variables in the core models.

For both the PtGA and HAQ-DI, a sensitivity analysis was performed using an expanded core model considering all noncoding patient-reported outcomes (PROs). For the PtGA, the expanded model included additional baseline patient characteristics and PROs including presence of DUs, patient VAS-DU, SHAQ-pain, SHAQ-breathing, SHAQ-DU, SHAQ-PtGA, mean daily Raynaud Condition Score (RCS), mean daily total duration of RP attacks, and mean daily number of RP attacks. Similarly, for the HAQ-DI, the expanded core model for sensitivity analysis included ILD, physician VAS-DU, patient VAS-DU, SHAQ-pain, SHAQ-breathing, SHAQ-DU, SHAQ-PtGA, mean daily RCS, and mean daily number of attacks.

Concordance between PtGA and PGA was assessed using ICC. The effect of coping strategies on discordance between the PtGA and PGA was assessed by comparing CSQ scores for patients whose PtGA and PGA differed by ≥ 20 points (in each direction). Discordance was defined by a difference between the PtGA and PGA ≥ 20 points based on previous literature in SSc and RA.^{7,19}

RESULTS

Study population. The RSS enrolled 107 patients with SSc (57 patients in Bath, UK; 50 patients from Salt Lake City, USA). Sufficient data were available for 91 patients who had completed the CSQ or PCS. The excluded patients were mostly from Bath (15 vs 1) but otherwise, there were similar distributions for the characteristics and physician scores used in the multivariate regression analysis. Patients were mostly female (88%), White (93%), and never smokers (67%), with a mean (SD) age of 61 (12) years and mean (SD) disease duration of 10 (9) years. The majority of patients had limited cutaneous SSc (85%), with a smaller subset having diffuse cutaneous SSc (15%). Across clinical care sites, patients had similar demographic and clinical characteristics including history of DUs, sclerodactyly, telangiectasias, PAH, ILD, and antibody profile status. A full description of patient characteristics has been reported previously.¹⁴

Across the whole cohort, the mean (SD) PtGA was 40 (27), the mean PGA was 32 (25) and the mean HAQ-DI was 0.87 (0.73), representing mild to moderate disability.

Effect of coping on PtGA. In our multivariable analysis, several coping strategies were significantly associated with the PtGA after controlling for patient demographic and clinical characteristics in our core model (Table 1). Specifically, patients who engaged in prayer or catastrophizing (as identified by the CSQ), and rumination, magnification, or helplessness (as measured by the PCS) had higher PtGA scores on average. In a limited sensitivity analysis, even when other clinical characteristics and PROs were included (DUs, RP number and duration of attacks, and components of the SHAQ), PCS domains (rumination, magnification, helplessness) and PCS total score remained significantly positively associated with the PtGA, indicating that the observed link between PCS and PtGA is robust to the choice of noncoping features included in the regression model.

Table 1. Multivariable models of the effect of coping skills and catastrophizing on PtGA, HAQ-DI, and PGA.

	PtGA*		HAQ-DI**		PGA***	
	β (SE)	P	β (SE)	P	β (SE)	P
CSQ						
Diversion	9.63 (5.73)	0.10	0.43 (0.16)	0.01	4.24 (4.88)	0.39
Reinterpreting	8.79 (5.37)	0.10	0.33 (0.16)	0.04	1.15 (4.65)	0.81
Catastrophizing	17.22 (5.51)	0.003	0.51 (0.16)	0.002	-2.19 (5.07)	0.67
Ignoring	-6.51 (5.42)	0.23	-0.22 (0.16)	0.18	-3.36 (4.68)	0.48
Praying	16.92 (5.27)	0.002	0.41 (0.16)	0.01	7.44 (4.68)	0.12
Coping	-1.70 (7.28)	0.82	0.50 (0.20)	0.01	8.99 (5.67)	0.12
Increased behavioral activities	2.77 (6.47)	0.67	0.43 (0.18)	0.02	4.89 (5.09)	0.34
PCS						
Total	0.90 (0.23)	< 0.01	0.02 (0.006)	< 0.01	0.22 (0.22)	0.33
Rumination	2.16 (0.62)	< 0.01	0.04 (0.018)	0.03	0.03 (0.56)	0.95
Magnification	3.19 (0.95)	< 0.01	0.07 (0.027)	0.02	1.16 (0.91)	0.20
Helplessness	2.14 (0.50)	< 0.01	0.05 (0.014)	< 0.01	0.90 (0.45)	0.05

Values in bold are statistically significant. * After adjusting for core model: age, sex, telangiectasia, physician global health VAS. ** After adjusting for core model: sex, disease duration, PAH, clinical diagnosis (limited vs diffuse), DUs, and physician VAS-DU. *** After adjusting for core model: age, sex, PAH, interstitial lung disease, telangiectasia, physician VAS-RP. CSQ: Coping Strategies Questionnaire; DU: digital ulcer; HAQ-DI: Health Assessment Questionnaire-Disability Index; PAH: pulmonary arterial hypertension; PGA: physician global assessment; PCS: Pain Catastrophizing Scale; PtGA: patient global assessment; RP: Raynaud phenomenon; SE: standard error; VAS: visual analog scale.

Effect of coping on self-administered patient assessment of disability.

In the multivariable analysis, multiple coping styles were also associated with the HAQ-DI, even after controlling for sex, research site, disease duration, PAH, clinical diagnosis (limited vs diffuse), DUs, and physician VAS-DU (Table 1). Specifically, higher HAQ-DI scores were associated with patients who employed diversion, reinterpreting, catastrophizing, praying, coping self-statements, and increased behavioral activities (distraction). Consistent with sensitivity analyses for the PtGA, PCS domains (rumination, magnification, helplessness) and the PCS total score remained significantly associated with the HAQ-DI when other clinical characteristics and PROs were included. This indicates that the association between HAQ-DI and PCS total is also robust to the choice of noncoping features included in the regression model.

Relationship between PtGA and PGA. There was weak/moderate positive correlation between the PGA and PtGA (Spearman $r = 0.39$, $P < 0.001$; Figure 1A). Stronger positive correlations were found between the PtGA and PCS (total; $r = 0.47$, $P < 0.001$; Figure 1B) and between the PCS (total) and the HAQ-DI ($r = 0.42$, $P < 0.001$; Figure 1D). The PGA, meanwhile, had a weak positive correlation with HAQ-DI ($r = 0.24$; $P = 0.03$; Figure 1C) and the PCS ($r = 0.06$, $P = 0.60$). The overall concordance between the PGA and PtGA was low (ICC 0.387). Patients whose PtGA was ≥ 20 units higher than PGA ($n = 33$, 36%) had significantly higher CSQ scores than patients whose PtGA was ≥ 20 lower than PGA ($n = 15$, 16%), particularly in terms of catastrophizing (18 vs 2 patients in high catastrophizing category, $P = 0.01$). The same primary analysis strategy with PGA as the response in the multivariable model was performed, in which none of the PCS domains was associated with PGA (Table 1). The strongest factors influencing PGA were age, sex, PAH, ILD, telangiectasia, and physician VAS-RP.

DISCUSSION

The findings of this multisite, cross-sectional study of patients with SSc indicate an important association between coping strategies and patient perceptions of disability and overall health status. Patient-perceived disease severity may not be dependent on SSc disease severity alone and is influenced by other important (and potentially modifiable) factors such as coping skills. This study builds upon an earlier analysis in which we reported a strong relationship between catastrophizing (according to both CSQ and PCS) and SSc-RP symptom severity.¹⁴ Pain catastrophizing has similarly been associated with patient-reported severity of pain, disability, and poor treatment outcomes in other rheumatic diseases.^{20,21} A limited number of studies have examined coping strategies utilized by people living with SSc. Qualitative studies have indicated that patients with SSc utilize similar coping strategies as patients with other rheumatic disease but lack access to support services that could help improve self-esteem, resilience, and self-efficacy.^{22,23} As expected, we found that passive coping strategies (catastrophizing, praying) are most strongly associated with the PtGA. However, “active” coping strategies (generally labeled as adaptive), were more strongly associated with patient-reported assessment of functional impairment measured using the HAQ-DI. Additional work is required to better understand the role of specific coping strategies (and interventions that might favorably modify these) on patient perceptions of global health and functional impairment.

Our findings may, in part, explain the poor concordance between the PtGA and PGA, which was reported previously⁷ and is replicated in this work. Our analysis indicates that coping strategies, as might have been expected, do not generally influence PGA, which is more strongly influenced by disease-related factors such as age and organ-specific manifestations of SSc. In contrast, both the PtGA and HAQ-DI were strongly influenced

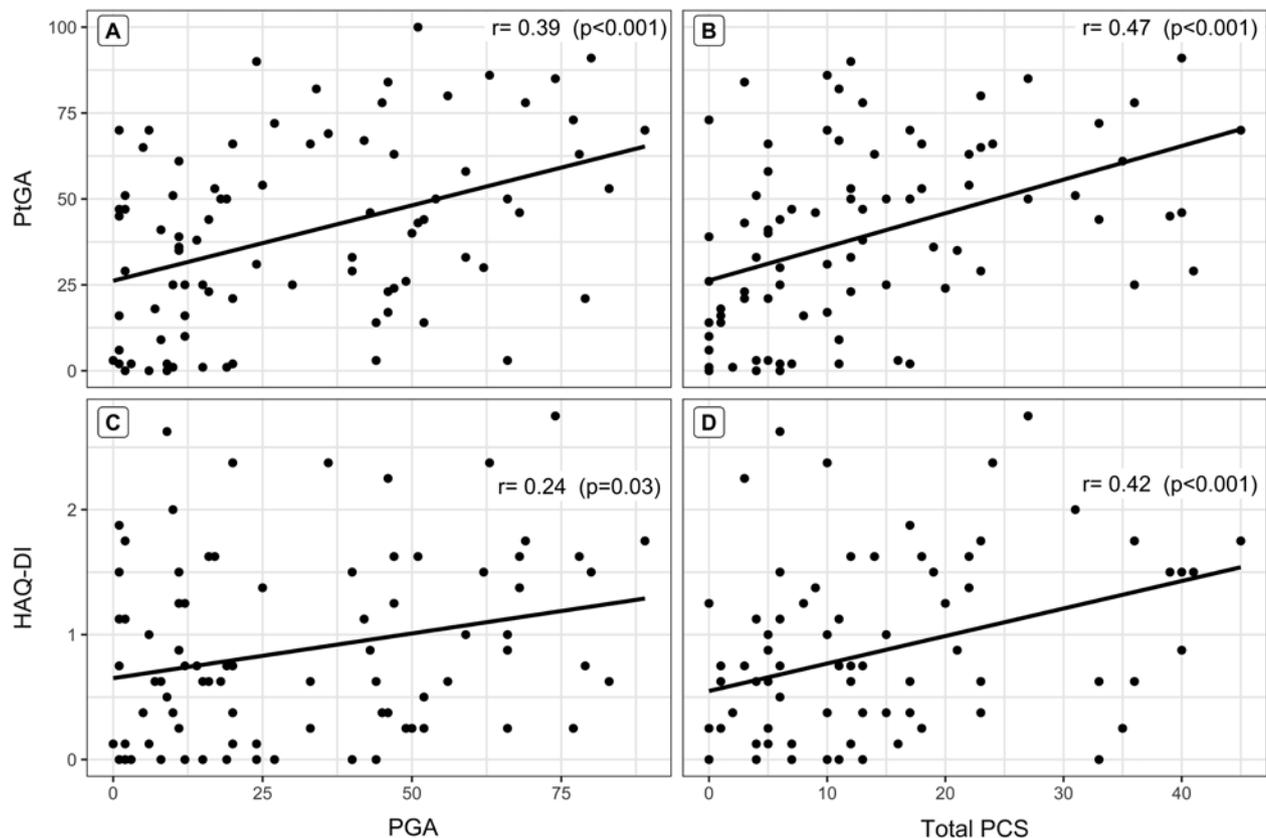


Figure 1. Correlations between (A) PtGA and PGA; (B) PtGA and PCS (total); (C) HAQ-DI and PGA; and (D) HAQ-DI vs PCS (total). HAQ-DI: Health Assessment Questionnaire–Disability Scale; PCS: Pain Catastrophizing Scale; PGA: physician global assessment; PtGA: patient global assessment.

by catastrophizing habits (rumination, magnification, helplessness) and each had a stronger positive correlation with the PCS (total) than the PGA, a surrogate for disease activity. Our findings necessitate the need for larger, longitudinal studies, especially as coping strategies could influence the ACR CRISS, which incorporates the PtGA, HAQ-DI, and PGA.⁶ The ACR CRISS does, however, focus on change of these patient-reported variables over time, which may be less influenced by coping; further longitudinal studies are required to evaluate the effect of coping strategies on PRO instrument change following intervention. Coping and emotional functional PROs should be considered as potentially relevant outcome measures to facilitate the design and interpretation of future SSc trials.

Given the associations we have identified between coping and patient perceptions of global disease activity and disability, we would support previous calls for patient-centered approaches to enhance self-esteem, resilience, and self-efficacy to improve health and quality of life outcomes in SSc.²² These interventions have been studied in arthritis and other chronic disease patient populations including cognitive behavioral therapy, mindfulness, and other mixed-method self-management approaches. Evidence is greatly lacking regarding utility of behavioral change interventions designed to modify pain catastrophizing and maladaptive coping behaviors in SSc. However, SSc focus group studies endorse patient interest for increased access to support groups and intervention.²⁴

This study benefits from being a relatively large study of carefully phenotyped patients from 2 tertiary clinical care sites, but larger studies are required to explore these associations across larger cohorts of patients. However, the patients included in this study had mild to moderate disease according to PGA, and conclusions may not be generalizable to those with severe disease. Further, an accurate measurement of SSc disease severity, such as the Medsger Severity Scale, was not available to guide interpretation. While the utilization of baseline data from a study designed to evaluate effects of RP may have resulted in selection bias, almost all patients with SSc have RP; thus, this is thought to be a representative sample of the general population. The cross-sectional approach also limits our ability to predict long-term outcomes and the natural evolution of coping strategies in established disease. Moreover, this study included predominantly White individuals and may not be generalizable to other races and ethnicities who may differ in coping strategies based on culture. Additional studies are also needed to determine whether nonpharmacologic approaches (i.e., behavioral health interventions) may be utilized in a multidisciplinary fashion to improve patient-perceived global disease severity and disability in SSc.

Maladaptive coping strategies, particularly catastrophizing, are associated with worse overall patient-perceived disability and PtGA after controlling for patient demographics, clinical phenotype, and PGA of disease severity. Coping strategies may influence the outcome of composite measures of disease severity

such as the ACR CRISS. Further large-scale studies and longitudinal assessments are warranted to better understand the role of coping in long-term outcomes in SSc.

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