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Mental Health Care Use and Associated Factors in Systemic Sclerosis: A Scleroderma Patient-Centered Intervention Network Cohort Study

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Objective. Systemic sclerosis (SSc) has significant psychosocial implications. We aimed to evaluate the proportion of participants in a large international SSc cohort who used mental health services in a 3-month period and to evaluate demographic, psychological, and disease-specific factors associated with use.

Methods. Baseline data of participants enrolled in the Scleroderma Patient-Centered Intervention Network Cohort were analyzed. We determined the proportion that used mental health services and the source of services in the 3 months prior to enrollment. Multivariable logistic regression was used to identify variables associated with service use.

Results. Of the 2319 participants included in the analysis, 417 (18%) used mental health services in the 3 months prior to enrollment. General practitioners were the most common mental health service providers (59%), followed by psychologists (25%) and psychiatrists (19%). In multivariable analysis, mental health service use was independently associated with higher education (odds ratio [OR] 1.07, 95% confidence interval [CI] 1.03-1.11), smoking (OR 1.06, 95% CI 1.02-1.11), being retired (OR 0.60, 95% CI 0.38-0.93), having limited SSc (OR 1.39, 95% CI 1.02-1.89), and having higher anxiety symptom scores (OR 1.04, 95% CI 1.03-1.06) and lower self-efficacy scores (OR 0.90, 95% CI 0.83-0.97). Variables not significantly associated included age, race, disease manifestations, depression symptom scores, and body image distress.

Conclusion. About 18% of participants in a large international cohort received mental health services in a 3-month period, of whom the majority received these services from a general practitioner.

INTRODUCTION

Systemic sclerosis (SSc) is a rare chronic systemic disease characterized by dysregulated fibrosis, autoimmunity, inflammation, and vasculopathy (1). Its two major clinical forms are limited cutaneous, dominated by vascular manifestations, and diffuse cutaneous, characterized by progressive fibrosis of the skin and internal organs. Both forms can result in significant disfigurement, pain, disability, organ failure, and accelerated mortality (1). SSc carries the highest case-fatality rate among the rheumatic diseases, with lung disease as the leading cause of SSc-related mortality (2).

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SIGNIFICANCE & INNOVATIONS

- Systemic sclerosis (SSc) has substantial psychosocial implications. There is limited information about mental health service use in SSc.
- Approximately 18% of participants in a large international SSc cohort received mental health services in the 3 months prior to enrollment in the cohort.
- General practitioners were the most common providers of mental health care, followed by psychologists and psychiatrists.
- Mental health service use was associated with higher education, smoking, the limited form of the disease, higher anxiety symptom score, and lower self-efficacy. Being retired was associated with a lower rate of mental health services use.

Faced with significant morbidity, high mortality, and a paucity of effective pharmacotherapy, people with SSc experience significant psychosocial consequences and emotional distress (3) The prevalence of current (30-day), 12-month, and lifetime major depressive disorder has been estimated at 4%, 11%, and 23%, respectively, in Canadian Scleroderma Research Group Registry participants (4). These rates are considerably higher than the rates of depression in the general population and in other chronic rheumatic diseases, such as rheumatoid arthritis (5). In one study, people with SSc (n = 85) were significantly more likely to score above 16 on the Center for Epidemiological Studies Depression Scale (48%) compared with people with rheumatoid arthritis (n = 120; 36%) and healthy controls (n = 125; 20%) (5). Multiple disease-specific factors, including active and more severe disease, lung dysfunction, skin involvement, esophageal problems, and decreased oral aperture, have been associated with more depressive symptoms and psychosocial impact (5,6). Other sociodemographic factors, such as being unmarried and having lower education, and psychological factors, including body image distress, were also associated with greater psychological distress in SSc (6). The lifetime prevalence of anxiety disorders has been estimated at 64% in people with SSc, which is much higher than that observed in the general population (7,8). Among anxiety disorders, generalized anxiety and social phobia were found to be most common, with lifetime prevalence of 19% and 15%, respectively (8). Among people with SSc, disease-associated disfigurement is associated with body image distress and social anxiety (6).

Addressing psychosocial concerns that affect quality of life is an essential aspect of patient-centered care for people with SSc (7). Although developing and testing mental health interventions is challenging in SSc, such interventions have been shown to reduce disability and improve the quality of life in more prevalent autoimmune diseases, such as rheumatoid arthritis (7). There is also limited information on the frequency of mental health services (MHS) use in SSc. In this study, we aimed to determine the proportion of participants enrolled in the Scleroderma Patient-Centered Intervention Network (SPIN) Cohort who used MHS in a 3-month period and to evaluate demographic, psychological, and disease-specific factors associated with use.

MATERIALS AND METHODS

Participants and procedures. The study sample included participants enrolled in the SPIN Cohort (9). The SPIN Cohort comprises participants recruited from more than 45 centers in Canada, the USA, the UK, France, Spain, Mexico, and Australia. Eligible participants must meet the 2013 American College of Rheumatology/European League Against Rheumatism (ACR/EULAR) classification criteria for SSc (10) and be 18 years of age or older. They must be able to complete questionnaires in English, Spanish, or French and have the ability to provide informed consent, access the Internet, and respond to the SPIN Cohort questionnaires online. Eligible participants are recruited and enrolled and provide consent at SPIN centers. The attending physician or supervising nurse or research coordinator who initiated enrollment in the SPIN Cohort completes medical variable forms. Subsequently, participants receive an email invitation to register online and complete the SPIN Cohort questionnaires on enrollment and subsequently every 3 months. The present study included participants who completed baseline SPIN questionnaires from January 2014 to May 2020. The SPIN Cohort study was approved by the ethical boards of the Jewish General Hospital, Montreal, Canada (ethics protocol CODIM-FLP-12-123), and all other participating centers. All participants provided written informed consent.

Measures. *MHS use.* Along with the questionnaires and demographic information, participants were asked, "In the last 3 months, have you seen any of the following health professionals to address a mental health concern?" If they answered yes, they were asked to check all that applied (psychiatrist, psychologist, general practitioner or family doctor, other [specify]) as well as respond to the question "How many times for each in the last 3 months?" Types of providers listed in the "other" option were categorized for statistical analysis.

Demographic variables. Enrolled participants provided demographic variables at baseline, including information on race and ethnicity, marital status, years of education, current occupation, housing location (urban or nonurban), smoking status, and alcohol intake. Race and ethnicity were entered differently at different sites according to the corresponding country standard procedure. A consolidated race and ethnicity variable with three categories (White, Black, and other) was created for statistical analysis. Enrolling physicians or site staff captured the site of enrollment, sex, and date of birth.

Medical variables. The enrolling SPIN investigators completed the disease-specific variables, including disease subtype (diffuse or limited), disease duration since first non-Raynaud

disease manifestation, presence of Raynaud's phenomenon, modified Rodnan skin score (MRSS), presence of sclerodactyly, facial telangiectasia, abnormal skin pigmentation, gastrointestinal and cardiopulmonary involvement, and history of scleroderma renal crisis. MRSS measures skin thickness in 17 body areas on a scale from 0 to 51, with higher scores indicating more severe thickness (11). Gastrointestinal symptoms included esophageal (eg, dysphagia, heartburn, reflux), stomach (eg, early satiety, vomiting), and intestinal (eg, diarrhea, bloating, constipation) symptoms. The diagnosis of pulmonary arterial hypertension was established on the basis of right-sided heart catheterization, and diagnosis of interstitial lung disease was established on the basis of high-resolution computed tomography, radiography, or chest auscultation findings.

Mental health measures. Participants completed questionnaires to evaluate symptoms of depression, anxiety, and body image distress.

The eight-item Patient Health Questionnaire (PHQ-8) was used to evaluate symptoms of depression (12). The PHQ-8 is derived from the nine-item Patient Health Questionnaire (PHQ-9), which is validated in SSc (13). A large individual participant data meta-analysis found that the correlation between PHQ-8 and PHQ-9 scores was 0.996 (14). PHQ-8 scores can range from 0 to 24, with higher scores indicating more depressive symptoms. Previous studies have divided PHQ-9 score into categories of 0 to 4, 5 to 9, 10 to 14, 15 to 19, and 20 or greater to reflect increasing severity (12,15). As a screening tool for major depression, PHQ-9 scores of 10 or greater were found to have a sensitivity of 88% and a specificity of 85%. However, for a prevalence of 10%, only about 40% of people who screen positive would have major depression (16).

Patient-Reported Outcomes Measurement Information System-29 profile version 2.0 (PROMIS-29v2) domains were used to evaluate symptoms of anxiety, fatigue, sleep disturbance, and pain. PROMIS-29v2 is a short form that generates standardized scores of patient-reported health status over the past 7 days, with a mean of 50, which represents the average of a general US population, and a standard deviation of 10. Higher scores indicate more of the measured domain (17).

Social interaction anxiety was assessed using the Social Interaction Anxiety Scale–6 (SIAS-6). The scale rates respondents' experiences in social situations from 0 to 24, with higher scores indicating higher distress due to social interactions (18).

Participants completed the Satisfaction with Appearance (SWAP) scale to measure body image distress. Scores can range from 0 to 84, with higher scores indicating greater dissatisfaction with appearance (19).

The PROMIS-29v2, SIAS-6, and SWAP are validated in SSc (17,19–22).

Disability. The Scleroderma Health Assessment Questionnaire (SHAQ) was used to assess functional disability (23,24). The SHAQ assesses eight disability categories over the past 7 days (dressing and grooming, arising, eating, walking, hygiene, reach, grip, common daily activities). Items are rated on a 4-point scale ranging from 0 (without any difficulty) to 3 (unable to do). The total score is the mean of the highest scores of each of the eight categories, ranging from 0 (no disability) to 3 (severe disability), with higher scores indicating greater functional disability. The SHAQ is validated in SSc (23,24).

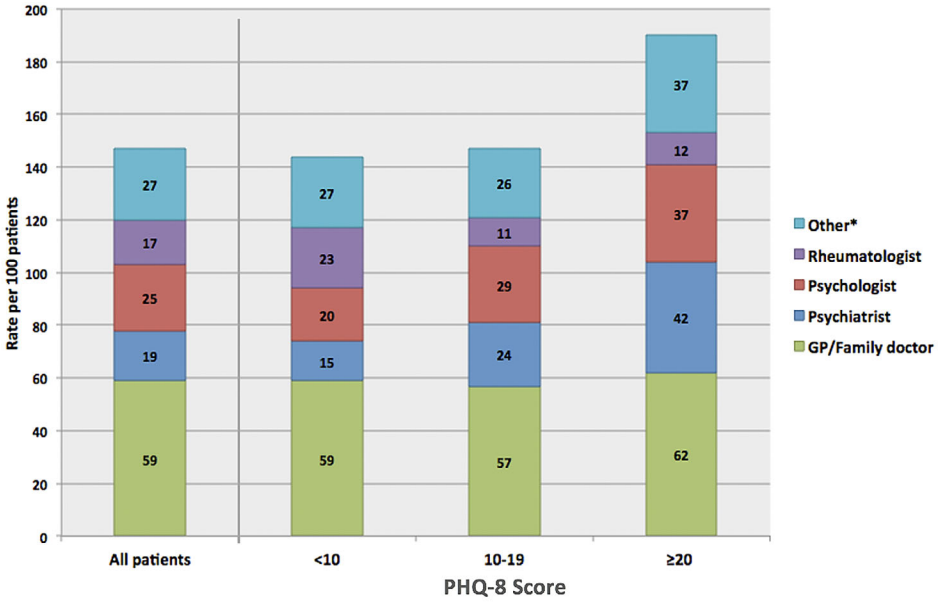
Self-efficacy. Participants completed the Self-Efficacy for Managing Chronic Disease (SEMCD) scale to assess their confidence in self-managing SSc despite fatigue, physical discomfort, emotional distress, and other disease-specific symptoms. Each item is rated on a 10-point rating scale ranging from 1 (not confident at all) to 10 (totally confident). The score for the scale is the mean of all items, ranging from 1 to 10, with higher scores indicating higher self-efficacy. The SEMCD scale has been validated in SSc (25).

Statistical analysis. Participant characteristics, rate of MHS use, and type of mental health provider were assessed using descriptive analyses, including means, standard deviations, minimum, and maximum for continuous variables and frequencies and percentages for discrete variables. We also determined the rate of MHS use and type of mental health provider by stratum of increasing depression symptom score (PHQ-8 scores <10, 10-20, and ≥ 20).

Demographic, psychological, disability, and medical variables were compared between participants who received MHS in the 3 months prior to enrollment and those who did not using a χ^2 or Fisher's exact test and independent samples *t*-test as appropriate. Effect size for each of the variables was determined and reported as Cramr's *V* for categorical variables and Cohen's *d* for continuous variables. Multivariable binary logistic regression was subsequently used to identify variables independently associated with MHS use using an a priori–defined model that included age, sex, education level, marital status, disease subset, disease duration, and scores on the PHQ-8, PROMIS-29v2 anxiety domain, SWAP, SHAQ, and SEMCD. These factors were selected because of their likely impact on MHS use on the basis of previous studies (6) or clinical importance. We subsequently adjusted the models in an exploratory backward stepwise procedure and assessed each secondary model for improvement of fit to the model. Because of the exploratory nature of the analysis, variables that achieved a *P* value of 0.10 or below were retained in the final model, with those that had a *P* value of 0.05 or below considered statistically significant factors. The association between MHS use and country or site of enrollment was analyzed post hoc. Models' goodness-of-fit was assessed using the –2 log-likelihood (–2LL) statistic. Missing variables were not imputed or replaced. All statistical analyses were performed using SAS version 9.3 (SAS Institute, Inc.).

RESULTS

Sample characteristics. At time of data extraction, 2334 SPIN Cohort participants had completed baseline assessments, and 2319 (99%) of these answered the MHS use questions and were included in the analysis. The majority of participants (36%) were from the USA, 25% were from France, 24% were from



Total N in each group (%)	2,319 (100%)	1,691 (76%)	466 (21%)	63 (3%)
Used MHS (%)	417 (18%)	229 (14%)	139 (30%)	24 (38%)

Figure 1. Rate of mental health services (MHS) use in the 3 months prior to enrollment and type of mental health provider in the entire cohort and by depression symptom score. Thirty-seven percent of participants received MHS from more than one type of provider, adding up to a total of more than 100%. Patient Health Questionnaire–8 (PHQ-8) scores were available for 2220 participants and 392 of those who used MHS. *The "other" provider group included social workers, physical and occasional therapists, gastroenterologists, pulmonologists, cardiologists, and other subspecialists. GP, general practitioner.

Canada, 11% were from the UK, and 2% or less each were from Spain, Australia, and Mexico. Female participants constituted 88% of the cohort. The mean age was 54.6 ± 12.7 years, 81% were White, and 40% of participants had diffuse SSc. The mean time since the first non-Raynaud disease manifestation was 11.1 ± 8.7 years. Raynaud's phenomenon, esophageal symptoms, and sclerodactyly were the most commonly reported disease manifestations at 98%, 85%, and 81%, respectively. The mean MRSS was 7.8 ± 8.2. Interstitial lung disease and pulmonary arterial hypertension were reported in 36% and 9% of participants, respectively.

MHS use and mental health provider. Eighteen percent (n = 417) of the 2319 participants used MHS in the 3 months prior to enrollment in SPIN, with 37% (n = 153) receiving MHS from more than one type of provider (Figure 1). Of these 417 participants, 59% reported addressing a mental health concern with a general practitioner or family doctor, 25% with a psychologist, and 19% with a psychiatrist. Rheumatologists, captured under "other," were the source of mental health care for 17% of these participants. The "other" category also included social workers and other medical subspecialists, including pulmonologists and gastroenterologists. When stratified by country of enrollment (Table 1), general practitioners were the most common provider of MHS in all countries and reached 46% (77 of 166) in the USA, 75% (88 of 117) in Canada, 70% (23 of 33) in the UK, 57% (49 of 86) in France, and 67% (10 of 15) in the other countries. The rate of MHS by a psychiatrist ranged from 6% in the UK to 40% in France; a psychologist, from 6% in the UK to 47% in Mexico, Spain, and Australia; and a rheumatologist, from 7% in France to 21% in the USA.

Table 1. MHS service provider by country of enrollment

Type of provider	USA (n = 166)	Canada (n = 117)	UK (n = 33)	France (n = 86)	Mexico, Spain, Australia (n = 15)
GP or family doctor	77 (46%)	88 (75%)	23 (70%)	49 (57%)	10 (67%)
Psychiatrist	29 (17%)	14 (12%)	2 (6%)	34 (40%)	2 (13%)
Psychologist	49 (30%)	23 (20%)	2 (6%)	22 (26%)	7 (47%)
Rheumatologist	35 (21%)	23 (20%)	4 (12%)	6 (7%)	3 (20%)
Other	43 (26%)	33 (28%)	13 (39%)	17 (20%)	5 (33%)

Abbreviations: GP, general practitioner; MHS, mental health services.

Table 2. Differences between participants who received MHS and those who did not (n = 2319)

Variable	MHS (n = 417)	No MHS (n = 1902)	*P*	Effect size[a]
Age (years)	53.5 (12.6)	54.9 (12.7)	0.051	0.11
Sex				0.00
Female	365 (18%)	1666 (82%)	Reference	
Male	52 (18%)	236 (82%)	0.97	
Country of enrollment				
USA	166 (20%)	665 (80%)	Reference	0.08
Canada	117 (21%)	429 (79%)	0.51	
UK	33 (13%)	218 (87%)	0.01	
France	86 (15%)	503 (85%)	0.01	
Mexico	4 (18%)	18 (82%)	0.99	
Spain	5 (13%)	35 (88%)	0.25	
Australia	6 (15%)	34 (85%)	0.46	
Race and ethnicity[b]				
White	336 (18%)	1549 (82%)	Reference	0.02
Black	35 (21%)	131 (79%)	0.30	
Other	44 (17%)	213 (83%)	0.78	
Marital status				
Married or common law	281 (17%)	1347 (83%)	Reference	0.05
Single	52 (17%)	254 (83%)	0.91	
Separated or widowed	84 (22%)	293 (78%)	0.02	
Education (years)	15.4 (3.6)	14.8 (3.7)	0.01	0.00
Current occupation				
Employed	158 (17%)	788 (83%)	Reference	0.11
Unemployed or on disability	114 (24%)	370 (76%)	<0.01	
Retired	76 (13%)	504 (87%)	0.06	
Other	69 (23%)	232 (77%)	0.01	
Housing location				
Nonurban	120 (15%)	674 (85%)	Reference	0.06
Urban	296 (20%)	1216 (80%)	0.01	
Smoking				
No	369 (17%)	1773 (83%)	Reference	0.08
Yes	48 (28%)	121 (72%)	<0.01	
Alcohol				
No	231 (17%)	1091 (83%)	Reference	0.02
Yes	186 (19%)	803 (81%)	0.41	
Disease subtype				
Limited	255 (19%)	1076 (81%)	Reference	0.04
Diffuse	143 (16%)	757 (84%)	0.048	
Disease duration[c] (years)	10.5 (8.8)	11.3 (8.7)	0.12	0.09
MRSS	7.8 (8.6)	7.8 (8.1)	0.88	0.01
Raynaud's phenomenon				
No	9 (21%)	34 (79%)	Reference	0.01
Yes	402 (18%)	1855 (82%)	0.60	
Sclerodactyly				
No	86 (20%)	346 (80%)	Reference	0.03
Yes	319 (17%)	1515 (83%)	0.22	
Telangiectasia				
No	138 (20%)	568 (80%)	Reference	0.03
Yes	261 (17%)	1272 (83%)	0.15	
Abnormal skin pigmentation				
No	270 (18%)	1198 (82%)	Reference	0.01
Yes	121 (17%)	579 (83%)	0.53	
Gastrointestinal symptoms				
Esophageal				
No	44 (13%)	295 (87%)	Reference	0.05
Yes	362 (19%)	1588 (81%)	0.01	
Stomach				
No	252 (16%)	1304 (84%)	Reference	0.07
Yes	148 (22%)	530 (78%)	<0.01	
Intestinal				
No	212 (15%)	1163 (85%)	Reference	0.08
Yes	195 (22%)	692 (78%)	<0.01	

(Continued)

Table 2. (*Cont'd*)

Variable	MHS (n = 417)	No MHS (n = 1902)	*P*	Effect size[a]
Interstitial lung disease				
No	243 (17%)	1213 (83%)	Reference	0.04
Yes	160 (20%)	653 (80%)	0.07	
Pulmonary hypertension				
No	360 (18%)	1636 (82%)	Reference	0.01
Yes	32 (16%)	165 (84%)	0.53	
Scleroderma renal crisis				
No	392 (18%)	1801 (82%)	Reference	0.01
Yes	16 (17%)	79 (83%)	0.80	
Depression (PHQ-8)	9.1 (6.0)	5.8 (5.1)	<0.01	−0.60
PROMIS-29				
Anxiety	57.4 (10.0)	51.1 (9.6)	<0.01	−0.63
Fatigue	59.5 (10.0)	53.9 (11.0)	<0.01	−0.51
Sleep disturbance	55.0 (7.9)	51.9 (8.7)	<0.01	−0.35
Pain	58.0 (9.0)	55.0 (9.7)	<0.01	−0.30
Body image distress (SWAP)	35.1 (18.5)	30.9 (18.7)	<0.01	−0.23
Social anxiety (SIAS-6)	3.9 (5.0)	2.4 (3.7)	<0.01	−0.38
Disability index (SHAQ)	0.9 (0.7)	0.7 (0.7)	<0.01	−0.22
SHAQ score ≤1	230 (16%)	1,240 (84%)	Reference	0.08
SHAQ score >1	163 (22%)	581 (78%)	<0.01	
Self-efficacy (SEMCD)	5.5 (2.3)	6.7 (2.2)	<0.01	0.52

Note: Values are presented as n (%) for categorical variables and mean (SD) for continuous variables. Response rates varied from 83% to 100% for the different variables.
Abbreviations: MRSS, modified Rodnan skin score; PHQ-8, Patient Health Questionnaire–8; PROMIS-29, Patient-Reported Outcomes Measurement Information System–29; SEMCD, Self-Efficacy for Managing Chronic Disease; SHAQ, Scleroderma Health Assessment Questionnaire; SIAS-6, Social Interaction Anxiety Scale–6; SWAP, Satisfaction with Appearance.
[a]Effect size is reported as Cramr's *V* for categorical variables and Cohen's *d* for continuous variables.
[b]Consolidated variable accounting for the different understanding of race and ethnicity in different parts of the world.
[c]Disease duration since first non-Raynaud's manifestation.

The rate of MHS use in the preceding 3 months increased with increasing strata of PHQ-8 scores (Figure 1), including 14% (229 of 1691) among participants with PHQ-8 scores <10, 30% (139 of 466) of participants with PHQ-8 scores of 10 to 19, and 38% (24 of 63) with PHQ-8 scores greater than or equal to 20. General practitioners were the most common MHS providers regardless of depression symptoms score category, although the percentage of participants who received MHS from psychiatrists and psychologists increased with increasing PHQ-8 score.

The mean (SD) number of visits to an MHS provider was 4.6 (3.9) for psychologists, 2.4 (2.7) for rheumatologists, 2.2 (1.7) for psychiatrists, and 2.1 (2.7) for general practitioners.

Factors associated with MHS use. In bivariate analyses (Table 2), when compared with participants who did not use MHS in the 3 months prior to enrollment in SPIN, those who did were more likely to be separated, divorced, or widowed than married (22% vs 17%); unemployed or on disability than employed (24% vs 17%); and living in an urban setting than nonurban (20% vs 15%). The MHS group had more years of education (15.4 ± 3.6 vs 14.8 ± 3.7) and a higher prevalence of smokers compared with nonsmokers (28% vs 17%). Differences were seen in the country of enrollment: the MHS group included fewer participants from the UK (13%) and France (15%) compared with the USA (20%). Although statistically significant, these demographic variables had an overall small effect size on MHS use. Participants who used MHS were slightly more likely to have the limited form compared with the diffuse form of the disease (19% vs 16%) and were more likely to have esophageal (19% vs 13%), stomach (22% vs 16%), and intestinal symptoms (22% vs 15%), with a small effect size.

Compared with participants who did not use MHS, participants who did had statistically significantly higher symptoms of depression (9.1 ± 6.0 vs 5.8 ± 5.1), anxiety (57.4 ± 10.0 vs 51.1 ± 9.6), and fatigue (59.5 ± 10.0 vs 53.9 ± 11.0) and lower self-efficacy scores (5.5 ± 2.3 vs 6.7 ± 2.2), with a medium effect size. They had higher scores on the sleep disturbance (55.0 ± 7.9 vs 51.9 ± 8.7) domain, greater pain interference (58.0 ± 9.0 vs 55.0 ± 9.7), and more body image distress (35.1 ± 18.5 vs 30.9 ± 18.7), social anxiety (3.9 ± 5.0 vs 2.4 ± 3.7), and functional disability (0.9 ± 0.7 vs 0.7 ± 0.7), with a small effect size.

A priori and exploratory multivariable regression models are described in Table 3. In both models, MHS use was significantly associated with higher education, higher anxiety symptom scores, and lower self-efficacy. Higher depression symptom scores were significantly associated with MHS use in the a priori model (odds ratio [OR] 1.04, 95% confidence interval [CI] 1.01-1.08), but only a trend toward statistical significance was observed in the exploratory model (OR 1.03, 95% CI 1.00-1.07). Of the additionally explored variables, the odds of MHS use was significantly lower for participants who were retired versus employed and enrolled in the UK or France versus

Table 3. Factors associated with MHS use in the SPIN Cohort

	Model 1[a]		Model 2[b]	
Variable	OR (95% CI)	*P*	OR (95% CI)	*P*
Age	1.00 (0.99–1.01)	0.85	1.01 (1.00–1.03)	0.14
Sex (female)	1.06 (0.70–1.61)	0.77	1.11 (0.71–1.72)	0.66
Country of enrollment				
USA			Reference	
Canada			0.99 (0.71–1.40)	0.98
UK			0.48 (0.27–0.83)	0.01
France			0.64 (0.43–0.94)	0.02
Spain, Mexico, Australia	-	-	0.56 (0.24–1.33)	0.19
Marital status				
Married or common law	Reference		Reference	
Single	0.80 (0.52–1.24)	0.31	0.91 (0.58–1.42)	0.67
Separated or widowed	1.34 (0.95–1.87)	0.09	1.39 (0.98–1.99)	0.07
Education	1.06 (1.02–1.10)	<0.01	1.07 (1.03–1.11)	<0.01
Employment status				
Employed			Reference	
Unemployed or on disability			1.17 (0.81–1.70)	0.40
Retired			0.60 (0.38–0.93)	0.02
Other	-	-	1.38 (0.91–2.08)	0.13
Housing location				
Nonurban			Reference	
Urban	-	-	1.14 (0.84–1.55)	0.41
Smoking	-	-	1.85 (1.15–2.98)	0.01
Disease duration	0.99 (0.98–1.01)	0.49	0.99 (0.97–1.01)	0.24
Limited disease (vs. diffuse)	1.18 (0.88–1.57)	0.26	1.39 (1.02–1.89)	0.04
Gastrointestinal symptoms				
Esophageal			1.28 (0.82–2.00)	0.28
Stomach			1.12 (0.81–1.56)	0.49
Intestinal	-	-	1.17 (0.85–1.60)	0.33
Interstitial lung disease	-	-	1.27 (0.95–1.72)	0.11
Depression (PHQ-8)	1.04 (1.01–1.08)	0.02	1.03 (1.00–1.07)	0.06
Anxiety (PROMIS-29)	1.04 (1.02–1.06)	<0.01	1.04 (1.03–1.06)	<0.01
Body image distress (SWAP)	0.99 (0.99–1.00)	0.12	1.00 (0.99–1.01)	0.42
Disability index				
SHAQ score ≤1	Reference		Reference	
SHAQ score >1	0.94 (0.69–1.28)	0.71	0.87 (0.62–1.22)	0.42
Self-efficacy (SEMCD)	0.89 (0.82–0.95)	<0.01	0.90 (0.83–0.97)	0.01

Abbreviations: CI, confidence interval; MHS, mental health services; OR, odds ration; PHQ-8, Patient Health Questionnaire–8; PROMIS-29, Patient-Reported Outcomes Measurement Information System–29; SEMCD, Self-Efficacy for Managing Chronic Disease; SHAQ, Scleroderma Health Assessment Questionnaire; SPIN, Scleroderma Patient-centered Intervention Network; SWAP, Satisfaction with Appearance.
[a]A priori defined model.
[b]Final model included additional significant variables following a stepwise regression procedure.

the USA. Being a smoker and having the limited form of the disease, on the other hand, increased the odds of MHS use. On goodness-of-fit testing, Model 1 had a – 2LL value of 1463.1, whereas Model 2 had a – 2LL of 1347.3, indicating a better fitting model.

DISCUSSION

The main finding of this study was that fewer than 20% of participants with SSc in a large international cohort used MHS in the 3 months prior to enrollment, with general practitioners being the most common providers of these services. We also found that MHS use was associated with smoking, more years of education, the limited form of the disease, higher anxiety symptom scores, and lower self-efficacy. Being retired was associated with lower odds of MHS use. Finally, differences in the rates of MHS use were observed between countries of enrollment, with use more common in Canada and the USA.

Limited information about MHS use in SSc has been previously reported. In a cross-sectional survey that included 198 Dutch patients with SSc, 38 patients (19%) had contacted a psychologist since the onset of their disease, and only 14 patients (7%) had done so in the prior 12 months (26). Mental health care provided by other professionals was not assessed in that study. In another study, 12 of 13 patients with current (30-day) major depressive disorder (92.3%) and 32 of 37 with 12-month major depressive disorder (88.9%) had talked to a professional about their depression at some point in their life (4). In that study, the evaluation was limited to patients who met the *Diagnostic and Statistical Manual of Mental*

Disorders, Fourth Edition criteria for major depressive disorder and did not include patients with milder depressive symptoms, anxiety disorders, or other forms of emotional distress.

Similar observations have been made in other rheumatic diseases. In the Netherlands, a survey study of 869 patients with rheumatoid arthritis showed that the rate of psychosocial care in the preceding 12 months ranged from 8% to 18%, with a trend toward lower use rates among patients with lower socioeconomic status and shorter disease duration (27). In a cross-sectional study of 50 pediatric patients with lupus and mixed connective tissue disease in the USA, 34% of patients had any symptoms of depression or anxiety; among these patients, about 24% (or 8% of all patients) had previous mental health care (28).

An important observation in our study was the high rate of MHS use provided by general practitioners and family doctors seen in the entire cohort and when stratified by country of enrollment and PHQ-8 score stratum. This reflects the important role primary care physicians play in the delivery of mental health care (29). It might also indicate barriers to specialized MHS, which needs exploring in future studies.

Previous studies identified the presence of a chronic disease, race, socioeconomic status, insurance, cost, and availability of primary and mental health services to have a significant impact on MHS use (27,30–33). The association between smoking, lower rates of smoking cessation, and major depression is also well recognized (34). The effect of retirement on mental health and well-being, on the other hand, is complex, with potential for bidirectional associations (35). Epidemiological studies have shown inconclusive results so far, with many suggesting lower rates of depressive symptoms with retirement (36).

No previous studies, to our knowledge, explored the association between MHS use and disease-specific variables in SSc. In this cohort, the diffuse form of the disease, compared with limited SSc, was associated with a lower OR of MHS use in our study. Although both disease forms carry significant disability and impact on mental health, the difference in the magnitude of this impact between the two forms is still not well understood. In a previous study looking at determinants of health-related quality of life in SSc, diffuse SSc was associated with a significantly worse Medical Outcome Short Form–36 (SF-36) physical component score compared with limited SSc (37). The two forms, however, did not differ in the SF-36 mental component score.

Another interesting observation in our study was the association between higher MHS use and lower self-efficacy, which was previously shown to correlate with lower function and more emotional distress in SSc (25). A recent study on physical and occupational therapy use in patients with SSc enrolled in the SPIN Cohort similarly showed lower self-efficacy scores in patients who used these services in the preceding 3 months (38). These findings are in agreement with previous data showing a correlation between higher self-efficacy and lower health services use and cost in arthritis and other chronic diseases (39).

Differences were seen in the rate of MHS use between the countries of enrollment, most likely because of a number of factors, including cultural differences relating to perceptions around mental health care, access, and cost, among other factors. Future studies are needed to explore the impact of these factors on MHS use and on the association between MHS use and the other demographic and disease-specific variables in SSc.

The large number of evaluated factors and the large sample size is an important strength of the present study. We included participants from several countries with variable health care systems. We evaluated the association of MHS use with multiple demographic factors, psychological variables using validated measures, and a wide range of disease-specific variables, including those with an impact on morbidity, mortality, and body image. SSc diagnoses and all disease-specific variables were ascertained by enrolling physicians. In addition, all variables were obtained at one time point, allowing for a more accurate assessment of MHS need and use.

Our study has several limitations to recognize when interpreting the results. The SPIN Cohort includes a convenience sample of participants from specialized SSc centers. These participants might be different from the general SSc population in other less specialized health care settings and might have higher access to specialized health care, including mental health care. Our evaluation was limited to the 3 months prior to enrollment only, with no available data on ever use. The evaluation was also limited to self-reported use of MHS, which might have resulted in an underestimation of the rate of use given the sensitive nature of mental health care. We were not able to evaluate the impact of health insurance, cost, access, and MHS availability on use in the SPIN Cohort. The cohort does not collect information on mental health disorders either, which is an important factor to consider when evaluating the rate of MHS use. In addition, some of the differences we observed between participants who used MHS and those who did not were small, with a small effect size despite the statistical significance, which might be due to the large sample size.

In conclusion, we showed that about 18% of patients with SSc in a large international cohort used MHS in the 3 months prior to enrollment, with general practitioners and primary care physicians being the most common providers of mental health care. We identified factors that showed an association with higher MHS use, some of which were previously found to be predictive of MHS use in other populations. Additional studies are needed to explore these factors as well as the rate of MHS use in patients with SSc and a clinical diagnosis of major depressive disorder or other mental health disorders. The effects of these services in this unique patient population are also important to explore in future research.

AUTHOR CONTRIBUTIONS

All authors were involved in drafting the article or revising it critically for important intellectual content, and all authors approved the final version to be published. Dr. Becetti had full access to all of the data in the

study and takes responsibility for the integrity of the data and the accuracy of the data analysis.

Study conception and design. Becetti, Nguyen, Kwakkenbos, Gordon, Mancuso, Welling, Mouthon, Bartlett, Malcarne, Thombs, Spiera.

Acquisition of data. Kwakkenbos, Carrier, Tao, Welling, Mouthon, Bartlett, Malcarne, Thombs, Spiera.

Analysis and interpretation of data. Becetti, Nguyen, Kwakkenbos, Gordon, Mancuso, Thombs, Spiera.

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