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Patient Acceptable Symptom State for Burden From Appearance Changes in People With Systemic Sclerosis: A Cross-sectional Survey

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ABSTRACT. ***Objective.*** People with systemic sclerosis (SSc) often report substantial burden from appearance changes. We aimed to estimate the patient acceptable symptom state (PASS) for burden from appearance changes in people with SSc.

Methods. We conducted a secondary analysis of the SCISCIF II study, a cross-sectional survey of 113 patients with SSc from France enrolled in the Scleroderma Patient-centered Intervention Network Cohort. Burden from appearance changes was assessed with a self-administered numeric rating scale (0, no burden to 10, maximal burden). Acceptability of the symptom state was assessed with a specific anchoring question. Participants who answered yes were in the group of patients who considered their symptom state as acceptable. The PASS for the burden from appearance changes was estimated with the 75th percentile method.

Results. Assessments of burden from appearance changes and answers to the anchoring question were available in 82/113 (73%) participants from the SCISCIF II study. Median age was 55 (IQR 24) years, mean disease duration 9.6 (SD 6.5) years and 32/80 (40%) participants had diffuse cutaneous SSc. The PASS estimate for the burden from appearance changes was 4.8 (95% CI 1.0-7.0) of 10 points.

Conclusion. Our study provides a PASS estimate for burden from appearance changes. Our estimate could serve as a binary response criterion to assess the efficacy of treatments targeting burden from appearance changes.

Key Indexing Terms: disability, rehabilitation, scleroderma

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Systemic sclerosis (SSc) is an autoimmune disease of the vascular and connective tissues. Skin involvement is a key feature of SSc and includes sclerosis, telangiectasia, depigmentation, hand flexion contractures, digital ulcers (DUs), pitting scars, and calcinosis. Because cutaneous lesions most often involve the face and hands, they are associated with a meaningful burden from appearance changes in people with SSc, including physical, psychological, and participative repercussions.[1] Correlates of the burden from appearance changes may include symptoms of anxiety and depression[1] as well as activity limitations.[2] Variables that may cause burden from appearance changes are extended and visible skin involvement (eg, hands and face)[1,3-5] and mouth-specific impairments (eg, microstomia and perioral grooves).[6]

In order to assess the response to treatments in clinical trials and in clinical practice, by prioritizing patients' perception of their own condition, the patient acceptable symptom state (PASS) has been defined as "the highest level of symptoms beyond which patients consider themselves well."[7,8] PASS estimates for the most frequently used patient-important outcomes have been previously reported in SSc.[9] However, the PASS estimate for burden from appearance changes, a meaningful outcome for people with SSc, is unknown.

The aim of this study was to estimate the PASS for burden from appearance changes in people with SSc.

METHODS

Design. We conducted a cross-sectional analysis of the SCISCIF II study,[10] an online survey of 113 patients with SSc enrolled through French sites in the Scleroderma Patient-centered Intervention Network (SPIN) Cohort,[11] which was primarily designed to develop a new patient-reported outcome (PRO) to assess activities and participation. The survey was not modified after study commencement. Results of our internet e-survey were reported in accordance with the Checklist for Reporting Results of Internet E-Surveys (CHERRIES; Supplementary Data, available from the authors upon request). The methods and results of the main SCISCIF II study have been published.[10]

Participants. Participants in the SCISCIF II study were recruited into the SPIN Cohort.[11] Briefly, the SPIN Cohort is an online international cohort of patients with SSc that started enrollment in 2014. Eligibility criteria are patients aged ≥ 18 years and classified as having SSc according to the 2013 American College of Rheumatology/European Alliance of Associations for Rheumatology criteria,[12] applied by a physician expert in SSc. For the SCISCIF II study, only French patients who were enrolled through the Internal Medicine Department of Cochin Hospital in Paris were included.[10]

Assessments. Clinical variables were collected at baseline as previously described and provided by a physician upon enrollment in the SPIN Cohort.[10,11] Acceptability of the symptom state was assessed with an external, self-administered, validated specific anchoring question, based on patients' perspectives[8,13]: "Taking into account all the activities you have in your daily life, your level of pain and your functional disability, if you were to remain in your condition for the next few months, would you consider your current condition to be satisfactory?" Participants who answered yes were in the group of patients who considered their symptom state as acceptable. Participants also completed online self-administered scales and questionnaires:

- Three impairment scales, with higher scores indicating higher impairment: (1) numeric rating scale (NRS) for the burden from appearance changes ranging from 0 to 10; (2) Hospital Anxiety Depression Scale (HADS) subscales for Anxiety (HADS-A) and Depression (HADS-D),[14] ranging from 0 to 21; and (3) NRS for pain ranging from 0 to 10.
- Four activity limitation scales, with higher scores indicating higher limitations: (1) Health Assessment Questionnaire (HAQ)[15] ranging from 0 to 3; (2) Scleroderma HAQ (sHAQ)[16] ranging from 0 to 3; (3) Cochin Hand Function Scale (CHFS)[17,18] ranging from 0 to 90; and (4) Mouth Handicap in Systemic Sclerosis scale (MHISS)[2] ranging from 0 to 48.
- One health-related quality of life (HRQOL) scale, with higher scores indicating better HRQOL: the 12-Item Short Form Health Survey (SF-12), with its 2 components, the physical component summary (PCS) score ranging from 9.95 to 70.02, and the mental component summary score ranging from 5.89 to 71.97.[19-21]

Statistical analyses. Analyses were conducted using data from SCISCIF II participants for whom answers to the NRS for burden from appearance changes and the anchoring question were both available. For descriptive analyses, quantitative variables were described by their means and SDs, and qualitative variables by their absolute and relative frequencies. The quantitative variables that were not normally distributed were described by their medians and IQRs. The PASS for the burden from appearance changes was estimated as the 75th percentile of the distribution of burden from appearance changes values for participants who answered yes to the anchoring question.[22] The 95% CI of the PASS was estimated by a normal approach. All analyses were conducted using SYSTAT 13 for Windows (Systat Software). The normal approach was conducted using the XLSTAT version 2017.3 (Addinsoft).

After review, a bivariate comparative analysis was carried out to compare the groups according to whether the level of symptoms was acceptable or not, for the burden from appearance changes (PASS+ group/PASS− group). No statistical comparison was made between the PROs; considering they are self-reported measures of burden, they tend to correlate with each other, and a high level of association could be found, even if not relevant.

Ethical consideration. Our study received ethics board approval (CPP Île-de-France I, no. 2012-juin-12945). All participants provided written informed consent to publish the material.

RESULTS

Participants. Assessment of burden from appearance changes and the answer to the anchoring question were both available in 82/113 (73%) participants from the SCISCIF II study. Overall, 74/82 (90%) participants were women, 32/80 (40%) had diffuse cutaneous SSc and 6 (7%) participants had sine scleroderma forms, but among them, only 2 had no cutaneous sign at all (2 had telangiectasias, 1 had digital ulceration and joint stiffening of small joints, and 1 had joint stiffening of small joints). Median age was 55 (IQR 24) years and mean disease duration 9.6 (SD 6.5) years. The mean modified Rodnan skin score (mRSS) was 8.5 (SD 9.0) of 51 points, and 61/81 (75%) participants had sclerodactyly. Telangiectasias were present in 52/80 (65%) participants, 35/81 (43%) had DUs, and 26/77 (26.0%) had abnormal pigmentation. Mean burden from appearance changes was 4.2 (SD 3.3) of 10 points (Table 1).

PASS for the burden from appearance changes. Overall, 40/82 (49%) participants answered yes to the anchoring question. Using the 75th percentile method, the PASS estimate for the burden from appearance changes was 4.8 (95% CI 1.0-7.0) of 10 points. Based on this estimate, 41/82 (50%) participants reached the PASS for burden from appearance changes (PASS+ group) and 41/82 (50%) did not (PASS− group). The percentage of women and the disease duration were numerically

Table 1. Demographic, clinical, and functional assessment of participants (n = 82).

	Values
Women, n/N (%)	74/82 (90)
Age, yrs, median (IQR)	55 (24)[a]
BMI, kg/m²	23.3 (4.9)[a]
Disease duration, yrs	9.6 (6.5)[a]
mRSS (0-51)	8.5 (9.0)[b]
SSc subtypes, n/N (%)	
Diffuse cutaneous	32/80 (40)
Limited cutaneous	42/80 (53)
Sine scleroderma	6/80 (7)
Clinical manifestations, n/N (%)	
Sclerodactyly	61/81 (75)
Telangectasia	52/80 (65)
Digital ulcers	35/81 (43)
Abnormal pigmentation	26/77 (34)
Small joints arthritis[c]	25/77 (33)
Large joints arthritis[c]	17/76 (22)
Associated visceral damage, n/N (%)	
Upper digestive tract manifestations[d]	65/81 (80)
Lower digestive tract manifestations[e]	19/80 (24)
Interstitial lung disease	32/81 (40)
Pulmonary hypertension	5/81 (6)
Scleroderma renal crisis	6/81 (7)
Overlap syndrome	17/81 (21)
Primary biliary cirrhosis	4/81 (5)
Lupus	6/81 (7)
Autoimmune thyroiditis	8/81 (10)
Sjögren syndrome	11/81 (14)
Autoimmune inflammatory myopathies	6/81 (7)
Patient-reported outcomes	
Burden from appearance changes (0-10)	4.2 (3.3)
HADS-A (0-21)	7.7 (4.3)[f]
HADS-D (0-21)	6.2 (4.5)[f]
Pain NRS (0-10)	4.5 (3.0)[a]
HAQ (0-3)	1.1 (0.8)[g]
SHAQ (0-3)	1.0 (0.7)[h]
CHFS (0-90)	18.3 (18.8)[a]
MHISS (0-48)	19.0 (12.5)[i]
SF-12 PCS (9.95-70.02)	36.6 (15.0)[j]
SF-12 MCS (5.89-71.97)	44.0 (11.6)[j]

Values are expressed as mean (SD) unless indicated otherwise. [a] n = 81. [b] n = 78. [c] Can include swelling and/or stiffness and/or pain. [d] Includes gastroesophageal reflux, bloating, fullness, nausea, vomiting. [e] Includes diarrhea and/or constipation. [f] n = 70. [g] n = 76. [h] n = 75. [i] n = 77. [j] n = 74. CHFS: Cochin Hand Function Scale; HADS-A: Hospital Anxiety and Depression–Anxiety subscale; HADS-D: Hospital Anxiety and Depression–Depression subscale; HAQ: Health Assessment Questionnaire; MHISS: Mouth Handicap in Systemic Sclerosis; MCS: mental component summary; mRSS: modified Rodnan skin score; NRS: numeric rating scale; PCS: physical component summary; SF-12: 12-item Short Form Health Survey; SHAQ: Scleroderma Health Assessment Questionnaire; SSc: systemic sclerosis.

higher in participants who did not reach the PASS than in those who did. The percentages of most SSc-specific impairments (eg, sclerodactyly, DUs, joint, digestive and lung involvement), and levels of pain intensity, symptoms of anxiety and depression, global and location-specific activity limitations, and alterations in health-related quality of life were numerically higher in participants who did not reach the PASS than in those who did (Table 2). There was no significant difference between the

Table 2. Description of participants reaching or not reaching the patient acceptable symptom state (PASS) for the burden from appearance changes.

	Burden From Appearance Changes < 4.8 of 10 Points (PASS+ Group)	Burden From Appearance Changes ≥ 4.8 of 10 Points (PASS− Group)	*P*[*]
Women, n/N (%)	34/41 (83)	40/41 (98)	0.031
Age, yrs	56.5 (14.9)	55.3 (13.9)	0.713
BMI, kg/m²	23.6 (4.4)	23.1 (5.4)	0.340
Disease duration, yrs	8.6 (6.2)	10.6 (6.7)	0.114
mRSS (0-51)	6.0 (6.8)	10.9 (10.2)	0.017
SSc subtypes, n/N (%)			
Diffuse cutaneous	15/40 (37.5)	17/40 (42.5)	0.657
Limited cutaneous	19/40 (47.5)	23/40 (57.5)	0.502
Sine scleroderma	6/40 (15.0)	0/40 (0.0)	0.013
Clinical manifestations, n/N (%)			
Sclerodactyly	26/40 (65.0)	35/41 (85.4)	0.041
Telangectasia	27/40 (67.5)	25/40 (62.5)	0.815
Digital ulcers	15/40 (37.5)	20/41 (48.8)	0.372
Abnormal pigmentation	15/38 (39.5)	11/39 (28.2)	0.341
Small joints arthritis[a]	11/38 (29.0)	14/39 (35.9)	0.628
Large joints arthritis[a]	6/37 (16.2)	11/39 (28.2)	0.274
Associated visceral damage, n/N (%)			
Upper digestive tract manifestations[b]	27/40 (67.5)	38/41 (92.7)	0.005
Lower digestive tract manifestations[c]	10/40 (25.0)	9/40 (22.5)	1.000
Interstitial lung disease	13/40 (32.5)	19/41 (46.3)	0.258
Pulmonary hypertension	3/40 (7.5)	2/41 (4.9)	0.675
Scleroderma renal crisis	3/40 (7.5)	3/41 (7.3)	1.000
Overlap syndrome	6/40 (15.0)	11/41 (26.8)	0.276
Patient-reported outcomes			
Burden from appearance changes (0-10)	1.2 (1.4)	7.1 (1.4)	–
Pain NRS (0-10)	2.6 (2.4)	6.5 (2.1)	–
HADS-A (0-21)	6.9 (4.4)	8.4 (4.0)	–
HADS-D (0-21)	5.0 (4.2)	7.2 (4.6)	–
HAQ (0-3)	0.8 (0.6)	1.4 (0.8)	–
SHAQ (0-3)	0.7 (0.6)	1.4 (0.7)	–
CHFS (0-90)	10.1 (12.0)	26.8 (20.9)	–
MHISS (0-48)	11.8 (9.4)	25.7 (11.3)	–
SF-12 PCS (9.95-70.02)	40.3 (10.6)	33.7 (9.1)	–
SF-12 MCS (5.89-71.97)	48.4 (11.1)	39.5 (10.3)	–

Values are expressed as mean (SD) unless indicated otherwise. [a] Can include swelling and/or stiffness and/or pain. [b] Includes gastroesophageal reflux, bloating, fullness, nausea, vomiting. [c] Includes diarrhea and/or constipation. [*] *Corrected P* = 0.05/20, or 0.0025. CHFS: Cochin Hand Function Scale; HADS-A: Hospital Anxiety and Depression–Anxiety subscale; HADS-D: Hospital Anxiety and Depression–Depression subscale; HAQ: Health Assessment Questionnaire; MHISS: Mouth Handicap in Systemic Sclerosis; MCS: mental component summary; mRSS: modified Rodnan skin score; NRS: numeric rating scale; PCS: physical component summary; SF-12: 12-item Short Form Health Survey; SHAQ: Scleroderma Health Assessment Questionnaire; SSc: systemic sclerosis.

2 groups regarding clinical manifestations and associated visceral damage.

DISCUSSION

In our study, we provided a PASS estimate for the burden from appearance changes in people with SSc. We also found differences in frequencies and severity of some of the physical features between the PASS− and the PASS+ groups, such as a higher mRSS and more frequent sclerodactyly, respectively. Moreover, there were more women in the PASS− group. These findings add to the face validity of the instrument.

The PASS concept brings statistical significance closer to clinical relevance from the patient's point of view.[8] In people with SSc, because treatments are not curative but designed to reduce symptoms and improve quality of life (ie, bring them closer to an acceptable symptom state),[9] PASS estimates for patient-important outcomes, such as burden from appearance changes, may be useful for clinicians to capture patients' perspectives and improve treatments. Recent findings suggest a stability of the PASS estimates for a given outcome, across independent populations presenting with the same condition, reinforcing the relevance and the robustness of the PASS concept.[23] In our study, the PASS estimate for the burden from appearance changes was 4.8 of 10 points. Our estimate could serve as a binary response criterion to assess the efficacy of treatments targeting the burden from appearance changes in clinical practice and research.

Our study has limitations. Our anchoring question followed current recommendations. However, whether the anchoring question should remain general or be symptom-specific is unclear. In our study, the use of the words "pain" and "functional disability" in the anchoring question may have influenced participants' answers.[8] Participants' skin color was not recorded. Yet, some authors reported that people with SSc with white skin may have a lower burden from appearance changes than others.[24] All participants were followed in a referral center for patients with SSc and may not be representative of all patients with SSc in France. Further, the robustness of the study is narrowed by the limited number of participants (41 patients in each group). Finally, including participants with sine scleroderma or with overlap syndrome may have influenced our results because (1) some participants had no cutaneous abnormalities, and (2) systemic lupus erythematosus and inflammatory myopathies can, on their own, be associated with changes in physical appearance.

In summary, to our knowledge, our study is the first to provide a PASS estimate for the burden from appearance changes in people with SSc. This estimate may be useful in interpreting the clinical relevance of outcomes related to the burden from appearance changes.

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