Development of the Fatigue Coping Strategies Questionnaire: a Scleroderma Patient-Centred Intervention Network (SPIN) cohort cross-sectional study

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Abstract

Objective

To develop and validate the Fatigue Coping Strategies Questionnaire (FCSQ), a self-report measure to assess coping with fatigue in systemic sclerosis (SSc).

Methods

We generated an initial pool of items by combining content from existing coping questionnaires and fatigue management programs. Items were added, removed, or modified according to Nominal Group Technique (NGT) sessions conducted with individuals with SSc. Candidate items were administered to SPIN Cohort participants. Exploratory factor analysis (EFA) was used to determine factor structure, with item reduction based on factor loadings, cross-loadings, and conceptual overlap. Measurement properties were assessed using confirmatory factor analysis, differential item functioning (DIF) by language and disease subtype, and Cronbach's alpha.

Results

73 items were reviewed during the 5 NGT sessions (2 English-language, 3 French-language) with 19 participants. 36 items were retained and administered to 645 SPIN Cohort participants. EFA identified a 7-factor structure, resulting in a 21-item questionnaire across 7 domains: Rest and Energy Conservation (2 items), Focus on Fatigue (3), Time and Activity Management (6), Ignoring Fatigue (4), Faith-Based Coping (2), Stress Management (2), and Physical Activity (2). Internal consistency was close to or above acceptable across domains (α=0.66 to 0.83). Five items showed significant DIF by language, but none meaningfully influenced scores (r>0.99 between DIF-adjusted and unadjusted models). No DIF was observed by disease subtype.

Conclusion

The FCSQ is a valid and reliable measure of fatigue-related coping in SSc. Future research should evaluate the measure's responsiveness to change and potential adaptation for other chronic conditions.

Key words

coping skills, fatigue, systemic sclerosis, self-assessment

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Introduction

Systemic sclerosis (SSc) is a rare rheumatic disease involving microvascular damage and fibrosis of the skin and internal organs (1). Fatigue, defined as persistent exhaustion exceeding exertion and not relieved by sleep, is one of the most prevalent and burdensome symptoms, affecting approximately 90% of people with SSc (2). Fatigue moderately to severely limits daily activities in about 75% of people with SSc and is strongly associated with pain, sleep disturbance, psychological distress, reduced physical functioning, and poorer quality of life (3-5).

Individuals with chronic conditions, including autoimmune rheumatic diseases, develop coping mechanisms to manage illness-related stress (6). Coping involves behavioural and cognitive efforts to manage, reduce, or tolerate stressful situations (7). Most coping assessment tools for chronic illnesses (8) focus on cognitive and emotional strategies rather than behavioural approaches (9-12). We previously adapted the 27-item Coping Strategies Questionnaire-Revised (12) for fatigue (CSQ-R-Fatigue) in SSc (13), which includes 6 factors: coping self-statements (4 items), distancing (4 items), catastrophising (6 items), distraction (5 items), ignoring (5 items), and praying (3 items). We found substantial differential item functioning (DIF) by language and disease subtype, indicating that scores reflected fatigue plus other factors (*e.g.* language, disease severity), limiting comparability. Additionally, participants and patient research partners highlighted that the CSQ-R-Fatigue omits key behavioural strategies, including resting, planning, and staying active, which align with evidence-based fatigue management programs in autoimmune rheumatic diseases (14, 15).

The Illness Management Questionnaire was developed for chronic fatigue syndrome and includes several active strategies supported in fatigue management programs (14, 15). It includes 45 items across 4 factors: maintaining activity (17 items), accommodating to the illness (13 items), focusing on symptoms (9 items), and information-seeking (6 items) (16). However, coping in chronic fatigue syndrome and SSc may differ. Furthermore, the questionnaire omits potentially important psychological strategies, was developed with only 207 participants (16) without external validation, and its length may burden participants.

Our objective was to develop the Fatigue Coping Strategies Questionnaire (FCSQ) to assess coping with fatigue in SSc and evaluate its factor structure, DIF, and reliability.

Methods

We 1) developed preliminary fatigue-coping items for SSc, 2) refined items through nominal group technique (NGT) sessions plus researchers' and patient advisors' input, and 3) administered the items in the multinational Scleroderma Patient-Centred Intervention Network (SPIN) Cohort (17, 18). We selected final FCSQ items based on item performance, used exploratory factor analysis (EFA) to identify content domains, evaluated measurement properties by assessing DIF by language (French, English) and disease subtype (diffuse, limited or sine), and evaluated internal consistency within each domain (Supplementary Fig. S1 for a flow chart of the methods).

The SPIN Cohort was approved by the Research Ethics Committee of the Centre Intégré Universitaire de Santé et de Services Sociaux du Centre-Ouest-de-l'Île-de-Montréal (no. MP-05-2013-150) and by the ethics committees of all recruiting sites. The present study was approved as an amendment.

Identification of candidate items

We created an initial item list using the CSQ-R-Fatigue (12) and Illness Management Questionnaire (15), which assess fatigue-related coping but capture different components. Overlapping items were consolidated by research team consensus. We additionally reviewed effective fatigue-management programs in rheumatic diseases (14, 15) to identify missing strategies. One investigator converted strategies into first-person action statements (*e.g. Plan lighter activities and rest breaks around [bigger tasks]* was transformed to *I plan lighter activities and rest breaks around*

Table I. Sociodemographic and disease characteristics for the full sample and by assessment language.

Characteristics	**Full sample** (n=645)		**English** (n=345)		**French** (n=300)	
	n with data	Mean (SD) or N (%)	n	Mean (SD) or N (%)	n	Mean (SD) or N (%)
Sociodemographic variables						
Age (years)	645	62.6 (11.8)	345	64.2 (11.1)	300	60.7 (12.3)
Female sex	645	576 (89.3%)	345	312 (90.4%)	300	264 (88.0%)
Education (years)	601	15.7 (4.6)	324	16.2 (3.4)	277	15.0 (5.6)
Married or living as married	604	417 (69.0%)		232 (71.6%)		185 (66.0%)
White race or ethnicity[a]	609	511 (83.9%)	327	284 (86.9%)	282	227 (80.5%)
Country	645		345		300	
USA		167 (25.9%)		167 (48.4%)		0 (0%)
France		255 (39.5%)		2 (0.6%)		253 (84.3%)
Canada		159 (24.7%)		112 (32.5%)		47 (15.7%)
UK		52 (8.1%)		52 (15.1%)		0 (0%)
Australia		12 (1.9%)		12 (3.4%)		0 (0%)
Body mass index (kg/m^2)	642	24.9 (5.3)	344	25.8 (5.7)	298	23.9 (4.6)
Years since first non-Raynaud's symptoms	645	17.0 (9.4)	345	19.4 (9.7)	300	14.2 (8.1)
Limited or sine disease subtype	645	423 (65.6%)	345	213 (61.7%)	300	210 (70.0%)
Gastrointestinal involvement	636	550 (86.5%)	339	302 (89.1%)	297	248 (83.5%)
Digital ulcers	619	81 (13.1%)	328	39 (11.9%)	291	42 (14.4%)
Tendon friction rubs	569		298		271	
Current		47 (8.3%)		25 (8.4%)		22 (8.1%)
Past		47 (8.3%)		33 (11.1%)		14 (5.2%)
Never		475 (83.5%)		240 (80.5%)		235 (86.7%)
Small joint contractures	608		317		291	
None or mild		453 (74.5%)		252 (79.5%)		201 (69.1%)
Moderate		123 (20.2%)		52 (16.4%)		71 (24.4%)
Severe		32 (5.3%)		13 (4.1%)		19 (6.5%)
Large joint contractures	591		312		279	
None or mild		527 (89.2%)		287 (92.0%)		240 (86.0%)
Moderate		52 (8.8%)		20 (6.4%)		32 (11.5%)
Severe		12 (2.0%)		5 (1.6%)		7 (2.5%)
History of SSc renal crisis	631	19 (3.0%)	338	7 (2.1%)	293	12 (4.1%)
Interstitial lung disease	551	174 (31.6%)	307	87 (28.3%)	244	87 (35.7%)
Pulmonary arterial hypertension	617	42 (6.8%)	325	23 (7.1%)	292	19 (6.5%)

[a]Race or ethnicity data were self-reported in each country using standard categories used in that country. Therefore, categories differed between countries.

my bigger tasks), and three investigators refined items until consensus.

Two bilingual English-French speakers (one European, one Canadian) independently translated items and reconciled discrepancies into a unified French version. A third bilingual speaker back-translated items into English to ensure meaning was preserved.

Item selection for testing

We used the NGT, a stakeholder-driven consensus method used previously in SSc (19-21), to ensure items reflected patient experiences. We planned four to six 60-90-minute sessions, with the final number determined by data redundancy and consistency. Sessions were conducted via Zoom in English or French to enable broad participation without travel.

Eligibility and recruitment of NGT session participants

Eligible participants had physician-confirmed SSc, were fluent in English or French, and reported at least "a little bit" of fatigue on ≥2 of 4 PROMIS-29 v. 2.0 Fatigue items (response options: not at all, a little bit, somewhat, quite a bit, very much) (22-24). Recruitment involved emails to SPIN Cohort participants, posts on SPIN's Facebook and Instagram pages, and emails to SPIN patient partner organisations linking to an online consent and eligibility form.

SPIN Cohort eligibility requires meeting the 2013 American College of Rheumatology/European League Against Rheumatism SSc classification criteria (25); age ≥18 years; fluency in English, French, or Spanish; and internet access. Since the NGT sessions were in English and French, Spanish-speaking participants were not contacted. Participants are recruited at 54 sites in seven countries (Australia, Canada, France, Mexico, Spain, UK, USA). Written informed consent permits future contact. Sites submit an online medical form, after which participants activate their accounts and complete online measures every three months.

Consent and pre-NGT survey

An online Qualtrics consent form detailed the study and NGT process, and individuals could contact the study coordinator with questions. Consenting individuals completed the 4 PROMIS-29 v.2.0 Fatigue items to determine eligibility. Non-SPIN participants also completed sociodemographic and medical questions (sex, gender, age, race or ethnicity, country, relationship status, education, occupation, household income, SSc subtype, years since diagnosis), while SPIN participants provided their SPIN-linked email to access these data. All respondents provided availability for NGT sessions. We assigned participants to sessions based on availability, aiming for soci-

odemographic and disease diversity. Invitation emails confirmed session dates and times, with reminders sent after one week. Upon confirmation, participants completed a pre-NGT survey rating the importance of each candidate item for managing SSc-related fatigue on a 0–10 scale (0 = not at all important; 10 = extremely important), suggested modifications, and proposed additional strategies.

One day before their session, participants received a reminder email to join Zoom 15 minutes early and have materials for brainstorming. Their completed pre-NGT survey was attached. Researchers reviewed pre-NGT survey responses and prepared session-specific agendas highlighting low- or mixed-importance items, new strategies, suggested modifications, and other comments.

NGT sessions

Each English and French NGT session was co-led by two bilingual moderators knowledgeable about SSc and experienced in discussion-based research. One moderator facilitated discussion while the other took notes.

Sessions began with introductions and an agenda overview, followed by a round-robin format. Low- or mixed-importance items were reviewed for modification or removal, conceptually similar items were considered for retention, removal, or combination, and newly proposed strategies were discussed.

The research team reviewed participant ratings and NGT feedback to finalise items for SPIN Cohort administration. Items with clear consensus were retained or removed; those with mixed feedback were reviewed by researchers and patient advisors for conceptual overlap, clarity, and perceived importance. Since only two faith-based items remained, one additional item was adapted from the Brief RCOPE (9) to ensure adequate representation. Final items were selected by researcher consensus.

SPIN cohort administration, final item selection, evaluation of measurement properties

English- and French-speaking SPIN Cohort participants were invited via email and a SPIN platform posting to complete selected items outside their regular assessment, as done previously (21, 26, 27). The email described the study and included a Qualtrics link. Invitations were sent April 24, 2025, with reminders on April 29, May 6, and May 28. The survey closed June 26.

Participants indicated how often they used each fatigue-coping strategy, regardless of perceived effectiveness, using a 7-point Likert scale (0–6, 0 = Never, 3 = Sometimes, and 6 = Always). Instructions advised taking breaks if fatigued.

Statistical analyses

We computed descriptive statistics to characterise the total sample and English- and French-language participants separately. We calculated means and standard deviations (SD) for continuous variables and frequencies with percentages for categorical variables. Item means, SDs, and response frequencies were also computed.

Selection of final FCSQ items and domains

Exploratory factor analysis (EFA) was conducted in the total sample to identify coping domains and inform item selection (28). EFA employed weighted least squares mean and variance adjusted estimation, appropriate for ordinal data, with conventional standard errors, chi-square test statistic, and geomin oblique rotation to allow correlated factors (29). The number of factors was determined using Cattell's scree test, eigenvalues >1, model fit, and interpretability, with eigenvalues reflecting how much variance each factor explains. Model adequacy was assessed using the Tucker-Lewis Index (TLI) (30), the Comparative Fit Index (CFI) (31), and the Root Mean Square Error of Approximation (RMSEA) (32). TLI and CFI values near 0.95 and RMSEA near 0.06 indicate good fit (33). CFI near 0.90 (34) and RMSEA near 0.08 (35) indicate acceptable fit.

Consistent with best practices in scale development, items were considered for removal if they had i) a corrected item-total correlation <0.50 (36-38); ii) a factor loading <0.60 (36, 37); or iii) high conceptual overlap with other items (36). Investigators retained or removed items based on interpretability, redundancy, and cross-loadings.

Evaluation of measurement properties

We conducted DIF analyses to assess whether measurement properties varied by language (English, French) or disease subtype (diffuse, limited or sine) and to evaluate the influence of any DIF on domain scores. DIF occurs when individuals with the same trait respond differently to an item because of group membership. DIF was examined using Multiple-Indicator Multiple-Cause model, which incorporates group variables into a confirmatory factor analysis (CFA). The base model includes the CFA structure and a direct effect of group on the latent factor to adjust for group differences. DIF was evaluated separately for each domain with ≥3 items (39). For each domain, we regressed the latent factor on language and subtype and added direct paths from each grouping variable to individual items. Items were first tested individually by regressing them on language; significant paths (p<0.05) indicated DIF. When DIF was detected, the item with the largest effect was retained, and remaining items were re-assessed iteratively until no additional items exhibited significant DIF. This procedure was repeated for disease subtype. Domains with fewer than three items were not tested because 2-item CFA models are not identifiable.

After identifying items with significant DIF, we assessed influence on domain scores by comparing latent factor scores (standardised mean differences; SMD) between language and disease-subtype groups in baseline and DIF-adjusted CFA models. We evaluated associations between factor scores from each model using Pearson's correlations and agreement using intraclass correlation coefficients (ICCs).

Since we found no substantive DIF, measurement properties were analysed in the full sample. For each domain, we examined floor and ceiling effects (≥15% of participants at the lowest or highest scores) to show extreme scores (40, 41), internal consistency using Cronbach's alpha (42), and item-rest

Table II. Item characteristics of all 36 items administered to the Scleroderma Patient-centred Intervention Network Cohort.

Items	Mean ± SD score[a]	Item-rest correlation[b]	EFA factor loading
Items included in the questionnaire			
Rest and energy conservation	9.2 ± 2.3		
1. I try my best to get a good night's sleep	4.9 ± 1.3	0.50	0.61
2. I try to strike a balance between resting and staying active	4.3 ± 1.4	0.50	0.72
Focus on fatigue	8.0 ± 4.0		
4. I spend a lot of time thinking about my fatigue	2.3 ± 1.7	0.46	0.72
5. I am constantly aware of my fatigue level	3.6 ± 1.7	0.54	0.57
7. I try to explain my fatigue to others	2.0 ± 1.7	0.69	0.51
Time and activity management	22.5 ± 6.7		
3. I break things up into smaller tasks	3.7 ± 1.6	0.56	0.55
6. I do my most important tasks first in case I feel too fatigued to finish everything	3.8 ± 1.7	0.54	0.61
8. I plan lighter activities and rest breaks around bigger tasks	3.4 ± 1.6	0.58	0.82
11. I manage my time so that I don't have to do too much in one day	3.6 ± 1.6	0.44	0.73
13. I do bigger tasks when I have less fatigue	4.2 ± 1.4	0.69	0.52
15. I do something I enjoy, such as watching TV or listening to music to distract myself when I am fatigued	3.8 ± 1.6	0.44	0.51
Ignoring fatigue	12.7 ± 4.9		
9. Even though fatigued, I just go on as if I were feeling OK	3.7 ± 1.5	0.57	0.80
10. I try to ignore my fatigue	3.6 ± 1.5	0.49	0.82
12. I push myself until I can do no more	2.9 ± 1.7	0.63	0.51
20. I pretend that my fatigue is not a part of me	2.5 ± 1.8	0.69	0.49
Faith-based coping	4.9 ± 5.7		
14. I pray to God that my fatigue won't last long	1.8 ± 2.2	0.44	0.67
19. I rely on my faith in God to help me cope with my fatigue	1.6 ± 2.1	0.69	0.97
Stress management	7.2 ± 2.9		
16. I try to reduce my stress and anxiety levels	3.6 ± 1.6	0.71	0.70
18. I try to control how much stress there is in my life	3.6 ± 1.5	0.86	0.95
Physical activity	5.9 ± 3.6		
17. I follow an exercise routine to improve my strength and reduce my fatigue	3.0 ± 1.9	0.87	0.76
21. I do physical activities such as yoga or sports to help with my fatigue	2.9 ± 2.0	0.67	0.81
Items not included in the final questionnaire			
Focus on fatigue			
E1. I tell myself to be brave and carry on despite the fatigue	3.8 ± 1.8		0.47
E4. I think of people, activities, experiences, or things I enjoy distracting myself from my fatigue	2.8 ± 1.8		0.29
E7. I seek support from others with similar experiences with fatigue	1.1 ± 1.4		0.27
E10. I seek psychological help to cope with my fatigue	0.9 ± 1.5		0.25
E11. I use lists, charts, or apps to recognize trends in my fatigue levels	0.4 ± 1.0		0.25
E15. I look for information on managing fatigue	1.9 ± 1.8		0.36
Time and activity management			
E2. I pay attention to my limitations due to fatigue	3.6 ± 1.5		0.46
E3. I ask for help with work or chores	2.8 ± 1.7		0.43
E5. I follow the advice of my medical professionals on managing my fatigue	3.4 ± 1.8		0.24
E9. I take naps to recharge my energy	3.0 ± 1.9		0.27
E13. I accept that my life is no longer the same as before the fatigue	3.7 ± 1.7		0.34
Ignoring fatigue			
E6. I do something I want to do, even though I know I will feel worse after	3.6 ± 1.5		0.46
E8. I push myself to stay active	4.4 ± 1.4		0.42
Faith-based coping			
E14. I turn to my faith to cope when I'm feeling fatigued	1.5 ± 2.0		0.94
Stress management			
E12. I control my negative feelings	3.5 ± 1.5		0.48

[a] On a 7-point scale, where 0 = Never, 3 = Sometimes, and 6 = Always; [b] Item-rest correlations were done within subscales.

correlations (correlations between each item and the sum of remaining domain items).

We conducted the EFA using Mplus 7 (28); all other analyses were done in R-studio version 2023.12.1.402 (43).

Involvement of people with lived experience

The SPIN Cohort is a patient-researcher partnership whose Steering Committee, including 11 people with SSc, identified fatigue coping as a research priority. In our previous CSQ-R-Fatigue study (13), participants noted missing coping strategies and recommended developing a new measure to better capture coping with fatigue in SSc.

Table III. Fatigue Coping Strategies Questionnaire confirmatory factor analysis base model and DIF-corrected model factor loadings and DIF evaluation for items by domains.

	Base model[a]		DIF-corrected model[b]	
	Factor loading	95% CI	Factor loading	95% CI
Rest and energy conservation				
1. I try my best to get a good night's sleep	0.56	0.46, 0.68	0.57	0.46, 0.68
2. I try to strike a balance between resting and staying active	0.88	0.77, 0.98	0.88	0.77, 0.98
Focus on fatigue				
4. I spend a lot of time thinking about my fatigue	0.59	0.52, 0.65	0.59	0.52, 0.65
5. I am constantly aware of my fatigue level	0.73	0.65, 0.80	0.73	0.65, 0.80
7. I try to explain my fatigue to others	0.66	0.59, 0.73	0.66	0.59, 0.73
Time and activity management				
3. I break things up into smaller tasks	0.62	0.56, 0.69	0.61	0.55, 0.68
6. I do my most important tasks first in case I feel too fatigued to finish everything	0.66	0.60, 0.72	0.66	0.59, 0.72
8. I plan lighter activities and rest breaks around bigger tasks	0.80	0.76, 0.85	0.81	0.77, 0.85
11. I manage my time so that I don't have to do too much in one day	0.62	0.55, 0.69	0.62	0.55, 0.69
13. I do bigger tasks when I have less fatigue	0.56	0.47, 0.65	0.56	0.47, 0.65
15. I do something I enjoy, such as watching TV or listening to music to distract myself when I am fatigued	0.52	0.43, 0.60	0.53	0.45, 0.61
Ignoring fatigue				
9. Even though fatigued, I just go on as if I were feeling OK	0.74	0.67, 0.81	0.74	0.66, 0.81
10. I try to ignore my fatigue	0.79	0.73, 0.86	0.80	0.74, 0.86
12. I push myself until I can do no more	0.63	0.56, 0.70	0.62	0.55, 0.69
20. I pretend that my fatigue is not a part of me	0.51	0.43, 0.58	0.53	0.46, 0.60
Faith-based coping				
14. I pray to God that my fatigue won't last long	1.01	0.92, 1.11	1.01	0.91, 1.11
19. I rely on my faith in God to help me cope with my fatigue	0.70	0.62, 0.78	0.70	0.62, 0.78
Stress management				
16. I try to reduce my stress and anxiety levels	0.86	0.81, 0.92	0.86	0.81, 0.92
18. I try to control how much stress there is in my life	0.80	0.73, 0.87	0.80	0.72, 0.87
Physical activity				
17. I follow an exercise routine to improve my strength and reduce my fatigue	0.94	0.87, 1.01	0.93	0.86, 1.00
21. I do physical activities such as yoga or sports to help with my fatigue	0.71	0.64, 0.79	0.72	0.65, 0.79
Direct effects on items associated with French language[c]				
Time and activity management				
3. 1 break things up into smaller tasks	-	-	-0.15	-0.21, -0.08
6. I do my most important tasks first in case I feel too fatigued to finish everything	-	-	-0.09	-0.15, -0.02
15. I do something I enjoy, such as watching TV or listening to music to distract myself when I am fatigued	-		-0.09	0.02, 0.16
Ignoring fatigue				
12. I push myself until I can do no more	-	-	-0.23	-0.30, -0.15
20. I pretend that my fatigue is not a part of me	-	-	0.14	0.07, 0.22

[a]Unstandardised model with fixed variance and regression of the latent coping domains (Rest and energy conservation, Focus on fatigue, Time and Activity management, Ignoring fatigue, Faith-based coping, Stress management, Physical activity) on language and disease subtype, not corrected for differential item functioning (DIF). [b]Unstandardised model with fixed variance and regression of the latent coping domains (Rest and Energy Conservation, Focus on Fatigue, Time and Activity Management, Ignoring Fatigue, Faith-Based Coping, Stress Management, Physical Activity) on language (corrected for DIF on items 3, 6, 12, 15, 20) and on disease subtype. [c]Positive parameters reflect higher item scores among French-language.

Results

Candidate items

The pre-NGT survey included 73 candidate items; 13 from the CSQ-R-Fatigue, 36 from the Illness Management Questionnaire, 7 combined from both, and 17 developed from fatigue management programs (Supplementary Table S1 for the item list, their source, and their translations).

Selection of items for testing

Thirty-three individuals with SSc expressed interest in NGT sessions, and 19 attended one of 5 sessions (3 French, 2 English) held December 9-13, 2024. Sessions included 3-5 participants. Participants were aged 26-81 years (median 50); 16 (84%) were female and 17 (89%) were White. The mean (SD) education was 15 (5) years. Mean time (SD) since diagnosis was 7 (6) years, and 9 participants had limited SSc (47%).

From the 73 candidate items in the pre-NGT survey, 22 were excluded, 12 added, and 4 modified by NGT consensus. The research team reviewed ratings and comments on the remaining 63 items and selected 36 for SPIN Cohort testing (Suppl. Fig. S2). Of these, 6 items came from the CSQ-R-Fatigue, 12 from the Illness Management Questionnaire, 2 from both, 1 from the Brief-RCOPE, 9 from fatigue management programs, and 6 from NGT sessions.

SPIN cohort administration, final item selection, and measurement properties

Of 1366 active SPIN Cohort participants invited, 645 (47%) completed the questionnaire. There were 576 female participants (89%), with a mean (SD)

Table IV. Standardised mean difference, intra-class correlations and Pearson's correlations of the Fatigue Coping Strategies Questionnaire by domain, with and without DIF adjustment.

Domain	Language[a]		ICC	Pearson's correlation coefficient
	Without DIF adjustment SMD (95% CI)	With DIF adjustment SMD (95% CI)		
Rest and energy conservation	-0.15 (-0.49, -0.12)	-0.14 (-0.47, -0.10)	>0.99	>0.99
Focus on fatigue	-0.05 (-0.28, 0.09)	-0.10 (-0.39, 0.04)	>0.99	>0.99
Time and activity management	0.00 (-0.17, 0.18)	0.02 (-0.15, 0.22)	>0.99	>0.99
Ignoring fatigue	-0.05 (-0.27, 0.08)	0.01 (-0.16, 0.22)	>0.99	>0.99
Faith-based coping	-0.13 (-0.43, -0.09)	-0.13 (-0.43, -0.09)	>0.99	>0.99
Stress management	-0.12 (-0.41, -0.06)	-0.11 (-0.40, -0.03)	>0.99	>0.99
Physical activity	-0.03 (-0.23, 0.11)	-0.00 (-0.18, 0.17)	>0.99	>0.99

CI: confidence interval; DIF: differential item functioning; ICC: intraclass correlation coefficient; SMD: standardised mean difference. [a]French-English latent factor scores.

age of 62.6 (11.8) years and mean (SD) time since first non-Raynaud's phenomenon symptom onset of 17.0 (9.4) years. 222 individuals had diffuse SSc (34%). Participants were from France (n=255, 40%), Canada (n=159, 25%), the United States (n=167, 26%), the United Kingdom (n=52, 8%), and Australia (n=12, 2%). Most sociodemographic and disease characteristics were similar for English-language (n=345, 53%) and French-language participants (n=300, 47%), although French-language participants had fewer years since first non-Raynaud's symptoms (14.2 years, SD=8.1 years) than English-language participants (19.4 years, SD=9.7 years) (Table I).

Selection of final FCSQ items and domains

Means and SDs for all 36 items are shown in Table II. Mean item scores ranged from 0.4 for Item E11 (*I use lists, charts, or apps to recognise trends in my fatigue levels*) to 4.9 for Item 1 (*I try my best to get a good night's sleep*). The EFA of the 36 items yielded 7 eigenvalues >1 (7.12, 3.24, 3.00, 2.35, 1.49, 1.30, 1.23). Based on the scree plot and factor loadings, a 7-factor solution provided the best interpretability and fit (CFI = 0.94; TLI = 0.90; RMSEA = 0.05). Domains included Rest and Energy Conservation (2 items), Time and Activity Management (6 items), Focus on Fatigue (3 items), Ignoring Fatigue (4 items), Faith-Based Coping (2 items), Stress Management (2 items), and Physical Activity (2 items). Item loadings and cross-loadings are shown in Supplementary Table S2. Based on factor loadings, cross-loadings, item correlations, and conceptual overlap, fifteen items (E1-E15) were removed, resulting in a 21-item FCSQ (Table II), including 4 items from the CSQ-R-Fatigue, 6 from the Illness Management Questionnaire, 2 from both, 7 from fatigue management programs, and 2 from NGT sessions. The English and French versions of the FCSQ are shown in Supplementary Fig. S3.

Evaluation of measurement properties

The DIF analysis of the 7-factor model with latent domains regressed on language and disease subtype, demonstrated good fit (CFI 0.94, TLI 0.95, RMSEA 0.05). Five items across two domains demonstrated statistically significant language-based DIF, but none by disease subtype (Table III).

Standardised mean differences between French- and English-language respondents on domain scores were minimal when comparing unadjusted and DIF-adjusted models (0.00 for Faith-Based Coping [-0.13 for both] to 0.05 for Focus on Fatigue [-0.05 *vs*. -0.10]); positive values indicated higher scores among French-language respondents. Pearson's and ICC correlations between unadjusted and DIF-adjusted scores exceeded 0.99 for all domains (Table IV). Since no substantive DIF by language or any DIF by disease subtype was detected, we evaluated measurement properties for the overall sample.

For the 21 final FCSQ items (Table II), mean scores ranged from 1.6 (Item 19: *I rely on my faith in God to help me cope with my fatigue*) to 4.9 (Item 1: *I try my best to get a good night's sleep*). Inter-item correlations within domains ranged from 0.24 (Items 3 [*I break things up into smaller tasks*] and 15 [*I do something I enjoy, such as watching TV or listening to music to distract myself when I am fatigued*] in Time and Activity Management and Items 12 [*I push myself until I can do no more*] and 20 [*I pretend my fatigue is not a part of me*] in Ignoring Fatigue) to 0.71 (Items 14 [*I pray to God that my fatigue won't last long*] and 19 [*I rely on my faith in God to help me cope with my fatigue*] in Faith-Based Coping) (Suppl. Table S3). Item-rest correlations ranged from 0.44 (Items 11 [*I manage my time so that I don't have to do too much in one day*] and 15 [*I do something I enjoy, such as watching TV or listening to music to distract myself when I am fatigued*] in Time and Activity Management and Item 14 [*I pray to God that my fatigue won't last long*] in Faith-Based Coping) to 0.87 (Item 17 [*I follow an exercise routine to improve my strength and reduce my fatigue*] in Physical Activity). Correlations between mean domain scores ranged from 0.01 between Rest and Energy Conservation and Ignoring Fatigue to 0.44 for Focus on Fatigue and Time and Activity Management.

The percentage of participants with the lowest possible domain score ranged from 1% for Rest and Energy Conservation and Time and Activity Management to 45% for Faith-Based Coping. The percentage with the highest possible score ranged from 1% for Focus on Fatigue and Time and Activity Man-

Table V. Response distributions for all 36 items administered to the Scleroderma Patient-centered Intervention Network Cohort by domain (n=645).

Item	Item responses						
	0 (never) N (%)	1 N (%)	2 N (%)	3 (sometimes) N (%)	4 N (%)	5 N (%)	6 (always) N (%)
Items included in the questionnaire							
Rest and energy conservation							
1. I try my best to get a good night's sleep	9 (1.4%)	2 (0.3%)	9 (1.4%)	81 (12.6%)	117 (18.1%)	154 (23.9%)	273 (42.3%)
2. I try to strike a balance between resting and staying active	14 (2.2%)	7 (1.1%)	27 (4.2%)	139 (21.6%)	140 (21.7%)	171 (26.5%)	147 (22.8%)
Focus on fatigue							
4. I spend a lot of time thinking about my fatigue	113 (17.5%)	107 (16.6%)	107 (16.6%)	184 (28.5%)	61 (9.5%)	41 (6.4%)	32 (5.0%)
5. I am constantly aware of my fatigue level	32 (5.0%)	54 (8.4%)	63 (9.8%)	171 (26.5%)	103 (16.0%)	105 (16.3%)	117 (18.1%)
7. I try to explain my fatigue to others	175 (27.1%)	103 (16.0%)	69 (10.7%)	199 (30.9%)	53 (8.2%)	27 (4.2%)	19 (2.9%)
Time and activity management							
3. I break things up into smaller tasks	43 (6.7%)	16 (2.5%)	33 (5.1%)	202 (31.3%)	142 (22.0%)	117 (18.1%)	92 (14.3%)
6. I do my most important tasks first in case I feel too fatigued to finish everything	51 (7.9%)	28 (4.3%)	28 (4.3%)	149 (23.1%)	122 (18.9%)	138 (21.4%)	129 (20.0%)
8. I plan lighter activities and rest breaks around bigger tasks	54 (8.4%)	33 (5.1%)	36 (5.6%)	216 (33.5%)	146 (22.6%)	95 (14.7%)	65 (10.1%)
11. I manage my time so that I don't have to do too much in one day	35 (5.4%)	42 (6.5%)	42 (6.5%)	191 (29.6%)	137 (21.2%)	128 (19.8%)	70 (10.9%)
13. I do bigger tasks when I have less fatigue	19 (2.9%)	12 (1.9%)	9 (1.4%)	156 (24.2%)	152 (23.6%)	176 (27.3%)	121 (18.8%)
15. I do something I enjoy, such as watching TV or listening to music to distract myself when I am fatigued	45 (7.0%)	21 (3.3%)	35 (5.4%)	159 (24.7%)	146 (22.6%)	147 (22.8%)	92 (14.3%)
Ignoring fatigue							
9. Even though fatigued, I just go on as if I were feeling OK	25 (3.9%)	26 (4.0%)	52 (8.1%)	191 (29.6%)	135 (20.9%)	137 (21.2%)	79 (12.2%)
10. I try to ignore my fatigue	36 (5.6%)	20 (3.1%)	48 (7.4%)	218 (33.8%)	130 (20.2%)	125 (19.4%)	68 (10.5%)
12. I push myself until I can do no more	79 (12.2%)	47 (7.3%)	89 (13.8%)	209 (32.4%)	96 (14.9%)	84 (13.0%)	41 (6.4%)
20. I pretend that my fatigue is not a part of me	157 (24.3%)	51 (7.9%)	69 (10.7%)	209 (32.4%)	59 (9.1%)	56 (8.7%)	44 (6.8%)
Faith-based cping							
14. I pray to God that my fatigue won't last long	316 (49.0%)	56 (8.7%)	25 (3.9%)	91 (14.1%)	44 (6.8%)	41 (6.4%)	72 (11.2%)
19. I rely on my faith in God to help me cope with my fatigue	348 (54.0%)	65 (10.1%)	26 (4.0%)	80 (12.4%)	33 (5.1%)	34 (5.3%)	59 (9.1%)
Stress management							
16. I try to reduce my stress and anxiety levels	35 (5.4%)	33 (5.1%)	52 (8.1%)	192 (29.8%)	134 (20.8%)	109 (16.9%)	90 (14.0%)
18. I try to control how much stress there is in my life	37 (5.7%)	26 (4.0%)	55 (8.5%)	204 (31.6%)	136 (21.1%)	116 (18.0%)	71 (11.0%)
Physical activity							
17. I follow an exercise routine to improve my strength and reduce my fatigue	106 (16.4%)	59 (9.1%)	77 (11.9%)	148 (22.9%)	94 (14.6%)	81 (12.6%)	80 (12.4%)
21. I do physical activities such as yoga or sports to help with my fatigue	145 (22.5%)	45 (7.0%)	50 (7.8%)	157 (24.3%)	87 (13.5%)	73 (11.3%)	88 (13.6%)
Items not included in the questionnaire							
E1. I tell myself to be brave and carry on despite the fatigue	62 (9.6%)	23 (3.6%)	34 (5.3%)	134 (20.8%)	127 (19.7%)	136 (21.1%)	129 (20.0%)
E2. I pay attention to my limitations due to fatigue	36 (5.6%)	25 (3.9%)	49 (7.6%)	187 (29.0%)	152 (23.6%)	121 (18.8%)	75 (11.6%)
E3. I ask for help with work or chores	98 (15.2%)	63 (9.8%)	45 (7.0%)	229 (35.5%)	96 (14.9%)	79 (12.2%)	35 (5.4%)
E4. I think of people, activities, experiences, or things I enjoy distracting myself from my fatigue	118 (18.3%)	67 (10.4%)	52 (8.1%)	184 (28.5%)	97 (15.0%)	78 (12.1%)	49 (7.6%)
E5. I follow the advice of my medical professionals on managing my fatigue	75 (11.6%)	39 (6.0%)	41 (6.4%)	166 (25.7%)	127 (19.7%)	110 (17.1%)	87 (13.5%)
E6. I do something I want to do, even though I know I will feel worse after	35 (5.4%)	22 (3.4%)	44 (6.8%)	222 (34.4%)	135 (20.9%)	126 (19.5%)	61 (9.5%)
E7. I seek support from others with similar experiences with fatigue	321 (49.8%)	125 (19.4%)	80 (12.4%)	82 (12.7%)	23 (3.6%)	6 (0.9%)	8 (1.2%)
E8. I push myself to stay active	12 (1.9%)	13 (2.0%)	18 (2.8%)	129 (20.0%)	150 (23.3%)	135 (20.9%)	188 (29.1%)
E9. I take naps to recharge my energy	103 (16.0%)	69 (10.7%)	47 (7.3%)	169 (26.2%)	78 (12.1%)	101 (15.7%)	78 (12.1%)
E10. I seek psychological help to cope with my fatigue	406 (62.9%)	83 (12.9%)	50 (7.8%)	59 (9.1%)	20 (3.1%)	15 (2.3%)	12 (1.9%)
E11. I use lists, charts, or apps to recognize trends in my fatigue levels	519 (80.5%)	55 (8.5%)	22 (3.4%)	32 (5.0%)	6 (0.9%)	9 (1.4%)	2 (0.3%)
E12. I control my negative feelings	37 (5.7%)	31 (4.8%)	40 (6.2%)	238 (36.9%)	120 (18.6%)	115 (17.8%)	64 (9.9%)
E13. I accept that my life is no longer the same as before the fatigue	46 (7.1%)	36 (5.6%)	43 (6.7%)	172 (26.7%)	115 (17.8%)	109 (16.9%)	124 (19.2%)
E14. I turn to my faith to cope when I'm feeling fatigued	356 (55.2%)	62 (9.6%)	31 (4.8%)	88 (13.6%)	28 (4.3%)	37 (5.7%)	43 (6.7%)
E15. I look for information on managing fatigue	224 (34.7%)	89 (13.8%)	52 (8.1%)	166 (25.7%)	55 (8.5%)	39 (6.0%)	20 (3.1%)

agement to 19% for Rest and Energy Conservation. For Faith-Based Coping, distributions among participants not at the floor level resembled other domains. Item and domain score distributions are presented in Table V and Supplementary Figure S4.

Cronbach's alpha was 0.66 (95% CI 0.61, 0.72) for Rest and Energy Conservation, 0.70 (95% CI 0.66, 0.74) for Focus on Fatigue, 0.80 (95% CI 0.77, 0.82) for Time and Activity Management, 0.75 (95% CI 0.71, 0.78) for Ignoring Fatigue, 0.83 (95% CI 0.80, 0.86) for Faith-Based Coping, 0.82 (95% CI 0.79, 0.85) for Stress Management, and 0.80 (95% CI 0.77, 0.83) for Physical Activity.

Discussion

Principle findings

The FCSQ was developed to assess how individuals with SSc cope with fatigue, addressing gaps in existing measures. The 21-item FCSQ captures 7 domains: Rest and Energy Conservation, Time and Activity Management, Focus on Fatigue, Ignoring Fatigue, Faith-Based Coping, Stress Management, and Physical Activity. We found no evidence that FCSQ performance differed by language (English or French) or disease subtype. Internal consistency was acceptable across domains (α=0.66-0.83). This is notable given Cronbach's alpha is sensitive to item count, and our domains included only 2-6 items (36, 44). No floor or ceiling effects were observed except a floor effect in Faith-Based Coping (45%), likely reflecting that some individuals do not use religious coping rather than issues with item relevance. Among those who endorsed these strategies, response distributions resembled other domains, indicating meaningful variability.

Findings in context

Of the 7 FCSQ domains, Focus on Fatigue, Ignoring Fatigue, and Faith-Based Coping overlap with domains in existing coping questionnaires commonly used in chronic illness populations (*e.g.* Brief-COPE, Ways of Coping Checklist, Multidimensional Coping Inventory, CSQ-R-Fatigue) (9-12). The FCSQ adds four domains (Rest and Energy Conservation, Time and Activity Management, Stress Management, Physical Activity) (13).

Some items in these new domains were adapted from the Illness Management Questionnaire (Suppl. Table S1), although it did not assess them as distinct domains. These domains align with evidence-based fatigue self-management strategies, including goal setting, pacing, prioritisation, and gentle exercise (14, 15). They also reflect feedback from participants in our previous CSQ-R-Fatigue study, which noted that existing items did not fully capture their experiences (13). By incorporating these domains, the FCSQ more comprehensively reflects the multifaceted ways people with SSc manage fatigue.

Our findings have important implications. The FCSQ enables more nuanced assessment of coping behaviours and their associations with fatigue and related outcomes in SSc. This tool is intended for research use and does not assess fatigue severity but could be administered alongside established fatigue severity scales to provide a more complete picture of fatigue experiences. Future work should validate the scale in an independent SSc sample and in other autoimmune rheumatic diseases, identify factors associated with coping strategies, and examine how these strategies relate to fatigue outcomes. Coping profiles should also be explored to determine whether existing autoimmune rheumatic diseases fatigue interventions (14, 15) are applicable to individuals with SSc, or require adaptations based on distinct coping patterns.

Strengths and limitations

Our study has several strengths. It used a large, multinational sample with English- and French-speaking participants and different SSc subtypes. Importantly, measure development was guided by patient feedback and SPIN's Steering Committee, with item selection shaped by people with SSc through NGT sessions. Limitations should be considered. First, the SPIN Cohort is a convenience sample, which may limit generalisability. However, prior work has shown that the demographic and clinical characteristics of the SPIN Cohort are broadly comparable to those reported in other major SSc cohorts (45). Second, because item development did not involve individuals with other chronic conditions, applicability beyond SSc remains unknown. Third, some FCSQ domains include only two items, allowing calculation of sum scores but not factor scores or DIF. Fourth, our analyses examined exclusively uniform DIF, which assumes consistent effects across the trait continuum; while non-uniform DIF could offer additional insight, it is more complex to model and less relevant for sum-score tools (46). Lastly, we did not evaluate the time required to complete the FCSQ.

Conclusions

To conclude, our findings support the validity of the 21-item FCSQ for assessing coping with fatigue in SSc. This represents an important contribution, as fatigue is a common and debilitating symptom in SSc that often remains unaddressed in treatment. Because fatigue is central in many illnesses, future research should validate the FCSQ in other patient populations to improve generalisability and examine which coping domains are most strongly linked to positive outcomes.

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