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# Validity and reliability of the Swedish version of the Self-Efficacy for Managing Chronic Disease scale for individuals with systemic sclerosis

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**Objective:** To investigate aspects of validity and reliability of the Swedish version of the Self-Efficacy for Managing Chronic Disease (SEMCD-Swe) scale in systemic sclerosis (SSc).

**Method:** A forward–backward translation procedure was used. Content validity was assessed through interviews with 11 people with SSc and 10 healthcare professionals. Construct validity, internal consistency, test–retest reliability, and floor and ceiling effects were evaluated in 104 SSc patients.

**Results:** The content validity of the SEMCD-Swe was interpreted as satisfactory, but some adjustments were made to increase the understanding. Confirmatory factor analysis supported a single-factor structure. Moderate to strong correlations between the SEMCD-Swe and Scleroderma Health Assessment Questionnaire; Multidimensional Assessment of Fatigue; Patient Health Questionnaire-8 ( $r_s = -0.4$  to  $-0.7$ ), and RAND-36 subscales ( $r_s = 0.5$  to  $0.7$ ) were found. Weak correlations were found between SEMCD-Swe and modified Rodnan skin score; and disease severity of peripheral vascular and lung ( $r_s = -0.1$  to  $-0.2$ ) and kidney ( $r_s = 0.1$ ) systems (Medsker severity scale). Cronbach's alpha was sufficient (0.85) and corrected item-to-total correlations were good ( $\geq 0.50$ ). The intraclass correlation coefficient for the total score was sufficient (0.82). No floor or ceiling effects were found.

**Conclusion:** Support for construct validity was indicated, as the SEMCD-Swe in SSc show a single-factor structure and is more strongly associated with pain, fatigue, depressive symptoms, interferences with daily activities, disability, and quality of life than with disease severity. Our results also indicate support for content validity and reliability. However, the responsiveness of the SEMCD-Swe needs to be tested.

Systemic sclerosis (SSc) is a rare autoimmune inflammatory disease characterized by vasculopathy and fibrosis in skin and internal organs. The disease is commonly divided into two subtypes with regard to the extent of skin involvement: limited cutaneous (lcSSc) or diffuse cutaneous systemic sclerosis (dcSSc) (1). The clinical course can vary from limited skin thickening to severe organ damage and high mortality (2). Common disease manifestations are Raynaud's phenomenon, digital ulcers (1), joint

involvement, and reduced hand function (3). Pain, fatigue (4), gastro-oesophageal reflux, exertional breathlessness (1), and proximal muscle weakness (5) are also common. Depressive symptoms, emotional distress, and concerns about appearance due to skin changes have also been described (4, 6). Thus, people with SSc may face a diversity of disease manifestations, with limitations in their daily lives (7, 8) and reduced health-related quality of life (HRQoL) (9).

Self-efficacy, which is the belief in one's capabilities to produce given achievements (10), is an essential factor for self-management of chronic diseases, behaviours, and behavioural changes (11). Among people with SSc, a relatively low self-efficacy for managing the disease has been found compared with other chronic conditions (12). Assessments

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of self-efficacy are of interest to capture patients' need for support in managing the disease (13) and in the evaluation of self-management programmes (13, 14). Self-efficacy has been assessed with different patient-reported outcome measures (PROMs) in SSc, including the Arthritis Self-Efficacy Scale (15) and the Self-Efficacy for Managing Chronic Disease (SEMCD) scale (16). The SEMCD has been psychometrically evaluated extensively across diseases, such as arthritis, diabetes, and heart and lung diseases (17–19). The SEMCD in English has also been used extensively to evaluate chronic disease self-management programmes (18). To our knowledge, only the English version has been validated in SSc (20). The aim of the study was to investigate aspects of the validity and reliability of the Swedish version of the SEMCD scale for individuals with SSc.

## Method

### Participants and procedure

Data for this study were collected from three rheumatology centres in Sweden between September 2017 and March 2020. Patients were included if they fulfilled the 2013 American College of Rheumatology/European League Against Rheumatism (ACR/EULAR) classification criteria for SSc (21):  $\geq 18$  years of age, with a disease duration  $\geq 1$  year, who were able to understand and speak Swedish. To evaluate content validity, 11 patients and 10 healthcare professionals (HPs) participated (Table 1 and Table 2). In the assessment of construct validity and aspects of reliability, 104 patients were involved (Table 1). These sample sizes for content and construct validity as well as reliability have been described as appropriate (22). Patients were enrolled during their visit at the rheumatology centre. A convenience sample of patients was used for content validity, where potential patients according to a rheumatologist were invited by letter and those who consented to participate were controlled for inclusion by a rheumatologist. For construct validity and reliability, a convenience sample of patients on treatment or follow-up was used at one centre. At the other centre, a consecutive sample of patients from an outpatient clinic was used. Informed consent was obtained from all study participants according to the Declaration of Helsinki, and the study was approved by the regional ethics committee in Umeå (2017/149-31).

### Disease severity variables

A rheumatologist collected the following assessments (23).

The modified Rodnan Skin Score (mRSS) was used to assess skin involvement (24). Skin thickness is assessed by palpation at 17 body areas, and higher scores represent greater skin involvement.

The Medsger Severity Scale (MSS) evaluates disease severity of nine organ systems (25). In our study, the assessment was reduced to the following organ systems, which were included in routine clinical practice:

peripheral vascular, lung, heart, and kidney. Each organ system is scored separately, with 0 representing normal, 1 mild, 2 moderate, 3 severe, and 4 end-stage. The assessment of the organ system skin in the MSS is assessed by the mRSS. We used the mRSS as a continuous score (24), without converting it to the MSS categories 0–4.

### Patient-reported outcome measures

Patients completed the following PROMs on paper.

The 6-item SEMCD covers respondents' confidence (self-efficacy) in keeping fatigue, physical discomfort or pain, emotional distress, and other symptoms or health problems from interfering with things that they want to do. This PROM also covers confidence to reduce the need to see a doctor and to reduce how illness affects everyday life. Each item is scored from 1 (not at all confident) to 10 (totally confident), and the total score is calculated by taking the mean of the items (18, 19). The SEMCD in English has been validated for measuring self-efficacy in patients with SSc (20).

The Scleroderma Health Assessment Questionnaire (SSc HAQ) was used to evaluate disability, pain, and disease interference with daily activities, and higher scores (score range 0–3) represent greater difficulties (26). The SSc HAQ consists of the Health Assessment Questionnaire Disability Index (HAQ-DI), with 20 items that cover daily activities and a visual analogue scale (VAS) for assessing pain. Furthermore, five VASs are included, assessing interference with daily activities from gastrointestinal symptoms, lung symptoms, Raynaud's phenomenon, digital ulcers, and overall disease severity. The English version of SSc HAQ has demonstrated psychometric properties in SSc (27) and it has also been validated in Swedish among patients with SSc (28).

The Multidimensional Assessment of Fatigue (MAF), with 16 items, was used to evaluate fatigue. The score ranges from 1 to 50 and higher scores signify greater fatigue. The MAF in Swedish has been validated in SSc (29).

The Patient Health Questionnaire-8 (PHQ-8) was included to assess symptoms of depression. Scores can range from 0 to 24 and higher scores indicate more depressive symptoms (30). The PHQ-8 in Swedish has been validated for individuals with SSc (31).

The RAND 36-item (RAND-36) Health Survey assessing HRQoL was included. The RAND-36 items are divided into eight subscales: physical function, physical role function, bodily pain, general health, vitality, social function, emotional role function, and mental health. Higher scores (score range 0–100) indicate greater HRQoL; for example, a higher score on bodily pain means less pain. The RAND-36 is comparable with the Medical Outcomes Study 36-item Short-Form Health Survey (SF-36) (32), which has been validated in SSc (33, 34).

Table 1. Characteristics of individuals with systemic sclerosis (SSc).

	Content validity (n = 11)*	Construct validity, reliability, floor/ceiling effects (n = 104)†
<b>Sociodemographic data</b>		
Gender, female	10 (91)	87 (84)
Age (years)	60 (48–68)	62 (51–70)
Civil status		
Married or living together	8 (73)	76 (73)
Single or other	3 (27)	28 (27)
Educational level		
College or university	5 (46)	56 (55)
High school	5 (46)	32 (31)
Vocational school or other education	1 (9)	3 (3)
Elementary school	0 (0)	11 (11)
Professional status		
Working full or part time	6 (55)	39 (38)
Student or unemployed	0 (0)	1 (1)
Sick listed full or part time	1 (9)	14 (14)
Early retirement full or part time	3 (27)	13 (13)
Retired	3 (27)	45 (44)
<b>Disease-related variables</b>		
Disease duration‡ (years)	11 (6–18)	8 (5–15)
Limited/diffuse cutaneous SSc	7 (64)/4 (36)	82 (79)/22 (21)
mRSS, score 0–51	14 (6–26)	2 (0–4)
MSS, score 0/1/2/3/4§		
Peripheral vascular	0/6/3/2/0	1 (1–2)
Lung	1/1/6/2/1	2 (2–3)
Heart	6/4/0/0/0	0 (0–1)¶
Kidney	11/0/0/0/0	0 (0–0)
<b>Patient-reported outcome measures</b>		
SSc HAQ, score 0–3	Not assessed	
HAQ-DI		0.38 (0.13–0.75)
HAQ VAS Pain**		0.64 (0.06–1.40)
SSc HAQ VAS**		
Gastrointestinal symptoms		0.16 (0.02–1.06)
Lung symptoms		0.14 (0.02–0.96)
Raynaud's phenomenon		0.56 (0.11–1.28)
Digital ulcers		0.02 (0.00–0.33)
Overall disease severity		0.72 (0.22–1.40)
MAF, score 1–50		23.9 (15.6–33.9)
PHQ-8, score 0–24		4 (2–9)
RAND-36, score 0–100**		
Physical function		70 (50–85)
Physical role function		25 (0–100)
Bodily pain		78 (53–90)
General health		45 (35–65)
Vitality		60 (40–75)
Social function		75 (63–100)
Emotional role function		100 (33–100)
Mental health		80 (64–92)

Data are shown as n (%) or median (interquartile range), unless otherwise indicated.

\* Patients from one centre, not included in the test of construct validity, reliability, floor/ceiling effects; † patients from two centres, n = 35, n = 69; ‡ disease duration refers to the time from the first non-Raynaud's symptom; § numbers; median (interquartile range).

|| One or two missing values in the n = 104 sample; ¶ one missing value; \*\* three to seven missing values.

mRSS, modified Rodnan Skin Score; MSS, Medsger Severity Scale; SSc HAQ, Scleroderma Health Assessment Questionnaire; HAQ-DI, Health Assessment Questionnaire Disability Index; VAS, visual analogue scale (VAS is 15 cm; the value of the VAS is multiplied by 0.2 to attain a score from 0 to 3); MAF, Multidimensional Assessment of Fatigue; PHQ-8, Patient Health Questionnaire-8; RAND-36, RAND 36-item Health Survey.

### Translation of the SEMCD into Swedish

The translation of the SEMCD into Swedish was performed in several steps using a well-accepted method with some adjustments (35). (i) The English original of the SEMCD was translated into Swedish by

a professional translator native in the Swedish language. The translation was permitted by the original developer (Kate Lorig, personal communication, 2017). (ii) The translation from the English original version into Swedish was compared, by the research team, with a Swedish

Table 2. Characteristics of health professionals.

	Content validity (n = 10)
Gender, female	8 (80)
Age (years)	56 (42–63)
Years in the profession*	21 (12.3–32.3)
Years working within rheumatology	11 (4.8–19.5)
Years working with patients with SSc	5.5 (3.5–15.0)

Data are shown as n (%) or median (interquartile range).

\* Two of each profession – nurses, occupational therapists, physicians, physiotherapists, and social workers – were recruited from two centres.

SSc, systemic sclerosis.

version of the SEMCD for transplantation surgery (36). The translation procedure of the SEMCD for transplantation surgery has not been described; therefore, an independent forward translation was performed in our study. (iii) The comparison of the Swedish version for transplantation surgery and the Swedish translation performed in our study resulted in adjustments of wording to develop the Swedish version of the SEMCD for SSc. An example of an adjustment concerned the English expression ‘needed to manage your health condition so as to reduce your need to see a doctor’ (item 5), which was changed to read ‘... need for healthcare and to see a doctor’. The addition of the word ‘healthcare’ was found to be more relevant in the Swedish context because patients can contact healthcare professionals (e.g. nurses) without first seeing a doctor. This was in line with the Swedish version of the SEMCD for transplantation surgery. (iv) Finally, the Swedish version of the SEMCD for SSc was back-translated into English and compared with the English original, which resulted in further minor changes in wording. The first Swedish version of the SEMCD for SSc was then evaluated for content validity.

### Content validity and linguistic adjustments

To assess the content validity of the first Swedish version of the SEMCD, a semi-structured interview guide was developed, tested, and refined in a pilot interview with one HP. Thereafter, 11 patients with SSc and 10 HPs participated in individual interviews (22). Examples of interview questions are: ‘What do you think about the comprehensibility?’, ‘Are any items difficult to understand?’, ‘How do you experience the introduction and response set?’, ‘Do the items cover relevant aspects of self-efficacy in SSc?’, ‘Are there any items you want to include/exclude?’, and ‘How do you experience the questionnaire generally?’ Follow-up questions were also used. The patients completed the first Swedish version of the SEMCD, before the interviews, and HPs read and reflected upon the questionnaire based on their experiences of patients with SSc.

The interviews (by MM) were sound-recorded, transcribed verbatim, and analysed by qualitative deductive content analysis (37). The text was divided into meaning units, coded, and sorted with respect to the domains: comprehensibility, relevance, and comprehensiveness (22). The content analysis was completed by the first author in consultation with the last author.

As a result of the interviews, changes in wording of the first Swedish version of the SEMCD were made by the research team (see Results, Content validity and linguistic adjustments). Two patient research partners commented on the Swedish version of the questionnaire. A professional translator conducted a back-translation of the adapted version into English that was then compared with the English original and resulted in minor adjustments in wording of the final Swedish version of the SEMCD for individuals with SSc (SEMCD-Swe; Supplementary file).

### Construct validity, aspects of reliability, and floor and ceiling effects

The SEMCD-Swe was tested for construct validity, internal consistency, test–retest reliability, and floor and ceiling effects in 104 patients with SSc. Test–retest reliability was assessed by patients completing the SEMCD-Swe on two separate occasions.

### Statistical analysis

Construct validity was evaluated through confirmatory factor analysis (CFA). A single-factor structure was expected based on a previous study in SSc (20). The data were ordinal; thus, a CFA with diagonally weighted least squares and robust standard errors was conducted. In addition, a second CFA was performed with a modification based on an assessment of modification indices and from previous findings (20), to evaluate whether model fit would be improved by identifying a pair of items for which the error estimate was free to covary. The fit of the model was assessed by the chi-squared test, comparative fit index (CFI), Tucker–Lewis index (TLI), and standardized root mean square residual (SRMR). The following cut-off values were considered as an indication of sufficient model fit: CFI and TLI > 0.95 and SRMR < 0.08 (38). The construct validity was also evaluated using Spearman’s rank correlation coefficient ( $r_s$ ). Correlations were interpreted as follows: 0 = none, 0.1–0.3 = weak, 0.4–0.6 = moderate, 0.7–0.9 = strong, and 1.0 = perfect (39). From previously reported results of the SEMCD scale in SSc (20) and clinical rationale, we hypothesized for convergent validity (22) that the total score of the SEMCD-Swe would have at least a moderate correlation with the SSc HAQ, MAF, PHQ-8, and RAND-36. For divergent validity (40), weak correlations were



hypothesized between the SEMCD-Swe and disease duration, the mRSS, and the MSS. Thus, we expected higher correlations between the SEMCD-Swe and self-reports than between the SEMCD-Swe and physician reports.

Internal consistency was analysed using Cronbach's alpha coefficient, and an alpha coefficient  $\geq 0.70$  was interpreted as sufficient (38). In addition, corrected item-to-total correlation was assessed, and item correlations  $> 0.30$  were interpreted as good (41).

The test-retest reliability was analysed with the sign test to evaluate whether there were any significant differences between test occasions for the total score and each item. The total score was also assessed using the intraclass correlation coefficient (ICC) with a two-way mixed model and absolute agreement (42). An ICC  $\geq 0.70$  was evaluated as sufficient (38). The items in the SEMCD-Swe were evaluated by weighted kappa with quadric weights (40). Kappa was interpreted as follows:  $< 0.00$  = poor,  $0.00$ – $0.20$  = slight,  $0.21$ – $0.40$  = fair,  $0.41$ – $0.60$  = moderate,  $0.61$ – $0.80$  = substantial, and  $0.81$ – $1.00$  = almost perfect (43).

Any floor and ceiling effects were defined as cases in which  $> 15\%$  of the patients achieved the lowest or highest possible total score on the SEMCD-Swe (44).

The level of significance was specified at  $p \leq 0.05$ . Statistical analyses were performed using SPSS version 26 and the R-packages vcd and lavaan for the kappa and CFA.

## Results

### Participants

Of the total 115 patients involved ( $n = 11$  for content validity,  $n = 104$  for psychometric evaluation), the majority had lcSSc and were women. The median MSS scores indicated mild peripheral vascular disease severity and normal heart and kidney scores (Table 1). Patients in the assessment of content validity had a median mRSS value of 14 and moderate lung severity, and patients in the psychometric analyses had a median mRSS value of 2 and mild lung severity. Characteristics of HPs participating in the assessment of content validity are described in Table 2.

### Content validity and linguistic adjustments

Overall, patients and HPs experienced the first Swedish version of the SEMCD to be reasonable to understand, and that items were relevant and covered important aspects of self-efficacy in managing SSc (Table 3). However, some changes in words and expressions were made. The first sentence in the introduction to the questionnaire was deleted to avoid misunderstandings in the Swedish language. A clarification of the response set was added. To ease the understanding,

the translation of the English expression 'Emotional distress' in item 3 was further adjusted and item 5 was shortened. Item 6 was clarified to avoid the possible misunderstanding that medication was not necessary. In addition, as a result of comments made by patient research partners, the translation process, and discussions among the research team, some further changes were made. For example, the words 'your disease', 'your health condition', and 'your illness' were translated into 'your disease condition' in order to use the same term consistently.

### Construct validity

The initial CFA had an insufficient model fit for a single-factor structure with fit indicators: chi-square [9] = 117.45,  $p < 0.001$ , CFI = 0.87, TIL = 0.79, and SRMR = 0.09. The highest modification index was found for adding a covariance term between items 5 and 6. Thus, a second CFA was performed in which the error terms of items 5 and 6 were free to covary, consistent with the previous SEMCD validation (20). The model fit improved, and a sufficient fitting model was obtained with fitting indicators: chi-squared [8] = 21.39,  $p = 0.006$ , CFI = 0.98, TIL = 0.97, and SRMR = 0.04.

Strong correlations between the SEMCD-Swe and vitality (RAND-36) and symptoms of depression (PHQ-8) were found (Table 4). Moderate correlations were found between the SEMCD-Swe and pain (HAQ VAS, RAND-36), fatigue (MAF), disability (HAQ-DI), and disease interference with daily activities (SSc HAQ VAS), in addition to other aspects of physical and mental HRQoL (RAND-36). Weak correlations between the SEMCD-Swe and skin involvement (mRSS), and disease severity of the organ systems of peripheral vascular, lung, and kidney (MSS) were found (Table 4); however, only the relation between the SEMCD-Swe and lungs was significant. No correlations were found between the SEMCD-Swe and disease duration and heart involvement (MSS).

### Internal consistency, test-retest reliability, and floor and ceiling effects

Cronbach's alpha was 0.85, and corrected item-to-total correlation ranged from 0.50 (item 5) to 0.69 (items 1 and 3). Of the 104 patients who completed the SEMCD-Swe at baseline, 91% completed it a second time (retest), with a mean of 11 (sd  $\pm 7.0$ ) days between the two tests. No significant differences between test occasions on the total scores ( $p = 0.39$ ) or on the items ( $p = 0.30$ – $0.90$ ) were found (Table 5). The ICC for the total score was 0.82, and the weighted kappa for the items had a median of 0.71. The SEMCD-Swe median score at baseline was 6.9 [interquartile range (IQR) 5.5–8.3, min–max 2.0–10.0] and at retest, the median value

Table 3. Content validity of the first Swedish version of the Self-Efficacy for Managing Chronic Disease scale for individuals with systemic sclerosis (SSc).

Domain (22)	Results from the analysis of interviews of patients with SSc (patients) and healthcare professionals (HPs), and examples of quotes
Comprehensibility	<p>Overall, the introduction, response set, and items were described as reasonable to understand. However, concerning the introduction, difficulties were expressed in how to understand what activities were in focus in the expression 'certain activities'. The response set was experienced as extensive and among patients the anchor words at each end of the scale could be interpreted as a response. In item 4, it could be difficult to understand which the 'other symptoms or health problems' were. Among patients, it was expressed as challenging to distinguish the similarly worded items 1–4. Items were extensively worded; in particular, item 5 was experienced as extensively worded and could therefore be difficult to understand. Further, it was expressed among patients that item 6 suggested that medication was not necessary. HPs wondered how patients would interpret items 6 and 5. Despite items being understandable, it could be difficult to complete them, for example because items were experienced as indirect when asking 'How confident are you ...?' and not what the person could actually do. Among patients, it was also expressed as difficult to estimate whether the interference with the things you want to do (items 1–4) was caused by the disease, or by other things such as insufficient motivation or ageing.</p> <p>'It was not difficult to understand [the items], but to answer them was very difficult, for example which activity to think about [when it comes to the things you want to do] because it varies among different activities' (Patient 7)</p> <p>'How confident are you at the present time that you can do what is described ... and also regularly ... what does it mean, regularly? ... It will also be difficult to answer ... when that particular word [regularly] ... is included' (HP 8)</p>
Relevance	<p>Overall, the items were experienced as relevant, especially as they covered common symptoms in SSc and self-management which were seen as important. Thus, generally, no items were suggested to be removed. However, patients who interpreted item 6 as a suggestion that medication was not necessary suggested removal of this item. Reducing the need for healthcare and to see a doctor (item 5), especially in severe illness, was not experienced as possible. Further, when reading item 5, it was expressed among HPs that healthcare should be available for the patients' needs. Both patients and HPs described that items in the questionnaire might be more challenging to complete in recent disease onset due to limitations in experiences in managing the disease. HPs expressed that item 5 might be especially difficult. Furthermore, items could lead to thoughts about the future, and HPs considered that a newly diagnosed patient might be worried. Among patients, it was expressed that in a more severe disease with greater limitations, items would perhaps be more relevant and less demanding to complete. It was also expressed that the absence of a health problem, such as emotional distress, made item 3 easy to complete.</p> <p>'When I read it [the items] I recognized ... it is my illness, it is exactly my problems that I have experienced all my life' (Patient 2)</p> <p>'I think that they [items 5 and 6] overlap each other ... so you can in some way put them together' (HP 8)</p>
Comprehensiveness	<p>Overall, the items were experienced as comprehensive enough and additional items were not generally suggested to be included. However, among patients, it was suggested to add an item covering confidence in finding trustworthy advice and support to manage the disease. HPs suggested adding items covering confidence in managing specific activities, such as social relationships and work life, housework, leisure-time activity, and physical activity, and adding items of confidence in making adjustments and changes in life goals. Furthermore, HPs suggested adding confidence in managing disease-specific symptoms, such as temperature issues, breathing problems, skin involvement, joint mobility, and gastrointestinal problems. In addition, HPs expressed that the questionnaire did not capture the strategies that patients used while managing the disease.</p> <p>'I think it [the items] actually took in most of it ... it took a pretty big sweep over the most important thing' (Patient 9)</p> <p>'You could go into details about breathing and such, but ... it's so different what they [patients with SSc] have for organ involvement, so ... it might be difficult' (HP 9)</p>

HP, health professional.

was 7.2 (IQR 5.5–8.3, min–max 2.0–10.0). At baseline, no patients with the lowest possible total score were noted, and two patients (1.9%) scored the highest possible score.

## Discussion

The findings from this study indicate that the SEMCD-Swe is a valid and reliable measure to assess self-

efficacy for managing SSc. The results support the content and construct validity, internal consistency, and test–retest reliability of the SEMCD-Swe for individuals with SSc, and there were no floor and ceiling effects.

The content validity of the first Swedish version of the SEMCD was interpreted as satisfactory overall. However, some experiences with regard to the comprehensibility may be important to consider. Participants reported that it was challenging to estimate self-

Table 4. Construct validity of the Swedish version of the Self-Efficacy for Managing Chronic Disease scale (SEMCD-Swe) for individuals with systemic sclerosis, expressed as correlations with patient-reported outcome measures and disease variables, respectively.

	SEMCD-Swe	
	Spearman's rank correlation coefficient, $r_s^*$	p
<b>Patient-reported outcome measures</b>		
Disability, pain, and disease interference with daily activities SSc HAQ		
HAQ-DI	-0.55	< 0.001
HAQ VAS Pain‡	-0.63	< 0.001
SSc HAQ VAS‡		
Gastrointestinal symptoms	-0.38	< 0.001
Lung symptoms	-0.46	< 0.001
Raynaud's phenomenon	-0.36	< 0.001
Digital ulcers	-0.45	< 0.001
Overall disease severity	-0.60	< 0.001
Fatigue, MAF§	-0.59	< 0.001
Depressive symptoms, PHQ-8§	-0.67	< 0.001
Health-related quality of life, RAND-36‡		
Physical function	0.53	< 0.001
Physical role function	0.56	< 0.001
Bodily pain	0.63	< 0.001
General health	0.55	< 0.001
Vitality	0.65	< 0.001
Social function	0.63	< 0.001
Emotional role function	0.51	< 0.001
Mental health	0.46	< 0.001
<b>Disease variables</b>		
Disease duration†	-0.01	0.921
Skin involvement, mRSS	-0.14	0.160
Disease severity, MSS		
Peripheral vascular	-0.09	0.363
Lung	-0.23	0.018
Heart	0.03	0.757
Kidney§	0.10	0.298

\* When interpreting the calculated correlation coefficients (39), the values were rounded to one decimal place.

† Disease duration referred to the time from the first non-Raynaud's symptom.

‡ Three to seven missing values; § one or two missing values.

SSc HAQ, Scleroderma Health Assessment Questionnaire; HAQ-DI, Health Assessment Questionnaire Disability Index; VAS, visual analogue scale (VAS is 15 cm; the value of the VAS is multiplied by 0.2 to attain a score from 0 to 3); MAF, Multidimensional Assessment of Fatigue; PHQ-8, Patient Health Questionnaire-8; RAND-36, RAND 36-item Health Survey; mRSS, modified Rodnan Skin Score; MSS, Medsger Severity Scale.

efficacy, and suggested that it would have been easier to estimate capability. Nevertheless, self-efficacy is of interest to assess (10, 13), because it can influence a person's health behaviour, health status (11), affective tendencies, and view of the social environment (10). Another concern expressed was which activity to consider in relation to '... the things you want to do' (items 1–4). Indeed, self-efficacy is directed towards separate areas of functioning (10). PROMs may be used to stimulate dialogue between the patient and the clinician (45); thus, the SEMCD may be used to discuss self-efficacy in relation to the patient's goals and activities. Concerning relevance, respondents expressed that it was difficult to understand items 5 and 6: '... reduce your need for healthcare and to see a doctor ...' and '... do things other than just taking medication to reduce how much your illness affects your everyday life'. Healthcare was described as being needed and

ought to be at patients' service, and medications were considered unavoidable, especially in severe disease. Item 6 has been previously described by other authors as an example of a complex item (46). Regarding comprehensiveness, the inclusion of confidence in finding trustworthy advice and support to manage the disease was suggested. In the original chronic disease self-efficacy scales (10 scales, 33 items), an item covering confidence in obtaining information about the disease is included (18, 46). However, the SEMCD scale, which is restricted to six items, is less burdensome for patients to complete. Self-efficacy in managing common problems in SSc, such as temperature issues and breathing and gastrointestinal problems, was also suggested to be included in our study. Nevertheless, the SEMCD is applicable across different chronic diseases (18), thereby making it possible to compare self-efficacy among diseases (12). Suggestions for additional SSc-



Table 5. Test–retest reliability of the Swedish version of the Self-Efficacy for Managing Chronic Disease scale (SEMCD-Swe) for individuals with systemic sclerosis (SSc).

We would like to know how confident you are in doing certain activities. For each of the following questions, please choose the number that corresponds to your confidence that you can do the tasks regularly at the present time. <i>Vänligen besvara varje fråga genom att ringa in den siffra som överensstämmer med hur säker du, i nuläget, känner dig på att du regelbundet kan göra det frågorna nedan handlar om. Skalan går från 1 till 10, där siffran 1 motsvarar 'Inte alls säker' och siffran 10 motsvarar 'Helt säker'.</i>	Test 1–10 scores Median (IQR) (n = 104)	Retest 1–10 scores Median (IQR) (n = 95)	Weighted kappa (n = 95)	Sign test p (n = 95)
1. How confident are you that you can keep the fatigue caused by your disease from interfering with the things you want to do? <i>Hur säker är du på att du kan göra det du vill utan att begränsas av den trötthet som orsakas av ditt sjukdomstillstånd?</i>	7 (4–8)	7 (4–9)	0.78	0.53
2. How confident are you that you can keep the physical discomfort or pain of your disease from interfering with the things you want to do? <i>Hur säker är du på att du kan göra det du vill utan att begränsas av kroppsliga obehag eller smärta som orsakas av ditt sjukdomstillstånd?</i>	7 (4–8)	7 (4–8)	0.69	0.90
3. How confident are you that you can keep the emotional distress caused by your disease from interfering with the things you want to do? <i>Hur säker är du på att du kan göra det du vill utan att begränsas av känslomässig påfrestning som orsakas av ditt sjukdomstillstånd?</i>	8 (6–10)	8 (5–9)	0.73	0.30
4. How confident are you that you can keep any other symptoms or health problems you have from interfering with the things you want to do? <i>Hur säker är du på att du kan göra det du vill utan att begränsas av andra symtom eller hälsoproblem?</i>	7 (5–8.8)	7 (5–9)	0.53	0.46
5. How confident are you that you can do the different tasks and activities needed to manage your health condition so as to reduce your need to see a doctor? <i>Hur säker är du på att du själv kan göra det som behövs för att hantera ditt sjukdomstillstånd så att du kan minska ditt behov av sjukvård?</i>	7.5 (5–9)	8 (5–9)	0.60	0.70
6. How confident are you that you can do things other than just taking medication to reduce how much your illness affects your everyday life? <i>Hur säker är du på att du själv kan göra annat, utöver att ta din medicin, för att minska ditt sjukdomstillstånds påverkan på dagliga livet?</i>	8 (6–9)	8 (6–9)	0.72*	0.90

The English version of the SEMCD (52) is used with kind permission from Professor Kate Lorig at Stanford University, USA (personal communication, June 2020), who also recommended to refer to reference (19). Professor Kate Lorig also permitted the translation into Swedish (personal communication, February 2017).

\* Response options 1 and 2 were combined in item 6 when calculating kappa owing to the lack of score 1 at the retest. IQR, interquartile range.

specific items could be considered in future studies if an SSc-specific measure were to be developed.

The evaluation of the construct validity of the SEMCD-Swe confirmed a single-factor structure, in line with previous findings in SSc (20) and other diseases (18). Construct validity was further supported by moderate or strong correlations between the SEMCD-Swe and pain, fatigue, depressive symptom, disability, disease interference with daily activities, and HRQoL. Similar associations were found for the SEMCD in English in SSc (20). Weak correlations were found between the SEMCD-Swe and skin involvement and several aspects of disease severity in our study, thus supporting divergent validity. The assessed organ systems showed median values of normal or mild disease severity, which could explain the weak correlations. Weak correlations between the SEMCD and disease duration and physician-rated disease severity have

been reported in other chronic conditions (47), and our results are in line with these findings.

The internal consistency expressed by Cronbach's alpha coefficient was sufficient (38) and corrected item-to-total correlations were good (41), as found by others (20). The test–retest reliability was sufficient for the total score and substantial for the majority of items, and no significant differences between test occasions were noted, suggesting stability between completion sessions of the SEMCD-Swe. The latter is a similar result to that reported in a chronic neurological disease (48). Self-efficacy is described as changeable and therefore attention should be paid to the time interval, which should be kept as short as possible in a test–retest procedure (49). In our study, the time interval was a mean of 11 days, which is similar to others (48), and is described as common when evaluating PROMs (40). The absence of floor and ceiling effects of the total

score suggests that the SEMCD-Swe can detect both improvements and deterioration in self-efficacy.

The total score of the SEMCD-Swe in our study was comparable to the study of the SEMCD in English in SSc (20). The participants in the study by Riehm et al (20) were similar in age, skin scores, and symptoms of depression and disability; however, it included 20% more patients with dcSSc.

Most patients in our study had the lcSSc subtype, which may present a study limitation. However, the proportion of lcSSc in our study is in line with the results from a previously published population-based report regarding SSc prevalence in Sweden (50), indicating that this is not a selection bias. In the test of content validity, the patients had, in absolute values, higher skin scores and more severe pulmonary involvement than patients in the evaluation of construct validity and reliability. Nevertheless, disease subtypes do not seem to be associated with the SEMCD (51). Another limitation was that the SEMCD-Swe was not compared with another self-efficacy PROM when assessing construct validity, but this type of assessment was not possible owing to the lack of validation in Swedish of any other PROM assessing self-efficacy in SSc. The Patient-Reported Outcome Measurement Information System Self-efficacy for managing chronic conditions measures has demonstrated moderate to strong correlations with the SEMCD among patients with chronic conditions, including arthritis (47).

## Conclusion

The results from this study indicate that SEMCD-Swe is valid and reliable for assessing self-efficacy for managing SSc among patients with this disease. Our results support construct validity, internal consistency, and floor and ceiling effects, and are in line with previous findings using the English version of the SEMCD in SSc. In addition, the content validity and test–retest reliability of the SEMCD were established, which, to our knowledge, have not been evaluated previously in SSc. However, its responsiveness needs to be tested. As healthcare professionals struggle to support patients with SSc with respect to self-management, the SEMCD-Swe could be used to identify the level of self-efficacy and inform interventions.

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## Disclosure statement

No potential conflict of interest was reported by the authors.

## Supplementary material

Supplemental data for this article can be accessed [here](#).

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