# Addressing patient health care demands in systemic sclerosis: pre-post assessment of a psycho-educational group programme

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## ABSTRACT

**Objective.** *Patients diagnosed with systemic sclerosis (SSc) report a high need for education and support. To address these needs, a short, group-based psycho-educational programme for patients with SSc was developed and evaluated.*

**Methods.** *A pre-post test design was utilised. Participants completed questionnaires on physical and psychological functioning. Furthermore, patients were asked to evaluate the content of the programme by questionnaire.*

**Results.** *Data from 41 patients were available for analysis. Patients reported less helplessness after the intervention, and higher acceptance of their limitations. However, no difference in depressed mood and physical functioning was observed. Patients reported high satisfaction with the content of the programme.*

**Conclusion.** *Despite the limited changes in psychological and physical functioning, this psycho-educational programme addresses patients' needs reported in previous study and therefore contributes to the improvement of care for patients with SSc.*

## Introduction

Systemic sclerosis (SSc, scleroderma) is a rare multisystemic connective tissue disease of unknown etiology, characterised by vascular abnormalities and fibrosis. The disease affects many areas of life resulting in high levels of disease burden in the individual patient (1). The hallmark feature of SSc is thickening of the skin (2) caused by the fibrosis of connective tissue. The fibrotic process can affect internal organs and leads to morbidity and decreased life expectancy in the majority of the patients (2). Although advances in medical treatment have been made, medical interventions as yet have a limited effect on disease progression and symptom manifestation (3). In most patients, physical functioning is impaired (4, 5) and patients report high levels of pain, fatigue and impaired health-related quality of life (6, 7). In addition to these physical impairments and symptoms, the disease often results in psychological problems as well (8), including low appearance self esteem (9-11), problems adjusting to the disease (12) and increased levels of anxiety (13). Not surprisingly, the prevalence of depressive symptoms in SSc is high, with 36 to 65% of patients scoring above a cut-off threshold on self-reported questionnaires (14, 15).

Apart from a high need for information about the condition and its treatment, high unmet needs of education and support about anxiety and stress, fear of the future, coping with symptoms, fatigue, feeling down, and change in appearance have been reported (16, 17). Therefore, the urgency to develop educational and psycho-educational interventions in patients with SSc is increasingly recognised (10, 18).

As yet, little is known about the effect of psycho-educational interventions in SSc. In other rheumatic conditions, in particular rheumatoid arthritis (RA), psycho-educational interventions have been shown to be successful on functional disability, patient global assessment, psychological status and depression (19). One could expect a psycho-educational intervention to have similar effects in SSc as well.

Only three published studies addressed interventions targeting psycho-social needs (20-22). In two studies an interdisciplinary group education programme was described, whereas the third study described a cognitive-behavioural self help programme for scleroderma, consisting of 2 in-person sessions and 5 telephone sessions with a psychologist and home assignments.

The efficacy of a psycho educational intervention in SSc was reported in only one study, including six patients (20). Therefore, the current study was conducted to determine changes between pre- and post treatment in a larger sample of patients participating in a psycho-educational intervention for SSc.

The short intervention under study was developed with the aims to increase patients' knowledge about the disease and its treatment, to familiarise patients with multidisciplinary treatment options and to facilitate patient interaction.

The aims of this pre-post test study were to study the effects of the intervention on disease related cognitions, depressed mood and physical functioning and to evaluate the patients' satisfaction with the programme.

## Materials and methods

*Development of the programme*

The intervention was based on one of the previously developed programmes (21), but tailored to the setting and results of earlier research in our hospitals. In a previous study, patients' needs for education and support were assessed in all patients with a definitive diagnosis of SSc according to the preliminary ARA-classification criteria (23) under treatment in the rheumatology wards of the Sint Maartenskliniek and Radboud University Medical Center in Nijmegen, the Netherlands (16). Patients rated their need for education and training of 16 potential relevant topics at a 4-point Likert scale ranging from 1 (not al all) to 4 (very much). Results of this study revealed that many patients reported a need for professional support; 78.6% of the patients indicated that they 'much' or 'very much' needed education or support (score 3 or 4) on at least one of the topics. The most frequently reported topics were information about the disease, information on medication, coping with pain, perception of the future, changes in appearance, information on social services, coping with stress, ADL scheduling and planning, interpreting signals of pain and fatigue, and alternative medicine, respectively.

The results of this questionnaire study and the organisation of the programme were discussed in 3 individual interviews and a focus group including 6 patients. These patients indicated that they preferred a group based intervention of short duration, accessible for all patients, regardless of disease duration or physical status. They also suggested that the partner should be present when information about the disease is provided and that the programme should involve active elements like physical exercises. Finally, patients suggested that the sessions of the programme should address broadly defined topics as determined in an earlier study (16) and that interactive discussions should be encouraged. On the basis of these results, a multidisciplinary, group based psycho-educational programme was developed.

*Content of the programme*

Groups consist of 6 to 10 patients. The programme consists of modules of 1.5 hours each, covering 13 different topics, scheduled over three weekends. Patients are invited to bring their partner or a significant other person at the first day (Table III).

For each topic, a short protocol was written to give structure to the intervention. At the start of each session, the participating patients' questions and problems related to that topic are individually assessed to determine the exact content of the session.

The programme consists of the following broad topics: goal setting and evaluation (social worker), education about disease characteristics, diagnosis and treatment (rheumatologist), education about joint protection and energy conservation (occupational therapist), discussing psychosocial aspects of the disease (psychologist) and education about the benefits of exercise (physical therapist). Furthermore, an introduction lesson of Tai Chi was provided to give patients the opportunity to practice and experience this form of low intensity exercise. The detailed programme is available on request by the first author.

*Patients and procedure*

Patients were informed about the intervention through publications in the magazine of the patient organisation and leaflets distributed by their attending rheumatologists. Patients with a diagnosis of SSc for more than one year were able to subscribe for the programme, or could be referred by their rheumatologist of the Sint Maartenskliniek and the Radboud University Medical Centre. It was chosen to include patients with a diagnosis of at least one year, to give patients the opportunity to acclimate to their diagnosis before participation. After subscription, an intake assessment took place with a social worker, nurse and psychologist. Information was given about the programme and its evaluation. The psychologist examined whether there were dominating psychopathological problems or whether patients had serious concerns about meeting other patients that made participation in a group impossible. The intervention was scheduled over 3 weekends. The measurements took place before, 6 weeks after the intervention and 6 months post-intervention. Between the three consecutive intervention weekends, there were no measurement occasions.

Patient gave their oral consent. In the Netherlands, no approval from the medic-ethical review board is required for studies with a pre-post test design utilising questionnaires.

*Measures*

*Demographics*. The following demographics were assessed: age, sex, disease duration, marital status and employment.

*Physical functioning* was assessed with the Dutch version of the Scleroderma Health Assessment Questionnaire (SHAQ) (24), consisting of the Health Assessment Questionnaire (HAQ) (25) and 6 Visual Analogue Scales measuring subjective severity of disease symptoms. A VAS was added for fatigue, because this was rated as an important problem in previous studies (7, 9). The Disability Index score consists of 20 items, measuring 8 dimensions of functioning ranging from 0 (best function) to 3 (worst function). The mean of these scores can be calculated as an indicator of overall physical functioning (HAQ-DI). The HAQ was originally developed for use in Rheumatoid

Arthritis (26) but has recently demonstrated good reliability and validity in patients with SSc (24, 27).

*Psychological mood* was measured with the Depressed Mood subscale of the Impact of Rheumatic Diseases on General Health and Lifestyle (IRGL) (28), a Dutch questionnaire that is frequently used in patients with rheumatic conditions. Participants rate the extent to which they experienced six mood states (depressed, gloomy, disheartened, low spirited, disconsolate and sad) during the last week, using a 5-point Likert scale ranging from 0 (not at all) to 4 (a lot). The six items are summed to calculate the depressed mood scale. Higher scores at this scale depict higher levels of depressed mood. A score >4 on the Depressed Mood subscale of the IRGL represent clinical or subclinical depression.

*Illness cognitions* were measured using the Illness Cognitions Questionnaire (ICQ) (29) and Acceptance Limitations Scale (ALS) (30). The ICQ is an 18-item questionnaire measuring three generic illness cognitions: helplessness, acceptance and disease benefits. Participants rate the extent to which they agree with the statements on a 4-point Likert scale, ranging from 1 (not at all) to 4 (completely). Higher scores at subscales reflect higher levels of agreement with that generic illness cognition. The scale has excellent construct and internal validity (29). In this study we used the subscales acceptance and helplessness.

The Acceptance Limitations Scale (ALS) measures acceptance of limitations perceived by the patient. The ALS is a 10-item questionnaire. Patients rate their agreement with the statements (*e.g.* 'The limitations of my disease are annoying') on a 4-point Likert scale ranging from 1 (totally disagree) to 4 (totally agree). The questionnaire has shown good internal consistency (30).

*Coping* was assessed using the active coping (7 items) and avoidant coping (8 items) subscales of the Utrechtse Coping List (UCL) (31). All items are rated at a 4- point Likert scale ranging from 1 (seldom or never) to 4 (very often). Higher scores depict more use of the particular coping style. The UCL has shown to be valid and reliable (31).

The IRGL, ICQ, ALS and UCL have not been validated in SSc, and no information is available about validity and sensitivity to change in SSc.

*Patient satisfaction*. A self-constructed single-item question was used to measure the usefulness of each distinct module. Three answers were possible: very useful, rather useful, not useful. In addition, a single item was used to ask patients about their experience of meeting other patients with SSc (What was your experience meeting other patients?). Five answer categories were available: very pleasant, pleasant, neutral, unpleasant, very unpleasant. Furthermore, for each distinct profession, the question was asked how well their individual questions were answered (answer categories: good, reasonable, bad).

*Statistical analysis*

Descriptive statistics are provided as mean and standard deviation (SD) for continuous variables and percentages for categorical variables.

Missing data were imputed using the last observation carry forward (LOCF) method.

To test whether cognitions changed between pre- and post-treatment assessment, a repeated measures MANOVA was conducted with acceptance, helplessness and acceptance of limitations as dependent variables, and time (3) as within-subject factor. Furthermore, repeated measures ANOVAs and post-hoc tests were conducted on each cognition separately. A repeated measures ANOVA was conducted with depressed mood (IRGL) as dependent variable and time (3) as within-subject factor to test the hypothesis that depressive mood changed between pre- and post-treatment assessment. Furthermore, repeated measures ANOVAs were conducted with physical functioning (HAQ-DI), pain (VAS) and fatigue (VAS) as dependent variables respectively, and time (3) as within-subject factor Significance levels were set at $p<0.05$. In line with our specified hypothesis, all $p$-values reported are one-tailed. Effect size (Cohen's d) (32) was calculated for each variable. Cohen's d could be interpreted as small (d = 0.2), medium (d = 0.5) or large (d = 0.8).

All analyses were repeated with data of completers only. Since both methods revealed the same results overall, only the analyses using the LOCF method are presented. The Statistical Package for the Social Sciences (SPSS), Windows version 15.0 was used.

## Results

*Participants*

Data were gathered between June 2006 and May 2009. In total, 46 patients attended an intake. Of these patients, three were advised not to participate as they suffered from serious emotional and psychopathological problems that were unrelated to SSc. Furthermore, one participant dropped out because of hospitalisation after completing the first questionnaire and was excluded from analysis. One participant was excluded from analysis as a result of structural outliers in data (deviation of ≥1.5 IQR at more than 40% of the relevant measures). This patient died as a result of progression of SSc shortly after completing the last questionnaire. So, data from 41 patients of 6 groups were available for analysis. Patient satisfaction questionnaires were available from 36 participants.

*Demographics*

The majority of the participants were married woman of middle age, and one-third of the patients was employed at baseline (34%) (Table I). Thirteen patients had a diagnosis of dSSc (31.7%), 26 (63.4%) patients had lSSc and of 2 patients, disease type was unknown at baseline (4.9%).

**Table I.** Patient characteristics at baseline (n=41).

| | |
|---|---|
| Mean age in years | 52.8 (SD=12.2, range = 23–76) |
| Mean disease duration in years | 9.5 (SD=10.5, range = 1–62) |
| Female | 83% |
| Patients with limited SSc | 63% |
| Currently employed | 34% |
| Marital status | |
| Married | 73% |
| Never married | 17% |
| Divorced | 5% |
| Widowed | 5% |

**Table II.** Results of the repeated measures ANOVAs for cognitions and depressed mood (n=41)[1].

| | Mean (SD) Pre | $Mean_{diff}$ [95% CI] Post-Pre | ES* | $Mean_{diff}$ [95% CI] FU-Pre | ES* | *p*-value** |
|---|---|---|---|---|---|---|
| Acceptance (ICQ[a]) | 15.7 (3.8) | 0.53 [-0.43, 1.49] | 0.13 | 0.75 [-0.14, 1.65] | 0.21 | 0.13 |
| Helplessness (ICQ[a]) | 13.1 (4.2) | -1.24 [-2.27, -0.22] | -0.32 | -1.05 [-2.03, -0.08] | -0.26 | 0.02 |
| Acceptance of limitations (ALS[b]) | 29.0 (4.9) | -1.60 [-3.22, 0.02] | -0.28 | -2.24 [-3.73, -0.75] | -0.44 | 0.01 |
| Depressive mood (IRGL[c]) | 4.2 (4.6) | 0.13 [-1.07, 1.32] | 0.02 | -.05 [-1.47, 1.37] | -0.02 | 0.48 |
| Physical functioning (HAQ-DI[d]) | 0.89 (0.6) | 0.03 [- 0.07, 0.14] | -0.06 | -.05 [-0.06, 17] | -0.09 | 0.52 |
| Pain (VAS[e]) | 30.2 (25.0) | 2.41 [-4.5, 9.3] | 0.10 | 2.97 [-3.2, 9.14] | 0.13 | 0.58 |
| Fatigue (VAS[e]) | 44.3 (23.1) | -.40 [-7.3, 6.5] | 0.02 | 1.28 [-3.9, 6.4] | 0.05 | 0.85 |

[1]The intervention was scheduled over 3 weekends. The measurements took place before, 6 weeks after the intervention and 6 months post-intervention. Between the three consecutive intervention weekends, there were no measurement occasions.
[a] ICQ: Illness Cognitions Questionnaire; [b]ALS: Acceptance Limitations Scale; [c] IRGL: Impact of Rheumatic Diseases on General Health and Lifestyle; [d] HAQ: Health Assessment Questionnaire; [e] VAS: Visual Analogue Scale.
*ES: $M_{post}$-$M_{pre}$ / $SD_{pooled}$ (Negative sign denotes improvement); ***p*-values reported: repeated measures ANOVA with time (3) as within-subject factor.

*Comparison of pre-, post and follow-up measures*

Table II shows mean scores on disease cognitions and depressed mood for each assessment.

A repeated measures MANOVA with time (3) as within-subject factor and acceptance, helplessness and acceptance of limitations as dependent variables revealed a trend in change of cognitions, $F(6,33)=1.74$, $p=0.07$.

Acceptance did not change significantly over time. Compared to baseline, average levels of helplessness were lower at post-treatment assessment, $F(1,40)=6.0$, $p=0.01$ and 6 months after the intervention, $F(1,40) = 4.7$, $p=0.02$. Acceptance of limitations scores decreased significantly between pre- and post-treatment assessment, $F(1,40) = 4.0$, $p=0.03$ and after 6 months, $F(1,40) = 9.2$, $p<0.01$. Because scores at this questionnaire are reversed, this decrease in average scores depicts an increase in acceptance of limitations. Effect sizes show that the improvement post-intervention as well as follow-up was of small magnitude for both helplessness (d = -0.32 and d = -0.26, respectively) and acceptance of limitations (d = -0.28 and d = -0.44, respectively).

Changes in depressive mood were assessed with a repeated measures ANOVA with time (3) as within-subject factor and depressive mood (IRGL) as dependent variable. Results revealed no change in depressive mood. Also, no changes in physical functioning (HAQ-DI, pain and fatigue) were found. Furthermore, there were no changes in coping (results not shown).

**Table III.** Usefulness (% of patient rating 'very useful' and 'rather useful') of the different topics.

| | % Very useful | % Rather useful |
|---|---|---|
| *General* | | |
| Goal setting | 83% | 17% |
| *Rheumatologist* | | |
| Characteristics of the disease | 89% | 11% |
| Diagnosis | 89% | 11% |
| Medical treatment | 86% | 14% |
| *Physical therapist* | | |
| Theoretical background | 83% | 17% |
| Exercises | 89% | 11% |
| Relaxation training | 75% | 25% |
| TaiChi | 49% | 36% |
| *Occupational therapist* | | |
| Practical aids | 89% | 11% |
| Individual questions | 92% | 8% |
| *Psychologist* | | |
| Psychosocial aspects of disease | 83% | 17% |
| Stress | 75% | 25% |
| Social aspects | 89% | 11% |

*Patient satisfaction*

Percentages on the usefulness of the different modules are displayed in Table III. Results reveal high patient satisfaction with the content of the programme (75–92%), except for the session on TaiChi (49%).

The majority (80%) of the patients evaluated meeting other patients as very pleasant. Only one patient judged meeting other patients as unpleasant. Satisfaction with the answers on questions put forward by the participants ranged from 79–100% for the different topics.

## Discussion

The results of our study revealed that a psycho-educational intervention results in small changes in two disease-related cognitions: patients reported more acceptance of disease-related limitations and less helplessness after the intervention. No changes were found in depressive symptoms, physical functioning and coping.

Remarkably, a discrepancy was found between change in acceptance of the disease and acceptance of limitations. Acceptance of the disease did not change between assessments, whereas acceptance of limitations improved. One possible explanation is that acceptance of the disease SSc is particularly hard to achieve because of the serious and possible life-threatening character of the disease. The disease might evoke abstract cognitions including worst case scenarios (*e.g.* early death), that are not easy to get to terms with. This

suggestion is supported by an earlier study showing that acceptance of the disease in patients with SSc is lower than acceptance in patients with RA (15). It could be argued that acceptance of consequences of the SSc in everyday life may be easier to achieve.

In contrast to the effects of psycho-education in RA (19), no effect of the intervention on depressed mood was observed. One explanation is that psycho-education in general, and the intervention we developed in particular, does not target depressed mood using psychological intervention techniques such as used in cognitive behavioural therapy. As a result, the intervention may be insufficient for patients with elevated levels of depressed mood in SSc.

Our results can be generalised to other populations of SSc patients. Characteristic of participants concerning physical or psychological functioning, including coping in our study did not differ from a cohort of SSc patients in a previous study (9). Therefore, it seems that the programme did not include patients with a specific physical or psychological profile.

To our knowledge, our study is the first evaluating the effects of a psycho-educational programme in a relatively large group of patients with SSc. However, the study is not without its limitations. Not having a comparison group limits the conclusions that can be made. As a result, the observed changes cannot be attributed to the intervention with absolute certainty. The lack of a control group in the present study makes it difficult to interpret and understand the observed changes. As yet, there are no data available on the stability of cognitions in usual care. Future intervention studies in patients with SSc should include a control group.

Another limitation of the study is that we did not assess all variables that might be positively effected by the intervention, like fear for the future (16, 17), use of non-pharmaceutical treatment options and knowledge about SSc.

Since this study reveals no changes in depressive mood, we suggest an alternative, more intensive intervention for patients with SSc suffering from depressed mood. As depressive mood is a common problem in SSc (14, 15), development of such an intervention is recommended. Due to the heterogeneity of the disease, an intervention targeting depression should preferably be individual. Cognitive-behavioural interventions have shown to be effective in other rheumatic conditions, like RA (33). Therefore, one would expect a cognitive-behavioural intervention to be effective in decreasing depressed mood in patients with SSc as well. Also, the present intervention could be adapted to improve outcome. Possibly, increasing the period between the weekends or including a booster weekend could help patients to incorporate the information in daily life.

In conclusion, although changes in psychological functioning were limited, this psycho-educational programme addresses patients' needs reported in previous studies (16, 17) and therefore contributes to improvement of care for patients with SSc.

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