

Taking Charge of Systemic Sclerosis: A Pilot Study to Assess the Effectiveness of an Internet Self-Management Program

JANET L. POOLE,¹ CINDY MENDELSON,¹ BETTY SKIPPER,¹ AND DINESH KHANNA²

Objective. To assess the effects of an internet self-management program for systemic sclerosis on self-efficacy, health efficacy, and management of care, pain, fatigue, functional ability, and depression.

Methods. Participants logged on to a password-protected web site and completed modules and learning activities at their own pace over 10 weeks. Participants were encouraged to log on to the discussion board, participate in an interactive component of the web site, and respond to questions posted for each module. Participants completed pre- and post-intervention questionnaires on perceived self-efficacy, health efficacy, ability to manage care, functional disability, depression, pain, and fatigue. They also completed an 8-question evaluation form regarding satisfaction with the web site, program content, discussion boards, and learning activities.

Results. Sixteen participants completed the study and postintervention measures. There were significant improvements in mean scores for ability to manage care (effect size [ES] 0.62, $P = 0.025$) and health efficacy (ES 0.72, $P = 0.012$), and significant decreases in fatigue (ES -0.55 , $P = 0.045$) and depression (ES -0.71 , $P = 0.013$). Self-efficacy improved, but not significantly. The evaluation of the program revealed mean scores ranging from 4.2 (web site was visually appealing) to 4.9 (information presented clearly) on a 5-point scale, where 5 is most satisfied.

Conclusion. These findings from this pilot study suggest that a self-management program delivered using an internet format can lead to statistically significant changes in health efficacy and management of care, fatigue, and depression. These results need to be confirmed with a larger randomized controlled trial with a longer followup period.

Introduction

People living with chronic conditions such as systemic sclerosis (SSc; scleroderma) must cope not only with the medical management of the disease, but also its effects on daily life activities. The disfigurement and disability caused by SSc is often severe, leading to stigmatization, self-isolation, and depression. There is no cure for SSc, and current therapeutics do little to alter its course. Therefore, the disease is often overwhelming for patients and their families because of the variable course and potential

for disability and morbidity. Because the prevalence is low, some states in the US do not have a chapter of the Scleroderma Foundation, support groups are frequently unavailable and, in many cases, persons with SSc may never have met someone with the same diagnosis (1–3). Consequently, persons with SSc are often emotionally and geographically isolated from sources of support and disease self-management education (3).

Education programs specifically for persons with SSc were developed in Sweden (4), the UK (5), and The Netherlands (6). However, all 3 programs were delivered using the traditional group format, which is dependent on people traveling to central locations. Furthermore, there may not be a sufficient number of people with SSc in a geographic area to justify an education program. Mail-delivered and internet versions have been developed for other chronic diseases, such as the Arthritis Self-Management Program and the Chronic Disease Self-Management Program, and have shown benefits similar to those achieved with the group format (7,8). The advantages of these versions are that they are available to anyone at any time of the year and in any community.

We previously developed a mail-delivered self-management program for SSc that included a workbook

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¹Janet L. Poole, PhD, OTR/L, Cindy Mendelson, PhD, RN, Betty Skipper, PhD: University of New Mexico, Albuquerque; ²Dinesh Khanna, MD, MSc: University of Michigan, Ann Arbor.

Address correspondence to Janet L. Poole, PhD, OTR/L, School of Medicine, University of New Mexico, MSC09 5240, Albuquerque, NM 87131-0001. E-mail: jpoole@salud.unm.edu.

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Significance & Innovations

- This pilot study is the first and only study to evaluate the effects of an internet self-management program for people with systemic sclerosis.
- The internet program is feasible and may be an effective method to reach people with systemic sclerosis who are emotionally and geographically isolated from sources of support and disease self-management education.

and exercise DVD (2,9). This program was shown to be effective in improving pain, depression, fatigue, and hand function, but the only significant improvement was in self-efficacy for pain (9). Participants were positive about the program, content, reading level, and exercise DVD. However, because the program did not have an interactive component, there was no interaction among the participants. Subsequently, the workbook was modified and converted to an interactive internet format. This article reports on a pilot study designed to evaluate the effectiveness of the interactive internet-based SSc self-management program.

Materials and methods

Study design and participants. The study used a pre- and posttest design and was in compliance with the Helsinki Declaration and approved by the University of New Mexico Institutional Review Board. Individuals with SSc were recruited from the Scleroderma Foundation web site and through a state chapter of the Scleroderma Foundation. Participants were included if they resided in the US, had been diagnosed with SSc, were age ≥ 18 years, possessed basic computer literacy and had access to a computer with internet and e-mail capabilities, had the ability to communicate in English, had moderate to severe pain (pain score of >3 on a 0–10 visual analog scale [VAS], where 10 = severe pain), had poor self-efficacy pain scores (score of <7 on a 0–10 VAS, where 10 = better self-efficacy for pain), and were willing to complete the study protocol. To prevent ceiling effects, the cutoff point for the pain VAS was no to minimal pain and for the self-efficacy pain VAS was good self-efficacy pain scores.

Intervention. A specialized web site was constructed for this study that translated the content from the self-management workbook into an internet format and incorporated a feedback form for participants to evaluate the self-management program. The final internet program had 10 modules, an exercise video, worksheets, and resources. The topics of the modules are listed in Supplementary Appendix A (available in the online version of this article at <http://onlinelibrary.wiley.com/doi/10.1002/acr.22192/abstract>). Each of the modules featured written material, learning activities/action plans, and/or homework and forms to apply strategies. Participants proceeded through the modules at their own pace and could read or listen to

the main content. Questions were posted on a discussion board for each module. Participants were notified when questions were posted.

Outcome measures. Demographic information was collected on age, sex, type of SSc (diffuse, limited, or overlap disease), length of time since disease onset, self-rated health (0–5 scale), education level, marital status, and ethnicity.

The Chronic Disease Self-Efficacy Scale (SE Scale) measured perceived self-efficacy to perform specific tasks or behaviors to cope with the consequences of chronic disease (10). The SE Scale has 33 items in categories related to self-efficacy: exercise, disease information, support, communication, disease management, chores, social/recreational activities, symptom management, and depression management. Items are scored on a scale ranging from 1–10, where 1 = not at all confident and 10 = totally confident. Higher scores indicate higher self-efficacy.

The Health Education Impact Questionnaire (heiQ) (11) was used to measure self-management knowledge and skills. The heiQ consists of 42 items in 8 domains: positive and active engagement in life, health-directed behavior, skill and technique acquisition, constructive attitudes and approaches, self-monitoring and insight, health service navigation, social integration and support, and emotional well-being. Items are scored on a 6-point Likert scale from 1–6, where 1 = strongly disagree and 6 = strongly agree. Higher scores indicate higher self-management and knowledge.

The Patient Activation Measure (PAM) (12) assessed confidence in self-management of one's chronic condition. The short form consists of 13 items, each scored from 1–4, where 1 = strongly disagree and 4 = strongly agree. Higher scores indicate more confidence and knowledge for managing the condition.

The Center for Epidemiologic Studies Depression Scale (CES-D) was used to measure depression (13). This 20-item self-report questionnaire assessed perceived mood and level of functioning during the previous week.

The Health Assessment Questionnaire (HAQ) disability index was used to assess functional limitations in 8 categories of daily living: dressing and grooming, arising, eating, walking, hygiene, reach, grip, and outside activity (14).

Pain was assessed by a 10-cm horizontal pain VAS. Pain severity was rated from 0–10, where 0 = no pain and 10 = very severe pain. Fatigue was assessed by a 10-cm horizontal VAS, in which fatigue was rated from 0–10, where 0 = no fatigue and 10 = severe fatigue.

Program evaluation. Program evaluation focused on the participants' perceptions of the value and usefulness of the self-management program and the content and presentation of each module, suggestions for improvement, and other feedback.

Study procedures. Participants who met the inclusion criteria were sent the consent form and preintervention questionnaires. Once consent was obtained and partici-

Table 1. Demographic variables of the participants at baseline (n = 16)*

	Value
Age, mean \pm SD years	52.2 \pm 10.2
Disease duration, mean \pm SD years	7.8 \pm 8.1
Education, mean \pm SD years	16.6 \pm 3.7
Type of SSc, %	
Diffuse SSc	37.5
Limited SSc	54.4
Unknown	6.2
Women, %	87.5
White, %	93.7
Married, %	68.8
Working full time, %	37.5

* SSc = systemic sclerosis.

pants completed and returned the preintervention questionnaires, participants were sent the link to the self-management web site and a password. Participants were expected to complete the program in 10 weeks. At the end of the intervention period, participants were sent the postintervention questionnaires and the program evaluation questionnaire.

Statistical analysis. Data were entered into an Excel database (Windows) and then transferred to SAS for analysis. The outcome measures (SE Scale, heiQ, PAM, HAQ, pain, fatigue, and CES-D) were scored, and pre- and postintervention differences were calculated. Descriptive statistics were computed for demographic characteristics and outcome measures. We used *t*-tests to assess the differences in the changed scores. Effect sizes (Cohen's *d*) were calculated for the outcome measures. Descriptive statistics were also computed for the variables on the program evaluation questionnaire. An evaluation of time spent in intervention activities and downloading resource material, which was gathered during the biweekly logins, was also tallied.

Results

Fifty-seven individuals were screened for eligibility; 34 were excluded because they did not meet the inclusion

Table 3. Program evaluation

Evaluative statement	Mean score (range 1–5)
Information was presented clearly.	4.9
The web site was easy to use.	4.6
The web site was visually appealing.	4.2
The web site had modules of importance to me.	4.6
Modules were presented at the appropriate reading levels.	4.8
The learning activities were helpful.	4.3
The action plans contributed to my learning.	4.3
The discussion boards were helpful.	4.4

criteria. A major reason for exclusion was a score of <3 on the pain VAS. Consent forms and preintervention questionnaires were mailed to 23 individuals who met the inclusion criteria. Of those 23, 1 withdrew due to hospitalization and 1 did not return the consent form or preintervention questionnaire. The 21 participants who returned the forms were issued a password and sent the link to the password-protected web site. Five participants were lost to followup (3 never logged on to the web site and 2 did not return the postintervention questionnaires). The demographic characteristics for the 16 participants who completed the program and returned the postintervention questionnaires are shown in Table 1.

Table 2 shows the results of *t*-tests comparing the pre- and postintervention scores on the outcome measures. There were significant improvements in the heiQ and PAM and significant decreases in the fatigue VAS and CES-D. Self-efficacy increased, but not significantly. There were no significant changes in self-reported health, pain, and functional ability. Effect sizes show that the improvements postintervention were of moderate magnitude for the heiQ, PAM, fatigue VAS, and CES-D, and small for disability, pain, and self-reported health.

The program evaluation also showed that participants were satisfied with the program (Table 3). The web site was clear, easy to use, and written at the appropriate level. The most common downloaded resources were the Raynaud's travel kit, my scleroderma module, instructions for the paraffin wax treatment, quick medication review,

Table 2. Pre- and postintervention changes for outcome measures*

	Preintervention, mean \pm SD	Postintervention, mean \pm SD	Change	Effect size	<i>P</i>
SE Scale (range 0–100)†	57.3 \pm 11.7	63.9 \pm 13.1	6.52	0.46	0.084
heiQ (range 0–168)†	114.6 \pm 9.9	120.6 \pm 7.7	6.03	0.72	0.012
PAM (range 0–52)†	38.5 \pm 5.2	41.5 \pm 5.0	3.00	0.62	0.025
CES-D (range 0–60)	20.7 \pm 9.6	16.4 \pm 8.9	-4.25	-0.71	0.013
HAQ DI (range 0–3)	1.0 \pm 0.6	1.1 \pm 0.5	0.01	0.02	0.93
Pain VAS (range 0–10)	6.7 \pm 1.6	6.3 \pm 1.5	-0.48	-0.31	0.24
Fatigue VAS (range 0–10)	8.1 \pm 1.4	7.6 \pm 1.4	-0.52	-0.55	0.05
Self-rated health (range 0–5)	3.8 \pm 0.8	3.8 \pm 0.7	0	0	–

* SE Scale = Chronic Disease Self-Efficacy Scale; heiQ = Health Education Impact Questionnaire; PAM = Patient Activation Measure; CES-D = Center for Epidemiologic Studies Depression Scale; HAQ = Health Assessment Questionnaire; DI = disability index; VAS = visual analog scale.
† Higher scores indicate better self-efficacy, knowledge, and management of disease.

managing ulcers, developing a support system, exercise log, and self-advocacy ideas. Participants also volunteered feedback that the discussion board created a mechanism to communicate and share problems and solutions with others with SSc.

Discussion

Our internet self-management program for people with SSc was shown to improve knowledge, skills, and confidence in managing health and to decrease fatigue and depressive symptoms. In addition, participants found the program to be feasible and satisfactory.

Very few previous studies examined the effect of self-management programs for SSc. In these programs, which all used the group format, participants reported greater self-efficacy and increased knowledge and satisfaction (4–6). Only 1 study that had a large enough sample to analyze the data statistically showed less helplessness and greater acceptance of the limitations from SSc as a result of the self-management program (5). However, confidence and skills in managing SSc were not assessed.

In contrast to the other studies with SSc programs (4–6), we found changes in knowledge, skills, and confidence in managing health, which has been associated with actively performing self-management behavior, such as adhering to medications, managing stress, and so forth. The improvements in the heiQ and PAM scores indicated that participants were starting to make changes in self-management behaviors, such as doing the stretching exercises and implementing the suggestions for communication and advocacy.

Objective improvements in fatigue were not reported in the other studies on self-management in persons with SSc. Our internet program had 1 module specifically devoted to the management of fatigue and suggestions for energy conservation. The resource, “Developing a plan to improve ease in performing daily tasks,” was one of the most frequently downloaded resources; therefore, the addition of an application exercise might account for the reduction of fatigue. Reduction of depression symptoms was also not reported in the other self-management programs for SSc, although all of them had sessions on coping. The discussion board might have provided an avenue for support and sharing of experiences in a “safer” way for some people to reveal their feelings and concerns than face-to-face formats.

Similar to the group format self-management studies, participants responded positively to the program. The online format can overcome geographic barriers, provide an avenue for support by sharing stories and experiences through the discussion boards, and provide information on coping, changes in appearance, self-advocacy, exercise, fatigue, and daily living. These topics and the online format have been identified as essential and of value to people with SSc (2,3,15). The success of and satisfaction with our program also support findings by van der Vaart et al (15) regarding the need for online programs for people with SSc.

This is the first study evaluating the effectiveness of an internet self-management program for people with SSc.

However, there are several limitations. First, the sample size was small, since we wanted to explore the effect of a self-management program. However, our sample was representative of the population of people with SSc (16). Also, a previous study by our group found ceiling effects for pain in participants with minimal pain (9). In order to observe changes in pain, we set our pain level criterion at >3 (moderate pain on a 0–10 scale). Furthermore, pain (overall and joint) is a major symptom in people with SSc in survey data and focus groups and cognitive interviews (16,17). We did not require confirmation of a diagnosis of SSc because community-based self-management programs such as ours will be used by people who self-identify as having SSc. Second, the attrition rate was 30%. We were not able to ascertain why 3 individuals did not log on to the web site or why 2 did not return postintervention questionnaires, despite repeated attempts to contact the participants by phone and e-mail. Another limitation was the lack of a control group. Therefore, it is not known whether the observed changes can be attributed to the intervention. Future studies should include a large sample size and control group and a longer followup period. A larger, well-powered study may help determine whether the program helps change the psychosocial and fatigue aspects of SSc more than physical disability or pain.

The results from this pilot study suggest that an internet self-management program for people with SSc was effective in improving knowledge, skills, and confidence in managing health. The program also decreased fatigue and depressive symptoms in this group of participants. Participants were also satisfied with the content and format. Therefore, an online format should be further explored as a method to meet the self-management needs for people with SSc and might be a valuable addition to health care for these individuals.

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AUTHOR CONTRIBUTIONS

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

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