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The evaluation of a home-based program for hands in patients with systemic sclerosis

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ABSTRACT

Study Design: This study used a quasi-experimental design where patients were evaluated before and after participation in the self-management program.
Introduction: Hands are commonly affected in systemic sclerosis (SSc). Strategies to maintain or improve hand function are indicated upon diagnosis and throughout the course of the disease.
Purpose of the Study: The purpose of this study was to develop and evaluate a home-based program for hands in patients with SSc.
Methods: A home-based self-management program that consisted of concise instructions about SSc and hand exercises was developed and evaluated in a group of patients with SSc during 8 weeks. Primary outcome measures were hand pain (Visual Analogue Scale) and hand function (Cochin Hand Function Scale). Secondary outcome measures were disability (Scleroderma Health Assessment Questionnaire), finger motion (delta finger-to-palm), grip strength, tip and key pinch strength, Raynaud phenomenon and digital ulcers impact, quality of life (Short Form Health Survey). For comparisons between different times analysis of variance for repeated measures was used. To calculate the effect size (ES), the Cohen's test was performed. To evaluate skin moisturizing and warming habits before and after intervention, the McNemar test was used. Statistical significance was set at $P \leq .05$.
Results: Twenty-two SSc patients (19 women: 3 men; 16 limited scleroderma: 6 diffuse scleroderma) completed the program. Significant improvements were noted for hand pain (3.97 vs 2.21, ES: 0.69), Cochin Hand Function Scale (19.24 vs 12.48, ES: 0.48), Scleroderma Health Assessment Questionnaire (0.95 vs 0.48, ES: 1.01), delta finger-to-palm (92.86 vs 106.33, ES: 0.40), grip strength (14.43 vs 19, ES: 0.58), tip pinch strength (2.49 vs 4.18, ES: 1.15), key pinch strength (4.01 vs 5.22, ES: 0.76), Raynaud phenomenon impact (0.94 vs 0.47, ES: 0.75), Short Form Health Survey—role physical (47.38 vs 60.14, ES: 0.61), physical functioning (34.62 vs 61.9, ES: 0.18), social functioning (60.71 vs 75.6, ES: 0.64), bodily pain (50.55 vs 63.38, ES: 0.58), vitality (45.95 vs 62, ES: 2.22), mental health (56.62 vs 72.38, ES: 0.84) moisturizing, and cold avoidance habits. Patients considered the program easy to follow with no adverse effects related to exercises.
Discussion: We developed a home based hand care program to be offered to SSc patients. Improvements in hand function, strength, disability, motion, and overall quality of life were independent of age, income, education level, disease duration, and skin score. Our findings support those of other studies that reported the benefits of hand exercises in SSc. Some study limitations include the lack of a control group, the small number of subjects and the short-time follow up.
Conclusions: This home-based program for patients with SSc improved hand pain, function, mobility, and strength at the end of 8 weeks. Patient adherence and sustained efficacy is still to be determined.

Introduction

Systemic sclerosis (SSc) is a multisystem disease characterized by skin induration, internal organ damage, and musculoskeletal involvement.[1] SSc can be classified as diffuse and limited subtypes.[2]

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Loss of hand function occurs with both subtypes, which has a negative impact on most of daily living activities.[3-5] Skin changes in the hands can result in a claw type of deformity, generally with decreased flexion of the metacarpophalangeal joints, decreased extension of the proximal and distal interphalangeal joints, decreased thumb motions (abduction, flexion, and opposition), and limited wrist motion.[6,7]

Strategies to maintain or improve hand function in SSc are indicated upon diagnosis and throughout the course of the disease.[8] The few clinical studies that have evaluated rehabilitation techniques in SSc have reported improvements in hand motion and function[9-14] Interventions for skin hydration, cold avoidance, fatigue control, joint protection techniques, and hand exercises have been highly recommended.[8-14] Most of the rehabilitation programs include face-to-face sessions with health professionals such as an occupational therapist. This can be a limitation especially when patients live far from the outpatient clinics and/or are not able to attend regular appointments.

Thus, the purpose of the study was to develop and evaluate a home-based self-management program, with an emphasis on hand exercises, for Brazilian patients with SSc.

Material and methods

Study design and settings

This study used a quasi-experimental design where patients were evaluated before and after participation in the self-management program. The study was conducted from January 2015 to October 2015 in the outpatient clinic of Rheumatology Division of the University of Campinas/Unicamp with approval of the ethics committee, Faculty of Medical Sciences of Unicamp (CAAE: 44635212.5.0000.5404) in accordance with the Declaration of Helsinki. All patients provided a written informed consent.

Participants

Eligible participants were adult patients ($\geq$ 18 years) with a diagnosis of SSc according to the 2013 ACR/EULAR Classification Criteria,[15] with hand involvement (presence of skin thickening with or without joint synovitis, joint contractures, digital ulcers [DU]), stable drug therapy in the last 3 months, and willingness to complete the study protocol. Patients were excluded if they had been enrolled in any other rehabilitation program in the previous 3 months, had hand disability due to other pathologies other than SSc, or could not perform the proposed exercises due to medical conditions or advanced hand deformities.

Patients were invited to take part in this study during their routine appointments at our rheumatology outpatient clinic. Those who fulfilled the inclusion criteria were asked to read and sign the informed consent. Sociodemographic and clinical data were collected.

Skin thickness was assessed using the modified Rodnan skin score,[16] which involves palpation of 17 anatomic sites. Each site is scored on a 0–3 scale, where 0 = normal, 1 = thickened, 2 = thickened and unable to pinch, and 3 = thickened immobile skin. The scores from all sites were summed to yield a total skin score, ranging from 0 to 51 points.[15] Since hands were the focus of this study, regional skin thickness (upper limbs skin score) was also used considering only fingers, hands, forearms, and arms with a possible maximum score of 24 points.

All the patients received the program and were instructed to follow the instructions in the program. Outcome measures were assessed at enrollment and reassessed at 4 (t1) and 8 weeks (t2).

Intervention

We developed a home-based self-management program with an emphasis on hand exercises for SSc patients. The program was designed so that patients could follow the program at home without assistance from a health professional.

The first version of the program was submitted to a committee composed of 3 rheumatologists and 2 occupational therapists regarding its clarity, coverage and relevance. Based on the committee suggestions, the program was revised. The final version, named in Portuguese “Mãos à obra—um programa de orientação e exercícios para as mãos na Esclerose Sistêmica” (Hands on—a hand care guide in SSc) consisted of a booklet that contained a brief introduction and information about SSc followed by instructions on hand exercises. A DVD with hand exercises was included as part of the program.

The booklet was written in simple language with short sentences and included a brief definition of SSc, main symptoms, and treatment. We also included some objective recommendations:

- To manage Raynaud phenomenon (RP): keep the body warm not only in the winter but also in places with air conditioning; keep doors and windows closed; wear layers of clothes; avoid contact with cold water—use an electric faucet heater if necessary; drink warm or hot drinks; avoid caffeine; and stop smoking and try to control emotional distress.
- To maintain well-hydrated skin: moisturize your hands every time after washing them and moisturize your body at least once a day.
- To prevent digestive discomfort: eat slowly and chew thoroughly and eat several small meals instead of a few large ones.
- To treat dry mouth: drink more water/liquids and chew/suck sugar-free gums and candies to help improve salivation.
- To maintain oral health: brush the teeth after meals; use alcohol-free mouthwashes; and get periodical dental care assistance.
- To avoid fatigue: plan and organize daily activities, establish priorities, avoid overexertion, and use proper household devices (such as a vacuum cleaner, washer, dryer, and so forth).
- Physical activity: physical activity may help manage symptoms. Stretching, walking, cycling, swimming, and weight training are the most common activities recommended. Always start with low intensity, with care, avoiding pain and overdoing. Get advice from your health care professional before beginning a physical activity program.

In the second part, hand involvement (thick skin and claw deformity) was highlighted as a common SSc feature and that daily performance of hand exercises could help maintain joint motion, strength, and function.

1. Active finger flexion and extension (Figs. 1A and 1B): Place your arms on a table, with your palm faced up. Flex your fingers as much as you can. Hold this position for 2 seconds. Then, extend your fingers as much as possible. Hold this position for 2 seconds. Repeat these movements 5 times. If there is no discomfort, repeat up to 10 times. Do the same movement with the other hand.
2. Wrist flexion stretch (Fig. 1C): With your arm extended in front of you and the hand palm faced down, gently flex your wrist with the other hand until you feel your muscles stretching, without pain. Hold this position for 5 seconds. Relax and repeat the exercise once more. Do the same exercise with the other wrist.

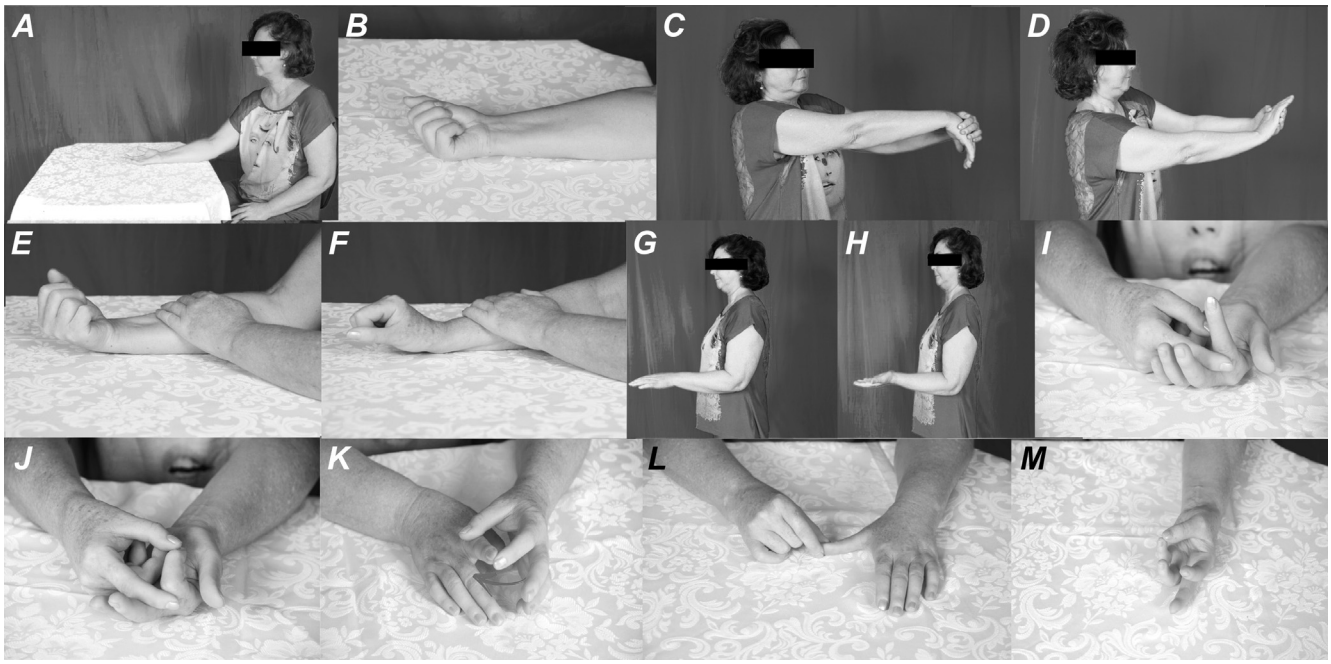

Fig. 1. Exercises: active finger extension (**A**) and flexion (**B**), wrist flexion stretch (**C**), wrist extension stretch (**D**), active wrist flexion (**E**), active wrist extension (**F**), active fore arm pronation (**G**) and supination (**H**), finger flexion (**I, J**) and extension (**K**) stretches, Opening of the first commissure (**L**), and active finger pinch (**M**).

3. Wrist extension stretch (Fig. 1D): With your arm extended and the hand palm faced down, gently extend your wrist with the other hand until you feel your muscles stretching, without pain. Hold this position for 5 seconds. Relax and repeat the exercise once more. Do the same exercise with the other wrist.
4. Active wrist flexion (Fig. 1E): With your fingers flexed, palm facing up, and the forearm supported by the other hand on a table, flex your wrist as much as you can. Repeat this exercise 5 times. If there is no discomfort, repeat until 10 times. Do the same exercise with the opposite wrist.
6. Active wrist extension (Fig. 1F): With your fingers flexed, palm facing down, and your forearm supported by the other hand on a table, extend your wrist as much as possible. Repeat this exercise 5 times. If there is no discomfort, repeat up to 10 times. Do the same exercise with the opposite wrist.
7. Active forearm pronation and supination (Figs 1G and 1H): With your elbow flexed and your arm resting against the side of the body, turn your palm up as far as you can. Then, turn your palm down as far as you can. Repeat this exercise for 5 times. If there is no discomfort, repeat up to 10 times. Do the same exercise with the opposite forearm.
8. Finger flexion stretching (Figs 1I and 1J): Bend the base of the finger (metacarpophalangeal joint) as far as possible with the help of the forefinger of the other hand. Hold this position for 2 seconds. Then, with your thumb, bend also your fingertip (proximal and distal interphalangeal joints). Hold this position for 2 seconds and release your finger. Repeat this exercise 3–5 times for each finger.
9. Finger extension stretching (Fig. 1K): With the contralateral index finger against the tip of the finger and the contralateral thumb against its dorsal base metacarpalphalangeal joint, extend your finger joints as far as you can. Hold this position for 2 seconds and release your finger. Repeat this exercise for 3–5 times for each finger.
10. Opening of the first commissure (Web space or thumb extension) (Fig. 1L): With your hand flat on the table, with the opposite hand, move your thumb away from the hand as far as you can. Hold this position for 2 seconds. Repeat this exercise for 5 times. Do the same exercise with the other thumb.
11. Active finger pinch (Fig. 1M): Bring the tip of your thumb to touch the tip of your little finger until they touch or as far as you can. Now, slide the tip of the thumb toward the base of the little finger, or as close as you can. Do the same movement by placing the tip of the thumb on the tip of each one of the other fingers (ring finger, middle finger, and forefinger).

Patients were instructed to practice the exercises daily, as a routine. In case of pain or discomfort when performing any of the exercises, they were advised to stop doing it and to contact the researchers.

Figures (in the workbook) and videos (DVD) were provided to the patients to demonstrate the exercises.

Outcome measures

Our primary outcome measures were hand pain (Visual Analogue Scale, pain-VAS) and hand function (Cochin Hand Function Scale, CHFS). Secondary outcome measures were disability (Health Assessment Questionnaire, HAQ; and Scleroderma-HAQ, SHAQ), quality of life (Short Form Health Survey, SF-36), finger motion (delta finger-to-palm, d-FTP), grip and pinch strength, and self-reported warming and moisturizing habits.

Pain

Hand pain was assessed using a 10-cm horizontal pain-VAS. Pain severity was rated from 0 to 10, where 0 = no pain and 10 = very severe pain.[17]

Cochin Hand Function Scale

CHFS is a self-administered instrument to assess the hand function that has previously found to be valid and reliable in SSc.[18,19] It contains 18 items regarding hand ability in the kitchen, during dressing, while performing personal hygiene, while performing office tasks, and other general items. Each question is

scored from 0 (no difficulty) to 5 (impossible to do). A total CHFS score is obtained by adding the scores from all questions (range: 0-90). The Brazilian-Portuguese version was used.[20]

HAQ disability index

The HAQ, a self-report measure, consists of 20 items grouped into 8 categories of daily living: dressing and grooming, arising, eating, walking, hygiene, reach, grip, and outside activity.[21] Persons indicate how much difficulty they have with each item from 0 (no difficulty) to 3 (cannot do). The score for each category is the highest score for any question in the category. A disability index is calculated by adding the category scores and dividing by the number of categories answered. This yields a disability index from 0 (less disabled) to 3 (more disabled). Validity of the HAQ for use in SSc has been previously reported.[22] The HAQ Brazilian-Portuguese version was used.[23]

Scleroderma Health Assessment Questionnaire, RP, and digital ulcers (DU)

The Scleroderma Health Assessment Questionnaire (SHAQ) is a SSc-specific tool that consists of the 20 items from the HAQ and 5 additional visual analogue scales (VAS) regarding the impact of symptoms caused by SSc (RP, digital tip ulcers, gastrointestinal and lung symptoms, as well as overall disease symptoms). Scores on the VAS range from 0 (does not interfere with activities) to 3 (very severe limitations with activities). The overall score is the sum of each of the 5 VAS subscores and the scores for the 8 HAQ domains divided by 13.[24] The SHAQ Brazilian-Portuguese version was used.[25]

Since RP and digital ulcers (DU) are expected to improve with intervention, these questions from SHAQ were also analyzed separately, before and after intervention (score range: 0-3).

Short Form Health Survey

The Brazilian-Portuguese version of The Medical Outcomes Survey SF-36 was used to assess health-related quality of life.[26,27] This is a multidimensional questionnaire with 36 items, measuring health in 8 domains (general health perception, physical and social functioning, role limitations by physical or emotional problems, mental health, vitality, and pain). Scores for each domain range from 0 (worst health) to 100 (best health). The SF-36 has been previously validated in SSc.[28]

Delta finger-to-palm

The d-FTP is the difference of the distance measured between the third fingertip and the distal palmar crease with fingers in full extension and the distance with fingers in full flexion (in cm). It is a valid and reliable measure of finger motion in patients with SSc.[29] For analysis, we used the measurements for the dominant hand.

Hand strength

Hand grip strength, tip pinch strength (the thumb tip to the index fingertip), and the key pinch strength (thumb pad to the lateral aspect of middle phalanx of index finger) were tested in the dominant hand. The digital dynamometer Jamar (Takei Scientific Instruments Co, Tokyo, Japan) was used to measure the grip strength and the B&L pinch gauge (B&L Engineering, Santa Clara-CA) was used to measure tip and key pinch. For each of the grip and pinch items, the mean of 3 trials for each of the hands is calculated. Measurements of grip and pinch were taken at 3 points in time (t0, t1, and t2) by the same trained occupational therapist (Landim), in accordance to the American Society of Hand Therapists recommendations.[30]

Warming and moisturizing habits for the hands and body

Moisturizing and warming the body, especially the hands, are important to maintain hand function for patients with SSc. Patients' habits were assessed at the beginning (t0) and at the end of the study (t2) using the following questions: "How often do you moisturize your body?"/"How often do you moisturize your hands?"/"How often do you keep your body warm?"/"How often do you keep your hands warm?"

Program evaluation

Patients' impressions of the program were evaluated at the end of the study (8 weeks—t2), with the following questions: "The workbook and DVD were easy to understand?"/"How would you rate the quality of the material?"/"Did the program improve your knowledge about systemic sclerosis?"/"Were you able to follow the program's guidance in your daily life?"/"Were the workbook exercises easy to perform?"/"Do you intend to continue practicing the exercises after this study?"

Adverse effects

Patients were asked about adverse effects related to hand exercises at week 2 (telephone call) and at weeks 4 and 8 (scheduled appointments).

Statistical analysis

Data were entered into an Excel database (Windows) and then transferred to The SAS System for Windows, version 9.4 (SAS Institute Inc, Cary, NC) for analysis. Descriptive statistics consisting of mean, median, maximum and minimum values, and standard deviations were computed for all demographic characteristics and outcome measures. Preintervention and postintervention differences were calculated for the outcome measures (VAS, CHFS, SHAQ, d-FTP, and SF-36). For comparisons between different times (t0, t1, and t2), analysis of variance for repeated measures was performed. Because of the absence of a normal distribution, variables were transformed into ranks. The effect size was obtained using the Cohen's test. To investigate the influence of disease and demographic data in outcome measures, Spearman correlation coefficients were used. To evaluate skin moisturizing and warming habits before and after intervention, McNemar test was used. Statistical significance was set at $P \leq .05$.

Results

Forty-seven patients were approached during their regular appointments in our outpatient clinic and asked to be in the study. As shown in flow diagram (Fig. 2), 20 patients were excluded, 15 did

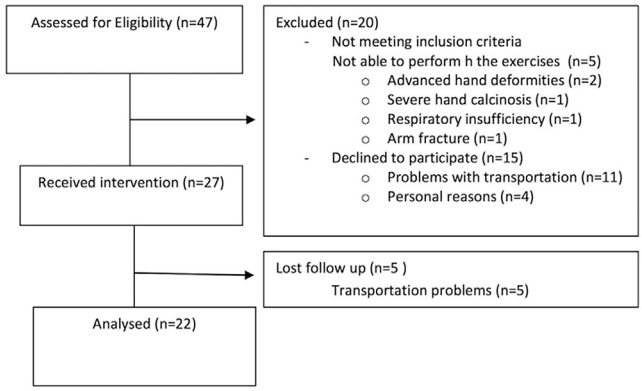

Fig. 2. Flow diagram.

Table 1
Characteristics of patients ($n = 22$)

Age (y)[a]	48.09 (50, 27-70, ±11.67)
Disease duration (y)[a]	11.19 (10, 3-27, ±5.9)
Education (y)[a]	8.29 (9, 1-14, ±3.51)
Type of SSC[b]	
Limited (l-SS)	16 (71.43)
Diffuse (d-SS)	6 (28.57)
Women[b]	18 (85.71)
White[b]	13 (61.90)
Married[b]	15 (66.67)
Employment[b]	
Employed	9 (40.90)
Housewife	5 (22.73)
Disability	5 (22.73)
Retired	3 (13.64)
Income (per month)[a]	R$1.400.00 (~US$400.00) (870, 720-4000, ±943.73)
Medication[b]	22 (100) Immunosuppressants (7 methotrexate, 6 azathioprine, 5 cyclophosphamide, and 4 mycophenolate) 2 (9) Endothelin receptor antagonist (Bosentan) 5 (22.73) Phosphodiesterase-5 inhibitors (Sildenafil) 12 (59.09) Calcium channel blockers (7 Nifedipine, 3 amlodipine, and 2 diltiazem)
Modified Rodnan skin score—MRSS[a]	22.52 (21, 13-39, ±6.66)
Upper limbs skin score—ULSS[a]	13.10 (12, 4-28, ±6)

[a] Mean (median, minimum-maximum value, ±standard deviation).
[b] Number of subjects (%).

not have interest in taking part of the study, and 5 were not able to perform the exercises. Twenty-seven patients met the inclusion criteria and were evaluated and instructed in use of the program. Five patients did not return for the reevaluations and were excluded. Twenty-two patients completed the protocol and were included in the final analysis. Characteristics of patients who completed the study are shown in Table 1. None of the patients had received any previous or current occupational therapy intervention. No drug modifications occurred for any patients during the period of the study.

Table 2 shows the preintervention and postintervention scores on the outcome measures. Significant improvements were noted after 4 and 8 weeks for CHFS, d-FTP, hand grip strength, tip pinch strength, key pinch strength, pain-VAS, SHAQ, RP, DU, HAQ, and SF-36 (role physical, physical functioning, social functioning, bodily pain, physical role, social functioning, vitality, and mental health domains). A nonsignificant trend toward improvement was noted for DU and SF-36 emotional function component. These results were independent of age, income, and education level and were noted even when patients with limited or diffuse SSc were analyzed separately (data not shown).

Figures 3 and 4 show the patients' answers to questions about moisturizing and warming habits at baseline (t0) after 8 weeks (t2). A significant improvement ($P < .05$) could be noted between times.

As shown in Table 3, the workbook/DVD was considered very easy or easy to understand. The quality of the material was rated as very good/good, and most subjects reported that they improved very much their knowledge about SSc. All subjects reported that they had followed the program guidance in their daily life. Exercises were considered very easy/easy to perform. All patients reported the intention to continue practicing the exercises after the end of the study. Patients did not complain about pain or any other adverse events related to hand exercises.

Discussion

When creating a rehabilitation program, a common dilemma is what information to include and the depth of information to provide. Programs should be attractive and easily available.[31] Many tertiary hospitals serve large geographical areas. Most of the attention at clinical appointments is spent on physical examinations and medication reviews; rehabilitation needs are frequently overlooked. Patients are not instructed in or referred to self-management programs. Lack of adherence to prescribed rehabilitation programs is often due to geographical distances, inadequate public transportation and/or lack of social support. None of the patients in this study had been informed about the benefits of hand exercises, and none of them had been referred to an occupational therapist. Although some patients reported they had some knowledge about the disease, very few received adequate instructions related to cold prevention and skin care. Therefore, the intention of our program was to create a home-based self-management program focusing on scleroderma hand care that could be offered to patients without the need of face-to-face meetings or participation from any health professional. We opted to focus mostly on instructions about skin care, cold prevention, and hand

Table 2
Preintervention and postintervention changes for outcome measures ($N = 22$)

Outcome measures	t0[a]	t1[a]	t2[a]	*P* value	ES
Pain-VAS	3.97 (4.5, 0-10, ±2.92)	2.61 (2.5, 0-7.5, ±2.11)	2.21 (3, 0-7, ±2.07)	.0022	0.6953
CHFS	19.24 (13, 1-54, ±15.78)	16.86 (11, 0-49, ±15.42)	12.48 (6, 0-38, ±12.04)	<.0001	0.4816
SHAQ	0.95 (1.12, 0.02-1.8, ±0.53)	0.70 (0.70, 0.02-1.7, ±0.39)	0.48 (0.50, 0.09-1.40, ±0.39)	<.0001	1.0101
HAQ	1.08 (0.80, 0-3, ±0.88)	0.77 (0.80, 0-2.30, ±0.68)	0.67 (0.50, 0-1.60, ±0.62)	.1524	0.5386
d-FTP	92.86 (110, 25-125, ±34.70)	101.67 (115, 30-130, ±33.63)	106.33 (123, 40-130, ±32.43)	<.0001	0.4010
Hand grip strength	14.43 (14, 0-25, ±6.87)	17.84 (15.75, 5-30, ±6.87)	19 (18.50, 5-33, ±7.09)	.0022	0.5830
Tip pinch strength	2.49 (2.20, 0-5, ±1.62)	3.66 (3.40, 1-5.60, ±1.20)	4.18 (4, 1-6, ±1.28)	<.0001	1.1576
Key pinch strength	4.01 (4, 1-6.50, ±1.62)	4.80 (5, 1.50-7, ±1.64)	5.22 (5.70, 1.50-8, ±1.56)	<.0001	0.7609
RP	0.94 (0.80, 0-2.50, ±0.67)	0.79 (0.80, 0-2.20, ±0.61)	0.47 (0.20, 0-2.20, ±0.58)	.0122	0.7501
DU	0.71 (0.60, 0-2.20, ±0.73)	0.44 (0.30, 0-1.60, ±0.54)	0.40 0.20, 0-1.50, ±0.48	.0970	0.5018
SF-36 general health	52.81 (52, 0-97, ±20.33)	59.67 (57, 27-82, ±13.28)	58.29 (60, 25-87, ±16.15)	.1974	0.2986
SF-36 role physical	47.38 (45, 15-95, ±21.25)	55 (55, 15-95, ±23.61)	60.14 (60, 15-100, ±20.06)	.0421	0.6175
SF-36 physical functioning	34.62 (25, 0-100, ±38.30)	61.90 (75, 0-100, ±41.65)	61.90 (100, 0-100, ±45.84)	.0022	0.1803
SF-36 emotional role	39.67 (33.30, 0-100, ±41.65)	58.72 (62.60, 0-100, ±42.04)	53.96 (66.60, 0-100, ±47.70)	.0642	0.3191
SF-36 social functioning	60.71 (62.50, 12.50-100, ±27.47)	70.84 (75, 37.50-100, ±21.04)	75.60 (75, 37.50-100, ±17.44)	.0434	0.6472
SF-36 bodily pain	50.55 (51, 0-100, ±24.22)	60.14 (62, 22-100, ±20.21)	63.38 (62, 22-100, ±19.37)	.0022	0.5851
SF-36 vitality	45.95 (40, 10-80, ±19.91)	49.76 (50, 10-95, ±23.05)	62 (70, 20-90, ±20.86)	.0072	2.2231
SF-36 mental health	56.62 (56, 28-88, ±17.37)	56.57 (52, 24-92, ±21.51)	72.38 (80, 32-100, ±19.75)	.0005	0.8474

ANOVA = analysis of variance; CHFS = Cochin Hand Function Scale; d-FTP = delta finger-to-palm; DU = digital ulcers impact; HAQ = Health Assessment Questionnaire; pain-VAS = pain Visual Analogue Scale; RP = Raynaud phenomenon impact; SF-36 = Short Form 36; SHAQ = Scleroderma Health Assessment Questionnaire.
[a] t0 = baseline; t1 = 4 weeks; t2 = 8 weeks—mean (median, minimum-maximum value, ±standard deviation); *P* value: ANOVA for repeated measures; ES (effect size): Cohen's test.

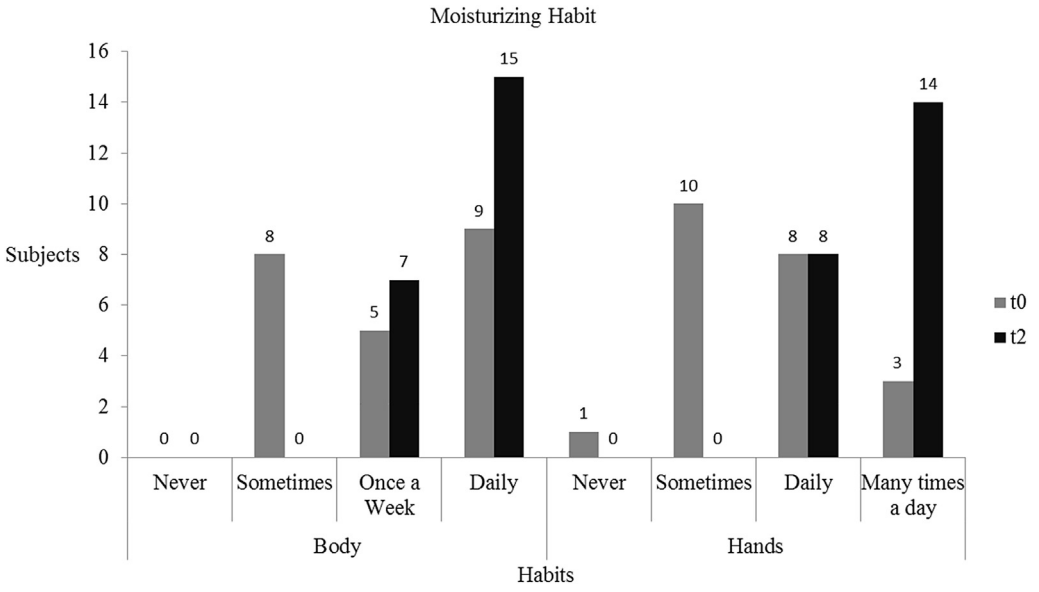

Fig. 3. Body and hand moisturizing habit at initial visit (t0) and after 8 weeks of intervention (t2).

exercises using a workbook and DVD. After 8 weeks, improvements in hand function, strength, disability, motion, and overall quality of life were observed.

Skin care, especially moisturizing hands and body, and cold avoidance measures to prevent RP were emphasized. Skin thickening and RP in the hand are 2 of the most important SSc symptoms. Although most patients disclosed RP complaints and upper limb skin thickening, they did not routinely moisturize their skin nor use cold prevention techniques. Behavior changes were noted in most patients regarding moisturizing and cold prevention habits. This may have contributed to the decreases in RP impact and improvements in hand function (CHFS), overall disability (Scleroderma Health Assessment Questionnaire), and quality of life (SF-36).

The self-management program also included 10 hand exercises, the majority of which involved stretching. Patients considered them easy to perform and planned to continue with the exercises after the conclusion of the study. There were no complaints of pain or discomfort. Our findings support those of other studies which reported the benefits of hand exercises in SSc. Mugii et al[11] studied the effect of a self-administered finger stretching program and observed improvements in joint motion, eating, and grasping objects after 1 month which were sustained at the 1-year follow-up. Stefanantoni et al,[14] in a 3-month randomized controlled trial, also reported that finger stretching program resulted in improvements in functional ability. Bongi et al[13] who studied the benefits of an exercise program combined with McMennell joint manipulation (a kind of connective tissue massage that stretches articular capsule and ligaments) also reported improvements in the CHFS, the Hand Mobility in Scleroderma Test, HAQ, and SF-36, compared to the control group who only received a home-hand exercise program. Antonioli et al[12] also found that a tailored program consisting of

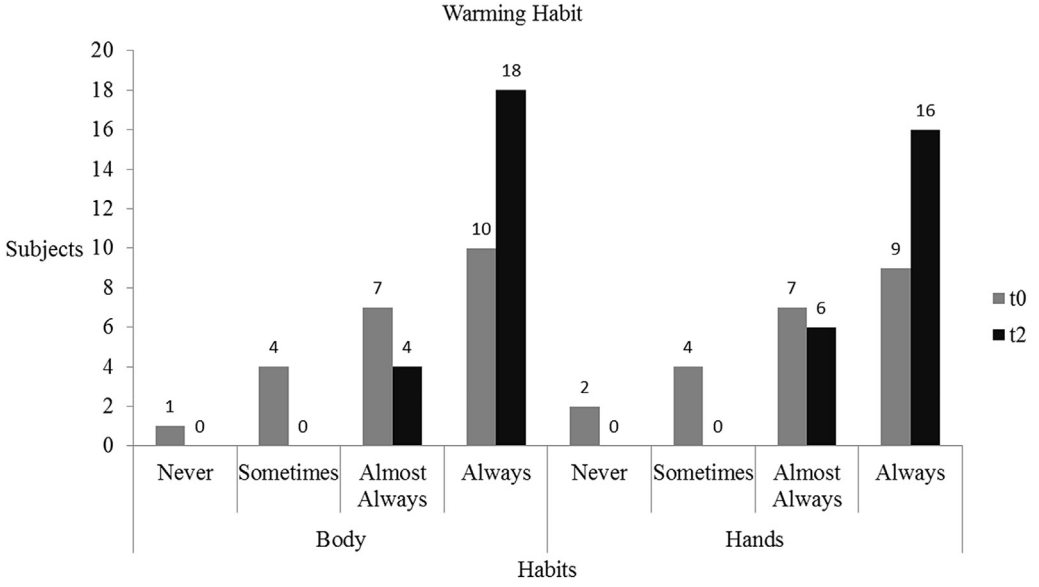

Fig. 4. Body and hand warming habits at initial visit (t0) and after 8 weeks of intervention (t2).

Table 3
Answers to program evaluation ($n = 22$).

Questions	Answers (%)
(1) The workbook and DVD were easy to understand?	Yes, it was very easy, 18 (82%)
(No, it was very difficult/No, it was difficult/So so/Yes, it was easy/Yes, it was very easy)	Yes, it was easy, 4 (18%)
(2) What about the quality of the material?	Very good, 21 (90.91%)
(Very bad/Bad/Good/Very Good)	Good, 1 (8.09%)
(3) Did the program improve your knowledge about systemic sclerosis?	Yes, very much, 21 (90.91%)
(No/Yes, a little/Yes, very much)	Yes, a little, 1 (8.09%)
(4) Were you able to follow the program's guidance in your daily life?	Yes, very much, 17 (77.27%)
(No/Yes, a little/Yes, very much)	Yes, a little, 5 (22.73%)
(5) Were the workbook exercises easy to perform"?	Yes, very easy, 14 (63.64%)
(No, it was very difficult/No, it was difficult/So so/Yes, it was easy/Yes, it was very easy)	Yes, easy, 8 (36.36%)
(6) Do you intend to continue practicing the exercises	Yes, daily, 19 (86.36%)
after this study?	Yes, sometimes, 3 (13.64%)
(No/Yes, sometimes/Yes, daily)	

motor training and finger stretching resulted in improvements in hand mobility after 4 months. Recently, Rannou et al[32] published the results of a randomized controlled trial about the effect of a personalized physical therapy program that included hand exercises and an occupational therapy program. Improvements in Scleroderma Health Assessment Questionnaire, hand function, mobility, and disability were noted in the first month but were not sustained at the 1-year follow-up. Most of the programs included in the previous research consisted of home exercises in conjunction with face-to-face sessions that were not included in our program.

Self-management programs developed for people with SSc have been shown to improve self-efficacy, to reduce helplessness, and to empower patients' control of their disease.[9,10,31,33,34] Although self-efficacy was not analyzed in this study, patients reported that they enjoyed the program, and above all, they were satisfied with the results. Improvements were achieved despite age, income, education level, disease duration, and skin score suggesting that this program can be widely used.

This study has several limitations. The study was an uncontrolled observational study with a small number of subjects. Even though it is difficult to recruit a large number of patients with SSc due to the rarity of this condition, the effectiveness of this intervention should be evaluated in a randomized controlled trial. Many of the outcome measures used in this study are self-reports, however, they are reliable and valid in persons with SSc and have been used as outcomes in other studies on rehabilitation interventions in SSc.[11-14,32] The study duration was brief, and adherence and sustained efficacy still need to be determined. We are continuing to follow these patients and hope to conduct follow-up evaluations. Although patients reported that they were practicing the exercises, we cannot assure that the exercises were done on a regular basis or performed correctly. Although better results might be achieved with sessions under direct supervision of an occupational therapist, the workbook format can reach a large number of people and be available for patients that do not have access to rehabilitation services.

In conclusion, this concise home-based program with hand exercises for SSc was well accepted and resulted in short-term improvements in outcome measures. It is still uncertain if these benefits would be sustained over longer follow-up periods. SSc continues to be a chronic condition with suboptimal treatment results, a challenge for patients and health care providers. Further studies are needed to continue to develop and assess rehabilitation interventions for this population.

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1. The study design is
   a. RCTs
   b. a quasi-experimental model
   c. a full-blown scientific model
   d. qualitative
2. Outcomes were
   a. a VAS for pain
   b. the CHFS hand function scale
   c. the d-FTP measure
   d. all of the above, and more
3. The intervention program was
   a. clinically based
   b. administered by a CHT on a BIW basis
   c. a highly structured home exercise regime
   d. performed in a group therapy setting
4. An ANOVA was used to analyze differences between
   a. the experimental and control groups
   b. times of evaluation
   c. methods of supervision
   d. age groups
5. The investigators were encouraged by the improved outcomes but viewed them as preliminary after this one isolated study
   a. true
   b. false

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