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 $P < 0.05$.

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.

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Introduction

Systemic sclerosis (SSc) is a multisystem disease characterized by skin induration, internal organ damage, and musculoskeletal involvement. SSc can be classified as diffuse and limited subtypes.
Loss of hand function occurs with both subtypes, which has a negative impact on most of daily living activities. 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.

Strategies to maintain or improve hand function in SSc are indicated upon diagnosis and throughout the course of the disease. The few clinical studies that have evaluated rehabilitation techniques in SSc have reported improvements in hand motion and function. Interventions for skin hydration, cold avoidance, fatigue control, joint protection techniques, and hand exercises have been highly recommended. 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 (≥ 18 years) with a diagnosis of SSc according to the 2013 ACR/EULAR Classification Criteria, 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, 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. 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 periodontal 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.
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