








## Systemic scleroderma patient education: a booklet report

*Educação de pacientes com esclerodermia sistêmica: relato de cartilha*

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**ABSTRACT**

**Objective:** This study aims to describe the development and online distribution of a patient education booklet about systemic scleroderma focused on occupational therapy orientations. **Methods:** The research-action methodology was applied and divided into the following five steps: analysis of patients' requests, preparation of the content, choice of illustrations and graphic design, developers' approval of the education booklet, and online distribution. **Results:** The education booklet entitled "Occupational Therapy Guidelines for People with Systemic Sclerosis" was developed, and its online distribution reached nearly 5000 people. **Conclusion:** Educational materials serve as adjuncts to the treatment of chronic diseases, as systemic scleroderma. The online distribution of these materials expands its reach among these patients.

**Keywords:** Scleroderma, Systemic, Occupational Therapy, Self Care, Educational and Promotional Materials, Patient Education as Topic

**RESUMO**

**Objetivo:** Este estudo visou descrever o desenvolvimento e distribuição online de uma cartilha educativa para pacientes com esclerodermia sistêmica com foco em orientações da terapia ocupacional. **Métodos:** A metodologia de pesquisa-ação foi aplicada e dividida em cinco etapas: análise das solicitações dos pacientes, elaboração do conteúdo, escolha das ilustrações e do projeto gráfico, aprovação dos autores da cartilha educativa e distribuição online. **Resultados:** Foi desenvolvida a cartilha educativa intitulada "Orientações da Terapia Ocupacional para Pessoas com Esclerose Sistêmica" e sua distribuição online atingiu quase 5.000 pessoas. **Conclusão:** Os materiais educativos constituem recurso útil no tratamento de doenças crônicas, como a esclerodermia sistêmica. A distribuição online desses materiais expande seu alcance entre os pacientes.

**Palavras-chaves:** Escleroderma Sistêmico, Terapia Ocupacional, Autocuidado, Materiais Educativos e de Divulgação, Educação de Pacientes como Assunto

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Submitted: February 11, 2021

Accepted: June 1, 2021

**How to cite**

Chaves CC, Marcelino ALFO, Silva LCC, Andrade JA, Santos FPST, Ferreira GA, et al. Systemic scleroderma patient education: a booklet report. *Acta Fisiatr.* 2021;28(2):92-96.



10.11606/issn.2317-0190.v28i2a181801



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## INTRODUCTION

Also known as systemic sclerosis, systemic scleroderma (SSc) is a rare, multisystemic, autoimmune, inflammatory, chronic disease, with prevalence ranging from 7 to 489 cases / 100,000 inhabitants and incidence ranging from 0.6 to 122 cases per million inhabitants per year in different populations. It mainly affects women and usually begins between the third and sixth decades of life.<sup>1</sup>

SSc affects the skin, with fibrotic hardening and the occurrence of calcinosis, in addition to other organs, such as the lung, heart, gastrointestinal tract, and kidneys.<sup>2</sup> It presents vasculopathy and generalized fibrosis, which can result in marked dysfunction. The most typical vascular alteration is Raynaud's phenomenon, which manifests in about 90% of patients, and can evolve in moderate to severe cases with ulcerations in the extremities.<sup>2</sup>

Patients with SSc often evolve with impaired hand function due to multiple factors: Raynaud's phenomenon - which can be painful in itself, ischemic ulcers in distal extremities, arthritis, arthralgias, tendinitis, in addition to calcinosis and thickening of the skin with retraction of the subcutaneous tissue.

Acrosteolysis, or amputation of extremities, can interfere with varying degrees of performance, reducing the precision in handling objects and the performance at all types of tasks that require the use of the hands.<sup>1-3</sup> Thus, most patients report loss of pinching capacity and weakening of the hands, which can cause severe limitations in daily-life activities.<sup>3-5</sup> A previous study suggested some degree of difficulty in daily activities attributed to SSc in 82.56% of the patients. Also, 10.86% of the interviewees considered themselves unable to do any activity with their hands due to the disease.<sup>3</sup>

Occupational Therapy (OT) has an essential role in interventions for dysfunctions in patients' hands and upper extremities. Many small randomized control trials, case reports, and case series suggest OT rehabilitation measures to diminish pain and increase joint motion, such as motion exercises, joint manipulation, connective tissue massages, splinting and paraffin wax baths.<sup>6</sup>

It helps to recover sensory-motor functions through guidance on joint protection, energy conservation, hand manipulation and therapeutic activities, considering each individual's occupational history.<sup>4</sup> Also, OT provides the use of orthoses and adaptations, in order to improve the functionality of these patients, providing greater independence and better quality of life.<sup>3,4,5,7</sup>

However, the patients' understanding of their illness and self-care techniques is essential for the success of the OT. The best knowledge about the disease and the self-care measures must be provided to prevent or interrupt the impairment of hand and upper extremities function. It allows patients to take a more active role in treatment, striving to maintain functional integrity and reduce pain.

Once well informed, patients improve their adherence to the treatment and their occupational capacity, acquiring greater independence and better quality of life.<sup>7</sup> Studies have shown that patient education programmes are associated with self-efficacy - which is the capacity to achieve valued behavioural outcomes<sup>8</sup> - by providing the patients with the necessary knowledge, skills and self-confidence to deal with

the problems correlated with chronic diseases.<sup>9-11</sup>

Throughout patient care, the health professionals of the rheumatology outpatient clinic of the university hospital recognised as the principal necessity to teach patients about preventive measures to reduce impairment and avoid SSc complications, as self-care measures for the skin and hands.

In previous studies, SSc patients presented other educational needs: guidance regarding mouth and dental hygiene;<sup>12</sup> information on digital pulp ulcers treatment;<sup>13</sup> instructions on hand hygiene to prevent ulcer infection rate;<sup>14</sup> education about foot care;<sup>15</sup> and information about medical tests and treatment.<sup>16</sup> One study pointed out that it is important to train patients to recognise drugs' adverse effects as well internal organs' symptoms and signs of exacerbations.<sup>17</sup>

There are various ways to promote patient education, such as direct verbal communication, pamphlets, manuals, booklets, and, more recently, computational resources.<sup>18</sup> The multidisciplinary team of the rheumatology outpatient clinic recognized the production of booklets as an instructive and straightforward manner of delivering essential information to the subjects, making the educational process more creative and engaging.

Thus, the team produced a booklet focused on occupational therapy guidelines for patients with SSc, such as self-care measures to prevent Raynaud's phenomenon, digital pulp ulcers, calcinosis and joint lesion, as well as skincare, energy conservation, massages, stretching, and strengthening exercises for the hands. The process of creation and distribution of the booklet is described in this article.

## OBJECTIVE

Present the development, content, and online dissemination of an informative/educational material in a booklet format about occupational therapy guidelines for people with SSc.

## METHODS

This is a descriptive study about the development, content, and online dissemination of an education booklet, which clarifies some of the most recurring doubts of SSc patients treated at the Rheumatology outpatient clinic of a Brazilian university hospital. The booklet also presents suggestions on measures to control Raynaud's phenomenon, digital pulp ulcers and hand impairment.

The study used the action research methodology, developed in five stages: analysis of the demand for information, preparation of the content, choice of illustrations and graphic design, approval of the booklet by the developers, and digital dissemination. Its development respected the ethical precepts of human research and complied with national and international standards of Research Ethics Involving Human Beings.

The booklet's topics were chosen to address the most frequent demands for information from patients with SSc treated at the University Hospital. For the content preparation, a bibliographic search was initiated on materials that included scientific articles, a book chapter,<sup>1</sup> and an educational material aimed at patients.<sup>20</sup> Based on the booklet's initial text and the choice of illustrative photos of the topics covered, the graphic

project was developed by one of the authors using the Canva Pro graphic design program. To ensure the material's interactivity and attractiveness, simple language and easy to understand images were used. It is noteworthy that the content was designed for different age groups. The final version was then reviewed and approved by its developers.

One hundred booklets were printed and distributed to patients with SSc at the Rheumatology outpatient clinic during their medical appointments. However, due to the pandemics caused by the new coronavirus disease (COVID-19), in-person appointments were cancelled or postponed since March 2020.

The booklet's digital dissemination was then implemented, with the proposal to keep information to them during social distancing.

## RESULTS

The education booklet entitled "Occupational Therapy Guidelines for People with Systemic Sclerosis" was produced and then made available on a Brazilian medical school website. It has six pages, including cover, development/content, references, and back cover. An adaptation of the booklet is available in Figures 1 to 3. Diverse themes were addressed, including definitions of SSc, Raynaud's phenomenon and calcinosis (Figure 1), The information included self-care measures that to skincare and prevention of Raynaud's phenomenon, digital pulp ulcers, calcinosis and joint lesion (Figure 2). It also covers skin care, energy conservation measures, massages, stretching, and strengthening exercises for the hands (Figure 3).

The booklet's online publication was made through a Brazilian medical school website, a rheumatoid arthritis blog, social networks, and groups of patients with rheumatic diseases. According to these social networks' access information, 4149 accounts were reached on Facebook and 1619 in Instagram, until November 15, 2020.

There were 495 single page views on a Brazilian medical school website and 95 visits to a rheumatoid arthritis blog publication. Through reactions, likes (139 on Facebook and 44 on Instagram), and online or in-person comments, it was noted that patients who accessed the printed or digital booklet were satisfied. New demands for information have emerged, and there is a proposal to develop new booklets that will address other aspects of the disease, including oral health, the involvement of the gastrointestinal and pulmonary systems.

## DISCUSSION

In the sixties and seventies, health professionals were responsible for the diagnosis, treatment, and monitoring of patients, the latter being considered passive participants in the process of diagnosis and decision-making in treatment. From the eighties onwards, several countries established laws that gave the patient the right to know about their health condition and give their opinion on treatment.

Since the nineties, patients have been actively involved in promoting their health, sharing health professionals' responsibility for treatment decisions and goals, eliciting a more balanced dialogue instead of a paternalistic model. At this time, the importance of the patients' self-regulatory behaviors in their daily life and treatment became evident,

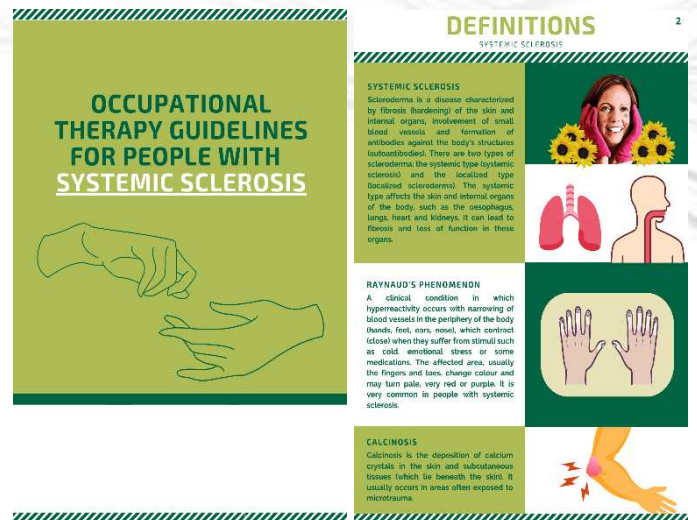


Figure 1. Cover and 2<sup>nd</sup> page of the booklet - Definitions of systemic sclerosis, Raynaud's



Figure 2. 3<sup>rd</sup> and 4<sup>th</sup> page of the booklet - Self-care measures to prevent Raynaud's phenomenon, digital pulp ulcers, calcinosis and joint lesion



Figure 3. 5<sup>th</sup> page and back cover of the booklet - Guidance on energy conservation measures, massages, stretching, and strengthening exercises for the hands

leading to a more significant concern with the patient education process. It allowed a critical change in the health professional-patient relationship, focusing more on the individual and its necessities.<sup>18,19</sup>

Patient education is defined as “any set of planned educational activities designed to improve patients health behaviours and/or health status”.<sup>11</sup> Its benefits include improvement of their knowledge about the disease, better communication between the patient and the health professionals, and better awareness of the need for treatment and follow up consultations.

Educated patients can develop their own opinions and take an active role in decision making. It improves their self-care abilities, crisis management capacity, and problem-solving skills, generating emotional well-being and improving quality of life. Health education reduces the need for screening and diagnosis procedures, leading to better use of time and resources.<sup>18,19</sup>

Nevertheless, there are some challenges in educating patients with SSc. It demands a lot of effort and patience from the health professionals since it is a complicated disease with a complex pathophysiological mechanism that concerns several physiological systems and requires monitoring by multiple specialties. Furthermore, there is a deficiency in good-quality information about SSc on the internet, leading to misconceptions about its repercussions and its prognosis.

One study investigating the quality and readability of internet-based information relating to Raynaud’s phenomenon and SSc showed that overall the data is of low quality (including treatment choices) and is very difficult to read (i.e., only suitable for higher education grade users).<sup>21</sup> In another study, patients with SSc have recognised the need for good quality information and support to help them to manage the physical, psychological, and social difficulties they face.<sup>22</sup>

Another difficulty is to teach patients with a low level of literacy, as they have more information needs<sup>23</sup> and more difficulty in understanding education materials.<sup>24</sup> To succeed in health education, it is necessary to produce materials with an appropriate level of complexity. Materials written in easy-to-understand language contribute to greater patient satisfaction with clinical follow-up and enable greater autonomy in self-care and treatment.<sup>25</sup>

It is recommended to avoid complex words and technical terminologies in patient education materials, to make the reading easier, inviting and understandable.<sup>26,27</sup> Furthermore, the extent of the materials should not be too short nor too long. The design and illustrations of the material should help in understanding the text and reinforce the comprehension of the information, contributing to the educational process. They must be aesthetically pleasing, easy to understand and suitable for the target audience, without being infantilizing or condescending.<sup>28</sup>

During the COVID-19 pandemics, health professionals faced the challenge of informing patients by distance, since the in-person appointments became limited to patients with complications and severe conditions. Once not possible to keep some of the in-person activities, one solution was to promote patient education through digital resources. Although there was a concern with patients' access to the internet, people are increasingly using online sources of information and

support.<sup>22,29</sup>

Thus, it turned out to be an opportunity to test new vehicles to disseminate health education. In this study, the booklet's online dissemination expanded its reach and proved to be well accepted by the patients. It evidenced that online education is a good alternative for patients' education, informing them about their condition and their treatment, especially when there is a restriction on in-person distribution.

However, the present study has some limitations. It lacks a validation process to assess the degree of satisfaction of the patients and their level of understanding of the booklet. Also, it doesn't present a validation process with health professionals to assess the quality of the content.

No design professionals rated the quality of the diagramming and illustrations. Thus, an objective analysis of the final result of the booklet and its impacts was not carried out. In addition, the booklet did not cover all patients' demands, remaining some regarding oral, oesophageal and pulmonary involvement, which we aim to address in future works.

## CONCLUSIONS

All health professionals who integrate the multi-professional team involved in treating these patients must provide them and their families with information about their condition, their treatment, and the prevention of possible complications.

Once patients are well-informed, they can make conscious choices about their self-care and manage their condition, taking an active role in their treatment.<sup>18,19</sup> The production of materials, like this one, that addresses multidisciplinary self-care measures of patients with SSc is necessary.

The education booklet, whose development process was described in this study, provides essential educational information about SSc in response to patients' demands at the Rheumatology Outpatient Clinic. Its distribution through digital means made it possible to reach people from distant locations and turned the dispersal process faster. There was a good acceptance of the information covered in this material, which improved patients' education and generated new demands, stimulating new educational strategies.

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