## Title
Living with Systemic Sclerosis: A Patient and Physician Perspective



## Journal
Rheumatology and Therapy, 10(4)

## ISSN
2198-6576

## Authors
Young, Arissa
Rudy, Brittany
Volkmann, Elizabeth R

## Publication Date
2023-08-01

## DOI
10.1007/s40744-023-00555-z

Peer reviewed

Rheumatol Ther (2023) 10:785–792
https://doi.org/10.1007/s40744-023-00555-z

COMMENTARY

# Living with Systemic Sclerosis: A Patient and Physician Perspective

Arissa Young · Brittany Rudy · Elizabeth R Volkmann

Received: February 25, 2023 / Accepted: April 20, 2023 / Published online: May 13, 2023


## ABSTRACT

The fears associated with being diagnosed with a disease unfamiliar to many, systemic sclerosis, is described by a patient living with systemic sclerosis. The patient, a coauthor, also describes the challenges of being a young person diagnosed with a chronic and, at times, debilitating disease. Despite initially being told that she had 6 months to live, she has embraced life and has become a fierce advocate for others living with systemic sclerosis. The physician perspective is provided by two rheumatologists who specialize in systemic sclerosis and work at a scleroderma center of excellence. This section details the current challenges in diagnosing systemic sclerosis early and the dangers of a delayed diagnosis. It also reviews the importance of multidisciplinary specialty centers in the care of patients with systemic sclerosis as well as empowering patients through education.

**Keywords:** Advocacy; Education; Patient perspective; Systemic sclerosis; Scleroderma

**Key Summary Points**

This article describes the journey of one of the co-authors, a patient living with systemic sclerosis.

She describes her journey from her diagnosis at 20 years old to her life today as an advocate for others living with systemic sclerosis.

The physician perspective discusses challenges in diagnosing systemic sclerosis as well as keys to a timely diagnosis.

The physician perspective also emphasizes the importance of multi-disciplinary care and patient education in the care of patients with systemic sclerosis.

## MY STORY

"I'm so sorry, you're so young, you have scleroderma", turned out to be the second most impactful statement on my life and I had no clue at the time. Those words were closely followed by, "I'm giving her 6 months and that's

A. Young · Elizabeth RVolkmann (✉)
University of California, Los Angeles, 200 Medical Plaza Suite 365-C, Los Angeles, CA 90095, USA
e-mail: evolkmann@mednet.ucla.edu

B. Rudy
Patient Author, Los Angeles, CA, USA

pushing it" and a hug from a doctor upon our first meeting, turned out to be the first.

At 20 years old, I sat in a cold rheumatologist's office with my mom after experiencing various symptoms over the last year. A year prior I had been diagnosed with Raynaud's phenomenon, as no other symptoms had presented themselves. Within a year of that diagnosis, symptoms started to randomly show up: heart burn, difficulty swallowing, dry eye and mouth, joint pain, weight loss, tiredness, and a constant dry cough. With a referral to the rheumatologist, I took all symptoms and the minimal blood work that had been run, to see if we could get an answer. Nothing could have prepared me for what came next. My purple/numb fingers were about to become the least of my worries.

He asked me what seemed like 100 questions and none of them made sense or fit together. I answered each question, wondering what he was getting at. He listened to my lungs and felt my skin, the "pinch test". Then he looked at my mom and I, with defeat in his eyes and said, "I'm so sorry, you're so young, you have scleroderma". We had never heard of it, so asked what it was, what this meant. He didn't explain much, he handed us a stack of papers and told us not to Google it. My Mom asked, "so what's next, what does the long-term diagnosis look like?" He answered with "there is no long term. I'm giving her 6 months and that's pushing it.". CRUSHED is an understatement. I was completely numb. He informed us I needed a specialist and that he knew one at a well-known scleroderma center. He would put the call in for us along with the referral and he hugged us and sent us on our way.

I'm not sure if you've ever been hugged by a doctor, but it's different when it's your first time meeting them, and they just put an expiration date on your life. I was 20 years old; 3 months shy of my 21st birthday.

I was given a devastating diagnosis, with no proper testing and minimal blood work. He recognized from my symptoms (hardened skin and the sound of my lungs) that I was already deep into the disease and needed more medical attention than he could properly provide. For that I am forever thankful. He was an asset in my medical diagnosis and a vital part of my journey with scleroderma and how my life turned out.

By the next month, with his referral and many calls from my mom, I was able to be seen by my *lifesaver* and the team of amazing doctors whom I can't even express enough thankfulness for! Many tests were run and a crazy amount of blood work later, my final diagnosis was confirmed, diffuse systemic scleroderma with pulmonary fibrosis (SSc-ILD); the damage was extensive and the disease was progressing quickly. We needed to be aggressive with treatment. My doctor, my lifesaver, made sure to reassure us that this diagnosis was not a death sentence; it would not be easy, but there was hope.

I was diagnosed in May of 2016, officially confirmed in June of 2016, and I started aggressive treatment in July of 2016. My worries went from what I'd wear when we went to the bar for my 21st birthday, to how I'd feel each day waking up and if I'd make it through the day without getting sick. From what color to dye my hair next, to waking up every morning scared to lift my head off the pillow in fear that I'd seen my first chunk of hair falling out. From whom I was going to marry and what career I'd have, to if I'd live long enough to experience those joys. Some would argue that I was more focused on the vain parts of life than actually living and I'd say you are correct, but I was 20 years old and I'm human. In a sense, I was forced to grow up quicker than I wanted to. Having to make life-altering decisions and accept a disease that I did nothing to cause was not easy.

At some point, not long after diagnosis, I was sent a quote. "She is clothed in strength and dignity and she laughs without fear of the future", now I had seen this many times before, but it didn't resonate with me, until then. I kept reading that over and over and realized that "she" was who I wanted to become "she" was who I wanted to be. The she, who was strong, resilient and fights with all that she has, takes all the chances, she also does all that she can to make her life, hers. I no longer wanted to be someone who has a life controlled by scleroderma, rather a life with scleroderma, and so I

became her, so much so that the quote is tattooed on my shoulder as a daily reminder, that I am her.

I went from not even taking a daily vitamin to a medication regimen that needed to be closely followed. Treatment began to halt the disease and it was terrifying, knowing what I had to pump into my body, just to try to slow the progression, with no guarantees that it would work. It helped, but wasn't sufficient, and another medication had to be added to the regimen. I was hesitant to add the second medication, thinking that if the first wasn't working, how would adding the second help? My doctor brought in the big guy, my second lifesaver, to explain to me that this was basically our only option. He understood my hesitations, all the side effects, and possible complications that could come with these and he explained it all in depth. By the end of the discussion, it was agreed that we would try it. It ended up being the best decision that we could have made. It is part of the reason I am where I am today.

Although my doctor has so much knowledge of the disease, other specialists were added to my team as well. A pulmonologist and gastroenterologist who also have extensive knowledge in the disease and are at the same clinic, were the first to be added. Soon after a dentist with knowledge of scleroderma, along with an ENT. A physical therapist and occupational therapist, whom both had little knowledge of the effects, worked very hard to learn and adapt my care. We did seek a second opinion from a doctor out of state, not because we didn't trust my doctor here, more so just to get a fresh pair of eyes on my case. He was impressed with the care I was receiving and believed we were on the right track; he did suggest a slight change to a medication, and it's been how I've done it ever since. My medical team is the best, we have been so fortunate.

With treatment, countless medications and vitamins, amazing doctors, physical and occupational therapy, positivity, knowledge, and so much support, I am here today. It's been almost 11 years since my devastating diagnosis. That's 10.5 years past, what was "expected", and he thought 6 months was pushing it? I will continue to push it, if it means I get to continue on this journey. Scleroderma, ILD, Raynaud's disease… none of these diseases are easy. They are hard and devastating, but I can't help but think where my life would be without them. Within the last 10 years I: graduated college with my bachelors in Child and Adolescent Development, witnessed the growth of all the new baby cousins and have had the joy of being part of their lives, witnessed my sister find her calling and grow with her career, have the ability to continue to work full-time while also having the chance to share my story, became a Co-Leader of the Young Adults Support Group and working towards giving patients what I didn't have when I was diagnosed, have had opportunities to witness my family hit so many amazing milestones together and create and grow in a "normal" relationship that I always thought I'd miss out on. Scleroderma taught me how to live, love, and how to accept. I've lived a lot of the last almost 11 years, like they really were my last 6 months. I learned love, a hardcore love, a love that doesn't give up and gives you strength when you need it most, my support system (my entourage), and how to accept the unknown and take what life gives you and make the most of it!

## PHYSICIAN PERSPECTIVE

### Delayed Diagnosis—Challenges and Future Directions

Systemic sclerosis (SSc) is an autoimmune fibrosing disease that affects 24.4 in 100,000 people in the United States [1]. Given its rarity in the general population, delays in diagnosis are common. Early in the SSc disease course, patients often present to their primary care physicians with a constellation of non-specific signs and symptoms, including fatigue and Raynaud phenomenon [2]. Depending on the cutaneous subtype of SSc (e.g., limited versus diffuse cutaneous disease), the timing of the evolution of symptoms varies. For example, in patients with limited cutaneous sclerosis, patients may present with isolated Raynaud phenomenon, and it may take 5–10 years for the next manifestation of SSc to occur [3]. Both

the non-specific nature of the symptoms and the variable course of the disease make it a challenging diagnosis for both rheumatologists and non-rheumatologists alike. In fact, a study of patients with scleroderma in Canada found that the average time to diagnosis was 2.4 years [4].

Delays in diagnosis often lead to increased morbidity and mortality, as early therapeutic intervention may prevent progression of internal organ involvement. Given the importance of early diagnosis, developing criteria for the early diagnosis of SSc has been the subject of intense investigation. In a study by Koenig and colleagues, investigators followed 586 patients with Raynaud phenomenon for 26 years and found that 65.9% of patients with abnormal nailfold capillaroscopy and SSc-specific autoantibodies at baseline developed definite SSc at 5 years [5]. More recently, the European League Against Rheumatism (EULAR) Scleroderma Trial and Research (EUSTAR) group established a proposed workflow for the diagnosis of very early SSc. In their proposed algorithm, Raynaud phenomenon, puffy fingers, and positive antinuclear antibodies are considered red flags and should trigger referral to a rheumatologist for further evaluation [6]. Thus, a reasonable approach for a primary care provider would be to obtain antinuclear antibodies in patients with a history of Raynaud phenomenon and/or puffy fingers along with prompt referral to a rheumatologist. Rheumatologists can then perform nailfold capillaroscopy and more specific and comprehensive autoantibody testing to confirm the diagnosis. This workflow will hopefully minimize delays in diagnosis and facilitate earlier therapeutic intervention and appropriate monitoring of the disease.

## Specialty Centers—Access to Experts and Clinical Trials

Once a diagnosis of SSc has been made, referral to a center that specializes in the care of patients living with SSc is essential. According to the National Scleroderma Foundation, there are currently 61 Designated Scleroderma Research & Treatment Centers in the United States [7]. To be listed as a Scleroderma Center, facilities are required to have physicians with expertise in scleroderma, conduct scleroderma research, and provide educational activities and information for patients and families of patients with scleroderma [7]. Seeking care at a specialty center has several advantages. First, it allows patients to be monitored and treated according to the latest evidence in scleroderma research. Second, specialty centers are a way for patients to learn about and enroll in clinical trials. Lastly, many specialty centers allow patients to access multiple specialists with expertise in SSc in one place.

One caveat, however, is that at present, scleroderma specialty centers only exist in 21 out of 50 states. This presents a challenge for patients who are living outside of these states to access expert care. It is therefore critical that physicians, allied healthcare professionals, and patients in these areas arm themselves with information about this disease and its associated complications. For example, knowledge about the appropriate baseline screening assessments for interstitial lung disease and pulmonary hypertension are essential since these manifestations contribute to the highest morbidity and mortality associated with the disease [8]. Patients with SSc should undergo baseline high-resolution computed tomography (HRCT) scans of the chest, pulmonary function tests, and echocardiogram to screen for the presence of one or both of these complications. These tests should be repeated throughout the disease course based on patient-specific factors, disease progression, and symptoms [9]. Additionally, telemedicine presents an opportunity for patients who do not live in a state with a scleroderma specialty center to seek the expert opinion of scleroderma specialists. Alternatively, patients can contact their country's scleroderma patient advocacy group to inquire about the nearest specialty center where they can be seen once or twice a year [7]. It is vital, however, that patients who are seen remotely by a scleroderma specialist or who travel only once or twice a year to a specialty center also have a local rheumatologist to help execute and coordinate their care.

## Multidisciplinary Care—Communication is Key

As noted previously, specialty centers offer the advantage of bringing together multiple specialists with expertise in caring for patients with SSc. Given that SSc affects multiple organ systems, it is critical that the healthcare team caring for these patients reflects the multidisciplinary nature of the disease. Health professionals who are needed in the care of patients with SSc include rheumatologists, pulmonologists, dermatologists, gastroenterologists, hematologist/oncologists, radiologists, pathologists, and cardiologists among others. With such a diverse team of experts, communication among providers is an essential piece of providing optimal care. Patients and physicians benefit from interdisciplinary rounds where multiple specialists gather to discuss complex cases and develop treatment plans.

Many patients with SSc also benefit from having nutritionists, respiratory therapists, physical and occupational therapists, and psychologists as members of their healthcare team. Patients with this disease suffer from disability as a result of skin disease and joint contractures, and participation in physical and occupational therapy programs can decrease long-term disability [10, 11]. Patients with SSc are also at higher risk than the general population to develop depressive symptoms. In a study by Benrud-Larson et al., investigators surveyed 142 patients with SSc and found that 50% of patients reported at least mild depressive symptoms [12]. Additionally, fatigue is one of the most common symptoms of SSc and has a significant impact on patients' quality of life. A multidisciplinary task force in the Netherlands developed recommendations for the non-pharmacological treatment of fatigue in patients with SSc. Per their recommendations, patients with SSc who report fatigue should be educated about maintaining a physically active lifestyle, good sleep hygiene, as well as relaxation techniques, healthy diet, and the association between fatigue and certain medications. Additionally, they recommended that patients with persistent fatigue that affects their daily life receive psychoeducational interventions (by a nurse, social worker, or occupational therapist), cognitive behavioral therapy, participation in group classes, and assistance with modifying their work environment or switching to a different work environment [13]. Lastly, GI dysmotility, decreased absorption, and decreased oral aperture can make it difficult for patients to meet their nutritional requirements and as a result, 18% of patients with SSc suffer from malnutrition [14]. Registered dieticians and nutritionists can help prevent and/or reverse malnutrition in these complex patients.

## Patient Education—Knowledge is Power

Optimal management of SSc requires an ongoing partnership between patients and physicians. In order to be an active participant in their care and make informed treatment decisions, it is imperative that patients become knowledgeable about their disease. Given how rare SSc is, many patients with the disease first learn about it in their initial rheumatology visit. As such, the responsibility for educating patients largely lies with rheumatologists. This is especially important in the age of the Internet, a time in which patients have access to nearly unlimited information, much of which may not be relevant to them. Educating patients up front may lessen the fear and devastation around their diagnosis as they are able to understand their individual disease instead of looking to the internet for answers [15].

Patient education is also critical for the early detection of complications of SSc. For example, interstitial lung disease (ILD) affects 47–84% of patients with SSc and is the leading cause of SSc-related death [10]. As such, all patients should have a baseline high-resolution chest CT to screen for ILD. Specific patient factors are associated with an increased risk of developing ILD, including diffuse cutaneous SSc, male sex, Afro-Caribbean ethnicity, and anti-topoisomerase I positivity [16]. However, patients without these risk factors (e.g., female patients, patients with limited cutaneous disease) can develop ILD. With the expansion of therapeutic options for managing SSc-ILD, patients should receive education regarding the risks and benefits of

these different therapies, and efforts should be made to personalize the care for patients based on their unique disease features and underlying co-morbidities. Nonpharmacologic treatments for ILD should also be discussed with patients, including the importance of staying up to date on age-appropriate vaccinations and abstaining from smoking or vaping. Other nonpharmacologic treatments such as occupational therapy, physical therapy, nutritional guidance, psychological support, pulmonary rehabilitation, and oxygen therapy should also be offered when appropriate [17]. Patients should also be educated about the importance of controlling gastroesophageal reflux disease (GERD), as there has been some evidence that uncontrolled GERD is associated with progression of ILD [18, 19]. Treatment of GERD should also include both pharmacologic treatment with proton pump inhibitors and non-pharmacologic treatments [20] including dietary adjustments and lifestyle changes (avoiding eating close to bedtime and elevating the head of the bed).

Patient education is also important for symptom management. For example, a study examining the effects of an Internet-based educational program found that patients with SSc who participated in the program experienced significant decreases in fatigue and depression [21]. Additionally, another study evaluated a home-based program for hand exercises in patients with SSc. The investigators observed a significant improvement in hand pain and hand function at the end of 8 weeks [22].

Lastly, it is important for rheumatologists to provide information about support groups. Although some patients may find it challenging and at times frightening to spend time with others whose disease is more advanced, many patients find support groups immensely helpful. Given the rarity of SSc, connecting with others who have shared experiences can be tremendously comforting.

Providing patients with information and resources empowers them to participate in the shared decision-making process and fosters their sense of autonomy. Additionally, patients who are aware of the complications of SSc are able to better advocate for themselves when they are seeing other providers who may not be as knowledgeable about their disease.

## ACKNOWLEDGEMENTS

***Funding.*** Elizabeth Volkmann is supported by the National Heart, Lung, and Blood Institute (grant number K23 HL150237), the funds of which were used to support the writing of this manuscript. No funding was received for the publication of this article.

***Authorship.*** The authors are fully responsible for all content. All named authors meet the International Committee of Medical Journal Editors (ICMJE) criteria for authorship for this article, take responsibility for the integrity of the work as a whole, and have given their approval for this version to be published. The opinions expressed in the manuscript are those of the authors.

***Author Contributions.*** Writing—original draft preparation: Arissa Young; Writing – original draft preparation: Brittany Rudy; Writing—review and editing: Elizabeth Volkmann.

***Disclosures.*** Arissa Young and Brittany Rudy declare that they have no competing interests. Elizabeth Volkmann reports the following financial relationships outside of the submitted work: Consulting (Boehringer Ingelheim, Roche, CSL Behring, GSK); Speaking (Boehringer Ingelheim); Institutional support received for performing studies in systemic sclerosis for Kadmon, Forbius, Boehringer Ingelheim, Horizon, Prometheus. Dr Volkmann is currently supported by the National Heart, Lung, and Blood Institute (grant number K23 HL150237).

***Compliance with Ethics Guidelines.*** This article does not contain any new studies with human or animal subjects performed by any of the authors.

***Data Availability.*** Data sharing is not applicable to this article as no datasets were generated or analyzed during the current study.

## REFERENCES

1. Fan Y, Bender S, Shi W, Zoz D. Incidence and prevalence of systemic sclerosis and systemic sclerosis with interstitial lung disease in the United States. J Manag Care Spec Pharm. 2020;26(12):1539–47. https://doi.org/10.18553/JMCP.2020.20136.

2. Distler O, Allanore Y, Denton CP, Matucci-Cerinic M, Pope JE, Hinzmann B, Khanna D. Factors influencing early referral, early diagnosis and management in patients with diffuse cutaneous systemic sclerosis. Rheumatology. 2018;57(5):813–7. https://doi.org/10.1093/RHEUMATOLOGY/KEX504.

3. Volkmann ER, Andréasson K, Smith V. Systemic sclerosis. Lancet. 2023;401(10373):304–18. https://doi.org/10.1016/S0140-6736(22)01692-0.

4. Johnson SR, Carette S, Dunne JV. Scleroderma: health services utilization from patients' perspective. J Rheumatol. 2006;33(6):1123–7.

5. Koenig M, Joyal F, Fritzler MJ, Roussin A, Abrahamowicz M, Boire G, Senécal JL. Autoantibodies and microvascular damage are independent predictive factors for the progression of Raynaud's phenomenon to systemic sclerosis: A twenty-year prospective study of 586 patients, with validation of proposed criteria for early systemic sclerosis. Arthritis Rheum. 2008;58(12):3902–12. https://doi.org/10.1002/art.24038.

6. Avouac J, Fransen J, Walker UA, Riccieri V, Smith V, Muller C, Sampaio-Barros P. Preliminary criteria for the very early diagnosis of systemic sclerosis: Results of a Delphi consensus study from EULAR scleroderma trials and research group. Ann Rheum Dis. 2011;70(3):476–81. https://doi.org/10.1136/ard.2010.136929.

7. "Find a treatment center." National Scleroderma Foundation, 2022, https://scleroderma.org/find-a-treatment-center/. January 20, 2023.

8. Solomon JJ, Olson AL, Fischer A, Bull T, Brown KK, Raghu G. Scleroderma lung disease. Eur Respir Rev. 2013;22(127):6–19. https://doi.org/10.1183/09059180.00005512.

9. Volkmann E. Systemic sclerosis. Lancet. 2023;401(10373):304–18. https://doi.org/10.1016/S0140-6736(22)01692-0.Systemic.

10. Liem SIE, Vlieland TPMV, Schoones JW, de Vries-Bouwstra JK. The effect and safety of exercise therapy in patients with systemic sclerosis: a systematic review. Rheumatol Adv Pract. 2019;3(2):1–13. https://doi.org/10.1093/rap/rkz044.

11. Stefanantoni K, Sciarra I, Iannace N, Vasile M, Caucci M, Sili Scavalli A, Massimiani MP, Passi L, Maset L, Riccieri V. Occupational therapy integrated with a self-administered stretching program on systemic sclerosis patients with hand involvement. Clin Exp Rheumatol. 2016;34(5):157–61.

12. Benrud-Larson LM, Haythornthwaite JA, Heinberg LJ, Boling C, Reed J, White B, Wigley FM. The impact of pain and symptoms of depression in scleroderma. Pain. 2002;95(3):267–75. https://doi.org/10.1016/S0304-3959(01)00409-2.

13. Stöcker JK, Schouffoer AA, Spierings J, Schriemer MR, Potjewijd J, De Pundert L, Van Den Ende CHM. Evidence and consensus-based recommendations for non-pharmacological treatment of fatigue, hand function loss, Raynaud's phenomenon and digital ulcers in patients with systemic sclerosis. Rheumatology. 2022;61(4):1476–86. https://doi.org/10.1093/rheumatology/keab537.

14. Keane N, Ghannam A, Fragkos KC, Rahman F. Oral, enteral and parenteral nutritional therapies in scleroderma: a systematic review. Clinical Nutrition ESPEN. 2022;51:174–84. https://doi.org/10.1016/j.clnesp.2022.06.108.

15. Nakayama A, Tunnicliffe DJ, Thakkar V, Singh-Grewal D, O'Neill S, Craig JC, Tong A. Patients' perspectives and experiences living with systemic sclerosis: a systematic review and thematic synthesis of qualitative studies. J Rheumatol. 2016;43(7):1363–75. https://doi.org/10.3899/jrheum.151309.

16. Distler O, Assassi S, Cottin V, Cutolo M, Danoff SK, Denton CP, Maher TM. Predictors of progression in systemic sclerosis patients with interstitial lung disease. Eur Respir J. 2020. https://doi.org/10.1183/13993003.02026-2019.

17. Khanna D, Lescoat A, Roofeh D, Bernstein EJ, Kazerooni EA, Roth MD, Denton CP. Systemic sclerosis-associated interstitial lung disease: how to incorporate two food and drug administration-approved therapies in clinical practice. Arthr Rheumatol. 2022;74(1):13–27. https://doi.org/10.1002/art.41933.

18. Tashkin DP, Volkmann ER, Tseng CH, Roth MD, Khanna D, Furst DE, Elashoff RM. Improved cough and cough-specific quality of life in patients treated for scleroderma-related interstitial lung disease: results of scleroderma lung study II. Chest. 2017;151(4):813–20. https://doi.org/10.1016/j.chest.2016.11.052.

19. Volkmann ER, Tashkin DP, Leng M, Kim GHJ, Goldin J, Roth MD. Association of symptoms of gastroesophageal reflux, esophageal dilation, and progression of systemic sclerosis-related interstitial lung disease. Arthritis Care Res (Hoboken). 2022. https://doi.org/10.1002/acr.25070.

20. Hughes M, Allanore Y, Baron M, Galdo F, Del Denton CP, Frech T, Matucci-cerinic M. Viewpoint Proton pump inhibitors in systemic sclerosis : a reappraisal to optimise treatment of gastro-oesophageal reflux disease. 2022;4: 795–803.

21. Poole JL, Mendelson C, Skipper B, Khanna D. Taking charge of systemic sclerosis: a pilot study to assess the effectiveness of an internet self-management program. Arthritis Care Res. 2014;66(5):778–82. https://doi.org/10.1002/acr.22192.

22. Landim SF, Bertolo MB, Marcatto de Abreu MF, Del Rio AP, Mazon CC, Marques-Neto JF, de Paiva Magalhães E. The evaluation of a home-based program for hands in patients with systemic sclerosis. J Hand Therapy. 2019;32(3):313–21. https://doi.org/10.1016/j.jht.2017.10.013.