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Educational leaflet to promote physical activity in patients with systemic sclerosis

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Preface

My primary motivation throughout this project has been my passion for enhancing patient education, particularly within the realm of physiotherapy. The desire to empower patients through effective exercise regimens and educational tools has driven this work, and I am grateful for the opportunity to contribute to this important field.

I extend my heartfelt thanks to my supervisor, Prof. Dr. Vanessa Smith, and my co-supervisor, Prof. Dr. Jessica Van Oosterwijck, for their invaluable guidance and support throughout this research. Their expertise and encouragement have been instrumental in shaping the direction and success of this project.

I am also deeply appreciative of Axelle Van Cayseele for her exceptional graphic design work, which greatly enhanced the visual appeal and effectiveness of the educational materials. Her creative contributions were essential in bringing the project to life.

Special thanks go to my partner for his unwavering support and assistance in producing the instructional videos, and to my father for his help in creating and printing the educational leaflets. Their support has been a cornerstone of this project's success.

Finally, I would like to express my gratitude to everyone who has been involved in this journey. Your contributions have made this thesis possible and have significantly enriched the learning experience for both myself and the patients we aim to support.

Lena De Moor

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List of Abbreviations

SSc	Systemic sclerosis
cNCDs	chronic Non-Communicable Diseases
HRQoL	Health Related Quality of Live
RP	Raynauds Phenomenon
PF	Physical Functioning
HRmax	Maximal Heart Rate:
HIIT	High-Intensity Interval Training
RV	Right Ventricular
RM	Repetitions Maximum
Borg RPE	Borg Rating of Perceived Exertion
MCP	Metacarpophalangeal
IP	Interphalangeal
PIP	Proximal interphalangeal
HAQ	Health Assessment Questionnaire
HAMIS	Hand Mobility of Scleroderma
VAS	Visual Analogue Scale
ROM	Range Of Motion
RCT	Randomized Controlled Trial
PILs	Patient Information Leaflets
P-PILs	Pictogram-based Patient Information Leaflets

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Abstract

Systemic sclerosis (SSc) is a rare autoimmune disease that significantly impacts patients' physical and psychosocial well-being. Despite the potential benefits of non-pharmacological interventions like exercise in managing SSc symptoms, current integration of physical therapy into SSc care is inadequate. This study aimed to summarize existing recommendations and evidence on physical activity for SSc patients and to develop an educational leaflet to promote self-management and physical activity. A comprehensive literature review was conducted to identify safe and effective exercises, which were then refined through consultations with rehabilitation specialists, rheumatologists, and SSc patients. The leaflet focuses on various exercise modalities including aerobic, muscle strengthening, stretching, hand exercises, and mouth opening exercises. Additionally, the study explores patients' perceptions of exercise and the barriers they face, emphasizing the importance of patient education and empowerment. The findings suggest that while physical activity is crucial for improving health-related quality of life in SSc patients, further research is needed to develop specific exercise recommendations and evaluate the efficacy of educational leaflets in both patient and professional education.

Abstract (NL)

Systemische sclerose (SSc) is een zeldzame auto-immuunziekte die de fysieke en psychosociale gezondheid van patiënten aanzienlijk beïnvloedt. Ondanks de potentiële voordelen van niet-farmacologische interventies zoals oefeningen bij het beheersen van SSc-symptomen, is de huidige integratie van fysieke activiteit in de SSc-zorg onvoldoende. Deze studie had als doel de bestaande aanbevelingen en evidentie over fysieke activiteit voor SSc-patiënten samen te vatten en een educatief leaflet te ontwikkelen om zelfmanagement en fysieke activiteit te bevorderen. Een uitgebreide literatuurstudie werd uitgevoerd om veilige en effectieve oefeningen te identificeren, die vervolgens werden verfijnd door middel van consultaties met revalidatiespecialisten, reumatologen en SSc-patiënten. Het leaflet richt zich op verschillende oefenmodaliteiten, waaronder aerobics, spierversterking, stretching, handoefeningen en mondopeningsoefeningen. Daarnaast onderzoekt de studie de percepties van patiënten over oefeningen en de obstakels die zij ondervinden, waarbij het belang van patiënteneducatie en empowerment wordt benadrukt. De bevindingen suggereren dat hoewel fysieke activiteit cruciaal is voor het verbeteren van de gezondheidsgerelateerde kwaliteit van leven bij SSc-patiënten, verder onderzoek nodig is om specifieke oefenaanbevelingen te ontwikkelen en de doeltreffendheid van educatieve leaflets te evalueren in zowel patiënten- als professionele educatie

Introduction

Systemic sclerosis (SSc) is a rare autoimmune disease characterized by skin fibrosis and internal organ involvement, posing significant challenges to patients' health and well-being. It can be classified under the chronic non-communicable diseases (cNCDs). Predominantly affecting women, SSc has a profound impact on both the physical and psychosocial aspects of patients' lives(Bairkdar et al., 2021). Symptoms of SSc that have a high impact on the Health Related Quality of Live (HRQoL) are respectively Raynauds Phenomenon (RP), pain, fatigue, breathlessness, exercise intolerance and cough(Saketkoo et al., 2021). Despite its debilitating nature, non-pharmacological interventions, particularly exercise, show promise in managing SSc-related symptoms such as pain and fatigue(Saketkoo et al., 2021).

Currently, the integration of non-pharmacological care, in management of persons affected by SSc, including physical therapy, remains inadequate, highlighting unmet healthcare needs among SSc patients. Recognizing the importance of patient education and empowerment, there is a critical need for accessible resources that promote self-management and increase awareness of non-pharmacological interventions(Smith et al., 2018; Spierings et al., 2019).To address this gap, this thesis advocates for the development (together with persons affected by SSc) of educational materials, such as leaflets supplemented with animations and pictures, tailored to the specific needs of SSc patients(Spierings et al., 2019).

Given the chronic and multifaceted nature of SSc, a comprehensive approach that encompasses multidisciplinary care and rehabilitation interventions is essential to optimize patient outcomes and quality of life. However, despite advancements, challenges persist. SSc patients often exhibit limited exercise capacity compared to healthy individuals and low levels of physical activity in daily life(S. I. E. Liem, Vliet Vlieland, Schoones, & de Vries-Bouwstra, 2019). To mitigate these limitations and improve functional ability, holistic management strategies emphasizing rehabilitation interventions are imperative. By fostering greater awareness, education, and access to non-pharmacological support, healthcare professionals can significantly enhance the care and well-being of individuals living with SSc, empowering them to navigate the complexities of their condition and pursue healthier lifestyles(Saketkoo et al., 2021).

Health education is a cornerstone in fostering individual and community well-being by imparting the knowledge and skills essential for promoting healthy lifestyles(Hasanica et al., 2020). Recognized as a cost-effective and rational approach to healthcare, health education aims to expand awareness of personal health and instigate positive behavioral changes conducive to sustained well-being. In the realm of population health, diverse educational methods are employed to disseminate health-related information effectively, with didactic approaches playing a pivotal role. Didactic methods encompass a wide array of educational tools, including medical lectures, health films, multimedia advertising, and notably, leaflets. These materials serve as tangible resources, offering concise yet comprehensive information on various health topics. Designed to supplement traditional educational approaches, leaflets provide accessible, digestible, and visually appealing content.

This article aims to summarize the current recommendations regarding physical activity for patients with systemic sclerosis and contribute to their self-management by providing a comprehensible tool to promote physical activity.

Literature Review

The effects of physical activity on systemic sclerosis

A critical predictor of HRQoL in patients with SSc is physical functioning (PF). Physical activity improves circulation, reduces inflammation, and enhances mobility by increasing strength, reducing stiffness, and boosting aerobic capacity(Pettersson et al., 2021). Even with mild pulmonary involvement, increasing physical activity (e.g., through exercise) and reducing sedentary behavior are essential for self-management in SSc patients(de Oliveira, Portes, Pettersson, Alexanderson, & Boström, 2017).

A systematic review by Liem et al. (2019)(S. I. E. Liem et al., 2019) emphasizes the importance of pre-screening patients and ensuring exercise is supervised by qualified health professionals, particularly for those with cardiopulmonary involvement. Current evidence suggests that physical exercise in SSc patients is generally safe. The pathological changes in affected muscles include atrophy, inflammation, vasculopathy, fibrosis, and necrosis, reflecting the heterogeneous nature of SSc-related myopathy. Proximal muscle groups, in particular, show reduced strength and endurance, especially in patients with cardiopulmonary involvement(Pettersson et al., 2017; Pettersson et al., 2019).

Physical therapy has been recommended by Saketkoo et al. (2021)(Saketkoo et al., 2021) as a crucial component in managing SSc-related muscle involvement, focusing on enhancing muscle strength and preventing large joint contractures. This approach highlights the importance of addressing both functional impairments and structural deformities associated with SSc, thereby improving overall patient outcomes and quality of life.

Additionally, a study by van Leeuwen et al. (2021)(van Leeuwen, Ciaffi, Liem, Huizinga, & de Vries-Bouwstra, 2021) underscores the significant functional impairment associated with SSc-related hand and mouth involvement, as evidenced by decreased mouth opening and hand function, both of which independently contribute to reduced HRQoL.

Clinical trials evaluating various exercise modalities, including mouth exercises, hand exercises, aerobic training, and muscle strengthening, show promising results in improving daily functioning among SSc patients. However, SSc-specific exercises are underutilized compared to generic exercise approaches, raising questions about their inclusion in home exercise regimens prescribed to SSc patients(S. Liem et al., 2022).

In the following paragraphs, the evidence for various exercise modalities will be described.

Aerobic exercise

Petterson et al. (2021)(Pettersson et al., 2021) summarized exercise recommendations and modalities for the general population and individuals with rheumatic and musculoskeletal diseases, as outlined by the American College of Sports Medicine(Garber et al., 2011; Metsios, Moe, & Kitas, 2020).

For aerobic exercise, the goal is to improve aerobic capacity. The recommended training intensity is 55%-90% of the maximal heart rate (HRmax), with sessions lasting 20-90 minutes, performed 3-5 times per week. However, cardiopulmonary involvement must be considered. According to Liem et al. (2019)(S. I. E. Liem et al., 2019), patients with mild to moderate cardiopulmonary involvement can safely perform aerobic exercise, while those with severe symptoms require individualized modifications in exercise intensity and duration.

Liem et al.'s systematic review(S. I. E. Liem et al., 2019) identified only two studies(Mitropoulos, Gumber, Crank, Akil, & Klonizakis, 2018; Oliveira, dos Santos Sabbag, de Sá Pinto, Borges, & Lima, 2009) that investigated the effects of aerobic exercise alone, without combining it with other exercises such as resistance training. Both studies reported positive outcomes on peak oxygen uptake. Mitropoulos et al. (2018)(Mitropoulos et al., 2018) examined the effects of high-intensity interval training (HIIT) using an arm crank ergometer and a stationary home cycle. The program consisted of 30-minute HIIT sessions, with 30 seconds of high-intensity exercise followed by 30 seconds of passive recovery, conducted twice a week for 12 weeks.

Oliveira et al. (2009)(Oliveira et al., 2009) conducted an 8-week program of moderate-intensity (50%-70% of HRmax) aerobic exercise on a treadmill, demonstrating positive results.

Water-based exercises can also be a valuable addition to an exercise regimen(Pettersson et al., 2021). Evidence indicates that aquatic exercise is safe and effective for patients with autoimmune diseases, reducing stiffness, pain, muscle spasms, fatigue, and improving cardiovascular endurance and physical function(Becker, 2009; Lima et al., 2013; Maddali Bongi et al., 2009; Salem et al., 2011; Severin, Burkett, McKean, & Sayers, 2016; Wang, Belza, Elaine Thompson, Whitney, & Bennett, 2007).

However, only one study has examined the effects of aquatic exercises in patients with SSc(Maddali Bongi et al., 2009), showing significant improvements in HRQoL, physical function, and activity.

In this study, the aquatic exercise regimen included a 10-minute warm-up (walking in various directions and swimming), followed by 20 minutes of stretching and pulmonary rehabilitation in the pool. The next 20 minutes focused on treating local and global pain with individualized exercises to enhance mobility, muscle strength, body awareness, coordination, and balance. Each session concluded with a 10-minute relaxing hydromassage in a 35°C Jacuzzi pool.

However, water's rapid heat conduction can pose issues for patients with SSc, considering RP. This can lead to logistical concerns regarding oxygenation, fatigue, and mobility challenges related to dressing, drying, and skincare(Racine, Hudson, Baron, & Nielson, 2016).

Combined aerobic exercise and resistance training

Three out of five studies included in the systematic review by Liem et al.(2019) (S. I. E. Liem et al., 2019) investigated the effects of combined aerobic and muscle strengthening exercises. One such study by Mitropoulos et al.(2019) (Mitropoulos, Gumber, Akil, & Klonizakis, 2019) combined HIIT on an arm crank ergometer (Fig.1A) with upper limb resistance training. This regimen was performed twice a week for 12 weeks. The resistance training included five exercises: 1) chest press with dumbbells on a 30° inclined bench (Fig.1B), 2) lateral raises with dumbbells in a seated position (Fig.1C), 3) biceps curls with dumbbells (Fig.1D), 4) triceps extensions on a pulley from a standing position (Fig.1E), and 5) handgrip exercises with a dynamometer (Fig.1F). These exercises were performed in a circuit format for three rounds, with 2–3 minutes of rest between each round. The intensity was maintained at 10 maximum repetitions, with weights adjusted to account for strength improvements. The exercise group showed significant improvements in peak oxygen uptake and transcutaneous oxygen pressure compared to the control group.

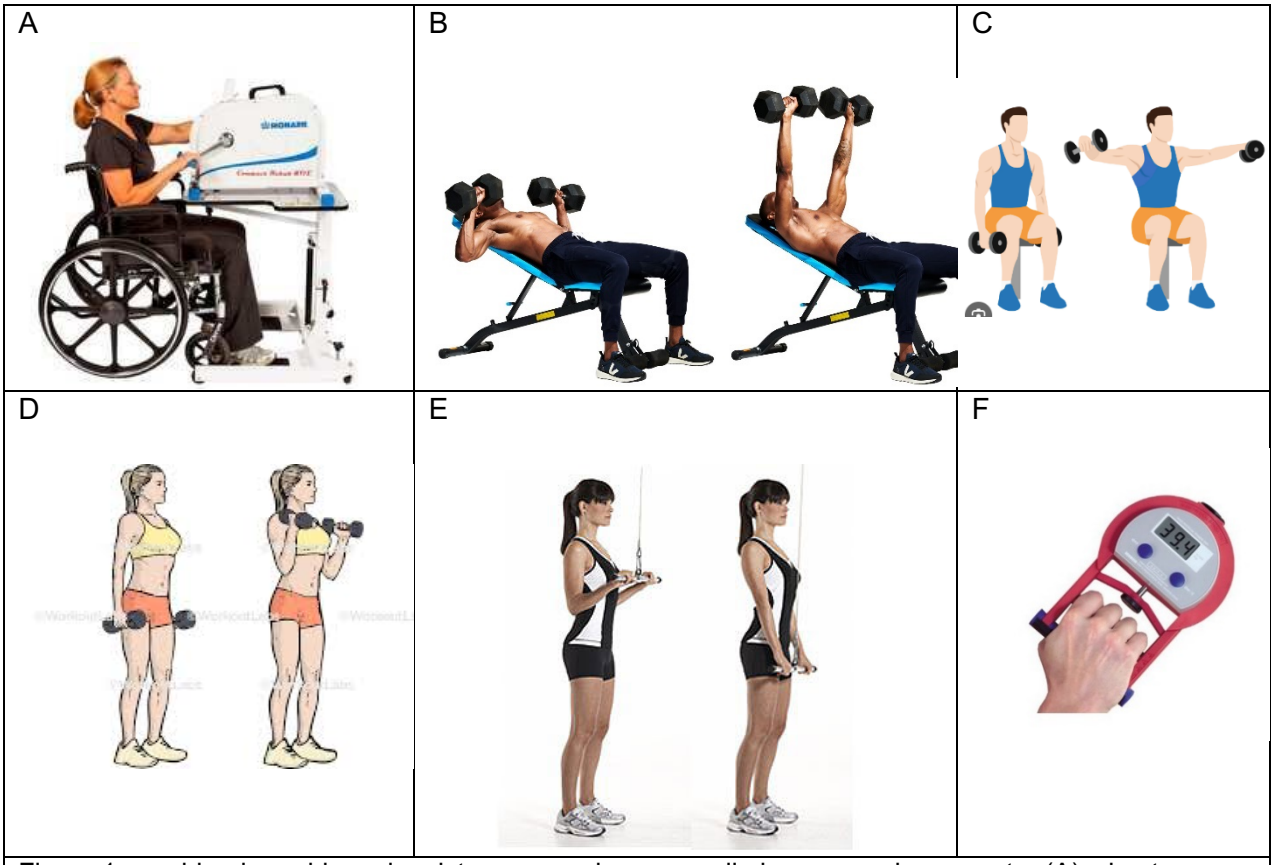

Figure 1. combined aerobic and resistance exercises upper limb: arm crank ergometer (A), chest press with dumbbells on a 30° inclined bench (B), lateral raises with dumbbells in a seated position (C), biceps curls with dumbbells (D), triceps extensions on a pulley from a standing position (E), handgrip exercises with a dynamometer (F)

A recent study by Anifanti et al. (2023)(Anifanti et al., 2023) evaluated the effects of this combined exercise program on aerobic capacity and right ventricular (RV) systolic function in patients with subclinical RV systolic dysfunction. The study found significant improvements in cardiorespiratory efficiency and RV systolic function in SSc patients following the training program. Another study by Mitropoulos et al. (2022)(Mitropoulos et al., 2022) aimed to investigate the effects of this program on pain and fatigue in SSc patients, although the results have not yet been published (as of February 2024).

Pinto et al. (2011)(Pinto et al., 2011) conducted a 12-week intervention program with sessions twice a week, combining aerobic exercise and resistance training. Their training sessions consisted of a 5-minute treadmill warm-up, 30 minutes of resistance training, 20 minutes of treadmill aerobic training, and 5 minutes of stretching.

The resistance training included exercises for the main muscle groups: bench press, leg press, lateral pulldown, leg extension, and seated row, with patients performing four sets of 8–12 repetitions maximum (RM), except during the first week, when they performed only two sets of approximately 15–20 RM to adapt to resistance training. Progression to greater resistance levels was implemented when subjects could perform 12 or more repetitions in the last set for two consecutive workouts. Aerobic training intensity was set at approximately 70% of peak oxygen uptake. Patients showed significant improvements in muscle strength and function, time to exhaustion, resting heart rate, workload, and exercise duration at ventilatory thresholds and peak exercise.

Alexanderson et al. (2014)(Alexanderson, Bergegård, Björnådal, & Nordin, 2014) also conducted a combined exercise program consisting of aerobic exercise on a stationary bike and muscular endurance training for the shoulder and hip flexors. This 8-week program was performed three times a week. The Borg Rating of Perceived Exertion (Borg RPE) scale was used to measure intensity. The program began with a 10-minute warm-up biking session at an intensity corresponding to perceived light exertion (10 on the Borg RPE scale). The load was then increased to reach an intensity corresponding to perceived heavy exertion (15 on the Borg RPE scale) for an additional 15 minutes. The final five minutes of biking were at a reduced load corresponding to light exertion. Following the biking exercises, participants performed repetitive dynamic muscle resistance training, aiming for as many shoulder flexion repetitions as possible in a sitting position without back support with a 1-kg weight cuff around the wrist, and in hip flexion, lifting one leg at a time while lying supine. If participants reached the maximum number of repetitions (60) for shoulder flexion, a heavier cuff was used. For hip flexion, a weight cuff of 0.5–1.0 kg was attached to the ankle. Repetitions were adjusted every other week based on systematic assessments. Only four patients participated in this study. Three patients showed significant improvements in muscular endurance for hip and shoulder flexion. One patient demonstrated significant improvement in aerobic capacity as measured by a treadmill test, and another patient showed clinical improvements in aerobic capacity.

Muscle strengthening exercises

In a study by Saketkoo et al. (2021)(Saketkoo et al., 2021), the general recommendation for resistance training in patients with SSc is to follow a basic strengthening program. They advise performing more than 15 repetitions for 3 sets at least twice a week to increase muscle mass and preserve overall muscle strength.

A systematic review by Liem et al. (2019)(S. I. E. Liem et al., 2019) summarized the effects of resistance training in patients with SSc, focusing on studies that examined combined exercise programs. The resistance training exercises described in these studies are detailed in the combined exercise programs section.

Hand exercises

According to Saketkoo et al. (2021)(Saketkoo et al., 2021), the hands in patients with SSc are particularly susceptible to diffuse morphological changes, impairment, and pain due to inflammation, vasculopathy, and fibrosis.

Consequently, hand exercises are crucial for patients with SSc. These exercises improve hand function and muscle strength, enhance circulation, and promote healthy vascular and skin repair. Additionally, they increase warmth and help reduce stiffness and inflammation.

Saketkoo et al. (2021)(Saketkoo et al., 2021) recommend focusing stretching exercises on the flexion of metacarpophalangeal (MCP) and interphalangeal (IP) joints, extension of proximal interphalangeal (PIP) joints, first commissure, finger web space (interdigital), and wrist flexion and extension. Resistance exercises such as squeezing and pinching foam, finger extension, and rolling exercises contribute to improving hand strength.

In a systematic review by Liem et al. (2019)(S. I. E. Liem et al., 2019), two studies investigated specific hand exercises. The first study by Piga et al. (2014)(Piga et al., 2014) implemented strengthening and mobility hand exercises, showing improvement in the Health Assessment Questionnaire (HAQ) and Hand Mobility of Scleroderma (HAMIS). The exercises (Appendix 1) were performed using the Re.Mo.Te device for 50 minutes, five days a week for 12 weeks. Four strengthening exercises were included: 1) finger pinch bilaterally, one set of 10 repetitions (where a sensor of the Re.Mo.Te device was pressed for at least 1 second between the thumb and other fingers, alternating thumb-index, thumb-middle finger, etc.), 2) hand grip, 3) hand pinch, both done bilaterally for two sets of 10 repetitions, and 4) isometric hand rotation bilaterally for two sets of five repetitions. The three mobility exercises were: 1) hand abduction, 2) dynamic rotation, and 3) piano-like movements. The mobility exercises were performed bilaterally for two sets, with 10 repetitions for exercises 1 and 2, and 20 repetitions for exercise 3.

The second study included in the systematic review by Liem et al. (2019)(S. I. E. Liem et al., 2019) was conducted by Landim et al. (2019)(Landim et al., 2019).

This study noted improvements in hand pain (measured by the Visual Analogue Scale (VAS)), Cochin Hand Function Scale, Scleroderma Health Assessment Questionnaire (sHAQ), and grip strength. The study consisted of an 8-week home-based self-management program, with patients performing the hand exercises daily. The specific exercises (Appendix 2) included:

Active finger flexion and extension for 5-10 reps (depending on pain) (App. 2A & B)

Wrist flexion stretch, holding for 5 seconds for 2 reps bilaterally(App. 2C)

Wrist extension stretch, holding for 5 seconds for 2 reps bilaterally (App. 2D)

Active wrist flexion for 5-10 reps (depending on pain) (App. 2E)

Active wrist extension for 5-10 reps (depending on pain) (App. 2F)

Active forearm pronation and supination for 5-10 reps (depending on pain) (App. 2G&H)

Finger flexion stretching, holding for 2 seconds and repeating 3-5 times for each finger (App. 2I&J)

Finger extension stretching, holding for 2 seconds and repeating 3-5 times for each finger (App 2K)

Opening of the first commissure (thumb extension), holding for 2 seconds and repeating 5 times (App. 2L)

Active finger pinch (App.2M)

These structured exercise regimens have shown to be effective in improving hand function, reducing pain, and enhancing overall hand mobility in patients with SSc.

Mouth-opening exercise

Saketkoo et al. (2021)(Saketkoo et al., 2021) recommend exercises focusing on mouth opening and facial grimaces (such as smiling and puckering lips) for patients with SSc. Additionally, isometric hold exercises to strengthen the mouth musculature are advised. These oral stretches combined with facial exercises have been shown to improve mouth opening (Maddali-Bongi et al., 2011).

In the systematic review by Liem et al. (2019)(S. I. E. Liem et al., 2019), two studies evaluated the effects of mouth-opening exercises.

The first study by Yuen et al. (2012)(Yuen et al., 2012) involved manual mouth stretching and oral-augmentation exercises performed for 6 minutes, twice daily, over 26 weeks. According to Yuen et al. (2012), the manual mouth-stretching exercise involved placing the right thumb at the left corner of the mouth and the left thumb at the right corner, then stretching both sides of the mouth horizontally as far as possible and holding this position for 15–20 seconds, followed by a 10-second rest before repeating. The oral augmentation exercise involved inserting a wooden stick (2 cm × 1.5 cm × 9.5 cm) between the upper and lower teeth at one side of the mouth, then stretching the mouth opening by turning the stick at the corner and gently pushing it as far back towards the posterior teeth as possible. Participants held the stick in this position for 15–20 seconds, removed it, and rested for 10 seconds before repeating the process on the opposite side. This study showed an increase in oral aperture after 3 months in the exercise group, although the effects did not persist after 6 months.

The second study included in the systematic review by Liem et al. (2019)(S. I. E. Liem et al., 2019), conducted by Pizzo et al. (2003)(Pizzo, Scardina, & Messina, 2003), used the same exercises as the first study. In this study, the movements were performed bilaterally and simultaneously for at least 15 minutes, twice daily, over 18 weeks. This study also reported an improvement in oral aperture.

Stretching

Stretching exercises are generally recommended for both the upper and lower extremities in patients with SSc, with a focus on areas with impaired range of motion (ROM)(Pettersson et al., 2021; Saketkoo et al., 2021). Saketkoo et al. (2021)(Saketkoo et al., 2021) indicate that stretching can reduce inflammation, edema, contractures, and skin tightness in the hands, fingers, shoulders, chest, hamstrings, and hips, as well as increase ROM in patients with SSc. According to the American College of Sports Medicine(Garber et al., 2011), effective stretching involves holding each stretch for 30-60 seconds, synchronized with breath cycles to facilitate relaxation. They recommend a total duration of 10 minutes of stretching exercises, performed at a frequency of at least 2-3 times per week(Garber et al., 2011; Pettersson et al., 2021; Saketkoo et al., 2021).

Due to the specific stiffness associated with SSc, it is advisable to perform stretching exercises after other aerobic or strengthening exercises, or after warming up the muscles with heating elements such as a sauna, paraffin wax, or warm water(Pettersson et al., 2021; Saketkoo et al., 2021).

How patients perceive exercise

In general, physical activity is perceived by patients as an essential element of their daily lives. However, certain barriers contribute to a sedentary lifestyle. These barriers include disease-related manifestations during and after exercise, such as joint pain, digital ulcers, and restricted range of motion. Additionally, fear of these manifestations and a lack of knowledge about which exercises are safe further contribute to reduced activity levels(Pettersson, Nordin, Svenungsson, Alexanderson, & Boström, 2020).

Furthermore, patients often worry about breathlessness and what it might signify(Pettersson et al., 2021). There is a need for reassurance that aerobic exercises are safe and can help reduce breathlessness over time.

Self-management interventions

A systematic review by Wojeck et al. (2021)(Wojeck, Bailey, Somers, & Knisely, 2021) assessed the use and implementation of self-management programs in patients with SSc. Due to the high heterogeneity in reported self-management outcomes, no general recommendation could be made. Nonetheless, the review underscores the importance of self-management for patients with chronic conditions such as SSc.

A recent randomized controlled trial (RCT) by Parniyan et al. (2023)(Parniyan, Pasyar, Rambod, Momennasab, & Nazarinia, 2023) evaluated the effect of a three-month self-management program on patients with scleroderma. The results demonstrated a significant improvement in the quality of life for these patients. Similarly, Shao et al. (2021)(Shao, Yu, & Chen, 2021) emphasize the necessity of establishing self-management abilities through structured training programs and continuous evaluations. Their study indicates that a self-management program based on the theory of self-efficacy leads to enhancements in self-management skills, self-efficacy beliefs, and physical performance over six months. This suggests that interventions targeting self-efficacy can effectively empower patients to manage their condition and improve their overall well-being.

Optimizing health literacy is crucial in addressing the global burden of chronic conditions (Heine et al., 2021). By prioritizing health literacy initiatives, healthcare systems can empower individuals with chronic conditions to take control of their health, leading to improved self-management, better health outcomes, and more sustainable healthcare interventions.

Despite the potential of health education interventions, there is a notable underappreciation of health education among both the general population and healthcare professionals. Health education is often overlooked despite its numerous possibilities and methods. This highlights the need for greater recognition and utilization of health education as a valuable tool in promoting health and preventing disease across various demographic groups.

Methods

1. Literature search – Educational leaflet

Based on a literature search, articles were selected to investigate the value of educational leaflets in patient education, specifically for patients with cNCDs and SSc. The aim was to identify the essential elements that need to be included in educational leaflets to ensure their effectiveness. The results of this investigation were summarized.

Search terms: patient, education, educational intervention, chronic non communicable diseases, systemic sclerosis, systematic review, rheumatology

2. Exercise selection

The initial exercise selection was based on a systematic review conducted by Liem et al. (2019)(S. I. E. Liem et al., 2019), provided by Prof. Dr. SV. This review summarized various exercise modalities and types suitable for patients with SSc. Additional manual searches were conducted to further refine the exercise selection.

Based on the systematic reviews(S. I. E. Liem et al., 2019; Pettersson et al., 2021; Saketkoo et al., 2021), a preliminary list of exercises was compiled, including commentary and practical tips for performing the exercises at home. A graphic designer (VCA) created two layout drafts (Appendix 3) to ensure user preferences and enhance motivational value.

Following the initial literature-based selection, feedback was gathered on the preliminary exercise list, the accompanying commentary and practice tips, and the layout designs. A feedback group consisting of five patients with SSc (with varying degrees of musculoskeletal involvement) (n = 5) and three experts (Prof. Dr. SV, a professor of rheumatology and SSc expert; Prof. VOJ, a professor of rehabilitation sciences and physiotherapy; and DML, a physiotherapist and master's degree student in education) (n = 3) were consulted to provide their insights.

2.1 Feedback on the preliminary exercise list

Each exercise in the preliminary list was evaluated for its feasibility for patients with SSc and its practicality for home performance using yes/no questions:

Do you find this exercise achievable? Yes or no
Can you perform this exercise at home, without supervision? Yes or no

Exercises that received the maximum score for both achievability and practicality at home (8 yes-votes) were included in the educational leaflets without modifications.

Exercises that received 8 yes-votes for practicality at home and more than 4 yes-votes for achievability were included in the educational leaflets with necessary adjustments and practice tips to enhance their achievability.

Exercises that did not receive 8 yes-votes for both achievability and practicality at home were excluded from the educational leaflets.

2.2 Feedback Commentary and Practice Tips

Feedback was solicited on both the commentary and practice tips provided for each exercise.

2.3 Feedback on Layout

Feedback was also gathered on the two layout designs created by the graphic designer (VCA). The two designs were presented to the five patients with SSc and the three experts. Participants were asked, "Which layout do you find most motivating?" The layout receiving the majority of votes was selected for further development.

3. Developing and Testing the educational leaflets

3.1 Educational leaflet – first version

Using the patient's and expert's feedback, an initial version of an educational leaflet was developed.(Appendix 4)

The leaflet included:
Exercise instructions: Clear, step-by-step instructions for each exercise.
Exercise modalities: How often these exercises are recommended per week, how long these exercises take to perform and how many repetitions every exercise should be done.

Practice tips: Precautions to avoid injury, tips on how to better achieve the goals and alternatives when the exercises are too difficult
Visuals: Illustrations and videos demonstrating the proper exercise techniques.

3.2 Pilot Testing with Larger Patient Group

The educational leaflets were presented at World Scleroderma Day at Ghent University Hospital, organized by the Ghent University Hospital Scleroderma team. Ninety patients with SSc (n = 90) attended the presentation and were given the opportunity to provide feedback either through individual one-on-one conversations with DML or via an anonymous Google form to obtain broader feedback. The evaluation focused on:

Visual Appeal: Assessing the clarity and attractiveness of the visuals.
Content Clarity: Ensuring the instructions and practice tips were easily understood.
Usability: Gathering feedback on the practicality of performing the exercises at home.

4. **Practice of the Exercises**
Following the presentation, patients were invited to volunteer to trial all the exercises consecutively over a period of 2 weeks. After this testing period, individual feedback was collected regarding the exercises.

5. **Incorporating Feedback and Finalizing the Leaflet**
Based on the feedback from both the larger patient group and the practice group, necessary revisions were made to the leaflet to enhance its effectiveness and usability.

Results

1. **Literature search – Educational leaflet**
   Articles found: 4

   The distribution of health education leaflets has been suggested as a promising approach for newly diagnosed cases of cNCDs. Individuals who have recently discovered their condition are often highly motivated to learn about their illness, making this an opportune moment for health education interventions(Hasanica et al., 2020). While distributing health education posters is recommended for reaching a wide audience over an extended period, the effectiveness of this method may vary depending on factors such as the location and protection of the poster. Additionally, targeted approaches may be necessary when selecting methods for health education interventions, considering the specific needs, age, and motivations of the target audience(Hasanica et al., 2020). For example, incorporating health education into other television content is considered a valuable tool to reach a wide audience(Vukić & Youens, 2015).

   Patient information leaflets (PILs) serve as vital communication tools, bridging the gap between patients and healthcare providers and facilitating the retention of crucial information regarding disease management, medications, and lifestyle modifications. These leaflets play a pivotal role in ensuring patients understand and remember information conveyed during their regular healthcare visits(Shaji et al., 2024).

   The introduction of pictogram-based Patient Information Leaflets (P-PILs) represents a significant advancement in medical practice. A study by Shaji et al.(Shaji et al., 2024) demonstrated a noteworthy improvement in patient knowledge scores across various language versions after the implementation of P-PILs. This improvement underscores the effectiveness of P-PILs in enhancing patient understanding of their health condition and treatment options. P-PILs offer multifaceted benefits for medical practice; they not only enhance patient knowledge but also facilitate communication between patients and healthcare providers. By providing accessible and comprehensible information, these leaflets empower patients to actively participate in their healthcare decision-making process. Moreover, P-PILs promote shared decision-making, ensuring that treatment plans align with patients' preferences and values(Sustersic et al., 2019).

Furthermore, P-PILs play a crucial role in reducing healthcare disparities by providing consistent and accurate information to patients from diverse backgrounds. Incorporating these leaflets into routine practice promotes patient-centered care, ultimately leading to improved therapeutic outcomes(Protheroe, Estacio, & Saidy-Khan, 2015).

2. Exercise Selection for Patients with Systemic Sclerosis

Based on current evidence(S. I. E. Liem et al., 2019; Mitropoulos et al., 2018; Pettersson et al., 2021; Saketkoo et al., 2021), three types of exercises have demonstrated positive effects on individuals with SSc: stretching exercises (specifically for the hand and mouth), muscle strengthening exercises for the upper limbs, and endurance exercises. These findings form the foundation for developing a set of home-based exercises that can be easily explained in an educational leaflet.

The following exercises were included in the preliminary exercise list:

Hand Exercises:

Frequency: Every day

Duration: 3 sets of 30 seconds hold

Types: Flexion of IP and MCP joints, extension of PIP joints, interdigit space stretch

Orofacial Exercises:

Frequency: Every day

Duration: 3 sets of 30 seconds hold

Types: Opening the mouth as wide as possible, making extreme facial grimaces

Strengthening Exercises:

Frequency: 2 times per week

Duration: 3 sets of 10-15 repetitions

Intensity: 70% of 1-rep max

Types: Shoulder lateral raise, biceps curl, triceps extension, hand grip strength, bench press in a 30° supine position

Aerobic Exercises:

Frequency: 5 times per week

Duration: 30 minutes of moderate cardio intensity (50% - 70% HRmax)

Modalities: Walking, cycling, swimming

Alternative: HIIT, 2 times per week on an arm crank ergometer, consisting of 30 seconds of high-intensity cranking followed by 30 seconds of rest

Feedback on the preliminary exercise list

Feedback on feasibility and practicality at home is displayed in Table 1

Table 1 – Feedback on preliminary exercise list

Exercises		Questions					
		Achievable			Practicality at home		
		Exp FB (n=3)	Pt FB (n = 5)	**Results Ach**	Exp FB (n = 3)	Pt FB (n = 5)	**Results Pract. at home**
Stretch exercises							
Mouth	Mouth opening	Y (n = 3) N (n = 0)	Y (n = 5) N (n = 0)	**Y (n = 8)** N(n = 0)	Y(n = 3) N (n = 0)	Y (n = 5) N(n = 0)	**Y (n = 8)** N (n = 0)
	Frowning the face	Y (n = 3) N (n = 0)	Y (n = 5) N (n = 0)	**Y (n = 8)** N (n = 0)	Y (n = 3) N (n = 0)	Y (n = 5) N (n = 0)	**Y (n = 8)** N (n = 0)
Hand	Flexion IP and MCP joints (making a fist)	Y(n = 3) N (n = 0)	Y (n = 5) N (n = 0)	**Y(n = 8)** N (n = 0)	Y (n = 3) N (n = 0)	Y (n = 5) N (n = 0)	**Y (n = 8)** N (n = 0)
	Extension PIP joint (making a roof)	Y (n = 3) N (n = 0)	Y (n = 5) N (n = 0)	**Y (n = 8)** N (n = 0)	Y (n = 3) N (n = 0)	Y (n = 5) N (n = 0)	**Y (n = 8)** N (n = 0)
	Interdigit space (making a hook)	Y (n = 3) N (n = 0)	Y (n = 5) N (n = 0)	**Y (n = 8)** NO (n = 0)	Y (n = 3) N (n = 0)	Y (n = 5) N (n = 0)	**Y (n = 8)** N (n = 0))
Strengthening exercises							
Shoulder lateral raise		Y (n = 3) N (n = 0)	Y (n = 4) N (n = 1)	**Y (n = 7)** N (n = 1)	Y (n = 3) N (n = 0)	Y (n = 5) N (n = 0)	**Y (n = 8)** N (n = 0)
Biceps curl		Y (n = 3) N (n = 0)	Y (n = 5) N (n = 0)	**Y (n = 8)** N (n = 0)	Y (n = 3) N(n = 0)	Y (n = 5) N (n = 0)	**Y (n = 8)** N(n = 0))
Triceps extension (hands behind head)		Y (n = 2) N (n =1)	Y (n = 4) N (n = 1)	**Y (n = 6)** N (n = 2)	Y (n = 3) N (n = 0)	Y (n = 5) N (n = 0)	**Y (n = 8)** N (n = 0))
Hand grip strength		Y (n = 3) N (n = 0)	Y (n = 4) N (n = 1)	**Y (n = 7)** N (n = 1)	Y (n = 3) N (n = 0)	Y (n = 5) N (n = 0)	**Y (n = 8)** N (n = 0)
Bench press in 30° supine position		Y (n = 3) N (n = 0)	Y (n = 5) N (n = 0)	**Y (n = 8)** N (n = 0)	Y (n = 0) N (n = 3)	Y (n = 0) N (n = 5)	Y (n = 0) **N (n = 8)**
Aerobic							
Moderate intensity 30 min	Walking	Y (n = 3 N (n = 0))	Y (n = 4) N (n = 1)	**Y (n = 7**) N (n = 1)	Y (n = 3) N (n = 0)	Y (n = 5) N (n = 0)	**Y (n = 8)** N (n = 0)
	Cycling	Y (n = 3) N (n = 0)	Y (n = 3) N (n = 2)	**Y (n = 6)** N (n = 2)	Y (n = 3) N (n = 0)	Y (n = 5) N (n = 0)	**Y (n = 8)** N (n = 0)
	Swimming	Y (n = 3) N (n = 0)	Y (n = 1) N (n = 4)	**Y (n = 4)** **N (n = 4)**	Y (n = 0) N (n = 3)	Y (n = 0) N (n = 5)	Y (n = 0) **N (n = 8)**
HIIT	Arm crank ergometer	Y (n =3) N (n = 0)	Y (n = 3) N (n = 2)	**Y (n = 6**) N (n = 2)	Y (n = 0) N (n = 3)	Y (n = 0) N (n = 5)	Y (n = 0) **N (n = 8)**

Exercises that were included in the educational leaflets without modifications:

- ➔ Stretching exercises for hand and mouth

Exercises that were included in the educational leaflets with necessary adjustments and practice tips to enhance their achievability:

- ➔ Shoulder Lateral Raise:
  Issue: One patient with SSc could not lift both arms to 90° shoulder abduction.
  Adjustment: It is recommended to attempt the exercise even if the preferred range of motion is not feasible. This advice is supported by the G-FoRSS Guidance(Pettersson et al., 2021).
  Triceps Extension:
  Issue: Two patients with SSc could not lift both arms above their heads.
  Adjustment: An alternative method using a chair for triceps extension was found to be achievable during patient testing. This alternative method was included in the educational leaflets.
  Hand Grip Strength:
  Issue: One patient with SSc could not open their hand wide enough to fit a stress ball.
  Adjustment: A thick towel, which fit the patient's hand, was suggested as an alternative. This advice was included in the educational leaflets, recommending the use of a thick towel if a stress ball does not fit.
  Walking:
  Issue: One patient found walking for 30 minutes without a walking aid unachievable.
  Adjustment: The use of walking aids was added to the commentary and practice tips in the educational leaflet. Additionally, another patient noted the cold environment as a barrier due to Raynaud's Phenomenon. The advice to consider indoor walking on a treadmill was included as a solution.
  Cycling:
  Issue: Two patients voted against the achievability of cycling outside.
  Adjustment: When asked if cycling on a stationary home trainer (exercise bike) at home was feasible, both patients agreed it was. This option was also included as advice in the educational leaflets.

Exercises that were excluded from the educational leaflets:

- ➔ Bench press in 30° supine position, swimming, HIIT on an arm crank ergometer

Feedback Commentary and Practice Tips

Stretching Exercises

Based on literature(Pettersson et al., 2021; Saketkoo et al., 2021), specific notes and considerations regarding stretching exercises were highlighted. Consequently, the educational leaflets recommend warming the limbs before performing stretching exercises. Warming can be achieved by taking a hot shower or a warm bath, as these are accessible at home. Additionally, 3 out of 5 patients reported that using a heating pad works best for them to warm their bodies. This option was thus included in the educational leaflets.

Strengthening Exercises

For optimal benefit from strengthening exercises, it is recommended to use weights at 70-80% of 1RM(Pinto et al., 2011; Saketkoo et al., 2021). The educational leaflets suggest starting with a weight of 0.5 kg for two reasons: clinical experience with rheumatology patients shows this weight is manageable, and a 0.5 kg weight can be easily substituted with a 500 ml water bottle, which is readily available at home. To maximize strength gains, the leaflets also advise increasing the weight if the initial weight becomes too easy. This aligns with general recommendations to "amp it up" by increasing physical activity intensity and/or duration as fitness improves(Pettersson et al., 2021; Saketkoo et al., 2021).

Incorporating Daily Activities

An expert raised the question of whether household chores could count towards the recommended 30 minutes of exercise. According to Pettersson et al. (2021)(Pettersson et al., 2021), replacing sedentary moments with any form and intensity of physical activity throughout the day is encouraged. Therefore, general examples of incorporating more physical activity into daily routines were added to the educational leaflets. Suggestions include adding small movements to everyday tasks (e.g..standing on tiptoes 10 times while brushing teeth) and adding tasks to daily activity (e.g. walking to fetch water more often)

Feedback on layout

Two types of layouts (Appendix 3) were designed by the graphic designer (VCA). Feedback on preferences from the patient-group (n = 5) and expert-group (n = 3) is presented in Table 2.

Table 2 – Feedback on layout

	Motivational appeal		
	Exp vote (n = 3)	Patient vote (n = 5)	Results (n= 8)
Layout 1	2	1	3
Layout 2	1	4	**5**

The second layout received more votes, particularly from patients with SSc. Therefore, this layout was chosen for further development

3. Educational Leaflet Development – First Version (Appendix 4)

Based on the feedback from patients and experts, educational leaflets were created. Three types of postcards were developed, each featuring a different type of exercise: stretching exercises (specific for hand and mouth), muscle strengthening exercises, and aerobic exercises. The leaflets also included practice tips, pictograms, and a QR code linking to videos demonstrating the correct execution of the exercises.

4. Pilot Testing with Larger Patient Group

On June 29, 2024, during World Scleroderma Day at Ghent University Hospital, organized by the Ghent University Hospital Scleroderma Unit, the first version of the educational leaflets (see attachment) was distributed and demonstrated to 90 patients with systemic sclerosis.

During the presentation, patients actively participated by performing the exercises outlined in the leaflets. After the presentation, patients had the opportunity to provide feedback on the educational materials.

Results of Individual Feedback:

Two patients requested exercises specifically for the lower limbs.

One patient suggested that hiking poles are a useful tool to make walking more achievable.

Four patients expressed their gratitude and motivation to try the exercises.

Results of Anonymous Feedback via Google Form

The feedback form received one response. This response is presented in Table 3.

Table 3 – Results of Anonymous Feedback via Google Form

	Answers	
Questions	Yes	No
Do you find the lay out of the educational leaflets visually appealing?	X	
Do you find the instructions and pictograms of the educational leaflets clear? In other words, do you feel competent with these instructions to do the exercises at home without supervision.	X	
Do the educational leaflets motivate you to do the exercises?	X	
Are the comments and tips added to the educational leaflet sufficient to execute the exercises?	X	

5. Practice of the Exercises

Two patients with SSc (n = 2) volunteered to test the educational leaflets over a period of two weeks. After this testing period, individual feedback was collected regarding the exercises.

One patient reported improvements in the range of motion of both the hand and mouth, while both patients experienced a reduction in stiffness. No adverse events were reported following the exercise regimen. However, one patient experienced temporary discomfort during the shoulder lateral raise exercise, which resolved after completing the exercise. Both patients indicated that the educational leaflets effectively motivated them to perform the exercises. Additionally, one patient noted that the leaflets lacked exercises targeting the lower limbs.

Discussion

This thesis aimed to address the critical need for clear and effective patient education on physical activity for individuals with SSc(Smith et al., 2018; Spierings et al., 2019). Our approach began with a systematic review by Liem et al (2019)(S. I. E. Liem et al., 2019)., which served as the foundation for selecting exercises. However, as noted in the review, the evidence supporting specific exercises remains limited. The absence of large-scale randomized controlled trials and the small sample sizes of existing studies hinder the generalization of exercise recommendations for SSc patients(S. I. E. Liem et al., 2019; Willems et al., 2015; Wojeck et al., 2021).

Acknowledging these gaps (S. I. E. Liem et al., 2023), our research aimed to compile and summarize exercises that have demonstrated positive effects in SSc patients thus far. We particularly focused on upper body exercises, as most SSc manifestations affect this region. Nevertheless, we recognize the need to include lower limb exercises in future research to provide a more comprehensive physical activity regimen for SSc patients.

In addition to compiling these exercises, we developed educational leaflets to disseminate this information to patients (Smith et al., 2018; Spierings et al., 2019). These leaflets were reviewed with SSc patients to assess their practicality and effectiveness. Preliminary feedback from a small patient group was positive, suggesting that the leaflets were well-received and potentially beneficial. However, further extensive qualitative research is needed to evaluate the true impact and value of these educational materials in a larger, more diverse patient population, using standardized evaluation tools.

It is also important to note that the educational leaflets were initially developed in Dutch for a Belgian cohort of SSc patients. To enhance their generalizability and assess their effectiveness across a broader patient population, future research should include translations and adaptations of these materials.

By addressing these gaps and providing a foundation for future research, this thesis contributes to ongoing efforts to improve patient education and outcomes in SSc (Spierings et al., 2019) through targeted physical activity recommendations. Future studies should explore the role of educational leaflets in patient education and their potential as effective tools for rheumatologists and physiotherapists to integrate into their patient education strategies.

Conclusion

This study attempted to summarize the recommendations and current evidence regarding exercises for patients with systemic sclerosis and translate this information into an educational leaflet. Due to the limited evidence, it was challenging to identify generalizable exercises. Further research is needed to recommend more specific exercises and to investigate the value of these leaflets in patient education as well as in the training of future physiotherapists and rheumatologists.

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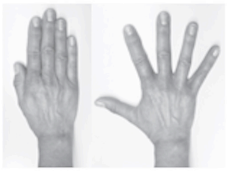
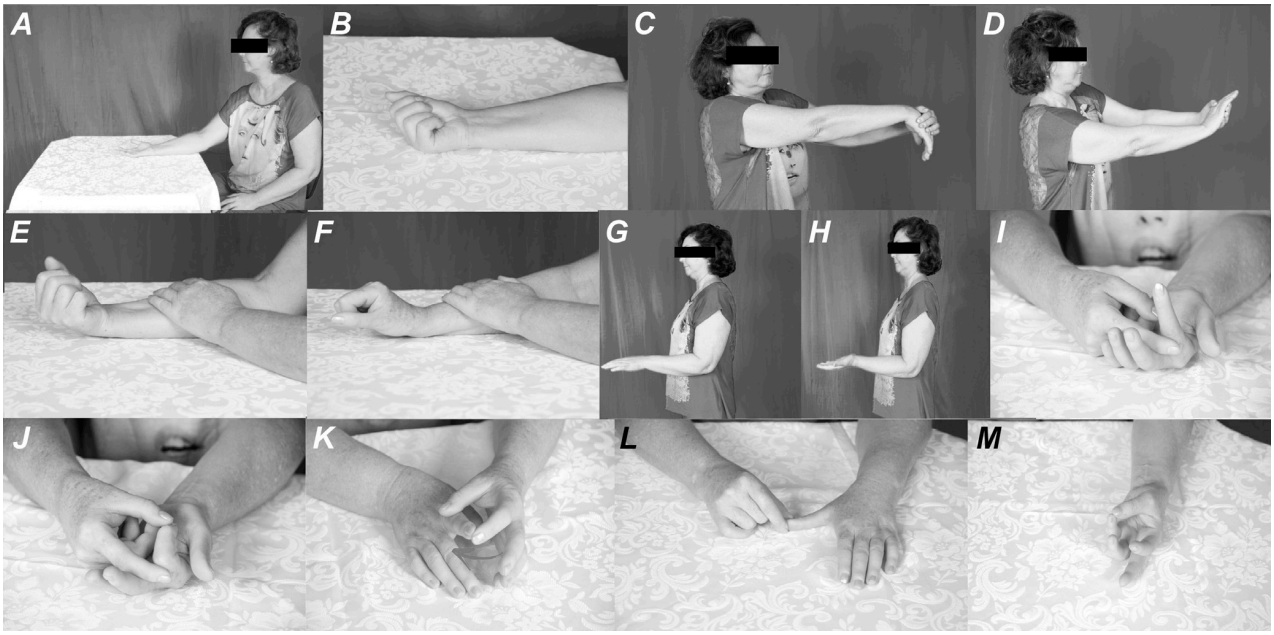
Appendix

Appendix 1 Hand Exercises on the Re.Mo.Te device - study of Piga et al. (2014)(Piga et al., 2014)

Exercise description	Control Arm	Experimental arm	Tool Description
E1. Hand abduction (mobility). Starting from the position of max adduction, spread the fingers as possible and narrow them up to the max abduction, repeating the exercise rhythmically and fluently (bilaterally 2 sets, 20 repetitions).			**A1**. The tool for the abduction of the hand; to assess the max abduction of the hand (against constant resistance). **EP:** extension
E2. Finger pinch (strength). Press, for at least 1 sec, the sensor (coin) between the thumb and other fingers alternating thumb-index, thumb-middle finger etc.. (bilaterally 1 sets, 10 repetitions)			**A2**. The tool for finger pinch; to assess the strength of the fingers in opposition to the thumb. **EP**: force
E3. Dynamic rotation (mobility). Turn the knob (cap) clockwise (10 laps) and counterclockwise (10 laps) without rotating the wrist. Objective: attempt in a quick and precise movement (bilaterally 2 sets, 10 repetitions)			**A3.** The tool for dynamic rotation, to evaluate the manipulative ability of the patient (against low-resistance). **EP**: Rotation angle and speed
E4. Hand grip (strength). Grab the instrument (cylinder) between the thumb and the other fingers, as it would hold a nutcracker, then try to tighten into a fist, for at least 1 sec. (bilaterally 2 sets, 20 repetitions).			**A4.** The tool for hand grip, to assess the strength of the hand grip. **EP**: force
E5. Hand pinch (strength). Grab the instrument (cylinder) between the thumb and the other fingers holding them lie flat, as shown in figure, then try to tighten it for at least 1 sec. (bilaterally 2 sets, 20 repetitions)			**A5**. The same tool, to assess the strength of the hand pinch. **EP**: force
E6. Isometric rotation (strength). Try to turn the knob, for at least 1 sec, clockwise (E6a) and then counterclockwise (E6b) acting only with the fingers (bilaterally 2 sets, 5 repetitions).	Not required for control arm		**A6**. The tool for isometric rotation, to evaluate the torque applied in a isometric rotation imparted with the fingers. **EP**: torque
E7. Piano-like (mobility). To perform the exercise correctly touch, as fast as possible, the sensitive areas (table) in sequence pinky-ring-middle-index-thumb, like playing a piano (bilaterally 2 sets, 20 repetitions).			**A7**. Finger tapping tool, to evaluate the hand dexterity in a movement piano-like (without counter-resistance). **EP:** touches per second, correct touches

Appendix 2 Home-based hand exercises - study of Landim et al. (2019)(Landim et al., 2019)



Appendix 3 Layout drafts, designed by Van Cayseele Axelle

App. 3 - Layout design 1

App. 3 – Layout design 2

Appendix 4 Educational leaflets to promote physical activity in patients with systemic sclerosis.

App. 4 Educational leaflet 1 – Muscle strengthening Exercises

App. 4 Educational leaflet 2 - Stretching Exercises

App. 4 Educational leaflet 3 – Aerobic Exercises

Lena De Moor, Dr. Ine Deslimpele, Axelle Van Cayseele,
Dr. Annick Viaene, Prof. Jessica Van Oosterwijck, Prof. Dr. Vanessa Smith

Versterk je lichaam!

WANDEL OF FIETS

WANDELEN EN FIETSEN VERHOOGT JE UITHOUDING EN VERMINDERT SPIERPIJNEN EN -STIJFHEID

UZ GENT UNIVERSITEIT GENT Vlaanderen

30 minuten

5x per week

TIPS

Hulpmiddelen die je misschien kunnen helpen:

- Fietsen op een hometrainer.
- Wandelen op een loopband.
- Wandelen met wandelstokken of een rollator.

Steek meer beweging in je dagelijkse activiteiten.
Bijvoorbeeld:

- Ga 10 keer op je tenen staan tijdens het tandenpoetsen.
- Ga vaker water halen in de keuken.
- Sta 2 keer recht uit je stoel in de plaats van 1 keer.

1. FIETSEN

Iets is beter dan niets! Doe de bewegingen in de mate van het mogelijke.

2. WANDELEN

Iets is beter dan niets! Doe de bewegingen in de mate van het mogelijke.

UITGAVE VAN DE SYSTEEMSCLEROSE UNIT UZ GENT