Use of the Nominal Group Technique and a Cohort-based Survey to Identify Important Barriers and Facilitators to Physical Activity for People with Scleroderma

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Abstract

Background: Physical activity is often recommended to enhance health in people living with the rare chronic, autoimmune rheumatic disease of systemic sclerosis (SSc; scleroderma). However, approximately 50% of patients in a large international SSc cohort were inactive, and patients who were active rarely engaged in activities other than walking. The diverse medical presentation of SSc creates many possible physical and psychological barriers to physical activity. However, there are no physical activity promotion interventions designed to support individuals with SSc in overcoming their specific barriers, and no studies have researched barriers or facilitators to physical activity in SSc. Therefore, the objective of *Phase 1* (manuscript 1) was to identify barriers and facilitators to physical activity for people with scleroderma. The objectives of *Phase 2* (manuscript 2) were to determine the (1) prevalence and importance of different barriers experienced in SSc, and (2) likelihood that people with SSc would use different barrier-specific and general facilitators to be physically active.

Methods: *Phase 1:* We conducted nominal group technique sessions with 3-8 SSc patients per session. Participants identified, shared, and discussed physical activity barriers and facilitators (barrier-specific and general). They rated importance of barriers and likelihood of using facilitators, and indicated whether they had tried facilitators. Similar barriers and facilitators across sessions were merged; edited by investigators, patient advisors, and clinicians; and categorized (qualitative content analysis) based on relevant literature. *Phase 2*: We invited 1,707 SSc patients enrolled in the Scleroderma Patient-centered Intervention Network Cohort to complete a survey of barriers and facilitators (from *Phase 1)* to (1) rate their experienced barriers for importance; (2) rate corresponding barrier-specific facilitators, and general facilitators for likelihood of use; and (3) indicate whether they tried facilitators.

Results: *Phase 1:* We conducted 9 sessions (n=41 participants) and initially generated 181 barriers, 457 barrier-specific facilitators, and 20 general facilitators. The number of merged barriers (barrier-specific facilitators in parentheses) per category were: 14 (61) for health and medical; 4 (23) for social and personal; 1(3) for time, work, and lifestyle; and 1 (4) for environmental. There were 12 merged general facilitators. *Phase 2:* Among 721 respondents, 13 barriers (12 medical-related and 1 motivation-related) were experienced by ≥ 25% of total participants. Raynaud's phenomenon and fatigue were considered 'important' or 'very important' by ≥ 50% of total participants; 7 other barriers (related to limited hand function, activity restrictions due to various pathologic changes, and low motivation) were considered by 26-50% to be 'important' or 'very important'. Overall, 23 of 103 (22% of total) facilitators were rated by ≥ 75% as 'likely' or 'very likely' to use among those who experienced corresponding barriers; these facilitators focused on adapting exercise, taking care of one's body, keeping warm, and protecting skin. All facilitators were rated by ≥ 50% as 'likely' or 'very likely' to use among those who experienced the barrier and had tried them, versus 12 of 103 facilitators among those with the barrier who had not tried them.

Conclusion: People with SSc most commonly experienced (and considered important) medical-related barriers to being physically active. Raynaud's phenomenon and fatigue were most common, and other common barriers addressed compromised hand dexterity and activity restrictions due to various pathologic changes. Facilitators widely rated as likely to be used often addressed adapting the exercise type or setting, using health behaviours to take care of the body, and using clothing/materials to protect the skin or to keep warm. Our online interactive Excel file (https://osf.io/2mxj5/) allows health care providers to easily identify relevant facilitators for

common barriers to physical activity experienced by individuals with SSc. Results of this thesis will inform the development of a SSc-specific physical activity promotion intervention.

Résumé

Contexte : L'activité physique est souvent recommandée pour améliorer la santé des personnes atteintes de la rare maladie auto-immune chronique débilitante qu'est la sclérose systémique (sclérodermie). Cependant, environ 50 % des patients d'une vaste cohorte internationale ayant la sclérodermie étaient inactifs, tandis que les patients actifs pratiquaient rarement des activités autres que la marche. La diversité de la présentation médicale de la sclérodermie crée de nombreux obstacles physiques et psychologiques à l'activité physique. Cependant, il n'existe pas d'interventions de promotion de l'activité physique conçues pour aider les personnes atteintes de la sclérodermie à surmonter leurs obstacles spécifiques et aucune étude n'a fait des recherches sur les obstacles ou les facteurs facilitant l'activité physique en la sclérodermie. Par conséquent, l'objectif de la phase 1 (manuscrit 1) était d'identifier les obstacles et les facilitateurs de l'activité physique pour les personnes atteintes de la sclérodermie. Les objectifs de la phase 2 (manuscrit 2) étaient de déterminer (1) la prévalence et l'importance des différentes barrières rencontrées dans la sclérodermie et (2) la probabilité que les personnes atteintes de la sclérodermie utilisent de différents facilitateurs spécifiques aux obstacles et généraux pour être physiquement actives.

Les méthodes : *Phase 1* : Nous avons mené des séances de technique du groupe nominal avec 3 à 8 patients atteints de la sclérodermie par séance. Les participants ont identifié, partagé et discuté des obstacles à l'activité physique et des facilitateurs (pour facilitateurs spécifiques aux obstacles et généraux). Ils ont évalué l'importance des obstacles et la probabilité d'utiliser des facilitateurs et ont indiqué s'ils avaient essayé des facilitateurs. Les obstacles et les facilitateurs similaires d'une session à l'autre ont été fusionnés, édités par les chercheurs, les conseillers aux patients et les cliniciens et classés (analyse qualitative du contenu) en fonction de catégories tirées de la littérature pertinente. *Phase 2* : Nous avons invité 1 707 patients atteints de sclérodermie inscrits dans la cohorte du Réseau d'intervention centré sur le patient sclérodermique à répondre à une

enquête sur les obstacles et les facilitateurs (de la *phase 1*) afin (1) d'évaluer l'importance des obstacles qu'ils ont rencontrés ; (2) d'évaluer la probabilité d'utilisation des facilitateurs spécifiques aux obstacles et des facilitateurs généraux ; et (3) d'indiquer s'ils ont essayé les facilitateurs.

Résultats : *Phase 1* : Nous avons mené 9 sessions (n=41 participants) et avons initialement généré 181 barrières, 457 facilitateurs spécifiques aux obstacles et 20 facilitateurs généraux. Le nombre d'obstacles fusionnés (facilitateurs spécifiques aux obstacles entre parenthèses) par catégorie était : 14 (61) pour la santé et le domaine médical ; 4 (23) pour le domaine social et personnel ; 1 (3) pour le temps, le travail et le mode de vie ; et 1 (4) pour conditions environnementales. Il y avait 12 facilitateurs généraux fusionnés. *Phase 2* : Parmi les 721 répondants, 13 obstacles (12 liés à la santé et 1 à la motivation) ont été rencontrés par ≥ 25 % de tous les participants. Le phénomène de Raynaud et la fatigue ont été considérés comme "importants" ou "très importants" par ≥ 50 % de tous les participants ; 7 autres obstacles (liés à une fonction limitée de la main, aux restrictions d'activité dues à divers changements pathologiques et à une faible motivation) ont été considérés comme "importants" ou "très importants" par 26 à 50 % des participants. Dans l'ensemble, 23 des 103 facilitateur (22 % du total) ont été évalués par ≥ 75 % comme "susceptibles" ou "très susceptibles" d'utiliser parmi ceux qui ont rencontré des obstacles correspondants ; ces facilitateurs se sont concentrés sur l'adaptation de l'exercice, le soin du corps, le maintien au chaud et la protection de la peau. Tous les facilitateurs ont été évalués par ≥ 50% comme "susceptibles" ou "très susceptibles" d'utiliser parmi ceux qui ont fait face à la barrière et qui les ont essayés, contre 12 des 103 facilitateur parmi ceux qui ont fait face à la barrière et qui ne les ont pas essayés.

Conclusion : Les personnes atteintes de la sclérodermie ont le plus souvent rencontré (et considéré comme important) des obstacles médicaux à l'activité physique. Le phénomène de Raynaud et la fatigue étaient les plus fréquents et d'autres obstacles courants concernaient la dextérité compromise des mains et des restrictions d'activité en raison de divers changements pathologiques. Les facilitateurs largement considérés comme susceptibles d'être utilisés ont souvent abordé l'adaptation du type ou du cadre d'exercice, l'utilisation de comportements de santé pour prendre soin du corps, ou l'utilisation de vêtements/matériaux pour protéger la peau ou pour se tenir au chaud. Notre fichier Excel interactif en ligne (https://osf.io/2mxj5/) permet aux prestataires de soins de santé d'identifier facilement les facilitateurs pertinents pour les obstacles courants à l'activité physique rencontrés par les personnes atteintes de la sclérodermie. Les résultats de cette thèse serviront de base à l'élaboration d'une intervention de promotion de l'activité physique spécifique aux sciences sociales.

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Contributions of Authors

Manuscript #1: *Identifying Barriers and Facilitators to Physical Activity for People with Scleroderma: a Nominal Group Technique Study*

Sami Harb (primary author): study conception and design; acquisition of data; analysis and interpretation of data; drafting manuscript and critical revision; approval of final version to submit for publishing

Julie Cumin: study conception and design; acquisition of data; critical revision of manuscript; approval of final version to submit for publishing

Danielle B. Rice: study conception and design; acquisition of data; critical revision of manuscript; approval of final version to submit for publishing

Sandra Peláez: study conception and design; analysis and interpretation of data; critical revision of manuscript; approval of final version to submit for publishing

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Ian Shrier (corresponding author): study conception and design; analysis and interpretation of data; critical revision of manuscript; approval of final version to submit for publishing

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Manuscript #2: *Barriers and Facilitators to Physical Activity for People with Scleroderma: a Scleroderma Patient-centered Intervention Network (SPIN) Cohort Study*

Sami Harb (primary author): study conception and design; acquisition of data; analysis and interpretation of data; drafting manuscript and critical revision; approval of final version to submit for publishing

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Brett D. Thombs: study conception and design; analysis and interpretation of data; critical revision of manuscript; approval of final version to submit for publishing

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SPIN Investigators (group author): acquisition of data

Chapter 1 - Physical Activity in Scleroderma

1.1 Introduction

The overarching objective of the present thesis is to explore the views about physical activity of people living with systemic sclerosis (SSc; scleroderma).

People with rare diseases face unique challenges related to gaps in knowledge about their disease, lack of evidence-based clinical guidelines, and limited resources and treatment options [1-3]. SSc is a rare chronic, autoimmune rheumatic disease characterized by abnormal fibrotic processes and excessive collagen production that can affect the skin, musculoskeletal system, and internal organs, including the heart, lungs, and gastrointestinal tract [4, 5]. People with SSc are classified in limited (skin involvement of face, neck, and areas distal to the knees and elbows) or diffuse cutaneous subtype (skin involvement proximal and distal to the knees and elbows or trunk). Patients with diffuse SSc typically have earlier onset of internal organ involvement and more rapidly progressive disease [6]. Since there is no cure for SSc, treatment focuses on ameliorating symptoms and delaying disability while improving health-related quality of life [7].

Most people with SSc can perform aerobic and resistance exercise safely [8]. As with virtually all people, including those with chronic diseases, physical activity is thought to enhance health, and it is often encouraged as a key component of SSc self-management. Health benefits of physical activity training programs for autoimmune rheumatic diseases such as SSc may include reduced inflammation, better clinical outcomes, and improved health-related quality of life [8, 9]. However, many people with SSc experience disease-specific physical and psychological barriers that impede their engagement in physical activity [10]. While barriers to being active likely differ across patients due to the heterogeneous symptom presentation of SSc

[11], common barriers may include limitations in physical mobility, respiratory symptoms, gastrointestinal manifestations, fatigue, pain, and depression and anxiety [12-14]. Although programs to support physical activity have been designed for the general population [15] and for people with common chronic diseases [16], the specific barriers experienced by people with SSc do not allow them to benefit from those programs. Therefore, the importance of the present thesis pertains to identifying physical activity barriers (challenges) and facilitators (potential strategies to overcome the challenges) experienced by SSc patients as a first step in the development of a physical activity program that addresses the needs and safety concerns of SSc patients.

1.2.1 Literature Review - Challenges for People with SSc: Living with a Rare Disease

Rare diseases are conditions that affect fewer than 1 person in 2,000 [17]. There are over 7,000 known rare diseases [18] and approximately 25 million people in North America and 30 million in Europe are affected by a rare disease [19]. This information demonstrates that there is a large collective impact of rare diseases. Rare disease patients experience the same challenges as those with common conditions, including physical and psychological symptoms that require them to modify their family, professional, and social roles and routines [20, 21]. Compared with more common chronic disease, patients with rare conditions typically face substantial additional challenges [1-3, 22-29]. There are gaps in knowledge regarding evidence-based standards of care in rare diseases, and treatment and management services are scarce, including psychosocial and rehabilitation interventions. Because there are a limited number of trained health professionals with expertise in caring for rare disease patients, many patients travel long distances and wait long periods of time for care.

SSc is a rare chronic, autoimmune rheumatic disease characterized by vascular injury, immune dysfunction, and abnormal fibrotic processes that can affect multiple organ systems, including the skin, lungs, gastrointestinal tract, and musculoskeletal system [4, 5]. The clinical manifestations of SSc are heterogeneous and highly debilitating [11], and mean survival time is approximately 12 years post-diagnosis [30]. Prevalence of SSc ranges from 7-489 cases per million [31]. Approximately 80% of cases are women [32], and disease onset is most commonly in people 40-50 years of age [33]. Disease-modifying treatments for SSc mostly target inflammatory and vascular pathways, but their clinical efficacy varies [34]. In comparison to the general population, SSc is associated with high levels of depressive symptoms and poor health-related quality of life [13]. Since there is no cure for SSc, health care focuses on reducing symptoms and disability, as well as improving health-related quality of life [3]. SSc self-management is thus essential to help patients cope with the disease [7].

1.2.2 Physical Activity Enhances Health

It is well known that regular physical activity enhances health in the general population and is also a component of self-management for people with chronic diseases [35-42]. Physical activity reduces the risk of cardiovascular and pulmonary disease, metabolic disease, hypertension, type 2 diabetes, osteoporosis, stroke, cancer, and all-cause mortality. In addition, physical activity reduces disability and improves musculoskeletal fitness, health-related quality of life, and psychosocial and emotional well-being.

Due to its physical and psychosocial benefits, healthcare guidelines acknowledge the importance of regular physical activity in patients with rheumatic diseases, including rheumatoid arthritis, osteoarthritis, fibromyalgia, and ankylosing spondylitis [43-48]. Particularly for people with autoimmune rheumatic diseases such as SSc, health benefits of physical activity training

programs may include reduced inflammation, better clinical outcomes, and improved health-related quality of life [9]. Most people with SSc can perform aerobic and resistance exercise safely [8], and physical activity is often encouraged as a key component of SSc self-management. There is, however, limited research on the effects of physical activity specifically in SSc. Such research mostly involves small-sample studies that demonstrate improvements in patients' exercise tolerance, muscle strength, health-related quality of life, and reduced disability [8].

1.2.3 Difficulty Being Physically Active with Scleroderma

Barriers to physical activity in the general population have been similarly reported by people with autoimmune rheumatic diseases, including fear of injury, cost of exercise, lack of motivation, and lack of time [49-55]. People with autoimmune rheumatic diseases experience substantial additional disease-specific barriers, such as fatigue, pain, stiffness, joint symptoms, and reduced mobility or functional ability [49-52].

SSc clinical manifestations can lead to individual (e.g., physical and psychosocial health) and contextual (e.g., socio-cultural) barriers to engaging in physical activity [51, 56, 57]. In particular, pulmonary involvement is common in SSc and may contribute to reduced exercise tolerance [58]. The gastrointestinal tract is affected in approximately 90% of patients [59], and some specific exercises would be expected to trigger reflux and heartburn when performed on the floor (e.g., Pilates) or in particular positions (e.g., yoga downward dog). Hand function is often compromised and may cause pain and numbness [12, 60, 61]. This could make it difficult to use brakes when cycling, to hold onto weights, or to manipulate other gym-related equipment. Swimming may trigger Raynaud's phenomenon even in heated pools [62] and can increase the risk of infection in patients with active digital ulcers [63]. Further, SSc is associated with more

general issues such as fatigue, poor sleep, high levels of sustained pain, pruritus, and intolerance to cold temperatures [11, 13, 64, 65]. SSc is also associated with psychological issues such as depression and anxiety, as well as body image concerns [13, 66] which may prevent some patients from exercising around others. In accordance with some of the aforementioned symptoms and issues that may complicate physical activity, decreased activity in SSc is associated with high levels of fatigue, pain, muscle weakness, and disability [67, 68]. Data from a large international SSc cohort reflect that approximately 50% of SSc patients are completely inactive, and most of the remaining patients rarely engage in activities other than walking [67].

1.2.4 Development of a Scleroderma-specific Physical Activity Program

A Cochrane review found that programs designed to promote physical activity (versus just prescribing specific exercises) in sedentary adults have a moderate positive effect on activity levels (19 studies, 7,598 participants, standardised mean difference = 0.28, 95% CI 0.15 to 0.41) [15]. One widely successful online program designed to enhance physical activity for sedentary people in the general population, the Active Living Every Day (ALED) program, was developed based on barriers and facilitators to physical activity [69-72]; it focuses on helping individuals make lifestyle changes to support sustained physical activity, and has been shown to be as effective as less feasibly delivered highly structured and costly programs for increasing physical activity and cardiorespiratory fitness, even 24 months post-randomization and when delivered via internet [73, 74]. Online physical activity promotion programs have been designed for more common chronic diseases [75], some of which are also based on barriers and facilitators (e.g., rheumatoid arthritis programs [76]). However, people with SSc experience unique barriers that are not addressed by any existing programs, and there are no studies on programs designed to provide guidance to SSc patients on how to select and adapt physical activities to accommodate

their individual difficulties. Patients have accordingly expressed the need for an accessible, professionally guided, patient-centered physical activity program [77].

In summary, this literature review has unveiled that although regular physical activity is an important health behaviour for people with SSc, they experience severe and diverse clinical manifestations with substantial physical and psychological consequences that may impede their engagement in physical activity. Thus, an effective strategy to support physical activity in SSc would require tailoring a physical activity promotion program to meet individual patients' capacity, needs, and safety concerns. While information on barriers and facilitators has informed the development of such programs in the general population and for those with more common chronic conditions, little is known about what impedes or helps physical activity for SSc patients. The present thesis will address that knowledge gap. In providing an understanding of the barriers and facilitators experienced by people with SSc, this work will help tailor the ALED program for those patients.

1.3 Research Questions

The present thesis aims to answer the following research questions:

1. Manuscript 1: What are the barriers and facilitators to physical activity experienced by people with SSc?
2. Manuscript 2:
    i. What are the prevalence and importance of different physical activity barriers experienced in SSc?
    ii. What is the likelihood that people with SSc would use different barrier-specific and general facilitators to be physically active?

1.4 Connecting Text

The benefits of physical activity are well-known in chronic diseases in general and physical activity is often encouraged in SSc, but patients face substantial barriers becoming physically active. The present thesis comprises the first 2 phases of the Scleroderma Patient-centered Intervention Network – Physical ACtivity Enhancement (SPIN-PACE) research program, the aim of which is to develop, test, and distribute free-of-charge an online SSc-specific physical activity promotion intervention to people with SSc. In the first phase, we conducted nominal group technique sessions with SSc patients to identify barriers and facilitators to physical activity. The nominal group technique is a formal consensus development method that, similar to a focus group, allows participants to share and compare experiences–leading to more effective idea generation [78]. However, we used the nominal group technique because it involves more structured discussion than a focus group and is designed specifically to allow stakeholders to directly generate items for a needs assessment survey [79] to be administered in the second phase of this thesis. Furthermore, in comparison to a focus group, the nominal group technique limits the influences of the researcher and group dynamics, and it promotes equal participation by all group participants [80]. In the second phase, we administered a large-scale survey to an international SSc cohort to determine the (1) prevalence and importance of different physical activity barriers experienced in SSc, and (2) the likelihood that people with SSc would use different barrier-specific and general facilitators to be physically active.

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Chapter 2 - Manuscript 1

2.1 Identifying Barriers and Facilitators to Physical Activity for People with Scleroderma: a Nominal Group Technique Study

Paper published in *Disability and Rehabilitation* (March 2020):

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Implications for Rehabilitation:

- People with scleroderma experience difficulty being physically active due to the diverse and often severe manifestations of the disease, including involvement of the skin, musculoskeletal system, and internal organs.
- In addition to regular care of scleroderma-related symptoms, patients overcome many exercise challenges by selecting physical activities that are comfortable for them, adjusting the intensity and duration of activities, adapting activities, and using adapted equipment or other materials to reduce discomfort.
- Rehabilitation professionals should help people with scleroderma to tailor activity options to their capacity and needs when providing care and advice to promote physical activity.

Abstract

Purpose: People with systemic sclerosis (scleroderma) face difficulties being physically active. This study identified physical activity barriers and facilitators experienced by people with scleroderma.

Materials and Methods: We conducted nominal group technique sessions with scleroderma patients who shared physical activity barriers, barrier-specific facilitators, and general facilitators. Participants rated importance of barriers and likelihood of using facilitators from 0-10, and indicated whether they had tried facilitators. Barriers and facilitators across sessions were merged to eliminate overlap; edited by investigators, patient advisors, and clinicians; and categorized using qualitative content analysis.

Results: We conducted 9 sessions (n=41 participants) and initially generated 181 barriers, 457 barrier-specific facilitators, and 20 general facilitators. The number of consolidated barriers (barrier-specific facilitators in parentheses) per category were: 14 (61) for health and medical; 4 (23) for social and personal; 1 (3) for time, work, and lifestyle; and 1 (4) for environmental. There were 12 consolidated general facilitators. The consolidated items with ≥ 1/3 of participants' ratings ≥ 8 were: 15 barriers, 69 barrier-specific facilitators, and 9 general facilitators.

Conclusions: Scleroderma patients reported many barriers related to health and medical aspects of scleroderma and several barriers in other categories. They reported facilitators to remain physically active despite the barriers.

Keywords: Exercise; nominal group technique; physical activity; scleroderma; systemic sclerosis

Introduction

Regular physical activity is recommended to enhance health among people in the general population [1,2] and for those with chronic diseases [3]. For people with autoimmune rheumatic diseases, health benefits of physical activity training programs may include reduced inflammation, better clinical outcomes, and improved health-related quality of life [4].

Systemic sclerosis (scleroderma) is a rare chronic, autoimmune rheumatic disease characterized by abnormal fibrotic processes and excessive collagen production that can affect the skin, musculoskeletal system, and internal organs, including the heart, lungs, and gastrointestinal tract [5,6]. People with scleroderma are classified as having limited (skin involvement of face, neck, and areas distal to the knees and elbows) or diffuse cutaneous scleroderma (skin involvement proximal and distal to the knees and elbows or trunk). Patients with the diffuse subtype typically have earlier onset of internal organ involvement and more rapidly progressive disease [7].

Most people with scleroderma can perform aerobic and resistance exercise safely [8], and regular physical activity is often encouraged [8]. Many, however, face barriers to being physically active [9]. Barriers to being active likely differ across people with scleroderma, but common barriers may include limitations in physical mobility, respiratory problems, gastrointestinal problems, fatigue, pain, and depression and anxiety [10-12].

Interventions to promote physical activity have been shown to increase activity levels in both the general population [13] and among people with chronic diseases [14]. However, there are no studies on interventions designed to provide guidance to scleroderma patients on how to select and adapt physical activities to accommodate their individual difficulties. The objective of the present study was to identify barriers (challenges) and facilitators (potential strategies to

overcome the challenges) for scleroderma patients becoming more physically active, to help rehabilitation therapists provide appropriate care to these patients, and to generate survey items to be used in a survey that will guide the development of a physical activity promotion program for people with scleroderma.

Materials and Methods

The present study is reported in line with the Consolidated Criteria for Reporting Qualitative Research Checklist [15].

Participants and Procedures

We conducted a series of 90-120 minute face-to-face nominal group technique sessions at provincial and national scleroderma patient conferences in Canada and the United States, and at an international scleroderma patient conference in France. The nominal group technique was originally designed to structure group discussions so that participants can share and compare experiences and reach consensus [16,17]. Typical nominal group technique sessions involve presenting a specific question to a group of participants who individually write lists of items in response to the question. Participants then are invited to share one item at a time from their lists in a round-robin format, and the group's list of items is presented for all participants as it develops. Once all items from each participant's list are shared, they discuss to clarify the meaning of items or to refine the items. Following this, participants evaluate the items by ranking or rating them based on importance or relevance to the nominal group technique question. More recently, the nominal group technique has been used as a method for directly generating items for needs assessment surveys, including in scleroderma [18].

For each nominal group technique session, we attempted to recruit a convenience sample of up to 8 participants. Eligible participants had received a diagnosis of scleroderma, were ≥18

years of age, and were fluent in English or French, depending on the conference setting. Prior to each patient conference, we recruited participants through online announcements to participants in the Scleroderma Patient-centered Intervention Network (SPIN) Cohort, a large international scleroderma cohort; emails and website posts from scleroderma patient organization partners; and social media (Twitter and Facebook). People with scleroderma who expressed interest in the study were contacted via email by the study coordinator to confirm eligibility and to provide them with details about the study. At each conference, we also recruited via a table and direct investigator-patient contact. All participants provided written consent and were given the opportunity to ask questions about the study. This study was approved (approval number: 2018-777) by the Research Ethics Committee of the Jewish General Hospital in Montreal, Quebec, Canada.

Prior to beginning each nominal group technique session, participants were asked to complete a brief questionnaire to obtain information on sex, age, race/ethnicity, relationship status, highest level of educational attainment (primary, secondary, some college /university, college /university degree, or postgraduate degree), occupational status, scleroderma diagnosis subtype, and years since scleroderma diagnosis (number of years or 25+ years). Participants were also asked to select the physical activities that they perform from a list (walking, jogging, aerobics, swimming, cycling, yoga or similar exercises) and to add activities if they were not listed. For each activity, they indicated the usual amount of time spent (number of months per year and hours per week). In the context of our study, physical activity refers to activities that are traditionally considered "exercise" (e.g., jogging or tennis) and other activities that involve energy expenditure (e.g., gardening or active transportation) [19].

Nominal Group Technique Protocol

We adapted a nominal group technique topic guide from a previously successful study using the same strategy (see Supplementary material) [18]. Before the first nominal group technique session, investigators pilot tested the adapted nominal group technique topic guide. Nominal group technique sessions were held in private hotel conference rooms and were moderated by 2 study investigators who were knowledgeable about scleroderma and had previous experience with discussion-based research. The moderators for each session always included a female doctoral student in clinical psychology (DBR) and either a female research assistant (JC), a male master's student in psychiatry (SH), or a male clinical psychologist (BDT). The final number of nominal group technique sessions was determined based on the redundancy and consistency of data obtained.

Participants were informed that the objectives of the nominal group technique session were to: (1) develop a list of key barriers to physical activity that they have experienced related to scleroderma, and (2) develop a list of possible facilitators to overcome the barriers to promote and support physical activity among people with scleroderma. Participants were first presented with the question: "Think about those barriers or challenges that you have experienced related to scleroderma. What barriers have you experienced when thinking about or actually being physically active?" They were asked to individually write on a piece of paper, without consultation with other group members, their personal list of examples of barriers to physical activity. Then, they were invited to share one barrier at a time from their lists in a round-robin format until all barriers from each participant's list had been shared. They were instructed not to repeat barriers that were verbatim to barriers provided by others but to share any barriers that seemed to differ, even if only minimally. If clarification was necessary, moderators used probes [20] to gain a clearer understanding of the barriers shared (e.g., "can you elaborate on that?"). As

they were shared, barriers were simultaneously typed on a computer by one moderator and projected onto a screen to be viewed by the moderators and participants. Once all barriers had been shared, moderators led an interactive discussion of the barriers among participants to reword unclear barriers, add any new barriers, remove or merge overlapping barriers, or separate individual barriers with multiple components into more than one barrier. Barriers were revised based on group feedback until agreement was reached for decisions on all barriers.

Next, participants were presented with the second research question: "Think about possible facilitators or strategies to overcome these barriers to promote and support physical activity among people with scleroderma. What barrier-specific facilitators would be helpful to overcome each barrier, and what general facilitators would be helpful to overcome multiple barriers and address physical activity in general?" For instance, the barrier-specific facilitator example of "electric heated gloves" could address the barrier of "Raynaud's phenomenon (cold, wind, and humidity)", whereas the general facilitator example of "exercising with other people" could apply to multiple barriers and physical activity in general. Participants were asked to write any examples of possible barrier-specific and general facilitators, and the same sharing and discussion process used for answering the first research question was then applied to this research question.

Once a final list of unique barrier and facilitator examples was agreed upon, one moderator printed a copy of the list for each participant. In all sessions, participants were asked to independently rate the importance of each barrier on a scale from 0 to 10, with 0 representing barriers that were not personally important to them when thinking about or being physically active, and 10 representing barriers that were extremely important to them when thinking about or being physically active. They rated the likelihood that they would use each barrier-specific

facilitator to overcome the barrier to be physically active on a scale from 0 to 10, with 0 representing facilitators that they would not likely use at all, and 10 representing facilitators that they would very likely use. Using the same scale, they also rated the likelihood that they would use each general facilitator. In all but the first two sessions, participants indicated whether they had or had not tried each facilitator.

Data Processing, Revision, and Analysis

Sociodemographic characteristics and physical activity levels of participants were presented descriptively. We report medians (range) for age, years of educational attainment (primary = 7, secondary = 12, some college /university = 14, college /university degree = 16, postgraduate degree = 20), and years since diagnosis (25+ years converted to 30 years) because the data were not normally distributed. We also report means (SD) for age, years of educational attainment, and years since diagnosis in order to facilitate comparisons with the SPIN Cohort [24,24], which is a convenience sample and has published data from > 1,000 participants with scleroderma from 29 sites in 3 countries.

All barrier and facilitator examples generated across nominal group technique sessions were compiled into a single list of examples. Many barriers and facilitators identified from individual nominal group technique sessions were similar to those identified in other sessions. Therefore, similar barriers and facilitators were merged into single items, and a merged initial list of items was generated by consensus among investigators. For instance, the barrier item of "difficulty grasping objects" could capture multiple participant examples (e.g., "difficulty gripping weights or bars" and "difficulty grasping things with my hands").

The initial list of items received 3 stages of revision by (1) study investigators, (2) 9 members of a SPIN Patient Advisory Team, and (3) 23 health care providers affiliated with SPIN

(12 rheumatology physicians, 5 internal medicine physicians, 2 psychologists, 2 physiotherapists, one physical and rehabilitation medicine physician, and one vascular physician). First, investigators reworded unclear items and excluded items that were too vague (e.g., get a cleaner) or not directly related to physical activity (e.g., surgery), which could not inform the development of a physical activity intervention in scleroderma. Following this, patient advisors and then health care providers made recommendations to reword items and exclude items. In addition, because the participants in the nominal group technique sessions were almost all active, we asked these contributors to further suggest additional barriers and facilitators experienced by inactive scleroderma patients. Patient advisors and health care providers evaluated whether barrier items met two criteria: (1) they would affect some people with scleroderma meaningfully (versus only trivially) and (2) they would plausibly be a reason why people with scleroderma do not participate in physical activity, and whether facilitator items met three criteria: (1) they would be feasibly and realistically used by some people with scleroderma, (2) they would plausibly address the corresponding barrier (general facilitators would plausibly address multiple barriers and physical activity in general) to support physical activity, and (3) they could be accessed or safely applied by many people with scleroderma. Very low item ratings were also used to inform item exclusion in consideration of the barrier and facilitator criteria. Study investigators used an iterative process at each stage to implement suggested revisions until consensus on a final list of items was attained. To group together barriers that share a common basis, one investigator performed a qualitative content analysis [21] of barriers using 4 categories described by Lascar et al. [22]: (1) health and medical; (2) social and personal; (3) time, work, and lifestyle; and (4) environmental. Investigators reviewed and attained consensus on classification of barrier items.

All processing and analyses were conducted with Microsoft Excel version 16.16.

Results

Between September 2017 and September 2018, 9 nominal group technique sessions were held at the 2017 Scleroderma Society of Nova Scotia Patient Education Forum (one session; Halifax, Canada); 2017 Scleroderma Foundation Tri-State Chapter Fall Research Forum (one session; New York, USA); 2018 Systemic Sclerosis World Congress (2 sessions; Bordeaux, France); 2018 Scleroderma Foundation National Patient Education Conference (4 sessions; Philadelphia, USA); and 2018 Scleroderma Canada National Conference (one session; Calgary, Canada). The number of participants per session ranged from 3 to 8. Eight sessions were in English and one in French (Bordeaux, France).

Participant Characteristics and Engagement in Physical Activity

A total of 41 people with scleroderma (34 females, 7 males) participated in the 9 nominal group technique sessions (table 1). The median age of participants was 60 (range 27 to 76 years). Most participants were retired (34.1%), employed full-time (22.0%), or on disability (19.5%). The majority were diagnosed with diffuse scleroderma (58.5%).

[Insert table 1 here]

All but one participant reported performing at least one type of physical activity (table 2). Most participants engaged in gentle aerobic exercises such as walking, yoga, and swimming. Participants also reported that they performed other physical activities not stated in the questionnaire (n=22) such as tennis, skiing, and gardening.

[Insert table 2 here]

Barriers and Facilitators to Physical Activity

The 9 nominal group technique sessions generated an initial list of 181 examples of physical activity barriers, 457 examples of barrier-specific facilitators, and 20 examples of general facilitators experienced by participants, including similar examples shared in different sessions (see Supplementary Table S1). Figure 1 illustrates the steps used to derive the final survey items from participant examples. Similar examples were merged to attain an initial list of items comprised of 48 barriers, 299 barrier-specific facilitators, and 14 general facilitators. There were 109 facilitator items that participants described as barrier-specific which were deemed as general, merged with existing general facilitator items, and used to inform the description of the 14 initial general facilitators. There were 28 excluded barrier items (most were not directly related to physical activity), 116 excluded barrier-specific facilitator items (most were vague, potentially harmful, or not generally accessible), and 4 excluded general facilitator items (vague or not generally accessible). Additionally, 17 new barrier-specific facilitator items and 2 new general facilitator items were recommended and added. Therefore, the final list of items (see Supplementary Table S2) consisted of 20 barriers, 91 barrier-specific facilitators, and 12 general facilitators. The number of barrier-specific facilitator items per barrier item ranged from 2 to 10.

[Insert figure 1 here]

Of 20 total barriers in the final list of items, 14 (70%) were health and medical barriers which addressed symptoms (e.g., fatigue) as well as medical conditions (e.g., Raynaud's

phenomenon) and activity restrictions (e.g., activities involving water may worsen condition of hands or skin on other areas of the body). Of 61 health and medical barrier-specific facilitators, most involved strategies to beginning and selecting physical activities (e.g., exercise at a time of day when you have the most energy – fatigue barrier), adapting the conduct of activities (e.g., for acid reflux, modify exercise positions to keep your body upright – gastrointestinal problems barrier), adjusting the intensity and duration of activities (e.g., lower the intensity of the exercise to not experience shortness of breath – shortness of breath barrier), using adapted equipment or other materials to reduce discomfort (e.g., insert warmers in gloves or mittens or socks – Raynaud's phenomenon barrier), and health behaviours to reduce the impact of barriers (e.g., do gentle stretching and movement to warm up the joints before exercise – joint stiffness and contractures barrier).

There were 4 social and personal barriers (20% of total barriers) that addressed feelings about physical activity (e.g., fear of injury or extended recovery time) and being in social settings (e.g., feeling embarrassed or discouraged due to physical ability, appearance, or judgement from others). Of 23 social and personal barrier-specific facilitators, most were methods to feel comfortable with physical activity (e.g., have an introductory session with a qualified exercise trainer to discuss your fears and get an assessment – fear of injury or extended recovery time barrier) and to increase physical activity (e.g., keep an exercise log to track your progress – lack of motivation and difficulty committing to exercise barrier).

There was one time, work, and lifestyle barrier related to one's life circumstances (finding time available to schedule exercise). There were 3 related facilitators, which included exercising at home or work to eliminate travel time, and breaking the exercise into several short periods (also listed as a facilitator to address the fatigue barrier) if one long period was not feasible

because of family, work and so on. Lastly, there was one environmental barrier related to preventing access to physical activity opportunities (costs related to exercise) with 4 facilitators about free exercise resources and opportunities (e.g., sign up for free activities or exercise classes organized by your community).

Figure 2 shows the distribution of ratings of importance of barrier items from the nominal group technique sessions. The number of ratings per item depended on the number of sessions that identified examples related to the item, the number of examples of experiences related to the item in those sessions (some sessions elicited multiple examples captured by one item), and the number of participants in the sessions where those examples were elicited. The 3 most-rated barriers were health and medical barriers: (1) fatigue, (2) joint stiffness and contractures, and (3) shortness of breath. The 3 most-rated barrier-specific facilitators were also in the health and medical category: (1) wear heated or non-heated warm gloves or mittens and socks (Raynaud's phenomenon barrier), (2) get enough sleep and plan to take a nap during the day (fatigue barrier), and (3) do strength training exercises (muscle weakness and difficulty with mobility barrier). The 3 most-rated general facilitators related to adapting physical activity were: (1) consult with your health care provider or exercise professional to discuss any concerns and/or custom design an exercise program that is matched to your capacity and needs, (2) exercise at a pace or intensity that is comfortable for you - start easy, progress slowly - if you have pain, adapt the exercise or seek advice, and (3) adapt the exercise or try a new exercise. There were 15 barrier items, 69 barrier-specific facilitator items, and 9 general facilitator items for which at least 1/3 of ratings were ≥ 8 for importance (barriers) or likelihood of using them (facilitators). In addition, there was 1 barrier item, 60 barrier-specific facilitator items, and 9 general facilitator items for which at least 50% of ratings were ≥ 8.

[Insert figure 2 here]

Discussion

Using the nominal group technique method, we identified a list of survey items comprised of 20 barriers, 91 barrier-specific facilitators, and 12 general facilitators to physical activity as experienced by people with scleroderma. Most barriers fell into the health and medical category, but there were also others grouped into 3 categories: social and personal; time, work, and lifestyle; and environmental. The list contains previously identified barriers and facilitators from studies of other patient groups or the general population, as well as scleroderma-specific barriers and facilitators not previously identified in the literature. Taken together, these barriers and facilitators provide insight on the physical activity experience of scleroderma patients in that they select and adapt activities to overcome their individual difficulties in order to perform, or adhere to, physical activity.

Participants' sociodemographic characteristics were generally similar to those of participants in the SPIN Cohort [23,24]. There was less than a 5% difference between our sample and the SPIN Cohort with respect to sex, race, and marital status categories. The mean age was approximately the same, and both mean years of educational attainment and years since scleroderma diagnosis were within two years. They differed on full- or part-time employment (29% of participants versus 41% of cohort) and diffuse scleroderma subtype (59% of participants versus 41% of cohort). Approximately half of SPIN Cohort patients are completely inactive, and most of the active patients engage in low intensity activities such as walking [9]. Although there was only one completely inactive patient in the present study, there were 8 patient examples of barriers (across 4 nominal group technique sessions) related to non-adherence to physical

activity, including hopelessness due to physical limitations, depression, motivation when not feeling well, and fluctuations in health making it difficult to keep a consistent routine.

Barriers in the health and medical category were generally related to scleroderma disease manifestation or pathology; 12 of 14 health and medical barriers reflect symptoms common in scleroderma [10]. This study was the first to elicit barriers and facilitators to physical activity directly from people with scleroderma, but the health and medical barriers identified are consistent with results from other studies that have found that decreased physical activity in scleroderma is associated with fatigue, pain, muscle weakness, and disability [9,25]. They are also similar to barriers to physical activity reported by people with other autoimmune rheumatic diseases, including fatigue, pain, stiffness, joint symptoms, and reduced mobility or functional ability [26-29]. Some health and medical barriers are in line with exercise testing and prescription studies in scleroderma that indicate physical activity difficulties such as pulmonary involvement (captured by "shortness of breath" in our study), pain, and fatigue [8].

Barriers in the social and personal; time, work, and lifestyle; and environmental categories were similar to perceived barriers reported by people in the general population and people with other autoimmune rheumatic diseases. These included fear of injury, cost of exercise, lack of motivation, and lack of time [26-32]. One social and personal barrier, feeling embarrassed or discouraged due to physical ability, appearance, or judgement from others, may more closely reflect the experience of people with scleroderma, including visible changes to their appearance [33].

General facilitators, such as individually adapted physical activity, exercise partners, group exercise, and support from exercise instructors and health care providers, were similar to those identified by people with other autoimmune rheumatic diseases [26-29]. Previous studies have

not elicited facilitators to address scleroderma-specific problems; therefore barrier-specific facilitators identified in the present study will be useful for patients and rehabilitation therapists who are searching for effective strategies to address these barriers.

Information on barriers and facilitators has been used to develop physical activity interventions for the general population [34] and for people with other diseases (e.g., rheumatoid arthritis [35]). The present study was the first phase of the SPIN - Physical Activity Enhancement Project, the aim of which is to develop, test, and disseminate free-of-charge an online scleroderma-specific intervention to promote and support physical activity. Based on the results of the present study, a survey will be administered via the SPIN Cohort, an international cohort of over 1,800 people with scleroderma. This will provide information on how common the barriers identified in the present study are and their importance in hindering or impeding engagement in physical activity, as well as the likelihood of using the proposed barrier-specific and general facilitators that were identified. The survey results will inform the development of the planned intervention so that it addresses barriers experienced by people with scleroderma.

Limitations

Interpretation of results should consider study limitations. First, although our study generated a list of potentially important barriers and facilitators, it is a qualitative study with selected patients, and readers should be cautious about making quantitative comparisons and inferences about the commonality or importance of the barriers and facilitators. In brief, we recruited study participants from among people attending patient conferences, and they may not be representative of all people with scleroderma. In comparison to the SPIN Cohort, a smaller proportion of participants in our study were inactive or full- or part-time employed, and a larger proportion of participants had the diffuse scleroderma subtype. We will administer our planned

large-scale survey via the SPIN Cohort to obtain results that will be generalizable to the larger scleroderma population. Second, all but one participant reported performing at least one type of physical activity. It is possible that we did not identify important barriers or facilitators for people with scleroderma who do not engage in physical activity at all. However, the 17 barrier-specific facilitators and 2 general facilitators added by patient advisors and health care providers affiliated with SPIN likely minimized this limitation. Third, although 41 people with scleroderma participated in the present study and many barriers and facilitators were similar across nominal group technique sessions, it is possible that some potentially important barriers and facilitators were not identified. Therefore, in our planned survey using the SPIN Cohort, we will also ask respondents to suggest new barriers and facilitators.

Conclusion

In summary, people with scleroderma reported many barriers related to health and medical aspects of scleroderma, as well as social and personal; time, work, and lifestyle; and environmental barriers. They further reported facilitators that have helped them remain physically active despite the barriers. The list of barriers and facilitators will be used to survey a much larger number of people with scleroderma via the SPIN Cohort, which will inform the development of an online physical activity intervention for people with scleroderma.

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Table 1. Participant characteristics.

Variable	Participants (n=41)
Female, *n (%)*	34 (82.9)
Age in years	
Mean (SD)	56.2 (12.2)
Median (range)	60 (27-76)
Race/ethnicity,[a] *n (%)*	
White	35 (85.4)
Black	3 (7.3)
Asian	2 (4.9)
Hispanic or Latino	2 (4.9)
Aboriginal	1 (2.4)
Relationship status, *n (%)*	
Never married	7 (17.1)
Married or common law	29 (70.7)
Separated or divorced	5 (12.2)
Highest Level of Education, *n (%)*	
Primary school	1 (2.4)
Secondary school	5 (12.2)
Some college or university	12 (29.3)
College or university degree	13 (31.7)
Postgraduate degree	10 (24.4)
Years of educational attainment	

Mean (SD)	15.7 (3.0)
Median (range)	16 (7-20)
Occupational status,[b] *n (%)*	
Unemployed	3 (7.3)
Part-time employed	3 (7.3)
Full-time employed	9 (22.0)
Homemaker	1 (2.4)
Retired	14 (34.1)
On leave of absence	4 (9.8)
On disability	8 (19.5)
Systemic sclerosis subtype, *n (%)*	
Localized	1 (2.4)
Limited	13 (31.7)
Diffuse	24 (58.5)
Unknown	3 (7.3)
Years since systemic sclerosis diagnosis, *n (%)*	
0 to 5	15 (36.6)
5.1 to 10	9 (22.0)
> 10	17 (41.5)
Years since systemic sclerosis diagnosis	
Mean (SD)	11.5 (9.8)
Median (range)	8 (1-30)

[a] Participants could select more than one race/ethnicity. One participant identified as White and Aboriginal, and another identified as White and Hispanic or Latino.

[b] Participants could select more than one occupation. One participant reported being on disability and part-time employment.

Table 2. Participant engagement in physical activity.

Type of physical activity	**Number of participants (n=41)**	**Number of months per year** ***median (range)***[a]	**Number of hours per week** ***median (range)***[a]
Walking	34	12 (4 to 12)	4 (0.25 to 14)
Yoga or similar exercises	16	12 (8 to 12)	3 (1 to 14)
Swimming	13	6 (3 to 12)	2.75 (0.5 to 5)
Cycling	11	10 (4 to 12)	2 (0.75 to 9)
Aerobics	10	12 (6 to 12)	2.5 (1 to 5)
Jogging	5	12 (4 to 12)	6.5 (2 to 16.5)
Other physical activity	22	12 (1 to 12)	3 (0.67 to 10)

[a] If participants stated more than one other physical activity, the data refer to the activity that was performed most frequently per year.

Figure 1. Flow diagram from participant examples to final items.

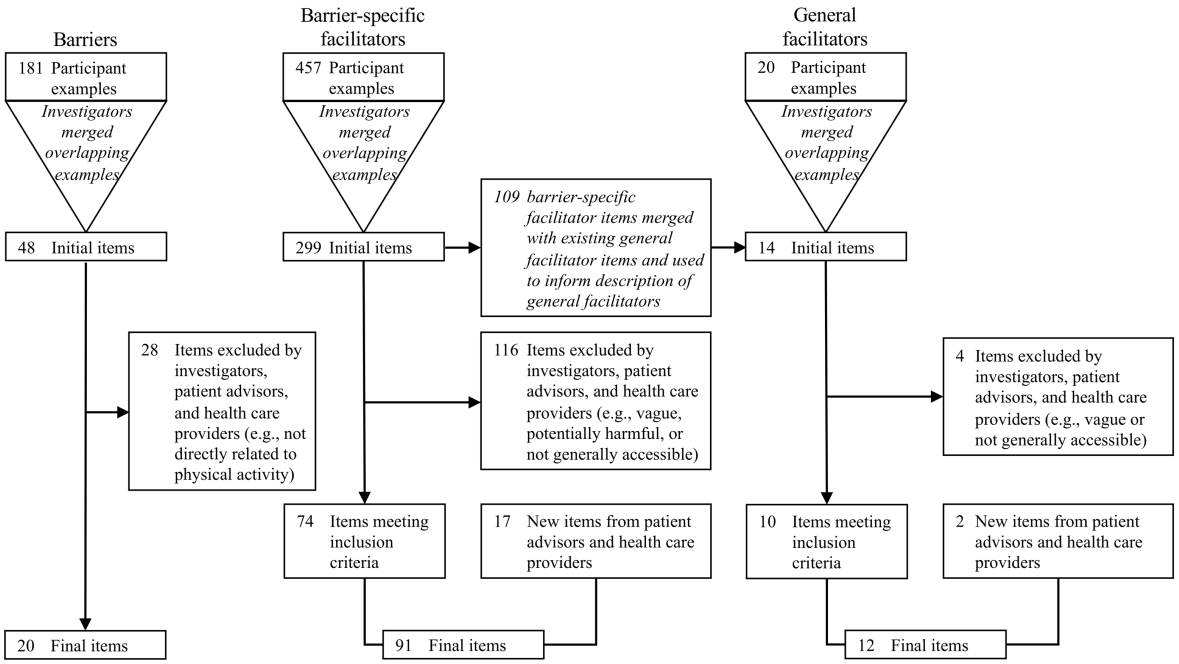
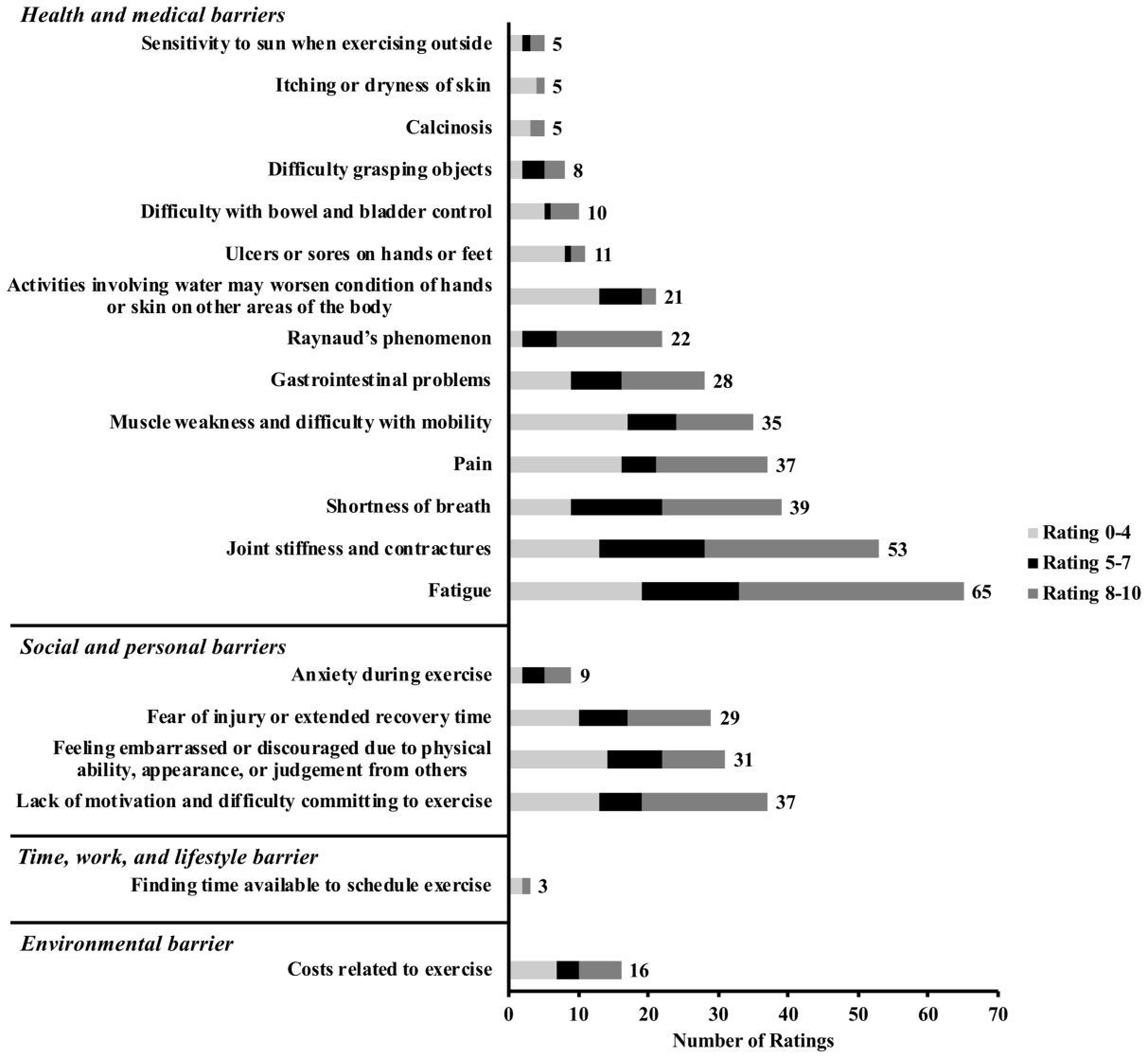


Figure 2. Distribution of ratings for barriers. Numbers to the right of each bar indicate the number of ratings for participant examples captured by the corresponding barrier item. Examples were only rated by participants in sessions where the examples were elicited. The number of ratings can exceed the total of 41 participants because examples were rated before we merged them together into single items. If 3 examples subsequently merged into a single item were each rated by 6 people, then the merged item would have 18 ratings.



Supplementary material. Nominal group technique topic guide.

General Introduction

Welcome to our session. We want to thank you all for taking the time to join us in talking about your experiences and thoughts on physical activity as someone living with scleroderma. My name is [NAME] and I will be leading the session today along with [NAME]. We are both from McGill University in Montreal, Canada. We would like to develop, test, and make available an online program to promote and support participation in physical activity for people with scleroderma. In order to develop an effective program, we need to begin by understanding the barriers and facilitators to physical activity related to scleroderma. The session that we are holding today is the first step, and we are going to have similar sessions with additional groups of people at other scleroderma patient conferences.

You were invited to participate as someone with scleroderma regardless of your level of physical activity. In our session today, there are no wrong answers but rather differing points of view. Please feel free to share your point of view even if it differs from what others have said. Although you may not agree with what others have said, we ask that you listen respectfully as others share their views and that there is only one person speaking at a time. We also ask that you turn your cell phones on silent.

Although we will be on a first name basis, we will not use any names in our reports. We would also like for everyone to keep the discussions that we have today in this room confidential. Our discussions should not be shared with others to respect the privacy of everyone participating. Does anyone have any questions?

Nominal Group Technique Protocol

Introduction

Let's begin by going around the table to introduce ourselves. Tell us your name and where you live.

Now, our main topic of interest concerns barriers and facilitators to physical activity specifically as it relates to your scleroderma. We have two objectives for today's session: (1) develop a list of key barriers to physical activity that you have experienced related to scleroderma, and (2) develop a list of possible facilitators to overcome the barriers to promote and support physical activity among people with scleroderma. We want to construct an online survey to understand what we need to address when developing a physical activity program for people with scleroderma, and today's session will help us to create this survey that will be sent to over 1,800 people living with scleroderma around the world. The format of today's session will allow us to develop a list of barriers and facilitators to physical activity.

Session Format

We will ask two research questions about your experiences with physical activity. We will start by asking you to make a list of examples of barriers to physical activity, which should take around five to ten minutes. Then we will go around the table and ask people to share one barrier at a time from their list until all barriers have been shared, which should take around 25 minutes. We will present the barriers on the screen at the front of the room, and might ask you to clarify certain barriers. If someone has already shared the same barrier from your list, there is no need to repeat it, but please share your barrier if you think it differs, even minimally. If you think of additional barriers as we are talking, feel free to add those to your list and share. After sharing, we will discuss the list to clarify and revise as needed. Then, we will ask you to write a list of examples of facilitators that address each barrier as well as general facilitators that address multiple barriers and physical activity generally, and the same process of sharing and discussion

will be repeated. Following this, the list of barriers and facilitators will be printed for everyone to rate. Overall, this session will last around 90 to 120 minutes. Does anyone have any questions?

Brainstorming Barriers

Barriers involve what discourages or prevents you from engaging in physical activities that you otherwise would enjoy. Here is our first research question: Think about those barriers or challenges that you have experienced related to scleroderma. What barriers have you experienced when thinking about or actually being physically active? *(Type this question on the computer to display on the screen at the front of the room.)* Please individually write down all your experienced barriers without consultation with other group members. For example, some people living with scleroderma have mentioned that specific symptoms can interfere such as Raynaud's attacks when trying to go swimming, difficulty lifting weights due to stiff hands, or acid reflux that occurs during yoga. Other people have mentioned general lifestyle barriers related to living with a chronic illness such as experiencing intense fatigue or difficulty setting up a consistent routine due to flare-ups and health changes.

Sharing and Discussing Barriers

Now I would like everyone to share one barrier on their list and we will continue going around in this format until all barriers on each of your lists have been shared. We ask for you to only share barriers that have not been mentioned yet. If you think of additional barriers while we share, just add them to your list. *(Type the barriers.) (Both moderators can ask for clarification of barriers if necessary.) (Once all barriers have been shared, have the participants discuss to reword unclear barriers, add any new barriers, remove or merge overlapping barriers, and separate individual barriers with multiple components into more than one barrier.)*

Brainstorming Facilitators

Since we have our list of barriers presented on the screen, let's move on to brainstorming examples of facilitators for each barrier. Facilitators allow people with scleroderma to be more active despite the barriers. Here is the next research question: Think about possible facilitators or strategies to overcome these barriers to promote and support physical activity among people with scleroderma. What barrier-specific facilitators would be helpful to overcome each barrier, and what general facilitators would be helpful to overcome multiple barriers and address physical activity in general? *(Type this question.)* Please write down all facilitators that you think would be helpful. You can write down more than one barrier-specific facilitator per barrier. For example, barrier-specific facilitators to acid reflux when doing yoga could be to adapt the yoga exercises and to make dietary adjustments.

Sharing and Discussing Facilitators

Now we will go through each barrier to share facilitators, and we will share general facilitators afterwards. We will make sure everyone gets a chance to speak before moving on to the next barrier. It is possible that for some barriers, no one will have any facilitators. That is fine, in which case we will move on to the next barrier. *(Type the facilitators.) (Both moderators can ask for clarification of facilitators if necessary.) (Once all facilitators have been shared, have the group discuss to reword unclear facilitators, add any new facilitators, remove or merge overlapping facilitators, and separate individual facilitators with multiple components into more than one facilitator.) (Then, one of the moderators will print the final list for each participant.)*

Rating Barriers and Facilitators

Now, we would like you all to look at your printed copy of the list and rate each barrier independently on a scale from 0 to 10, with 0 representing barriers that are not personally important to you when thinking about or actually being physically active, and 10 representing

barriers that are extremely important to you when thinking about or actually being physically active. Then, indicate whether you have or have not tried each facilitator by marking the appropriate box. Rate the likelihood that you would use each barrier-specific facilitator to overcome the barrier to be physically on a scale from 0 to 10, with 0 representing facilitators that you would not likely use at all, and 10 representing facilitators that you would very likely use. Using the same scale, also rate the likelihood that you would use each general facilitator to be physically active. Let us know if you have any questions, and make sure you individually rate every barrier and facilitator.

Conclusion

We have come to the end of our session now. We would like to thank you for your participation today. Does anyone have any final questions?

Supplementary Table S1. List of original barrier examples, facilitator examples and their ratings from nominal group technique sessions. Barriers will not have any barrier-specific facilitators if participants in the session did not elicit any facilitators, or the facilitators did not meet the inclusion criteria. Examples were only rated by participants in sessions where the examples were elicited. In all but the first two sessions, participants also indicated whether they had or had not tried the elicited facilitators.

Participant example	Session number	Number of ratings between 8 and 10 / total number of ratings	Number of times that participants had tried the facilitator / total of had and had not tried
Barriers and facilitators			
1. Barrier: Bloating, discomfort and pain from gastrointestinal problems.	1	0/3	
2. Barrier: Calcification in my joints.	1	0/2	
3. Barrier: Chlorine in pools aggravates itching.	1	0/2	
4. Oversized wet suits.	1	0/0	0/0
5. Salt water pools.	1	0/0	0/0
6. Barrier: Confidence that I can exercise safely.	1	0/2	
7. Barrier: Constant fatigue.	1	1/3	
8. Taking naps.	1	1/2	0/0
9. Barrier: Difficulty grasping things with my hands.	1	2/3	
10. Do exercises to strengthen hands.	1	0/0	0/0
11. Select activities that don't require as much hand mobility.	1	0/0	0/0
12. Barrier: Difficulty paying for a personal trainer.	1	0/2	
13. Barrier: Difficulty paying for costs of activities.	1	0/2	

14.	Barrier: Difficulty paying for physiotherapy.	1	0/2	
15.	Barrier: Feeling embarrassed about my appearance.	1	0/2	
16.	Barrier: Feeling embarrassed about not being able to do things that others can.	1	0/2	
17.	Barrier: Hopelessness because my physical limitations are permanent.	1	0/2	
18.	Barrier: Incontinence aggravated by exercise.	1	1/2	
19.	Barrier: Joint weakness.	1	0/2	
20.	Barrier: Lack of flexibility.	1	1/3	
21.	Barrier: Limited range of motion.	1	0/3	
22.	Barrier: Loss of muscle mass.	1	0/3	
	23. Qigong.	1	0/0	0/0
24.	Barrier: Low endurance and fatiguing quickly.	1	1/3	
	25. Ensuring I get enough sleep.	1	0/0	0/0
26.	Barrier: Motivation when I'm not feeling well.	1	0/3	
27.	Barrier: Muscle weakness.	1	0/2	
28.	Barrier: Not wanting to hold up the group in group exercise classes.	1	0/2	
29.	Barrier: Reflux with bending or laying down.	1	0/2	
30.	Barrier: Sensitivity to sun exposure.	1	1/2	
31.	Barrier: Showering after exercise dries out skin.	1	0/2	
32.	Barrier: Extreme fatigue.	2	3/5	
	33. Sleep.	2	2/4	0/0
34.	Barrier: Gastrointestinal issues (e.g., heart burn, celiac, bloating, gassy dysmotility).	2	5/5	
	35. Smaller meals.	2	3/5	0/0
36.	Barrier: Gym expenses.	2	4/5	
	37. Finding free activities for physical activity.	2	3/5	0/0
38.	Barrier: Hand contractures (i.e., can’t pick up exercise objects, can’t use many exercise machines).	2	3/5	
	39. Paraffin.	2	1/5	0/0

40.	Barrier: Increased recovery time from non-scleroderma related health concerns (e.g., wisdom teeth removal).	2	2/4	
41.	Get the rest you need.	2	3/4	0/0
42.	Barrier: Injury related to scleroderma (e.g., major joints - needing knee replacement).	2	2/5	
43.	Barrier: Lack of physical flexibility (e.g., impacts the type of exercises you can do, being able to do classes such as yoga).	2	4/5	
44.	Adapted equipment (e.g., stretching band).	2	4/5	0/0
45.	Stretches.	2	3/5	0/0
46.	Yoga.	2	1/5	0/0
47.	Barrier: Muscle weakness.	2	2/5	
48.	Daily routine for strength training.	2	2/5	0/0
49.	Strength training.	2	5/5	0/0
50.	Barrier: Pain.	2	3/5	
51.	Barrier: Sleep changes (e.g., lack of sleep, disrupted sleep).	2	2/5	
52.	Barrier: Stamina (e.g., shortness of breath).	2	2/5	
53.	Pulmonary therapy.	2	3/5	0/0
54.	Barrier: Being breathless.	3	1/3	
55.	Barrier: Calcinosis (reduces amplitude of movements).	3	2/3	
56.	Barrier: Difficult to exercise with healthy people because of different abilities.	3	2/3	
57.	Barrier: Exercise makes it difficult to control bowel movements.	3	2/3	
58.	Communicate that you need to go to the restroom.	3	1/1	1/1
59.	Barrier: General fatigue.	3	2/3	
60.	Barrier: Joint pain.	3	1/3	
61.	Controlled movements.	3	2/2	2/2
62.	Barrier: Joint stiffness.	3	2/3	
63.	Controlled movements.	3	2/3	3/3

64.	Barrier: Malabsorption (not getting the energy from food to exercise).	3	1/3	
65.	Barrier: Muscle weakness.	3	2/3	
66.	Barrier: Other people's judgements (e.g., staring).	3	0/3	
67.	Barrier: Skin stiffness (hand contractures).	3	2/3	
	68. Wax paraffin bath.	3	1/3	1/3
69.	Barrier: Breathlessness.	4	1/3	
70.	Barrier: Fatigue.	4	2/3	
	71. Nap or rest.	4	3/3	3/3
	72. Relaxation.	4	3/3	3/3
73.	Barrier: Motivation.	4	3/3	
74.	Barrier: Pain in muscles and joints.	4	1/3	
	75. Heat (hot water bottle, hair dryer, bath, microwave gel bag).	4	1/2	2/2
	76. Relaxation.	4	1/3	3/3
77.	Barrier: Raynaud's phenomenon (cold, wind, and humidity).	4	2/3	
	78. Electric heated gloves.	4	3/3	1/3
	79. Sheepskin gloves.	4	0/3	1/3
	80. Sheepskin soles.	4	0/2	0/2
	81. Silk under gloves.	4	2/3	3/3
82.	Barrier: Risk of injury (hands).	4	1/3	
83.	Barrier: Stiffness in muscles and joints.	4	1/3	
	84. Yoga and stretching.	4	2/3	3/3
85.	Barrier: Ulcers (hands and feet).	4	0/3	
	86. Protection.	4	2/3	3/3
87.	Barrier: A lack of sensitivity from other people exercising at same facility or in the same classes.	5	1/2	
	88. Get help to come to terms with the illness (e.g., support groups).	5	2/3	2/3
89.	Barrier: Difficulty doing housework from inability to reach due to stiffness in arms (e.g., can’t extend arms, low range of motion).	5	0/2	

90.	Barrier: Difficulty going up steep hills or doing housework due to breathlessness.	5	2/2	
91.	Pulmonary rehabilitation.	5	3/3	2/3
92.	Splitting the task/exercise up and taking breaks.	5	2/3	2/3
93.	Barrier: Difficulty holding equipment or cleaning materials (e.g., vacuum, clothes basket, exercise equipment).	5	0/2	
94.	Adapting equipment/materials.	5	1/3	1/3
95.	Bring your own adapted weights.	5	1/3	1/3
96.	Do exercises without weights.	5	2/3	3/3
97.	Use ankle or wrist weights.	5	1/3	0/3
98.	Use bigger weights (not heavier but larger area to grip).	5	1/3	1/3
99.	Barrier: Difficulty running or walking due to toe contractures.	5	1/2	
100.	Barrier: Fatigue making getting to the gym difficult (e.g., preventing attendance at the gym).	5	0/2	
101.	Break up the exercise.	5	1/3	3/3
102.	Try to do exercise from home.	5	1/3	2/3
103.	Barrier: Fatigue making it difficult to complete a workout (e.g., complicating the completion of planned workout).	5	1/2	
104.	Break up the exercise.	5	2/3	3/3
105.	Barrier: Feeling discouraged due to judgement from exercise teachers.	5	0/2	
106.	Barrier: Feeling discouraged due to judgement from other group during group exercise classes.	5	0/2	
107.	Barrier: Feeling embarrassed due to not being able to keep up with others in a group setting (e.g., dance class).	5	0/2	
108.	Try to do similar classes at home first to see if able to do it in person.	5	0/3	2/3
109.	Barrier: Feeling out of breath due to pulmonary fibrosis.	5	2/2	

110. Pulmonary rehabilitation - gives access to oxygen, helps to determine limits and adapt exercise.	5	3/3	2/3
111. Barrier: Gastroesophageal reflux disease issues during certain positions in yoga (especially while upside down).	5	1/2	
112. Modify positions.	5	2/3	1/3
113. Modify what, when, and how much you eat prior to yoga.	5	2/3	1/3
114. Barrier: Increased concerns of injury.	5	0/2	
115. Have an introductory session with a personal trainer to get an assessment.	5	1/3	0/3
116. Watch the class.	5	1/3	1/3
117. Barrier: Increased severity of consequences of injury and recovery time (e.g., can't ice injury).	5	1/2	
118. Barrier: Pain.	5	1/2	
119. Braces or bandages.	5	0/3	0/3
120. Hot showers/baths.	5	1/3	3/3
121. Barrier: Raynaud's phenomenon triggered by exercise in general (e.g., ambient temperature, from motion of arms).	5	1/2	
122. Dress in layers (try to keep core warm).	5	3/3	3/3
123. Long pants and shirts instead of short sleeve or shorts.	5	2/3	2/3
124. Wear mittens/gloves.	5	3/3	3/3
125. Wear warm socks.	5	3/3	3/3
126. Barrier: Raynaud's phenomenon triggered during water exercise (e.g., water aerobics).	5	1/2	
127. Gloves that protect hands and keep them warm for swimming.	5	2/3	0/3
128. Try a heated pool.	5	2/3	1/3
129. Water socks to help keep feet warm.	5	2/3	1/3
130. Wet suits (or wet tops) for swimming.	5	2/3	1/3
131. Barrier: Reduced flexibility making yoga difficult (e.g., stiffness with joints and muscles).	5	1/2	

132. Do stretches to try and increase flexibility (stretches given by occupational therapist/physiotherapist for example).	5	2/3	2/3
133. Schedule gym times for when less stiff during the day.	5	1/3	1/3
134. Barrier: Ulcers on feet restricting ability to exercise.	5	1/2	
135. Specialized shoes (e.g., slip-on shoes, stretched shoes).	5	3/3	1/3
136. Try to take pressure off the parts of the feet through orthotics or pads.	5	3/3	1/3
137. Barrier: Acid reflux when doing exercises (e.g., burpees, downward dog yoga position).	6	1/3	
138. Stay more vertical (e.g., doing wall push-ups rather than push-ups on the ground).	6	3/4	2/4
139. Barrier: Anxiety while exercising (e.g., fear of having a panic attack).	6	1/3	
140. Being mindful of breathing and heartbeat.	6	3/4	3/4
141. Barrier: Breathlessness.	6	2/3	
142. Barrier: Difficulty gripping weights/bars.	6	1/3	
143. Put pool noodle around weight bars to make it easier to grip.	6	2/4	2/4
144. Use tool with u-hooks that is placed on wrist to grab bar (weight lifting hooks).	6	3/4	2/4
145. Using stretch bands that come with hooks to use arms for pulling.	6	2/4	1/4
146. Barrier: Fatigue.	6	2/3	
147. Lay down and rest each day.	6	4/4	4/4
148. Take rest breaks when there is time.	6	4/4	4/4
149. Barrier: Fear of consequences of exercise (e.g., fear of getting stuck on chairlift and being cold).	6	1/3	

150.	Barrier: Fear of inconveniencing others (e.g., cutting exercise short to let the next person use the machine).	6	1/3	
151.	Barrier: Finding time (scheduling).	6	1/3	
152.	Break it up into smaller increments (e.g., some exercise on lunch break).	6	4/4	3/4
153.	Incorporating exercise into other activities (e.g., stretches while watching TV, when getting out of bed).	6	3/4	2/4
154.	Barrier: Joint stiffness.	6	3/4	
155.	Bath with epsom salts.	6	3/4	3/4
156.	Doing yoga.	6	3/4	4/4
157.	Tai chi.	6	2/4	4/4
158.	Barrier: Not pushing self hard enough out of fear (e.g., fear of limitations).	6	2/3	
159.	Finding a teacher who you trust (e.g., understands limitations but will push you).	6	3/4	3/4
160.	Barrier: Pain.	6	2/3	
161.	Barrier: Pushing self too hard when trying to keep up with others in a group exercise setting.	6	3/3	
162.	Barrier: Raynaud's phenomenon - air conditioning at the gym.	6	2/2	
163.	Dress in layers.	6	4/4	4/4
164.	Wear handwarmers.	6	4/4	4/4
165.	Barrier: Difficulty bending over due to gastrointestinal problems.	7	0/3	
166.	Avoid bending over.	7	2/3	2/3
167.	Barrier: Difficulty breathing with high humidity or coldness in the air when doing outside activities.	7	0/3	
168.	Barrier: Difficulty doing activities with water as it makes hands worse (e.g., difficulty doing dishes or swimming).	7	1/3	
169.	Use cream on fingers and leave it overnight (cream and saran wrap).	7	1/3	2/3

170. Use gloves.	7	2/3	3/3
171. Wear a wet suit to stay warm.	7	1/3	1/3
172. Barrier: Difficulty drinking water and eating due to gastrointestinal problems.	7	1/3	
173. Limit yourself.	7	3/3	2/3
174. Barrier: Difficulty with outdoor activities or air-conditioned gym due to Raynaud's phenomenon (e.g., skiing).	7	1/3	
175. Using hot pads in gloves.	7	2/3	3/3
176. Using mittens.	7	3/3	3/3
177. Barrier: Dryness of fingers limiting ability to do physical activity.	7	1/3	
178. Use cream on fingers and leave it overnight (cream and saran wrap).	7	2/3	2/3
179. Use gloves.	7	3/3	3/3
180. Barrier: Fatigue after physical activity.	7	0/2	
181. Barrier: Flare-ups resulting in swelling and pain (e.g., flare-ups in tendons when walking).	7	1/3	
182. Learning to recognize warning signs.	7	2/3	3/3
183. Barrier: Itching and sores making physical activity difficult.	7	0/2	
184. Barrier: Joint pain (e.g., knees).	7	1/3	
185. Barrier: Lower body de-conditioning due to lack of exercise (i.e., lower body is weaker than upper body which is evident when biking).	7	2/3	
186. Strengthen lower body (e.g., squats, lunges - suggested from gym instructor).	7	3/3	3/3
187. Barrier: Pain.	7	1/3	
188. Heating pads.	7	2/3	3/3
189. Barrier: Sensitivity to the sun and increased chance of sun burns (e.g., when gardening).	7	1/3	
190. Clothes with SPF in them.	7	1/3	1/3
191. Cover-up (e.g., wear sunglasses, hat).	7	2/3	3/3
192. Go outside in the evening.	7	2/3	3/3

193. Sunblock.	7	2/3	3/3
194. Barrier: Sensitivity to the sun resulting in fatigue making outdoor activities difficult.	7	0/3	
195. Barrier: Balance difficulties.	8	1/5	
196. Strengthen core.	8	4/4	3/4
197. Barrier: Body stiffness.	8	3/5	
198. Stretching.	8	4/4	4/4
199. Barrier: Depression.	8	2/5	
200. Find hobbies that you like doing (e.g., gardening).	8	4/5	3/5
201. Barrier: Difficulty committing to physical activities as the way you'll feel varies day-to-day.	8	2/5	
202. Adjusting the length of planned activity.	8	4/4	3/4
203. Find more feasible options for activity (e.g., walking).	8	4/4	3/4
204. Barrier: Difficulty with outdoor activities (e.g., skiing) due to Raynaud's phenomenon.	8	4/5	
205. Adjustable heated gloves.	8	4/5	3/5
206. Avoid the outdoors.	8	4/5	5/5
207. Hand warmers.	8	4/5	4/5
208. Having warm pairs of socks available.	8	5/5	5/5
209. Layering clothes (especially to keep core warm).	8	5/5	5/5
210. Barrier: Embarrassment due to physical limitations.	8	2/5	
211. Do activities that are not in a group setting.	8	3/4	2/4
212. Barrier: Fatigue/low energy/low stamina.	8	4/5	
213. Get enough sleep.	8	3/4	4/4
214. Barrier: Fear of unknown related to potential injury.	8	3/5	
215. Barrier: Fecal incontinence when trying to work out.	8	1/5	
216. Work out from home.	8	3/3	2/3

217. Barrier: Financial issues.	8	2/5	
218. Checking options available for reimbursement (e.g., if attending a gym) or reduced rates for medication.	8	3/4	2/4
219. Community classes.	8	3/4	3/4
220. Finding free resources online.	8	4/4	3/4
221. Barrier: Impacted breathing ability.	8	2/5	
222. Barrier: Lost muscle.	8	3/5	
223. Build muscle (know this may happen slowly).	8	3/4	4/4
224. Train different groups of muscles.	8	4/4	3/4
225. Barrier: Low motivation.	8	3/5	
226. Listen to podcasts or watch shows while exercising to distract self from exercise.	8	3/4	4/4
227. Reward self with listening to podcasts or books only when being active.	8	3/4	2/4
228. Use technology (e.g., smart watches).	8	3/4	4/4
229. Barrier: Pain.	8	2/5	
230. Working around the pain (pain management).	8	4/4	2/4
231. Barrier: Anxiety when exercising in groups (e.g., cannot keep up with the group).	9	3/6	
232. Find exercise options that are developed for people with medical limitations.	9	5/6	3/6
233. Let the instructor know about your limitations.	9	5/7	7/7
234. Barrier: Can't wear a closed toe shoe due to ulcers.	9	1/6	
235. Barrier: Difficulties with balance.	9	1/7	
236. Do exercise to improve balance (e.g., tai chi).	9	4/5	4/5
237. Exercise in a pool.	9	4/6	2/6
238. Using a support (e.g., chair, wall, bar).	9	4/7	4/7

239.	Barrier: Difficulty swimming in pools that are chlorinated due to irritation of skin and lungs.	9	0/7	
240.	Finding a pool that has salt water.	9	2/6	1/6
241.	Barrier: Fatigue.	9	5/7	
242.	Exercise in the morning when there may be less fatigue.	9	4/7	5/7
243.	Get enough sleep.	9	4/7	6/7
244.	Honour your fatigue and rest when you need to.	9	5/6	6/6
245.	Barrier: Feeling tired after exercising (e.g., need to rest after exercise).	9	5/7	
246.	Exercise in the morning when there may be less fatigue.	9	3/7	7/7
247.	Get enough sleep.	9	2/7	7/7
248.	Honour your fatigue and rest when you need to.	9	6/7	7/7
249.	Barrier: Fluctuations in health making it difficult to keep a consistent routine.	9	5/7	
250.	Barrier: Gastroesophageal reflux disease limited types of activities that can be done (e.g., horizontal or downward position activities).	9	4/7	
251.	Adapting exercise so that head is above body (sitting on a chair for elevating self when doing exercise).	9	5/7	2/7
252.	Other yoga positions that aren't downward.	9	3/6	3/6
253.	Barrier: Had to stop swimming activity due to skin sensitivity (i.e., edge of pool is too rough).	9	1/7	
254.	Can wear water friendly gloves.	9	3/5	0/5
255.	Barrier: Lack of motivation.	9	3/7	
256.	Keeping a journal of when you exercised.	9	4/8	2/8
257.	Listen to motivating music.	9	4/7	4/7
258.	Personal trainer.	9	2/8	4/8
259.	Thinking about positive events (e.g., reading gratitude journal).	9	6/8	6/8

260.	Barrier: Lactic acid in legs during exercise fully inhibiting the ability to continue the activity.	9	3/7	
261.	Barrier: Low levels of hemoglobin, and vascular involvement resulting in lack of energy.	9	2/7	
262.	Barrier: Lung involvement (e.g., resulting in limited activities and less intense exercising).	9	3/6	
263.	Rest when needed.	9	6/7	6/7
264.	Barrier: Pain inhibiting the start of exercising or resulting in difficulty during exercise (e.g., sporadic foot pain and joint pain).	9	3/7	
265.	Orthotics.	9	3/7	3/7
266.	Pause the movement causing pain.	9	7/7	7/7
267.	Barrier: Raynaud's being triggered and limiting any activities (including those in warm weather, e.g., cannot add layers to go swimming, air conditioning in the gym).	9	4/5	
268.	Being prepared and having layers (gloves, handwarmers).	9	5/7	6/7
269.	Electric heated clothing (e.g., socks, gloves, vest).	9	3/7	4/7
270.	Barrier: Shortness of breath.	9	2/7	
271.	Barrier: Skin tightening results in limited range of motion.	9	2/7	
272.	Consistently stretching the joints (daily, developing a routine and setting reminders, incorporate into other activities).	9	4/6	3/6
273.	Relaxation after exercise with gentle movement.	9	6/6	3/6
274.	Barrier: Stiffness (e.g., joint stiffness).	9	2/6	
275.	Moving the joint prior to exercising (warming up).	9	5/7	7/7

General facilitators

276.	Anti-depressant.	7	1/2	1/2
277.	Consult with a nutritionist or naturopath.	1	1/3	0/0

278.	Having a therapist available to help discuss barriers with (e.g., anxiety, understanding limits).	6	3/4	2/4
279.	Don't be afraid to not finish.	5	3/3	3/3
280.	Know your limits.	3	3/3	3/3
281.	Minimal activity with moderation.	4	1/1	1/1
282.	Modifying expectations.	5	3/3	3/3
283.	Pacing activities.	1	0/3	0/0
284.	Choose activities that work for you.	3	3/3	3/3
285.	Choosing activities where I have fewer limitations.	1	1/3	0/0
286.	Activity with other people.	4	2/2	2/2
287.	Bring a friend.	5	2/3	1/3
288.	Ask for trials at gyms or classes.	5	2/3	3/3
289.	Scheduling physical activity.	1	0/3	0/0
290.	Maintaining your goal and progress.	3	3/3	3/3
291.	Set manageable, realistic goals.	3	3/3	3/3

Barrier-specific facilitators merged with general facilitators

Ratings were given for barrier-specific facilitators that each address one barrier. Ratings may not apply to multiple barriers or physical activity generally.

292.	Accommodation from exercise facilities (e.g., could get doctor's note describing that this flexibility is helpful/necessary).	9	1/6	1/6
293.	Accommodation from exercise facilities (e.g., if you sign up for group sessions having flexibility in the exact days, could get doctor's note to demonstrate health, options to not commit to the classes).	9	2/7	1/7
294.	Call facility ahead of time to ask if they have adapted equipment or lower weights.	5	1/3	0/3
295.	Explore options with staff at the pools to prepare (e.g., is the air conditioning on, are there hot showers available?).	5	0/3	0/3
296.	Speak to facility supervisor to try and connect you to someone.	9	3/8	1/8

297.	Adapt exercise with physiotherapist (communicate well).	3	3/3	3/3
298.	Artificial tears.	4	1/2	1/2
299.	Ask medical professional for options.	8	3/4	1/4
300.	Braces.	2	1/4	0/0
301.	Cardiac rehabilitation - take pulse and heart rate to know if you're going past your limits.	5	3/3	1/3
302.	Check to make sure with the pharmacist that the medications don't interact.	2	4/5	0/0
303.	Consider taking medication for depression.	8	3/5	3/5
304.	Consult with a physiotherapist. (x2)	1	0/4	0/0
305.	Consult with knowledgeable professionals to develop an individualized exercise program.	9	5/7	1/7
306.	Counselling or therapy. (x2)	1	1/5	0/0
307.	Cream - arnica, traumeel.	6	2/4	2/4
308.	Creams.	5	2/3	2/3
309.	Early medical care.	5	2/3	2/3
310.	Find trainers/physiotherapists who will connect with other medical professionals aware of scleroderma.	8	4/4	3/4
311.	Follow the prescribed recovery plan.	5	1/3	1/3
312.	Get orthotics made. (x2)	5	6/6	1/6
313.	Glucosamine Chondroitin.	7	1/3	1/3
314.	Go to podiatrist for special soles.	5	3/3	1/3
315.	Hemp oil (CBD) to help with Raynaud's phenomenon.	6	3/4	1/4
316.	Hemp oil (CBD) to help with sleep.	6	3/4	2/4
317.	Knee injections.	7	0/3	1/3
318.	Learn strategies from a physiotherapist and then apply them independently within a gym.	2	1/5	0/0
319.	Massaging the hands.	2	2/5	0/0
320.	Medication. (x7)	2, 3, 5, 7, 8	10/22	8/18
321.	Medication (prescribed and over the counter).	2	5/5	0/0
322.	Medication before exercise.	2	1/4	0/0

323.	Nutritionist/dietician.	2	3/5	0/0
324.	Occupational therapy. (x2)	2	6/10	0/0
325.	Oil – CBD.	6	3/4	2/4
326.	Opioid treatment.	7	1/3	1/3
327.	Pain killers. (x2)	2, 9	6/12	6/7
328.	Physical therapy. (x3)	2	11/15	0/0
329.	Physiotherapy exercise.	4	0/3	2/3
330.	Prednisone.	7	2/3	3/3
331.	See a physiotherapist. (x2)	1	0/0	0/0
332.	See an osteopath.	1	0/0	0/0
333.	Seek out teachers that have a background in therapeutic yoga.	5	1/3	1/3
334.	Speak to instructors for help.	9	5/8	5/8
335.	Speak with doctor and physiotherapist first to see if they think it is okay or if they can provide other suggestions.	5	2/3	1/3
336.	Splinting to straighten hands.	1	0/0	0/0
337.	Stretching assisted by physiotherapist.	9	6/8	3/8
338.	Talk to your medical professional.	8	3/4	3/4
339.	Therapeutic massages.	5	3/3	3/3
340.	Topical cream.	9	2/7	2/7
341.	Using medicated tape to put on the joint(s).	9	3/7	1/7
342.	Working with a physiotherapist to identify the source of reduced flexibility and get solutions.	5	2/3	2/3
343.	Accepting that set-backs will occur.	8	3/4	3/4
344.	Accepting that you may need to ask for help (e.g., ask a trainer).	8	3/4	4/4
345.	Activity pacing.	3	0/1	2/2
346.	Adapt expectations due to limitations (be kind to self). (x2)	5	2/6	5/6
347.	Adjust your expectations.	8	2/4	4/4
348.	Allowing yourself to take the time you need for self-care.	6	4/4	4/4
349.	Any movement, even mild (keep active). (x2)	3	5/5	5/5

350.	Break it up into smaller increments (e.g., some exercise on lunch break).	6	4/4	3/4
351.	Building from your new baseline.	8	4/4	3/4
352.	Do activities within your limits (use pain as a signal to stop or adapt the exercise).	9	6/6	4/6
353.	Doing what you can and lowering expectations.	8	4/4	4/4
354.	Educate yourself to know what you're able to do.	8	4/4	4/4
355.	Find a less vigorous session.	9	5/6	5/6
356.	Finding a new normal over time.	1	0/0	0/0
357.	Focus on what you can do.	9	7/8	4/8
358.	Know your limitations and sensitivities.	2	3/5	0/0
359.	Knowing and accepting your limits. (x2)	8	6/8	6/8
360.	Knowing and listening to your limitations.	8	4/4	3/4
361.	Learning from and adhering to your own limits. (x2)	6	7/8	8/8
362.	Light weights.	1	0/0	0/0
363.	Listen to when your body needs to stop.	2	4/5	0/0
364.	Low-intensity exercise options. (x2)	6	8/8	6/8
365.	Maintaining a minimum amount.	3	0/1	2/2
366.	Manage expectations.	8	3/4	3/4
367.	Minimal activity with moderation.	4	1/1	1/1
368.	Pace yourself.	7	2/3	2/3
369.	Pacing yourself. (x2)	9	9/13	12/13
370.	Push yourself to a bit (some is better than none).	8	4/4	4/4
371.	Reminding yourself that movement will help with fatigue.	8	3/4	3/4
372.	Slow down the pace.	4	1/1	1/1
373.	Take the time needed.	8	4/4	3/4
374.	Trying to do a bit of exercise per day. (x2)	9	9/14	14/14
375.	Adapt exercises.	9	6/7	4/7
376.	Adapt the environment. (x2)	4	0/2	2/2

377.	Adapted equipment (e.g., sock aid, long shoe horn).	2	3/5	0/0
378.	Adapted exercises.	2	3/5	0/0
379.	Adjust intensity.	9	5/7	4/7
380.	Adjust the activity or intensity of the activity.	9	6/7	6/7
381.	Alternate type of exercise (e.g., non-weight bearing exercise).	9	6/6	6/6
382.	Bring your own adapted weights.	5	1/3	1/3
383.	Choosing activities or adapting exercises that will not worsen stiffness.	8	4/4	4/4
384.	Find new activities.	8	3/4	3/4
385.	Gadgets/adaptable materials.	5	1/3	1/3
386.	Hold the weight differently.	5	1/3	1/3
387.	Learn the activities that you can do.	8	4/5	5/5
388.	Make adaptations to activities. (x2)	1	0/0	0/0
389.	Modify exercise to what you can do.	5	2/3	3/3
390.	Modify exercises.	9	6/8	6/8
391.	Modify poses (can ask instructor for help or try to modify on own).	5	2/3	2/3
392.	Modifying exercises.	5	6/8	3/3
393.	Remember the things you can do.	3	1/1	1/1
394.	Starting a new activity (so that there are no comparisons).	8	4/4	3/4
395.	Try something new when you are alone.	3	1/1	1/1
396.	Activity with others.	4	2/3	3/3
397.	Arrange to do activities with a partner or friend.	1	1/2	0/0
398.	Bring a friend to the class.	5	1/3	1/3
399.	Doing activities with others who will support you.	8	3/3	3/3
400.	Doing exercise with others with scleroderma.	1	0/0	0/0
401.	Find people with common symptoms.	9	3/7	3/7
402.	Go with a friend or group of people for support.	5	0/3	2/3
403.	Group (or friend) based commitments.	9	3/7	5/7

404.	Group registration.	4	2/2	2/2
405.	Attend class with people who are near intended age (e.g., 50+).	5	2/3	2/3
406.	Choose a class that's comfortable and fits your level (e.g., gentle yoga).	5	2/3	2/3
407.	Find classes in the area and attend with friends similar in age.	5	1/3	0/3
408.	Finding a location that is open and accepting to the restrictions/limitations people may have (e.g., finding adaptive or accessible classes). (x2)	6	5/7	6/7
409.	Take new classes including beginner classes.	5	1/3	1/3
410.	Trials of classes. (x2)	5	2/6	2/6
411.	Consistency in daily routine. (x2)	9	7/14	14/14
412.	Planning ahead of time. (x2)	9	10/14	12/14
413.	Scheduling with alarms and reminders.	2	1/4	0/0
414.	Take advantage of time when available (e.g., on weekends).	6	3/4	4/4
415.	Balanced diet. (x2)	9	6/11	11/11
416.	Eating properly.	8	4/4	3/4
417.	Getting enough nutrition.	1	0/0	0/0
418.	Good nutrition.	8	4/4	4/4
419.	Proper diet. (x3)	2	10/13	0/0
420.	Proper diet (e.g., whole grains, vegetables, water).	8	3/4	4/4
421.	Adjust meal time.	2	3/5	0/0
422.	Distancing the time from eating to the time of exercising.	9	4/8	5/8
423.	Scheduling around when you eat meals.	8	4/4	2/3
424.	Scheduling meals.	3	1/1	1/1
425.	Timing meals.	7	2/3	2/3

Supplementary Table S2. Final list of barriers, facilitators and their ratings from nominal group technique sessions. Superscript numbers refer to original participant examples (displayed in Supplemental Material 2) captured by each item. Examples were only rated by participants in sessions where the examples were elicited. In all but the first two sessions, participants also indicated whether they had or had not tried the elicited facilitator examples. The total number of ratings and times that participants indicate they had or had not tried each facilitator can exceed the total of 41 participants because the examples were rated before we merged them together into single items. If 3 examples were each rated by 6 people, then the merged item would have 18 ratings. Barriers and facilitators generated from the SPIN-PACE Patient Advisory Team or health care providers affiliated with SPIN are indicated by "Not applicable".

Barriers and facilitators	**Number of ratings between 8 and 10 / total number of ratings**	**Number of times that participants had tried the facilitator / total of had and had not tried**
Category: Health and medical		
Barrier: Activities involving water may worsen condition of hands or skin on other areas of the body.[3, 31, 168, 239, 253]	2/21	
Wear a wet suit, gloves, or socks designed for water exercises to stay warm.[4, 170, 171, 254]	6/11	4/11
If you have skin wounds such as ulcers on hands or feet, wear watertight gloves (e.g., occlusive gloves) or socks.	Not applicable	
Use a well-heated pool to exercise in water.	Not applicable	
If you are sensitive to chlorine, use a salt water pool to exercise in water.[5, 240]	2/6	1/6
Moisturize regularly or as needed (e.g., use lotion, or wear moisturizing gloves or socks).[169]	1/3	2/6
Barrier: Calcinosis.[2, 55]	2/5	

Do gentle exercises that move body parts affected by calcinosis through their maximum range of motion.	Not applicable	
Modify exercise to minimize pressure on body parts affected by calcinosis.	Not applicable	
Wear padding over areas of calcinosis.	Not applicable	
Barrier: Difficulty grasping objects.[9, 93, 142,]	3/8	
Do hand exercises.[10]	0/0	0/0
Ask your health care provider about mechanical stretch devices to reduce hand or wrist stiffness.	Not applicable	
Use adapted exercise equipment (e.g., weights with a larger handle, or wrist weights).[94, 97, 98, 143, 144, 145, 382]	8/20	0/0
Identify exercises that do not require grasping (e.g., stationary exercise bike).[11, 96]	2/3	3/3
Barrier: Difficulty with bowel and bladder control.[18, 57, 215]	4/10	
Wear a pad or underwear designed for bowel and bladder control issues.	Not applicable	
If participating in an exercise class, advise the exercise instructor beforehand that you may have to leave the class to use the restroom.[58]	1/1	1/1
Do exercises at home.[216]	3/3	2/3
Barrier: Fatigue.[7, 24, 32, 51, 59, 64, 70, 100, 103, 146, 180, 194, 212, 241, 245, 260, 261]	32/65	
Break exercise into several short periods (e.g., three 10-minute walks) rather than a single long period (e.g., one 30-minute walk).[101, 104]	3/6	6/6
Take rest breaks while exercising (e.g., between activities).[72, 148, 244, 248]	18/20	20/20
Get enough sleep and plan to take a nap during the day.[8, 25, 33, 71, 147, 213, 243, 247]	19/31	24/25
Exercise at a time of day when you have the most energy.[242, 246]	7/14	12/14
Exercise at home or work to eliminate travel time.[102]	1/3	2/3
Barrier: Gastrointestinal problems.[1, 29, 34, 111, 137, 165, 172, 250]	12/28	
Modify how much and what you eat before exercise.[35, 113, 173]	8/11	3/6
For acid reflux, modify exercise positions to keep your body upright (e.g., do push-ups against the wall instead of push-ups against the ground).[112, 138, 166, 251, 252]	15/23	10/23
Barrier: Itching or dryness of skin.[177, 183]	1/5	

Moisturize regularly or as needed (e.g., use lotion, or wear moisturizing gloves or socks).[178]	2/3	2/3
Wear appropriate clothing to cover and protect skin (e.g., gloves or mittens).[179]	3/3	3/3
Barrier: Joint stiffness and contractures.[20, 21, 38, 43, 62, 67, 83, 93, 99, 131, 154, 197, 271, 274]	25/53	
Apply heat (e.g., heating pad or wax bath).[39, 68]	2/8	1/3
Take a warm shower or bath before and/or after exercise.[155]	3/4	3/4
Use adapted exercise equipment (e.g., resistance band with handle grips).[44]	4/5	0/0
Ask your health care provider about mechanical stretch devices to reduce joint stiffness.	Not applicable	
Do daily gentle stretching and exercises that move your joints through their maximum range of motion.[45, 132, 198, 272]	13/18	10/13
Do gentle stretching and movement to warm up the joints before exercise.[275]	5/7	7/7
Do gentle stretching and movement after exercise.[273]	6/6	3/6
Exercise at a time of day when your joints feel less stiff.[133]	1/3	1/3
Do whole body exercises (e.g., yoga or tai chi) that are comfortable for you.[46, 84, 156, 157]	8/16	11/11
Use controlled, slow movements that are comfortable for you.[63]	2/3	3/3
Barrier: Muscle weakness and difficulty with mobility.[19, 22, 27, 47, 65, 185, 195, 222, 235]	11/35	
Do strength training exercises (e.g., use weights or a resistance band).[48, 49, 186, 196, 223, 224]	21/25	13/15
Do whole body exercises (e.g., yoga or tai chi) that are comfortable for you.[23, 236]	4/5	4/5
Exercise in a pool if you can do this safely.[237]	4/6	2/6
Take rest breaks while exercising (e.g., between activities).	Not applicable	
If you have difficulty with balance, place a hand against an immovable object (e.g., wall or pole) for support, or exercise while sitting on an immovable chair or seat.[238]	4/7	4/7
If you have difficulty with balance, use assistive devices (e.g., hiking poles).	Not applicable	
Barrier: Pain.[50, 60, 74, 118, 160, 181, 184, 187, 229, 264]	16/37	
Apply heat (e.g., heating pad or wax bath).[75, 188]	3/5	5/5

Take a warm shower or bath before and/or after exercise.[120]	1/3	3/3
Modify exercise so it does not cause pain (e.g., use lighter weights or walk slower).[182, 230, 266]	13/14	12/14
Use controlled, slow movements that are comfortable for you.[61]	2/2	2/2
Take rest breaks while exercising (e.g., between activities).[76]	1/3	3/3
If you have joint pain, ask your health care provider about orthotics, braces, or splints.[119, 265]	3/10	3/10
Barrier: Raynaud's phenomenon.[77, 121, 126, 162, 174, 204, 267]	15/22	
Exercise in an area with a temperature that is comfortable for you.[206]	4/5	5/5
Dress to stay warm (keep your core warm and cover areas of the body that become cold – e.g., wear a warm hat, gloves, or mittens).[80, 122, 123, 163, 209]	14/17	14/17
Wear heated or non-heated warm gloves or mittens and socks.[78, 79, 124, 125, 176, 205, 208, 268, 269]	29/39	29/39
Insert warmers (i.e., liners, or electric or chemical warmers) in gloves or mittens or socks.[81, 164, 175, 207]	12/15	14/15
If you are exercising in water, use a well-heated pool.[128]	2/3	1/3
If you are exercising in water, wear a wet suit, gloves, or socks designed for water exercises to stay warm.[127, 129, 130]	6/9	2/9
Barrier: Sensitivity to sun when exercising outside.[30, 189]	2/5	
Exercise outside in the morning or evening when the sun is not too intense for you.[192]	2/3	3/3
Use sun protection (e.g., sunglasses, sunscreen, hat, or clothing that covers most skin).[190, 191, 193]	5/9	7/9
Barrier: Shortness of breath.[52, 54, 69, 90, 109, 141, 167, 221, 262, 270]	17/39	
Ask your health care provider about pulmonary rehabilitation.[53, 91, 110]	9/11	4/6
Lower the intensity of the exercise to not experience shortness of breath.	Not applicable	
Take rest breaks while exercising (e.g., between activities).[92, 263]	8/10	8/10
Barrier: Ulcers or sores on hands or feet.[85, 134, 234]	2/11	
Apply non-adhesive bandages to cover and protect ulcers or sores.	Not applicable	

Wear appropriate clothing to cover and protect ulcers or sores (e.g., gloves or mittens).[86]	2/3	3/3
Ask your health care provider about hand or foot orthotics.[136]	3/3	1/3
If you have foot ulcers or sores, put pads in shoes or wear specialized soles or shoes (e.g., open toe shoes).[135]	3/3	1/3

Category: Social and personal

Barrier: Anxiety during exercise.[139, 231]	4/9	
Identify the issues making you feel anxious and modify the exercise situation (e.g., seek advice from a professional).	Not applicable	
Use relaxation techniques (e.g., deep breathing exercises) before exercise.[140]	3/4	3/4
If attending an exercise class, watch the class before participating, and arrange to meet with the exercise instructor before participating to review the exercises and discuss any concerns.[233]	5/7	7/7
Participate in gentle exercise classes that may be intended for new exercisers or people with limitations for exercising.[232]	5/6	3/6
Barrier: Fear of injury or extended recovery time.[6, 40, 42, 82, 114, 117, 149, 158, 214]	12/29	
Have an introductory session with a qualified exercise trainer to discuss your fears and get an assessment.[115]	1/3	0/3
Take rest breaks while exercising (e.g., between activities).[41]	3/4	0/0
Participate in gentle exercise classes that may be intended for new exercisers or people with limitations for exercising.[159]	3/4	3/4
If attending an exercise class, watch the class before participating, and arrange to meet with the exercise instructor before participating to review the exercises and discuss any concerns.[116]	1/3	1/3
Barrier: Feeling embarrassed or discouraged due to physical ability, appearance, or judgement from others.[15, 16, 28, 56, 66, 87, 105, 106, 107, 150, 161, 210]	9/31	
Attend a scleroderma support group to discuss your feelings of embarrassment and discouragement.[88]	2/3	2/3
Discuss your feelings of embarrassment and discouragement with your health care provider.	Not applicable	
If attending an exercise class, watch the class before participating, and arrange to meet with the exercise instructor	0/3	2/3

before participating to review the exercises and discuss any concerns.[108]		
Participate in gentle exercise classes that may be intended for new exercisers or people with limitations for exercising.	Not applicable	
Do exercises that are not in a group setting.[211]	3/4	2/4
Barrier: Lack of motivation and difficulty committing to exercise.[17, 26, 73, 199, 201, 225, 249, 255]	18/37	
Exercise for shorter periods of time.[202]	4/4	3/4
Identify exercises that you enjoy.[200]	4/5	3/5
Try simple and convenient options for exercise (e.g., walking).[203]	4/4	3/4
Keep an exercise log to track your progress.[256]	4/8	2/8
Use a wearable device to track exercise (e.g., a watch that records the number of steps walked).[228]	3/4	4/4
Remind yourself that exercise is important to achieving health goals.	Not applicable	
Think about positive events that inspire you to exercise.[259]	6/8	6/8
Listen to music that motivates you.[257]	4/7	4/7
Reward yourself for exercising regularly.[226, 227]	6/8	6/8
Work with a qualified exercise trainer for a few sessions.[258]	2/8	4/8
Category: Time, work, and lifestyle		
Barrier: Finding time available to schedule exercise.[151]	1/3	
Break exercise into several short periods (e.g., three 10-minute walks) rather than a single long period (e.g., one 30-minute walk).[152]	4/4	3/4
Incorporate exercise into daily life activities (e.g., while watching television, or walk to work instead of driving).[153]	3/4	0/0
Exercise at home or work to eliminate travel time.	Not applicable	
Category: Environmental		
Barrier: Costs related to exercise.[12, 13, 14, 36, 217]	6/16	
Check options available for insurance reimbursement or reduced costs to exercise.[218]	3/4	2/4
Find free exercise resources online or in books.[220]	4/4	3/4
Identify free opportunities for exercise (e.g., walking).[37]	3/5	0/0

Sign up for free activities or exercise classes organized by your community.[219]	3/4	3/4
General facilitators		
Ask the exercise facility staff about any potential accommodations or concerns.[292-296,]	7/27	3/27
Exercise under supervision of a qualified professional.	Not applicable	
Consult with your health care provider or exercise professional to discuss any concerns and/or custom design an exercise program matched to your capacity and needs.[276-278, 297-342]	129/219	70/140
Exercise at a pace or intensity that is comfortable for you. Start easy, progress slowly. If you have pain, adapt the exercise or seek advice.[279-283, 343-374]	131/164	132/153
Adapt the exercise or try a new exercise.[284, 285, 375-395]	65/90	59/77
Exercise with a partner or group that may have similar activity levels as you do.[286, 287, 396-404]	19/35	22/33
Sign up for an exercise class.[288, 405-410]	15/28	13/28
Sign up for an online group exercise class to do at home, or do an online home-based exercise program.	Not applicable	
Maintain an exercise routine by scheduling specific times to exercise.[289, 411-414]	21/39	30/32
Set manageable and realistic exercise goals.[290, 291]	6/6	6/6
Eat a healthy diet. Consult with your health care provider about what foods to eat.[415-420]	27/36	22/23
Eat at times that compliment your exercise routine.[421-425]	13/20	10/15

2.2 Connecting Text

We identified a comprehensive list of physical activity barriers and facilitators as experienced by people with SSc. Most barriers were related to the medical manifestations of the disease, while others fell into 3 categories: social and personal; environmental; and time, work, and lifestyle. Facilitators varied in form, including strategies to select or adapt exercises, to take care of the body, to keep warm, or to protect sensitive areas of the body (e.g., ulcers or calcinosis). Although rating data were collected on importance of barriers and likelihood of using facilitators, the sample size was only 41 participants and is therefore too small to make quantitative inferences. In the second and final study of this thesis, we administered a survey of the previously identified barriers and facilitators to a large international SSc cohort in order to assess (1) the prevalence and importance of different barriers experienced in SSc, and (2) the likelihood of people with SSc using different barrier-specific and general facilitators to keep active.

Chapter 3 - Manuscript 2

3.1 Barriers and Facilitators to Physical Activity for People with Scleroderma: a Scleroderma Patient-centered Intervention Network (SPIN) Cohort Study

Working paper:

Harb S, Peláez S, Carrier M-E, Kwakkenbos L, Bartlett SJ, Hudson M, Mouthon L, Sauvé M, Welling J, Shrier I, Thombs BD, Scleroderma Patient-centered Intervention Network (SPIN) – Physical Activity Enhancement Patient Advisory Team, SPIN Investigators. Barriers and facilitators to physical activity for people with scleroderma: a Scleroderma Patient-centered Intervention Network (SPIN) Cohort study. Manuscript currently under review by co-authors – to be submitted to *Arthritis Care & Research* (July 2020).

Barriers and facilitators to physical activity for people with scleroderma: a Scleroderma Patient-centered Intervention Network (SPIN) Cohort study

Running head: Barriers and facilitators

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ABSTRACT

Objective: To support physical activity among people with systemic sclerosis (SSc; scleroderma), we sought to determine the (1) prevalence and importance of barriers to physical activity experienced by people with SSc and (2) likelihood of using barrier-specific and general facilitators to physical activity.

Methods: We invited 1,707 participants enrolled in an international SSc cohort to complete a separate survey to (1) rate importance of experienced barriers; (2) rate likelihood of using corresponding barrier-specific facilitators and general facilitators and whether they have previously tried them.

Results: Among 721 respondents, 13 barriers (12 medical-related, 1 motivation-related) were experienced by ≥ 25% of total participants. Fatigue and Raynaud's phenomenon were considered 'important' or 'very important' by ≥ 50% of all participants; 7 other barriers, addressing limited hand function, activity restrictions due to various pathologic changes, and low motivation were considered 'important' or 'very important' by 26-50%. Overall, 23 of 103 facilitators were rated by ≥ 75% as 'likely' or 'very likely' to use among those who experienced corresponding barriers; these facilitators focused on adapting exercise, taking care of one's body, keeping warm, and protecting skin. All facilitators were considered 'likely' or 'very likely' to use by ≥ 50% of those who experienced the corresponding barrier and had tried them versus 12 of 103 among those with the barrier who had not tried them.

Conclusion: Medical-related barriers were common and considered important. Facilitators rated as most likely to be used involved adapting exercise, taking care of one's body, keeping warm, and protecting skin.

Significance and Innovations

- Based on a survey of 721 people with scleroderma, barriers to physical activity most commonly considered important involved compromised hand dexterity or condition (e.g., Raynaud's phenomenon), general symptoms (e.g., fatigue) or localized symptoms (e.g., gastrointestinal problems), and low motivation.
- Barrier-specific physical activity facilitators most commonly considered likely to be used addressed adapting the exercise type or setting; using health behaviours to take care of the body; and strategies to keep warm and protect the skin.
- Generally, facilitators were perceived as likely to be used by participants who experienced the linked barrier and had previously tried them, but facilitators were perceived as far less likely to be used by participants who experienced the linked barrier and had not tried them.
- Health care providers can use facilitators identified in this study to adapt physical activity options so that people with scleroderma can overcome barriers to physical activity.

Systemic sclerosis (SSc; scleroderma) is a rare chronic, autoimmune rheumatic disease characterized by abnormal fibrotic processes and excessive collagen production that can affect the skin, musculoskeletal system, and internal organs, including the heart, lungs, and gastrointestinal tract (1, 2). People with SSc experience significantly lower health-related quality of life in comparison to the general population (3).

Although regular physical activity is important to enhance everyone's health (4, 5), including those with autoimmune rheumatic diseases (6), people with SSc experience a wide range of barriers that may impede engagement. Data from a large SSc cohort demonstrated that approximately 50% of patients were physically inactive, but patients who were active rarely engaged in activities other than walking (7).

For health care providers to advise SSc patients on how to be physically active, they need to be able to identify possible facilitators, or strategies, to overcome specific barriers faced by individual patients. We previously conducted a nominal group technique study to identify barriers to physical activity, along with potential facilitators, experienced by people with SSc (8). That study included 41 people and did not allow to draw conclusions on the prevalence of barriers and likelihood that people with SSc would use identified facilitators. The present study evaluated the prevalence of barriers and perceived utility of facilitators to help tailor physical activity recommendations to the specific needs of people with SSc. Specific objectives were to determine (1) the prevalence and importance of different barriers experienced in SSc, and (2) likelihood that people with SSc would use different patient-generated barrier-specific and general facilitators to support physical activity.

Patients and Methods

This was a cross-sectional study in which survey results from the SPIN Physical Activity Survey were linked using participant user names (email addresses) to participant sociodemographic, medical, and patient-reported outcome measure data from the ongoing SPIN Cohort.

Participants and Procedures

We surveyed participants enrolled in the Scleroderma Patient-centered Intervention Network (SPIN) Cohort. Eligible SPIN Cohort participants must be classified with SSc according to the 2013 ACR/EULAR criteria (9); ≥ 18 years of age; fluent in English, French, or Spanish; and able to respond to online questionnaires. Eligible individuals are invited by their attending physician or supervised nurse coordinator to participate in the SPIN Cohort, and written informed consent is obtained. The local SPIN physician or supervised nurse coordinator completes a medical data form that is submitted online to initiate participant registration. After completion of online registration, an automated welcoming email is sent to participants with instructions for activating their SPIN account and completing SPIN Cohort measures online. SPIN Cohort participants complete online outcome measures upon enrollment and subsequently every 3 months.

For the present study, in July 2019 we invited SPIN Cohort participants to complete a survey, separately from their routine cohort assessments. We sent email invitations to all 1,707 SPIN Cohort participants who had activated their SPIN accounts and who complete assessments in English or French. We sent follow-up emails 2, 4, and 8 weeks later to those who had not completed the survey. In addition, we advertised the survey through an announcement presented to SPIN Cohort participants when they logged into the SPIN Cohort portal to complete their routine online assessments. To promote participation, we informed participants that one survey

respondent would be randomly selected to win a trip to the 2020 SSc World Congress in Prague, Czech Republic. The email invitation and announcements provided a link to the survey on *Qualtrics* (10). In *Qualtrics*, participants entered their SPIN username (email address) in order to access and complete the survey questions. The survey was closed in October 2019. We excluded participants who only partially completed the survey. SPIN Cohort assessment data were obtained from the most recently completed assessments prior to completing the SPIN Physical Activity Survey for participants and prior to the initial survey invitation for non-participants, without time restriction.

The SPIN Cohort was approved by the Research Ethics Committee of the Centre intégré universitaire de santé et de services sociaux du Centre-Ouest-de-l'Île-de-Montréal (#MP-05-2013-150) and by the research ethics committees of each participating centre. The present study was approved as an amendment to the SPIN Cohort by the Research Ethics Committee of the Centre intégré universitaire de santé et de services sociaux du Centre-Ouest-de-l'Île-de-Montréal.

Measures

Sociodemographic and Medical Characteristics

Medical data included time since first non-Raynaud's phenomenon symptoms, time since SSc diagnosis, SSc subtype, degree of joint contractures for small and large joints, tendon friction rubs status, interstitial lung disease status, pulmonary arterial hypertension status, Raynaud's phenomenon status, digital ulcer status (digital pulp and anywhere else on the finger), and gastrointestinal tract involvement status (esophageal, stomach, and intestinal). For each participant, we calculated the time from when sociodemographic and medical characteristics were obtained at entry into the SPIN Cohort to survey completion.

Physical Activity

The SPIN Cohort includes an item, “Compared to other people your age, how would you rate your physical activity during the past year” (physically inactive; somewhat active; moderately active; quite active; very active), followed by the item, “Do you exercise at present?” (yes; no). Among participants who reported exercising at present, 2 additional items were administered, “On the average, how many hours per week do you exercise” and “What type(s) of exercise(s) do you do?” [walking; jogging; aerobics; swimming; other (specify)]. For the “other” option, participants could indicate more than 1 type of exercise. All exercises described by participants in the “other” option were classified based on the 2011 Compendium of Physical Activities (11).

Physical Function

We used the 4-item PROMIS Physical Function 4a v2.0 to evaluate self-reported physical activity capability. Each item is scored on a 5-point scale (1-5), where higher scores reflect better physical function over the previous 7 days. The total raw score is obtained by converting the sum of item scores into T-scores standardized from the general United States population [mean = 50, SD = 10]. The PROMIS Physical Function 4a v2.0 has been validated in SSc (12-14).

Functional Disability

The Disability Index of the Health Assessment Questionnaire (HAQ-DI) assesses 8 disability categories over the past 7 days. Each item is rated on a 4-point scale, ranging from 0 (without any difficulty) to 3 (unable to do), where higher scores reflect greater functional disability. The highest score from each category determines the score for that category, and the total score is the mean of the 8 category scores, ranging from 0 (no disability) to 3 (severe disability). The HAQ-DI is a valid measure of functional disability in SSc (15).

SPIN Physical Activity Survey

We developed the SPIN Physical Activity Survey (https://osf.io/2mxj5/) to evaluate whether possible physical activity barriers are experienced and, if so, their importance, and to evaluate possible facilitators for likelihood of use. An initial list of barriers and facilitators was generated via 9 nominal group technique interview sessions with 41 people with SSc at patient conferences in Canada, the United States, and France (8). Study investigators consolidated overlapping items, reworded unclear items, and excluded vague or unrelated items. Next, the 9-member SPIN Physical Activity Patient Advisory Team and SPIN-affiliated health care providers made recommendations to reword, exclude, or add barrier and facilitator items. The item list included 20 barriers classified into 4 categories (16);14 were health and medical barriers; 4 social and personal; 1 time, work, and environment; and 1 environmental. There were 91 barrier-specific facilitators and 12 general facilitators. Patient advisors pilot tested the survey and provided feedback on usability; survey instructions were revised accordingly. The survey was then translated into French using a standard forward–backward translation process (17).

In the survey, participants were asked to select up to 10 of the 20 total barriers that they have experienced and believe are important for them, to initially order selected barriers from most to least important by dragging them into position, and to rate each selected barrier on a 4-point Likert scale based on importance to them when thinking about or actually being physically active (not important; somewhat important; important; very important). We next presented participants with all barrier-specific facilitators that corresponded to their selected barriers, and they rated the likelihood that they would use each barrier-specific facilitator to overcome the corresponding barrier (not likely; somewhat likely; likely; very likely) and indicated whether they had previously tried it. Participants similarly rated general facilitators. At the end of the survey, participants could provide suggestions for additional barriers and facilitators.

Data Analysis

We used descriptive statistics. We summarized continuous variables using medians (ranges) and categorical variables using percentages. We listed additional barriers and facilitators provided by participants. We conducted all analyses with Microsoft Excel version 16.16.

Results

Participant Characteristics

A total of 721 of 1707 (42%) SPIN Cohort participants completed the full survey and were included in analyses; 70 who partially completed the survey were excluded. The median (range) age was 59 (22 – 89), almost 90% were women, and almost half were employed full- or part-time (see Table 1). Time since SSc diagnosis was 10.4 years, and approximately 40% had diffuse SSc. Approximately a third of participants were at least one standard deviation below the United States population mean on the PROMIS Physical Function 4a v2.0, and half had at least mild functional impairment (median HAQ-DI score = 0.6). As shown in Table 2, walking was performed by 47% of participants, and conditioning exercises by 26%.

As shown in Table 1, sociodemographic and medical characteristics of respondents were similar to non-respondents; the range of differences for categorical variables was 0% to 7%. However, there were some differences in physical activity characteristics between respondents and non-respondents. There was a 15% difference in the proportion who reported currently exercising (61% of respondents versus 46% of non-respondents), as well as differences in the proportion who performed specific types of exercises.

[Insert Table 1 here]

[Insert Table 2 here]

Physical Activity Barriers

There were 172 (24%) participants who experienced and selected 10 barriers for rating and 549 (76%) who selected fewer than 10; the median number of barriers selected was 7. As shown in Figure 1, there were 4 barriers, all health and medical barriers, that were experienced and selected for rating by ≥ 50% of 721 total participants, including Raynaud's phenomenon, fatigue, joint stiffness and contractures, and difficulty grasping objects. Of these, fatigue (58%) and Raynaud's phenomenon (57%) were selected for rating and classified as 'important' or 'very important' by ≥ 50% of total participants. Joint stiffness and contractures was selected and rated as 'important' or 'very important' by 49%, shortness of breath by 38%, gastrointestinal problems by 36%, both difficulty grasping objects and pain by 33%, muscle weakness and difficulty with mobility by 29%, and lack of motivation and difficulty committing to exercise by 26%. See Supplemental Appendix A for summary of initial sorted rankings of barriers, rather than ratings, of importance.

[Insert Figure 1 here]

Physical Activity Facilitators

Overall, of 103 facilitators rated by participants who had experienced the linked barrier, 23 (22%) were rated as 'likely' or 'very likely' to use by ≥ 75% of participants and an additional 58 (56%) facilitators were by ≥ 50%. The full list of barriers, their facilitators, and participant ratings is available in Supplemental Appendix B. It is also accessible online as an interactive

spreadsheet (https://osf.io/2mxj5/) that facilitates sorting and identifying facilitators for different barriers. Table 3 presents the 12 health and medical barriers that were experienced and selected for rating by ≥ 25% of total participants and a selection of corresponding barrier-specific facilitators that were commonly rated as 'likely' or 'very likely' to use among those who tried them. The most common facilitators overall and among those presented in Table 3 involved strategies for adapting exercise type, conduct or setting; changing health behaviours to take care of the body; keeping warm; and protecting the skin. Supplemental Appendix C presents additional barrier and facilitator suggestions to those presented in our survey that were provided by survey respondents and were substantively different from those included in the survey.

[Insert Table 3 here]

The majority (62/103; 60%) of facilitators had been tried by ≥ 50% of participants who rated them. Among those who tried facilitators, 103/103 facilitators were rated by ≥ 50% as 'likely' or 'very likely' to use and 65/103 facilitators were rated by ≥ 80% as 'likely' or 'very likely' to use. In contrast, only 12/103 facilitators were rated as 'likely or very likely to use by ≥ 50% of participants who had not tried them previously.

Discussion

The main results of our study include prevalence of barriers to physical activity among over 700 people with SSc, along with their ratings of the importance of each barrier and of the likelihood that they would use corresponding and more general facilitators of physical activity. The most common barriers to physical activity were Raynaud's phenomenon and fatigue, followed by compromised hand dexterity and challenges related to respiratory, gastrointestinal

and skin pathologies. Among the 103 barrier-specific and general facilitators in the survey, for participants who had tried each of them, at least 50% of participants said they would be 'likely' or 'very likely' to use them to facilitate physical activity. Health care providers can use our interactive Excel spreadsheet (https://osf.io/2mxj5/) to review physical activity barriers and identify patient-generated facilitators to address them and support physical activity among individuals with SSc.

Although this was the first study to evaluate patient-generated physical activity barriers and possible facilitators to overcome them in a large SSc sample, results are consistent with findings from previous studies. A previous study with the SPIN Cohort (n = 752) found that presently reported exercise was associated with fatigue, pain, degree of skin thickening, and functional disability (7), all of which were identified by participants in the present study as barriers. Facilitators rated widely as likely to be used for such barriers were often related to adapting the: exercise form (e.g., use controlled, slow movements for pain), conduct (e.g., take rest breaks for fatigue, pain, and muscle weakness and difficulty with mobility), and equipment (e.g., use wrist weights for difficulty grasping objects). Consistent with the shortness of breath barrier, lung involvement (18) and pulmonary hypertension (19) have been found to be associated with reduced aerobic capacity in 2 small exercise studies (n = 46 and 18 SSc patients). Two of our barrier-specific facilitators ('take rest breaks while exercising' and 'lower the intensity of exercise to not experience shortness of breath') directly address reduced aerobic capacity.

Barriers outside the medical category were generally less common than medical barriers. The most common was 'lack of motivation', which was rated 'important' or 'very important' by 26% of total participants, followed by 'finding time available to schedule exercise' (16%) and

‘feeling embarrassed or discouraged due to physical ability, appearance, or judgement from others’ (12%). While motivation- and time-related barriers have been reported as important barriers to physical activity in the general population (20, 21), the barrier about feeling embarrassed or discouraged seems to more directly reflect the unique experiences of people with SSc, particularly psychosocial consequences due to concerns about visible changes to one’s appearance (22).

All facilitators were rated by at least half of participants who tried them as ‘likely’ or ‘very likely’ to use. Some facilitators commonly rated as likely to be used are consistent with widely recommended strategies, such as for warming in Raynaud’s phenomenon (23), and identifying enjoyable activities for people who have difficulty with motivation or exercise adherence (24). On the other hand, there were novel barrier-specific facilitators widely perceived as likely to be used that, to our knowledge, have not been reported in the literature but could be helpful for health care providers promoting physical activity to individuals with SSc. Many novel facilitators addressed adapting the exercise, either by adapting the exercise conduct, type, or setting, including ‘use adapted exercise equipment’ (barriers of difficulty grasping objects and joint stiffness and contractures), and ‘participate in gentle exercise classes that may be intended for new exercisers or people with limitations for exercising’ (barrier of fear of injury or extended recovery time).

In general, participants who tried facilitators rated them favourably as ‘likely’ or ‘very likely’ to use in comparison to those who had not tried them. This suggests some challenges may exist when proposing new facilitators to SSc patients. Communication skills and strategy may be very important. A widely used intervention to support physical activity in the general population, Active Living Every Day (ALED) (25), uses a social modelling component when exposing

individuals to new facilitators. This involves sharing the personal experiences of people who describe how they overcame specific barriers to leading a more active lifestyle. We expect that such social modelling would be a potentially effective strategy to promote physical activity in SSc, especially for those patients who had not tried a proposed facilitator.

There are limitations to take into account in interpreting results of the present study. First, the results may not be generalizable to people who do not speak English or French, reside outside of North America and Europe, or do not have access to a device with Internet. Second, a higher proportion of respondents (61%) reported currently exercising in comparison to SPIN Cohort non-respondents (46%). Third, participants were presented with 20 possible barriers, but in order to reduce respondent burden, we only allowed them to select up to 10 barriers which they had experienced. Almost 25% of participants selected 10 barriers and might have experienced and selected additional barriers, if that had been permitted, although these would have been of lesser importance to the participant than the ones they selected. Fourth, although participants were asked to select the barriers for rating that they experienced and feel are important, some participants rated at least one of their selections as 'not important'. Lastly, although participants rated the importance of barriers and likelihood of using facilitators, the survey did not elicit explanations for why they rated barriers and facilitators as they did. Such explanations might help to fine-tune guidance to better address physical activity difficulties experienced by individuals with SSc.

In summary, medical-related barriers to activity were most commonly experienced and considered important; Raynaud's phenomenon and fatigue were the most commonly experienced. Facilitators widely considered likely to be used addressed adapting exercise type or setting, using health behaviours to take care of the body, and using clothing or materials to

protect the skin or to keep warm. Participants who had tried facilitators were generally more likely to use them again compared to participants who had never tried them. Our online interactive Excel file (https://osf.io/2mxj5/) allows health care providers to easily identify relevant facilitators for common barriers to physical activity experienced by individuals with SSc.

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Table 1. Participant sociodemographic and medical characteristics. Percentages refer to the percent of data recorded.

Variable	SPIN Cohort respondents (N = 721)	SPIN Cohort non-respondents (N = 986)
Sociodemographic variables		
Age in years, *median (range)*	59 (22 to 89)	57 (21 to 91)
Women, *n (%)*	640 (89%)	865 (88%)
White race/ethnicity, *n (%)*	603 (85%)[a]	717 (79%)[b]
Years of education completed,[c] *median (range)*	16 (3 to 27)[d]	15 (0 to 28)[e]
Employed full- or part-time, *n (%)*	323 (46%)[d]	369 (41%)[f]
Married or living as married, *n (%)*	455 (64%)[d]	547 (61%)[f]
Geographic region, *n (%)*		
North America	429 (60%)	584 (59%)
Europe	292 (40%)	401 (41%)
Australia	0 (0%)	1 (0%)
English survey language, *n (%)*	447 (62%)	649 (69%)[g]
Medical variables		
Time in years since baseline assessment when medical data were recorded, *median (range)*	3.1 (0.4 to 5.8)	3.1 (0.4 to 6.7)
Time in years since first non-Raynaud's phenomenon symptom, *median (range)*	12.3 (0.4 to 47.3)[h]	11.3 (1.6 to 58.8)[i]

Time in years since systemic sclerosis diagnosis, *median (range)*	10.4 (0.4 to 43.8)[j]	9.8 (0.8 to 58.8)[k]
Diffuse systemic sclerosis subtype, *n (%)*	279 (39%)[l]	409 (42%)[m]
Body mass index, *median (range)*	24.0 (14.7 to 60.7)	24.6 (13.0 to 64.4)
Raynaud's phenomenon, *n (%)*	695 (98%)[n]	963 (98%)[m]
Digital ulcers (distal pulp), *n (%)*	238 (34%)[o]	364 (38%)[p]
Digital ulcers (anywhere else on the finger), *n (%)*	101 (15%)[q]	184 (19%)[r]
Current or past tendon friction rubs, *n (%)*	154 (25%)[s]	210 (24%)[t]
Moderate or severe contractures of small joints, *n (%)*	172 (26%)[u]	253 (27%)[v]
Moderate or severe contractures of large joints, *n (%)*	79 (12%)[w]	136 (15%)[x]
Any gastrointestinal involvement, *n (%)*	621 (87%)[y]	873 (89%)[z]
Interstitial lung disease, *n (%)*	228 (33%)[aa]	346 (36%)[ab]
Pulmonary arterial hypertension, *n (%)*	45 (7%)[ac]	80 (9%)[ad]
Physical function domain score of the Patient Reported Outcomes Measurement Information System (PROMIS-29) profile version 2.0, *median (range)*	43.4 (22.9 to 56.9)[ae]	41.8 (22.9 to 56.9)[af]
Total score of the Disability Index of the Health Assessment Questionnaire (HAQ-DI), *median (range)*	0.6 (0.0 to 3.0)[ag]	0.6 (0.0 to 3.0)[ah]

Due to missing data: [a] N = 714; [b] N = 912; [d] N = 708; [e] N = 900; [f] N = 903; [g] N = 935; [h] N = 666; [i] N = 899; [j] N = 697; [k] N = 939; [l] N = 713; [m] N = 979; [n] N = 711; [o] N = 703; [p] N = 970; [q] N = 692; [r] N = 944; [s] N = 618; [t] N = 865; [u] N = 673; [v] N = 934; [w] N = 657; [x] N = 918; [y] N = 706; [z] N = 983; [aa] N = 692; [ab] N = 974; [ac] N = 691; [ad] N = 937;[ae] N = 705; [af] N = 876; [ag] N = 701; [ah] N = 862.

[c] Years of education completed beginning from elementary/primary school and including all levels of formal education.

Table 2. Participant physical activity characteristics. Percentages refer to the percent of data recorded.

Variable	SPIN Cohort respondents (N = 715 due to missing values)	SPIN Cohort non-respondents (N = 933)
Participants' perception of their physical activity level in the past year compared to other people their age, *n (%)*		
Physically inactive	85 (12%)	155 (17%)[a]
Somewhat active	199 (28%)	316 (34%)[a]
Moderately active	233 (33%)	270 (29%)[a]
Quite active	148 (21%)	115 (12%)[a]
Very active	50 (7%)	66 (7%)[a]
Currently exercise, *n (%)*	433 (61%)	421 (46%)[b]
Average hours per week of exercise (among participants who currently exercise), *median (range)*	4 (1 to 15)[c]	4 (1 to 15)[d]
Types of exercises performed, *n (%)*		
Walking	333 (47%)	328 (35%)
Jogging	24 (3%)	25 (3%)
Aerobics	75 (11%)	64 (7%)
Swimming	59 (8%)	41 (4%)
Other	275 (39%)	209 (22%)

Categories of "other" exercises (selected participant examples in parentheses),[e] *n (%)*		
Bicycling (biking, cycling, spinning)	42 (6%)	29 (3%)
Conditioning (elliptical, gym, Pilates, stretching, tai chi, weight lifting, yoga)	183 (26%)	152 (16%)
Lawn and garden (gardening, landscaping, yard work)	16 (2%)	9 (1%)
Sports (badminton, racquetball, bowling, golf)	25 (4%)	26 (3%)
Walking (Nordic walking)	13 (2%)	9 (1%)
Water activities (aquatic classes, kayaking, pool exercises)	14 (2%)	7 (1%)
Other categories[f]	52 (7%)	12 (1%)

Due to missing data: [a] N = 922; [b] N = 921.
[c] N = 433 who reported currently exercising and their average hours per week of exercise.
[d] N = 418 who reported currently exercising and their average hours per week of exercise.
[e] Participants could indicate > 1 exercise and each exercise was classified into one category.
[f] Other categories of activities performed by ≤ 2% of participants were dancing, fishing and hunting, home activity, miscellaneous, music playing, and winter activities.

Table 3. The 12 medical barriers experienced and selected for rating by ≥ 25% of participants, and a subset of corresponding novel and common facilitators (n = 721 total participants). See interactive Excel file (https://osf.io/2mxj5/) for the full list.

Barrier and (%) N who experienced and selected for rating	Facilitators	Tried facilitator and 'likely' or 'very likely' to use it,[a] % *(N)*
Raynaud's phenomenon 78% (564)	• Dress to stay warm (keep your core warm and cover areas of the body that become cold – e.g., wear a warm hat, gloves, or mittens)	93% (501 of 539)
	• Exercise in an area with a temperature that is comfortable for you	90% (451 of 502)
	• Wear heated or non-heated warm gloves or mittens and socks	92% (452 of 494)
	• Insert warmers (i.e., liners, or electric or chemical warmers) in gloves or mittens or socks	86% (334 of 387)
Fatigue	• Take rest breaks while exercising (e.g., between activities)	83% (333 of 403)

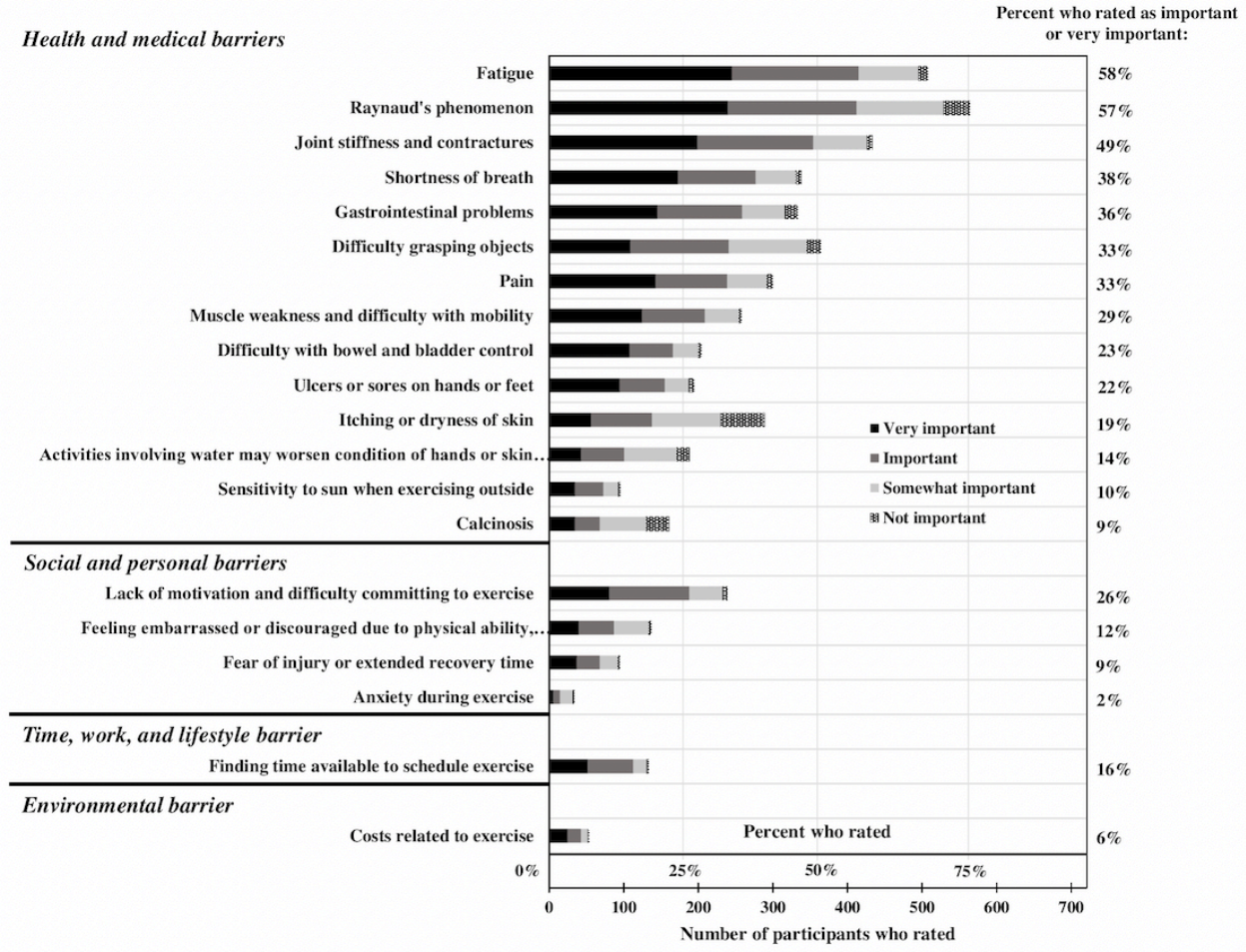
71% (508)		
	• Break exercise into several short periods (e.g., three 10-minute walks) rather than a single long period (e.g., one 30-minute walk)	82% (235 of 286)
	• Get enough sleep and plan to take a nap during the day	80% (273 of 342)
Joint stiffness and contractures 60% (434)	• Do daily gentle stretching and exercises that move your joints through their maximum range of motion	82% (256 of 312)
	• Use controlled, slow movements that are comfortable for you	85% (263 of 309)
Difficulty grasping objects 51% (365)	• Use adapted exercise equipment (e.g., weights with a larger handle, or wrist weights)	82% (108 of 132)
Shortness of breath 47% (338)	• Lower the intensity of the exercise to not experience shortness of breath	86% (251 of 291)
Gastrointestinal problems 46% (334)	• If you have acid reflux, modify exercise positions to keep your body upright (e.g., do push-ups against the	89% (148 of 166)

	wall instead of push-ups against the ground)	
Pain 42% (300)	• Modify exercise so it does not cause pain (e.g., use lighter weights or walk slower)	87% (223 of 256)
Itching or dryness of skin 40% (289)	• Moisturize regularly or as needed (e.g., use lotion, or wear moisturizing gloves or socks)	89% (223 of 251)
Muscle weakness and difficulty with mobility 36% (258)	• If you have difficulty with balance, place a hand against an immovable object (e.g., wall or pole) for support, or exercise while sitting on an immovable chair or seat	88% (151 of 172)
	• If you have difficulty with balance, use assistive devices (e.g., hiking poles)	81% (77 of 95)
Difficulty with bowel and bladder control 28% (205)	• Wear a pad or underwear designed for bowel and bladder control issues	90% (132 of 146)
Ulcers or sores on hands or feet 27% (195)	• Apply non-adhesive bandages to cover and protect ulcers or sores	92% (140 of 153)

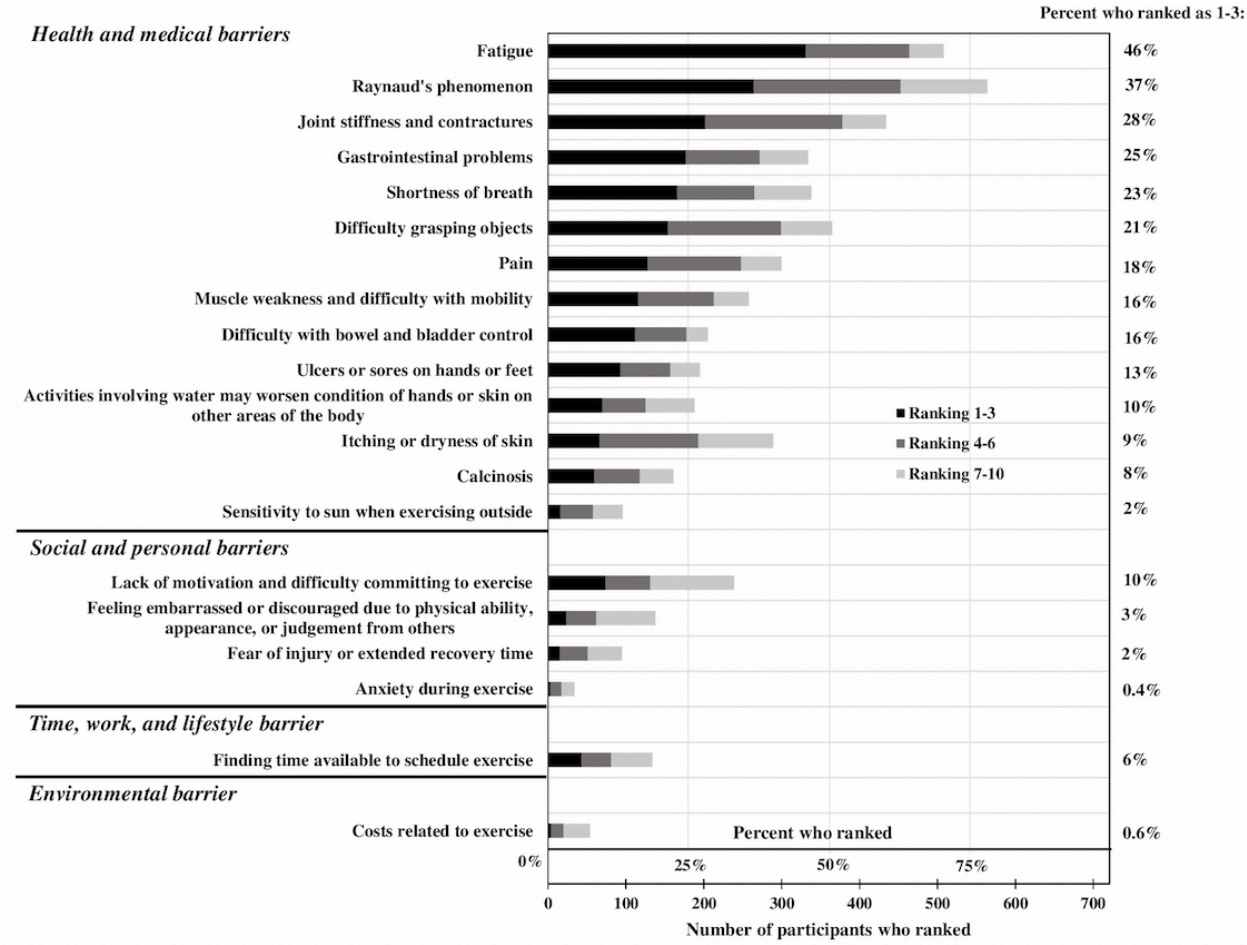
	• Wear appropriate clothing to cover and protect ulcers or sores (e.g., gloves or mittens)	90% (148 of 165)
	• If you have foot ulcers or sores, put pads in shoes or wear specialized soles or shoes (e.g., open toe shoes)	87% (65 of 75)
Activities involving water may worsen condition of hands or skin on other areas of the body 26% (188)	• Wear a wet suit, gloves, or socks designed for water exercises to stay warm	72% (33 of 46)

[a] We present the percentage and number of participants who rated the facilitator as 'likely' or 'very likely' to use among those who experienced the barrier and had tried the facilitator. Participants rated on a 4-point Likert scale the likelihood that they would use each barrier-specific facilitator to overcome the corresponding barrier to be physically active (not likely; somewhat likely; likely; very likely).

Figure 1. Distribution of ratings for barriers (n = 721 total participants). Participants only rated up to a maximum of 10 barriers which they experienced and selected for rating. Using a 4-point Likert scale, they rated each of their selected barriers based on how important it is to them personally when thinking about or actually being physically active (not important; somewhat important; important; very important). Because 172 participants rated the maximum of 10 barriers, it is possible that they experienced other barriers as well. Percentages refer to the percent of 721 participants who rated the adjacent barrier as 'important' or 'very important'.



Supplemental Appendix A. Distribution of rankings for barriers (n = 721). Participants only ranked up to a maximum of 10 barriers which they experienced and selected for rating. They assigned a ranking of 1 to the barrier that was most important to them, and they ranked the remaining barriers in order of decreasing importance. A ranking of 1 was assigned if participants only selected 1 barrier. Percentages refer to the percent of 721 participants who ranked the adjacent barrier as 1, 2, or 3.



Supplemental Appendix B. Facilitator ratings (n = 721 total participants). Participants only rated barrier-specific facilitators corresponding to barriers that they experienced and selected for rating. They rated on a 4-point Likert scale the likelihood that they would use each barrier-specific facilitator to overcome the corresponding barrier to be physically active (not likely; somewhat likely; likely; very likely). Participants also used the same scale to rate their perceived likelihood of using each general facilitator to be physically active. Percentages refer to the percent of participants who either had or had not tried the facilitator, depending on the column heading. Within each barrier category, barriers are listed in order of decreasing proportion of participants who experienced the barrier and feel it is important. Barrier-specific and general facilitators are listed in order of decreasing proportion of participants who rated the facilitator as 'likely' or 'very likely' to use.

	Likely or very likely to use facilitator, *% (n)*		
Barriers and facilitators	**Tried facilitator**	**Not tried facilitator**	**Combined**
Category: Health and medical			
Barrier: Raynaud's phenomenon - experienced by 78% (521) of participants			
Dress to stay warm (keep your core warm and cover areas of the body that become cold – e.g., wear a warm hat, gloves, or mittens)	93% (501 of 539)	40% (10 of 25)	91% (511)
Exercise in an area with a temperature that is comfortable for you	90% (451 of 502)	45% (28 of 62)	85% (479)
Wear heated or non-heated warm gloves or mittens and socks	92% (452 of 494)	33% (23 of 70)	84% (475)
Insert warmers (i.e., liners, or electric or chemical warmers) in gloves or mittens or socks	86% (334 of 387)	39% (69 of 177)	72% (403)
If you are exercising in water, use a well-heated pool	83% (241 of 291)	32% (88 of 273)	58% (329)
If you are exercising in water, wear a wet suit, gloves, or socks designed for water exercises to stay warm	78% (58 of 74)	20% (97 of 490)	28% (155)
Barrier: Fatigue - experienced by 70% (508) of participants			

Barriers and facilitators	Likely or very likely to use facilitator, *% (n)*		
	Tried facilitator	**Not tried facilitator**	**Combined**
Take rest breaks while exercising (e.g., between activities)	83% (333 of 403)	31% (32 of 105)	72% (365)
Exercise at a time of day when you have the most energy	82% (305 of 371)	37% (51 of 137)	70% (356)
Exercise at home or work to eliminate travel time	84% (283 of 337)	30% (51 of 171)	66% (334)
Break exercise into several short periods (e.g., three 10-minute walks) rather than a single long period (e.g., one 30-minute walk)	82% (235 of 286)	43% (96 of 222)	65% (331)
Get enough sleep and plan to take a nap during the day	80% (273 of 342)	33% (55 of 166)	65% (328)
Barrier: Joint stiffness and contractures - experienced by 60% (434) of participants			
Do daily gentle stretching and exercises that move your joints through their maximum range of motion	82% (256 of 312)	62% (75 of 122)	76% (331)
Do gentle stretching and movement to warm up the joints before exercise	82% (250 of 304)	62% (80 of 130)	76% (330)
Use controlled, slow movements that are comfortable for you	85% (263 of 309)	45% (56 of 125)	74% (319)
Do gentle stretching and movement after exercise	81% (214 of 265)	56% (95 of 169)	71% (309)
Exercise at a time of day when your joints feel less stiff	81% (208 of 257)	43% (76 of 177)	65% (284)
Apply heat (e.g., heating pad or wax bath)	81% (201 of 249)	38% (71 of 185)	63% (272)
Take a warm shower or bath before and/or after exercise	81% (195 of 241)	37% (72 of 193)	62% (267)

Barriers and facilitators	Likely or very likely to use facilitator, *% (n)*		
	Tried facilitator	**Not tried facilitator**	**Combined**
Do whole body exercises (e.g., yoga or tai chi) that are comfortable for you	77% (153 of 198)	39% (92 of 236)	57% (245)
Use adapted exercise equipment (e.g., resistance band with handle grips)	87% (123 of 142)	41% (119 of 292)	56% (242)
Ask your health care provider about mechanical stretch devices to reduce joint stiffness	75% (88 of 118)	42% (131 of 316)	51% (219)
Barrier: Difficulty grasping objects – experienced by 51% (365) of participants			
Do hand exercises	80% (232 of 291)	50% (37 of 74)	74% (269)
Identify exercises that do not require grasping (e.g., stationary exercise bike)	80% (175 of 218)	37% (55 of 147)	63% (230)
Use adapted exercise equipment (e.g., weights with a larger handle, or wrist weights)	82% (108 of 132)	42% (98 of 233)	56% (206)
Ask your health care provider about mechanical stretch devices to reduce hand or wrist stiffness	71% (88 of 124)	43% (103 of 241)	52% (191)
Barrier: Shortness of breath – experienced by 47% **(**338) of participants			
Take rest breaks while exercising (e.g., between activities)	86% (262 of 306)	47 (15 of 32)	82% (277)
Lower the intensity of the exercise to not experience shortness of breath	86% (251 of 291)	47 (22 of 47)	81% (273)
Ask your health care provider about pulmonary rehabilitation	82% (121 of 147)	47 (89 of 191)	62% (210)
Barrier: Gastrointestinal problems – experienced by 46% (334) of participants			

Barriers and facilitators	Likely or very likely to use facilitator, *% (n)*		
	Tried facilitator	**Not tried facilitator**	**Combined**
Modify how much and what you eat before exercise	90% (230 of 255)	43% (34 of 79)	79% (264)
If you have acid reflux, modify exercise positions to keep your body upright (e.g., do push-ups against the wall instead of push-ups against the ground)	89% (148 of 166)	48% (81 of 168)	69% (229)
Barrier: Pain – experienced by 42% (300) of participants			
Use controlled, slow movements that are comfortable for you	89% (218 of 246)	46% (25 of 54)	81% (243)
Modify exercise so it does not cause pain (e.g., use lighter weights or walk slower)	87% (223 of 256)	36% (16 of 44)	80% (239)
Take rest breaks while exercising (e.g., between activities)	83% (211 of 253)	47% (22 of 47)	78% (233)
Apply heat (e.g., heating pad or wax bath)	81% (153 of 190)	44% (48 of 110)	67% (201)
Take a warm shower or bath before and/or after exercise	83% (149 of 179)	36% (43 of 121)	64% (192)
If you have joint pain, ask your health care provider about orthotics, braces, or splints	79% (89 of 113)	37% (69 of 187)	53% (158)
Barrier: Itching or dryness of skin – experienced by 40% (289) of participants			
Moisturize regularly or as needed (e.g., use lotion, or wear moisturizing gloves or socks)	89% (223 of 251)	47% (18 of 38)	83% (241)
Wear appropriate clothing to cover and protect skin (e.g., gloves or mittens)	86% (200 of 232)	37% (21 of 57)	77% (221)
Barrier: Muscle weakness and difficulty with mobility –			

Barriers and facilitators	Likely or very likely to use facilitator, *% (n)*		
	Tried facilitator	**Not tried facilitator**	**Combined**
experienced by 36% (258) of participants			
If you have difficulty with balance, place a hand against an immovable object (e.g., wall or pole) for support, or exercise while sitting on an immovable chair or seat	88% (151 of 172)	41% (35 of 86)	72% (186)
Take rest breaks while exercising (e.g., between activities)	81% (165 of 204)	35% (19 of 54)	71% (184)
Do strength training exercises (e.g., use weights or a resistance band)	79% (127 of 161)	44% (43 of 97)	66% (170)
Do whole body exercises (e.g., yoga or tai chi) that are comfortable for you	77% (91 of 118)	38% (53 of 140)	56% (144)
If you have difficulty with balance, use assistive devices (e.g., hiking poles)	81% (77 of 95)	33% (54 of 163)	51% (131)
Exercise in a pool if you can do this safely	66% (83 of 126)	22% (29 of 132)	43% (112)
Barrier: Difficulty with bowel and bladder control – experienced by 28% (205) of participants			
Wear a pad or underwear designed for bowel and bladder control issues	90% (132 of 146)	17% (10 of 59)	69% (142)
Exercise at home	78% (130 of 166)	28% (11 of 39)	69% (141)
If participating in an exercise class, advise the exercise instructor beforehand that you may have to leave the class to use the restroom	79% (42 of 53)	20% (30 of 152)	35% (72)
Barrier: Ulcers or sores on hands or feet **(n = 195)**			

Barriers and facilitators	Likely or very likely to use facilitator, *% (n)*		
	Tried facilitator	**Not tried facilitator**	**Combined**
Apply non-adhesive bandages to cover and protect ulcers or sores	92% (140 of 153)	50% (21 of 42)	83% (161)
Wear appropriate clothing to cover and protect ulcers or sores (e.g., gloves or mittens)	90% (148 of 165)	30% (9 of 30)	81% (157)
Ask your health care provider about hand or foot orthotics	84% (68 of 81)	42% (48 of 114)	60% (116)
If you have foot ulcers or sores, put pads in shoes or wear specialized soles or shoes (e.g., open toe shoes)	87% (65 of 75)	34% (41 of 120)	54% (106)
Barrier: Activities involving water may worsen condition of hands or skin on other areas of the body – experienced by 26% (188) of participants			
Moisturize regularly or as needed (e.g., use lotion, or wear moisturizing gloves or socks)	85% (126 of 149)	44% (17 of 39)	76% (143)
Use a well-heated pool to exercise in water	81% (88 of 109)	46% (36 of 79)	66% (124)
If you are sensitive to chlorine, use a salt water pool to exercise in water	78% (38 of 49)	31% (43 of 139)	43% (81)
If you have skin wounds such as ulcers on hands or feet, wear watertight gloves (e.g., occlusive gloves) or socks	77% (41 of 53)	19% (26 of 135)	36% (67)
Wear a wet suit, gloves, or socks designed for water exercises to stay warm	72% (33 of 46)	18% (26 of 142)	31% (59)
Barrier: Calcinosis – experienced by 22% (161) of participants			

Barriers and facilitators	Likely or very likely to use facilitator, *% (n)*		
	Tried facilitator	**Not tried facilitator**	**Combined**
Modify exercise to minimize pressure on body parts affected by calcinosis	82% (77 of 94)	42% (28 of 67)	65% (105)
Do gentle exercises that move body parts affected by calcinosis through their maximum range of motion	76% (67 of 88)	48% (35 of 73)	63% (102)
Wear padding over areas of calcinosis	82% (58 of 71)	31% (28 of 90)	53% (86)
Barrier: Sensitivity to sun when exercising outside – experienced by 13% (96) of participants			
Use sun protection (e.g., sunglasses, sunscreen, hat, or clothing that covers most skin)	91% (80 of 88)	50% (4 of 8)	88% (84)
Exercise outside in the morning or evening when the sun is not too intense for you	91% (64 of 70)	39% (10 of 26)	77% (74)
Category: Social and personal			
Barrier: Lack of motivation and difficulty committing to exercise – experienced by 33% (239) of participants			
Try simple and convenient options for exercise (e.g., walking)	85% (180 of 211)	46% (13 of 28)	81% (193)
Identify exercises that you enjoy	85% (150 of 176)	62% (39 of 63)	79% (189)
Exercise for shorter periods of time	79% (125 of 158)	54% (44 of 81)	71% (169)
Listen to music that motivates you	86% (119 of 139)	49% (49 of 100)	70% (168)
Remind yourself that exercise is important to achieving health goals	70% (115 of 165)	46% (34 of 74)	62% (149)

Barriers and facilitators	Likely or very likely to use facilitator, *% (n)*		
	Tried facilitator	**Not tried facilitator**	**Combined**
Think about positive events that inspire you to exercise	78% (90 of 116)	31% (38 of 123)	54% (128)
Use a wearable device to track exercise (e.g., a watch that records the number of steps walked)	81% (79 of 97)	28% (39 of 142)	49% (118)
Reward yourself for exercising regularly	76% (51 of 67)	34% (58 of 172)	46% (109)
Work with a qualified exercise trainer for a few sessions	68% (44 of 65)	31% (53 of 174)	41% (97)
Keep an exercise log to track your progress	58% (21 of 36)	28% (57 of 203)	33% (78)
Barrier: Feeling embarrassed or discouraged due to physical ability, appearance, or judgement from others – experienced by 19% (138) of participants			
Do exercises that are not in a group setting	86% (80 of 93)	36% (16 of 45)	70% (96)
Participate in gentle exercise classes that may be intended for new exercisers or people with limitations for exercising	80% (37 of 46)	33% (30 of 92)	49% (67)
Discuss your feelings of embarrassment and discouragement with your health care provider	62% (34 of 55)	29% (24 of 83)	42% (58)
If attending an exercise class, watch the class before participating, and arrange to meet with the exercise instructor before participating to review the exercises and discuss any concerns	70% (23 of 33)	29% (30 of 105)	38% (53)
Attend a scleroderma support group to discuss your feelings	75% (21 of 28)	28% (31 of 110)	38% (52)

Barriers and facilitators	Likely or very likely to use facilitator, *% (n)*		
	Tried facilitator	**Not tried facilitator**	**Combined**
of embarrassment and discouragement			
Barrier: Fear of injury or extended recovery time – experienced by 13% (95) of participants			
Take rest breaks while exercising (e.g., between activities)	77% (58 of 75)	40% (8 of 20)	70% (66)
Participate in gentle exercise classes that may be intended for new exercisers or people with limitations for exercising	74% (29 of 39)	46% (26 of 56)	58% (55)
Have an introductory session with a qualified exercise trainer to discuss your fears and get an assessment	82% (22 of 27)	44% (30 of 68)	55% (52)
If attending an exercise class, watch the class before participating, and arrange to meet with the exercise instructor before participating to review the exercises and discuss any concerns	68% (15 of 22)	43% (31 of 73)	48% (46)
Barrier: Anxiety during exercise – experienced by 5% **(**34) of participants			
Identify the issues making you feel anxious and modify the exercise situation (e.g., seek advice from a professional)	77% (17 of 22)	42% (5 of 12)	65% (22)
Use relaxation techniques (e.g., deep breathing exercises) before exercise	70% (14 of 20)	57% (8 of 14)	65% (22)
Participate in gentle exercise classes that may be intended for new exercisers or people with limitations for exercising	67% (12 of 18)	50% (8 of 16)	59% (20)

Barriers and facilitators	Likely or very likely to use facilitator, *% (n)*		
	Tried facilitator	**Not tried facilitator**	**Combined**
If attending an exercise class, watch the class before participating, and arrange to meet with the exercise instructor before participating to review the exercises and discuss any concerns	79% (11 of 14)	40% (8 of 20)	56% (19)
Category: Time, work, and lifestyle			
Barrier: Finding time available to schedule exercise – experienced by 19% (134) of participants			
Exercise at home or work to eliminate travel time	84% (83 of 99)	49% (17 of 35)	75% (100)
Incorporate exercise into daily life activities (e.g., while watching television, or walk to work instead of driving)	82% (64 of 78)	46% (26 of 56)	67% (90)
Break exercise into several short periods (e.g., three 10-minute walks) rather than a single long period (e.g., one 30-minute walk)	82% (53 of 65)	49% (34 of 69)	65% (87)
Category: Environmental			
Barrier: Costs related to exercise – experienced by 7% (54) of participants			
Identify free opportunities for exercise (e.g., walking)	80% (39 of 49)	80% (4 of 5)	80% (43)
Find free exercise resources online or in books	74% (25 of 34)	50% (10 of 20)	65% (35)
Sign up for free activities or exercise classes organized by your community	91% (21 of 23)	39% (12 of 31)	61% (33)

Barriers and facilitators	Likely or very likely to use facilitator, *% (n)*		
	Tried facilitator	**Not tried facilitator**	**Combined**
Check options available for insurance reimbursement or reduced costs to exercise	70% (14 of 20)	35% (12 of 34)	48% (26)
General facilitators (n = 721)			
Exercise at a pace or intensity that is comfortable for you. Start easy, progress slowly. If you have pain, adapt the exercise or seek advice	86% (483 of 564)	44% (69 of 157)	77% (552)
Adapt the exercise or try a new exercise	85% (443 of 521)	41% (82 of 200)	73% (525)
Eat a healthy diet. Consult with your health care provider about what foods to eat	85% (437 of 514)	42% (87 of 207)	73% (524)
Set manageable and realistic exercise goals	82% (405 of 497)	46% (102 of 224)	70% (507)
Eat at times that compliment your exercise routine	84% (392 of 465)	42% (107 of 256)	69% (499)
Maintain an exercise routine by scheduling specific times to exercise	80% (298 of 374)	34% (119 of 347)	58% (417)
Consult with your health care provider or exercise professional to discuss any concerns and/or custom design an exercise program matched to your capacity and needs	77% (198 of 257)	32% (150 of 464)	48% (348)
Exercise with a partner or group that may have similar activity levels as you do	77% (206 of 267)	27% (122 of 454)	46% (328)
Exercise under supervision of a qualified professional	76% (221 of 291)	24% (102 of 430)	45% (323)
Sign up for an exercise class	74% (202 of 272)	22% (100 of 449)	42% (302)
Ask the exercise facility staff about any potential accommodations or concerns	79% (154 of 195)	21% (109 of 526)	37% (263)

Barriers and facilitators	Likely or very likely to use facilitator, *% (n)*		
	Tried facilitator	**Not tried facilitator**	**Combined**
Sign up for an online group exercise class to do at home, or do an online home-based exercise program	74% (81 of 109)	26% (161 of 612)	34% (242)

Supplemental Appendix C. Participants' suggestions for new barriers and facilitators.

Barriers and facilitators
New barriers
Kidney problems.
Loss of sensitivity in fingers and toes.
New barrier-specific facilitators for barriers already presented in the survey
Barrier: Difficulty grasping objects.
Wear compression gloves.
Barrier: Feeling embarrassed or discouraged due to physical ability, appearance, or judgement from others.
Exercise at the facility when it is less busy.
Barrier: Joint stiffness and contractures.
Use a foam roller for stretching.
Barrier: Pain.
Wear compression gloves.
New barrier-specific facilitators for new barriers
Barrier: Dizziness.
Do exercises that do not involve standing (e.g., sitting, or laying on the ground).
Barrier: Foot problems.
Do toe and ankle stretches and exercises.
Ask your health care provider to provide material to place in the shoes to support the big toe.
Place your feet in a tub of warm water with epsom salt.
New general facilitator
If you are exercising at a facility, use their hot tub or sauna before or after exercise.

[a] We recorded participants' suggestions for new barriers and facilitators that were different from those presented in the survey and met 2 criteria (for barriers): (1) they would affect some people with scleroderma meaningfully (versus only trivially) and (2) they would plausibly be a reason why people with scleroderma do not participate in physical activity, or 3 criteria (for facilitators):

(1) they would be feasibly and realistically used by some people with scleroderma, (2) they would plausibly address the corresponding barrier (general facilitators would plausibly address multiple barriers and physical activity in general) to support physical activity, and (3) they could be accessed or safely applied by many people with scleroderma. For example, the barrier suggestion of 'financial issues' was not recorded since it overlaps with the survey item of 'costs related to exercise', and the barrier suggestion of 'driving' was not recorded because it does not meet the barrier criteria.

Chapter 4 – Thesis Summary and Future Directions

4.1 Summary of Main Findings

In the first study of this thesis, we conducted nominal group technique sessions to identify a final list of survey items consisting of 20 barriers, 91 barrier-specific facilitators, and 12 general facilitators to physical activity as experienced by people with SSc. Most barriers (14 barriers) were medical-related while others fell into 3 categories: social and personal (4 barriers); time, work, and lifestyle (1 barrier); and environmental (1 barrier). The medical-related barriers addressed a range of functional restrictions (e.g., difficulty grasping objects) and symptoms impeding exertion (e.g., shortness of breath) that stem from SSc manifestations, whereas the social and personal barriers addressed psychosocial-related issues of exercise. Medical-related facilitators addressed a variety of strategies to mitigate discomfort, which generally involved selecting appropriate activities, adapting the conduct or setting of activity, or health behaviours to take care of the body. Social-and-personal-related facilitators generally addressed methods: to feel comfortable with physical activity, to select appropriate activities, and to increase physical activity adherence.

Findings of the second and final study of this thesis demonstrate that SSc patients enrolled in the SPIN Cohort most commonly experienced (and considered important) medical barriers to activity; among them, Raynaud's phenomenon and fatigue were most commonly experienced and considered important, by > 50% of the 721 participants. Common barriers were related to compromised hand dexterity or symptoms reducing physical exertion, while just one non-medical barrier, lack of motivation and difficulty committing to exercise, was experienced and considered 'important' or 'very important' by > 25% of participants. Overall, facilitators widely rated favourably as 'likely' or 'very likely' to be used often addressed adapting the

exercise type or setting, using health behaviours to take care of the body, or using clothing/materials to protect the skin or to keep warm. The list of facilitators was rated as 'likely' or 'very likely' to use among the majority of participants who tried facilitators, but not among participants who had not tried facilitators.

4.2 Conclusion

Taken together, people with SSc experience a wide range of medical-related barriers to physical activity, and those commonly considered important had mainly addressed hand condition/dexterity and activity restrictions of various etiologies; among them, Raynaud's phenomenon and fatigue were most commonly experienced and considered important. Although less common, SSc patients experience psychosocial barriers related to their feelings about physical activity that prevent adherence. Facilitators widely considered as likely to be used often addressed adapting the exercise type or setting, using health behaviours to take care of the body, and using clothing/materials to protect the skin or to keep warm. Participants who had tried facilitators were generally more likely to use them again compared to participants who had never tried them. Our online interactive Excel file (https://osf.io/2mxj5/) allows health care providers to easily identify relevant facilitators for common barriers to physical activity experienced by individuals with SSc.

4.3 Future Directions

This thesis comprised the first 2 steps of the SPIN-PACE research program, with the goal to develop, test, and disseminate free-of-charge an online SSc-specific physical activity promotion intervention to people with SSc worldwide. The results of this thesis will be used to adapt a widely successful behavioural modification program designed to enhance physical activity for sedentary people in the general population, the Active Living Every Day (ALED)

program (http://www.activeliving.info), to the needs and preferences of people with SSc. Specifically, we will work with the following people to add SSc-oriented modules to the ALED program in an online format: (1) the SPIN-PACE Patient Advisory Team (comprised of 9 SSc patients); SPIN researchers and health care providers with expertise in SSc, some of whom also have expertise in physical activity; and the developers of the ALED program, who are collaborators on the SPIN-PACE project. The intended function of the adapted program is not to prescribe specific exercises, but to influence behaviour change to incorporate physical activity into one's lifestyle. This would help people with SSc to select activities that they can perform, or adapt activities so that they can perform them despite their symptoms. Once developed, we will test the adapted program in a large randomized controlled trial conducted via the SPIN Cohort and, if effective, the program will be distributed free-of-charge to people with SSc worldwide via the websites of SPIN's patient organization partners.