Barriers and Facilitators to Physical Activity for People With Scleroderma: A Scleroderma Patient-Centered Intervention Network Cohort Study

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Objective. To support physical activity among people with systemic sclerosis (SSc [scleroderma]), we sought to determine the prevalence and importance of barriers and the likelihood of using possible facilitators.

Methods. We invited 1,707 participants from an international SSc cohort to rate the importance of 20 barriers (14 medical, 4 social or personal, 1 lifestyle, and 1 environmental) and the likelihood of using 91 corresponding barrier-specific and 12 general facilitators.

Results. Among 721 respondents, 13 barriers were experienced by ≥25% of participants, including 2 barriers (fatigue and Raynaud’s phenomenon) rated “important” or “very important” by ≥50% of participants, 7 barriers (joint stiffness and contractures, shortness of breath, gastrointestinal problems, difficulty grasping, pain, muscle weakness and mobility limitations, and low motivation) by 26–50%, and 4 barriers by <26%. Overall, 23 of 103 facilitators (18 medical-related) were rated by ≥75% of participants as “likely” or “very likely” to use among those who experienced corresponding barriers. These facilitators focused on adapting exercise (e.g., using controlled, slow movement), taking care of one’s body (e.g., stretching), keeping warm (e.g., wearing gloves), and protecting skin (e.g., covering ulcers). Among those participants who had previously tried the facilitator, all facilitators were rated by ≥50% as “likely” or “very likely” to use. Among those participants with the barrier who had not tried the facilitator, only 12 of 103 facilitators were rated by >50% of participants as “likely” or “very likely” to use.

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

INTRODUCTION

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). Disease onset typically occurs at ~50 years of age, and ~80% of people with SSc are women (4,5).

Although regular physical activity is important to enhance health for all people (6,7), including those with autoimmune
rheumatic diseases (9), people with SSC experience a wide range of barriers that may impede engagement. Data from a large international SSC cohort demonstrated that ~50% of patients were physically inactive, and patients who were active rarely engaged in activities other than walking (9). This study, by Azar et al (9), and other studies on physical activity in SSC (10–12) have not addressed barriers or facilitators to being physically active.

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 (13). That study included only 41 people, which did not allow conclusions to be drawn about the prevalence of barriers and likelihood that people with SSC would use identified facilitators. The aim of the present study was to obtain information on 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 the prevalence and importance of different barriers experienced in SSC and the likelihood that people with SSC would use different patient-generated, barrier-specific, and general facilitators to support physical activity.

PATIENTS AND METHODS

The present study was cross-sectional, in which survey results from the Scleroderma Patient-Centered Intervention Network (SPIN) Physical Activity Survey were deterministically linked (using participant usernames [email addresses]) to participant sociodemographic, medical, and patient-reported outcome measures data from the ongoing SPIN Cohort.

Participants and procedures. Eligible SPIN Cohort participants had to be: classified as having SSC according to the 2013 American College of Rheumatology/European Alliance of Associations for Rheumatology criteria (14), ≥18 years of age, fluent in English, French, or Spanish, and able to respond to questionnaires via the internet. Eligible individuals are invited by their attending physician or supervised nurse coordinator to participate in the SPIN Cohort, and written informed consent was obtained. The local SPIN physician or supervised nurse coordinator completed a medical data form that was submitted online to initiate participant registration. After completion of online registration, an automated welcoming email was sent to participants with instructions for activating their SPIN account and completing SPIN Cohort measures online. SPIN Cohort participants completed online outcome measures upon enrollment and subsequently every 3 months.

For the present study, in July 2019 we invited active 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 active SPIN accounts and who completed 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 1 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 the Qualtrics survey platform (15). 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 nonparticipants, 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 center. 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 were provided by SPIN physicians upon enrollment in the SPIN Cohort, and included time since first non-Raynaud’s

SIGNIFICANCE & INNOVATIONS

- Based on a survey of 721 people with scleroderma, barriers to physical activity that were 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 that were most likely to be used, as evidenced by adapting the exercise type or setting, were health behaviors to take care of the body, and strategies to keep warm and protect the skin.
- Generally, participants who experienced the barrier and had tried the linked facilitator were likely to use it, whereas participants who experienced the barrier and had not tried the linked facilitator were not likely to use it.
- 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.

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Measures. Sociodemographic and medical characteristics. Medical data were provided by SPIN physicians upon enrollment in the SPIN Cohort, and 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 assessment included the following 2 items: 1) “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); and 2) “Do you exercise at present?” (yes, no). Among participants who reported exercising at present, 2 additional items were administered: 1) “On the average, how many hours per week do you exercise?”, and 2) “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 (16).

Physical function. We used the 4-item Patient-Reported Outcomes Measurement Information System (PROMIS) physical function domain 4a (profile version 2.0) 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 score is obtained by converting the sum of raw item scores into T scores standardized from the general US population (mean ± SD 50 ± 10). The PROMIS physical function domain 4a (profile version 2.0) has been validated in SSc (17–19).

Functional disability. The Health Assessment Questionnaire disability index (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 (20).

SPIN Physical Activity Survey. We developed the SPIN Physical Activity Survey to evaluate whether possible physical activity barriers were experienced and, if experienced, their importance and to evaluate possible facilitators for likelihood of use (see Supplementary Appendix A, available on the Arthritis Care & Research website at http://onlinelibrary.wiley.com/doi/10.1002/acr.24567). An initial list of barriers and facilitators was generated via 9 nominal group technique sessions with 41 people with SSc at patient conferences in Canada, the US, and France (13). Study investigators consolidated overlapping items, reworded unclear items, and excluded vague or unrelated items. Next, the 9-member SPIN Physical Activity Patient Advisory Team (see Appendix A for advisory team members) 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 (21), including health and medical (n = 14); social and personal (n = 4); time, work, and lifestyle (n = 1); and environmental (n = 1). 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 (22).

In the survey, to reduce burden, participants were asked to select up to 10 of the 20 total barriers that they had experienced and believed were important for them, initially order selected barriers from most to least important by dragging them into position, and 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 were able to provide suggestions for additional barriers and facilitators.

Data analysis. We used descriptive statistics, summarized continuous variables using medians (ranges) and categorical variables using percentages, and listed additional barriers and facilitators provided by participants. To gain further insights, we stratified the analyses related to barriers by whether participants exercised or not and by sex. In addition, because we believed that those who tried a facilitator that helped their physical activity would be likely to use it again, we stratified the analyses based on the likelihood of using facilitators separately by those who had experienced the barrier and previously tried the facilitator in comparison to those who had experienced the barrier but had not tried the facilitator.

We classified barriers using the same 4 categories used to classify them in the nominal group technique study where the list was generated (13). Also, based on consensus among investigators and the SPIN Physical Activity Patient Advisory Team, we applied descriptive labels in the text to similar barriers and facilitators in order to clearly and succinctly summarize results. All analyses were conducted with Microsoft Excel, version 16.16.

RESULTS

Participant characteristics. Of 1,707 invited SPIN Cohort participants, 721 (42%) completed the full SPIN Physical Activity Survey and were included in analyses. A total of 70 participants who partially completed the survey were excluded. The
median age of participants was 59 years (range 22–89 years), ~90% were women, and almost half were employed full- or part-time (Table 1). Median time duration since SSC diagnosis was 10.4 years, and ~40% of participants had diffuse SSC. Approximately one-third of participants were ≥1 SD below the US population mean score on the PROMIS physical function domain 4a (profile version 2.0), 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%.

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

**Physical activity barriers.** There were 172 participants (24%) who experienced and selected 10 barriers for rating and 549 (76%) who selected fewer than 10. The median number of barriers selected was 7. There were 4 barriers, all health and medical barriers, that were experienced and selected for rating by ≥50% of the 721 total participants, including Raynaud’s phenomenon, fatigue, joint stiffness and contractures, and difficulty grasping objects. Of these 4 barriers, fatigue (58%) and Raynaud’s phenomenon (57%) were selected for rating and classified as important or very important by ≥50% of total participants. The joint stiffness and contractures barrier was selected and rated as important or very important by 49% of participants, shortness of breath by 38%, gastrointestinal problems by 36%, difficulty grasping objects

| Table 1. Participant sociodemographic and medical characteristics* |
|-------------------------------------------------------------|
| **Variable**                                                | **Respondents (n = 721)** | **Nonrespondents (n = 986)** |
| Sociodemographic variables                                  |                            |                                |
| Age, median (range) years                                   | 59 (22–89)                 | 57 (21–91)                     |
| Women                                                       | 640 (89)                   | 865 (88)                       |
| White race/ethnicity                                        | 602 (85); n = 714†         | 717 (79); n = 912‡             |
| Education completed, median (range) years§                 | 16 (3–27); n = 708†        | 15 (0–28); n = 900‡            |
| Employed full- or part-time                                 | 323 (46); n = 708†         | 369 (41); n = 903‡             |
| Married or living as married                                | 455 (64); n = 708‡         | 547 (61); n = 903‡             |
| Geographic region                                           |                            |                                |
| North America                                              | 429 (60)                   | 584 (59)                       |
| Europe                                                      | 292 (40)                   | 401 (41)                       |
| Australia                                                   | 0 (0)                      | 1 (0)                          |
| English survey language                                     | 447 (62)                   | 649 (69); n = 935‡             |
| Medical variables                                           |                            |                                |
| Time in years since baseline assessment, median (range)     | 3.1 (0.4–5.8)              | 3.1 (0.4–6.7)                  |
| Time in years since non-Raynaud’s phenomenon symmetric, median (range) | 12.3 (0.4–47.3); n = 666† | 11.3 (1.6–58.8); n = 899‡      |
| Time in years since systemic sclerosis diagnosis, median (range) | 10.4 (0.4–43.8); n = 697† | 9.8 (0.8–58.8); n = 939‡       |
| Diffuse systemic sclerosis subtype                          | 279 (39); n = 713†         | 409 (42); n = 979‡             |
| Body mass index, median (range)                             | 24.0 (14.7–60.7)           | 24.6 (13.0–64.4)               |
| Raynaud’s phenomenon                                       | 695 (98); n = 711†         | 963 (98); n = 979‡             |
| Digital ulcers (distal pulp)                               | 238 (34); n = 703‡         | 364 (38); n = 970‡             |
| Digital ulcers (anywhere else on the finger)                | 101 (15); n = 692‡         | 184 (19); n = 944‡             |
| Current or past tendon friction rubs                        | 154 (25); n = 618‡         | 210 (24); n = 865‡             |
| Moderate or severe contractures of small joints             | 172 (26); n = 673‡         | 253 (27); n = 934‡             |
| Moderate or severe contractures of large joints             | 79 (12); n = 657‡          | 136 (15); n = 918‡             |
| Any gastrointestinal involvement                            | 621 (87); n = 706‡         | 873 (89); n = 983‡             |
| Intestinal lung disease                                     | 228 (33); n = 692‡         | 346 (36); n = 974‡             |
| Pulmonary arterial hypertension                             | 45 (7); n = 691†           | 80 (9); n = 937‡                |
| PROMIS physical function domain score, median (range)       | 43.4 (22.9–56.9); n = 705‡ | 41.8 (22.9–56.9); n = 876‡     |
| Total HAQ DI score, median (range)                          | 0.6 (0.0–3.0); n = 701†    | 0.6 (0.0–3.0); n = 862‡        |

* Values are the number (%) of data recorded of participants unless indicated otherwise. HAQ DI = Health Assessment Questionnaire disability index; PROMIS = Patient Reported Outcomes Measurement Information System (profile version 2.0).
† No. of Scleroderma Patient-Centered Intervention Network (SPIN) respondents due to missing data.
‡ No. of SPIN nonrespondents due to missing data.
§ Years of education completed beginning from elementary/primary school and including all levels of formal education.

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by 33%, pain by 33%, muscle weakness and difficulty with mobility by 29%, and lack of motivation and difficulty committing to exercise by 26%. A summary of the initial sorted rankings of barriers by importance, rather than by ratings, is available (see Supplementary Appendix B, available on the Arthritis Care & Research website at http://onlinelibrary.wiley.com/doi/10.1002/acr.24567).

The distribution of barrier ratings separately for participants who did (n = 433) and did not (n = 282) report presently engaging in exercise is shown (see Supplementary Appendices C and D, available at http://onlinelibrary.wiley.com/doi/10.1002/acr.24567). The importance of barriers tended to be rated higher by those who did not exercise. The 3 largest differences in the percentage of participants rating barriers as important or very important were for lack of motivation (21% difference), fatigue (14% difference), and difficulty grasping objects (11% difference).

The distribution of barrier ratings for male (n = 81) and female (n = 640) participants is shown (see Supplementary Appendices E and F, available on the Arthritis Care & Research website at http://onlinelibrary.wiley.com/doi/10.1002/acr.24567). Overall, the distributions of barrier ratings for male and female participants were generally similar. The 2 barriers with the largest differences were gastrointestinal problems (12%) and Raynaud’s phenomenon (10%), which both had a higher percentage of female participants rating the barrier as important or very important (Figure 1).

**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 rated the same by ≥50% of participants. The full list of barriers, their facilitators, and participant ratings is available (see Supplementary Appendix G at http://onlinelibrary.wiley.com/doi/10.1002/acr.24567); it is also accessible online as an interactive spreadsheet (https://osf.io/2mx5/) that facilitates sorting and identifying facilitators for different barriers. Table 3 shows 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 (e.g., using controlled, slow movement), changing health

### Table 2. Participant physical activity characteristics (n = 721)*

| Variable                                      | SPIN Cohort respondents | SPIN Cohort nonrespondents |
|-----------------------------------------------|-------------------------|----------------------------|
| Participants’ perception of their physical activity level in the past year compared to other people their age |                         |                            |
| Physically inactive                           | 85 (12)                 | 155 (17)                   |
| Somewhat active                               | 199 (28)                | 316 (34†)                  |
| Moderately active                             | 233 (33)                | 270 (29†)                  |
| Quite active                                  | 148 (21)                | 115 (12†)                  |
| Very active                                   | 50 (7)                  | 66 (7†)                    |
| Currently exercise                            | 433 (61)                | 421 (46‡)                  |
| Hours per week of exercise, median (range)    | 4 (1–15)§               | 4 (1–15)¶                 |
| Types of exercises performed                  |                         |                            |
| 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)                   |
| “Other” exercises (selected examples)#        |                         |                            |
| 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**                            | 52 (7)                  | 12 (1)                     |

* Values are the number (% of data recorded) of participants unless indicated otherwise. N = 715 for Scleroderma Patient-Centered Intervention Network (SPIN) Cohort respondents (due to missing data) and n = 933 for SPIN Cohort nonrespondents.
† N = 922 (due to missing data).
‡ N = 921 (due to missing data).
§ Participants who reported currently exercising and their average hours per week of exercise (n = 433).
¶ Participants who reported currently exercising and their average hours per week of exercise (n = 418).
# Participants could indicate >1 exercise, and each exercise was classified into 1 category.
** Other categories of activities performed by ≤2% of participants were dancing, fishing and hunting, home activity, miscellaneous, music playing, and winter activities.
behaviors to take care of the body (e.g., stretching), keeping warm (e.g., wearing gloves), and protecting the skin (e.g., covering ulcers). Additional barrier and facilitator suggestions to those presented in our survey, which were provided by survey respondents and were substantively different from those included in the survey, are shown (see Supplementary Appendix H, available on the Arthritis Care & Research website at http://onlinelibrary.wiley.com/doi/10.1002/acr.24567).

The majority of the facilitators (62 of 103 [60%]) had been tried by ≥50% of participants who rated them. Among those participants who 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 these barriers 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 such barriers 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 (9), 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 (23) and pulmonary hypertension (24) have been found to be associated with reduced aerobic capacity in 2 small exercise studies (n = 46 and n = 18 participants). Two of our barrier-specific facilitators (“take rest breaks...
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)*

| Barriers                                      | Participants who experienced and selected barrier for rating¹ | Facilitators                                                                 | Participants who tried facilitator and “likely” or “very likely” to use it† |
|-----------------------------------------------|--------------------------------------------------------------|-------------------------------------------------------------------------------|-------------------------------------------------------------------------------|
| 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 (501/539)                                                                  |
|                                               |                                                              | Exercise in an area with a temperature that is comfortable for you            |                                                                               |
|                                               |                                                              | Wear heated or nonheated warm gloves or mittens and socks                    |                                                                               |
|                                               |                                                              | Insert warmers (i.e., liners, or electric or chemical warmers) in gloves or mittens or socks |                                                                               |
| Fatigue                                       | 71 (508)                                                     | Take rest breaks while exercising (e.g., between activities)                 | 83 (333/403)                                                                  |
|                                               |                                                              | Break exercise into several short periods (e.g., three 10-minute walks)      | 82 (235/286)                                                                  |
|                                               |                                                              | Rather than a single long period (e.g., one 30-minute walk)                  |                                                                               |
|                                               |                                                              | Get enough sleep and plan to take a nap during the day                      | 80 (273/342)                                                                  |
| Joint stiffness and contractures              | 60 (434)                                                     | Do daily gentle stretching and exercises that move your joints               | 82 (256/312)                                                                  |
|                                               |                                                              | through their maximum range of motion                                        |                                                                               |
|                                               |                                                              | Use controlled, slow movements that are comfortable for you                 | 85 (263/309)                                                                  |
| Difficulty grasping objects                   | 51 (365)                                                     | Use adapted exercise equipment (e.g., weights with a larger handle or wrist weights) | 82 (108/132)                                                                  |
| Shortness of breath                           | 47 (338)                                                     | Lower the intensity of the exercise to not experience shortness of breath    | 86 (251/291)                                                                  |
| Gastrointestinal problems                     | 46 (334)                                                     | If you have acid reflux, modify exercise positions to keep your body upright (e.g., do push-ups against the wall instead of push-ups against the ground) | 89 (148/166)                                                                  |
| Pain                                          | 42 (300)                                                     | Modify exercise so it does not cause pain (e.g., use lighter weights or walk slower) | 87 (223/256)                                                                  |
| Itching or dryness of skin                    | 40 (289)                                                     | Moisturize regularly or as needed (e.g., use lotion or wear moisturizing gloves or socks) | 89 (223/251)                                                                  |
| 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 (151/172)                                                                  |
|                                               |                                                              | If you have difficulty with balance, use assistive devices (e.g., hiking poles) | 81 (77/95)                                                                    |
| Difficulty with bowel and bladder control     | 28 (205)                                                     | Wear a pad or underwear designed for bowel and bladder control issues        | 90 (132/146)                                                                  |
| Ulcers or sores on hands or feet              | 27 (195)                                                     | Apply nonadhesive bandages to cover and protect ulcers or sores               | 92 (140/153)                                                                  |
|                                               |                                                              | Wear appropriate clothing to cover and protect ulcers or sores (e.g., gloves or mittens) | 90 (148/165)                                                                  |
|                                               |                                                              | If you have foot ulcers or sores, put pads in shoes or wear specialized soles or shoes (e.g., open-toe shoes) | 87 (65/75)                                                                    |
| 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 (33/46)                                                                    |

* 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). See interactive Excel file [https://osf.io/2mxj5/](https://osf.io/2mxj5/) for the full list.
† Values are the % (number) of participants who experienced and selected the barrier for rating.
‡ Values are the % (number/total 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.

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 nonmedical barrier 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 (25,26), 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 (27).

Subgroup analyses revealed that a substantially larger proportion of inactive participants had rated 2 health and medical barriers (fatigue, difficulty grasping objects) and 1 social and personal barrier (lack of motivation) as important or very important.
compared to active participants. These 3 barriers could be targeted when developing general interventions to promote physical activity in SSc patients.

All facilitators were rated by at least half of participants who tried the facilitators 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 (28), and identifying enjoyable activities for people who have difficulty with motivation or exercise adherence (29). 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 of 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). Importantly, individuals with SSc should consult a qualified clinician about how to exercise safely.

In general, participants who tried facilitators rated them favorably, as likely or very likely to use, in comparison to those who had not tried them. This finding suggests that 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 (30), uses a social modeling component when exposing individuals to new facilitators. This intervention 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 modeling would be a potentially effective strategy to promote physical activity in SSc, especially for those patients who had not tried a proposed facilitator.

Our findings suggest barriers that could be targeted to facilitate physical activity. Strategies to treat fatigue in rheumatoid arthritis include exercise, cognitive behavioral therapy, and self-management programs (31). SPIN is currently testing a SSc self-management program (SPIN-SELF) (32). Strategies to reduce the effects of Raynaud’s phenomenon include keeping a diary and identifying activities that trigger attacks, keeping the body and hands warm (e.g., layered clothing, gloves), and avoiding smoking (33). Limitations in mobility, which are common in the hands (34), may be addressed through hand stretches and exercises, and SPIN has developed the SPIN-HAND program, which is available online, free-of-charge (35). Social support is a strong predictor of exercise intention and stage of behavior change for exercise (36). Many people with SSc attend support groups (37), and the SPIN-SELF program also contains a group component.

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 nonrespondents (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 that 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 felt were important, some participants rated at least 1 of their selections as “not important.” Fifth, 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. Sixth, although our measure of physical activity behavior was modeled after part of an existing validated questionnaire (38,39), we did not administer a validated measure of physical activity behavior, which would have allowed us to better characterize participants and to compare their physical activity behavior with other samples. This was an effort to reduce respondent burden because there were constraints on the number of items that we were able to add to a preexisting cohort assessment. One area of future research could include comparison of general levels of physical activity behavior in SSc patients to the published norms in the general population.

In summary, medical-related barriers to activity were most commonly experienced and considered important; Raynaud’s phenomenon and fatigue were the most commonly experienced among them. Facilitators widely considered likely to be used addressed adapting exercise type or setting, using health behaviors 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.

**AUTHOR CONTRIBUTIONS**

All authors were involved in drafting the article or revising it critically for important intellectual content, and all authors approved the final version to be submitted for publication. Dr. Thombs had full access to all of the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis.

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