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Identifying barriers and facilitators to physical activity for people with scleroderma: a nominal group technique study

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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 to 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 $\geq 1/3$ 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.

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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.

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 min 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], which is a convenience sample and has published data from >1000 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, nine 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 27–76 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%).

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.

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 (%)	
0–5	15 (36.6)
5.1–10	9 (22.0)
>10	17 (41.5)
Years since systemic sclerosis diagnosis	
Mean (SD)	11.5 (9.8)
Median (range)	8 (1–30)

^aParticipants could select more than one race/ethnicity. One participant identified as White and Aboriginal, and another identified as White and Hispanic or Latino.

^bParticipants 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 (4–12)	4 (0.25–14)
Yoga or similar exercises	16	12 (8–12)	3 (1–14)
Swimming	13	6 (3–12)	2.75 (0.5–5)
Cycling	11	10 (4–12)	2 (0.75–9)
Aerobics	10	12 (6–12)	2.5 (1–5)
Jogging	5	12 (4–12)	6.5 (2–16.5)
Other physical activity	22	12 (1–12)	3 (0.67–10)

^aIf participants stated more than one other physical activity, the data refer to the activity that was performed most frequently per year.

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.

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

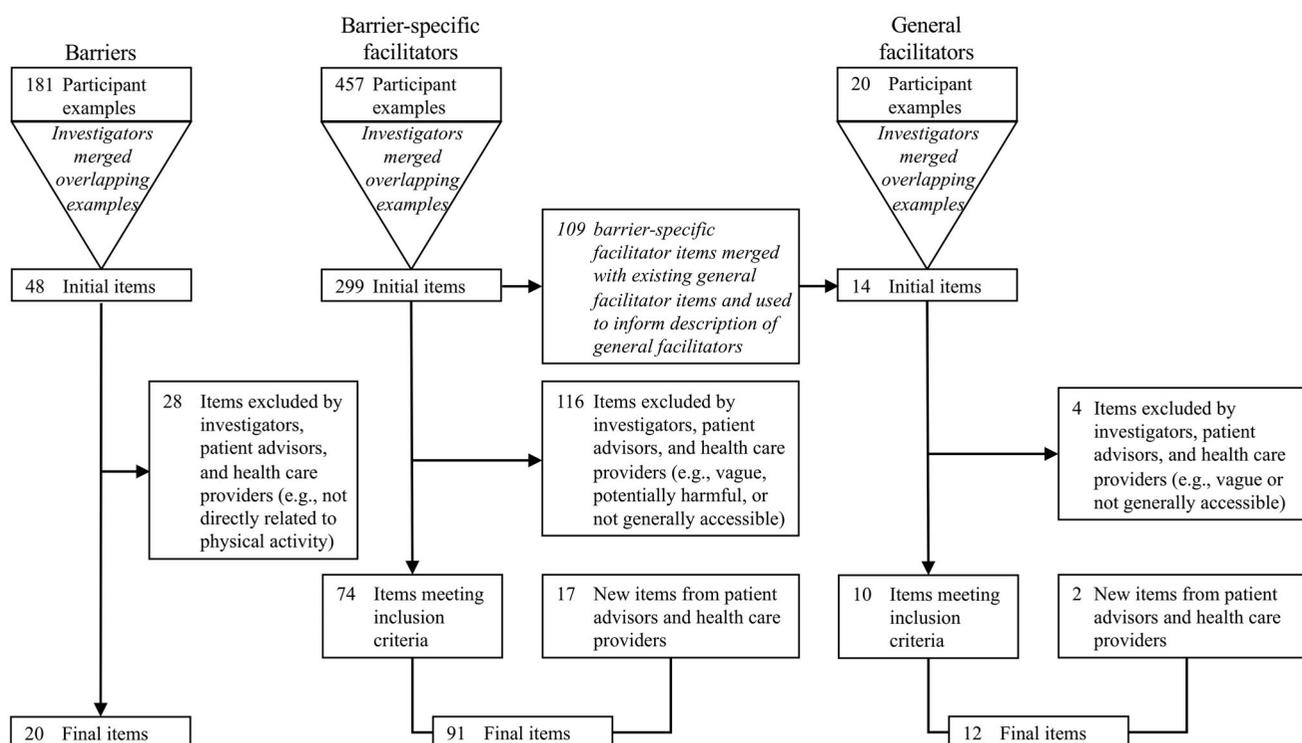


Figure 1. Flow diagram from participant examples to final items.

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 .

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

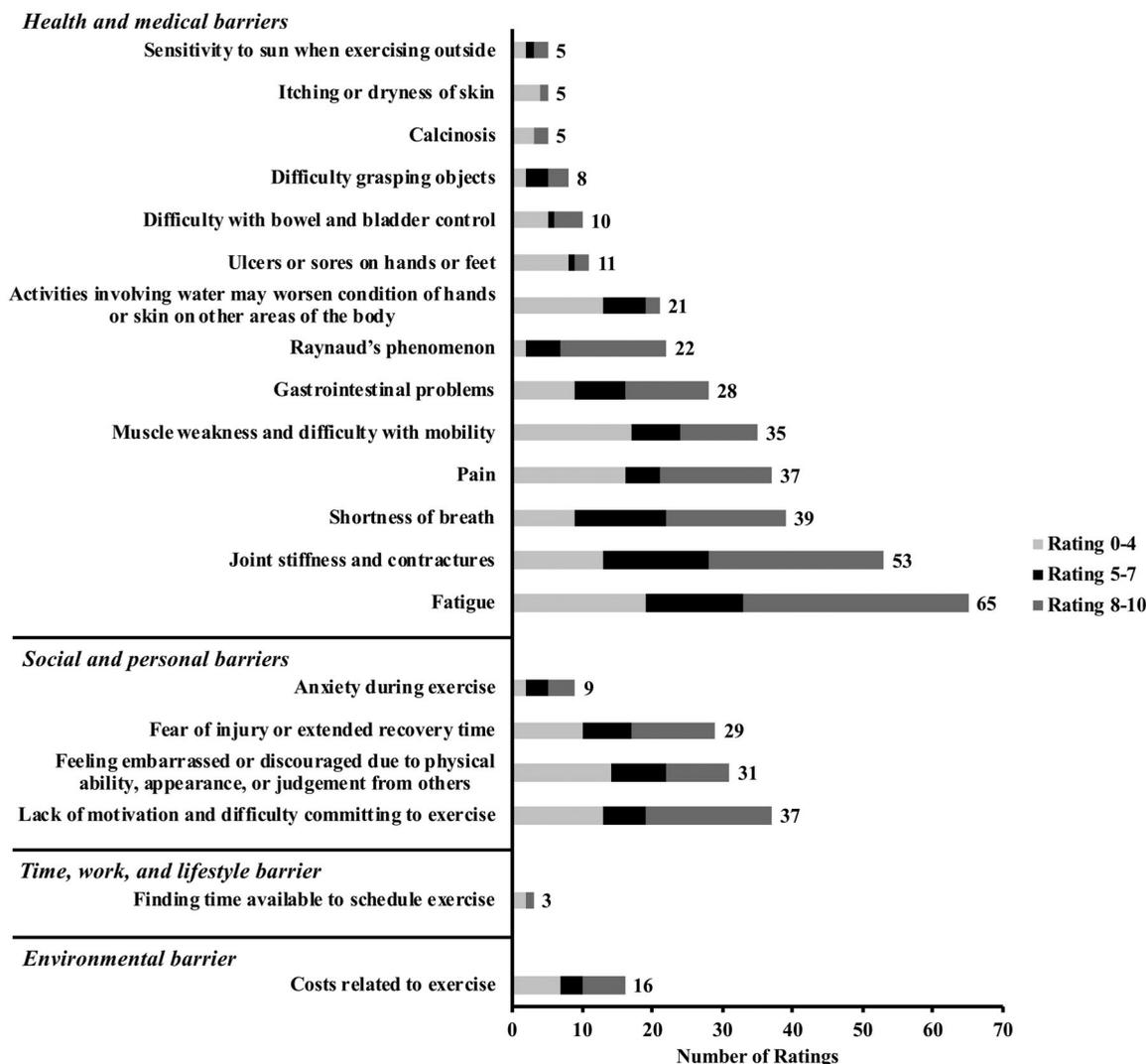


Figure 2. Distribution of ratings for barriers. Numbers to the right of each bar indicate the number of ratings for participant examples captured by the corresponding barrier item. Examples were only rated by participants in sessions where the examples were elicited. The number of ratings can exceed 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.

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 1800 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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