

Views of Exercise in People With Systemic Sclerosis: A Qualitative Study

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ABSTRACT

Background: Systemic sclerosis (SSc) is a connective tissue autoimmune disease that results in significant reduction in physical function and quality of life. Exercise may offer health benefits in people with autoimmune disease, yet approximately 50% of people with SSc are physically inactive and experience a wide array of barriers that may impede their exercise engagement. Currently, there are no exercise recommendations or guidelines for this population. In this qualitative study, we explore and describe barriers and facilitators to exercise in adults with SSc, aiming to provide person-centered exercise recommendations for people with SSc.

Methods: Adults with SSc were purposefully recruited to represent diversity in disease type, duration, and manifestations. Three online focus groups were conducted to explore barriers and facilitators to exercise in people with SSc, transcribed, and thematically analyzed.

Results: Twenty-three adults with SSc (mean age 59 ± 11 years, 91% female) participated. Four themes emerged: (a) disease-related and general barriers to exercise, (b) perceived change in personal exercise capacity postdiagnosis, (c) beneficial effects of exercise, and (d) preference for modified supervised exercise.

Conclusion: SSc imposes disease-related barriers that, combined with general barriers, impede exercise engagement. People with SSc understand that exercise is potentially beneficial. Key recommendations and advice to counter these barriers include (a) ensuring a comfortable temperature to exercise, (b) using modified equipment (e.g., adjustable weighted straps), (c) individually supervising and modifying exercise as required, and (d) keeping people with SSc accountable and motivated to exercise. *J Clin Exerc Physiol.* 2023;12(2):46–53.

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INTRODUCTION

Systemic sclerosis (SSc), also called scleroderma, is a heterogeneous connective tissue autoimmune disease characterized by excessive collagen production and infiltration causing organ and skin fibrosis, and vascular injury (1,2). Physical function can be severely diminished by tendon and skin contractures, myositis or myopathies, as well as diverse impairments arising from ischemic circulatory dysfunction, leading to painful skin ulceration and calcinosis (subcutaneous calcium deposits), and pulmonary hypertension causing

severe dyspnea (1,2). SSc is a rare and unpredictable illness that is currently not curable and results in significant morbidity and mortality (2–4). People with SSc describe debilitating physical limitations due to skin hardening, painful skin ulcerations, and pervasive exhaustion (5,6). SSc can also result in distressing appearance transformation because of radical facial changes and subsequent identity loss (5,6). SSc can hinder one's ability to perform activities of daily living and disrupts 3 critical life areas: work, family, and social or leisure. SSc also affects psychological well-being and health-related quality of life (5).

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Although physical activity (PA) is considered important for health benefits in healthy persons (7) and those with an autoimmune disease (8), data from a large SSc national cohort demonstrated that approximately 50% of those with SSc are physically inactive (9), and among those who reported to be exercising, walking was most often reported (9). Another study comparing all PA (including sport, commuting, work or school, household, and leisure) in people with SSc to their healthy counterparts demonstrated a significant difference in time spent in all PA ($1,704 \text{ min} \cdot \text{wk}^{-1}$ vs $2,614 \text{ min} \cdot \text{wk}^{-1}$, respectively, $P > 0.001$) (10). Notably, PA and *exercise* are often used interchangeably; however, they are different concepts (11). Exercise is a subset of PA that is planned, structured and repetitive, and usually includes a dosage (frequency, intensity, time, and type) and an objective to improve and/or maintain one or more components of physical fitness (11).

People with SSc experience a wide array of barriers that may impede their engagement in PA and exercise (12,13). Skin tightening and stiffness, shortness of breath, painful digital ulcerations, tiredness, and fatigue have been identified as disease consequence barriers (12,13). The risk of adverse effects from PA and exercise, including resultant *pain* and *severe muscle soreness*, are also reported to barriers (13). Furthermore, aerobic capacity, measured by $\text{Vo}_{2\text{peak}}$, was demonstrated to be significantly lower ($P = 0.04$) in those with SSc (without pulmonary or cardiac involvement), compared to healthy controls (14). The evidence on exercise safety and effectiveness in SSc is scarce. However, exercise appears safe and beneficial, with no reported adverse events associated with exercise (15–19) in adults with SSc (both with and without lung involvement) (14), including improvements in the peak amount of oxygen used during intense exercise ($\text{Vo}_{2\text{peak}}$) (16–18) and aerobic capacity (15), self-reported quality of life (17), muscle strength and function (15), and a reduction in self-reported fatigue (15).

Considering the wide array of potential barriers that impede PA and exercise engagement in adults with SSc, in conjunction with the scarcity of exercise trials, the absence of clinical exercise guidelines, and the promising benefits of exercise in people with SSc (10,20), tailored exercise advice for this population is warranted. In this qualitative study we explore and describe barriers and facilitators to exercise in adults with SSc, with an aim to provide person-centered and tailored exercise recommendations and advice for people with SSc.

METHODS

Study Design

A qualitative research study comprising online participant focus groups in adults with SSc was developed and conducted to capture barriers and facilitators to exercise experience by people with SSc. This study was approved by the University of Southern Queensland Human Research Ethics Committee (ethics approval number: H21REA094, approved June 2021).

Participants

The study inclusion criteria included participants aged ≥ 18 years old; English speaking; access to a laptop, tablet, or mobile phone device; ability to provide informed consent; and diagnosed with SSc according to the European League Against Rheumatism (EULAR) or America College of Rheumatology (ACR) classification criteria (3,4). Enrollment decisions were guided by a purposive sampling framework (21), developed by the research team, to ensure a representative participant cohort with respect to disease subtype (mixture of limited and diffuse), disease duration (< 10 and ≥ 10 years), demographic location within Australia (mixture between states), and exercise participation (mixture between *exercisers* and *nonexercisers*). Participants were recruited via snowball sampling through advertisement in the Scleroderma New South Wales (NSW) and Scleroderma Australia social media groups, websites, and newsletters. Each focus group was limited to a maximum of 8 participants to ensure all participants had the opportunity to express their personal views and could confidently challenge alternate or opposing experiences expressed within the group. A minimum of one focus group was originally planned, with an intention to undertake additional focus groups until thematic saturation was achieved (22).

Data Collection

Participant demographic information was collected by the principal investigator (SF) prior to the focus groups to guide purposive sampling. Information included demographics such as age, sex, work status, home location, disease type, duration, and manifestations, and exercise participation. Each of the 3 focus groups lasted approximately 1 hour in duration, were conducted on Zoom (online video communication software, San Jose, California) between August 2021 and September 2021, led by author SF, and were audio-recorded, transcribed, and anonymized. An interview guide was developed by the research team (authors SF, MC) and reviewed by a registered psychologist.

Data Analysis

Qualitative analysis of the focus group transcripts was undertaken by all members of the research team (SF, CC, SB, MC) to ensure a fair and unbiased appraisal of the experiences expressed. Reflexive thematic analysis was adopted in accordance with qualitative research guidelines, ensuring findings were grounded in shared person experiences rather than imposed from existing concepts (23–26). Data analysis software (NVivo, QSR International, release 1.5.1, Burlington, Massachusetts) was used to facilitate qualitative analysis. During the transcription phase, participants were deidentified using alphanumeric codes characterized by disease duration (For example, F01). Initially, anonymized transcripts were read multiple times independently by authors SF and CC, and initial words or phrases (codes) that captured important

TABLE. Participant characteristics (N = 23).

Participant	Sex	Age, yr	Disease Duration, yr	Disease Type ^a	Lung Involvement	Currently Exercising ^b	Currently Working	Location
1	F	72	29	Limited	No	Yes	No	NSW
2	F	65	47	Diffuse	Yes	Yes	No	NSW
3	F	68	9	Diffuse	No	Yes	No	NSW
4	M	51	13	Diffuse	Yes	Yes	Yes	NSW
5	F	50	4	Limited	No	No	No	QLD
6	F	63	9	Limited	Yes	Yes	No	NSW
7	F	68	20	Diffuse	Yes	No	No	QLD
8	F	66	8	Limited	No	Yes	No	SA
9	F	56	7	Diffuse	Yes	Yes	Yes	NSW
10	F	77	21	Limited	No	No	No	NSW
11	F	67	13	Limited	No	Yes	Yes	SA
12	F	75	25	Limited	Yes	Yes	No	NSW
13	F	54	3	Diffuse	Yes	Yes	Yes	WA
14	F	48	1	Diffuse	No	Yes	Yes	ACT
15	F	46	12	Diffuse	Yes	Yes	No	NSW
16	F	48	9	Diffuse	Yes	Yes	Yes	NSW
17	F	59	25	Limited	No	Yes	Yes	NSW
18	F	58	1	Diffuse	Yes	Yes	Yes	WA
19	F	36	12	Diffuse	No	Yes	Yes	NSW
20	M	60	7	Diffuse	Yes	Yes	No	NSW
21	F	56	32	Limited	Yes	Yes	No	NSW
22	F	46	1	Diffuse	No	Yes	Yes	NSW
23	F	76	30	Diffuse	No	Yes	Yes	NSW

ACT = Australian Capital Territory; F = female; M = male; NSW = New South Wales; QLD = Queensland; SA = South Australia; WA = Western Australia

^aWe limited the description of organ involvement in this table to “lung.” Note that all participants each experienced multiple symptoms and all participants had one or more organ involvement, including the skin. All participants had Raynaud’s phenomenon

^bExercise dosage included various frequencies, intensities, time, and type; settings including group-based or 1:1, in-person or online, home-based or in-clinic, water or land-based, supervised, or unsupervised. Variations of exercise described included walking, aerobics (e.g., Zumba), resistance training (e.g., TheraBand and free weights), Bikram yoga, chair yoga, tai chi, Pilates, hydrotherapy, stretch therapy, golf, and dancing

experiences derived from the research questions were independently applied to each transcript to ensure a rigorous analysis and to minimize researcher bias. The codes were then explored and refined during several discussions between authors SF and CC to see how conceptually related codes could be grouped to form themes and sub-themes (23). This process was an iterative one, undertaken concurrently with data collection, allowing emerging themes to be explored in subsequent groups. After a preliminary independent analysis of the data and several discussions, revisions of the themes were conducted by the research team (authors SF, CC, MC, SB) to derive consensus. Deidentified key quotations from the

transcripts were selected to illustrate themes and sub-themes (Supplemental Material).

RESULTS

Participants

Twenty-three adults with SSc met study inclusion criteria and participated in one online focus group (Group 1, n = 8; Group 2, n = 8; Group 3, n = 7). Following a total of 3 focus groups including 23 participants, thematic saturation was reached. The mean age of participants was 59 ± 11 years (range 36-77), and 91% (n = 21) were female. Purposive sampling ensured broad and representative participation in terms of SSc disease type (diffuse SSc n = 14, 61%; limited SSc n = 9, 39%), disease duration (<10 years, n = 11, 48%;

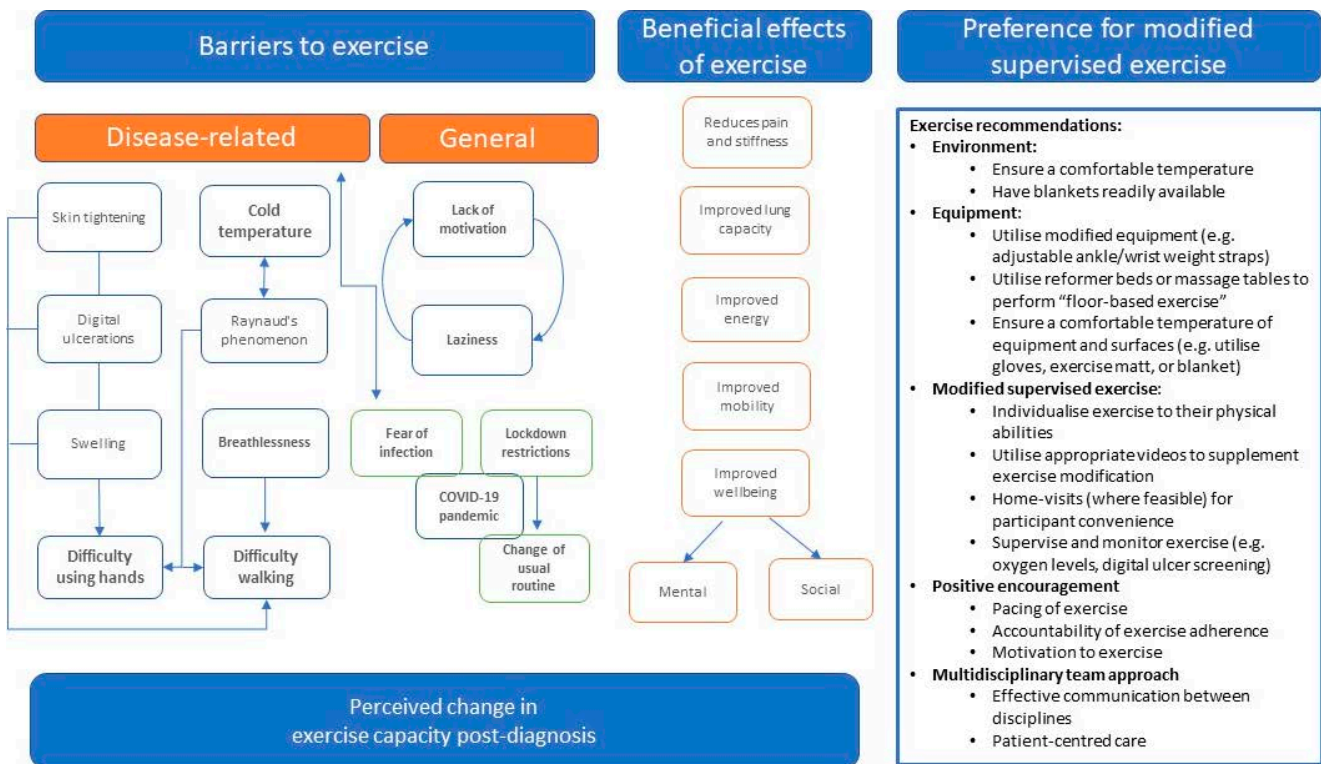


FIGURE. Thematic schema: barriers and facilitators to exercise for people with systemic sclerosis.

≥10 years, $n = 12$, 52%) and lung involvement ($n = 12$, 52%). Most participants were currently engaged in exercise ($n = 20$, 87%) and from New South Wales, Australia ($n = 16$, 70%). See Table for further details about individual participant characteristics.

Themes

Four themes emerged following thematic analysis of the focus group data, that together constitute barriers and facilitators to exercise in adults with SSc. The themes identified are (a) disease-related and general barriers to exercise, (b) perceived change in personal exercise capacity postdiagnosis, (c) beneficial effects of exercise, and (d) preference for modified supervised exercise. Each theme and subtheme are described in further detail below. Illustrative quotations for each subtheme are included in the Supplemental Material, and a thematic schema summarizing the relationship between the themes are presented in the Figure.

Theme 1-Disease-Related and General Barriers to Exercise. Participants reported several barriers and challenges to engaging in, adhering to, and performing exercise, with this being the predominant theme amongst all 3 focus groups. The subthemes are further illustrated using key quotations in Supplemental Table S2.

Disease-Related Barriers. The cold weather (Q1-5) pertaining to Raynaud's phenomenon (RP), which was a disease manifestation experienced by all participants in our study, was expressed as "a huge factor," and "...stops me doing a lot," and affecting exercise. This barrier was described to affect exercise engagement all year around,

however RP was described to be particularly problematic during the winter months and was influenced by where participants lived in Australia (i.e., participants who live in Queensland did not report the cold weather as a significant barrier for them to exercise because the average temperature is generally higher than other states in Australia) (27). Skin tightening causing difficulty or the inability to perform exercises that involved gripping objects with their hands (for example, holding a dumbbell or the handle of a gym-based machine), or bearing weight down onto their hands (for example, a floor push-up position), largely attributed to disease manifestations such as hand and/or finger ulcerations, calcinosis, or sclerodactyly (Q8-14). Further, digital ulcerations on the feet were also hindrances to do certain exercise such as meaningful walking. Lung capacity restrictions due to pulmonary fibrosis or interstitial lung disease were reported to cause "shortness of breath" while trying to perform aerobic exercise such as walking long distances and/or walking up a hill (Q15-19), making it difficult to engage in exercise. Fatigue and exhaustion before and resulting from exercise (Q20-22), and skin and tendon tightening or restrictions (Q23-27) were other deterrents to engage in exercise.

General Barriers. The following barriers are categorized independent to the disease-related barriers because they are not considered to be related to manifestations of the disease itself and could apply to people without SSc. Participants transparently expressed "laziness" and a lack of motivation (Q28-32) as reasons for not exercising or being a barrier to exercise. A "new" barrier to exercise expressed strongly by participants was the recent COVID-19 outbreak

and subsequent lockdown restrictions (Q33-35). This barrier was twofold; participants were fearful of being exposed to the community and contracting the virus, “I’m being extra careful”; and because the lockdown restrictions meant that their usual exercise routine was compromised. Other barriers included the “expensive” cost of exercise, and difficulty in “accessing” exercise because of a lack of services available for those who live in rural and remote areas of Australia.

Perceived Change in Personal Exercise Capacity Post-diagnosis. A discussion that formed within each of the focus groups focused on a perceived change in their exercise participation and capacity following their diagnosis with SSc (Supplemental Table S3). Participants described exercise(s) that they used to do before they were diagnosed with SSc and commented on how it has significantly differed following their diagnosis (Q1-9). Sport such as tennis, squash, dancing, athletics, or soccer used to be played, and since diagnosis they have stopped because of reasons such as “joints are no good,” “tightness and swelling in legs,” and descriptions such as “but that’s all gone now,” “... but no longer,” and “not as strong as I used to be” were made. There was a mixed description between acceptance of this change, and conversely disappointment and frustration that they could no longer do what they used to do. An expectation that they “should” be able to do more than what they can currently do, and expressions such as “I’ll cry because I should be able to do this stuff” were made. On the contrary, comments such as “accepting our bodies’ limits” and self-talk to remind themselves that “whatever we’re doing is sufficient” were described. Remarks were made about the importance of having a “different mental attitude” and changing their own mindset from “I should be able to do it” to “at least I do it” were highlighted. Furthermore, participants suggested to one another that they should “try and pace” and understand when they can “keep going” and when to “pull back.”

Beneficial Effects of Exercise. Participants acknowledged that exercise is beneficial in countering their disease-related barriers and have been categorized into several sub-themes for a more comprehensive view (Supplemental Table S4). An improvement in mental well-being and physical mobility were described to be beneficial from engaging in regular exercise (Q1-5). Participants’ also described exercise to be beneficial in improving their lung capacity and fitness (Q6-8) and in improving their energy levels and sleep, with some describing exercise as “invigorating” and expressed that not performing exercise can make them feel “more fatigued” (Q9-11). Participants also described exercise to help reduce overall pain and stiffness, improve circulation, and make them feel “warmer internally,” “feel accomplished,” and that exercising regularly also helped them to “eat healthier” (Q12-16). Participants who performed group exercise expressed that the social aspect was a benefit to exercising, with descriptions such as “it’s a good social outlet” and that exercise gives you a sense of “togetherness” (Q17-19), highlighting the social benefit of exercise.

Preference for Modified Supervised Exercise. This theme was categorized into several subthemes according to participants’ specific suggestions that would facilitate their engagement in exercise (Supplemental Table S5), however, the consensus was that participants expressed the importance of and preference for modified supervised exercise. Participants conveyed the need for accountability to keep them “motivated” (Q1-3). A lack of interest in going to a gym or performing exercise that was “structured” were described, and participants reported a preference in incidental exercise such as walking or gardening, especially if it’s walking outdoors in the fresh air and sunlight, or with a friend. A preference to exercising in a group or with a partner was highlighted, or having a health professional come to their house, again keeping them “accountable.” An emphasis was placed on exercises and/or environments to exercise that were modified to suit their needs (Q4-6). For example, performing Pilates on a reformer bed or standing to perform an exercise, instead of getting on the floor, or turning on the heater before they commence exercise. Suggestions such as having exercise videos online were described as an effective strategy in assisting exercise engagement (Q7-9). For example, using YouTube and performing chair yoga online to engage in exercise at home effectively. This theme was enhanced by the recent COVID-19 pandemic, where, for many, exercising in a gym or clinic was either not an option due lockdown restriction, or they were fearful of being exposed to infection. Another suggestion to facilitate exercise was to come prepared in suitable clothing for the cold (Q10-11), for example, wearing “hoodies,” “gloves,” or “orthopedic boots,” with comments such as “being appropriately clothed adds to the benefit of the exercise.” Participants also held high value in the health professional team having a good understanding about their disease and pointing them in the right direction with exercise (Q12-13). Other suggestions about ways to exercise effectively included finding the right balance, pacing, and knowing “...when to pull back and when to just push yourself.”

DISCUSSION

For adults with SSc, disease-related barriers were among the most discussed impeding factors to exercise and were highlighted in our study findings. Cold temperature, described as “more” problematic during the winter months, was a major deterrent for people with SSc to engage in exercise, often making it difficult to exercise comfortably, or exercise at all. This is not a surprising finding from this study considering RP occurs in virtually all patients (~96%) with SSc (28,29), and in fact, all participants in our study reported RP as a disease manifestation (Table). Furthermore, typical descriptors of RP are episodic vasospasm occurring in response to cold exposure (30). This barrier may have been pronounced in our findings because the focus groups took place in winter. A small (n = 18) longitudinal study identified “RP attacks” to double in frequency (2.9 vs. 1.5 attacks per day) during winter compared with summer despite similar rates of outdoor exposure across seasons (31). It is therefore

imperative that exercise professionals acknowledge that the cold temperature is a barrier to exercise and address accordingly. For example, warming up the temperature of the environment in which your patient will be exercising and/or using blankets to keep surfaces or equipment warm before use. One participant explained that her exercise instructor would always turn on the heaters in the room prior to commencing their group exercise class to ensure the room was comfortable. Other participants explained that wearing appropriate clothing (thermal underlayers, heated jackets, gloves, long socks) is vital for them to be able to engage in exercise, especially during winter. Exercise professionals can encourage and/or remind people with SSc to come prepared to exercise with warmer clothing, particularly when controlling the temperature is beyond our control (e.g., community-based gym). Importantly, participants in our study described exercise to improve “circulation” and “body warmth,” consistent with other qualitative findings (13), and to quantitative results that demonstrated improvements in microvascular endothelial function following upper body high intensity interval training in adults with limited SSc (16,17). Furthermore, consistent with other quantitative findings of exercise in SSc (14–18), participants described a reduction in pain and stiffness and improved lung capacity, aerobic fitness, strength, and mental well-being following exercise. People with SSc consider PA or exercise to be an effective treatment, reduces fear of deterioration, and makes them feel healthy and satisfied with themselves (13). To enhance the benefits of exercise in people with SSc, a suitable strategy is to ensure that there is clear communication between the multidisciplinary team. The multidisciplinary team for someone with SSc usually comprises, but is not limited to, a rheumatologist, pulmonologist, cardiologist, gastroenterologist, exercise physiologist, physiotherapists, hand therapist, and specialized nurse (32). Significant improvements in grip strength, aerobic or walking capacity measured by a 6-minute walking test, and functional ability measured by the health assessment questionnaire have been demonstrated in people who underwent a multidisciplinary team (MDT) program. This MDT program included one day per week of individualized treatment and group exercise, compared to usual outpatient clinic care (33).

Other disease-related barriers were physical disabilities associated with SSc (e.g., digital ulcerations, skin tightening, swelling), making it difficult to use the hands effectively to exercise, or do meaningful walking. For example, participants with sclerodactyly reported it to be difficult, painful, and merely impossible to hold exercise equipment (e.g., dumbbells, barbells, resistance bands) because of the “curling” of the fingers and lack of mobility. Sclerodactyly, among other physical disabilities (such as widespread skin tightening; digital ulcerations located on feet, hands, elbows, knees; and pervasive fatigue), were also expressed as particularly impeding factors to exercise in another qualitative study (13). Participants in our study shared a consistent view among each other that their ability to perform exercise “now” (postdiagnosis) is very different to “before”

(prediagnosis). This theme did not constitute a barrier to exercise, per se, but was a distinctive perception that many of the participants shared in the group discussions. Focus groups encourage open discussion and debate among participants, allowing convergent and divergent views to be clarified where necessary during the discussion (34). The dynamic nature of focus group interactions, particularly with people who share a rare disease, facilitates unique patient experiences that may not always be expressed in one-on-one interview settings.

Participants in our study expressed the importance of modified supervised exercise, consistent with recommendations from rheumatology practitioners who strongly advised that exercise is individualized and supervised for this population (35). Participants in our study also provided suggestions on how to facilitate exercise. For example, there was a preference for exercise professionals to provide a home-visit to exercise as this would alleviate the additional stress and energy required to commute to a clinic or gym. Participants also suggested the use of modified equipment (e.g., “reformer bed or massage table to perform floor-based exercise”), and to adapt the exercise to suit their physical abilities (e.g., “standing to perform an exercise instead of having to get down on the floor”). Participants also valued the use of modified exercise videos so that they could perform exercise comfortably at home, with some suggesting YouTube to perform modified exercises such as chair yoga.

Interpretation of results should consider our study strengths and limitations. Our study sampling method allowed us to include diversity of views among participants with varying types of SSc, duration of disease, and manifestations. However, despite a purposive sampling framework, this study only included individuals with SSc from Australia, and therefore it is not representative of adults with SSc worldwide who may have provided other views of exercise. Also, this study included mostly female ($n = 21$, 91%) participants who exercise ($n = 20$, 87%), perhaps inherent due to the sex-related bias of SSc (36,37) and the nature of the study. We performed online focus groups, which although is becoming increasingly common as a cost-effective method and opportunity to recruit geographically far-flung participants (38), online interviews pose some limitations including not being able to respond easily to participants’ body language and emotional cues, as well as technological difficulties (39). However, the gathered data provided rich content that summarized barriers and facilitators to exercise and fulfilled the aims of the study.

SSc imposes disease-related barriers that, combined with general barriers, impede exercise engagement. People with SSc understand that exercise is potentially beneficial. Key recommendations and advice to counter these barriers include (a) ensuring a comfortable temperature to exercise, (b) using modified equipment (e.g., adjustable weighted straps), (c) individually supervising and modifying exercise as required, and (d) keeping people with SSc accountable and motivated to exercise. To improve our understanding

about the barriers, facilitators, and benefits to exercise in people with SSc, exercise trials using mixed methodology that captures both quantitative and qualitative outcomes, is recommended.

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