

Rheumatology Practitioners' View of Exercise in Adults With Systemic Sclerosis or Systemic Lupus Erythematosus

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ABSTRACT

Background: Exercise is part of the general recommendations for care of people with most arthropathies or connective tissue diseases, but it does not feature specifically in the clinical guidelines for management of systemic lupus erythematosus (SLE) and systemic sclerosis (SSc) by rheumatology practitioners. In this study, we sought to explore rheumatologists' (RHs') and rheumatology nurses' (RNs') perspectives and use of exercise interventions for adults with SLE or SSc.

Methods: Semistructured interviews were conducted with Australian RHs and RNs online using Zoom (video conferencing software). Interviews were transcribed verbatim, then coded and analyzed using NVivo for content analysis of themes.

Results: Seventeen participants completed the interviews (RHs n = 12, RNs n = 5). Five themes were identified: rheumatology practitioners perceive that (1) exercise is beneficial for adults with SLE or SSc, especially in managing fatigue, pain, and wellbeing; (2) exercise presents some general, structural, and disease-related barriers for adults with SLE or SSc; (3) rheumatology practitioners are confident in providing general exercise advice but lack time and confidence in prescribing exercise; (4) rheumatology practitioners' concerns about exercise are limited to those with heart and lung disease, inflamed joints, ulcerated fingertips, and severe contractures; and (5) to facilitate safe and attainable exercise, rheumatology practitioners recommend long-term, supervised, gradual, and affordable exercise options. There were no clear differences identified between the views of RNs and RHs.

Conclusion: Rheumatology practitioners require information and options for long-term and affordable exercise for adults with SLE or SSc that are supervised, individualized, and focus on a gradual progressive approach. *Journal of Clinical Exercise Physiology*. 2021;10(4):134–141.

Keywords: rheumatologists, rheumatology nurses, exercise physiologists, autoimmune disease, physical activity

INTRODUCTION

Systemic lupus erythematosus (SLE) and systemic sclerosis (SSc) are chronic autoimmune diseases grouped together in this research because they share similar clinical features including inflammation of joints and internal organs (1), disabling pain, mental deterioration, and debilitating fatigue (2,3), and subsequent physical inactivity, deconditioning,

and reduced health-related quality of life. There is also a higher risk of developing comorbidities such as osteoporosis (4) and atherosclerotic cardiovascular disease (CVD) (5).

People with SLE are less physically active than their healthy counterparts, with 60% of those with SLE not meeting the World Health Organization (WHO) recommendations of sufficient physical activity (6). Similarly, people with SSc are significantly less physically active than those

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without (1704 min/wk versus 2614 min/wk), and nearly three-quarters of people with SSc without pulmonary involvement are insufficiently active compared with only 27% age-matched controls (7). Joint stiffness and contractures, shortness of breath, fatigue, and pain have been identified as barriers for people with SSc to engage in exercise (8).

Regular moderate-intensity exercise appears to be safe and effective in adults with SSc (9) or SLE (10,11). Exercise is beneficial in reducing fatigue (10–14) and improving symptoms of depression (15,16), quality of life (15–17), and aerobic fitness (15) in adults with SLE. Comparably, exercise is effective in improving cardiovascular fitness (18–20), quality of life (9), muscle strength and function (20), and reducing fatigue (21) in adults with SSc. Exercise is part of general recommendations for care in people with most connective tissue diseases, i.e., cardiorespiratory and strength training is recommended as routine care in rheumatoid arthritis (22), with significant improvements in aerobic capacity, physical function, and fatigue (23). Benefits of exercise are similar in other rheumatic conditions with improvements in quality of life (17), reduced inflammation (1,24,25), and joint symptoms (25) and no evidence of worsening joint damage.

Despite these benefits, little is known of what rheumatology practitioners think about exercise or whether they recommend it routinely to their patients with SLE or SSc. This is valuable information to know, considering rheumatology practitioners are the primary care specialists for this population and the key source of health care information identified by their patients (26). The aim of this study is to understand how rheumatology practitioners view and discuss exercise with their SLE and SSc patients, potentially prompting the need for further research in exercise prescription for this population.

METHODS

This study was approved by the University of Southern Queensland (USQ) Human Research Ethics Committee (H20REA009).

Recruitment

Snowball sampling was used as the method for recruiting Australian rheumatology practitioners. Three investigators (SO, MC, SF) sent individual e-mails inviting known rheumatology practitioners to participate in this study, who were then encouraged to ask other known colleagues.

Participants

Demographic details, not obtained from the interviews, were extracted from the Australian Health Professions Registration Agency to categorize participants (Table 1).

Interviews and Data Collection

Fully informed written and verbal consent was obtained from all participants in this study. Twenty-minute semistructured interviews with consenting participants were completed between April 2020 and August 2020 and undertaken

Table 1. Participant characteristics.

Characteristics (Total n = 17)	Values
Years of practice (mean, range)	26.7 (8–49)
State of work within Australia (n)	
Tasmania	1
Victoria	2
Queensland	1
South Australia	1
New South Wales	12
Practice type (n)	
Hospital	5
Private practice	2
Hospital and private practice	10
Rheumatology practitioner focus (n)	
SSc and/or SLE	6
General or special interest in other conditions or not specified	6
Rheumatology nurse focus (n)	
SSc and/or SLE	2
General or special interest in other conditions or not specified	3
Sex (n)	
Female	10
Male	7

SLE = systemic lupus erythematosus; SSc = systemic sclerosis.

online using Zoom Video Communications, Inc. (San Jose, CA, USA) at the participants' preferred day and times. The principal investigator (SF) conducted all interviews, which were audio recorded, then transcribed verbatim using Otter (transcription software version number 2.3.36; Los Altos, CA, USA). All data were stored securely as per USQ's Research Data Management policy. Transcriptions were returned to the participants for memory checking, with a 2-week period allowed for review. For an unknown reason, 1 participant asked to withdraw their transcript and wrote a summary letter instead, consenting its inclusion in data analysis in lieu of the interview transcript. Sixteen finalized transcripts and the letter were used in content analysis and formed the dataset. Transcriptions were de-identified using alphanumeric codes to represent each participant (rheumatologists [RH] and rheumatology nurses [RNs]). Participants were recruited and interviews conducted until thematic saturation was reached (i.e., the point at which no new themes were elicited).

Data Analysis

All 16 finalized transcripts and 1 summary letter were uploaded into NVivo (scientific software Release 1.5.1 (940); QSR international, Melbourne, Australia) to facilitate content analysis of themes. Content analyses were undertaken by SF and

reviewed by co-investigator MC to ensure that the themes captured were not biased and that there was a fair representation of the matters raised in interviews. Key quotations from the transcripts were selected to illustrate major themes.

RESULTS

Participants

Seventeen participants completed the interviews (RHs $n = 12$, RNs $n = 5$). Of the 17 participants, 6 RHs and 2 RNs had a focused practice or special interest in SLE or SSc. The average years of practice of all participants was 26.7, ranging between 8 and 49. Ten participants worked in both hospital and private practice, 2 worked solely in private practice, and 5 worked only in the hospital. Twelve rheumatology practitioners were from New South Wales (NSW), 1 from Queensland, 2 from Victoria, 1 from South Australia, and 1 from Tasmania (Table 1).

Themes

Five common themes were identified, with no apparent differences between the views of RHs and RNs, practitioners from different states within Australia, or the number of years of practice. However, the practitioners with a focused practice in SLE or SSc seemed to address more barriers and safety concerns for their patients that were disease related i.e., resultant pulmonary fibrosis, pulmonary hypertension, and joint contractures. This was observed during the interviews and when SF and MC reviewed the participants' transcripts.

Theme 1: Exercise Is Beneficial for Adults With SSc and SLE

Common thoughts on exercise were mostly positive, with 1 participant summarizing, "If they comply with regular exercise, they generally just feel better in themselves (RH05)." Another participant stated, "I think exercise is good for everything, and exercise is really underrated (RN04)." Participants perceive exercise to have many benefits for adults with SSc and SLE, including improvements in energy, bone density, metabolism, sleep, muscular strength, cardiovascular health, joint range of motion, exercise tolerance, activities of daily living, blood flow and breathing, and reduced feelings of anxiety and depression.

When discussing exercise, most described low-impact and light-intensity exercise, giving examples such as walking and aqua aerobics. One participant stated, "People feel better after a bit of a workout, even a gentle one (RH08)." Exercise was identified to help patients lose weight, cope with their illness, provide a sense of empowerment, and encourage social wellbeing. One participant stated:

For a patient with chronic disease, I think it's even more important for them to exercise because, when they have joint pain, lung or heart involvement, having good baseline fitness and muscle strength makes it easier for them to cope with their illness (RH01).

Another participant commented, "Hand therapists/physiotherapists may have value in the vascular aspects of hand function in scleroderma by encouraging hand exercise and therefore blood flow (RH12)."

Theme 2: Exercise Presents Some Barriers for Adults With SSc and SLE

This theme appeared to divide into 3 subthemes: (a) general barriers, (b) structural barriers, and (c) disease-related barriers.

Participants perceived general exercise barriers as conflicting commitments in life, lack of motivation, cultural restrictions, not having exercised for a long time, reduced exercise capacity, and time of year or day (e.g., too cold). One participant commented that exercise is an active form of treatment requiring effort from the individual:

I find people are more ready for the passive type of treatment. They are more ready to see the podiatrist to cut their nails than they are to see an exercise physiologist, physiotherapist, or a dietician because they involve more active self-work (RH09).

Perceived structural exercise barriers included cost and limited sustainable, long-term exercise options for people with SSc and SLE. One participant stated:

I think the biggest barrier for exercise in [SSc] and [SLE] is that there is no system set up for these patients to continue exercise long term. . . I don't think the health system is properly set up to help patients get into good habits with exercise, especially in long term (RN04).

Disease-related barriers included pain and fear avoidance, with participants expressing that people with SLE or SSc fear that exercise may exacerbate their pain or disease. One participant stated, "Some people might just be worried that pain equals doing harm or damage (RH06)." Another participant stated:

It is certainly hard to get patients to engage in any sort of exercise whether it is physiotherapy or exercise physiologists led. Patients are often scared, and they are worried that they are going to do damage (RN02).

Other disease-related barriers included fatigue, physical deformities such as finger ulcerations or skin tightening, general malaise, breathlessness, and muscle weakness. One participant stated:

If somebody has quite significant symptoms, such as fatigue and other lupus or scleroderma-related symptoms, they're not going to be necessarily feeling up to exercise. . . (RH11).

The multifactorial nature of these diseases is a barrier to exercise, particularly in the early stages of being diagnosed:

When you are diagnosed with these severe diseases, it can be quite a life-changing event. I think patients

are overwhelmed. . . there is a lot of concentration on what medical therapy you are going to go on and preventing complications. . . exercise is probably down the list. . . it is not prioritized by the medical staff and maybe then less by the patients. . . trying to fit exercise into their life is probably difficult (RH07).

Theme 3: Rheumatology Practitioners Are Confident in Providing General Exercise Advice but Lack Time and Confidence in Exercise Prescription

Participants reported being confident in providing general advice on exercise to their patients such as goal setting and prescribing low-intensity exercise such as walking, stretching, and balance, but lacked time and sufficient knowledge on prescribing specific exercises. One participant stated, “. . . from a rheumatology perspective, time offers a big barrier (RH07).” Another said:

As [RHs], we are not well trained in knowing what specific program is good for what condition, but I think our role is to remind them to exercise, identify patients who are not exercising and then refer them on (RH01).

Another participant reported, “I wouldn’t be confident to give them an upper limb strengthening program, but I would be confident to [offer advice] on a regular walking program. . . (RH02).”

Some participants reported difficulties in discussing exercise with patients who have active disease because they need to prioritize disease management, and given the time constraint during a consultation, discussion of exercise may be missed. Exercise seems to be discussed when disease is well controlled. One participant explained:

For someone with [SSc], if they have terrible skin involvement and worsening skin disease and shortness of breath from lung disease, exercise is hard to introduce as a major component before you’ve treated those manifestations (RH02).

Some participants reported that there is a lack of evidence or knowledge of evidence on exercise in SSc and SLE, “I don’t really have full evidence on the role of exercise in these 2 diseases or what would be the best type of exercise. . . (RH11).”

Hospital-based participants tend to refer patients to in-house-physiotherapists, pulmonary rehabilitation, or heart failure programs, and private-based participants tend to refer to private physiotherapists or accredited exercise physiologists (AEPs) in the community.

Most practitioners asserted value in exercise for their patients, however, sought support with exercise information. One participant suggested, “I think some guidance specifically around exercise. . . , even if it’s leaflets or some practical steps to get people started [with exercise] or how to use an exercise physiologist. . . (RH09).” Another stated, “I

think there is probably a role for education. . . on the role of exercise physiology with our patients. . . (RH07).”

Theme 4: Limited and Specific Disease-Related Concerns for Exercise

Most participants did not view exercise as problematic for adults with SLE or SSc. One participant stated, “I wouldn’t have any concerns that exercise would exacerbate the disease (RH07),” and another confirmed, “At times, some people are worried that exercise might make their disease worse, and I would say, to the contrary, exercise is good (RH08).”

Most participants emphasized the importance of individualization and supervision because of the heterogeneity of SLE and SSc. One participant indicated, “My concern is the types of exercises that they’re doing. . . for those with aches and pains, high-impact exercises might not be well tolerated and could make their pain worse (RH04).” Another explained, “The main concern is that we have guidance for these patients and that they can feel like they’re exercising in a safe environment (RN02).”

Awareness of exercise environment was frequently raised:

. . . if somebody wants to go to the park to exercise, sunlight exposure could be a concern for them, as they might get a [skin] rash, or winter colds might set off Raynaud’s syndrome (RH06).

Another participant explained, “. . . with Lupus, [ultra-violet] can activate the illness, not only just cutaneous, but systemically. . . (RH08).” Another participant asserted, “I’m not wanting patients with Raynaud’s to go running in the cold (RH11).” Further, participants advised that those with necrotic or ulcerated fingertips avoid exercising in water to minimize infection risk.

Participants raised concerns for those with severe disease manifestations, including pulmonary hypertension, pulmonary fibrosis, interstitial lung disease, severe skin and joint contractures, inflamed joints, and ulcerated fingertips and toes. One participant stated, “. . . if [patients] have inflammation in their joints, that can affect the proprioception of the joints, and they are more likely to injure themselves (RH04).” Another participant asserted:

We know pulmonary hypertension is a serious condition. . . and for that reason, vigorous exercise training or exercise that is not monitored is not suitable for these patients because they are risk of arrhythmias and death (RH09).

Another reported:

The patients that you want to be more careful with exercise are usually the ones who have had it for a long time and who have some limitations such as lung disease or pulmonary hypertension, where their oxygen saturation may not be 100% (RN04).

Theme 5: Facilitation of Exercise

Practitioners see value in sustained exercise, suggesting, “. . . exercise really does need to be long term; exercise needs to be forever to improve and maintain their function, flexibility, strength, and fitness. . . exercise is a treatment (RN04),” and yet they understand that exercise presents some barriers for people with SLE or SSc. Participants suggested strategies to facilitate safe and achievable exercise with the support of their medical and allied health care team.

Supervision during exercise was particularly favored. One participant said:

. . . patients with diffuse [SSc], with body wide involvement, need more guidance, supervision, and support with exercise. . . I do think supervision would be important, particularly if they had lung disease as well (RN05).

Another participant suggested that exercise could be facilitated by “. . . having a group of allied health [practitioners] who are versed in [SSc] and particular strategies to help those patients (RH07).” Another participant said, “. . . [patients] need to increase [their] exercise in a sensible way, and under supervision is best (RN04).”

Participants identified choices that adults with SLE or SSc could make themselves to facilitate exercise, including those with SSc could choose warmer periods of the day and locations where they feel warm, safe, and comfortable to exercise, and those with SLE could choose times of the day when ultraviolet light is low for outdoor exercise. Pacing and selecting achievable exercises were identified as key self-management strategies, “It’s a matter of getting them to do exercises that they can manage (RH05).” One participant explained, “We usually tell [patients] to pace it throughout the day and accept bad days as ‘bad days’ and to work with their bodies instead of against them (RN03).” Another participant recommended “. . . making sure [patients] are resting properly, not going too hard, and not doing anything [they] are not comfortable with (RN04).”

Following advice from rheumatology practitioners in this study, key recommendations for exercise practitioners working with adults with SLE or SSc have been summarized in the Box.

DISCUSSION

Exercise prescription is not a substantial component of the training required by rheumatology practitioners, with participants acknowledging a lack of expertise in this area. We suggest that multidisciplinary care teams (e.g., RH led and including clinical exercise physiologists and other exercise practitioners) could be ideally constructed to offer support to each other in education and referrals. We recommend that multidisciplinary care teams ensure that they are collaborative, communicate well, and reduce burdens such as repetition of tasks on patients. Schouffoer et al. (2011) identified the needs and preferences of health care delivery perceived by people with SSc and found that most people (75%) identified their RH as their key source of health care information (26),

BOX. KEY RECOMMENDATIONS FOR EXERCISE PRACTITIONERS WORKING WITH PEOPLE WITH SYSTEMIC LUPUS ERYTHEMATOSUS OR SYSTEMIC SCLEROSIS

- Exercise should be long term and sustainable.
- Exercise should be structured with an appropriate dose for the individual and progressed using a graded approach. Given the scarcity in evidence on the safety of high-intensity exercise, commence with low to moderate intensity, and progress accordingly and within the individual’s limits.
- Closely monitor physiological responses during exercise through heart rate or rating of perceived exertion, while modulating an appropriate dose (frequency, intensity, timing, and type) to promote physiological change.
- Exercise should be individually supervised by exercise practitioners (e.g., clinical exercise physiologists) who are versed in systemic sclerosis (SSc) or systemic lupus erythematosus (SLE). As this may not always be the case, it is suggested to actively familiarize oneself with information about these diseases. Some online resources include <https://arthritisaustralia.com.au/types-of-arthritis/lupus-systemic-lupus-erythematosus/> and <https://www.sclerodermaustralia.com.au/>.
- For adults with SLE, exercise should be performed during times of the day when ultraviolet rays are lower. It is suggested to use Websites and apps such as <https://www.sunsmart.com.au/uvalert/> to keep up to date about the current ultraviolet light wherever you are located.
- For adults with SSc or SLE who experience Raynaud’s phenomenon, exercise should be performed in temperate environments, and avoid times of the day or places when and where it is too cold.
- For adults with SSc who experience digital ulcerations, it is advised to avoid engaging in water-based exercise where they could be exposed to infections.
- For adults with SLE or SSc with joint pain or contractures, it is advised to avoid high-impact exercise that may exacerbate their pain.
- For adults with SSc that experience sclerodactyly (curling of the fingers), it is suggested to use exercise equipment such as ankle or wrist straps as an alternative to handheld weight to still encourage resistance training.
- It is important that exercise prescribed for someone with SLE or SSc is comfortable, and they should be advised to take adequate rest breaks when necessary and pace themselves appropriately.

emphasizing the importance of RHs being versed in exercise and being part of a multidisciplinary team inclusive of exercise practitioners, particularly clinical exercise physiologists.

During the interviews, participants offered innovative ideas on ways to engage adults with SLE and SSc in exercise. One participant suggested “. . . monthly support groups, and instead of sitting down and having coffee, they have a warm room and perform a fun exercise program together (RN05).” There is currently a support group in Australia called “Café conversations” led by the Autoimmune Resource and Research Centre and another Sydney-based support group led by Scleroderma NSW. These current support groups could be an opportunity for exercise practitioners to lead safe, achievable, and affordable exercise for people with SLE or SSc.

Despite individualized and supervised exercise being the preferred model of care for people with SLE or SSc by participants in this study, cost was addressed as a potential barrier. In Australia, where our study was undertaken, clinical exercise physiology and physiotherapy services are available in both the private and public health settings. Gym services do not attract public health funding. Comparative average costs are \$65 (\$48 in US currency) per month for open access to a gym for independent, unsupervised exercise (27) or \$70+ (\$52 in US currency) for an individual exercise session with an AEP (28). Although open gym access appears the most affordable option, it generally does not include individualized supervision or exercise prescription, and it is not usually within the scope of practice of a fitness instructor to prescribe exercise to manage medical conditions. However, individually supervised exercise sessions several times per week by a clinical exercise physiologist or physiotherapist can be an economic burden on people who already require substantive clinical care and may not command a full-time income.

Nguyen et al. (2010) conducted a cross-sectional survey of 87 ($n = 72$ female) individuals with SSc in France to assess employment status and socioeconomic burden of disease; 60.9% of adults with SSc were on full-time sick leave, and 35.6% received disability pensions. Sick leave was associated with poor health status, and receiving a disability pension was associated with decreased income (29). Most disability pensions do not constitute 100% wage replacement, and when people cease working, it is often because they require increased clinical care, which may come at increased cost.

Exercise can be an effective tool to treat fatigue (11–14,21) and improve quality of life (9,10,15,17) in people with SLE or SSc; however, in most studies, exercise interventions were undertaken at moderate to high intensity, while people with SLE or SSc in these studies had low to mild disease activity or a different disease type. For example, high-intensity interval training (HIIT) was found to improve microvascular function in those with limited cutaneous SSc experiencing Raynaud’s phenomenon (18). Questions remain as to whether those with diffuse SSc are safe, willing, and comfortable enough to perform HIIT. Low- to moderate-intensity continuous or interval training could be an effective strategy to sustain long-term exercise; however, it is unlikely to drive physiological change. As such, a skilled clinical exercise physiologist can closely monitor physiological

responses during exercise, while modulating an appropriate dose (frequency, intensity, timing, and type) to promote physiological change.

Due to COVID-19 restrictions in Sydney, Australia, we modified our intended method of recruitment and conduction of interviews. We had originally planned to recruit and interview participants during the 2020 Australian Rheumatology Association annual scientific meeting; however, the conference was cancelled, and we resorted to snowball recruitment through e-mail, and subsequent online interviews with Zoom online conferencing software. We anticipated that a 20-minute interview could be scheduled into a practitioner’s clinical roster without being overly burdensome. Our consideration of practitioners’ time was appreciated when COVID-19 pandemic was affecting Australia because practitioners were particularly busy at this time. A possible limitation of snowball recruitment is that it is likely to result in selection bias, as we may have unintentionally selected participants who share the authors’ views on exercise. Future studies that use similar methods could be externally validated by other rheumatology practitioners to see whether they agree with the presented views. Online interviews are becoming increasingly common as both a cost-effective method and opportunity to recruit geographically distant participants (30); however, conducting interviews online poses some limitations including not being able to respond easily to participants’ body language and emotional cues as well as technological difficulties (31).

CONCLUSIONS

Rheumatology practitioners highly value exercise for people with SSc or SLE, with many perceived benefits, some specific barriers for exercise engagement, and limited safety concerns specific to their disease. Rheumatology practitioners offer recommendations to facilitate safe exercise for people with SLE or SSc and express the potential for exercise practitioners to provide more information and options for their patients to engage in long-term and affordable exercise that is supervised and individually tailored.

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Study Conception and Design: Stephanie Frade, Dr Melainie Cameron, Dr Sean O’Neill, Dr David Greene.

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