ABSTRACT 1

Higher Resource Utilization in Systemic Sclerosis Complicated by Digital Ulcers

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Status of presenting author: Resident

Abstract:

Background:
Digital ulcers are present in half of the patients with systemic sclerosis and require medical interventions for treatment and monitoring of possible complications which can include infections.

Objective:
We investigated the impact of digital ulcers on resource use including hospitalizations, outpatient visits and procedures within a large systemic sclerosis Canadian cohort.

Methods:
1698 systemic sclerosis patients who completed one or more 84-item Resource Utilization Questionnaire for a 12-month period between September 2005 and February 2020 were included (9077 questionnaires). We assessed the extent of organ involvement by disease severity scores using the Medsger scale.

Results:
Questionnaires in 104 systemic sclerosis patients with active digital ulcers at two consecutive annual visits were compared with 104 patients without digital ulcers. Patients were matched in a 1-to-1 format for age, sex, disease subtype and duration. Over one-year, digital ulcers were associated with a higher number of tests ($p<0.05$) and visits to health professionals, especially to a rheumatologist ($p<0.0001$) and internist ($p=0.003$), a greater need for an accompanying person ($p<0.05$) and aids purchased or received ($p<0.05$). Having digital ulcers was associated with more severe disease, even after excluding the peripheral vascular domain from total disease severity scores (9.7 ± 4.5 vs 5.6 ± 2.7, $p<0.0001$).

Key Messages for Patients:
Patients with digital ulcers used significantly more medical resources per year even when taking disease severity in other organ systems into account. Although uncertain, it is possible that treating digital ulcers optimally may decrease the medical resources used.

ABSTRACT 2

Talking to participants and peer-leaders to find out what they thought of the SPIN-CHAT Program, a videoconference-based supportive care program

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Status of presenting author: Medical student and research assistant

Abstract:

Background and Objective: The 'Scleroderma Patient-centered Intervention Network COVID-19 Home-isolation Activities Together' (SPIN-CHAT) Program was developed to protect mental health in people with scleroderma at the beginning of the pandemic. The program provided professionally sourced mental health education (delivered by healthcare professionals) and was facilitated by trained peer-leaders. A study assessed the effect of the SPIN-CHAT Program on mental health. There was no change in mental health immediately after the program, but small improvements in symptoms of anxiety and depression 6 weeks later. Attendance to the program was very high. We decided to conduct this follow-up study to talk to participants and peer-leaders in the program to understand what they liked and disliked.

Methods: We invited a subset of participants and all peer-leaders from the SPIN-CHAT Program to take part in videoconference-based interviews. We audio recorded the interviews and afterwards wrote them out word-for-word. We then explored all interview comments and summarized what participants and peer-leaders liked and disliked about the program.

Results: Thirty SPIN-CHAT participants and 12 peer-leaders shared their thoughts about the SPIN-CHAT Program. Participants and peer-leaders said that the SPIN-CHAT Program helped lower feelings of anxiety, stress, loneliness, and boredom and improved mood. Being around other people with scleroderma, and learning more about scleroderma, COVID-19, and mental health helped participants feel better during the program. For the most part, participants enjoyed the leisure activities, education sessions, and group discussions. Peer-leaders appreciated the training they received and felt it gave

them confidence to facilitate the program. Participants and peer-leaders also identified important areas to consider for improvement. For example, the leisure activities were described as not always being accessible to everyone, and so there is a need to choose a broader range of activities suitable for all abilities. As well, peer-leaders said that they would have liked access to ongoing peer-leader training to manage complex group dynamics, and further support during the program (e.g., a co-peer-leader or someone they could share the role with).

Key Messages for Patients: Our follow-up study helps us to better understand what participants and peer-leaders liked and disliked about the SPIN-CHAT Program. The program was well-liked, and participants and peer-leaders shared that the program may have protected mental health at the beginning of the pandemic. Considering participant accessibility to online group activities, and how to better support peer-leaders who facilitate such programs, is important for continued delivery of a successful SPIN-CHAT Program.

ABSTRACT 3

Two Year of Anxiety and Depression Symptoms Prior to and During COVID-19: A Scleroderma Patient-centered Intervention Network (SPIN) Cohort Study.

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Status of presenting author: Fellow

Abstract:

Background and Objective: COVID-19 has harmed mental health. However, only small changes were found in mental health symptoms early in the pandemic for individuals with rheumatic disease. For individuals with systemic sclerosis (SSc), anxiety spiked early in COVID-19. Since then, we have seen more waves of COVID-19, the rise of variants, reinfection concerns, scaling back of restrictions, and increased access to COVID-19 vaccinations and treatments. All of these could impact mental health and

pose new challenges. We display levels of anxiety and depression symptoms for individuals with SSc from late 2019 through March 2022.

Methods: From April 9 to April 27, 2020, we recruited individuals into the Scleroderma Patient-centered Intervention Network (SPIN) COVID-19 cohort. Out of 800 individuals with SSc, 435 had pre-COVID-19 anxiety or depression data from the larger SPIN Cohort. Participants filled out surveys every two weeks initially, and then every 4 weeks. We graphed the anxiety and depression symptoms from pre-COVID-19 through March 2022.

Results: Anxiety symptoms spiked from pre-COVID-19 to April 2020. Anxiety symptoms decreased after this spike and remained at the pre-COVID-19 level through March 2022. Depression symptoms did not change from pre-COVID-19 to April 2020 but then were slightly lower than pre-pandemic levels. Patterns of anxiety symptom did not differ when looking at age, sex, country, and SSc subtype.

Interpretation: Anxiety symptoms spiked early during the COVID-19 pandemic, then returned to pre-COVID-19 levels. Depression symptoms did not see a large increase and then dropped slightly lower than the pre-pandemic level. These are collective patterns. Some people with SSc may be facing new mental health challenges as a result of COVID-19. This is especially true as the world enters a new stage of the pandemic. This brings new challenges including for mental health, managing health care, employment and financial well-being, and social pressures.

ABSTRACT 4

Effects of non-pharmacological interventions on outcomes important to people with scleroderma: An evidence summary

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Status of presenting author: Master's student

Abstract:

Background:
No known cure exists for scleroderma. Therefore, a primary care goal is to reduce disability and maximize health-related quality of life. Non-pharmacological and non-surgical interventions may potentially improve quality of life in scleroderma. As the name implies, these include any types of interventions that do not have a pharmacological or surgical component to them. Examples include psychological, educational, rehabilitation, physiotherapy, dentistry, and diet/nutrition interventions. Recently, several large clinical trials of different non-pharmacological and non-surgical interventions in scleroderma have been published, and many are in progress. However, people with scleroderma do not typically have access to these trial results or the necessary scientific background to understand them and apply them to make decisions. Similarly, most health care providers cannot readily synthesize all that is known and present it to patients in an easily comprehensible, patient-friendly format. This poses a significant barrier to the shared decision-making process that should be happening between scleroderma patients and their health care providers about attempting or not attempting such interventions. In addition, single trials, on their own, tell only part of the story, and do not typically provide the evidence needed for decision-making. Rather, high-quality reviews, reviewing all available trial results, are needed.

Objectives:
To address these gaps, we aimed to: (1) conduct a rigorous, continually updated "living systematic review" of all trials evaluating the effectiveness of non-pharmacological and non-surgical interventions

in scleroderma and (2) continually disseminate results in a patient-friendly way to support shared decision-making in clinical practice.

Methods:
First, we will conduct a regularly updated "living systematic review" of all trials evaluating the effectiveness of non-pharmacological and non-surgical interventions in scleroderma. Second, as we update our review, we will create a patient-friendly website featuring easily comprehended and engaging information on results from our review. Importantly, we will actively collaborate with patient and health care provider members of our team to design the website.

Results:
Results are still in progress but will be made available at the conference.

Key Message for Patients:
This project was selected as a priority by our patient partners, who will be involved in all stages of the project. It will address a critical patient need and will be conducted using robust and rigorous methods. As we update our review, we will engage in continually updated dissemination strategies with the goal of translating our results into clinical practice to support shared decision-making between scleroderma patients and their health care providers.

ABSTRACT 5

Testing the effectiveness of the Scleroderma Patient-centered Intervention Network Self-Management (SPIN-SELF) Program: Empowering patients to improve their scleroderma management skills

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Status of presenting author: Clinical research coordinator

Abstract:

Background and Objective:
Self-management programs can help people with chronic diseases become better at managing their disease and improving their quality of life. Currently, there are few self-management programs available to people living with scleroderma. To address this need, we collaborated with patient organizations and experts in scleroderma research to develop the Scleroderma Patient-centered Intervention Network Self-Management (SPIN-SELF) Program. The SPIN-SELF Program includes 9 online educational modules that focus on helping participants improve their self-management techniques related to different areas (e.g., managing fatigue issues, managing pain, coping with emotions and stress etc.). We feasibility tested this program in 2019 as a self-learning online program, but few people used the modules on their

own. Since then, SPIN has delivered successful programs through videoconference groups. These include a COVID-19 mental health support program and an education and training program for support group leaders. We've updated the SPIN-SELF program to include 8 videoconference group sessions, in addition to the online educational modules, to allow participants to share their experiences with self-management with their peers and support each other to accomplish goals. We are currently testing this reformatted SPIN-SELF Program in a trial. We will evaluate the effect of the SPIN-SELF Program on disease management self-efficacy, or confidence in taking care of personal health challenges (primary outcome), as well as other emotional (e.g., anxiety) and physical health outcomes (e.g., physical activity, pain).

Methods:
We are actively recruiting participants from the SPIN Cohort and through social media to take part in the ongoing SPIN-SELF trial. We are currently feasibility testing the reformatted SPIN-SELF program, and we will be progressing to a full trial in the Fall 2022. Participants are randomly assigned either to the intervention group, where they access the online modules and take part in videoconference sessions, or to a control group, where they are placed on a waiting list. Participants in the waiting list can access the online program at the end of the study.

Results:
Pending; this trial is ongoing.

Key Message for Patients:
Developing disease-management skills can improve quality of life, particularly in a rare disease context. The SPIN-SELF Program may improve disease management self-efficacy, as well as emotional and physical health outcomes in people living with scleroderma. At the end of the trial, SPIN will work with partner patient organizations in Canada and around the world to make the program available free-of-charge.

ABSTRACT 6

Effectiveness of the Scleroderma Patient-centered Intervention Network Support Group Leader EDucation (SPIN-SSLED) Program Among Scleroderma Support Group Leaders

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Status of presenting author: Patient Advocate

Abstract:

Background and Objectives:
Many people with scleroderma rely on peer-led support groups to learn about scleroderma for support. Peer support groups may increase healthy behaviors, confidence in managing one's disease and mental health. However, accessing support groups can be difficult, and some do not meet participants' needs or are not sustained due to challenges that could be addressed by training support group leaders. The Scleroderma Patient-centered Intervention Network Scleroderma Support group Leader EDucation (SPIN-SSLED) Program was designed to educate experienced leaders and people interested in leading a support group on how to organize, lead, and grow a support group. The aim of this study was to evaluate the effectiveness of the SPIN-SSLED Program.

Methods:
SPIN partnered with scleroderma patient organization leaders, leaders of support groups, patient advisory team members, and researchers to develop the SPIN-SSLED Program. The SPIN-SSLED Program is a 3-month weekly group videoconference training program. People participating in the study were experienced or interested support group leaders recruited from scleroderma patient organizations. To evaluate the effectiveness of the SPIN-SSLED Program, participants were randomly divided into two groups; one group received the SPIN-SSLED Program and the other group did not. Those that did not could receive the training after the trial.

Results:

A total of 148 experienced or candidate leaders participated. Over 90% attended at least 10 of 13 sessions. Overall, participants' satisfaction with the program was high. The program improved support group leader self-efficacy, which is the leader's confidence that they have the knowledge and skills to successfully carry out important leader tasks. It also improved their satisfaction that they were benefiting others and reduced emotional distress. Interestingly, participants who were already experienced as leaders were more satisfied that their role as a support group leader benefited others.

Key Message for Patients:
Peer-led support groups are used by people with scleroderma around the world. The SPIN-SSLED Program is the first evidence-based leader training program for people with any medical condition in the world. The SPIN-SSLED Program increased participants' confidence in their ability to perform their role as leaders. A key benefit for people who completed the program was that additional training support was made available after the program ended. Based on the positive results, the SPIN-SSLED Program is being provided on an ongoing basis through SPIN's partnership with its scleroderma patient organization partners. The SPIN-SSLED Program is now mandatory for support group leaders in some scleroderma patient organizations.

ABSTRACT 7

More Effective Ways to Engage Patients in Scleroderma Research: A Scleroderma Patient-centered Intervention Network (SPIN) Project

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Status of presenting author: Postdoctoral fellow

Abstract:

Background and Objectives
Working with patients to plan, conduct, and communicate research is important to improve the quality and usefulness of research. The Scleroderma Patient-centered Intervention Network (SPIN) collaborates with more than 20 patient organisations worldwide and engages patients in research to improve the lives of people with scleroderma. SPIN's work in patient engagement is limited by a lack of proof on the most effective ways to engage patients. To address this gap, SPIN launched a 'Patient Engagement Project' to develop better ways to engage patients in scleroderma research that reflects patients' preferences. This will maximise SPIN's ability to produce meaningful patient-oriented research. The

objectives are to: (1) increase knowledge on ways to effectively engage patients in scleroderma research; (2) identify best methods for sharing scleroderma research to patients and stakeholders; (3) improve the quality of patient engagement in SPIN.

Methods

There are three key activities: (1) Evidence synthesis: this gathers information from various sources to show what is currently known on strategies for engaging patients in research and advantages/disadvantages of these strategies; (2) Knowledge Translation: this involves a series of trials to determine what methods for sharing information (e.g., lay abstracts, infographics, podcasts) are most engaging, easily used, and easily understood by patients with scleroderma; (3) Program Development and Evaluation: this brings together people with scleroderma, patient organisation leaders, researchers, and clinicians to develop a framework for patient engagement in SPIN based on the evidence collected.

Expected Results

To our knowledge, this project is the first to work in partnership with patients to develop a strong model for patient engagement in health research. We expect this project will provide evidence on how to best engage patients in health research. The results can be used to advise researchers on how to effectively engage patients in research on scleroderma and other diseases.

Key Message for Patients

It is important that patients have a voice in health research, to improve the usefulness and quality of research and the accessibility of results. This project will provide up-to-date, practical, evidence-based guidance on how to best engage patients with scleroderma in research about their health. This will help to maximise the quality of research in scleroderma and improve the translation of research to clinicians, organisations, and patients, which will improve knowledge and health outcomes. Patients who are interested in participating in this project or in SPIN research more broadly are encouraged to contact the researchers.

ABSTRACT 8

Reviewing Research Evidence on Oral Health in Scleroderma

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Status of presenting author: Student

Abstract:

Background: Oral health is a critical component that contributes to the quality of life of people with scleroderma. People with scleroderma experience a range of oral health problems. These include changes in the appearance of the mouth, limited mouth opening, gum and tissue changes, and other problems. Unfortunately, little systematic, high-quality research has been done on oral health in scleroderma. The limited research on oral manifestations and lack of care resources makes oral self-care difficult and reduces the ability to obtain appropriate dental care. To identify areas of oral health where we have quality research and to identify gaps where research is needed, we reviewed existing research.

Methods: We searched 4 medical publication databases to identify articles on oral health of people with scleroderma. We recorded information from each study. After that, we classified each article as related to prevalence (how common a symptom is), comparing people with scleroderma to healthy people or people with another disease, evaluating factors associated with the oral health problems, or testing scleroderma oral health treatments.

Results: We found 77 relevant publications. Most articles included too few individuals with scleroderma to draw conclusions with confidence, and there were no studies with even 200 people with scleroderma. There was a series of eight studies from the Canadian Scleroderma Research Group (CSRG) with more than 150 people in each. The CSRG found that 63% of participants reported a subjective feeling of oral dryness, 38% had widening of the ligaments that anchor teeth to the jaw, and 11% had full dentures. These identified many factors associated with poor oral health in scleroderma, such as overall disease severity, number and space between teeth, and saliva production. People with scleroderma had more missing teeth, greater gum erosion, and more often had periodontal disease compared to people without scleroderma. The studies concluded that worse oral health significantly impacts quality of life and psychological outcomes in individuals with scleroderma. No high-quality interventions to prevent or reduce oral health problems were found.

Key Messages for Patients: There is a need for well-designed and conducted studies on oral health in scleroderma so that evidence-based care guidelines can be developed. Meanwhile, patients can discuss with their doctors how to find a qualified dentist with experience in scleroderma and can refer to patient-friendly resources on dental care in scleroderma.

Depression and Anxiety in People with Scleroderma: A SPIN Study

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Status of presenting author: Master's student

Abstract:

Background: Depression and anxiety are common and reduce quality of life for many people with scleroderma. However, there are few studies that have examined factors linked to depression and anxiety in scleroderma. The goal of this study was to identify personal (e.g., age, sex, education) and disease factors (e.g., gastrointestinal involvement, itch) associated with symptoms of depression and anxiety among people with scleroderma.

Methods: Participants in the Scleroderma Patient-centered Intervention Network (SPIN) Cohort completed depression (Patient Health Questionnaire-8) and anxiety (Patient-Reported Outcomes Measurement Information System - Version 2) questionnaires when they first enrolled in the Cohort. We used a statistical model to examine associations of personal and scleroderma disease variables, plus overlap syndromes (e.g., rheumatoid arthritis, Sjogren's syndrome) with depression and anxiety, separately.

Preliminary Results: 1501 participants were included in the depression analysis. The majority were White (82.4%) and female (87.8%) with an average age of 55 years. Higher levels of depressive symptom scores were associated with personal factors (younger age, smoking, higher alcohol consumption, higher body mass index, less exercise), scleroderma disease factors (more small joint contractures, more gastrointestinal involvement, more severe itch), and having rheumatoid arthritis overlap. 1515 participants were included in the anxiety analysis. Higher levels of anxiety symptoms were associated with personal factors (younger age, smoking, higher body mass index) and scleroderma disease factors (more gastrointestinal involvement, less time since scleroderma onset, more severe itch). All links between personal and disease characteristics and anxiety or depression, however, were very small. Anxiety and depression symptoms were not associated with sex, marital status, race or ethnicity, country, education level, disease subtype (limited versus diffuse), digital ulcers, tendon friction rubs, small joint contractures, history of renal crisis, pulmonary arterial hypertension, Sjogren's syndrome, idiopathic inflammatory myositis, primary biliary cirrhosis or autoimmune thyroid disease.

Key Messages for Patients: Many factors are associated with symptoms of depression and anxiety, but the link between any one factor and those symptoms is small. Thus, there is no way to predict who might have depression or anxiety from personal characteristics or disease severity. People with scleroderma who are concerned that they may have depression or anxiety should discuss their concerns with their health care provider.

ABSTRACT 10

Anxiety and depression in people living with systemic sclerosis: did anything change after the COVID-19 pandemic began?

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Status of presenting author: PhD candidate

Abstract:

Background: The COVID-19 pandemic was a tough time for people around the world. People living with chronic disease may have felt more anxious or depressed after the pandemic started. Past research has shown that the pandemic negatively affected the mental health of people living with systemic sclerosis (SSc).

Methods: We used data from the Scleroderma Patient-centered Intervention Network (SPIN) study. All participants were diagnosed with SSc before they joined the study. Participants answered online surveys every few months. These surveys started before the COVID-19 pandemic began and went on until December 2021. We measured anxiety and depression levels based on how participants answered the surveys. We used statistical models to look at how anxiety and depression changed. We were interested to see if there were any big changes after the COVID-19 pandemic started. We also wanted to know if the effects of factors such as age and gender changed after the start of the pandemic.

Findings: 1,315 participants were included in our study. Half of participants were in the study for at least 4.5 years. There was an increase in anxiety levels at the start of the pandemic. Depression levels did not increase. On average, older participants with more education and higher alcohol use experienced greater increases in anxiety over time after the pandemic started. How anxiety levels changed was different by country where participants lived.

Key Message for Patients: Study participants had higher levels of anxiety but not depression once the pandemic started. There were large differences in how their anxiety changed during the pandemic. Age, alcohol use, education, and country affected people's anxiety differently after the pandemic began. These findings of this study are meaningful because they can show patients how individual mental health experiences may be very different. These findings also highlight how lots of different factors may affect mental health during difficult times such as the COVID-19 pandemic.

ABSTRACT 11

Self-Efficacy to Manage Chronic Disease in Scleroderma: A Scleroderma Patient-Centered Intervention Network (SPIN) Study

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Status of presenting author: Doctoral student

Abstract:

Background and Objective: Self-efficacy is an individual's confidence in their ability to perform actions to achieve a certain goal, such as managing the challenges associated with a chronic disease. Self-efficacy is important to study because it is a strong predictor of health behaviors (e.g., exercise, sleep) that are part of chronic disease management. Self-management programs aim to increase self-efficacy, which can help patients to improve their quality of life. The purpose of this study was to describe self-efficacy in adults with scleroderma (SSc) and its relation to demographic (e.g., age) and health-related (e.g., pain, fatigue, anxiety) outcomes.

Methods: Persons with SSc who were enrolled in the SPIN Cohort completed study questionnaires in English or French, including the Self-Efficacy to Manage Chronic Disease Scale (SEMCD). The SEMCD contains 6 items rated on a scale from 1 (not at all confident) to 10 (totally confident). Participants report how confident they feel in their ability to manage fatigue, physical discomfort/pain, emotional distress, and other symptoms; to manage their disease to minimize the number of medical visits; and to manage their disease with approaches other than medication. Participants also completed questionnaires that measured aspects of their health (physical function, anxiety, depression, fatigue, sleep disturbance, social participation, pain) and disability (difficulty with completing daily activities such as dressing, grooming, eating, walking).

Results: A total of 2,159 persons with SSc were included in the current study. On average, participants reported moderate levels of self-efficacy on the SEMCD (average total score = 6.5). We found that levels of self-efficacy were similar across language (English and French) and sex (female and male). However, we found that participants who were older and had limited SSc reported higher levels of self-efficacy than people who were younger and had diffuse SSc. Our study showed that participants with higher levels of self-efficacy also reported higher levels of physical function and social participation, and lower levels of anxiety, depression, fatigue, sleep disturbance, pain, and functional disability.

Key Message for Patients: Self-efficacy, a patient's belief that they do things that will change their disease experience, is an important factor in successful management of SSc. Increasing self-efficacy may help patients to improve their health and quality of life. This may be particularly important for younger patients and those with more severe disease. In order to improve their sense of self-efficacy and learn ways to better manage their scleroderma, patients can consider: participating in self-management programs (e.g., SPIN-SELF Program; Self-Management Resource Center, which also offers a mailed tool kit of a self-guided version of the Chronic Disease Self-Management Program), engaging in problem solving therapy with a mental health professional, setting goals around important health behaviors (e.g., exercise, nutrition, medication management), and reaching out for support from their loved ones and healthcare team. Patients may also use the SEMCD to measure their own self-efficacy and monitor any changes over time.

ABSTRACT 12

Characteristics Associated with Loneliness for Patients with Systemic Sclerosis during the COVID-19 Pandemic: A Scleroderma Patient-Centered Intervention Network Cohort Study

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Abstract:

Background and Objective: Individuals with scleroderma frequently experience loneliness due to challenging symptoms such as fatigue and frailty, which make it more challenging to participate in social and work-related interactions. Loneliness can worsen anxiety and depression symptoms, making it an important issue to address. This is an especially pressing issue because of the consequences of COVID-19 for immunocompromised patients. For example, individuals with scleroderma face increased COVID-19 related risks due to factors such as higher rates of interstitial lung disease, resulting in an increased

likelihood of isolating from others. This study sought to characterize experiences of loneliness for individuals with scleroderma during the COVID-19 pandemic.

Methods: Participants were enrolled in the SPIN COVID-19 sub-cohort. To measure loneliness, participants completed the UCLA Loneliness Scale-6 item (ULS-6). The ULS-6 contains 6 items that participants rate on a scale from 0 to 18, with higher scores indicating greater loneliness. Participants also completed questionnaire that measured factors that might relate to loneliness, such as depression, social support, and number of social conversations on a typical day in the past week). Further, information was collected on participant demographics (ethnicity, marriage status, employment, age, number of people living in one's household, country) and clinical factors (years since diagnosis, diffuse vs. limited disease).

Results: This study used findings from 775 adults with scleroderma. The average score on the ULS-6 was 7.00, suggesting moderate levels of loneliness. We found that levels differed between English and French speakers, with English speakers reporting greater loneliness. We also found that participants with diffuse subtype of scleroderma, higher levels of depression, less social support, and fewer conversations with multiple people in a day tended to have greater levels of loneliness. Interestingly, participants who had fewer conversations with one person in a typical day did not tend to be lonelier. Additionally, contrary to expectations, married individuals tended to be more lonely than non-married individuals.

Key Message for Patients: Loneliness is an important issue that individuals with scleroderma may face, especially as a consequence of the COVID-19 pandemic. It is valuable to understand what might increase or decrease loneliness in order to better support patient experiences as society continues to navigate COVID-19 related burden. Our findings provide helpful insights for future studies that can explore loneliness more deeply and potentially develop programs to reduce loneliness in individuals with scleroderma.