

Challenges and Strategies for Coping with Scleroderma: Implications for a Scleroderma-specific Self-management Program

Running Head: Challenges and Strategies Coping with Scleroderma

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Abstract

Purpose: The purpose of this study was to explore challenges faced **by patients with** systemic sclerosis, also called scleroderma, in coping with their disease and the strategies they used to face those challenges.

Method: Five focus groups were held with scleroderma patients (4 groups, n = 34) and health care professionals who have experience treating scleroderma (1 group, n = 8). Participants' discussions were recorded, transcribed, and analyzed using thematic analysis.

Results: Participants reported challenges accessing information (e.g., knowledgeable specialists), dealing with negative emotions (e.g., stress due to misunderstandings with loved ones), and accessing resources (e.g., helpful products or devices). Strategies for overcoming challenges were also discussed (e.g., advocating for own needs).

Conclusion: When faced with **significant** challenges **while** coping with scleroderma, patients develop strategies to manage better and improve their quality of life. **To help them cope**, patients would benefit from easier access to supportive interventions, including tailored scleroderma self-management programs. Although the challenges **experienced by patients with** scleroderma are unique, findings from this study might help better understand patients' perspectives regarding coping and disease management for other chronic diseases as well.

Keywords: *scleroderma, systemic sclerosis, coping, self-management programs, patient perspectives, health care professional perspectives*

Introduction

Scleroderma, or Systemic Sclerosis (SSc), is a rare, **diverse**, and chronic connective tissue disease that affects the skin and **may also affect** multiple internal organs, including kidneys, lungs, and gastrointestinal tract[1, 2]. SSc onset typically occurs between the ages of 30-50, the disease is more prevalent among White Europeans, and rates for women are 3-5 times higher than rates among men[1, 3]. In North America alone there are approximately 16,000 Canadians[4] and 300,000 Americans[5] affected by this disease. The median survival time after diagnosis is 11 years and there is no known cure[1-3].

Although most adults diagnosed with SSc will develop the localized subtype, which affects only the exterior skin, one third will develop the systemic subtype, which affects both the skin and the internal organs[5, 6]. The systemic form of the disease includes two separate subtypes: Limited SSc and Diffuse SSc[3, 6, 7]. Common manifestations **of the systemic form** include Raynaud's phenomenon, ulcers, joint contractures, arthritis, gastroesophageal reflux, pulmonary hypertension, pulmonary vascular disease, and interstitial lung disease[8]. In addition, SSc patients face psychosocial challenges (e.g., depression, stigma, emotional distress, employment) and health care-related barriers (e.g., limited numbers of trained professionals and available treatment options) that impact their daily life[9-16].

Structured self-management programs have been developed for people living with common chronic diseases, including arthritis, diabetes, and asthma[17-19]. **The ultimate purpose of chronic disease self-management programs is to help patients with illness self-regulation by providing them** with skills and resources to better cope with the daily challenges associated with their disease, including those related to medical management, emotional management, and **social** role management[20-27]. They typically include education concerning the disease and its

treatment, as well as education to support exercise, nutrition management, stress management, and emotion regulation[28-30]. Although not all self-management programs are grounded in theory, most are based on illness self-regulation theories, including Bandura's social cognitive theory and Leventhal's perceptual-cognitive model of illness self-regulation[30-32]. According to these theories, illness self-regulation occurs when cues from the environment cause a threat to the person (e.g., new physical symptoms, new diagnosis) and a problem solving process is initiated that involves goal formulation and action planning[32].

Research has examined patient experiences with disease burden, functional impairments, and psychosocial distress in SSc patients[14, 15, 33, 34], but there is little research on the unique challenges faced by patients with SSc while coping with their disease and the strategies they employ to overcome coping challenges, more specifically[35]. A better understanding of SSc patients' experiences, needs, and concerns related to coping with and managing their disease could be achieved by allowing patients to engage in an open discussion eliciting their perspectives[36, 37]. The purpose of the current study was therefore to explore challenges and strategies related to coping with SSc to inform the development of a SSc-specific self-management program through focus group discussions with SSc patients and health care professionals who have experience working with SSc patients. The overarching research question guiding the current study was: what are the challenges faced and the strategies used by SSc patients related to coping with the disease?

Methods

This study was conducted as part of the Scleroderma Patient-centered Intervention Network. This network is an international collaboration of patient organizations, health care professionals, and researchers that is dedicated to developing, testing, and disseminating

educational, psychological, and self-management interventions intended to help SSc patients manage their disease better in daily life[38].

Study Design

Focus groups were used to elicit open discussion and exchange among patients with SSc and health care professionals who have worked with SSc patients, separately. Focus groups were chosen because they are a methodological strategy that: (a) allows for relatively rapid and effective assessment of ‘hard-to-reach’ participants[39]; (b) has been increasingly used in health research within the context of rare diseases, including SSc [10, 14, 15, 40-43]; (c) provides participants a collective sense of power that enhances the expression of sensitive issues [44]; (d) represents an ideal methodology for exploring “‘why not...’-type of questions... [as well as] ... ‘non-compliance-related’ [problematics]” [44]; and (e) offers room to develop and elaborate on participants’ shared experiences through the exchange of personal thoughts and reactions[44, 45]. The study was performed from a social constructionist framework[45].

Participants

Five focus groups were conducted: four with SSc patients and one with health care professionals who work with people with SSc. The focus groups were conducted in the context of two large North American conferences where many SSc patients were expected to be in attendance. Two patient focus groups took place in the United States at the Scleroderma Foundation’s National Patient Education Conference in July 2012, and two took place in Canada at the Scleroderma Society of Canada’s Annual National Scleroderma conference in September 2012. All focus groups were conducted in rooms in the same hotels as the conferences. Participants were not compensated monetarily; however, refreshments and/or meals were

provided. For each focus group, we aimed to recruit 6 to 12 participants for discussions that were intended to last 60-90 minutes.

Eligibility criteria for patients with SSc included fluency in English, being 18 years old or older, and having a diagnosis of SSc. Study recruitment ads were posted in SSc newsletters, emailed directly to registered conference attendees by conference organizers, and were included in conference gift bags.

One focus group of health care professionals was conducted to complement patients' viewpoints and perspectives[46]. Health care professionals with experience working with SSc patients were eligible if they were registered as a clinical member of the Canadian Scleroderma Research Group. Recruitment emails were sent to clinical members of the Canadian Scleroderma Research Group prior to the annual research meeting of this research group, which was held in conjunction with the Scleroderma Society of Canada's Annual National Scleroderma conference in September 2012.

Data Collection and Procedures

The study was approved by the research ethics committee of the Jewish General Hospital in Montreal, Canada. Before starting the focus groups, participants read and signed the informed consent form and completed a socio-demographic questionnaire. A standard statement explaining the purpose of the study and procedures to participants was followed by a basic introduction to chronic disease self-management support and common program structures. Next, a discussion that revolved around participants' perspectives concerning coping with and managing SSc in daily life took place. The interview guide included a series of questions and prompts to encourage discussion but remained flexible enough to allow the individual expression of thoughts and experiences to emerge through group discussions and interactions. For example,

a focus group discussion might start with the following question: “For the standard self-management programs that we mentioned, to what extent would receiving information on each of the different topics and learning these skills help you cope better with scleroderma?”

Consistent with standard methods for focus group research, each group had two moderators, which included a graduate level trainee in psychology who led the discussion and either a rheumatologist or psychologist who observed, took notes, and contributed to the discussion as needed[47, 48]. The focus groups were audio and video recorded, transcribed verbatim by an external trained professional, and reviewed for accuracy of content[48].

Data Analysis

Transcripts were uploaded to Atlas.ti[49] to help with data storage, coding, organization, and coding retrieval, and a thematic analysis [50] was conducted. The first phase of analysis aimed at developing a preliminary codebook containing a list of codes (i.e., smaller manageable segments), categories (i.e., group of codes that are descriptive of content), and themes (i.e., abstracted data that represents main product of data analysis) [51]. All transcripts were read multiple times to become familiar with the content and identify codes to be later grouped into a preliminary set of categories and themes. Categories and themes identified were inspired by both pre-existing concepts in the research literature and original ideas discussed by the participants. In this phase and during the prior data collection, reflexivity in the form of field and analytic memos was conducted and used to enhance the analysis[52].

The second phase of the thematic analysis aimed at refining the codebook. For that purpose, an external member acted as a second coder, while the main moderator of the focus groups acted as a first coder. The second coder independently read the transcripts and coded them using the preliminary codebook. The coders met on an ongoing basis to compare and

discuss the coding system. Discrepancies between coders were discussed until both researchers came to an agreement or via consultation with a third party, an experienced qualitative researcher. The discussions resulted in the refinement of the codebook, which was then presented to the rest of the research team and adjusted for the purpose of clarity when needed.

For the purposes of the current study, only the codes and quotes that corresponded with the research question of interest **are** presented. For instance, descriptions of SSc patient experiences with disease manifestation (e.g., chronic pain, chronic fatigue, gastrointestinal symptoms) and disease burden (e.g., physical limitations, emotional distress, lifestyle) were excluded **from this research report** while those that focused on challenges and strategies while engaged in coping and disease management, more specifically, **are** included. In addition, to better illustrate the participants' views, we provide a detailed summary of the discussions and representative quotes from the transcripts. When **necessary**, quotes were corrected to adjust for grammatical errors or verbal fillers that may occur in natural conversation, paying attention to preserve the original meaning[53]. Since the SSc community is small in size across both Canada and the United-States, no individual socio-demographic characteristics **are** shared and the participants were **assigned** false names to preserve their anonymity.

Results

Participant Characteristics

Patients Diagnosed with SSc

A total of 34 SSc patients (32 females, 2 males) participated in the focus groups (1st focus group = 4 females, 1 male; 2nd focus group = 5 females; 3rd focus group = 12 females; 4th focus group = 11 females, 1 male). The age of participants ranged from 35 to 75 years old, with a mean age of 59.5 years (Standard Deviation [SD] = 10.5). The mean number of years since receiving a

SSc diagnosis was 12.7 years ($SD = 8.4$). Some participants had been diagnosed for only one year while others had been diagnosed for over 30 years. Fifteen participants reported a diagnosis of diffuse SSc (44%); four reported limited SSc (12%); 12 reported CREST syndrome (35%), another term used, *mostly in the past*, for limited SSc *and an acronym that stands for the five main features of the disease, including Calcinosis, Raynaud's phenomenon, Esophageal dysmotility, Sclerodactyly, and Telangiectasia*; one reported an “undifferentiated connective tissue disease”; and two did not specify their SSc subtype. The majority described themselves as White (88%) and indicated that they had completed at least some college/university education (91%). Seven participants were employed on a full-time basis (21%), five were employed part-time (15%), and 20 reported being retired and/or on disability (59%). A more detailed summary of SSc patient characteristics is provided in Table 1.

[Table 1 about here].

Health Care Professionals

A total of eight health care professionals participated in the focus group (4 females, 4 males). Ages ranged from 37 to 69 years old, with a mean age of 52.5 years ($SD = 10$). The mean number of years of work experience was 21.1 years ($SD = 10.3$), the mean number of years working with SSc patients was 15.9 years ($SD = 10.7$), and the mean percentage of time at work spent with SSc patients was 16% ($SD = 10.1$). The participants represented health care professionals who worked in five different Canadian provinces. The majority were rheumatologists (63%). Additionally, there were two registered nurses and one person currently working as a SSc research administrator. Four reported being involved in both SSc research and clinical work (50%), three were exclusively involved in SSc research, and one was involved in clinical work only. A mixed group of health care professionals was used to generate discussion

and reflections about SSc patients' experiences coping with the disease across different health care contexts. See Table 2 for a detailed summary of healthcare professional characteristics.

[Table 2 about here].

Participant Perspectives on Challenges and Strategies While Coping with SSc

Participants discussed their experiences coping with and managing SSc by bringing up a series of challenges as well as potential strategies to address these challenges. The challenges and strategies were grouped into four *categories* that were related to the patient, their loved ones, the community, and the health care system. In addition, three *themes* that represented larger concepts spanning across categories were identified, namely: accessing information, dealing with negative emotions, and accessing resources. Notably, although both patients and health care professionals discussed similar challenges faced and strategies used **by patients with SSc** while coping with the disease, they approached them differently. For this reason, in this section, we present first the patients' perspectives and then provide a succinct comparison to the perspectives of health care professionals. A diagram illustrating the relationships between the main themes, categories, and codes for challenges and strategies while coping with SSc are provided in Figure 1.

[Figure 1 about here].

SSc Patient Perspectives

Accessing information

According to the patients, since SSc is a rare, under-researched disease, it was a key *challenge* for them to find accurate information, either in the community or in the health care system, on how to manage the disease and deal with daily symptoms. Even patients who described themselves as being highly proactive faced difficulties coping. For instance, internet

searches would often lead patients to inaccurate and misleading information. In this regard, Samantha (65 years old, CREST syndrome, employed part-time) shared the explicit warning she received from her treating physician: “My doctor was very careful to say: ‘Don’t go on the internet and read everything you see because a lot of it is going to be false information.’” Furthermore, the limited evidence-based information that was available was difficult to locate and would frequently not address all patient concerns, since SSc involves a large and varied spectrum of symptoms.

Some SSc patients are not followed by health care professionals who are knowledgeable or specialize in SSc. They mentioned that because their health care professionals were not sufficiently knowledgeable about the disease, they felt they were not being properly followed in terms of their medical care. Lack of disease-related knowledge by the SSc patients themselves further contributed to problems during medical visits, including not being well prepared to ask for more information and not knowing how to speak up about their needs. Jamie (71 years old, CREST syndrome, retired) explained her experience: “When I was first diagnosed, I didn’t have [any of the symptoms] yet and so I didn’t know what to ask [my doctors] because I didn’t know what I was going to get.”

Advocating for their own needs and adopting a proactive attitude was a crucial *strategy* that these patients implemented for accessing information on how to manage specific symptoms. This included looking for alternative approaches, tips, or easy-to-implement solutions for managing the impact of symptoms in daily life. In addition, for these patients, it was crucial to learn how to better prepare for their medical appointments. This included strategies like being assertive when asking about treatment- and care-related needs from different health care professionals (e.g., general practitioners, dentists), as well as booking convenient medical

appointments to facilitate symptoms management. In this vein, some patients reported that having the appointment in the afternoon gave them enough time to both get appropriately prepared for the medical interview and deal with chronic fatigue.

These patients also found helpful advice when interacting with other SSc patients. For instance, blogs created and developed by SSc patients often provided responses and suggestions on how to manage common symptoms. Frances (47 years old, diffuse SSc, retired) also reflected on the value of listening to someone else's story: "[You would be] able to see yourself and [see] your story reflected back to you; [...] I can hear all these stories and start identifying [with them]."

Connecting to SSc societies and reputable organizations was identified as another helpful strategy for accessing critical evidence-based information. John (53 years old, diffuse SSc, employed full-time) explained: "I learned very early just to rely mostly on the Scleroderma Foundation because I knew that it would be accurate, truthful, and not misleading." Moreover, these patients seemed to agree that support groups run through organizations would often provide more help and assistance than health care professionals. Jean (67 years old, CREST syndrome, employed full-time) said in this regard:

I find that support groups have sometimes given me more valuable information on the day-to-day living than my physicians do... [Physicians just give] me a diagnosis and then just put me out into the wind, like: "Just take this medicine and don't call me anymore."

Dealing with Negative Emotions

SSc patients in the current study often experienced negative emotions such as anger, frustration, fear, and anxiety that contributed to *challenges* while attempting to cope with the disease in daily life. More specifically, when negative emotions were experienced, SSc patients

could feel overwhelmed or too depressed to put in place effective coping strategies. One source of stress for patients was the unpredictability of the disease progression and impact of SSc symptoms, since both forced them to adapt and change their coping strategies continually over time. Another disadvantage involved the need to repeatedly research information online in order to learn about new symptoms as this contributed to patients frequently panicking due to the nature of the content presented online. According to these patients, interacting with health care professionals who were overly reliant on medications and eager to engage them in ‘trial-and-error’ treatments also resulted in negative emotions that could subsequently affect patients’ ability to cope. As well, patients could experience negative emotions while dealing with health care professionals who did not provide sufficiently detailed information about the evolution of the disease, medication side effects, or drug interactions. Samantha (65 years old, CREST syndrome, employed part-time) shared her experience of feeling overwhelmed: “Well, I worry about the [potential] interactions of all the medicines I take. [But] sometimes [I] become so desperate [that I’m] willing to try anything, [which is] not necessarily a good idea.”

Next, as acknowledged by many patients, social interactions and communication with their loved ones was not an easy task and often resulted in misunderstandings, feelings of disconnection, and emotional distress that could make coping more difficult. Pat (48 years old, diffuse SSc, employed full-time) shared:

As long as you can play cards here or there [...], [loved ones] think you’re good and fine. But inside, [...] to lift the card is hard. [...] And they don’t see it, but how do you say it? You know, “I’m still sick. I’m sick.” [...] You don’t want to keep saying [it] [...] ‘cause then you get depressed yourself.

Although patients also described making efforts to help loved ones learn and come to

terms with their fears about the diagnosis, family and close friends would often feel overwhelmed and react by openly questioning the patient's ability to adapt. River (71 years old, diffuse SSc, on leave of absence) reported that when it came to organizing activities, she was often left to do so alone because loved ones were "frightened enough to say: 'I can't go with you. I can't take you. I'm too scared. You're too much responsibility.'" As a result of the negative emotions caused by these difficult social interactions, many SSc patients avoided communicating with or reaching out to loved ones for help managing and staying socially active.

Among the *strategies* reported by SSc patients to help them tackle the negative emotions that can affect their ability to cope, some patients discussed the importance of learning to relax in the face of perceived challenges. They reported that relaxing when feeling overwhelmed helped them stay calm when making important decisions about treatments or interacting with their loved ones and health care professionals. For instance, Toby (44 years old, CREST syndrome, retired) shared the following:

Relaxation for [me,] I mean [just deep] breathing [...] really [...] helps. [...] All this is going through your head all the time: "I'm swelling, I'm [...] having all these issues going on. What do I do?" I just need a second to stop and [...] I need to relax.

Finding ways to discuss SSc more openly was raised as another possible solution in relation to negative emotions, since loved ones might need help understanding and accepting the patients' health diagnosis. Communicating effectively with others might both minimize emotional distress caused by misunderstandings or negative judgements from others and fuel the channels for more positive social interactions in the future.

Finally, according to patients in the current study, connecting to people with SSc or other rare diseases and/or SSc societies and reputable organizations, not only led to accessing more

information, but also to finding emotional support and personal strength for dealing with daily struggles. As a result of this, SSc patients reported feeling less anxious and engaged more in efforts to cope with the disease. From their perspectives, improved mood and increased self-confidence seemed to lead many SSc patients to advocate for their own needs more effectively and become more active problem-solvers.

Accessing Resources

SSc patients reported *challenges* coping with the disease related to accessing SSc-related resources, such as specialized self-help books, peer-led groups, community programs and facilities, websites, and television programs that responded to their needs. For instance, SSc patients who tried to swim to keep themselves physically active mentioned that cold temperatures both in pools and air-conditioned locker rooms frequently resulted in severe symptom flare-ups and the need to immediately use emergency symptom management strategies. Difficulties accessing community resources could further be aggravated by a lack of patient knowledge about available resources. Samantha (65 years old, CREST syndrome, employed part-time) explained: “There are resources in [the] community that you don’t even know about because you don’t even know [who] to ask [about them].” If SSc patients do not know about helpful exercise programs or do not know how to search for that information online themselves, they might never know that there are, for example, senior swim programs or free yoga classes offered in the nearby community centers.

The patients also discussed difficulties accessing specialized treatment centers and connecting to allied health professionals who were appropriately trained to help them (e.g., physical, occupational, and sleep specialists; dentists). Diana (50 years old, diffuse SSc, retired) explained that despite living in a major metropolitan city: “... you would think [we] would have

a Scleroderma Center; [but] we don't." In addition, many SSc patients reported physical pain and other problems while undergoing routine tests and follow-ups from health care professionals because of the lack of specialized skills or knowledge about SSc in the medical field. River (71 years old, diffuse SSc, on leave of absence) shared: "Look at my arm here. See?" There are bruises from the other day, when the nurses took blood because: "I have a port, [a portacath, but] they couldn't draw from [it] because they're not specialized." Even when SSc patients successfully accessed appropriate services, they often experienced additional challenges managing hospital bills as well as the elevated cost of and limited access to medications for rare diseases.

SSc patients brought up some *strategies* that helped them access available resources. Once again, connecting to individuals with SSc or other chronic diseases, as well as SSc societies and reputable organizations, allowed SSc patients to be informed regarding annual educational conferences, products, and practical services. For instance, Diana (50 years old, diffuse SSc, retired) explained that upon having discussions with other SSc patients, she gained access to information about all sorts of potential resources, including resources that should be avoided: "I decided to order [a nutrition product and] everybody I asked about it [said:] 'Oh no! That's a waste of your money. It doesn't work.'"

Actively looking for resources across both the community and health care system was another strategy implemented by these patients. They highlighted the importance of taking time to explore different products and services that might help them manage symptoms or improve their functioning and quality of life. Examples of resources these patients discussed included: specific exercise programs (e.g., seated yoga classes) and local facilities that could provide necessary accommodations (e.g., pools that kept warm-water temperatures of 83-90°F to prevent

problems with circulation). Paula (50 years old, diffuse SSc, on disability) explained that advocating and problem solving helped her access more resources and she subsequently felt more empowered: “You feel like you’re regaining some control after you’ve just been told you have this major chronic illness. [...] There are things that you can do. [...] It’s not complete gloom and doom.”

Health Care Professional Perspectives Compared to SSc Patient Perspectives

Health care professionals shared many views regarding patient challenges and strategies while coping with SSc, as they had witnessed or heard many detailed reports when working with SSc patients. Although health care professionals shared many similar perspectives as participating patients, they seemed to adopt a somewhat different angle during their discussion.

For instance, among the coping challenges discussed, unlike SSc patients, health care professionals did not consider that the impact of medications side effects and SSc symptoms on daily life was associated with negative emotions and subsequent difficulties coping. Although health care professionals did report that negative emotions experienced by SSc patients interfered with effective coping, they did not discuss specific contributors to those negative emotions. For instance, Jesse (57 years old, rheumatologist, working in a hospital) shared that she frequently has patients who feel so overwhelmed that they wind up falling back into old habits involving maladaptive coping strategies: “[SSc patients] hurt and they’re miserable. They’re scared, they’re anxious, [and] they need that cigarette. [Even though] this is actually making today worse too.” Some health care professionals even shared how ongoing emotional difficulties, like depression, could be ignored or minimized by SSc patients, contributing to delays in connecting to helpful resources.

Health care professionals also referred to possible challenges related to accessing information and accessing resources in the health care system. For instance, Adam (61 years old, rheumatologist, working in a clinic and private office) explained how difficult it could be for SSc patients to seek medical care when most health care professionals do not have specialized knowledge about the disease: “Going to a primary health care provider or more often [than] not the walk-in clinic or [emergency room], where they even know less, is not the way to go.”

Health care professionals also brought up some coping *strategies* that could be used by patients. Overall, three broad strategies were discussed, including: 1) connecting to people with SSc or other similar diseases, 2) connecting to SSc societies or reputable organizations, and 3) advocating and engaging in active problem-solving. When discussing problem-solving strategies health care professionals, unlike SSc patients, focused on different organizational issues related to medical appointments. For instance, they suggested that keeping lists, like the names of doctors, current medications, and previous medical tests and results, could help SSc patients better track medical care and effectively advocate when necessary. Maxine (37 years old, SSc research Administrator, working in a hospital) explained that when patients were more organized and aware of ongoing issues they could subsequently better advocate for their needs: “[Patients feel] empowered enough to just say to the [...] doctor: ‘This is what needs to happen, I need to get sent [to this place] or I need to see this [...] kind of a doctor.’”

Discussion

The ability of patients with chronic diseases to cope with and manage their disease are crucial for handling daily struggles and adapting successfully to their new life. However, overcoming challenges related to coping and implementing helpful strategies can be difficult. Findings from the current study provide a deeper understanding of the unique challenges faced by

SSc patients as well as key strategies used to address coping difficulties in daily life. Challenges discussed by our participants referred to situations that hindered the possibility of coping well, including issues such as: *accessing information* (e.g., not finding responses about how to address certain symptoms), *dealing with negative emotions* (e.g., frustration due to the unpredictability of the disease progression), and *accessing resources* (e.g., hard to find exercise facilities that are safe and address the needs of SSc patients). Participants also provided a look into strategies for overcoming these challenges, including the importance of advocating for needs, engaging in active problem-solving, connecting to other patients and reputable organizations, using relaxation strategies, and learning to communicate assertively.

In the context of this study, the views of health care professionals complemented the perspectives of patients with SSc regarding challenges and strategies in coping. Health care professionals and patients agreed that negative emotions and difficulties accessing information and resources complicated efforts to cope with the disease; however, health care professionals did not consider them in the same ways as patients did. For instance, health care professionals neither discussed the burden SSc patients faced while dealing with their loved ones, nor how their loved ones overwhelming emotions affected the patients' ability to cope. In addition, health care professionals only discussed a few broad strategies for overcoming challenges while coping with SSc, including connecting to both people with SSc or other similar diseases, connecting to SSc societies or reputable organizations, and advocacy and active problem-solving, especially regarding organizational strategies.

To our knowledge, this is the first study to investigate the specific challenges that patients with SSc face related to coping with the disease in daily life by looking at the perspectives of both SSc patients and health care professionals with experience treating SSc patients.

Interestingly, our findings seem to corroborate those from a previous study investigating patient perspectives about disease management in the context of medical care based on a sample of SSc patients from France (16 individual interviews, 1 focus group, N = 25) [35]. Mouthon et al. [35] identified some common challenges for patients while receiving care, including issues navigating the doctor-patient relationship as well as problems while receiving their diagnosis, information about SSc symptoms and treatment options, and complimentary or follow-up exams. Our findings are also aligned with those coming from previous studies investigating other, more common, chronic diseases. For instance, many chronic disease patients experience problems coping with and managing the disease because of elevated health care costs, limited time with doctors, poor coordination of care, and ongoing frustrations with doctors[54-58].

Concerning coping strategies, the previous study by Mouthon et al.[35] also corroborated some strategies for improving disease management identified in the current study, such as making changes in the material environment and improving the organization of time/schedule. Mendelson & Poole [43] performed the only other focus group study that investigated experiences of patients living with SSc and learning to become better disease managers, using a small sample of SSc patients from the United-States (3 focus groups, N = 11). Although some strategies for improving the ability to cope with SSc were discussed in both Mendelson & Poole's[43] study and the current study, including the importance of fostering a good relationship with health care professionals to ensure secure and effective medical management, as well as the importance of becoming your own advocate for managing life with the disease, specific challenges discussed were different. Most importantly, while the previous study focused on challenges related to living with the disease and its symptoms[43], the current study focused on challenges when actively engaging in disease management efforts, specifically. For instance,

Mendelson & Poole[43] identified challenges related to negative emotions about the diagnosis and dealing with functional limitations, while the current study focused on challenges dealing with negative emotions that occur in the context of active coping and disease management (e.g., clearing up misunderstandings about SSc when interacting with others, repeatedly adapting self-management plans and medical management plans to account for symptom changes).

Although the reported challenges and strategies from the current study appear to represent important experiences of SSc patients while coping with the disease in daily life, alternative explanations to these findings are important to consider. Experiences related to disease manifestation versus coping represent distinct theoretical concepts, but they may be more intertwined than we know. For instance, many of the challenges and strategies discussed in this study, which are related to coping with SSc, could equally be caused by challenges with disease manifestation and burden that have been reported in previous qualitative SSc studies, such as disease progression, patient expectations of the disease, social isolation, depression, reduced mobility, medication issues, and the costs of drugs[9-15, 34, 42, 43, 59-61]. In addition, it is possible that making changes to the health care system and medical care, such as by emphasizing patient-centered care during the training of health care professionals, would lead to significant benefits for SSc patients while coping, more than solely providing non-pharmacological interventions to teach specialized knowledge and skills.

Study Limitations

A few limitations should be considered when interpreting the current findings. First, while the final sample used might be seen as small[62], this should be considered in the context of SSc being a rare disease and that it can be challenging to identify and bring together a large number of SSc community stakeholders[40]. Second, to increase the likelihood of patients

participating in the study, we held the focus groups on location during conferences and research meetings, which may have increased the likelihood that patient participants represented people who experienced less severe disease involvement, were physically able to travel, and were interested in learning about the disease. In this vein, differences in perspectives between patients connected to the SSc community and those who are not, or patients living in metropolitan cities versus those living in remote towns, younger versus older SSc patients, or people diagnosed with different SSc sub-types could not be assessed in this study[44]. The current study was not designed for the purpose of analyzing differences between or within participant sub-groups[44]. Third, the fact that we used a semi-structured interview to allow for a natural flow of discussion among participants prevented us from having a more detailed comparison of discussions across the conducted focus groups. Instead, this strategy, specifically chosen to respond to the nature of this exploratory study, was designed to pursue participants' interests during data collection[48]. Finally, the semi-structured interview guide was not piloted prior to beginning data collection[47]; however, the research team members reviewed it several times before it was used with the participants.

Future Directions for Research

Based on data generated, there are many more areas of research to explore in order to better understand SSc patient experiences and, therefore, better support them to be empowered managers of their disease. For instance, some studies have identified gender-based differences in terms of patient experiences with disease burden, psychological distress, and coping[63, 64]. Since men with SSc are often under-represented in research, future investigations using male SSc patient samples could provide a better understanding of the unique ways to support men versus women learning to cope better. Second, a larger sample of health care professionals, including

professionals across different disciplines and specialties (i.e., occupational therapy, physical therapy, psychology, cardiology, endocrinology, general practice), could provide different insight related to coping with SSc[65]. Finally, investigating the different ways that social support can impact SSc disease management efforts might also be beneficial[66-69] as this has been identified as a key factor for improving patient health[70, 71] and self-management behaviours[72] for patients diagnosed with more common chronic diseases.

Practical Implications

Helping SSc patients become better managers of their disease is one possible way to reduce the burden of the disease and improve quality of life. Improving access to community-based resources and developing tailored programs that address the unique needs of SSc patients would be a great contribution in this regard. Therefore, developing online tools that can help with disease and emotion-related management, like those currently being developed by the Scleroderma Patient-centered Intervention Network, represents an important initiative for the SSc community[38, 73]. Support groups are also an important community-based initiative that might help SSc patients find emotional support and become more skilled at disease management[74]. Although past research has found that not all patients with SSc are interested in support groups, most of them are[75]. However, individuals interested in benefiting from support groups tend to experience difficulties finding helpful support groups in their area, especially SSc-specific groups, either due to a lack of availability, lack of awareness, or other practical barriers[75]. Therefore, improving access and addressing potential barriers to using supportive interventions, whether self-management programs or support groups, might improve patient coping and quality of life.

Conclusions

In addition to SSc patients experiencing daily life challenges caused by the disease and symptom burden, SSc patients also experience challenges while attempting to actively engage in behaviours to cope with their disease better. This study provides a roadmap for SSc patients, health care professionals, and family members to better understand the coping-related challenges these patients **face**, as well as key strategies to address them. While coping with the challenges related to disease management is key to appropriately handling the symptoms and struggles associated with the disease, from an encompassing perspective, the patient should not be considered in a vacuum. The loved ones, the community, and the health care system play a crucial role for both hindering and facilitating the process of coping with a disease. Therefore, non-pharmacological interventions aiming at offering the patient tools to handle the disease, as well as promoting better communication between health care professionals, patients, and loved ones seem to be a promising approach to be considered by health care decision-makers.

Declaration of Interest Statement

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Figure 1. Participant perspectives on challenges and strategies while coping with scleroderma

Table 1. Socio-demographic characteristics of patients diagnosed with **scleroderma** (n=34)

Variables	
Age, mean (<i>standard deviation</i>)	59.5 (10.5)
Female gender, n (%)	32 (94.0)
White race/ethnicity, n (%)	30 (88.0)
Level of Education, n (%)	
High school graduate	3 (9.0)
Some college/university	7 (21.0)
College/university degree	18 (53.0)
Postgraduate degree	6 (18.0)
Occupational status*, n (%)	
Homemaker	2 (6.0)
Retired	15 (44.0)
On disability	6 (18.0)
On leave of absence	1 (3.0)
Full-time employed	7 (21.0)
Part-time employed	5 (15.0)
Scleroderma subtype, n (%)	
Diffuse scleroderma	15 (44.0)
Limited scleroderma	4 (12.0)
CREST	12 (35.0)
Other/not specified	3 (9.0)
Years since diagnosis, mean (<i>standard deviation</i>)	12.7 (8.4)

*Total n (%) for occupational status is greater than 34 (100%)

because some participants reported more than one occupational

status

Table 2. Socio-demographic characteristics of healthcare professionals with experience working with patients **with scleroderma** (n=8)

Variables	
Age, <i>mean (standard deviation)</i>	52.5 (10.0)
Female gender, <i>n (%)</i>	4 (50.0)
Province of Work, <i>n (%)</i>	
Ontario	2 (25.0)
Manitoba	1 (12.5)
Alberta	2 (25.0)
New Brunswick	1 (12.5)
Nova Scotia	2 (25.0)
Current occupation, <i>n (%)</i>	
Rheumatologist	5 (62.5)
Nurse	2 (25.0)
Scleroderma research administrator	1 (12.5)
Work facilities, <i>n (%)</i>	
Clinic	3 (38.0)
Hospital	4 (50.0)
University	1 (12.5)
Years of work experience, <i>mean (standard deviation)</i>	21.1 (10.3)
Years of work experience with scleroderma , <i>mean (standard deviation)</i>	15.9 (10.7)
Percentage of work with scleroderma patients, <i>mean (standard deviation)</i>	16 (10.1)
Number of scleroderma patients seen per week, <i>mean (standard deviation)</i>	3.2 (3.2)

Current interactions with **scleroderma** patients, *n* (%)

Research only	3 (38.0)
Clinical only	1 (12.5)
Both	4 (50.0)
