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Become your own advocate: Advice from women living with scleroderma

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Abstract

Purpose—Systemic sclerosis (SSC) affects 300,000 people in the USA and has a significant effect on an individual's functional ability. The purpose of this study was to outline the key components of living with the illness and to identify the information that those who are newly diagnosed would need to initiate a successful course of disease self-management. The results will provide the groundwork for development and testing of a self-paced education program for patients with SSC.

Method—Focus groups were conducted with 11 women diagnosed with SSC.

Results—Analysis of the transcripts yielded three themes, *Secure Effective Medical Management*, *Live Your Life*, and *Learn Everything You Can.* The thread *Become Your Own Advocate* wove these three themes together and illustrated that taking control of SSC is ultimately a function of self-advocacy.

Conclusion—For patients with SSC, taking control of their illness was a necessary component of maintaining the highest quality of life possible. A positive attitude, a strong support system, a commitment to moving forward with life, and access to high-quality, timely information all provided the participants with the tools to develop and implement a strategy of self-advocacy in disease management.

Keywords

Scleroderma; advocacy selfmanagement; women; focus groups

Introduction

Systemic sclerosis (SSC) is an autoimmune connective tissue disease that afflicts approximately 300,000 people in the USA. It affects multiple systems and results in thickening of the skin, vascular insufficiency, and fibrotic changes in the muscles, joints, and internal organs. In the USA, 4000 – 5000 new cases of SSC are diagnosed each year [1]. The disease is four times more common in women than in men, and the average age of onset is usually between 30 and 50 years.

There are two subtypes of SSC: diffuse and limited cutaneous. In diffuse SSC, the classic subtype of the disease, there is symmetrical and generalized thickening of the skin affecting the trunk, face, and extremities and relatively early involvement of the internal organs. The

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systemic form is the more serious form. Pulmonary, renal, gastrointestinal tract, and cardiac fibrosis may occur, and interstitial lung disease is the usual cause of mortality. In limited cutaneous SSC, the other major subtype, skin thickening is generally restricted to the face and hands, and internal manifestations may not be present for a prolonged period of time [2].

SSC can have a significant effect on an individual's functional ability. Pain, finger ulcers, Raynaud's phenomenon, esophageal reflux, and internal organ involvement, particularly decreased pulmonary function, make it difficult to perform daily tasks. Indeed, the degree of disability seen in persons with SSC is typically greater than the disability observed in persons with rheumatoid arthritis [3] and systemic lupus erythematosus [4]. Clements et al. [5] reported that in the first 18 months after the onset of SSC, persons with the disease become moderately to severely disabled. Activities requiring hand and arm function are more difficult to perform than activities requiring lower extremity function [6]. The characteristic 'claw' hand deformities, along with painful fingertip ulcers and pain, interfere with the performance of everyday tasks requiring grasp, pinch, and object manipulation and lead to limitations in work and social activities, psychological distress, and ultimately decreased quality of life [4,7–10].

Psychosocial sequelae of SSC have been studied to a lesser extent than physical and functional disability [11]. For many persons, SSC is disfiguring. The shiny, thickened, tight facial skin gives the face a pinched appearance and decreases the aperture of the mouth. The severe retraction of the facial skin along with telangiectasias (small, dilated blood vessels near the surface of the skin that appear as small red or purple cherry-like spots) change the aesthetic aspect of the face and influence body image [3,8]. Indeed, persons with SSC are more dissatisfied with their body image than persons with severe burn injuries [12]. The dissatisfaction with body image has been shown to be directly related to depressive symptoms and poorer psychosocial function.

The disfigurement and disability caused by SSC is often severe, leading to stigmatization, self-isolation, and depression [13]. There is no cure for SSC; medications do little to alter its course. Thus, the disease is often overwhelming for patients and their families due to the variable course and potential for disability and morbidity. Because the prevalence is low, support groups are frequently unavailable, and, in many cases, persons with SSC may never have met someone with the same diagnosis [13,14]. Persons living outside of major metropolitan areas additionally may not have access to rheumatologists or other health professionals with a specialized knowledge of SSC. Consequently, persons with SSC are often emotionally and geographically isolated from sources of support and disease self-management education.

Educational self-management programs

Disease-related educational information is available for persons with SSC from Websites supported by the National Institute of Arthritis and Musculoskeletal and Skin Diseases. The Scleroderma Foundation publishes *The Scleroderma Book* [1] and numerous pamphlets containing helpful information. Although these resources are excellent, they lack information about living with and managing a chronic disease. Boutaugh and Brady [15] state that the most effective education programs include not only information but coping strategies that focus on behavior change and self-management. To date, there are no self-management programs available for persons with SSC in the United States.

During the last decade, the value of patient education intervention programs has received growing recognition. Self-management programs have been successful in managing the effect of arthritis, primarily rheumatoid arthritis, osteoarthritis, lupus, and fibromyalgia [16–19]. Lorig and colleagues developed the Arthritis Self-Management Program (ASMP) and the Chronic Disease Self-Management Program. Typically, these group format programs consist of six to eight weekly classes for 2.5 h and are led by a trained group leader and a person with

a chronic disease. Self-efficacy theory [20,21] is the conceptual basis for these programs. According to Bandura [20], coping with the challenges of having a chronic disease requires a belief in one's ability to organize and use cognitive, social, and behavioral skills and the use of these skills will produce desired outcomes. Twelve years of experience and research with the ASMP programs showed that program participants reported reduced pain, used health care providers less frequently, and demonstrated increased self-efficacy [22–24].

Although they have demonstrated value, these programs tend to be limited, vary with geographic location, and rarely target people outside of urban centers. Additionally, these programs are dependent on people coming to central locations, which can be difficult for individuals with mobility issues or who are suffering from disease-related fatigue. Mail-delivered versions of these programs have been developed, which consist of self-management plans, self-care books, and relaxation audiotapes and videotapes. Mail-delivered programs have also shown benefits similar to those achieved with the group format [24–26]. The advantage of the mail-delivered format is that it is available to anyone at any time of year and in any community.

Although generic chronic illness self-management programs have demonstrated that a course based on common problems in coping across illness can be effective, the opportunity to provide disease-specific management information is lost. The physical manifestations of SSC, along with the consequent disability and stigma, make a disease-specific program that incorporates the principles of self-management in coping along with content specific to the unique aspects of SSC optimal. To address this gap, three focus groups were conducted with people with SSC as part of a research project to develop and test a self-paced education program. The purpose of this paper is to report on the focus group findings.

Methods

As a prelude to the development of a self-help program, three focus groups were conducted with individuals diagnosed with SSC to outline the key components of living with the illness and to identify the information that those who are newly diagnosed would need to initiate a successful course of disease self-management. Focus groups were chosen as the primary means of data collection because they are an appropriate mechanism for gathering normative topic-specific data [27] and for uncovering the values, attitudes, and beliefs of groups of participants.

The study was reviewed and approved by the university institutional review board. Participants were recruited from the local community through the contacts of the second author and with the assistance of a local community member active in SSC support activity. Because SSC is a relatively rare disorder, the pool of potential participants was limited. To enhance participation, three groups were held at different times and on different days across a 3-week period. There is no consensus on the size of the groups [28,29] or the number of groups needed [28]. A total of 11 women participated in the groups, five in the first group, four in the second, and two in the third. Four participants were scheduled for the third group; however, two cancelled due to illness. Prior to the beginning of each group, all the participants signed consent forms, completed a demographic questionnaire, and had an opportunity to ask questions about the study and the consent process. The first two groups lasted approximately 2 h, and the third group lasted just over an hour because of the limited group process with only two participants.

The focus groups, which were audiotaped, were facilitated by the first author, and the second author took field notes of speaker order and nonverbal group interaction. The groups began with an explanation of the project, the purpose of the focus groups, and a discussion of issues associated with confidentiality and group etiquette. Each group began with participants introducing themselves and briefly sharing components of their personal stories. Following

introductions, the first author then initiated group discussion. The following five questions guided group interactions: (a) What were your initial thoughts and concerns upon first learning of your diagnosis? (b) When you were first diagnosed with SSC, what was the key information that you felt that you needed? (c) What have you learned about living with SSC that you wish had been explained to you when you were diagnosed? (d) A self-management program is being planned. What content would you like to be included? (e) What type of support do you think you would need to be able to successfully complete the proposed program at home? Probes and follow-up questions were used to fully develop the responses of the participants and to follow up on participant-initiated responses and queries.

Group dynamics are important to focus group interactions. The three groups were all friendly and cordial; participants were grateful for the opportunity to meet others with the illness. Several exchanged phone numbers and made arrangements to meet socially. The first and second groups each had participants who took the lead in the discussions; however, all members participated, even though some encouragement was needed at times.

The focus group audiotapes were transcribed verbatim by a typist. The transcripts were compared with the audiotapes to ensure accuracy and were dimensionalized by adding salient verbal and non-verbal elements present on the tape and in the field notes, but not captured on the transcripts (i.e., meaningful pauses, laughter, crying, etc.). Cleaned transcripts were then entered into the qualitative analysis software package ATLAS TI v.5 to aid in the management and retrieval of data.

Data were initially reviewed for key concepts in response to each of the guiding questions. However, the focus group process revealed information that was important to the participants that was not anticipated in the original questions. To identify the issues that crossed questions and to identify the primary areas of concern to the participants (rather than the researchers' primary interests), thematic analysis of the transcripts was conducted by the first author using a qualitative analysis technique called immersion and crystallization [30]. Immersion and crystallization is an iterative, contemplative, and reflexive approach to data analysis, in which researchers immerse themselves in the data 'leading to the emergence of insights and interpretations' (p. 23) and an intuitive understanding of how the data fit together [31]. The initial review of the data provided a gestalt of the experience from the participants' perspectives [32]. Successive readings of, and reflection upon, the data assisted in the process of crystallization of insight and meaning. Thematic statements that reflect the crystallized findings were then generated. Themes were conceptualized as abstract entities 'that bring meaning and identity to a recurrent experience and its variant manifestations. As such, a theme captures and unifies the nature or basis of the experience into a meaningful whole' (p. 362) [33].

The crystallized findings, in the form of thematic statements, were systematically applied to the data by reviewing the transcripts line-by-line. This was done to ensure that the crystallized findings fully accounted for the central concepts and discordance in the data, and to ensure that they accurately reflected the individual and collective wisdom that arose as a consequence of the focus group discussions. This process enhanced credibility by directly applying the crystallized findings to each section of data and helped to develop the dimensions of the themes by identifying data-driven descriptive codes. Data from the demographic questionnaire was analyzed using SPSS v.13.

Participants

Eleven women participated in three focus groups. Seven of the participants had limited SSC, one characterized her illness as diffuse, and three had unclassified SSC. Three participants were Hispanic, seven were White non-Hispanic, and one described herself as mixed race. The participants ranged in age from 43 to 84 years; the median age was 55.64 (SD, 12.25) years.

Nine participants were married, one was single, and one was divorced. Three of the participants worked at least 20 h per week, five were on disability, and three were retired. The sample was generally well educated; one participant finished ninth grade, one completed high school, and the rest had attended college; of those who attended college, five attended graduate school. The sample was also experienced with the illness; the mean number of years since diagnosis was 16.3 (SD, 3.72) years. Participants had an average of nine health care visits in the previous 6 months (SD, 9.38). When asked to self-assess their health status on a 1 – 5 scale (1 = excellent, 5 = poor), the mean assessment was 3.54 (SD, 0.93). Although participants had concerns about their health, these concerns were not strongly felt (Table I) [34].

Findings

The women in the focus groups shared a wealth of wisdom about living with SSC. Each had spent many years managing the physical and emotional ramifications of SSC, and they were aware of the challenges of living with the illness. Because the participants were chosen for their expertise with the disease, as they discussed their experiences, it was apparent that not only were they sharing their own experiences, but they were providing a guide for others who must learn to live with SSC. Consequently, the themes are presented as directives for others learning to live with the illness. Taking control of their illness was a necessary component of maintaining the highest quality of life possible. As one participant noted, ‘The disease doesn’t control you, you control the disease’, which was an attitude shared by most of the participants. This is not to say that all aspects of SSC can be controlled. The disease is often unpredictable and progressive; however, the women shared their strategies for controlling what could be controlled and managing the rest. Analysis of the focus group transcripts revealed three themes: *Secure Effective Medical Management; Live Your Life*; and *Learn Everything You Can.* The thread *Become Your Own Advocate* wove these three themes together and illustrated that taking control of SSC is ultimately a function of self-advocacy. These themes represent unique aspects of experience but their component parts interact and to a certain extent overlap (Figure 1). Although they will be discussed separately for heuristic purposes, they are best viewed as a holistic approach to living with SSC.

Secure effective medical management

The theme *Secure Effective Medical Management* captures the importance of medical management of the illness and also highlights the problems that the participants encountered with the health care system. The process of securing medical management began with diagnosis. The participants had varied diagnostic experiences; most were tentatively diagnosed by their primary care physicians and then referred to specialists for definitive diagnosis and medical management. One participant, who was diagnosed rapidly, said, ‘I’m really lucky in that I literally was diagnosed on the first visit when all I had was swollen hands. I had a miraculously amazing family practice doctor that was very intuitive’. For most, however, diagnosis was a slow process. As is the case with many connective tissue disorders, the symptoms of SSC frequently evolve over time. Consequently, definitive diagnosis is often delayed until a full range of symptoms and supportive laboratory values develop. According to one participant:

> It had taken eight months to figure out that it was the SSC. Of course, the doctor said they had to wait for other symptoms to show up. It started out my hands swelled up, so you go for that because they don’t go down – they give you diuretics and all that kind of stuff and you say ‘no that’s not working’. So anyway my skin started really tightening up and I was almost looking like a mannequin before they realized that it was the scleroderma.

A diagnosis of SSC was the beginning of a long relationship with the health care system and meant a future filled with medical intervention. The mean number of health care visits in the previous 6 months for the women in this study was nine (range, 3 – 35). Although the participants desired a collaborative relationship with their physicians in which they worked jointly toward illness management, most found this relationship elusive. Rather, the participants had come to view their physician's role in disease management as providing drug therapy and monitoring disease progress through laboratory work. They did not see their physician as a resource for information on either disease pathophysiology or on how to live with the illness. Although most expressed a high degree of dissatisfaction with the general medical management of their illness, several indicated that they have or had developed a good working relationship with at least one of their physicians.

The participants confronted problems common to many individuals with chronic illness. The illness changes over time, so symptoms are not always stable and other illnesses arise that have symptoms similar to SSC. Many felt that they had health conditions that were not being treated because all their symptoms were attributed to 'being part of SSC', and some felt that their SSC was being mistreated because unrelated symptoms were being taken as evidence of disease exacerbation. When they reported new symptoms, they were either prescribed a new medication or it was dismissed as something that they would have to learn to live with. This sense of dismissal was exacerbated by a lack of investigation into new symptoms. One participant said, 'When I go to physicians, when I have a problem and they can't seem to find it, they just say, "Oh well, it's probably SSC", and I get pretty upset with that but I have no recourse'. Another participant, who had 18 years of experience with illness, was concerned that she was being treated with a powerful immunosuppressant for knee pain that she did not believe was related to her SSC:

> I feel that I have probably been taking medication that I shouldn't have been taking in the last three or four years. I went in because my knees were really hurting, and they gave me the prednisone treatment, and that helped. But then my rheumatologist started me on penicillamine, which is for the immune system … I didn't think was necessary and my rheumatologist [said], 'Oh no, you have to keep taking it, you have to keep taking it'. I don't know if I should keep taking it or not. I'm uncomfortable, everything is linked to the SSC, and it could be a case of arthritis, you know, like rheumatoid or osteoarthritis, where I don't think that you need to be taking all the other medication for that.

An important part of self-advocacy was finding a doctor who understood the illness, and in the case of primary care physicians, finding ones who were comfortable making referrals. One participant felt that self-advocacy in regards to medical management means:

> really learning how to question your doctors and understand what you need in your doctor. A primary care physician, the minute you say you have an autoimmune disorder, says, 'Oh what kind of specialist do we need to get for you', not, 'Oh, we can manage that'.

The participants were generally satisfied with their ability to access medical specialists; however, few had access to specialized allied health providers. A few of the participants were referred to physical therapists following a surgical procedure, but only one had seen an occupational therapist, despite the prevalence of hand deformity among people with SSC and the key role that such deformities play in self-management. Although all the participants dealt with frequent and poorly healing wounds, only one had been referred to a wound care specialist, and that was after years of trial and error self-management:

> I finally got to see someone about wound care. After 25 years, I got to see someone. I believe it was October of this last year. And it was because I had an open sore on

> one finger which has now multiplied … but that was after years of fiddling around with the wrong kind of treatments and the wrong kind of ointments and whatnot and but I finally got to see a wound care person – finally.

In addition, most were unaware of the roles of either occupational therapy or enterstomal therapy (nurses who specialize in wound and ostomy management). In discussions, the participants felt that these allied health providers had a role in providing holistic illness management and providing specific advice on problem solving many of the manifestations of SSC that they felt their physicians did not adequately address. However, without a better understanding of how various professionals contribute to the management of SSC, they were unable to effectively advocate for referrals to these specialists.

Participants felt that they were operating as effective self-advocates when they were able to locate a physician with whom they were comfortable working, when they were able to secure appropriate referrals, and when they had sufficient information to make informed decisions about medications usage. Self-advocacy in medical management often meant taking the lead in solving problems that required medical oversight. One participant explained how she advocated for herself in the management of the pain associated with the wounds on her hand:

> I was the one with the ulcers that said let's try a topical anesthetic, and so we started doing a liquid lidocaine, and I like soaked my fingers with lidocaine – like 10 years ago, and now they have a lidocaine ointment. He's offering me codeine, which means I can't function the way I want to function, when really we know exactly where the pain is, I don't need my whole body numbed down, I need this [points to fingers] numbed down.

Another participant, who was to undergo fusion of three of her finger joints, discussed how she advocated for her needs while working with her surgeon, who was receptive to her desired expectations. The participant had been a musician for years and was unwilling to give up this important component of her life. She explained how she handled her presurgical appointment: 'I took my cello to his office. I was sitting in the waiting room with the cello case. When they called me in, I carried my cello in. I said I need my fingers to at least bend enough to play'. She worked with her surgeon to determine the position of the fusion that would enable her to continue to play, an option that would have been lost had she not been an effective self-advocate.

Live your life

At present, there is no cure for SSC, and medications, which may provide symptom relief, do little to alter the course of the illness. Consequently, effective coping is essential to maintaining a high quality of life. The theme *Live Your Life* encompasses the physical and emotional challenges of living life with chronic illness. An immediately noticeable characteristic of all three focus groups was their positive attitudes and resolve to live as well as possible with the illness. Many felt that, in retrospect, they were quite lucky because, for example, they had been able to work until retirement eligibility, whereas others were so much worse, or because the disease remained mild for many years. In fact, only one participant, whose symptoms had recently become very active after a change in medications, did not share this attitude. Their interests in attending the focus groups were reflective of this attitude, in which they wanted to meet others with the illness to be a source of support and wanted to shed light on the experiences and challenges of living with SSC.

Because of the protracted diagnostic period of many autoimmune illnesses, the process of learning to live with illness of necessity often precedes diagnosis. However, learning to live specifically with SSC begins with a formal diagnosis. Uncertainty and fear about the future framed the initial reaction to the diagnoses. One participant, whose sister died from SSC, cried

when she heard the diagnosis because she had watched her sister suffer and had a sense of what she might lose. Others had never heard of the illness, and their initial reaction was based in uncertainty and fear of the unknown. One participant said, 'I had never heard of SSC, and that doctor just told me, "Uh you've got CREST, and it's not toothpaste", and I'm like, "What are you talking about?"' Several participants, especially those whose initial symptoms were mild, described their initial coping process as maintaining a state of denial, and while not denying the presence of the illness, they tried not to deal with the ramifications of the illness and endeavored to live life as before until forced to reexamine this approach by a worsening of the disease. They adopted an attitude of living in the present, rather than focusing on what might happen in the future. One participant said:

> When I was first diagnosed, ignorance was kind of bliss early on. They thought it was going to be very progressive lung-wise and, for whatever reason, it really wasn't, 'cause I didn't have bad lung trouble till just a couple of years ago, so 13 years with not any trouble, so I think that sort of fed my denial – like you know SSC, what the heck!

Despite initial approaches and attitudes, all the participants felt that developing a system of support was critical to effectively living with the illness, although there was no universal agreement on what types of support were most effective. Support came in many forms: from emotional comfort and the assurance of a loving network, to a sense of community with other people with SSC, to assistance with necessary physical tasks. Several credited their partners and other family members with being important sources of support, a few discussed the role of friends, and others credited SSC support groups.

Many of the participants had physical limitations, and they had to depend on others for help with household and personal tasks. For example, one participant said, 'My husband's retired, so he helps me a lot. I can't vacuum 'cause I have arthritis … and then like my fingers, I can't open like a can of soda … I can't do a lot of things'. None of the participants indicated that this type of support was not available to them when needed. However, participants had to balance their desire to have a supportive network and physical assistance when needed with their personal need to maintain self-sufficiency. Many found it difficult negotiating the fine line between accepting or asking for help but also maintaining as much independence as possible. A fear of dependency was common, and in their attempt to maintain self-sufficiency many did not allow family members to provide offered assistance and risked alienating these important sources of both physical and emotional support.

> In the very beginning, I had to fight my husband. He wanted to smother me, wait on me. I don't want to be waited on, I want to cook dinner until I just can't stand anymore, and that's the way I am. I don't want to be smothered with sympathy or help. I want to keep doing.

Most participants felt that support groups could be an effective component of coping, although not all found these groups to be physically available or personally useful. Because the community of people with SSC is relatively small, local support groups are not available in many communities. Although the local community had been unable to sustain a group over time, some of the participants had been involved with a local group that had disbanded or had been involved in support groups in other communities. The participants reported that getting to face-to-face support groups could be difficult due to factors unrelated to SSC, such as family and work obligations, and due to factors related to illness, such as difficulty driving in the evening, fatigue, and pain. Those who had attended face-to-face support groups found them to be both supportive and frightening. One participant said:

> When I was attending the support group meetings, there was a lot of patients that their symptoms were pretty far advanced, and then every once in a while, we'd go to a

> meeting and find out that nice lady down the road had already passed on. It was getting to where I almost hated to go because I hated to see people that I was getting to know getting worse, even though the support group was good cause everyone shared experiences, but on the other hand, it was frightening.

Online support groups provided participants another option. They were available when the participants needed or wanted them, and because they draw from an international audience, they were not hindered by the small number of people living with SSC in any single community. They also allowed participants to discuss the issues associated with SSC without having to confront the physical deformities often associated with SSC, which many indicated was a frightening aspect of support groups, especially early in the course of the illness. One participant, talking about an online group, said, 'You feel like in the Internet you don't have to face, sit face to face with people anymore. You can just talk to them and one of the things it's, it's outstanding in my mind'.

SSC affects the body in many ways; dealing with changes in bodily function and body image was an important component of living with the illness. One participant summed up the challenge of coping with this disease when she said, 'My biggest struggle has been that my mind has not figured out yet that my body doesn't keep up any more. My mind thinks it should still be able to do what we used to do and you can't'.

Most of the participants had moderate to severe reflux that affected both diet and sleep, all had Raynaud's, which made dealing with temperature fluctuations caused by changing seasons or air conditioning an ongoing challenge, and many routinely lived with pain and fatigue. Additionally, several of the participants had changes in their mouths and facial appearance, including telangiectasia, and changes in their hands that included swelling, contractures, discoloration, and ulcers. Three participants came to the focus groups with oxygen, and one had recently suffered an amputation as a result of wounds that would not heal; another used a walker. Consequently, the physical challenges of SSC were not only ever present but, in many cases, highly visible to others. Living with the illness meant not only dealing with their physical limitations and altered future, but also having to respond to how they were viewed by others. Many participants were able to relate to others' reactions because they experienced those reactions early in the course of their illness. One participant described how encounters with women at support group meetings affected her:

> I had no idea what SSC was. I had no idea if I was going to die, be in a wheelchair, I had no idea … I saw a lady, I was 31 at the time, but there was a girl, probably in her 20s, that was in a wheelchair, and it looked like she was on her death bed. She was so thin; she had oxygen, a wheelchair, and I thought, oh my gosh, that's going to happen to me. But I kept on going to these support group meetings, and at one of the meetings, I met a lady who was probably about my age now and said she had had SSC for 25 years, and she was full of life and just going on, and I thought okay, I'm going to be like her.

However, other people's reactions were often cruel, and dealing with them at times left participants feeling stigmatized. A participant shared the following experience:

> I was teaching in a men's school, and we had a large meeting, and the principal asked me to sit in the hallway during this meeting, that way, nobody would have to look at my hands. I said, 'So do you even want me coming to the meeting?' 'Well you have to talk'. 'But you don't want me in the room?' 'Right'.

A supportive network and a strong sense of self were all factors that helped participants to not only deal with the changes in their bodies but also with the reactions of others. One participant,

who described her hands as 'funny looking', worked with severely mentally ill children and was taken by their honesty and concern for her. She said:

> Some of these kids are profoundly psychotic. This one said, 'Your hands, are you gonna be okay?' I'm worried about them being okay, but them putting the spin on it in terms of it being okay to talk about stuff, okay to be different, being okay to just put yourself out there and not be so guilty or weird about how people judge you. I think that's what's supported by my clients as well as the people that I work with, as well as my family.

Another important component of living effectively with the illness was using time- and energy-saving devices. Many of the participants struggled, at least for a time, with the notion that using time-saving devices, such as microwaveable meals or precut salads, was a sign of laziness or 'giving in', rather than a way to extend energy. Classes and publications from the Arthritis Foundation helped the participants to appreciate the value of assistive devices. Interestingly, many felt better about using these 'short-cut' items when given permission to do so. One participant described having an epiphany after reading an article put out by the Arthritis Foundation: 'I was reading this [article] where they talk about self-care and coping – they say go out and buy chopped vegetables because there's times when you can't or you don't want to or your hands don't allow – and I said to myself, "Wow, you know, I don't have to feel guilty about that anymore"'. Another participant described the benefits of a class she attended: 'They gave you ideas on how to take shortcuts and not run yourself ragged'.

Learning about SSC

Comprehensive, accurate, and timely information about SSC was viewed as essential to taking control of the illness. However, many of the participants received inadequate or inappropriate information on diagnosis. The participants believed that their physicians should have been the primary source of information about the illness on diagnosis; however, only one participant felt that she had received the appropriate level of information. Although some participants were given no disease-specific information, most were provided with pamphlets to read at home; however, few recalled a discussion about the illness. One participant reported that, on diagnosis, her doctor put his arm around her and said, 'You're so young, I'm so sorry dear', but did not provide her with any substantive information about the diagnosis. Consequently, most of the information seeking that was conducted by the participants was done without guidance from their physicians or other knowledgeable professionals. Many participants initially located inappropriate sources of information because they did not have the skills to filter through dated information or to identify how the general information that they read applied specifically to the manifestations of their illness. For example, one participant recounted:

> I went to the library and got a book, and it was some old book, and started flipping through it and saw these pictures of people with extreme cases and SSC faces. I just sat down on the floor and cried, I just thought it was a death sentence, that I wouldn't be around very long.

Over time, most found sources of information in which they had confidence. Sources that participants found especially helpful were the publications from the National SSC Foundation and the Foundation's Website. Participants found the supplements on medication information especially useful, and many were in the habit of using these publications to look up new medications. The Arthritis Foundation publications were also discussed as a valuable source of information on gadgets and time-saving devices, and the American Lung Association was useful to participants with pulmonary fibrosis.

Almost all of the participants turned to the Internet, with mixed results, at some point in their quest for disease information. One participant indicated that the computer opened up a whole new world of information to her. The participants with higher levels of formal education or who worked in health care seemed to be more adept at filtering information from the Web, whereas others had a difficult time sifting through the abundance of conflicting information. Many of the participants were unaware of how to evaluate Websites for accuracy and bias. As previously mentioned, some of the participants found support groups, either face to face or online, to be a beneficial venue for learning about the illness and tips on illness management. A few of the participants also attended the national meeting of the Scleroderma Foundation, in which they were able to network with other affected individuals and professionals. Interestingly, all learned new things about disease management by sharing in the focus groups, information that they had not encountered from other sources, despite an average of 16 years of living with the illness.

Discussion

The women in this study shared their insights into and experience with living with SSC. The value of this study is not only that it brought the lives of women living with this uncommon and disfiguring illness to light, but it also provides insight into how women have learned to manage the illness over time and how health care providers can assist people with SSC to learn to manage life with the illness. The findings support the importance of developing a disease – specific self-management program to enhance self-efficacy and increase skills necessary for self-advocacy, which the participants identified as essential to effective self-management. Limitations of this study include the relatively small sample size, which was drawn from a single geographic area, and the inherent limitations of focus groups, which tend to normalize responses and to more strongly reflect the opinions of the more assertive group members.

Although these women can generally be viewed as successful in disease management, it took many years of experimentation and difficulty to reach this point. One could argue that an important role for health care providers in assisting individuals with SSC is to shorten this learning curve. Much of what the participants learned over the course of years could have been provided by their health care providers in a comprehensive approach to disease management that included not only medical management of illness progression, but comprehensive management of the illness in the context of the affected individual's life activities. A return appointment postdiagnosis for the purpose of disease education would allow the newly diagnosed individual to learn about the illness after the initial shock of the diagnosis had faded, to have an opportunity to ask basic questions, and to bring a support person to the appointment to help reinforce provided information.

Additionally, comprehensive illness management would include referrals to occupational therapy to provide exercise to maintain function, anticipatory guidance in the use of assistive devices, and treatment of specific disabilities as they occur. Individuals diagnosed with scleroderma would also benefit from referrals to mental health services to discuss issues associated with adjusting to the physical changes in their bodies and an altered future. Newly diagnosed individuals also need to be made aware of organizations that can support the myriad of changes that they will face in managing activities of daily life. Such resources include, Arthritis Foundation classes, reliable Websites, and support groups, both locally and online. Additionally, anticipatory guidance in terms of programs to help them to maintain employment, such as the Family and Medical Leave Act, accommodations through the Americans With Disability Act, and the process of securing Social Security disability benefits, should also be provided, if necessary. This comprehensive approach would go a long way in securing the partnership that participants desired to have with their physicians, but felt was lacking.

Conclusion

The results of focus groups with 11 women diagnosed with SSC for the purpose of discovering essential content for a self-management showed that taking control of their illness was a necessary component of maintaining the highest quality of life possible. A positive attitude, a strong support system, a commitment to moving forward with life, and access to high-quality, timely information all provided the participants with the tools to develop and implement, over time, a strategy of self-advocacy in disease management that enabled them to access needed information and services. Future research should examine the themes identified in this article across a larger sample drawn from geographically diverse areas. Additionally, in-depth individual interviews with women with SSC might uncover divergent ideas that were not expressed in the group context.

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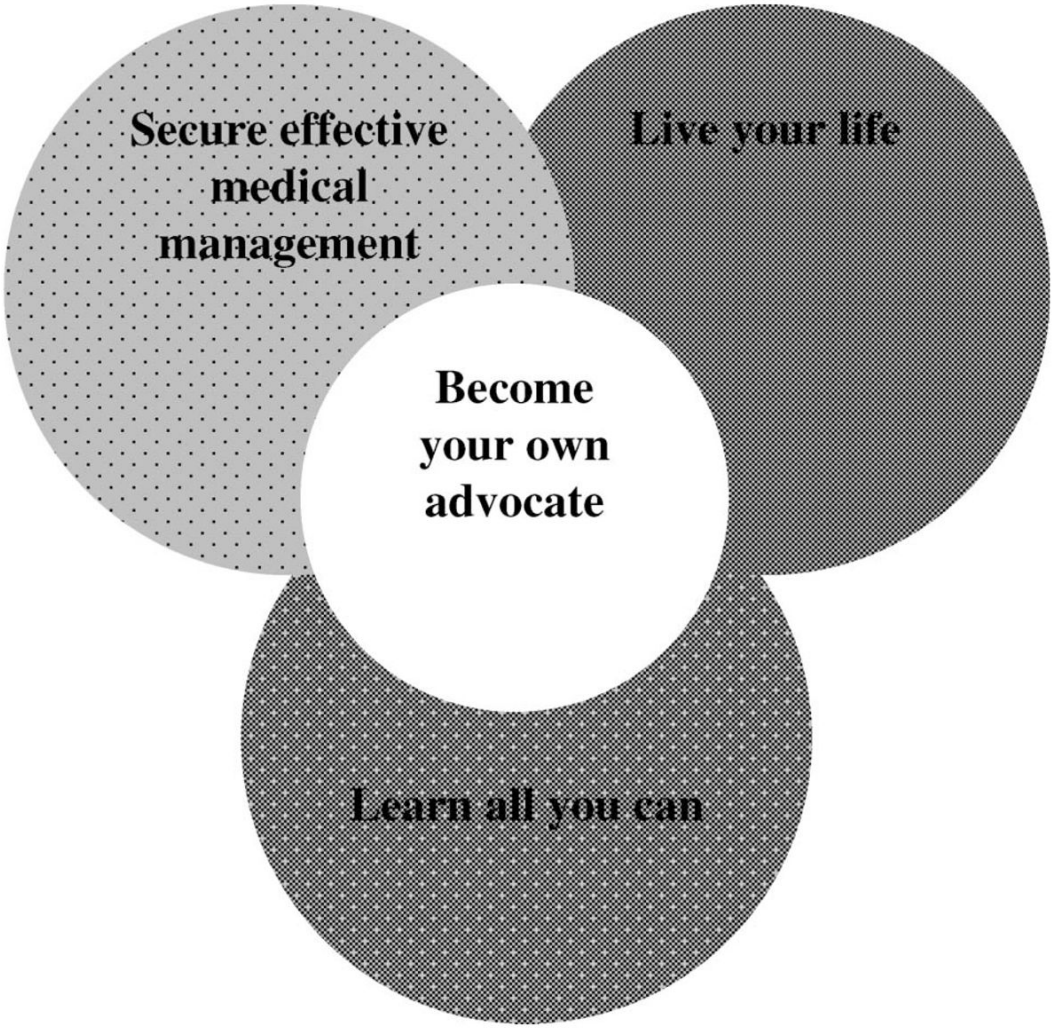

Figure 1.
Taking control of SSC.

Table I

Health distress scale.

	Mean	SD
How much time during the past month:		
Were you discouraged by your health problem?	2.0	1.34
Were you fearful about your future health?	2.36	1.20
Was your health a worry in your life?	2.63	1.36
Were you frustrated by your health problems?	2.54	1.43

0 – 5-point scale: 0 = none of the time, 5 = all of the time. SD = standard deviation.