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# Engagement of patients with scleroderma to revise an internet self-management program

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### Abstract

Systemic sclerosis (SSc) or scleroderma is a rare connective tissue disease. Many people do not have access to education programs. A self-management program was developed several years ago based on the literature and input from people with SSc. However, new therapies and treatment options have been developed since the program was developed. The purpose of this qualitative study was to identify and remedy gaps in an internet SSc self-management program to improve the quality of critical information relevant to effective management of the disease. Six focus groups with 30 participants with SSc were conducted: 2 telephone groups and 4 face-to-face groups. Prior to the focus group meetings, participants reviewed the existing website. A semi-structured interview guide elicited participants' responses. Gaps were expressed in affect and positive affirmation; disease and symptom management; self-advocacy; information for caregivers, families, coworkers and strangers; tracking systems; information about local support groups; pictures and information on underrepresented groups; and general format. Discussants were positive regarding the audio voice over, exercise module, current content, health logs and checklists. People with SSc identified additional content to improve the internet self-management program. Many of the suggestions were incorporated into the existing program as modifications and additions to existing modules, patient testimonials, worksheets, resources sheets, and/or links to additional websites. People with rare, chronic conditions such as SSc need education and reliable sources of information and self-management skills.

### Keywords

Patient engagement, patient experience, systemic sclerosis, self-management, focus groups

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### Introduction

Systemic Sclerosis (SSc) is a rare connective tissue disease affecting the skin, vasculature and internal organs.<sup>1</sup> SSc is 4 times more common in women than men and the prevalence is higher and disease activity is more severe in African Americans.<sup>2</sup> Because SSc is a rare disease, many people do not have access to education programs or support groups. To address the lack of educational programs, a self-management program consisting of a workbook and exercise DVD was developed based on a

search of the literature and input from people with SSc.<sup>3</sup> The modules included the following topics: scleroderma, self-advocacy, coping and body image/appearance, fatigue, activities of daily living, mouth and teeth care, exercise, emergencies, and management of Raynaud's phenomenon, digital ulcers, skin, and gastrointestinal issues. The DVD showed exercises for the face, mouth, and upper and lower extremities that were demonstrated by a woman with SSc. A pilot study showed that the program improved pain and hand function and reduced pain, fatigue and depressive symptoms.<sup>4</sup> Feedback from the participants was positive

and they voted on a name for the program: Taking Charge of Systemic Sclerosis (TOSS). The print format was subsequently converted to an internet version. A specialized website was constructed that transformed the content from all modules into an internet self-management program; an interactive component, a discussion board, was added. In a pilot study of the internet format of the program, participants logged on to a password-protected website and proceeded through the modules and learning activities at their own pace over the course of 10 weeks.<sup>5</sup> Participants were encouraged to log on to the Discussion Board and respond to discussion questions posted for each module. Positive changes were observed for self-efficacy, ability to manage care, health efficacy, fatigue, and depression and the program was well received by the participants.<sup>5</sup>

However, some of the content for the workbook had become outdated as new therapies and recommendations for laboratory and diagnostic tests and pharmacological treatment have been developed.<sup>1,6</sup> Thus, the need to revise the self-management program. A revision would provide more opportunities to systematically engage and get input from potential patient users and stakeholders to ensure that the content and product was valuable and useful.<sup>7</sup> The purpose of this study was to assess whether the internet self-management program had the information people with SSc perceived they need to manage and effectively cope with their disease and to provide comments on the structure and format of the website. The goal was to gather input to inform a revision of the program.

## Methods

Data were gathered through focus group discussions using semi-structured interviews. Focus groups allowed researchers to assess the substantive content of verbally expressed opinions, attitudes, and experiences.<sup>8</sup>

### *Participants*

Persons with scleroderma were recruited from the Scleroderma Foundation website, the Michigan and Southern California Chapters of the Scleroderma Foundation, and patients who were seen at the University of Michigan and the Medical University of South Carolina. Inclusion criteria were 18 years of age or older, a diagnosis of systemic sclerosis (scleroderma), access to a computer and the internet, and English speaking. Focus groups were constructed to represent different groups of people with scleroderma (Hispanic and non-Hispanic whites, African Americans, and women and men) and from stakeholder organizations (Scleroderma Foundation, Scleroderma Research Foundation).

Human subject institutional review board approvals were obtained from the University of New Mexico, University of Michigan and the Medical University of South Carolina.

After participants gave written consent, they completed a demographic questionnaire. Approximately 1 month before the focus group meetings, participants were sent a link to the internet self-management program. Participants were expected to look at all the modules, learning activities and resources and consider content, format and additional content needed before the focus group meeting.

### *Focus group procedure*

Six focus groups were conducted: 2 telephone groups and 4 face-to-face groups. Teleconferencing was conducted with men as there were not enough men at a single location to convene a face-to-face group. Also, previous research has shown that men have different coping styles and educational preferences than women.<sup>9,10</sup> For the teleconference groups, participants called in to a conference call number at a previously determined date and time while for the face-to-face groups, participants attended a meeting at a previously determined place, date, and time. A trained moderator led both the teleconference and face-to-face focus groups along with a local patient partner on the team who had SSc. Before each focus group began, the moderator made introductions and confirmed with the group that the discussion would be audio taped with de-identification of transcripts prior to sharing with the study team and analysis. This procedure was followed for both the teleconference and face-to-face groups.

Semi structured interview questions were used to generate conversations about the TOSS internet self-management website, specifically gaps in the content of the 10 modules and associated learning activities; to learn if the structure and format of the website was user-friendly in terms of navigation through the modules and ease of use (Table 1). Probes focused on specific gaps in content or topics for which more information was needed based on current literature and medical practice. Focus groups were audiotaped and the moderator took notes of focus group discussions. Each focus group lasted about 2 ½ hours. The tapes were transcribed and all identifying information was removed from the transcripts during the verification process.

### *Content analysis*

The de-identified transcripts were imported into NVivo 11 (QSR International, Melbourne, Australia) and analyzed for emergent themes through two stages of content analysis: 1) coding by one researcher to create an initial coding structure grounded in the discussion topics described above and 2) a team process to verify and expand this coding to include sorting of discussions into emergent themes and categories. A second team member

**Table 1. Semi-structured Interview Guide**

- Share your opinion about the existing content. What additional content should be added or expanded on in more detail?
- What do you think of the learning activities? How can we improve the learning activities?
- What, if any, other instructional videos, resources, worksheets, etc. are needed?
- What questions do you think should be posted on the Discussion Board?
- Does the content/format meet the needs for people from underrepresented groups? If not, what format or additional information is needed?
- How can we encourage participation/completion of the program by people from underrepresented groups?

conducted an independent reading of transcripts and edited the initial coding structure. The final coding structure was then shared with all other members of the research team who served as external auditors. Our final consensus on coding appears in Table 3.

## Results

A total of 30 subjects participated in 6 focus groups. The size of the focus groups ranged from 4 to 7. Table 2 shows the demographics of the participants. Content analysis resulted in three major themes descriptive of gaps and

suggested remedies. These are detailed below in the order of predominance found in the discussions:

Content Needed, Under-represented Groups, and Format Changes (Table 3). Each theme and emergent categories (and subcategories) are described using quotes from the discussions.

### *Specific Content Needed*

Gaps in content were voiced in several areas: affect and positive affirmation; disease and symptom management; self-advocacy; information for caregivers, families, coworkers and strangers; tracking systems; and

**Table 2. Demographics of Participants**

Variable	
Mean Age (yrs) $\pm$ SD	48.8 $\pm$ 13.4
Mean Disease Duration (yrs) $\pm$ SD	11.4 $\pm$ 10.0
Mean Education (yrs) $\pm$ SD % $\leq$ 12 grade (N)	15.8 $\pm$ 3.6 26.7 (8)
Type of SSc % Diffuse SSc % Limited SSc % Unclassified	66.7 30.0 3.3
Gender % Female (N) % Male (N)	63.3 (19) 36.7 (11)
Race % Caucasian (N) % African American (N) % Asian (N)	70.0 (21) 23.3 (7) 3.3 (1)
Ethnicity % Hispanic/Latina/o (N) % non-Hispanic/non-Latina/o (N)	10.0 (3) 90.0 (27)
% Married	66.7 (20)
% Working full time	46.7 (14)

**Table 3. Major Themes, Associated Categories and Changes to TOSS**

<b>3 Themes</b>	<b>Category</b>	<b>Subcategories</b>	<b>Changes</b>
<b>Specific Content Needed</b>	Improving personal agency	Affect voice Be own advocate, including asking for help	Testimonials of successful experiences Sections on keeping a positive attitude. Inspirational quotes Work sheets developed on asking for help, delegating, advocate
		Intimacy & sex Pregnancy and child rearing	New module on Sexuality and Intimacy
		Information for families & caregiver	Added module for families/caregivers
		How to explain to strangers, coworkers	Testimonials/examples added on how people have told others about scleroderma.
	Managing and improving QOL	Symptoms <ul style="list-style-type: none"> <li>stages of disease progression</li> <li>relief &amp; pain management</li> </ul>	Antibodies and relation to organ systems New module pain Relaxation, guided imagery
			Adaptive strategies and tools for daily living and increased quality of life
		Medications and drugs	Pain medications Other medications listed in other modules
		Emerging therapies	Clinical trials module
		Medical Care Providers (i.e., insurance OT & PT)	Example of advocating Resources on finding OT or PT
		Record keeping or log	Link to the Healthcare Management Binder -Scleroderma Foundation website
		Raising Awareness	Local support groups
	Need to increase awareness		Links to the SF and SRF provided
	<b>Underrepresented Groups</b>	Men, people of color, non-English speaking, rural	Added pictures and testimonials of people of color and men Male sexual function Module on African Americans Module in Spanish Module is web-based so accessible to all geographic locations with internet.
<b>Format Changes</b>	More pictures and testimonials	Pictures added showing diverse groups with scleroderma added throughout modules	
	Add titles to modules	Each module has a name as well as a number	
	Hyperlinks	Hyperlinks continue to be provided; several added	
	More interactive	The Discussion board will increase the interaction	

aggregated into 3 categories, each containing subcategories detailed below: Improving personal agency, managing, and improving quality of life (QOL), and raising awareness.

**Improving Personal Agency:** This category comprised individual level suggestions needed for improving personal agency or self-efficacy and contained three subcategories: affect and advocacy, intimacy and sex and pregnancy and child rearing, and information for families and caregivers.

*Affect and advocacy* revolved around the recommendations for more positive messages and ways to accept limitations, ask for help and delegate daily tasks. One woman said, “*As women, we always put our wants and needs at the bottom of the list. It’s okay to ask for help. That’s also something that some people have trouble with, especially initially, I think.*”

Participants expressed a need for more content on *intimacy, sexuality, pregnancy and child rearing*. Sexual function and information on relationship building was often placed on the “back burner” at doctors’ visits because there were so many other needs to be addressed: “*If you’ve only got X amount of minutes in a doctor’s office and you’re asking about your medication and everything else and maybe you’ve got your significant other, your life partner, whatever and you don’t have the comfort to say, things aren’t going okay in the bedroom, then you put that on the backburner.*” One man stated “*...men won’t go around telling you that they have sexual dysfunction... but it’s important quality of life issue.*” A woman said “*There are other ways that you can come together as a couple... to be intimate without any acts... that’s really important to really spell out in a module.*” Women, in particular, expressed the need for information on pregnancy and child rearing: “*...you can be pregnant, you can have a normal life... That was information that I wanted from my doctor and I received just a little bit.*” But another woman’s doctor told her “*... there are so many scleroderma patients who have absolutely healthy babies.*”

*Information for families and caregivers* and *how to explain to strangers, coworkers, etc.* revolved around communication and helping others understand a disease that few people have heard about: “*...I need my family and my colleagues to understand what I’m going through, too.*” Well-meaning family members searched for SSc on the internet and found information that was frightening and misleading: “*...when I found out about my disease, my sister was very concerned, but she did it all the all wrong way. So, my family’s been totally petrified of this so it’s hard for me to talk about it because they get too upset about it.*” Other participants mentioned concerns about disclosing information to co-workers and/or strangers: “*...how should you communicate your illness at work? We all know the laws protect us as individuals; we don’t have to go around to our coworkers and let them know that we have an illness, we’re protected. But that doesn’t always work because there are days that I just don’t feel well and I’m very open about what the disease is.*” Others mentioned comments made by friends and/or strangers as

SSc can lead to deformities in the fingers and changes in facial appearance: “*I’ve had people stare at my hands or somebody mention like, ‘wow your fingers are, I don’t know what, tiny little sausages... And so, how do you respond to that?’*”

**Managing and improving QOL:** This was the largest category under the Specific Content theme, with several subcategories specifically related to needed information on the website regarding *symptoms (disease progression, pain management), adaptive strategies for daily living and coping, medications and drugs (including emerging therapies), record keeping, support groups* and *raising awareness*.

SSc is a rare condition and not well known. Participants recognized that SSc affects everyone differently but expressed the need for information on disease progression and symptom management. Pain management was a specific topic that participants said was lacking: “*... pain is one of my biggest problems and so I’m usually prescribed opiates.*”

Participants asked for more information in the content areas of *Adaptive strategies, Tools for daily living, and Coping*. Participants shared their challenges with activities of daily living but also shared successful solutions: “*... that was the part I didn’t expect at all. Like when you first read online I was like, ‘my lungs could go bad or I’ll have GI problems or things with my skin,’ but I didn’t realize that in a year I wouldn’t be able to hook my own bra. I always have to wear a front hooking bra now. How am I supposed to teach my daughter how to tie her shoes when I can’t do it every day?*” A mother said, “*...you have to do things a different way. S hooks are handy. I couldn’t open refrigerator or the cupboards, ‘cause I got too weak, so I put an S hook on my belt loop and then I tied loops, shoestring loops everything and you put the S hook on it and you back off and it opens it, and you don’t have to use your arms or your hands.*” Another woman suggested providing links for products for persons with SSc.

Within the subtheme of *Medications and drugs*, including *emerging therapies*, participants shared the need to understand their medications, the side effects, options and new treatment options for SSc. Participants were also interested in new treatment options: “*What are some of the new experimental trials that are going on? How do I get involved in that? Just having it a link to those kinds of trials would be good.*” And “*I think that we have to stress that we have to be our own advocates and our own educators and that’s another thing with the doctors. A lot of the doctors don’t understand it and we have to educate our own doctors about, what we’re dealing with so that they, have a better understanding of how to treat us.*”

Several participants stated that people with SSc should be given information on *record keeping* to track medications, results from laboratory and other tests, and resources, etc.: “*I remember Dr. [XX] said to me, ‘you should be keeping a binder and every lab result, everything you should be keeping it in there,’ ‘One of the first things that as a patient that helps for me was to make a medical binder. And this is one of the ways I would be able*

*to take charge, take control, to the best of my ability... it helped me emotionally because I felt like I was in control just a little bit by doing that."*

**Support groups and raising awareness:** The final category involved increasing the understanding and visibility of scleroderma through providing information in the internet program about support groups that act nationally as well as on the local level and adding suggestions about how to raise awareness. One man said "...advise people that they should search out local support groups and support meetings." Another woman expressed a need to "have this community of those of us that have scleroderma share some of our advice and information because I don't meet people with scleroderma every day in my everyday life."

### **Underrepresented Groups (Men, people of color, non-English speaking, rural)**

Discussions involving underrepresented groups indicated that more information was needed, including images of African Americans and men with SSc: One male noted "this is supposed to be for men who have scleroderma, I found that most of the references are for women. They are not directly applicable for men." A woman who was African American said "... Asian, even Indian Americans get this, definitely African Americans. If I were new to being diagnosed with scleroderma I would think that this disease does not affect me just by that website, just by that alone". Underrepresented to some participants also meant reaching people in rural areas and those who do not access to support groups of rheumatologists with expertise in SSc. While the internet program does provide access to information to patients who do not live close to scleroderma centers or support groups, internet programs are not available for people who do not have computers or internet access: "Um, but if you have someone that lives in a rural area that doesn't have internet, how would they even know about something like this?" Participants suggested ways to "repackage" the content to reach those without access to the internet such as phone apps, DVDs, computers in doctor's offices, or audiobooks.

### **Format Changes**

Participants commented on both the positive aspects of the format as well as recommended general changes in the *format changes* to make it more user-friendly. They liked the organization, the content of the modules, checklists, the voice over and the video of the exercises. They commented that the website needed more visual materials including pictures, testimonials from people with SSc and titles to the modules (the modules had numbers) and hyperlinks to useful websites. High level insights from the focus group discussions concerned the overall 'personality' of the website and the intended outcomes for the user. For example, many discussants found the text dense and "textbooky". However, discussants were positive regarding the audio voice over, exercise module, current content, health logs and checklists.

## **Discussion**

Focus groups of people with SSc evaluated an existing internet self-management program to ascertain whether it contained information needed by people with SSc and whether the format was appropriate. Key findings that emerged from the discussions were:

Participants were positive and confirmed that the content of the TOSS internet self-management program was relevant and useful for people with SSc. They liked having the internet self-management program as a place to easily find reliable and accurate information. They also identified changes needed in content, representation of people affected with SSc, and format (Table 3). In regard to content needed, participants said that people with SSc must be knowledgeable about SSc and their health needs as they are living with a rare disease that few people have heard about. Participants wanted information on advocacy, pain management, sexuality, intimacy, disease progression, and strategies for daily living and information for families/caregivers. Focus groups members also stated that the pictures and information on the website did not represent all people with SSc. Men wanted more pictures of men, examples of challenges faced by men and a discussion of male sexual function. African Americans participants requested pictures of African Americans and people of color, and more specific information regarding the antibodies found in African Americans with SSc and the corresponding organ system involvement (lung and muscle).<sup>11,12</sup>

The feedback from the participants was used to create a revision of the TOSS internet program (Table 3). For the revision, additional modules and resources were developed on pain management, muscle and lung disease in SS, clinical trials, intimacy and sexual function and tips for caregivers. Research team members with SSc created testimonials of positive and successful responses to challenges, advocacy examples, and how to explain SSc to family friends and co-workers. Feeling obligated to "explain" one's disease or change in appearance has been reported in other studies to lead to social isolation as people begin to distance themselves from social events.<sup>13-16</sup> Hyperlinks to the Scleroderma Foundation and Scleroderma Research Foundation websites were added; these websites contain credible information and resources. Additional resources and/or links were created or added for guided imagery and relaxation, assistive devices, prevention of burnout, navigation of clinical trials, occupational and physical therapy, etc.

Our findings add to the literature regarding the needs of people with SSc and strategies used to manage SSc.<sup>17-19</sup> Psychosocial and physical consequences, treatment options, self-advocacy and strong communication skills are common themes. These themes are confirmed in other

studies which found that while physical and medical needs are often met by health care providers, people with SSc want psychological, emotional and social support as well.<sup>18,20</sup> Indeed, healthcare providers might gain insight into the impact of SSc on the “person” from reviewing the modules and testimonials in the TOSS revision. People with SSc expressed that having knowledge is powerful and increases one’s sense of control. Thus, a self-management program available for people with SSc can increase knowledge, self-confidence and teach skills to become managers of their disease. Indeed, access to on-line resources and support were frequently identified as unmet needs for people with SSc.<sup>3,17-19,21</sup>

Our participants reviewed the original version of the TOSS internet program developed 10 years ago. The changes suggested by the participants also showed that self-management programs need to be reevaluated by people with SSc and revised on a regular basis to make sure programs continue to meet the needs of people with SSc, are current, and are based on the best evidence for pharmacological and nonpharmacological treatments. Format changes and/or repackaging may be needed to reach people who do not access to internet, support groups or rheumatologists with expertise in SSc. However, we did not survey our participants as to whether they preferred to receive health information via the internet versus a paper format. A study in the Netherlands, reported that the preferred method for delivery of health information was the rheumatologist, followed by books/paper format and the internet.<sup>19</sup> While print formats may be preferred by some people, it is much quicker to make revisions to an internet website as new information becomes available than to revise printed books. Translations into other languages, such as Spanish, may be needed. Furthermore, because SSc is a rare condition, health care providers might also benefit from the information contained in the program. Several studies suggested that primary care physicians could benefit from education on diagnosis and management of SSc and concerns of patient with SSc;<sup>22,23</sup> another study suggested better understanding of SSc and patients’ needs might lead to referrals by physicians to health professionals, such as physical and occupational therapists and psychologists, to better meet the psychosocial, physical and self-management an advocacy needs of patient with SSc.<sup>24</sup> Thus, patients and stakeholders and the authors should be encouraged to share the link of the final revision of TOSS with all levels of primary care providers.

There are several limitations to the study. First, the sample was one of convenience and limited to people with SSc who had access to the internet. We attempted to recruit people who were African Americans and Hispanic, however, our sample was largely Caucasian which limits the generalization of the findings. Our findings might have been different if we had more people of color. We also

only included English speaking participants in our study. Therefore, further investigation of the specific needs of non-white and non-English speaking populations is warranted.

There may also have been differences between the teleconference groups and face to face groups as participants may have felt more comfortable voicing their needs and experiences and giving feedback on the phone than in person.

## Conclusions

People with rare chronic conditions, such as SSc, need education and reliable sources of information. Having a rare chronic disease requires self-management skills such as advocacy, management of symptoms, lab work and medications. Input from people with SSc helped inform a revision of the existing program. They identified additional content to improve and revise the internet self-management program. They were also positive about the program and volunteered to provide testimonials, pictures, and resource materials and to author and review newly developed materials. Continuing to engage patients with SSc and stakeholders in continual revisions, to self-management and educational programs such as TOSS will insure the program meets the needs of people with SSc.

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