Mia Pépin et al, Reasons for attending support groups and organizational preferences: A replication study using the North American Scleroderma Support Group Survey, Journal of Scleroderma and Related Disorders (4, 3) pp. . Copyright © 2019. DOI: 10.1177/2397198319849806

Reasons for attending support groups and organizational preferences: A replication study using the North American Scleroderma Support Group Survey

Short Title: Reasons for attending support groups

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Financial Support: This study was supported by funding from the Scleroderma Society of Ontario. Dr. Thombs was supported by a Fonds de Recherche Québec - Santé researcher awards outside of the present work.

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Word Count: 3178

ABSTRACT

Peer-facilitated support groups are an important source for receiving disease-related information and support for people with systemic sclerosis (SSc, or scleroderma). A recent survey explored reasons for attending SSc support groups in Europe and Australia and used exploratory factor analysis to group reasons for attendance into three main themes: (1) interpersonal and social support, (2) disease treatment and symptom management strategies, and (3) other aspects of living with SSc. The objective of the present study was to replicate this study in a sample of patients from North America using confirmatory factor analysis (CFA). A 30-item survey was used to assess reasons for attendance and organizational preferences among SSc patients in Canada and the United States. In total, 171 members completed the survey. In the CFA, the three-factor model showed good fit to the data ($\chi^2[399] = 646.0$, $P < 0.001$, TLI = 0.97, CFI = 0.97, RMSEA = 0.06). On average, respondents rated 22 of 30 items (73%) as 'Important' or 'Very Important' reasons for attending support groups. Among organizational preferences, respondents emphasized the importance of the ability to share feelings and concerns, as well as educational aspects. Findings of our study suggest that reasons for attending support groups are similar for patients from Europe, Australia and North America and that support groups should facilitate social support as well as disease education. These results inform the development of training programs for current and future SSc support group leaders across the globe.

KEYWORDS: Systemic sclerosis; patient support resources; scleroderma; social support; support groups

INTRODUCTION

Rare diseases are chronic, disabling medical conditions that affect fewer than 1 in 2000 people (1). As many as 7000 rare diseases have been identified, together affecting approximately 8% of the world population (2). People with rare diseases face the same challenges as people with more common diseases. In addition, they often face extraordinary challenges related to gaps in knowledge about their disease and its treatment, as well as navigating health care, educational, and social welfare systems that do not have knowledge of their condition and are not designed to meet their needs (2-6). Thus, patients living with a rare disease often have difficulty accessing resources to help them manage their symptoms (2).

Systemic Sclerosis (SSc, or scleroderma) is a rare autoimmune disease that affects the blood vessels and cause excessive quantity of collagen that cause thickening of the skin and severe damage to the internal organs (7,8). It can affect digestive, respiratory, and circulatory systems, as well as cause changes in appearance, chronic pain, and fatigue, amongst other problems for patients (9,10). SSc patients experience many challenges, including limited knowledge of the disease among many health care providers, difficulty obtaining a diagnosis, and unpredictable progression of the symptoms and the disease (10). It is particularly hard for SSc patients to find accurate information about treatment options and support services that could help them deal with their symptoms and improve their well-being (10).

Many people with SSc have organized peer-facilitated support groups to share and receive information and support (10-16). There are currently over 200 SSc support groups across United States and Canada (14,15), for instance. Support groups provide an environment for patients to share and receive SSc-specific practical information and support addressing their emotional needs. A recent survey was developed to explore reasons why people with SSc from Europe and Australia

join and continue to participate in SSc support groups as well as the organizational factors that people consider important for successful groups (16). Using exploratory factor analysis, the survey items were grouped into 3 general themes that reflected reasons for attending a support group: 1) obtaining interpersonal and social support (e.g., openly talking about fears and feelings regarding living with scleroderma), 2) learning about disease treatment and symptom management (e.g., learning strategies that may help to reduce of control medication side effects); and 3) discussing other aspects of living with SSc (e.g., learning about how to fill out insurance and health forms). The most common organizational factors that people considered important for a successful group found in this study were: 1) that there is an opportunity for members to openly discuss their feelings and concerns, 2) having guest speakers address SSc related topics, and 3) how support group membership is constituted (e.g., patients only, patients and their family members and loved ones).

The exploratory analysis that was used in the European study is a data-driven approach, and results should be replicated. Therefore, to ensure that the results can be generalized more broadly, we replicated the study in another sample of patients with SSc administering the same survey and analyzing survey structure using confirmatory factor analysis (CFA) (17,18). The objective of the present study was to assess if the findings of the European and Australian version of the Scleroderma Support Group Study on reasons for joining and continuing to attend SSc support groups can be generalized to SSc support group members from North America. In addition, we evaluated the organizational factors that patients with SSc in North America believe are important for successful support groups.

METHODS

The study sample consisted of people with SSc who completed an anonymous survey through the online survey tool *Qualtrics* between April and August 2015. Respondents were

recruited through: (1) postings on the Scleroderma Canada, Scleroderma Foundation, and Canadian provincial SSc society websites; (2) postings on Scleroderma Canada and Scleroderma Foundation social media platforms (e.g., Facebook, Twitter); (3) distribution of flyers at the 2015 Scleroderma Foundation Annual Conference; (4) announcements in SSc patient newsletters; (5) emails to support group leaders and members across Canada and the United States; and (6) postings in SSc-related chat rooms.

Respondents could complete the survey in English or French. After clicking on the survey link and selecting their preferred language, a brief consent form was shown that described study objectives and provided instructions on how to complete the survey. Respondents were given the option to close their browser and not participate or to provide consent by clicking an arrow to continue with the survey. The survey was set up using cookies to prevent respondents from completing the survey more than once, to reduce the possibility of duplicate responses. To be included in the present analysis, survey respondents had to confirm that they had been diagnosed with SSc, that they were support group members, and indicate that they resided in Canada or the United States.

The study was approved by the Research Ethics Committee of the Jewish General Hospital in Montréal, Québec. Respondents were not required to provide written informed consent because the survey was done anonymously and did not involve collection of any data that could be used to identify respondents, such as names, dates of birth, or telephone numbers.

The Scleroderma Support Group Members Survey

The survey was the same one used in the previously published European Support Group Survey (16). Initial items for the survey were obtained from items that were used in a similar survey related to cancer support groups [19], which was the only previous survey we identified;

generated from published results of a qualitative study on reasons for not attending cancer support groups [20], and generated from responses to a single item on reasons for not attending SSc support groups, which was administered as part of the Canadian Scleroderma Patient Survey of Health Concerns [12]. In that survey, respondents who indicated that they had not participated in SSc support groups were asked to specify their reasons for not attending from the following response options: (1) I'm not interested; (2) None are easily available; and (3) Other (please specify). Respondents' open-ended responses to the "Other" option were analyzed using thematic analysis [12].

All initial survey items were reviewed by research team members, who edited individual items, made recommendations to remove items that were less relevant for SSc or were repetitive, and generated new items to reflect content important to SSc that was not included in the initial item set. Items were reviewed iteratively on several occasions by all research team members until consensus on a final item pool was reached. Team members who participated in this process included representatives from the Scleroderma Society of Canada, the Scleroderma Society of Ontario, and the Scleroderma Foundation; a Patient Advisory Board that consisted of six current SSc support group peer facilitators; and researchers with expertise in SSc.

The final SSc Support Group Members Survey (see Appendix 1) consisted of a demographics questionnaire and survey that assessed: (A) importance of possible reasons for joining and continuing to attend SSc support groups, and (B) organizational factors that respondents believed are important for successful support groups. Part A included 30 items that assessed possible reasons for attending SSc support groups, rated on a 4-point scale (*Not Important (0)*, *Somewhat Important (1)*, *Important (2)*, and *Very Important* (*3*)). Part B of the SSc survey consisted of 9 items assessing organizational and structural preferences for SSc support groups

including aspects such as the location, length, and frequency of the group meetings, rated on a 4-point scale (*Not Important (0), Somewhat Important (1), Important (2),* and *Very Important (3))*. For five of the items, follow-up questions with multiple choice response options were administered to assessed preferences for who patients prefer to be included in the support group (*scleroderma patients only, scleroderma patients and their family members or other loved ones*), location of the group meetings (*hospital, community center, church, private home, library, other*), preferred number of participants (*less than 10, 11-20, more than 20*), and the length (*0-1 hours, 1-2 hours, 2-3 hours*) and frequency of the support group meetings (*once a week, once a month, once every 3 months, once every six months, other*).

Surveys were translated from English into French using a forward-backward translation method. One translator who is a French native speaker from Québec was responsible for translating the questionnaire from English into French, emphasizing their conceptual understanding rather than engaging in literal translations. Following this, the French version was reviewed by a native French speaker from France to make sure the vocabulary used was suitable for participants from France as well. The questionnaire was then translated back to English by a second translator who is an English native speaker and who had no knowledge of the initial questionnaire. The back-translated survey items were then compared with the original English version by members of the research team to evaluate conceptual equivalence of the translation. No conceptual differences were identified.

Statistical analyses

Descriptive statistics were computed to characterize the sample and item responses using SPSS version 22. Confirmatory factor analysis (CFA) was performed to evaluate the fit of the three factors that were previously identified for the support group members survey, using the weighted

least squares estimator with a diagonal weight matrix, robust standard errors, and a mean- and variance-adjusted chi-square statistic with delta parameterization in MPlus version 7 (21). Model fit was assessed with the chi-square test, the Tucker-Lewis Index (TLI) (22), the Comparative Fit Index (CFI) (23) and the Root Mean Square Error of Approximation (RMSEA) (24). Since the chi-square test is highly sensitive to sample size and can lead to the rejection of well-fitting models (25), the TLI, CFI and RMSEA fit indices were emphasized. Good fitting models are indicated by a TLI and CFI ≥ 0.95 and RMSEA ≤ 0.06 (26). Modification indices were used to identify pairs of items for which model fit would improve if error estimates were freed to covary and for which there appeared to be theoretically justifiable shared method effects (e.g., similar wording or conceptual overlap) (27).

RESULTS

Sample Characteristics

Complete survey data were available for 171 patients including 23 (13%) men and 148 (87%) women, with the majority being White (86%) and married (57%). Of these, 104 respondents resided in the United States (61%) and 67 respondents were from Canada (39%). The mean age was 56.3 years (SD = 10.1), the mean time since diagnosis was 10.1 years (SD = 7.5), and the mean years of support group membership was 4.9 (SD = 5.2). Demographic and disease characteristics are shown in Table 1.

Confirmatory Factor Analysis

In the initial CFA, in which measurement errors between all items were specified as uncorrelated, model fit for the hypothesized three-factor model was suboptimal ($\chi^2[402] = 748.8$, $P < 0.001$, TLI = 0.95, CFI = 0.95, RMSEA = 0.07). Inspection of the modification indices indicated that model fit would be improved if the error terms of item pairs 4 and 5, 13 and 14, and

15 and 17 were freed to covary. For these three pairs of items, there was clear conceptual overlap. Items 4 ("*Openly talking about my fears and feelings regarding living with scleroderma*") and 5 ("*Having a safe place where I can freely express my emotions*") both address expressing emotions, items 13 ("*Learning about medications used in scleroderma treatments and their potential side-effects"*) and 14 (*"Learning strategies that may help to reduce or control medication side effects"*) both assess the importance of learning about medication and side-effects, and items 15 ("*Learning helpful nutrition and food preparation tips for people with scleroderma"*) and 17 ("*Learning about alternative healing practices, such as acupressure, herbs, and vitamins, that can complement my medical treatment"*) both address nutrition. Therefore, the model was refitted to the data, allowing the error terms of these item pairs to covary. These changes resulted in a model with good fit to the data ($\chi^2[399] = 646.0$, $P < 0.001$, TLI = 0.97, CFI = 0.97, RMSEA = 0.06).

The three factors representing the reasons for joining and continuing to attend SSc support groups were labelled: (1) Obtaining Interpersonal and Social Support (10 items), (2) Learning about Disease Treatment and Symptom Management Strategies (11 items), and (3) Discussing Other Aspects of Living with SSc (9 items). Factor loadings ranged from 0.61 (item 19) to 0.88 (item 21). See Table 2. The correlation between the "*Obtaining Interpersonal and Social Support"* and "*Learning about Disease Treatment and Symptom Management Strategies"* factors was r = 0.85 ($P < 0.001$), and with the *"Others Aspects of Living with Scleroderma*" factor the correlation was r = 0.72 ($P < 0.001$). The correlation between "*Learning about Disease Treatment and Symptom Management Strategies*" and "*Others Aspects of Living with Scleroderma"* was r = 0.81 ($P < 0.001$).

As shown in Table 3, on average, respondents rated 21.8 of 30 items (73%) as *Important* or *Very Important* reasons attending support groups. The three items most commonly rated as

Important or *Very Important* were 1) Learning how other group members deal with issues related to scleroderma (97%), 2) Learning about current scleroderma research (92%) and 3) Knowing that I'm not alone (91%).

Organizational factors

Table 4 shows the organizational factors that respondents believed are important for successful support groups. The three most commonly items rated as *Important* or *Very Important* were 1) that there is an opportunity for members to openly discuss their feelings and concerns (89%), 2) having guest speakers come discuss scleroderma related topics (84%), and 3) types of people who make up the group (for example scleroderma patient only, scleroderma patients and their family members or other loved ones) (77%). Examination of multiple-choice responses (N=171) indicated that participants preferred that support groups included both SSc patients and their family members or loved ones (N=141; 82%), and that the support groups have between 11-20 members (N=109; 64%). With regards to location, frequency, and length, participants preferred that the support group meetings be held in community centres (60; 35%), occur once a month (N=114; 67%), and last between 1-2 hours (N=133; 78%). See Appendix 2 for a complete list of organizational preferences.

CONCLUSIONS

The main finding of our study was that the reasons for attending support groups and the preferences in terms of organizational factors were similar for people living with SSc in North America as for European and Australian patients. The three main reasons to attend support groups that were identified in a previous study (16) replicated well in the current study. These reasons can be described as: 1) to obtain interpersonal and social support, 2) to learn about disease treatment and symptom management strategies, and 3) to discuss other aspects of living with SSc outside of

symptom management. The organizational factors considered the most important were also the same as in the European and Australia version of the survey. Patients find it important that there is an opportunity for members to openly discuss their feelings and concerns and to have guest speakers come discuss scleroderma related topics. Preferences of North American SSc patients were also similar to those from Europe and Australia in terms of the types of people who make up the group (including both SSc patients and their family members or loved ones), the duration of meetings (1-2 hours), and the location and frequency of meetings.

The findings of our study, suggesting that organizational preferences of support groups are the same in European countries, Australia and North America, imply that support groups could be organized similarly across these countries and that patient organizations who facilitate these support groups may benefit from collaborating and exchange of experiences. This is especially important given that SSc is a rare disease and consequently, resources needed to improve and sustain support groups are scattered. Therefore, using more comprehensive strategies will benefit the greatest number of SSc patients while providing support addressing their needs.

Training and education for support group leaders is one way to ensure that support groups meet members' needs. Most peer leaders of support groups, including leaders of SSc support groups, however, do not receive any training. A systematic review published in 2016 (28) identified only one randomized controlled trial that involved training peer leaders of support groups for people with cancer (29). That trial compared the effects of a 2-day face-to-face group training workshop and 4-month access to a website and discussion forum (N = 29; high resource) to 4 months of website access and discussion forum alone (N = 23; low resource). The trial did not find evidence that the high-resource program was more effective. However, the trial was substantially underpowered, not enough information was provided to determine the content of

the intervention or how it was delivered, and risk of bias was rated as high due to methodological limitations (28).

Based on the knowledge generated from the present study as well as previous studies (11-13, 16), the Scleroderma Patient-centered Intervention Network (SPIN) developed the Scleroderma Support group Leader EDucation (SPIN-SSLED) Program (30). SPIN-SSLED is a training program for SSc support group leaders that provides them with the skills necessary to develop and maintain support groups that meet the organizational preferences and emotional and informational needs of members. The SPIN-SSLED program recently underwent feasibility testing (30), and SPIN has received funding from the Canadian Institutes of Health Research for a full-scale randomized controlled trial (http://webapps.cihr-irsc.gc.ca/decisions/p/project_details.html?applId=388187&lang=en). The trial will assess whether this training program will allow patient SSc support group leaders to feel more confident and supported in their roles as group leaders. This, in turn, would in theory improve support groups, allow for the development of more SSc support groups worldwide in order to increase access, and reduce burden on individual support group leaders. Patient organizations who are participating in the trial include Scleroderma Canada and Canadian provincial organizations, the Scleroderma Foundation of the United States, Scleroderma & Raynaud's UK, the Scleroderma Association of New South Wales (Australia), and Scleroderma New Zealand.

There are a number of limitations related to our study. First, we recruited mostly through patient organizations that may have resulted in over-representation of SSc patients that are more actively involved in self-management of their disease and the SSc community. Second, the survey was only available online, which may have limited access for some people and could influence the generalizability of our results. It is possible that survey respondents may not have been

representative in important ways, such as age, race/ethnicity, level of education, or disease severity. Third, the SSc diagnosis was self-reported by respondents. Consequently, there is a risk that some of the respondents may not have been diagnosed with SSc, although this does not differ from criteria for participating in SSc support groups. Finally, we did not include any open-ended response options, which may have provided additional information.

In conclusion, the results of this study confirm that the reasons for attending support groups and organizational preferences for those groups are similar in two large international samples of SSc patients, and thus, it could be beneficial to centralize resources from both European, Australian and North American SSc organizations to improve the structure of support groups and their ability to meet SSc patients' needs.

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Table 1. Sociodemographic and Disease-Related Characteristics (N = 171)

Variable	
Female, *n (%)*	148 (86.6%)
Age in years, *mean (SD)*	56.3 (11.3)
Location, *n (%)*	
Canada	67 (39.2%)
United States	104 (60.8%)
Race/ethnicity, *n (%)*	
White	147 (86%)
Black & African American	10 (5.8%)
Asian	2 (1.2%)
Two or more	6 (3.5%)
Other	6 (3.5%)
Marital status, *n (%)*	
Never married	20 (11.7%)
Married	102 (59.6%)
Living with partner in committed relationship	12 (7.0%)
Separated	3 (1.8%)
Divorced	27 (15.8%)
Widowed	7 (4.1%)
Highest level in school completed, *n (%)*	
Elementary/primary school	1 (0.6%)
Secondary/High School	24 (14.0%)

Some college/University	59 (34.5%)
University degree	62 (36.3%)
Postgraduate degree	25 (14.6%)
Occupational status, *n (%)*	
Homemaker	10 (5.8%)
Full-time student	3 (1.8%)
Part-time employed	14 (8.2%)
Full-time employed	31 (18.1%)
On leave of absence	0 (0.0 %)
On disability	54 (31.6%)
Retired	50 (29.2%)
Unemployed	9 (5.3%)
Scleroderma diagnosis, *n (%)*	
Limited scleroderma	98 (57.3%)
Diffuse scleroderma	51 (29.8%)
Not known	22 (12.9%)
Years since scleroderma diagnosis, *mean (SD)*	10.13 (7.5)
Years of group membership, *mean (SD)*	4.92 (5.2)

Table 2: Confirmatory Factor Analysis: Factor Loadings

Item and Factor Groupings	Factor 1: Interpersonal/ Social Support	Factor 2: Disease Treatment/ Symptoms Management	Factor 3: Management of Other Scleroderma Related Tasks
Factor 1: Interpersonal and Social Support			
1: Getting suggestions from other group members.	0.75		
2: Providing suggestions to other group members.	0.69		
3: Learning how other group members deal with issues related to scleroderma.	0.78		
4: Openly talking about my fears and feelings regarding living with scleroderma.	0.75		
5: Having a safe place where I can freely express my emotions.	0.86		
6: Knowing that I am not alone.	0.85		

7: Developing relationships with other people with scleroderma.	0.75	
8: Spending time with people who understand what it is like to live with scleroderma.	0.86	
9: Getting comfort and reassurance from other scleroderma patients in the group.	0.87	
29: Providing comfort and reassurance to other scleroderma patients in the group.	0.83	
30: Enjoying fun social activities.	0.69	
Factor 2: Disease Treatment and Symptom Management Strategies		
10: Learning techniques such as meditation, relaxation, or yoga that can complement my medical treatment.		0.70
11: Learning how to more effectively discuss my medical care with my physician and other health care providers.		0.86

12: Learning about other people's experiences with common scleroderma tests and treatments.	0.85
13: Learning about medications used in scleroderma treatments and their potential side-effects.	0.82
14: Learning strategies that may help to reduce or control medication side effects.	0.80
15: Learning helpful nutrition and food preparation tips for people with scleroderma.	0.78
16: Learning about current scleroderma research.	0.74
17: Learning about alternative healing practices, such as acupressure, herbs, and vitamins, that can complement my medical treatment.	0.66
18: Finding out how other people with scleroderma have handled changes to their appearance.	0.77

27: Obtaining information about medical specialists who are knowledgeable about scleroderma.	0.76	
Factor 3: Other Aspects of Living with Scleroderma		
19: Discussing religious or spiritual concerns.		0.61
20: Discussing issues related to death and dying.		0.75
21: Learning how to talk with family and friends about my scleroderma.		0.88
22: Learning how to handle financial issues associated with living with scleroderma.		0.78
23: Learning about sexual issues that may arise as a result of my scleroderma.		0.70
24: Learning about how to fill out insurance and health forms.		0.87
25: Being able to borrow books, tapes, and videos through the support group.		0.72

26: Learning ways to communicate to my employer or work colleagues about my scleroderma.	0.64
28: Learning ways to cope with unwanted attention from having scleroderma.	0.75

Table 3: Items and Frequencies for Part A: Reasons for Attending SSc Support Groups (N = 171)

	Not Important n (%)	Somewhat Important n (%)	Important n (%)	Very Important n (%)	Item Mean (SD)
Factor 1: Interpersonal and Social Support (11 items)					
1: Getting suggestions from other group members.	1 (0.6%)	15 (8.8%)	62 (36.3%)	93 (54.4%)	1.56 (0.68)
2: Providing suggestions to other group members.	9 (5.3%)	25 (14.6%)	78 (45.6%)	59 (34.5%)	1.91 (0.83)
3: Learning how other group members deal with issues related to scleroderma.	1 (0.6%)	5 (2.9%)	38 (22.2%)	127 (74.3%)	1.30 (0.55)
4: Openly talking about my fears and feelings regarding living with scleroderma.	5 (2.9%)	30 (17.5%)	47 (27.5%)	89 (52.0%)	1.71 (0.86)
5: Having a safe place where I can freely express my emotions.	10 (5.8%)	26 (15.2%)	47 (27.5%)	88 (51.5%)	1.75 (0.92)
6: Knowing that I am not alone.	2 (1.2%)	13 (7.6%)	33 (19.3%)	123 (71.9%)	1.38 (0.68)

7: Developing relationships with other people with scleroderma.	5 (2.9%)	28 (16.4%)	68 (39.8%)	70 (40.9%)	1.81 (0.81)
8: Spending time with people who understand what it is like to live with scleroderma.	2 (1.2%)	20 (11.7%)	58 (33.9%)	91 (53.2%)	1.61 (0.74)
9: Getting comfort and reassurance from other scleroderma patients in the group.	2 (1.2%)	28 (16.4%)	68 (39.8%)	73 (42.7%)	1.76 (0.76)
29: Providing comfort and reassurance to other scleroderma patients in the group.	3 (1.8%)	24 (14.0%)	75 (43.9%)	69 (40.4%)	1.77 (0.75)
30: Enjoying fun social activities.	24 (14.0%)	32 (18.7%)	55 (32.2%)	60 (35.1%)	2.12 (1.04)
Factor 2: Disease Treatment and Symptom Management Strategies (10 items)					
10: Learning techniques such as meditation, relaxation, or yoga that can complement my medical treatment.	7 (4.1%)	35 (20.5%)	68 (39.8%)	61 (35.7%)	1.93 (0.85)

11: Learning how to more effectively discuss my medical care with my physician and other health care providers.	6 (3.5%)	27 (15.8%)	52 (30.4%)	86 (50.3%)	1.73 (0.85)
12: Learning about other people's experiences with common scleroderma tests and treatments.	0 (0.0%)	16 (9.4%)	57 (33.3%)	98 (57.3%)	1.52 (0.66)
13: Learning about medications used in scleroderma treatments and their potential side-effects.	4 (2.3%)	11 (6.4%)	53 (31.0%)	103 (60.2%)	1.51 (0.72)
14: Learning strategies that may help to reduce or control medication side effects.	6 (3.5%)	25 (14.6%)	44 (25.7%)	96 (56.1%)	1.65 (0.86)
15: Learning helpful nutrition and food preparation tips for people with scleroderma.	8 (4.7%)	26 (15.2%)	48 (28.1%)	89 (52.0%)	1.73 (0.89)
16: Learning about current scleroderma research.	1 (0.6%)	13 (7.6%)	44 (25.7%)	113 (66.1%)	1.43 (0.66)

17: Learning about alternative healing practices, such as acupressure, herbs, and vitamins, that can complement my medical treatment.	11 (6.4%)	33 (19.3%)	50 (29.2%)	77 (45.0%)	1.87 (0.94)
18: Finding out how other people with scleroderma have handled changes to their appearance.	7 (4.1%)	35 (20.5%)	59 (34.5%)	70 (40.9%)	1.88 (0.88)
27: Obtaining information about medical specialists who are knowledgeable about scleroderma.	3 (1.8%)	14 (8.2%)	42 (24.6%)	112 (65.5%)	1.46 (0.72)
Factor 3: Other Aspects of Living with Scleroderma (9 items)					
19: Discussing religious or spiritual concerns.	88 (51.5%)	47 (27.5%)	24 (14.0%)	12 (7.0%)	3.23 (0.94)
20: Discussing issues related to death and dying.	50 (29.2%)	61 (35.7%)	47 (27.5%)	13 (7.6%)	2.87 (0.93)
21: Learning how to talk with family and friends about my scleroderma.	19 (11.1%)	51 (29.8%)	60 (35.1%)	41 (24.0%)	2.28 (0.95)

22: Learning how to handle financial issues associated with living with scleroderma.	27 (15.8%)	48 (28.1%)	55 (32.2%)	41 (24.0%)	2.36 (1.01)
23: Learning about sexual issues that may arise as a result of my scleroderma.	42 (24.6%)	55 (32.2%)	48 (28.1%)	26 (15.2%)	2.66 (1.01)
24: Learning about how to fill out insurance and health forms.	55 (32.2%)	40 (23.4%)	43 (25.1%)	33 (19.3%)	2.68 (1.12)
25: Being able to borrow books, tapes, and videos through the support group.	58 (33.9%)	55 (32.2%)	40 (23.4%)	18 (10.5%)	2.89 (0.99)
26: Learning ways to communicate to my employer or work colleagues about my scleroderma.	81 (47.4%)	37 (21.6%)	36 (21.1%)	17 (9.9%)	3.06 (1.04)
28: Learning ways to cope with unwanted attention from having scleroderma.	36 (21.1%)	45 (26.3%)	56 (32.7%)	34 (19.9%)	2.49 (1.04)

Table 4: Items and Frequencies for Part B: Organizational Features Important for Successful Scleroderma Support Groups (N = 171)

	Not Important n (%)	Somewhat Important n (%)	Important n (%)	Very Important n (%)	Item Mean (SD)
1: That the group facilitator has received training or accreditation.	25 (14.6%)	43 (25.1%)	64 (37.4%)	39 (22.8%)	2.32 (0.99)
2: Types of people who make up the group (for example, scleroderma patients only, scleroderma patients and their family members or other loved ones).	9 (5.3%)	30 (17.5%)	77 (45.0%)	55 (32.2%)	1.96 (0.84)
3: Location of the group meetings (for example, hospital, community centre, church).	27 (15.8%)	41 (24.0%)	64 (37.4%)	39 (22.8%)	2.33 (0.99)
4: Number of participants in a group.	38 (22.2%)	57 (33.3%)	59 (34.5%)	17 (9.9%)	2.68 (0.93)
5: Length of the group meetings.	22 (12.9%)	58 (33.9%)	73 (42.7%)	18 (10.5%)	2.49 (0.85)

6: How often meetings are held (for example, once a week, once a month).	20 (11.7%)	48 (28.1%)	85 (49.7%)	18 (10.5%)	2.41 (0.83)
7: Having guest speakers come discuss scleroderma related topics.	6 (3.5%)	22 (12.9%)	71 (41.5%)	72 (42.1%)	1.78 (0.80)
8: That there is an opportunity for members to openly discuss their feelings and concerns.	3 (1.8%)	16 (9.4%)	69 (40.4%)	83 (48.5%)	1.64 (0.73)

Appendix 1: Demographics and Scleroderma Support Group Members Survey

STEP 1: Please indicate if you prefer to take the survey in English or French using the drop down list at the top right of the screen.

STEP 2: Once you have chosen your preferred language, please click below to start the survey.

□ □Start the survey!

DEMOGRAPHICS

Directions: The following demographic questions are necessary for us to gain a better understanding of who has completed the survey. The items below will not require you to report any information that could lead to your identification.

1. Please indicate your gender: □ Male □ Female
2. Please indicate your age in years: .....
3. In which country do you live?
   - o Canada
   - o United States
   - o Other……

4. In which Canadian province or territory do you live?

o AB	o NS	o QC
o BC	o NT	o SK
o MB	o NU	o YT
o NB	o ON	
o NL	o PE	

5. In which American state do you live?

o AL	o GA	o ME
o AK	o HI	o MD
o AZ	o ID	o MA
o AR	o IL	o MI
o CA	o IN	o MN
o CO	o IA	o MS
o CT	o KS	o MO
o DE	o KY	o MT
o FL	o LA	o NE

- o NV
- o NH
- o NJ
- o NM
- o NY
- o NC
- o ND
- o OH
- o OK
- o OR
- o PA
- o RI
- o SC
- o SD
- o TN
- o TX
- o UT
- o VT
- o VA
- o WA
- o WV
- o WI
- o WY

6. **For Canadians:** What is your racial or ethnic background? (Please check all that apply)
   - o White
   - o Black
   - o Asian
   - o Aboriginal
   - o Other. Please specify: _____

7. **For Americans:** What is your racial or ethnic background (Please check all that apply):
   - o White
   - o Black or African-American
   - o American Indian/Alaska Native
   - o Asian
   - o Native Hawaiian/Other Pacific Islander
   - o Other. Please specify: _____

8. What is your current relationship status?
   - o Never married
   - o Married
   - o Living with partner in committed relationship
   - o Separated
   - o Divorced
   - o Widowed

9. What is the highest level in school that you completed?
   - o Elementary/primary school
   - o Secondary/high school
   - o Some college/university
   - o University degree
   - o Postgraduate degree

10. What is your current occupational status?
    - o Homemaker
    - o Unemployed
    - o Retired

- On disability
- On leave of absence
- Full-time employed
- Part-time employed
- Full-time student only

11. **For Canadians:** What is your family household income (from all sources):
    - Less than $20,000 CAD
    - Between $20,001 and $40,000 CAD
    - Between $40,001 and $60,000 CAD
    - Between $60,001 and $80,000 CAD
    - $80,001 or greater CAD
    - Prefer not to answer

12. **For Americans:** What is your family household income (from all sources):
    - Less than $20,000 USD
    - Between $20,001 and $40,000 USD
    - Between $40,001 and $60,000 USD
    - Between $60,001 and $80,000 USD
    - $80,001 or greater USD
    - Prefer not to answer

13. What is your scleroderma diagnosis?
    - Limited Scleroderma
    - Diffuse Scleroderma
    - CREST
    - I don't know
    - Other

14. How many years has it been since you first received your scleroderma diagnosis?
    - 0-1
    - 1
    - 2
    - 3
    - 4
    - 5
    - 6
    - 7
    - 8
    - 9
    - 10
    - 11
    - 12
    - 13
    - 14
    - 15
    - 16
    - 17
    - 18
    - 19
    - 20
    - 21
    - 22
    - 23
    - 24

Scleroderma Support Group Members Survey

1. How many years have you been a member of this scleroderma support group?
    a. Dropdown list from 0-1, 2, 3,…..25+

Part A: Reasons for Participating in Scleroderma Support Groups

Directions: We would like to know more about the reasons why you joined and continue to attend a support group. Please indicate the importance of the following reasons.

Response Options:

□ Very Important □ Important □ Somewhat Important □ Not Important

1. Getting suggestions from other group members.
2. Providing suggestions to other group members.
3. Learning how other group members deal with issues related to scleroderma.
4. Openly talking about my fears and feelings regarding living with scleroderma.
5. Having a safe place where I can freely express my emotions.
6. Knowing that I am not alone.
7. Developing relationships with other people with scleroderma.
8. Spending time with people who understand what it is like to live with scleroderma.
9. Getting comfort and reassurance from other scleroderma patients in the group.
10. Learning techniques such as meditation, relaxation, or yoga that can complement my medical treatment.
11. Learning how to more effectively discuss my medical care with my physician and other health care providers.
12. Learning about other people's experiences with common scleroderma tests and treatments.
13. Learning about medications used in scleroderma treatments and their potential side-effects.
14. Learning strategies that may help to reduce or control medication side effects.
15. Learning helpful nutrition and food preparation tips for people with scleroderma.
16. Learning about current scleroderma research.
17. Learning about alternative healing practices, such as acupressure, herbs, and vitamins, that can complement my medical treatment.
18. Finding out how other people with scleroderma have handled changes to their appearance.
19. Discussing religious or spiritual concerns.
20. Discussing issues related to death and dying.
21. Learning how to talk with family and friends about my scleroderma.
22. Learning how to handle financial issues associated with living with scleroderma.
23. Learning about sexual issues that may arise as a result of my scleroderma.
24. Learning about how to fill out insurance and health forms.
25. Being able to borrow books, tapes, and videos through the support group.
26. Learning ways to communicate to my employer or work colleagues about my scleroderma.

27. Obtaining information about medical specialists who are knowledgeable about scleroderma.
28. Learning ways to cope with unwanted attention from having scleroderma.
29. Providing comfort and reassurance to other scleroderma patients in the group.
30. Enjoying fun social activities.

Part B: Organizational Features Important for Successful Scleroderma Support Groups

Directions: We would like to know more about how important you think the following factors are to having a positive support group experience.

Response Options:

□ Very Important □ Important □ Somewhat Important □ Not Important

1. That the group facilitator has received training or accreditation.
2. Types of people who make up the group (for example, scleroderma patients only, scleroderma patients and their family members or other loved ones).
    a. Who would you prefer to be included in the support group?
        - Scleroderma patients only
        - Scleroderma patients and their family members or other loved ones
3. Location of the group meetings (for example, hospital, community centre, church).
    a. Where would you prefer group meetings to be held?
        - Hospital
        - Community Centre
        - Church
        - Private Home
        - Library
        - Other….
4. Number of participants in a group.
    a. What is your preferred number of participants in a group?
        - Less than 10
        - 11-20
        - More than 20
5. Length of the group meetings.
    a. How long would you prefer the group meetings to last?
        - 0-1 hours
        - 1-2 hours
        - 2-3 hours
6. How often meetings are held (for example, once a week, once a month).
    a. How frequently would you prefer the meetings to be held?
        - Once a week
        - Once a month
        - Once every three months
        - Once every six months
        - Other…
7. Having guest speakers come discuss scleroderma related topics.

8. That there is an opportunity for members to openly discuss their feelings and concerns.
9. That group meetings follow a pre-determined agenda.

Appendix 2: Organizational and Structural Preferences of support groups (N=171)

1. Who would you prefer to be included in the support group?
    a. Scleroderma patients only (30; 17.5 %)
    b. Scleroderma patients and their family members or other loved ones (141; 82.5%)

2. Where would you prefer group meetings to be held?
    a. Hospital (33; 19.3%)
    b. Community Centre (60; 35.1%)
    c. Church (4; 2.3%)
    d. Private Home (12; 7.0%)
    e. Library (10, 5.8%)
    f. Other (52; 30.4%)

3. What is your preferred number of participants in a group?
    a. Less than 10 (34; 19.9%)
    b. 11-20 (109; 63.7%)
    c. More than 20 (28; 16.4%)

4. How long would you prefer the group meetings to last?
    a. 0-1 hours (22; 12.9%)
    b. 1-2 hours (133; 77.8 %)
    c. 2-3 hours (16; 9.4%)

5. How frequently would you prefer the meetings to be held?
    a. Once a week (4; 2.3%)
    b. Once a month (114; 66.7%)
    c. Once every three months (37; 21.6%)
    d. Once every six months (6; 3.5%)
    e. Other (10; 5.8%)