Training and support needs of scleroderma support group facilitators: The North American Scleroderma Support Group Facilitators Survey

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Abstract

Purpose: Peer-facilitated support groups are an important resource for people with scleroderma, but little is known about challenges faced by support group facilitators. The objective was to identify training and support needs of scleroderma support group facilitators to inform the development of an educational training program.

Methods: A 32-item survey assessed confidence of support group facilitators to execute tasks necessary for successfully facilitating support groups. Survey items were grouped into seven themes using content analysis.

Results: Eighty North American scleroderma support group facilitators completed the survey. Facilitators were generally confident in their ability to complete tasks related to: 1) Organizing, Structuring, and Facilitating the group; 2) Addressing Individual Member Needs and Diversity of the Group; 3) Helping Members Cope with Grief and Loss; and 4) Attaining and Responding to Member Feedback. They were less confident in their ability to perform tasks related to 1) Managing Difficult Group Dynamics; 2) Promoting and Sustaining the Group; and 3) Balancing Personal and Group Needs.

Conclusion: Results suggest that a training program for scleroderma support group facilitators should address a broad range of topics, including managing difficult group interactions, promotion and maintaining the group, and balancing personal and support group needs.

Keywords: scleroderma, systemic sclerosis, support groups, self-help groups, patient support resources, social support

Introduction

Scleroderma, or systemic sclerosis (SSc), is a rare, chronic, multi-system connective tissue disorder characterized by abnormal fibrotic processes and excessive collagen production that manifests in thickening of the skin and damage to the internal organs, including the kidneys, lungs, heart, and gastrointestinal tract [1, 2]. SSc is typically diagnosed between the ages of 30 and 50 years, and approximately 80% of people with the disease are women [2]. There is no cure for SSc, and the median survival time from diagnosis is approximately 11 years, with patients 3.7 times more likely to die within 10 years of diagnosis (44.9% mortality) than age, race, and sex-matched persons without the disease (12.0% mortality) [3].

People with rare diseases, including SSc, experience many of the same challenges as those with more common diseases, but also face unique challenges, including gaps in knowledge about their disease, difficulty obtaining an accurate diagnosis, and limited treatment and support options [4, 5]. Professionally organized support services, which are often provided to people with more common diseases, are typically not available for SSc patients [6]. Thus, many people with SSc have organized peer-facilitated support groups in order to help them cope with and manage their disease [7, 8].

Illness-based support groups, including SSc support groups, adhere to the principle that people who face similar disease-related challenges can empower one another through social contact and support [9]. Activities of support groups typically involve an educational or information-sharing component, and the giving and receiving of emotional and practical support. Support groups can be configured in a variety of ways; in addition to being facilitated by professionals or peers, they may be held face-to-face, online, or via teleconference and have a structured or unstructured format [10, 11].

There are almost 200 SSc support groups across Canada and the United States, the majority of which are facilitated by peers [7, 8]. Many people with SSc, however, do not have access to support groups [12]. Where support groups are available, they sometimes have difficulty sustaining themselves due to having a single leader whose health worsens or because of shortcomings related to untrained patient leaders. Furthermore, some patients report that they prefer not to attend support groups because the group in their area is poorly organized or is overly negative and not constructive [12].

Education and training for peer facilitators of support groups could enhance the self-efficacy and improve the ability of peer facilitators to carry out their leader-related tasks and reduce the burden they experience in their leadership roles. This, in turn, could enhance access to support groups and the ability of these groups to consistently meet the needs of members. To develop an education and training program, however, information is needed regarding the training and support needs of SSc support group peer facilitators. The present study was conducted to evaluate those needs.

Participants and Methods

Participant sample

People with SSc were recruited to complete an anonymous survey, which was accessible via the online survey tool *Qualtrics* between April and August 2015. Respondents were recruited through 1) postings on Scleroderma Canada’s and the Scleroderma Foundation’s websites, as well as on Canadian provincial SSc society websites; 2) postings on Scleroderma Canada’s and the Scleroderma Foundation’s social media venues (e.g., Facebook, Twitter); 3) distribution of flyers at the Scleroderma Foundation’s annual conference; 4) announcements in SSc patient newsletters; 5) emails to support group facilitators and members across Canada and the United States; and 6) postings in SSc-related chat rooms.

Respondents who accessed the survey website had the option to complete the survey in English or French. After clicking on the survey link and selecting their preferred language, respondents were shown a brief consent form 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 in order 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 resided in Canada or the United States, and that they were a facilitator of a SSc support group at the time they completed the survey.

The survey was approved by the 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 Facilitators Survey

Initial items for the Scleroderma Support Group Facilitators Survey were obtained from the Group Leader Self-Efficacy Instrument (GLSI), which is a 37-item self-report questionnaire that assesses self-efficacy for performing group facilitator skills on a 6-point Likert scale ranging from 1 (Strongly Disagree) to 6 (Strongly Agree) [13]. These were complimented by items obtained from a similar questionnaire that was administered to facilitators of cancer and multiple sclerosis support groups [14], as well as items generated from the published results of a study on the experiences of facilitators of cancer support groups [15].

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 by all members of the research team until a consensus on the final item pool was reached. Team members who participated in this process included representatives from Scleroderma Canada, the Scleroderma Foundation, and the Scleroderma Society of Ontario; a Patient Advisory Board that consisted of six current SSc support group peer facilitators from Canada and the United States; and researchers with expertise in SSc.

The final survey consisted of 32 core items that assessed the confidence of SSc support group facilitators to carry out tasks necessary for facilitating a support group successfully (for full survey, see Appendix). Item response options included Strongly Disagree, Disagree, Slightly Disagree, Slightly Agree, Agree, and Strongly Agree (scored 1-6). In addition, there were three questions that asked respondents to report 1) how long they had been a SSc support group facilitator; 2) whether they had received training for their facilitator role; and 3) whether they had been a group member prior to being a facilitator.

Data analysis

Self-reported sociodemographic and disease-related characteristics were documented. For each item, the number and percentage of participants who responded “Agree” and “Strongly Agree” were tallied. In addition, the mean and standard deviation of item scores were calculated.

To assist in the interpretation of the results, one investigator independently grouped the items into themes. Next, the item groupings and themes were reviewed iteratively by all members of the research team until a consensus was reached. The following seven themes were identified: 1) Organizing, Structuring, and Facilitating the Group; 2) Addressing Individual Member Needs and Diversity of the Group; 3) Managing Difficult Group Dynamics and Members; 4) Helping Members Cope with Grief and Loss; 5) Promoting and Sustaining the Group; 6) Attaining and

Responding to Member Feedback; and 7) Balancing Personal and Group Needs. We did not conduct a factor analysis to attempt to identify themes because our sample was too small.

Results

Sample characteristics

Altogether, 94 peer facilitators completed the survey. Of these, 1 (1%) was excluded because the respondent resided outside of Canada or the United States, 5 (5%) were excluded because respondents reported a diagnosis other than SSc, and 8 (9%) were excluded because respondents were missing some of the 35 survey items (range 6-33 missing items). The sociodemographic and disease-related characteristics of the 80 respondents included in analyses are presented in table 1. Most respondents were female (89%), White (93%), from the United States (78%), married (68%), and had some college or university education (45%). The mean age of respondents was 59 years, and the mean number of years since diagnosis of SSc was 15 years.

The mean number of years that respondents had been facilitating a SSc support group was 8 years (SD = 7). Only 30% of respondents had received any training for their role as a group facilitator, and approximately half (51%) had been a group member prior to being a facilitator.

[Insert table 1 about here]

Item response frequencies

The frequencies of item responses are shown in table 2. The percentage of respondents who agreed or strongly agreed that they were confident in their ability to carry out the 32 group facilitator tasks ranged from 41% to 91%.

[Insert table 2 about here]

Organizing, structuring, and facilitating the group. Overall, respondents were confident in their ability to execute tasks related to organizing, structuring, and facilitating the group. More than 80% of respondents were confident in their ability to help the group establish appropriate group rules (e.g., maintaining confidentiality) (91%), facilitate the group meetings so that all members have an opportunity to speak (90%), provide the structure needed for successful group meetings (86%), and help the group stay focused on topics that are relevant to members (85%). Between 70% and 80% of respondents were confident in their ability to keep the group meetings interesting and relevant to both new and returning members (78%) and to organize and plan activities for group members (e.g., having guest speakers) (71%).

Addressing individual member needs and diversity of the group. The majority of respondents were confident in their ability to implement tasks related to addressing individual member needs and diversity of the group. At least 80% of respondents were confident in their ability to help members feel comfortable in the group and relate to one another (90%), help overly shy group members feel comfortable interacting with the group (89%), help group members relate to other members of a different gender (86%), help group members relate to other members of a different age (86%), and help group members relate to other members of a different cultural background (80%). Fewer than 70% of respondents, however, were confident in their ability to address the different needs of group members at varying stages of the disease (65%).

Managing difficult group dynamics and members. The percentages of respondents that were confident in their ability to perform various tasks related to managing difficult group dynamics and members were quite varied. For example, over 80% of respondents were confident in their ability to intervene effectively when group rules are not being followed (81%). Between 70% and 80% of respondents were confident in their ability to manage group members who oversimplify or minimize the concerns of other members (79%), manage group members who are overly talkative or monopolize the discussion (74%), and manage group members who assume the role of the “know-it-all” (70%). Fewer than 70% of respondents, however, were confident in their ability to manage conflicts and disagreements between group members (63%), talk to a group member about his or her behaviour if it is disruptive to the group (55%), and ask a member to leave the group due to his or her disruptive behaviour (41%).

Helping members cope with grief and loss. Many respondents were confident in their ability to execute tasks related to helping members cope with grief and loss, including supporting members who are grieving (89%) and helping group members cope with difficult events (e.g., death of a member) (78%).

Promoting and sustaining the group. In general, the confidence of respondents in their ability to implement tasks related to promoting and sustaining the group was lower than for other themes. Between 70% and 80% of respondents were confident in their ability to promote the group to health professionals as an important resource for patients (79%). Fewer than 70% of respondents, however, were confident in their ability to effectively publicize the group (55%), obtain financial or other resources needed to run the group (55%), or effectively recruit new members (48%).

Attaining and responding to member feedback. Many respondents were confident in their ability to perform tasks related to attaining and responding to member feedback, such as obtaining feedback from members about the group (80%) and responding constructively to feedback from group members (88%). Obtaining feedback about one’s leadership, however, appeared slightly more difficult to do, as between 70% and 80% of respondents felt confident in their ability to carry out this task (71%).

Balancing personal and group needs. Another area where the percentage of respondents that were confident in their ability to perform tasks was wide-ranging was balancing personal and group needs. For instance, over 80% of respondents were confident in their ability to communicate reasonable boundaries about their availability outside of the group (86%). Between 70% and 80% of respondents were confident in their ability to share responsibilities, including administrative and practical tasks, with a co-facilitator or other group members (76%). Less than 70% of respondents, however, were confident in their ability to recruit a co-facilitator or other group members to help them with leadership responsibilities (66%) and to obtain the support they need to cope with the emotional demands of leading the group (60%).

Discussion

The main finding of this study was that SSc support group facilitators had a high level of confidence in their ability to carry out many support group leader-related tasks; however, they reported lower confidence in their ability to perform tasks in several important areas. SSc support group facilitators were generally confident in their ability to carry out tasks related to the themes 1) Organizing, Structuring, and Facilitating the group; 2) Addressing Individual Member Needs and Diversity of the Group; 3) Helping Members Cope with Grief and Loss; and 4) Attaining and Responding to Member Feedback. On the other hand, support group facilitators were less confident in their ability to perform tasks related to 1) Managing Difficult Group Dynamics; 2) Promoting and Sustaining the Group; and 3) Balancing Personal and Group Needs. Many facilitators expressed having lower confidence in their ability to manage conflicts and disagreements between group members, talk to a member about his or her behaviour if it is disruptive to the group, and ask a member to leave the group due to his or her disruptive behaviour. In addition, facilitators indicated having lower confidence in their ability to effectively publicize the group and recruit new members, as well as obtain financial or other resources needed to run the group. They also had lower confidence in their ability to obtain support to cope with the emotional demands of leading the group.

The findings of this study were generally consistent with those of previous studies that have explored the challenges reported by facilitators of illness-based support groups. We identified several studies that sought to understand the difficulties experienced by cancer support group facilitators [14-16]. The support group facilitators in those studies reported personal challenges, such as maintaining personal balance, preventing burn out, and managing one's own health condition while supporting others; practical challenges, such as access to new and relevant information and guest speakers, lack of resources, and lack of support and referrals from medical professionals; and difficulties with group leadership tasks, including managing complex group dynamics and dealing with the worsening health or death of group members. These challenges are magnified for facilitators of rare disease support groups, including SSc support groups, who often face logistical problems related to small numbers of potential group members, even in urban settings, and limited support from healthcare and patient organizations, which are not as well resourced as organizations for people with more common diseases. This and the finding that SSc support group facilitators reported having lower confidence in their ability to carry out a number of important leader-related tasks, underscores the importance of increased education and training for support group facilitators.

The findings of this study will inform the development of an educational and training program to provide information and skills to support the ability of SSc peer support group facilitators to lead effective, sustainable support groups; reduce the emotional and physical toll on leaders; and encourage new leaders to set up support groups where none exist. Scleroderma Canada and the Scleroderma Foundation in the United States are committed to enhancing the accessibility of SSc support groups, improving the experience of SSc support group facilitators, and improving the ability of SSc support groups to meet patient needs. The training of peer facilitators of support groups could help to improve access to support groups, increase their effectiveness, and reduce facilitator burden, but no well-conducted trials have evaluated the effectiveness of training programs for peer support group leaders. Our research team has partnered with the Scleroderma Canada and the Scleroderma Foundation to develop the

Scleroderma Support group Leader EDucation (SSLED) Program. The SSLED Program will be a 3-month-long, group training program that will be delivered using videoconferencing in order to provide information and skills to improve patient support group leaders' confidence and self-efficacy to carry out their leadership roles.

There are a number of limitations to consider when interpreting the results of this study. First, respondents were recruited through national and provincial SSc organizations, SSc-related chat-rooms and newsletters, and emails to support group facilitators across Canada and the United States. It may have been the case that SSc support group facilitators who were more active within the SSc community and more involved with SSc organizations participated in the study, and these facilitators could differ from other facilitators. Second, the sample size in this study was small. There are fewer than 200 SSc support groups in Canada and the United States [7, 8], however, so the sample represents close to half of all SSc support group facilitators in these two countries. Third, the grouping of items into themes was done on the basis of content because the sample was too small to conduct a factor analysis. However, the item groupings and themes were reviewed iteratively by all members of the research team, which included representatives from the Scleroderma 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. Thus, we feel confident that thematic groupings provided a reasonable structure for interpreting item responses.

Conclusion

Peer-facilitated support groups are an important resource for many people living with SSc. Facilitators of SSc support groups, reported having lower confidence in their ability to carry out a number of important leader-related tasks, including managing difficult group dynamics, promoting and sustaining the group, and balancing personal and group needs.

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Declaration of interest statement

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References

[1] Seibold JR. Scleroderma. In: Harris ED, Budd RC, Firestein GS, et al., editors. Kelley's textbook of rheumatology. 7th ed. Philadelphia (PA): Elsevier; 2005. p. 1279-1308.

[2] Mayes MD. Systemic sclerosis: clinical features. In: Klippel JH, Stone JH, Crafford LJ, et al., editors. Primer on the rheumatic diseases. 13th ed. New York (NY): Springer and Arthritis Foundation; 2008. p. 343-50.

[3] Mayes MD, Jr Lacey JV, Beebe-Dimmer J, et al. Prevalence, incidence, survival, and disease characteristics of systemic sclerosis in a large US population. Arthritis Rheum. 2003;48:2246-55.

[4] European Organisation for Rare Diseases [Internet]. Rare diseases: understanding this public health priority; [cited 2017 Jan 05]. Available from: http://www.eurordis.org/IMG/pdf/princeps_document-EN.pdf

[5] Kole A, Faurisson F [Internet]. The voice of 12,000 patients: experiences and expectations of rare disease patients on diagnosis and care in Europe; [cited 2017 Jan 05]. Available from: http://www.eurordis.org/IMG/pdf/voice_12000_patients/EURORDISCARE_FULLBOOKr.pdf

[6] Kwakkenbos L, Jewett LR, Baron M, et al. The Scleroderma Patient-centered Intervention Network (SPIN) Cohort: protocol for a cohort multiple randomised controlled trial (cmRCT) design to support trials of psychosocial and rehabilitation interventions in a rare disease context. BMJ Open. 2013;3:e003563.

[7] Scleroderma Foundation [Internet]. Support groups; [cited 2017 Jan 05]. Available from: http://www.scleroderma.org/site/PageServer?pagename=patients_supportgroups#.Vbec7RZvdFw

[8] Scleroderma Canada [Internet]. Find a support group; [cited 2017 Jan 05]. Available from: http://www.scleroderma.ca/Support/Find-A-Support-Group.php

[9] Davison KP, Pennebaker JW, Dickerson SS. Who talks? The social psychology of illness support groups. Am Psychol. 2000;55:205.

[10] Aymé S, Kole A, Groft S. Empowerment of patients: lessons from the rare diseases community. Lancet. 2008;371:2048-51.

[11] Barg FK, Gullatte MM. Cancer support groups: Meeting the needs of African Americans with cancer. Semin Oncol Nurs. 2001;17:171-8.

[12] Delisle VC, Gumuchian ST, Peláez S, et al. Reasons for Non-Participation in Scleroderma Support Groups. Clin Exp Rheumatol. 2016;34:56-62.

[13] Page BJ, Pietrzak DR, Lewis TF. Development of the Group Leader Self-efficacy Instrument. The Journal for Specialists in Group Work. 2001;26:168-84.

[14] Zordan RD, Juraskova I, Butow PN, et al. Exploring the impact of training on the experience of Australian support group leaders: current practices and implications for research. Health Expect. 2010;13:427-40.

[15] Butow P, Ussher J, Kirsten L, et al. Sustaining leaders of cancer support groups: the role, needs, and difficulties of leaders. Soc Work Health Care. 2005;42:39-55.

[16] Kirsten L, Butow P, Price M, et al. Who helps the leaders? Difficulties experienced by cancer support group leaders. Support Care Cancer. 2006;14:770-8.

Table 1. Sociodemographic and disease-related characteristics (N = 80)

Variable	
Female, *n (%)*	71 (88.8%)
Age in years, *mean (SD)*	58.5 (12.2)
Location, *n (%)*	
Canada	18 (22.5%)
United States	62 (77.5%)
Race/ethnicity, *n (%)*	
White	74 (92.5%)
Other	5 (6.3%)
Two or more	1 (1.3%)
Marital status, *n (%)*	
Never married	5 (6.3%)
Living with partner in committed relationship	3 (3.8%)
Married	54 (67.5%)
Separated	0 (0.0%)
Divorced	10 (12.5%)
Widowed	8 (10.0%)
Highest level of education, *n (%)*	
Elementary/primary school	0 (0.0%)
Secondary/high school	8 (10.0%)
Some college/university	36 (45.0%)
University degree	22 (27.5%)
Postgraduate degree	14 (17.5%)
Occupational status, *n (%)*	
Homemaker	5 (6.3%)
Full-time student	0 (0.0%)
Part-time employed	3 (3.8%)

Full-time employed	13 (16.3%)
On leave of absence	0 (0.0%)
On disability	30 (37.5%)
Retired	26 (32.5%)
Unemployed	3 (3.8%)
Scleroderma diagnosis, *n (%)*	
Limited scleroderma	39 (48.8%)
Diffuse scleroderma	36 (45.0%)
Not known	5 (6.3%)
Years since scleroderma diagnosis, *mean (SD)*	14.8 (7.8)

Table 2. Item response frequencies

Item	**Rank**^{a}	**“Agree” and “Strongly Agree” n (%)**	**Mean (SD)**
I am confident in my ability to…			
Theme 1: Organizing, Structuring, and Facilitating the Group			
…help the group establish appropriate group rules, such as maintaining confidentiality	1	73 (91.3%)	5.26 (0.81)
…facilitate the group meetings so that all members have an opportunity to speak	2	72 (90.0%)	5.30 (0.80)
…provide the structure needed for successful group meetings	7	69 (86.3%)	5.18 (0.76)
…help the group stay focused on topics that are relevant to members	11	68 (85.0%)	5.07 (0.91)
…keep the group meetings interesting and relevant to both new and returning members	17	62 (77.5%)	4.99 (0.82)
…organize and plan activities for group members, such as having guest speakers	21	57 (71.3%)	4.96 (1.08)
Theme 2: Addressing Individual Member Needs and Diversity of the Group			
…help members feel comfortable in the group and relate to one another	2	72 (90.0%)	5.32 (0.69)
…help overly shy group members feel comfortable interacting with the group	4	71 (88.8%)	5.22 (0.63)

…help group members relate to other members of a different gender	7	69 (86.3%)	5.11 (0.78)
…help group members relate to other members of a different age	7	69 (86.3%)	5.10 (0.69)
…help group members relate to other members of a different cultural background	13	64 (80.0%)	5.02 (0.89)
…address the different needs of group members at varying stages of the disease	25	52 (65.0%)	4.91 (1.01)
Theme 3: Managing Difficult Group Dynamics and Members			
…intervene effectively when group rules are not being followed	12	65 (81.3%)	4.93 (0.91)
…manage group members who oversimplify or minimize the concerns of other members	15	63 (78.8%)	4.93 (0.90)
…manage group members who are overly talkative or monopolize the discussion	20	59 (73.8%)	4.83 (0.91)
…manage group members who assume the role of the “know-it-all”	23	56 (70.0%)	4.79 (0.95)
…manage conflicts and disagreements between group members	26	50 (62.5%)	4.65 (1.03)
…talk to a group member about his or her behaviour if it is disruptive to the group	28	44 (55.0%)	4.47 (1.15)
…ask a member to leave the group due to his or her disruptive behaviour	32	33 (41.3%)	4.00 (1.51)
Theme 4: Helping Members Cope with Grief and Loss			
…support members who are grieving	4	71 (88.8%)	5.35 (0.78)
…help group members cope with difficult events, such as the death of a member	17	62 (77.5%)	4.87 (0.95)
Theme 5: Promoting and Sustaining the Group			
…promote the group to health professionals as an important resource for patients	15	63 (78.8%)	4.93 (1.19)

…effectively publicize the group	28	44 (55.0%)	4.60 (1.15)
…obtain financial or other resources needed to run the group	28	44 (55.0%)	4.19 (1.41)
…effectively recruit new members	31	38 (47.5%)	4.44 (1.26)
Theme 6: Attaining and Responding to Member Feedback			
…respond constructively to feedback from group members	6	70 (87.5%)	5.14 (0.79)
…obtain feedback from members about the group	13	64 (80.0%)	4.99 (0.95)
…obtain feedback from members about my leadership	21	57 (71.3%)	4.80 (0.92)
Theme 7: Balancing Personal and Group Needs			
…communicate reasonable boundaries about my availability outside of the group	7	69 (86.3%)	5.06 (0.75)
…share responsibilities, including administrative and practical tasks, with a co-facilitator or other group members	19	61 (76.3%)	4.87 (1.28)
…recruit a co-facilitator or other group members to help me with leadership responsibilities	24	53 (66.3%)	4.69 (1.18)
…obtain the support I need to cope with the emotional demands of leading the group	27	48 (60.0%)	4.56 (1.19)

[a] Items are ranked based on the number and percentage of participants that answered “Agree” and “Strongly Agree.”