Reasons for non-participation in scleroderma support groups

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ABSTRACT

Objective. *Peer-led support groups are an important resource for people living with many rare diseases, including scleroderma (systemic sclerosis, SSc). Little is known, however, about the accessibility of SSc support groups and factors that may discourage people from participating in these groups. The objective of this study was to identify reasons why people with SSc do not participate in SSc support groups.*

Methods. *Canadians with SSc were recruited to complete the Canadian Scleroderma Patient Survey of Health Concerns and Research Priorities. Data from respondents who answered the question "Have you participated in SSc support groups?" with "No" were analysed. Frequencies of participants who responded (1) I'm not interested, (2) None are easily available, and (3) Other (please specify) were tallied. A content analysis approach was used to code the open-ended responses to this question.*

Results. *A total of 280 respondents provided a reason for non-participation in SSc support groups. Key reasons for not participating in support groups included: (1) Not interested or no perceived need (36%); (2) No local support group available (35%); (3) Lack of awareness of the existence of SSc support groups (13%); (4) Practical barriers (6%); (5) Emotional factors (4%); (6) Uncertainty about whether to attend (4%); and (7) Negative perceptions about support groups (3%).*

Conclusion. *SSc organisations may be able to address current limitations in the accessibility and effectiveness of SSc support groups by implementing online support groups, as well as by providing support group leaders training to help establish and sustain successful SSc support groups.*

Introduction

People with rare diseases, including scleroderma (systemic sclerosis; SSc), experience many of the same challenges as people with common diseases. These include physical and psychological symptoms that require them to modify their family, social, and professional roles (1-4). Additionally, due to gaps in knowledge about their disease, people with rare diseases often face substantial delays in diagnosis (6-8) and, limited treatment and support options (7-9).

In the absence of professionally organised and delivered support services (1), people with rare diseases have mobilised their own support systems in the form of peer-led support groups (9). Peer-led support groups adhere to the principle that people who face similar disease-related challenges can empower one another through social contact (10). Group activities typically involve educational or information-sharing components, and the giving and receiving of emotional and practical support (11, 12).

Peer-led support groups are an important resource for many people with SSc (13). SSc is a rare chronic autoimmune connective tissue disease characterised by abnormal fibrotic processes and excessive collagen production, which manifests itself in skin thickening and internal organ damage, and vascular implications (14). The prevalence of SSc in Canada is 44 cases per 100,000 (15). As with many other rare diseases, people with SSc initially experience debilitating symptoms, and may struggle to obtain a diagnosis (6). Once diagnosed, the future is uncertain, as disease course is unpredictable (16). Marked disfigurement from the disease sets many people with SSc apart, and some have described changes in physical appearance so drastic that they are no longer recognised by acquaintances (17-19).

Currently, there are approximately 30 SSc support groups in Canada and 150 in the US, and all of them are peer-led (20, 21). The Scleroderma Society of

Canada and the Scleroderma Foundation in the US help SSc patients locate support groups, but provide almost no information regarding starting a support group or formal training and support to peer facilitators. These organisations are committed to developing an infrastructure, including a training and support programme for peer facilitators, to improve access to support groups and the ability of these groups to meet members' needs. To do this, information is needed regarding SSc support group accessibility and factors that may discourage people from utilising them. We identified only two studies that assessed factors that influence participation in support groups (22, 23), but both involved cancer patients. No studies have been done with rare disease patients. Thus, the objective of this study was to explore, among SSc patients who do not attend SSc support groups, reasons for non-participation.

Patients and methods

Canadians with SSc completed an anonymous online questionnaire, the Canadian Scleroderma Patient Survey of Health Concerns and Research Priorities, between September 2008 and August 2009 (24, 25). Recruitment occurred through advertisements (1) in Canadian Scleroderma Research Group (CSRG) physicians' offices; (2) at the Scleroderma Society of Canada's annual conference; (3) in newsletters and on websites of the Scleroderma Society of Canada and Sclérodermie Québec; (4) in Canadian magazines; and via (5) emails to support group facilitators. Participants could complete the survey online or by requesting a paper version. Respondents were included in the present study if they reported a diagnosis of SSc by a healthcare provider, were ≥18 years old, resided in Canada, and answered the survey question "Have you participated in SSc support groups?" with "No". Respondents who selected "No" were asked to specify their reasons for not attending. Response options included: (1) I'm not interested; (2) None are easily available; and (3) Other (please specify). We did not evaluate the proportion of patients who reported participating in SSc support groups because some respondents were recruited through support groups. Thus, this proportion would not provide an accurate reflection of the proportion of Canadians with SSc who attend these groups.

The McGill University Institutional Review Board approved the study. Participants did not provide written informed consent because the survey was anonymous.

Data analysis

Among participants who answered the question "Have you participated in SSc support groups?" with "No," we documented self-reported sociodemographic and disease-related characteristics. Frequencies of participants who responded (1) I'm not interested, (2) None are easily available, and (3) Other (please specify) were tallied. A content analysis approach was used to code the open-ended responses. This allowed data from the open-ended response option, "Other (please specify)," to be synthesised with data from the closed-ended response options.

Content analysis is a method used to codify interpretation of content from text data (26-28). This method is most useful when existing theory or research literature on a phenomenon is limited because researchers can approach the data without preconceived categories, instead allowing categories and themes to be generated from the data (26-28). Since research on why people do not attend support groups is limited, this method was appropriate.

Two investigators independently analysed participants' open-ended responses. First, responses were coded into categories and then categories were grouped into themes. To identify categories, responses were first read numerous times by each investigator in order to obtain a sense of the data as a whole. Next, one investigator read responses and highlighted statements that appeared to capture key thoughts or concepts. Then, the investigator re-read the responses to develop codes indicative of potentially significant categories and coded the data using these categories. Following this, a second investigator independently read the responses and coded the data using the same categories. The two investigators discussed their coding in order to achieve consensus on categories and resolve any discrepancies in text codings. In cases where consensus was not reached, a third investigator was included. The two closed-ended response options, "I'm not interested" and "None are easily available," were coded as the categories "Not interested" and "No local support group," respectively. These codes were also used for open-ended responses that reflected category content.

After assigning response categories, the first investigator grouped the categories into themes. This process was repeated by the second investigator. Then, the assignment of categories into themes was discussed to resolve any uncertainties.

Results

Sample characteristics

Altogether, 856 surveys were completed with most (n=669, 78%) done online. Of the 856 total surveys, 65 (8%) were classified as likely duplicates based on matching demographic data and were excluded. This generally occurred when respondents began the online survey, submitted part of it, and subsequently started again. Of the 791 people who completed all or part of the survey, 88 (11%) were excluded because they did not report having been diagnosed with SSc by a healthcare provider; 19 (2%) because they answered demographic questions only; 62 (8%) because they were <18 years of age or did not report their age; 59 (7%) because they were not from Canada; 41 (5%) because they did not answer the question "Have you participated in SSc support groups?"; and 225 (28%) because they answered the question "Have you participated in SSc support groups?" with "Yes."

A total of 297 people answered the question "Have you participated in SSc support groups?" with "No". Sociodemographic characteristics of the sample are presented in Table I.

Reasons for non-participation

Of the 297 people who indicated they had not participated in SSc support

Table I. Sociodemographic characteristics (n=297)*.

Variable	
Female gender, n (%)	254 (85.5%)
Age in years, mean (standard deviation)	52.3 (13.9)
Race/ethnicity, n (%)[¥]	
White	191 (84.9%)
Other	30 (13.3%)
White and other[¶]	4 (1.8%)
Level of education, n (%)	
Less than high school	36 (12.1%)
High school graduate	179 (60.3%)
University graduate	82 (27.6%)
Marital status, n (%)	
Single	35 (11.8%)
Married	210 (70.7%)
Separated/divorced/widowed	52 (17.5%)
Primary spoken language, n (%)	
English	217 (73.1%)
French	80 (26.9%)
Working (full time or part time), n (%)	116 (39.1%)
Treated by rheumatologist, n (%)[·]	152 (51.5%)
Years since SSc diagnosis, mean (standard deviation)[‖]	9.5 (10.0)

*For variables with data missing, the sample size is indicated in the footnotes.
[¥]n=225; [·]n=295; [‖]n=296. [¶]Individuals who selected "White," as well as another race/ethnicity.

groups, 3 (1%) did not provide a reason for non-participation and 14 (5%) provided a reason that was unclear (*e.g.*, "I don't know"). Of the 280 respondents who provided a reason, 78 (28%) chose the response option "I'm not interested;" 95 (34%) chose the response option "None are easily available;" and 107 (38%) chose the response option "Other (please specify)".

An analysis of the text of the 107 open-ended responses resulted in 96 (90%) respondents receiving one code; 9 (8%) receiving two codes; and 2 (2%) receiving three codes. Thus, 120 coded responses were generated from the open-ended response option "Other (please specify)." Based on content analysis, 16 categories were generated to capture reasons for non-participation, including: (1) Not aware of support groups generally (n=30, 25%); (2) SSc symptoms not severe (n=13, 11%); (3) Other demands or too busy (n=12, 10%); (4) No need for support (n=10, 8%); (5) Newly diagnosed or diagnostic uncertainty (n=7, 6%); (6) Not aware of local support groups (n=7, 6%); (7) Discomfort facing others with SSc (n=6, 5%); (8) No local support group (n=6, 5%); (9) Support groups too negative (n=6, 5%); (10) Already have alternative source of support (n=5, 4%); (11) Not ready (n=5, 4%); (12) SSc symptoms too severe (n=4, 3%); (13) Support groups not helpful (n=3, 3%); (14) Currently looking for information on support groups (n=2, 2%); (15) Not comfortable (n=2, 2%); and (16) Planning on attending (n=2, 2%).

Themes

Based on the 16 response categories, 7 themes were identified: (1) Not interested or no perceived need; (2) No local support group; (3) Lack of awareness of support groups; (4) Practical barriers; (5) Emotional factors; (6) Uncertainty and contemplation; and (7) Negative perceptions. Thematic groupings and corresponding response categories are provided in Table II. Frequencies of responses for each theme include the total number of patient responses for included categories, including responses to the closed-ended (n=173) and open-ended (n=120) survey items.

Not interested or no perceived need (n=106, 36%). Seventy-eight (27%) people selected the closed-ended response option "I'm not interested." Thirteen (4%) people indicated they were in good health or experienced minimal symptoms and, therefore, did not feel the need to attend a support group. For example, one respondent mentioned being "very healthy." Ten (3%) people made general statements about not needing support without a more specific reason. Five (2%) respondents reported they were already receiving support through means other than a support group and did not require additional support (*e.g.*, "I keep busy and receive support from my family and friends").

No local support group (n=101, 35%). This included people who selected the closed-ended response option "None are easily available" (n=95, 32%), and those who selected the open-ended response option "Other (please specify)" and then indicated there was no support group in their area (n=6, 2%).

Lack of awareness of support groups (n=37, 13%). Thirty (10%) people indicated they were not aware of support groups generally (*e.g.*, "I didn't know they exist") and 7 (2%) indicated they were not aware of local support groups (*e.g.*, "I don't know of any in my area"). The coding category "Not aware of local support groups" included in this theme and the category "No local support group" included in the previous theme differ in that the former included statements suggesting a lack of awareness about whether or not there may be a group, whereas the latter included statements that indicated a clear lack of availability.

Practical barriers (n=16, 6%). Twelve (4%) people indicated they were too busy with other commitments, such as family or work, to attend a support group (*e.g.*, "I work and don't have time") and 4 (1%) indicated that they were too ill or disabled to participate in a support group.

Emotional factors (n=13, 4%). Six (2%) people indicated they did not attend a support group because they were afraid to interact with or see others with SSc who were worse off. For instance, one respondent mentioned, "It scares me to see myself in others." Five (2%) people made general statements about being emotionally unprepared to attend a support group, but did not elaborate further. Two (1%) respondents reported they were not comfortable attending a

Table II. Response categories and themes.

Theme	Response categories	n (%)	Definitions
Not interested or no perceived need	Not interested	78 (26.6%)	Selected the close-ended response option "I'm not interested."
	SSc symptoms not severe	13 (4.4%)	Any reference to an individual not needing a SSc support group because they are in good health or experience only minimal symptoms.
	No need for support	10 (3.4%)	Any reference to an individual not currently needing support.
	Already have alternative source of support	5 (1.7%)	Any reference to an individual currently receiving support through means other than a support group. Examples might include support from family, friends, and health care professionals.
No local support group	No local support group	101 (34.5%)	Selected the closed-ended response option "None are easily available" or selected the open-ended response option "Other (please specify)" and then indicated that there were no SSc support group in their area.
Lack of awareness of support groups	Not aware of support groups generally	30 (10.2%)	Any reference to an individual not being aware of the existence of SSc support groups in general.
	Not aware of local support groups	7 (2.4%)	Any reference to an individual not being aware of the existence of local SSc support groups.
Practical barriers	Other demands or too busy	12 (4.1%)	Any reference to an individual being too busy with other commitments, such as family or work.
	SSc symptoms too severe	4 (1.4%)	Any reference to an individual being unable to attend a SSc support group due to disability or the severity of their symptoms.
Emotional factors	Discomfort facing others with SSc	6 (2.0%)	Any reference to an individual being afraid to interact with or see others with SSc, such as people with a more severe diagnosis or more severe symptoms. Patients may express being afraid to see how bad the disease can get or what their future may hold.
	Not ready	5 (1.7%)	Any statement indicating that an individual is not yet emotionally prepared to attend a SSc support group.
	Not comfortable	2 (0.7%)	Any reference to an individual not being comfortable attending a SSc support group due to general concerns about social comfort not necessarily related to SSc (*e.g.*, discomfort in groups).
Uncertainty and contemplation	Newly diagnosed or diagnostic uncertainty	7 (2.4%)	Any reference to an individual being recently diagnosed, in the process of being diagnosed, or just learning about SSc.
	Currently looking for information on support groups	2 (0.7%)	Any reference to an individual attempting to learn more about SSc support groups before deciding whether or not to attend.
	Planning on attending	2 (0.7%)	Any reference to an individual planning on attending a SSc support group in the near or distant future.
Negative perceptions	Support groups too negative	6 (2.0%)	Any reference to the tone of SSc support groups being negative.
	Support groups not helpful	3 (1.0%)	Any reference to the idea that an individual does not believe that attending a SSc support group would be helpful.

support group because they "preferred to deal with the condition privately" or due to concerns about social discomfort not necessarily related to SSc.

Uncertainty and contemplation (n=11, 4%). Seven (2%) people indicated they had been recently diagnosed with SSc or were in the process of being diagnosed with or learning about SSc and, therefore, had not attended a support group. For example, one respondent said, "When I find out more about my condition I will decide." Two (1%) respondents indicated they were attempting to learn more about support groups before deciding whether to attend (*e.g.*, "I am currently investigating") and 2 others (1%) mentioned they planned to attend a support group in the future.

Negative perceptions (n=9, 3%). The most frequent (n=6, 2%) negative perception mentioned by respondents was that the atmosphere or tone of support groups is negative (*e.g.*, "Too depressing and fixated on the disease"). The second most frequent (n=3, 1%) negative perception reported was that attending a support group would not be helpful (*e.g.*, "I don't feel it would benefit me").

Discussion

Among people with SSc who do not participate in SSc support groups, the most common reason for non-participation was not being interested in SSc support groups or not perceiving a need for additional support because of good health, minimal symptoms, or already receiving support through other means.

The second most common reason was lack of availability of local SSc support groups, and the third most common reason was lack of awareness of the existence of SSc support groups. Other reasons for non-participation included: practical barriers, such as alternative commitments or being too ill or disabled; emotional factors, such as being afraid to interact with or see others with SSc; being recently diagnosed or attempting to learn more about SSc support groups before deciding whether to attend; and having negative perceptions about the tone or helpfulness of SSc support groups.

We were unable to identify previous studies examining reasons why people with a rare disease, such as SSc, do not attend illness-based support groups. However, we did identify two studies exploring factors that influence participation in cancer support groups (22, 23). The first study (22) used a combination of focus groups and telephone interviews to assess reasons for not attending cancer support groups among 26 patients with any form of cancer who had never attended a support group and who were recruited through oncology clinics in Sydney, Australia. Reasons for non-attendance were categorised into individual and group factors. Individual factors included: resisting the position of "cancer patient;" personality factors, such as being an introvert or preferring to cope alone; and already having enough support. Group factors included: believing that support groups are negative places; lacking knowledge about what support groups involve; needing more in common with other group members than having cancer; and practical issues, such as the availability of the respondent, and the location and timing of the group.

In the second study (23), authors interviewed 93 women with breast cancer recruited from oncology and radiology clinics at a hospital in Adelaide, Australia, of whom 55 reported that they did not plan to attend a support group. The most common reasons for not planning to attend included: currently having enough information or support; practical issues, such as the location and timing of the group; and not wanting to focus on having cancer. Other less commonly endorsed reasons included: being in good health; being too sick; disliking groups; and worrying about seeing others who are worse off.

Although the nature of SSc and cancer differ significantly, and SSc support groups are almost exclusively peer-led whereas cancer support groups are typically professionally led, the findings from the present study and the two studies of cancer patients have a number of similarities. In particular, all three studies found that many patients report already having good support networks and do not believe that they would benefit from attending a support group. While on one hand this type of response may reflect good existing support networks, it may also be the case that some people who do not attend support groups may not understand that these groups can address needs that other forms of support cannot, such as the ability to share experiences with others undergoing similar disease-related experiences. Additionally, the three studies found that practical issues, such as the accessibility and timing of the groups, influence participation.

The most notable difference between the findings of the present study and the two studies of cancer patients is that in the this study, a common reason for not participating in support groups was not being aware of the existence of SSc support groups in general or the existence of local SSc support groups. Lack of awareness was not identified as a reason for non-participation in cancer support groups. One possible explanation is that because SSc support groups are not available in many locations and are not typically available through healthcare settings, people who live in settings where there are no groups may not be aware that they exist at all. A second possible explanation is that since existing SSc support groups are almost all peer-organised and led, they may not be advertised as frequently or widely as support groups for common diseases, such as cancer, that are professionally led and provided through the healthcare system. A third possible explanation is that because SSc is a rare disease, many patients may not have the opportunity to meet other people with SSc who can tell them about the disease and helpful resources, such as support groups.

Findings from the present study suggest a number of ways in which SSc patient organisations may be able to address current limitations in the accessibility and effectiveness of SSc support groups. Given that many SSc patients do not have access to support groups due to geographical distance or physical disability, implementing online support groups may be an economical and feasible option for delivering support to those with SSc. For many common medical illnesses, such as cancer, online groups have become increasingly popular (29, 30). Data are not available for Canadian SSc patients, but a recent study found that 85% of Dutch SSc patients use the internet for disease-related purposes (31).

Another possible way to increase the availability and success of SSc support groups is to provide training for peer facilitators of these groups. This would provide SSc patients with skills to successfully establish and manage support groups where none exist. Moreover, many participants in this study indicated they do not participate in support groups because they are afraid to interact or see others with SSc or because they have negative perceptions about these groups. Trained peer facilitators could address these concerns more effectively and, thus, improve the ability of existing groups to meet patients' needs. Finally, a number of participants in this study reported that they were not aware of support groups; it may be possible to improve awareness of existing groups through advertisements at annual conferences, in patient newsletters, or on the websites of SSc patient organisations.

There are several limitations that should be considered when interpreting the results of this study. First, people who participated in this study constitute a convenience sample of SSc patients. Specifically, recruitment occurred through CSRG physicians, national and provincial SSc organisations, and SSc support groups, which may have influenced the characteris-

tics of respondents. Furthermore, the majority of survey dissemination and response collection was electronic, which may have also influenced the representativeness of the sample. Second, given the self-report nature of the survey, there is no way to be certain that all participants had SSc. Third, a majority of survey respondents did not know their SSc diagnosis subtype, likely because physicians do not often use this terminology with patients. Therefore, we were unable to explore whether the reasons for non-participation may have differed between people with varying degrees of symptom severity. Fourth, female and male participants were combined in this study, and it is possible that the reasons for non-participation may differ between sexes. Given the small number of men in this study, however, it was not possible to examine this. Fifth, most of our sample was White and, as such, our results may not be representative of people from different racial or ethnic backgrounds. Sixth, we did not ask participants whether their physician had informed them about SSc support groups, which could be useful for understanding non-attending. Seventh, participants who answered the question "Have you participated in SSc support groups?" with "No" were required to choose one of three answer options and the two closed-ended response options did not allow respondents to elaborate or explain their choice. Thus, given the format of the survey, we were able to elicit a broad list of reasons for non-participation, but could not be certain about the relative proportion of reasons. Future studies using more systematic methods for assessing reasons for non-participation, such as survey methods that query all respondents about the importance of possible reasons for non-participation, are needed. The present study provides important background information that could be used to develop such a survey. Finally, this study did not explore the reasons why people do participate in scleroderma support groups. This is also an important topic for future studies.

In conclusion, peer-led support groups are an important resource for many SSc patients. However, there is limited research on the factors that may discourage them from attending these groups. This study found that many patients reported (1) they were not interested in support groups or did not perceive a need for support because they were in good health, experienced minimal symptoms, or already received support through means other than a support group; (2) there was not a support group available locally; or (3) they were not aware of the existence of support groups, generally, or of local groups. Other reasons for non-attendance included being too busy, being afraid to interact with or see others with SSc, being recently diagnosed or in the process of being diagnosed with SSc, and having negative perceptions about SSc support groups. These findings will inform SSc organisations on how they may be able to enhance access to support groups and improve their ability to meet members' needs on a sustained basis.

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