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Reasons for not participating in scleroderma patient support groups: a comparison of results from the North American and European scleroderma support group surveys

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ABSTRACT

Purpose: Many people with scleroderma rely on peer-led support groups as a coping resource. Reasons for not attending support groups in scleroderma have been investigated only in North American participants. This study assesses reasons for nonattendance in European countries and compares results with previously published North American findings.

Materials and Methods: The same 21-item survey as used in the North American sample assessed possible reasons for not attending scleroderma support groups. Proportions of items rated *Important* or *Very Important* were compared between samples.

Results: Consistent with the North American survey findings ($N = 242$), the two items most commonly rated as (Very) Important reasons for nonattendance among 228 European participants were (1) already having enough support (57%), and (2) not knowing of any local scleroderma support groups (58%). Compared to North American non-attenders, European patients were significantly more likely to rate not knowing enough about what happens at support groups (46% vs 19%), not having reliable ways to get to meetings (35% vs 17%), and being uncomfortable sharing experiences with a group (22% vs 11%) as (Very) Important reasons for nonattendance.

Conclusions: Improving access to European support groups, providing education about support groups and group leader training may encourage participation.

➤ IMPLICATIONS FOR REHABILITATION

- Rehabilitation professionals might help develop local support groups for people with systemic sclerosis (scleroderma) to address the lack of access to these groups for many patients.
- The need for transportation and limited local accessibility may also be addressed by implementing online systemic sclerosis support groups.
- Professionals in the field of rehabilitation may work with people with systemic sclerosis and patient organizations to provide education about support groups to improve support group attendance in Europe.

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Introduction

Systemic sclerosis (SSc, or scleroderma) is a rare, chronic autoimmune disease characterized by abnormal fibrotic processes and excessive collagen production that affect the skin and internal organs, including the lungs, kidneys, heart, and gastro-intestinal tract [1,2]. Disease manifestations include problems with hand functioning, mobility limitations, pain, fatigue, psychological distress, and body image concerns [3,4]. In addition to these difficulties, people with SSc face challenges related to the rarity of the disease, such as delays in obtaining an accurate diagnosis, limited treatment options, and few disease-specific support services [5,6].

Many people with SSc have turned to peer-led support groups as a resource in coping with the disease [7–9], and there are

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more than 150 SSc support groups listed on the web pages of Canadian and American patient organizations [8,9]. Support group members can provide each other with practical and emotional support and share information and educational resources [5,7,10,11]. Two recent studies reported that people with SSc in Europe [7] and North America [12] attend support groups for reasons that can be described as (1) obtaining interpersonal and social support (e.g., openly discussing SSc-related fears and concerns); (2) learning about disease treatment and symptom management strategies (e.g., learning about others' experiences with SSc treatments); and (3) other aspects of living with scleroderma, outside of symptom management (e.g., discussing financial issues associated with SSc).

While reasons for participation in support groups have been studied in patients from Europe and North America [7,12], reasons for nonparticipation in SSc support groups have been investigated in two studies that both included only North American participants [13,14]. In the first study [13], a single question, "Have you participated in SSc support groups?", was administered to Canadians with SSc as part of the Canadian Scleroderma Patient Survey of Health Concerns and Research Priorities; 297 Canadians with SSc indicated that they had not previously attended a support group and of these, 280 respondents provided a reason for not attending. Possible responses were "I'm not interested", "None are easily available", and "Other: please specify". Qualitative content analysis of responses to the "Other" option was conducted. Three main themes were identified: (1) no interest in support groups or no perceived need for additional support, (2) lack of availability of local SSc support groups, and (3) lack of awareness of the existence of SSc support groups [13]. Other reasons included practical barriers (e.g., inability to attend due to severity of symptoms), emotional factors (e.g., being afraid to interact or see others with SSc), uncertainty and contemplation (e.g., wanting to learn more about SSc support groups before joining), and negative perceptions (e.g., believing the tone of support groups is too negative).

In the second study, 242 non-attenders from North America responded to the 21 items on reasons for nonattendance in the North American Scleroderma Support Group Survey [14]. Exploratory factor analysis identified three themes related to nonattendance: (1) personal reasons (e.g., already having enough support), (2) practical reasons (e.g., SSc symptoms being too severe, no local support group), and (3) beliefs about support groups (e.g., thinking support groups are too negative). The two most commonly reported reasons for nonattendance were (1) already having enough support from family, friends, or others ($N = 122$, 50%), and (2) not knowing of any SSc support groups offered in their area ($N = 117$, 48%).

It is important to determine the degree to which reasons for not attending support groups among North American support group non-attenders explain reasons for nonattendance among European non-attenders or if barriers to participation differ. If barriers for participation are similar across Europe and North America, SSc patient organizations who facilitate these support groups may benefit from collaborating to develop strategies to improve accessibility to support groups for patients with SSc who may wish to join. Additionally, local patient organizations can tailor their approaches to overcome barriers specific to their area. The objective of the present study was to assess reasons for nonattendance in European countries and to compare results from the European Scleroderma Support Group Survey to results from the North American Scleroderma Support Group Survey [14].

Patients and methods

Participant sample

An open survey was completed by a convenience sample of people with SSc who were not current members of support groups. Participants were recruited to voluntarily complete an anonymous survey via the online survey tool *Qualtrics* between March and July 2016. Respondents were recruited through: (1) flyers and direct patient contact at the 4th Systemic Sclerosis World Congress in Lisbon, Portugal, which was held in February 18-20, 2016; (2) email referrals from the Federation of European Scleroderma Associations and postings on their website and social media sites (e.g., Facebook); (3) announcements in SSc patient newsletters; (4) emails to support group facilitators and members throughout Europe; and (5) postings on European SSc society websites.

Respondents who accessed the survey website were able to complete the survey in English, French, German, Italian, Dutch, Portuguese, or Spanish. After clicking on the survey link and selecting their preferred language, respondents were shown a brief consent form that described study objectives and provided survey instructions. Respondents were given the option to close their browser to decline participation or to provide consent by clicking an arrow to continue the survey. To reduce the possibility of duplicate responses, the survey was set up using cookies to prevent respondents from completing the survey more than once. The 28 survey items were distributed over 5 pages with 3–6 items each. Completeness of item responses for each page was checked using the validation feature in *Qualtrics* and participants were required to answer each question before continuing to the next page. Participants were not able to go back to the previous page to review and change their answers. To be included in the present analysis, survey respondents had to confirm that they had been diagnosed with SSc, they were not current support group members, and they resided in Europe. Participants did not receive incentives for completing the survey.

The study 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.

The European Scleroderma Support Group Non-attenders Survey

The survey was the same as the survey used in the previously published North-American Scleroderma Support Group Survey [14]. Initial items for the survey were obtained from items that were used in a similar survey related to cancer support groups [15], generated from published results of a qualitative study on reasons for not attending cancer support groups [16], and from responses to a single item on reasons for not attending SSc support groups, which was administered previously as part of the Canadian Scleroderma Patient Survey of Health Concerns [13].

There were 20 initial survey items generated by three members of the research team. These 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 patient organization representatives from Scleroderma Canada, the Scleroderma

Society of Ontario, and the Scleroderma Foundation; six members of the Scleroderma Patient-centered Intervention Network – Scleroderma Support Group Patient Advisory Team who were support group leaders; and researchers with expertise in SSc (9 patient organization representatives/patients; 6 researchers). There were 17 items that were not changed, 3 that were edited (including one that was divided into 3), and 6 new items added.

The final survey (see Supplementary material) consisted of 21 core items that assessed possible reasons for not attending SSc support groups, clustered in three themes relating to (1) personal reasons, (2) practical reasons, and (3) beliefs about support groups. In addition, there were three items that assessed reasons for not attending support groups among survey respondents who had previously attended a SSc support group. There were also four additional items that were only relevant to subgroups of survey respondents (respondents with children and respondents who differed from most other patients due to age, sex, or race/ethnicity). Response options for all 28 items included *Not Important*, *Somewhat Important*, *Important*, and *Very Important* (scored 0–3).

The survey was translated from English into French, German, Italian, Dutch, Portuguese, and Spanish using an accepted forward-backward translation method [17]. In this method, a first translator, who was a native speaker of the target language and fluent in English, was responsible for translating the questionnaire from English into the target language by emphasizing items' conceptual meaning rather than engaging in literal translations. Following this, the questionnaire was then back-translated to English by a second translator who was a native English speaker, fluent in the target language, 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. If conceptual differences were identified, the translators were consulted to reach consensus on an alternative translation of the item. A pilot-test of the technical functionality of the survey in *Qualtrics* was conducted by team members prior to data collection.

Data analysis

Descriptive statistics were used to characterize the sample and assess item responses. Proportions of patients rating an item as *Important* or *Very Important* versus *Not Important* or *Somewhat Important* reasons for not attending a support group were compared between the previously published data of the North American survey [14] and the current European sample using the two-sample test of proportions in Stata version 14.2, which is a Z-test of independent proportions. Since availability of support groups may differ by country, the item "I do not know of any scleroderma support groups offered in my area" was compared between respondents from different European countries. In addition, subgroup analyses for four items that were only relevant to subgroups of survey respondents (respondents with children and respondents who differed from most other patients due to age, sex, or race/ethnicity) were performed. No mathematical correction was made for multiple comparisons in our study, due to the exploratory and descriptive nature of our study.

Results

Sample characteristics

Demographic characteristics of 228 European respondents who did not attend support groups are shown in Table 1. Compared with respondents to the North American survey ($N = 242$), respondents from the European sample had a significantly shorter time since diagnosis with a mean (standard deviation) of 9.3 (6.9) vs 11.5 (7.8) years ($p = 0.001$), and were significantly younger 52.0 (13.0) vs 55.9 (12.7) years ($p = 0.001$), more likely to be White ($N = 216$, 94.7% vs $N = 209$, 86.4%, $p = 0.002$), and less likely to be on disability ($N = 34$, 15.4% vs $N = 55$, 22.7%, $p = 0.042$).

Item responses

Response frequencies for survey items, including comparisons between the current European sample and North American sample, are shown in Table 2 (detailed information is shown in Supplementary Tables S1 and S2). For European respondents, among Personal Reasons, the two items most commonly rated as *Important* or *Very Important* were "I already have enough support from family, friends, or others" ($N = 130$, 57%) and "I do not know enough about what happens at a support group" ($N = 105$, 46%), whereas the most important Practical Reasons were "I do not know of any scleroderma support groups offered in my area" ($N = 131$, 58%) and "Getting to and from the meetings is inconvenient due to weather, distance, or other factors" ($N = 91$, 40%). Regarding Beliefs about Support Groups, the items "I do not think I would learn more about scleroderma than I already know now" ($N = 76$, 33%) and "I do not think support groups provide educational information that is current and relevant" ($N = 50$, 22%) were most commonly rated as *Important* or *Very Important* reasons for nonattendance.

For the Personal Reasons theme, European non-attenders rated 5 of 9 items significantly more frequently as *Important* or *Very Important* compared with North American non-attenders, including "I do not know enough about what happens at a support group" (46% vs 19%), "I am uncomfortable sharing my experiences with a group (22% vs 11%), "I do not feel comfortable in a group environment (31% vs 19%), "I prefer not to see myself as a scleroderma patient" (26% vs 16%), and "I do not need a support group because my symptoms are not very severe" (31% vs 22%). For the Practical Reasons theme, "I do not have a reliable way to get to the meetings" (35% vs 18%) and "I do not know of any scleroderma support groups offered in my area" (58% vs 48%) were significantly more frequently rated as *Important* or *Very Important* by European non-attenders. There were no significant differences between the samples for any of the items in the Beliefs about Support Group theme.

There were 30 respondents in the European sample who had previously attended a SSc support group (13%). As shown in Table 2, 1 in 5 of these respondents reported having had a bad experience with a support group in the past as an *Important* or *Very Important* reason for nonattendance. Approximately 15% indicated that not liking the local support group leader or members of the support group was *Important* or *Very Important* to them as a reason for current nonattendance. These rates were similar for the European and North American subsamples.

Item frequencies for the items that were primarily relevant to subgroups of survey respondents (respondents with children and respondents who differed from most other patients due to age, sex, or race/ethnicity) are presented in Table 3 except for item 22 ("I do not have available childcare during the meetings") because data were not collected on whether or not respondents had children. The percentage of respondents with concerns about group makeup was higher among males compared to females as well as younger (age groups 18–29 and 30–39) and older respondents (age group 70–85). There were no statistically significant

Table 1. Sociodemographic characteristics of European ($N = 228$) and North American non-attenders ($N = 242$) [14].

Variable	European sample ($N = 228$)	North-American sample ($N = 242$)
Female gender, *n (%)*	199 (87.3)	202 (83.5)
Age in years, *mean (standard deviation)*	52.0 (13.0)	55.9 (12.7)
Country of residence, *n (%)*		
Netherlands	69 (30.3)	–
Spain	46 (20.2)	–
United Kingdom	45 (19.7)	–
France	24 (10.5)	–
Italy	20 (8.8)	–
Portugal	15 (6.6)	–
Germany	4 (1.8)	–
Switzerland	4 (1.8)	–
Belgium	1 (0.4)	–
Race/ethnicity, *n (%)*		
White	216 (94.7)	209 (86.4)
Other	7 (3.1)	23 (9.5)
Two or more	5 (2.2)	10 (4.1)
Marital status, *n (%)*		
Married	142 (62.3)	153 (63.2)
Never married	32 (14.0)	23 (9.5)
Living with partner in committed relationship	25 (11.0)	18 (7.4)
Divorced	21 (9.2)	34 (14.0)
Widowed	6 (2.6)	10 (4.1)
Separated	2 (0.9)	4 (1.7)
Years of education completed, *mean (standard deviation)*	14.9 (4.3)	–
Level of education, *n (%)*		
Elementary/primary school	–	3 (1.2)
Secondary/high school	–	41 (16.9)
Some college/ university	–	101 (41.7)
University degree	–	59 (24.4)
Postgraduate degree	–	38 (15.7)
Occupational status, *n (%)*		
Full-time employed	59 (25.9)	49 (20.2)
Retired	51 (22.4)	67 (27.7)
On disability	35 (15.4)	55 (22.7)
Part-time employed	34 (14.9)	24 (9.9)
Homemaker	16 (7.0)	24 (9.9)
Unemployed	12 (5.3)	9 (3.7)
Full-time student only	12 (5.3)	10 (4.1)
On leave of absence	9 (3.9)	4 (1.7)
Scleroderma diagnosis, *n (%)*		
Limited Scleroderma	119 (52.2)	126 (52.1)
Diffuse Scleroderma	65 (28.5)	79 (32.6)
Not known	44 (19.3)	37 (15.3)
Years since SSc diagnosis, *mean (standard deviation)*	9.3 (6.9)	11.5 (7.8)

differences for any of these items compared with the North American sample.

The percentage of respondents who rated the item "I do not know of any scleroderma support groups offered in my area" as *Important* or *Very Important*, by European country, is shown in Supplementary Table S3.

Discussion

The main finding of this study was that the most commonly reported reasons for not being able to attend or choosing not to attend support groups among European non-attenders, reported by more than half of the respondents as being important or very important, were: (1) already having enough support from family, friends, or others, and (2) not knowing of any SSc support groups in their area. In addition, approximately 40% of respondents reported that not knowing enough about what happens at a support group was an important or very important reason for nonattendance, as was the practical barrier of getting to and from the meetings.

The two most common reasons for nonattendance reported in our sample of patients from Europe are consistent with findings from a previous study including patients with SSc from North America [14]. There were also differences between the samples, most remarkably for the item "I do not know enough about what happens at a support group" (Europe = 46%, North America = 19%). Furthermore, patients from Europe were twice as likely to rate the items "I do not have a reliable way to get to the meetings" (35% vs. 17%) and "I am uncomfortable sharing my experiences with a group" (22% vs. 11%) as important or very important reasons for nonattendance compared with patients from North America [14].

The knowledge generated from the present study as well as from previous studies [13,14] can be used to develop strategies to improve accessibility to support groups for patients with SSc who may wish to join. Because the most important barriers are similar across Europe and North America, SSc patient organizations who facilitate these support groups may benefit from collaborating and exchanging experiences, which is particularly important in a rare disease context where resources are scarce. In addition to initiatives that can be shared across continents, local patient organizations can tailor their approaches to overcome barriers specific to their area.

Across medical conditions, support groups are delivered in a variety of ways, including face-to-face groups and groups that are conducted online or via teleconference, for instance. Access to

Table 2. Comparison of proportion of patients rating an item as "Important" or "Very Important" between European ($N = 228$) and North American non-attenders ($N = 242$) [14].

	European sample ($N = 228$)	North-American sample ($N = 242$)	Mean difference in proportions [95% Confidence interval]
Theme 1: Personal Reasons			
Item 2: I do not need a support group because my symptoms are not very severe.	70 (30.7%)	53 (21.9%)	**0.09 [0.01–0.17]**
Item 3: I am too busy with other responsibilities, such as work or children, to attend a support group.	77 (33.7%)	65 (26.9%)	0.07 [−0.01–0.15]
Item 4: I am uncomfortable seeing other people with scleroderma who may be worse off than me.	85 (37.3%)	74 (30.6%)	0.07 [−0.02–0.15]
Item 6: I already have enough support from family, friends, or others.	130 (57.0%)	122 (50.4%)	0.07 [−0.02–0.16]
Item 10: I do not feel comfortable in a group environment.	70 (30.7%)	47 (19.4%)	**0.11 [0.03–0.19]**
Item 13: I prefer not to see myself as a "scleroderma patient."	59 (25.9%)	39 (16.1%)	**0.10 [0.02–0.17]**
Item 14: I do not know enough about what happens at a support group.	105 (46.1%)	45 (18.6%)	**0.27 [0.19–0.35]**
Item 17: I feel too depressed or emotionally overwhelmed to attend a support group.	40 (17.8%)	33 (13.6%)	0.04 [−0.03–0.10]
Item 20: I am uncomfortable sharing my experiences with a group.	50 (21.9%)	27 (11.2%)	**0.11 [0.04–0.17]**
Theme 2: Practical reasons			
Item 1: I do not know of any scleroderma support groups offered in my area.	131 (57.5%)	117 (48.3%)	**0.09 [0.00–0.18]**
Item 7: My scleroderma symptoms are severe and make it difficult to attend the meetings.	46 (20.2%)	52 (21.5%)	−0.01 [−0.09–0.06]
Item 11: The time of the meetings does not fit in my schedule.	56 (24.6%)	79 (32.6%)	−0.08 [−0.16–0.00]
Item 12: I do not have a reliable way to get to the meetings.	80 (35.1%)	43 (17.8%)	**0.17 [0.09–0.25]**
Item 18: I am worried that my privacy will not be respected.	34 (14.9%)	28 (11.6%)	0.03 [−0.03–0.09]
Item 21: Getting to and from the meetings is inconvenient due to weather, distance, or other factors.	91 (39.9%)	76 (31.4%)	0.09 [−0.00–0.17]
Item 28: I am uncomfortable with how I look.	26 (11.4%)	21 (8.7%)	0.03 [−0.03–0.08]
Theme 3: Beliefs about support groups			
Item 5: I think support groups are too negative.	53 (23.2%)	59 (24.4%)	−0.01 [−0.09–0.07]
Item 9: I do not think support groups are helpful.	50 (21.9%)	61 (25.2%)	−0.03 [−0.11–0.04]
Item 16: I do not think I would learn more about scleroderma than I already know now.	76 (33.3%)	62 (25.6%)	0.08 [−0.01–0.16]
Item 23: I do not think support groups provide educational information that is current and relevant.	50 (21.9%)	44 (18.2%)	0.04 [−0.03–0.11]
Item 24: I think support groups spend too much time discussing non-scleroderma related topics.	41 (18.0%)	45 (18.6%)	< −0.01 [−0.08–0.06]
Additional items:			
Item 8: I do not think the group would have enough people of a similar cultural background in it.	20 (8.8%)	25 (10.3%)	−0.02 [−0.07–0.04]
Item 15: I do not think the group would have enough people of a similar age to my age.	38 (16.7%)	25 (10.3%)	**0.06 [0.00–0.13]**
Item 19: I do not think the group would have enough people of the same gender as me in it.	14 (6.1%)	12 (5.0%)	0.01 [−0.03–0.05]
Item 22: I do not have available childcare during the meetings.	31 (13.6%)	14 (5.8%)	**0.08 [0.03–0.13]**
	European sample ($N = 30$)	North-American sample ($N = 67$)	
Item 25: I attended a support group in the past and had a bad experience.	6 (20.0%)	16 (23.9%)	−0.04 [−0.21–0.14]
Item 26: I do not like the current leader of the local support group.	5 (16.7%)	8 (11.9%)	0.05 [−0.11–0.20]
Item 27: I do not like the members of the local support group.	5 (16.7%)	7 (10.5%)	0.06 [−0.09–0.21]

Bold indicates $p < 0.05$.

support groups in SSc can potentially be improved by offering them in a virtual format. Indeed, a scoping review of facilitators and barriers for support groups across rare diseases found that holding support groups via teleconference was an important facilitator [18]. A recent systematic review of 17 studies of support groups for chronic health conditions concluded that using videoconferencing to deliver support groups is feasible and may improve the accessibility of support group interventions [19]. Rare disease patients, including SSc, are adept at using online resources to find information about their disease. As an example, a 2013 study found that 85% of Dutch patients with SSc used the internet to search for information about SSc [20]. Online support groups may also reduce potential stressors associated with sharing experiences with a group in a face-to-face context [21], which was also a highly rated concern in the current study.

Among European participants, not knowing enough about what happens at a support group was significantly more frequently rated as an important or very important reason for not

Table 3. Subgroup Analyses for subgroup-relevant Items and comparison of proportion of patients rating an item as "Important" or "Very Important" with North American non-attenders ($N = 242$) [14].

	Current sample (*n*)	Important and very important (*n*, %)	North-American sample (*n*)	Important and very important (*n*, %)	Mean difference in proportions [95% Confidence interval]
Item 8: I do not think the group would have enough people of a similar cultural background in it.					
Ethnicity/Race					
White	216	19 (8.8%)	209	15 (7.1%)	0.02 [−0.04–0.07]
Other	12	1 (8.3%)	33	10 (30.3%)	−0.22 [−0.44–0.00]
Item 15: I do not think the group would have enough people of a similar age to my age.					
Age					
18–29	8	5 (62.5%)	10	5 (50.0%)	0.13 [−0.33–0.58]
30–39	31	9 (29.1%)	13	2 (15.4%)	0.14 [−0.12–0.39]
40–49	58	7 (12.0%)	37	4 (10.8%)	0.01 [−0.12–0.14]
50–59	63	8 (12.7%)	90	7 (7.8%)	0.05 [−0.05–0.15]
60–69	47	5 (10.6%)	58	3 (5.1%)	0.05 [−0.05–0.16]
70–85	21	4 (19.0%)	34	4 (11.7%)	0.07 [−0.13–0.27]
Item 19: I do not think the group would have enough people of the same gender as me in it.					
Gender					
Male	29	6 (20.7%)	40	6 (15.0%)	0.06 [−0.13–0.24]
Female	199	8 (4.0%)	202	6 (3.0%)	0.01 [−0.03–0.05]

attending compared to participants from North America. This suggests that improving education about support groups and what they entail may be an important strategy to improve support group attendance in the European context. There are currently more than 150 support groups for people living with SSc in North America affiliated with Scleroderma Canada and the United States affiliated with the Scleroderma Foundations that can be found on these organizations' websites [8,9]. On the contrary, no information on support groups is listed on many European SSc patient organization websites, including the Federation of European Scleroderma Associations [22], which is an umbrella organization of European national patient organizations. We were only able to identify clear information on the availability, aims and locations of support groups on the websites of SSc patient organizations in the UK [23] and Germany [24]. SSc patient organizations may be able to increase education about support groups, as well as awareness of existing groups through information and advertisements at annual conferences, in patient newsletters, or on their websites.

European respondents were also twice more likely than North American participants to rate being uncomfortable sharing their experiences with a group as an important or very important reason for nonattendance. This could potentially be related to the lack of knowledge about what happens at a support group, as well as to fears about personal intrusion and privacy, or fears about the future and disease progression. Skilled support group leaders could help patients overcome these issues by discussing these types of fears with new participants, as well as by managing groups in a way that ensures that participants' privacy is protected. Furthermore, as some patients may be more comfortable participating in an online environment, Internet-based groups could also help reduce discomfort.

While support groups have the potential to address some of the information needs in SSc [25], 1 in 3 patients in the current study did not expect to learn more about scleroderma than they already knew, and 1 in 5 did not think that support groups provide educational information that is current and relevant. Support group leaders have an important role in determining the success of SSc support groups, but leaders typically receive little to no training for their role [26] and therefore may be unable to facilitate the education and information sharing that are important components of support groups [5,7,10,11]. Providing training and support to peer group leaders could help address this. The Scleroderma Patient-centered Intervention Network, in partnership with SSc patient organizations, has developed the Scleroderma Support group Leader EDucation Program, 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 [26]. The effect of the Scleroderma Support group Leader EDucation Program is currently being tested in a randomized controlled trial [26] among support group leaders from Canada, the United States, the United Kingdom, Australia, and New Zealand. If effective, providing training to support group leaders across the globe could address the concerns of patients regarding the information provision and education in these groups.

There are a number of limitations related to our study. First, we recruited mostly through patient organizations, which could have resulted in over-representation of people with SSc who are more actively involved in the self-management of their disease and in 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. 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 offered through patient organizations. Fourth, we combined responses from respondents from different European countries, and the reasons for non-attending support groups may differ. Subsamples for individual countries, however, were too small for analysis.

In conclusion, the results of this study confirm that the reasons for not attending support groups are overlapping between two large international samples of patients with SSc, and thus, that it could be beneficial for European and North American SSc organizations to work together to identify ways to improve access to support groups and their ability to meet needs of people with SSc. In addition, improving education about support groups and what they entail may be an important strategy to improve support group attendance in the European context.

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Authors' contribution

LK and BDT were responsible for the study conception and design; data acquisition, analysis, and interpretation; and drafting and revising the manuscript. ACJ also contributed to drafting and revising the manuscript. MEC and MP were responsible for acquisition of data. SP, VLM, GEB, and the Scleroderma Patient-centered Intervention Network Support Group Project Advisory Team were responsible for interpretation of data analysis. All authors reviewed, provided critical input, and approved the final version of this manuscript.

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