The Scleroderma Support Group Survey: Understanding People’s Experiences with Scleroderma

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What is a Support Group?

- A gathering of people who share common experiences.
- Activities involve an educational component and the giving and receiving of emotional and practical support.
- They may be held in person or online; led by patients or professionals; and structured or unstructured.
Scleroderma Support Groups

- There are 30 scleroderma support groups in Canada and 150 in the U.S.; most are held in person and led by patients.

- The Scleroderma Society of Canada and the Scleroderma Foundation offer basic information on how to start a support group, but do not provide training to group leaders.

- These organizations are committed to addressing these limitations in hopes of increasing the accessibility and effectiveness of scleroderma support groups.
Our Mission

- To develop a training program for scleroderma support group leaders.

- To do this, we need to know why people with scleroderma attend or do not attend support groups.

- We also need to understand some of the challenges that scleroderma support group leaders face.
The Scleroderma Support Group Survey

- Adults with scleroderma were recruited through the Scleroderma Society of Canada and the Scleroderma Foundation in the United States.

- Patients were asked to complete an anonymous online survey.

- Separate surveys were administered to:
  1) Support group members
  2) People with scleroderma who do not attend support groups
  3) Support group leaders
Scleroderma support group members?
Scleroderma Support Group Members

- 171 participants

**Aim of the Survey**

- To assess the reasons why people join and continue to attend support groups, as well as the organizational factors that they consider important for a successful group.

**Example Item:**

<table>
<thead>
<tr>
<th></th>
<th>Not Important</th>
<th>Somewhat Important</th>
<th>Important</th>
<th>Very Important</th>
</tr>
</thead>
<tbody>
<tr>
<td>Openly talking about my fears and feelings regarding living with scleroderma.</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
</tbody>
</table>
Scleroderma Support Group Members: Reasons for Attending

- Learning how other group members deal with issues related to scleroderma: 97%
- Learning about current scleroderma research: 92%
- Knowing that I am not alone: 91%
- Learning about medications used in scleroderma treatments and their potential side-effects: 91%
- Getting suggestions from other group members: 91%
Scleroderma Support Group Members: Reasons for Attending

<table>
<thead>
<tr>
<th>Item</th>
<th>Percentage</th>
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</thead>
<tbody>
<tr>
<td>Spending time with people who understand what it is like to live with scleroderma.</td>
<td>87%</td>
</tr>
<tr>
<td>Learning helpful nutrition and food preparation tips for people with scleroderma.</td>
<td>80%</td>
</tr>
<tr>
<td>Finding out how other people with scleroderma have handled changes to their appearance.</td>
<td>75%</td>
</tr>
<tr>
<td>Enjoying fun social activities.</td>
<td>67%</td>
</tr>
<tr>
<td>Learning how to talk with family and friends about my scleroderma.</td>
<td>59%</td>
</tr>
</tbody>
</table>
Scleroderma Support Group Members: Organizational Factors

- That there is an opportunity for members to openly discuss their feelings and concerns: 89%
- Having guest speakers come discuss scleroderma related topics: 84%
- Types of people who make up the group (e.g., scleroderma patients only): 77%
- That the group leader has received training or accreditation: 60%
- Location of the group meetings (e.g., community center): 60%
Summary

- Reasons people with scleroderma attend support groups:
  - Emotional support
  - Practical support
  - Sense of community

- The training program we develop should help group leaders structure meetings so that both components (the emotional and the practical support) are touched upon, as well as give them the skills and resources necessary to go out and recruit guest speakers and to stay up-to-date on scleroderma research.
People with scleroderma who do not attend support groups?
Scleroderma Support Group Non-attenders

- 242 participants

**Aim of the Survey**
- To assess the factors that influence people’s decision to not attend support groups.

**Example Item:**

<table>
<thead>
<tr>
<th></th>
<th>Not Important</th>
<th>Somewhat Important</th>
<th>Important</th>
<th>Very Important</th>
</tr>
</thead>
<tbody>
<tr>
<td>I prefer not to see myself as</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>a “scleroderma patient.”</td>
<td></td>
<td></td>
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</tbody>
</table>
Scleroderma Support Group Non-attenders: Reasons for Not Attending

- I already have enough support from family, friends, or others. (50%)
- I do not know of any scleroderma support groups offered in my area. (48%)
- The time of the meeting does not fit in my schedule. (33%)
- Getting to and from the meetings is inconvenient due to weather, distance, or other factors. (31%)
- I am uncomfortable seeing other people with scleroderma who may be worse off than me. (31%)
Scleroderma Support Group Non-attenders: Reasons for Not Attending

Selected “Important” and “Very Important”

- I do not think I would learn more about scleroderma than I already know. 26%
- I think support groups are too negative. 24%
- I do not know enough about what happens at a support group. 19%
- I think support groups spend too much time discussing non-scleroderma related topics. 19%
- I am worried that my privacy will not be respected. 12%
Summary

- Reasons people with scleroderma do not attend support groups:
  - Already have enough support
  - Availability and accessibility issues
  - Discomfort seeing others with scleroderma

- Attending a scleroderma support group may address needs that other types of support cannot.

- Online support groups may be an economical and feasible option for delivering support to those with scleroderma.
Scleroderma support group leaders?
Scleroderma Support Group Leaders

- 80 participants

Aim of the Survey
- To assess the training and support needs of current group leaders.

Example Item:

<table>
<thead>
<tr>
<th></th>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Slightly Disagree</th>
<th>Slightly Agree</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>I am confident in my ability to obtain feedback from members about the group.</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
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Example Item:
Scleroderma Support Group Leaders: Strengths

I am confident in my ability to help the group establish appropriate group rules, such as maintaining confidentiality. 91%

I am confident in my ability to facilitate the group meetings so that all members have an opportunity to speak. 90%

I am confident in my ability to help members feel comfortable in the group and relate to one another. 90%

I am confident in my ability to support members of the group who are grieving. 89%

I am confident in my ability to help overly shy group members feel comfortable interacting with the group. 89%
Scleroderma Support Group Leaders: Challenges

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<tr>
<th>Item</th>
<th>Percentage</th>
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<tbody>
<tr>
<td>I am confident in my ability to obtain the support I need to cope with the emotional demands of leading the group.</td>
<td>60%</td>
</tr>
<tr>
<td>I am confident in my ability to obtain financial or other resources needed to run the group.</td>
<td>55%</td>
</tr>
<tr>
<td>I am confident in my ability to effectively publicize the group.</td>
<td>55%</td>
</tr>
<tr>
<td>I am confident in my ability to talk to a group member about their behavior if it is disruptive to the group.</td>
<td>55%</td>
</tr>
<tr>
<td>I am confident in my ability to effectively recruit new members.</td>
<td>48%</td>
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</tbody>
</table>
Summary

- Leaders may struggle with:
  - Managing complex group dynamics
  - Tasks that maintain the group in the long-term (e.g., publicizing)

- Therefore, the training program we will develop will focus on these challenges.
Conclusion

- Our findings will guide the development of a formal training program for group leaders.

- Ultimately, this will increase the accessibility and effectiveness of scleroderma support groups.

- It will also help group leaders feel more comfortable and supported in their roles.
Conclusion

- Based on the results of this study and previous studies, some of the areas that will be covered by the program include:

  - The Leader’s Role
  - Scleroderma 101
  - Successful Support Group Culture
  - Grief and Crisis in Scleroderma
  - Starting a Support Group
  - Managing Group Dynamics
  - Structuring Support Group Meetings
  - Resources for Leaders and Members
  - The Continuity of the Group
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