

6. The Scleroderma Support Group Non-Attendees Survey: A Cross-sectional Study

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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.

The Scleroderma Support Group Non-Attendees Survey is a 21-item questionnaire developed to assess reasons for not attending SSc support groups. The survey was administered anonymously to SSc patients living in Canada and the United States (US) using the online surveying tool Qualtrics. Participants were primarily recruited through the Scleroderma Society of Canada and the Scleroderma Foundation in the US. An exploratory factor analysis was conducted using the software MPlus to identify factors that explained reasons for non-attendance.

A total of 242 (Female=202; Male=40) people with SSc completed the survey. A three-factor model (CFI=0.91, TLI=0.88, RMSEA=0.07; factor intercorrelations 0.10 to 0.16) fit substantially better than a two-factor model (CFI=0.84, TLI=0.80, RMSEA=0.08), and a four-factor model did not improve fit substantively (CFI=0.94, TLI=0.91, RMSEA=0.06). The three identified factors representing key reasons for not attending SSc support groups included: (1) Personal Reasons (9 Items), (2) Practical Reasons (7 Items), and (3) Support Group Factors (5 Items). Example items within Personal Reasons included “I do not need a support group because my symptoms are not severe”, “I prefer not to see myself as a ‘scleroderma patient’”, “I already have enough support from family, friends, or others”, and “I do not feel comfortable in a group setting”. Example items within Practical Reasons included “I do not know of any scleroderma support groups offered in my area”, “I am uncomfortable with how I look”, “I do not have a reliable way to get to the meetings”, and “The time of the meetings does not fit in my schedule”. Example items within Support Group Factors included “I think support groups are too negative”, “I do not think support groups are helpful” and “I do not think I would learn more about scleroderma than I already know”.

SSc organizations 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.