

Feasibility Trial of the Scleroderma Patient-centered Intervention Network Support Group Leader Education (SPIN-SSLED) Program



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Background

- Scleroderma (SSc) is an example of a rare disease where peer-led support groups play an important role for people with the disease (Delisle et al., 2016; Kwakkenbos et al., 2015).
- Many people with SSc join support groups in order to learn how to better manage physical and emotional aspects of living with the disease. However, many cannot access a group.
- Many existing groups are not sustainable due to reliance on a single leader whose health worsens or shortcomings related to untrained peer leaders; others prefer not to attend support groups because of negative beliefs about the group in their area. (Delisle et al., 2016)
- Some challenges related to leading a support group reported by peer leaders include (Butow et al. 2005; Galinsky & Schopler, 1994; Coreil & Behal, 1999; Kirsten et al., 2006; Zordan et al. 2010):
 - Practical difficulties: lack of resources, poor coordination with medical professionals
 - Difficulties with leading the group: managing group dynamics, dealing with changing health of group members
 - Personal challenges: balancing personal and group demands, preventing burnout and stress, managing one's own health condition while supporting others
- A training and educational program could provide peer leaders with the necessary information and skills to improve their ability to lead sustainable, effective support groups; reduce their emotional and physical burden

Objective

The objectives of the SPIN-SSLED feasibility trial were (1) to evaluate the feasibility of steps needed to take place in the full-scale trial, including the *required resources, management issues, and scientific aspects*; (2) to make any necessary modifications to the SPIN-SSLED Program based on participant feedback.

Methods

- Eligible participants were current support group leaders or individuals identified by patient organization partners as a new leader. Scleroderma Canada and the Scleroderma Foundation provided us a list of 12 leaders to invite to participate. The 10 first participants to respond were selected to be trained in two groups of 5.
- The SPIN-SSLED program includes 13 modules that are delivered live via webinar over the course of the 3-month program. Modules are delivered in 60- to 90-minute sessions and the feasibility trial ran from April through July 2018.

Table 1. Outcomes Measures

Outcomes Measures	Description
Accessibility, barriers to participating and leaders' experiences	Post-trial individual semi-structured participant interviews
Leader self-efficacy	Scleroderma Support Group Leader Self-efficacy Scale (SSGLSS) (Pal et al., 2018), scored on a 6-point Likert scale from 1 (strongly disagree) to 6 (strongly agree) with higher scores indicating greater self-efficacy
Burnout	Oldenburg Burnout Inventory (OLBI) (Demerouti, 2005; Halbesleben et al. 2005)
Emotional Distress	Patient Health Questionnaire-8 (PHQ-8) (Kroenke et al., 2005)
Physical Function	Physical function subscale of the Patient Reported Outcomes Measurement Information System (PROMIS-29)
Participant Program Satisfaction	Client Satisfaction Questionnaire-8 (Larsen et al., 1979), which is scored on a Likert scale from 1 (low satisfaction) to 4 (high satisfaction).

Results

Table 2. Participant Characteristics

Characteristics	Value (n=10)
Female sex, n (%)	10 (100%)
Age in years, mean (SD)	57.7 (11.1)
Country, n (%)	
Canada	6 (60%)
United States	4 (40%)
Years since diagnosis, mean (SD)	10.9 (7.4)

- Participant feedback was quite positive with an average overall grade of 9.4/10 on a single item rating. On a per item basis, the CSQ-8 mean item score was 3.83 also reflecting a very high level of satisfaction.
- Resource demands were relatively low. Once participants enrolled and trained in using the GoToMeeting platform, minor additional support was only needed 4-5 times, and the platform worked fluidly and supported the training groups well.
- Program fidelity was high. Two independent coders reviewed 7 randomly selected training sessions to assess instructor adherence to the program content, confirming that the instructor covered 58 of the 60 subtopics addressed in the manuals.

Table 3. Results for pre- vs post-trial measures

Measure	Pre-trial Mean (SD)	Post-trial Mean (SD)	Standardized Mean Difference Effect Size
Self-efficacy (SSGLSS)	124.4 (22.0)	159.2 (17.1)	1.70
Burnout (OLBI)	33.20 (4.61)	31.00 (4.92)	-0.44
Emotional Distress (PHQ-8)	10.80 (2.66)	9.80 (2.44)	-0.38
Physical Function (PROMIS-29)	17.10 (2.23)	18.20 (2.44)	-0.45

Conclusions

The SPIN-SSLED Program has the potential to significantly improve the effectiveness and sustainability of existing SSc support groups and to increase the number of available support groups by giving people with SSc the skills they need to establish support groups where none exist.



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