



Support Groups in Scleroderma

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Abstract

Purpose of Review This review presents evidence on support group effectiveness in common diseases, research on support groups in systemic sclerosis (SSc), and work underway by the Scleroderma Patient-centered Intervention Network in collaboration with patient organizations to train SSc support group leaders in order to improve support group access and the experiences of support groups for members and leaders.

Recent Findings Giving and receiving emotional and practical support from others with SSc is an important reason that individuals with SSc attend support groups, but many patients cannot access support groups. SSc support group leaders report confidence in their ability to facilitate groups, but are less confident in tasks such as managing group dynamics and sustaining the group.

Summary The Scleroderma Support group Leader EDucation (SPIN-SSLED) Program was developed to provide training to support group leaders and was recently tested through a feasibility trial. A full-scale trial will commence in 2019.

Keywords Scleroderma · Systemic sclerosis · Support groups · Rare disease · Social support

Introduction

There are currently more than 175 support groups for people living with systemic sclerosis (SSc, scleroderma) in North America, including approximately 25 affiliated with Scleroderma Canada [1] and more than 150 in the USA affiliated with the Scleroderma Foundation [2]. Many people with SSc join support groups, which are led almost exclusively by peers, in order to share their experiences living with SSc and

to provide each other with emotional and practical support [1–6]. Support groups can also provide members with information and educational resources to help them better manage physical and emotional aspects of living with the disease [7••, 8]. Many people with SSc, however, cannot access support groups because none are available where they live or because groups are initiated but not sustained. Furthermore, many SSc health professionals are reluctant to refer patients to SSc support groups due to concerns that the support groups may be poorly organized, and are sometimes overly negative, or may provide inaccurate information about SSc, its management, and the healthcare professionals who care for people with SSc. In this article, we describe evidence on the effectiveness of support groups in common diseases, research on support groups in SSc, and work that the Scleroderma Patient-centered Intervention Network (SPIN) is doing in partnership with patient organizations across the world to improve access to support groups and the experiences of support group members and leaders.

Support Groups in Common Diseases

Support groups are a common resource in many chronic diseases [9, 10]. Support groups for people with medical conditions are guided by the principle that people who face similar disease-related challenges can encourage and empower one

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another through creating a social network [3, 4]. The mental health consumer movement of the 1970s was the first to strongly influence the widespread implementation of support groups [11, 12]. In this context, former psychiatry inpatients began to organize groups to improve patient rights, decrease stigma and discrimination, and promote peer-run services as an adjunct to medical care. The goals of those original support groups were to offer support in a community setting and employ local peers in the development, implementation, and evaluation of the support groups themselves [13]. By the 1980s, support groups for mental health concerns were linked with government and professional organizations, which resulted in increased funding and infrastructure to sustain the groups [12].

Support groups quickly expanded to other chronic diseases, and currently, support groups are commonly available to people with common physical and mental health conditions such as cancer [14–16], diabetes [17], heart disease [18], and depression [19]. 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. Activities in support groups are typically designed to facilitate emotional support via expressions of caring and empathy among members and practical support through education and information sharing [4, 7, 10, 20].

There is some evidence that support group members may experience improved health outcomes including emotional and psychological well-being [21, 22] and that they may be more likely to make behavior changes required to manage or cope effectively with their medical conditions [23, 24], although not all evidence suggests that support groups produce their desired effects. A Cochrane review assessed the effects of online support groups delivered in real time or via chat rooms by professionals or peers for women with breast cancer on emotional distress, uncertainty, anxiety, depression, and quality of life as compared to inactive control groups. A total of six trials (492 women) were included, and results from two primary studies ($N = 120$) were pooled, but no significant differences between women in support groups and control conditions were found based on the small, low-quality trials evaluated [25]. A systematic review of HIV support groups narratively summarized results of 20 primary studies that evaluated the impact of support groups in resource-limited settings and addressed health or cost-effectiveness outcomes of interest [26]. Although 18 of 20 included studies reported largely positive results, such as reduced mortality and morbidity and increased retention in care, most included studies had very small samples and were based on cross-sectional or qualitative analyses [26]. Two reviews have synthesized support group evidence for dementia [27, 28]. Of these reviews, one included trials of support groups for people with dementia and mild cognitive impairment as compared to usual care or attention-control groups [27], while a second review included

qualitative studies of informal caregivers to people with dementia [28]. Among the review of trials, two met the inclusion criteria; however, one of the included trials involved support groups delivered along with cognitive behavioral therapy and an exercise program [26]. Nonetheless, the authors concluded that support groups may be beneficial for reducing depression and improving quality of life and self-esteem among individuals with dementia [26]. Synthesized results of qualitative studies of informal caregivers of adults with dementia described support groups as (1) being a source of positive emotional support, (2) providing an opportunity to express negative feelings and gain additional perspectives, and (3) encouraging members to embrace the future [28]. Poor study quality, small sample size, and substantial heterogeneity, however, were noted as limitations of included primary studies in each of the reviews, which contributes to a lack of understanding for the relative effectiveness of support groups among individuals with chronic diseases [25–28].

Peer-Led Support Groups in Rare Diseases

In common diseases, support groups are frequently offered via the healthcare system and are organized and delivered by professionals who are knowledgeable about the condition. In rare diseases, including SSc, however, professionally organized support services are typically not available or readily accessible [8]. In the absence of these services, people with rare diseases have often created and mobilized their own support systems in the form of locally organized peer-led support groups [20]. As opposed to support groups led by medical professionals, peer support groups offer individuals support and advice grounded in experiential knowledge specific to a particular condition [4] to supplement professional health services.

Many people with rare diseases rely on peer-led support groups for emotional and practical support, given the complexities of living with a rare disease [8, 10, 14, 20]. Indeed, living with a rare disease, such as SSc, involves substantial challenges, including physical and psychological manifestations that require modifications to one's social, family, and professional roles. Compared to people with more common diseases, those with rare diseases, including SSc, typically face unique challenges and increased burden due to gaps in knowledge about the disease [29, 30]. They also often experience challenges obtaining an accurate diagnosis, which can involve consulting multiple doctors and repeated medical tests over several years [29, 31, 32]. Once an appropriate diagnosis is obtained, other major challenges can include uncertain prognosis, limited treatment options, and few available professional support resources [30]. Some patients and their caregivers describe feeling isolated from friends and family who may not understand the challenges they face [29].

A 2017 scoping review mapped available evidence on the benefits of participating in peer-led support groups for people with rare diseases and barriers and facilitators to establishing and maintaining these groups [33•]. Names of approximately 7000 rare diseases were searched in two databases to obtain relevant studies that included persons with rare diseases taking part in peer-led support groups. A total of 10 publications were included in the review. There were no trials, however, that examined the effects of organized support programs for patients with any rare disease [33•]. Overall, seven different perceived benefits of participating in rare disease support groups were identified, including meeting other people with the same rare disease and similar experiences; learning about the disease and its treatments; having a place to speak openly about the disease and one's feelings; and advocating to improve healthcare for other rare disease patients, among others [33•]. Several facilitators and barriers of establishing and maintaining these groups were also identified. Holding support groups via teleconference was an important facilitator, because many people with rare diseases may live far from specialized treatment centers and because there are often few people with a given rare disease in any single setting. Virtual support groups can serve to connect individuals who may experience isolation due to the rarity of their disease and can facilitate attendance for people with challenges related to mobility. Other facilitators included providing training to leaders of support groups and having more than one leader for groups [33•].

Peer-Led Support Groups in Scleroderma

SSc is a rare, chronic, and autoimmune connective tissue disease characterized by abnormal fibrotic processes and excessive collagen production [34–37]. Onset typically occurs between the ages of 30 and 50 years, and approximately, 80% of people with SSc are women. Abnormal fibrotic processes that occur in SSc can affect multiple organ systems, including the skin, lungs, gastrointestinal tract, and heart and can cause immune dysfunction and vascular injury [35, 36]. Common manifestations include Raynaud's phenomenon [36, 37], esophageal disease and gastrointestinal symptoms [38, 39], and pulmonary disease [36]. People with SSc commonly experience hand function and mobility limitations, pain, fatigue, sleep problems, pruritus, depression, and body image distress from disfigurement (e.g., skin tightening, pigment changes, hand contractures) [36, 40–50]. The presentation of SSc is extremely heterogeneous, and the disease course is highly unpredictable [34–36]. The number of peer-led support groups across North America suggests that these groups play an important role for many people with SSc [7•, 34].

In partnership with patient organization partners and with the goal of identifying ways of improving access and the quality of support groups, SPIN has conducted research on (1)

reasons why people with SSc attend or do not attend support groups, (2) the perceived benefits and limitations of participating in SSc support groups, and (3) the training and support needs of SSc support group leaders. SPIN also developed and recently conducted a feasibility trial of a training and education program for SSc support group leaders. To conduct this research, SPIN initially formed a support group leader advisory team comprised of 10 people with SSc who have been involved in SSc support groups, and this team worked with SPIN investigators in all phases of this research.

As a first step in this research, SPIN researchers conducted a series of one-on-one interviews with SSc support group leaders, support group members, and people who did not attend support groups. Then, a survey was developed with items generated from the interview data and from surveys that have been used to study support groups in more common diseases. In collaboration with the support group leader advisory team, individual items were revised or removed if duplicative or less relevant for SSc, and new items were generated to reflect content important to SSc that were not reflected in the initial item pool. The survey was disseminated to SSc support group leaders, members, and non-attenders from North America and internationally through postings on SSc organization websites and social media venues (e.g., Facebook, Twitter), announcements in patient newsletters, and emails to support group members and leaders. Approximately, 1300 persons with SSc completed the survey (approximately 45% non-attenders, 40% support group members, and 15% leaders).

A total of 242 individuals with SSc from North America who did not attend support groups completed the survey [51•]. Three main themes that reflected reasons for not attending were identified, including personal reasons (e.g., too busy with other responsibilities), practical reasons (e.g., lack of known support groups in the area), and beliefs about support groups (e.g., support groups perceived to be too negative or unhelpful) [51•]. Common reasons for not attending SSc support groups included not having access to a local support group, and 117 (48%) respondents reported this as an important or very important reason they did not attend. Having enough support from family, friends, or others was also commonly reported, and 123 (50%) individuals described this as important or very important reason. Difficulty getting to and from meetings due to weather, distance or other factors was also reported as being important or very important by 71 (31%) of respondents [51•]. These results were replicated in a sample of 241 individuals with SSc from Europe [52].

One implication of these findings is that access might be improved by providing support groups through telephone or videoconferencing. Consistent with this, 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 [53].

Current members of SSc support groups ($n = 384$) who responded to the survey included 213 from Europe and 171 from North America. The survey asked support group participants about the most important reasons for attending SSc support groups and factors that they believed were important for successful support groups [7••, 54]. Similar to other rare diseases, important reasons for attending SSc support groups included the giving and receiving emotional and practical support from others with SSc, learning how to manage SSc-related challenges, feeling supported by others with the same condition, and learning about SSc and SSc research from group members and guest speakers [7••]. Organizational preferences for support groups included having educational components as part of the support group sessions and having the opportunity to share information and support other members [7••]. Among North American and European support group members, 86% indicated that it was important that SSc support groups have trained leaders [7••].

There were 80 current support group leaders who completed the survey, which inquired about their confidence in executing tasks necessary to successfully facilitate support groups and to take care of themselves as leaders [55••]. Support group leaders had a high level of confidence in their ability to carry out many tasks related to facilitating a support group, such as establishing group rules (91%), helping members feel comfortable in the group (90%), helping members cope with grief and loss, and attaining and responding to member feedback. They were less confident, however, in tasks related to managing difficult group dynamics (63%) and promoting and sustaining the group through recruiting new members (55%), for instance. Only 60% reported feeling confident in their ability to successfully cope with the burden that resulted from demands placed on them as group leaders [55••].

The SPIN—Scleroderma Support Group Leader Education Program

SPIN's research in SSc and research in other diseases, including cancer, has established that leading a support group is challenging and can result in a high level of burden for patient leaders, often resulting in burnout. Peer leaders of illness-based support groups across diseases report challenges that include practical difficulties, including a lack of resources or poor coordination with medical professionals; difficulties with group leadership tasks, such as managing complex group dynamics or dealing with the worsening health or death of group members; and personal challenges, such as balancing personal and group demands, preventing burnout and stress, and managing one's own health condition while supporting others [50, 56–60]. These challenges can be magnified for peer leaders of rare disease support groups, who also face logistical problems related to small numbers of potential group members and limited support from healthcare and patient organizations.

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. Many support groups may be unable to facilitate the education and information sharing and emotional and practical support that these groups aim to provide due to shortcomings of untrained patient leaders and logistic difficulties, such as difficulty recruiting individuals to present educational material to the support groups. Health professionals are in a position to promote peer-led support groups for individuals with SSc, however, some healthcare providers describe being reluctant to refer patients to these types of groups. Reasons for this seem to relate to concerns that members of peer-led support groups may sometimes provide inaccurate information or give medical recommendations or that support groups may be limited by a lack of organization or an overly negative focus within the groups (e.g., “doctor bashing”).

SPIN has partnered closely with Scleroderma Canada and the Scleroderma Foundation to improve the experience of support group leaders, enhance support group access, and improve the ability of SSc support groups to meet patient needs. Providing training to peer group leaders could accomplish this, but no well-conducted trials have evaluated the effectiveness of training programs for peer support group leaders [61•]. As a result, SPIN, in partnership with Scleroderma Canada and the Scleroderma Foundation, developed the SPIN Scleroderma Support group Leader EDucation (SPIN-SSLED) Program.

The SPIN-SSLED Program is a 3-month-long group training program delivered via videoconferencing to provide information and skills to improve patient support group leaders' confidence and self-efficacy to carry out their leadership roles. Training is delivered to groups of 5–6 support group leaders, and the program includes 13 modules that are delivered live via webinar over the course of the 3-month program. Each module is delivered in a 60- to 90-min session. Module topics include the following: (1) the leader's role, (2) starting a support group, (3) structuring a support group meeting, (4) scleroderma 101, (5) successful support group culture, (6) managing support group dynamics, (7) grief and loss: the support group leader, (8) grief and loss in scleroderma: supporting group members, (9) advertising and recruitment for the support group, (10) the continuity of the group, (11) supporting yourself as a leader, (12) remote support groups, and (13) transitions in support groups. In addition to the live modules, SPIN-SSLED participants receive a program manual that summarizes didactic material that is provided in the sessions. Modules include filmed vignettes demonstrating effective group facilitation techniques and ways to respond to support group issues. SPIN-SSLED participants also have access to an online resource center that includes a range of helpful tools for leaders including files of SSc-related videos to show at meetings. There is also an online forum for leaders to post

questions, which is open only to leaders who have taken part in the SPIN-SSLED program.

Recently, SPIN tested the program through a feasibility trial [62], and a full-scale SPIN-SSLED trial, which was recently funded by the Canadian Institutes of Health Research, will commence in 2019 in partnership with Scleroderma Canada, the Scleroderma Foundation, Scleroderma & Raynaud's UK, and the Scleroderma Association of New South Wales. 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. If effective, the SPIN-SSLED Program will be adopted by SPIN's patient organization partners so that it can be provided to affiliated support group leaders.

Conclusion

Many patients with rheumatic diseases, including SSc, turn to peer-led support groups to cope with their condition and access educational resources. Important barriers to sustaining support groups exist, including the lack of access to local support groups, burden on peer leaders, and a lack of confidence among health professionals about the ability of some groups to meet patient needs successfully. Training and educational programs for support group leaders could provide the necessary information and skills to improve the ability of SSc peer support group leaders to lead sustainable, effective support groups; reduce the emotional and physical toll on leaders; and encourage new leaders to set up support groups where none exists, physically or via the Internet. In partnership with national SSc organizations, SPIN has developed a training program to improve patient support group leaders' confidence and self-efficacy to carry out their leadership roles. This program will be tested through a randomized controlled trial, beginning in 2019, and, if effective, will be implemented by SPIN's patient organization partners. It may also be adapted for leaders of support groups in other rheumatic diseases.

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Compliance with Ethical Standards

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