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RESEARCH ARTICLE

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A qualitative interview study exploring the psychological health impacts of the SPIN-CHAT program among people with systemic sclerosis at the onset of COVID-19: perceptions of trial participants and research team members

Amanda Wurz[a,b], Delaney Duchek[b], Kelsey Ellis[b], Mannat Bansal[b], Marie-Eve Carrier[c], Lydia Tao[c], Laura Dyas[d], Linda Kwakkenbos[e,f,g,h], Brooke Levis[c,i,j], Ghassan El-Baalbaki[k], Danielle B. Rice[c,l], Yin Wu[m], Richard S. Henry[c,l], Laura Bustamante[n], Sami Harb[c,m], Shannon Hebblethwaite[n], Scott B. Patten[o,p], Susan J. Bartlett[q,r], John Varga[s], Luc Mouthon[t,u], Sarah Markham[v], Brett D. Thombs[c,i,l,q,w], S. Nicole Culos-Reed[b,x,y], SPIN-CHAT Patient Advisory Team[*] and Program Facilitators[†] on behalf of the Scleroderma Patient-centered Intervention Network Investigators[‡]

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ABSTRACT

Purpose: Explore trial participants' and research team members' perceptions of the impact of the videoconference-based, supportive care program (SPIN-CHAT Program) during early COVID-19 for individuals with systemic sclerosis (SSc).

Methods: Data were collected cross-sectionally. A social constructivist paradigm was adopted, and one-on-one videoconference-based, semi-structured interviews were conducted with SPIN-CHAT Trial participants and research team members. A hybrid inductive-deductive approach and reflexive thematic analysis were used.

Results: Of the 40 SPIN-CHAT Trial participants and 28 research team members approached, 30 trial participants (Mean age = 54.9; SD = 13.0 years) and 22 research team members agreed to participate. Those who took part in interviews had similar characteristics to those who declined. Five themes were identified: (1) The SPIN-CHAT Program conferred a range of positive psychological health outcomes, (2) People who don't have SSc don't get it: The importance of SSc-specific programming, (3) The group-based format of the SPIN-CHAT Program created a safe space to connect and meet similar others, (4) The structure and schedule of the SPIN-CHAT Program reduced feelings of boredom and contributed to enhanced psychological health, (5) The necessity of knowledge, skills, and tools to self-manage SSc and navigate COVID-19.

Conclusion: Participants' and research team members' perspectives elucidated SPIN-CHAT Program benefits and how these benefits may have been realized. Results underscore the importance of social support from similar others, structure, and self-management to enhance psychological health during COVID-19.

Trial Registration: clinicaltrials.gov (NCT04335279)

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➤ IMPLICATIONS FOR REHABILITATION

- The videoconference-based, supportive care SPIN-CHAT Program enhanced psychological health amongst individuals affected by systemic sclerosis.
- SPIN-CHAT Program participants and research team members shared that being around similar others, program structure, and self-management support were important and may have contributed to enhanced psychological health.
- Further efforts are required to explore experiences within supportive care programs to better understand if and how psychological health is impacted.

Introduction

Initially observed at the end of 2019 [1], the novel coronavirus (SARS-CoV-2), designated as COVID-19 by the World Health Organization, reached the level of a pandemic in March 2020. In the wake of this world-wide health crisis, public health officials and leaders implemented a number of extraordinary measures (e.g., restrictions, regulations) to mitigate the spread of COVID-19 [2]. Although effective for containing the virus, these measures were feared to negatively impact a range of psychological health outcomes including loneliness, boredom, grief, worry, fear, and anxiety [3–6]. In the general population, psychological health was unchanged or decreased by only small amounts when data from pre-COVID-19 were compared to data collected from the same populations during the pandemic [7–10].

A systematic review and meta-analysis [7,8], however, found that symptoms of anxiety (standardized mean difference [SMD] = 0.27, 95% confidence interval (CI) 0.01 to 0.54; 3 studies; $N = 2{,}053$), but not depression (SMD = 0.01, 95% CI −0.06 to 0.08; 3 studies; $N = 2{,}006$), increased among people with chronic medical illnesses, including systemic sclerosis (SSc; more commonly known as scleroderma). SSc is an autoimmune disease characterized by abnormal fibrotic processes affecting multiple organ systems [11]. People with SSc are at risk of potentially worse COVID-19 symptoms and negative outcomes due to their compromised respiratory system, underlying frailty, and use of immunosuppressant drugs [12]. Though depression symptoms were stable compared to pre-COVID-19, anxiety symptoms increased substantially in April 2020 compared to late 2019 in an international cohort of over 400 people with SSc (SMD = 0.51, 95% CI 0.37 to 0.64; $N = 435$,) [13,14]. Further, anxiety symptoms returned to pre-pandemic levels by late 2020 [14]. Nevertheless, efforts to protect psychological health during and after COVID-19 among individuals with SSc, and other populations with pre-existing medical conditions, are required [15].

Multi-faceted interventions that include strategies for maintaining a daily routine, healthy information consumption, staying connected with others, physical activity, and anxiety-reduction were recommended by public health officials and organizations to protect psychological health during COVID-19 [16–19]. Aligning with these recommendations, the multi-faceted Scleroderma Patient-centered Intervention Network COVID-19 Home-isolation Activities Together (SPIN-CHAT) Program was rapidly developed and implemented in April 2020 to reduce anxiety symptoms (primary outcome) and improve other psychological health outcomes [20,21]. The program was group-based and delivered via videoconference 3 times per week over 4 weeks with sessions lasting 60–90 min. Each session included: (i) group leisure activities; (ii) education and information; and (iii) group discussion (an overview of SPIN-CHAT Program content is available at https://osf.io/62vut/files/). Sessions were facilitated by patient support group leaders who were either living with SSc or involved in SSc patient organizations, and all leaders were previously trained in the Scleroderma Support Group Leader EDucation (SPIN-SSLED) training program [20,22]. A two-arm partially nested randomized controlled trial (PN-RCT) was used to evaluate the SPIN-CHAT Program [20,21]. No significant improvements in the primary outcome of anxiety or secondary outcomes of depression, fear, loneliness, boredom, and physical activity levels were observed immediately post-intervention. Yet, at a 6-week follow-up, anxiety (SMD = 0.31, 95% CI 0.03 to 0.58) and depression symptoms (SMD = 0.31, 95% CI 0.07 to 0.55) significantly improved [21].

These findings suggest there may be a beneficial, albeit delayed, effect of the SPIN-CHAT Program on some psychological health outcomes. This is bolstered by other studies that have found improved psychological health outcomes following interventions delivered via videoconference or over the internet (e.g., mind-body, cognitive behavioural) to individuals with pre-existing medical conditions during COVID-19 [23,24]. However, much remains unknown about participants' experiences navigating their pre-existing medical condition amidst COVID-19 and whether psychological health benefits may have been accrued within the SPIN-CHAT Program for some people, even if not captured with the quantitative assessments. Indeed, many psychological health outcomes, such as symptoms of anxiety and depression, vacillate over time with periods of higher and lower symptomatology. It is possible that due to the timing of questionnaire administration, some effects of the program were not captured. Further, there may have also been an ongoing process of improvement that was not explored, given the finding that symptom reduction was greatest six weeks after the end of the intervention period (the last assessment done). Finally, questionnaires assessing common psychological health outcomes may fail to provide a comprehensive understanding of phenomena [25] and interpretations often focus on aggregate-level comparisons, which could detract from personally meaningful changes [26].

Studies using qualitative approaches have the potential to address some of these gaps by exploring participants' unique experiences. In addition, studies using qualitative approaches can offer deeper insights into the processes underlying the acquisition of benefits experienced by some participants. Enabling participants to describe their lived experience in their own words can elucidate the pathways to enhanced psychological health outcomes. Similarly, capturing perspectives from research team members involved in program design or delivery – a group often overlooked in quantitative and qualitative research – could facilitate corroboration with regards to observed psychological health changes amongst program participants. Therefore, the purpose of this study was to gather perspectives from SPIN-CHAT Trial participants who received the SPIN-CHAT Program and research team members to explore potential benefits accrued.

Methods

The qualitative data analyzed and reported herein were collected as part of a larger cross-sectional, multiple perspectives follow-up study exploring the SPIN-CHAT Trial [27], which had two distinct foci resulting in two manuscripts (see [28] for the other manuscript). A social constructivist paradigm was adopted [29], which views reality as a construction by and of the mind and knowledge as influenced by social relationship. Semi-structured interviews were conducted with SPIN-CHAT Trial participants and research team members (e.g., patient facilitators, professional educators, and trial management staff). The follow-up study was reported consistent with the consolidated criteria for reporting qualitative research (COREQ) checklist [30] (see Supplementary File 1).

Participants

Following relevant Research Ethics Board approvals from the Conjoint Health Research Ethics Board (REB21-0067) and the Research Ethics Committee of the Centre intégré universitaire de santé et de services sociaux du Centre-Ouest-de-l'Île-de-Montréal (F1-17306), a purposeful sample of SPIN-CHAT Trial participants was recruited. Members of the follow-up study team (AW, DD, KE, MB) screened all SPIN-CHAT Trial participants based on variables of interest, including anxiety and depression symptom score levels (at baseline and after the SPIN-CHAT Program) and program attendance, allocation to intervention or waitlist control group, and demographic characteristics, including sex, geographic location, age, and race and ethnicity. This was done to collate experiences of a wide range of individuals living with SSc who took part in the SPIN-CHAT Program and the Trial. Selected participants were invited by email to participate in an interview by a member of the study team within 8 weeks of completing the SPIN-CHAT Program (whether in the trial intervention group or after receiving the program as part of the waitlist control group post-trial). Research team members involved in the design or delivery of the SPIN-CHAT Trial were recruited based on convenience sampling, wherein the principal investigator (BDT) of the larger SPIN and SPIN-CHAT Trial contacted all research team members ($n = 28$) by email, inviting them to contact members of the follow-up study team (KE, DD, MB) if they were interested and willing to participate in an interview. Research team members were assured that BDT (and all other relevant investigators within the larger SPIN and SPIN-CHAT Trial) would be unaware of their participation.

SPIN-CHAT Trial participants were eligible to participate if they were interested, and willing and able to complete verbal informed consent and a one-on-one, videoconference-based interview in French or English. To meet participation criteria for the SPIN-CHAT Trial, individuals had to: (i) score ≥ 55 on the Patient-

Reported Outcomes Measurement Information System Anxiety 4a v1.0 [31]; (ii) have not tested positive for COVID-19 before trial start, as that could require distinct psychological health support; and, (iii) verify they were not actively partaking in psychotherapy or counselling services. Research team members were eligible if they were involved in delivering (i.e., facilitating, leading educational sessions) or designing and developing (i.e., carrying out logistical aspects) the SPIN-CHAT Program and Trial and were willing and able to provide verbal informed consent.

Data collection

After data were extracted from the SPIN-CHAT Trial database to describe the sample, trial participants and research team members took part in one-on-one, semi-structured qualitative interviews over videoconference. For SPIN-CHAT Trial participants, the interview guide was designed by the research team to explore their experiences with the program and trial and whether any benefits were accrued (and if they were, the process of benefit accrual). For research team members, the interview guide was designed to explore their experiences designing or delivering the program. Questions focused on the strategies used, educational tools and skills they sought to impart, and whether they perceived participants were or were not benefiting from the program as a whole or from specific strategies. The interview guide was piloted amongst the research team prior to use. See Supplementary File 2 for the interview guide.

Private, one-on-one, semi-structured interviews were scheduled at participants' and research team members' convenience and were performed using GoTo Meeting (a videoconference software). To foster rapport in the context of the larger cross-sectional follow-up study [32], female graduate students who received extensive study-specific training, had completed graduate course work covering qualitative methodologies, and were involved with delivering physical activity education as part of the SPIN-CHAT Trial (DD, KE) or who were living with SSc (MB), conducted the interviews. Every effort was made to ensure that those who delivered the physical activity education sessions did not interview trial participants with whom they had previously interacted. In five cases this was not possible due to language constraints (i.e., only one study team member spoke French; KE). In these cases, KE interviewed (in French) participants with whom she had also delivered physical activity education sessions. Across all interviews conducted, interviewers explained to participants that they did not design the SPIN-CHAT Program or Trial. Interviewers stressed that they were tasked with evaluating the SPIN-CHAT Program and Trial and desired all forms of feedback. This was done to minimize potentially desirable responses. All interviews were audio recorded, and no repeat interviews were conducted.

Data analysis

Quantitative data collected from SPIN-CHAT Trial participants were analyzed descriptively using SPSS (Version 26). With regards to qualitative data, the transcribed verbatim interviews were analyzed using inductive and deductive elements following principles of interpretive description and following guidance for reflexive thematic analysis [33,34]. Four authors (DD, KE, MB, AW) read each transcript several times to familiarize themselves with the data. Next, DD, KE, and MB independently generated codes using an inductive approach wherein themes were derived from the raw data. Deductive reasoning was then applied to align interpretations with results from the trial [21] and relevant literature [35–37] by four authors (DD, KE, MB, AW). Afterwards, DD and AW met to discuss the findings and embark on an iterative process to generate main themes and subthemes. The authors engaged in critical dialogue, explored alternative ways of understanding and interpreting the data, developed semantic-level themes, and compared and contrasted perspectives between participants and research team members. Following this, KE and MB reviewed the themes and subthemes and offered critical reflections and alternative interpretations. During this stage, DD, KE, MB, and AW exchanged drafts several times before mutually agreeing upon main themes, subthemes, and representative quotes, which were reviewed to ensure they were internally consistent and had minimal conceptual overlap. Finally, the generated themes, subthemes, and representative quotes were shared with NCR, BDT, and members of the larger SPIN Patient Advisory Team from the trial who acted as critical friends and challenged researcher interpretations.

Several strategies recommended in the literature were used to enhance rigour and transparency of reporting this follow-up study [32,38]. First, semi-structured interviews were used to allow participants to freely discuss the important aspects of their experience with the program. Second, thick, rich descriptions were developed to describe each theme. This was done to bolster resonance while using unedited participant quotes to highlight the alignment between the data and researcher interpretations. Third, an attempt was made to clearly describe all aspects of the research setting and process, so readers have sufficient details and explanations to judge transferability and limitations. Fourth, several critical friends who share differing perspectives and lived experiences were involved. This was done to evoke critical dialogue and prompt reflection on the themes and subthemes. Finally, the authors actively practiced reflexivity at each step of the research process to critically examine their positions related to and interacting with the findings.

Results

Participants

Of the 172 SPIN-CHAT Trial participants, 40 were contacted and 10 did not reply. SPIN-CHAT Trial participants who did not participate were similar in terms of anxiety and depression symptom score levels (at baseline and after the SPIN-CHAT Program), program attendance, allocation to intervention or waitlist control group, and demographic characteristics (e.g., sex, age, and race and ethnicity) to those who agreed to participate. The 30 adults with SSc who agreed to take part in this follow-up study were on average 54.9 years (SD = 13.0; range = 36.0 to 77.0 years). Table 1 provides further details regarding trial participants' characteristics. Briefly, participants were from 10 countries. Most self-identified as White ($n = 20$; 67%), were highly educated (11+ years of education; $n = 29$; 97%) and were not working ($n = 20$; 67%). Attendance to the SPIN-CHAT Program was reflective of the high attendance documented in the PN-RCT. Most participants in this follow-up study attended 10 or more of 12 session ($n = 25$; 83%); though perspectives from individuals with moderate (i.e., 7–9 of 12 sessions; $n = 4$; 16%) and low attendance (i.e., <6 of 12 sessions; $n = 1$; 4%) were also captured. Finally, participants in this study reported anxiety (Mean at baseline = 62.18, 95% CI 55.80 to 71.20) and depression (Mean at baseline = 7.63, 95% CI 1.00 to 23.00) symptoms, which ranged in severity, but on average represented moderate to high anxiety and depression symptoms. Twenty-eight research team members were initially contacted. Twenty-five responded, and 22 agreed to participate. Research

Table 1. SPIN-CHAT Trial participants' characteristics.

Variable	Mean (SD), [range][a] *n* (%)[b]
Age[a]	54.87 (13.01), [36.0–77.0]
Sex[b]	
Male	5 (16.7)
Female	25 (83.3)
Race[b]	
White	20 (66.7)
Black	3 (10.0)
Other	7 (23.3)
Education[a]	15.57 (4.12), [0.0–22.00]
<10 years[b]	1 (3.00)
11–15 years[b]	13 (43.0)
16–20 years[b]	12 (40.0)
>20 years[b]	4 (13.0)
Employment status[b]	
Employed	10 (33.3)
Unemployed	20 (66.7)
Location[b]	
Philippines	2 (6.7)
New Zealand	1 (3.3)
United States of America	6 (20.0)
Canada	7 (23.3)
United Kingdom	4 (13.3)
Australia	3 (10.0)
France	3 (10.0)
India	1 (3.3)
Germany	2 (6.7)
Norway	1 (3.3)
Trial allocation[b]	
Intervention group	15 (50)
Waitlist control group	15 (50)
Attendance (/12 sessions)[a]	11.00 (1.64), [5.00–12.00]
High attenders (i.e., 10 to 12/12 sessions)[b]	25 (83.0)
Moderate attenders (i.e., 7 to 9/12 sessions)[b]	4 (16.0)
Low attenders (i.e., <6/12 sessions)[b]	1 (4.0)
Anxiety	
Scale range = 4–20; score range = 16–80[c]	
Baseline[a]	62.18 (3.92), [55.80–71.20]
Post-intervention[a]	56.58 (6.66), [40.30–73.30]
Depression	
Scale range = 0–24; Score range = 1–23[d]	
Baseline[a]	7.63 (6.24), [1.00–23.00]
Post-intervention[a]	6.40 (5.22), [1.00–20.00]

SD: standard deviation; [a]Mean (SD), [range]; [b]*n*(%); [c]higher anxiety scores indicate higher anxiety levels; [d]higher depression scores indicate higher depression levels.

team members who participated were representative, in terms of roles, to the larger SPIN-CHAT research team and were classified as educators ($n = 4$), trial management staff (e.g., program coordinators, designers, and support; $n = 6$), and group moderators ($n = 12$). Of the moderators, 10 of 12 were individuals living with SSc and 2 were engaged in patient organizations supporting individuals living with SSc.

Main results

Trial participants and research team members offered insights into their experiences within the SPIN-CHAT Program, and the processes and factors they perceived to be underlying positive psychological benefits accrued. Interviews lasted, on average, 58:32 min (range approximately 27–101 min) and 36:52 min (range approximately 14–53 min) for trial participants and research team members, respectively. Five overarching and overlapping themes were identified reflecting participants' and research team members' perspectives and researcher interpretations. These themes are described in detail below and illustrated via representative quotes from each perspective within the text and with additional quotes in Table 2.

The SPIN-CHAT program conferred a range of positive psychological health outcomes

Participants' perspective. When reflecting upon their participation in the SPIN-CHAT Program, participants described a range of psychological health benefits and expressed a deep sense of gratitude for the opportunity to take part in the program and accrue benefits. Specifically, participants described noticing decreased feelings of anxiety, which for many were amplified at the onset of COVID-19. For example, one participant (age <50 years) commented: "*[My anxiety levels] were really high in the beginning [of the pandemic]. I have to credit the SPIN-CHAT Program for lowering them significantly. [The SPIN-CHAT Program] was exactly what I needed, because there was so much fear and so many unknowns.*" As well, participants described feeling lower levels of depression and stress after the program had ended. One participant (age <50 years) indicated: "*I felt more secure [after the program] emotionally and it almost helped me snap out of moods. So, If I was feeling a bit gloomy that day, I would come out of the meeting feeling rejuvenated.*" Another (age <50 years) stated: "*I think without me joining this [the SPIN-CHAT Program], […] I might not be able to cope up with all of the stress that's come up.*" Beyond noticing these positive psychological health benefits, participants also commented on how taking part in the SPIN-CHAT Program helped them feel connected during a time that was otherwise isolating and lonely. This was captured by one participant (age <50 years) who said: "*The most useful [element of the program] was just the regular contact with other people.*" Finally, participants expressed gratitude that the SPIN-CHAT Program was a place where they could focus on and discuss psychological health.

Research team members' perspective. Research team members echoed participants' sentiment and described seeing or hearing positive psychological health changes amongst participants. Some research team members heard firsthand from either the participants in their groups or who they interacted with, that they were doing better. Other research team members witnessed the positive changes amongst participants during their videoconference calls, which were part of the program. Research team members described seeing (or hearing) greater joy, happiness, and lightheartedness amongst participants. They also saw (or heard) a sense of lessened or managed anxiety and depression. Finally, research team members observed and felt for themselves a deep sense of togetherness amongst program participants. This was captured by one research team member who stated:

> *We can't change their lives, but for four weeks, we did change their environment. We changed their lives by just being there […] and showing them care […]. That gave them the sense of purpose, a sense of self-esteem, it helped them to be a little bit more courageous in some cases. And yes, that would affect depression […] You heard laughter, […] having fun, and I think amid COVID, where they were all stuck at home and couldn't see their loved ones, to share that sense of laughter, I think you just see people weren't bored, they were happy. And that's success.*

Of note, despite witnessing enhanced psychological health outcomes, many research team members mentioned that talking to participants about psychological health directly was initially difficult for them because of the inherent psychological health challenges that come with SSc. Thus, research team members were mindful about when and how they broached the topic of psychological health to be sensitive to participants' needs and experiences, as captured when a research team member shared: "*That [speaking about mental health] was a challenge for us […]. Some people are more open to discussing that sort of stuff and some aren't, so [the educators] were really, really gentle with everybody*

Table 2. Representative quotes for SPIN-CHAT Trial participants and research team members.

Themes	Participants	Research Team Members
The SPIN-CHAT Program conferred a range of positive psychological health outcomes	***I felt better after participating in the program*** But I just try and go over what I have learned in the SPIN-CHAT Program, so that, more of my anxiety will be lessened […]. [My anxiety] changed definitely after the program. (Age $<$50 years) [The SPIN-CHAT program] helped me to be less anxious […]. During COVID-19 it was difficult. The first few months when everything was closed, we stayed in the house and I was afraid, I was really afraid to get it […]. But it [the SPIN-CHAT program] helped me get through it, even though COVID-19 is still out there. (Age $\geq$60 years) ***I felt more connected and less isolated and lonely*** I liked it [the group] a lot and it is good that you can connect with other people […]. With COVID, it's been really hard maintaining connections. (Age $\geq$60 years) [The SPIN-CHAT Program] was something I looked forward to in the pandemic because I was socially dysfunctional. I'm so used to seeing a lot of people […] that for me it was really something I started looking forward to. (Age $\geq$60 years) ***I felt less depressed and in a better mood*** I had a big depression, [it's something], I have to work on it so that I don't go back to the same place. For sure I have difficulties, but during the SPIN-CHAT Program it went well and afterwards as well […]. My morale is better. (Age 50–59 years) [The SPIN-CHAT Program] made me more aware of [my psychological health]. Maybe I do have [feelings] of anxiety or of depression. [I could] start to notice the warning signals of what's happening. (Age $\geq$60 years) ***My feelings of stress were improved*** Exercise, meditation, [were important to teach me] how to deal with anxiety, stress. (Age $\geq$60 years) I learned how to manage my stress. Before COVID I had several stomach spasms. I have learned to reduce the stress a little, stress is normal […]. (Age 50–59 years)	***I saw or heard participants experience reduced anxiety, depression, and isolation*** I think you know four weeks sometimes can be an intense thing. I think people do develop a connection with each other, and so I think that probably lessened the anxiety. Knowing you had a group that you were connected with, and that you could share those anxieties or fears if you needed to and felt safe and comfortable enough to do that. I did, I think for some, because of the ongoing things […] in their life, they continue to have that depression, but because of their group, they were able to handle it better […]. And it did, it changed all of their lives for the better, every one of them. ***Speaking about mental health, though difficult, was important to address and discuss*** When we were looking at our mental health […], because we're all going through such an emotional and challenging time [during the pandemic], that could be challenging […], but not in a bad way. [Looking at our mental health] was in a good way. That was a challenge for us, but I don't think it was a bad thing. I think it was a necessary evil, so to speak. Bad things were going on [COVID-19 panedmic]. […] For the most part, we laughed a lot. But the two times that it got heavy, you know, it went there. But, I would say it was uplifting for the most part, and I always tried to keep it that way. But I was not fake. So, like the time that it got heavy, it actually got heavily, heavy. It's not like I laid it on, but I did also didn't hide it. And that's what's important too.
People who don't have SSc don't get it: The importance of SSc-specific programming	***Being around similar others helped to validate my feelings*** [The] most useful and beneficial part was the whole idea of meeting on a formal basis with other people with scleroderma […]. It made me feel that I was important and that other scleroderma groups were caring about me. (Age $\geq$60 years) [I joined the program] to meet other people [with scleroderma], […] and also by way of meeting other people to try and size up my own scenario and place myself within the great realm of scleroderma patients. That was a total success […]. It did help me through a bad patch where I was trying to accept the diagnosis, but deal with my personal image of myself. (Age $\geq$60 years) I think because we were all in the same situation, it was easy for us all to speak to each other without feeling like there was any sort of judging or implications. So, it was really nice. […] I mean you can speak with your family and that but sometimes they still don't really understand or get like the whole situation. (Age 50–59 years) ***Learning how others deal with their scleroderma helped me to refine my coping skills and better equipped me to take control of and accept my diagnosis*** Well, I just believe [this program was] an opportunity to hear about other people with scleroderma […]. It gives you a chance to hear what other people are dealing with and also what someone is successful dealing with […]. To hear how they were doing with their isolation, what it meant to them, and how they could keep busy with doing things […]. (Age $\geq$60 years) Listening to other people's stories and things, it sort of spurs you on and actually gives you that sense of […] we can do this, we're all different but we have the same umbrella over us. (Age $<$50 years) ***I know I am not alone and now feel more capable of taking care of and advocating for myself***	I believe that this is the most important need for people with scleroderma […] the importance of exchanges between people who understand what we are going through. So, for me it's the most important thing, the support, the strength of us, to feel less alone. I love the fact that the group together were so supportive of each other. They just wanted to help one another. And I think they felt better. I would say, almost all of them have never met another scleroderma patient. I think it was the most interesting part [during the pandemic]. We could break the loneliness, because we were a small group of people with something in common […]. So that was my favorite part, well, all of it was my favorite part, but that was my most favorite part.

(*continued*)

Table 2. Continued.

Themes	Participants	Research Team Members
	The [SPIN-CHAT] Program has taught me how to manage the decline in, I don't know how to say it. The decline in mental acuity. If it should happen, I now know how to manage it, so I'm less afraid and I'm not worried about dealing with it right now. (Age <50 years) I think [the SPIN-CHAT Program] has been a very positive experience. It's given me, personally, a little bit of confidence and a little bit of hope that even though sometimes you do feel a bit low, […] there's things that you can work through, and that motivation to do it. So yeah, definitely it [the SPIN-CHAT Program] has given me a sense of positivity. (Age 50–59 years)	
The group-based nature of the SPIN-CHAT Program created a safe space to connect and meet similar others	***Opening up and interacting with one another took time, but was necessary to build relationships and feelings of support*** At first, I was so nervous, and I wouldn't say much […]. By the end, you get to know everyone, and now they can't stop me talking […]. It's actually been rewarding. The main thing I think I got [from the SPIN-CHAT Program] was having that group of people that we joined with every week […]. Every two weeks, we still get together. And we still talk about things […]. Just having that continuation of other people to be able to talk to and understand you […] was terrific. (Age 50–59 years) Yes, at first, [I am] definitely more hesitant to talk to people, especially about my particular disease. So, until I get comfortable with people it takes a little longer to open up about talking about my disease. (Age <50 years) ***My group offered an ear to listen and a shoulder to cry on*** It was emotional support, it was fun, it was like a security blanket as well […]. I've said it for a long time […] there is very little emotional support […]. (Age <50 years) With my mental health, I've started opening [up] to friends […] because I have a tendency to keep it on myself. And yeah, I find it better now to talk about it and to be open […]. Because during that time [the pandemic] you could feel the effect when you speak […] whatever you have in mind. And after the [SPIN-CHAT Program], then it feels like it's lightened up and you're not carrying it on yourself, but it's being released […]. It's that experience that makes me realize that it's easier to let it go and speak about it than just having it on my mind. Because before that, I didn't really have any chances to speak to somebody […] especially […] those people who also have the same experience. (Age <50 years)	***I sought to make my participants comfortable*** And at the end, I would [ask] what was your favorite part of this [session]? Or talk about something in my personal life that had to do with what we learned so that they would […] feel more comfortable to talk about themselves. Because you know, people don't really want to talk about themselves right off the bat. The facilitators would […] say, 'I tried this last week' or, 'I did this last time' […] and I think that helped to get people on board with things that maybe they wouldn't have felt comfortable with. ***I am offering ongoing support and engagement with my group*** I think once we started this program, our facilitators really wanted to be part of it. They saw the growth, they saw how their participants were engaging. And in fact, the majority of people continued far after this trial. They are still working with their groups from the SPIN-CHAT Program. And I think that says a lot about the bonding process. But the good thing is that they can always themselves keep doing it afterwards […]. there are a lot [of groups] that continue to meet each other. Some groups that do it once a week, […] I feel like they have a group that they could go back to. They have a moderator who cares for them […] and checks up on them. So, I feel like they have that system of social support. They know that scleroderma exists, that there's other people with it, that they're not alone, that there's actually support groups that exist for them.
The structure and schedule of the SPIN-CHAT Program reduced feelings of boredom and contributed to enhanced psychological health	I would have to say that whoever came up with this program was genius because it seemed […] to be at the right point in time where, 'hey this is something to do'. (Age ≥60 years) I love it extremely much and just getting [online] three days a week. It is all I can do [right now] and has been like really beneficial for me. (Age 50–59 years) Yes, [my boredom] got significantly better because it was something to look forward to and do. Whereas [before, without the SPIN-CHAT Program] I didn't have that. (Age <50 years)	***We all played roles: the importance of the whole team*** I loved talking to everyone, the moderators, the educators. Everyone was so amazing, so helpful,so understanding, and so quick to respond to emails […] I was super grateful of the team I had behind all this. I liked the fact that there was more than one person delivering more than one type of information […] there was the icebreaker […] bringing a fun element into it. I like that there was a learning thing, […] whether it be exercise, or mindfulness, […] there was another different element delivered by somebody different. And then having the time to […] review that, that day's topic with the participants and how they can apply it to their day […]. ***We wanted to offer structure during a time of uncertainty and lack of structure*** But I do believe that […] having some sort of structure, […] I think that really was a key ingredient to SPIN-CHAT because it created something that they could become more comfortable with […] and it created some sort of routine in their lives where they didn't necessarily have with everything that was happening. And most people that were in the program, were staying home or in confinement. So, it was good for them to have that routine three times a week where they would go back as their safety net. It was great that [there] was a curriculum that there was planned activities. It helped broke up the monotony.

(*continued*)

Table 2. Continued.

Themes	Participants	Research Team Members
The necessity of knowledge, skills, and tools to self-manage SSc and navigate COVID-19	I just try and go over what I have learned in the SPIN-CHAT [Program], so that more of my anxiety will be lessened […]. It changed definitely after the Program because […] I had the full tool skills from your tools that I used every time that I feel it, so I have been using exercises and […] I'm managing it well. (Age <50 years) Those resources were very valuable […]. I thought was a really smart thing to do. To give the resources to people. And there were things I put in my mind that I'd like to use someday. That'll be good. (Age ≥60 years)	***We provided relevant information in the most engaging way possible to encourage participants to share and learn relevant skills*** I think because people left the meetings trying to put regiments in place [based on what was covered], whether it was stretching exercises, managing worry and not letting it overwhelm them, media burnout […] there were so many components […]. And because those are things that were tools to keep people prepared for what they were going through during COVID-19 […], I think this program enriched each and every person that was in it. I'd present for 5–10 min, but then another 5–10 min would be trying to get peoples examples of when maybe they use these skills, or ways they're struggling that we could work through together. Again, show them some coping skills. but also do that all together, to build some sort of therapeutic alliance. ***The importance of education delivered by engaging and empathetic experts*** And they [expert educators] took all that [scleroderma specific considerations] into account […]. So, the delivery, the staff members that were all presenters that were working, they had obviously picked them all really well, because they handled with all the differences [within the group]. It wasn't just, let me spew this stuff at you. It was let me bring you into the discussion. And I think that's really important. And I think everybody [expert educators] did that. Whether it was the mindfulness or the exercise, or whatever. I mean, it was all, it all came across as, let me help you […]. I may not have it, but I get it.

on what states they're in. We had a few members, it was just too emotional for them, and they had to back off. Our team was really good. We accepted all of that and dealt with it beautifully."

People who don't have SSc don't get it: the importance of SSc-specific programming

Participants' perspective. Participants reflected positively on the fact that their SPIN-CHAT Program group was developed and led by individuals with (or affected by) SSc and all groups were comprised of other individuals living with SSc. Participants felt it was important to be around similar others and noted that it enabled deeper connections to be formed. Participants also appreciated feeling less alone navigating their condition and were able to learn from others' experiences, which served to bolster their confidence in managing their own condition during early COVID-19. This was captured by one participant (age ≥60 years) who said: "*And just the best part to me is interacting with other people that have scleroderma. Because the biggest thing is people that don't have it, don't get it. And when you're around people that have it, we get it.*"

In addition, participants explained how being around similar others normalized their experience, offered them the opportunity to learn from others and share their own coping strategies, and to voice condition-specific needs without fear of recourse. As an example, one participant (age ≥60 years) stated: "*It was nice to learn about it [how others were coping] and to get some examples of what I could do […]. So that was interesting to see. And just to hear other people's ideas.*" Ultimately, being with others with SSc enhanced participants' confidence in themselves to self-manage their condition, refined their coping skills, and enabled them to advocate for their wellbeing, as expressed by one participant (age ≥60 years) when they shared: "*I've always known that scleroderma patients have a voice. But after the program my voice got stronger. I have the power to speak out. […]. It's given me the courage to keep on talking and keep on pushing for answers.*"

Research team members' perspective. Research team members felt strongly about participants having the opportunity to meet and connect with other individuals living with SSc. Indeed, this was deemed as important and central to the success of the SPIN-CHAT Program. Some research team members described their experience witnessing participants meet others with SSc for the first time, underscoring the importance of recognizing that one is not alone in their condition. "*I think having a chronic illness in the first place can be a really lonely prospect […]. So, […] having that connection and support and understanding, having a chronic illness that nobody knows what it is, being with people that understand exactly [pause], you don't have to explain that. You just say one word that everybody understands. So, it was a great emotional […] and understanding support.*"

Research team members also observed a sense of catharsis amongst participants when they had the opportunity to share their own SSc-specific experiences, and a sense of normalization when participants heard from similar others. To capitalize on the SSc-specific nature of the program, research team members described offering words of validation, acceptance, and normalization. For example, one research team members said: "*What I think I saw was validation for a lot of things […] they were feeling or were concerned about […]. it was almost like, 'okay I'm not alone'.*"

The group-based format of the SPIN-CHAT program created a safe space to connect and meet similar others

Participants' perspective. Beyond the condition-specific nature of the program, participants also described how being a part of a group was beneficial. The group was seen as a conduit to receiving social support that was caring among participants. One participant (age <50 years) shared: "*The sympathy, from the team and the other people in the group [made it easier for me to participate]. The way we could talk between us in confidence, to confide in each other, the state of mind, really [it was beneficial].*" Although participants acknowledged initial hesitations about joining a group-based program and the amount of time and effort required to build relationships, it was deemed well worth it to reap the rewards of feeling a sense of belonging and support. Notably, many participants described wishing for or actively pursuing an ongoing connection within their group to maintain and further strengthen feelings of belonging and connectedness after the program concluded. Indeed, one participant (age <50 years) shared: "*The unknown is always scary, I was curious […] who will I get to meet? Will we have chemistry? […]. I had a bit of anxiety during the first meeting, […] then we got along pretty well […]. It was better than what I expected. I thought after the program I would not have contact with anyone else anymore, but we continued, we have managed to meet every week, […] to talk. I did not expect that.*"

Research team members' perspective. Research team members believed fostering social support amongst group members was important and described witnessing connections between participants, and the resultant social benefit. Research team members also described the various ways they sought to impart and facilitate social support for participants, which included using encouragement, enthusiasm, and validating participants' feelings. Research team members acknowledged their role as critical for fostering an understanding and welcoming group environment. Research team members shared that they arrived at each session ready to try and build strong, sustainable social connections: "*I was trying to make people comfortable […].So, it was really about trying to ensure that there was some type of comfort that people were feeling, even though we were doing it virtually […]. We don't want people to hold back or be reserved, we want them to feel comfortable and be open, so if I reflect that to them, then they were able to […] be more engaged.*"

Given the valued social support witnessed among participants and requests to continue meeting, some of the moderators indicated that they continued gathering with their group members after the end of the SPIN-CHAT Trial, describing wanting to offer ongoing support and connection. "*We still meet. Our group still meets every two weeks, and we do some of the activities that [NAME] taught us […] and I always bug them every time I see them, 'are you doing your visualization?' 'Are you doing your yoga?' You know, following up with them.*"

The structure and schedule of the SPIN-CHAT program reduced feelings of boredom and contributed to enhanced psychological health

Participants described how the multi-faceted SPIN-CHAT Program provided structure and routine within their day-to-day schedule that alleviated the boredom they were experiencing since the onset of COVID-19. The routine of consistent meetings, afforded by the program, was described as a welcome distraction and provided participants with something to look forward to. One participant (age ≥60 years) stated: "*It [the SPIN-CHAT Program] was an activity that kept me from feeling pain, in that I was busy with something else.*" Participants reported that this, in turn, lifted their mood and contributed to improved psychological health.

Research team members' perspective. Research team members felt that the structure of the program, wherein different components were led by different team members (e.g., therapeutic recreation leader, educators, and moderator), was important for alleviating feelings of boredom. For example, one research team member stated: "*The way the program was structured in having three educators per session […] it offered that sense of variety, participants kept engaged and strong […]. I think having the three leaders or the educators […] allowed for variety. No one ever got bored […]. Then we allowed open-ended discussion at the end, which gave the facilitators time to kind of wrap up things.*"

Research team members also spoke about the schedule of the SPIN-CHAT Program, which they perceived as offering a source of routine and support for participants at the outset of COVID-19, a time when maintaining a routine and normalcy was challenging (particularly among those who were unemployed and seeking to fill their time). "*Regarding the pandemic, it was a good distraction for them [participants]. I heard […] several times people say, 'I was just so glad to do something' […]. It seemed that people were pretty glad to have some regular outlet to escape from the pandemic, I would say those were the main benefits […].*"

The necessity of knowledge, skills, and tools to self-manage SSc and navigate COVID-19

Participants' perspective. Participants spoke how acquiring knowledge, skills, and tools to manage their SSc reduced feelings of stress and anxiety and helped them feel less overwhelmed by their condition. Participants described acquiring a newfound ability to self-manage through the educational sessions and listening to other participants and moderators share their personal coping strategies. This was captured by a participant (age <50 years) when they said: "*[My feelings of anxiety] changed definitely after the program because […] I had the full toolset of skills from the tools taught that I can use every time that I feel it. So, I have been using exercises and […] I'm managing it well.*" Participants described how gaining self-management knowledge, skills, and tools improved their ability to self-manage their condition, and how they saw this translate into improved psychological health. Many participants commented that they felt their new 'toolbox' would provide them with strategies they could use for years ahead, offering lifelong capacity to manage their condition. As one participant (age <50 years) indicated: "*I can really say that it changed my life. Because it introduced new elements of reflection, in relation to my own management of the disease, medical follow-up, human encounters, and relationships with others.*"

Research team members' perspective. Research team members described how they shared knowledge, skills, and tools with their participants through the three program components (i.e., leisure activities, informal discussion, education sessions with experts). Research team members sought to share only important, timely, and relevant educational information to avoid overwhelming participants, which was deemed particularly important amidst the COVID-19 pandemic and the associated infodemic (i.e., rapid spread of both accurate and inaccurate information). This was captured by one research team member when they said:

> *Given COVID […], I think the topics were incredible, timely, helpful, but they're also going to be useful way past COVID. These are tips and tools that our patient population can use every day of their lives, […]*

> *something that they can […] continue to use […]. So, I knew that whatever I was going to deliver had to be relevant, it had to have a high element of engagement, it had to be interesting, and it also had to have some level of fun in it.*

Research team members also highlighted the importance of having content experts deliver evidence-based education sessions in an engaging and empathetic manner, which was indicated when a research team member stated: "*I think everybody delivered [education sessions] with understanding […]. It came across as really understanding what the participants were going through in their lives. I think that was really important*."

Finally, another strategy used amongst research team members to promote participant engagement and knowledge uptake was to design interactive sessions: "*When they are interactive it's excellent, you need to have people a part of the segments too. So, the more interactive people could be, that was great […]. The more you can engage the group to be participant[s] in it, I think it works better, people retain more of course when you're able to experience it*."

Discussion

Initiatives to address poor psychological health at the onset of the COVID-19 pandemic were needed, yet scarce [39]. This is particularly true for populations with pre-existing medical conditions, such as individuals living with SSc. The SPIN-CHAT Program was designed and delivered early within the context of the COVID-19 pandemic to mitigate anxiety and other negative psychological health outcomes in the SSc population. Findings from this follow-up study suggest psychological health improved within the program, and that the social support, opportunity to be around similar others, structure, and access to experts and carefully sourced information may underlie these benefits.

Within the larger PN-RCT [20,21], post-intervention results were not statistically significant. Nevertheless, psychological health was described by participants and research team members in this follow-up study as improving over the course of the program. This is perhaps unsurprising given other reports of supportive care interventions enhancing psychological health in adults experiencing enhanced anxiety, depression, loneliness, or worry caused by COVID-19 [23,24]. Further, in this sample, reduced loneliness and boredom, greater social support, and access to self-management tools were described as inherently valuable for psychological health and the range of benefits accrued. Looking ahead, finding ways to capture participants' and research team members' lived experiences alongside quantitative data could guide study priorities (e.g., determining meaningful outcomes) and afford more nuanced understandings of intervention effects.

With regards to the ways in which psychological health was affected within the SPIN-CHAT Program, social support and the SSc-specific nature of groups were deemed integral by participants and research team members. Greater perceived social support is associated with reduced feelings of depression among individuals living with SSc [40,41] and in the context of COVID-19, may attenuate or buffer negative psychological health effects [42–44]. Further, being around similar others may offer a chance for individuals to connect over their shared disease experience [45–47], which was clearly iterated by participants and research team members in this follow-up study. Consequently, participants desired ongoing access to the SSc-specific social support they received within the SPIN-CHAT Program, and in many cases, continued to connect with their groups. This continuation of social support, beyond the program-period, may partially explain the delayed intervention effects documented in the PN-RCT [21] wherein benefits were realized six weeks post-program. Fostering opportunities to experience prolonged supportive social relationships with similar others will be important to continue promoting psychological health amongst individuals with SSc.

Beyond SSc-specific social support, participants and research members lauded the routine and structure provided by the program for its role in alleviating feelings of boredom and decreasing feelings of anxiety, depression, and loneliness. Breaking up the day and engaging in meaningful tasks have been recommended to protect psychological health during the pandemic [17], and this sample underscored the critical importance of both. Findings also extend the literature by elucidating how having *something* to look forward to instilled a sense of hope, which in turn improved psychological health. Consequently, ensuring routine and structure within programs is important [16–19]. Looking beyond programs, there remains a need to determine how to best equip participants to create their own routine and structure – so that they may continue receiving the benefits beyond the intervention/program period.

Finally, participants and research team members in this follow-up study described the support they received as a conduit to developing increased confidence, knowledge, and skills for self-managing their condition. Self-management has been defined as a person's ability to manage the symptoms and negative consequences that ensue when living with a chronic condition [48]. The finding that self-management support enhanced psychological outcomes is consistent with previous self-management support interventions conducted with individuals with SSc [49] and other chronic diseases, such as diabetes [50], cancer [38], and congestive heart failure [51]. However, what is notable about the results from this follow-up study is that participants described positive changes in self-management after a relatively brief, 4-week program delivered via videoconference amidst a pandemic, which is similar to results seen after longer, face-to-face interventions (i.e., 6 months, 3 times/week [52]; 12 months, daily sessions [53]; 12 weeks, daily sessions [54]); thus, providing support for the role of shorter interventions, with frequent sessions (i.e., 3 times/week), delivered via videoconference to enhance self-management.

There are important strengths associated with this follow-up study. The inclusion of multiple perspectives provided depth of insight into program and trial experiences beyond the single lens of participants. Though participants and research team members held similar perspectives with regards to the benefits accrued and the factors that may explain benefit acquisition, including multiple perspectives can provide rich, nuanced, and multi-dimensional understanding of complex phenomena [55]. Second, conducting one-on-one interviews may have encouraged more candid responses from participants about their experiences, as opposed to focus groups in which participants may feel pressured to respond in certain ways and have concerns about dissenting with the group majority.

Notwithstanding these strengths and the contributions this follow-up study makes, there are also important considerations to keep in mind when interpreting the results. First, participants in this follow-up study were predominantly White, highly educated, and not working – reflective of the larger researched SSc population [56,57] – who had high levels of attendance to the SPIN-CHAT Program. Though every attempt was made to recruit a diverse sample via purposeful sampling techniques, in the future, further efforts to diversify samples will be needed. Second, the semi-structured interview guide asked questions related to the primary and secondary outcomes measured within the larger PN-RCT. Although participants were given opportunities to share additional possible effects noticed, no other psychological outcomes (positive or negative) were discussed. Third, individuals participating in this follow-up study were either SPIN-CHAT Program participants or research team members, many of whom had longstanding interactions with the greater SPIN organization. This could have led to bias in responses and a desire to share only positive experiences. Despite interviewers being individuals with limited participation and experience with the larger SPIN cohort, this still could have influenced participants' desires to only discuss positive program aspects.

Taken together, the findings from this follow-up study suggest the SPIN-CHAT Program improved several aspects of psychological health and that a SSc-specific program fostering social support, self-management skills, and routine may contribute to these benefits. This is among the first qualitative research projects to explore and evaluate experiences of participants and research team members in an intervention designed to mitigate negative psychological health effects of COVID-19. Findings represent an important step towards better understanding the impact of videoconference-based programs developed to support psychological health among those living with a chronic condition amidst COVID-19.

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Disclosure statement statements

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Data Availability statement

The data cannot be shared as SPIN-CHAT Program participants and research team members were assured that their data would be kept private and confidential, and that only the research team would have access to their raw data. However, summaries of the de-identified data are available upon reasonable request to the corresponding author, Dr. Nicole Culos-Reed.

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