

# Acceptability of an Adolescent Self-Management Program for Juvenile Idiopathic Arthritis

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**Objective.** The study objective was to test the acceptability of a self-management program (SMP) for adolescents with juvenile idiopathic arthritis (JIA) focused on disease information, self-management, and social support needs.

**Methods.** This study was conducted using inductive qualitative methods to explore the acceptability of an in-person/videoconference SMP. Two groups of four adolescents with JIA (mean age = 13.5, SD = 0.8) and two groups of pediatric rheumatology health care professionals (n = 4, n = 5) participated in four feedback sessions each. The SMP was presented to study participants, and feedback was provided on the content, format, and structure of the program. Thematic analysis was used to analyze the data.

**Results.** Adolescents felt that the content was appropriate and would be effective in supporting self-management of their arthritis. Participants advised that the trustworthiness of the information would be increased if a rheumatology health care provider facilitated the session. Potential barriers to participation included distance and availability (week-days and times), but the option for videoconference-based participation was an appropriate solution to both of these issues. Minor changes were made to content and format, and required changes were made to address participant recommendations for improvement.

**Conclusion.** This study confirmed the acceptability of an in-person/videoconference SMP for patients with JIA. Modifications were made to the SMP based on the focus group feedback, and future directions include a pilot randomized controlled trial to assess feasibility and preliminary effectiveness of the program.

## INTRODUCTION

Juvenile idiopathic arthritis (JIA) is the most common childhood rheumatic disease with an estimated incidence of 1 to 22 per 100,000 children under the age of 16 years (1). Although treatments for JIA have improved over the last decade, affected children experience continued disease activity and related morbidity, long-term disability, and psychosocial complications as they enter adulthood (2). Adolescence is a critical period of physical, cognitive, and psychosocial development as youth develop life skills, emotional regulation, and independence to manage

changes in responsibilities and as they prepare to assume adult roles (3). This period of increasing autonomy translates to a requirement for additional disease self-management skills for adolescents with JIA (eg, decision-making skills for disease and treatment management, patient–health care provider communication) to prepare for transition into adulthood and adult health care. Needs assessments have revealed gaps in self-management skills and in peer support for adolescents with JIA (4–8).

Self-management programs (SMPs) have the potential to be an effective method to address the educational, self-

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### SIGNIFICANCE & INNOVATIONS

- This was the first, to our knowledge, self-management program to offer combined in-person and videoconference self-management participation for adolescents with juvenile idiopathic arthritis.
- The self-management program was well received, and the inclusion of a videoconference option was an acceptable solution to improve accessibility.

management, and peer support needs for adolescents with JIA (9,10). SMPs for adolescents with chronic illness (eg, asthma, diabetes) have included a variety of intervention components and delivery formats; however, the content has largely centered on medical management, which has been posited to improve disease knowledge and adherence outcomes (9). When studied in adults with arthritis, in-person SMPs have resulted in improved health behavior, self-efficacy, and certain health status outcomes (11). An in-person SMP affords the opportunity to instantly react to participant feedback, tailor the amount and complexity of information to participants' needs (12), and immediately address information that participants do not understand. Furthermore, an in-person SMP in a small-group format allows for interaction and discussions among participants, which in turn builds social support (13). Although face-to-face or in-person delivery may be desired, this mode of program delivery introduces geographical and logistical barriers to SMP implementation. Remotely delivered SMPs in the form of videoconferencing represent an evolving technology that can improve the accessibility of self-management education, especially for patients commuting from rural or remote communities (14). Videoconference-based SMPs have been shown to be a feasible (15,16) and acceptable (14,16) option for adults with a chronic illness and/or physical disability, and multiple studies have demonstrated high program adherence rates (15,16). Increased adoption of remote videoconference technology owing to the coronavirus disease 2019 (COVID-19) pandemic (17,18) and advances in videoconferencing technology and security may encourage future participation in remote interventions and may serve as a low-cost alternative to in-person sites (19).

No evidence-based interactive in-person or videoconference SMPs exist for adolescents with JIA. To fill this care gap, we previously designed a group-based adolescent JIA SMP to be delivered to participants in person, via videoconference or blended in-person and videoconference programming (20). The objective of this study was to determine the acceptability (content, format, and structure) of the SMP through focus groups, from the perspective of adolescents with JIA and pediatric rheumatology health professionals.

## PATIENTS AND METHODS

**SMP.** The SMP was previously developed using the Public Health Ontario Program Planner Program Planner framework

(21) with Lorig's self-management theory (11) applied as the theoretical basis. A previously conducted needs assessment of adolescents with JIA (7,22) and a systematic review by our research team were used to identify the structures and effectiveness of existing SMPs. Additional input was obtained from working groups with five adolescents with JIA and eight pediatric rheumatology health professionals (20,23).

The development of the in-person and videoconference adolescent SMP resulted in a four-session multifaceted program encompassing JIA disease education (eg, JIA symptoms), self-management strategies (eg, physical activities, coping with pain, managing medications), and associated social support (eg, group discussions and interactive activities). The sessions were titled (i) Overview and Diagnosis of JIA (symptoms, diagnosis, types, and complications of JIA, health care team), (ii) Daily Living and Exercise (physiotherapy/occupational therapy, managing symptoms, staying active, services, school/work), (iii) Coping Strategies (managing emotions/stress, coping with diagnosis, self-esteem/body image, goal setting, mental health, and accessing support/resources), and (iv) Treatment and Lifestyle Management (managing medications, types of JIA medication, and lifestyle). The SMP included slides for content presentation, interactive activities, and group discussions and was designed to be delivered in person or by videoconference.

The aim of this study was to evaluate the acceptability (content, format, and structure) of the SMP through focus groups.

**Participants.** Two populations were included: (i) pediatric rheumatology health professionals and (ii) adolescents with JIA. Health professionals were recruited from two pediatric tertiary center sites at the Alberta Children's Hospital in Calgary and the Stollery Hospital in Edmonton, Canada, to ensure adequate sample size, discipline representation, and data saturation. The following health professional demographic characteristics were collected: sex, professional designations, and years in practice. A representative from an arthritis advocacy organization was included in the health professionals group. Adolescents were recruited from the pediatric rheumatology clinic at the Alberta Children's Hospital using purposive sampling and meeting the following inclusion criteria: (a) being an adolescent between the ages of 12 years and 17 years inclusive, (b) having a confirmed diagnosis of JIA according to the International League of Associations for Rheumatology JIA classification criteria (2), and (c) having sufficient English reading and speaking skills. Participants were excluded if they had untreated psychiatric or comorbid disorders or major cognitive impairments that may have impacted their ability to understand materials and participate in the focus group, as determined by the medical provider. Adolescent demographic characteristics were obtained from health records and included age, sex, diagnosis, and disease duration.

**Study design.** This study was conducted using inductive qualitative methods (24,25) to gain a deeper understanding of

the acceptability (content, format, structure) of the in-person/videoconference SMP. Adolescents and health professionals were recruited to experience the proposed SMP program. Adolescents were divided into two groups based on the recommended criteria for adolescent focus group composition, which indicate a small group size of approximately 4-5 participants and a maximum of a 2-year age span between participants (26). Health professionals were divided into two small groups based on the pediatric tertiary care site location (one in Edmonton and one in Calgary, Alberta, Canada) for convenience. Once participation was confirmed, dates were arranged for each of the four sessions for each individual group via email and/or telephone according to participants' availability.

All participants provided written informed consent according to the Declaration of Helsinki. This study was approved by the Conjoint Health Research Ethics Board of the University of Calgary (18-0713).

**Data collection.** Focus groups were delivered in person and via videoconference and were videotaped (with consent) using BlueJeans, a web-based videoconferencing software program that supports call recording. The focus groups were held either in person at the Alberta Children's Hospital, via videoconference, or a combination of both, in accordance with participant preference and location. Each was 60 to 90 minutes long. Both the adolescent and health care provider groups participated in four focus groups to review the four sessions of the SMP. One SMP session was presented at the beginning of each focus group, and following the presentation, an interview guide was used to obtain feedback about that session by participants. The focus groups were led by a trained moderator and study author using an interview guide that the research team developed, based on our literature review, to include open-ended questions relevant to the acceptability of the program's content, format, structure, design aesthetics, features, and desire to attend the SMP in the future (24). See Appendix A for the patient interview guide; questions were modified to the health professional perspective in those focus groups.

The moderator incorporated behavioral techniques to foster a positive environment (eg, relaxed body language, patience, pleasant tone, friendly approach) and to minimize power differentials (eg, did not patronize or berate participants) throughout the focus groups (27). The moderator used additional techniques to make adolescents feel comfortable (28), including the structure of the focus group (eg, introduction, icebreaker activity, seating arrangement) and verbal and nonverbal techniques (eg, using her first name, maintaining eye contact, communicating in plain language, acknowledging contributions, encouraging equal contribution of participants, and seeking clarification).

The moderator recorded brief field notes, and the note-taker recorded detailed field notes, which were both expanded within 24 hours after the completion of the focus groups (24). The note-taker led a debriefing session with the moderator after the

focus groups to enhance the internal validity of the findings (24). Recordings were transcribed verbatim by a research assistant to supplement the field notes (24). Identifiers collected in the focus groups were numerically coded to maintain confidentiality.

**Data analysis.** An inductive qualitative approach was used to derive emergent themes from raw text data (29) by systematically applying a thematic content analysis methodology to the qualitative data (25). Key terms and phrases were underlined in the transcripts and coded accordingly by the study author and submitted to a disclosure analysis. A thematic analysis was conducted, with the support of NVivo version 12.0 (30), to identify what participants stated about the acceptability of the program, and the text fragments were grouped based in semantic affinity. Open coding of the focus group transcripts was conducted by the first author (KC), and the identified themes were reviewed by the moderator (SFN) to ensure that they were reflective of the focus group discussions following the completion of the analysis. Members of the research team reviewed coding of the transcripts on a consistent basis to increase the internal consistency of the findings (31). Disagreements were resolved by discussion to reach consensus. The trustworthiness of this study was enhanced by debriefing sessions (27), review of transcription samples with various members of the research team (31), and analyst triangulation (eg, using multiple researchers in data analysis).

**Reflexivity.** The primary researcher (KC) was diagnosed with JIA and is an advocate and volunteer in the arthritis community. Her research interests center on improving self-management for adolescents with JIA, and her motivation for this study stemmed from the challenges she has had to overcome as a patient. She acknowledges that her position in the research community and personal experience as a patient may have influenced the interpretation and collection of data in this study owing to her potential underlying assumptions of the self-management needs of adolescents with JIA. The use of an experienced moderator and methods to improve the trustworthiness were applied to this study to mitigate the potential for bias.

## RESULTS

### Demographics and characteristics of the sample.

Two groups of four adolescents with JIA participated in four feedback sessions each. The mean age of participants was 13.5 years (SD = 0.8, 50% female). Adolescents were diagnosed with various JIA subtypes, including oligoarticular persistent and extended JIA ( $n = 2$ ), rheumatoid factor negative polyarticular JIA ( $n = 2$ ), and enthesitis-related JIA ( $n = 4$ ). The mean disease duration was 2.9 years (SD = 2.3).

Two focus groups of rheumatology health professionals from the two pediatric tertiary care sites (group size:  $n = 4$  and  $n = 5$ , respectively) participated in four feedback sessions each. Health

professionals included pediatric rheumatologists ( $n = 4$ ), a physiotherapist ( $n = 1$ ), an occupational therapist ( $n = 2$ ), a social worker ( $n = 1$ ), and the representative from the nonprofit arthritis advocacy organization. All health professionals were females with a mean of 11.2 years ( $SD = 8.6$ ) of practice in rheumatology.

**Qualitative themes.** Analysis focused on six key themes related to the acceptability of the SMP: format, structure, design aesthetics, content, features, and desire to attend the SMP in the future. Subthemes were found for each theme and are described in detail subsequently. Some differences emerged in responses between patients and health professionals, and they are highlighted subsequently.

**Format.** Two subthemes were identified under the broad theme of format: group-based SMP and delivery method (in person or videoconference). Adolescents and health professionals expressed that a group-based SMP would provide the opportunity for participants to share similar experiences and self-management skills, which would normalize their feelings and provide support. All adolescents agreed that a group-based SMP delivered in person and/or via videoconference was an acceptable format and expressed that the option to participate via videoconference would be helpful to overcome barriers to participation, including geographic location and time commitment. Health professionals preferred the in-person SMP intervention format

because they felt this would result in improved communication and would foster peer relationships; however, a videoconference option was seen as an acceptable option to improve accessibility for patients. See Table 1 for adolescent and health professional illustrative quotes about format.

**Structure.** Four subthemes were identified for feedback on the SMP structure, including age range, facilitator, group size, and session components (eg, number of sessions, session length, time and date of sessions). Health professionals expressed that the educational needs would vary between 12- and 17-year-old participants and that it would be important to ensure that the SMP included developmental and age-appropriate material. One health professional suggested separating age groups as required during select discussions (eg, medications and pregnancy). In contrast, adolescents felt the age range of 12 to 17 years was acceptable.

Both patient and health professional groups recommended that a rheumatology health professional facilitate the sessions to increase the accuracy and trustworthiness of the information provided and be available to respond to questions according to their expertise. Furthermore, health professionals related their concern about the spread of misinformation, either between participants or by a lay leader facilitating the SMP. Both groups suggested that JIA patients could share their “lived experience” with JIA during the session. In regard to group size, a small group (approximately

**Table 1.** Illustrative quotes of participant perceptions of SMP format and subsequent changes made

Format	Sample Adolescent Comments	Sample Health Care Provider Comments	Subsequent Changes Made
Group-based	<p>“I think it’s smart to have the group-based [SMP], because then you know that you’re not alone and that if you have problems with how your pain is you can help other people and then they can learn from that and learn that maybe that’s not the smartest thing to do.” (Patient 1, 14 years old)</p> <p>“Yeah, I agree with them about how it’s good to be with someone and even if they are not helping you with it, it’s good to at least know that someone else is going through the same thing.” (Patient 4, 13 years old)</p>	<p>“I like the idea of the group based because then you have peer relation, you can mention your concerns and then others can say, ‘Oh, well this worked, or this didn’t work.’ So, I do like that there’s a peer kind of participation with the group.” (HCP 2)</p> <p>“I think it is a great idea. ...One thing I like is that it allows other kids to meet other people with similar diagnoses so they cannot be so alone.” (HCP 7)</p>	No changes required.
Delivery method	<p>“I think for me it’s hard to get to Calgary to attend it in person, so I would-distance would be a barrier, if there was an option to do a video chat like this and be a part of the discussion, but not be there, that would be helpful.” (Patient 2, 14 years old)</p> <p>“I think it would be fine with either [in-person or videoconference] because the main point is that you are still there. You are still communicating.” (Patient 6, 14 years old)</p>	<p>“I think it might foster a better community within the kids if they are seeing each other in-person and then they might be interested in building friendships or sharing contact information. That might be something that would be easier done in-person than in telehealth. I think in-person would allow more of an interaction outside the clinic session between the health care provider and the group of kids who are in that session.” (HCP 8)</p> <p>“Ideally in-person I think is the best because communication is so much easier, but that doesn’t always work because a lot of people are from out of town. In that case, like telehealth is a great way as well.” (HCP 9)</p>	No changes required.

Abbreviations: HCP, health care providers; SMP, self-management program. Delivery method was in-person and video conference.

**Table 2.** Illustrative quotes of participant perceptions of SMP structure and subsequent changes made

Structure	Sample Adolescent Comments	Sample Health Care Provider Comments	Subsequent Changes Made
Age range of participants	Patient Group 1 and Group 2 all agreed that the age range of 12-17 years was acceptable.	"I think you need to be really careful, like there lots of difference between what a 12-year-old needs and what a 17-year-old needs. So, thinking about the questions and maybe ... break them up for two groups for part of it. Talking about the impact of pregnancy on methotrexate might be different ... when you have a 12-year-old. So just recognizing that in that age group there's still different needs." (HCP6)	Certain material may need to be tailored to the age of registered participants.
Facilitator selection	<p>"I would prefer it being delivered by the doctors, or like the physical therapists. Just because they might know a little bit more about arthritis, and they can tell us more ways to deal with it." (Patient 3, 13 years old)</p> <p>"Yeah, I liked having a health care provider present; adds credibility." (Patient 6, 14 years old)</p> <p>"Yeah, I liked having the HCP there just in case there was questions the presenter can't answer, the HCP can." (Patient 5, 14 years old)</p> <p>"I also think there should also be some patients who present their stories or their opinions in order to have the health care team provide information and the patients delivers an experience or an example because they have the knowledge of what it's like to live it." (Patient 2, 14 years old)</p>	<p>"I think that's the best to have people from your health care team presenting. It should be coming from a health care provider to provide accurate information. ... If you have people asking questions you want somebody from health care team to be answer those questions. ... There's lots of positives with having the kids together and meeting other kids, but I feel it is really important for the group to still be facilitated by someone who has expertise and working in treating kids with arthritis just for that fact of misinformation ... so the information doesn't get derailed by someone who has had a really bad experience." (HCP6)</p> <p>"I think here a patient who's got the condition would be best to deliver... even somebody from the adult clinic that has graduated and has coped with different things." (HCP1)</p>	<p>Facilitated by interdisciplinary pediatric rheumatology health professionals.</p> <p>Young adult with JIA will be invited to share their lived experience during the sessions.</p>
Group size	<p>"I think four or five people, because it's still small enough ... people may not be scared that it's a big group, ... but it's also big enough that people could ... still have a sense of community." (Patient 2, 14 years old)</p> <p>"Smaller group size, more welcoming when there is a smaller group of people." (Patient 8, 14 years old)</p>	<p>"Five to 10 participants so they feel included but not on their own." (HCP5)</p> <p>"I think 4 to 5 [participants]." (HCP7)</p>	Smaller group size (fewer than 10 adolescents).
Session components	<p>"Yeah, I would say four sessions is a lot. You could group a few together." (Patient 5, 14 years old)</p> <p>"Yeah, you could do three and add 10 minutes to each one." (Patient 7, 12 years old)</p> <p>Patient Group 1 and Group 2 agreed that sessions should be approximately 1.5 hours long and held on a weekday evening or weekend.</p>	<p>"Even three sessions, depending on what you want to cover, would be enough. We do cover a lot of individualized information when they come to the clinic, and that time when they are being diagnosed is a quick turnaround before you want to get them educated." (HCP7)</p> <p>Both health care provider groups agreed that sessions should be approximately 1.5 hours long and held on a weekday evening.</p>	The program was adapted to be used as separate 1.5-hour sessions based on individual need and patient availability. The recommended time to host the SMP is a weekday evening.

Abbreviations: HCP, health care providers; JIA, juvenile idiopathic arthritis; SMP, self-management program.

4-5 adolescents) was advised by patient and health professional groups to encourage peer interactions and provide the opportunity for each adolescent to participate in group discussions.

The components of the sessions (eg, number of sessions, session length, time and date of sessions) were important considerations to improve attendance. Both adolescents and health professionals expressed concerns about attendance to all sessions and provided recommendations to increase the likelihood

of attendance (eg, reduce to three sessions to improve efficiency, offer videoconference). Both groups supported each session being 1.5 hours long, provided there was still the opportunity for breaks, group discussions, and interaction among participants. Weekday evenings or weekend afternoons were identified as the preferred times to attend the SMP by the adolescents to accommodate participants' schedules (eg, unavailable during the school day, extracurricular activities); however, the SMP facilitator may

need to accommodate delivery times based on registered participants' availability. Additional suggestions included recording sessions to be viewed when a participant was unable to attend a full-day workshop and optional versus mandatory session attendance. Based on feedback, proposed changes to the SMP were made. See Table 2 for illustrative quotes related to the structure.

**Design aesthetics.** Four subthemes were discussed under the broad theme of design aesthetics, including color, images, layout and slide order, and visual appeal. The overall design aesthetics of the SMP PowerPoint presentation were well received, with some changes recommended for slides (Table 3).

**Content.** Five subthemes were discussed under the broad theme of content, including quality and credibility, amount and detail of information, completeness, comprehensibility, and relevance. The content of the SMP was well received by the adolescents, whereas the health professionals provided detailed feedback on the content.

Both groups were satisfied with the quality and credibility of the information. Patient participants felt the completeness of the information was acceptable; however, health professionals expressed that the amount and/or detail of the information on

certain slides was too much. Health care professionals provided suggestions for content that was missing from the SMP and outlined site differences in rheumatology care that should be taken into consideration when delivering the SMP.

Certain health care providers felt that the understandability of the information (eg, language, medical terminology) might be too advanced for adolescents; however, adolescents felt that the language was appropriate. Changes were made to the SMP to improve understandability (eg, explanation of medical terminology, use of lay language). All participants expressed that the information would be effective in supporting self-management for adolescents with JIA. See Table 4 for illustrative quotes and changes made to the content.

**Features.** The features of the SMP referred to the group discussions, interactive activities (eg, goal setting), relaxation audio clips, videos, resources, and handouts. Both groups were satisfied with the features and believed that group discussions and interactive activities would encourage peer support. Both groups highlighted the importance of having age-appropriate resources for adolescents (eg, apps) and material that could be taken home for review following the SMP. Based on these suggestions, a copy of the slides would be provided to participants following each session.

**Table 3.** Illustrative quotes of participant perceptions of SMP design aesthetics and subsequent changes made

Design Aesthetics	Sample Adolescent Comments	Sample Health Care Provider Comments	Subsequent Changes Made
Color	<p>"Maybe you could have more color make it more interesting, but the way it was easy to read and straightforward." (Patient 1)</p> <p>"The colors were good. ... There was a lot of blue so maybe adding a color or two?" (Patient 5, 14 years old)</p>	<p>"Could include more colors." (HCP3)</p> <p>"I have no complaints about the look. ... Maybe a bit more color, a lot of the pictures had neutral colors, that would be my only comment." (HCP3)</p>	Added more color to PowerPoint slides.
Images	<p>"It looked all pretty good to me, I liked the pictures and my favourite one was probably where it showed the erosion on ... the knee joint." (Patient 3, 13 years old)</p> <p>"I liked the photos and stuff. It felt welcoming, and when you were talking about the splints and stuff that you would show photos about them." (Patient 6, 14 years old)</p>	<p>"I like the visuals for the comparison of what a normal joint looks like to an arthritic joint looks like, so actually what damages, so we can talk about ... what that actually means to them. So, I do like the visuals." (HCP2)</p> <p>"There was a slide that talked about the relaxation with tension. Can we have pictures for that?" (HCP3)</p>	Added or replaced images.
Layout and slide order	<p>"Maybe a little less information, and a bit more straightforward?" (Patient 4, 13 years old)</p> <p>"I liked it all, there were a couple things where I might've changed just the order that the slides were in, but I think it was all good." (Patient 2, 14 years old)</p> <p>"Yeah, I liked the layout of the slides. It was in a good order, which was nice." (Patient 5, 14 years old)</p>	<p>"I thought the slides overall were easy follow; nice presentation. As I mentioned before, some of the slides were quite wordy; a bit overwhelming." (HCP7)</p> <p>"This might be a personal preference, it is nice that you started with a shared experience and that they can talk about it, but I think it would make more sense to talk first about coping with a JIA diagnosis then coping with the psychological impact and the pain impact because it just flows better to me that way." (HCP8)</p>	Reduced content on select slides and changed slide order.
Visual appeal	<p>"I really liked the design of it. It's a bit technical, but there's a lot of photos and stuff which is nice." (Patient 5, 14 years old)</p>	<p>"The look and layout were good and nice, clean, but I think the interactive part of it... doing that will really stick in people's brains." (HCP3)</p>	No changes required.

Abbreviations: HCP, health care providers; SMP, self-management program.

**Table 4.** Illustrative quotes of participant perceptions of SMP content and subsequent changes made

Content	Sample Adolescent Comments	Sample Health Care Provider Comments	Subsequent Changes Made
Quality and credibility: the extent to which participants viewed the information as accurate and trustworthy	<p>“I thought the information was accurate, and I like that there was multiple different ways you could cope with arthritis and manage your pain.” (Patient 2, 14 years old)</p> <p>“I thought it sounded really trustworthy and accurate.” (Patient 7, 12 years old)</p>	<p>“The content was accurate.” (HCP4)</p> <p>“I think it was overall really good and accurate.” (HCP8)</p>	No changes required.
Amount and detail of information	<p>“I think that it’s a good amount of information for the amount of time that we have, and it definitely taught me about stuff that I can use later on.” (Patient 3, 13 years old)</p> <p>“It was nice, I liked the amount of information, it could help people who are newly diagnosed” (Patient 7, 12 years old)</p>	<p>“All the information to me was accurate. I just thought maybe you went into too much details when you were talking about cognitive behavioral therapy and different psychotherapy methods. ... It is good information, I just don’t know if the person relates to the topic, and if you’re tight on time that area can be summarized or shortened just to say that there are different ways that the psychologist can help you with your pain and stress.” (HCP8)</p>	Summarized and reduced the amount of information on certain PowerPoint slides. Removed detailed information on certain PowerPoint slides.
Completeness: the extent to which the SMP content contained all the desired information	<p>“No, I don’t think there’s anything you really missed. I think most of it was covered.” (Patient 2, 14 years old)</p>	<p>“I can’t say there’s a category of medication or lifestyle that you didn’t cover. ... You didn’t really talk about acne with prednisone, which is important for the teenagers.” (HCP4)</p> <p>“When you are talking about post-secondary, it might be a good time to bring up the UCBeyond Scholarship. ... It is good for kids to be aware of that.” (HCP6)</p>	Additional information (eg, disease-specific content, scholarship resources) was added to the content.
Transferability of information between tertiary care sites	Not applicable.	<p>“We do a lot of purchased splints; we don’t make lot of custom splinting. ... You say occupational therapists make splints, but I would say recommend splints because we don’t make a lot of them.” (HCP 7)</p> <p>“I don’t know about any of our kids having IEPs. IEPs would not be common for our kids up here, so I don’t know if that is a difference between sites. We do have school letters that are templated for each diagnosis.” (HCP6)</p>	The PowerPoint can be adapted to address site-specific needs as required.
Understand-ability: eg, readability (reading level), use of plain language, and explanation of medical terminology	<p>“I think it was well laid out, it was very simple. It was like easy to read, and it wasn’t overwhelming.” (Patient 1, 14 years old)</p> <p>Moderator: “Do you think it was easy to understand and read?”</p> <p>Response: “Yeah, it was great.” (Patient 8, 14 years old)</p>	<p>“Use the word <i>counselor</i> not <i>therapist</i>.” (HCP9)</p> <p>“If we are going to use certain terminology, they would have to be explained up front (eg, symptoms, inflammation).” (HCP5)</p>	Defined medical terminology and/or replaced with lay terms.
Relevance: applicability of the content of the SMP to the needs of adolescents with JIA	<p>“Yeah, I think this information will because they gave a lot of examples from different things I could do to help me ... in terms of like, if I’m in pain or if I’m tense, I</p>	<p>“I think it’s very practical knowledge. Like, people will probably consider drinking at some point. Or someone will be telling them all about, you know, this new diet.</p>	No changes required.

(Continued)

**Table 4.** (Cont'd)

Content	Sample Adolescent Comments	Sample Health Care Provider Comments	Subsequent Changes Made
	could do these things to take my mind off the pain a little and help me relax.” (Patient 2, 14 years old) “Yeah, I think this information is helpful, maybe not for me as much as I've been diagnosed for a long time, but for newly diagnosed patients it would be really helpful.” (Patient 5, 14 years old)	That's just everyday life stuff that is going to happen. So, I think it's very practical and important when they won't necessarily think to ask it at a rheumatology appointment. So, the fact that you have it in a session will be really helpful.” (HCP3)	

Abbreviations: HCP, health care providers; IEP, individualized education plan; JIA, juvenile idiopathic arthritis.

**Desire to attend an SMP in the future.** Overall, the SMP was well received, and all adolescents expressed a desire to attend in the future. Moreover, adolescents stated that they would recommend the SMP to a friend with JIA. For example, one adolescent commented, “I liked that I got to learn about JIA and not my parent. In appointments my parent is usually taught and not me” (Patient 1, 14 years old). Both groups of participants felt that the program would be helpful for patients newly diagnosed with JIA or patients who wanted more information about their disease. Potential barriers to participation included distance and availability, but the option for videoconference-based participation was an appropriate solution for both groups. Adolescents expressed that they would not need incentives (eg, gift cards, prizes) to attend the SMP and that a desire to learn more about their JIA would be motivation enough. In contrast, health professionals felt that adolescents might need incentives (eg, gift cards, prizes) to be encouraged to attend the program.

## DISCUSSION

To our knowledge, this is the first SMP developed for adolescents with JIA with the option to be delivered in person and/or via videoconference. This study assessed the acceptability of this intervention aimed to facilitate education, self-management, and peer support in adolescents with JIA. Adolescents and health professionals provided strong support for this group-based, in-person and videoconference SMP for adolescents with JIA. It should be noted that this work was completed prior to the in-person gathering restrictions of the COVID-19 pandemic; the inclusion of a videoconference option for participation was an acceptable solution to improve accessibility, and this becomes more relevant as virtual sessions are likely to be promoted during the pandemic recovery.

A qualitative study by Guilcher et al (14) examined the overall experience of adult participants with chronic diseases (eg, arthritis, chronic lung disease) who attended a remotely delivered chronic disease SMP, and one study demonstrated the feasibility and acceptability of a Skype-based iPeer2Peer support program for adolescents with JIA (32). Their findings highlighted important implications for remotely delivered interventions, including the importance of

positive group dynamics and strong program facilitators to facilitate group discussions between sites. Comprehensive videoconferencing training workshops can be used to teach facilitators how to use videoconferencing technology and develop patient education strategies to engage remote participants (33). Stinson et al (34) highlighted the importance of flexibility in number of calls and length of the intervention to accommodate the individual needs of participating adolescents. Potential patient barriers to home-based telehealth include technical challenges, internet access, and speed (35), especially in rural or remote communities. Further research is needed to determine participant and facilitator satisfaction (eg, videoconference quality, interaction between two groups), to identify optimal videoconferencing methods to maximize engagement, to determine feasibility and effectiveness of our combined in-person and videoconference intervention for adolescents with JIA, and to determine the differences in engagement and patient outcomes between face-to-face and remotely delivered groups.

Participants advised that rheumatology health professionals facilitate the sessions to increase the trustworthiness of the information provided and respond to questions. Previous in-person and group-based cognitive behavioral programs and family retreats for JIA have also been facilitated by health professionals (36–38), with two using multidisciplinary care teams (37,38). In contrast, individual internet-based interventions have incorporated a trained health coach for telephone support (34, 39, 40). Health professionals are recognized as a credible source to provide information, respond to questions, and provide social support to children and adolescents with JIA (7,8,41). However, health professionals often have limited availability to deliver self-management interventions, and it may be important to explore the feasibility, acceptance, and efficacy of using trained health coaches or lay leaders in comparison to health professionals for program implementation on a broad scale.

Based on the collective feedback for suggested changes and supported elements and features, a final SMP program is presented (Appendix B). The SMP will consist of four 1.5-hour weekly group sessions (4–5 adolescents) delivered in person or by videoconference by pediatric rheumatology health professionals,

and each session will be recorded for later viewing if participants are unable to attend a session. In addition, a patient representative will be invited to share their lived experience with JIA during the program. Each session will include a PowerPoint presentation, available for review following the session, along with interactive activities and facilitated group discussions. The SMP sessions can be used separately based on individual need.

The potential limitations of this study need to be considered in the interpretation of these findings. The small group size and recruitment of adolescents from one tertiary pediatric hospital site may impact the generalizability of the study. Certain subtypes of JIA were not represented in this study, which may have resulted in the SMP not addressing subtype specific challenges. Adolescent responses in the focus group may be biased because of a “need for peer approval, declining social trust, short attention span, and reliance on concrete operations thinking” (p. 671) (42). Furthermore, the gender composition of the adolescent focus groups may have impacted the group dynamic (26). However, the adolescents in our focus groups appeared attentive and engaged in conversation throughout the sessions. Future feasibility and randomized controlled trials on the effectiveness of this SMP will explore differences in effects of sociodemographic and patient characteristics (eg, gender, age, disease duration) on patient outcomes and engagement with the intervention.

This study presents the first in-person/videoconference SMP designed for adolescents with JIA. The SMP was well received, and the study participants felt that offering a videoconference option was an acceptable approach to improve accessibility. The recommendations of the adolescents and health professionals were used to revise the SMP, which demonstrates the importance of conducting a qualitative acceptability study prior to evaluating the feasibility and effectiveness of the intervention for implementation in controlled trials. If proven effective, this SMP could be expanded and implemented across pediatric rheumatology centers for patients and be adapted to site-specific needs to address the self-management needs of adolescents with JIA.

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## AUTHOR CONTRIBUTIONS

All authors were involved in drafting the article or revising it critically for important intellectual content, and all authors approved the final version to be published. Dr. Schmeling had full access to all of the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis.

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