Asking the Experts: Exploring the Self-Management Needs of Adolescents With Arthritis

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Objective. To explore the self-management needs of adolescents with juvenile idiopathic arthritis and the acceptability of a Web-based program of self-management aimed at improving quality of life.

Methods. A descriptive qualitative design was used. A convenience sample of 36 adolescents (male and female) who varied in age, disease onset subtype, and disease severity were recruited from 4 Canadian tertiary care pediatric centers. Individual (n = 25) and 3 focus-group (n = 11) interviews were conducted with adolescents using semistructured interview guides. After each interview session, the audiotaped interview data were transcribed verbatim. NUD*IST 6.0 was used to assist with the sorting, organizing, and coding of the data. Data were organized into categories that reflected emerging themes.

Results. Adolescents articulated how they developed effective self-management strategies through the process of “letting go” from others who had managed their illness (health care professionals, parents) and “gaining control” over managing their illness on their own. The 2 strategies that assisted in this process were gaining knowledge and skills to manage the disease and experiencing understanding through social support. Five further subthemes emerged around skills to manage the disease, including knowledge and awareness about the disease, listening to and challenging care providers, communicating with the doctor, managing pain, and managing emotions.

Conclusion. Adolescents were united in their call for more information, self-management strategies, and meaningful social support to better manage their arthritis. They believed that Web-based interventions were a promising avenue to improve accessibility and availability of these interventions.

INTRODUCTION

Juvenile idiopathic arthritis (JIA) is the most common chronic pediatric rheumatic disease (1) and can negatively impact quality of life (QOL) (2). Disease management is often complex, involving diverse and multiple therapies, and requires constant monitoring. Adolescents are expected to assume greater responsibility for disease management than when they were younger due to their growing independence and autonomy (3). However, adolescent adherence to disease management activities is less than

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optimal (4). Poor adherence and inappropriate self-management behaviors may reduce the potential benefits of treatment (4). The vast majority of adolescents do not receive comprehensive disease education linked with self-management therapy (5). Enhanced awareness and greater self-management early in the disease trajectory may prevent or diminish illness exacerbation and associated adverse health outcomes.

Because there is no consistent definition of self-management, we defined self-management as “the individual’s ability to manage the symptoms, treatment, physical, and psychological consequences and life style changes inherent in living with a chronic illness” (6). Self-management interventions typically encompass information-based material and cognitive-behavioral strategies designed to increase participants’ knowledge, self-efficacy, and use of self-management behaviors (6). Studies in both adult chronic illness (6–11) and pediatric chronic illness (12,13) have demonstrated that comprehensive interactive interventions that augment medical treatments with self-management lead to better health outcomes and improved QOL than care that is strictly medically focused.

Although these therapies have been effective in adults with arthritis (7–9), evidence for their effectiveness in JIA is sparse (14–17). Barlow et al (18) reported that self-management interventions for JIA were typically 1) limited in scope, 2) directed at parents rather than adolescents, 3) delivered in individual or group sessions in specialty clinics by highly trained personnel, and 4) not suitable for widespread distribution in community- and/or home-based settings. This paucity of studies may be underscored by the scarcity of resources available to support these therapies, as well as issues of accessibility, acceptability, and applicability of these interventions to adolescents.

E-health technologies offer an innovative approach to improving the health service delivery and acceptability of self-management interventions for adolescents with JIA (10). Traditionally, these types of interventions have been developed by health care professionals with little input from the end users. However, we posit that a preliminary needs assessment with adolescents is essential to inform the design and development of an effective Web-based home program of self-management, with the ultimate goal of improving QOL in adolescents with JIA. Therefore, the purpose of this study was to explore 1) the self-management needs of adolescents with JIA and 2) the acceptability of a Web-based program of self-management.

PATIENTS AND METHODS

Patient selection. Participants were recruited from 4 large rheumatology clinics in university-affiliated pediatric tertiary care centers across Canada. Adolescents were eligible to participate if they were 1) 12–20 years of age, 2) diagnosed with JIA by a rheumatologist (19), and 3) able to speak and read English and/or French. Adolescents were excluded if they had major cognitive impairments or comorbid medical or psychiatric illnesses. The study was approved by research ethics boards at all sites.

We aimed to conduct 5–7 individual interviews and 1 focus-group interview with 5–7 adolescents at each of the 4 sites. Convenience sampling was used, supplemented by purposive sampling to achieve maximum variation in age, disease severity, and disease onset subtype and to determine if these factors, as well as regional differences, would influence perceived self-management needs. This sampling strategy provided information-rich cases and encompassed the varying needs of a heterogeneous group across sites (20).

Methods. The study of adolescents’ experiences living with and managing their arthritis lends itself to a qualitative study design (20). A descriptive exploratory qualitative design described by Sandelowski (21) was implemented across the 4 sites over a 9-month period. Individual semistructured interviews were conducted to gain an appreciation of the perspectives of the individual adolescents and to gain deeper insights into self-management issues (22). Focus-group interviews were conducted to capitalize on shared interaction between adolescents and to confirm insights gained from individual interviews (23).

At each interview, consent was obtained and participants completed a brief questionnaire on demographic characteristics and use and level of comfort with computers and the Internet. The research assistants at each site gathered additional demographic and disease-related data from the adolescents’ medical charts. Physician global assessment of disease severity ratings was obtained prior to or at the time of the interview (24). These ratings were used to ensure a heterogeneous sample was obtained by stratifying for disease severity.

Adolescents participated in individual or focus-group interviews based on their preference. Individual interviews lasted between 20 and 40 minutes and focus-group interviews lasted between 40 and 75 minutes. All interviews were conducted in a quiet room in the hospital clinic or meeting room. One investigator (JNS) and a bilingual research coordinator (PCT) conducted the interviews at each site. The interviewers were trained in interviewing children and used techniques to minimize the power differential (25). All interviews were audiotaped and field notes were made during or immediately after the interview to record the interviewer’s impression of the adolescent’s responses to the questions and comfort level with the interview process.

A general introductory question was asked, followed by a broad question and probes to encourage the adolescents to elaborate on their experiences (Table 1). Questions were compiled from the literature and the clinical experience of the research team. Finally, adolescents were asked how they would feel about getting arthritis management information from an Internet-based self-management program. This list of questions was modified during the course of the research in light of emerging themes.

Statistical analysis. The quantitative data from the questionnaires were coded, scored, and entered into a Statistical Package for the Social Sciences (SPSS) database.
These data were analyzed to determine measures of central tendency and the distribution of values for the research sample. Interviews were audiotaped and transcribed verbatim. The French interviews were transcribed directly into English by a bilingual transcriptionist. All transcripts were verified against the tapes by one researcher (PCT) and imported into NUD*IST 6.0 (27), a qualitative analysis computer program that helps to organize, code, and retrieve data. Field notes taken during the interviews were also transcribed and included in the analytic process. The analysis was first conducted by one author (SK), an experienced qualitative analyst. Two other members of the research team (JNS and PCT) also reviewed all of the transcripts. Disagreements (e.g., wording of themes) were handled through consensus of all analysts.

The thematic analysis was an iterative process whereby codes were identified and then revised as more interviews were conducted across the 4 sites. Using accepted qualitative tools and approaches (28,29), the data for all the participants were coded according to the study objectives and by age and were organized into categories that reflected the emerging themes. The raw data were revisited on a regular basis throughout the analytic process to ensure that the codes and resulting themes were grounded in the data (28). Charts and matrices were used to construct a more unified and integrated understanding of the data (29).

Initially, the individual interviews and the focus-group interviews were analyzed separately; however, the codes from these data sets were compared continually throughout the analytic process. As the analysis progressed, it became clear that the data were similar and thus provided a strong source of triangulation for the developing themes. Accordingly, the data from the focus groups and individual interviews are presented together. To ensure anonymity, all participants are identified by pseudonyms. Quotes are identified by text units (TU) indicating line of transcript.

### Table 1. Broad questions and probes in semistructured interview guide

<table>
<thead>
<tr>
<th>Broad questions</th>
<th>Interviewer’s probes</th>
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<tbody>
<tr>
<td>1. Can you tell me how long you have had arthritis and what it has been like for you?</td>
<td>What do you find to be the biggest challenges of living with arthritis? What ways have you learned to cope or deal with that (these) challenge(s)?</td>
</tr>
<tr>
<td>2. What do you think is important to know and do so that you can learn to manage or take care of your arthritis on your own?</td>
<td>What do you need to know about your arthritis in general in order to feel comfortable managing it on your own?</td>
</tr>
<tr>
<td>3. How would you feel about getting this information on ways to better manage your arthritis from an Internet-based self-management program? You know where you could log in and learn about how to take care of your arthritis and know that the information is accurate. You could also chat with people your age who have arthritis.</td>
<td>What would you like to see on that Web site? What would be most helpful? What would be least helpful? What would be some of the challenges in using such a Web site? What would motivate you to use the site? How should the information be arranged on this Web site? Would you be interested in a chat room for adolescents with arthritis as part of this program? Can you tell me more about why you think a chat room might be helpful? Would you be interested in being able to talk to a health care professional or have a coach who could help you learn some of the things we have talked about as part of this Web site?</td>
</tr>
<tr>
<td>4. Is there anything else you would like to tell us about what you think is important to know and do so that you can learn to manage or take care of your arthritis on your own?</td>
<td>If you had to tell someone else about how to manage or cope with their arthritis what would you tell them?</td>
</tr>
</tbody>
</table>

(26). These data were analyzed to determine measures of central tendency and the distribution of values for the research sample.

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RESULTS

Demographic and disease characteristics of the sample. Thirty-six adolescents participated in the individual interviews (n = 25) and 3 focus-group interviews (n = 11) across the 4 sites. Of the 107 adolescents approached, 66 refused to participate (acceptance rate 38.3%). Reasons for refusal included busy (n = 41), not interested (n = 20), or lived too far away (n = 5). We also had to cancel 1 focus group (n = 5) due to inclement weather and were unable to reschedule due to financial constraints. Demographic characteristics for the sample are summarized in Table 2. All of the adolescents had a computer at home with Internet access and 100% reported being comfortable or very comfortable using a computer and the Internet to find information. These findings are consistent with recent data revealing that 88% of 15-year-old Canadian students have at least 1 computer at home and are comfortable using the computer (30).

Table 2. Demographic characteristics of the sample (n = 36)*

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age, mean ± SD years</td>
<td>15.1 ± 2.1</td>
</tr>
<tr>
<td>Sex</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>12 (33.3)</td>
</tr>
<tr>
<td>Female</td>
<td>24 (66.7)</td>
</tr>
<tr>
<td>Disease severity</td>
<td></td>
</tr>
<tr>
<td>Inactive</td>
<td>1 (2.8)</td>
</tr>
<tr>
<td>Mild</td>
<td>10 (27.8)</td>
</tr>
<tr>
<td>Moderate</td>
<td>16 (44.4)</td>
</tr>
<tr>
<td>Severe</td>
<td>9 (25.0)</td>
</tr>
<tr>
<td>JIA onset subtype</td>
<td></td>
</tr>
<tr>
<td>Oligoarthritis</td>
<td>7 (19.5)</td>
</tr>
<tr>
<td>Oligoarthritis, extended</td>
<td>5 (13.8)</td>
</tr>
<tr>
<td>Polyarthritis (RF negative)</td>
<td>8 (22.2)</td>
</tr>
<tr>
<td>Polyarthritis (RF positive)</td>
<td>6 (16.7)</td>
</tr>
<tr>
<td>Systemic</td>
<td>5 (13.8)</td>
</tr>
<tr>
<td>Psoriatic arthritis</td>
<td>1 (2.8)</td>
</tr>
<tr>
<td>Enthesitis related</td>
<td>4 (11.1)</td>
</tr>
<tr>
<td>Other</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Duration of illness, mean ± SD years</td>
<td>7.16 ± 2.58</td>
</tr>
</tbody>
</table>

* Values are the number (percentage) unless otherwise indicated. JIA = juvenile idiopathic arthritis; RF = rheumatoid factor.

Views on developing effective self-management strategies. Adolescents articulated how they developed effective strategies to better manage their disease that centered on “letting go” from other individuals (e.g., parents and health care professionals) who had managed their illness and “gaining control” over managing their arthritis independently. Adolescents reported varying degrees of proficiency in this process. The 2 main strategies used to assist with this process were 1) acquiring knowledge and skill to manage the disease and 2) experiencing understanding through social support. Five subthemes were further identified under acquiring knowledge and skill to manage the disease and will be elaborated below. There were no apparent age differences in these themes.

Acquiring knowledge and skill to manage the disease. Listening to and challenging care providers. Some adolescents indicated that they traditionally managed their disorder by passively listening to their health care providers or parents. This approach provided them with a sense of security while they were trying to assume a more active role in their care. The following example illustrates how one adolescent engaged in developing a more collaborative partnership with her care providers: “Well, that . . . not to care what anyone says because you’ll get better if you do what your doctor tells you. If you have problems with your medications . . . well, um, if—if you don’t like how it is, like, you don’t wanna gain weight or whatever, just ask your doctor” (Pat, age 15, TU 301). However, when this same adolescent talked about some of the undesirable side effects of her medications she stated, “I asked them [care providers] if they could put me on something else instead” (Pat, age 15, TU 254).

Acquiring skills to communicate with the doctor. In most situations, the parents were the conduit between the adolescent and doctor. Most adolescents indicated they felt uncomfortable communicating information about their current health status independently; however, they recognized the need to learn these skills so that they could communicate and transition to adult centers. The adolescents varied in their development of these skills. One adolescent welcomed her mother’s presence during her appointments because she was afraid she would forget important information: “Right now my mom still does come in because I forget things” (Marsha, age 12, TU 451). Another adolescent who was more independent stated, “Uh when I was younger my mom did most of the talking but now that I’m getting older I do most of the talking. And if I get it wrong she just corrects me” (Kerry, age 15, TU 474).

Managing pain and discomfort. The participants explained that acquiring knowledge and skills to manage their pain and discomfort was a critical aspect in learning to self-manage their disease. As one participant explained, “I just wanna know about what type of therapies to ease the pain because sometimes the pain can be really bad” (Kerry, age 15, TU 145). In addition, all of the participants identified that learning more about how the medications worked and their side effects was an important issue in learning how to control the pain and discomfort associated with the disease. Many adolescents also used physiotherapy, exercise, ice packs, and assistive devices to help manage their pain. Despite the recognized importance, many of the adolescents indicated that they had trouble sustaining their motivation to exercise and viewed it as “boring.” There was some interest in learning about complementary and alternative care.

Managing emotions. Adolescents described feelings of isolation (e.g., feeling different from others), pain and suffering (emotional distress related to physical symptoms), and uncertainty about their future, as well as issues related to self-esteem (e.g., negative body image) and communicating with others (teachers, friends) about their illness.
One adolescent in the focus group explained: “Well...I they experienced in their lives as a result of their arthritis. The social support was communicated to them

cial support from family, peers, teachers, and health care

The adolescents described the experience of receiving so-

You’re not completely in the dark” (Lorraine, age 19, TU 103). Another adolescent explained: “It’s not the worse thing out there, and I remember, there’s always one, at least one other person worse than me” (Marsha, age 12, TU 245).

Acquiring knowledge and awareness about arthritis. The participants clearly were interested in acquiring more knowledge about their disease. Most indicated that they primarily learned about arthritis from their doctors and parents; however, a few motivated participants had taken the initiative and used books and the Internet. Overall, they understood and recognized the importance of develop-

ing knowledge about their disease to become more in-
dependent and to advocate for themselves by explaining

their disease to others with more confidence and comfort. For example, one adolescent explained: “When I was little I was really shy and when I started telling people [about arthritis], well I guess I was shy about having it, but then my friends asked me if there was anything wrong, I finally got it out, then I got more, um, confident” (Leanne, age 12, TU 103).

Another adolescent explained that knowing more about her disease might not take the pain away, but it would help her to more effectively cope with the pain: “You would understand what is going on. You’d be able to be okay this is what is happening in my body. . .When you don’t know you get anxious and kind of a bit scared. If you were to know you wouldn’t be less in pain, but you’d be more relaxed. You’d be like okay; I know what is going on. You’re not completely in the dark” (Lorraine, age 19, TU 111).

Experiencing understanding through social support. The adolescents described the experience of receiving so-
cial support from family, peers, teachers, and health care providers. The social support was communicated to them through understanding and compassion of the obstacles they experienced in their lives as a result of their arthritis. One adolescent in the focus group explained: “Well . . .I started in elementary school and everyone I was with helped me like carrying my school bag. I could not walk up the stairs . . . and there were people who literally dragged me up. I received a lot of help” (Anna, focus group, age range 13–17, TU 40).

Some adolescents used distraction to cope with difficult situations. Some would engage in another activity as a way of distracting themselves and others would ignore the situation. The following participant explained how she managed her uncomfortable emotions at school: “Because sometimes when you’re at school you like wanna go home but you don’t wanna miss the work and you don’t wanna have to catch up and stuff so you just put it in the back of your mind and then eventually you just forget about it over time” (Kerry, age 15, TU 609).

A few adolescents developed a method of “self-talk” or a way of changing their internal negative thoughts to more positive and encouraging ones when they were experienci-

ing troubling emotions: “Uh huh cause I would just keep going, no matter what. I am determined. Other than mentally saying I can [do] it [it] doesn’t hurt” (John, age 14, TU 177). Another participant asserted: “It’s not the worse thing out there, and I remember, there’s always one, at least one other person worse than me” (Marsha, age 12, TU 245).

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A few of the adolescents indicated that their need for social support from their peers was so strong that they were very tempted to give into peer pressure to experiment with drugs, alcohol, and unsafe sex; however, they used arthritis and medications as a convenient excuse not to participate in these risky behaviors, as they would have adverse effects if they mixed their prescriptions with drugs and alcohol. One adolescent openly revealed: “It’s so much easier to say no to peer pressure when you know you can’t have it. Not just cause your parents say you can’t have it, but because you know yourself that your body can’t handle that” (Lorraine, age 19, TU 539).

Views on Web-based approach to learning about self-

management. Adolescents were also asked about the acceptability of a Web-based approach to providing self-

management interventions and social support. All adolescents thought that having a Web-based approach to learning about their arthritis would be a good way to overcome some of the current barriers to accessing self-

management information and skills (e.g., lack of time and resources, group format not appealing, and associated direct and indirect costs of these therapies). They commented that a Web site would enable the delivery of trustworthy and current information about their disease and self-management strategies from credible sources (i.e., trusted health care professionals). They felt strongly that a Web-based program (i.e., chat room or discussion board) would be a great vehicle for social support. They thought that hearing positive stories about how others learned to live with JIA and learning ways to talk to others (family, friends, and teachers) about their arthritis would be helpful. The essential components that adolescents thought should be included on the Web site are outlined in Table 3. Finally, adolescents thought that the Web site had to be geared to teenagers by being visually appealing and inter-

active (e.g., animations, games) to motivate use.

DISCUSSION

Adolescents clearly articulated the physical and psycho-

social impact that living with arthritis had upon their daily lives and were able to identify strategies they had learned to gradually take over control of the management of their illness from their parents and health care professionals. Furthermore, to better manage their arthritis, adolescents were aware that they needed to acquire knowledge and skills as well as obtain understanding through social support. Finally, adolescents whole-heartedly endorsed the use of the Internet as a way to deliver self-management interventions.

Similar to our findings, Barlow et al, in a qualitative exploratory study, found that children with arthritis called
for more comprehensive self-management interventions with greater availability and access (5). Respondents in both studies wanted interventions that included disease information (etiology and symptoms), strategies to deal with the psychological and social impact of arthritis, and disease management (medical and self-management strategies), as well as social and communication skills training. In keeping with our findings, adolescents in the study by Barlow et al had an “unquenchable thirst” for acquiring information and skills as well as emotional support from peers. However, we extended these findings by identifying the essential information, self-management strategies, and preferred methods of providing social support using a Web-based medium.

Although health care professionals were cited as trusted advisors and important sources of information about their

<table>
<thead>
<tr>
<th>Components</th>
<th>Specific examples</th>
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<tbody>
<tr>
<td>Information about arthritis</td>
<td>What is JIA? What are the different types of arthritis in children? Who gets JIA and what causes it? Symptoms of JIA? Complications of JIA?</td>
</tr>
<tr>
<td>Treatments for JIA</td>
<td>Medications (what they do and their possible side effects) Physical therapies and exercise Nutrition Psychological therapies Complementary and alternative therapies How to use medications and other therapies effectively (i.e., ways to enhance adherence)</td>
</tr>
<tr>
<td>Procedures and tests associated with JIA</td>
<td>Blood tests Radiographs MRI Joint injections Other tests and procedures</td>
</tr>
<tr>
<td>Managing symptoms</td>
<td>Managing common symptoms (pain, stiffness, and fatigue) How to recognize symptoms When to call the doctor Managing symptoms at home and school Cognitive-behavioral strategies (e.g., breathing, distraction, relaxation, imagery)</td>
</tr>
<tr>
<td>Managing emotions</td>
<td>Managing common emotions (stress, depression, frustration, anger, and uncertainty) Understanding stress, negative thoughts, and unrealistic beliefs and goals Using cognitive-behavioral strategies to manage emotions (e.g., learning how to evaluate events, becoming aware of thoughts, and challenging negative thoughts) Goal setting and problem solving</td>
</tr>
<tr>
<td>Lifestyle</td>
<td>Exercise and Fitness Sexuality Body image Teasing and bullying Recreational drugs and smoking Alcohol and caffeine Looking ahead to the future (postsecondary education, work, having a family) Transitioning to adult centers Participating in research</td>
</tr>
<tr>
<td>Social support</td>
<td>Communicating with members of the health care team, teachers, and employers Making it easier to communicate about illness (e.g., assertiveness, communication, and social skills training) Relationships with peers (e.g., talking to friends about arthritis) Support systems (e.g., family, friends, health care team) Accessing support services (vocational, educational, psychosocial)</td>
</tr>
</tbody>
</table>

* JIA = juvenile idiopathic arthritis; MRI = magnetic resonance imaging.
disease, respondents often felt unable to ask questions or communicate effectively with these professionals. Similarly, when Beresford and Sloper interviewed 63 adolescents with chronic illness about their experiences communicating with doctors, the respondents were reluctant to discuss personal or sensitive issues or to ask questions that revealed poor adherence (31). It would seem to be important, then, to provide adolescents with communication skills and assertiveness training to enhance their ability to be more active participants in decision making.

Seeking understanding through social support was an important way respondents managed their arthritis. The importance of social support in psychosocial adjustment has been demonstrated in several studies (32–34) indicating that social support may be effective in reducing general and illness-related stress. Social support from parents, nurses, physicians, and friends has also been associated with improved adherence in adolescents with JIA (35). Several reviews have documented that peer support strategies can improve health and well-being in individuals with a wide range of chronic medical conditions (36–38). Therefore, self-management programs should provide opportunities for peer support (e.g., monitored discussion boards, video clips of adolescents modeling successful self-management behaviors and problem solving).

Adolescents believed that Web-based interventions were a promising avenue to improve accessibility and availability of these programs. Furthermore, the Internet has emerged as one of the main health information sources for this age group (39). Despite their appeal, few self-administered multimedia programs for children and adolescents with chronic illnesses have been developed and validated compared with those for adults (9,40). There is some early evidence that computer-based, self-administered treatments for children and families are efficacious in children with asthma (41,42), diabetes (43,44), and headaches (45). For example, Gerber and colleagues recently demonstrated the feasibility (e.g., utilization and acceptability) of an Internet diabetes self-management program for adolescents and young adults transitioning to adult medical care centers (44).

This research also has implications for theory regarding the mechanisms underlying self-management programs. Adolescents strongly endorsed the need to let go and gain control to better manage their arthritis. Researchers have postulated that enhanced self-efficacy (a person’s belief in their capacity to carry out a specific action) and empowerment (process whereby individuals gain control over their own lives) are key mediators in effective self-management programs (10,11,28). Marks and colleagues have recently developed a pathway for change whereby self-management interventions are hypothesized to work by combining information with peer, decision-making, and behavioral change supports to allow internalization and interpretation of the information by the user (11). A combination of enhanced self-efficacy with motivation and knowledge enables users to change their health behaviors, leading to changes in clinical outcomes (11). Further research is needed to examine not only how these programs work but the essential components of the programs.

The rigor of this study was enhanced by using analyst triangulation (e.g., using several researchers in data analyses) and methodologic triangulation (e.g., using multiple methods: individual interviews, focus groups). This integrated multifaceted process provided different types of cross-data validity checks and reduced the likelihood of bias (20). Limitations included the heterogeneous sample in terms of wide age range, disease severity, and geographic variation that might have lead to our inability to find any differences in the themes based on these factors. Further research on the influence of these factors on adolescents’ self-management needs is warranted. Finally, we were only able to interview each participant once and were not able to perform member checking to verify the themes.

In conclusion, exploring the perceptions of adolescents with JIA was crucial in laying the foundation for the development of the content of the Web-based self-management intervention and will help ensure that the content and format are relevant and acceptable. Adolescents with chronic arthritis also believe that Web-based self-management treatments are a promising avenue to improve the accessibility and availability of JIA management strategies. The next step will be to test the usability and feasibility of the online self-management intervention for teenagers with JIA prior to conducting a definitive multicentered randomized controlled trial. If effective in improving health outcomes, this program could be used as a template for other pediatric chronic illnesses as the psychosocial challenges facing adolescents are similar across disease categories.

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AUTHOR CONTRIBUTIONS


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