Jointly managing arthritis: Information needs of children with juvenile idiopathic arthritis (JIA) and their parents

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Jointly managing arthritis:
Information needs of children with juvenile idiopathic
arthritis (JIA) and their parents

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Abstract
The objective of this article is to explore information needs of children with juvenile idiopathic arthritis (JIA) and their parents in order to develop a web-based psychoeducational program aimed at improving their quality of life. A qualitative study design was used. A purposive sample of children (n = 41; 8–11 years) with JIA and parents (n = 48) participated in parent–child interviews (n = 29), and four child-focus and four parent-focus group interviews. Transcribed data were organized into categories that reflected emerging themes. Findings uncovered three major themes: “living with JIA”, “jointly managing JIA”, and “need for a web-based program of JIA information and social support”. Subthemes for “Living with JIA” were as follows: “impact on participation”, “worry and distress”, and “receiving social support”. Subthemes under “Jointly Managing JIA” included “obtaining JIA information”, “communication and advocacy”, and “strategies to manage JIA”. Participants endorsed a web-based program as a way to access JIA information and social support. In order to jointly manage JIA, participants expressed the need for disease-specific information, management strategies, and social support and felt that the Internet was acceptable for delivering these disease-management strategies. Findings from this study will inform development and evaluation of an online program to help children and parents jointly manage JIA.

Keywords
focus groups, health promotion, qualitative approaches, child health, chronic illness

Introduction
Juvenile idiopathic arthritis (JIA) is the most common pediatric rheumatic disease (Sacks et al., 2007). JIA can impact all aspects of quality of life and can affect the entire family (Brunner and Giannini, 2003; Bruns et al., 2008; Gutiérrez-Suárez et al., 2007; Pres et al., 2002; Sawyer et al., 2004; Waite-Jones and Madill, 2008). In early to middle childhood, activities necessary to manage JIA are shared by the child and family with support from health-care professionals (Brunner and Giannini, 2003; Sawyer et al., 2004). Improved shared management early on could assist with symptom control (e.g. managing pain and pain-related activity limitations) and help optimize management, thereby improving quality of life. In addition, engaging children at this age may help them to become knowledgeable and capable participants in their own care as they move into the adolescent period where they will be expected to take more control over managing their arthritis (Stinson et al., 2008). For these reasons, it is important to develop programs to make it easier for school-age children with JIA and their parents to jointly manage the disease.

The Internet constitutes a widely available, affordable, and interactive multimedia medium that is well suited to teaching shared disease-management skills and can easily address barriers such as inaccessibility and unavailability (Ritterband et al., 2003a). Positive outcomes have been found for Internet self-management interventions for adult (Cuipers et al., 2008; Lorig et al., 2008; Ngugen et al., 2004; Palmqvist et al., 2007; Spek et al., 2007; Superio-Cabuslay et al., 1996; Wantland et al., 2004) and pediatric (Cushing and Steele, 2010; Stinson et al., 2010a) health problems across a range of outcomes related to knowledge, behavioral change (improved treatment adherence), symptom management, and health status. Our group has developed and tested an Internet self-management program for adolescents with JIA (Stinson et al., 2010a; Stinson et al., 2010b). Findings from our pilot randomized controlled trial support the feasibility (high acceptability, user satisfaction, and compliance) and initial effectiveness of the Internet self-management program.
In improving knowledge and decreasing pain in youth with JIA. In this study, participants were also united in their call for a similar program for school-age children and their parents. However, there is currently no Internet-based psychoeducational program targeting children with JIA and their parents.

In a previous study by Barlow et al. (1999), qualitative interviews were done with 10 children (8–15 years) with JIA and their parents to identify their information needs; however, it was not clear how many of the children were school aged (8–11 years) and whether the information needs of this group differed from the older adolescents. Furthermore, while the information needs of adolescents with JIA (Stinson et al., 2008) and parents of children with JIA have also been previously explored (Barlow et al., 1999; Thon and Ullrich, 2009), the unique information needs of school-aged children with JIA are not known. Therefore, the purpose of this study was to explore the information needs of parents and school-age children with JIA and to determine whether an Internet-based psychoeducational program would meet these identified needs.

Patients and methods

Patient selection

Participants were recruited from four large Canadian tertiary rheumatology clinics in university-affiliated care centers (Vancouver, Toronto, Montreal, and Halifax). Children were eligible to participate if they were (a) 8–11 years of age, (b) diagnosed with JIA, and (c) able to speak and read English and/or French and one of their parents was able to speak and read English and/or French. Children were excluded if they had severe cognitive impairments or major comorbid medical or psychiatric illnesses that would preclude assessment of information and care needs. The study was approved by research ethics boards at all sites.

We aimed to conduct five to seven individual interviews with children and caregivers, and one child and one parent-focus group at each of the four sites. Convenience sampling was used, supplemented by purposive sampling to achieve variation in age, sex, disease severity, and disease onset subtype to determine if these factors would influence perceived information and care needs. This sampling strategy provided information-rich cases and encompassed the varying needs of a heterogeneous group across sites.

Methods

The study of patient experiences living with and managing JIA lends itself to a qualitative study design (Creswell, 1998). A descriptive exploratory qualitative design described by Sandelowski (2000) was implemented over a 5-month period. Individual dyad (child–parent) semistructured interviews were conducted to gain an appreciation of the perspectives of the individual families and to gain deeper insight into how they managed their JIA (Kvale, 1996). Focus-group interviews were conducted separately with children and parents to capitalize on shared interaction between children and parents and to confirm insights gained from the individual dyadic parent–child interviews (Morgan, 1997).

Consent was obtained prior to each interview, and participants completed a brief questionnaire on demographic characteristics and use of and level of comfort with computers and the Internet. Additional demographic and disease-related data were gathered from the patients’ medical chart by a research assistant. Physicians’ global assessment of disease severity ratings were obtained.
prior to or at the time of the interview (Magni-Manzoni et al., 2005). These ratings were used to determine if a heterogeneous sample was obtained with regard to disease severity.

Child–caregiver dyads participated in individual or focus-group interviews based on their preference. Individual interviews lasted between 14 and 48 min (mean = 27 min) and focus-group interviews lasted between 51 and 72 min (mean = 65 min). All interviews were conducted in a quiet room in the hospital clinic or meeting room. The interviewers were trained in interviewing children, and techniques were used to minimize the power differential such as allowing children to complete the interview with their parents, sitting at eye level with the children, and spending time prior to the start of the interview in order to “get to know” the child and parent and to ensure they were comfortable (Morgan, 1997). All interviews were audio-taped, and field notes were made during or immediately following the interviews to record the interviewer’s impression of the participant’s responses to the questions and comfort level with the interviewing process.

A general introductory question was asked followed by broad questions and probes to encourage the children to elaborate on their experiences (see Table 1). Questions were compiled from the literature and the clinical experience of the research team. Finally, children and parents were asked specifically how they would feel about getting JIA management information from an Internet-based program to build upon our existing program for youth with JIA. Additional probes were added to the list of questions during the course of research in light of emerging themes; however, all participants were asked the same introductory and broad questions.

**Statistical analysis**

The quantitative data from the questionnaires were coded, scored, and analyzed using SAS version 9.1.3 (2006). These data were analyzed to determine the measures of central tendency and the distribution of values for the sample.

Interviews were audio-taped and transcribed verbatim. All transcripts were verified against the tapes by one author (M.W.) and imported into NVivo 8.0 (QSR NVivo 8.0, 2008), a qualitative analysis software 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 (A.V.), an experienced qualitative analyst. Two other members of the research team (N.B. and J.S.) also reviewed all of the transcripts. Disagreements (e.g. wording of themes) were handled through consensus of all analysts. Using accepted qualitative tools and approaches (Miles and Huberman, 1994; Morse and Field, 2005), the data for all the participants were coded according to the study objectives 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 (Kvale, 1996). Charts and matrices were used to construct a more unified and integrated understanding of the data (Kvale, 1996).

Initially, the individual dyad 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 dyadic interviews are presented together. To ensure anonymity, all participants are identified by pseudonyms.
Table 1. Broad questions and probes in semistructured interview guide

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<tr>
<th>Broad questions</th>
<th>Interviewer’s probes</th>
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<tbody>
<tr>
<td>Can you tell me how long you have had arthritis and how you feel about having arthritis?</td>
<td>What is hard about having arthritis? Can you tell me more about that? How did that (insert problem) make you feel? What ways you have learned to make yourself feel better when things get tough because of your arthritis? What does your mom or dad do to make you feel better? Can you tell me about your day yesterday? Did your arthritis get in your way of doing the things you wanted to? Can you tell me more about that?</td>
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<tr>
<td>What do you think is important to know and do so that you can learn to manage (or take care of) your arthritis?</td>
<td>Whose job is it to manage your arthritis? What do you do to manage your arthritis? Can you tell me more about that? What does your mom or dad do to help you manage your arthritis? Are there things you would like to learn to better manage your arthritis? When do you think kids should start trying to manage their arthritis on their own, you know without any help from their mom or dad?</td>
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<td>What do you want to know about your arthritis?</td>
<td>Can you tell me more about that? Would you like to know what causes arthritis? Would you like to know about the different types of arthritis that children get? Would you like to know how doctors know when a child has arthritis? Are there things that you don’t know about your arthritis that you would like to know more about? Do you ever worry about your arthritis? Can you tell me more about that?</td>
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<td>What would you like to know about your medicines or any of the other things you do to help with your arthritis?</td>
<td>Can you tell me more about that? Do you take any medicines to help with your arthritis? Do you know what those medicines do? Are there any things you don’t like about taking medicine? What helps you remember to take your medicines? Whose job is it to manage your medicines? What would you like to know about other treatments for arthritis (exercises, ways to learn how to relax, ways to reduce pain, herbal medicines, etc.)? Can you tell me more about that?</td>
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<tr>
<td>Can you tell me about how arthritis affects your life?</td>
<td>How does it affect your mood or how you feel inside yourself, relationships with friends, school, how you feel about your body, and relationships with your parents or brothers/sisters? Can you tell me more about that? Can you tell me about the ways you’ve learned to deal with these things? Can you give me an example of how you learned to deal with that? What things does your mom or dad do to help you with these problems? Have you ever been teased or bullied at school because of your arthritis? How did you learn to deal with that? Are there things you can’t do because of your arthritis? How have you learned to deal with that?</td>
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## Table 1 (continued)

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<tr>
<th>Broad questions</th>
<th>Interviewer’s probes</th>
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<tr>
<td>If you had to tell someone else about what it’s like to have arthritis and how</td>
<td>Can you tell me more about that?</td>
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<td>to deal with it what would you tell them?</td>
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<tr>
<td>What is it like to talk about your arthritis to your doctors and nurses? Family?</td>
<td>Can you tell me more about that? Can you give me an example of that? What do you think would make it easier for you to talk about your arthritis? How have your mom or dad helped you to talk about your arthritis to others? Have you ever done a school presentation on your arthritis? Can you tell me more about that?</td>
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<tr>
<td>Friends? Teachers?</td>
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<tr>
<td>How have you learned about your arthritis and how to deal with it?</td>
<td>From doctors, nurses, physical therapists, and social workers! What things can the doctors, nurses, and other members of the health-care team do to help you? From the Internet? From books? From others who have arthritis? Can you tell me more about that? What have you learned from your mom or dad about your arthritis? Can you tell me more about that? Which ways were the best? Can you tell me more about why they were the best?</td>
</tr>
<tr>
<td>What do you think it would be like to learn more about your arthritis from a website</td>
<td>How would you see a website like that helping you learn how to deal with your arthritis? Can you tell me more about that? What would you like to see on that website? Would you like words or pictures and cartoons to help you learn about your arthritis? What would be most helpful? What would be least helpful? Would you like a website to learn more about your arthritis? What would make you want to use the site? How should the information be arranged on this website? Would you be interested in a chat room for kids with arthritis as part of this program where you can talk online with other kids with arthritis? 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 different health-care professionals or have a coach who could help you learn some of the things we have talked about as part of this website? Can you tell me more about that? Would you like to use this program with your mom or dad or on your own? Can you tell me more about that?</td>
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<tr>
<td>made just for kids with arthritis and their parents? Where you could log in and</td>
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<tr>
<td>learn about different ways to manage or take care of your arthritis with your</td>
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<td>parents? You could also chat with other kids who have arthritis.</td>
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<tr>
<td>Is there anything else you would like to tell us about what you think is</td>
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<td>important to know and do so that you can learn to take care of your arthritis</td>
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Results

Demographic and disease characteristics of the sample

A total of 41 children and 48 parents participated in the parent–child interviews ($n = 29$) and separate child- and parent-focus groups interviews ($n = 8$) across the four sites. The recruitment period lasted from August 2009 to January 2010. Of the 97 families approached to participate in the study, 56 refused to participate (accrual rate of 42%). Reasons for not participating included time constraints or lack of interest. Demographic and disease characteristics of the sample are listed in Table 2. Nearly all of the families (98%) had a computer with Internet access at home. A total of 98% of children and all of the parents reported being comfortable using a computer and using the Internet.

Qualitative themes

Analysis uncovered three major themes: “living with arthritis”, “jointly managing arthritis”, and “the need for a web-based program of JIA information and social support”. Three subthemes were found under each of the first two main themes and will be elaborated below. There were no differences in responses by the parents and children or with respect to age of child or the duration of illness.

Living with JIA

Living with JIA captured what it was like to live with childhood arthritis and the impact it had on aspects of participants’ everyday lives during times of diagnosis, flare-ups, and periods of remission. Three subthemes arose regarding the areas impacted by living with JIA, which included impact on participation, worry and distress, and receiving social support. Each of these subthemes will be described in more detail below.

Impact on participation. Most participants felt that JIA (i.e. symptoms like pain, stiffness, and fatigue) had at some point negatively impacted their participation in sports and other activities, both at school and outside of school. Missing out on activities affected children’s perceived connection to peers. One child said that “it’s hard to watch my friends running around in the schoolyard or playing handball. I used to play handball too, and I don’t like sitting on the sidelines doing nothing. Being alone makes me sad” (James, age 11).

Worry and distress. This subtheme focused on the worries that parents and their children experienced as a result of JIA, and the emotional effects that worrying caused. Both parents and children talked about worries, and all participants felt a number of distressing emotions, such as sadness, frustration, and anger.

Children worried about being different from their peers and wanted to be normal. Some participants said that they did not tell their friends or classmates to avoid “standing out”. For example, one child said “I don’t really talk about it that much anymore because I don’t want people getting scared and everything and stopping being my friend and so... I just keep it to myself” (Pina, age 9). Other children were excluded from their peer groups because of bullying or teasing due to their JIA. As one girl stated,
At school when people look at my fingers ... and see how they are swelling ... they kind of make fun of me, especially these guys in our class ... saying that I have sausage fingers and saying I'm being slow. (Marian, age 10)

Children also wondered about their future and whether their JIA would ever go away. One child summed up these thoughts by saying, “I want to know like if it will ever go away or if it will affect me for the rest of my life, or if it will get worse if I don’t treat it soon” (Connor, age 11).

Parents felt overwhelmed or even “devastated” by the initial diagnosis. They worried about administering medications (especially injections), and the short- and long-term side effects of treatments. One parent stated,

It just becomes so overwhelming. And what I wrestle with is, I made decisions for a developing body to be on significant medications... the guilt ... you make the decision for the day, so he can walk and can get out of bed, but I'm terrified at what the repercussions of that might be. (Tracy, parent)
Finally, although children wondered whether their arthritis would ever go away, parents had different, more specific questions about the future. They thought ahead to puberty, teenagehood, their child’s future career options and potential to have children, future disability, and the long-term side effects of medications. For example, one mother said,

*"I wish we had a crystal ball to know where you’re going to go in the future . . . As we’re getting into the older grades, and going into puberty . . . and dealing with medication if you want to have pregnancy and stuff like that . . . There’ll be more questions that we’ll need answered."* (Patti, parent)

**Receiving social support.** Most participants were receiving social support from a variety of sources as a way to learn to cope with JIA and reduce its impact on their life. Health-care providers at the rheumatology clinics the children attended were viewed as the strongest sources of support for children and their parents. Family members were the people that children would talk to about issues related to their JIA. School was considered for the most part to be “accommodating” (Sam, parent). For example, one parent said “[The gym teacher] modified his entire curriculum, and for the few activities in which she can’t participate, she spends her time writing” (Jean, parent). However, some families reported negative experiences with teachers at school as was reflected by one parent’s comment that “based on our experience . . . we feel that the teachers are unreceptive, they don’t believe us. They think the kid is faking” (Kate, parent).

**Jointly managing JIA**

In this age group, management of the disease was viewed as a shared responsibility between parent and child. While most of the responsibility usually seemed to lie with the parent, several children had already become engaged in their care, particularly the older ones in the participant sample. This was summarized eloquently by an older school-age participant:

*"It’s mine and my parent’s job . . . once they [kids] know a lot about it and they know that like it’s just something that kids get then they could start taking care of it by themselves, like I know everything really that I have, so now I am just starting to do it by myself."* (Chantelle, age 11)

The subthemes under jointly managing arthritis included obtaining information on JIA, communication and advocacy, and strategies for managing JIA.

**Obtaining JIA information.** Parents took on the role of actively obtaining information about their child’s JIA. Face-to-face with health-care professional was preferred, followed by Internet websites and pamphlets as the most frequent sources of information, although participants mentioned looking at books and seeking information from family and friends as well. Children, however, mostly looked to their parents when they had questions about JIA; parents would distil information down to them or find the answers for them. However, many parents commented that they often felt “overwhelmed” looking up JIA information and questioned the credibility of the information found. One mother stated, “It’s crazy in terms of what it is, and what it can be, and what the treatments are, and who knows if it’s accurate or not . . . It’s kind of overwhelming” (Maggie, parent).
**Communication and advocacy.** Parents and children both participated in communicating and advocating about JIA. For the parents, this included playing the role of an advocate for their children, particularly at school. One parent summarized this notion of advocacy by stating the following:

> There have been years where it’s been less . . . teachers change, and there are some years that some of them think she’s just making it up. You have to explain the problem and persist until they understand. As a parent, I had to make sure that they understood the situation. But you have to be insistent. (Janette, parent)

Children, however, played active roles in informing their close friends or classmates about their unique needs and their experience with JIA. Children varied in how and who they told about their JIA. The methods the children chose to tell their friends included class presentations, books, or in conversation on a “need to know basis”. One child stated,

> Only the ones I usually hang out with know; I haven’t told anyone who’s not really my friend and who I only see sometimes. This year, I tried to tell more people, like the ones who would ask, but there are still a lot of people who don’t know. (Gabriel, age 11)

**Strategies to manage JIA.** Participants had developed a variety of strategies and coping mechanisms in order to manage their disease. Strategies were used to maintain participation and to cope with or manage their JIA.

At school, children developed strategies to limit the impact that their JIA had by finding creative ways to maintain participation. Some children took breaks while writing, did stretches, or brought heating pads to school. Another child described her methods for reducing the pain in her fingers:

> If I’m in school normally I’ll ask to go to the bathroom and I’ll just kind of like go to the sink and if it’s hurting sometimes it helps me if I just kind of put it in warm water and just kind of like if it’s my fingers, stretch out my fingers kind of in the water and that makes it feel a little better. (Leah, age 11)

Meanwhile, at home, families had jointly developed disease-management strategies. This included methods to remember and to administer medications, “tricks” for reducing their pain, and strategies for maintaining their activity levels. For example, one child described the strategies he used to remember to take his medications:

> If you’re like taking pills and stuff then like I suggest after like when you are going to brush your teeth then maybe um, that’s the best time to take them because if you put them by your sink so their tooth brush is there and their pills are there and there’s your water . . . and put your pills like also by the container so like you know you don’t have to go upstairs to fill them up. (Chris, age 10)

**Need for a web-based program of JIA information and social support**

Participants were unanimous in their desire for further information on JIA and social support, and thought that a web-based program would be an effective way to meet these unmet needs. The essential components that children and their parents thought should be included on a website are outlined in Table 3.
Both parents and children felt that the information presented on the website needed to be easy to understand and user friendly, but they differed in how they wanted the information presented. Parents generally wanted as much information as possible: “I think the more information and choices you have the better” (Paul, parent). Parents also liked the idea of having credible information in one comprehensive website: “One central spot . . . that would be credible . . . It would be specific. It would be funnelled down to our needs” (Tony, parent). However, children wanted a fun

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<th>Table 3. Essential components of a website program for school-age children with JIA and their parents</th>
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<td><strong>Components</strong></td>
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</table>
| General disease information | What is JIA?  
What are the different types of JIA?  
What causes JIA?  
Statistics on JIA  
Prognosis: Will it go away? Is there a cure? |
| Treatments for JIA | Medications (types, how they work, side effects)  
Physiotherapy, exercise, and activities  
Psychological therapies  
Tips and tricks to improve adherence (e.g. remembering medications and giving injections)  
Nutrition  
Complementary and alternative therapies |
| Tests and procedures | How is arthritis diagnosed?  
Blood work  
X-rays and MRIs  
Joint injections (what they are and how to cope with them) |
| Managing symptoms | How to manage pain (medicines, exercises, and psychological strategies)  
How to manage managing stiffness (medicines, exercises, and psychological strategies) |
| Emotional effects of JIA | Strategies for dealing with emotions  
How to talk to friends about JIA  
Fitting in (friends and school) |
| Current research | Section that is consistently updated with new research developments on JIA  
Current practices |
| Information for others | Information for others to read (e.g. teachers, siblings)—printable PDFs for teachers |
| Social support | Discussion board for parent  
Stories of hope/testimonials for children |
| Parent section | Strategies and skills to help parents help their children begin to take on more responsibility as they move into adolescence  
Strategies to help parents promote JIA management in kids  
Strategies to help parents promote a healthy lifestyle  
Strategies to help parents deal with impact of their child’s JIA on them and their family |

Note: JIA = juvenile idiopathic arthritis; MRI = magnetic resonance imaging.
adventure theme-based version of the website that incorporated games, animations, and videos, and did not have a lot of text. As one boy stated, “There should be like kid sections, so kids can go on, and they can play the game, look at pictures, watch videos with the kid [with JIA], they can talk to the kids” (Nathan, age 9). Many families wanted to work through the children’s site together with the parent acting as a guide or coach, “I think it is something that the parents could sit down with them [their children] and you know explore the website together” (Antonia, parent).

Finally, participants were looking forward to the social support that they would receive from the website (i.e. discussion board, stories of hope from other families). As one parent explained,

*I think it’s just important to have other people that are going through what you’re going through and be able to talk to them . . . It’s hard finding another family that has . . . experienced similar to what we’ve gone through.* (Lisa, parent)

However, children generally were not interested in discussion boards but thought that would be good for their parents.

**Discussion**

School-aged children with JIA and their parents clearly articulated the physical and psychosocial impact that living with childhood arthritis had upon their daily lives and were able to identify strategies they had learned to jointly manage their illness. Furthermore, to better jointly manage their JIA, children and their parents wanted to acquire further knowledge and skills as well as obtain understanding through social support. Finally, both children and parents believed that the Internet is a good way to deliver psychoeducational interventions that could meet their unmet needs; however, children and parents have different views on how the website should be developed to better meet their needs.

The findings of this study further support the call of patients and families for more widely available and accessible comprehensive psychoeducational interventions for JIA (Barlow et al., 1999; Stinson et al., 2008), while in addition, highlighting the unique unmet information needs of school-age children and their parents. In comparing the current findings with our previous study, which explored the information needs of adolescents with JIA (Stinson et al., 2008), we were able to see how age and developmental stages influence the nature of unmet needs and intervention delivery preferences. While children and parents prefer to have health information provided through face-to-face interactions with their health-care providers, their next preferred method of delivery would be using the latest in information and communication technologies (Internet) rather than traditional paper-based educational materials. In terms of differences in information needs, school-age children thought the web-based intervention should be a theme-based adventure game with information on how to maintain/improve participation and activity levels, whereas adolescents just wanted “the facts” and information on lifestyle issues like sexuality, diet, and alcohol with opportunities for social interaction using discussion boards (Stinson et al., 2008).

In young children with JIA, the burden of disease management lies primarily with parents. However, as children grow and mature, there is a movement toward a shared responsibility for disease management during the school-age years (Gall et al., 2006; Kieckhefer and Trahms, 2000). Parents and children must jointly learn to deal with illness-related stressors (frequent medical visits, demands of the multicomponent treatment regimen) and the unpredictable nature of the illness course. Parents may influence self-efficacy by providing support and encouragement and assisting
school-age children to interpret the JIA-specific education and disease-management strategies (i.e. coping skills; Barak et al., 2009). Psychoeducational interventions that promote shared management and provide children and parents with disease-specific education, strategies to manage symptoms, and social support have the potential to promote optimal child and family health outcomes (Barlow and Ellard, 2004; Barlow et al., 1998).

There is a solid empirical foundation for cognitive and behavioral interventions that can equip individuals with the coping skills necessary for reducing pain and disability in children with JIA (Jensen, 2010). Rarely, however, do children with JIA have access to comprehensive disease education and coping skills training as a standard part of their JIA treatment (Barlow et al., 1999; Lineker et al., 1996). Historically, barriers to accessing comprehensive JIA-specific education and cognitive-behavioral coping skills training have included difficulty accessing these services because of (a) limited services available in many geographic areas (including the rural and remote regions, language barriers (only offered in English), and long-wait times), (b) limited availability of trained professionals such as nurses and psychologists, (c) time restrictions limiting the content of what can get discussed during regular rheumatology clinic visits, and (d) additional costs (direct and indirect), including time off school and work for children and their parents associated with these therapies.

Psychoeducational interventions lend themselves well to transformation via the Internet given its structured procedures and format (Anderson et al., 2004; March et al., 2009; Proudfoot, 2004). The Internet has emerged as one of the top health information resources and mode of social communication for children and youth and continues to be increasingly integrated into the provision of health-care services (Drotar et al., 2006; Gray et al., 2005; Griffiths et al., 2006). The Internet provides patients, families, and health-care professionals with unparalleled opportunities to (a) learn, inform, and communicate with one another; (b) receive meaningful social support; (c) fulfill the rising demand for expedient access to evidence-based health information; and (d) achieve greater involvement in health-care decision making (Griffiths et al., 2006; Ritterband et al., 2003a). Using the Internet to deliver health interventions uniquely eliminates geographic constraints, provides opportunities for access regardless of language spoken, and provides 24-hour access to information that can help patients feel less isolated and more in control of managing their chronic condition (Griffiths et al., 2006; Ngugen et al., 2004). Although a potential limitation of exclusive online health interventions relative to traditional face-to-face health interventions is reduced human collaboration, adding human support via brief telephone/email contact with a therapist, or in the case of school-aged children support from parents, and/or including social networking opportunities for intervention participants has improved motivation and adherence to online health-care services, thereby optimizing achievement of desired outcomes (Ngugen et al., 2004; Palmqvist et al., 2007; Spek et al., 2007).

Internet interventions have been developed and evaluated for school-age children and their parents for asthma (Jan et al., 2007; Krishna et al., 2006), encopresis (Ritterband et al., 2003b), anxiety (Anderson et al., 2004), and physical activity (in JIA; Lelieveld et al., 2010) that have shown significant positive effects across a variety of health outcomes. However, these types of interventions have traditionally been developed by health-care professionals with little input from the end-users (Barlow et al., 1999; Stinson et al, 2008). Furthermore, Cushing and Steele (2010) recently conducted a meta-analytic review of educational and behavioral e-health interventions for pediatric health behaviors and associated outcomes. They found that e-health interventions that incorporate behavioral methods (e.g. self-monitoring, goal setting, immediate feedback, contingency management) produce larger effect sizes for health behaviors and their associated outcomes than
interventions that rely solely on education (produced no significant changes in health behavior). Therefore, this preliminary work was essential to help us design, construct, and implement a web-enabled home program of shared disease-management strategies (cognitive-behavioral therapies), JIA-specific education, and social support to improve quality of life, tailored to the developmental needs of school-age children with JIA and their parents.

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, including individual and focus-group interviews). This integrated multifaceted process provided different types of cross-data validity checks and reduced the likelihood of bias (Creswell, 1998). A limitation of this study was that we were only able to interview each participant/dyad once and were not able to perform member checking to verify the themes. In addition, the majority of study participants reported “inactive” or “mild” disease severity, this limited variation in disease severity seen among the participants is a major limitation of the study. While participants were encouraged to recall and refer to past flares during the interviews, further interviews with participants reporting “moderate” to “severe” disease should be conducted to increase the generalizability of the findings.

In the absence of a medical cure, the prevention and management of disease symptoms is often a lifelong process requiring active engagement of children with JIA starting in the school-age years (Gall et al., 2006; Kieckhefer and Trahms, 2000). Although many children with JIA are regularly reminded of the importance of regular exercise or wearing splints for maintaining joint health (Takken, 2010), rarely are they equipped with strategies to improve pain and reduce the physical and emotional impact of disease symptoms over their life span. Exploring the perceptions of school-age children with JIA and their parents was a crucial first step in laying the foundation for the development of the content of the Internet-based psychoeducational program to equip them with necessary coping skills to begin to reduce the impact of their illness. School-age children with JIA and their parents believed that Internet-based treatments are a promising avenue to improve the accessibility and availability of programs to help parents and children with JIA jointly manage their arthritis. The next step will be to test the usability and feasibility of the online psychoeducational intervention for parents and children 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 children and their parents are similar across disease categories.

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