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Parental Perspectives about Research and Knowledge Translation in Juvenile Idiopathic Arthritis

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Objective. To identify barriers and facilitators to the uptake of information from research by parents of children with juvenile idiopathic arthritis (JIA).

Methods. Parents of children with JIA participated in focus group and telephone interviews at four Canadian pediatric rheumatology centers. The semistructured interviews focused on perceptions about JIA research, how new information about JIA was obtained and used, and what information was of most interest. Transcripts were analyzed using a general inductive approach.

Results. Twenty-eight parents participated in the study. Parents were very interested in research that addresses the outcomes of JIA and side effects of medications. Parents communicated an expectation that information from research be communicated to them by their child's pediatric rheumatologist as part of clinical care. Parents felt that it would be helpful to have information available to them in a variety of formats including written, video, and online. The timing of information delivery is an important factor, with parents being most interested and engaged in learning about new information about JIA at diagnosis and disease flares. We found that parents were overall unaware of new findings from JIA research and therefore may not be optimally utilizing this potentially helpful information in the care of their children.

Conclusion. This study has led to an understanding of Canadian parents' perceptions about research and existing gaps in the translation of research knowledge. This information will facilitate the development, implementation, and evaluation of future knowledge translation interventions aimed at improving the uptake of research information in the care of children with JIA.

INTRODUCTION

The existence of a "Knowledge-To-Action" (KTA) gap, which refers to the failure or slow adoption of research findings into practice and policy, has been well established across health research disciplines (1,2). Although health research encompasses a broad scope of purpose, a key overarching goal is to improve health outcomes. This requires the meaningful uptake and use of new research knowledge by relevant stakeholders, a process referred to as knowledge translation (KT). To bridge the KTA gap, a wide variety of KT strategies have been developed and implemented across multiple disciplines. KT strategies are often directed at health care professionals and can consist of single or multiple intervention approaches. This can include educational components, personal audits and feedback, reminders, and computerized decision supports (2–4). In contrast, patient-mediated KT strategies aim to engage patients in their own care, increase patient knowledge and satisfaction with the health care experience, promote adherence and other behaviors, and improve health outcomes (5–8).

A well-recognized KT framework is the Knowledge-To-Action Process (KTAP), which conceptualizes the relationship between

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knowledge creation and action (Figure 1) (1). The knowledge creation funnel is at the center, surrounded by the action cycle, which highlights key phases pertaining to the application of knowledge. This includes adapting the knowledge to the local context and determining potential barriers and facilitators to knowledge uptake.

We used the KTAP framework as the foundation for this study and began by focusing on information derived from the Research on Arthritis in Canadian Children, emphasizing Outcomes (ReACCh-Out) Study (9). Grimshaw et al suggest that the optimal basic unit of KT is an up-to-date systematic review or other synthesis of global evidence (2). We argue that information from a single high-quality research study could be very meaningful for patients and parents. This may be particularly applicable to rare diseases in pediatric rheumatology in which large-scale syntheses of research information are less likely to exist (10). Looking to the literature on preferences for the return of research results, we found a desire for broader sharing of this information. In a qualitative study of adult research participants' perceptions and preferences regarding research dissemination, participants felt they had a right to receive research findings, and these rights extended to the broader disease community, regardless of whether a patient had participated in the research study (11). Finally, and perhaps the most compelling reason to translate the results of the ReACCh-Out study, is the potential to improve care.

The primary aim of the ReACCh-Out study was to describe clinical outcomes of juvenile idiopathic arthritis (JIA) in a prospective inception cohort of children in order to better counsel families of newly diagnosed patients (9,12). JIA, the most common chronic rheumatic disease of childhood, is characterized by joint swelling and stiffness, chronic pain, decreased quality of life, the need for long-term medications, and frequent flares (13,14). There is a high burden of emotional distress associated with a diagnosis of JIA for both patients and parents. Parents of newly diagnosed children express difficulty coming to terms with the diagnosis, have described the unpredictable nature of JIA as an "emotional rollercoaster," and are very concerned for their child's future (15). We propose that one of the major contributions of this type of cohort study, which focuses on outcomes in routine clinical practice, is to inform high-quality evidence-based disease counseling in the care of children with JIA. We hypothesize that information from observational studies, such as the ReACCh-Out study, could meet some of the information needs of parents, help to allay some of the distress that is associated with the fear of the unknown, and improve the decision-making process.

In this study, we looked at the action cycle of the KTAP, specifically the step of assessing barriers and facilitators to knowledge uptake by parents. A thorough understanding of these factors will help to inform the development of future KT strategies. We recently reported our findings pertaining to the uptake of research knowledge by another group of relevant knowledge users, the health

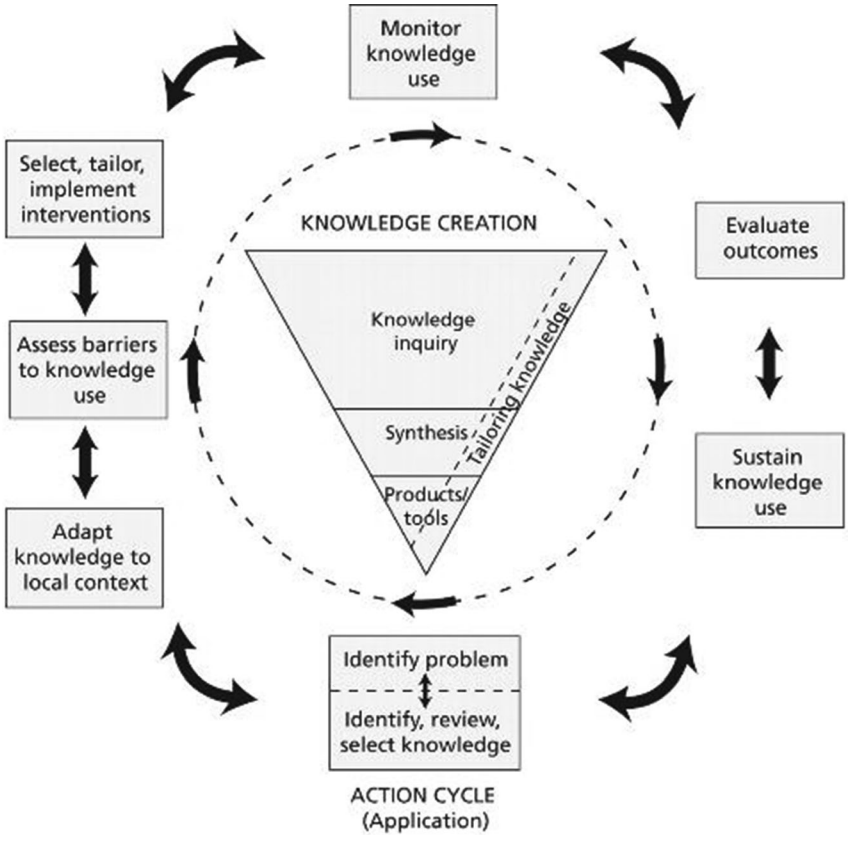

Figure 1. Knowledge-To-Action Process (Source: Graham et al 2006 (1)).

care providers caring for children with JIA (16). The objective of this study was to identify barriers and facilitators to the uptake of information from research by parents of children with JIA.

MATERIALS AND METHODS

Parents of children with JIA from four Canadian pediatric rheumatology centers (IWK Health Centre, Halifax; McMaster Children's Hospital, Hamilton; Children's Hospital of Eastern Ontario, Ottawa; and British Columbia Children's Hospital, Vancouver) were eligible to participate in this qualitative study. The study received ethics approval at each site. Purposeful sampling was used to create a sample approximating the known distribution of JIA subtypes (9). The aim was to include parents of newly diagnosed patients (less than 1 year since diagnosis) as well as parents with different levels of experience caring for a child with JIA (1-4 years since diagnosis and more than 4 years since diagnosis). We also aimed to include parents of children with varying levels of disease severity and thus used medications ever taken as a proxy for this. French-speaking participants were recruited for focus groups in Ottawa, and English-speaking parents were recruited at the other sites. The only exclusion criterion was non-French- or non-English-speaking parents at the respective sites. The attending rheumatologists identified potential participants at each site and introduced the study to parents. Parents who indicated interest in participating were approached by each center's research assistant for further information. Written informed consent was obtained for parents participating in the focus groups, and verbal informed consent was obtained from those participating in telephone interviews.

At each site, we aimed for six to eight participants per focus group (17,18). The research protocol was amended to include 10 individual telephone interviews (6 in Hamilton and 4 in Halifax to supplement low focus group turnout). A semistructured interview guide was developed for use in both the focus group interviews and telephone interviews. The guide was developed by the investigators and included five broad questions to elicit overall experiences followed by multiple probes to get a better and deeper understanding of the meaning of responses (Table 1) (19). General introductory questions about research were asked, followed by questions focusing on perceptions about JIA research, how information about JIA (including new information from research) was obtained and used, and what information was of the most interest to them. The focus groups and interviews were audio-recorded, transcribed verbatim, and deidentified for analysis. The French focus group interviews were transcribed directly into English by a bilingual transcriptionist.

The data from the transcriptions were analyzed using a general inductive approach (20). An inductive approach allows research findings to emerge from the frequent, dominant, or significant themes inherent in raw data, without the restraints imposed by structured methodologies. Each transcript was read in its entirety by two investigators (JW, BRD). Open coding in NVivo 11 software (QSR International Pty Ltd., version 11) was used to capture key thoughts (eg, text segments) related to the primary research question (barriers and facilitators to the use of information from JIA research). This was an iterative process whereby the identified text segments were sorted into meaningful categories/subcategories (codes/subcodes) and revised as more interviews were conducted across the four sites. The two investigators (JW, BRD) worked independently and met after coding each transcript to compare results. Coding differences were resolved through discussion, and a third investigator (ES) was consulted as necessary.

Table 1. Guiding questions and probes used in the focus groups and telephone interviews

Broad Questions	Probes
How do you get new information about JIA?	Do you ask your doctor or members of the health care team for new information about childhood arthritis? Do you wait for your doctor to give you any important new information about childhood arthritis? Do you get information from websites? Support groups? The Arthritis Society? Handouts, articles, or books? How do you know what information you can trust? What makes it easier or harder for you to understand or remember new information about JIA?
What type of information about JIA is of most interest to you?	Are you interested in information about how children and teenagers with arthritis usually do and what happens as they grow up? Are you interested in information about quality of life? Pain? Medications and treatments for JIA? Complications of JIA? Is the information you search for on websites, through support groups, or from other sources different from the questions you might ask your health care team? How?
How do you use this new information about JIA?	Does this information help to decrease any worries you have about JIA? Does it increase worries about JIA? Does this information make it easier to cope with the condition or know what to expect? Do you use this information to help make decisions? What types of decisions? How else?
Do you look for new research findings about JIA?	Where have you found it? How do you look for this type of new research? Have you found anything that makes it easier for you to get new research findings about JIA? Is learning about new research about JIA important for you? Do you think your doctor or the health care team would inform you of any important new information that you should know about?
Can you tell us what you know about research on JIA?	Do you think it's important to know about research specifically on Canadian children and teenagers? What would you want to know specifically from Canadian research about JIA? Were you aware that there were results from a large Canadian study on outcomes of kids with JIA published in the last couple of years?

Abbreviation: JIA, juvenile idiopathic arthritis.

A code book, which aims to operationalize a set of codes, was developed and acted as a guide to help analyze interview data (21). The final code book consisted of 17 codes and 47 subcodes.

RESULTS

In total, 28 parents of 23 children with JIA participated in the study (18 in focus group interviews and 10 in individual telephone interviews). The median duration of the focus group interviews was 65 minutes (range: 59-70). The median duration of the individual telephone interviews was 19 minutes (range: 11-43). Disease and demographic characteristics are summarized in Table 2.

We identified four overarching themes that captured potential facilitators and barriers to the uptake of information from research: 1) parents are generally unaware of the nature of JIA research (barrier), 2) outcomes research is of high priority to parents (facilitator), 3) there are preferred methods of dissemination of JIA-related information, including research-related information (facilitator), and 4) disease status affects the information needs of parents (facilitator). Detailed descriptions of these themes and subthemes (italicized) follow with illustrative quotes in Table 3.

Table 2. Demographic characteristics of the parent group (n = 28)

Characteristic	Value
Mean age (years)	44.7 (range 32-59)
Male	6 (21.4%)
Female	22 (78.6%)
Highest level of education	
Prefer not to answer	1
High school	1
Apprenticeship/trade/community college	5
Postsecondary or professional degree	21
Number of participants per focus group	
Halifax[a]	3
Ottawa	8
Hamilton[a]	3
Vancouver	4
Child with JIA (n = 23)	
Male	9
Female	14
Mean age (years)	11.5 (range 1-18)
JIA subtype	
Oligoarticular	11
Polyarticular RF+	0
Polyarticular RF-	4
Psoriatic	1
Enthesitis related	4
Systemic	2
Undifferentiated	1
Duration of JIA (years)	
Median	2.4 (range 0.7-14.2)
<1	7
1-4	9
>4	7
Medications ever taken	
NSAIDS	22
Corticosteroid Injections	13
Oral corticosteroids	3
IV corticosteroids	3
DMARDS	17
Biologics	6

Abbreviation: DMARD, disease-modifying antirheumatic drug; IV, intravenous; JIA, juvenile idiopathic arthritis; NSAID, nonsteroidal anti-inflammatory drug; RF, rheumatoid factor.
[a]Halifax supplemented with four telephone interviews; Hamilton supplemented with six telephone interviews.

Parents are generally unaware of the nature of JIA research (barrier). There was a lack of awareness amongst participants about JIA research (eg, topics of research, findings from research). Some parents were aware that JIA research was being conducted within Canada, but none of the participants were familiar with the ReACCh-Out study or other research findings on JIA. If parents were to become more aware of the types of research being conducted, particularly if they align with their own research priorities, we hypothesize that parents may be more inclined to initiate discussions with their child's pediatric rheumatologist about research findings or actively seek further information in these areas.

Outcomes research is of high priority to parents (facilitator). *(i) Knowing the "landscape" and what the future holds are important to parents*. Having a sense of what to expect for their child in the short and long term was extremely important to parents. Parents reported a need to understand the potential disease trajectories for their child. Parents also focused on what life would be like for their child in adulthood in relation to function, pain, and chances of "outgrowing" JIA.

(ii) The long-term side effects of medications are important to parents. Parents wanted information regarding other children's experiences with medications in relation to side effects and efficacy, as well as how the medication will affect their child in the long term. Taken together, we viewed this overall theme as a facilitator because the information needs of parents align with ongoing initiatives by multiple groups around the world that are following cohorts of children with JIA (22).

There are preferred methods of dissemination of any JIA-related information, including research-related information (facilitator). *(i) JIA-related information from the internet is not considered trustworthy unless endorsed by a trusted source*. Parents described a distrust and fear of the internet regarding disease-related information. They voiced concerns about the validity of the information presented online as well as the potential to be led astray with too much or irrelevant information. In contrast, if the online material is endorsed by a trusted source (eg, the doctor, the hospital, or an organization such as The Arthritis Society), they would be more likely to use the internet as an information-finding tool.

(ii) Parents value the health care providers as the most trustworthy source of JIA-related information, including new information from research. Parents indicated that they strongly value the information delivered by the health care team, particularly the

Table 3. Themes and subthemes with illustrative quotes (quote is from parent in focus group unless specified as interview that refers to the individual telephone interview)

Theme 1: Parents are generally unaware of the nature of JIA research (barrier)
[BCCH]: *I don't know the research studies.*
[IWK]: *I believe there is research going on here about JIA... I don't know a lot about the individual studies going on.*
[McM]: *There's lots of work being done in research for JIA which is good and there's recognition that maybe research has been done, but there's not been the communication of it. It hasn't been as effective as you would hope.*
[interview IWK]: *I'd just like to know where it's at [research] or what the breakthroughs are.*
Theme 2: Outcomes research is of high priority to parents (facilitator)
Subtheme: Knowing the "landscape" and what the future holds is important to parents
[BCCH]: *there is a lot of interest in that sort of statistical history....one of the rheumatologists showed a graph about the different subtypes of arthritis and the timeline from diagnosis to remission. I certainly was looking at it going, okay, I'm six months in to what on average is two years before things will settle. That's useful information.*
[BCCH]: *Is this a month from now? Is this 5 years from now? When? Where my child possibly fits helps you figure it out and help you navigate it. Your child is specific but at least you can kind of have a better landscape.*
[CHEO]: *In the long term, what are the risks or how are they going to confront this situation once they're adults. There are probably children who started medication before. There might be generations of women and men where you could ask this question. Surely it needs some research.*
[IWK]: *I think it was good to just see different possibilities, different outcomes, that type of thing.*
[IWK]: *I just had to know everything. I wanted to know what category, what are the risks, what is the prognosis?*
[IWK]: *I went through all the possibilities and the scale of progression of things getting worse. I tried to get a full picture of what is going on.*
[interview IWK]: *Maybe laying out what potentially could be ahead. Everybody's different but I think I would have liked to know a bit more of the possibilities that are out there and maybe the different ways it can go.*
[interview IWK]: *It's not something that we have any experience with. It's all kind of new, so you go through thinking what are the chances of remission, does it steadily progress, does it plateau?*
[interview McM]: *How many kids outgrow it? Does it hinder them when they become older? Will she totally outgrow it or will it come back? Will it be painful for her? Will she be able to continue like she does and people don't even know that she has arthritis that meet her?*
(Subtheme) The long-term side effects of medications are important to parents
[IWK]: *I would like to know more about how the medications she has taken and is taking will impact her physically down the road.*
[IWK]: *Yeah, the long term, it is the big one for most people when you are looking at medicine for sure.*
[IWK]: *I wanted to know sort of long term what it is going to be, what is going to be the result even some of the lesser medications like naproxen. He's 15 months and he is on naproxen twice a day for a year. What is going to happen to his stomach and that sort of stuff wasn't in the information that we got.*
[BCCH]: *I would like to go and look at people's experience of medication, side effects of medications, because we've got a lot of side effects.*
[CHEO]: *In terms of medication, maybe numbers on the percentage of when it doesn't work, how many people take it, to give an idea of success.*
[CHEO]: *Yes, the methotrexate is a good drug and it's been out for a while, we know it works well for arthritis. But what I would be interested to know is the effects of taking it long term.*
[McM] *Like what happens with her being on the medication? Is this gonna be something that she's not going to be able to have kids? She's thinking about stuff like that. If she could get some reliable information. They might be a bit shy about asking the doctor that kind of stuff.*
Theme 3: There are preferred routes for JIA-related information dissemination, including research-related information (facilitator)
(Subtheme) JIA-related information from the internet is not considered trust worthy unless endorsed by a trusted source.
[IWK]: *I don't use the internet a lot just because there is so much misinformation on it too. I think the only two sites that I've probably looked at would have been the IWK site and then the Arthritis Society.*
[IWK]: I *am very reluctant of going on the internet. I would go to the Arthritis Society or if the doctor gave me a good reputable website I would go to, because you can just go from one thing to the next.*
[IWK]: *Some people just jump on WebMD which I wouldn't even think of looking at because it is going to diagnose you with anything from a hangnail to cancer.*
[CHEO]: *I like to go to the arthritis sites, because Google always brings up lots of different things.*
[BCCH]: *When my son was first diagnosed I turned to the internet and it was very confusing because there is so much and some sources make it sound horrific. It's really scary some of the stuff that's out there so that is was really hard to filter through. Like what can I actually use and what do I just not need to know at this time.*
[McM]: *I have used the internet to a certain extent but I find it either overwhelming or not knowing what actually might apply to my daughter and that type of thing.*
[McM]: *I like to stick to just the Arthritis Society because we know it's the actual Arthritis Society that has put out the information so we trust what we read from that website for sure.*
[McM]: *There are not a lot of resources online that I would really trust.*
(Subtheme): Parents value the health care providers as the most trust worthy source of JIA-related information including new information from research
[IWK]: *I think getting information from the source, like from the hospital is ideal. I put a lot of trust in it. I feel it is proven and I can trust it so that would be my main source.*
[IWK]: *We take the doctor's word for it that, you know, it is good and that a lot of children are on this similar medication that she is on. We put our trust in them.*
[IWK]: *I feel that the doctor that she is seeing is kept current with information and that if anything changes with her, we are given the options of what to proceed with next if we want to.*
[BCCH]: *[the nurse] at the rheumatology clinic is a huge source of information in a very practical way. She's pointed me to different websites and explained that this one might be for a little bit later.*

(Continued)

Table 3. (*Cont'd*)

[CHEO]: *the doctor would talk to us about it [research breakthrough]. Because we have confidence in her professional advice, if something were to come out, they would share it with us.*
[CHEO]: *I trust a lot in the advice of the doctors and nurses.*
[interview IWK]: *You know, I'm not the expert. I really do rely on having a doctor to say, hey there is a really positive study coming out of such and such a spot or something like that.*
[McM]: *I have really relied on the doctor for kind of letting us know what's out there and what's happening and what might benefit.*
[McM interview]: *I guess if it has come from a medical professional, the doctor or the physiotherapist or the nurse, those pieces of information we're going by.*
(Subtheme): Preferences for delivery of research-related information vary among parents
[CHEO]: *But now that they know everyone is on the internet, why couldn't they send us the information when there is something new? We are a group and we are interested because our children are sick. Why couldn't they send us an email?*
[CHEO]: *In a simple language where everyone understands, that would be ideal.*
[IWK]: *An email would be fine for me. If I had a notification by email saying this study is available here, I would read it.*
[McM]: *For me, a lot of stuff gets lost in the email but if you hand me a piece of paper.*
[McM]: *Videos are good I guess especially if its easily accessible and you come back to it whenever you want. You don't have to watch the whole thing all at once.*
[interview McM] *It would certainly be nice for, especially for studies that you have been a part of, if maybe there was an email link, you know, as things were published in that study I guess...it would be nice, you know, for studies that you have taken part in, even just an email link and an update that this information is now out in the public would be nice.*
[Interview IWK]: *I would definitely read it [results from research]. If there was stuff out there that I could access and understand, I definitely would.*
[Interview McM]: *I'm not a social media kind of girl but maybe have the parents connected so that we could visit a site, maybe have a user name and password to get into the site if it was just for that purpose. If it were just for sharing information with parents of kids with JIA.*
[McM]: *Well I would assume that people are seeing their medical practitioners fairly regularly so that would be the preferred route for our family.*
(4) Disease status affects the information needs of parents
(Subtheme) At the time their child is diagnosed with JIA and during disease flares are key time-points when parents are most interested in receiving disease-related information.
[IWK]: *When we first got the diagnosis, I just had to know everything. I wanted to know what category, what risks, prognosis, and I was trying to get all the information I could to understand it.*
[IWK]: *I am sure I will start reading it again when there is a flare up.*
[IWK]: *I know there will probably be a point in time when she needs her medications changed or she has a flare-up or something because she's young and I know it is just not going to go away, so I think I am prepared for that to happen mentally at this point, but I think only because I've been able to give myself a break for a little while.*
[IWK]: *They described some of the medications like Humira and methotrexate... It was overwhelming. It's like, oh my goodness, I am possibly going to have to put my daughter on some of this? This I when I really need to do my research.*
[BCCH]: *I also think when your child is diagnosed you research and you try and find everything you can.*
[BCCH]: *Unless you go on new medication or there's a reason for something specific, you don't look for new research actively.*
[CHEO]: *With the diagnosis, we did a lot of research.*
[CHEO]: *At the beginning, yes, I remember at the beginning you need to understand what it is. We searched for a lot of information.*
[interview McM]: *I asked tons of questions when my son was diagnosed. I did lots of research and I would come prepared for every appointment with written questions.*
(Subtheme) During periods of stable disease, parents are less likely to seek or need new information about JIA
[CHEO]: *At the beginning we looked, but now the condition is more routine.*
[McM]: *In the last little bit, she's been on a really good medication regime for a while now that has been really working and we haven't had any flare ups or anything like that so not really [looking for new research findings] as much in the last little bit.*
[CHEO]: *We were a bit saturated with all the information and once we were stabilized, we said, well we're functioning.*
[IWK]: *I know there will probably be a point in time when she needs her medications changed or she has a flare-up or something because she's young and I know it is just not going to go away, so I think I am prepared for that to happen mentally at this point, but I think only because I've been able to give myself a break for a little while.*
[BCCH]: *I'm realizing I haven't read about it in a year maybe I must go and see if there was something new in the year unless you go on new medication or there's a reason for something specific you don't look for new research actively.*

Abbreviation: BCCH, British Columbia Children's Hospital; CHEO, Children's Hospital of Eastern Ontario; IWK, IWK Health Centre; JIA, juvenile idiopathic arthritis; McM, McMaster Children's Hospital.

pediatric rheumatologist. This pertained to information in general, but there was also a belief and expectation that any new relevant information from research would be communicated directly to them by their child's doctor.

(iii) Preferences for delivery of research-related information varies among parents. We received a wide variety of responses when parents were asked how they would prefer to receive new research information about JIA. In addition to communication from their health care team, some parents would also like to have information emailed to them, whereas others valued having a piece of paper in hand. Being able to watch a video or log into a website was suggested by some parents. Having the ability to tailor the information (eg, type of information, flexible access to information) also emerged as a desirable attribute. Finally, not surprisingly, parents noted that any information presented must be easy to understand and accessible to them. The findings presented within this theme represent parent preferences for how they would like to receive JIA-related information, including new information derived from research. We viewed this theme as a facilitator because it can help to inform the development of KT initiatives.

Disease status affects the information needs of parents (facilitator). *(i) At the time their child is diagnosed with JIA and during disease flares are key time points when parents are most interested in receiving disease-related information*. Parents identified diagnosis and disease flares as time points when they were more likely to seek out new information about JIA. Seeking information appeared to stem from a need to have a thorough understanding of the disease, both as a coping mechanism and as a way to provide the best care for their child. Parents recalled that making decisions about starting new medications was particularly challenging. Concern for their child and the emotional toll of making these decisions motivated parents to seek out all the available information. These time points during the disease trajectory could be leveraged as facilitators for KT as parents are likely to be highly interested and engaged in learning about JIA. We speculate that this would include learning about new developments from research if they were to help parents have a comprehensive picture of possible disease outcomes and inform the decision-making process.

(ii) During periods of stable disease, parents are less likely to seek or need new information about JIA. Contrasting with the need for information at diagnosis or during flares, parents were less inclined to want or seek out new information when their child's disease was stable. There was a sentiment of needing some respite from thinking about JIA. Overall, we feel that an improved understanding of the preferences for the timing of information delivery as described in this theme will inform the design of interventions in the future.

DISCUSSION

This is the first study to evaluate the barriers and facilitators to the use of knowledge from research by parents of children with JIA using the KTAP framework. We discovered that parents were generally unaware of information coming from JIA research and therefore may not be fully benefiting from new knowledge as it becomes available. Parents are most keenly interested in understanding what the future holds for their children in terms of the disease course and medication side effects. It is imperative that researchers communicate this knowledge effectively to parents as we believe it has the potential to improve the care and experience of families of children with JIA.

An important theme that emerged from our study was the overall lack of knowledge about the nature of specific research studies, although many parents knew that research was taking place. The parents in this study (all of whom were linked to academic centers with active clinical research programs) were generally unaware of the ReACCh-Out study and its results, despite it being the first pan-Canadian inception cohort study. Reasons for this KT gap are potentially multifactorial. Our group has performed a related study examining the barriers faced by Canadian pediatric rheumatologists (PRs) and allied health professionals (AHPs) when translating research findings into clinical care (23). Many PRs could not remember all of the specific results of the ReACCh-Out study, despite some participants being ReACCh-Out investigators. Limited time available to spend with patients and families in the clinic was also felt to be a barrier to sharing research findings with parents during clinical encounters. In addition, PRs and AHPs often limited the amount of information presented during a clinical encounter to avoid overwhelming parents.

Another obvious theme identified by our study was parents' desire for outcomes-based research. This complements the direction of many present-day research initiatives, specifically national and multinational JIA cohort studies. Beukelman et al (22) have recently identified and characterized 18 prospective JIA cohort studies, representing 37 countries and over 60 000 children. Four of these studies appear to have the ability to follow patients into adulthood, and 7 of the 18 studies have a specific focus on pharmacovigilance, which will also help to fill knowledge gaps about medication side effects. This type of JIA research is precisely aligned with several of the information needs identified by parents in this study. It is incumbent upon the research community to communicate this information to patients and families in a meaningful way.

The third theme of our study encompassed important information about preferences for receiving information about JIA, including research-related information. The internet was not perceived as a trustworthy source of disease-related information for parents unless a health care provider or other trusted source had endorsed a specific site. Similarly, in a study of 400 adults surveyed in Australia, the most preferred mode of online navigational support was involvement of health professionals (24). Parents have a belief and expectation that any new relevant information from research will be communicated directly to them by their child's doctor; however, given the known barriers that PRs face in providing research knowledge to parents in the clinical care setting, PRs are unlikely to be able to fully meet this expectation.

Many KT strategies focus on the behavior of health care professionals; however, an emerging approach to KT is to direct research information to health care consumers (8). This approach could help to overcome the barriers to KT cited by health care providers (16). In our study, parents described the modalities by which they would prefer to receive information, including emails from their health care team, written handouts, videos, and secure websites, and they noted that the ability to tailor the information to their specific context would be highly desirable. Two recent reviews evaluating patient-mediated KT interventions in adults and children, respectively, showed a range of effects (positive, mixed, unclear) in relation to changes in knowledge, communication, decision making, and behavior (7,8). Although patient-mediated KT tools offer a promising approach to communicating health information, both reviews cited a need for more research in this area, with a focus on increased methodological rigor.

Some of the KT gaps identified in our study may be addressed in the future by looking at contemporary best practices in KT. Passive modes of KT are insufficient, and a more transparent and engaged approach to knowledge creation and translation are required (25). This model of having patient and other knowledge-user engagement throughout the research process is called integrated KT (IKT). The ReACCh-Out study was designed over 10 years ago and employed conventional end-of-grant KT practices to disseminate knowledge (eg, conference presentations, manuscripts). Since then, there has been a shift toward engaging patients early in the research process as evidenced by large organizations, such as the United States–based Patient-Centered Outcomes Research Institute (PCORI) (26). In Canada, Outcome Measures in Rheumatology (OMERACT) has been a pioneer in including patients as stakeholders in research for over a decade (27).

Although there is emerging evidence that IKT can lead to improved application of research knowledge through various mechanisms, there is still a paucity of evidence to inform best practices for conducting IKT (28). Therefore, although we speculate that an IKT approach has the potential to improve uptake of JIA research information by parents, it is important to acknowledge the lack of a solid evidence base to inform IKT activities in general. In a scoping review of IKT interventions, Gagliardi et al found that, overall, the interventions were poorly described, evaluated, and reported (5). The lack of evidence-based methodologies was also highlighted in a recent paper examining parent coengagement in pediatric research (29). Engaging patients ineffectively or poorly does not come without risk, particularly the false appearance of inclusiveness or "tokenism," which undermines and threatens the fundamental underpinnings of patient engagement (30). Second, without evidence to support best IKT practices, there is a risk of wasting valuable resources, such as people's time and funding, on ineffective practices. It is therefore critical for researchers and groups who are leaders in IKT to systematically evaluate their approaches and share their findings with the broader research community to move the science of IKT forward.

The final theme that we identified in this study suggests that the timing of information delivery is important in the uptake of JIA knowledge. KT interventions should be timed when parents are most inclined to use information from research, such as at the time of medication change, disease flare, or when first receiving the diagnosis of JIA. Parents in this study highlighted a need for this information to be accessible beyond the confines of the clinic visit and tailorable to their specific needs. Optimal information delivery is therefore likely to require a combination of face-to-face communication with health care providers and the ability to access this information following the visit for further review and reinforcement. Parents also expressed a desire to take a break from seeking or receiving new information about JIA when their child was medically stable. This may present a potential barrier to the success of a KT intervention if patients and families are targeted when the disease is stable.

Limitations of this study include the absence of participants from community-based rheumatology clinics because most children with JIA in Canada receive most or part of their care in university-based clinics. The parents in this study were highly educated with three-quarters having a bachelor's degree or higher. Because of self-selection, we speculate that participants could be more interested in research than the general clinic population. Finally, this study occurred in the context of Canadian pediatric rheumatology centers and may not be indicative of other jurisdictions in the world.

This study has led to a better understanding of Canadian parents' perceptions of research in the area of JIA, and existing gaps in the translation of research knowledge. We have begun to identify parent preferences of how and when they would like information presented to them about JIA, including new findings from research. With this information as a foundation, we can now move onto the next phase of the KTAP, which is to select, tailor, and implement a KT strategy. We plan to bring together a multidisciplinary team that includes patients, parents, health care providers, KT scientists, and health informatics experts to define what is needed in this phase and then co-create the intervention. Simultaneously, we will evaluate the co-creation process to build on the existing literature on best practices in patient engagement and IKT.

AUTHOR CONTRIBUTIONS

All authors were involved in drafting the article or revising it critically for important intellectual content. All authors gave final approval of the version of the article to be published.

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REFERENCES

1. Graham ID, Logan J, Harrison MB, Straus SE, Tetroe J, Caswell W, et al. Lost in knowledge translation: time for a map? [research support]. J Contin Educ Health Prof 2006;26:13–24.
2. Grimshaw JM, Eccles MP, Lavis JN, Hill SJ, Squires JE. Knowledge translation of research findings. Implement Sci 2012;7:50.
3. Rader T, Pardo Pardo J, Stacey D, Ghogomu E, Maxwell LJ, Welch VA, et al. Update of strategies to translate evidence from cochrane musculoskeletal group systematic reviews for use by various audiences. J Rheumatol 2014;41:206–15.
4. Campbell A, Louie-Poon S, Slater L, Scott SD. Knowledge translation strategies used by healthcare professionals in child health settings: an updated systematic review. J Pediatr Nurs 2019;47:114–20.
5. Gagliardi AR, Berta W, Kothari A, Boyko J, Urquhart R. Integrated knowledge translation (IKT) in health care: a scoping review. Implement Sci 2016;11:38.
6. Street RL Jr, Makoul G, Arora NK, Epstein RM. How does communication heal? Pathways linking clinician-patient communication to health outcomes. Patient Educ Couns 2009;74:295–301.
7. Gagliardi AR, Légaré F, Brouwers MC, Webster F, Badley E, Straus S. Patient-mediated knowledge translation (PKT) interventions

for clinical encounters: a systematic review. Implement Sci 2016; 11:26.

8. Albrecht L, Scott SD, Hartling L. Knowledge translation tools for parents on child health topics: a scoping review. BMC Health Serv Res 2017;17:686.
9. Guzman J, Oen K, Tucker LB, Huber AM, Shiff N, Boire G, et al. The outcomes of juvenile idiopathic arthritis in children managed with contemporary treatments: results from the ReACCh-Out cohort. Ann Rheum Dis 2015;74:1854–60.
10. Cellucci T, Lee S, Webster F. Adapting knowledge translation strategies for rare rheumatic diseases. J Rheumatol 2016;43:1462–8.
11. Purvis RS, Abraham TH, Long CR, Stewart MK, Warmack TS, McElfish PA. Qualitative study of participants' perceptions and preferences regarding research dissemination. AJOB Empir Bioeth 2017;8:69–74.
12. Guzman J, Oen K, Huber AM, Watanabe Duffy K, Boire G, Shiff N, et al. The risk and nature of flares in juvenile idiopathic arthritis: results from the ReACCh-Out cohort. Ann Rheum Dis 2016;75:1092–8.
13. Moorthy LN, Peterson MG, Hassett AL, Lehman TJ. Burden of childhood-onset arthritis. Pediatr Rheumatol Online J 2010;8:20.
14. Gowdie PJ, Tse SM. Juvenile idiopathic arthritis. Pediatr Clin North Am 2012;59:301–27.
15. Gómez-Ramírez O, Gibbon M, Berard R, Jurencak R, Green J, Tucker L, et al. A recurring rollercoaster ride: a qualitative study of the emotional experiences of parents of children with juvenile idiopathic arthritis. Pediatr Rheumatol Online J 2016;14:13.
16. Rose-Davis B, Curran J, Wright J, Cellucci T, Duffy CM, Tucker LB, et al. Factors influencing the uptake of Canadian research findings into the care of children with arthritis: a healthcare provider perspective. J Rheumatol 2019;46:294–300.
17. Francis JJ, Johnston M, Robertson C, Glidewell L, Entwistle V, Eccles MP, et al. What is an adequate sample size? Operationalising data saturation for theory-based interview studies. Psychol Health 2010;25:1229–45.
18. Malterud K, Siersma VD, Guassora AD. Sample size in qualitative interview studies: guided by information power. Qual Health Res 2016;26:1753–60.
19. Kreuger RA, Casey MA. Focus groups: a practical guide for applied research. Thousand Oaks (CA): SAGE Publications; 2014.
20. Hsieh HF, Shannon SE. Three approaches to qualitative content analysis. Qual Health Res 2005;15:1277–88.
21. DeCuir-Gunby JT, Marshall PL, McCulloch AW. Developing and using a codebook for the analysis of interview data: an example from a professional development research project. Field Methods 2011;23:136–55.
22. Beukelman T, Anink J, Berntson L, Duffy C, Ellis JA, Glerup M, et al. A survey of national and multi-national registries and cohort studies in juvenile idiopathic arthritis: challenges and opportunities. Pediatr Rheumatol Online J 2017;15:31.
23. Wright J, Rose-Davis B, Curran J, Cellucci T, Duffy C, Tucker L, et al. Knowledge translation in juvenile idiopathic arthritis in Canada: a focus on parents of children with JIA. Arthritis Rheumatol 2017; 69 Suppl 10. URL: https://acrabstracts.org/abstract/knowledge-translation-in-juvenile-idiopathic-arthritis-in-canada-a-focus-on-parents-of-children-with-jia/.
24. Lee K, Hoti K, Hughes JD, Emmerton L. Dr Google and the consumer: a qualitative study exploring the navigational needs and online health information-seeking behaviors of consumers with chronic health conditions. J Med Internet Res 2014;16:e262.
25. Banner D, Bains M, Carroll S, Kandola DK, Rolfe DE, Wong C, et al. Patient and public engagement in integrated knowledge translation research: are we there yet? Res Involv Engagem 2019;5:8.
26. Sheridan S, Schrandt S, Forsythe L, Hilliard TS, Paez KA, Advisory Panel on Patient Engagement. The PCORI Engagement Rubric: Promising Practices for Partnering in Research. Ann Fam Med 2017;15:165–70.
27. De Wit M, Kirwan JR, Tugwell P, Beaton D, Boers M, Brooks P, et al. Successful stepwise development of patient research partnership: 14 years' experience of actions and consequences in Outcome Measures in Rheumatology (OMERACT). Patient 2017;10: 141–52.
28. Graham ID, Kothari A, McCutcheon C, Integrated Knowledge Translation Research Network Project Leads. Moving knowledge into action for more effective practice, programmes and policy: protocol for a research programme on integrated knowledge translation. Implement Sci 2018;13:22.
29. Shen S, Doyle-Thomas KA, Beesley L, Karmali A, Williams L, Tanel N, et al. How and why should we engage parents as co-researchers in health research? A scoping review of current practices. Health Expect 2017;20:543–54.
30. Hahn DL, Hoffmann AE, Felzien M, LeMaster JW, Xu J, Fagnan LJ. Tokenism in patient engagement. Fam Pract 2017;34:290–5.