Knowledge Translation in Juvenile Idiopathic Arthritis Research in Canada: Comparing and Contrasting Parent and Adolescent Perceptions

Benjamin Rose-Davis[1], Julia Wright[1], Janet Curran[1], Michelle Batthish[2], Tania Cellucci[2], Ciarán M. Duffy[3], Lori Tucker[4], Adam Huber[1], Bianca Lang[1], Deborah M. Levy[5], Dax Rumsey[6], Karen N Watanabe Duffy[3]and Elizabeth Stringer[1]
[1]IWK Health Centre, [2]McMaster Children's Hospital, [3]Children's Hospital of Eastern Ontario, [4]BC Children's Hospital, [5]The Hospital for Sick Children, [6]Stollery Children's Hospital

Background

- JIA is the most common chronic rheumatic disease of childhood
  - Prevalence of ~ 1/1000
  - Can lead to disability, chronic pain, decreased quality of life, ongoing need for medications, frequent flare-ups, irreversible joint damage, and emotional distress
  - Parents report an 'emotional rollercoaster' while dealing with the unpredictable nature of JIA[1]
- The Research in Arthritis in Canadian Children Emphasizing Outcomes Study
  - The ReACCh-Out Cohort Study followed over 1000 children with newly diagnosed JIA for 5 years
  - One of the primary goals of the study was to summarize results for healthcare providers to use when counselling patients and their families around early outcomes of JIA[2]
  - Little is known regarding the uptake of this information for use in clinical care in Canada Pediatric Rheumatology Clinics
- Knowledge Translation (KT)
  - KT is a dynamic process built upon synthesis, dissemination, exchange, and application of knowledge to improve health outcomes
  - To inform the design of KT interventions, it is critical to establish the barriers and facilitators to the behavior of interest
- Study Overview
  - The study examined barriers and facilitators for the uptake of Canadian JIA Research for Pediatric Rheumatologists, Allied Health Professionals, Parents of children with JIA, and Adolescents with JIA.
  - A parallel study of examining barriers and facilitators for health care professionals across Canada has been conducted

Objective

- To compare and contrast barriers and facilitators to the uptake of Canadian JIA research findings for Parents of children with JIA (PJIA) and Adolescents with JIA (AJIA)

Methods

- Participants were recruited from 4 Academic Pediatric Rheumatology Centres across Canada
  - Halifax (IWK), Ottawa (CHEO), Hamilton (McM), Vancouver (BCCH)
  - Telephone interviews supplemented low turnout in Halifax parent group, and Hamilton parent and adolescent groups
- PJIA and AJIA participated in focus group interviews using a semi-structured interview guide

Question 1	• What does research mean to you? What is the purpose of research?
Question 2	• How do you get information about JIA?
Question 3	• What type of information about JIA is of most interest to you?
Question 4	• How do you use the information you find about JIA?
Question 5	• Do you look for new research findings on JIA?
Question 6	• Can you tell us what you know about research on JIA?
Question 7	• Have you/your child been involved in any research studies on JIA?

  - Focus groups in Ottawa were conducted in French
- Transcripts were reviewed and coded using NVivo 11 by two independent coders (BRD, JW)
  - Themes in the data were identified using an open coding and general inductive approach
  - Themes with potential to overcome barriers, or facilitators on which to build, were reported for both PJIA and AJIA
  - Themes from PJIA and AJIA were compared and contrasted

Results - Demographics

Characteristic	PJIA	AJIA
Participants	N = 28 (18 in Focus Groups)	N = 19 (16 in Focus Groups)
Age (years)	Mean 45.0, Range 32-59	Mean 14.3, Range 13-17
Sex	6 Male, 22 Female	6 Male, 13 Female
Disease Duration (years)	Median 2.4, Range 0.7-14.2	Median 4.9, Range 0.3-14.4
JIA Subtype		
Oligoarticular	11	8
Polyarticular RF+	0	1
Polyarticular RF-	4	2
Psoriatic	1	2
Enthesitis Related	4	3
Systemic	2	2
Undifferentiated	1	1
Medications (ever taken)		
NSAIDs	22	19
Corticosteroid Injections	13	10
Oral corticosteroids	3	3
IV corticosteroids	3	2
DMARDs	17	15
Biologics	6	8

References:
[1] Gomez-Ramirez O, Gibbon M, Berard RA, et al. The roller coaster of juvenile idiopathic arthritis: a qualitative examination of parents' emotional responses to the disease and its management. Arthritis Rheumatol. 2014 Mar;66 Suppl 11:S131
[2] 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. Annals of the rheumatic diseases 2014

Results Continued

Legend: Major Theme | Sub Theme | Quote

Theme 1 : Understanding and Awareness

PJIA and AJIA share a general understanding of the purpose and value of research

P[McM]: *"It's studies to better determine what is going on and determine how disease is caused, how it progresses, how we can treat it and for now and for the future."*

A[CHEO]: *"Finding information, trying to find more information and the answers to problems."*

PJIA are not aware of JIA studies

P[IWK]: *"I don't know a lot about the individual studies going on, but I would trust that the practitioners … are doing the research that is needed"*

AJIA do not look for or use results from research; they rely on parents and/or HCPs for information

A[McM]: *"My doctors usually … notify my mom, she will notify me and then we just talk about it a little"*

Theme 2 : Adolescent Information Needs

AJIA are primarily interested in knowing the day-to-day impact of JIA and pain management

A[CHEO]: *"At the beginning it hurts a lot, so I would like information on how to make is so it hurts less."*

A[CHEO]: *"If I do research, it is usually on what will help me manage."*

A[McM]: *"It's important to me to not be in pain during sports"*

AJIA identified peer-to-peer interaction as a benefit and need

A[BCCH]: *"[It's] kind of good when we have these research groups and we're able to…meet new people and I think that's important…being able to just know that you're not alone and that it's treatable."*

Theme 3 : Delivery of Information

PJIA and AJIA put their trust in information from their healthcare team

P[CHEO]: *"I trust a lot in the advice of the doctors and nurses."*

A[IWK]: *"If the doctor mentions something that will be helpful towards you then I know I can trust it."*

PJIA feel overwhelmed with the volume of information

P[McM]: *"Getting the package with the information…it was all explained in the office but to be completely honest it was overwhelming."*

The internet, apart from 'reputable' sites, is not widely trusted

P[McM]: *"That's why 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."*

A[BCCH]: *"The whole internet thing is not knowing what to trust which is why I've gotten to trust my doctors and to trust what they're saying and if they say something on the internet is not trustworthy then that's what I'm gonna go with."*

Key time points in the disease course influence the information-seeking behavior of parents

P[IWK]: *"When we first got the diagnosis, I just had to know everything. I wanted to know what category, what risks, prognosis..."*

PJIA feel a deep sense of responsibility when making decisions around medication changes

P[IWK]: *"It's like, oh my goodness, I am possibly going to have to put my daughter on some of this, this is like I really need to do my research."*

PJIA are less inclined to want or seek out new information when their child's disease is stable

P[CHEO]: *"Once things were stabilized, we were a bit saturated with all the information and once we were stabilized, we said, well we're functioning. "*

Conclusions

- The timing and delivery method of information aimed at PJIA and AJIA must be considered when designing interventions to translate research knowledge into clinical care.
- AJIA are unlikely to seek information on their own and overall their interests lie in the day to day management of their disease and impact on their life
- This study along with its parallel study of pediatric rheumatologists and allied health professionals has identified barriers and facilitators in the translation of knowledge from JIA research into clinical practice and will provide the foundation for designing KT initiatives in the care of children with JIA moving forward.

This study was supported by a CIORA grant