



What Matters the Most for Parents, Patients and Clinicians in Predicting the Course of Juvenile Idiopathic Arthritis?

Funded by CIORA:
Canadian Initiative for
Outcomes in
Rheumatology Care

Jaime Guzman, Susanne Benseler, Roberta Berard, Rollin Brant, Ciaran Duffy, Roman Jurencak, Kiem Oen, Ross Petty, Natalie Shiff, Lori Tucker

Introduction

Juvenile Idiopathic Arthritis (JIA) is divided in seven onset types, but the onset types do not necessarily predict the course of the disease

Large cohorts and new biomarkers might help predict the disease course with greater accuracy to counsel families and tailor treatment plans.

Prior to developing a clinical tool to predict the course of JIA, we gathered the opinions of parents, youth with JIA and clinicians about:

- the clinical features that should be used to define the course of JIA;
- terms that should be used to describe the course to families; and
- desirable attributes of a course prediction tool.

Methods

• Six professionally facilitated audience-specific focus groups/ reciprocal interview sessions:

- Youth with JIA (n=9)
- Experienced English-speaking parents (n=9)
- Experienced French-speaking parents (n=5)
- Novice English-speaking parents (n=8)
- Pediatric Rheumatologists, Rheum (n=8)
- Arthritis Health Professionals, AHP (n=9)

• Sessions held in different cities across Canada with participants recruited to reflect all JIA types and varied severity of the disease.

• Lists and definitions of JIA features, terms and tool attributes were provided to guide discussions.

• Transcripts, facilitator reports and participants' interview reports underwent content analysis.

Findings

- There were important similarities and differences in the priority of clinical features across groups as shown in Table 1.
- Most participants preferred lay terms that were "honest yet left room for hope" and advised against overtly negative terms (e.g. refractory).
- The following descriptive course terms were supported by most: remitting, controlled and persisting; and mild, moderate and severe.
- Parents and AHP felt JIA is unpredictable. AHP worried that parents would feel "cheated" when predictions did not materialize.
- Youth with JIA would prefer a prediction tool that is responsive to changes over time, simple and available on the internet.
- Parents would prefer a tool that links them with resources that fit with their child's JIA
- Pediatric rheumatologists would like a prediction tool that is reliable, accurate, well-tested and simple to use.

Table 1. Top priority features to be used to define the course of JIA according to different audiences participating in focus groups.

Disease Features	Parents	Youth	Rheum	AHP
Med requirements and side effects	✓	✓	✓	✓
Disease remission	✓*	✓	✓	✓
Pain, symptoms	✓	✓	✓	
Disease activity			✓	✓
Joint counts		✓	✓	✓
Parents global			✓	✓
Need for assistance		✓		
School attendance		✓		

* Parents were mostly concerned about flares

Discussion

All groups proposed that medication requirements and side effects, and periods of disease remission and flare have top priority in defining the course of JIA.

While clinicians prioritized disease activity measures, parents and patients raised different priorities.

Straightforward, positive terminology was preferred by most groups when describing the course of JIA to families.

The experience of parents and AHP with JIA as an unpredictable disease should be carefully considered in developing and introducing a JIA course prediction tool.

Conclusions

The top features listed in Table 1 should be given priority in defining the course of JIA.

Describing JIA course with terms such as remitting, controlled and persisting would allow meaningful communication across patients, parents and clinicians.

Ease of use, accuracy, and explanation of the tool's role in reducing uncertainty are important for a JIA prediction tool.

Conflict Disclosure

Authors of this presentation have no relevant conflicts to disclose concerning financial or personal relationships with commercial entities that may have an interest in the subject matter of this presentation: