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

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ABSTRACT. ***Objective.*** To assess which clinical features are most important for patients, parents, and clinicians in the course of juvenile idiopathic arthritis (JIA).

Methods. Forty-nine people participated in 6 audience-specific focus group discussions and 112 reciprocal interviews in 3 Canadian cities. Participants included youth with JIA, experienced English- and French-speaking parents, novice parents (< 6 mos since diagnosis), pediatric rheumatologists, and allied health professionals. Participants discussed the importance of 34 JIA clinical features extracted from medical literature. Transcripts and interview reports underwent qualitative analysis to establish relative priorities for each group.

Results. Most study participants considered medication requirements, medication side effects, pain, participant-defined quality of life, and active joints as high priority clinical features of JIA. Active joint count was the only American College of Rheumatology core variable accorded high or medium priority by all groups. Rheumatologists and allied health professionals considered physician global assessment as high priority, but it had very low priority for patients and parents. The parent global assessment was considered high priority by clinicians, medium to high by parents, and low by patients. Child Health Assessment Questionnaire scores were considered low priority by patients and parents, and moderate or high by clinicians. The number of joints with limited motion was given low to very low priority by all groups. Parents gave high priority to arthritis flares.

Conclusion. If our findings are confirmed, medication requirements, medication side effects, pain, participant-defined quality of life, and active joint counts should figure prominently in describing the course of JIA. (J Rheumatol First Release Sept 15 2014; doi:10.3899/jrheum.131536)

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Juvenile idiopathic arthritis (JIA) encompasses conditions that share chronic arthritis of unknown cause as their defining characteristic[1,2]. The course of the disease and eventual outcomes vary among and within each of the International League of Associations for Rheumatology JIA categories[3,4,5,6]. Despite the advent of effective treatments and trends toward more favorable outcomes, our ability to predict the course of JIA remains limited[7,8,9,10,11].

Currently, the course, outcomes, and response to treatment in JIA are described by focusing on 6 core variables endorsed by the American College of Rheumatology (ACR; Table 1). These variables were chosen based on the expert opinion of researchers and pediatric rheumatologists, and on the variable's statistical performance[12]. The current definition of JIA improvement is based on these variables[12], and recent definitions of inactive disease and remission use a subset of them[13]. The opinions of patients, parents, and allied health professionals about what is important in the course of JIA are less well

Table 1. Core variables currently endorsed by the ACR for the assessment of patients with JIA, and current proposed definitions for disease improvement, flare, inactive disease, and disease remission.

ACR core variables[12]	1) physician global assessment of disease activity 2) parent/patient assessment of overall well-being 3) functional ability (often assessed with the CHAQ) 4) number of joints with active arthritis 5) number of joints with limited range of motion 6) ESR (or CRP)
Definition of improvement	At least 30% improvement from baseline in 3 of any 6 variables in the core set, with no more than 1 of the remaining variables worsening by > 30%.
Definition of flare	Worsening of at least 3 of the 6 ACR core measures by at least 30% without concomitant improvement of more than 1 core measure by 30% or more.
Definition of clinical inactive disease[13]	No joints with active arthritis. No fever, rash, serositis, splenomegaly, or generalized lymphadenopathy attributable to JIA. No active uveitis as defined by the Standardization of Uveitis Nomenclature Working Group. ESR or CRP level within normal limits in the laboratory where tested or, if elevated, not attributable to JIA. Physician global assessment of disease activity score of best possible on the scale used. Duration of morning stiffness of 15 min or less.
Definition of clinical remission	Remission on medication: a minimum of 6 continuous mos of inactive disease while receiving medication. Remission off medication: 12 mos of inactive disease while not receiving any antiarthritis or antiuveitis medication.

ACR: American College of Rheumatology; JIA: juvenile idiopathic arthritis; CHAQ: Child Health Assessment Questionnaire; ESR: erythrocyte sedimentation rate; CRP: C-reactive protein.

known and were not formally elicited in selecting these 6 variables or the definitions of improvement, inactive disease, and remission.

In our study, first, we used qualitative research methods to assess which clinical features are most important for patients, parents, and clinicians in the course of JIA. Second, we also elicited their opinions about terms used to name JIA disease course and desirable attributes of clinical tools to predict JIA course.

MATERIALS AND METHODS

We conducted 6 study sessions in 3 Canadian cities between March and November 2012. Each session consisted of a focus group discussion and reciprocal interviews (participants interviewed each other). Participants were asked to address 3 questions: (1) what clinical features should be used to define JIA disease course (the experience of JIA and its treatment over time)? (2) what words should be used to describe the expected course of JIA to newly diagnosed children and their parents? (3) If we had a tool that would allow us to give better predictions of how JIA would turn out, what features of this tool would you think would be important?

We chose a qualitative research approach because this methodology allows for the gathering of complex, in-depth perspectives that are otherwise lost in formal surveys and hypothesis-driven quantitative research[14,15,16]. Our study was approved by the University of British Columbia's Behavioural Research Ethics Board.

Subject recruitment. We recruited youth with JIA (YJIA) and parents of children with JIA during regular rheumatology clinic visits. We sought study participants with different types of JIA, varied disease severity, and different disease duration. Pediatric rheumatologists (PR) and allied health professionals (AHP) were recruited by contacting their professional associations and all academic pediatric rheumatology centers in Canada. To be included, they had to have at least 30% of their current practice focused on counseling and managing patients with JIA.

Study sessions. Sessions were professionally facilitated and audience-specific. Each consisted of a focus group discussion and reciprocal interviews. This format allowed researchers to document interactions, and similarities and differences in opinion within a group. It also allowed participants to hear and consider arguments from other participants in formulating their own opinions. Participants were provided with a list of definitions for 34 JIA clinical features often recorded in cohort studies and clinical trials. These 34 items were extracted from published literature by the authors as important items in monitoring cohorts of children with JIA. For patients and parents, disease course was defined as "the experience over time related to symptoms, signs and consequences of the disease and its treatment in a person". In each session, the facilitator asked participants to review all the definitions provided, add any additional items considered important, and discuss what items were most important to them. Most groups were able to reach consensus on a number of high priority items, but did not rank all items.

Reciprocal interviews, modeled after Redelmeier, *et al*[17], were used to focus discussions at a personal level, facilitate peer interactions, and allow correlation of perceived severity of JIA course with data extracted from medical records (data not shown). Clinicians were asked to do reciprocal role-play interviews, taking the role of the parent of a child with JIA. This was particularly helpful in assessing terms that should be used in discussing disease course with families.

Focus group and reciprocal interview probes used in our study are included in the supplementary data (available online at jrheum.org). To address our secondary aims, participants also received lists of terms used to name JIA disease course and of attributes of prediction tools (supplementary data available online at jrheum.org)[18], and 2 examples of prediction tools[19,20]. A prediction tool was defined for patients and parents as "a way of using a combination of features about a person known today to provide an educated guess of what will happen years later".

Analysis. Transcripts of focus group audio recordings, detailed facilitator's session notes, participant-generated lists of high priority items, and reciprocal interview answers underwent detailed analysis as follows[21]. First, major themes discussed in each session (emerging themes) were identified

by OGR and discussed with JG. This provided interpretative context before focusing on the prioritization of items. Second, analytical tables were created for each session. These tables reported the supporting and/or counter-arguments about the relative priority of each item discussed by participants. Third, drawing on these tables, relative high, medium, low, or very low priority were assigned to each item by 2 investigators (JG, OGR). In general, high-priority items were those explicitly chosen by participants as top priority; medium priority were those that were initially identified by participants as important, but after discussion were thought less important than those in the top priority list; low priority were those that were not substantively addressed in the discussion or did not draw enough qualitative supporting arguments in our analysis; and very low priority were those that were not discussed to any extent during the session. Fourth, session summaries were discussed with all investigators. These summaries contained descriptions of emerging themes, illustrative quotes, and items listed in order of priority with the supporting rationale for their assigned priority. Finally, after all sessions had been individually examined, investigators met to discuss overall findings and key messages of our study.

RESULTS

A total of 49 people participated in 1 of the 6 focus groups and in 2 or 3 of the 112 reciprocal interviews carried out for our project. Characteristics of study participants are listed in Table 2.

Clinical features. Table 3 shows the relative priority of all clinical features discussed, according to each group. All groups agreed that the medications required for controlling the disease and the side effects of these medications were high priority features of the JIA disease course.

The number of swollen or active joints was seen as high priority by most groups, except YJIA who saw it as medium priority. Pain and quality of life were also seen as high priority by most groups, except by AHP who accorded these features medium priority. It should be noted that AHP focused on clinical features they felt predicted later outcomes. Interestingly, while quality of life assessed by the simple Quality of My Life scale was seen as high priority, the total Juvenile Arthritis Quality of Life Questionnaire (JAQQ) score was not.

With the exception of the number of active joints, ACR core variables were not given high priority across groups. The parent global assessment was given high priority by PR and AHP, medium to high priority by parents, and low priority by YJIA. Both PR and AHP considered the physician global assessment had high priority, but this was hardly discussed or given any priority by patients and parents, although they said the concept of disease activity was important. Functional ability, defined as Child Health Assessment Questionnaire (CHAQ) scores, was given low priority by patients and parents, medium priority by PR, and high priority by AHP. The number of joints with limited motion was given low to very low priority by all groups. Laboratory markers of inflammation were not included in the list of items for discussion.

As requested, study participants added other clinical

Table 2. Characteristics of study participants.

Study Session	Participants
Youth with juvenile idiopathic arthritis (Vancouver)	9 patients (7 females). 16 to 23 yrs old. Diagnosed with JIA 2 to 12 yrs earlier. Two had systemic arthritis, 2 enthesitis-related arthritis, 2 polyarthritis, and 1 each had oligoarthritis, psoriatic arthritis, or undifferentiated arthritis.
Experienced English-speaking parents (Ottawa)	10 parents (5 females, 2 couples). Their children were 6 to 15 yrs old and had been diagnosed with JIA from 9 mos to 14 yrs earlier. Four had oligoarthritis, and 1 each had enthesitis–related arthritis, psoriatic arthritis, polyarthritis, or undifferentiated arthritis. Two parents and the spouse of a third parent had arthritis themselves.
Experienced French-speaking parents (Ottawa)	5 parents (3 females, 1 couple). Their children were 4 to 11 yrs old and had been diagnosed 2 to 5 yrs earlier. All 4 children had oligoarthritis.
Novice English-speaking parents (Vancouver)	8 parents (5 females, 1 couple). Their children were 2 to 16 yrs old and had been diagnosed 2 to 6 mos earlier. Two children had oligoarthritis, 2 had undifferentiated arthritis, and 1 each had systemic arthritis, enthesitis–related arthritis, or psoriatic arthritis.
Pediatric rheumatologists (Victoria)	8 physicians (6 female). During a national professional meeting. At least 10 yrs of experience caring for children with arthritis. Practicing in 5 Canadian provinces.
Allied health professionals (Victoria)	9 professionals (all female). During a national professional meeting. At least 5 yrs of experience caring for children with arthritis. It included 5 nurses, 1 social worker, 1 occupational therapist, 1 physiotherapist, and 1 research associate occupational therapist. Practicing in 3 Canadian provinces.

JIA: juvenile idiopathic arthritis.

Table 3. Relative priority of clinical features of JIA according to different groups. Priorities were assigned to each item by 2 investigators based on review of focus group transcripts and reciprocal interview answers. High priority items were those explicitly chosen by participants as top priority; medium priority were those that were initially identified by participants as important, but after discussion were thought less important than those in the top priority list; low priority were those that were not substantively addressed in the discussion or did not draw enough qualitative supporting arguments in our analysis; and very low priority were those that were not discussed to any extent during the session. Items are listed in order of overall relative priority across all groups.

Clinical Feature	Youth with JIA, n = 9	Experienced English-speaking Parents, n = 10	Experienced French-speaking Parents, n = 5	Novice Parents, n = 8	Pediatric Rheumatologists, n = 8	Allied Health Professionals, n = 9
Medications required: The most aggressive treatments required over 5 yrs. From 1 = antiinflammatories only to 4 = biologic agents such as etanercept or infliximab +.	H	H	H	H	H	H
Medication side effects: As reported by the doctor; from no side effects at all to side effects requiring hospitalization.	H	H	H	H	H	H
Pain: Severity of pain marked by the child or parents in a line at each visit. From 0 = no pain to 10 = worst pain imaginable.	H	H	H	H	H	M
Quality of my life: The answer of the child to the following question (assisted by parent as needed): "Considering my health, my life is…" From 0 = the best to 10 = the worst.	H	H	H	H	H	M
Swollen joints/active joint count: Number of inflamed joints.	M	H	H	H	H	H
Current medications: The actual medications taken at a given point in time, for example 5 yrs after diagnosis.	H	H	H	M	M	H
Active JIA: Number of visits to the clinic where the disease was "active". JIA is called active when there are swollen joints, eye inflammation, fevers, rash or enlarged glands, the doctor thinks the disease is active, or the bloodwork is abnormal.	H	M	M	M	H	H
Parent global: The answer of the parents to the following question: "Considering all the ways that arthritis affects your child, rate how your child is doing..." From 0 = very well to 10 = very poorly.	L	M	H	M	H	H
Missing school: Missing any school because of arthritis or its treatment, except for medical appointments.	M	H	M	M	L	M
Clinical remission: At least 12 mos with inactive JIA after stopping all treatment.	H	L	L	VL	H	H
Remission on medications: At least 6 mos with inactive JIA while taking treatment.	H	L	L	VL	H	H
Symptom difficulties: Score in the JAQQ for symptoms related to arthritis or its treatment. From 1 = no difficulties to 7 = 50% or more of the time.	M	L	H	H	VL	M
Psychosocial difficulties: Score in the JAQQ for psychosocial difficulties. From 1 = no difficulties to 7 = 50% or more of the time. Psychosocial includes emotions and interactions with family, teachers, and other children.	VL	H	H	M	VL	M
Stiffness: Number of visits the child or parents report "Stiffness" because of arthritis or its treatment.	M	M	H	L	VL	M
Inactive JIA: Number of visits to the clinic where the disease was "inactive". JIA is called inactive when there are no swollen joints, no eye inflammation, no fevers, rash or enlarged glands, the doctor thinks the disease is inactive, and the bloodwork is normal.	M	L	VL	VL	H	H
Specific joints: Swelling or limitation in specific joints. For example a knee joint instead of a finger joint. Do certain joints matter more than others?	M	M	VL	M	VL	H
Uveitis*	—	M	M	—	M	H
Poor function: The score in the CHAQ. From 0 = normal function to 3 = severely affected function because of arthritis.	L	L	L	L	M	H

Table 3. Continued

Clinical Feature	Youth with JIA, n = 9	Experienced English-speaking Parents, n = 10	Experienced French-speaking Parents, n = 5	Novice Parents, n = 8	Pediatric Rheumatologists, n = 8	Allied Health Professionals, n = 9
Gross motor difficulties: Score in the JAQQ for gross motor functional difficulties. From 1 = no difficulties to 7 = 50% or more of the time. Gross motor includes walking, sitting, riding a bike.	M	M	M	M	VL	VL
Fatigue: Number of visits the child or parents report the child "Tires easily" because of arthritis or its treatment.	L	L	H	L	VL	M
MD global: The doctor's opinion of how active JIA is at a given visit. From 0 = not active to 10 = very active.	VL	VL	VL	VL	H	H
Needing help: The child or parents report need for help with dressing and grooming, arising, eating, walking, hygiene, reach, gripping and opening things, or errands and chores.	M	VL	VL	M	M	L
Flares*	—	H	H	—	—	—
Flare triggers*	—	H	M	—	—	—
PE problems: Difficulty participating in physical education class because of arthritis or its treatment.	VL	M	M	M	VL	VL
Total JAQQ: Combination of JAQQ gross motor, fine motor, psychosocial, and symptoms scores. From 1 = no difficulties because of arthritis or its treatment to 7 = difficulties more than 50% of the time.	VL	VL	VL	L	M	M
Oral corticosteroids: Number of visits the child was prescribed any form of cortisone or prednisone.	L	VL	L	VL	M	L
Nonadherence and compliance*	—	—	—	—	—	H
Joint injections: Number of joint injections required over 5 yrs.	VL	L	L	M	VL	VL
Limited joints: Number of joints with decreased movement.	L	L	VL	L	L	VL
Micrognatia: Small jaw because of previous arthritis of the jaw joints.	L	L	L	VL	L	VL
Leg length discrepancy: Difference in the length of the legs of 1 cm or more because of previous arthritis of the knee or hip.	L	VL	VL	VL	L	L
Achilles enthesitis: Inflammation where the Achilles tendon joins the heel bone at the back of the foot.	VL	L	VL	VL	VL	L
Lumbar limitation: Abnormal movement of the low back measured by the doctor.	L	VL	VL	VL	VL	L
Fine motor difficulties: Score in the JAQQ for fine motor functional difficulties. From 1 = no difficulties to 7 = 50% or more of the time. Fine motor includes writing, grasping, holding objects.	VL	VL	VL	L	VL	VL
Non-Achilles enthesitis: Inflammation where tendons other than the Achilles tendon join a bone.	VL	VL	VL	VL	VL	L
Tenderness: Number of visits the child or parents report "Joint tenderness or pain" because of arthritis or its treatment.	VL	VL	VL	L	VL	VL
Weakness: Number of visits the child or parents report "Decreased or limited strength" because of arthritis or its treatment.	VL	VL	VL	L	VL	VL
Eye drops*	—	L	—	—	—	—

+Drug brand names were used in the printed materials for focus groups, since those were the names participants were most familiar with. *These items were not included in the list provided to participants, but were added by at least 1 group during the discussion. The dash (—) means the item was not included in the list and not discussed by this group. JIA: juvenile idiopathic arthritis; H: high; M: medium; L: low; VL: very low; JAQQ: Juvenile Arthritis Quality of Life Questionnaire; CHAQ: Child Health Assessment Questionnaire.

features they deemed important. These included uveitis by experienced parents, PR, and AHP, and nonadherence and compliance by AHP. Experienced parents were particularly interested in identification of disease flares and flare triggers.

Most groups struggled with the overlap among clinical

features. It was argued that some were different ways of saying the same thing, and some were parts or components of others. For example: the Quality of My Life scale and the JAQQ seemed to aim at the same idea, and some YJIA stated that quality of life included things such as needing help, symptom difficulties, and missing school. Because of this overlap, participants sometimes argued that a particular feature should not go into the top priority list because it was a component of, or equivalent to, another feature already in the list.

Secondary aims. When discussing terms used to describe JIA course to families, all groups agreed that positive, easy-to-understand terms were preferable. Yet, this was tempered by parents and AHP stating that terms needed to be honest and direct, especially for children with more severe forms of JIA, so that the seriousness of the disease was not misjudged, potentially compromising adherence to treatment. "Active JIA", "Inactive JIA", and "Remission" were terms accorded medium to high priority by all groups. "Controlled", "Mild", "Moderate", and "Severe JIA" were seen as helpful terms by YJIA, PR, and AHP, but parents were concerned they lacked specificity and felt that the term "Severe JIA" was too pessimistic.

"Ease of use", defined as "using the tool requires little time and training," was the only tool attribute accorded high priority by all groups. "Inclusion of Guidelines" and "Consistency" were seen as important by most groups.

Developing a JIA course prediction tool was seen as a worthwhile undertaking, but participants differed in their opinions about what the tool should look like and its potential uses. Experienced parents, PR, and AHP expressed skepticism about the feasibility of developing an accurate prediction tool of JIA course at diagnosis. Reasons for this skepticism included intrinsic unpredictability of JIA, insufficiency of current knowledge, and management decisions that will change the disease course. Although prediction tools provided as examples took the form of risk calculators (i.e., Centor and Framingham scores)[19,20], more creative formats were envisioned during the discussions. Experienced parents argued that the tool should be a checklist they could use to detect JIA flares and flare triggers; AHP visualized an educational tool about the course of JIA that could be used in counseling families; and PR suggested a road map showing decision points as forks in the road, and not just the destination or final outcome.

Additional details of the prioritization of terms and tool attributes are included in the supplementary data (available online at jrheum.org).

Emerging themes. Analysis of transcripts revealed several emerging themes important in contextualizing the discussions that took place and the resulting prioritization of items (Table 4). YJIA were concerned about making their views heard, and thus gave lower priority to standard questionnaires and scores that did not allow much space for them to express themselves. Similarly, parents also voiced dissatisfaction with numerical indicators of outcome.

Experienced parents still recalled how shattering it had been when receiving a JIA diagnosis and felt that dealing with JIA was a time-consuming roller coaster. This likely influenced their interest in knowing what precipitated flares and how to prevent them. For novice parents, the recent diagnosis was a shocking experience and prioritizing clinical features was a very difficult task. They were just beginning to come to terms with the nature of the disease and what it would mean for their child's future. Experienced and novice parents highlighted their role in monitoring their children's disease, and this may be why they selected the parent global assessment as an important feature.

PR discussed in depth how to use indices and scores to reflect the course of JIA. AHP emphasized their role in educating families about JIA and some stated it was important to say that JIA is unknown and unpredictable, to avoid offering false hope.

DISCUSSION

Our study describes the opinions of groups of Canadian patients, parents, and clinicians about what matters most in the course of JIA. Their priorities often differed from traditional priorities reported in the literature, and there were important similarities and differences among groups.

The most obvious similarity among groups was that medication requirements and medication side effects were considered very important in describing the course of JIA. This suggests that a qualitative change in how we describe disease course may be needed, because traditional descriptions have focused on features of the disease itself, with relatively little attention to required treatments and side effects. The risk of side effects needs to be balanced with medication-induced improvements. Burnett, *et al*[22] found that parents of children with JIA favored effective treatments that reduced pain and improved functioning despite their risk of side effects.

Most patients, parents, and clinicians in our study agreed on the importance of the number of active joints, pain, and participant-defined quality of life. This finding is consistent with previous studies[23,24,25,26,27,28,29,30,31] and, if confirmed in other populations, would argue for the inclusion of pain and quality of life as core features in describing the course of JIA[32].

Study groups differed in the significance accorded to the ACR core variables. While PR and AHP considered active joint count, parent global, physician global, and CHAQ to have medium to high priority, patients and parents only agreed on the importance of the active joint count. Despite its low rating by patients and parents, in our view, the physician global assessment should not be discarded from research studies and clinical trials as our study and others show it is important for clinicians[33,34]. Erythrocyte

Table 4. Emerging themes important in interpreting the prioritization of clinical features by study participants.

Group and Theme	Illustrative Quote
YJIA: My experience with juvenile arthritis does not fit well on a scale. Youth with JIA expressed dissatisfaction with scales and questionnaires as the main way to assess their experiences with juvenile arthritis; they felt that their own words were more appropriate to convey their JIA situation.	"…It's one thing for your parents…or for a physician or someone to write down on a scale, like 'Do you feel like you are maybe a 5 out of 10 today?' but that's maybe good for children who are really small and can't vocalize that themselves, but the problem I have with scales like that is that it takes away a lot of your own ability to say how you're really feeling or how to put it to your own words."
EEP: Arthritis is a time-consuming roller coaster. Many experienced English-speaking parents initially thought the disease would eventually go away, only to realize this was not the case. While they knew this was a chronic disease, they did not anticipate the disease would fluctuate markedly and/or unexpectedly. Many Experienced English-speaking parents described their experience with the disease as a roller coaster. Some expressed frustration and despair at the reality that they had to deal with it for long periods of time without a break.	"I think over time, I become more comfortable. Not really, because… […] You can digest it, you research it, you read about it. You have all the information, but it's still a roller coaster ride for 8 yrs now, so…"
EEP: An orientation map or monitoring checklist may be more helpful than a prediction tool. Experienced English-speaking parents expressed the desire to have a tool that would help them anticipate some of the challenges (i.e., flares, flare triggers) their children would face. Some Experienced English-speaking parents spoke of the need to develop a monitoring "checklist" or an orientation "map" rather than a "prediction tool". These instruments were often understood as tools that would help them measure or assess daily disease status and anticipate needs (in "logs" or "journals"), as well as connect/direct them to appropriate resources. It was also mentioned that a tool that would be relevant for all its users (or different audiences) would be useful.	"Yeah, but just the statement of…Like when you get diagnosed and you say, '…75% grow out of it at this age and then 25% don't,' or whatever, that's…I don't think that's enough information…But if there's more mapping for the different types to kind of say… 'Okay, if this is what we've diagnosed your child as having this type of juvenile arthritis, then this is kind of what you can expect,' you know?" "What might be helpful is for each person to develop a kind of a checklist. Once the disease is established and you know what you're kind of looking at, these are the 5 things that she can't do when she's not doing well."
NEP: Why us? Are you sure this is arthritis? Novice English-speaking parents were still processing their children's juvenile arthritis diagnosis. Many expressed shock, denial, and disbelief. Their first reaction had been to ask themselves why this was happening to them.	"Right now, everything is so fresh and so new. Like right now, I'm an emotional roller coaster. Even just sitting here listening to the stories, it's emotional, like I cry a lot at home. I cry looking at the things other children are doing that my son sometimes is limited with. And it's very scary, you know?"
PR: How we crunch numbers matters in capturing the complexity of juvenile arthritis. Pediatric rheumatologists devoted detailed discussions to discern what kind of measurements or calculations would actually capture "disease course". It was thought that neither averages nor cumulative numbers (e.g., number of visits with active disease over 5 yrs) provided a full account of what happened during the course of JIA. For example, its continuity or intermittency, its severity, its frequency, length and presence of periods of activity and inactivity, its recurrence, or the bare existence of swollen joints.	"…I'm going back and revising in my head all the things that I thought, is that all of those things like quality of life and parent global and MD global and swollen joints, this suggests that all of those are averages over 5 yrs as opposed to a map of…which is how I would think of using them, more in a map of the course of the disease. So if you were a 10 in Yr 1, and a 2 in Yr 2,, and a 5 in Yr 3, and an 8 in Yr 4, and a 0 in Yr 5, that would average out to…I don't know what, 4 over 5 yrs. But it describes more of a cyclic course than it does a persistent 4 over 5–yr period. And I think that's information that I would find useful, is not just the average, but the variability in each of those things."
AHP: Juvenile arthritis is unknown and unpredictable, isn't it? Allied health professionals emphasized that in order to not offer false hope, they would highlight the fact that juvenile arthritis was an unknown and unpredictable disease in their discussions with patients and parents. The idea that JIA was variable, fluctuating, and not fully determined right at diagnosis also came across in the role-play interview data.	We have to give them hope, but I think we have to be very upfront and honest and say, 'You know, it's unpredictable. There are unknowns, and this is severe juvenile arthritis.' You can follow that with a 'But we have some excellent treatments that we know will offer significant results.' But…you have to tell them it's severe because if they don't hear that, then where are they going to go in terms of, 'Oh, well, it's fine. Everything will be hunky-dory. I don't need to take this medication that will cause my child cancer,' because that's what they always come back with."
AHP: What do you mean by defining the JIA course? Are you asking us to identify predictors? Allied health professionals had some difficulty understanding the aims of the session and in the end many of them appeared to conceive of the first question as asking for the most critical determinants or "predictors" of good and bad disease outcomes later on in the disease. The results of our study session were filtered through this somewhat more dominant lens of wanting to choose items that would predict outcomes (predictors), as opposed to items that would define or describe important features for the course (descriptors).	"Disease course is not something that you establish at the start, and you end up 10 yrs later with a result. It's going to change all the time, the disease. That's kind of why…you know, when we're thinking, 'Is it at the start? Is it later on? All decisions over time will have an impact.' That's why I'm kind of…can you really look at some things that will predict overall?"

JIA: juvenile idiopathic arthritis; YJIA: youth with JIA; EEP: experienced English-speaking parents; NEP: novice parents within 6 months of their children being diagnosed with JIA; PR: pediatric rheumatologists; AHP: arthritis health professionals, including nurses, social workers, and therapists.

sedimentation rate was not included in the list of features provided to participants, and thus we are unable to comment on its priority.

It could be argued that the question we asked study participants (what clinical features should be used to define the course of JIA?) has a different purpose than the ACR core variables (to provide standard outcome measures to assess biologic response and treatment efficacy)[12]. We agree that standard measures are essential for research in JIA. Yet, if our findings of low prioritization of ACR core variables by patients and parents were confirmed, it would mean that treatments for JIA can be deemed beneficial because they improved measures of little relevance to patients and parents. From their point of view, it would seem illogical that improvements in pain and quality of life are not considered when confirming that arthritis treatments work. In our opinion, it is appropriate to ask that criteria used to define improvement and demonstrate treatment efficacy in JIA include the issues that matter most to patients and their parents.

It is possible that the discrepancies between the ACR core variables and the priorities reported in our paper are not as profound as our findings might suggest. For example, it could be argued that the parent/patient assessment of overall well-being included in the ACR core set is a good proxy for quality of life. Although this may be a reasonable assumption, the question used in most studies to assess overall well-being (Considering all the ways that arthritis affects your child, rate how your child is doing.) was included in our list (parent global assessment), and was seen as different from directly asking the child how their health has affected their quality of life. In general, assessing the conceptual equivalence between ACR core variables and the priorities reported in our present study would require (1) demonstration that patients, parents, and clinicians agree with the proposed equivalence of concepts; and (2) empirical demonstration of close correlation of the respective measures in patients over time.

One other interesting difference among groups was that "Remission on Medications" and "Clinical Remission" had low priority for parents, while they were high priority for patients and clinicians. We believe this is partly explained by the high priority given by parents to disease flares, the contrary to remission. A similar explanation could be proposed for the differences in the priority of "Active Disease" and "Inactive Disease"; while parents considered "Active Disease" had moderate priority, "Inactive Disease" was barely discussed. It should be pointed out that Consolaro, *et al* have shown that parents and physicians have somewhat differing views about what constitutes inactive disease[33].

Study strengths and limitations. Our study provides a summary of the opinions of groups of Canadian patients, parents, and clinicians about the relative priorities of JIA clinical features, but does not provide estimates of the proportions of patients, parents, or clinicians endorsing each opinion. The latter would require a followup survey with a larger sample. We included participants from different JIA categories, degree of severity and length of experience with the disease, and clinicians with diverse background and location of practice. Participants from Canadian cultural or ethnic minorities were included, but their views were not analyzed separately. The opinions of people in other countries may differ. Additional surveys or focus groups are needed to confirm whether our findings hold across populations.

Caution is warranted in interpreting differences in priorities among study groups for at least 3 reasons: (1) it is possible that an item received little discussion by a group (and, thus, was assigned a low or very low priority) because participants felt the item overlapped with or was embedded into another important item, and not because the item itself was unimportant; (2) it is possible that more in-depth knowledge of an item would convince a group of participants to change their mind about its priority (for example, if participants had more intimate knowledge of the components of the JAQQ and how carefully the components were selected, they may accept the JAQQ as a better reflection of quality of life than a simple direct question); and (3) the differentiation of high priority items was discussed in-depth during the sessions, but the distinctions between moderate, low, and very low priority were made by researchers analyzing transcripts and interview responses; thus, the difference between 1 group giving a moderate priority to 1 item and another group giving it a low priority may not be substantial.

One of the strengths of our qualitative design is that it allows for unexpected results to emerge. We found that conventional terms used to describe clinical features and disease course were often used by patients and parents with a different meaning. Sometimes there was clear disagreement between participants' understanding of a concept and its intended use in scientific reports. For instance, when patients said that the effect of arthritis on their quality of life was very important, they did not mean that the JAQQ score was very useful. Patients clearly preferred to use their own words (qualitative) instead of standardized scores and scales (quantitative) developed for rigorous measurement. These discordances reflect the differing ways in which qualitative and quantitative studies detect and express clinical data, and how they may supplement each other[14,15,16].

With only 1 study session per group, we cannot assure thematic saturation[21], or that an additional study session would result in the same emerging themes. However, our study was not designed to reach thematic saturation, but to allow thoughtful prioritization of clinical features.

Implications for practice. In our opinion, the points of view of patients and parents should be systematically considered in designing JIA care plans, outcome measures for research

and clinical care, and in developing prediction tools. If our findings of low prioritization of ACR core variables by patients and parents are confirmed in other settings, it would mean that definitions of improvement, inactive disease, and remission derived from these variables have little relevance for them. To make them more relevant, core variables would need to include measures of pain and quality of life, and perhaps exclude less relevant measures, such as the number of joints with limited movement or the CHAQ score. Simple, positive terminology should be used in discussing JIA disease course with families, and innovative ways of describing the course of JIA in verbal narratives, in addition to numbers, may help better engage patients and parents in meaningful decision-making. This could be achieved with the use of clinical vignettes, analogous to the ones used in case-based learning in medical schools.

Patients, parents, and clinicians participating in our study identified medication requirements, medication side effects, pain, participant-defined quality of life, and active joint counts as top priorities in the course of JIA. Some ACR core variables were accorded low priority by patients and parents. If our findings are confirmed in other populations, this would suggest that current definitions of JIA improvement, inactive disease, and remission have little relevance for patients and parents, and that their relevance could be increased by explicitly including changes in the child's pain and quality of life into those definitions.

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ONLINE SUPPLEMENT

Supplementary data for this article are available online at jrheum.org.

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