



What Is the Relative Priority of the ACR Pediatric Core Set Measures for Youth With Juvenile Idiopathic Arthritis and Their Parents?

Funded by:



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Background/Purpose

The American College of Rheumatology (ACR) has endorsed a core set of six variables to assess the course of Juvenile Idiopathic Arthritis (JIA) and the impact of treatment: active joint count, limited joint count, physician's global assessment of disease activity, functional ability, parent/patient assessment of well being and ESR.

We sought to determine the relative priority given by patients, and by parents, to the core set variables in relation to other features used to describe the course of JIA.

Methods

- Four separate study sessions consisting of focus group discussions and reciprocal interviews (participants interview each other)
- A list of 34 clinical features often used for the monitoring of JIA (including the ACR core set) was discussed
- Participants were asked to add any other relevant features, and discuss the features' relative priority in describing the course of JIA.
- Focus groups were professionally facilitated, recorded, and transcribed. Reciprocal interview responses were reported in standard forms.
- Transcripts and interview responses underwent content analysis by two investigators; themes and priority rankings were discussed with all co-authors.

Participants

Youth: 7 females and 2 males aged 16 to 23 years old; 2 to 12 years after their diagnosis (1 oligo, 2 poly, 2 systemic, 2 ERA, 1 psoriatic, 1 undifferentiated).
 English-speaking parents: 5 females and 5 males (2 couples); 9 months to 14 years after their child's diagnosis (4 oligo, 1 poly, 1 ERA, 1 psoriatic, 1 undifferentiated).
 French-speaking parents: 3 females and 2 males (1 couple); 2 to 5 years after their child's diagnosis (4 oligo).
 Novice parents: 5 females and 3 males (one couple); 2 to 6 months after their child's diagnosis (2 oligo, 1 systemic, 1 ERA, 1 psoriatic, 2 undifferentiated).

Findings

- Priority of core set measures is shown in Table 1. Top priorities are shown in Table 2.
- The physician global assessment was not discussed to any extent, although the concept of disease activity was considered important.
- Youth felt visual analogue scales and standardized questionnaires did not reflect their experiences with JIA.
- Experienced parents were particularly interested in disease flares and flare triggers.
- Novice parents were still coming to terms with the diagnosis and found the prioritizing task difficult.

Table 1. Priority of the ACR Core Set Measures according to patients and parents

ACR Core Measures	Youth with JIA	English-speaking Parents	French-speaking Parents	Novice Parents
Active Joint Count	medium	high	high	high
Parent Global Assessment	low	medium	high	medium
Functional Ability (CHAQ)	low	low	low	low
Limited Joint Count	low	low	low	low
Physician Global Assessment	very low	very low	very low	very low
ESR	not listed	not listed	not listed	not listed

Table 2. Top priority JIA features according to patients and parents

Feature	Youth with JIA	English-speaking Parents	French-speaking Parents	Novice Parents
Pain	high	high	high	high
Quality of Life	high	high	high	high
Medications Required	high	high	high	high
Medication Side-effects	high	high	high	high

Conclusions

Active joint count was the only ACR core set measure deemed highly relevant by youth with JIA and parents of children with JIA as a central feature of the disease course.

To increase relevance to patients and parents, pain and quality of life indicators should be included as core set measures.

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: