

Commentary on “Child and Caregiver Beliefs of Importance of Physical Function and Quality of Life in Juvenile Idiopathic Arthritis: A Survey Study”

“How could I apply this information?”

Disease monitoring in children with juvenile idiopathic arthritis (JIA) consists mainly of examining joint symptoms, pain levels, joint imaging, and laboratory markers. This core set of measures is developed by physicians and researchers, without input from children with JIA and/or caregivers.¹ By incorporating child and caregiver beliefs about important measures, children with JIA and their caregivers will receive more meaningful, real-life information about their disease. Information about physical activity and quality of life is considered almost as important by children with JIA and caregivers as the core set of measures. This indicates that clinicians should also provide specific information about children's physical activity and quality of life. In doing so, children with JIA and their caregivers will receive more practical and meaningful information about physical activity participation and/or quality of life.

“What should I be mindful about when applying this information?”

The study team designed a survey with 4 domains: (a) medication, (b) gait and physical activity, (c) objective measures, and (d) well-being. Whether children with JIA and/or caregivers were consulted in the development of this survey is unclear; however, the importance of incorporating child and caregiver beliefs was the main motive for this study. Mean scores of importance are described for all domains, but differences among families can be present. For example, information about physical activity is considered important in some families but might not be important in others. Instead of just providing information about all domains, clinicians should ask which domains are considered important by the child and the caregiver in order to give more individualized advice. Future studies should investigate whether clinicians who match with family preferences are more positively evaluated. The effect of this individualized advice can be investigated by measuring change in children's daily behavior.

REFERENCE

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