

# Do children with Juvenile Arthritis and their parents agree about their quality of life?

childhood  
disability  
LINK



## Glossary

**Health Related quality of life:** How an individual views their health and functioning and the extent to which they are satisfied with their life overall.

## Summary

Juvenile idiopathic arthritis is a common disease in childhood and a leading cause of childhood disability. An important measure used to evaluate outcomes in juvenile idiopathic arthritis is health-related quality of life. The aim of the study was to determine the level of agreement between the perceptions of children with juvenile idiopathic arthritis and their parent's perceptions of their child's quality of life. A group of patients and their parents, who attended the juvenile idiopathic arthritis clinic at the Montreal Children's Hospital, completed the Juvenile Arthritis Quality of Life Questionnaire. The results were that parents seemed to be aware of their children's perception of quality of life except for activities involving fine motor function (e.g. writing, cutting paper with scissors, turning the handle to open the door, fastening shirt or coat buttons). This could be due to the fact that some of these activities are mostly done at school or are daily activities that are done privately. The authors also found that parents and children had stronger agreement with respect to the presence of pain if the children had a more severe disease. This may be because children with more severe disease have more pain and complain more often, or that parents are more attentive to children with severe disease.

## What families and clinicians should know

Evaluating the perceptions of children over nine years old about their quality of life and pain can be done easily in a clinical setting by a health care professional. Using a validated tool with both parents and children separately will help health care professionals gather children's opinions without being biased by those of their parents. A better understanding of the entire family's perceptions may benefit the therapeutic relationship between the service provider and the patient, and more effectively address the concerns of children with disabilities and their families.

## Reference

[Toupin April, K., Feldman, D., Platt, R.W., & Duffy, C.M. \(2006\). Comparison between children with juvenile idiopathic arthritis \(JIA\) and their parents concerning perceived quality of life. \*Quality of Life Res\*, 15, 655-661.](#)

