

Using Patient-Reported Outcome Measures to Capture the Patient's Voice in Research and Care of Juvenile Idiopathic Arthritis



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KEYWORDS

- Juvenile arthritis • Health outcomes • Patient-centered care • Self-report
- Quality of life • Pediatric rheumatology • Chronic disease
- Comparative effectiveness research

KEY POINTS

- Incorporating patient-reported outcome (PRO) measures into routine clinical care of patients with juvenile idiopathic arthritis can help facilitate movement from physician-centered to patient-centered care.
- PRO measures relevant to juvenile idiopathic arthritis provide information germane to evaluating treatment outcomes and comparative effectiveness of therapies.
- Valid and reliable PRO measures are available that capture the experience of juvenile idiopathic arthritis from the perspective of patients and parents.
- Length, age, potential discordance between parent and child responses, and clinical validity are among the issues that need to be considered when selecting PRO measures.

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INTRODUCTION

Juvenile idiopathic arthritis (JIA) is the most common cause of acquired disability in the United States and the fifth most common chronic childhood disease.¹ Children with JIA experience an unpredictable disease course, with periods of improved disease control intermixed with episodes of flare.^{2–4} Over the past decade, assessing patient-reported outcomes (PROs) has become increasingly important in the context of clinical care and research centered on JIA.^{5–7}

Several factors are driving the evolution of PRO measures and their adoption within pediatric health care and research efforts. Studies in the general population indicate that PROs are predictive of future health care utilization for adults and children.^{8–10} Measures of health behaviors and mental health status—domains suitable to PRO assessment—can predict future disease activity, as may levels of stress, adequacy of sleep, and availability of coping supports.¹¹ These issues are often reported by patients; however, they are not captured by routine clinical measures. At a system level, capturing a broad range of information about symptoms, side effects, and treatment outcomes is thought to contribute to more patient-centered care, improved patient experience, and potentially better treatments, particularly when this information is used to assess comparative effectiveness. Recognizing this, infrastructure has been developed to support patient-centered outcomes research. In addition, the development and validation of PROs has been prioritized through federal initiatives and investment.^{12,13} Capturing the knowledge and voice of patients through high-quality, standardized, and validated measures may provide information to guide interventions and improve disease trajectories.

In this review, the authors provide an overview of the major domains of PRO assessment in JIA (pain, health-related quality of life, physical functioning and medication side effects, and commonly used measures in these domains) and the rationale for incorporating PROs into JIA clinical care and research.

JUVENILE IDIOPATHIC ARTHRITIS

Currently there are 7 categories of JIA as defined by the International League of Associations for Rheumatology's classification criteria.¹⁴ The JIA subtypes vary with regard to associated clinical features, laboratory studies, and severity of disease; however, the common clinical feature across the categories of JIA is arthritis in one or more joints presenting before 16 years of age. Like adult patients with arthritis, pediatric patients with arthritis experience inflammation of their joints leading to pain, swelling, stiffness, and loss of range of motion. Unique to pediatrics is the impact these symptoms can have on physical development (eg, learning to walk) and social development (eg, attending school, playing sports). Appropriate assessment of pediatric patients' experience with arthritis is crucial to understanding the impact of the disease on patients, their families, disease course, and outcomes.

DOMAINS OF PATIENT-REPORTED OUTCOME MEASURES

Examples of generic and JIA-specific PROs by measurement domain are provided in [Table 1](#). When selecting a particular PRO measure for clinical or research use, in addition to considering whether a given domain is represented by a generic or disease-specific measure, factors such as length, target age for administration, response format, and recall period may be relevant.

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