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Measures of Pediatric Function and Physical Activity in Arthritis

Anna E. Greer¹ and Maura D. Iversen² 

INTRODUCTION

Physical function can be assessed through physical examination with the use of performance-based measures and patient-reported outcome measures (PROMs). Each form of assessment provides a unique contribution to the understanding of the impact of rheumatologic conditions on the patient. PROMs of physical function (PF) are an important component of the assessment of children with arthritis and have been included in the recommended core set of measures for childhood arthritis and musculoskeletal conditions. These measures provide the child's or parent's perspective of function within the context of daily living. Measures of PF include both generic measures, which are designed for use across a spectrum of diseases and within healthy individuals, and disease-specific measures, which are developed intentionally for children with a rheumatologic or musculoskeletal condition. Most PF PROMs include items that relate to daily functional activities, but not all include aspects of daily living, play, and recreation, which are activities essential to the physical, social, and emotional development of children.

The use of PROMs for children with arthritis is influenced by many factors. First, pediatric rheumatologic conditions are heterogeneous. For example, juvenile idiopathic arthritis (JIA) has seven established subtypes, including oligoarticular, systemic, polyarticular rheumatoid factor (RF)-positive, polyarticular RF-negative, psoriatic, enthesitis-related, and undifferentiated arthritis (1). Each subtype has distinct clinical features and differing ages of onset. Other diseases, such as juvenile idiopathic inflammatory myositis (IIM) and systemic lupus erythematosus (SLE), also vary in clinical presentation. In diseases with an early age of onset, children's cognitive abilities will limit the use of self-report, requiring the use of proxy respondents (parent or guardian). Additionally, the performance of PROMs within JIA subtypes is variable (2), and measures are less available for the transition from childhood to adulthood. Using the International Classification of Functioning, Disability, and Health developed by the World Health Organization,

the measures (3–12) described below include the following domains: impairment (pain), activity limitations (activities of daily living [ADLs]), participation restriction, and overall health status (1,2) for use in children with JIA, juvenile IIM, and other musculoskeletal conditions. Some of these PROMs are generic measures of PF (the Patient-Reported Outcomes Measurement Information System-Physical Function Scale [PROMIS-PF], Pediatric Outcomes Data Collection Instrument [PDOCI], and Activity Scale for Kids [ASK]), whereas others have been developed specifically for children with juvenile arthritis (the Juvenile Arthritis Functional Assessment Scale [JAFAS] and Child Health Assessment Questionnaire [C-HAQ]) and for children with musculoskeletal conditions (the Knee Osteoarthritis Outcome Survey for Children [KOOS-Child] and International Knee Documentation Committee Subjective Knee Evaluation Form in Children [Pedi-IKDC]).

CHILDHOOD HEALTH ASSESSMENT QUESTIONNAIRE

Description

Purpose. Singh et al (8) developed the C-HAQ to examine functional health status in children (ages 1 to 18 years) with JIA. The C-HAQ has since been evaluated in a variety of conditions, including in children with chronic musculoskeletal pain, juvenile dermatomyositis (DM), juvenile IIM, and SLE (13–17). The C-HAQ is a core set measure recommended by the international research networks in pediatric rheumatology (the Paediatric Rheumatology International Trials Organization [PRINTO]) (18).

Content or domains. The C-HAQ includes a disability index, which assesses the following eight domains of PF: dressing and grooming, arising, eating, walking, hygiene, reach, grip, and activities. The disability index is supplemented with two visual analog scales (VAS) as follows: one for pain (the discomfort index) and one for global assessment of overall well-being (the health status index).

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Number of items. The disability index includes 30 items. The discomfort index and health status index add one item each to the tool.

Response options/scale. Each item within the C-HAQ disability index is scored on a four-point scale (0 = without any difficulty, 1 = with some difficulty, 2 = with much difficulty, and 3 = unable to do). Respondents are prompted to indicate if assistance or aids are needed to complete each task. Reporting the use of assistance or aids within a domain sets the score to a minimum of two for that domain. Activities that the child is unable to do because he/she is too young are marked as not applicable (N/A) for age.

Recall period. Respondents are asked to consider the completion of tasks within the past week.

Cost to use. There is no cost when using the tool for research purposes.

How to obtain. The C-HAQ can be obtained by contacting Gurkirpal Singh (gsingh@leland.stanford.edu) or via websites such as <http://www.niehs.nih.gov/research/resources/collab/imacs/diseaseactivity.cfm>.

Practical application

Method of administration. The C-HAQ is typically administered via paper and pencil using self-report for children aged 8 years or older and proxy report (eg, parent or guardian) for children less than 8 years of age. The C-HAQ is sometimes administered via interview, particularly when it is being completed for research purposes (19). Geerdink et al (20) developed a digital version of the C-HAQ for the purpose of systematic monitoring in clinical settings. The digital version was found to be both reliable and user friendly (20).

Scoring. Within each of the eight domains, the item with the highest disability score determines the score for that domain. The global disability index is then obtained by calculating the mean of the eight functional domains, with a range of 0 to 3. The two VAS items (the discomfort index and the health status index) are measured on separate 15-cm scales. The distance from the left end of the scale to the respondent's mark is measured and multiplied by 0.2 to calculate the score, with a possible range of 0 to 3. Additional information on scoring can be found at https://www.niehs.nih.gov/research/resources/assets/docs/chaq_instructions_508.pdf.

Score interpretation. The disability index score ranges from 0 (no disability) to 3 (disabled). A higher score indicates a greater disability. This is a criterion-referenced test; however, Dempster et al (21) found that the median C-HAQ scores

corresponding with mild, mild to moderate, and moderate disability were 0.13, 0.63, and 1.75, respectively.

Respondent time to complete. The time to complete the C-HAQ is 5 to 10 minutes.

Administrative burden. The administrative burden is low because no special equipment or training is needed to administer the C-HAQ. It takes approximately 2 minutes to score.

Translations/adaptations. Two alternate versions of the C-HAQ exist (22). Groen et al (23) studied one of these alternative versions of the C-HAQ, the C-HAQ-38, to address limitations related to ceiling effects when working with high-functioning patients with JIA. The C-HAQ-38 includes the addition of eight items, which ask respondents to indicate the amount of difficulty performing tasks more challenging than those included in the original list of 30 tasks. The other alternate version of the C-HAQ, the VAS_{CHAQ}, was modified from the C-HAQ-38 by removing the consideration for aids and devices or help, using response options in which questions are asked in relation to the child's peers, and using a 10-cm visual analog rating scale for each question.

The C-HAQ has been translated and culturally adapted for use in more than 30 countries, including Argentina, Austria, Belgium, Brazil, Bulgaria, Chile, Croatia, Czech Republic, Denmark, Finland, France, Georgia, Germany, Greece, Hungary, Israel, Italy, Korea, Latvia, Mexico, Netherlands, Norway, Poland, Portugal, Russia, Slovakia, Spain, Sweden, Switzerland, Turkey, the United Kingdom, Yugoslavia (19), Saudi Arabia (24), and Costa Rica (25) (Table 1).

Psychometric information

Floor and ceiling effects. The main limitation of the C-HAQ is the potential for a ceiling effect, particularly when assessing functional improvements among higher-functioning children (ie, those scoring closer to zero). Several authors have developed revised versions of the C-HAQ to address the ceiling effect. Recommendations to avoid a ceiling effect and improve discriminant validity include removing 12 redundant items (26), ignoring the domain structure and the use of aids and assistance (13,26,27), and using the C-HAQ-38, which includes eight additional items examining respondent's ability to complete more challenging tasks (23).

Reliability. Internal consistency has been demonstrated among children with JIA with Cronbach's α ranging from 0.88 to 0.96 (8,26,28–30). Takken et al (26) evaluated shorter versions of the C-HAQ disability index and found good internal consistency for both the 29-item and 18-item versions (Cronbach's $\alpha = 0.93$ for both). Among children with juvenile IIM, there were

significant item-total correlations ranging from 0.35 to 0.81, with only four items with a correlation coefficient of less than 0.50. Each C-HAQ domain also correlated well with the total C-HAQ ($r = 0.59-0.84$) (14).

For the test-retest reliability, which was studied at a 2-week interval, *t*-tests revealed virtually identical disability index scores measured on the two occasions (0.96 versus 0.96; $P > 0.9$; Spearman's rank correlation coefficient = 0.8; $P < 0.002$) (8). Stephens et al (31) examined test-retest reliability at 2 to 6 weeks among children with JIA and found very high reliability (intraclass correlation coefficient [ICC] of 0.82). For patients with juvenile IIM and less than a 10% change in VAS of overall illness severity, the ICC was 0.96 (17).

Several studies have examined the correlation between C-HAQ disability index scores from questionnaires administered to parents and from questionnaires given to their children. All correlations were moderate to strong ($r = 0.54-0.84$; $P < 0.05$), demonstrating good interrater reliability (8,21,32,33).

Validity. The face validity of the instrument was first evaluated by a group of 20 health professionals and the parents of 22 healthy children (8).

To establish convergent validity, C-HAQ scores were compared with a variety of other PF measures. Van Mater et al (34) conducted a systematic review of studies published between 1947 and 2010 that examined the validity of the C-HAQ and found moderate correlations of the C-HAQ with the active joint count (median correlation of 0.45 from seven studies) and limited range of motion (ROM) (median correlation of 0.49 from nine studies). The C-HAQ was most strongly correlated with the parent/patient assessment of global well-being (median correlation of 0.54 from six studies). Since this systematic review, Sontichai and Vilayuk (35) identified a good correlation between the C-HAQ disability index and the patient's global assessment, physician's global assessment, and 27-joint Juvenile Arthritis Disease Activity Score in all JIA subtypes during active disease ($P < 0.05$) but a poor correlation between the C-HAQ disability index and disease activity variables during inactive disease.

Regarding construct validity, Pouchot et al (36) examined the validity of the C-HAQ in the following two age groups: children aged 10 years and younger and children older than 10 years of age. They found that the difficulty of eight of 30 items of the C-HAQ depends on the responder's age. However, the impact of this age-related variation on the C-HAQ disability index score remained low (-0.25). As such, the authors concluded that the C-HAQ design and scoring system remove most of the expected bias related to physical development (36).

Responsiveness. C-HAQ responsiveness is variable in children with JIA, with effect sizes ranging from 0 to 0.5 (27,32,37–40), and responsiveness is better among children with polyarticular JIA

than those with oligoarticular JIA (34). In a study examining three versions of the C-HAQ, the C-HAQ, $VAS_{\text{C-HAQ}}$, and C-HAQ-38 all demonstrated strong responsiveness when using self-report and proxy report. The $VAS_{\text{C-HAQ}}$, however, was found to be approximately 25% more responsive than both the original C-HAQ-30 and the C-HAQ-38 (41). In a study of children with juvenile IIM enrolled at diagnosis, the responsiveness coefficient was 0.90 (17).

Minimally important differences. Among 92 families with a child with JIA, the minimally clinical important difference (MCID) for improvement of the C-HAQ was 0.188 at most; the MCID for worsening was at most +0.125 (42). The authors concluded that the C-HAQ is relatively insensitive to important short-term changes in children with JIA. In children with juvenile IIM considered by their physician to have improved over 6 months, the C-HAQ showed a standardized response mean (SRM) of 1.3 (43).

Generalizability. The C-HAQ has been validated for use with other disease conditions that impact PF among children, including juvenile DM (17), active juvenile SLE (16), juvenile IIM (17), and cerebral palsy (CP) (44), and with generalized musculoskeletal pain.

Use in clinical trials. The C-HAQ can be used to examine the natural history of disease as well as improvements in PF in children with JIA and juvenile IIM after participation in exercise training interventions (45) (Table 2).

Critical appraisal of overall value to the rheumatology community

The C-HAQ's major strength is its multidimensionality, including eight domains of PF. In addition, the C-HAQ is brief, simple, and easy to administer and score. The C-HAQ is the most widely used outcome measure by the rheumatology community and is included as a pediatric rheumatology core set measure for JIA, juvenile DM, and SLE. The C-HAQ has been culturally adapted for use in more than 30 countries and is useful for both clinical and research purposes. Bekkering et al (28) demonstrated no advantages of a performance test of PF as opposed to the C-HAQ to measure functional disability in children with JIA.

The major limitation of the C-HAQ is the potential for a ceiling effect; the scale is less sensitive to milder levels of disability. Modified versions include eight high-level functional items to address the ceiling effect and have removed the items referring to the use of aids and devices for activities. The revised version allows for more normalized scores and demonstrated better psychometric properties. Dempster et al (21) suggested that clinicians as well as researchers consider a minimum improvement

of 0.13 in C-HAQ scores to indicate functional improvement in children with arthritis.

Summary/recommendations

The C-HAQ is one of the most often used PROMs of PF among children with JIA and other pediatric rheumatology conditions. The C-HAQ and its revised versions demonstrate good reliability, validity, and responsiveness, suggesting its usefulness in clinical decision-making and in research. They are simple, brief, easy to use, and have been adapted for use in over 30 countries. The original C-HAQ is limited by its ceiling effect. The revised versions demonstrate better psychometric properties and, thus, are preferred to the original C-HAQ (13,23,26,27).

JUVENILE ARTHRITIS FUNCTIONAL ASSESSMENT SCALE

Description

Purpose. The JAFAS was developed by Lovell et al (5) as the first normalized measure to assess disability in children with JIA ages seven years and older in clinical settings. The JAFAS was developed for use in the US Bureau of Maternal and Children Health and Resources Development Project.

Content or domains. The JAFAS requires the assessor to observe the child performing 10 ADLs deemed difficult for children with arthritis to perform (eg, getting out of bed, dressing, picking an object up off the floor).

Number of items. The JAFAS includes 10 items.

Response options/scale. The therapist observes the child performing activities and records the time it takes for the child to complete each task.

Recall period. Not applicable.

Cost to use. There is no cost to use the JAFAS for research purposes.

How to obtain. The JAFAS and its scoring manual can be obtained in the article by Lovell et al (5).

Practical application

Method of administration. The JAFAS is an observation measure that is to be administered by a physical or occupational therapist in a clinical or office setting. Activities are timed and compared with a criterion value noted on the form.

Scoring. The JAFAS is scored by hand. If a task is completed in less than or equal to the criterion time, then the task is scored as 0; if it is completed but requires longer than the criterion time, the task is scored as 1; if the patient is unable to perform the task, the task is scored as 2. The scores for each task are then summed for a total JAFAS score. The possible range of scores is 0 to 20.

Score interpretation. A higher score indicates a greater level of disability. When the JAFAS was initially tested, control-group patients scored a mean of 0.43 (SD 0.86) and patients with JIA scored a mean of 3.39 (SD 3.42).

Respondent time to complete. It usually takes a child approximately 10 to 15 minutes to complete the activities.

Administrative burden. The JAFAS is relatively easy to administer and only takes 10 to 15 minutes. It does require a trained professional (training time is minimal) and standardized equipment, making the administrative burden higher than that of a paper-and-pencil questionnaire.

Translations/adaptations. The JAFAS has been culturally adapted for use among Indian children (46). The Indian version has internal consistency reliability similar to that of the C-HAQ (Table 1).

Psychometric information

Floor and ceiling effects. To date, no floor or ceiling effects have been reported for the JAFAS.

Reliability. Lovell et al (5) found that the mean inter-item correlation of the JAFAS in the population with JIA was 0.36, indicating that the items capture different aspects of function. Internal consistency for the JAFAS varies from moderate to good, with a Cronbach's α ranging from 0.81 to 0.92 (5,28,30).

Validity. Regarding content validity, the JAFAS was developed from a range of tasks derived from the McMaster Health Index Questionnaire, the Arthritis Impact Measurement Scale, and the Health Assessment Questionnaire. An expert panel of pediatric physical and occupational therapists experienced in working with children with JIA reviewed items to ensure that the activities involved all aspects of the body during daily activities and were easy to measure objectively.

Lovell et al (5) established convergent validity among a group of patients with JIA; they found that the JAFAS was significantly correlated with the number of involved joints ($r = 0.40$; $P = 0.003$),

Steinbrocker functional class ($r = 0.59$; $P = 0.0001$), and disease activity ($r = -0.32$; $P = 0.01$).

Bekkering et al (28) examined disability in 28 children with JIA and found that JAFAS and C-HAQ scores were positively correlated ($r = 0.55$; $P < 0.01$). The JAFAS was also correlated with measures of disease activity and joint counts, including swollen joints ($r = 0.47$; $P < 0.05$), physician's evaluation of disease activity ($r = 0.41$; $P < 0.05$), joint count on motion-restricted joints ($r = 0.44$; $P < 0.05$), and the pediatric Escola de Paulista de Medicina ROM scale (47) ($r = 0.50$; $P < 0.01$), demonstrating convergent validity. There was no significant association between JAFAS scores and erythrocyte sedimentation rate and joint count on tender joints. There does appear to be a floor effect when using the JAFAS in relatively high-functioning children.

Responsiveness. The ability of the JAFAS to capture change in children's PF was assessed in a study examining the impact of intra-articular injections in 92 children with JIA and was found to be moderate at the 6-week evaluation (SRM 0.41; 95% confidence interval [CI] 0.18-0.64) (48).

Minimally important differences. Minimally important differences have not been reported for the JAFAS.

Generalizability. Although the JAFAS was developed for children with JIA, it can be used to assess function and musculoskeletal involvement in children with SLE who have compromised PF.

Use in clinical trials. The JAFAS has been used in studies of exercise in children with JIA (49) (Table 2).

Critical appraisal of overall value to the rheumatology community

The JAFAS provides reference values for the 10 ADLs performed by the child and scores the child based on the time it takes to complete the activity. The JAFAS has clear, concise, and understandable directions for use and has been shown to correlate well with other measures of disease activity and movement. The biggest limitation is the need for a trained observer and standardized equipment in the clinical setting. The JAFAS also does not include play and recreation items and is limited to 10 activities. There is no information on how to handle missing items. The JAFAS has been used in clinical trials of intra-articular joint injections in children with JIA. Bekkering et al (28) indicated the Juvenile Arthritis Functional Assessment Report (JAFAR) could be as useful as the JAFAS and has less administrative burden.

Summary/recommendations

Although the JAFAS has been shown to be reliable and valid, there are limited data on its ability to assess change following an intervention, and it requires the use of a trained observer. The JAFAS measures function as it relates to 10 ADLs and may be best suited for children with limited ROM and strength deficits. The JAFAS does not provide an assessment of the child's ability to engage in play and recreation. Other existing measures such as the C-HAQ and JAFAR may be more efficient for use in clinical practice and research because the C-HAQ has the added benefit of having responsiveness data.

JUVENILE ARTHRITIS FUNCTIONAL STATUS INDEX (JASI)

Description

Purpose. The JASI assesses PF status and ADLs in children with JIA, ages 8 to 18 years (50). Items for the JASI were developed based on interviews of children, parents, teachers, and clinicians.

Content or domains. The JASI Part I includes 100 items divided into five activity categories (self-care, domestic, mobility, school, and extracurricular). The JASI Part II is a priority function section in which children are asked to identify and score activities for which they want to see improvement (51).

Number of items. Part I includes 100 items, and Part II includes five items.

Response options/scale. A seven-point degree of difficulty rating scale is used for responses (6 = as well as friends/family without arthritis; 5 = it is a little difficult; 4 = it is very difficult; 3 = using special equipment; 2 = with a little help from someone; 1 = with a lot of help from someone; 0 = someone has to do it for me or I cannot do it because of my arthritis).

Recall period. The recall period of time is the current status.

Cost to use. There is a fee for the training manual and software, which can be obtained from the developer.

How to obtain. The JASI can be obtained from Dr. Wright at Bloorview Research Institute, Holland Bloorview Kids Rehabilitation Hospital, 150 Kilgour Road, Toronto, Ontario M4G 1R8, Canada (vwright@hollandbloorview.ca).

Practical application

Method of administration. The child completes Part I on a computer; Part I takes approximately 20 to 45 minutes to complete. For Part II, the child is interviewed; the interview takes approximately 20 minutes to complete.

Scoring. Part I is automatically scored using computer software. Part II is scored by hand according to the test manual. The Part I range of scores is 0 to 600. The Part II range of scores is 0 to 30.

Score interpretation. Lower scores reflect greater disability. This is a criterion-referenced test.

Respondent time to complete. Time to complete is not reported in the literature.

Administrative burden. The test is relatively time-consuming, taking approximately 40 minutes to administer, and requires computer software and a test manual, which can be obtained from the authors who developed the tool.

Translations/adaptations. The JASI has not been translated or culturally adapted (Table 1).

Psychometric information

Floor and ceiling effects. The JASI has no reported floor or ceiling effects.

Reliability. To determine test-retest reliability, Wright et al (51) administered the JASI to 30 children with JIA between 8 and 19 years of age at baseline, 3 weeks, and 3 months (51). Reliability of the JASI Part I was excellent at 3 weeks (ICC = 0.98) and 3 months (ICC = 0.99). Reliability was lower for respondents with mild disease than those with polyarticular JIA. Test-retest reliability for the JASI Part II was fair ($\kappa = 0.57$).

Validity. Seventeen clinicians reviewed the questionnaire and rated the index as a credible functional measure of JIA, establishing content validity (50). When tested for construct validity, JASI Part I scores correlated strongly with joint count ($r = 0.51$), grip strength ($r = 0.64$), hip synovitis ($r = 0.64$), timed walk and run ($r = 0.83$), and American College of Rheumatology functional class ($r = 0.80$) (51).

Responsiveness. Brown et al (32) examined the responsiveness of the JASI during a 4-year prospective study in which children with JIA were receiving intra-articular steroid injections and methotrexate treatment. The JASI demonstrated weak to moderate responsiveness to change, with an SRM of 0.36.

Minimally important differences. Minimally important differences have not been established in the literature.

Generalizability. The JASI is not appropriate for use in children aged 7 years or younger.

Use in clinical trials. Because of the time to administer, the need for training and special equipment, and its weak to moderate responsiveness, its use in clinical trials has been limited (Table 2).

Critical appraisal of overall value to the rheumatology community

The major strength of the JASI is that it examines function across a range of environments (eg, home, school, and play). The JASI was developed using rigorous methodology and involved patients, parents, clinicians, and teachers in the item generation. Limitations of the JASI include the length of time it takes for children to complete both portions of the JASI, the reliance on computer software for Part I, and although minimal, the cost for the software, which might deter some from using the JASI versus other valid and reliable assessments of functional status available for free. The JASI is also not appropriate for use in children aged 7 years or younger.

Summary/recommendations

JASI is a well-developed PF measure for children with arthritis. It provides a comprehensive picture of function across a spectrum of activities and allows the child to rank what the child perceives are the most important issues to change. Given its length and equipment/training needs, its use in daily clinical practice is limited.

PEDIATRIC ORTHOPEDIC SURGEONS OF NORTH AMERICA (POSNA) PODCI, FORMERLY THE PEDIATRIC MUSCULOSKELETAL FUNCTIONAL HEALTH QUESTIONNAIRE

Description

Purpose. The POSNA PODCI, formerly known as the POSNA Pediatric Musculoskeletal Functional Health Questionnaire, assesses functional health outcomes, specifically musculoskeletal health (pain, participation in daily activities as well as vigorous activities) for both healthy children and adolescents and those with musculoskeletal conditions (52). The PODCI was developed as a patient-centered measure that could be used across a wide range of ages and musculoskeletal disorders for the clinical assessment of treatment effectiveness

and musculoskeletal research. The PODCI has a child version to be completed by a parent/physician proxy and two surveys for adolescents (one that can be completed by a proxy and one that can be completed by self-report). For the purpose of this measure, a child is defined as being 2 to 10 years old, and an adolescent is between 11 and 18 years old.

Content or domains. The PODCI includes the following subscales that examine upper extremity (UE) and PF, transfers and basic mobility (TBM), sports and PF (SPF), pain/comfort (PC), happiness (HAP), and a global function score (GFS). The original questionnaire included a treatment expectations scale (52), but this was excluded in later versions (53).

Number of items. The original questionnaire had a total of 114 items, and the average time to complete was approximately 15 minutes for the adolescent version and 10 to 12 minutes for parent versions. The newer version (PODCI) has 83 items and five subscales for the adolescent version and 86 for the parent versions. Within the five scales, the TBM has 11 items, the SPF has 21 items, the PC has three items, the UE has eight items, and the HAP subscale has five items.

Response options/scale. The response options vary, with some nominal items (yes/no) and some ordinal scales. The range for the ordinal scales is either a four-point or five-point scale, depending on the question. For the additional comorbidity scale, there is a list of diseases, and the proxy or adolescent responds to whether the child/adolescent has the condition, is receiving treatment for the condition, and whether it limits activity. For a few items, there is the option to select that the child is too young to do the activity. If this is selected for an item, the item is treated as missing and omitted from the score.

Recall period. The reference period is 1 week for all items except for one item that asks for recall over 1 year.

Cost to use. There is no cost to use this questionnaire.

How to obtain. The PODCI can be obtained from the American Academy of Orthopedic Surgeons (AAOS) website (http://www.aaos.org/research/outcomes/outcomes_peds.asp).

Practical application

Method of administration. The PODCI is a pen-and-paper survey. The survey provides clear instructions regarding the reference time period and response categories. A proxy (parent or guardian) completes the parent/child questionnaire for children aged 2 to 10 years. The parent/adolescent questionnaire can be completed either by the parent as a proxy or by the adolescent as self-report.

Scoring. A formula is provided and is used to compute a standardized score for each subscale using the raw score. In brief, all items in the subscales are converted so that the values range from 0 to 5. Then, the scores for all items in a subscale are averaged for those items that are not missing. The mean of the subscales is multiplied by a constant value to generate a score range of 0 to 100 (52). A minimum of 50% of the items in a scale must have a response for the scale score to be computed. When assessing a young child using the parent proxy, roughly 0% to 25% of items are often missing because of the inability to score the child in specific domains, including HAP and satisfaction. The GFS is calculated by taking the mean of the “mean of items” in the first four subscales. Comorbidity subscales and a comorbidity index, which computes an average of the responses, are calculated. The AAOS provides an Excel file on its website to score the raw data. Each worksheet has the formula embedded for the specific subscale.

Score interpretation. Higher scores indicate more of the specific trait measured by the subscale. Haynes and Sullivan (53) used the questionnaire with 57 healthy children and 27 healthy adolescents and determined that a child scoring in the low 80s or lower is functioning at a different level than a healthy child. The AAOS has a large national database that uses the PODCI and provides access to normative data and enables analysis by age, sex, and comorbidity (54). Normative values exist for the PODCI (53,55). To calculate a normative value for a patient, subtract the population standardized mean from the patient’s score and then divide this value by the population SD and multiply the new value by 10 and add 50 to the final value.

Respondent time to complete. It takes approximately 15 minutes to complete (56).

Administrative burden. The administrative burden is low because no special equipment or training is needed. The scoring is calculated using the Excel file available from AAOS.

Translations/adaptations. The PODCI has been translated and culturally validated in Korean (57), Spanish (58), Dutch (59), Polish (60), Turkish (61), and Brazilian Portuguese (62) (Table 1).

Psychometric information

Floor and ceiling effects. Floor and/or ceiling effects have not been identified for this outcome measure.

Reliability. Daltroy et al (52) examined test-retest reliability over 1 to 2 days using Pearson’s correlation coefficients. Test-retest reliability was good to excellent among both parents and adolescents for the following subscales: GFS (parents = 0.97; child = 0.95), UE (parents = 0.94; child = 0.96), SPF (parents = 0.93;

child = 0.87), TBM (parents = 0.96; child = 0.97), PC (parents = 0.83; child = 0.89), HAP (parents = 0.71; child = 0.87), and expectations (parents = 0.83; child = 0.76).

Based on parent report, Cronbach's α ranged from 0.82 to 0.95 across subscales. Based on child report, Cronbach's α ranged from 0.76 to 0.92 across subscales. Overall, internal consistency was stronger when parents reported on outcomes than when children did. Parent-child agreement was good for the GFS and PC ($r = 0.84$), UE ($r = 0.83$), SPF ($r = 0.87$), TBM ($r = 0.86$), and PC ($r = 0.76$) but was weak for HAP ($r = 0.50$) and the expectations scale ($r = 0.45$). The Dutch PODCI UE and SPF subscales and total GFS showed good internal consistency (Cronbach's α 0.695-0.781) and reliability (ICC = 0.97-0.80) and were significantly associated with active ROM and the Mallet score in neonates with brachial plexus palsy. After surgery, a significant change of the total score (effect size 0.57; SRM 1.23; change of 4.22 points, 95% CI 1.04-7.4) was seen (59).

Validity. Convergent validity was established by Daltroy et al (52), who found that the physician's pain score was correlated with the parent's pain score and that the physician's score of global function and diagnosis severity were correlated with parent's and adolescent's function scores. Boyer et al (63) also demonstrated convergent validity because post-traumatic stress severity correlated with all subscales and global function and post-traumatic stress disorder diagnosis was significantly related to two subscales, as well as global function, among individuals with pediatric spinal cord injury. Daltroy et al (52) established discriminant validity because the physician's pain measure was not correlated with function, HAP, or expectations scores, and the physician's assessments of function were not correlated with the parent's or adolescent's HAP, PCF, or expectations scores.

Responsiveness. Daltroy et al (52) assessed responsiveness by examining changes in musculoskeletal function over 9 months, using the Child Health Questionnaire as a comparison and found it was sensitive to change among patients with moderate to severe musculoskeletal issues at baseline.

Minimally important differences. An MCID was calculated for 381 ambulatory children with CP with gross motor function classifications of I to III and a mean age of 11 years (64).

Generalizability. The PODCI can be used for children with a variety of musculoskeletal and neuromuscular conditions (eg, idiopathic scoliosis, osteogenesis imperfecta, UE amputation, congenital UE differences, CP, and sports injuries) and with healthy children.

The PODCI subscales differentiated between the various topographical types of vertebral palsy among children (65), indicating the measure is a valid and useful for assessing function among children with CP.

Use in clinical trials. The PODCI has been used in clinical trials and research and to establish normative data in healthy children (Table 2).

Critical appraisal of overall value to the rheumatology community

The PODCI was developed using rigorous methodology; items were created that included domains important to children and their parents and with consensus of experts. The questionnaire was pilot tested with 112 parents and 64 adolescents, and following completion of the survey, each participant was debriefed to gather feedback on the structure and content. Strengths of the PODCI are as follows: no cost nor equipment is needed, it is clear and easy to read, it includes a wide breath of domains, it uses higher-level PF activities, it has response sets which can be used by various age groups, it can be used in various musculoskeletal conditions, it has the ability to compare parent and adolescent scores, and normative data exist to assist in interpretation of scores. One study has reported the MCID for the PODCI in ambulatory children with CP. The scoring is complex, but the AAOS provides clear directions for scoring and an Excel file with the formulas embedded. The proportion of children with arthritis in the sample used to examine the initial testing of psychometric properties of the PODCI was limited (~5%). When using the PODCI, results should be considered in the context of age, sex, and comorbidity impacts (52) on scores.

Summary/recommendations

The PODCI subscales demonstrate good reliability, construct validity, and sensitivity to change over 9 months, making it well suited for clinical research. The PODCI is relatively brief and can be completed in approximately 15 minutes. The PODCI can be used for children of various ages and musculoskeletal conditions. The PODCI appears to be useful to assess function and intervention efficacy following surgical orthopedic interventions as well as medical and rehabilitation interventions. Given its strong psychometric properties, the PODCI can be used in clinical practice, with scoring completed using the published Excel scoring format.

JUVENILE ARTHRITIS MULTIDIMENSIONAL ASSESSMENT REPORT (JAMAR)

Description

Purpose. The JAMAR is used to examine disease activity and disability among children with JIA (66), and it contains items deemed relevant by parents and children. The JAMAR is recommended by the PRINTO.

Content or domains. The JAMAR includes items addressing well-being, pain, function, health-related quality of life, morning stiffness, disease activity, disease status, joint and extraarticular disease, compliance, side effects, and overall satisfaction with illness outcome.

Number of items. The JAMAR includes 15 components. Some of the components are single-item measures; the longest component within the JAMAR is 15 items.

Response options/scale. The response options/scale for each of the 15 components within the JAMAR are listed by subscale. The PF subscale has 15 items that score the child's ability to complete each task as follows: 0=without difficulty, 1=with some difficulty, 2=with much difficulty, 3=unable to do, and N/A if it was not possible to answer the question or the patient was unable to perform the task because of their young age or for reasons other than JIA. The total PF score has three components: PF lower limbs (PF-LL); PF hand and wrist (PF-HW), and PF upper segment (PF-US), each scoring from 0-15 (37). Pain intensity is rated on a 21-numbered circle VAS (0 = no pain; 10 = very severe pain) (67). The Pediatric Rheumatology Quality of Life Scale (HRQoL) (68) includes two subdimensions, physical health (PhH) and psychosocial health (PsH). Each component has five items. The responses are never (score = 0), sometimes (score = 1), most of the time (score = 2), and all the time (score = 3). Overall well-being is measured using a 21-numbered circle VAS (0 = very well; 10 = very poorly), and disease activity is measured on a 21-numbered VAS (0 = no activity; 10 = maximum activity) (67).

Joint pain and swelling are indicated by their presence or absence for the following joints: cervical spine, lumbosacral spine, shoulders, elbows, wrists, small hand joints, hips, knees, ankles, and small foot joints. Morning stiffness and extraarticular symptoms (eg, fever or rash) are also recorded as present or absent. Disease status at the clinical visit is noted as remission, continued activity, or relapse. The patient's disease course is compared with the prior visit and recorded as much improved, slightly improved, stable, slightly worsened, or much worsened. The JAMAR includes a list of medications the child may be taking along with a list of side effects of medications and difficulties with taking medications. A list of items related to problems with school due to the child's JIA is provided, and the final component is an item regarding satisfaction with the outcome of the illness (yes/no).

Recall period. The recall period within JAMAR differs according to the specific measure. The measures within the JAMAR ask respondents to consider their symptoms and experiences in the moment, today, in the past week, in the past 4 weeks, and since their last doctor visit.

Cost to use. The JAMAR is free to use.

How to obtain. The JAMAR can be obtained from the original article (66), available at <http://www.jrheum.org/content/38/5/938.long#app-1>.

Practical application

Method of administration. The JAMAR can be used as both a proxy report and a patient self-report, with the suggested age range of 7 to 18 years for use as a self-report. The JAMAR is simple and language-level appropriate (ie, 80% of the children could read the survey without difficulty).

Scoring. Responses to the scales and subscales (PF-LL, PF-HW, PF-US, HRQoL, HRQoL-PH and HRQoL-PsH) are summed. The total PF score ranges from 0 to 45. The HRQoL total score ranges from 0 to 30. A separate score for the PhH and PsH subscales (range: 0-15) can be calculated.

Score interpretation. Higher scores on any scale indicate greater disability.

Administrative burden. Both parents and children have reported that the questionnaire was simple and easy to understand (66). It takes under 15 minutes to complete the questionnaire and 5 minutes to score the questionnaire. No special equipment or training is needed. Because of this, administrative burden is low.

Translations/adaptations. The original measure was developed in Italian and then translated into English (66). Bovis et al (69) culturally adapted and translated the JAMAR into 54 languages for use in 52 different countries that are members of the PRINTO. The countries included in the validation study were Algeria, Argentina, Belgium, Brazil, Bulgaria, Canada, Chile, Colombia, Croatia, Czech Republic, Denmark, Ecuador, Egypt, Estonia, Finland, France, Georgia, Germany, Greece, Hungary, India, the Islamic Republic of Iran, Israel, Italy, Latvia, Libya, Lithuania, Mexico, Netherlands, Norway, Oman, Paraguay, Poland, Portugal, Romania, the Russian Federation, Saudi Arabia, Serbia, Slovakia, Slovenia, South Africa, Spain, Sweden, Switzerland, Thailand, Turkey, Ukraine, the United Kingdom, and the United States. The JAMAR demonstrated good psychometric properties across adaptations (Table 1).

Psychometric information

Floor and ceiling effects. No floor or ceiling effects have been reported.

Reliability. With regard to agreement between parent proxy and child self-reported data in paired questionnaires, findings are mixed (66,70). Filocamo et al (66) found that responses for parent-child pairs were similar for most items

other than one question about medication side effects, in which parents more often reported hypertrichosis as a side effect. Vanoni et al (70) found an increased number of items with disagreement between parents and children when the disease was more active.

Filocamo et al (66) examined whether the child's age affected the reliability of completion of the questionnaire. Results across the three age groups (less than 10, 10-15, and more than 15 years) were comparable, with the exceptions of a lower correlation of functional ability assessment in the younger age group and of psychosocial HRQoL assessment in the older age group. Internal consistency for the US English version of JAMAR was adequate. Specifically, Cronbach's α was 0.88 for PF-LL, 0.87 for PF-HW, and 0.72 for PF-US. Cronbach's α was 0.86 for HRQoL-PH and 0.77 for HRQoL-PsH. In the English version, test-retest reliability assessed a median of 3 days after initial measure was excellent (ICC = 0.92). Additionally, the ICC for the HRQoL-PhH and for the HRQoL-PsH was almost perfect (ICC = 0.92 and ICC = 0.83, respectively) (71).

Validity. Face validity was established first by content review of medical personnel, including 12 physicians (eight pediatric rheumatologists and four pediatric residents), four physical therapists, three specialist nurses, and one clinical psychologist. Additionally, a sample of 49 children with JIA and their parents completed the draft questionnaire and provided comments about the design, content, structure, and response scale (66).

JAMAR scores were compared with clinical measures of disease activity and severity to determine discriminant validity. Specifically, the functional ability and HRQoL scores and VAS worsened as the number of affected joints increased. In addition, in patients with more affected joints, the frequency of remission was lower, and the frequency of continued activity and disease flare was higher (66). With regard to the US English version of the JAMAR, the JAMAR components discriminated well between healthy subjects and patients with JIA. Patients with JIA had a greater level of disability and pain as well as a lower HRQoL than their healthy peers (71). With regard to external validity, Spearman's correlations of the PF and HRQoL scales with measures in the JIA core set were weak to moderate (71).

Responsiveness. Hussein et al (72) used the JAMAR to examine the experiences of 44 children with JIA who attended the pediatric rheumatology clinic in Alexandria University Children's Hospital in Egypt from baseline to 6 months. They found the JAMAR to be sensitive to changes in disease activity from baseline to 6 months.

Minimally important differences. Minimally important differences have not been established for the JAMAR.

Generalizability. The JAMAR has been used to examine disease activity among patients with JIA in 52 countries around the world (72).

Use in clinical trials. To date, the JAMAR has not been used in clinical trials (Table 2).

Critical appraisal of overall value to the rheumatology community

The JAMAR is a valid tool for the assessment of children with JIA and has been translated in numerous languages and culturally validated. The JAMAR provides a systematic review of the child's status, enabling a more efficient clinical visit and assessment of JIA and its management. The JAMAR demonstrates strong psychometric properties and is suitable for use in both clinical practice and clinical research. However, the JAMAR might not obtain sufficient detail regarding patient outcomes related to sleep disturbances, fatigue, coping, and family life (37).

Summary/recommendations

The JAMAR is a comprehensive tool used to assess the impact of JIA and its treatment on functional performance in children with JIA. It is easy to read, with understandable response sets. The psychometric properties are good, although responsiveness needs further evaluation. This PROM is one of the most translated and culturally adapted measures designed for children with arthritis.

KNEE OSTEOARTHRITIS OUTCOME SCORE FOR CHILDREN

Description

Purpose. The KOOS-Child was designed to assess perception of knee and associated knee problems among children ages 10 to 16 years old. The original KOOS-Child LK was replaced with an updated version, LK 2.0, to account for a flip of response scales.

Content or domains. There are five subscales of the KOOS-Child: knee pain, knee symptoms, ADLs, sports and play, and quality of life. No composite score is reported.

Number of items. The KOOS-Child includes 39 items, including seven items regarding symptoms, eight items regarding pain, 11 items regarding ADLs, seven items regarding sports and play, and six items regarding quality of life.

Response options/scale. Each item uses a five-point Likert scale. The average scores for each subscale are normalized and range from least severe to most severe (0-4) or never to always (0-4), depending on the item.

Recall period. Respondents are asked to recall symptoms over the past 7 days.

Cost to use. The KOOS-Child is free to use.

How to obtain. The KOOS-Child can be obtained online for free at <http://www.koos.nu/>.

Practical application

Method of administration. The KOOS-Child is completed using paper and pen and can be administered in person or via postal mail.

Scoring. Each subscale within the KOOS-Child is scored separately and normalized to create a score ranging from 0 to 100 for each subscale. This enables the clinician or researcher to create a profile for each patient or report in the aggregate. To calculate a subscale score, sum the scores of the specific subscale items (eg, seven symptom items) and calculate the mean of subscale. Next, multiply the mean of the subscale by 100, divide by 4, and subtract this value from 100 (73). Note that there was an edit to the primary scale, so check scoring depending on the version used. Questions regarding scoring of the KOOS-Child can be directed to the web manager at web-manager@koos.nu.

Score interpretation. A score of 100 indicates no symptoms, and a score of 0 indicates extreme symptoms. In a study of 1000 healthy individuals (adults and children) ages 8 to 101 years, normative data are reported for children 8 to 17 years, stratified by sex for each of the subscales (74). Scores for the male children's pain, symptoms, ADL, sport/recreation, and quality of life subscales and KOOS total scale were as follows: mean 95.7 (SD 10.7), mean 95.8 (SD 8.3), mean 99.1 (SD 3.4), mean 97.8 (SD 5.8), mean 97.3 (SD 7.2), and mean 97.1 (SD 6.1), respectively. Scores for the female children's pain, symptoms, ADL, sport/recreation, and quality of life subscales and KOOS total scale were as follows: mean 92.2 (SD 14.0), mean 93.1 (SD 11.4), mean 96.4 (SD 7.6), mean 93.2 (SD 13.7), mean 94.4 (SD 13.7), and mean 93.8 (SD 11.0), respectively.

Respondent time to complete. The KOOS-Child is simple to complete and takes roughly 10 to 20 minutes, with younger children taking closer to the longest window of completion time (75). Younger children may also need some help with reading the items.

Administrative burden. The KOOS-Child takes about 10 to 20 minutes for a child to complete. The scores can be calculated by hand. No special software is needed to calculate the KOOS-Child subscales.

Translations/adaptations. The KOOS-Child is available in Danish, Dutch, English, Finnish, Greek, Norwegian, Persian, and Swedish (Table 1).

Psychometric information

Floor and ceiling effects. No floor to ceiling effects were found using a threshold of 15% or less (73). In the Dutch version, low floor and ceiling effects (scores between 5 and 95, except for the KOOS-Child subscales for ADLs and sport/play) were identified (76).

Reliability. Internal consistency was good to excellent across all subscales (Cronbach's $\alpha = 0.80-0.90$) except for the symptoms subscale (Cronbach's $\alpha = 0.59$). Test-retest reliability was assessed among 72 children with an average of 11 days from the first to the second administration. The ICC for the symptoms subscale was 0.78; for all other subscales, the ICC ranged from 0.85 to 0.91 (73). In the Dutch version, the KOOS-Child showed an adequate test-retest reliability (ICC = 0.8-0.9; SEM = 8.9-16.9; smallest detectable change [SDC] = 24.7-46.9), depending on the subscale (76).

Validity. Comprehensibility and content validity of the KOOS-Child were assessed in 34 Swedish children aged 10 to 16 years who had symptomatic knee injuries (74). The original KOOS was not well understood by children. As such, modifications related to comprehension, mapping of responses, and jargon were made based on qualitative feedback from the children in order to develop the KOOS-Child. Content validity was later established in the Dutch version (75) of the KOOS-Child (more than 75% relevant, except for the KOOS-Child ADLs subscale).

In original psychometric testing (73), construct validity was confirmed by convergence with similar items from the C-HAQ, the EuroQol for youth, and five purpose-specific VAS items. All a priori hypotheses were confirmed during psychometric testing, indicating that there was excellent construct validity. Greater effect sizes were seen in those reporting improved clinical status. In the Dutch version, there was adequate construct validity (75% confirmed hypotheses) (76).

Responsiveness. To assess responsiveness, a KOOS-Child questionnaire was mailed with a global perceived-effect (GPE) scale 3 months after the initial assessment (73). This time frame was selected because it is often when a clinical improvement in the study sample can be expected. Changes in the final KOOS-Child subscale scores between baseline and 3 months administration were assumed to correlate 0.3 or more with the subscale-specific GPE scores. All subscales demonstrated responsiveness to change, with a moderate effect size (0.42-0.78) in patients who reported an improvement in their symptoms and a small effect size (0.12-0.21) in patients who reported stable symptoms. In the Dutch version, moderate responsiveness was found (40% confirmed hypotheses) (76).

Minimally important differences. The SDC of the KOOS-Child subscales ranged from 24.7 to 46.9 (76).

Generalizability. The KOOS-Child can be used to assess children with a variety of knee injuries, including but not limited to anterior cruciate ligament injuries, patella dislocations, meniscal tears, and chondral injuries. The KOOS-Child is designed to assess both individual change and group change and to assess short-term and long-term changes in knee function, symptoms, and quality of life. The KOOS-Child can be used for children with a variety of symptomatic knee conditions.

Use in clinical trials. The KOOS-Child has been used in both surgical and nonsurgical intervention trials (77) and has shown strong psychometric properties (Table 2).

Critical appraisal of overall value to the rheumatology community

The KOOS-Child is recommended for use in clinical practice and research to evaluate knee function, symptoms, and knee-related quality of life in children with knee disorders. A change of 2 to 3 and 15 to 23 KOOS-Child points is needed at group and individual levels, respectively, to detect a true change over time. A major strength of the KOOS-Child is that it can be used to create a profile for an individual using each subscale. Additionally, the inclusion of the sports and recreation scale provides needed data not obtained with standard measures of PF in children. However, the KOOS-Child should not be used in children younger than 7 years. The KOOS-Child is not intended for use as a parent proxy measure.

Summary/recommendations

The KOOS-Child has strong psychometric properties and provides the clinician and researcher with the ability to create a physical activity profile. The comprehensibility of the KOOS-Child was assessed and ensures children ages 7 to 16 years can clearly understand the items and select an appropriate response. The inclusion of sports and play in the measure provides important information not typically found in PF PROMs. The KOOS-Child is well suited for assessment of intervention, clinical decision-making, and clinical research.

PEDIATRIC INTERNATIONAL KNEE DOCUMENTATION CLASSIFICATION

Description

Purpose. The Pedi-IKDC was the first knee-specific PROM to be rigorously validated in a pediatric population. It was designed to assess knee pathology in children ages 10 to 18 years. It has

not been modified since its initial publication. The Pedi-IKDC is written at the fifth- to sixth-grade reading level.

Content or domains. The Pedi-IKDC was developed using qualitative interviews among children to critically evaluate the comprehension and relevance of the International Knee Documentation Classification (IKDC) for use in children and then modified accordingly (78). The Pedi-IKDC examines PF, participation in sports/recreation, and ADLs. The form also includes some demographic and medical history items.

Number of items. The Pedi-IKDC includes 13 items.

Response options/scale. The Pedi-IKDC uses a mix of response sets. Some items use a Likert scale ranging from 1 to 5; whereas others use a 10-point VAS with verbal anchors at each end to indicate level of difficulty performing an activity (not able to perform or extreme symptoms to no symptoms). There are two dichotomous items in the symptom scale.

Recall period. Most items ask children to recall symptoms and function over the past 4 weeks. Some items ask children to estimate symptoms/function based on whether they believe they could do the activity today.

Cost to use. There is no cost to use the Pedi-IKDC.

How to obtain. The Pedi-IKDC form can be obtained at https://www.sportsmed.org/aossmimis/Staging/Research/IKDC_Forms.aspx.

Practical application

Method of administration. The Pedi-IKDC is administered via paper and pencil.

Scoring. Persons scoring the Pedi-IKDC should assign the appropriate numerical scores to the individual's response for each item such that lowest score of 0 represents the lowest level of function or the highest level of symptoms. Next, the raw score is calculated by summing the numerical equivalents of the responses for each item (however, item 12 is not included in the calculation because there are no numeric equivalents for that item). Then, the raw score is transformed to a 0 to 100 scale as follows: the total raw score is divided by the total maximum score multiplied by 100. A score can still be calculated as follows using the same method if there are missing responses as long as there are responses to at least 90% of the items: (sum of the completed items)/(maximum possible sum of the completed items) × 100. For details see <https://www.sportsmed.org/AOSSMIMIS/members/downloads/research/ScoringInstructions.pdf>.

Score Interpretation. Scores range from 0 to 100, with higher scores indicating better function and fewer symptoms. A score of 100 is interpreted to mean no limitation with sporting activities or daily living and the complete absence of symptoms. In a cross-sectional survey of 2000 US children and adolescents aged 10 to 18 years who reported data on their “index knee” and reported recent (4-week) activity limitations, the mean \pm SD score was 86.7 ± 16.8 , and the median was 94.6. Participants who reported prior surgery or limited activity in the index knee had median Pedi-IKDC scores that were approximately 25 points lower than participants without these histories ($P < 0.0001$ for both comparisons) (79).

Respondent time to complete. The Pedi-IKDC takes approximately 10 minutes to complete.

Administrative burden. It takes approximately 10 minutes to administer the Pedi-IKDC and roughly 5 minutes to score by hand. No software or special equipment is needed to administer or score the Pedi-IKDC.

Translations/adaptations. The Pedi-IKDC is available in English, Danish, and Dutch. There is no short form version of the Pedi-IKDC. Sabatino et al (80) developed an electronic version of the Pedi-IKDC and found it correlated highly with the paper version (0.946; $P < 0.001$). The electronic version does not require manual scoring and was preferred by patients over the paper form. Mellor et al (81) examined agreement between the paper format and a text message delivery format of the Pedi-IKDC; the ICC between the paper and mobile phone delivery of the Pedi-IKDC was 0.96 ($P < 0.001$; 95% CI 0.93-0.98) (Table 1).

Psychometric information

Floor and ceiling effects. For the Pedi-IKDC total score, the floor effect was 0% and the ceiling effect was 1%. There were five individual items that demonstrated a ceiling effect greater than 30% and 16 items that were over 15%. None of the 18 items demonstrated an unacceptable floor effect of more than 30%; however, six items had a floor effect greater than 15% (82). In the Dutch version, low floor or ceiling effects (scores between 5 and 95) were observed (76).

Reliability. The Pedi-IKDC has high internal consistency (Cronbach's α coefficients ranged from 0.90 to 0.91). The test-retest reliability is excellent (ICC = 0.9) (82). The SEM has been reported at 4.1 (83) and 8.6 (76).

Validity. Face validity was assessed with cognitive interviewing. Content validity of the IKDC was examined with 30 children experiencing a primary knee injury. Children found the IKDC Subjective Knee Evaluation Form difficult to comprehend

and answer. Modifications to directions, item formatting, and definitions were recommended for the Pedi-IKDC to ensure comprehensibility and validity (78). The Dutch translation of the Pedi-IKDC demonstrated adequate content validity (more than 75% relevant) and adequate construct validity (75% confirmed hypotheses) (76). Discriminant validity was established because children who reported prior surgery or limited activity in the index knee had median Pedi-IKDC scores that were significantly lower, by approximately 25 points, than participants without these histories (79).

Responsiveness. A large effect size (1.36) was found for children undergoing surgical treatment for their knee condition with an SRM of 0.9 to 1.35 (82,83). Adequate responsiveness was found in the Dutch translation (more than 75% confirmed hypotheses) (76).

Minimally important differences. The MCID 12.0 (SD 1.35) (82). The SDC has been reported as 23.8 (76) and 11.3 (83).

Generalizability. The Pedi-IKDC is not to be used with children under 10 years of age or children with literacy limitations. The Pedi-IKDC can be used to detect changes in knee outcomes following surgical procedures (84–87) and rehabilitation (76).

Use in clinical trials. The Pedi-IKDC has been used in studies of surgical interventions (84–88) and nonsurgical interventions (76) in children with ligamentous injuries and other musculoskeletal conditions (Table 2).

Critical appraisal of overall value to the rheumatology community

The lack of a sex-based effect and the minor variation in scores with age within a sample 2000 US children suggest that the Pedi-IKDC may be easy to interpret and Pedi-IKDC score distributions can provide assumptions for use in sample size or power calculations for research. Additionally, in a study comparing Dutch children with knee disorders, the Pedi-IKDC appeared to demonstrate slightly better psychometric properties (76). Limitations of the Pedi-IKDC are that the tool can demonstrate large ceiling effects (82) and that it is lengthy and can potentially fatigue patients.

Summary/recommendations

The Pedi-IKDC is simple to administer and easy to comprehend and to score. It demonstrates excellent psychometric properties, including an MCID, and has published normative values. The Pedi-IKDC has been used in numerous studies of orthopedic interventions. It is not to be used in children younger than 10 years of age.

PATIENT-REPORTED OUTCOMES MEASUREMENT INFORMATION SYSTEM PEDIATRIC PHYSICAL FUNCTION SCALE

Description

Purpose. The PROMIS-PF is a generic PF PROM that has been used for patients or clients with musculoskeletal disorders, including arthritis. The PROMIS-PF, a component of the overall Patient-Reported Outcomes Measurement System (PROMIS), is a comprehensive measurement set based on item response theory (IRT) that is designed to evaluate physical, mental, and social health in both adults and children. The PROMIS-PF pediatric version measures PF (mobility and UE function) through a grading scale of ADLs. Note that there are different versions of PROMIS available, and PROMIS measures are copyrighted. There are two versions of the pediatric PROMIS-PF; version 2 has replaced the original version.

Content or domains. The PF subscale includes mobility and UE function items.

Number of items. There are 24 items in the item bank for PF, with the short form having eight items (88). The number of items can be variable depending on whether the static short form, off-the-shelf or customized, or the computerized adaptive IRT format is used. The computerized IRT format calibrates each item of the trait along a measurement continuum and characterizes the probability of the respondent's level on the construct based on the response option chosen for a calibrated item (eg, if a child indicates he/she can run a block then the child can skip the item regarding walking).

Response options/scale. A five-point ordinal scale is used to indicate ability to perform the activity, with values ranging from 5 (without any difficulty) to 1 (unable to do). Note that version 1.0 used a 0 to 4 ordinal scale that was updated to the 1 to 5 scale in version 2.

Recall period. Respondents are asked to consider their experiences over the past 7 days.

Cost to use. English and Spanish PROMIS versions are publicly available for use in research, clinical practice, educational assessment, or other application without licensing or royalty fees. Commercial users must seek permission to use, reproduce, or distribute measures. Integration into proprietary technology also requires written permission. For details, please see http://www.healthmeasures.net/images/PROMIS/Terms_of_Use_HM_approved_1-12-17_-_Updated_Copyright_Notices.pdf.

How to obtain. To access the various versions of the PROMIS-PF go to <http://www.healthmeasures.net/explore-measurement-systems/promis/obtain-administer-measures>.

Practical application

Method of administration. In the pediatric population, the PROMIS-PF can be administered to children without help from anyone else or if they are unable to complete the survey on their own, a parent/guardian proxy report can be obtained (89). The PROMIS website provides best practices for the administration of the survey. PROMIS can be completed with pen and paper (short form and profiles), via computer adaptive testing, and via an app. The computer adaptive versions, also referred to as the computer adaptive test (CAT) short forms and profiles, can be administered using Research Electronic Data Capture (REDCap), a secure web system that can build surveys, manage administration, and calculate scores from the PROMIS surveys. Please visit <https://projectredcap.org/software/> for more information about REDCap and the REDCap Library or contact the REDCap team at redcap@vumc.org. PROMIS has also been integrated into Epic[®] an electronic medical record system in version 2012 and onward. With respect to use of apps, PROMIS is available via the PROMIS iPad app and the National Institutes of Health Toolbox iPad app. Please visit http://www.healthmeasures.net/index.php?option=com_content&view=category&layout=blog&id=132&Itemid=936.

Scoring. It is strongly recommended to use the automated scoring system, which is freely available after registration (90). The HealthMeasures scoring service is especially useful when the short form is administered and participants skip items, different groups of participants respond to different items, or you create a new subset of questions from one of the HealthMeasures (eg, PROMIS) item banks. PROMIS has a published scoring manual that can be found at http://www.healthmeasures.net/images/PROMIS/manuals/PROMIS_Physical_Function_Scoring_Manual.pdf.

Score interpretation. Scores are standardized using a T score metric in which 50 is the mean of a relevant reference population and 10 is the SD of that population. Thus, a higher T score reflects higher (better) PF and a lower T score reflects lower (worse) PF. Normative values exist for this measure. Morgan et al (91) established cut points for the PROMIS- PF among children with JIA for UE function as follows: more than 35 = no problems, 35 to 25 = mild problems, 24 to 20 = moderate problems, and less than 20 = severe problems. For the mobility scale the values include the following: more than 40 = no problems, 40 to 30 = mild problems, 29 to 25 = moderate problems, and less than 25 = severe problems.

Respondent time to complete. Time to complete is variable depending on the format used (eg, the short form is estimated to take 15 minutes, and the CAT IRT format depends on the respondent's functional level because items can be eliminated based on the respondent's answers).

Administrative burden. Time for child or parent proxy to complete is 15 minutes. There is software to provide a computer-based version (see above) of the PROMIS-PF pediatric version. For software needed for scoring see Scoring.

Translations/adaptations. The PROMIS-PF is available in English, Spanish, French, German, and many other languages. For a full list of languages see <http://www.healthmeasures.net/explore-measurement-systems/promis/intro-to-promis/available-translations>. Only the English and Spanish versions are available to download for free. To request any other language, please contact translations@HealthMeasures.net. (Table 1)

Psychometric information

Floor and ceiling effects. The PROMIS-PF showed acceptable floor and ceiling effects (less than 15%) in 100 youth presenting with knee pain (92). In a population of children from general and specialty pediatric clinics, a ceiling effect was found (93). The short form version had less variability of scores than the CAT version did, indicating that the CAT version is better able to measure function for children at the high ends of the scale.

Reliability. Varni et al (93) examined the psychometric properties of the PROMIS-PF in 331 children ages 8 to 17 years who were recruited from general pediatric and subspecialty clinics. The internal consistency, as measured by Cronbach's α of the mobility and UE subscales, ranged from 0.62 to 0.77. The test-retest reliability of the PROMIS-PF was assessed in 54 children at baseline and 2 weeks later and was found to be good, with a correlation of 0.70 (93).

Validity. Content validity was confirmed via an extensive literature search followed by focus groups, cognitive interviews, and pilot testing among a diverse group of individuals, which were performed to enhance the relevance of items and clarify language. In a prospective study of 100 individuals with knee pain, Schafer et al (92) collected PROMIS scores and Pedi-IKDC scores and found that Pedi-IKDC scores correlated with the mobility ($r = 0.42$) and pain interference ($r = -0.49$) PROMIS scales. When seven highly functioning individuals with significant pain were removed for a secondary analysis, the mobility and pain interference correlations improved to 0.69 and -0.67 , respectively.

Waljee et al (94) examined construct validity of the PROMIS-PF UE scale in 33 children (ages 6-17 years) with

congenital hand differences and reported good construct validity. The short form and CAT versions were highly correlated with disabilities of the arm, shoulder, and hand scores ($r > 0.80$; $P < 0.001$) and all PODCI domains except for sports ($r > 0.70$; $P < 0.001$). Correlation with the Michigan Hand Questionnaire was moderate ($r > 0.40$; $P < 0.05$). PROMIS short form and CAT scores also correlated with grip strength ($r \geq 0.60$; $P < 0.001$) and pinch strength ($r \geq 0.50$; $P < 0.001$).

Responsiveness. The pediatric PROMIS-PF responsiveness has been assessed in a variety of patient groups (eg, children with asthma, sickle cell disease, following abdominal surgery, and chronic pain).

Minimally important differences. Thissen et al (95) identified a MCID of 2 to 3 points on the mobility scale, whereas Morgan and colleagues (91) found that estimates of minimally important differences varied by domain, the severity of symptom/dysfunction, and by who was making the judgment (pediatric patient, parent, or clinician).

Generalizability. The pediatric PROMIS-PF is a generic PF measure for children and their parent proxy and has been used in healthy and numerous health conditions.

Use in clinical trials. The PROMIS-PF has been shown useful in measuring the PF (mobility and UE function) of children with various conditions in numerous studies of the effectiveness of interventions and quality of clinical care in routine practice (Table 2).

Critical appraisal of overall value to the rheumatology community

The PROMIS-PF is a generic PF measure for children and their parents that has many advantages. First, item banks can be created for each health attribute to allow for greater precision of measurement at various levels of an attribute, whereas respondents need only answer a subset of relevant items related to their ability to perform a specific trait. Secondly, a CAT format is more time efficient and less burdensome. PROMIS has an electronic scoring system that converts scores to standardized values, minimizing administrative burden. The psychometric properties are well established and strong, and normative values exist for comparison. There is an established MCID for the pediatric PF score, and the PROMIS-PF is available in numerous languages.

Summary/recommendations

The pediatric PROMIS-PF is a generic measure of mobility and UE function in children. It has strong psychometric properties, is easy to comprehend, and can be administered in various

formats. The PROMIS-PF for children has been extensively used in clinical trials and in clinical practice across the globe and has established normative values. Thus, the PROMIS-PF allows for comparison of treatment effectiveness across a variety of conditions. Although the scoring is complex, a training manual and an Excel file with embedded formulas are available to assist researchers and clinicians.

ACTIVITY SCALE FOR KIDS

Description

Purpose. The ASK was developed to assess various ADLs and physical activity-related function in children ages 5 to 15 years with musculoskeletal disorders (96). The ASK includes two versions, one that measures a child's physical capability in his/her daily environment (the ASK capability [ASKc]) and one that measures the child's performance of the same activities in their daily environment (the ASK performance [ASKp]).

Content/domains. The ASKc measures activities the child could have done (capability), and the ASKp measures activities the child actually did do over the past week. The ASK includes seven domains, including personal care, dressing, other skills, locomotion, play, standing skills, and transfers.

Number of items. There are 30 items in the original version of the ASK. The revised version contains 38 items (97).

Response options/scale. Both versions include a five-point ordinal scale response option (range: 0-4). The response options depend on the ASK version. For the ASKc, 0 = with no problem, 1 = with a little problem, 2 = with a moderate problem, 3 = with a big problem, and 4 = I could not. For the ASKp, 0 = all of the time, 1 = most of the time, 2 = sometimes, 3 = once in a while, and 4 = none of the time.

Recall period. The recall period is over the past week.

Cost to use. The cost to use ASK is variable and depends upon purpose for use (clinician versus funded researcher). Prices can be found at the ASK website (<http://www.activitiesscaleforkids.com/>).

How to obtain. Those interested in obtaining the ASK must visit the ASK website (<http://www.activitiesscaleforkids.com/>) and register to use the tool. It is free to academics and students for student projects or teaching purposes. Researchers and clinicians must provide payment. The cost for clinicians is less than for researchers, and researcher fees vary depending on whether a researcher is funded or not (costs range from 150 Canadian dollars [CAD]/year to 900 CAD/year).

Practical application

Method of administration. Children are given a booklet to complete using a pen or pencil. Children under 9 years of age and those with cognitive impairments may require assistance with reading the items; however, the child is expected to record the response. The ASK should be completed in a child's home environment. The ASK can also be administered via postal mail.

Scoring. Each version (the ASKp and the ASKc) includes instructions in the test booklet and an instruction card the child can use while completing each item. The five-point (0-4) ordinal scale is scored as follows: 4 points for 0, 3 points for 1, 2 points for 2, 1 point for 3, and 0 points for 4. The summary score does not include the N/A option. Scores on the 30 individual activity items (or the number completed by the child minus any N/A items) are tabulated by averaging the responses and then multiplying by 25 in order to convert the score to a 0 to 100 range.

Score interpretation. A lower score indicates greater disability. The ASK was given to 122 healthy children; the average score was 93.12 (SD 6.45) (98). This score was significantly higher than the mean summary score for children with mild disability in previous studies ($P = 0.005$) (98).

Respondent time to complete. The ASK takes approximately 30 minutes to complete for the first time but takes as little as 10 minutes on subsequent administrations (97).

Administrative burden. Administrative burden is low because the ASK is not lengthy and does not require any special equipment or training. Administrators should read the instruction manual prior to the administration of the ASK.

Translations/adaptations. Feldman et al (96) created a revised version of the ASK, which was rescaled from the original. The ASK website indicates that the ASK is available in Canadian English, Canadian French, UK English, Spanish, and Dutch (Table 1).

Psychometric information

Floor and ceiling effects. The ASK shows no floor effects and minimal ceiling effects (99).

Reliability. In a study of 74 children with JIA of mixed subtypes, the test-retest reliability of the revised ASK demonstrated excellent reliability (ICC = 0.91) (31). In a study by Young et al (100) in which the ASK was mailed to 40 parents and children twice, the test-retest reliability was also good (ICC = 0.97 for ASKp and ICC = 0.98 for ASKc.) Internal consistency reliability was excellent, with a Cronbach's α of 0.99.

Validity. With regard to criterion validity, Young et al (100) found that when tested with a group of 200 children, the ASK was strongly correlated with parent-reported C-HAQ scores ($r = 0.81$) and clinician observation ($r = 0.92$). In addition, they found a significant difference in ASK scores according to the clinician's global ratings of disability ($P < 0.001$). Young et al (100) also demonstrated construct validity with Rasch analyses, which confirmed that all items measure the same construct.

Responsiveness. The responsiveness of the ASK was assessed with 34 children who completed the ASK and C-HAQ before and after a clinically important change. Twenty-three of the children improved and 11 children worsened. The resultant effect sizes indicate that the ASK performance is responsive. Specifically, the ASK_p was 16% more responsive than the C-HAQ, and the ASK_c was 2% less responsive than the C-HAQ (31).

Minimal important differences. Minimally important differences have not been established for the ASK.

Generalizability. The ASK has been used extensively to assess outcomes following interventions in children with various musculoskeletal disorders (CP, arthritis, fractures, scoliosis, dermatomyositis, and spina bifida).

Use in clinical trials. The ASK has been used in clinical trials to examine children's PF before and after treatment for their disability (101) (Table 2).

Critical appraisal of its overall use to the rheumatology community

The ASK is appropriate for use among children with JIA or other rheumatic diseases, including dermatomyositis, and demonstrates excellent reliability, validity, and responsiveness to change. The ASK is unique because it measures both performance and capability. It is easy to administer and is not burdensome because the tool is not time intensive to complete and is completed at home. As a caveat, the ASK_p is not appropriate as a measure of physical disability in children without musculoskeletal impairments because ceiling effects might occur. In addition, there is a fee associated with using the ASK. The ASK is appropriate for use in both clinical settings for decision-making regarding interventions and in research studies. Additionally, the ASK contains only two items regarding play and does not ask the child to rate their activity level compared with others of their age as seen in the KOOS-Child.

Summary/recommendations

The ASK demonstrates strong psychometric properties when used in children 5 to 15 years old with musculoskeletal disorders. The performance and capability versions of the ASK allow

clinicians and researchers an added dimension of PF. Although the ASK is easy to administer and score, the fees are quite high for researchers and clinicians compared with other measures with similar psychometric properties.

AUTHOR CONTRIBUTIONS

All authors drafted the article, revised it critically for important intellectual content, and approved the final version to be published.

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Table 1. Practical applications*

Measure	Number of Items	Content/Domains	Method of Administration	Recall Period	Response Format	Range of Scores	Score Interpretation	Availability of Normative Data	Cross-cultural Validation
C-HAQ	30 items for the C-HAQ-30; 38 items for the C-HAQ-38	The C-HAQ-30 has eight domains (dressing and grooming, arising, eating, walking, hygiene, reach, grip, and activities); the C-HAQ-38 has no domains.	Self-report for children 9 y old or older; guardian/proxy for children <9 y old	Past week	Four-point Likert scale	0-3	Higher score = greater disability	The median C-HAQ-30 scores corresponding with mild, mild to moderate, and disability were 0.13, 0.63, and 1.75, respectively (21).	Available in >30 countries (see Content)
JAFAS	10 ADLs	ADLs (getting out of bed, dressing, and picking an object up off the floor)	Observation by OT or PT of current function	N/A	Three-point scale based on task completion.	0-20	Higher score = greater disability	None	India
JASI	100 items for Part I; 5 items for Part II	JASI Part I has five domains (self-care, domestic, mobility, school, and extracurricular)	Child completes Part I on computer (20-45 min); child is interviewed for Part II (~20 minutes).	Current status	Seven-point degree of difficulty rating scale	Part I: 0-600; Part II: 0-30	Lower score = greater disability	Criterion-referenced test	None
PODCI	Original version had 114 items; newer version has 83 items for the adolescent version and 86 items for the parent version.	Subscales include upper extremity and physical function, transfers and basic mobility, sports and physical function, pain/comfort, happiness and a global function score.	Guardian proxy for children (2-10 y); self-report for adolescents (11-18 y)	Past week for all items except for one item that asks for recall of 1 y	Some nominal items (yes/no) and some Likert scales (either a four-point or five-point scale)	0-100	Higher score = less disability	Normative score of mean = 50 (SD = 10)	Available in Korean, Dutch, Spanish, Polish, Turkish, and Brazilian Portuguese
JAMAR	33 items	Total PF score has three components: PF lower limbs, PF hand and wrist, and PF upper segment; the HRQoL includes two subdimensions: physical health and psychosocial health.	Can be used as both a proxy report and a patient self-report (age 7-18 y for self-report)	Differs according to the specific measure	Some Likert scales, nominal items, and VAS scales.	PF score (0-45), HRQoL score (0-30)	Higher score = greater disability	None available	Available in >50 countries (see content description)

(Continued)

Table 1. (Cont'd)

Measure	Number of Items	Content/Domains	Method of Administration	Recall Period	Response Format	Range of Scores	Score Interpretation	Availability of Normative Data	Cross-cultural Validation
KOOS-Child	39 items	Five subscales: knee pain, knee symptoms, ADLs, sports and play, and quality of life	Completed using paper and pen and can be administered in person or via postal mail	Past week	Five-point Likert scales	0-100 for each subscale	A score of 100 = no symptoms; a score of 0 = extreme symptoms	Normative data are reported for children 8-17 y old (see Content)	Available in Danish, Dutch, English, Finnish, Greek, Norwegian, Persian, and Swedish
Pedi-IKDC	13 items	Physical function, participation in sports/recreation, ADLs, demographic, and medical history items	Paper-and-pencil administration	Most items over the past 4 wk; some items based on whether they could do the activity today	Some Likert scales; categorical items, VAS scales, and nominal items	0-100	Higher score = better function	In data on index knee among children who reported recent (4-wk) activity limitations the mean \pm SD score was 86.7 ± 16.8 , and the median was 94.6.	Available in English, Danish, and Dutch
ASK	30 items in the original version; 38 items in the revised version	Seven domains: personal care, dressing, other skills, locomotion, play, standing skills, and transfers	Completed by child (ages 9-15 y); parent may read items to child younger than 9 y	Past week	Children compare their ability to perform the activities with that of their healthy peers (-2 = much worse, 0 = the same as, and 2 = much better)	0-100	Higher score = less disability	Average score among healthy children was 93.12 (SD = 6.45).	Available in Canadian English, Canadian French, UK English, Spanish, and Dutch

* ADL = activity of daily living; ASK = Activity Scale for Kids; C-HAQ = Child Health Assessment Questionnaire; HRQoL = Pediatric Rheumatology Quality of Life Scale; JAFAS = Juvenile Arthritis Functional Assessment Scale; JAMAR = Juvenile Arthritis Multidimensional Assessment Report; JASI = Juvenile Arthritis Self-Report Index; KOOS-Child = Knee Osteoarthritis Outcome Survey for Children; N/A = not applicable; OT = occupational therapist; Pedi-IKDC = International Knee Documentation Committee Subjective Knee Evaluation Form in Children; PF = physical function; PODCI = Pediatric Outcomes Data Collection Instrument; PT = physical therapist; VAS = visual analog scale.

Table 2. Psychometrics*

Measure	Floor and Ceiling Effects	Reliability	Validity	Responsiveness	Minimally Important Differences	Generalizability	Used in RCTs
C-HAQ	Yes, for original C-HAQ; no, for revised version, C-HAQ38	Excellent reliability (Cronbach's $\alpha = 0.9$); test-retest $r_s = 0.8$; interrater strong (0.54-0.84)	Excellent content validity; moderate to good convergent validity with disease activity measures	Strong responsiveness for all three versions of the C-HAQ, with VAS _{C-HAQ} having the most responsiveness	For children with JIA, the MCID for improvement = 0.188 at most and the MCID for worsening = +0.125.	Used in a variety of arthritis conditions (JIA, juvenile DM, active juvenile SLE, juvenile IIM, CP, and generalized musculoskeletal pain)	Yes
JASI	None reported	Test-retest reliability is good to excellent for Part I (ICC = 0.98-0.99) and for Part II, ($\kappa = 0.57$)	Good content validity; construct validity moderate to good ($r = 0.51-0.80$)	Moderate SEM = 0.36	Not at this time	Not appropriate for children aged 7 years and younger	Limited
PODCI	None reported	Good to excellent internal consistency (Cronbach's $\alpha = 0.82-0.95$) Test-retest good to excellent (0.71-0.97)	Excellent content, convergent good, discriminant good	Good	Yes in children with CP	Used for children with a variety of musculoskeletal conditions	Yes
JAMAR							
KOOS-Child	Low (<15%)	Excellent internal consistency (Cronbach's $\alpha = 0.8-0.9$ except symptoms, $\alpha = 0.59$); good to excellent test-retest reliability (ICC = 0.78-0.91)	Excellent content validity; good construct validity (all hypotheses confirmed)	Moderate ES (0.42-0.78) for those with improvement and low ES for those with stable symptoms	MCID = 24.7-46.9	For use in children 10 to 16 years old with musculoskeletal conditions or injuries	Yes
Pedi-IKDC	Low; six items had a floor effect of >15% but did not hit critical threshold of 30%	Excellent internal consistency (Cronbach's $\alpha = 0.90-0.91$); excellent test-retest reliability (ICC = 0.9)	Excellent face and content validity (>75% relevant), adequate construct validity (75% hypotheses confirmed), and excellent discriminant validity	Excellent (ES = 1.36; SRM = 0.9-1.35)	MCID = 12 (SD = 1.35)	Not to be used in children under 10 years old or those with literacy limitations	Yes
PROMIS-PF	None (<15%)	Moderate internal consistency (Cronbach's $\alpha = 0.62-0.77$); moderate test-retest ($r = 0.7$)	Excellent content validity, moderate to good construct validity ($r = 0.4-0.8$), and moderate to good convergent validity ($r = 0.42-0.69$)	Established in a variety of conditions (eg, asthma and after abdominal surgery)	MCID = 2-3 points	Generic physical function measure for children and their parent proxy that has been used in healthy children and those with numerous health conditions	Yes
ASK	None reported	Excellent internal consistency (Cronbach's $\alpha = 0.99$), excellent test-retest reliability (ICC = 0.91-0.97), and excellent interrater reliability ($r = 0.99$)	Good to excellent content validity, excellent construct validity, and good to excellent convergent validity with measures of disease activity ($r = 0.81-0.92$)	Good to excellent (SRM = 1.1 for parent and SRM = 0.94 for child)	Not established	Used for children (ages 5-15 years) with musculoskeletal conditions, including arthritis	Yes

* ASK = Activity Scale for Kids; C-HAQ = Child Health Assessment Questionnaire; CP = cerebral palsy; ES = effect size; ICC = interclass correlation coefficient; IIM = idiopathic inflammatory myopathy; JAMAR = Juvenile Arthritis Multidimensional Assessment Report; JASI = Juvenile Arthritis Self-Report Index; JIA = juvenile idiopathic arthritis; KOOS-Child = Knee Osteoarthritis Outcome Survey for Children; MCID = minimal clinical important difference; Pedi-IKDC = International Knee Documentation Committee Subjective Knee Evaluation Form in Children; PODCI = Pediatric Outcomes Data Collection Instrument; PROMIS-PF = Patient-Reported Outcomes Measurement Information System-Physical Function Scale; RCT = randomized controlled trial; SLE = systemic lupus erythematosus; SRM = standardized response mean; VAS = visual analog scale.