Published in final edited form as:

Arthritis Care Res (Hoboken). 2011 November ; 63(0 11): S438–S445. doi:10.1002/acr.20560.

Measuring health related quality of life in juvenile rheumatoid arthritis

Adam C. Carle, PhD [Assistant Professor of Pediatrics],

University of Cincinnati School of Medicine, James M. Anderson Center for Health Systems Excellence, Cincinnati Children's Hospital Medical Center, 3333 Burnet Avenue, MLC 7014, Cincinnati, OH 45229

E. Morgan Dewitt, and

Cincinnati Children's Hospital Medical Center

M. Seid

Cincinnati Children's Hospital Medical Center

Abstract

Pediatric researchers and clinicians increasingly recognize the importance of measuring the impact of childhood disease across many aspects of a child's life. In this review, we describe four measures of health related quality of life (HRQOL) designed specifically for children with Juvenile Idiopathic Arthritis (JIA). HRQOL generally refers to how an individual feels about aspects of their life in relation to their health. The World Health Organization originally described HRQOL as minimally including: physical, mental, and social health dimensions.¹ Subsequent HRQOL definitions, while varied, have incorporated the notion that individuals have an important and distinct viewpoint regarding their disease and the quality of their life.² They have also often emphasized HRQOL's subjective nature.² These features present unique challenges when measuring HRQOL in children. Cognizant of these issues, we review the development and psychometric properties of the Pediatric Quality of Life Inventory (PedsQL) Rheumatology Module 3.0, the Juvenile Arthritis Quality of Life Questionnaire (JAQQ), the Paediatric Rheumatology Quality of Life Scale (PRQL), and the Childhood Arthritis Health Profile (CAHP).

Introduction

In this review, we describe four measures of health related quality of life (HRQOL) designed for children with Juvenile Idiopathic Arthritis (JIA). HRQOL generally refers to how an individual feels about aspects of their life in relation to their health. The World Health Organization originally described HRQOL as minimally including: physical, mental, and social health dimensions.¹ Subsequent definitions, while varied, have incorporated that individuals have an important and distinct viewpoint regarding their disease and quality of life.² They have also emphasized HRQOL's subjective nature.² These features present unique challenges when measuring HRQOL in children. A child's age and cognitive development may limit their ability to answer and understand questions, requiring proxy-report. Yet research suggests that parents and children do not always view HRQOL similarly and that these differences represent valid differences.^{3–5} Thus, for each of the measures below, users should evaluate strengths and weaknesses with respect to the perspective(s) they wish to measure and a child's developmental status.

Pediatric Quality of Life Inventory (PedsQL) Rheumatology Module 3.0

Purpose—Varni et al.⁶ designed the PedsQL Generic Core Scales as a generic HRQOL measure for use across the heterogeneous pediatric population, including healthy children and children with diseases. Whereas Varni et al.⁷ developed the PedsQL Rheumatology Module 3.0 to measure pediatric rheumatology-specific HRQOL. The Rheumatology Module measures HRQOL aspects uniquely important to children with rheumatic diseases and complements the core scales. The Rheumatology Module fits within Varni and colleague's broader efforts to measure HRQOL in pediatric health conditions using the PedsQL Generic Core Scales.^{6,8}

Content—The 22-item Rheumatology Module measures 5 dimensions: pain-hurt, daily activities, treatment, worry, and communication.

Number of Items—22 items comprise the Rheumatology Module: pain-hurt (4 items), daily activities (5 items), treatment (7 items), worry (3 items), and communication (3 items).

Recall Period for Items—Respondent's answers address the past month.

Endorsements—None.

Examples of use—Research has used the Rheumatoid Module to examine HRQOL for children with JIA and children generally,^{9,10} to investigate coping among children with JIA,¹¹ and explore outcomes,^{12,13} among other topics.

Practical Application

How to obtain: One can obtain a copy of the PedsQL Rheumatoid Module 3.0 online at www.pedsql.org. The site includes a detailed fee structure description.

Method of Administration: The PedsQL Rheumatology Module 3.0 uses parent (proxy) report and child self-report to measure HRQOL. Varni et al.⁷ argue that, when possible, one should measure both parent and child perspectives. Rheumatology Module questions use a 5-point ordinal (i.e., polytomous) scale for child (8–17) self- and parent proxy-report (ages 2–17). Options range from 0 (“Never a problem”) to 4 (“Almost always a problem”). Children aged 5–7 answer using a simplified 3-point scale, with each response anchored to a happy-to-sad-faces scale. A self-report form does not exist for children aged 2–5, relying instead on parent proxy-report to measure HRQOL for this age group. Additionally, for children aged 2–5, parent proxy-report does not include the worry and communication scales.

Scoring: Items are reverse coded and linearly transformed to a 0–100 scale (e.g., 0=100 to 4=0). Each scale score equals the average of the transformed items answered in a given scale. For scales with more than 50% missing data, one does not compute a scale score. However, research suggests little missing data occur.⁷

Score interpretation: High scores correspond to better quality of life. Cut-scores and minimally important clinical differences (MCIDs) have not been established.

Respondent burden: Administration takes approximately 15 minutes for child self-report and 10 minutes for parent proxy-report.

Administrative burden: No data available.

Translations/adaptations: In addition English, independent research groups have created French, German, Italian, Russian, Slovenian, and Spanish translations. Research has not yet validated these translations.¹⁴

Psychometric Information

Method of development: Varni et al.⁷ developed the Rheumatology Module using their experience developing previous HRQOL measures, a review of the literature, patient and parent focus groups, item generation, cognitive interviews, pretesting, and field testing of the final instrument in a sample of the target population.

Acceptability: Little missing data on the Rheumatology Module appear to occur (generally less than 2%) and sufficient proportions of respondents endorse each category.

Reliability: Varni et al.⁷ examined the reliability and validity of the PedsQL Rheumatology Module 3.0 in a sample of 231 children aged 5–18 and 244 parents of these (and additional) children aged 5–18. Parents and children (aged 8–18) self-administered the measures. An interviewer administered the measures to children aged 5–7. Cronbach's alphas across scales and forms generally demonstrated acceptable reliability for research, with the majority exceeding 0.70. Several parent proxy-report alphas exceeded 0.90. However, alphas for children aged 5–7 self-report were generally poor, limiting child self-report for this age range.

Validity: Varni et al.⁷ demonstrated construct validity by using ANOVA to compare groups of children known to differ in the investigated health construct. These analyses found statistically significant differences across several different groups of children with different types of rheumatic diseases (e.g., fibromyalgia vs. other rheumatic diseases) for both self- and proxy-report, supporting construct validity. The authors also established construct validity by examining intercorrelations among the PedsQL total score and the Rheumatology Module scale scores. They found medium to large effect size correlations.

Ability to detect change: The authors⁷ demonstrated responsiveness by examining change across time among patients for whom a change was expected. Repeated measures ANOVAs showed responsiveness for the pain and hurt scale.

Psychometric References: Varni, et al. The PedsQL^{TM} in pediatric rheumatology: reliability, validity, and responsiveness of the Pediatric Quality of Life Inventory^{TM} Generic Core Scales and Rheumatology Module. *Arthritis & Rheumatism*. 2002;46(3):714–725.⁷

Critical Appraisal

Strengths: The PedsQL Rheumatology Module 3.0 constitutes a relatively well validated measure of multiple dimensions of HRQOL specifically important to children with rheumatic diseases. When accompanied by the PedsQL Generic Core Scales, the two measures reliably and validly cover a broad range of HRQOL dimensions. Varni et al.⁷ specifically developed the Rheumatology Module to span a very broad age range for child self-report and an even broader age range when including parent-report. Moreover, they accomplished this while maintaining consistent items and scales across forms. This increases the comparability of scores across a wide range of ages and, for a given child, increases comparability across the child's life span.

Caveats: Some features limit the Rheumatology Module. Research has not used item response theory (IRT), structural equation modeling (SEM), or confirmatory factor analysis (CFA). Without this research, the internal validity of the Rheumatology Module remains

unestablished, which limits interpretability. Finally, the translations have not been examined.

Clinical usability: Research supports usability.

Research usability: Research supports usability.

Juvenile Arthritis Quality of Life Questionnaire (JAQQ)

Purpose—Duffy, et al.¹⁵ developed the JAQQ to measure HRQOL among children with juvenile rheumatoid arthritis (JRA) and juvenile spondyloarthritis (JSrA). They sought to create an easy to use, responsive instrument that measured multiple domains that could uniquely measure areas of importance to individual children.

Content—The JAQQ measures gross motor function, fine motor function, psychosocial function, and general symptoms.

Number of items: Total and subscales—The instrument includes 74 items: gross motor function (17), fine motor function (16), psychosocial function (22), and general symptoms (19).

Response options/scale—Each item uses a 7 point ordinal scale ranging from 1 (“None of the time”) to 7 (“All of the time”). The JAQQ also includes a measure of pain (100 mm pain Visual Analog Scale).

Recall period for items—No data available.

Endorsements—None.

Examples of use—Several avenues of research have included the JAQQ: research comparing parent and child perceptions of HRQOL,¹⁶ studies describing the HRQOL of children with JIA,¹⁷ and outcome studies.^{18–20}

Practical Application

How to obtain: One can obtain a copy of the JAQQ by writing Dr. Ciarán Duffy (ciaran.duffy@muhc.mcgill.ca), Director, Division of Rheumatology, Montreal Children’s Hospital, Rm C503, 2300 Tupper St., Montreal, Quebec, Canada H3H 1P3.

Method of administration: Parents and/or children (>9 years) self-administer the JAQQ.

Scoring: Respondents answer all items each time they receive the JAQQ. However, at first administration, patients to identify 5 items in each domain with which they have the most difficulty. Each dimension’s scores are computed as the unweighted average of the five items, at baseline and follow-ups. The total score equals the unweighted average of the dimension scores. Respondents can also volunteer items when completing the JAQQ. These patient generated items can become part of the dimensional score if they are among the five identified items. Duffy, et al.¹⁵ argue that this “ensures ... patient input is incorporated”. Change scores comprise differences between administrations.

Score interpretation: High scores correspond to poorer HRQOL.

Respondent burden: The measure takes approximately 20 minutes to complete at first administration and 5 minutes on subsequent administrations.

Administrative burden: Scoring takes approximately 5–10 minutes.

Translations/adaptations: English, French, and Dutch versions exist.

Psychometric Information

Method of development: An expert panel generated the initial item set. After translating into French and back translating into English, the authors pretested the English and French versions of the questionnaire by interviewing 10 rheumatology clinic patients (parents and children). Final development occurred among 91 patients from the Montreal Children's Hospital arthritis clinic. This included interviews with parents of 40 of the children. Initially generated items were classified into dimensions by expert opinion and reduced by expert opinion and cluster analysis. In this phase, a school/cognitive function dimension was deleted. The reduction process resulted in 85 items in the four domains.

Acceptability: No data available.

Reliability: Using a sample of 369 English children, Shaw et al.¹⁷ report Cronbach alphas of 0.94 for the gross motor domain, 0.97 for the fine motor domain, 0.93 for the psychosocial domain, 0.88 for the general domain, and 0.96 for the entire scale. To more validly estimate reliability, the authors computed these coefficients based on children's responses to all of the items in the JAQQ (rather than the individualized subset of most problematic items).

Validity: Pretesting and validation used a sample of 30 patients from the same clinic. To establish construct validity, Duffy et al.¹⁵ examined the correlation of the JAQQ dimension and total score with measures of joint disease activity and pain. The authors found moderate correlations between the JAQQ and measure of joint disease activity, with the highest correlations occurring between the JAQQ total score and the fine motor dimension with the sum of joint severity score ($r = 0.35$ and 0.36 respectively). JAQQ scores correlated relatively well with pain scores, while correlations for the psychosocial dimension were low to moderate with diseases activity ($r=0.19$) and pain ($r=0.34$). The authors observed mixed correlations for the general symptoms dimension with other scores. These correlations corresponded to the authors a priori hypotheses, indicating construct validity. With respect to face and content validity, 95% of the 20 experts agreed that the JAQQ addressed the dimensions it claims to measure and over 80% accepted each of the individual items.

Ability to detect change: To determine responsiveness, the authors compared correlations between JAQQ change scores and change scores on other included measures based on a priori predictions. They found that these correlations generally corresponded to the construct validity pattern (e.g., best between mean JAQQ and pain). Additionally, they indirectly demonstrated responsiveness by showing that the JAQQ discriminated among patients using physician-based global health categorizations. In other work (published as abstracts), Duffy and colleagues have further established the ability of the JAQQ to detect change.^{21,22} Research has not established cut-points or MCIDs for the JAQQ, nor do normative data exist.

Psychometric References: Duffy, et al. The Juvenile Arthritis Quality of Life Questionnaire-development of a new responsive index for juvenile rheumatoid arthritis and juvenile spondyloarthritis. *Journal of rheumatology*. 1997;24(4):738–746.

Shaw, et al. Health related quality of life in adolescents with juvenile idiopathic arthritis. *Arthritis Care & Research*. 2006;55(2):199–207.

Duffy, et al. Accuracy of functional outcome measures in defining improvement in juvenile idiopathic arthritis [abstract]. *Annals Rheum Dis*. 2000;59:724–725.

Critical Appraisal

Strengths: The JAQQ offers a rheumatology-specific measure that incorporates a range of items relevant to a child's physical and psychosocial health and functional status. Duffy et al.¹⁵ argue that the JAQQ presents a clinical advantage over other measures because it offers individualized assessment. Each child selects the 5 most problematic items in each domain and only these items are scored on the initial and subsequent administrations. This potentially increases the instrument's sensitivity to clinical change and may make it especially useful in clinical settings focused on an individual child. However, this essentially renders the instrument unusable in research. In essence, no two children complete the same measure making comparisons across children impossible. It also limits the JAQQ's discriminant validity. Duffy et al.¹⁵ have argued that the unique scoring system makes the JAQQ especially suited to clinical trials. However, it is not clear that this is an advantage because the meaning of a change score differs across children, obscuring results describing average change (see Crocker and Algina,²³ McDonald,²⁴ or Nunnally²⁵ for discussions of the psychometric properties scores should have to make them useful in research.)

Caveats: In pretesting, the authors identified items patients rarely or never endorsed, as well as items that appeared to measure similar things as other items on the 85 item questionnaire. As a result, they trimmed an additional 11 items, resulting in a total of 74 items in four dimensions (described above). Thus, while the current form of the JAQQ has 74 items, the validity data correspond to the 85 item version, warranting some caution regarding the validity of the present version. As another limit, published research has not used IRT, SEM, or CFA to evaluate the psychometric properties of the JAQQ. This transpires partly because of the unique method by which patients and parents complete the measure. Without this research, the internal validity and measurement structure of the JAQQ remains unclear, which limits the scales' interpretability. Perhaps future research will make use of IRT and develop a computerized adaptive test²⁶ version of the JAQQ, which would simultaneously offer an assessment tailored to a child while still delivering a score comparable across children. The JAQQ does not include a specific dimension to measure HRQOL with respect to school and cognitive ability, which limits the JAQQ's coverage of important HRQOL dimensions in childhood. Finally, research has not investigated the translations.

Clinical usability: The unique scoring system of the JAQQ may make it especially useful in clinical work. By including patient generated items, the JAQQ should capture important HRQOL issues.

Research usability: Currently unresolved key issues (e.g., reliability and a score's meaning across children) limit its application in research.

Paediatric Rheumatology Quality of Life Scale (PRQL)

Purpose—Believing that the length of existing pediatric HRQOL measures limits their use in clinical care, Filocamo, et al.²⁷ sought to develop and validate a short HRQOL measure specific to pediatric rheumatic disease (PRD).

Content—The Paediatric Quality of Life Scale (PRQL) measures physical health (PhH) and psychosocial health (PsH).

Number of items—The PRQL comprises 10 items total, 5 for each subscale.

Response options/scale—Both parent and child forms use a four-point ordinal scale (0-“Never” to 3 “All the time”) to measure the frequency of symptoms in the previous month for all items.

Recall period for items—Respondents apply their answers to the previous month.

Endorsements—None.

Examples of use—Other than the study describing its development, no examples of the PRQL’s use yet exist.

Practical Application

How to obtain: One can obtain a copy of the parent and child English versions of the instrument by downloading the supplemental material accompanying the article that describes the scale’s development.²⁷

Method of administration: The PRQL has parent proxy-report and child-self report forms.

Scoring: The PhH and PsH scores constitute the total sum of the item responses for each subscale respectively or the total sum for items within each subscale (with specific instructions for scoring items marked not applicable). The total score ranges from 0 to 30 and separate subscale (PhH and PsH) scores each range 0 to 15. The authors instruct users not to create a total score if more than two questions are marked inapplicable in a given scale. The PhH and PsH scores constitute the total sum of the item responses for each subscale respectively or the total sum for items within each subscale (with specific instructions for scoring items marked not applicable).

Score interpretation: High scores correspond to poorer functioning.

Respondent burden: Completion takes approximately 5 minutes or less.

Administrative burden: Scoring takes approximately 5 minutes or less.

Translations/adaptations: The PRQL has both Italian and English versions. However, research has not examined the psychometric properties of the English translation of the PRQL.

Psychometric Information

Method of development: A panel of six pediatric rheumatologists developed the PRQL. The panel initially identified and derived 389 items through a review of the literature and existing pediatric HRQOL measures, discussion, and semi-structured face-to-face interviews with 37 children with PRD and their parents. Subsequently, the panel kept 25 items relevant to the two desired domains, general to all PRDs, applicable to children of all ages, that expressed a single idea, and about which the entire panel agreed the questionnaire should include. The developers then asked another expert panel (which included pediatric rheumatologists and others) and a convenience sample of 42 children and their parents to comment on and criticize the draft measure. This resulted in the deletion of 15 additional items, ending at the final 10 item measure.

Acceptability: No data available.

Reliability: Using a predominantly female sample (77%) of 472 children with JIA, the authors evaluated the psychometric properties of the Italian PRQL. To assess reliability, Filocamo et al.²⁷ had 35 parents complete the PRQL a second time within 24 hours. This resulted in test-retest reliability coefficients of 0.91 for the total score, 0.85 for the PhH subscale, and 0.92 for the PsH subscale. These values support the use of the total score and PsH subscale for use in individual patient analyses and the PhH scale in research.²⁵

Validity: As part of the validation process, the authors report using exploratory factor analysis, with an orthogonal rotation (which forces all underlying factors to be uncorrelated) to examine the construct validity and internal structure of the PRQL. Internal validity refers to the extent to which data support the hypothesis that the question sets do indeed measure two separate constructs. These results indicated a two factor solution, providing support for creating two subscales. Subsequently, the authors evaluated construct validity by examining the extent to which the PRQL correlated with the Juvenile Arthritis Functioning Scale (JFAS), parent's and/or patient's global assessment of the child's well-being, and pain ratings. The authors predicted and generally observed moderate to high correlations in the expected direction for the PhH subscale with parent's assessment of both child's overall well-being, pain intensity, JAFS score, and tender and active joint counts. The remaining correlation for the PhH subscale and all correlations for the PsH subscale were poor.

In addition to construct validity, Filcarno et al. assessed discriminative validity. They did this by examining whether differences in the median total PRQL scores corresponded in the expected direction to physicians' ratings of disease course, changes in disease outcome from previous visit, and assessment of morning stiffness. They also examined whether the proportion of children with a score of 0 (i.e., good HRQOL) corresponded to theoretical expectations across these groups. These results generally supported the PRQL's ability to discriminate (e.g., patients with > 30 minutes of morning stiffness had the highest median scores). The authors also demonstrated responsiveness by examining whether patients and their parents rated HRQOL worse than healthy children rated their HRQOL. These results showed that only the PhH scale differentiated between these groups.

Finally, as part of the development process, the authors established face and content validity by consulting a panel of experts (which included pediatric rheumatologists). The entire panel indicated their support of the measure's face validity and the appropriateness and coverage of the measure's content. The authors also established face and content validity by asking a convenience sample of 42 children and their parents to complete and criticize the draft PRQL.

Ability to detect change: The authors used the standardized response mean (SRM: the mean change score across children divided by the standard deviation of the change scores) to evaluate responsiveness to clinical change using changes in parents' and patients' scores at a follow-up administration 3–9 months after baseline. The parents', patients', and physicians' ratings of disease course provided external criteria for the SRM. For patients rated as improved by a physician, the total score and both subscales were moderately responsive, however for patients rated as worsened, the total score and PhH subscale demonstrated small responsiveness and poor responsiveness for the PsH subscale. Filcarno et al. also identified MCIDs for the parent report. They computed MCIDs as the average change score that corresponded to a rating by the parent, patient, or physician as slightly improved or slightly worsened from the previous visit. MCIDs ranged from –1.7 (slightly improved) to 1.5 (slightly worsened) for the total score. However, the confidence intervals (CIs) for these overlapped the score for children with stable disease course. This problem was particularly pronounced for the subscale MCIDs, with the CIs for slightly improved and worsened

overlapping even with each other. This indicates that more work is needed to establish MCIDs that discriminate well. Research has not established cut-points or normative data.

Psychometric References: Filocamo, et al. A new short and simple health-related quality of life measurement for paediatric rheumatic diseases: initial validation in juvenile idiopathic arthritis. *Rheumatology*. 2010;49(7):1272.

Critical Appraisal

Strengths: The PRQL delivers a very short measure of two dimensions of HRQOL relevant to children with rheumatic diseases. While its brevity can be a strength (because patients can complete it quickly and clinicians can score it quickly), its brevity means that it does not cover the range of potentially important dimensions and aspects of HRQOL.

Caveats: Like other measures of HRQOL specific to pediatric rheumatology, published research has not yet applied IRT, SEM, CFA or other latent variable methods to evaluate the PRQL's internal validity. Though the authors report conducting exploratory factor analyses (EFA), it is unclear whether they used an appropriate analytic technique. They report using factor analysis, but provide a reference for principal components analysis (PCA). Factor analyses would more validly have examined the question of interest.²⁴ In addition, it is not clear whether they incorporated the ordered-categorical nature of the data in their model. Research shows that this can lead to spurious dimensions²⁸ and subsequently biased loading estimates. This limits the interpretability of the published results. Finally, while initial evidence seems to support the validity of the total and PhH subscale scores, the results did not strongly support the PsH subscale score. Finally, the psychometric properties of the English translation have not been examined.,

Clinical usability: The scale's brevity may make the total score and PhH scores potentially attractive in clinical settings.

Research usability: Several issues (see caveats above) limit the PRQL's use in research.

Childhood Arthritis Health Profile (CAHP)

Purpose—Tucker et al.²⁹ developed the Childhood Arthritis Health Profile (CAHP) to capture a broad range of health statuses in children with JIA.

Content—The CAHP measures physical functioning, psychosocial functioning, and the disease's effect on the family. It was developed and is intended to be used with the Childhood Health Questionnaire (CHQ). The CAHP includes 3 modules: generic health status (measured by the CHQ), JRA specific scales, and patient characteristics.

Number of items—No data available.

Response options/scale—No data available.

Recall period for items—No data available.

Endorsements—None.

Examples of use—Other than manuscripts discussing measures for measuring HRQOL among children with JIA, we found no examples of the CAHP's use.

Practical Application

How to obtain: No data available.

Method of administration: Parents or teens (13+) self administer the CAHP.

Scoring: No data available.

Score interpretation: No data available.

Respondent burden: No data available.

Administrative burden: No data available.

Translations/adaptations: No data available.

Psychometric Information

Method of development: The self-administered instrument was developed using prospective data from 80 children with juvenile rheumatoid arthritis (JRA) aged 5 to 15 years old. A multidisciplinary team that included a pediatric rheumatologist, physiotherapist, nurse, social worker, and a parent of a child with JRA generated the initial parent report CAHP items.³⁰

Acceptability: No data available.

Reliability: Tucker et al.,²⁹ report reliability coefficients ranged 0.84 to 0.97, supporting reliability.

Validity: Tucker et al.,²⁹ focusing on the functional status scales, used factor analysis and multitrait analysis to determine the internal consistency and discriminant validity of the parent report CAHP. Factor analyses identified 3 latent variables labeled: gross motor function, fine motor function, and usual role activities, and the authors used the factor analysis results to assign items to three scales measuring these variables. Additional analyses indicated that 96% of the items had higher correlations with their assigned scales than with other scales, supporting discriminant validity. Finally, the specific functional status scales correlated 0.73 with the CHQ's generic physical functioning scale, indicating that the CAHP may measure aspects not captured by generic scales.

Ability to detect change: No data available.

References: To date, only an abstract²⁹ and secondary sources describe the CAHP.^{30–32}

Critical Appraisal

Strengths: Too little data exist to identify strengths.

Caveats: Unfortunately, little detailed published work describes the psychometric properties of the CAHP or the methods by which previously reported psychometric properties were obtained. Research has not described the CAHP's response options, recall period, total number of items, scoring method, development or psychometric properties of the teen report version, psychometric properties of the CAHP's other scales, or other important features of the CAHP. Additionally, it is not clear how one obtains a copy of the CAHP. These features limit its clinical and research utility.

Clinical usability: Too little data exist to evaluate clinical usability.

Research usability: Too little data exist to evaluate research usability.

Conclusion

Summarily, investigators have developed a variety of HRQOL measures designed for assessing HRQOL in JIA. Table 1 briefly summarizes each measure reviewed here. Hopefully future research will address the psychometric properties and internal validity of these measures using SEM and IRT, as well the relative utility of a disease specific approach vs. a more generally approach (e.g., NIH's Patient Reported Outcomes Measurement Information System: PROMIS).

Acknowledgments

Adam Carle would like to thank Tara J. Carle, Lyla S. B. Carle, and Margaret Carle whose unending support and thoughtful comments make his work possible.

Grant Support: The following grants supported this work: NINR-R15NR10631 (Carle); U01AR057940-02 (Morgan Dewitt); U01AR057940-02S1 (Carle)

References

1. Organization WH. Constitution of the World Health Organization basic document. 1948.
2. Eiser C, Morse R. A review of measures of quality of life for children with chronic illness. *Archives of disease in childhood*. 2001; 84(3):205. [PubMed: 11207164]
3. Eiser, C.; Kopel, S. Perceptions of health and illness: Current research and applications. 1997. *Children's perceptions of health and illness*; p. 47-76.
4. Seid M, Opipari L, Huang B, Brunner H, Lovell D. Disease control and health related quality of life in juvenile idiopathic arthritis. *Arthritis Care & Research*. 2009; 61(3):393-399. [PubMed: 19248113]
5. Varni J, Katz E, Colegrove R Jr, Dolgin M. Adjustment of children with newly diagnosed cancer: Cross-informant variance. *Journal of Psychosocial Oncology*. 1995; 13(4):23-38.
6. Varni J, Seid M, Rode C. The PedsQL (TM): Measurement model for the pediatric quality of life inventory. *Medical Care*. 1999; 37(2):126. [PubMed: 10024117]
7. Varni J, Seid M, Smith Knight T, Burwinkle T, Brown J, Szer I. The PedsQL™ in pediatric rheumatology: reliability, validity, and responsiveness of the Pediatric Quality of Life Inventory™ Generic Core Scales and Rheumatology Module. *Arthritis & Rheumatism*. 2002; 46(3):714-725. [PubMed: 11920407]
8. Varni J, Seid M, Kurtin P. PedsQL (TM) 4.0: Reliability and validity of the Pediatric Quality of Life Inventory (TM) version 4.0 Generic Core Scales in healthy and patient populations. *Medical Care*. 2001; 39(8):800. [PubMed: 11468499]
9. Varni JW, Limbers CA, Burwinkle TM. Impaired health-related quality of life in children and adolescents with chronic conditions: a comparative analysis of 10 disease clusters and 33 disease categories/severities utilizing the PedsQL™ 4.0 Generic Core Scales. *Health and quality of life outcomes*. 2007; 5(1):43. [PubMed: 17634123]
10. Schwimmer JB, Burwinkle TM, Varni JW. Health-related quality of life of severely obese children and adolescents. *JAMA: the journal of the American Medical Association*. 2003; 289(14):1813. [PubMed: 12684360]
11. Sawyer MG, Whitham J, Robertson DM, Taplin J, Varni J, Baghurst PA. The relationship between health-related quality of life, pain and coping strategies in juvenile idiopathic arthritis. *Rheumatology*. 2004; 43(3):325. [PubMed: 14566031]
12. Powell M, Seid M, Szer IS. Efficacy of custom foot orthotics in improving pain and functional status in children with juvenile idiopathic arthritis: a randomized trial. *The Journal of rheumatology*. 2005; 32(5):943. [PubMed: 15868634]

13. Brunner HI, Taylor J, Britto MT, et al. Differences in disease outcomes between medicaid and privately insured children: possible health disparities in juvenile rheumatoid arthritis. *Arthritis Care & Research*. 2006; 55(3):378–384. [PubMed: 16739206]
14. Varni, J. [Accessed January 24, 2011] PedsQL 2011. 2011. www.pedsql.org
15. Duffy C, Arsenault L, Duffy K, Paquin J, Strawczynski H. The Juvenile Arthritis Quality of Life Questionnaire-development of a new responsive index for juvenile rheumatoid arthritis and juvenile spondyloarthritis. *Journal of rheumatology*. 1997; 24(4):738–746. [PubMed: 9101511]
16. April KT, Feldman DE, Platt RW, Duffy CM. Comparison between children with juvenile idiopathic arthritis (JIA) and their parents concerning perceived quality of life. *Quality of life research*. 2006; 15(4):655–661. [PubMed: 16688498]
17. Shaw K, Southwood T, Duffy C, McDonagh J. Health related quality of life in adolescents with juvenile idiopathic arthritis. *Arthritis Care & Research*. 2006; 55(2):199–207. [PubMed: 16583399]
18. Feldman DE, De Civita M, Dobkin PL, Malleson PN, Meshefedjian G, Duffy CM. Effects of adherence to treatment on short term outcomes in children with juvenile idiopathic arthritis. *Arthritis Care & Research*. 2007; 57(6):905–912. [PubMed: 17665485]
19. McDonagh J, Southwood T, Shaw K. The impact of a coordinated transitional care programme on adolescents with juvenile idiopathic arthritis. *Rheumatology*. 2007; 46(1):161. [PubMed: 16790451]
20. Takken T, van der Net J, Helders PJM. Do juvenile idiopathic arthritis patients benefit from an exercise program? A pilot study. *Arthritis Care & Research*. 2001; 45(1):81–85. [PubMed: 11308067]
21. Duffy C, Watanabe Duffy K, Gibbon M, Yang H, Platt R. Accuracy of functional outcome measures in defining improvement in juvenile idiopathic arthritis [abstract]. *Annals Rheum Dis*. 2000; 59:724–725.
22. Duffy C, Arsenault L, Watanabe Duffy K, Paquin JHS. Validity and sensitivity to change of the Juvenile Arthritis Quality of Life Questionnaire [abstract]. *Arthritis Rheum*. 1993; 36(Supplement 9):S144.
23. Crocker, L.; Algina, J. Introduction to classical and modern test theory. Holt, Rinehart and Winston; 6277 Sea Harbor Drive, Orlando, FL 32887 (\$44.75): 1986.
24. McDonald, RP. Test theory: A unified treatment. Mahwah, NJ: Erlbaum; 1999.
25. Nunnally, JC.; Bernstein, I. Psychometric theory. Vol. 2d. New York: McGraw-Hill; 1994.
26. Van Der Linden, W.; Glas, C. Computerized adaptive testing: Theory and practice. Springer; Netherlands: 2000.
27. Filocamo G, Schiappapietra B, Bertamino M, et al. A new short and simple health-related quality of life measurement for paediatric rheumatic diseases: initial validation in juvenile idiopathic arthritis. *Rheumatology*. 2010; 49(7):1272. [PubMed: 20338888]
28. Bernstein IH, Teng G. Factoring items and factoring scales are different: Evidence for multidimensionality due to item categorization. *Psychological Bulletin*. 1989; 105:465–477.
29. Tucker L, DeNardo B, Abetz L, Landgraf J, Schaller J. The Childhood Arthritis Health Profile (CAHP): validity and reliability of the condition specific scales. *Arthritis Rheum*. 1995; 38(Suppl 9):S183.
30. Duffy C, Tucker L, Burgos-Vargas R. Update on functional assessment tools. *The Journal of rheumatology Supplement*. 2000; 58:11. [PubMed: 10782850]
31. Duffy C, Watanabe Duffy K. Health assessment in the rheumatic diseases of childhood. *Current opinion in rheumatology*. 1997; 9(5):440. [PubMed: 9309200]
32. Duffy C. Assessing Outcome in Juvenile Idiopathic Arthritis. *Journal of the Canadian Rheumatology Association*. 2000 Jul 4–7.

Significance and Innovation

This manuscript shows the importance of using a reliable and valid measure when evaluating health related quality of life (HRQOL) among children with Juvenile Idiopathic Arthritis (JIA).

Table 1
Summary of measures designed to measure health related quality of life (HRQOL) for Juveniles with Rheumatoid Arthritis (JIA)

Scale	Purpose	Administration Method	Respondent burden	Administration burden	Interpretation of scores	Reliability evidence	Validity evidence	Ability to detect change	Strengths	Cautions
PedsQL Rheumatology Module	Measure a broad range of rheumatology specific HRQOL.	Parent proxy-report (ages 2–17) and child self-report (ages 5–17).	20 minutes.	Hand scored.	Scores range 0–100. High scores indicate better HRQOL.	Internal consistency good for most forms and excellent for some.	Face, content, and construct validity established.	Not established.	Sound psychometric properties. Appropriate for research use.	Internal validity not established.
Juvenile Arthritis Quality of Life Questionnaire (JAQQ)	Measure multiple rheumatology specific HRQOL domains and uniquely measure areas of importance to individual children.	Parent proxy-report and child self-report. For children 9 years of age and older.	20 minutes.	Hand scored.	High scores indicate poorer HRQOL.	Internal consistency good.	Face, content, and construct validity established.	Not established.	Several sound psychometric properties. Useful for incorporating individualized HRQOL measurement.	Scoring system limits interpretability and use. Internal validity not established.
Paediatric Rheumatology Quality of Life (PRQL) Scale	Briefly measure two HRQOL domains: physical health (PhH) and psychosocial health (PsH)	Parent proxy-report (2–17) and child self-report.	Less than 5 minutes to complete.	Hand scored in less than 5 minutes.	Total score ranges 0–30. Subscales range 0–15. High scores indicate poorer HRQOL.	Test retest excellent for total score and PsH. Good for PhH.	Face, content, discriminative, and construct validity established.	SRMs and MCIDs established (with caveats to MCIDs utility).	Short, easily and quickly administered and scored.	Limited support for PhS scale.
Childhood Arthritis Health Profile (CAHP)	Capture a broad range of health statuses in children with JIA.	Parent proxy-report and child self-report. Children aged 13 and older.	15 minutes.	Unknown.	Unknown.	Reliability coefficients range 0.84–0.97.	Internal and discriminant validity partially established.	Unknown.	N/A	Limited psychometric information. Not recommended for clinical or research use.