

## MEASUREMENT OF HEALTH STATUS IN CHILDREN WITH JUVENILE RHEUMATOID ARTHRITIS

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**Objective.** To develop and validate a self- or parent-administered instrument for measuring functional status in children with juvenile rheumatoid arthritis (JRA).

**Methods.** We adapted the Stanford Health Assessment Questionnaire (HAQ) for use in children ages 1-19 years, by adding several new questions, such that for each functional area, there was at least 1 question relevant to children of all ages. The face validity of the instrument was evaluated by a group of 20 health professionals and parents of 22 healthy children. The questionnaire was then administered to parents of 72 JRA patients (mean age 9.1 years, onset type systemic in 16, polyarticular in 21, pauciarticular in 35).

**Results.** The instrument showed excellent internal reliability (Cronbach's  $\alpha = 0.94$ ), with a mean inter-item correlation of 0.6. The convergent validity was demonstrated by strong correlations of the Disability Index (average of scores on all functional areas) with Steinbrocker functional class (Kendall's tau  $b = 0.77$ ,  $P < 0.0001$ ), number of involved joints (Kendall's tau  $b = 0.67$ ,  $P < 0.0001$ ), and morning stiffness (Kendall's tau  $b = 0.54$ ,  $P < 0.0001$ ). Spearman's correlation coefficient between Disability Index scores from questionnaires administered to parents and those from questionnaires administered to older children ( $>8$  years) was 0.84 ( $n = 29$ ;  $P < 0.001$ ), showing that parents can accurately report for their children. The test-retest

reliability, studied at a 2-week interval, revealed virtually identical Disability Index scores measured on the 2 occasions (0.96 versus 0.96;  $P > 0.9$  by paired  $t$ -test; Spearman's correlation coefficient = 0.8,  $P < 0.002$ ).

**Conclusion.** The Childhood HAQ, which takes less than 10 minutes to complete, is a valid, reliable, and sensitive instrument for measuring functional status in children with JRA.

Juvenile rheumatoid arthritis (JRA) is the most common rheumatic disease of childhood and a leading cause of childhood disability and blindness (1,2). Assessment of outcome in patients with JRA is currently limited to traditional "process" measures such as joint counts and erythrocyte sedimentation rates (3-5). Recent investigations have highlighted the shortcomings of these traditional outcome measures even within the restricted realm of prospective, controlled intervention trials (3-5). There are few instruments designed specifically for measuring health status in children, and instruments whose applicability to JRA patients has been studied have demonstrated poor measurement qualities (6) or have required skilled personnel to conduct expensive, time-consuming testing (7). The recently developed Juvenile Arthritis Functional Assessment Scale (JAFAS) and Juvenile Arthritis Functional Assessment Report do not enable assessment in children younger than 7 years and thus miss a substantial proportion of patients with JRA (8,9). JAFAS also requires skilled personnel to administer the test in an office or hospital-based setting, using special standardized equipment (8). Other instruments, such as the Hoskins and Squires Test for Gross Motor and Reflex Development (10), the Basic Gross Motor Assessment (11), and the Denver Development and Screening Test (12), were designed to assess developmental delays and cannot be easily adapted to provide a measure of disability. They are also age specific and cannot be applied across different age groups.

In this report, we describe the development and

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**CHILDHOOD HEALTH ASSESSMENT QUESTIONNAIRE**

In this section, we are interested in learning how your child's illness affects his/her ability to function in daily life. Please feel free to add any comments on the back of this page. In the following questions, please check the one response which best describes your child's usual activities (averaged over an entire day) **OVER THE PAST WEEK. ONLY NOTE THOSE DIFFICULTIES OR LIMITATIONS WHICH ARE DUE TO ILLNESS.** If most children at your child's age are not expected to do a certain activity, please mark it as "Not Applicable". For example, if your child has difficulty in doing a certain activity or is unable to do it because he/she is too young but NOT because he/she is RESTRICTED BY ILLNESS, please mark it as "Not Applicable".

	<u>Without ANY Difficulty</u>	<u>With SOME Difficulty</u>	<u>With MUCH Difficulty</u>	<u>UNABLE To Do</u>	<u>Not Applicable</u>
<b>DRESSING &amp; GROOMING</b>					
Is your child able to:					
-Dress, including tying shoelaces and doing buttons?	_____	_____	_____	_____	_____
-Shampoo his/her hair?	_____	_____	_____	_____	_____
-Remove socks?	_____	_____	_____	_____	_____
-Cut fingernails?	_____	_____	_____	_____	_____
<b>ARISING</b>					
Is your child able to:					
-Stand up from a low chair or floor?	_____	_____	_____	_____	_____
-Get in and out of bed or stand up in crib?	_____	_____	_____	_____	_____
<b>EATING</b>					
Is your child able to:					
-Cut his/her own meat?	_____	_____	_____	_____	_____
-Lift a cup or glass to mouth?	_____	_____	_____	_____	_____
-Open a new cereal box?	_____	_____	_____	_____	_____
<b>WALKING</b>					
Is your child able to:					
-Walk outdoors on flat ground?	_____	_____	_____	_____	_____
-Climb up five steps?	_____	_____	_____	_____	_____

\* Please check any AIDS or DEVICES that your child usually uses for any of the above activities:

- |                |   |
|----------------|---|
| ___ Cane       | ___ Devices used for dressing (button hook, zipper pull, long-handled shoe horn, etc) |
| ___ Walker     | ___ Built Up pencil or special utensils   |
| ___ Crutches   | ___ Special or Built Up chair   |
| ___ Wheelchair | ___ Other (Specify: _____)  |

\* Please check any categories for which your child usually needs help from another person BECAUSE OF ILLNESS:

- |                           |             |
|---------------------------|-------------|
| ___ Dressing and Grooming | ___ Eating  |
| ___ Arising               | ___ Walking |

Figure 1. The Childhood Health Assessment Questionnaire: Disability and Discomfort sections.

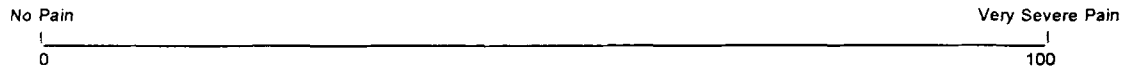
	<u>Without ANY Difficulty</u>	<u>With SOME Difficulty</u>	<u>With MUCH Difficulty</u>	<u>UNABLE To Do</u>	<u>Not Applicable</u>
<b>HYGIENE</b>					
Is your child able to:					
-Wash and dry entire body?	_____	_____	_____	_____	_____
-Take a tub bath (get in & out of tub)?	_____	_____	_____	_____	_____
-Get on and off the toilet or potty chair?	_____	_____	_____	_____	_____
-Brush teeth?	_____	_____	_____	_____	_____
-Comb/Brush hair?	_____	_____	_____	_____	_____
<b>REACH</b>					
Is your child able to:					
-Reach and get down a heavy object such as a large game or books from from just above his/her head?	_____	_____	_____	_____	_____
-Bend down to pick up clothing or a piece of paper from the floor?	_____	_____	_____	_____	_____
-Pull on a sweater over his/her head?	_____	_____	_____	_____	_____
-Turn neck to look back over shoulder?	_____	_____	_____	_____	_____
<b>GRIP</b>					
Is your child able to:					
-Write or scribble with pen or pencil?	_____	_____	_____	_____	_____
-Open car doors?	_____	_____	_____	_____	_____
-Open jars which have been previously opened?	_____	_____	_____	_____	_____
-Turn faucets on and off?	_____	_____	_____	_____	_____
-Push open a door when he/she has to turn a door knob?	_____	_____	_____	_____	_____
<b>ACTIVITIES</b>					
Is your child able to:					
-Run errands and shop?	_____	_____	_____	_____	_____
-Get in and out of car or toy car or school bus ?	_____	_____	_____	_____	_____
-Ride bike or tricycle?	_____	_____	_____	_____	_____
-Do household chores (eg, wash dishes, take out trash, vacuuming, yardwork, make bed, clean room)?	_____	_____	_____	_____	_____
-Run and play?	_____	_____	_____	_____	_____
<b>* Please check any AIDS or DEVICES that your child usually uses for any of the above activities:</b>					
_____ Raised Toilet Seat		_____ Bathtub bar			
_____ Bathtub Seat		_____ Long-Handled Appliances for Reach			
_____ Jar Opener (for jars previously opened)		_____ Long-Handled Appliances in Bathroom			
<b>* Please check any categories for which your child usually needs help from another person BECAUSE OF ILLNESS?</b>					
_____ Hygiene		_____ Gripping and Opening things			
_____ Reach		_____ Errands and Chores			

(Figure 1. Cont'd.)

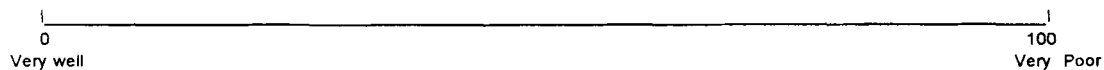
We are also interested in learning whether or not your child has been affected by pain because of his or her illness.

How much pain do you think your child has had because of his or her illness **IN THE PAST WEEK?**

Place a mark on the line below to indicate the severity of the pain.



Considering all the ways that arthritis affects your child, rate how your child is doing on the following scale by placing a mark on the line.



(Figure 1. *Cont'd.*)

validation of the Disability and Discomfort dimensions of a new parent- and/or patient-administered questionnaire designed to assess health status in children with JRA, the Childhood Health Assessment Questionnaire. This instrument has been adapted from the Stanford Health Assessment Questionnaire (HAQ), which is a standard component of the Arthritis, Rheumatism and Aging Medical Information System (ARAMIS). The Stanford HAQ has undergone extensive validation in more than 30 studies and has now been administered more than 100,000 times in various national and international settings (13–15). The HAQ attempts to quantitatively describe disability in terms that represent patient perceptions of this condition. We chose to adapt the Stanford HAQ rather than design another instrument since this will permit compatibility with the ARAMIS databases, facilitating comparison of functional status in various rheumatic diseases and allowing us to follow up patients into adulthood using the same conceptual and questionnaire structure.

## PATIENTS AND METHODS

**Patients.** Seventy-two children (27 boys, 45 girls) ages 1–19 years (mean  $\pm$  SEM  $9.1 \pm 0.6$  years) were studied. All patients had a diagnosis of JRA according to the American College of Rheumatology criteria (16). The onset type was systemic in 16, polyarticular in 21, and pauciarticular in 35 (a rather typical distribution at a large referral center). Disease activity was evaluated by physician's global assess-

ment, on a 4-point scale (0 = inactive, 1 = mild, 2 = moderate, 3 = severe disease); 9 patients were found to have inactive disease, while 32 had mild disease activity, 24 had moderate disease activity, and 7 had severe disease activity. Of the 72 patients, 38 were assessed to be in Steinbrocker functional class I, 18 in class II, 14 in class III, and 2 in class IV (17). Twenty-two healthy children (9 boys, 13 girls) ages 1–17 years (mean  $\pm$  SEM  $7.9 \pm 0.8$  years) served as control subjects during the face validation part of the study.

**Childhood health assessment questionnaire.** The Disability section of the Childhood HAQ assesses functions in 8 areas: Dressing and Grooming, Arising, Eating, Walking, Hygiene, Reach, Grip, and Activities (Figure 1). Three components are evaluated for each area: (a) ratings of the degree to which daily functions are difficult to perform, (b) reported use of special aids or devices, and (c) activities for which assistance of another person is required. This section has been adapted from the Stanford HAQ for use in children by adding several new questions such that for each functional area, there is at least 1 question that is relevant to children of all ages. Further, to eliminate discrepancies introduced by growth and development, parents are asked to note only those difficulties that are caused by arthritis. Each question is scored from 0 to 3, in parallel with Steinbrocker functional classification scores (0 = no difficulty, 1 = some difficulty, 2 = much difficulty, 3 = unable to do). The question with the highest score determines the score for that functional area. If aids or devices are used or help is needed to complete tasks in a certain area, a minimum score of 2 is recorded for the corresponding functional area. The scores for each of the 8 functional areas are averaged to calculate the Disability Index.

Discomfort is determined by the presence of pain and its severity in the past week, rated on a doubly anchored horizontal visual analog scale (with anchors of "no pain"



**Table 2.** Inter-component and component-versus-disability index correlations (Spearman) in the Childhood Health Assessment Questionnaire

	Dress	Arise	Eat	Walk	Hygiene	Reach	Grip	Activity	Disability Index
Dress	1.00								0.71
Arise	0.53	1.00							0.67
Eat	0.68	0.43	1.00						0.62
Walk	0.50	0.67	0.45	1.00					0.69
Hygiene	0.62	0.62	0.56	0.65	1.00				0.75
Reach	0.69	0.57	0.64	0.57	0.74	1.00			0.79
Grip	0.64	0.50	0.64	0.38	0.56	0.66	1.00		0.66
Activity	0.56	0.63	0.51	0.79	0.70	0.67	0.48	1.00	0.76

tion of any of the subscales caused the Cronbach's alpha for the remaining items to decrease, indicating that all functional areas included were relevant and necessary.

Table 2 shows the intercomponent and component-versus-Disability Index correlations. In the interest of coherence, we would hope that all of the components would have substantial positive correlations with the index. A negative correlation, or even a very low one, suggests that a given component is inappropriate to the particular index and is measuring something different. A perfect correlation of a component with an index would indicate that the remainder of the components are unnecessary. As seen in Table 2, the correlations were strongly positive, and yet insufficient to enable any one component to replace the index. Interestingly, these correlations were of a similar magnitude as those found with the adult HAQ (0.56–0.81) (14).

How do the individual components relate to each other? Correlations that are extremely high would suggest the possibility of redundancy between components and the possible elimination of 1 or more in the interest of conciseness. A component that correlates very poorly may belong in another index or may have limited usefulness for other psychometric or design reasons. As can be seen in Table 2, the inter-item correlations were in the moderate range, with a mean of 0.6.

**Construct validity measures.** Construct validity indicates whether a variable can be correlated with a "gold standard." Since there are no perfect "gold standards" in arthritis against which to compare a proposed variable, comparisons are generally made with another imperfect measure, a form of construct validity called convergent validity. The convergent validity of the Disability Index was demonstrated by strong positive concordance with Steinbrocker func-

tional class, number of involved joints, physician's assessment of disease activity, and morning stiffness (Table 3). However, none of these correlations was perfect, indicating that the index is not duplicating any conventional measure.

**Parent-child correlations.** Parent-child correlation was assessed by requesting the parents and older children to complete the questionnaire at the same visit. Twenty-nine children whose ages ranged from 8 to 19 years (mean  $\pm$  SEM 13.8  $\pm$  0.6 years) were studied. The mean Disability Index score on the parent-administered questionnaire was 0.83 (SEM 0.17), and that on the patient-administered questionnaire was 0.76 (SEM 0.16). Paired *t*-test showed no difference between the 2 assessments ( $P > 0.4$ ). A Spearman's correlation coefficient of 0.84 ( $P < 0.001$ ) between the 2 scores demonstrated that parents can reliably report for their children.

**Test-retest reliability.** Test-retest reliability was evaluated in 13 patients. After the parents completed the questionnaire in the clinic, they were given another copy, which they were requested to complete in 1 week's time and mail in. In actuality, the questionnaires were completed a mean of 12.8 days (SEM 2.1) subsequently. The mean Disability Index on the clinic-administered questionnaire was 0.96 (SEM 0.26); retest at home revealed a mean score of 0.96 and an SEM of 0.23. Paired *t*-test showed no difference in the

**Table 3.** Convergent validity of the Childhood Health Assessment Questionnaire: Concordance of Disability Index with Conventional measures of disease severity

	Kendall's tau b	<i>P</i>
Steinbrocker functional class	0.77	<0.0001
Number of involved joints	0.67	<0.0001
Disease activity (physician's assessment)	0.67	<0.0001
Morning stiffness	0.54	<0.0001

**Table 4.** Principal component weights in the Childhood Health Assessment Questionnaire

Functional area	First principal component	Second principal component
Dressing and grooming	0.36	0.30
Arising	0.34	-0.38
Eating	0.33	0.40
Walking	0.34	-0.53
Hygiene	0.38	-0.05
Reach	0.38	0.12
Grip	0.32	0.47
Activity	0.37	-0.30
Interperson variance explained	0.71	0.82

2 scores ( $P > 0.9$ ). A Spearman's correlation coefficient of 0.79 ( $P < 0.002$ ) between the 2 administrations showed strong test-retest reliability.

**Principal component analysis.** Principal component analysis was used to examine the multidimensional pattern of patient responses. Since there are 8 components in the Disability Index, the principal component method views each patient's questionnaire response as a point in an 8-dimensional space. If points in that space could be examined, one would find some directions along which patients are more spread out than others. These directions are generally not parallel to the axis that represents any one question, but represent the sum and difference of several. The directions delineate the underlying phenomena for which the questionnaire differentiates people most effectively. The physical meaning of the underlying phenomena is inferred from the relative weightings of the variables that describe the direction. By means of matrix algebra, the principal component procedure returns the weightings for the direction of the most spread (the first principal component), the weightings for the direction of the most spread perpendicular to the first (the second principal component), and so forth.

The first principal component of the Disability Index consisted of a weighted sum of all 8 questions, with large, positive, approximately equal weights on all questions (Table 4). Seventy-one percent of all interperson variability was accounted for in this one dimension. The second principal component had negative weights on questions involving lower extremity joints in large movements (e.g., walking) and positive weights on questions involving upper extremity joints in small movements. Thus, this dimension contrasts patients having only upper extremity problems with

those who have only lower extremity problems, placing patients with balanced problems in the middle. This dimension explained another 11% of interperson variability. The coefficients of further factors showed no interpretable patterns.

**Regression analysis.** Linear regression analysis modeling revealed that nearly 57% of the variance in the parent's global assessment was explained by the Disability and Discomfort Indices. In stepwise regression analysis, Disability Index entered the model first and explained 49% of the variance. Discomfort Index was the second variable and explained a further 8% of the variance. The  $P$  values for both were less than 0.0001.

## DISCUSSION

The Health Assessment Questionnaire outcome framework incorporating the complex problems of measurement of health status conceptualizes 5 major dimensions: death, disability, discomfort and symptom level, drug side effects and toxicity, and economic impact (13-15,18-23). Disability is the most important concern of patients with rheumatoid arthritis and accounts for as much as two-thirds of the adverse impact of the disease as reported by patients (21). Therefore, accurate definition of disability, with a means to measure it quantitatively and identify those factors which increase or retard its development, is of major importance to health status research in rheumatic diseases.

The assessment of disability in children has special problems not seen in studies performed in adults. Consideration must be given to the patient's age, which, as an indicator of developmental stage, will affect a child's ability to perform functional activities. Although several well-studied, validated, multidimensional outcome measures exist for adult rheumatic diseases, pediatric patients were not included when these measures underwent initial reliability and validity testing. Since these measures were not designed for use in children, in most instances the questions are not relevant to childhood illnesses, and therefore the instruments cannot be directly applied to children (14,18-22). For example, an evaluation of the Physical Disability and Pain dimensions of the Arthritis Impact Measurement Scales questionnaire administered to children yielded disappointing results since the vast majority of patients were able to perform all of the listed activities (6). Another important question to be resolved in the assessment of health status in

children is whether parents can serve as reliable proxy reporters of their child's capabilities.

We have developed the Childhood Health Assessment Questionnaire by modifying the Stanford HAQ. A total of 20 new questions have been added so that in each functional area, there is at least 1 question (activity) that is relevant to a child of any age group. In addition, a new response type, "not applicable," was added for those activities that a child is unable to perform because of developmental immaturity. These modifications and the method of scoring allow an assessment of functional status in children of all ages. For example, in the Dressing and Grooming section, the question on removing socks is relevant to a child of 1 year of age, but all the other questions will be marked as not applicable for a child this age. The score for this section will then be determined by this question. A child with significant disability may thus score 2 or 3. An older child (e.g., a teenager) with a similar level of disability will still be able to remove socks "with no difficulty," but may have significant problems with more complex tasks such as cutting fingernails. Since only the question with the highest score will determine the score for the dressing and grooming section, the teenager will be scored on a more complex activity and would score identically (2 or 3). Each child is thus judged on an age-appropriate complex activity, and this reduces the developmental bias. The advantages of being able to follow up a patient through the entire childhood and into adulthood using the same instrument are obvious.

The Childhood HAQ has strong reliability (Cronbach's coefficient alpha, test-retest), and validity (inter-item  $r$ , convergent correlations). In addition, we have documented that parents can serve as reliable proxy reporters for their children. Regression analysis showed that the Disability and Discomfort dimensions explained 57% of the total variance represented by parent-reported global values. In stepwise regression, Disability Index entered the model first and accounted for nearly 84% of the total variance explained. This indicates a high concordance between what is measured by the instrument and the personal values of the parents. Principal component analysis revealed that 71% of all interperson variability was explained by the first principal component, consisting of an approximately equal weighted sum of all functional areas. From this, it can be inferred that the Disability Index (an equal-weight average) is appropriate for measuring overall arthritis severity, and that the questionnaire is well focused for measurement of this severity. The

second principal component, with negative weights on questions involving lower extremity joints in large movements and positive weights on questions involving upper extremity joints in small movements, explained a further 11% of the variability. This indicates that the instrument assesses various components of the domain of disability and a wide range of tasks. Of interest, these results are very similar to those previously reported for the adult HAQ (14).

The sensitivity of the Childhood HAQ Disability Index to record shifts in functional status (e.g., due to therapeutic interventions) has yet to be determined in a scientific manner, and will be the subject of future reports. However, anecdotal clinical experience reveals that the index is sensitive to change and correlates well with clinical improvement/deterioration. The Stanford (adult) HAQ Disability Index has been shown to be extremely sensitive to treatment effects, and may be the most sensitive of all outcome measures (23).

In conclusion, we describe a new, simple, parent-administered questionnaire to evaluate functional status in children of all ages with JRA. The instrument may be equally well administered directly to older children. The Childhood HAQ, which takes less than 10 minutes to complete and less than 2 minutes to code, is a reliable, valid, and sensitive instrument. Further studies are in progress to develop scales for measuring iatrogenic side effects, economic impact, and psychosocial functioning of children with JRA.

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