Measuring Health Status in Early Juvenile Idiopathic Arthritis: Determinants and Responsiveness of the Child Health Questionnaire

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ABSTRACT. ***Objective.*** To assess the determinants and responsiveness of the Norwegian version of the Child Health Questionnaire (CHQ) in patients with early juvenile idiopathic arthritis (JIA) and to compare health status in patients and controls.

Methods. A total of 116 children (median age 8.4 yrs) with JIAand < 2.5 years of disease duration (median 11.0 mo) were examined by a pediatric rheumatologist and reassessed after a median of 10.0 months. Physical and psychosocial health were assessed by means of the CHQ, which provides summary scores for physical and psychosocial health, the Childhood Health Assessment Questionnaire (CHAQ), and the Child Behavior Checklist (CBCL, n = 32). Matched controls (n = 116), randomly selected from the general population, completed the CHQ at baseline.

Results. The patients with JIAhad poorer physical health and slightly impaired psychosocial health compared with the controls [41.2 ± 13.6 vs 55.2 ± 7.3 ($p < 0.001$) and 51.0 ± 7.5 vs 54.1 ± 5.7 ($p = 0.002$), respectively]. The most important determinants of the CHQ physical summary score were the child's pain, morning stiffness, the CHAQ disability index, erythrocyte sedimentation rate (ESR), overall well-being, and physician's global assessment of disease activity. The psychosocial summary score correlated with the CBCL level of internalizing, externalizing, and total behavior problems. The standardized response mean for the physical summary score was large (0.96) for those who improved, and moderate (–0.60) for those who became worse.

Conclusion. The CHQ discriminated between patients with early JIAand controls. The most important determinants of the CHQ physical summary score were the child's pain, morning stiffness, CHAQ, ESR, overall well-being, and physician's global assessment of disease activity. The CHQ was sensitive to clinical changes in children with JIA. (J Rheumatol 2003;30:1602–10)

Key Indexing Terms:
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Juvenile idiopathic arthritis (JIA) can lead to physical disability and reduced quality of life[1-3]. Functional status and quality of life have become important endpoints in clinical trials, epidemiological studies, and health care programs[4,5]. However, there are few validated instruments for measuring health related quality of life in children. The disease-specific instruments that have been developed during the last 10 years — the Childhood Health Assessment Questionnaire (CHAQ), the Juvenile Arthritis Functional Assessment Report (JAFAR), and the Juvenile Arthritis Self-Report Index (JASI)[6-8] — focus on physical functioning. Recently the Juvenile Arthritis Quality of Life Questionnaire (JAQQ) was described, which measures both physical and psychosocial function[9].

Generic instruments for measuring quality of life can be used independently of the presence of disease. Thus they make it possible to measure the quality of life in the general pediatric population and the impact of disease on different patient populations, and to compare the burden imposed by different diseases.

The Child Health Questionnaire (CHQ) is a generic instrument developed by Landgraf, *et al* for valid and reliable assessments of health status in children in general[10]. The questionnaire has been evaluated in children with cancer, cardiovascular defects, and asthma[11-14]. The CHQ has been translated, cross-culturally adapted, and evaluated according to international guidelines[15] for use in a number of countries[16-18]. We have used the Norwegian translation of the CHQ in children with juvenile arthritis and healthy controls as part of a large international study for the Paediatric Rheumatology International Trial Organisation (PRINTO)[19], in which the underlying framework and psychometric properties of CHQ were evaluated. A

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moderate correlation was found between the CHQ physical summary score and certain disease variables, and a weak correlation between these disease variables and the CHQ psychosocial summary score. However, demographic and clinical determinants of the CHQ were not assessed, nor was the relationship between psychosocial summary score and other measures of mental health explored.

An important feature of a questionnaire is to distinguish significant changes in the clinical state, for example when evaluating the efficacy of therapy. Responsiveness is the ability of an instrument to detect a clinically important change[20]. The responsiveness of CHQ in early juvenile arthritis has to our knowledge not yet been investigated.

We assessed physical health and psychosocial function in a cohort of children with early JIA as compared with a matched group of children from the general Norwegian population. We wanted to identify determinants of the CHQ in JIA and to assess the responsiveness of the instrument after a median followup of 10.0 months.

MATERIALS AND METHODS

Patients and controls. One hundred sixteen (69.9%) out of 166 children aged 4 to 17 years (median 8.4 yrs) with JIA and less than 2.5 years of disease duration (median 11.0 mo), who attended the Department of Rheumatology, Rikshospitalet University Hospital, Oslo, from November 1996 to August 2000, were included in the study. The patients were examined by a pediatric rheumatologist and reassessed after a mean of 10.0 ± 3.8 months.

Fifty (30.1%) out of 166 patients did not participate. Twelve of the parents of these children chose not to participate, 4 parents did not know the Norwegian language well, and 34 were not included due to incomplete data. The participants were comparable to the nonparticipants with regard to age, sex, onset type, and disease duration (data not shown).

One hundred five of the patients had juvenile rheumatoid arthritis (JRA) according to the American College of Rheumatology criteria[21], 11 had juvenile spondyloarthropathy (3 had juvenile ankylosing spondylitis[22], 7 had juvenile psoriatic arthritis[23], and one had arthritis associated with inflammatory bowel disease). Disease onset was defined as the date on which the physician documented arthritis or systemic features.

One hundred sixteen controls matched for age, sex, and geographic region were randomly chosen from the National Population Register.

The study was approved by the Regional Ethics Committee for Medical Research. Informed consent was obtained from all participants.

Measures of physical and psychosocial function. The CHQ was used to measure physical and psychosocial function in patients and controls[10]. The CHQ assesses the following 10 concepts: children's physical functioning, bodily pain, changes in role and in social functioning due to physical, emotional or behavioral problems, general health, mental health, behavior problems, self-esteem and the impact of the child's health on the parent's emotional well-being and on the parent's personal time. The scores in each area range from 0 to 100, where 0 means poor well-being and 100 means excellent well-being. The summary measures for physical function (PhS) and psychosocial function (PsS) have a mean of 50 and a standard deviation of 10 in the general US population. The PhS and PsS are calculated by aggregating and transforming the 10 concept scores using a linear T-score transformation method. The questionnaire consists of a parent form consisting of 50 questions (CHQ-pf50) and a child form consisting of 87 questions (CHQ-cf87). The 2 forms cover the same items except for the impact of the child's health on the parent's emotional well-being and personal time, which is only in the CHQ-pf50. Most of the data in this study are taken from the parents'questionnaires.

The impact of the arthritis on physical function was assessed by the Norwegian version of the CHAQ[6,24]. The CHAQ measures physical ability in 8 areas: dressing and grooming, arising, eating, walking, hygiene, reaching, gripping, and activities. At least one question in each area is relevant to children of all ages between age one and 18 years. The item with the highest score within each area (ranging from 0 to 3, where 0 means able to do with no difficulty, 1 means able to do with some difficulty, 2 means able to do with much difficulty, and 3 means unable to do) determined the score for the category unless aids or assistance were required (raising the score of that category to a minimum of 2). The average of the category scores provided the disability index, which had a value between 0 and 3.

The Child Behavior Checklist (CBCL) was used to measure psychosocial function. The CBCL provides scores for internalizing (withdrawal, anxiety, depression, and somatic complaints) and externalizing problems (delinquent and aggressive behavior) and a score for total behavior problems[25]. According to the American norm, corrected for age and sex, behavioral scores above the 90th percentile (T-score > 63) are considered to be within the clinical range. The questionnaire was completed by the parents of 32 randomly selected patients.

All the questionnaires were administered by a trained health professional to one or both parents of all patients and to the patients aged 12–17 years. The parents and patients completed the questionnaire with no help from the health professional. The parents of the controls received and returned the questionnaires by post. Mothers completed 71% of the forms, fathers 14%, both parents together 13%, and other people 2%. "Other people" were a foster mother, for the patients, and a stepfather, for the controls.

Clinical and laboratory data. The patients were examined by one of 4 pediatric rheumatologists (BF, DS, OV, or AMS). The clinical examination included registration of number of joints with swelling, tenderness and limited range of motion, number of active (swelling or both tenderness and limited range of motion) and affected (swelling or limited range of motion) joints, an arthritis severity index[21,26,27], morning stiffness (hours), and physician's global assessment of disease activity (on a 5 point Likert scale, where 1 means inactive, 2 mild, 3 moderate, 4 severe, and 5 very severe disease activity). Erythrocyte sedimentation rate (ESR) and C-reactive protein (CRP) were measured by standard methods.

Sensitivity to change. Clinical change was defined according to the preliminary ACR criteria for improvement in juvenile arthritis[4]. These are based on a core set of 6 response variables: physician's global assessment of disease activity, number of active joints, number of joints with limited range of motion, ESR, parent's assessment of the child's overall well-being, and functional ability (CHAQ). Improvement was defined as minimum 30% improvement from baseline to followup in at least 3 of the 6 response variables and a maximum of one variable indicating more than 30% worsening. Worsening was defined as the opposite: more than 30% worsening in at least 3 of the 6 response variables, and no more than one variable improving by 30% or more. As the percentage of change from zero cannot be estimated, a change from zero to the first step of the score was defined as a change of 30%. Variations within the normal range of the ESR (0–15 mm/h) were considered normal and unchanged. The standardized response mean (SRM) of the CHQ was calculated as the mean change score, i.e., the change in score from baseline to followup, divided by the standard deviation of the change[20]. A SRM around 0.2 is generally considered to be small, around 0.5 moderate, and ≥ 0.80 large[28].

There are several methods for assessing responsiveness, and the most commonly used are SRM and effect size (the mean change score divided by the standard deviation of the baseline score). When the correlation coefficient between the baseline and followup score is higher than 0.5, the SRM gives a higher level of responsiveness than effect size[20]. In this study the correlation coefficient between baseline and followup for the physical summary score was 0.645 and for the psychosocial summary score 0.621. We therefore chose to use the SRM instead of the effect size.

Statistics/methodological issues. The differences between patients and

controls were tested by the paired samples t test for continuous variables and McNemar's test for categorical variables (pairing patients and matched controls). The differences between patients and nonparticipants were measured by independent sample t test. The patient group, onset subgroups, and the control group were compared by one-way analysis of variance (ANOVA), using Bonferroni's correction for multiple comparisons. Correlations were expressed as Pearson correlation coefficients.

A multiple linear regression analysis was performed to identify determinants of the physical summary score (dependent variable). Morning stiffness, disability index, parent's assessment of the child's pain and overall well-being, number of swollen and tender joints, number of joints with limited range of motion, number of active and affected joints, arthritis severity index, physician's global assessment of disease activity, CRP, and ESR were chosen as possible determinants (independent variables). Interaction terms were also included. The regression methods enter, backward, and forward were used. In the regression analysis 15 cases were excluded because of missing data. A second regression analysis was therefore done after the missing values had been replaced by the mean of the value from 2 consultations before and/or after baseline.

We did not perform a regression analysis for the psychosocial summary score because the small number of statistically significant correlations indicated that there were very few explanatory variables.

Agreement between patient-completed and parent-completed questionnaires was measured by intraclass correlation coefficient.

Floor and ceiling effects were defined as the percentage of answers with the lowest and highest score, respectively. For all the analyses, p values < 0.05 (2 tailed tests) were considered statistically significant. All statistical analyses were performed with SPSS 9.0/10.0.

RESULTS

The characteristics of the patients with JIAand the controls, and the patients'disease variables, are shown in Table 1. The demographic variables of patients and controls were comparable except that a lower percentage of the patients' parents worked compared with those of the controls (75.9% vs 86.5%; p = 0.043). In the patient group the parents who did not work had children with a higher level of disease activity and pain than those who worked (data not shown).

CHQ scores. Patients with JIAhad lower physical summary scores than controls (mean 41.2 vs 55.2; p < 0.001; Figure 1). The physical summary score was lower in patients with the various JIA subtypes than in the controls (p < 0.001). Patients with polyarticular onset had lower physical summary scores than those with pauciarticular onset (p < 0.001). Patients with JIA had lower psychosocial summary scores than controls (mean 51.0 vs 54.1; p = 0.002).

We found no difference in physical summary scores and psychosocial summary scores when we compared sex, age, and parents'level of education (data not shown). The mean physical score of the patients with disease duration ≥ 6 months was 43.5 ± 12.5 compared with 36.0 ± 15.0 in those with < 6 months of disease duration (p = 0.009). No relation between psychosocial summary score and disease duration was found (data not shown).

The scores for each of the 10 CHQ concepts in patients and controls are shown in Table 2. The JIA patients had poorer physical health (physical function, bodily pain, role physical, and general health) (p < 0.001) and their health had more impact on parents (on parents'emotions and time) than controls (p < 0.01). The differences in psychosocial factors (mental health, behavior, and self-esteem) were not significant, except for role emotional/behavioral (p < 0.001).

Parent-patient agreement. The intraclass correlation coefficients between the concept scores of the children and those of the parents (n = 24) ranged from 0.69 to 0.87 (p < 0.001) for concepts related to physical function (physical functioning, bodily pain, role physical, general health) and from 0.38 to 0.53 (p = 0.038–0.003) for mental health, self-esteem and behavior. The intraclass correlation coefficient for role emotional/behavioral was not statistically significant.

Table 1. Demographic and clinical characteristics of patients with juvenile idiopathic arthritis (JIA) (n = 116) and controls (n = 116)*. Values refer to the number of subjects (%) unless otherwise stated.

	JIAPatients	Healthy Controls	p
Females, n	70 (60.3)	70 (60.3)	1.000
Age, mean yrs (SD)	9.2 (3.4)	9.3 (3.5)	< 0.001
Disease type			
Pauciarticular onset JRA	59 (50.9)		
Polyarticular onset JRA	41 (35.3)		
Systemic onset JRA	5 (4.3)		
Juvenile ankylosing spondylitis	3 (2.6)		
Juvenile psoriatic arthritis	7 (6.0)		
Juvenile enteropathic arthritis	1 (0.9)		
Disease duration, mo (SD)	12.1 (7.5)		
Parent's age, mean yrs (SD)†	37.6 (5.9)	37.2 (5.8)	0.452
Parents married/living together	95 (82.6)	99 (88.4)	0.230
Parents with > 12 years of education†	37 (32.5)	36 (48.0)	0.121
Parents working full or part-time†	88 (75.9)	96 (86.5)	0.043

* Patients with JIAand < 2.5 years of disease activity admitted to hospital between November 1996 and August 2000 and matched controls randomly selected from the National Population Register. † The parent completing the questionnaire.

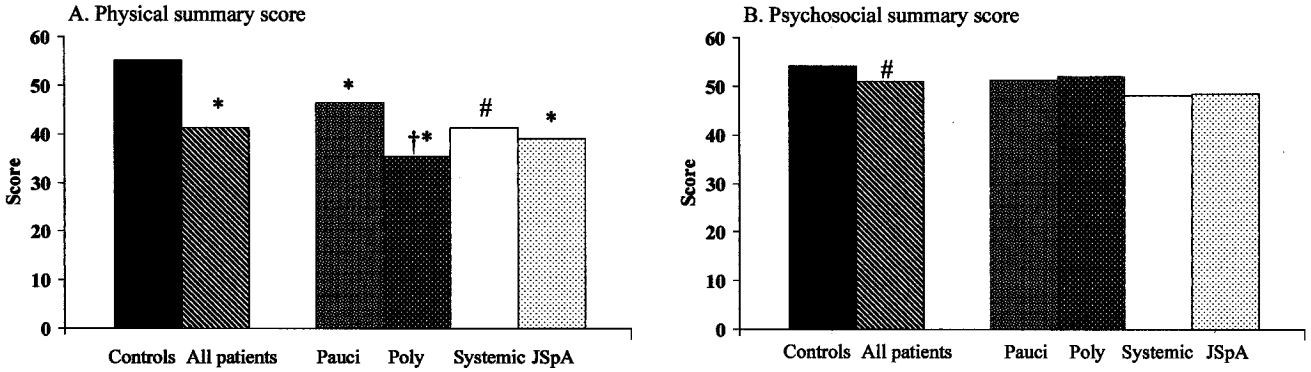

Figure 1. Physical and psychosocial health scores according to the Child Health Questionnaire in 116 children with juvenile idiopathic arthritis (JIA). For the physical and psychosocial summary score 50 corresponds to the mean in the general US population and 10 scores below or above the mean represent the standard deviation. Children with polyarticular onset JIA had poorer physical health than children with pauciarticular onset type. *$p < 0.001$ for the difference between physical score in controls and mean score for all the patients, pauciarticular onset type, polyarticular onset type, and juvenile spondyloarthropathy (JSpA). †$p < 0.001$ for the difference between physical score in pauciarticular vs polyarticular onset type. #$p < 0.05$ for the difference between physical score in controls and in systemic onset type and between psychosocial score in controls and the mean score for all the patients.

Table 2. Comparison of the mean of the Child Health Questionnaire's 10 concept scores* between patients and controls, showing significant differences in all physical and parental concepts, but not in psychosocial concepts, except for role emotional/behavioral (n = 116).

	Patients, Mean Score	Controls, Mean Score	Mean Difference	CI Difference	p
Physical concepts					
Physical functioning	83.8	96.2	–12.3	–16.7, –7.9	< 0.001
Bodily pain	63.6	83.1	–19.5	–26.0, –12.9	< 0.001
Role–physical	86.2	96.4	–10.2	–14.6, –5.8	< 0.001
General health	62.9	82.7	–19.7	–24.0, –15.4	< 0.001
Psychosocial concepts					
Role–emotional/behavioral	90.6	98.5	–7.8	–11.2, –4.4	< 0.001
Mental health	81.9	82.7	–0.8	–3.8, 2.2	0.587
Behavior	76.0	79.0	–3.1	–6.8, 0.6	0.103
Self-esteem	76.5	79.6	–3.2	–6.8, 0.5	0.088
Parental concepts					
Parental impact–emotional	72.4	87.6	–15.2	–20.6, –9.8	< 0.001
Parental impact–time	90.1	95.5	–5.5	–9.3, –1.6	0.006

* The scores in the 10 concepts range from 0 to 100, where 0 means poor well-being and 100 means excellent well-being.

Relationship between CHQ physical score and patient and disease characteristics. The CHQ physical summary score correlated well with measures of disease activity (Table 3), but not with age, sex, or parents'level of education (data not shown).

To identify the most important correlates of the CHQ physical summary score, we conducted a multiple linear regression analysis with the physical summary score as the dependent variable and with backward elimination of possible explanatory variables. The variables significantly associated with the physical score were analyzed as independent variables (morning stiffness, CHAQ disability index, parent's assessment of child's pain and overall well-being, number of swollen and tender joints, number of joints with limited range of motion, number of active and affected joints, arthritis severity index, physician's global assessment of disease activity, CRP, and ESR). Age and sex were not associated with the physical summary score and were not chosen as possible determinants.

In the final model the following variables were chosen as the most important determinants of the CHQ physical summary score (Table 3): parent's assessment of child's pain (standardized beta –0.285, $p < 0.001$), morning stiffness (standardized beta –0.257, $p < 0.001$), CHAQ (standardized beta –0.187, $p = 0.003$), ESR (standardized beta –0.173, $p = 0.005$), parent's global assessment of child's overall well-being (standardized beta –0.169, $p = 0.035$) and physician's global assessment of disease activity (standardized beta –0.145, $p = 0.037$). The set of determinants explained 72.6% (adjusted r^2) of the variance of the physical summary score. The same determinants were identified by a second multiple regression analysis using the forward selection method.

Because of the rather large proportion of missing values

Table 3. Relationships between the Child Health Questionnaire physical summary score (PhS) and measures of disease activity, n = 100.

Measures of Disease Activity	Mean (CI)	Univariate Analysis Pearson Correlation Coefficient with PhS	p	Multiple Regression Analysis* Standardized beta	p
Child HAQ (range 0–3)	0.52 (0.40, 0.63)	–0.574	< 0.001	–0.187	0.003
Parent's assessment of child's pain (0–10 cm VAS)	2.3 (1.9, 2.7)	–0.624	< 0.001	–0.285	< 0.001
Parent's assessment of child's fatigue (0–10 cm VAS)	2.5 (2.0, 2.9)	–0.541	< 0.001		
Parent's global assessment of child's well-being (0–10 cm VAS)	2.4 (2.0, 2.8)	–0.661	< 0.001	–0.169	0.035
Morning stiffness (range 0–5 h)	0.9 (0.7, 1.1)	–0.672	< 0.001	–0.257	< 0.001
Physician's global assessment of disease activity (Likert scale 1–5)	2.4 (2.3, 2.6)	–0.556	< 0.001	–0.145	0.037
No. of tender joints (range 0–68)	1.3 (0.9, 1.8)	–0.383	< 0.001		
No. of swollen joints (range 0–66)	2.2 (1.6, 2.8)	–0.382	< 0.001		
No. of joints with limited range of motion (range 0–69)	1.8 (1.3, 2.3)	–0.325	< 0.001		
No. of active joints (range 0–69)	2.2 (1.5, 2.8)	–0.360	< 0.001		
No. of affected joints (range 0–69)	2.7 (2.0, 3.4)	–0.335	< 0.001		
Arthritis severity index (range 0–668)	6.8 (4.8, 8.8)	–0.370	< 0.001		
CRP(normal < 5 mg/l)	9.3 (6.3, 12.3)	–0.262	< 0.01		
ESR (normal < 16 mm/h)	16.7 (13.7, 19.7)	–0.479	< 0.001	–0.173	0.005

* Results of the final model of multiple linear regression analysis with the physical summary score as the dependent variable. VAS: visual analog scale.

(16 cases excluded), we also did a regression analysis exchanging the missing value with the mean value before and after the study consultation. This analysis selected the same variables as the original analysis.

When examining the set of variables for possible interactions, we found that a model with the product of fatigue and ESR and the product of CHAQ and physician's global assessment of disease activity in addition to pain and morning stiffness explained the variance of the PhS slightly better than the original model (data not shown).

In a separate simple linear regression analysis with patients and controls grouped together, being diagnosed as having JIA explained 27.7% of the variance of the physical summary score (standardized beta 0.53, p<0.001).

Correlation between the CHQ psychosocial score and patient and disease characteristics. The CHQ psychosocial score correlated with the parent's assessment of physical function, fatigue, and overall well-being (r ranging from –0.219 to –0.315, p < 0.02) and other assessments of psychosocial functioning (r ranging from –0.620 to –0.694, p < 0.001), but not with other measures of disease activity (Table 4). The psychosocial score was not associated with age, sex, or parents'level of education (data not shown).

Sensitivity to change of the CHQ. From baseline to followup the clinical status improved in 45 patients, was unchanged in 57 patients, and worsened in 14 patients (Table 5). The mean physical summary score increased in those whose condition improved (p < 0.001), decreased in those who got worse (p = 0.043), and remained stable in those whose condition was unchanged (p = 0.249). The SRM for CHQ physical summary score were large (0.96) for those who improved, small (0.16) for those who were unchanged, and moderate (–0.60) for those who got worse. The SRM for the CHQ psychosocial summary score was moderate (0.67) for those who improved. There was no statistically significant change in the psychosocial score in patients whose condition remained unchanged or deteriorated.

Floor and ceiling effects. There was no accumulation of answers with the lowest score in any of the scales (floor effect). However, in some scales there was a high percentage of answers with the best score (ceiling effect): role physical (52%), role emotional/behavioral (56%), parental impact–time (46%), physical functioning (21%), and bodily pain (15%).

At followup 5 questionnaires were not sufficiently completed to give summary scores. The concepts missing were: role physical, 2 questionnaires (1.7%); bodily pain, 2 questionnaires (1.7%); and parental impact–time, one questionnaire (0.8%).

DISCUSSION

We found that the CHQ was sensitive to clinical change in children with recent onset JIA. The most important determinants of the physical summary score were the parent's assessment of the child's pain, morning stiffness, the CHAQ disability index, ESR, parent's global assessment of the child's overall well-being, and physician's global assessment of disease activity. Children with JIAhad poorer physical function than healthy controls. The children with polyarticular onset had the lowest physical score.

To our knowledge this is the first study to show that the CHQ is sensitive to clinical change. The sensitivity was high for those who improved and moderate for those who got worse. Responsiveness is an important feature of functional measurements. Up to now the CHAQ has been the instrument most commonly used for measuring physical function. Flatø, *et al* reported a small sensitivity to improvement (effect size 0.28) and a moderate sensitivity to worsening

Table 4. Correlation between the Child Health Questionnaire psychosocial score (PsS) and measures of disease activity and psychosocial functioning as measured by Child Behaviour Checklist (CBCL), in patients with idiopathic juvenile arthritis.

Measures of Disease Activity	N	Mean (CI)	Pearson's Correlation Coefficient with PsS	p
Child HAQ (range 0–3)	116	0.52 (0.40, 0.63)	–0.219	0.018
Parent's assessment of child's pain (0–10 cm VAS)	116	2.3 (1.9, 2.7)	–0.143	0.129
Parent's assessment of child's fatigue (0–10 cm VAS)	116	2.5 (2.0, 2.9)	–0.219	0.018
Parent's global assessment of child's well-being (0–10 cm VAS)	116	2.4 (2.0, 2.8)	–0.315	0.001
Morning stiffness (range 0–5 h)	116	0.9 (0.7, 1.1)	–0.148	0.115
Physician's global assessment of disease activity (Likert scale 1–5)	116	2.4 (2.3, 2.6)	–0.048	0.609
No. of tender joints (range 0–68)	116	1.3 (0.9, 1.8)	–0.097	0.307
No. of swollen joints (range 0–66)	116	2.2 (1.6, 2.8)	–0.044	0.639
No. of joints with limited range of motion (range 0–69)	116	1.8 (1.3, 2.3)	–0.103	0.276
No. of active joints (range 0–69)	116	2.2 (1.5, 2.8)	–0.024	0.802
No. of affected joints (range 0–69)	116	2.7 (2.0, 3.4)	–0.108	0.260
Arthritis severity index (range 0–668)	116	6.8 (4.8, 8.8)	–0.071	0.459
CRP(normal < 5 mg/l)	116	9.3 (6.3, 12.3)	0.070	0.474
ESR (normal < 16 mm/h)	116	16.7 (13.7, 19.7)	0.006	0.951
CBCL*				
Level of total behavior problems	32	47.4 (43.6, 51.6)	–0.694	< 0.001
Level of internalizing problems	32	50.8 (46.6, 54.9)	–0.620	< 0.001
Level of externalizing problems	32	43.7 (39.9, 47.4)	–0.641	< 0.001

* CBCLscores are given as T-scores, where the mean value in the normal population is 50.

Table 5. Sensitivity to change of the CHQ physical summary score (PhS)*.

	Clinical Status at Followup†		
	Improved, n = 45 (38.8%)	Unchanged, N = 57 (49.1%)	Worse, N = 14 (12.1%)
Mean PhS t1 (SD)	38.0 (15.0)	44.1 (11.4)	41.4 (12.1)
Mean PhS t2 (SD)	47.3 (10.6)	45.2 (11.2)	33.1 (14.1)
P for difference from t1 to t2	< 0.001	0.249	0.043
Mean change in PhS from t1 to t2 (SD)	9.3 (9.7)	1.1 (6.9)	–8.3 (13.8)
Standardized response mean ††	0.96	0.16	–0.60

* PhS is given as a T-score where 50 ± 10 corresponds to the mean value ± SD in the normal population. † Clinical change was defined according to the preliminary ACR definition of improvement in juvenile arthritis[4]. ††SRM is computed as the mean change in physical summary score from t1 to t2 divided by the standard deviation of the change.

(effect size 0.54) for the CHAQ[24]. The small sensitivity to improvement was related to a high percentage of patients with a disability index close to or equal to zero, which limits the potential for improvement. The scoring system for the CHQ is different and allows improvement to be observed even in the normal range.

The SRM for worsening was moderate. It was based on a small number of patients who got worse and a relatively high standard deviation.

We found that the generic instrument CHQ was more sensitive than the arthritis-specific instrument CHAQ[24]. The same tendency has been observed in studies of adults. Hagen, *et al* found no difference in responsiveness between generic and disease-specific instruments in patients with rheumatoid arthritis[29]. This is in contrast to the expectation that generic instruments contain more items that may be less relevant to any particular disease and are therefore less sensitive[30].

Parent and physician reported disease activity and laboratory variables correlated with physical function in our study, as described by others[31,32]. Pain and morning stiffness were the strongest of the determinants for the physical summary score. Pain, active disease, and articular severity score have been found to be predictors of functional outcome in other studies[2,24,33].

Analyzing patients and controls together, we found that being diagnosed as having JIAexplained 27.7% of the variance of the physical summary score. This indicates that other factors are important. A majority of our patients had physical function close to normal and had few joints with active disease. Our analysis of determinants showed that the level of disease activity was important for the variation of the physical summary score within the patient group.

When each of the 10 concepts in CHQ was compared between patients and controls, the major differences were found to lie in the physically related concepts. This was

according to expectation, as JIA is a physically disabling disease[34,35].

As for concepts related to psychosocial function, there were no statistically significant differences between controls' and patients' scores in mental health, self-esteem, or behavior. In the psychosocial summary score there was a small but statistically significant difference between patients and controls, but in our opinion this is of minor clinical importance. The summary score showed that children with early JIA adapt well psychosocially, as their mean score is close to the mean of the general US population.

Similar results have been reported by others, who have found children with juvenile arthritis to be comparable to healthy controls on measures of social functioning, emotional well-being, and behavior[36,37]. In longterm outcome studies, patients with JIAhave been reported to be socially on an equal level with and to have a psychosocial function close to that of healthy controls[38]. In a study by Peterson, *et al*, the patients reported themselves to be mentally, behaviorally, and socially similar to the controls, but had higher unemployment rates[3].

Some studies have reported reduced psychosocial well-being among patients with JIA. Vandvik, *et al* found that 51% of the children with juvenile arthritis in their study met the criteria for psychiatric diagnoses and 64% had psychosocial dysfunction[39]. However, these children had been recently diagnosed and were interviewed during their first hospitalization for the disease. A 9 year followup study on juvenile chronic arthritis by Aasland, *et al* reported that 17% fulfilled the criteria for a psychiatric diagnosis and 15% had mild to moderate impairment of psychosocial functioning[40]. David, *et al* found that 21% of patients with polyarticular juvenile chronic arthritis were clinically depressed[41]. These patients were adults with a mean disease duration of 20 years. Their depression was related to disability. None of these 3 studies included controls.

There were no strong associations between psychosocial summary score and disease variables. The only significant correlations were with parent's global assessment of the child's well-being, CHAQ, and fatigue. This is in accord with the findings of other studies. Aasland, *et al* found that psychosocial functioning correlated with CHAQ, but was not related to other measures of disease severity[40]. Baildam, *et al* reported that there was no clear link between the severity of physical disease and psychological function among a group of children with juvenile arthritis[42].

A strong correlation between the CHQ psychosocial summary score and a measure of psychosocial health, CBCL, was found in a subgroup of our patients, indicating that the CHQ is a valid instrument for measuring psychosocial function. The association between the psychosocial summary score and the CBCL could be partly explained by the fact that some of the CHQ questions on behavior are adapted from the CBCL.

The strength of this study lies in its design, which included matched controls and a followup period of almost a year. Because of this design we used a paired t test for comparisons of demographic data between patients and controls. This method has a disadvantage for large study groups. Small differences can become significant even if they are not clinically important, such as the ages of patients and controls, which differed in our study by 0.1 years.

More of the parents of controls worked outside the home than parents of patients. In the patient group, more parents were categorized in the "unemployed" and "other" group. This could influence the results, but it is difficult to assess whether this difference is a consequence of having a chronically ill child or whether it is due to socioeconomic differences.

Parents are usually used as a child's proxy by health professionals. They may have a better understanding of the health issues being investigated and the content of the questionnaire than the child, but it is the patient's experience that must be the main focus[43]. In our study the intraclass correlation between parents' and patients' answers was high for the physical concepts. This is in accord with other studies[6,44,45]. However, Ravelli, *et al* found that there was frequently a discrepancy between proxy-reported functional ability and functional ability observed by clinicians in their patients with JIA[46]. The children's functional ability tended to be overestimated by parents as the severity of arthritis increased, and underestimated as the level of pain increased.

It is important to keep in mind that a parent's health can influence how they judge their child's health[47]. Waters, *et al* reported a strong association between mothers with self-reported poor global health and poor child health scores in several domains of functioning, social role, and physical and emotional health as measured by the CHQ. This was not observed for fathers. It seems important to have both the parent's and the patient's version, when possible.

We compared our patients with a Norwegian control group, but the formulas for the summary scores are based on an American control group. Our Norwegian controls had about 7% higher scores than US children in all scales and therefore better summary scores.

The formula for the CHQ physical summary score was evaluated in an Australian study by Waters, *et al*[17]. This study showed that the summary score was more suitable for children with health problems than for the normal population. Thus Waters recommends the use of all 10 concept scores instead, especially in studies where healthy children are included.

The CBCLhas been widely used and is an accepted questionnaire for measuring psychosocial health, but it is intended for children with psychiatric diseases. Thus it could have limited sensitivity to minor behavioral problems encountered in children with chronic physical illnesses[48]. Comparing the psychosocial summary score with the

answers obtained in an interview might have been more sensitive[40]. Due to the small subgroup of patients completing the CBCL, these results should be interpreted with caution.

We found that the Child Health Questionnaire has an acceptable level of responsiveness: it discriminates between patients with different burdens of disease and between patients and controls. It seems to be a good measure of the physical aspects of JIAand it measures psychosocial health as a separate dimension. Pain and morning stiffness were the 2 major determinants of the physical score. Further studies are needed to establish the responsiveness and the physical and psychosocial determinants of the CHQ.

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