

# Functioning and Preferences for Improvement of Health Among Patients with Juvenile Idiopathic Arthritis in Early Adulthood Using the WHO ICF Model

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**ABSTRACT. Objective.** To evaluate functioning and preferences for health among young adult patients with juvenile idiopathic arthritis (JIA) and controls. The WHO International Classification of Functioning, Disability and Health (ICF) was used as a framework.

**Methods.** The patient files of a rheumatology hospital were screened to identify patients with juvenile arthritis born 1976 to 1980. Functioning was measured by the Finnish version of the Multidimensional Health Assessment Questionnaire (MDHAQ) within the framework of the ICF. Preferences in improvement of health were measured by the Finnish version of the Arthritis Impact Measurement Scales 2. Age and sex matched controls from the community were selected from the Finnish population registry.

**Results.** In all, 123 patients with a mean age of 23 (range 21–26) years participated in the followup study. The mean time from diagnosis to followup was 16.2 years. Among them, 35% (n = 43) were in remission at followup. Lower levels of functioning for 3 ICF components were found in patients with active disease compared to controls. JIA patients with active disease had more pain and lower levels of mobility, self-care, and domestic and social life compared to controls. Patients with active disease differed from those in remission with pain in preferences for improvement of health.

**Conclusion.** Patients with active disease need active treatment and rehabilitation to maintain functioning and decrease pain. The ICF offers a promising model to examine the outcomes of adult patients with JIA. Application of the MDHAQ is supported by our evaluation studies in young adults with JIA. (First Release June 1 2006; J Rheumatol 2006;33:1369–76)

## Key Indexing Terms:

HEALTH EVALUATION JUVENILE ARTHRITIS YOUNG ADULT FUNCTIONING  
INTERNATIONAL CLASSIFICATION OF FUNCTIONING, DISABILITY AND HEALTH

Research on outcomes in juvenile idiopathic arthritis (JIA) has increased significantly during the last decade, and the focus has shifted to broader outcomes such as the physical and psychosocial well-being of the individual<sup>1,2</sup>. Recent studies among adults indicate that the juvenile disease continues to be

active into adulthood in 40% to 60% of patients<sup>3–12</sup>. It becomes crucial to study more closely the characteristics and extent of disability of patients with JIA in the later stages of disease, in order to set relevant longterm goals for clinical care and rehabilitation in the earlier stages of the disease.

A promising and increasingly accepted means to understand the descriptions and comparisons of health outcome in the international context is the World Health Organization (WHO) International Classification of Functioning, Disability and Health (ICF)<sup>13</sup>. This classification provides a conceptual basis for studying health and functioning and also a common language in which to compare the health of populations. The ICF has 2 parts, each containing separate components. Part 1 covers Functioning and Disability, with components of body functions and structures and activities and participation. Part 2 comprises contextual factors including environmental and personal factors. The concept of functioning, as a neutral aspect of disability, is used in the ICF framework as an umbrella term indicating nonproblematic aspects of health and health-related states (i.e., body functions and structures, activity and participation). One novel aspect of the ICF model

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is that it integrates various aspects of health from biological, individual, and societal perspectives with bidirectional relationships<sup>13</sup> (Figure 1). Another important feature of the ICF is the new meaning of the disability concept. "Disability" has previously been in constant use but with several different meanings<sup>14</sup>, which can cause confusion in understanding the publications applying the ICF.

We examined the longterm functioning of young adult patients with JIA and controls with a traditionally derived function instrument adapted in a new conceptual model, the ICF, and also examined whether the patients and controls differ from each other in their level of functioning.

## MATERIALS AND METHODS

**Patients.** The Rheumatism Foundation Hospital (RFH) in Heinola, Finland, founded in 1951, provides services at a university-hospital standard nationwide, and also offers secondary-level care services for those living nearby. Multidisciplinary care and rehabilitation practice has been an important part of the treatment protocol for many decades at the RFH department for children, adolescents, and families. In this study, the files of juvenile patients (age < 16 yrs) treated at the RFH were used to identify children born 1976 to 1980 who were patients in this hospital for the first time during the years 1976-95. This cohort numbered 587. We identified those patients who had been diagnosed as having juvenile arthritis. Of this total, 189 were excluded as having some disease other than juvenile arthritis. Further, from among the remaining 398 patients we identified those in whom juvenile arthritis disease was diagnosed in the RFH. Here, 211 patients were excluded because their treatment had been initiated elsewhere. There were thus 187 patients with early untreated JIA whose diagnosis was made at the RFH and whose treatment was initiated there. This inception cohort of newly diagnosed patients with juvenile arthritis were reclassified using JIA criteria<sup>15</sup>.

Records of the patients in the RFH were reviewed to obtain clinical characteristics: onset of disease, subtype (course type)<sup>15</sup> of JIA, sex, age at onset, and time of first visit to the RFH. Four of the 187 untreated patients were excluded because they had Down syndrome. The exclusion was made because outcome of their social and educational problems would be difficult to distinguish from a possible rheumatic component. Two of the 187 patients had died in accidents. Thus 181 patients were invited by mail to take part in the study. Population controls were picked from the Finnish population registry to match the participating patients with respect to age, sex, and municipal district.

**Clinical methods.** The patients visited the RFH and were examined by a pedi-

atric rheumatologist. Examination included recording the number of swollen and tender joints and the physician's global assessment of disease activity on a 100 mm visual analog scale (VAS). Laboratory tests were carried out to assess disease activity. A patient was considered to be in remission at followup if the erythrocyte sedimentation rate (ESR) was  $\leq 20$  mm/h, morning stiffness  $\leq 15$  minutes, there were no tender and no swollen joints, and he or she had been without disease modifying antirheumatic medication and glucocorticoids for at least the past 2 years<sup>10</sup>. During the one-day visit to RFH, patients also completed the Finnish versions of the Multidimensional Health Assessment Questionnaire, Finn-MDHAQ<sup>16</sup>, and the Arthritis Impact Measurement Scales, Finn-AIMS2<sup>17</sup>.

**Instruments.** The Finn-MDHAQ<sup>16</sup> contains 14 items covering different levels of activities of daily living (ADL), one item on sleep, and 3 psychological items. Also included are two 100 mm VAS, one for the patient's overall assessment of pain and one for fatigue. The items of the Finn-MDHAQ questionnaire include standard 1-4 response options. Raw responses to the Finn-MDHAQ scales were recoded from 1-4 to 0-3, 0 representing good functional ability and 3 the poorest. All the Finn-MDHAQ items were linked to the categories of the ICF<sup>13</sup> divided into 3 components of functioning: body functions, activities, and participation (Table 1). The full version of the ICF, which provides all levels of classification, was applied in the study. The linking rules advocated by Cieza and colleagues<sup>18</sup> were applied. Linking of the Finn-MDHAQ items to the ICF was performed first by one of the authors (MAK). After that, 2 experts evaluated the result and made their own suggestions for the codes, if needed. Then discussion was carried out to reach consensus between the original coder and the experts. The ICF manual<sup>13</sup> (Annex 3) offers 4 alternative options for structuring the relationship between activities and participation categories. One of them was the partial overlap between sets of domains. The partial overlap between components of activities and participation means that mobility was the common domain in both categories in activity and participation. We chose to use partial overlap in coding the mobility domain for the wide range of mobility items used in the MDHAQ and for the social context connected with some of these items. Those items of mobility were linked to the Participation category, in which the character of mobility was related to creating the opportunities for social involvement (i.e., Getting in or out of a car, bus, train, or airplane). In the case of the term "mobility" referring to both activity and participation components, the letters "a" and "p" for activity and participation are marked here as an upper index after the word mobility (e.g., mobility<sup>a</sup>) to differentiate which is meant in each case.

Participants also completed the Finn-AIMS2 questionnaire<sup>17</sup>, from which item 60, "patient's preferences in seeing improvement in the areas of health," was used in this part of the study. Finn-AIMS2<sup>17</sup> contains 57 items that can be divided into 12 scales, representing 12 areas of health: mobility, walking and bending, hand and finger function, arm function, self-care, household

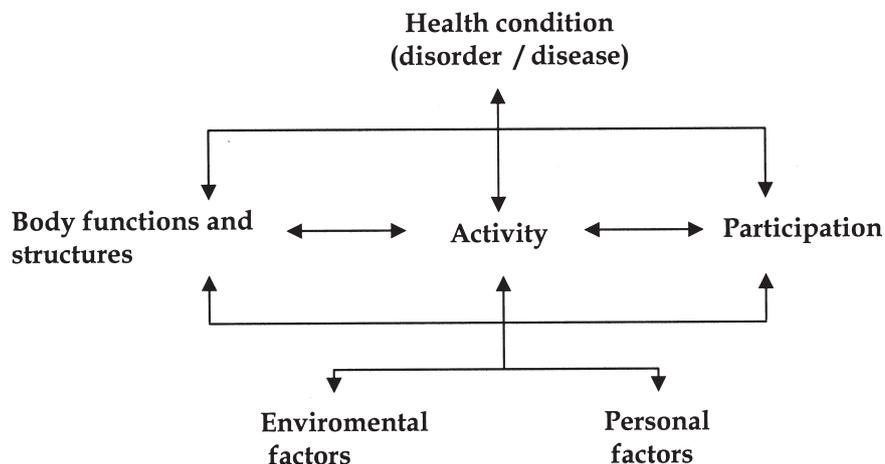


Figure 1. Framework of functioning: the ICF in juvenile idiopathic arthritis.

Table 1. MDHAQ items in the components and domains of the ICF, with individual codes.

Item	ICF Component	ICF Domain	ICF Code
a. Dress yourself, including tying shoelaces and doing buttons?	Activity	Self-care	a540
b. Get in or out of bed?	Activity	Mobility	a4100
c. Lift a full cup or glass to your mouth?	Activity	Mobility	a4450
d. Walk outdoors on flat ground?	Activity	Mobility	a450
e. Wash and dry your entire body?	Activity	Self-care	a5101
f. Bend down to pick up clothing from the floor?	Activity	Mobility	a4105
g. Turn regular faucets on and off?	Activity	Mobility	a4402
h. Get in or out of a car, bus, train, or airplane?	Participation	Mobility	p410
i. Run errands and shop?	Participation	Domestic life	p6200
j. Climb up a flight of stairs?	Activity	Mobility	a4551
k. Walk 2 miles?	Participation	Mobility	p4501
l. Run or jog 2 miles?	Activity	Mobility	a4552
m. Drive a car 5 miles from your home?	Participation	Mobility	p4751
n. Participate in sports and games as you would like?	Participation	Community, social and civic life	p9201
o. Get a good night's sleep?	Body structure and functions	Mental functions	b134
p. Deal with the usual stresses of your life?	Activity	General tasks and demands	a2401
q. Deal with the feelings of anxiety or being nervous?	Activity	General tasks and demands	a2401
r. Deal with the feelings of depression or feeling blue?	Activity	General tasks and demands	a2401
VAS pain	Body structure and functions	Sensory functions and pain	b280
VAS fatigue	Body structure and functions	Mental functions	b130

VAS: visual analog scale.

tasks, social activity, support from the family and friends, arthritis pain, work, level of tension, and mood. In item 60, the respondent is asked to report 3 out of 12 areas of health in which he or she would like to see improvement. These health areas were also linked to the categories of the ICF<sup>13</sup> according to the practical example of the area concerned given in parentheses (Table 2). Demographic data were collected using a questionnaire.

The healthy control subjects identified from the Finnish population registry were interviewed by mail. They completed the MDHAQ questionnaire<sup>16</sup> and gave demographic data. The design of the study was approved by the Ethical Committee of the Central Hospital of Päijät-Häme.

**Statistical methods.** The results were expressed as mean with standard deviation (SD) or range. Confidence intervals for the means were obtained by bias-corrected and accelerated bootstrapping (5000 replications). Differences in functioning between JIA patients and their matched controls were determined using the permutation test and multivariate analysis of variance with Hotelling-type permutation test for related samples. The Hotelling T-squared test is a method of comparing means of all variables of interest simultaneously (in our analysis the ICF components with 3 domains in each), while maintaining the chosen magnitude of Type I error<sup>19</sup>. The preferences for improvement in health were analyzed using the Fisher exact test with permu-

tation-based multiplicity-adjusted p values<sup>20</sup>. To support the validity and the rationale that the domains identified are suitable for statistical analysis the internal consistency was estimated by calculating Cronbach's alpha of the ICF components for the patients only. Data analysis was carried out with the statistical software package R2.0.1 (R Foundation for Statistical Computing, Vienna, Austria)<sup>21</sup> and SAS 9.1.

## RESULTS

One hundred twenty-three (68%) young adults with JIA participated in the study. There were 20 who refused, 12 could not be reached, and 26 could not make time for the visit. The comparability of the groups was analyzed with regard to age at onset, sex, onset type, and age at followup. We found no difference in the distribution of diagnoses (course type) between patients participating in the followup study and those not available. The only difference between the groups was in the distribution of men, 28% in the study group and 43% in the remainder. Of all 123 participating patients, 89 were

Table 2. Areas of health (AIMS2 item 60) as priorities for improvement in the components and domains of the ICF, with individual codes.

Areas of Health	ICF Component	ICF Domain	ICF Code
1. Mobility level (e.g., do errands)	Participation	Domestic life	p620
2. Walking and bending (e.g., climb stairs)	Activity	Mobility	a450
3. Hand and finger function (e.g., tie a bow)	Activity	Mobility	a440
4. Arm function (e.g., comb hair)	Activity	Self-care	a5202
5. Self-care (e.g., take a bath)	Activity	Self-care	a5101
6. Household tasks (e.g., housework)	Participation	Domestic life	p640
7. Social activity (e.g., visit friends)	Participation	Interpersonal interactions and relationships	p750
8. Support from family (e.g., help with problems)	Environmental factors	Support and relationships	e310
9. Pain (e.g., joint pain)	Body structure and functions	Sensory functions and pain	b280
10. Work (e.g., reduce hours)	Participation	Major life areas	p840
11. Level of tension (e.g., felt tension)	Body structure and functions	Mental functions	b152
12. Mood (e.g., "down in the dumps")	Body structure and functions	Mental functions	b152

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female (72%). The mean time from diagnosis to followup was 16.2 years. The patients with JIA had spousal relationship, education level, and employment status similar to controls at the time of followup as described<sup>22</sup>. Demographic data and main clinical characteristics of patients are given in Table 3.

In multivariate analysis, significant differences in functioning between patients and controls emerged in all 3 ICF components: body functions (including simultaneously sleep, pain, and fatigue),  $p = 0.045$ ; activity (general tasks and demands, mobility<sup>a</sup>, and self-care),  $p = 0.0021$ ; and participation (mobility<sup>p</sup>, domestic life, community, social and civic life),  $p < 0.001$ . In the univariate analysis, under each ICF component, in the component for body functions there was a higher level of pain among patients with JIA compared to controls ( $p = 0.036$ ); while in the activity component, JIA patients had lower levels of mobility<sup>a</sup> compared to controls ( $p = 0.0034$ ). Further, in the participation component lower levels

of functioning in the domains of mobility<sup>p</sup> ( $p = 0.0046$ ) and social life ( $p < 0.001$ ) were found in JIA patients compared to controls (Table 4). Cronbach's alpha results for ICF components in the JIA patient group were 0.72 for body functions, 0.76 for activity, and 0.70 for participation.

We divided patients with JIA into 2 separate groups regarding disease activity to compare their functioning with controls. In the group of patients with active disease versus controls, multivariate analysis revealed significantly lower levels of functioning in JIA patients in every component of functioning concerned: body functions,  $p = 0.0015$ ; activity,  $p < 0.001$ ; participation  $p < 0.001$ . JIA patients with active disease had a higher level of pain ( $p = 0.0011$ ), lower levels of mobility<sup>a</sup> ( $p < 0.001$ ) and self-care ( $p = 0.027$ ), and lower levels of participation in all domains concerned (mobility<sup>p</sup>,  $p < 0.001$ ; domestic life,  $p = 0.0039$ ; community, social, and civic life,  $p < 0.001$ ) (Figure 2). There were no significant differences in

Table 3. Demographic and clinical characteristics of patients.

Variables	Male, N = 34	Female, N = 89	All, N = 123
Age at onset, mean (SD), yrs	9.4 (4.0)	7.2 (4.5)	7.8 (4.4)
Diagnosis (course type), no (%)			
Oligoarthritis	26 (76)	52 (58)	78 (63)
Extended oligoarthritis	3 (9)	12 (13)	15 (12)
Polyarthritis RF-negative	4 (12)	19 (21)	23 (19)
Polyarthritis RF-positive	0 (0)	4 (4)	4 (3)
Sytemic arthritis	0 (0)	2 (2)	2 (2)
Psoriatic arthritis	1 (3)	0 (0)	1 (1)
Disease activity at followup, no. (%)			
Remission, no DMARD	17 (50)	26 (29)	43 (35)
No activity, taking DMARD	1 (3)	2 (2)	3 (2)
Active disease	16 (47)	61 (69)	77 (63)
Time from diagnosis to followup, mean (range), yrs	14.7 (6.7–22.6)	16.7 (6.0–23.8)	16.2 (6.0–23.8)
Age at followup, mean (range), yrs	23.2 (21–26)	23.4 (21–26)	23.3 (21–26)

RF: rheumatoid factor, DMARD: disease modifying antirheumatic drug.

Table 4. Components and domains of disability (MDHAQ items included in parentheses) in patients and controls.

ICF Components (MDHAQ item)	Patients, mean (SD)	Controls, mean (SD)	Univariate p*	Multivariate p**
Body structure and functions				0.045
Mental functions (o)	0.23 (0.44)	0.26 (0.49)	0.68	
Sensory functions and pain (Pain, VAS)	15 (21)	10 (14)	0.036	
Mental functions (Fatigue, VAS)	23 (27)	23 (24)	0.82	
Activity				0.0021
General tasks and demands (p, q, r)	0.29 (0.49)	0.34 (0.49)	0.47	
Mobility (b, c, d, f, g, j, l)	0.20 (0.26)	0.12 (0.15)	0.0034	
Self-care (a, e)	0.06 (0.21)	0.03 (0.15)	0.32	
Participation				< 0.001
Mobility (h, k, m)	0.15 (0.32)	0.05 (0.19)	0.0046	
Domestic life (i)	0.08 (0.30)	0.02 (0.13)	0.053	
Community, social, and civic life (n)	0.64 (0.88)	0.14 (0.35)	< 0.001	

\* Permutation test for related samples. \*\* Hotelling-type permutation test for related samples performed in 3 domains of the same ICF component simultaneously. VAS: visual analog scale.

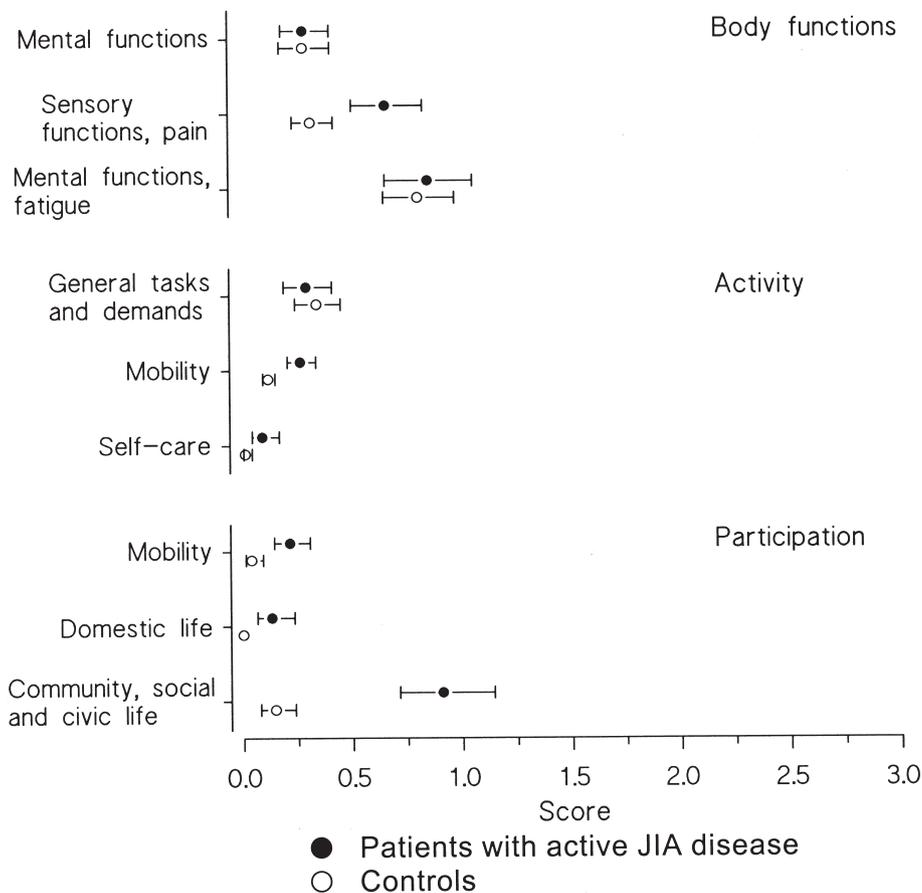


Figure 2. Level of functioning in patients with active JIA disease (N = 77) and age, sex, and domicile-matched controls. Pain and fatigue VAS are standardized from 0 to 3. Whiskers indicate 95% confidence interval.

any components of functioning between JIA patients in remission and controls in multivariate analysis (body functions,  $p = 0.051$ ; activity,  $p = 0.50$ ; participation,  $p = 0.46$ ).

In addition to the longterm outcome results of the patients with JIA, we were also interested in which 3 areas of health patients wanted to see improvement according to the Finn-AIMS2 instrument, and whether the patient groups with active disease and those in remission would differ from each other. The patients with active disease had the highest scores in arthritis for pain, level of tension, and walking and bending. Patients in remission had the highest scores in level of tension, mood, and social activity. The groups differed from each other in pain ( $p = 0.0025$ , corrected levels for multiple tests) and social activity ( $p = 0.032$ ) (Figure 3).

## DISCUSSION

Since the acceptance of the ICF classification by the World Health Assembly in May 2001, a growing number of reports have been published on the application of the classification to rheumatology and rehabilitation<sup>23-28</sup>. The use of the classification is a challenge, first, in view of the wide range of applicable categories, and second, by reason of the lack of experi-

ence to date in using the classification as a research tool. Linkage of the 18 items and 2 visual analog scales of the MDHAQ to the ICF categories produced 3 categories for each component of functioning (Tables 1 and 4). The majority of the items (12 out of 20) are directed to the activity component. Three and 5 items were directed to the body functions and participation components, respectively. The items concerning general tasks and demands, e.g., mental functions — anxiety, depression, and handling stress, were directed to the activity component because of the character of the questions, including the ability to deal with these feelings. The importance of the MDHAQ lies in inclusion of the mental and physical determinants of functioning in the same instrument, but from the ICF point of view the fact that 3 important mental aspects are assigned within one general ICF code could oversimplify mental functions. The overlapping of the mobility domain between the categories of activity and participation was one of the 4 options given in the ICF manual to code items into these categories. We chose to use partial overlap for the wide range of mobility items used in the MDHAQ and for the social context connected with some of these items. However, criticism has been presented concerning the confusion between the def-

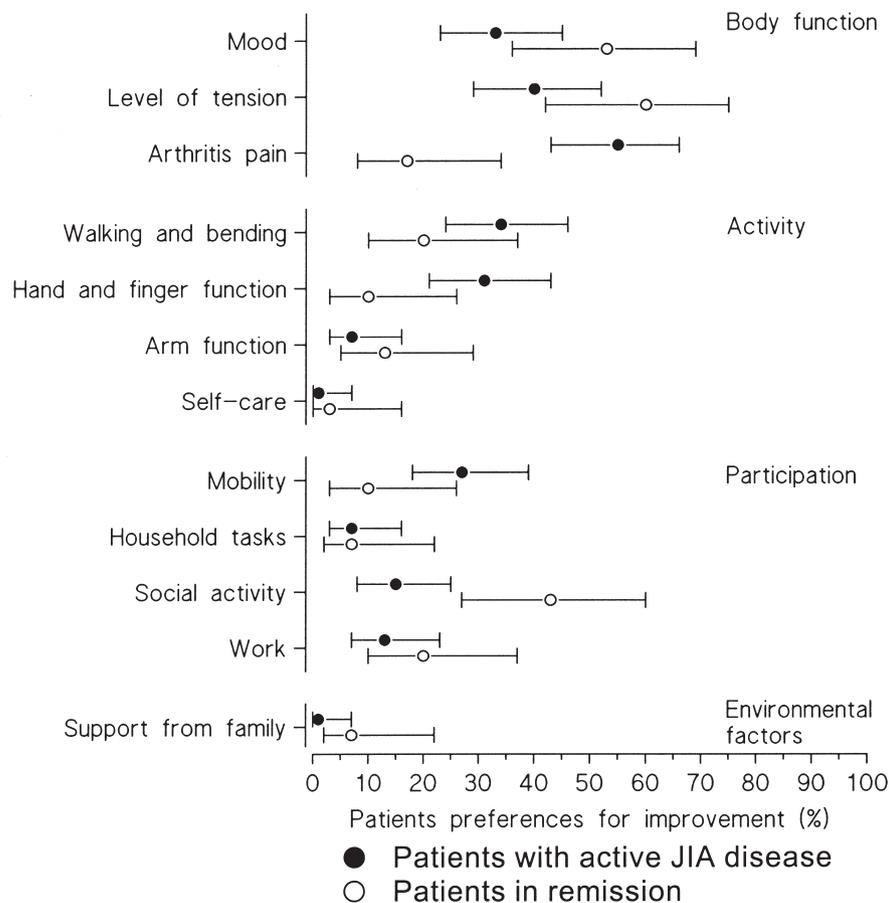


Figure 3. Preferences for improvement in 12 areas of health according to the Finn-AIMS2 in patients with active JIA disease (N = 77) and in remission (N = 46). Whiskers indicate 95% confidence interval.

initions of activity and participation and the lack of theoretical coherence<sup>29</sup> in this part of the ICF. Yet in the other clinical research area the components of activity and participation have been shown to be distinct dimensions<sup>30</sup>. Future development work on the ICF may clarify the definitions and the use of the categories. We believe that the ICF can offer a promising model to examine the outcomes of young adult patients with juvenile arthritis.

There are only a few studies<sup>8,9,11</sup> of JIA patients and healthy controls in age groups similar to those in our study. However, all studies<sup>8,9,11</sup> including ours have found higher levels of pain in JIA patients than in controls. The same finding was recorded here in the comparison between JIA patients with active disease and controls. Fatigue and sleep as psychological symptoms have to date not been studied as longterm outcomes among young adult JIA patients and healthy controls. The results for fatigue and sleep and the ability to handle stress show that patients with JIA have levels of mental adjustment similar to their controls, irrespective of the level of disease activity. Earlier findings with a broader psychological perspective than our study have shown that severity of disease has no association with adjustment<sup>31,32</sup> or psychosocial functioning<sup>33</sup> among young adults with juvenile arthritis.

This is the first study to date to employ the MDHAQ instrument as a research tool in young adults with JIA. In most studies of functional outcome among JIA patients<sup>4,6-11</sup> the Health Assessment Questionnaire (HAQ) has been applied. Besides questions on basic ADL, the MDHAQ includes items on advanced ADL; the instrument is thus equally amenable to use with healthy respondents. In the activity component we found lower levels of mobility<sup>a</sup> in JIA patients compared with controls, whereas there were similar results for mental functioning and self-care. In the JIA patients with active disease the differences between patients and controls became more distinct. Patients with active disease had lower levels of mobility<sup>a</sup> and self-care in the activity component. Peterson and colleagues<sup>11</sup> studied the health status of patients with juvenile rheumatoid arthritis (JRA) and controls and also found a lower level of functional status in patients compared with controls using the HAQ. Flato and colleagues<sup>8</sup> found 36% of JRA patients had impaired physical function. Ruperto, *et al*<sup>4</sup> found a large proportion of patients had little or no residual functional ability measured by the HAQ in a group with ages similar to our group.

In the participation component, JIA patients had lower levels of functioning compared to controls. Further, the JIA

patients with active disease had lower levels of functioning in all 3 domains of participation. The trend of increasing differences can be seen in the sequence of the components of body functions and activity compared to that of participation between JIA patients and controls, and further, between JIA patients with active disease and controls. Patients in remission compared to controls did not show this trend. Using a multi-dimensional instrument, the Finn-MDHAQ and the ICF classification, we determined that in patients with JIA more attention should be paid to the different aspects of functioning, especially to the level of participation. Clear differences in functioning were found in patients with active disease compared to controls. The similar results in all components of functioning in JIA patients in remission and controls indicate that reduction of disease activity in JIA patients and achievement of remission should be a high priority in treatment. Besides active treatment, patients with active disease also need active rehabilitation to maintain functioning.

Comparing our outcome data with the results of previous studies, we support the application of the MDHAQ rather than the HAQ in evaluation studies in young adult patients with JIA because of the contents and the item structure in the MDHAQ, and also for the balanced division of items into the different ICF components. We have also proved that the ICF can be applicable as a clinical model when comparing clinical outcome data across time, as the WHO has suggested<sup>13</sup>.

Patients with active disease and those in remission had in common the highest scores in their wishes for improvement in the items of mental functioning, level of tension, or mood. However, the groups differed from each other in that patients with active disease wished their pain would decrease, as noted also in 3 studies conducted among patients with rheumatoid arthritis and adults with JIA<sup>34-36</sup>. Patients in remission differed from those with active disease by wishing for the ability to visit their friends more often, which is understandable, in that in the absence of actual discomfort the more universal preferences available in the areas of health will be chosen.

Our findings bring out the areas of functioning in which patients with JIA can meet difficulties in everyday life and in social interaction. The results, with lower levels of functioning in JIA patients with active disease, indicate more pain and lower levels of mobility<sup>a-p</sup>, self-care, and domestic and social life compared with controls. Patients with active disease therefore need active treatment and rehabilitation to maintain functioning and decrease pain. Application of the MDHAQ rather than the HAQ is supported by our evaluation studies in young adult patients with JIA. Our study has proved that the ICF offers a promising model, with a wide view of functioning, to examining the longterm outcomes of adult patients with JIA. In future modifications of multi-dimensional instruments, more attention should be paid to a more balanced approach to different components of patient functioning.

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