EXTENDED REPORT

Favourable social functioning and health related quality of life of patients with JIA in early adulthood

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Objective: To evaluate the social functioning and health related quality of life (HRQoL) in patients with juvenile idiopathic arthritis (JIA) in early adulthood.
Methods: The patient files of the Rheumatism Foundation Hospital were screened to identify patients born in 1976–1980 diagnosed as having JIA. HRQoL was measured by the RAND 36-item health survey 1.0; spousal relationships and educational and employment status were assessed by questionnaire. The patients were invited to a follow up study. Age and sex matched controls from the community were identified in the Finnish population registry.
Results: Of 187 patients identified, 123 participated. Spousal relationships, educational level, and employment status were similar to controls. HRQoL in JIA patients was similar to controls except on the physical functioning scale. At follow up 35% of patients were in remission. Patients with active disease had poorer HRQoL in the physical component than those in remission or controls. The extended oligoarthritis group had the lowest physical and mental score in HRQoL compared with the other JIA subgroups. The patient's own evaluation was the explanatory factor in both the physical and mental component of HRQoL.
Conclusion: Social functioning and HRQoL were similar in JIA patients and age, sex, and municipality matched controls. However, patients with extended oligoarthritis attained significantly lower scores in the physical and mental component of HRQoL than oligo- or polyarthritis patients. Special attention in everyday care should be paid to those patients who have active disease or the extended oligoarthritis type of disease.

The long term outcome of young adults with juvenile idiopathic arthritis (JIA) is variable.[1–6] Differences in health care systems and in national care and rehabilitation disciplines, together with different recruitment protocols and heterogeneity of age cohorts, make comparison between different studies and conclusions a challenge.[1] Another challenge is to see the outcome of disease from both the individual's and society's point of view.[7] In research on the outcome of JIA the need for this is clear, in view of the multidimensional effects of the disease on growth, body composition, function, and social participation in childhood, adolescence, and adult life.[1–6] Level of education and employment are among the most important measures of long term outcome in juvenile rheumatic diseases,[1 3] indicating the possibilities for patients to participate equally in the life of the community. Although there is no consensus on the definition of health related quality of life (HRQoL),[8–11] it is, however, an important part of the multidimensional and subjective picture of the outcome of rheumatic patients.[12 13]

The third decade in a person's life is full of major life events. Educational goals are being achieved, entry into the labour force is realised, and new families are being set up. The life of a young adult with JIA is no exception. Although the importance of this period of life has been noted in paediatric rheumatology clinics,[14] the amount of research in the area of education, employment, and HRQoL is surprisingly small. As a part of larger study entity we have examined participation and HRQoL in an unselected cohort at the age of 21 to 26 years and compared the results with age, sex, and municipality matched controls.

METHODS

Patients

The Rheumatism Foundation Hospital (RFH), founded in 1951, is a Finnish institution specialising in the treatment and rehabilitation of people with musculoskeletal diseases. The hospital provides services of university hospital standard nationwide but also secondary level care services for those living nearby. Multidisciplinary care and rehabilitation practice with the services of, for example, social workers, psychologists, and career guidance 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 patient (aged less than 16 years) treated at the RFH were used to identify those born between 1976 and 1980 who were patients in this hospital for the first time during the years 1976 to 1995. There were 587 such patients. We collected those who had been diagnosed as having juvenile arthritis. Of these, 189 were excluded because they had a diagnosis other than juvenile arthritis. From the remaining 398 patients we collected those in whom juvenile arthritis was diagnosed in the RFH. This led to the exclusion of a further 211 patients because their treatment had been initiated elsewhere than in the RFH. Finally, therefore, there were 187 patients with early untreated JIA whose diagnosis was made at the RFH and whose treatment was initiated there. All these patients were reclassified using JIA[15] criteria.

The medical records of the patients in the RFH were reviewed to obtain their clinical characteristics: onset of the disease, subtype (course type) of JIA, sex, age at onset, and time of the first visit to RFH. There were no differences in sex or the mean age at the onset of disease between the early untreated JIA patient group (untreated group) and those whose treatment was initiated elsewhere than RFH (treated

Abbreviations: Finn-AIMS2, Finnish version of the arthritis impact measurement scales questionnaire; HRQoL, health related quality of life; JIA, juvenile idiopathic arthritis; MCS, mental component scales; PCS, physical component scales; QoL, quality of life; RAND-36, RAND 36 item health survey 1.0 questionnaire

Table 1 Demographic and clinical characteristics of patients with juvenile idiopathic arthritis

Variable	Disease activity at follow up		p Value
	Inactive (n = 46)	Active (n = 77)	
Demographic			
Female (n (%))	28 (61)	61 (79)	0.028
Age at onset (years) (mean (SD))	8.3 (4.4)	7.5 (4.4)	0.39
Clinical			
Diagnosis (course type) (n (%))			0.062
Oligoarthritis	33 (72)	45 (58)	
Extended oligoarthritis	1 (2)	14 (18)	
Polyarthritis, RF negative	10 (22)	13 (17)	
Polyarthritis, RF positive	1 (2)	3 (4)	
Systemic arthritis	1 (2)	1 (1)	
Psoriatic arthritis	0 (0)	1 (1)	
Time from diagnosis to follow up (years) (mean (range))	15.6 (6.6 to 23.6)	16.5 (6.0 to 23.8)	0.34
Age at follow up (years) (mean (range))	23.4 (21 to 26)	23.3 (21 to 26)	0.85
Patients receiving DMARDs (n (%))	3 (7)	68 (88)	<0.001
Measures of disease activity at follow up			
ESR (mm/h) (median (IQR))	4 (3 to 9)	9 (5 to 16)	<0.001
Duration of morning stiffness (min) (median (IQR))	0 (0 to 0)	0 (0 to 30)	<0.001
Number of swollen joints (median (IQR))	0 (0 to 0)	1 (0 to 3)	<0.001
Number of tender joints (median (IQR))	0 (0 to 0)	1 (1 to 3)	<0.001
Patient's global assessment (VAS) (median (IQR))	1 (0 to 2)	10 (1 to 25)	<0.001
Physician's global assessment (VAS) (median (IQR))	0 (0 to 1)	12 (3 to 23)	<0.001
Pain (VAS) (median (IQR))	0 (0 to 1)	5 (0 to 25)	<0.001
RAND-36			
Physical health summary scores (mean (SD))	53.9 (4.9)	47.6 (9.3)	<0.001
Mental health summary scores (mean (SD))	50.0 (9.2)	50.0 (8.3)	0.99

DMARD, disease modifying antirheumatic drug; ESR, erythrocyte sedimentation rate; IQR, interquartile range; RF, rheumatoid factor; VAS, visual analogue scale.

group). However, there were more patients with oligoarticular JIA in the untreated group (75%) than in the treated group (55%). Polyarticular JIA was less common (22% *v* 39%). Systemic disease was rare in both groups (2% and 6%, respectively). Compared with the untreated group, in whom therapy was started during the first visit to the RFH, therapy in the treated group was begun at a mean of 2.0 (range 0.1 to 13.6) years earlier, before their first visit to RFH.

Four of the 187 untreated patients had Down's syndrome. These were excluded because their social and educational problems would be hard to distinguish from a possible rheumatic component. In addition, two of the patients had died (in both cases from accidental causes). Thus 181 patients were invited by mail to take part in the study. In all, 123 patients (68%) participated. There were 20 refusals, 12 patients could not be reached, and 26 could not make time for the visit. The comparability of the groups was analysed with regard to age at onset, sex, onset type, and age at follow up. We found no difference in the distribution of diagnosis between the patients participating in the follow up 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. Population controls were identified in the Finnish population registry, matching the participating patients for age, sex, and domicile.

Table 2 Spousal relationships and educational and employment status of patients with juvenile idiopathic arthritis and controls

	Patients (n = 123)	Controls (n = 123)	p Value
Marriage or common law marriage (n (%))	62 (50)	75 (61)	0.12
Educational status at follow up (n (%))			0.67
Basic education only	8 (7)	8 (7)	
Vocational education	39 (32)	43 (35)	
Upper secondary school	47 (38)	30 (24)	
Upper secondary school and vocational education	12 (10)	25 (20)	
Higher education	17 (14)	17 (14)	
Employment status (n (%))			0.30
Employed	51 (41)	55 (45)	
Unemployed	12 (10)	19 (15)	
Student	58 (47)	48 (39)	
Disability pension	2 (2)	1 (1)	

Clinical methods

The patients visited the RFH and were examined by a paediatric rheumatologist (JH). The examination included a record of the number of swollen and tender joints and the physician's global assessment of disease activity on a 100 mm visual analogue scale. Laboratory tests were done to assess disease activity. A patient was considered to be in remission at follow up if the erythrocyte sedimentation rate (ESR) was $\leqslant$20 mm/h, morning stiffness lasted $\leqslant$15 minutes, there were no tender or swollen joints, and the patient had been off disease modifying antirheumatic drugs or glucocorticoids for at least the past two years.[16] The patients completed a Finnish version of RAND 36 item health survey 1.0 questionnaire (RAND-36)[17] and the Finnish version of the arthritis impact

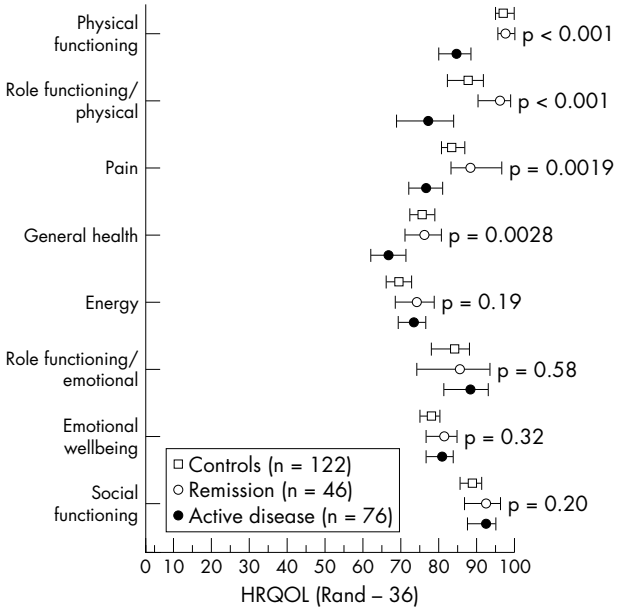

Figure 1 Mean health related quality of life scales with 95% confidence intervals in patients with juvenile idiopathic arthritis in remission and with active disease; p values adjusted using Hommel's method; confidence intervals obtained by bias corrected and accelerated bootstrapping (5000 replications).

measurement scales questionnaire (Finn-AIMS2),[18] from which the work scale was used in this part of the study.

The RAND-36[19] is a measure of health related quality of life containing 36 items on eight scales: physical functioning, bodily pain, role limitation due to physical health problems (hereafter called role functioning/physical), general health, energy, role limitation due to personal emotional problems (hereafter called role functioning/emotional), emotional wellbeing, and social functioning. The raw responses in a questionnaire were recoded according to the original version of RAND-36,[19] each item being scored on a 0 to 100 range with the lowest and highest possible scores set at 0 and 100. The higher the recoded value of the item is, the better the HRQoL. Physical and mental health summary scores were derived using factor analysis. The summary scores were calculated using T scores. Normalised T scores were created by multiplying standard scores by 10 and adding 50 to the product. This yields a distribution of scores with a mean of 50 and a standard deviation of 10.[19]

The work scale from Finn-AIMS2[18] is a five item scale covering the respondent's ability to work during the past month. The patients also completed two 100 mm visual analogue scales, one for their overall assessment of disease activity and the other for pain. Demographic and educational data were collected by questionnaire.

The control subjects identified from the Finnish population registry were interviewed by mail. They completed the RAND-36 questionnaire,[17] questions from the work scale in the Finn-AIMS2 questionnaire,[18] and provided demographic data.

The design of the study was approved by the ethics committee of the Central Hospital of Päijät-Häme.

Statistical methods

Results are expressed as mean or median, with standard deviation or interquartile range (IQR) and 95% confidence intervals (CI). Maximum likelihood factor analysis with varimax rotation was applied to construct the physical and mental components and their summary scales. Differences between JIA patients and their healthy matched controls were compared using McNemar's test and the marginal homogeneity test for categorical variables, and the paired *t* test and Hotelling's T^2 generalised means test for continuous variables. Statistical comparison between subgroups was made by unpaired *t* tests or the Mann–Whitney U test, analysis of variance (ANOVA), and multivariate analysis of variance (MANOVA) with Pillai's trace statistics. When assuming unequal variances, we used analysis of variance with general scores or Welch's test. We used Hommel's adjustments to correct significance levels for multiple testing. To determine the best predictors of RAND-36 dimensions, forward stepwise ordered logistic regression analysis was applied. We evaluated the normality of variables by the Shapiro–Wilk test.

RESULTS

In all, 123 patients participated in the study (89 female, 34 male; mean age 23 years). The median (IQR) time from the first symptoms to the first visit to RFH and diagnosis of the disease was 3 (1 to 5) months. The mean (SD) age at onset of disease was 7.8 (4.4) years, and mean time from diagnosis to follow up was 16.2 years (range 6.0 to 23.8). The disease types are listed in table 1.

At follow up, 28 (31%) of the female patients and 18 (53%) of the male patients were in remission (including those three patients who had had no disease activity for the past two years but were on DMARDs). The difference between the groups was 21% (95% CI, −40 to −2), $p = 0.028$.

Spousal relationships were similar between patients and controls (table 2). There was no significant difference in educational level between the two groups, nor was there any difference in the frequency of employment, unemployment, and disability pensions (table 2). There was no significant difference in the ability to work in the two groups, whether the subjects were in paid or home work or were classified as a student (data not shown).

The RAND-36 data on the patients and on the age, sex, and municipality matched controls are shown in table 3 (missing data in one patient). In the univariate analysis in the physical component scales (PCS) (including physical functioning, role functioning/physical, pain, and general health) the physical functioning score in the patient group was significantly lower (poorer) than in the control group. In the mental component scales (MCS) (including energy, role functioning/emotional, emotional wellbeing, and social functioning) no difference was found in univariate analysis between the groups. In multivariate analysis in the PCS we found a statistically significant difference (Hotelling T^2, $p = 0.0017$) between patients and controls. In multivariate analysis of the MCS no significant difference emerged between the groups (Hotelling T^2, $p = 0.15$).

When comparing the HRQoL between patients in remission (including the three in remission with no disease activity for the past two years but on DMARDs), those with active disease, and the controls we found differences in all scales of PCS in univariate analysis ($p<0.01$) but none in MCS between controls. There was, however, a difference between the groups in PCS (MANOVA Pillai's trace, $p<0.001$) in the multivariate analysis but none in the MCS between these three groups (MANOVA Pillai's trace, $p = 0.74$). In all scales of PCS there were localised statistical differences (post hoc: $\alpha = 0.05$) in controls and in patients in remission compared with patients with active disease. There was no difference between controls and patients in remission on the PCS scales (fig 1).

We compared HRQoL in patients with oligoarthritis, extended oligoarthritis, and polyarthritis, and in univariate analysis in PCS, differences between groups emerged on the

Table 3 Health related quality of life as measured by the RAND 36 item health survey in 122 young adults with juvenile idiopathic arthritis and controls

Domain	Patients (mean (SD))	Controls (mean (SD))	p Value*
Physical component scales†			
Physical functioning	89.6 (16.3)	96.8 (6.8)	<0.001
Role functioning/physical	84.4 (28.6)	87.5 (26.1)	0.37
Pain	81.6 (19.9)	83.7 (16.1)	0.36
General health	71.1 (19.4)	75.6 (18.2)	0.18
Mental component scales‡			
Energy	74.2 (15.9)	69.5 (18.4)	0.08
Role functioning/emotional	87.2 (22.2)	84.2 (29.1)	0.45
Emotional wellbeing	81.9 (14.1)	78.0 (14.7)	0.086
Social functioning	93.4 (13.1)	88.8 (16.1)	0.057

*Adjusted using Hommel's method.
†Hotelling's T^2 generalised means test for four scales: p = 0.0017.
‡Hotelling's T^2 generalised means test for four scales: p = 0.15.

scales of physical functioning and role limitations due to physical health problems. In univariate analysis the only difference between the respective JIA subgroups in MCS was in the social functioning scale. In multivariate analysis we found a difference between the groups in PCS (MANOVA Pillai's trace: p = 0.030) but not in MCS (MANOVA Pillai's trace: p = 0.071). The extended oligoarthritis group had the lowest value for HRQoL on all scales of PCS and MCS. The mean (SD) physical health summary score was 51.1 (7.5) in oligoarthritis patients, 42.2 (8.4) in extended oligoarthritis patients, and 50.5 (9.2) in polyarthritis patients (p<0.001), and the mean mental health summary scores were, respectively, 50.9 (8.1), 44.6 (10.3), and 49.6 (8.5) (p = 0.041) (fig 2).

A patient's global assessment (VAS) of <20 mm and remission at follow up were entered into the forward ordered logistic regression model as an explanatory variable for high (better) HRQoL in the physical health summary scales. In the mental health summary scales, likewise, a patient's global assessment (VAS) of <20 mm was entered as an explanatory variable for better HRQoL (table 4).

DISCUSSION

The population in this study was collected from second and third level hospital patients with early untreated JIA. The baseline for treatment and start of the prospective study in the study group was the first visit in RFH, whereas the patients who were excluded had been treated on the average for two years before their first RFH visit. The different distribution of diagnostic subgroups in these patients also showed that the excluded patients were biased towards having more severe disease with more polyarticular disease. The possibility of generalising the present results to the whole young JIA population in Finland may be limited because of the use of hospital material. This kind of material is often considered to be biased towards severe disease. To avoid this bias as least partly, we focused on the early untreated JIA population with a broad spectrum of disease. The potential limitation may also result from a skewed JIA subtype distribution (with lack of enthesitis related arthritis) and a skewed sex distribution in the study group compared with non participants.

At follow up after a mean of 16.2 years, 37% of the JIA patients were in remission. This is identical to the proportion in recent studies with similar patient age, follow up time, and study arrangements.[3 5] This might be taken as indirect evidence for absence of major bias in the patient selection.

Few studies have examined aspects of education, employment, and HRQoL (or quality of life, QoL) in JIA patients in early adult life. In addition, most have used a wider age range than in the present study. Findings on educational achievement in patients with juvenile arthritis reported during the preceding decade mainly showed a comparable or higher education level compared with controls.[1–3 6 20] In one study, a lower level of educational achievement was found in young adults with arthritis beginning in early adult life.[21] The level of unemployment has varied between reports: higher in JIA patients than in controls in four studies[1 2 6 20] and lower or

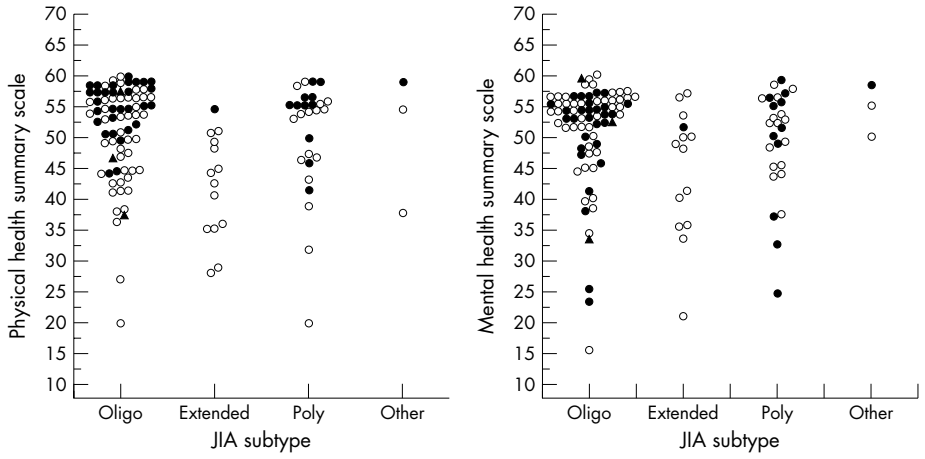

Figure 2 Physical and mental summary scales of patients in juvenile idiopathic arthritis subtypes. Empty circles, patients with active disease; filled circles, patients in remission, no DMARDs; filled triangles, patients with no disease activity for the past two years but on DMARDs.

Table 4 Ordered logistic regression models for the RAND 36 item health survey physical health and mental health component summary scales in 122 young adults with juvenile idiopathic arthritis

	Predictors of physical health and mental health summary scales			
	Univariate		Multivariate*	
Explanatory variable	Physical health OR (95% CI†)	Mental health OR (95% CI†)	Physical health OR (95% CI†)	Mental health OR (95% CI†)
Sex (female)	0.57 (0.28 to 1.16)	0.54 (0.25 to 1.15)		
Age at follow up (years)	0.85 (0.70 to 1.06)	0.82 (0.66 to 1.02)		
Educational years				
9	Reference	Reference		
9–12	3.12 (1.10 to 8.87)	1.87 (0.43 to 8.12)		
>12	2.79 (0.92 to 8.51)	2.32 (0.47 to 11.45)		
Marriage or common law marriage	1.25 (0.65 to 2.41)	1.95 (1.00 to 3.79)		
Age at onset (years)	1.04 (0.96 to 1.23)	1.02 (0.94 to 1.10)		
Diagnosis				
Oligoarthritis	Reference	Reference		
Extended oligoarthritis	0.17 (0.06 to 0.46)	0.22 (0.07 to 0.72)		
Polyarthritis	0.76 (0.33 to 1.77)	0.65 (0.27 to 1.56)		
Other arthritis	0.76 (0.08 to 7.11)	3.67 (0.47 to >20)		
Remission at follow up	3.70 (1.86 to 7.35)	1.10 (0.57 to 2.11)	2.23 (1.09 to 4.56)	
Pain, less than 20 mm in VAS	17.26 (4.86 to >20)	2.19 (0.89 to 5.41)		
Patient's global assessment, less than 20 mm in VAS	25.23 (5.94 to >20)	3.45 (1.52 to 7.83)	19.02 (4.36 to >20)	3.45 (1.52 to 7.83)
Physician's global assessment, less than 20 mm in VAS	5.19 (1.81 to 14.88)	2.39 (0.91 to 6.30)		

Dependent variables are divided into quartiles.
*Forward selection. Only those variables shown which entered the model.
†95% confidence interval calculated using robust standard error.
CI, confidence interval; OR, odds ratio; VAS, visual analogue scale.

similar in two others.[3 5] Our results confirm the majority of the earlier findings—that is, a similar educational level in JIA patients and controls. However, we also found that employment status was very similar to the control group. Our study population covered the whole spectrum of JIA patients and therefore patients who had severe disability in everyday life were in the minority. It is possible that such patients might be overrepresented in the group classified as students, because difficulty in finding employment could defer the completion of their studies. Our study showed that this was not the case, because no difference in the ability to work was found between JIA patients and controls when comparing those working and those studying. On the other hand in most other similar studies the mean age of the study population has been greater than in ours, and it is suggested that the employment rate falls with longer periods of follow up.[20] However, we show here that JIA patients have the preconditions for independent function and social life in adulthood, with stable spousal relationships and the possibility of earning a living, achieved through sufficient education and equal employment conditions.

The concept of QoL is controversial. Although there is a lack of international consensus on the definition of QoL or HRQoL, interest in studying it as an outcome measure increased considerably in the 1990s.[22–25] To measure HRQoL we used the RAND-36 questionnaire which contains the same items as the short form 36 item questionnaire (SF-36)[26] but with a slightly different scoring system. The results are nonetheless comparable.[19]

Foster and colleagues[1] compared QoL (HRQoL) in adult JIA patients with controls using the SF-36 instrument[26] and reported significantly worse scores in all physical scales (physical functioning, vitality, bodily pain, general health) and in the emotional role scale. Peterson *et al*,[6] also using SF-36, showed significantly lower scores in the physical domain, but there was no difference between cases and controls in mental functioning. Our results on HRQoL in JIA patients *v* controls are comparable with those reported by Foster *et al*[1] and Peterson *et al*,[6] although the two instruments differ slightly. Both research groups found differences in almost all physical scales of SF-36, while the only difference in our analysis was in one scale (physical functioning).

We found lower HRQoL in all physical components in patients with active disease than in those in remission or in controls. In the mental component of HRQoL no differences emerged between the groups. In the various JIA subgroups there was a clear difference in the physical component of HRQoL, but only a minor difference in the mental. The results underline the importance of effective suppression of the patient's disease activity, and also of attention to differences in the outcome in different subgroups of JIA. In contrast to results in one recent study,[1] we found the lowest HRQoL in the extended oligoarthritis group.

The patient's global assessment explained both the physical and the mental component of HRQoL. The importance of the patient's subjective evaluation in the assessment of HRQoL is thus supported by this cohort. Hence, the finding that JIA patients in early adulthood evaluate their mental component of HRQoL similarly to healthy controls is worthy of note—multidisciplinary care has achieved one very important goal. There is, however, much to be done in reducing the negative components of JIA in the health of our young patients. The WHO's *International Classification of Functioning, Disability and Health* (ICF)[27] is a promising tool and a developing scientific basis for studying and comparing health of populations in different kinds of personal and environmental contexts. It can also help us to understand better the negative components of JIA as a part of the patients' health outcome in the international and multidisciplinary context.

Conclusions

Education, employment, and spousal relationships in Finnish JIA patients in early adult life are similar to those in controls. JIA patients evaluate their HRQoL comparably to controls. JIA influences HRQoL in patients with active disease and in those with extended oligoarthritis, the latter having the lowest HRQoL. The patient's own evaluation was the explanatory variable in HRQoL. Although the outcome of the whole cohort was good, the results of patients with

extended oligoarthritis indicate that therapeutic interventions should be optimised during the active phase of the disease.

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REFERENCES

1 **Foster HE**, Marshall N, Myers A, Dunkley P, Griffiths ID. Outcome in adults with juvenile idiopathic arthritis. *Arthritis Rheum* 2003;**48**:767–75.
2 **Flato B**, Lien G, Smerdel A, Vinje O, Dale K, Johnston V, *et al*. Prognostic factors in juvenile rheumatoid arthritis: a case–control study revealing early predictors and outcome after 14.9 years. *J Rheumatol* 2003;**30**:386–93.
3 **Minden K**, Niewert M, Listing J, Biedermann T, Bollow M, Schontube M, *et al*. Long-term outcome in patients with juvenile idiopathic arthritis. *Arthritis Rheum* 2002;**46**:2392–401.
4 **Packham JC**, Hall MA. Long-term follow-up of 246 adults with juvenile idiopathic arthritis: functional outcome. *Rheumatology* 2002;**41**:1428–35.
5 **Gare BA**, Fasth A. The natural history of juvenile chronic arthritis: a population based cohort study. II. Outcome. *J Rheumatol* 1995;**22**:308–19.
6 **Peterson LS**, Mason T, Nelson AM, O'Fallon WM, Gabgiel SE. Psychosocial outcomes and health status of adults who have had juvenile rheumatoid arthritis. A controlled, population-based study. *Arthritis Rheum* 1997;**40**:2235–40.
7 **Spector TD**. Epidemiological aspects of studying outcome in rheumatoid arthritis. *Br J Rheumatol* 1988;**27**(suppl I):5–11.
8 **Carr AJ**, Gibson B, Robinson PG. Is quality of life determined by expectations or experience? *BMJ* 2001;**322**:1240–3.
9 **Andresen EM**, Meyers AR. Tools of disability outcomes research: health-related quality of life outcomes measures. *Arch Phys Med Rehabil* 2000;**81**(suppl 2):S30–45.
10 **Bowling A**. *Measuring disease: a review of disease specific quality of life scales*. Buckingham: Open University Press, 1995:1–19.
11 **Patrick DL**, Erickson P. *Health status and health policy. Quality of life in health care evaluation and resource allocation*. Oxford: Oxford University Press, 1993:76–8.
12 **Wilson IB**, Cleary PD. Linking clinical variables with health-related quality of life. *JAMA* 1995;**273**:1.
13 **Higginson IJ**, Carr AJ. Using quality of life measures in clinical setting. *BMJ* 2001;**322**:1297–300.
14 **Leak AM**. Improving adolescent rheumatology services in the UK. *Rheumatology* 2000;**39**:575–84.
15 **Petty RE**, Southwood TR, Baum J, Bhettay E, Glass DN, Manners P, *et al*. Revision of the proposed classification criteria for juvenile idiopathic arthritis: Durban, 1997. *J Rheumatol* 1998;**25**:1991–4.
16 **Zak M**, Pedersen FK. Juvenile chronic arthritis into adulthood: a long-term follow-up study. *Rheumatology* 2000;**39**:198–204.
17 **Aalto A-M**, Aro AR, Teperi J. RAND-36 as measure of health-related quality of life. Reliability and construct validity and reference values in the Finnish general population. (English summary). Helsinki: Stakes, Research reports 101, 1999.
18 **Arkela-Kautiainen M**, Kauppi M, Heikkila S, Kautiainen H, Malkia E, Leirisalo-Repo M. Evaluation of the arthritis impact measurement scales (AIMS2) in Finnish patients with rheumatoid arthritis. *Scand J Rheumatol* 2003;**32**:300–5.
19 **Hays RD**, Sherbourne CD, Mazel RM. The RAND-36-item health survey 1.0. *Health Econ* 1993;**2**:217–27.
20 **Packham JC**, Hall MA. Long-term follow-up of 246 adults with juvenile idiopathic arthritis: education and employment. *Rheumatology* 2002;**41**:1436–9.
21 **Archenholtz B**, Nordborg E, Bremell T. Lower level of education in young adults with arthritis starting in the early adulthood. *Scand J Rheumatol* 2001;**30**:353–5.
22 **Carr AJ**, Thompson PW, Kirwan JR. Quality of life measures. *Br J Rheum* 1996;**35**:275–81.
23 **Gill TM**, Feinstein AR. A critical appraisal of the quality of life measurements. *JAMA* 1994;**272**:619–26.
24 **Wade DT**. Outcome measures for clinical rehabilitation trials. Impairment, function, quality of life, or value? *Am J Phys Med Rehabil* 2003;**82**(suppl):S26–31.
25 **Editorial**. Quality of life and clinical trials. *Lancet* 1995;**346**:1–2.
26 **Ware JE**, Sherbourne CD. The MOS 36-item short-form health survey (SF-36). I. Conceptual framework and item selection. *Med Care* 1992;**30**:473–83.
27 **WHO**. *International classification of functioning, disability and health: ICF*. Geneva: World Health Organisation, 2001.