

Psychological Intervention for Adolescents with Juvenile Idiopathic Arthritis: For Whom and When?

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ABSTRACT. Objective. To study which adolescents with juvenile idiopathic arthritis (JIA) benefit from psychological intervention, and what is the best moment for it.

Methods. In 3 months, 28 adolescents with JIA and 14 healthy adolescents as a control group received psychological intervention with the Self-confrontation Method (SCM), which combines the personal narrative with its affective structure. The adolescents with JIA were split into groups with low health-related quality of life (HRQOL) and high HRQOL. The Child Health Questionnaire, Checklist Individual Strength, and Childhood Health Assessment Questionnaire were used to measure fatigue and physical and psychosocial functioning at baseline, and at 3 months and 9 months after baseline.

Results. Adolescents with JIA and low HRQOL at baseline reported less fatigue and better HRQOL after psychological intervention. These changes could not be explained by changes in disease activity. Low HRQOL at baseline was associated with a more recent onset of JIA, higher levels of pain, more severe physical disability, and higher levels of fatigue.

Conclusion. Two-thirds of adolescents with JIA function well before and after psychological intervention. One-third of adolescents with JIA reporting low HRQOL at baseline benefit from guided self-reflections and should be the focus of psychological intervention. The most effective moment for this psychological intervention is when the adolescent reports difficulties in HRQOL. (First Release Feb 15 2013; J Rheumatol 2013;40:528–34; doi:10.3899/jrheum.120741)

Key Indexing Terms:

JUVENILE IDIOPATHIC ARTHRITIS

ADOLESCENT

NARRATIVE

Adolescence is a period of personal exploration and change. The increase of autonomous behavior, the development of multiple peer relationships, experimentation with identity, and the development of emotional skills are important tasks of adolescence. Although it is commonly assumed that chronic illness influences adolescent development and social interactions because of repeated hospitalizations, poor health status, or changes in appearance¹, the findings in this field have been inconsistent. Many studies found little evidence for psychosocial deficits in adolescents with juvenile idiopathic arthritis (JIA) compared with normative or healthy control samples^{2,3}. At the same time, a number of investigations identified difficulties in some specific domains of adolescent functioning, reporting higher levels of depression⁴, frustration⁵, anxiety, withdrawal, fatigue and sleep disturbances⁶, and other internalizing problems⁷.

Further, young adults with arthritis report that JIA adversely affected employment^{8,9}, body image¹⁰, social interactions¹¹, mood⁴, and overall quality of life^{12,13}. In most pediatric rheumatology settings, youngsters are referred to a mental health professional at some time during their treatment. But which patients benefit most from psychological intervention and what is the best moment for referral?

To the pediatrician, the management of adolescents in daily clinical practice can be challenging, because the time to evaluate their overall well-being is limited. Adolescents generally do not easily disclose their psychosocial functioning. Most adolescents with JIA do not need acute psychological aid for a specific problem. Instead, the reason for referral to the mental health professional is mostly broader, e.g., stagnation of certain developmental tasks, coping with chronic disease, or noncompliance to longterm regimens. To address these issues, it has been suggested that the therapeutic focus should go beyond the symptoms and take the broader life stories of the patients into account^{14,15}. Personal narratives, emerging in adolescence, are essential aspects of identity¹⁶. Through such life stories, individuals understand events and make sense of themselves and their experiences¹⁷. It remains unclear how adolescents integrate a chronic disease such as JIA into their personal narrative. Therefore, in our study the Self-confrontation Method (SCM) is used as a psychological intervention method. The

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SCM, an evidence-based psychological intervention¹⁸, guides narrative self-reflections with special attention to the affective organization¹⁹. The method's theoretical background^{20,21}, its clinical use^{22,23}, its psychometric properties, validity and reliability²⁴, and its use to compare groups²⁵ have all been extensively reported. Further, the use of the SCM with children²⁶ and with a group of adolescents with a chronic illness²⁷ has been described.

The aim of our study was to discover which adolescents with JIA benefit from psychological intervention. The divergent findings of previous studies on adolescent psychosocial functioning might imply that the psychosocial development of not all but only a subgroup of adolescents is harmed by JIA. This subgroup might be detected by the members' self-reported health-related quality of life (HRQOL). Short HRQOL questionnaires measuring physical, psychological, and social functioning can be used as a general instrument to understand the effect of disease on daily life²⁸. We hypothesized that adolescents with JIA and low HRQOL would benefit more from psychological intervention than adolescents with JIA and high HRQOL and healthy adolescents; and that adolescents with JIA and high HRQOL have the same psychosocial functioning as their healthy peers. And finally, an additional hypothesis is that those adolescents with JIA receiving more sessions of psychological intervention would benefit most.

MATERIALS AND METHODS

Participants and study design. Adolescents with JIA (Table 1) were asked by their pediatrician in a university medical center to participate. As a

Table 1. General characteristics of adolescents with JIA at baseline.

Characteristics	Healthy, n = 14	JIA and Low HRQOL, n = 9	JIA and High HRQOL, n = 19
Age, yrs, mean (SD)	16.4 (0.7)	16.1 (1.7)	16.1 (1.4)
Girls*, n	14	8	17
Intensively coached, n	—	6	8
12 sessions			
Ethnicity, n			
White	13	8	18
African	1	1	—
Other	—	—	1
Disease duration at survey, yrs, median (IQR)	—	1.8 (1.0–12.3)	10.5 (5.7–13.6)
Age at diagnosis, yrs, median (IQR)	—	12.0 (3.0–16.5)	6.2 (2.9–10.0)
Type of JIA**, n			
Systemic [†]	—	0	2
Polyarticular ^{††}	—	8	10
Oligoarticular [#]	—	1	7

* The percentage of female participants is in accord with the general predominance of females in JIA²⁹. ** Diagnostic criteria of the European League Against Rheumatism³⁰. † Most severe form of arthritis with fever, rash, and inflammation of other organs. †† Affecting ≥ 5 joints. # Affecting < 5 joints. JIA: juvenile idiopathic arthritis; HRQOL: health-related quality of life.

control group, healthy adolescents were included. They were asked by the researcher in 2 local high schools to volunteer for our study. Study criteria dictated that each participant be between 14 and 19 years old at inclusion, and that the patients be diagnosed with JIA²⁹ by a pediatric rheumatologist. Excluded from participation were adolescents who had a primary psychiatric or psychological diagnosis, or healthy adolescents with a medical condition. Thirty-seven adolescents with JIA and 25 healthy adolescents received an invitation, of which 28 and 14, respectively, volunteered for the study. The study was approved by the ethical committee of the University Medical Center Utrecht. Informed consent was obtained from all participating adolescents and — if legally required — from their parents. The study design and time course are outlined in Figure 1.

Psychological intervention. The SCM^{27,31} was used as a psychological intervention method. The counselors were a child psychologist and a counselor/philosopher, both specially trained in the SCM in a 2-year post-master program.

Phase 1, first self-investigation. To elicit personal narratives, 3 open questions are presented, referring to the patient's past, present, and future (e.g., was there something in your past that has been of major significance for your life and that still plays an important part today?). In dialogue with the counselor, adolescents formulate their most important life experiences into written sentences. After the formulation of these experiences into sentences, a standard list of 24 affect terms (such as happiness, anxiety, pride, love) is presented. For each particular sentence, the adolescent is asked to indicate on a 6-point Likert scale (0 = not at all, and 5 = very much) to what extent each affect is experienced. This affective profile helps the adolescent to find the central theme in his or her personal narrative. In SCM theory, the process of self-confrontation by itself is seen as having an activating function. As a consequence of the reflection upon the personal narrative, the person is stimulated and has gained direction to gradually change by making new connections between experiences and emotions³¹. A full description of the use of the SCM with an adolescent with JIA is given in a published case study³².

Phase 2, process-promoting. The self-formulated central theme emerging from the first self-investigation serves as a guiding principle in this phase, which is completed only by the adolescents randomly assigned to the 12-session group. Adolescents assess daily situations and the way they cope with them. Subsequently, guided by the counselor, the adolescents are encouraged to gradually move from assessment to change. The adolescents are stimulated to create and engage in novel situations, to develop and reorganize their personal narratives. This phase consists of 6 weekly individual sessions of about 1 h each.

Phase 3, second self-investigation. For all adolescents, the consistencies and changes in their personal narratives are evaluated in a second self-investigation (in 3 weekly individual sessions of about 1 h each).

HRQOL assessment. The Child Health Questionnaire-Child Form (CHQ-CF87) was used to assess the HRQOL³³. The CHQ-CF87 is an 87-item generic self-administered instrument that measures physical, emotional, and social components of health status in children and adolescents, independently of the underlying disease³⁴. The following subscales were used: physical role functioning, measuring limitations in school work and daily activities as a result of physical health (Cronbach's $\alpha = 0.86$); emotional role functioning, measuring limitations in school work and daily activities as a result of emotional problems (Cronbach's $\alpha = 0.90$); behavioral role functioning, measuring limitations in school work and daily activities as a result of behavioral problems (Cronbach's $\alpha = 0.71$); bodily pain, measuring its severity and frequency (Cronbach's $\alpha = 0.85$); general behavior, measuring the exhibition of aggressive, delinquent, and immature behavior (Cronbach's $\alpha = 0.79$); mental health, measuring a diversity of positive and negative feelings (Cronbach's $\alpha = 0.86$); self-esteem, measuring satisfaction with abilities, looks, family/peer relations, and life overall (Cronbach's $\alpha = 0.89$); and the general health perception, measuring beliefs concerning health (Cronbach's $\alpha = 0.77$).

Fatigue assessment. The Checklist for Individual Strength (CIS-20), a

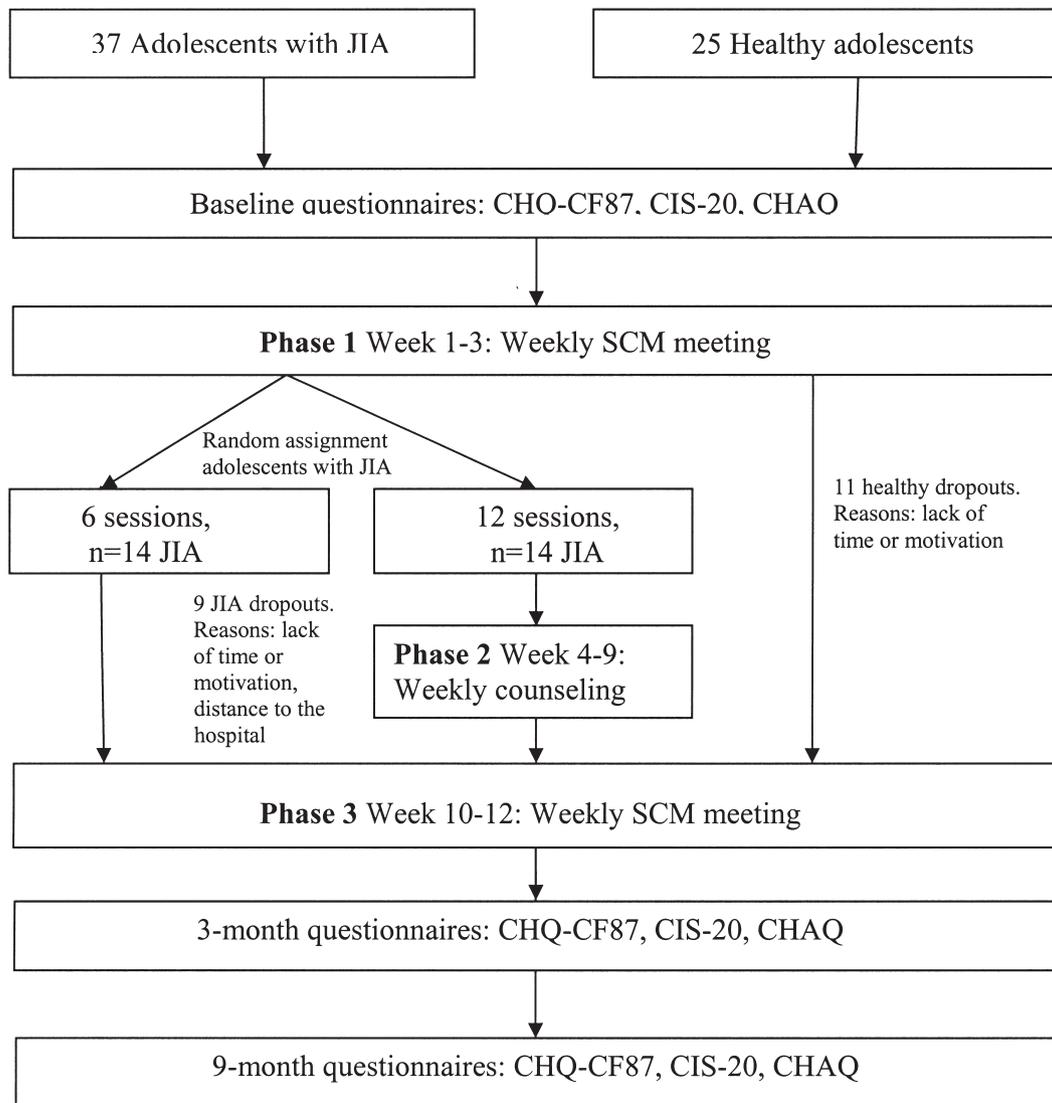


Figure 1. Design and time course of the study. CHQ-CF87: 87-item Child Health Questionnaire-Child Form; CIS-20: 20-item Checklist for Individual Strength; CHAQ: Child Health Assessment Questionnaire; SCM: Self-confrontation Method.

20-item self-report instrument, was used to measure the subjective experience of fatigue. This is a reliable, validated assessment measure, with good internal consistency (Cronbach's $\alpha = 0.93$), commonly used in research into pediatric chronic illness³⁵.

Functional ability assessment. The Child Health Assessment Questionnaire (CHAQ) was completed by each adolescent with JIA³³. The CHAQ measures the patients' ability to perform functions included in 8 areas of daily living, which are averaged to calculate the CHAQ disability index. Two horizontal 10-cm visual analog scales (VAS) are incorporated to assess the adolescent's overall well-being and the intensity of the adolescent's pain. Cronbach's α reliability coefficient of the total CHAQ is 0.94. Pediatric rheumatologists checked the disease activity at regular outpatient visits.

Clustering of adolescents with JIA. The hypothesis of our study is that HRQOL may predict which subgroup benefits most from psychological intervention. Therefore, the sample of adolescents with JIA was split into 2 clusters using hierarchical cluster analysis (Ward's method, squared

Euclidean distances) on the standardized CHQ-CF87 scales at baseline³⁶. To determine the stability of the solution, 2 nonhierarchical clusterings were performed: 1 with centroids from the hierarchical analysis as seeds and 1 with random seeds. Agreement between the 2 solutions was obtained by calculating Cohen's κ , which was 0.94, indicating almost perfect agreement. The sample was split into adolescents with JIA and low HRQOL ($n = 10$) and adolescents with JIA and high HRQOL ($n = 21$).

Statistical analysis. Descriptive statistics were reported as means and SD for the continuous variables and in terms of absolute frequencies for the categorical variables. To study whether psychological intervention improves psychosocial well-being of the sample, we used repeated measurement analysis with general linear models. We used the following outcome measures for psychosocial well-being: HRQOL, fatigue, functional ability, overall well-being, and pain. Statistical tests included 1-way ANOVA with post-hoc Bonferroni corrections. To report the strength of differences, partial η^2 was calculated, providing a measure of effect size. For partial η^2 , the traditional cutoffs of small, medium, and large effects of, respectively,

0.01, 0.06, and 0.14 are useful, although they might underestimate the effect size³⁷. All statistical analysis was performed using SPSS software, version 19.

RESULTS

Baseline. Thirty-seven adolescents with JIA and 25 healthy adolescents were invited to participate in this study. Nine adolescents with JIA (24.3%) and 11 healthy ones (44%) withdrew from the SCM procedure (Figure 1). The primary reason for withdrawal was a lack of time or motivation. Three adolescents with JIA and 2 healthy adolescents did not return followup questionnaires. Compared to randomized controlled trials, the percentage of individuals lost to attrition was higher, probably caused by the time-consuming procedure. The Cronbach's α reliability coefficients for the scales of the questionnaires of our sample were between 0.83 and 0.96. Cronbach's α for mental health was sufficient (0.66), but general health perceptions (0.29) and the CIS subjective fatigue (0.07) showed little internal consistency. So the results on fatigue have to be interpreted with caution.

Adolescents with JIA and low HRQOL had a higher mean age at onset [$t(26) = 2.31, p < 0.05$]; $t =$ Student's t test], and a shorter disease duration at survey [$t(26) = 2.21, p < 0.05$; Table 1]. In the low HRQOL group, 8 out of 9 adolescents had the more severe polyarticular arthritis, and only 1 out of 9 had milder oligoarticular arthritis. In the high HRQOL group, 12 out of 19 adolescents had polyarticular or systemic arthritis, and 7 out of 19 had oligoarticular arthritis. Most of the adolescents were in a situation of stable disease activity and stable treatment of the JIA.

Adolescents were randomly assigned in phase 2, resulting in 6 out of 9 with JIA and low HRQOL, and 8 out of 19 with JIA and high HRQOL being assigned to individual psychological intervention with 12 sessions.

Adolescents with JIA and high HRQOL reported almost similar HRQOL as their healthy peers (Table 2). The 2 clusters of adolescents with JIA differed at baseline in their functional ability (Table 3), with adolescents with low HRQOL reporting worse scores on CHAQ [$t(26) = -3.43, p < 0.05$], VAS pain [$t(20) = -4.64, p < 0.001$], and VAS overall well-being [$t(20) = -3.92, p < 0.05$]. Adolescents with JIA and low HRQOL reported worse subjective fatigue [$F(2, 40) = 19.28, p < 0.05, \text{partial } \eta^2 = 0.50$; $F =$ between-groups and within-groups degrees of freedom] than adolescents with JIA and high HRQOL and healthy adolescents (Table 2).

Effect of 12 versus 6 psychological intervention sessions. After analysis of the results at 3 months of the 2 different groups (6 or 12 sessions), no differences were observed in the outcome measures (functional ability, fatigue, pain). Therefore, because the total sample size was modest, the separation was left out of further analysis.

After psychological intervention and followup. Over time,

no significant improvements at $p < 0.05$ could be observed for the 2 groups in their physical functioning. At followup, adolescents with JIA and low HRQOL at baseline still had worse physical functioning, which is reflected in their higher CHAQ score [$t(26) = -3.10, p < 0.05$; Table 3]. The VAS scores of adolescents with low HRQOL at baseline improved. At 3 months of followup, adolescents with JIA and low HRQOL at baseline no longer reported worse VAS well-being and VAS pain scores, compared to the adolescents with high HRQOL at baseline. Clinically, the arthritis of the adolescents was stable, but the more subjective well-being and pain improved.

The subjective fatigue (Table 2), over time, improved for all 3 groups of adolescents, with a significant interaction (time \times cluster) for the adolescents with low HRQOL at baseline: CIS subjective fatigue [Wilks' lambda = 0.66, $F(4, 66) = 3.77, p < 0.05, \text{partial } \eta^2 = 0.19$].

The adolescents with low HRQOL at baseline improved significantly more compared to the healthy adolescents and the adolescents with JIA and high HRQOL at baseline on these subscales: physical role functioning [Wilks' lambda = 0.58, $F(4, 72) = 5.68, p < 0.001, \text{partial } \eta^2 = 0.24$] and emotional role functioning [Wilks' lambda = 0.75, $F(4, 70) = 2.69, p < 0.05, \text{partial } \eta^2 = 0.13$].

DISCUSSION

Our aim was to discover which adolescents growing up with JIA benefit from psychological intervention. A group of adolescents with JIA and a group of healthy adolescents participated. The choice was made to offer the adolescents psychological intervention with the SCM, a method that combines the personal narrative with the affective structure. While a psychological method such as cognitive behavioral therapy addresses the reduction of symptoms through a change of cognitive processes, the SCM aims to move beyond the symptoms by eliciting emotions and establishing personal narrative change³⁸.

Our first hypothesis was that adolescents with JIA and low HRQOL would benefit more from psychological intervention than would adolescents with JIA and high HRQOL and healthy adolescents. Literature on the effect of JIA is inconclusive. It is probable that not all but just a subgroup of adolescents with JIA experiences difficulties in psychosocial functioning. In our study, two-thirds of adolescents with JIA reported similar psychosocial functioning as their healthy peers. However, one-third of the adolescents with JIA reported low HRQOL at baseline. As in other studies, low HRQOL at baseline was associated with a more recent onset of JIA, higher levels of pain, more severe physical disability, and higher levels of fatigue^{5,39,40}. Adolescents with low HRQOL were older when diagnosed with JIA.

After psychological intervention, adolescents with JIA and low HRQOL at baseline improved more than adolescents with JIA and high HRQOL at baseline and their

Table 2. Changes over time for health-related quality of life (CHQ-CF87[†]) and fatigue (CIS-20^{††}). Values are the mean changes from baseline except for baseline values; all statistical analyses were performed on the raw data. All items were scored on a Likert scale. Means or mean changes with different superscripts differ significantly at $p < 0.05$.

	Healthy	JIA and Low HRQOL	JIA and High HRQOL	p
Physical Role functioning (3 items; 0–100)				
Baseline score (SD)	90.5 ^a (17.9)	50.6 ^b (24.3)	96.5 ^a (8.3)	< 0.001
3 months	5.5 ^a	27.2 ^b	2.9 ^a	< 0.001
9 months	6.3 ^a	33.4 ^b	1.2 ^a	< 0.05
Emotional Role functioning (3 items; 0–100)				
Baseline score (SD)	85.7 (17.7)	66.7 ^a (34.2)	91.8 ^b (16.9)	< 0.05
3 months	6.4	15.8	−4.4	0.50
9 months	0.8	22.2	5.3	0.22
Behavioral Role functioning (3 items; 0–100)				
Baseline score (SD)	96.8 (6.8)	80.2 ^a (34.2)	98.8 ^b (5.1)	< 0.05
3 months	1.6	12.9	−5.0	0.52
9 months	−4.7	12.4	−0.6	0.54
Bodily pain (2 items; 0–100)				
Baseline score (SD)	70.7 ^a (20.6)	32.2 ^b (20.5)	65.3 ^a (19.8)	< 0.001
3 months	4.3 ^a	16.6 ^b	5.3	< 0.05
9 months	11.4 ^a	15.6 ^b	2.6	< 0.05
General behavior (16 items; 0–100)				
Baseline score (SD)	81.3 (12.1)	73.4 ^a (6.8)	87.2 ^b (8.4)	< 0.05
3 months	−0.1	4.9	−1.6	0.24
9 months	−2.2	7.2	0.4	0.18
Mental health (16 items; 0–100)				
Baseline score (SD)	71.2 ^a (10.7)	60.6 ^b (11.6)	80.4 ^c (9.7)	< 0.001
3 months	1.6	3.4 ^a	0.2 ^b	< 0.05
9 months	0 ^a	6.2 ^a	2.7 ^b	< 0.05
Self-esteem (14 items; 0–100)				
Baseline score (SD)	71.1 ^a (8.4)	58.4 ^b (10.0)	74.4 ^a (9.2)	< 0.001
3 months	4.1	7.9	0.6	0.20
9 months	−0.5	9.5	2.4	0.13
General health perceptions (13 items; 0–100)				
Baseline score (SD)	77.9 ^a (11.4)	50.3 ^b (17.9)	65.0 ^c (12.2)	< 0.001
3 months	0.3 ^a	0.4 ^b	1.2	< 0.05
9 months	−0.8 ^a	2.2 ^b	6.8 ^a	< 0.05
CIS subjective fatigue (8 items; 8–56)				
Baseline score (SD)	26.0 ^a (11.3)	43.3 ^b (7.4)	19.6 ^a (8.6)	< 0.05
3 months	−4.0 ^a	−6.4 ^b	−1.7 ^a	< 0.05
9 months	−3.9	−10.5 ^a	1.4 ^b	< 0.05

[†] Higher scores indicate better physical or psychosocial well-being. ^{††} Higher score indicates a higher level of subjective fatigue. CHQ-CF87: 87-item Child Health Questionnaire-Child Form; CIS-20: 20-item Checklist for Individual Strength; JIA: juvenile idiopathic arthritis; HRQOL: health-related quality of life.

healthy peers. This improvement could not be explained by changes in disease activity, because most of the participating adolescents were in stable situations with no significant functional changes during the study period. Although their functional ability and disease activity status were stable, the subjective experience of pain and well-being improved in the group with low HRQOL. The reported subjective fatigue declined most for the adolescents with low HRQOL. After psychological intervention, the adolescents with JIA and low HRQOL at baseline reported a significant improvement in their HRQOL. These improvements in functioning may cause changes in daily life, such as full participation at

school after long periods of absence due to fatigue and pain. Further, as hypothesized, adolescents with JIA and high HRQOL and healthy peers reported comparable psychosocial functioning. Although we expected the intensity of the psychological intervention (6 or 12 sessions in 3 months) to have an influence on the outcome measures, no differences can be reported between the 2 conditions. So in general, adolescents with JIA already benefit from modest psychological intervention.

Being diagnosed with such a severe illness during the already tumultuous period of adolescence is imaginably challenging for these individuals. Chronic illness in adoles-

Table 3. CHAQ scores of adolescents with juvenile idiopathic arthritis subdivided in 2 clusters.

	JIA and Low HRQOL	JIA and High HRQOL	p
CHAQ score (range 0–3)*			
Baseline mean (SD)	1.5 (0.7)	0.6 (0.7)	< 0.05
3 months	–0.3	0	0.09
9 months	–0.2	0	< 0.05
VAS score overall well-being (0–10 cm)**			
Baseline mean, cm (SD)	5.1 (2.5)	1.5 (1.8)	< 0.05
3 months	–3.0	0	0.50
9 months	–1.9	–0.3	< 0.05
VAS score pain (0–10 cm)**			
Baseline mean, cm (SD)	6.3 (2.5)	1.9 (1.9)	< 0.0001
3 months	–3.2	–0.1	0.21
9 months	–3.1	–0.1	0.18

* 33 items (range 0–3), lower disability index indicates better functional ability. ** Lower VAS score indicates more optimal experience of well-being and less pain. VAS: visual analog scale; CHAQ: Child Health Assessment Questionnaire; JIA: juvenile idiopathic arthritis; HRQOL: health-related quality of life.

cence can limit the development of feelings of self-enhancement because of an increased dependence on adults as a result of physical limitations. The statements of some of the participating adolescents illustrated this dependence. Isabelle, 15 years old, said, “I’m ashamed when my mother has to bring me to school because I’m not able to go by myself.” Martha, 17, said, “I could not join summer camp with my friends because I could not sleep on the ground. I was one of the only ones in our class who still went on holiday with their parents.” Integrating experiences of autonomy and success into a personal narrative is generally needed to develop an adult identity and an enhanced independence from caregivers, 2 of the main tasks in adolescence⁴¹.

Defining the level of well-being from the adolescent’s perspective may be an important strategy for improving daily clinical management of these patients. Especially in the context of the adolescent’s development, repeated measurements of their well-being can be valuable to detect problems early so that psychological intervention can be offered before psychosocial problems increase. The CHQ-CF87 is simple and quick to administer. It can be routinely used in clinical practice, in particular for adolescents in the high-risk group (adolescents with a more recent onset of JIA, higher levels of pain, more severe physical disability, and higher levels of fatigue), to identify psychological adjustment problems. Appropriate psychosocial interventions such as the SCM can then be targeted to support these adolescents³⁹. However, the CHQ-CF87 must be used as an instrument to detect potential suffering of the adolescent, and not as a tool to reach a psychological diagnosis justifying intervention. A few adolescents gave

high scores for their HRQOL, whereas clinical observations did not match these reported high scores. During psychological intervention, these few adolescents held on to their positive coping strategy, leaving no room for change. For the adolescents in our study, the most effective moment for psychological intervention was when the adolescents themselves experienced and reported difficulties in their psychosocial functioning.

Some caveats of our study should be mentioned. The method requires adolescents to have a basic capacity for self-reflection, which is related to a certain developmental stage and cognitive level of functioning, thereby selecting a specific subgroup of adolescents. In addition, the rather large improvements in health, functioning, and emotional experience in the group of adolescents with JIA and low HRQOL could be partly due to a floor effect in the other 2 groups, who already functioned well with little room or need for improvement. Further, one of the aims was to discover whether adolescents could be self-reliant during phase 2. Retrospectively, however, the period between phase 1 and phase 3 might have been too long to keep all the participating adolescents involved. This might have caused the large attrition level among the controls. Alternative methods (e.g., generic telephone calls to establish an ongoing contact between phase 1 and 3 for the adolescents who do not participate in phase 2) should be added in future research to increase participation. Finally, for this exploratory study, the total sample size was modest and was formed by recruiting adolescents who wanted to participate in an intensive study performed at a university department of pediatric psychology. Our results have therefore probably been biased toward those adolescents having more interest in, or experiencing more problems with, psychosocial development. This has probably affected the selection of both adolescents with JIA and healthy controls. In future research, it would be appealing to study the psychosocial functioning of adolescents with JIA in a larger cohort.

Adolescents with JIA reporting low HRQOL benefit from psychological intervention. The current findings underline that two-thirds of the adolescents with JIA have emotional experiences similar to those of their healthy peers. Therefore, broad-based interventions to address psychosocial outcome are not necessary for all adolescents with JIA. Instead, the focus should be on those at risk. Our study underlines the value of HRQOL patient questionnaires in clinical practice; they provide important data from the patient perspective. Careful screening for adolescents who report the worst consequences of their disease on their quality of life helps to identify youngsters who benefit most from psychological intervention.

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