Pain-specific Beliefs and Pain Experience in Children with Juvenile Idiopathic Arthritis: A Longitudinal Study

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ABSTRACT. Objective. To assess longitudinal associations between pain-specific health beliefs and pain in children with juvenile idiopathic arthritis (JIA), and to compare a selected group of patients with high pain and low disease activity (high-pain patients) with the remaining group.

> Methods. Forty-seven children with JIA, aged 7-15 years, completed the children's version of the Survey of Pain Attitudes (SOPA-C) and a 3-week pain diary at study entry (T1) and in a followup study 2 years later (T2). Parents also rated the Childhood Health Assessment Questionnaire (CHAQ), and an arthritis activity score was calculated each time. Second-order principal component analysis was conducted to reduce the number of independent variables. Regression analysis of the dependent measure was performed. The use of health beliefs was compared using t test for independent samples.

> Results. T1 health beliefs predicted 7% of the variance in T2 pain scores after controlling for T1 pain, CHAQ, and disease activity. At T2, statistical differences were found between the scores of the high-pain group and the rest of the group for the health belief subscales of disability (mean ± SD 2.7 \pm 0.5 and 2.2 \pm 0.7, respectively) and harm (mean \pm SD 3.8 \pm 0.8 and 3.3 \pm 0.6).

> Conclusion. Our findings suggest that pain beliefs are influential on the longitudinal course of pain in children with JIA. Dysfunctional health beliefs in patients with high pain seem to be stable over time. (J Rheumatol First Release Oct 15 2010; doi:10.3899/jrheum.091375)

Key Indexing Terms: JUVENILE IDIOPATHIC ARTHRITIS

PAIN

DISEASE ACTIVITY

Pain has been found in recent studies to be highly prevalent in children with juvenile idiopathic arthritis (JIA)^{1,2}. Pain predicts impaired psychosocial function in these patients^{1,2,3}, and even minimal reduction in pain has been associated with improvements in the patients' quality of life⁴. Experience of recurrent pain may affect normal pain processing in patients with JIA^{5,6,7}. Measures of disease activity explain only a modest proportion of the variance in the pain ratings among patients with JIA³, and there may be psychosocial modulators of pain perception in children.

The use of pain-coping strategies and health beliefs in children with JIA has previously been found to be associated with both clinical and experimental pain reports^{6,8,9}.

Beliefs can be defined as assumptions about reality through which events are interpreted, and beliefs about a stressor such as pain are thought to influence an individual's

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coping responses¹⁰. In adult patients with chronic pain, pain-specific beliefs have been found to be associated with pain report as well as psychosocial and physical functioning¹⁰. We have reported¹¹ that cognitive health beliefs were significantly associated with pain in children with JIA even after controlling for disease-related variables and pain coping. In our previous study we also discovered that a highpain group (defined as a group of children with higher pain perception and lower disease activity than the median values of the total group of patients) compared to the rest of the patients in the sample perceived themselves as more disabled and believed that pain signified more damage and that exercise therefore should be restricted¹¹.

Consequently, our purpose was to examine whether significant longitudinal associations between health beliefs and pain among children with JIA could be identified. If health beliefs were found to significantly predict pain, beliefs could then represent a modifiable target of intervention. In addition, we wanted to examine whether the differences detected in our previous study between high-pain patients and the rest of the group concerning health beliefs could be replicated prospectively. A replication would further indicate that the pain experience in patients with JIA who have high pain experience despite low disease activity might partly be explained by the maladaptive health beliefs in this sub-

group of patients. This specific group would then be in particular need of intervention.

Given the findings of our previous study, we predicted a significant longitudinal association between pain, the Childhood Health Assessment Questionnaire (CHAQ), the health belief subscales of cognitive beliefs at study entry (Time 1, T1), and the child-reported pain diary at 24 months (Time 2, T2). More specifically, increased, supposedly adaptive cognitive beliefs (that one is in control over pain, that a medical cure for pain exists, that one is able to function despite pain, and finally that exercise and activity should not be restricted because of pain) would be associated with lower levels of pain when controlled for other independent variables. Further, we predicted that children with JIA who have high pain (pain scores equal to or above the median) and low disease activity (disease activity below the median) at T1 would perceive themselves as more disabled and would, consequently, be more likely to believe that pain signifies damage than would the rest of the group at T2.

MATERIALS AND METHODS

Patients. In total, 56 children with JIA according to the Durban criteria, as well as one of their biological parents (mother or father), participated at T1¹¹. The children were recruited during routine visits to the Pediatric Rheumatology Clinic at the Department of Pediatrics, Aarhus University Hospital. The inclusion criteria were a JIA diagnosis, age between 7 and 15 years, absence of comorbidity, and the ability to speak fluent Danish. All patients were given written information and verbally informed about the project, and all children and their parents signed an informed consent form. Forty-seven children (82.5%) and their parents completed measures in the followup study (T2). Among the children who did and did not participate at T2, no significant differences between pain, disease activity, and CHAQ were found at T1. The mean duration between T1 and T2 was 1.9 ± 0.3 years. The study sample consisted of 39 (83%) girls and 8 boys, including 6 with systemic-onset JIA, 19 with rheumatoid factor (RF)-negative polyarticular subtype, 12 with persistent oligoarticular, 9 with extended oligoarticular subtype, and 1 with psoriatic arthritis.

The study was approved by the local ethics committee.

Measure of disease activity. A composite arthritis activity score was calculated as the sum of the active joint score (zero active joints: 0; 1–2 active joints: 1; 3–4 active joints: 2; > 4 active joints: 3), morning stiffness (< 15 min: 0; 15–30 min: 1; 30–60 min: 2; > 60 min: 3), and erythrocyte sedimentation rate (ESR; < 15 mm/h: 0; 15–25 mm/h: 1; 25–40 mm/h: 2; > 40 mm/h: 3).

Questionnaires (children). A revised version of the Survey Of Pain Attitudes (SOPA)¹², the SOPA children's version (SOPA-C), was used, as described¹¹. For our current study, the subscales of control, disability, harm, and medical cure were chosen. Scores range between 0 and 4. The SOPA-C Control scale assesses the patient's belief that they have some personal control over pain (with higher scores indicating more belief in control). The SOPA-C Disability scale assesses the patient's belief in being unable to function because of pain (higher scores indicating less belief in functioning). The SOPA-C Harm scale assesses the patient's belief that pain signifies damage and that exercise and activity therefore should be restricted (higher scores indicating more belief in damage). Finally, the SOPA-C Medical Cure scale assesses the belief that a medical cure exists (higher scores indicating more belief in a medical cure). Chronbach's α internal consistency reliability coefficients were determined for each of the subscales at T1 and T2 and were rather low (ranging from 0.62 to 0.74), which can be considered as a possible limitation in the interpretation of the results. Pain measures. The children completed a pain diary each day during the 3 weeks, followed by the completion of the questionnaires. The child's pain was measured using the Faces Pain Scale¹³ with the endpoints labeled "no pain" and "most pain," range 0–5. The Faces Pain Scale has evidence of test-retest reliability, as well as content and structural validity, and it was reported as being well received by children aged 4–17 years¹⁴. The patients were instructed to measure pain experience every morning and evening for 3 weeks. Further, the parents were asked to help the child remember the procedure, but to avoid influencing the child's scoring. Subsequently, a mean pain intensity score based on the 42 pain ratings was calculated.

Questionnaires (parents). The CHAQ measures children's functional status. The CHAQ is reported to be reliable, valid, and sensitive, and has been validated in a Danish sample 15. The scale assesses performance in 8 areas, including, e.g., dressing, eating, walking, and gripping. Scores range between 0 and 3, higher scores indicating greater functional impairment.

All measures were completed at both T1 and T2.

Procedure. At both T1 and T2, the assessment instruments were administered in the pediatric outpatient clinic. An experienced pediatric nurse, who administered all questionnaires verbally to ensure the children understood the questions, also interviewed the children separately from their parents.

Data analysis. Data analysis proceeded in 4 steps. In step 1, paired sample t tests and correlations were conducted to determine the T1 and T2 differences of the variables. In step 2, zero-order correlations among the predictor variables and among the predictor and dependent variables (pain at T1 and T2) were computed. In order to reduce the number of health belief scales able to perform regression analyses, a second-order principal component analysis was conducted in step 3. In step 4, three hierarchical regression analyses were performed. The first model included the predictor variables at T1 and pain at T1 as the dependent variable. Equally, the second model included the predictor variables at T2 and pain at T2 as the dependent variable. The third model included the predictor variables at T1 (including pain at T1) and pain at T2 as the dependent variable. Only predictors with a significant zero-order correlation with the dependent variable were entered into the regression model. The distribution of all data was examined for normality using the Kolmogorov-Smirnov test, and those with a significant result suggesting a violation of normality were transformed to normalize them. This was required for the mean pain scores and the disease activity index at T1 and T2, which were normalized by square-root transformations. It was not possible to normalize the CHAQ. In step 4, the use of health beliefs by children with high pain (median pain diary ≥ 1.61) and low disease activity (median disease activity < 3, high-pain children) and the remaining patients was compared with t tests for independent samples.

RESULTS

Descriptive data on pain and the independent variables at T1 and T2 (Table 1). Significant correlations between T1 and T2 were found for all 3 disease-related variables (pain score, CHAQ, and disease activity). Disease activity was noticeably lower at T2 than at T1.

At the same time, significant correlations between T1 and T2 were also found for all health belief subscales. Children scored significantly higher on all health belief subscales at T2 than at T1.

Associations between pain, demographic, and disease-related variables and health beliefs at T1 and T2. At T1, significant correlations were obtained between the pain report and the CHAQ (p < 0.01), the pain belief subscales of disability (p < 0.005), harm (p < 0.05) and (inverse) control (p < 0.05), and (inverse) medical cure (p < 0.05). At T2, significant correlations were discovered between the pain report and the

Table 1. Disease-related variables and health belief measures at Time 1 and Time 2.

Variables and Measures	T1, Mean (SD)	T2, Mean (SD)	T (t test)	R
Disease-related variables				
Pain score	0.74 (0.70)	0.91 (0.86)	-1.54	0.53***
CHAQ	0.24 (0.35)	0.14 (0.20)	1.76	0.37*
Disease activity	3.00 (2.42)	1.51 (1.62)	4.26***	0.35*
Health belief measures				
Control	2.19 (0.76)	2.83 (0.71)	-5.68***	0.41**
Disability	1.23 (0.76)	2.29 (0.70)	-10.47***	0.56***
Harm	1.98 (0.85)	3.43 (0.69)	-14.18***	0.60***
Medical cure	2.82 (0.74)	3.27 (0.74)	-3.71**	0.38*

^{*} p < 0.05; ** p < 0.01; *** p < 0.001. R: Pearson correlation coefficient; T1: study entry; T2: 2-year followup; CHAQ: Childhood Health Assessment Questionnaire.

CHAQ (p < 0.01), disease activity (p < 0.01), the pain belief subscales of disability (p < 0.005), harm (p < 0.01), and (inverse) control (p < 0.05). Additionally, significant correlations were found between the pain belief subscales of disability (p < 0.005), harm (p < 0.005), and (inverse) control (p < 0.01) at T1 and the pain report at T2 (Table 2).

Second-order principal component analysis of the 4 health belief scales. At both T1 and T2, principal component analyses revealed the presence of only 1 component solution with eigenvalues exceeding 1, both accounting for 53% of the variance. The scales loaded between 0.44 and 0.85 on the component. This component, labeled cognitive beliefs, reflects the beliefs that one is disabled, that pain does signify harm, that one is unable to control the pain, and that a medical cure does not exist¹¹.

Health beliefs as predictors of pain report. The results of the 3 hierarchical regression analyses with mean pain diary as dependent variable are shown in Table 3. At T1, the regression model with all predictors explained 23% of the variance in pain. Disability measured by the CHAQ and disease activity did not make significant contributions to the predic-

tions of pain. At step 2, cognitive beliefs explained an additional and significant 12% of the variance. At T2, the model with all predictors explained 37% of the variance in pain. At step 1, disease-related variables predicted 29% of the variance. Disease activity was the only disease-related variable that contributed significantly to the prediction of pain. At step 2, cognitive beliefs explained an additional significant 9% of the variance. In the final regression model, which tested whether the variables measured at T1 could predict pain at T2, the regression model with all predictors explained 47% of the variance in pain. The disease-related variables in step 1 accounted for 40% of the variance. Pain at T1 was the only disease-related variable that contributed noticeably to the prediction of pain at T2. At step 2, cognitive beliefs at T1 explained an additional significant 7% of the variance of pain at T2.

Comparing patients with high pain and low disease activity with the rest of the group. A group of high-pain patients (pain scores equal to or above the median) who had low disease activity (disease activity below the median) at T1 (Group 1, n = 12) was compared to the remaining patients

Table 2. Correlations between pain and the disease-related and health belief variables.

Predictor Variables	Correlations Between T1 Mean Pain Report and T1 Predictor Variables	Correlations Between T2 Mean Pain Report and T2 Predictor Variables	Correlations Between T2 Mean Pain Report and T1 Predictor Variables	
Disease-related variab	bles			
CHAQ	0.40**	0.39**	0.25	
Disease activity	0.01	0.39**	-0.11	
Disease duration	-0.06	0.14	0.11	
Sex	-0.03	0.16	0.16	
Age	-0.05	-0.06	-0.06	
Health beliefs				
Control	-0.36*	-0.34*	-0.43**	
Disability	0.50***	0.53***	0.43***	
Harm	0.33*	0.39**	0.51***	
Medical cure	-0.29*	-0.14	-0.22	

^{*} p < 0.05; ** p < 0.01; *** p < 0.005. T1: study entry; T2: 2-year followup; CHAQ: Childhood Health Assessment Questionnaire.

Table 3. Hierarchical regression analyses predicting pain at T1 and T2.

Predictor	Pain at T1 ^a	Pain at T2 ^b	Pain at T2 ^c
Step 1 Disease-related variable	es		
R^2	0.12	0.29**	0.40***
Pain at T1 (B)			0.51***
CHAQ (B)	0.19	0.17	-0.02
Disease activity (B)	-0.02	0.31*	-0.18
Step 2 Cognitive beliefs (B)	0.38*	0.31*	0.31*
R ² change	0.12*	0.09*	0.07*
Cumulative R ²	0.23 ^d	0.37°	$0.47^{\rm f}$

 $[^]a$ Disease-related variables and cognitive beliefs at T1 predicting pain at T1. b Disease-related variables and cognitive beliefs at T2 predicting pain at T2. c Disease-related variables (including pain at T1) and cognitive beliefs at T1 predicting pain at T2. d F (3–43) = 4.37, p < 0.01. e F (3–43) = 8.32, p < 0.0005. f F (4–42) = 9.42, p < 0.0005. * p < 0.05; * ** p < 0.001; * *** p < 0.0005. B: Standardized betas for the model. T1: study entry; T2: 2-year followup; CHAQ: Childhood Health Assessment Questionnaire.

(Group 2, n = 35) with respect to the health beliefs subscales of disability and harm measured at T1 and T2 (Table 4). Substantial differences were found between the scores of high-pain patients and the rest of the group for both health belief subscales at T1 and T2. At T1, no significant differences between the 2 groups were found for age (Group 1: 127 ± 25 months; Group 2: 137 ± 25 months; p = 0.266), disease duration (Group 1: 60 ± 38 months; Group 2: $67 \pm$ 42 months; p = 0.634), or sex (Group 1: 3 boys, 9 girls; Group 2: 5 boys, 13 girls; p = 0.394). However, a significant difference between the 2 groups was found for disability as measured by the CHAQ (Group 1: 0.42 ± 0.5 months; Group 2: 0.18 ± 0.3 ; p = 0.047). Group 1 consisted of 3 with systemic-onset JIA, 4 with RF-negative polyarticular subtype, 3 with persistent oligoarticular, and 2 with extended oligoarticular subtype. Group 2 consisted of 3 with systemic onset JIA, 15 with RF-negative polyarticular subtype, 9 with persistent oligoarticular, 7 with extended oligoarticular subtype, and 1 with psoriatic arthritis.

DISCUSSION

To our knowledge, ours is the first longitudinal study to investigate the effects of health beliefs based on children's reports of pain over time among children with JIA.

With regard to disease-related measures, our results

showed that particularly the pain score, and to a lesser extent also the parent's assessment of the child's health (CHAQ), and the disease activity score showed high stability over the 2-year period. Further, no changes were detected in the level of pain experience and the disability of the child (which was low at both T1 and T2); however, the disease activity decreased significantly over the time period. The persistence of reported pain in children with JIA, despite low disease activity, has also been described by others¹. Schanberg and colleagues¹ found the percentage of pain days reported by children to be as high as 58% in children with minimal disease activity, and in children with JIA, who experienced remission during treatment with biological agents, we found that pain was still reported as a considerable problem¹⁶.

Children's pain-specific beliefs, particularly the belief that one is unable to function because of pain (disability belief), but also the belief that pain signifies damage and therefore activity should be restricted (harm belief), were rather stable over the 2-year span, showing moderate to large correlations¹⁷. We are not aware of other studies that have investigated the stability of specific pain beliefs in children, but measures of psychopathology often show rather high levels of stability over time in psychopathology research 18. The observed higher scores on the pain-specific belief subscales at T2 as opposed at T1, both on supposedly adaptive beliefs (that one is in control of one's pain and that a medical cure exists) and on supposedly nonadaptive beliefs (that one is unable to function because of pain and that pain signifies damage), suggest that pain-specific beliefs may change over time. To our knowledge, no other studies have investigated age differences in specific pain beliefs. However, similar age differences have been found in children's use of pain-coping strategies 19,20,21,22, with older children discovered to use a greater number of different strategies. Besides indicating the test-retest reliability of the SOPA-C, the results show that maladaptive pain beliefs in children with JIA may persist over a considerable timespan.

Our results also show that the cognitive health beliefs that one is disabled, that pain does signify harm, that one is unable to control one's pain, and that a medical cure does not exist, predicted a significant 7% of the variance in pain experience in children with JIA 2 years later, even after controlling for baseline pain, disease activity, and parents'

Table 4. Comparison of the scores of the health belief subscales of disability and harm at T1 and T2 in patients with median disease activity score < 3 and median pain diary score > 1.74 (high pain), and the rest of the group (Group 2) at T1.

Subscale	High Pain, n = 12	T1 Group 2, n = 35	p (t test)	High Pain, n = 12	T2 Group 2, n = 35	p (t test)
Disability	1.7 ± 0.7	1.1 ± 0.8	0.025	2.7 ± 0.5	2.2 ± 0.7	0.028
Harm	2.4 ± 0.8	1.8 ± 0.8	0.039	3.8 ± 0.8	3.3 ± 0.6	0.044

T1: study entry; T2: 2-year followup.

assessment of the child's health. Thus, our hypothesis that there would be a longitudinal association between health beliefs and pain was substantiated. This is an important finding and an indication of a causal relation between health beliefs and pain experience in this population. Since a randomized control group was not included, we have not been able to control for possible confounding factors that may explain the health beliefs in this group of children with JIA.

Our results are comparable with a previous longitudinal study of children with chronic pain in which depressive symptoms have been found to predict future child-reported pain in children with JIA (but only when T1 pain was relatively mild)²³. In a previous cross-sectional study, however, psychological factors of hopelessness and sadness were not associated with pain in children with JIA²⁴. It may be that pain in these children is more influenced by pain-specific beliefs than by general emotions.

We have previously found that a group of high-pain patients with more pain than expected from their disease activity differed from the rest of the group of patients by perceiving themselves as more disabled and were, therefore, more likely to believe that pain signifies damage¹¹. In our current study, we found the same difference 2 years later, which confirmed our hypothesis. The subgroup of children with JIA whose pain experience seems to be in discordance with the disease activity appears to be highly consistent over time.

One limitation to the interpretation of our findings may be that our disease activity index has not been validated in larger patient series. It might have been more appropriate to use the established core set of outcome variables as described by Giannini, $et\ al^{25}$ or even the newly published Juvenile Arthritis Disease Activity Score as described by Consolaro, $et\ al^{26}$. However, we considered it more appropriate to use the same disease activity index as in our previous report from 2005. Further, the disease activity index used in our study includes 2 of the core sets of the established outcome variables given by Giannini, $et\ al^{25}$ (number of active joints and erythrocyte sedimentation rate), which did not involve the component of pain as, for example, in the patient's global assessment by the visual analog scale.

Several clinical implications can be drawn from our data. First, assessment of pain-specific beliefs and other psychological factors that have been shown to be associated with pain such as depressive symptoms, as well as pain symptoms, may be useful in the optimal management of children with JIA, and also to identify children who may benefit from behavioral intervention. In addition, it may be important to identify and offer behavioral intervention to the subgroup of children whose pain experience is in discordance with the actual disease activity.

Few studies have investigated the possible effect of psychosocial intervention to improve the ability of children with JIA to cope with pain and enhance daily functioning²⁷.

Consequently, there is a need for future randomized controlled intervention research, both to test causal mechanisms between pain and psychological factors, and to clarify whether a modification of maladaptive pain-specific health beliefs may lead to improved pain and functional outcomes for children with JIA.

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