Juvenile Idiopathic Arthritis: Parent-Child Discrepancy on Reports of Pain and Disability

TONYA M. PALERMO, KATHY ZEBRACKI, SAMANTHA COX, ARTHUR J. NEWMAN, and NORA G. SINGER

ABSTRACT. ***Objective.*** To examine the incidence and nature of disagreements about pain and functional disability between parents and their children with juvenile idiopathic arthritis (JIA) and to identify demographic and psychosocial predictors of parent-child disagreement about pain and functional disability.

Methods. Participants comprised 63 children 8–16 years of age (mean 12.36 ± 2.61) and their parents, followed as part of a longitudinal study of pain in children. During routine rheumatology clinic visits, children and their parents completed validated measures of pain, depressive symptoms, and functional disability.

Results. Parents and children often disagreed as to the frequency and intensity of pain and to the degree of disability caused by arthritis. Child depressive symptoms ($p < 0.01$) and parental perceptions of child limitations ($p < 0.02$) predicted parent-child disagreement about the frequency of the child's pain. Parental perceptions of child limitations also predicted parent-child disagreement about the child's level of functional disability ($p < 0.04$). Those children who estimated their level of disability to be different than their parents' rating also were more depressed compared to children who agreed with their parents about their level of disability ($p < 0.01$).

Conclusion. Discrepancy between parent and child reports of pain and disability in children with JIA is common. Findings suggest that such disagreements in reporting of pain and functional disability by parents and their children with JIA are associated with underlying depressive symptoms in children. (J Rheumatol 2004;31:1840–6)

Key Indexing Terms:
PAIN JUVENILE IDIOPATHIC ARTHRITIS DISABILITY PARENT-CHILD AGREEMENT

Recent studies have shown that pain is quite common in children with different forms of arthritis including juvenile rheumatoid arthritis and juvenile chronic arthritis[1-3]. Because pain is an individualized and subjective event, when possible, children's self-reports of pain are now generally given precedence in pain assessment. In cases when children are unable to report their experience of pain due to factors such as developmental level, verbal limitations, and emotional distress, parents are relied on for proxy reports of their children's pain symptoms[4,5]. However, there is a lack of empirical data showing that parental reports of their child's pain are an accurate assessment.

Most research on parent and child agreement about pain has been conducted in healthy children (e.g., postoperative pain). Some studies have reported a high level of agreement between child and parent pain ratings[6-8], while other studies have reported significant mean differences in pain scores[5,9], with parents generally reporting lower levels of pain than their children[4,10]. At least one study has examined child and parent agreement in ratings of pain and disability in children with juvenile chronic arthritis[5]. In this small sample of patients (n = 20), children and their parents differed markedly on pain estimation and less so on degree of disability. To date, however, no studies have identified specific child or parent factors that explain why discrepancies in child and parental reports of pain or disability may occur.

Our objective was to provide a description of the incidence and nature of parent-child disagreements about the level of pain and disability experienced by children with juvenile idiopathic arthritis (JIA) and to obtain information concerning demographic and psychosocial factors that may explain potential discrepant perspectives. Further, since traditional approaches to assessing discrepancy between different informants (e.g., parents, children) utilize correlational techniques[11], which neither measure precise agreement or disagreement, nor indicate the magnitude or direction of the discrepancy, an additional aim of our study was to use a more refined methodological approach to

From the Department of Anesthesiology and Peri-Operative Medicine, Oregon Health and Sciences University, Portland, Oregon; the Departments of Psychology and Epidemiology and Biostatistics, and the Department of Pediatrics, Rainbow Babies and Children's Hospital, Case Western Reserve University School of Medicine, Cleveland, Ohio, USA.

Supported by NIMH grant K23 MH01837 awarded to Dr. Palermo.

T.M. Palermo, PhD, Assistant Professor, Department of Anesthesiology and Peri-Operative Medicine, Oregon Health and Sciences University; K. Zebracki, MA, Graduate Student, Department of Psychology; S. Cox, MPH, Research Associate, Department of Epidemiology and Biostatistics; A.J. Newman, MD, Professor of Pediatrics; N.G. Singer, MD, Assistant Professor of Pediatrics, Department of Pediatrics, Rainbow Babies and Children's Hospital, Case Western Reserve University School of Medicine.

Address reprint requests to Dr. T.M. Palermo, Department of Anesthesiology, UHS-2, Oregon Health and Sciences University, 3181 SW Sam Jackson Park Way, Portland, OR 97239, USA.

Submitted September 12, 2003; revision accepted April 24, 2004.

examine discrepancies in parent and child perceptions of pain and disability. We hypothesized that discrepancy between child and parent perspectives would be greater in children with depressive symptoms[12,13] and that we would therefore detect an increased rate of discrepancy between child and parent reports of both pain and disability in children with higher levels of depressive symptoms.

MATERIALS AND METHODS

Entry criteria. Families were recruited as part of a larger, institutional review board approved, longitudinal study of pain and disability in children with chronic health conditions. Children and adolescents were eligible for participation if they were between the ages of 8 and 16, had a diagnosis of JIA based on the Durban classification criteria[14], and were established patients in the pediatric rheumatology practice at a Midwest tertiary care children's hospital. Exclusion criteria included non-English speaking participants and current use of psychotropic medication. Children were recruited from one of 4 clinical sites (3 suburban and one inner-city) during a routine pediatric rheumatology visit. After giving informed consent, children and caregivers completed questionnaires and interviews while in the clinic. The child's rheumatologist completed a measure identifying disease classification, joint involvement, and physician perception of disease severity.

Sociodemographic measures. Caregivers completed a questionnaire that included child's age, ethnicity, sex, family income level, and parent marital and work status. Ethnicity was categorized as minority (African-American and biracial) versus nonminority (Caucasian) for all analyses.

Pain measures. Children and parents completed parallel questionnaires to assess the child's experience with pain over the previous 4 weeks. Pain frequency was measured using a Likert-type rating scale with 6 response options ranging from less than once a month to daily. Pain intensity was measured using the validated Faces Pain Rating Scale[15], which is a pictorial scale containing a series of 7 faces with anchors at the 2 ends representing no pain to worst pain. Pain duration was measured using a Likert-type scale with 4 response options ranging from less than 1 hour to all day. Emotional distress due to pain was assessed using a scale from McGrath[16] with 5 response options ranging from not at all to very much bothered by pain.

Provider assessment. The child's rheumatologist completed a form indicating the child's disease classification and his or her perception of the child's disease severity. Perceived disease severity was rated on a 10 cm visual analog scale (VAS). Respondents marked the point along the 10 cm line that showed the severity of the child's disease from not severe to extremely severe. Similar physician assessments of disease status have been widely used in JIA research[17].

Perceived limitations. Similar to the physician rating, children and parents completed a rating of their perception of the child's functional limitations due to JIA on 10 cm VAS lines with the anchors no limitations to extreme limitations. Previous investigators have used similar assessments of disease status in youth and adults with pain[18] and physical disability[19].

Depressive symptoms. The Revised Child Anxiety and Depression Scale (RCADS)[20] is a 47-item instrument designed to assess children's self-report of anxiety and depression corresponding to several *Diagnostic and Statistical Manual of Mental Disorders*, 4th edition, (DSM-IV) anxiety disorders as well as major depression. Each item involves rating symptom frequency on a 4-point scale from never to always. Items are scored 0–3, with higher scores indicating greater frequency. Raw scores are converted to T-scores using sex and grade scaling. The subscale assessing symptoms of major depressive disorder was used in the present analyses. Validity and reliability statistics have been described[20].

Functional disability. The Functional Disability Inventory (FDI)[21] describes the extent of restriction in performing 15 daily activities in the domains of school, home, recreation, and social interaction. Sample activities include walking to the bathroom, being at school all day, and reading and doing homework. Parallel child and parent versions were completed. Respondents rated how difficult it was for their child to perform each activity in the past few days on a 5-point scale with response categories ranging from 0 (no trouble) to 4 (impossible) to perform each activity. Scores range from 0 to 60, higher scores indicating more disability. Validity and reliability statistics have been described[21-23]. The FDI has been used to assess functional disability in studies of children with juvenile rheumatoid arthritis[22] and fibromyalgia[23].

Statistical analysis. Summary statistics, including means and standard deviations (SD) for continuous data and frequencies and proportions for categorical data, were used to describe the demographic and disease characteristics of the children and parents.

The kappa statistic and the intraclass correlation coefficient (ICC) were used for measuring agreement between informants. These statistics are preferred compared to correlational analyses[24,25], which indicate the extent to which rank orderings of symptom levels are similar across informant groups. The level of actual agreement between individual parent-child dyads for categorical data was estimated with the weighted kappa coefficient (κ). Level of agreement was categorized as follows: < 0.20, poor agreement; 0.21–0.40, fair agreement; 0.41–0.60, moderate agreement; 0.61–0.80 good agreement; and 0.81–1.00, almost perfect agreement using standard criteria[26]. The ICC was used to assess agreement between individual parent-child dyads on continuous data. Correlations of at least 0.75 were used to indicate an acceptable level of agreement[27].

Hierarchical regression analyses were computed to identify demographic and psychosocial predictors of the level of disagreement between parents and children about pain symptoms and disability. First, demographic variables and disease characteristics were entered (i.e., child's age, disease severity, and household income) into the regression equation. Second, parental perception of their child's functional limitations due to JIA was entered. Finally, child report of perceived functional limitations and symptoms of depression were entered on the last step in order to examine the influence of child variables after controlling for demographic and disease characteristics and parental perceptions.

Absolute discrepancy scores for each parent-child dyad were computed for pain and disability variables by subtracting the parent reported total score from the child reported total score. Higher scores indicate more discrepancy between parent and child reports. On the pain measures, parent-child dyads with raw difference scores equaling 0 were categorized as having exact levels of agreement (Parent = Child); dyads with raw difference scores greater than 0 were categorized as children reporting more symptoms than their parent (Child > Parent); and dyads with raw difference scores less than 0 were categorized as parents reporting more symptoms than their child (Parent > Child).

On the functional disability measure, parent-child dyads with raw difference scores between 0.5 SD above and below 0 were categorized as highly concordant (Parent = Child); dyads with raw difference scores greater than 0.5 standard deviations were categorized as children reporting more symptoms than their parent (Child > Parent); and dyads with raw difference scores less than 0.5 SD were categorized as parents reporting more symptoms than their child (Parent > Child).

To provide a more comprehensive description of the nature of the parent-child discrepancy[28], the direction of the discrepancy between child and parental reports of pain was determined. Two separate one-way analyses of variance (ANOVA) were computed to identify which direction of the discrepancy (Child > Parent, Parent > Child) accounted for child pain and disability outcomes. All data analyses were conducted using the Statistical Package for the Social Sciences, Version 11.0 (SPSS 11.0).

RESULTS

Participants. Sixty-six families were approached for participation between January 2001 and July 2002. Three families

declined to participate due to time constraints. Sixty-three children and their parents participated in this study. Demographic and clinical features of the study participants are shown in Table 1 and are representative of our clinic population of children with JIA. Children were primarily classified as having mild to moderate disease severity by their rheumatologist. Child and parent reports of child's pain symptoms are shown in Table 2. Parent and child reports indicated that about 60% of children experienced persistent pain occurring at least once per week, with a mild range of intensity, 2.0 (of 6.0). Most children experienced pain for less than a few hours (54%); however, more than one-third of children experienced pain for half the day or more. Further, most children experienced moderate levels of functional disability (mean 10.23 and 9.57, child and parent report, respectively) and emotional distress due to pain (54% and 59%, child and parent report, respectively).

Table 1. Demographic and disease characteristics of children.

Characteristic	n = 63
Age, mean (SD) yrs	12.36 (2.61)
Sex, female (%)	51 (80.9)
Ethnicity (%)	
Caucasian	55 (87.3)
African-American/other	8 (12.7)
Type of JIA (%)	
Systemic	3 (4.76)
Oligoarthritis	26 (41.27)
Polyarthritis (RF negative)	15 (23.81)
Polyarthritis (RF positive)	3 (4.76)
Enthesitis related arthritis	5 (7.94)
Other	11 (17.46)
Disease severity, mean (SD)	2.6 (2.0)
Parents' marital status* (%)	
Married	43 (70.5)
Single/divorced	18 (29.5)
Household income (%)	
< $20,000	7 (11.1)
$20,000–49,999	13 (20.6)
> $50,000	43 (68.3)

* n = 61 due to missing data. RF: rheumatoid factor.

The majority (91%) of children were being treated with medications. Medications included nonselective inhibitors (46%; e.g., sulindac, oxaprozin, ibuprofen), COX-2-specific inhibitors (25%; e.g., celecoxib, rofecoxib), steroids (8%; e.g., prednisone), biologics (8%; e.g., etanercept, infliximab), disease modifying antirheumatic drugs (48%; e.g., azathioprine, methotrexate, hydroxychloroquine), supplements (35%; e.g., folic acid, multivitamin), topical anesthetic (5%; i.e., EMLA creme-lidocaine 2.5 mg/g and prilocaine 2.5 mg/g), heartburn/acid reflux-related (6%; e.g., lansoprazole, ranitidine), and nonarthritis-specific (10%; e.g., albuterol, mesalamine, singulair montelukast sodium).

Disease characteristics. Age of disease onset was correlated with child reported pain frequency ($r = 0.28$, $p < 0.05$) and emotional distress due to pain ($r = 0.39$, $p < 0.01$), with older age at diagnosis associated with increased levels of pain frequency and emotional distress due to pain. Age of diagnosis was not correlated with depressive symptoms or other pain perception variables. Physician reported duration of JIA was negatively correlated with depressive symptoms ($r = –0.33$, $p < 0.05$), frequency of pain ($r = –0.27$, $p < 0.05$), and emotional distress due to pain ($r = –0.45$, $p < 0.001$). This indicates an association between a shorter length of diagnosis and more depressive symptoms, more frequent pain, and more emotional distress due to pain. Duration of illness was not correlated with child reported pain intensity

Table 2. Comparison of child and parent report on pain symptoms and disability. Results are expressed as n (%).

	Child Report	Parent Report	Kappa/ICC
Frequency (n = 62)			0.37 (Fair)
≤ 3 Times per month	23 (37.1)	23 (37.1)	
1–3 Times per week	12 (19.4)	24 (38.7)	
3–5 Times per week	9 (14.5)	4 (6.5)	
Daily	18 (29.0)	11 (17.7)	
Intensity (Faces Scale) (n = 62)			0.16 (Poor)
0–No pain	9 (14.5)	10 (16.1)	
2–3	26 (42.0)	23 (37.1)	
4–5	18 (29.0)	23 (37.1)	
6–7 (Worst pain ever)	9 (14.5)	6 (9.7)	
Duration (n = 55)			0.41 (Moderate)
A few hours or less	34 (61.8)	34 (61.8)	
Half of the day	6 (10.9)	8 (14.6)	
All day	15 (27.3)	13 (23.6)	
Emotional upset (n = 61)			0.26 (Fair)
Not at all	15 (24.6)	14 (23.0)	
A little—moderate	34 (55.7)	37 (60.6)	
A lot—very much	12 (19.7)	10 (16.4)	
Functional disability (n = 62)	10.23 (9.42)	9.57 (12.01)	0.40 (Not acceptable)

or pain duration, or parent reported pain symptoms. Depressive symptoms were negatively correlated with child's age ($r = –0.31$, $p < 0.05$), indicating that younger children may experience more depressive symptoms. Depressive symptoms were not correlated with disease severity or arthritis type.

Child and parent discrepancy on pain estimations and functional disability. As shown in Table 2, κ values measuring exact agreement between parents and children on pain scores indicated poor agreement for pain intensity ($\kappa = 0.16$), fair agreement for frequency of pain ($\kappa = 0.37$) and emotional upset ($\kappa = 0.26$), and moderate agreement for duration of pain ($\kappa = 0.41$).

The ICC for agreement between parent-child dyads on functional disability did not reach an acceptable level (ICC = 0.40; Table 2). Almost half the parent-child dyads showed disagreement on functional disability (48%). Parents were equally likely to underestimate functional disability (24%) compared to children's self-reports as they were to overestimate functional disability (24%).

Predicting parent-child discrepancy on estimates of pain and disability. Separate hierarchical regression analyses were conducted on each of the pain and disability measures to examine demographic and psychosocial predictors of parent-child disagreement (i.e., discrepancy between parents and children about the child's pain symptoms and disability). Table 3 shows only the final best regression model. Overall, a statistically significant amount of variance (28%) in the parent-child discrepancy on estimates of pain frequency was explained by the regression model ($p < 0.05$). Greater parent-child discrepancy about frequency of the child's pain was predicted by parental perception of fewer child functional limitations ($p < 0.02$) and higher levels of child reported depressive symptoms ($p < 0.01$).

The regression model also explained a statistically significant amount of variance (30%) in parent-child discordance on ratings of functional disability ($p < 0.05$). When parents reported higher levels of child limitations there was greater parent-child discordance on disability ratings ($p < 0.04$). The same regression model was not significant for predicting parent-child discordance on ratings of pain intensity, duration, or emotional distress due to pain.

Determining the direction of the parent-child discrepancy. To identify differences on psychosocial risk factors according to the direction of the parent-child discrepancy (e.g., parent overestimating symptoms vs child overestimating symptoms), separate one-way ANOVA were conducted (Table 4). There was a trend in both discordance groups (i.e., children and parents overestimating the frequency of the child's pain symptoms; Child > Parent and Parent > Child) for parents to report low levels of child functional limitations and for children to report higher levels of depressive symptoms compared to children and parents who agreed about the frequency of the child's pain (Child = Parent). On the FDI, the ANOVA showed significant group differences on both parental perception of child limitations ($p < 0.001$) and child depressive symptoms ($p < 0.01$). Parents and children who disagreed about the child's level of functional disability (Child > Parent and Parent > Child) had higher levels of parent perceived functional limitations in comparison to parents whose children agreed with them about their level of functional disability (Child = Parent). Children who reported more functional disability than their parents (Child > Parent) demonstrated higher levels of depressive symptoms (mean 52.5) than children and parents who agreed on the level of the child's functional disability (mean 41.31).

Table 3. Predictors of parent-child discordance on pain and disability variables.

Criterion Variable	Step	ß	R^2	R^2 Changed	F
Pain frequency	3				
Predictor variables					
Child's age		–0.12	0.28	0.12*	2.87*
Household income		0.07			
Disease severity		0.19			
Parent reported limitations		–0.47*			
Child reported limitations		0.04			
Depressive symptoms		0.41**			
Disability	3				
Predictor variables					
Child's age		0.01	0.30	0.04	3.08**
Household income		0.01			
Disease severity		0.12			
Parent reported limitations		0.46*			
Child reported limitations		–0.07			
Depressive symptoms		0.21			

* $p < 0.05$; ** $p \leq 0.01$.

Table 4. Differences on psychosocial risk factors by the direction of parent-child discrepancy on estimates of pain and disability.

Dependent Variable	Child > Parent Mean (SD)	Child = Parent Mean (SD)	Parent > Child Mean (SD)	F
Pain frequency				
Risk factor				
Parent reported limitations	1.86 (2.06) (n = 21)	3.27 (2.94) (n = 30)	1.95 (2.39) (n = 11)	2.21
Depressive symptoms	49.0 (13.79) (n = 20)	42.21 (9.11) (n = 29)	47.1 (11.13) (n = 10)	2.32
Disability				
Risk factor				
Parent reported limitations	3.20 (2.69) (n = 15)	1.25 (1.81) (n = 30)	4.82 (2.44) (n = 15)	13.66**
Depressive symptoms	52.5 (15.38) (n = 14)	41.31 (6.86) (n = 29)	45.79 (11.71) (n = 14)	5.20*

* $p < 0.01$; ** $p < 0.0001$.

DISCUSSION

We found that parent and child disagreement about pain related to JIA (i.e., how frequently the child's pain occurs, how long it lasts, how intense it is, and how much it bothers the child) is common. Similarly, parents and children often disagree about the level of functional disturbance due to JIA associated pain. These findings verify our hypotheses that parent-child disagreement concerning pain symptoms is widespread, extending previous research findings showing disagreement about pain intensity in different forms of chronic arthritis such as JIA[5].

Importantly, several predictors of increased parent-child discordance were identified in this study. As we hypothesized, child depressive symptoms predicted whether or not there was disagreement between children and parents about the frequency of pain. Children with depressive symptoms are likely to be more withdrawn and may have increased difficulties in communicating effectively with their parents. Moreover, parents of depressed children have been found to be more overprotective and more likely to have communication difficulties in the family[29]. It is also possible that depression exacerbates children's experience of pain and disability[12,13], similar to the experience of adult chronic pain[30]. Thus, it may be even more difficult for parents to have an accurate understanding of the level and impact of pain and disability in children with depressive symptoms.

Parental perception of their child's functional limitations was also predictive of disagreements in child and parent reports of pain frequency and functional disability. When parents perceived few limitations, there were more disagreements about the frequency of pain, but when parents perceived greater limitations, there were more disagreements about the level of disability. Parental impression of their children's level and frequency of pain and disability may be based in large part on the specific activities that they see their children participate in and how they respond to this. For example, if children seem to be participating in their usual activities, parents may assume the child does not have much pain. This hypothesis is supported by previous research[31] that found higher levels of agreement between parents and children in areas of physical function that are more readily observed by parents, and lower levels of agreement in areas that are less frequently observed by parents. On the other hand, children may be coping well with frequent pain and pushing themselves to participate in activities despite having a significant amount of pain. Parents may also be incorporating their own responses to their children's pain in order to estimate their child's level of functional disability. Parents who are overly solicitous to children's pain behaviors (e.g., providing extra attention) may perceive their child as having more functional disability. Additional research is needed to better understand the full range of family factors that explain the direction and nature of parent-child discrepancies in their reporting of pain and disability related to JIA.

There are several limitations of the study. First, our data are correlational and the direction of relationships is unclear. For example, it is possible that frequent intense pain causes depressive symptoms in children that in turn affect communication about pain symptoms to parents. It is also possible that depressive symptoms worsen pain. Second, since the study participants were part of a larger longitudinal study of pain and disability in children with a range of chronic health conditions (i.e., JIA, sickle cell, and recurrent headache), a generic noncategorical measure of functional disability (i.e., FDI) was used rather than the Childhood Health Assessment Questionnaire (CHAQ)[32]. The CHAQ is the only functional instrument that has been validated in children with arthritis and its use would have provided a more comprehensive description of children's disability and discomfort than the FDI, as well as allowing direct comparison to previous research that has used the CHAQ. Because the FDI did not include items concerning fine motor activities, our findings may be an underestimate of the true level of functional disability in children with JIA. Third, our sample was predominately Caucasian, reflecting the composition of JIA patients in our rheumatology clinics, as well as the ethnic distribution of patients found in large population-based

studies concerning the incidence of JIA[33]. It is unclear whether the findings would generalize to a more ethnically diverse sample. Finally, only a modest proportion (about 30%) of the variance in parent-child discrepancy on estimates concerning pain frequency and functional disability was explained by our hypothesized predictors. Thus, there remain other important variables (including potentially the quality of the parent-child relationship and emotional functioning of child and parent) unaccounted for that are contributing to a large portion of the variance.

The clinical implications of our findings suggest that reliance on parental report of pain and disability alone may contribute to inadequate treatment in children with JIA, since parents are likely to disagree with their children about the frequency of the child's pain and level of disability. While the gathering of information from multiple informants is recommended for assessing complex dimensions such as pain and disability, the integration of different perceptions is challenging. Our findings suggest that clinicians should independently assess pain and disability from the perspective of both the child and the parent. Moreover, we suggest that clinicians pay particular attention to any disagreements in the symptom reporting of their pediatric patients and parents, because these discordant viewpoints may be associated with depressive symptoms and higher levels of functional disability. Early detection of discordance in estimation of pain by parents and their children with JIA may help identify those families most in need of behavioral intervention and may have the potential to influence disability. Future research incorporating measures of both parental and child coping strategies[34] as determinants of pain and disability may be particularly relevant for designing and testing behavioral and family based interventions.

ACKNOWLEDGMENT

We sincerely thank the children and families for their interest and receptivity to participating in this study. We acknowledge Bill Swinderman, Duaré Valenzuela, and Tori Willard, who assisted with data collection and entry.

REFERENCES

1. Sherry DD, Bohnsack J, Salmonson K, Wallace CA, Mellins E. Painless juvenile rheumatoid arthritis. J Pediatr 1990;116:921-3.
2. Benestad B, Vinje O, Vierod MB, Vandvik IH. Quantitative and qualitative assessments of pain in children with juvenile chronic arthritis based on the Norwegian version of the Pediatric Pain Questionnaire. Scand J Rheumatol 1996;25:293-9.
3. Anthony KK, Schanberg LE. Pain in children with arthritis: a review of the current literature. Arthritis Rheum 2003;49:272-9.
4. Chambers CT, Reid GJ, Craig KD, McGrath PJ, Finley GA. Agreement between child and parent reports of pain. Clin J Pain 1998;14:336-42.
5. Doherty E, Yanni G, Conroy RM, Bresnihan B. A comparison of child and parent ratings of disability and pain in juvenile chronic arthritis. J Rheumatol 1993;20:1563-6.
6. McMillen Moinpour C, Donaldson G, Wallace K, Hiraga Y, Joss B. Parent/child agreement in rating child mouth pain. In: Tyler DC, Krane EJ, editors. Advances in pain research and therapy. Volume 15. New York: Raven Press; 1990:69-78.
7. O'Hara M, McGrath PJ, D'Astous J, Vair CA. Oral morphine versus injected meperidine (Demerol) for pain relief in children after orthopaedic surgery. J Pediatr Orthop 1987;7:78-82.
8. Schneider EM, LoBiondo-Wood G. Perceptions of procedural pain: parents, nurses and children. Child Health Care 1992;21:157-62.
9. Manne SL, Jacobsen PB, Redd WH. Assessment of acute pediatric pain: do children self-report, parent ratings, and nurse ratings measure the same phenomenon? Pain 1992;48:45-52.
10. Lollar DJ, Smits SJ, Patterson DL. Assessment of pediatric pain: an empirical perspective. J Pediatr Psychol 1982;7:267-77.
11. Achenbach TM, McConaughy SH, Howell CT. Child/adolescent behavioral and emotional problems: Implications of cross-informant correlations for situational specificity. Psychol Bull 1987;101:213-32.
12. Cuneo KM, Schiaffino KM. Adolescent self-perceptions of adjustment to childhood arthritis: The influence of disease activity, family resources, and parent adjustment. J Adolesc Health 2002;31:363-71.
13. Murphy H, Dickens C, Creed F, Bernstein R. Depression, illness perception and coping in rheumatoid arthritis. J Psychosom Res 1999;46:155-64.
14. Petty RE, Southwood TR, Baum J, et al. Revision of the proposed classification criteria for juvenile idiopathic arthritis: Durban, 1997. J Rheumatol 1998;25:1991-5.
15. Bieri D, Reeve RA, Champion GD, Addicoat L, Ziegler JB. The Faces Pain Scale for the self-assessment of the severity of pain experienced by children: development, initial validation, and preliminary investigation for ratio scale properties. Pain 1990;41:139-50.
16. McGrath PJ. Pain in children: Nature, assessment, and treatment. New York: Guilford; 1990.
17. Ravelli A, Viola S, Ruperto N, Corsi B, Ballardini G, Martini A. Correlation between conventional disease activity measures in juvenile idiopathic arthritis. Ann Rheum Dis 1997;56:197-200.
18. Oberlander TF, Gilbert CA, Chambers CT, O'Donnell ME, Craig KD. Biobehavioral responses to acute pain in adolescents with a significant neurologic impairment. Clin J Pain 1999;15:201-9.
19. Willen C, Grimby G. Pain, physical activity, and disability in individuals with late effects of polio. Arch Phys Med Rehabil 1998;79:915-9.
20. Chorpita BF, Yim L, Moffitt C, Umemoto LA, Francis SE. Assessment of symptoms of DSM-IV anxiety and depression in children: a revised child anxiety and depression scale. Behav Res Ther 2000;38:835-55.
21. Walker LS, Greene JW. The Functional Disability Inventory: Measuring a neglected dimension of child health status. J Pediatr Psychol 1991;16:39-58.
22. Reid GJ, Gilbert CA, McGrath PJ. The Pain Coping Questionnaire: preliminary validation. Pain 1998;76:83-96.
23. Kashikar-Zuck S, Vaught MH, Goldschneider KR, Graham TB, Miller JC. Depression, coping, and functional disability in juvenile primary fibromyalgia syndrome. J Pain 2002;3:412-9.
24. Fleiss JL. Statistical methods for rates and proportions. New York: John Wiley & Sons; 1981.
25. Shrout PE, Fleiss JL. Intraclass correlations: Uses in assessing rater reliability. Psychol Bull 1979;86:420-8.
26. Landis JR, Koch GG. The measurement of observer agreement for categorical data. Biometrics 1977;33:159-74.
27. Lee J, Koh D, Ong CN. Statistical evaluation of agreement between two methods for measuring a quantitative variable. Comput Biol Med 1989;19:61-70.
28. Ravelli A, Viola S, Migliavacca D, Pistorio A, Ruperto N, Martini

A. Discordance between proxy-reported and observed assessment of functional ability of children with juvenile idiopathic arthritis. Rheumatology Oxford 2001;40:914-9.
29. Magnussen MG. Characteristics of depressed and non-depressed children and their parents. Child Psychiatry Hum Dev 1991;21:185-91.
30. Wilson KG, Eriksson MY, D'Eon JL, Mikail SF, Emery PC. Major depression and insomnia in chronic pain. Clin J Pain 2002;18:77-83.
31. Duffy CM, Arsenault L, Watanabe Duffy KN. Level of agreement between parents and children in rating dysfunction in juvenile rheumatoid arthritis and juvenile spondyloarthritides. J Rheumatol 1993;20:2134-9.
32. Singh G, Athreya B, Fries J, Goldsmith D. Measurement of health status in children with juvenile rheumatoid arthritis. Arthritis Rheum 1994;37:1761-9.
33. Kwoh CK, Newman AJ, Singsen BH, Humbert L, Wu G. Ethnic differences in the incidence of juvenile chronic arthritis [abstract]. Arthritis Rheum 1999;42 Suppl: S137.
34. Schanberg LE, Lefebvre JC, Keefe FJ, Kredich DW, Gil K. Pain coping and the pain experience in children with juvenile chronic arthritis. Pain 1997;73:181-9.