# Pain Intensity, Psychological Inflexibility, and Acceptance of Pain as Predictors of Functioning in Adolescents with Juvenile Idiopathic Arthritis: A Preliminary Investigation

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**Abstract** Juvenile Idiopathic Arthritis (JIA) is a chronic rheumatic disease associated with pain and maladjustment. This study investigated whether pain, acceptance of pain, and psychological inflexibility uniquely predicted functional disability, anxiety, general quality of life (QOL), and health-related quality of life (HQOL) among adolescents with JIA. Twenty-three adolescents with JIA and pain were recruited from a pediatric rheumatology clinic. Participants completed self-report measures pertaining to the key study variables. A series of multiple regression analyses demonstrated that higher pain uniquely predicted higher funcdisability. Greater psychological inflexibility tional uniquely predicted higher anxiety, lower general QOL, and lower HQOL. Increases in acceptance of pain were found to be uniquely related to increases in general QOL. These data confirm prior findings that pain impacts functioning, and provide preliminary findings that psychological inflexibility and acceptance may be important targets of

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psychological intervention for youth with JIA and pain to improve functioning and QOL.

**Keywords** Pain · Psychological flexibility · Acceptance · Juvenile idiopathic arthritis · Chronic illness

Juvenile Idiopathic Arthritis (JIA) is a chronic inflammatory autoimmune disease with unknown etiology that typically begins before the age of 16 (Petty et al., 2004). It is the most common rheumatic disease of childhood and the fifth most common chronic disease among children, affecting as many as 300,000 youths under the age of 17 (Arthritis Foundation, 2007; Cassidy & Petty, 2005). One of the principal symptoms of JIA is pain. Pains fluctuates within and across individuals with JIA and data suggest that typical pain is in the mild to moderate range with one quarter of children experiencing severe pain (Anthony & Schanberg, 2003; Schanberg, Gill, Anthony, Yow, & Rochon, 2005; Schanberg, Lefebvre, Keefe, Kredich, & Gil, 1997; Stinson et al., 2008).

In youth with JIA, pain has been found to predict psychological adjustment (Billings, Moos, Miller, & Gottlieb, 1987; Sandstrom & Schanberg, 2004). Specifically, pain has been linked to functional disability (Gauntlett-Gilbert & Eccleston, 2007; Logan & Scharff, 2005), anxiety (Margetic, Aukust-Margetic, Bilic, Jeluis, & Bukovac, 2005; Schanberg, Anthony, Gil, & Maurin, 2003), quality of life (QOL; April, Feldman, Platt, & Duffy, 2006), and health-related quality of life (HQOL; Sawyer et al., 2005; Shaw, Southwood, Duffy, & McDonagh, 2006). Unfortunately, pain can be resistant to treatment in this population.

Drawing from the larger adult and adolescent chronic pain literature, psychological inflexibility and acceptance of pain have emerged as critical predictors of psychological adjustment (McCracken, Gauntlett-Gilbert, Eccleston, 2010; Vowles & Thompson, 2011). Psychological inflexibility can be defined as responding to internal (e.g., thoughts, emotions, sensations) or external situations in a reflexive, habitual, or impulsive manner, and often relying on avoidant coping strategies (Hayes, Luoma, Bond, Masuda, & Lillis, 2006). For example, a person might habitually stay home from school at the first experience of pain. In contrast, psychological flexibility is described as engaging in present-moment awareness and selecting action or inaction based on personal values (Hayes et al., 2006). The related construct of acceptance is defined as acknowledging and experiencing private or public experiences (e.g., anxiety, pain) without having to follow, reduce, or alter them (Hayes, Strosahl, & Wilson, 1999). Acceptance has been linked to better adjustment to chronic pain (Kratz, Davis, & Zautra, 2007; McCracken, 1998; McCracken, Vowles, & Eccleston, 2005). This theoretical model has guided treatment approaches such as Acceptance and Commitment Therapy (ACT; Hayes et al., 1999; McCracken, 2005). These approaches encourage psychological flexibility and acceptance in order to improve patient functioning. Employing these treatment modalities has been shown to improve psychological adjustment, such as functioning, anxiety, and quality of life in adults (Dahl, Wilson, & Nilsson, 2004; McCracken, 2005; McCracken & Eccleston, 2003; McCracken, MacKichan, & Eccleston, 2007; McCracken & Vowles, 2007; McCracken, Vowles, & Eccleston, 2004) and adolescents (Wicksell, Dahl, Magnusson, & Olsson, 2005; Wicksell, Melin, Lekander, & Olsson, 2009; Wicksell, Melin, & Olsson, 2007) with chronic pain.

Despite prior findings investigating psychological inflexibility and acceptance of pain in adults and adolescents with chronic pain, no research has investigated whether psychological inflexibility and acceptance of pain are useful concepts in understanding the psychological adjustment of adolescents with JIA and pain. The purpose of this preliminary study was to examine the independent roles of pain intensity, psychological inflexibility, and acceptance of pain in predicting four aspects of adjustment (i.e., functional disability, anxiety, quality of life, and health-related quality of life) in adolescents with JIA. Given potential intercorrelations among these variables, each was controlled for in regression analyses. The first aim was to replicate prior findings that pain is uniquely related to psychological adjustment in youth with JIA. Based on findings with children and adolescents with chronic pain including JIA (Gauntlett-Gilbert & Eccleston, 2007; Logan & Scharff, 2005; Margetic et al., 2005; Sawyer et al., 2005; Schenberg et al., 2003; Shaw et al., 2006), it was expected that pain would be positively related to functional disability, anxiety, poor QOL, and poor HQOL. The second aim was to investigate whether psychological inflexibility is a unique predictor of psychological adjustment. Paralleling the adult pain literature (McCracken & Velleman, 2010), it was expected that psychological inflexibility would be positively associated with higher functional disability, anxiety, and negatively associated with QOL and HQOL. Third, we examined whether acceptance is uniquely associated with adjustment. It was hypothesized that greater acceptance would be related to better functioning, lower anxiety, and higher QOL and HQOL.

## Method

## Participants

A power analysis revealed that 23 participants would be necessary with .80 power to detect a large effect size (.60) in a regression with 3 predictors: pain intensity, psychological flexibility, and acceptance of pain (Faul, 2007). A large effect size was selected to increase the likelihood that significant statistical findings would reflect clinical meaningfulness. The inclusion criteria consisted of the participants speaking English; being between 12 and 18 years old; having a diagnosis of systemic onset, oligoarthritis, polyarthritis, psoriatic arthritis, enthesitis-related arthritis, or undifferentiated arthritis for at least 6 months according to their pediatric rheumatologist or medical chart; and reporting any pain or functional impairments due to JIA. To assess for pain and functional impairment, the child and parent were verbally asked if the adolescent was experiencing current pain or interference with any life activities at the present time due to JIA. Participants were excluded if they carried another medical diagnosis that impaired their functioning more than JIA. Nurses screened patients according to these criteria and referred eligible families to a researcher. The researcher double-checked the inclusion and exclusion criteria with the adolescent and parent before proceeding. In total, five families initially identified by the nurse were excluded due to not meeting criteria (no current pain or impairment, n = 4; limited English proficiency, n = 1); no families were excluded or declined after being consented by the researcher.

The sample included twenty-three adolescents ranging in age from 12 to 18 (M = 15.00, SD = 2.04). Consistent with data suggesting that most subtypes of JIA are more common in females (Glass & Giannini, 1999; Ravelli & Martini, 2007), the sample was predominately female, as can be seen in Table 1. Grade in school ranged from 5<sup>th</sup> to 12<sup>th</sup>, with the greatest number of participants in 10th grade (n = 6). Characteristics of the sample including ethnicity, disease subtype, and parent-rated disease severity are displayed in Table 1. The duration of active disease ranged from 6 months to 16 years. Nine participants had JIA for

Table 1	Selected	demographic	variables
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Variable	%	Ν
Sex		
Female	91	21
Male	9	2
Ethnicity		
Caucasian	65	15
African-American	1	4
Hispanic	13	3
Asian	4	1
Disease subtype		
Polyarticular	52	12
Oligoarticular	22	5
Systemic onset	26	6
Parent-rated disease severity <sup>a</sup>		
Mild	52	12
Mild/moderate	9	2
Moderate	26	6
Severe	9	2

<sup>a</sup> Missing 1 participant's parent-rated disease severity

more than 10 years, followed by five individuals having the disease for 5 to 10 years. Another five participants had JIA for 1 to 5 years and three others had JIA for 6 months to 1 year. One participant's disease duration data was missing. Data extraction from chart reviews revealed that the majority of adolescents were rated by physicians as having moderate (n = 9; 39%) or mild (n = 8; 35%) disease severity. Fewer participants were rated as having severe disease (n = 4; 17%) and data were missing from two (9%) participants.

## Measures

## Basic Demographic Information

Parents of the participants completed a child background questionnaire, which included the following information about their child: age, ethnicity, gender, disease duration, and diagnosis. Chart reviews and discussions with the physician confirmed the diagnosis.

### Pain Intensity

Pain intensity was measured by the adolescent report versions of the Visual Analogue Scale (VAS) from Varni/ Thomson Pediatric Pain Questionnaire (PPQ): I (Varni, Thompson, & Hanson, 1987; Walco & Varni, 1991). The adolescent version of the VAS is a 10-cm horizontal line anchored at the end points by "no hurting, no discomfort, no pain" and "hurting a whole lot, very uncomfortable, severe pain." The PPQ-VAS has been shown to be both a reliable and valid measure of pediatric musculoskeletal pain (Thompson, Varni, & Hanson, 1987; Varni, Wilcox, Hanson, & Brik, 1988; Varni et al., 1987). In the current study, we used the measure of "average pain intensity" for analyses which assesses typical pain over the past week. A VAS score for average or typical pain intensity over the past week has been used in other studies (McCracken et al., 2010; Walco & Dampier, 1990) with children with chronic pain.

## Psychological Inflexibility

Adolescents completed the Avoidance and Fusion Questionnaire for Youth (AFQ-Y; Greco, Lambert, & Baer, 2008), a 17-item questionnaire that assesses psychological inflexibility. Specifically, this scale measures the degree of being entangled with the contents of private events (e.g., "The bad things I think about myself must be true"), experiential avoidance (e.g., "I push away thoughts and feelings that I don't like"), and inaction or behavioral ineffectiveness in the presence of unwanted internal experiences (e.g., "I can't be a good friend when I feel upset"). Scores range from 0 to 68 with higher scores indicating higher psychological inflexibility. Strong psychometrics of the AFQ-Y have been established in a series of studies with large samples of youth using confirmatory factor analysis, classical test theory, and Rasch modeling. Concurrent validity was shown with significant correlations between the AFO-Y and measures of anxiety, somatic complaints, quality of life and problem behavior. In addition, the authors have demonstrated good internal consistency with Cronbach's coefficient alphas ranging from .89 to .91 (Greco et al., 2008). In the current sample, the AFO-Y showed good internal consistency ( $\alpha = .91$ ).

# Acceptance of Pain

The Chronic Pain Acceptance Questionnaire-Adolescent form (CPAQ-A; McCracken et al., 2010) is a 20-item selfreport inventory based on the adult form of the Chronic Pain Acceptance Questionnaire (CPAQ; McCracken et al., 2004). It was utilized to provide an assessment of the adolescent's acceptance of his or her chronic pain and his or her engagement in daily life activities while experiencing pain, defined as two subscales in the adult CPAQ (Activity Engagement, and Pain Willingness; McCracken et al., 2004). Scores range from 0 to 80, with a higher score indicating greater acceptance of pain. Both the total scale and subscales from the adult CPAQ are internally consistent ( $\alpha = .78$ –.82) and have been demonstrated to reliably predict patient functioning (McCracken et al., 2004). Preliminary reliability estimates of the adolescent version have demonstrated good internal consistency for each of the subscales (Activity Engagement,  $\alpha = .86$ ; Pain Willingness,  $\alpha = .75$ ) as well as the total acceptance score ( $\alpha = .87$ ; McCracken et al., 2010). In the current sample, the CPAQ-A had adequate reliability ( $\alpha = .70$ ).

## Functional Disability

Adolescents completed the Functional Disability Inventory (FDI; Walker & Greene, 1991). The FDI is a 17-item self-report questionnaire that assesses interference with daily activities in children and adolescents with chronic pain. The scale is comprised of 15 items ranging from a score of 0 (*no trouble*) to a score of 4 (*impossible*). The FDI yields total scores ranging from 0 to 60, with higher scores indicating greater disability. The FDI has been demonstrated to have good reliability in youths ages 8–17 for the child-report version ( $\alpha = .85-.92$ ). Among the current sample, the adolescent version of the FDI demonstrated adequate internal consistency ( $\alpha = .90$ ).

#### Anxiety

The Revised Children's Manifest Anxiety Scale (RCMAS; Reynolds & Richmond, 1997) is a 37-item questionnaire that assesses the degree and quality of anxiety experienced by children and adolescents, including nine lie detection items. The total score ranges from 0 to 28 with higher scores indicating greater anxiety. A score of 18 or above may be indicative of the presence of an anxiety disorder. Reliability estimates for the full scale have been demonstrated to be between .81 and .85. (Reynolds & Richmond, 1997; Ryngala, Shileds, & Caruso, 2005). In the current sample the RCMAS demonstrated adequate internal consistency ( $\alpha = .81$ ).

# Quality of Life and Health-Related Quality of Life

The Quality of My Life Questionnaire (QoML; Gong, Young, Dempster, Porepa, & Feldman, 2007) is a 3-item questionnaire that assesses an individual's overall quality of life (QOL) and health-related quality of life (HQOL) as separate constructs in children and adolescents with chronic health conditions. Two of the three items from the QoML are visual analogue scales ranging from 0 to 100. The two visual analogue scales can be used as self-report or parent-report measures. In the current study, only childreported QOL and HQOL are described. For the QOL scale, participants were asked to describe how they feel about their life on a VAS by the prompt, "Overall my life is..." One end of the VAS was anchored by "the worst" whereas the other end was anchored by "the best." The HQOL question followed the same format and the participants were asked: "Considering my HEALTH, my life is..." The QoML was selected because of its brevity and the ease to administer in clinical settings relative to longer instruments. The self-report scales of the QoML have demonstrated convergent construct validity in samples of pediatric rheumatology patients ages 10 and older, in which QoML was significantly correlated with measures of disability, pain, and disease severity from the Child Health Assessment Questionnaire (CHAQ; Gong et al., 2007; Feldman, Grunland, McCullough, & Wright, 2000)

## Procedure

The study was carried out in a pediatric rheumatology clinic within a children's hospital in the Northeastern United States. The study was approved by the university Institutional Review Board. After completing proper consent and assent procedures, adolescent participants and their parents completed the questionnaires in a private clinic room. When patients and parents completed the questionnaires, they returned them to their physician or to the research investigator.

#### Results

## Preliminary Analyses

Measures of skewness and kurtosis were examined. Average pain intensity, acceptance of pain, functional disability, anxiety, and HQOL were found to have normal distributions. Psychological inflexibility (AFQ-Y) was found to be positively skewed (2.25), which indicates that the majority of participants reported themselves to be psychologically flexible. OOL was negatively skewed (-2.07), depicting that the majority of respondents rated their quality of life at the positive end. In accordance with recommendations provided for transforming moderately skewed data (Tabachnick & Fidel, 2007), psychological inflexibility was transformed using a square root transformation. Due to its negative skewness, QOL was reflected prior to applying the square root transformation (Tabachnick & Fidel, 2007). The following analyses are based on the transformed data. Other statistical assumptions were inspected including probing for homogeneity of variance and linearity. This was done to verify that the variances of examined variables were stable across all levels of the other variables and that they were linearly related to one another. Residuals were normally distributed and linearity was found among variables. Collinearity diagnostics were also explored yielding no multicolinearity between variables. Meeting of these assumptions supports a straightforward interpretation of the correlational statistics.

#### **Correlational Analyses**

Pearson product moment correlations, as found in Table 2, were conducted to examine associations among study variables. As expected, results revealed that average pain intensity was positively correlated with functional disability. Psychological inflexibility was positively related to anxiety, and inversely related to QOL and HQOL. Acceptance of pain was positively associated with QOL and HQOL. Additionally, results revealed a negative correlation between average pain intensity and acceptance of pain, and an inverse relation between acceptance of pain and psychological inflexibility.

## Multiple Regression Analyses

Four multiple regression analyses were performed to investigate whether pain intensity, psychological inflexibility, or acceptance of pain uniquely predicted functional disability, anxiety, QOL, or HQOL. Specifically, the three predictors were entered simultaneously to examine the unique variance of each controlling for the other predictors.

As shown in Table 3, results revealed that pain intensity accounted for a unique portion of the variance ( $\beta = .69$ ) in functional disability after accounting for the variance associated with psychological inflexibility and acceptance of pain. Greater pain intensity was found to be associated with greater functional disability. Psychological inflexibility was found to account for a unique variance of anxiety ( $\beta = .60$ ), QOL ( $\beta = -.44$ ), and HQOL ( $\beta = -.68$ ) when controlling for pain and acceptance of pain. Psychological inflexibility was positively associated with anxiety and inversely related to QOL and HQOL. Finally, acceptance of pain was also a unique predictor of QOL ( $\beta = .61$ ). Also displayed in Table 3, the large  $R^2$  values reveal that the variances accounted for by the overall model are consistently large across each of the dependent variables.

#### Discussion

Juvenile Idiopathic Arthritis (JIA) is a chronic rheumatic disease associated with pain (Schanberg et al., 1997, 2005; Stinson et al., 2008), disability (Varni et al., 1988), and decreases in psychosocial functioning (Billings et al., 1987; Margetic et al., 2005; Sandstrom & Schanberg, 2004; Schanberg et al., 2003; Shaw et al., 2006). Extending findings from adults (McCracken, 1998; McCracken & Eccleston, 2003; McCracken & Velleman, 2010; McCracken et al., 2005) and adolescents (Wicksell et al., 2005, 2007, 2009) with chronic pain, the purpose of the present study was to examine whether average pain intensity, psychological inflexibility, and acceptance of pain were uniquely related to functional disability, anxiety, QOL, and HQOL in youths with JIA.

Consistent with existing literature (Schanberg et al., 2003; Varni et al., 1988), the present study revealed that pain intensity was predictive of functional disability. Given that these are cross-sectional data, it could also be that higher disability is a factor precipitating greater pain experience or reporting of pain. Regardless of the direction, findings are consistent with other research linking pain and disability in adolescent populations.

Given previous literature (Margetic et al., 2005; Sawyer et al., 2005; Schanberg et al., 2003; Shaw et al., 2006), a somewhat surprising set of findings was that pain intensity was not a unique predictor of anxiety, QOL, or HQOL. Zero-order correlations revealed that pain intensity was, in fact, associated with these variables, although their relations were not statistically significant, which may be a result of the small sample size. The low associations between these variables may also reflect the restricted range (i.e., low disease severity) of the sample.

Psychological inflexibility was found to be predictive of higher anxiety, lower QOL, and lower HOQL; and acceptance predicted higher QOL. These findings support the growing theoretical framework suggesting that inflexibility,

Table 2 Descriptive statistics and correlations for all variables

		п	М	SD	1	2	3	4	5	6
1	Average pain intensity	23	4.98	2.36	_					
2	Acceptance of pain	23	43.78	12.56	60*	_				
3	Psychological inflexibility <sup>a</sup>	22	20.48	13.60	.35	54*	-			
4	Functional disability	23	12.04	9.70	.67*	38	.35	_		
5	Anxiety	20	11.30	6.84	.27	36	.63*	.29	_	
6	Quality of life <sup>a</sup>	23	6.88	2.44	29	.70*	69*	26	67*	_
7	Health-related quality of life	23	6.20	2.44	40	.59*	79*	54*	82*	.83*

Note: Correlations based on transformed variables

\*  $p \le .01$  (two-tailed)

<sup>a</sup> Based on transformed variables

Dependent variables	Predictor variables	β	SE B	t	р
Functional disability $(n = 22)$	Average pain intensity	.69	.85	3.28	.004
	Psychological inflexibility	.20	1.30	1.02	.323
$R^2 = .50$	Acceptance of pain	.13	.18	.57	.578
Anxiety $(n = 19)$	Average pain intensity	.05	.77	.17	.867
	Psychological inflexibility	.60	1.02	2.62	.019
$R^2 = .41$	Acceptance of pain	03	.15	12	.908
Quality of life $(n = 22)$	Average pain intensity	.22	.04	1.31	.206
	Psychological inflexibility	44	.06	-2.73	.014
$R^2 = .69$	Acceptance of pain	.61	.01	3.22	.005
Health related quality of life $(n = 22)$	Average pain intensity	05	.18	28	.780
	Psychological inflexibility	68	.27	-4.14	.001
$R^2 = .67$	Acceptance of pain	.20	.04	1.07	.298

Table 3 Multiple regression analyses for average pain intensity, psychological inflexibility, and acceptance of pain

lack of acceptance, and avoidance coping lead to negative cycles of increasing maladjustment (Vowles & Thompson, 2011). These data also support the growing body of acceptance-based treatment interventions for adults with chronic pain and more recently, research that has explored psychological flexibility and acceptance as targets of change in youth with chronic pain (Wicksell et al., 2005, 2007, 2009). Consistent with data with adults with chronic pain (McCracken & Keogh, 2009), there was a strong relation found between psychological inflexibility and anxiety. This is interesting as it could be that these two measures are tapping similar phenomenon. Specifically, both involve excessive identification with and avoidance of internal events (e.g., thoughts, feelings, body sensations). As this literature is growing, it will be important to clearly operationalize the constructs to best determine how anxiety and psychological inflexibility are similar and different.

In alignment with research that cites psychological inflexibility and acceptance of pain as predictors of quality of life (Wicksell, Renofalt, Olsson, Bond, & Melin, 2008), the current study also found QOL to be predicted by both constructs, and HQOL to be predicted by psychological inflexibility alone. Being more psychologically flexible suggests a greater ability to live in the present moment and engage with life fully, which may result in an increase in one's perception of QOL and HQOL. Despite having a chronic disease such as JIA, those participants who reported lower psychological inflexibility may be able to act in alignment with chosen values and activities despite healthrelated challenges and pain. A rather surprising finding was that acceptance of pain, which is conceptually linked to psychological flexibility, was found to predict only QOL and not HQOL. Literature suggests that the construct of QOL may be determined by a person's values, whereas the construct of HQOL may sometimes emerge as an indicator of one's subjective assessment of their health (Feldman et al.,

2000). Many of the items on the pain acceptance questionnaire reflect whether or not pain interferes with one's valued activities, linking this construct more soundly to general QOL. It is also important to emphasize that psychological inflexibility and acceptance emerged as better predictors of quality of life and health-related quality of life than pain. Thus, it appears essential to focus on an individual's cognitive relationship to the pain (e.g., enhancing pain acceptance), in addition to standard pain reduction in order to enhance QOL and HQOL in youth with JIA. Further, acceptance might be more amenable to intervention than pain in this population.

In contrast, psychological inflexibility and acceptance of pain were not associated with functional disability. This is most likely due to the limited power provided by the small sample size. Based on the rich literature demonstrating that psychological inflexibility and acceptance are important constructs in adult chronic pain-related disability (McCracken et al., 2007), additional work should be conducted in this area with adolescents with JIA pain.

Some caveats should be noted when interpreting these findings. The small sample size might not have allowed detection of all relations present among the variables and indicate caution must be taken when interpreting and generalizing findings that were noted. However, the statistically significant results found reflect large effects and the overall model was demonstrated to account for a large proportion of variance across aspects of functioning; thus results might be more clinically meaningful. Another limitation is that the majority of participants were reported to have "mild" or "moderate" levels of arthritis, and although this is consistent with other studies (Stinson et al., 2008), it decreases external validity of findings. The current study relied on patient-report, and additional indices (e.g., school absences due to pain) would have provided greater confidence in the findings. Given that some of these

concepts in youth are emerging areas of study, we had to rely on relatively newer measures to quantify psychological flexibility and acceptance.

In sum, research on the role of psychological inflexibility and acceptance is a new area of study in pediatric pain, which might inform patients' resiliency and painrelated functioning. Grounded in the recent success of interventions with adolescents with chronic pain (Wicksell et al., 2007, 2009) and these preliminary findings, it might be that interventions employing strategies to increase acceptance and psychological flexibility in youth with JIA and pain are fruitful. We hope that our study may facilitate the investigation of these processes and their link to various behavioral health outcomes in order to understand and promote the wellness of youth with JIA.

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