PREDICTORS OF PAIN AND ACTIVITY LIMITATIONS
IN CHILDREN AND ADOLESCENTS WITH CHRONIC PAIN CONDITIONS

by

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Predictors of Pain and Activity Limitations in Children and Adolescents with Chronic Pain Conditions

Abstract

by

AMY S. LEWANDOWSKI

The current study tested a single predictive model to examine the longitudinal relationship between pain and activity restriction in 89 children and adolescents with recurrent headache (HA) and juvenile chronic arthritis (JCA). Data collection in the 12 month study included administration of prospective and retrospective measures of pain, activity restriction and depressive symptoms. Linear regressions and hierarchical linear modeling (HLM) were used for data analysis. Results indicated that pain intensity predicted children’s degree of restriction in daily activities over time and across measurement type. Group differences between the pain conditions emerged with HA participants reporting significantly higher levels of pain, more depressive symptoms, and greater activity restriction that those with JCA. Participants with HA reported more activity restriction in social domains whereas those with JCA reported more limitation in physically demanding activities. Contrary to hypotheses, results did not reveal uniform biases in retrospective versus prospective reports. Moreover, individual characteristics particularly age, gender, income level, depressive symptoms and pain condition did not consistently impact the strength of the relationship between pain and activity restriction.
Preliminary findings suggest that retrospective reports may be an acceptable alternative to daily diary assessment. Clinical implications and recommendations for future research are discussed.
Prevalence and Impact of Chronic Pain on Children and Adolescents

According to recent estimates, 25% of children and adolescents report chronic pain (Perquin, Hazebroek-Kampschreur, Hunfeld, Bohnen, van Suijlekom-Smit, et al., 2000). Researchers distinguish acute pain from chronic pain, which is defined as pain that is present for a minimum of three to six months (McAlpine & McGrath, 1999). Chronic pain can be accompanied by specific features including compensatory posturing, activity restrictions, and depressive symptoms (Thompson & Gustafson, 1999).

The sources, symptoms, and frequency of chronic pain in children and adolescents are diverse and vary depending on whether the pain occurs in the context of injury, illness, chronic health condition, or in the absence of any identifiable etiology (Goodman & McGrath, 1991). In children with chronic health conditions, the intensity, impact, and duration of chronic pain can also vary considerably. For example, a patient with sickle cell disease typically reports relatively infrequent but very intense pain episodes (Lemanek, Ranalli, Green, Biega & Lupia, 2003), while a child with juvenile chronic arthritis often reports more frequent (e.g. daily) but less severe pain (Rapoff, McGrath & Lindsley, 2003). Individual differences in the quality and quantity of children’s pain reports depend on pain condition severity, stress, social support and individual characteristics such as temperament and coping style (e.g. Varni, Rapoff, Waldron, Gragg, Bernstein, & Lindsley, 1996; Roth-Isigkeit, Thyen, Stoven, Schwarzenberger, & Schmucker, 2005; Walker, Smith, Garber & Claar, 2005; Koegh & Eccleston, 2006).

The high prevalence of pain and accompanying activity limitations in our society has tremendous costs to the insurance and healthcare industries, and depending on the
pain condition, many children with chronic pain need continued treatment in adulthood (Brattenberg, 2004). The financial costs including medication, insurance reimbursements and lost work productivity are estimated to be $100 billion annually in the United States alone (Stewart, Ricci, Chee, Marganstein, & Lipton, 2003). In a sample of adolescents with chronic pain in the United Kingdom, Sleed, Eccleston, Beecham, Knapp, and Jordan (2005) found that the mean yearly cost of chronic pain treatment (including direct and indirect costs) was 8,000 pounds ($15,944) per child, per year. In addition to the significant financial burden associated with pain management, inadequate pain control can place significant psychological strain on the individuals and their families. Pain and its clinically relevant consequences are associated with lower quality of life, and elevated rates of depression and anxiety in both children and adults (e.g., Hunfeld, Perquin, Duivenvoorden, Hazebroek-Kampschreur, Passchier et al., et al., 2001; Gatchel & Dersh, 2002).

Pediatric chronic pain is predominantly managed through pharmacological treatment (Gatchel, 2005). While medications such as opioids may be effective in the short term, they are often ineffective for chronic pain management (Christiaens, 2003). Psychological treatments such as relaxation training, guided imagery and biofeedback are emerging as probable efficacious treatments for pediatric chronic pain (e.g., Walco, Varni & Illowite, 1992; Ball, Shapiro, Monheim, & Weydert, 2003; Fitchtel & Larsson, 2004). However, many children and adolescents do not seek and/or do not have access to specialized pain management services. Moreover, research demonstrates that pain disrupts children and adolescents’ physical and psychological functioning in clinically relevant domains. Palermo’s (2000) review concluded that chronic pain negatively
impacts children’s social relationships, academic performance, sleep, mood, and participation in activities.

Chronic Pain Conditions in Children and Adolescents: Recurrent Headaches and Juvenile Rheumatoid Arthritis as Examples

As described above, chronic pain in childhood and adolescence can stem from both known etiologies such as injury or chronic disease, or may be due to an unknown etiology. Two examples of chronic pain conditions that impact children and adolescents and that will be included in the current research study are recurrent headaches and juvenile chronic arthritis. These conditions are among the most prevalent chronic pain conditions for this age group, and a description of each of the conditions is provided below to give the reader an understanding of the prevalence, specific symptoms, and methods of treatment for each of the conditions. The conditions were selected for inclusion and comparison in the current study because of the differing presentation of pain and activity limitations typically associated with each group.

Recurrent Headache

Recurrent headache (HA) is the most prevalent type of chronic pain in the general pediatric population, being identified by as many as 18.9% of youth (Perquin, Hazebroek-Kampschreur, Hunfeld, Bohnen, van Suijlekom-Smit, et al., 2000). The term recurrent headache refers to patients with a variety of head pain conditions including chronic daily headaches and migraines. In clinical practice, headaches are categorized according to one of four subtypes: migraine, tension, cluster, or chronic daily headache. The criteria for each subtype vary depending on the frequency, intensity and duration of the pain as well as accompanying symptoms (Martin & Elkind, 2004). For example, in
children migraine-related pain usually involves both sides of the head and is often accompanied by nausea and vomiting whereas cluster headache (the least common and often most disabling type of headache in children) involves a sharp, stabbing pain on one side of the head that lasts less than three hours. Finally tension headaches are typically described as being less severe in intensity and the pain feels like a pressing tightness in the head and can last anywhere from 30 minutes to several days (ICHD-II).

A diagnosis of chronic daily headaches can be given when a child has headaches for more that 15 days/month for a minimum of 3 months. The treatment regimen for children with recurrent headache consists mostly of medication and behavioral strategies such as relaxation training and biofeedback for pain management (McAlpine & McGrath, 1999). Reviews of treatment studies using these behavioral strategies have shown effectiveness in treating recurrent head pain in children and adolescents (Trautman, Lackschewitz, & Kroner-Herwig, 2006). For purposes of the current study, children and adolescents with head pain will be grouped into a single category termed recurrent head pain. This group is distinguished from the comparison group, the disease-related pain condition of juvenile chronic arthritis that is described below.

**Juvenile Chronic Arthritis**

Juvenile chronic arthritis (JCA) is a chronic condition that consists of three subtypes: systemic-onset JCA, polyarticular JCA, and pauciarticular JCA. Between 30,000 and 50,000 children in the United States are diagnosed with JCA (irrespective of subtype) with an incidence of 1/10,000 children (Rapoff, McGrath & Lindsley, 2003). The primary etiology of the condition relates to inflammation in children’s musculoskeletal systems, blood vessels and skin; subtypes of JCA refer to the clinical
manifestation of the disease and the number of joints affected (Rapoff et al., 2003). Most children with JCA report mild to moderate levels of pain for a mean of 4 hours per day, however, in 25-30% of children with JCA pain is described as moderate to severe and can have a significant impact on children’s participation in activities (Rapoff et al., 2003). Patients with JCA typically take daily medication such as NSAIDS (non steroidal anti-inflammatory drugs) to control their symptoms and reduce inflammation. Children with JCA may experience milder pain than children with recurrent head pain. However, due to the nature of the disease, pain in children with JCA can occur for several hours daily, potentially limiting children’s activities more frequently than recurrent head pain.

*Physiology of Chronic Pain*

While many view pain with frustration/irritation, its purpose is to protect organisms from tissue damage by activating the spinal withdrawal reflex (Blackburn-Munro & Blackburn-Munro, 2001). When the receptors in the skin sense pain, they send an “alarm” that triggers the person to react and move away from the painful stimuli. With pain related to tissue damage such as arthritis, these pain signals convey to the individual that certain areas of the body are inflamed and activity may need to be limited. Three types of sensory neurons are implicated in the transmission of chronic pain signals. These 3 types of sensory neurons (Aβ, C and Aδ) respond to different intensities of pain signals at varying speeds. For example, Aβ fibers are myelinated neurons that transmit low-intensity signals quickly, whereas C fibers are unmyelinated, much slower, and are activated by high intensity pain. The third type Aδ, send signals at medium speed but like C fibers respond to only high pain levels (Blackburn-Munro & Blackburn-Munro, 2001). Ideally while these sensory neurons are sending pain signals, the limbic system
becomes activated to release pro-inflammatory molecules to the injury site to begin the healing process (Bomholt, Harbuz, Blackburn-Munro, & Blackburn-Munro, 2004). However, when pain is chronic or tissues are disrupted for an extended period (e.g. arthritis or nerve damage) the system can be disturbed and lead to long-term changes in the way the system responds to painful stimuli. For example these resulting changes can lead to either hypo or hyperactivation of the hypothalamo-pituitary-adrenal (HPA) axis, a system important in determining how the body responds to stressors such as pain. As a result, this dysregulation in the physiological system can lead to the increased nervous system sensitivity associated with some chronic pain conditions.

*Current Theories of Chronic Pain*

Researchers have developed theories and models to describe the complex interaction of biological and psychological variables that influence the level and impact of chronic pain that patients experience. These models include the gate control theory, and the neuromatrix and biopsychosocial models of pain (Gatchel, 2005). The model that best captures the interplay between the biological, psychological and socio-contextual variables explored in this current study is the biopsychosocial model. The biopsychosocial model contends that pain involves both a nociception component, the chemical or mechanical factors that cause painful nerve sensations, as well as a perceptive or psychological component, the manner in which the pain is identified and appraised. Furthermore, the biopsychosocial model posits that a complex relationship exists between how the biological, social and psychological factors, and self-reports of pain, physical functioning and emotional distress predict activity restriction (Gatchel, 2005). Specifically, it is believed that cognitive factors (e.g. psychological functioning,
pain attribution) and coping style can impact the perception of pain, and that when combined with biological influences and social factors (e.g. stress, social support systems, culture), these variables impact the level of pain-related disability or activity restriction patients experience. Turk and Okifuji (2002) explain that it is this combination of patients’ appraisals of their pain, their biological makeup, and the reactions of others in their social environment (e.g. parents or peers) to their pain that leads to patients’ pain behavior and pain-related disability.

Supporting the biopsychosocial model in adults with chronic pain, investigators have demonstrated that psychological factors and patient beliefs regarding their ability to tolerate pain can also influence pain perceptions and pain-related disability (Gatchel, 2005). Moreover, in support of the link between psychology and biology, scientific research has shown that pain and depression share common neurobiological mechanisms, specifically the neurotransmitters serotonin and norepinephrine. Osterweis, Kleinman and Mechanic (1987) explain that changes in levels of either neurotransmitter can lead to changes in both pain and depressive symptoms. Finally, pain research in adult populations has shown that the average correlation between pain, disability and impairment is approximately 0.6. This high but imperfect correlation suggests that other factors (e.g. social and psychological variables) can have a significant impact on pain response (Gatchel, 2005).

The Relationship between Pain and Psychological Functioning in Children and Adolescents with Chronic Pain: Applying Components of the Biopsychosocial Model

Researchers have argued in support of applying the biopsychosocial model of pain to children and adolescents in order to understand how decreased psychological and
emotional functioning is associated with chronic pain in this population (Kashikar-Zuck, 2006). Specifically, chronic pain has been associated with higher reports of anxiety, depression and somatization. Elevated depressive symptoms (e.g. Kashikar-Zuck, Goldschneider, Powers, Vaught, & Hershey, 2001; Kashikar-Zuck, Vaught, Goldschneider, Graham & Miller, 2002; Margetic, Aukst-Marketic, Bilic, Jelusic & Tambic Bukovac, 2005) and high levels of anxiety (Sharff, 1997; Huang, Palmer & Forbes, 2000) have been found in children and adolescents with recurrent headache and other forms of chronic pain. For example, in a study of children and adolescents with recurrent headache and abdominal pain, over 80% of participants met criteria for a psychiatric diagnosis, most commonly depression or anxiety (Liakopoulou-Kairis, Alifieraki, Protagora, Korpa, Kondyli et al., 2002). Another study by Eccleston, Crombez, Scotford, Clinch and Connell (2004) found that 70% of adolescents with chronic pain reported elevated levels of depressive symptoms, with 30.7% reporting moderate to severely elevated symptoms. Moreover, patients who reported chronic pain had anxiety levels double that of nonclinical samples.

Varni, Rapoff, Waldron, Gragg et al. (1996) reported that children and adolescents with chronic pain demonstrated lower levels of self-esteem and more internalizing and externalizing symptoms. Higher levels of internalizing behaviors including somatization and anxiety have also been reported in both children with sickle cell disease (Thompson, Gil, Gustafson, George & Kinney, 1994) and those with various recurrent pain conditions (Vaalamo, Pulkkinen, Kinnunen, Kaprio & Rose, 2002). Moreover, adolescents with chronic pain reported higher levels of neuroticism, fear of
failure and less social acceptance compared to controls (Merlijn, Hunfeld, van der Wooden, Hazebroek-Kampschreur, Koes et al., 2003).

Although the biopsychosocial model of chronic pain is applicable to children and adolescents with chronic pain conditions, it is a generic model that does not explicate the specific factors that account for the relationship between pain, psychological functioning and activity limitations in children and adolescents with chronic pain. To address this need, the proposed study will test a new model (see Figure 1) that was informed by the larger biopsychosocial model described previously. The proposed model will focus more specifically on the individual and psychological factors that are hypothesized to impact the relationship between pain and activity limitations, specifically testing the role of age, gender, income and pain-type; such factors have been previously shown to play an important role in the relationship between pain and activity in children and adolescents.

The proposed study will enable researchers to move beyond the broad-based conceptualization of pain and activity to a more focused, in depth examination of how these factors interact over time to predict the physical and psychological functioning of children with chronic pain conditions (see the specific hypotheses and predictions of the proposed study beginning on page 26). The next section will focus on 1) the measurement of pain in children, including an examination of retrospective and prospective assessment measures, and 2) the broader impact of chronic pain on children’s and adolescents’ daily lives, especially the impact on children’s physical and psychological functioning.

*The Measurement of Chronic Pain in Children and Adolescents: General Considerations*
Accurate pain assessment and measurement are critical for a valid examination of the predictors and outcomes associated with chronic pain in children and adolescents. In order to inform treatment planning reliable and valid measurement tools are needed to assess the frequency and intensity of pain and the domains of functioning that are affected by chronic pain (Palermo, Witherspoon, Valenzuela & Drotar, 2004). Commonly used methods of pain assessment include behavioral ratings or self-report forms which can be prospective or retrospective measurement instruments (Dahlquist & Switkin, 2003).

Achieving reliable and valid pain measurement in children and adolescents poses special challenges for researchers and clinicians. Pain is a subjective experience and substantial individual differences in pain tolerance exist. For this reason, self-report of pain has a prominent role in pain assessment. However, children’s cognitive and developmental level must be taken into account. Dahlquist & Switkin (2003) have noted that children may not understand the language adults use to describe pain symptoms (e.g. frequency, intensity and duration) and may not possess the ability to articulate the pain they are experiencing.

When assessing chronic pain in pediatric populations it is important to examine the history of the pain, the frequency and intensity of pain symptoms, and the impact that pain is having on the child’s functioning (Bursch, Walco, & Zeltzer, 1998). Self-report assessment tools such as visual analogue scales (VAS), faces scales, and Likert scales are the most frequently used instruments to assess the intensity of pain (McGrath & Gillespie, 2001). These instruments ask patients to rate their pain along a numbered continuum or based on a series of pictures (e.g. Bieri, Reeve, Champion, Addicoat, &
Ziegler’s (1990) Faces Pain Scale. For the assessment of pain intensity, these single item measures are the most commonly used measurement tool (Stinson, Kavanagh, Yamada, Gill & Stevens, 2006). Structured interviews or questionnaires are also used to assess factors related to the onset and duration of pain symptoms, and the impact of pain on children’s daily lives (Dahlquist & Switkin, 2003).

Methodological Issues in Measuring Pain in Children: Comparing Prospective and Retrospective Measures

The majority of research on chronic pain in children and adolescents has utilized retrospective measures to assess pain frequency, intensity, impact and duration. Such studies have typically measured pain using a single retrospective measure which asked participants to report on their pain over the previous week, two week, or month long period. Although retrospective measures provide a global account of pain experienced by children with chronic health conditions, these measures can also be inaccurate (Gil, Shand, Fuggle, Dugan & Davies, 1997). Biases associated with retrospective reports include improper recall of pain frequency, intensity and duration and activity limitations associated with pain (Palermo & Valenzuela, 2003). For example, Van den Brink, Bandell-Hoekstra and Abu-Saad (2001) compared pain scores on a 4-week prospective pain diary versus a retrospective questionnaire in a sample of adolescents with recurrent headaches. These investigators found that retrospective reports inflated pain duration and intensity in comparison to prospective reports.

While researchers have argued that overall self-report pain assessment tools are the “gold standard” for pain assessment (McGrath & Gillespie, 2001), the data presented above suggest that a new and important research question is to compare prospective and
retrospective measures of chronic pain. Recently researchers have argued that prospective pain measurement may be a more reliable, valid, and accurate method of assessing recurrent or chronic pain in children and adolescents (Palermo & Valenzuela, 2003); an assertion resulting from the broad implications that over-inflated pain reports can have for both research and clinical practice. To the extent that retrospective pain reports are over inflated and biased, this would lead to inappropriate conclusions regarding the associations between pain and functioning, or to misleading prevalence or incidence data. In addition, clinicians often make medication and treatment recommendations based on self-report pain measures and inaccuracies can lead to overmedication for symptoms.

**Prospective Pain Diaries: a Comparison of Electronic and Paper Formats**

Prospective pain measurement can take a variety of forms but pain diaries are most commonly used to record pain-related symptoms. Palermo & Valenzuela’s (2003) review of studies that utilized pain diaries, found that prospective diaries were a more accurate method of measuring pain than retrospective measures because they reduced biased recall. Studies have used pain diaries for children with a broad range of chronic conditions, with diary periods ranging from one week to two months (Van den Brink, Bandell-Hoekstra, & Abu-Saad, 2001; Dampier, Ely, Brodecki, & Neal, 2002). Although the optimal data collection periods vary, researchers have demonstrated that a one-week pain assessment is sufficient to measure chronic pain in children (Hunfeld, van der Wouden, den Deuwaarder, van Suijlekom-Smit, & Hazebroek-Kampschreur, 1997).

One important methodological issue in prospective diary measurement is the modality through which patients report pain and disability. For example, for children and
adolescents with chronic pain, studies have employed both paper and electronic diaries. In a randomized trial that compared compliance, accuracy and completeness of electronic versus paper diaries in children and adolescents with chronic pain, Palermo, Valenzuela and Stork (2004) found that paper diaries were less complete and contained more errors and omissions compared to data gathered electronically. Moreover, Stinson, Petroz, Tait, Feldman, Streiner et al. (2006) reported that in their sample of adolescents with juvenile idiopathic arthritis, electronic pain diaries were quick and easy to use, and patients reported that they were satisfying to complete. These data highlight the potential benefits of using electronic diaries in chronic pain assessment and suggest that they may increase the accuracy and validity of prospective pain measurement. While these studies suggest the benefits of electronic over paper formats, other researchers have noted the psychometric and statistical data equivalence of electronic and paper diaries with adult populations and asserted that differences in adherence and accuracy may be a product of participants’ motivation rather than the data-collection format (Green, Rafaeli, Bolger, Shrout & Reis, 2006). The current study will include both paper and electronic diary assessment.

Importance of Assessing Functional Limitations and Activity Restriction in Children and Adolescents with Chronic Pain

Because of the important link between pain and functioning, the assessment of the broader impact of chronic pain on functional disability and activity limitations is a critical component of future research studies of children with chronic pain. Specifically, studies of activity restrictions that result from pain are needed to enable clinicians and researchers to gain a greater understanding of the impact that pain has on children’s daily
lives in a variety of contexts. The World Health Organization described the four levels of functioning that may be impacted by chronic pain conditions (WHO). These include: 1) the chronic condition or physical cause of pain, 2) the pain symptoms (e.g., pain frequency, severity, duration), 3) degree of disability or activity restriction related to pain, and 4) the level of handicap or impact on children’s social functioning. In accord with the WHO’s description of levels of functioning, Palermo (2000) noted that it is useful to conceptualize and assess pain symptoms and functioning independently, as well as the impact of pain in the broad range of contexts in which children function including school, family and social activities, and sleep. For example, while levels 1 and 2 describe the physical cause of pain and nature of pain symptoms, levels 3 and 4 describe the functional impact (WHO).

Examining each of these domains is essential in order to document the differential impact that pain has in different contexts for children with various types of pain. For example, a child with chronic headaches may report more difficulties with school absences while a child with JCA may report higher pain-related restrictions in sports-related activities. An emerging body of research has documented that children and adolescents with chronic pain conditions often report disruption in a variety of domains (Palermo, 2000); for the purposes of this study the terms “activity restriction” and “activity limitations” will be used as umbrella terms for a range of problems in physical/social functioning and functional disability.

The Relationship between Pain and Activity Limitations in Children with Chronic Pain

Similar to research with adult samples, more frequent and intense pain in children and adolescents has also been associated with greater activity limitations and more
functional disability (Konijnenberg, Uiterwaal, Kimpen, van der Hoeven, Buitelaar, & Graeff-Meeder, 2005). The specific domains of activity restriction associated with chronic pain include decreased school attendance/academic functioning, sleep disturbances and less participation in physical and social activities (e.g. Walco & Dampier, 1987; Breuner, Smith & Womack, 2004; Lynch, Kashikar-Zuck, Goldschneider & Jones, 2006). For example, Breuner et al. (2004) reported that in a retrospective study of adolescents with chronic head pain, pain was associated with a higher number of absences and poorer academic performance. Similarly, in adolescents with SCD, pain was associated with impaired physical and social functioning, poorer school performance, more frequent absences and social isolation (Walco & Dampier, 1987). Similarly, in two separate samples of children with juvenile chronic arthritis and chronic back pain, frequent pain-related school absences were common (Fowler, Johnson & Atkinson, 1985; Lynch et al., 2006).

Chronic pain also has a significant impact on children’s participation in daily activities. In children with SCD, pain has been found to affect children’s willingness to engage in a variety of physical and social activities (Huygen, Kuis & Sinnema, 2000) such as eating and doing schoolwork (Graumlich, Powers, Byars, Schwarber, Mitchell & Kalinyak, 2001). The majority (72%) of children with unexplained chronic pain reported decreased participation in sports activities. In addition, 40% reported less participation in social activities and 34% reported sleep disturbances due to pain (Konijnenberg, Uiterwaal, Kimpen, van der Hoeven, Buitelaar, & Graeff-Meeder, 2005).

Both the frequency and intensity of pain have also predicted children’s functional status and activity participation (Hunfeld, Perquin, Duivenvoorden, Hazebroek-
Kampschreur, Passchier et al., 2001). Specifically, higher frequency and intensity of pain are associated with less participation in activities and poorer functioning. For example, in adolescents with chronic headaches, pain intensity was associated with a reduction in daily activities over a one month period (Langeveld, Koot, & Passchier, 1997).

Similarly, in children and adolescents with SCD, high pain intensity was associated with the greatest levels of activity restriction (Maikler, Broome, Bailey & Lea, 2001).

Tkachuk, Cottrell, Gibson, O’Donnell and Holyrod (2003) found that duration of head pain predicted degree of activity restriction and impairment in adolescents.

*The Interrelationship between Pain, Psychological Functioning and Activity Limitations in Children and Adolescents*

As outlined above, previous research supports the application of a pediatric chronic pain-specific biopsychosocial model of pain to understand the complex relationship among pain, activity and psychological functioning in children and adolescents with chronic pain conditions. For example, Kashikar-Zuck, Goldschneider, Powers, Vaught, and Hershey (2001) found a high correlation between activity restriction (as measured by Functional Disability Inventory scores) and depression levels in children and adolescents with either chronic daily headache or musculoskeletal pain. Similarly, researchers found that adolescents with frequent headache had significantly more anxiety and depressive symptoms, and higher levels of functional disability than those with infrequent headache (Fichtel & Larsson, 2002).

Although these studies suggest that the original biopsychosocial model of pain and its prediction of the relationship between social, biological and psychological factors and functioning may be applied to children and adolescents, specific components of the
model remain untested. One critical gap in the scientific knowledge is the causal and temporal relationships between pain and activity restriction. Research suggests a strong link between psychological factors (e.g. depression) and pain (e.g. Kashikar-Zuck, Vaught, Goldschneider, Graham & Miller, 2002; Margetic, Aukst-Margetic, Bilic, Jelusic & Tambic Bukovac, 2005). However, the specific processes by which activity limitation is influenced by pain and its associated problems is not clear. Three existing models on the causal relationship between depression and pain have emerged: 1) pain leads to increased depressive symptoms, 2) pain and depressive symptoms co-occur, and 3) depressive symptoms are a consequence of chronic pain (Osterweis, Kleinman, & Mechanic, 1987). One next step critical step in research is to examine the role of pain and depression in predicting activity restriction.

Some studies have suggested that in both child and adult populations, depressive symptoms may be more affected by the level of activity limitation associated with the pain than the presence of pain alone (Ehde, Jensen, Engel, Turner, Hoffman et al., 2003). For example, it has been suggested that pain does not directly cause depression, but children’s inability to participate in activities (e.g. school, sports, social events) due to high levels of pain leads to increased depressive symptoms. In support of this hypothesis, Walters & Williamson (1999) found that in a sample of children with various chronic pain conditions, functional disability mediated the relationship between pain and depression; Lewandowski, Palermo and Peterson (2006) achieved similar findings in a sample of children aged 8-12 years with chronic headaches. In both studies, mediational models were significant for children aged 8-12 but not adolescents aged 13-16. These findings indicate that level of activity restriction plays a significant role in the
relationship between pain and depression, but that this relationship may be age-dependent.

Previous research has underscored a gap in understanding of the relationship between pain and activity limitations, specifically the potential mediators and moderators in the relationship between pain and activity limitations. For example, age, gender and type of chronic pain are potential moderators in the amount (e.g. frequency, intensity) of chronic pain that children report (e.g. Linet, Stewart, Celentano, Ziegler, & Sprecher, 1989; Perquin, Hazebroek-Kampschreur, Hunfeld, Bohnen, van Suijlekom-Smit et al., 2000). Research examining individual factors that have been previously identified to impact pain and activity restriction in children and adolescents are reviewed below.

Age and Gender Differences in Children and Adolescents with Chronic Pain

As outlined above, previous research (e.g. Walters & Williamson, 1999; Lewandowski, Palermo & Peterson, 2006) suggests that age and gender are related to significant differences in reports of pain-related symptoms and functioning, and age and gender have been identified as potentially important factors affecting the prevalence, severity, and functional impact of chronic pain on children and adolescents. For example, in a population-based sample of children and adolescents with recurrent pain Perquin, Hazebroek-Kampschreur, Hunfeld, Bohnen, van Suijlekom-Smit et al. (2000) found higher pain prevalence, increased reports of multiple pains, and higher pain intensity in females compared to males. Moreover, in chronic headache samples, the majority of studies have found increased frequency of headaches, longer duration and higher reports of pain intensity for girls as compared to boys with headache (Linet, Stewart, Celentano, Ziegler & Sprecher, 1989; Merlijn, Hunfeld, van der Wooden,
Hazebroek-Kampschreur, Koes et al., 2003) with females experiencing more disability and more frequent school absences (Martin-Herz, Smith & McMahon, 1999). Studies of chronic pain in adolescents have also demonstrated higher reports of somatic symptoms in girls (Konijnenberg, Uiterwaal, Kimpen, van der Hoeven, Buitelaar & Graeff-Meeder, 2005). Moreover, girls with musculoskeletal pain have reported higher levels of pain and had a stronger association between pain and psychosomatic symptoms than boys (El-Metwally, Salminen, Auvinen, Kautiaien & Mikkelsson, 2004). Finally, with respect to the relationship between pain and functioning, Roth-Isigkeit, Thyen, Stoven, Schwarzenberger and Schmucker (2005) found a higher prevalence of activity restriction due to pain in girls compared to boys in all participants except those between ages four and nine.

Age-related effects have also been reported in children and adolescents with chronic pain. Peterson, Brulin and Bergstrom (2006) reported that prevalence of chronic pain symptoms increases with age. Several investigators have described adolescents with headaches as having more frequent and disabling pain, more missed activities and reduced quality of life compared to younger children (e.g., Nodari, Battistella, Naccarella, & Vidi, 2002; Tkachuk, Constance, Gibson, O’Donnell, & Holrody, 2003; Powers, Patton, Hommel & Hershey, 2004). White, Alday, and Spirito (2001) also found that adolescents reported headache pain interfered more with school than did younger children. Age-related pain differences have also been reported in children and adolescents with SCD, with researchers finding that older children reported more sickle cell pain than younger children (Sporrer, Jackson, Agner et al., 1994; Connor-Warren, 1996).
Importance of Understanding Causal Influences in the Impact of Pain on Functioning

Available research suggests that activity restriction plays an important role in the relationship between pain and depression. However, a paucity of research has been done examining the temporal and causal relationship between pain and activity limitations. The examination of such causal relationships is important not only for developing scientific models but also for the development of clinical interventions for patients with chronic pain. For example, in order to develop interventions that appropriately target pain and promote increased activity levels on a daily or weekly basis, it is imperative to determine whether the relationship between pain and activity restriction is consistent both within individuals and over time, and what characteristics of the child impact this relationship.

Recently researchers have been using multilevel daily process analyses to address these gaps in the field and have begun to study the outcomes associated with chronic pain using prospective diary data. Affleck, Zaura, Tennen and Armeli (1999) have noted that multilevel daily process analyses not only utilize prospective data that allow for the “real time” examination of pain and its associated factors but they can analyze within-person variability. In addition, multilevel daily designs reduce recall bias and confounding variables, and stronger inferences regarding the sequence or causality between variables can be made (Affleck et al., 1999)

Those studies that examined chronic pain using daily assessments have demonstrated important findings in both child and adult samples. For example in a study of adults with mixed chronic pain conditions, Litcher-Kelly, Stone, Broderick and Schwartz (2004) found that changes in pain were associated in a curvilinear manner with
sensory symptoms, affective distress, and activity limitations. Specifically, pain was associated with emotional distress and activity limitations at both low and high intensities, whereas sensory symptoms were associated only at high pain intensity. Multilevel daily process studies have also begun to be conducted with children. For example, using an 8 week diary of pain, fatigue, stiffness and activities, Schanberg, Anthony, Gil and Maurin (2003) assessed the relationship between daily pain and arthritis symptoms in children and adolescents. Schanberg et al. (2003) reported that 56% of children reduced their school activities on 10% of pain days, moreover, 12% of children reduced these activities on more than 40% of the days they reported pain. Furthermore, on 20% of pain days children reduced social activities, with 12% reducing their participation on more than 40% of pain days.

Studies have also studied the lag effects of pain, using both adult and child chronic pain samples. Lag effects refer to the relationship between variables such as pain, stress and coping on the previous day, to patient reports of pain, mood and disability on the following day. In a sample of adult patients with arthritis, Affleck, Tennen, Keefe, Lefebvre, Kashikar-Zuck, et al. (1999) found that pain did not predict mood the following day for the overall sample, however, for male participants, next day’s mood was more effected than for women. In addition, researchers found that for patients with chronic arthritis, emotion focused coping predicted pain the following day. In separate studies assessing children and adults with sickle cell pain, Gil, Carson, Porter, Ready and Valrie (2003) and Gil, Carson, Porter, Scipio, Bediako, and Orringer (2004) reported lagged effects with pain one day predicting higher stress and lower mood on the following day.
In the adult sample, mood on the previous day also predicted pain reports the following day (Gil et al., 2004).

While these results provide support for the relationship between pain, stress and mood on the current day as well as lag effects, additional research needs to be conducted to further examine the relationships between daily reports of pain and disability. Prior research using daily process models has been limited by the lack of data concerning psychological functioning which is a potentially important predictor of pain and activity limitations. The need for this examination of the causal relationships between the variables stems from research and theory that suggests a strong inter-relationship between pain, depression and activity restriction (e.g. Walters & Williamson, 1999; Ehde, Jensen, Engel, Turner, Hoffman et al., 2003). Importantly it is necessary to use longitudinal prospective measures to examine how pain impacts disability, a question that will enable researchers to determine if existing models of pain, psychological functioning and activity restriction adequately capture the daily experience of children with chronic pain. For example, current models of pain and activity restriction ignore the potentially important role of how pain changes over time and that it may be differentially related to inactivity or functioning at different times or pain levels. Moreover, these analyses can help us understand clinically what subgroups of patients are at highest risk for poor outcomes. For example, do patients who report moderate levels of daily pain or those who report infrequent but severe pain that significantly disrupts functioning have the poorest outcomes? Answering these questions will enable researchers to design and tailor new clinical interventions that can help to reduce the frequency of pain episodes and set appropriate daily activity targets to maximize patient outcome.
Rationale and Value Added Impact of Proposed Study

The current study is designed both to provide clinically important data on the temporal relationship between pain and activity levels in children and adolescents with chronic pain conditions, and to contribute to the theoretical understanding of the relationship between psychological functioning, pain, and activity limitations for this population. To achieve the first aim, this study will examine pain diary data to assess the consistency between pain intensity and activity restriction both within individuals and over time, and describe potential moderators (age, gender, type of pain, income level) in the relationship. This examination will help to clearly articulate how the components of the biopsychosocial model of pain apply to children and adolescents by increasing our understanding of the temporal relationship between pain and disability.

This temporal examination is important because no prior studies have used longitudinal diary analyses to look at the individual trajectories of daily pain and activity restriction over time. Moreover, this study will add to the research literature by conducting longitudinal analyses using both prospective daily diary reports and retrospective instruments. These data are clinically important because while the original biopsychosocial model of pain (see Gatchel, 2005) has articulated the relationship between pain, activity restriction and functioning on a broad scale, it is important to describe how/if these relationships both present on a daily basis and change over time. For example, children with chronic headaches may report infrequent but highly disabling pain, whereas children with JCA may report less intense but frequent pain and greater overall activity disruption. Moreover, we could see that pain is differentially associated with activity restriction over time depending on individual characteristics such as age,
gender or depressive symptoms. These data will provide valuable information for researchers designing future clinical interventions designed to target pain and decrease the impact of activity restriction for chronic pain populations.

The second aim of this study is to test the proposed theoretical model by comparing two types of current pain assessment tools, retrospective and prospective methods. This comparison is important for researchers and clinicians involved in pain assessment to demonstrate whether the different types of measurement tools 1) similarly assess pain intensity, 2) show similar relationships between pain, psychological functioning, activity limitations, and demographic variables for children and adolescents with chronic pain conditions, and 3) comparably predict patients’ functioning, specifically activity limitations.

In order to achieve these aims, this study will test the theoretical model (see Figure 1) described previously. This model was informed by the broader biopsychosocial model, and it will be used to articulate the relationships between pain, activity restriction and psychological functioning using both prospective and retrospective measures. Specifically the model proposed in the current study hypothesizes that depressive symptoms will predict both pain and activity limitations, and that the relationship between pain and activity will be moderated by age, gender, income level and type of pain. The model will be tested using both prospective and retrospective measurements of pain and activity restriction.

This comparison will add to scientific knowledge by demonstrating what types of measures are most sensitive in capturing the impact of daily pain on children’s physical and emotional functioning. Moreover, the findings will demonstrate whether the current
conceptualization of the relationship between pain and activity restriction (a model based solely on retrospective reports) describes the daily impact of chronic pain on children. To our knowledge, only one prior study (van den Brink, Bandell-Hoeskstra & Abu-Saad, 2001) has examined the relationship between pain diaries and retrospective reports using similar methodology. However, this study has limited generalizability because of its focus exclusively on a headache sample, the failure to assess for activity limitations, and the lack of longitudinal analyses.

A final benefit of both the daily process analyses and the comparison between retrospective and prospective measures is the potential clinical utility of the findings. Results of this study can inform future intervention studies by better articulating the relationship between daily pain and daily activity limitations. Information obtained from prospective reports of pain and activity can help researchers and clinicians determine how interventions should be conceptualized/individualized (e.g. when to boost social supports, activities) and how treatments should change over time.

This study will also address limitations of previous research by including two chronic pain conditions, particularly making a distinction between pain associated with a chronic illness (JCA) versus pain that is not associated with a chronic illness (HA). Utilizing two different conditions will allow for the generalizability of pain and activity limitations across pain conditions as well as the examination of potential between group differences. Children and adolescents diagnosed with two pain conditions were selected for this study: those with recurrent headache (HA) and JCA. As described earlier in this paper, these pain conditions represent diverse chronic pain conditions and it is anticipated that they will both adequately capture a range of chronic pain-related symptoms and
behaviors, and that analyses will enable us to test whether pain and functioning are similarly related in both samples.

Hypotheses

This study includes two sets of hypotheses that will test a theoretical model (see Figure 1) based on components of the broader biopsychosocial model described by Gatchel (2005).

Daily Process Analyses. The first set of hypotheses pertains to the relationship between daily prospective pain, disability and mood ratings. Based on previous findings from studies by Schanberg, Anthony, Gil and Maurin (2003) and Shapiro, Dinges, Orne, Bauer, Reilly, Whitehouse et al. (1995) it was hypothesized (1a) that prospective pain data would predict activity limitations. Specifically, higher levels of pain would be associated with more activity limitations. Previous research literature documenting the impact of same day pain on same day activity limitations (Maikler, Broome, Bailey & Lea, 2001; Anthony, Gil & Maurin, 2003) and the strong relationship between activity restriction and pain using retrospective reports (Hunfeld, Perquin, Duivenvoorden, Hazebroek-Kampschreur, Passchier et al., 2001; Kashikar-Zuck, Goldschneider, Powers, Vaught, & Hershey, 2001) provides support for this hypothesis.

It was also hypothesized (1b) that gender, age, income and pain condition-related differences would emerge. Specifically, children and adolescents with HA would show a stronger relationship between daily pain and activity restriction than participants with JCA. This hypothesis is based on the fact that by nature HA pain is typically more intense than JCA-related pain, and researchers using prospective data (e.g. Schanberg, Anthony, Gil and Maurin, 2003) have reported that the majority of children with JCA
reduced their activity on only 10% of pain days. Thus for children with JCA, pain may be less directly associated with activity restriction than for children with HA. Data indicating showing age, gender and income level related differences in studies of pain and activity limitations (e.g. Andrasik, Kabela, Quinn, Attanasio, Blanchard, & Rosenblum, 1988; Martin-Herz et al., 1999; Perquin, Hazebroek-Kampschreur, Hunfeld, Bohnen, van Suijlekom-Smit. et al., 2000; El-Metwally, Salminen, Auvinen, Kautiaien & Mikkelsson, 2004, Powers, Patton, Hommell, & Hershey, 2004) support the hypothesis that these variables would impact the relationship between daily pain and activity restriction in the current study.

Finally, hypothesis 1c proposed that children with higher depressive symptoms would have a stronger relationship between daily pain and activity restriction, and specifically that depressive symptoms would interact with pain to predict higher levels of daily activity limitation. This hypothesis is based on research showing that depressive symptoms play a role in how children respond to pain, and that increased depressive symptoms are significantly associated with increased activity limitations in child and adult samples (e.g. Walters & Williamson, 1999; Ehde, Jensen, Engel, Turner, Hoffman et al., 2003).

Comparison of Prospective and Retrospective Reports. The second set of hypotheses pertain to the relationship between reports of depressive symptoms, pain and activity limitations. First it was hypothesized (2a) that using both prospective and retrospective measures, depressive symptoms would predict pain intensity, and both depressive symptoms and pain intensity would predict activity restriction. Specifically it
was expected that more depressive symptoms and higher levels of pain would be associated with greater limitation in activities.

Hypothesis 2b posited that in prospective and retrospective reports, age, sex, pain condition, and income would moderate the relationship between pain and activity limitations. The age/gender hypotheses are based on data (as reported above) that show higher levels of pain, somatic symptoms and activity limitations in females compared to males, and for older children and adolescents compared to younger children. Because preliminary studies have shown a relationship between income level and activity restriction (e.g. Hoff, Palermo, Schluchter, Zebracki, & Drotar, 2006) hypothesis 2b also proposed that lower income levels would be associated with reports of higher pain intensity and activity limitations, and that income level would moderate the relationship between pain intensity and activity restriction on both prospective and retrospective reports. In addition, because research that has shown that children with HA report more intense levels of pain than other pain conditions it was hypothesized (2b) that children with HA would report higher levels of pain on both prospective and retrospective reports.

Moreover, it was hypothesized (2c) that participants who reported high levels of daily pain and activity restriction on prospective measures would also report higher levels of overall pain and activity limitations on retrospective measures. This hypothesis was based on prior studies utilizing the retrospective measures that have found that self-reports of pain predicted activity limitations (see Lewandowski, Palermo & Peterson, 2006; Hoff, Palermo, Schluchter, Zebracki, & Drotar, in press). However, while the relationship between prospective and retrospective measures was expected to be similar, based on data demonstrating bias associated with retrospective recall (Gil, Shand, Fuggle,
Dugan & Davies, 1997; Van den Brink, Bandell-Hoekstra and Abu-Saad, 2001), it was predicted that prospective measures would have lower means (showing less inflation) and greater standard deviations (demonstrating increased sensitivity).

Method

Participants

Data were gathered as a part of a larger study examining the longitudinal impact of chronic pain on the physical and psychological functioning of children and adolescents. The sample consisted of 89 children and adolescents recruited at a baseline clinic visit and who were diagnosed with recurrent headaches (HA) or juvenile chronic arthritis (JCA), with 69.7% of the total participants being female. At baseline, participants were 8-16 years old with a mean age of 12.5 years (SD=2.48), and the majority of families who participated in the study were Caucasian (80.9%) (see Table 2). The twelve month follow-up consisted of 68 participants; 21 children and adolescents who participated in the first phase of the study declined to participate or were unable to be contacted for the follow up phase. Participants who dropped out of the study did not differ from those who did not drop out on any of the demographic variables (e.g. age, gender, income level) or levels of pain, depressive symptoms or activity restriction at baseline.

Procedure

At baseline, participants were recruited from pediatric specialty clinics at a children’s hospital in a large Midwestern city. Children were eligible for participation if they were between 8 and 16 years old and were diagnosed with recurrent headaches or juvenile chronic arthritis. Participants were excluded from the study if they were not
between 8-16 years of age, were currently using any psychotropic medications, did not speak English or had a comorbid chronic health condition. After obtaining informed consent, self-report retrospective questionnaires were administered by a trained research assistant during the participants’ clinic visits. After completing the in-clinic questionnaires, participants were given prospective diaries to complete at home during the week that immediately followed their clinic appointment. The diary questionnaire assessed daily pain and activity limitations. Identical data collection procedures were used at the 12 month follow-up. At 6 months, diary data-only was collected to increase the amount of prospective data available for analysis. The rate of participation in the study at baseline was approximately 94%, and the primary reason for refusal was the time involved in completing questionnaires. Families received a $30 gift card at each data collection time point as compensation for their participation.

**Schedule for Administration of Measures**

See Figure 2 for a schematic representation of the study procedures and the descriptions of measures administered at each time point.

*Retrospective Data.* Retrospective measures asking participants to report on average pain intensity, activity limitations during the previous 4 weeks, and a demographics questionnaire were collected during the participants’ baseline and 12 month clinic visits. Retrospective assessments of depressive symptoms and physician ratings of pain condition severity were assessed only at baseline.

*Prospective Data.* Prospective diaries that assessed pain intensity and activity limitations due to pain were distributed during clinic visits. Participants were instructed to complete the diary daily for a one week period following their clinic appointments and
were asked to return the diary to the investigators via mail. The majority of participants completed paper diaries with a subset of 29 participants using an electronic PDA device at one or more time points in the study. Due to the small number of participants who completed electronic diaries and because mode of participation was not a focus of this study, differences between paper versus electronic diaries were not examined.

**Predictors**

*Depressive Symptoms.* Children and adolescents completed the Revised Child Anxiety and Depression Scale (RCADS; Chorpita, Yim, Moffit, Umemoto, & Francis, 2000) at baseline. The major depressive disorder (MDD) subscale was used to assess participants’ depressive symptoms. T-scores are calculated based on child gender and grade in school. This measure has demonstrated good internal consistency (alpha = 0.77 for the MDD subscale) and adequate one-week test-retest reliability. Validity has previously been established through relationships with other depression measures (Chorpita et al., 2000). The reliability coefficient alpha calculated for the current sample was 0.72.

*Pain Intensity.* Pain intensity was assessed retrospectively using the Faces Pain Scale that was administered at baseline and twelve months. The scale asked participants to report on pain intensity over the previous four weeks, and included a series of seven faces with anchors at the two ends representing “no pain” to “worst pain” (Bieri, Reeve, Champion, Addicoat, & Ziegler, 1990). Prospective reports of pain intensity were also collected using a diary-report version of the Faces Pain Scale. The diary report version asked participants to report on their level of pain intensity daily for a one-week time period that began following both their clinic appointments. The Faces Pain Scale has
demonstrated reliability and validity for prospective and retrospective pain assessment in similar samples (Reid, Gilbert & McGrath, 1998) and it has been shown to be the most psychometrically sound measure for assessing pain intensity in school-aged samples (Stinson, Kavanagh, Yamada, Gill & Stevens, 2006).

**Outcome Measures**

*Activity Limitations.* The Children’s Activity Limitations Interview (CALI) (Palermo, Witherspoon, Valenzuela & Drotar, 2004) was used to assess pain-related activity limitations. The measure has two formats, a prospective and a retrospective-report version, both of which were used in the current study. The retrospective version asks participants to report on 21 activity limitations in a variety of domains over the previous 4 weeks. The prospective report is a diary report of the 8 most difficult limitations identified by children. Children rate difficulty in completing each activity on a 5 point scale, ranging from 0 ‘not difficult’ to 4 ‘extremely difficult’. Children completed the prospective measure daily over a 1-week period following their clinic appointments. The CALI has demonstrated reliability and validity in assessing pain related activity limitation in school aged children and adolescents (Palermo et al., 2004). The reliability in the current sample was 0.87.

**Other Measures**

*Caregiver Information Form.* The participants’ caregivers completed a basic demographic form, which provided information on the child’s age, race, gender, family income level, and parent work status.
Physician Rating of Condition Severity. Physician rating of condition severity was assessed by a form completed by the child or adolescents’ subspecialty physician at their baseline clinic appointment. Physicians were blind to participant self-reports of pain, activity restriction and depressive symptoms. The measures also included questions on the child’s condition classification, medication and treatment regimen, and the physician’s perception of condition severity. The severity form was a condition specific 10 cm visual analogue scale with the anchors at the two ends labeled ‘not severe at all’ to ‘extremely severe.’ Similar measures of condition severity have also been used in other studies with children and adolescents with chronic health conditions (Ravelli, Viola, Ruperto, Corsi, Ballardini et al., 1997).

Plan for Statistical Analyses

Summary statistics were used to describe the demographic characteristics of the sample. Means and standard deviations were used for continuous data, and categorical items were described using frequency statistics. T-tests and chi-square analyses were conducted to determine whether there were any significant effects of age, gender, pain condition, or income level on pain intensity, depressive symptoms or activity limitations. Moreover, Pearson product moment correlations and regressions were used to assess the relationship between demographic characteristics and predictor and outcome variables.

Multi-level modeling was used to analyze the prospective diary data. Hierarchical Linear Modeling (HLM) is a type of multi-level modeling that enables researchers to concurrently examine the roles of time and individual factors in predicting the relationship between two variables. HLM assesses whether the level of association between the constructs is accounted for more by individual level characteristics (e.g.
pain-type, level of depressive symptoms, age) or variability across participants (longitudinal pain trajectories), and enables one to see the temporal relationship between variables (e.g., pain and activity limitations) over time. Data analysis was conducted using both Hierarchical Linear Modeling Version 6.0 (HLM 6) and the Statistical Package for the Social Sciences Version 13.0 (SPSS 13.0). Significance levels were set at p<.05.

Results

*Descriptive Data: Prospective Measures*

On prospective diary-report measures, participants completed an average of 14.26 days (SD = 5.71) of diary report data over the 21 day data collection period. Data from a total of 1091 diary days was used in the analyses. Average pain intensity and activity limitation were calculated by taking the average of all the pain scores across each participant’s diary data. On the prospective measures, participants reported low to moderate average pain intensity (M=3.04, SD=1.07, range 1.29-6.17) and average activity limitation on the diary report data was moderate (M = 13.76, SD=6.49, range 8-43) (See Table 3). On the FACES pain scale, a pain rating of 3-4 is considered to be clinically significant pain (Stinson, Kavanagh, Yamada, Gill & Stevens, 2006). Independent sample t-tests were used to examine group differences on predictor and outcome variables on the prospective measures. There were no differences in average pain intensity (t = 1.53 (83), p= n.s.) or activity restriction (t = .15 (76), p= n.s.) between the two groups.

*Baseline Descriptive Data: Retrospective Measures*
Means and Standard Deviations. For the total sample, the average level of pain intensity at baseline was 4.52 (SD=1.49, range = 1-7) indicating children and adolescents were reporting moderate levels of pain on retrospective reports. As a group, participants reported low levels of depressive symptoms (MDD total score) (M=7.88, SD=4.63, range = 0-19) overall. However, prior research has demonstrated that T-scores of 11+ can be used as a clinical cut-off for depression (Chorpita, Moffitt, & Gray, 2005) and in the current sample, 25 participants (28.1% of total sample) met this criterion (21 = HA, 4 = JCA).

At baseline, summary scores on the CALI suggested moderate amounts of activity limitation (M=14.47, SD=7.52, range= 0 – 30) (see Table 3). Significant correlations between baseline activity limitations and both pain intensity (r = .50, p<.001) and depressive symptoms (r = .44, p <.001) emerged, with higher levels of activity restriction associated with greater pain and more depressive symptoms (see Table 4). In terms of frequency, the total sample of children and adolescents identified gym, schoolwork, sports, running, ability to participate in after school practice, housework, reading and playing with friends as the activities most impacted by pain during the last 4 weeks. When asked to identify the most difficult activities in the last 4 weeks participants rated (in order) running, sports, gym, attending after school practice, schoolwork, staying up all day, reading and completing chores.

Tests of Group Differences. Independent samples t-tests, the Mann-Whitney U test, and chi-square were used to examine group differences between demographic, predictor and outcome variables on the retrospective measures. Independent samples t-tests revealed no significant age differences between the two pain conditions. Chi-square
analyses revealed significant gender differences ($\chi^2 (1, N = 89) = 7.52, p < 0.01$) with the JCA group consisting of significantly fewer males than the HA group. Using Chi-square, no group differences on racial background nor parent/guardian marital status were found. A two-tailed Mann-Whitney U test was conducted to evaluate whether the pain conditions differed in income level. No significant group differences on income level emerged between the two groups (U = 671.0, p = .074) indicating participants with HA and JCA were of similar socio-economic status.

Using an independent samples t-test there was a significant difference in depressive symptoms (MDD total score) between participants with recurrent HA and JCA ($t = 3.04 (74), p < .01$), with the HA group reporting higher levels of depressive symptoms. Groups also differed significantly in reports of both pain ($t = 5.13 (86), p < .001$) and activity limitations (total CALI score) at baseline ($t = 2.53 (79), p < .05$) with participants with recurrent HA reporting more pain and activity restriction than those diagnosed with JCA. In terms of specific activities, significant differences between HA and JCA groups emerged. HA participants reported significantly greater activity restriction ($p < .05$) on school attendance, reading, schoolwork, playing with friends, watching television, doing chores, doing activities with friends, eating meals, riding in a bus/car, sleeping, and staying awake all day. In comparison, JCA participants reported significantly more restriction in tasks that involved more vigorous activity including sports, running, climbing stairs, walking 1-2 blocks, and riding a bike ($p < .05$).

12 Month Follow-up Descriptive Data: Retrospective Measures

Means, Correlations and Tests of Group Differences. At 12 months, the average level of pain intensity was 2.41 (SD=1.21, range = 1-4) and the average activity
restriction was 5.97 (SD=6.31, range = 0-23). Comparing baseline and 12 month data revealed significant declines in both pain intensity and activity restriction reported at the two time points (p<.001) (see Table 3). In addition, the correlations between both pain intensity (r = .38, p<.01) and activity restriction remained significant at 12 months. In contrast to findings at baseline, no significant relationship between activity level and depressive symptoms (r = .13, p = n.s.) nor pain intensity and depressive symptoms (r = .06, p = n.s.) at 12 months emerged (see Table 4). T-tests were conducted to examine differences in pain intensity and activity limitations between participants with HA and JCA. There were no group differences in activity limitations at the 12 month follow-up, however participants with HA continued to report significantly higher pain intensity (t = 2.36 (56), p < .05) compared to children with JCA.

Tests of Hypotheses

Multilevel Random Effects Models with Prospective Data. To test the first set of hypotheses, the prospective diary data were analyzed using Hierarchical Linear Modeling (HLM). The prospective diary data were collected over 3 one-week time periods during the course of the yearlong study. For the current analyses, all diary data points from each participant were combined and assessed as a single trajectory for each participant. Using an approach described by Affleck, Zaura, Tennen and Armeli (1999) and Schwartz & Stone (1998), HLM was used to examine the relationship between daily reports of pain and activity restriction. Specifically an autoregressive error structure was used to account for differences across time in the longitudinal data (autoregressive error assumes that the correlation between data points decreases as time between points increases). In addition,
robust fixed effects results were used to protect against model misspecification which can underestimate standard error (Schwartz & Stone, 1998).

Based on recommendations by Schwartz & Stone (1998), for each predictor a person-centered predictor and a between person predictor were created. This process ensures that between person variance is not correlated with the between person factor. In addition, it ensures that the within-person effect is not biased by treating the intercept as a random factor. In the current study the main effect of pain intensity on activity restriction was examined first. In HLM models these variables are entered on level one and labeled as within person factors. Next, using series of separate multilevel random effects models, age, gender, depressive symptoms, income and pain condition were entered on level two to test if they had any impact on the relationship between pain and activity level. The multilevel model was fit assuming the first order autoregressive error structure. This model allows the within-person correlation of the repeated measures to be a function of the time between observations. To protect against misspecification of the error structure, robust standard errors of the regression coefficients were estimated.

The outcome variable activity restriction was calculated in two ways 1) using the average of the activity limitation data reported across each day in the diary collection period, and 2) using the peak level of activity restriction reported each day. Peak restriction was determined by using the highest level of restriction reported on one of the eight activities children were asked to monitor. For the total sample, peak activity restriction ($M = 2.21$, $SD = 1.26$) was higher that average activity restriction ($M = 1.55$, $SD = .75$). However, the correlation between the variables was extremely high ($r = .86$, $p$
45

<.001) indicating that separate analyses with the two variables would be redundant. As a result, only average activity restriction was used in subsequent analyses.

**Intensity as a Predictor of Activity Restriction.** In support of hypothesis 1a that hypothesized that prospective pain data would predict activity limitations (with higher levels of pain associated with more activity limitations), the HLM models indicated that pain intensity was a significant predictor of average activity restriction (t = 4.30, p <.001) and that the effect of pain intensity on activity level varied by age (t = 2.14, p <.05) and gender (t = 4.64, p <.001) with females and older participants showing a stronger relationship between pain intensity and activity restriction (see Table 5). Contrary to hypothesis 1b and 1c, when entered into the model pain condition, income and depressive symptoms were not significant covariates indicating that type of pain condition, income and level of depressive symptoms did not impact the daily relationship between pain intensity and activity restriction.

To test for interaction effects, new variables were created using the 2-way products of age and gender and the predictor variables. The predictors and these new interaction terms were entered in separate models with age and gender to determine their added role in impacting the relationship between pain intensity and average activity restriction. A significant interaction for age x depressive symptoms was found demonstrating the moderating effect of age and depressive symptoms on the association between pain intensity and activity limitations (t = -2.32, p <.05) and indicating that this relationship was more pronounced at lower levels of depressive symptoms than at higher levels. Also, the association (i.e., slope) between pain intensity and activity limitations
was greater in older compared to younger children when their depressive symptoms were lower.

HLM analyses also revealed a significant age x income interaction. Together age and income had a moderating effect on the relationship between pain intensity and income level \((t = 1.98, p<.05)\) indicating that the relationship is stronger when income is high (see Table 5). In addition, the association between pain intensity and activity restriction was higher for adolescents compared to children when income levels are higher.

*Analyses Comparing Prospective and Retrospective Data*

To test hypotheses 2a – 2c both prospective and retrospective data were analyzed using linear regression analyses. Hypothesis 2a proposed that using both prospective and retrospective data, depressive symptoms would predict pain intensity and similarly that pain intensity and depressive symptoms would predict activity limitations. Participants’ age, gender, pain condition and income were tested as covariates in both models. To reduce multicollinearity among predictor and outcome variables, continuous predictor variables were centered around zero and dichotomous variables were recoded (Rose, Holmbeck, Coakley & Franks, 2004). New variables were created using the 2-way products of the centered and dichotomous variables to test for interactions (Rose et al., 2004). The same regression model was used for both prospective and retrospective analyses.

To test hypotheses 2b- 2c, analyses examined the association between the daily prospective assessments of pain and activity limitations and the retrospective assessments. Hypotheses 2b – 2c proposed that regression pathways would be significant
using prospective and retrospective data, illustrating that the overall model tested would fit both types of data. Based on findings from van den Brink, Bandell-Hoesktra & Abu-Saad’s (2001) study, it was hypothesized that there would be significant, but low to moderate correlations between prospective and retrospective reports. However, hypothesis 2b also proposed that 1) the prospective analyses would show greater variability (larger ranges and standard deviations) in participants’ daily pain and activity showing that they are more sensitive to daily fluctuations in pain than retrospective assessment tools, and 2) that reports of pain and activity would be lower on the prospective measures because they would be less subject to inflation bias previously demonstrated in retrospective recall (Gil, Shand, Fuggle, Dugan & Davies, 1997; Van den Brink, Bandell-Hoekstra and Abu-Saad, 2001). Finally regressions were used to test Hypothesis 2c that children with HA would report higher levels of pain on both prospective and retrospective reports compared to those with JCA.

Linear Regression Analyses of Retrospective Data

*Pain Intensity.* Linear regressions tested the hypotheses (2a) that participants’ depressive symptoms would predict pain intensity, and this relationship would be impacted by the child’s age, gender, pain condition, and family income. To control for its effects, condition severity was entered on the first step of the regression model followed by MDD total score. Age, gender, pain condition, and income were entered on the third step, followed by the interaction terms on the final step. Separate regressions using the same model were conducted for reports collected at baseline and 12 months. As hypothesized (Hypothesis 2a), linear regressions indicated that at baseline depressive symptoms (B = .109, p < .01) predicted pain intensity, with higher depressive symptoms
associated with more pain. Furthermore, after controlling for depressive symptoms pain condition predicted pain intensity ($B = -.943, p < .05$). Hypothesis 2b was not supported and significant main effects for relationships between pain intensity and age, gender, pain condition, and income at baseline did not emerge. However, the interaction between age and pain condition approached significance ($B = -.272, p = .052$) with a trend for younger children showing a stronger relationship between pain condition and level of pain intensity.

As hypothesized (2b), at the 12 month follow-up gender ($B = -1.08, p < .01$) and family income ($B = .216, p < .05$) predicted pain intensity at 12 months. The role of pain condition as a predictor approached significance ($B = -.713, p < .07$). Moreover the interactions between depressive symptoms and income ($B = .035, p < .05$) and gender and income were significant ($B = -.403, p<.05$). The interaction between income and depressive symptoms indicates that at low income levels, there was a stronger relationship between pain intensity and depression than at higher income levels. The interaction between gender and income indicates that the relationship between income level and pain intensity is stronger for males than for females. Contrary to hypotheses, depressive symptoms, pain condition and age failed to emerge as significant main effect predictors (see Table 6).

**Activity Restriction.** Linear regressions tested the hypotheses that pain intensity and baseline depressive symptoms would predict activity restriction at both baseline and 12 months. To control for its effects, pain condition severity was entered first followed by pain intensity and depressive symptoms on the first step, age, gender, pain condition, and family income on the second step, and the interaction terms on the final step of the
regression model. Results indicated that as hypothesized (2a), baseline pain intensity (B = 1.77, p < .01), and depressive symptoms (B = .47, p < .05) predicted baseline activity restriction, with higher levels of pain and more depressive symptoms associated with greater levels of activity restriction. Neither age, gender, pain condition nor income emerged as a significant predictor of baseline activity restriction. However, the interaction between income and depressive symptoms (B = .207, p < .05) was significant indicating that the relationship between depressive symptoms and activity was stronger for participants with higher income levels (see Table 3). Regression analyses were repeated using the same model with data collected at the 12 month follow-up. Analyses using pain intensity as a predictor of activity restriction at 12 months approached significance (B = 1.42, p = .055) (see Table 7).

**Correlational Analyses Comparing Prospective and Retrospective Reports**

In support of hypothesis 2b, the findings from the regression models presented above showed that depressive symptoms and pain intensity similarly predicted activity limitation using both prospective and retrospective measures. Furthermore, correlations between the reports of pain intensity were significant, with pain on the prospective measures significantly related to retrospective reports of pain intensity at baseline (r = .35, p < .01) and at the 12 month follow-up (r = .33, p < .05). Similarly, reports of activity restriction on the prospective measures were significantly related to retrospective reports of activity restriction at baseline (r = .32, p < .01) and at the 12 month follow-up (r = .28, p < .05) (see Table 4). As hypothesized (2c), average pain intensity on the prospective report measures (M = 3.04, SD = 1.67) was significantly lower than the pain intensity on
the retrospective measures (M = 4.52, SD = 1.49) at baseline (p<.001). Comparisons between prospective pain and 12 month retrospective data failed to reach significance.

In terms of activity restriction, average prospective activity restriction was significantly correlated with retrospective reports at both baseline (r = .35, p<.01) and 12 months (r = .29, p<.05) (see Table 4). Contrary to hypothesis 2c, average prospective activity restriction (M = 13.78, SD = 6.49) was not uniformly different from retrospective activity restriction, with values obtained lying between baseline (M = 14.47, SD = 7.52) and 12 month (M = 5.97, SD = 6.31) reports; moreover, contrary to hypothesis 2c the variance in the prospective reports was not greater than that in the retrospective data. However, in support of the hypotheses participants using prospective measures reported a higher range of activity restriction scores, with 5 points greater variability than at baseline, and 12 points greater than at the 12 month follow-up.

The Hotelling-Williams test (Steiger, 1980) was used to test hypothesis 2c that hypothesized that 1) correlations between prospective and retrospective measures and the predictors would be significantly different and 2) that the correlations using the prospective measures would be stronger. Only significant correlations were used for these post-hoc analyses. Contrary to the hypothesis, results of the Hotelling-Williams test did not reveal significant differences between correlations of prospective and retrospective pain intensity and depressive symptoms (t=.12, p=n.s.). In addition, no significant differences between correlations of prospective and retrospective activity restriction and depressive symptoms (t=.76, p=n.s.) emerged.

Linear Regression Analyses Testing Model using Prospective and Retrospective Measures
To further test hypothesis 2b that prospective pain intensity and activity restriction would be associated with the same predictors and covariates as retrospective measures, linear regressions were used to test the role of depressive symptoms, age, gender, pain condition, and income in predicting prospective pain and prospective activity restriction. The pain and activity restriction variables used in the regression analyses were obtained by calculating the average level of pain and activity restriction reported by each participant across all of their diary days. Baseline depressive symptoms emerged as the only significant predictor of average prospective pain intensity (B = .088 < .01), with higher depressive symptoms associated with higher pain intensity (see Table 6). Similar to the baseline retrospective measures, pain intensity was significantly associated with activity restriction on the prospective diary report (B = 1.79, p < .05) (see Table 7) with higher pain intensity associated with greater activity restriction. Neither of the other hypothesized main effects nor interactions between the predictors was significant in predicting pain or activity restriction.

Discussion

Findings from the current study supported our hypotheses that the level of pain intensity reported by children and adolescents with HA and JCA predicted their degree of restriction in daily activities. This relationship was consistent both over the course of the 12 month study and across measurement type, showing that the significant association between pain and activity level remains consistent both within individuals and over time. This finding extends predominantly retrospective, cross-sectional research that has found pain predicts activity restriction in children and adolescents with chronic pain conditions (e.g., Breuner, Smith & Womack, 2004; Konijnenberg, Uiterwaal, Kimpen, van der
Hoeven, Buitelaar, & Graeff-Meeder, 2005). However, showing this relationship using both diary and retrospective data within a longitudinal prospective design illustrates that while pain and activity levels fluctuate within individuals over time, the association between pain and activity in both pain conditions remained significant.

This finding is important because it demonstrates that the relationship between pain and activity remains significant at different levels of pain. For example, activity restriction was not only related to pain intensity when levels are high, but also when pain was low. This demonstrates that even at low pain levels, chronic pain conditions impact children’s daily functioning in a variety of activities (e.g. sports, school, socialization with friends). In support of our hypotheses, this finding was significant for participants with both HA and JCA indicating that despite being different types of pain conditions (illness-related versus non illness-related) pain intensity acts as a similar predictor for both groups, and that the impact of pain on children’s functioning is generalizable across these chronic pain conditions.

Similar findings regarding the relationship between different levels of pain and activity have been reported in both child and adult samples. For example Litcher-Kelly, Stone, Broderick & Schwartz (2004) reported that at both high and low levels, pain impacted overall activity level. However, other studies have indicated that activity limitations are not universal and certain domains of activity restriction are more impacted by pain levels than others. For example, Maikler, Broome, Bailey and Lea (2001) found that children decreased participation in all activities (school, play, sports, social) when pain was high however they were able to maintain school attendance and social activities when pain levels were low. In conjunction with the findings from the current study this
data suggests that more research is needed to elucidate how different levels of pain are related to specific activity limitations.

In addition to supporting our hypotheses that pain intensity consistently predicted activity restriction within this sample, findings revealed that as hypothesized, individual characteristics (e.g. age, gender, depressive symptoms) influenced the relationship between the variables. Although findings supported general predictions posited by our model (see Figure 1), particularly the role of pain intensity as a predictor of activity restriction, the specific roles of age, gender, income, depressive symptoms and pain condition as covariates in this relationship were less clear, and in part depended on the time point data were collected. For example, in support of our hypotheses depressive symptoms significantly predicted activity level at baseline, however, main effects at 12 months and analyses using prospective diary data were not significant.

The failure of depressive symptoms to emerge as a consistent predictor could be due to several reasons. First depressive symptoms were assessed only at baseline, while pain intensity and activity restriction were measured at both baseline and 12 months. Because of the significant correlations between depressive symptoms and both pain intensity and activity restriction at baseline, it is likely that depressive symptoms would have also decreased at the 12 month follow-up. In addition, the smaller sample size at 12 months (due to attrition) may have affected the ability to detect significant effects. A priori effect size calculations indicated that the sample size of 89 at baseline was sufficient to detect a medium effect. However, with only 68 participants at the 12 month follow-up, the likelihood of detecting a medium effect was significantly reduced.
It is also possible that depressive symptoms did not emerge as a consistent predictor of activity restriction because depressive symptoms may be more important in influencing activity restriction in the short term compared to the long term. For example, elevated depressive symptoms one day may impact activity restriction that day however the relationship between depressive symptoms and activity level over time may be less powerful. Over time other factors (e.g., social stressors, physical health, or changes in peer/family interactions) could emerge and potentially influence both the level of depressive symptoms that children report and the relationship between depressive symptoms and activity restriction. To better clarify this relationship, future prospective diary assessment should include daily assessments of depressive symptoms along with daily measures of pain intensity and activity restriction.

Although contrary to hypotheses, depressive symptoms did not emerge as a main effect in prospective diary data, results using hierarchical linear modeling analyses demonstrated that depressive symptoms interacted with age in predicting the relationship between daily pain and activity level. This finding supports previous research indicating that the relationship between depressive symptoms and activity restriction is complex and that multiple individual characteristics including age and psychological functioning can impact children’s response to pain (Walters & Williamson, 1999; Ehde, Jensen, Engel, Turner, Hoffman et al., 2003). Moreover, it suggests that children’s levels of depressive symptoms do not uniformly impact their pain-related activity restriction, and that certain subgroups of children may be more impacted by depressive symptoms than others. To further clarify the role of individual differences in this relationship, studies examining additional variables such as a children’s coping skills (e.g. adaptive versus maladaptive
coping, role of catastrophizing/internalizing), temperamental characteristics (e.g. activity level, adaptability, sensitivity, mood), and levels of social support are warranted (e.g. Wallace, 1989; Schechter, Bernstein, Beck, Hart, & Scherzer, 1991; Koegh, & Eccleston, 2006; Lynch, Kashikar-Zuck, Goldschneider, & Jones, 2007). These data can both build upon our current understanding of predictors and causal responses to pain, and help us to create new models that explicate these relationships.

Contrary to our hypotheses, income, pain condition, age and gender all failed to consistently emerge as significant main effects in predicting activity restriction on prospective and retrospective reports. However, similar to depressive symptoms and age, interactions between these variables were significant suggesting that the relationship between individual characteristics, pain and activity restriction is complex. Specifically, analyses of diary data indicated that both age and gender interacted with pain intensity to predict activity restriction, with older children and females showing the strongest relationship between level of pain intensity and degree of activity limitations. These findings corroborate previous retrospective research with chronic pain samples that have documented age and gender differences in children with chronic pain conditions (Perquin, Hazebroek-Kampeschreur, Hunfeld, Bohnen, van Suijlekom-Smit, et al., 2000; Roth-Isigkeit, Thyen, Stoven, Schwarzenberger, & Schmucker, 2005). Moreover, results suggest that specific subgroups (e.g. older adolescent females) may be at highest risk for pain-related disability, and that the characteristics of the child and/or family (e.g., depressive symptoms, income level) can play an important role in how pain impacts activity level. The finding that individual characteristics play a role in level of pain and activity restriction reported by children and adolescents is not new, however, findings
from the current study demonstrated these significant relationships for the first time using prospective longitudinal data.

One explanation for the age-dependent findings in the relationship between pain and activity level is the developmental differences in children’s cognitive ability, coping, and autonomy and independence. For older children, pain reports were not only higher but pain may be perceived as imposing greater limitations on their ability to participate in activities because they expect more independence. This explanation is supported by data from studies (e.g. White, Alday, and Spirito, 2001; Nodari, Battistella, Naccarella, & Vidi, 2002; Powers, Patton, Hommell & Hershey, 2004; Tkachuk, Constance, Gibson, O’Donnell, & Holrody, 2003) that indicate adolescents with chronic pain report more missed school, greater disruption in activities, and lower quality of life compared to younger children.

The second aim of this study tested a single model (see Figure 1) to compare the predictive power of prospective and retrospective measures in assessing pain and activity restriction. Results indicated that the single model functioned similarly using both prospective and retrospective assessment tools. As hypothesized, depressive symptoms predicted pain, and pain predicted activity restriction using both types of assessment measures demonstrating that the relationships are not dependent on assessment type. However, contrary to our hypotheses, baseline and 12-month data were not uniformly inflated compared to prospective diary reports. While the hypothesis that retrospective reports of pain and disability would be higher on retrospective measures was supported with significantly higher levels of pain at baseline, this was not true at the 12-month follow up for either pain or activity restriction.
The failure to find a uniform inflation bias in retrospective versus prospective measures is potentially reassuring given that the majority of data collected for research studies and clinical purposes uses retrospective assessment measures. The results from the current study suggest that while prospective measures are a useful tool for collecting accurate pain and activity-related data, retrospective tools do a comparable job in assessment and predicting depressive symptoms and activity restriction. Moreover, while diary data can allow for the examination of daily fluctuations in pain levels, such methods are much more costly, labor intensive and often not feasible given the time or financial restrictions of the clinic or research setting. Given the limited sample size and use of only HA and JCA groups in this study this preliminary finding needs to be replicated, however tentatively it suggests that retrospective measures may be an appropriate alternative to more labor intensive diary measures when assessing pain and activity restriction.

It should be noted that although biases for prospective versus retrospective measures were not revealed overall, differences between prospective and retrospective measures at baseline were significant. It is possible that one would consistently find differences between prospective and retrospective assessments if assessments were done at only a single time point. However using a longitudinal design with more than one retrospective measure, it is possible that the retrospective reports showed more regression to the mean than the prospective measures and as a result, findings appeared more similar to prospective data. Future longitudinal studies comparing prospective and retrospective instruments and their stability over time are needed to better clarify this issue.
One unexpected finding that emerged from the study was that at the 12 month follow-up participants reported significantly less pain and less disability than at baseline, with the 12 month levels more similar to prospective data. This unexpected decline in symptoms cannot be explained by differential attrition, because the declines in levels of pain or activity restriction were similar for both groups. However, this finding could be a product of many factors including the smaller sample size at the follow-up, or the possibility that baseline reports of pain and disability were inflated and when asked to monitor their symptoms over the course of a study, participants became more accurate in their reports. Another important reason for this decline could be changes in disease symptoms across the one year data collection period of this study. Study participants were recruited during clinic visits, and for many children with HA, it was their first visit to the pediatric neurology clinic. As a result patients were presenting with a high level of symptomatology that may have decreased with the implementation of pharmacological treatment, or simply regressed to the mean of symptoms over time.

The explanation that participants with HA were largely first time treatment-seeking patients may also account for the baseline differences in headache and arthritis-related pain and activity restriction that emerged in this and other studies comparing children and adolescents with HA versus other chronic pain conditions. Although the finding that children and adolescents with HA reported more pain and activity limitation than those with JCA supported our hypotheses, it is possible that this finding reflected characteristics of medical treatment rather than the specific conditions. For example, in contrast to study participants with HA, all participants with JCA had been diagnosed with the illness prior to study entry and were receiving medical treatment. Unlike adult
arthritis in which the treatment goal is to manage daily symptoms, for patients with JCA treatment is aimed at putting symptoms into remission (Ilowite, 2002). Thus, because many patients with JCA were already under treatment, initial pain and activity restriction levels may have been lower, or over the 12 months of data collection participants may have obtained significant symptom remission.

While this issue of treatment effects may be a possible explanation for baseline differences between the groups, one would also expect some improvement with treatment for children and adolescents with HA during the course of the year long study. This role of differential treatment effects deserves further analyses, specifically how do different types of treatment influence the levels of pain, activity restriction and depressive symptoms children report? Moreover, do different treatments differentially impact pain and disability and what are the changes in these effects over time? In the current study the cell sizes of specific subgroups were too small to compare different treatments that children were receiving. While the majority of these treatments were primarily pharmacological in nature, the different treatments received both within and between groups varied considerably and may have impacted the findings.

While the multi-modal assessment and longitudinal design are strengths of this study, several limitations should be considered in interpreting our findings. First, the current study is limited by a small sample size which may have impacted our ability to detect significant effects. While power analyses indicated that with our baseline sample of 89 participants we could detect a medium effect size, attrition at 12 months may have impacted our ability to detect significant findings. In addition, the small number of participants in each chronic pain condition prevented separate regression and HLM
analyses for the participants with HA versus JCA, particularly at the 12 month follow-up. With a larger sample size we could have examined how individual characteristics (e.g. age, gender, income, depressive symptoms) differentially influenced relationships between pain and activity restriction for children within the HA and JCA groups.

An additional limitation of the study is that the 21 participants who participated in the baseline assessment but did not complete the follow-up not only decreased the sample size but also the variability of the data. The levels of pain intensity and activity restriction were significantly lower at the 12-month follow-up, and the range of scores on pain and activity were more restricted. While differential attrition did not occur, restricted range of the findings could have impacted our results. For example in restricting the range of scores you are not able to completely capture the variability in the sample, potentially leading to a null finding when a significant relationship was present. For this reason, future studies employing a larger, more heterogeneous sample size are needed to test both whether the predictors of activity restriction are similar for both JCA and HA groups, and to determine if these findings generalize to broader populations (e.g. other chronic pain conditions, minorities, lower income families).

As stated above, this study was also limited by the measurement of depressive symptoms at baseline only. While research has shown some stability in depressive symptoms in both clinical and nonclinical samples over time, it is likely that children who participated in the study would have reported different levels of depressive symptoms at 12-months given the positive changes in pain level and activity restriction. Finally, while the current study used two very different pain conditions to examine the potential differences in illness versus non-illness related pain, the inclusion of a broader
sample of children and adolescents with different chronic pain conditions (e.g. sickle cell disease, juvenile fibromyalgia and recurrent abdominal pain) may lead to different results. Future research on the association between pain and activity restriction, particularly the individual factors associated with this relationship both across and within different chronic pain conditions are needed to support and expand the findings of the current study.

Future directions suggested by this research also include examining the impact of pain on specific activity limitations, and determining whether individual characteristics of the child impact activity level in certain domains. For example, is there a stronger relationship between pain and school absences for girls versus boys? Moreover, are there certain domains of activities that are more impacted by participants with HA versus JCA? Although results from this study show that participants with JCA reported more limitations on vigorous physical activities (e.g. sports, gym, climbing stairs) than children with HA, the CALI does not have sufficient reliability/validity to use single items as predictors. The next steps are 1) to factor analyze the CALI to identify whether different factors of activity restriction emerge, and 2) to replicate this study with a larger and more diverse sample of children with chronic pain conditions.

In addition, future studies need to expand their examination of activity restriction to include domains of cognitive, social and educational functioning that were not included in the current study. In a recent review of chronic pain assessment tools Eccleston, Jordan and Crombez (2006) reported that these areas of functioning are often overlooked when assessing the impact of chronic pain in children and adolescents, and that poor functioning in the areas of social and cognitive development can have
potentially long-term impacts on children’s lives. Finally, given the impact that parental/family characteristics can have on children’s reports of pain and activity, future assessment and treatment of pain-related activity restriction needs to include the family system in which the child is embedded (Palermo & Chambers, 2005). Specific ideas to expand current assessment include the examination of: parental history of chronic pain, family-level factors such as family functioning (e.g. stability, cohesiveness, conflict), level of parental worry about their children’s conditions, and reinforcement for pain behavior (Palermo & Chambers, 2005; Lipani & Walker, 2006; Lynch, Kashikar-Zuck, Goldsneider, & Jones, 2006).

Our findings have several potentially important clinical implications, although replication of the results is needed before changes in current pain assessment and treatment can be recommended. First, the results of the study identify specific patient characteristics that may impact the relationship between pain and activity restriction, and clinicians can use this and future data to target high need groups. For example, this study supports previous findings that females and adolescents may be at the highest risk for problems related to chronic pain. Given the correlations between pain and depressive symptoms in this study, these data indicate that conducting routine assessments of depressive symptoms should be a priority for clinicians working with these populations. That said, conducting routine assessments for all patients including males, younger children and low income patients is warranted given the fairly high prevalence of depressive symptoms that emerged in this study.

A second clinically important finding is that when comparing the HA and JCA groups, very few significant differences between predictor and outcome variables for the
two groups emerged in the analyses. While differences between pain intensity and depressive symptoms were different between the groups at baseline, the only significant differential prediction was level of pain intensity at 12 months. This finding suggests that the model of chronic pain proposed for the current study holds for diverse pain conditions and that while HA and JCA pain may be quite different, children and adolescents have similar factors associated with pain (e.g. income, age), are experiencing comparable levels of activity restriction, and similar interventions may be acceptable for both populations.

Finally, the results of this study can also be used to guide how assessments of symptomatology and functioning are conducted clinically on patients with chronic pain conditions. First, as indicated previously, findings did not reveal consistent biases in retrospective compared to prospective measures. Although replication is necessary this indicates that current practice of using reliable and valid retrospective pain assessment tools in many clinic settings may be sufficient. In addition, results of this study suggest that assessment of activity limitations should be incorporated into clinical practice. Because chronic pain is clearly impacting children’s ability to participate in daily activities, clinicians need to assess the impact that pain levels are having on children’s lives to help develop new treatments and interventions to ameliorate these effects.
Table 1: Description of Measures

<table>
<thead>
<tr>
<th>Measure</th>
<th>Description</th>
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<tbody>
<tr>
<td><strong>Predictors:</strong></td>
<td></td>
</tr>
<tr>
<td><em>Depression</em></td>
<td>● The major depressive disorder (MDD) subscale was used to assess participants’ depressive symptoms.</td>
</tr>
<tr>
<td>MDD subscale, Revised Child Anxiety</td>
<td>● T-scores were calculated based on child gender and grade in school.</td>
</tr>
<tr>
<td>and Depression Scale (RCADS; Chorpita,</td>
<td>● Score of 11 indicates clinically significant symptoms</td>
</tr>
<tr>
<td>Yim, Moffit, Umemoto, &amp; Francis, 2000)</td>
<td></td>
</tr>
<tr>
<td><em>Pain Intensity</em></td>
<td>● Participants were asked to report on average pain intensity 1) retrospectively over the previous four weeks 2) using a prospective one week pain diary at baseline, 6 and 12 months</td>
</tr>
<tr>
<td>FACES Pain Scale (Bieri, Reeve,</td>
<td></td>
</tr>
<tr>
<td>Champion, Addicoat, &amp; Ziegler, 1990)</td>
<td></td>
</tr>
<tr>
<td><strong>Outcome Measure:</strong></td>
<td></td>
</tr>
<tr>
<td><em>Activity Limitations</em></td>
<td>● The measure was administered adolescents to assess pain-related activity limitations 1) retrospectively over the past month and 2) using a prospective one week pain diary at baseline, 6 and 12 months</td>
</tr>
<tr>
<td>The Children’s Activity Limitations</td>
<td></td>
</tr>
<tr>
<td>Interview (CALI) (Palermo, Witherspoon,</td>
<td></td>
</tr>
<tr>
<td>Valenzuela &amp; Drotar, 2004)</td>
<td></td>
</tr>
<tr>
<td><strong>Other Measures:</strong></td>
<td></td>
</tr>
<tr>
<td><em>Physician Rating of Condition Severity</em></td>
<td>● Completed by participants’ subspecialty physicians</td>
</tr>
<tr>
<td></td>
<td>● Included questions on the child’s illness classification, medication and treatment regimen, and physician’s perception of pain condition severity.</td>
</tr>
<tr>
<td></td>
<td>● The severity form was a 10 cm VAS with the anchors at the two ends labeled ‘not severe at all’ to ‘extremely severe.’</td>
</tr>
<tr>
<td><strong>Proposed Moderators:</strong></td>
<td></td>
</tr>
<tr>
<td><em>Age, Gender, Income and Pain Condition</em></td>
<td>● The participants’ caregivers completed a basic demographic form, which provided information on the child’s age, race, gender, family income level, and parent work status.</td>
</tr>
<tr>
<td>Caregiver Information Form.</td>
<td></td>
</tr>
</tbody>
</table>
Table 2: Demographics

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Total Sample</th>
<th>HA</th>
<th>JCA</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>27 (30.0%)</td>
<td>23 (40.4%)</td>
<td>4 (12.5%)</td>
</tr>
<tr>
<td>Female</td>
<td>62 (69.7%)</td>
<td>34 (59.6%)</td>
<td>28 (87.5%)</td>
</tr>
<tr>
<td><strong>Age, years (baseline)</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean</td>
<td>12.53</td>
<td>12.29</td>
<td>12.98</td>
</tr>
<tr>
<td>SD</td>
<td>2.48</td>
<td>2.39</td>
<td>2.63</td>
</tr>
<tr>
<td>Range</td>
<td>8.09 – 16.77</td>
<td>8.29 – 16.55</td>
<td>8.09 – 16.77</td>
</tr>
<tr>
<td><strong>Child Ethnicity</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Caucasian</td>
<td>72 (80.9%)</td>
<td>44 (77.2%)</td>
<td>28 (87.5%)</td>
</tr>
<tr>
<td>African-American</td>
<td>14 (15.7%)</td>
<td>11 (19.3%)</td>
<td>3 (9.4%)</td>
</tr>
<tr>
<td>Hispanic</td>
<td>2 (2.2%)</td>
<td>2 (3.5%)</td>
<td>0 (0.0%)</td>
</tr>
<tr>
<td>Other</td>
<td>1 (1.1%)</td>
<td>0 (0.0%)</td>
<td>1 (3.1%)</td>
</tr>
<tr>
<td><strong>Pain Condition</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Recurrent Headache</td>
<td>57 (64.0%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Juvenile Chronic Arthritis</td>
<td>32 (36.0%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Condition Severity (baseline)</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean</td>
<td>4.11</td>
<td>4.84</td>
<td>2.89</td>
</tr>
<tr>
<td>SD</td>
<td>2.01</td>
<td>1.91</td>
<td>1.52</td>
</tr>
<tr>
<td>Range</td>
<td>0.1 – 9.0</td>
<td>0.4 – 9.0</td>
<td>0.1 – 7.0</td>
</tr>
<tr>
<td><strong>Family Income</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt; $19,000</td>
<td>8 (8.9%)</td>
<td>5 (8.8%)</td>
<td>3 (9.4%)</td>
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<td>$20,000 – $29,000</td>
<td>9 (10.1%)</td>
<td>8 (14.0%)</td>
<td>1 (3.1%)</td>
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<td>$30,000 – $39,000</td>
<td>16 (18%)</td>
<td>12 (21.1%)</td>
<td>4 (12.5%)</td>
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<tr>
<td>$40,000 – $59,000</td>
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<td>10 (17.6%)</td>
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<td>$60,000 – $69,000</td>
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<td>&gt; $70,000</td>
<td>28 (31.5%)</td>
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<tr>
<td>Missing data</td>
<td>4 (4.5%)</td>
<td>2 (3.5%)</td>
<td>2 (6.3%)</td>
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Table 3. Means and Standard Deviations of Predictor and Outcome Variables

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<th>Variable</th>
<th>Total Sample</th>
<th>HA</th>
<th>JCA</th>
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<td><strong>Pain Intensity</strong></td>
<td></td>
<td></td>
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<tr>
<td>Baseline</td>
<td>4.53 (1.49)</td>
<td>5.05 (1.23)</td>
<td>3.55 (1.46)</td>
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<tr>
<td>12 months</td>
<td>2.41 (1.21)</td>
<td>2.71 (1.24)</td>
<td>2.00 (1.06)</td>
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<tr>
<td>Prospective (Average)</td>
<td>3.04 (1.07)</td>
<td>3.18 (1.34)</td>
<td>2.81 (0.91)</td>
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<tr>
<td><strong>CALI sum score</strong></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Baseline</td>
<td>14.47 (7.52)</td>
<td>16.12 (11.94)</td>
<td>11.94 (6.94)</td>
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<tr>
<td>12 months</td>
<td>5.97 (6.31)</td>
<td>6.42 (6.73)</td>
<td>5.31 (5.70)</td>
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<tr>
<td>Prospective (Average)</td>
<td>13.76 (6.49)</td>
<td>13.87 (6.65)</td>
<td>13.63 (6.37)</td>
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<td><strong>MDD total score</strong></td>
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<tr>
<td>Baseline</td>
<td>7.88 (4.63)</td>
<td>9.09 (4.58)</td>
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<td>12 months</td>
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<tr>
<td>Prospective (Average)</td>
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Table 4. Intercorrelations among the Demographic and Retrospective Variables

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<td>4. Family Income</td>
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<td>.04</td>
<td>.22*</td>
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<td>-.29*</td>
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<td>.43**</td>
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<td>.18</td>
<td>.18</td>
<td>.42**</td>
<td>.35**</td>
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<td>-.27*</td>
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Table 5: Summary of Multivariate Random Effects Analyses of Associations between Pain and Activity Restriction

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<td>-0.005</td>
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<td>Age x Depression</td>
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<td>Age x Income</td>
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*p<.05
**p<.01
Table 6. Model of Linear Regressions for Effects of Depressive Symptoms on Pain Intensity

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<thead>
<tr>
<th>Predictors</th>
<th>Retrospective Data</th>
<th>12 months</th>
<th>Prospective Data</th>
<th>Diary Data (Bsln – 12 mo)</th>
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<td>SE</td>
<td>P</td>
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<td>Income x Gender</td>
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*p<.05, **p<.01
Table 7. Model of Linear Regressions for Effects of Pain Intensity and Depressive Symptoms on Activity Restriction

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<tr>
<th>Predictors</th>
<th>Retrospective Data</th>
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<th></th>
<th>Prospective Data</th>
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<td>B</td>
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<td>P</td>
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<td><strong>.055</strong></td>
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<td><strong>.007</strong></td>
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Figure 1: Model of the Hypothesized Relationship between Depressive Symptoms, Pain and Activity Restriction: Testing Age, Gender, Income and Pain Condition as Moderators.
Figure 2: Schematic Representation of Recruitment and Study Procedures

**Baseline**

- Participants recruited for participation
- Participants complete baseline questionnaire in clinic:
  - Demographics form
  - Retrospective FACES
  - Retrospective CALI
  - Retrospective RCADS
- Diaries distributed to patients following completion of retrospective measures
- Participants send completed diaries to research team
- Participants complete condition severity questionnaire
- Physicians complete condition severity questionnaire
- Participants complete diary data at home for one week
  - Prospective FACES
  - Prospective CALI
Figure 2 continued: Schematic Representation of Recruitment and Study Procedures

**12 Month Follow-up**

Original participants contacted for follow up to take place at patient’s next scheduled clinic appt

Participants completed 12 mo questionnaires in clinic:
- Retrospective FACES
- Retrospective CALI

Diaries distributed to patients following completion of retrospective measures

Participants complete diary data at home for one week
- Prospective FACES
- Prospective CALI

Participants sent completed diaries to research team
Figure 3: Longitudinal Changes in Pain Intensity and Activity Restriction
Bibliography


Merlijn, Hunfeld, van der Wooden, Hazebroek-Kampschreur, Koes, & Passchier,


Perquin, C., Hazebroek-Kampschreur, A., Hunfeld, J., Bohnen, A., van Suijlekom-Smit,


