A RE-EXAMINATION OF PARENT-CHILD ADJUSTMENT IN JUVENILE RHEUMATIC DISEASES USING DEPRESSION-SPECIFIC INDICES OF PARENT DISTRESS

By

MARGARET SWEENEY BONNER

Bachelor of Arts in Psychology

University of Cincinnati

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Thesis Approved:

John M. Chaney, Ph.D.

Thesis Adviser

Larry L. Mullins, Ph.D.

Melanie C. Page, Ph.D.

Sheryl Tucker, Ph.D.

Dean of the Graduate College

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CHAPTER I

INTRODUCTION

Juvenile Rheumatic Diseases (JRDs) represent a group of chronic autoimmune disorders that cause persistent inflammation of the joints, restriction in functional ability, and intermittent pain (Cassidy & Petty, 2005). JRDs consist of four disease subtypes: juvenile idiopathic arthritis (JIA), systemic lupus erythematosus (SLE), juvenile spondylarthropathy (JAS), and juvenile dermatomyositis (JDMA). JRDs as a group possess distinct clinical characteristics, such as analogous arthritic features, inflammation of the gastrointestinal tract, and muscle weakness. Of these, JIA is the most prevalent chronic childhood illness and most commonly diagnosed JRD, affecting as many as 150 per 100,000 children in the U.S. (Cassidy & Petty, 2005).

One hallmark characteristic of JRDs is the unpredictable, episodic course that requires affected youth to engage in extensive disease management aimed at improving range of motion, controlling pain and inflammation, and maintaining muscle strength and function to facilitate typical physical development (Cassidy & Petty, 2005). These functional limitations present as considerable psychosocial stressors that can exacerbate adjustment-related issues for children with JRDs. Specifically, children with JIA report multiple illness-related stressors, such as school difficulties and fears for the future (Rapoff & Lindsley, 2009). Additionally, youth with JRDs report significantly poorer

quality of life than their healthy peers (Sawyer et al., 2004) and display substantial psychological adjustment difficulties (LeBovidge, Lavigne, Donenberg, & Miller, 2003; Mullick, Nahar, & Haq, 2005).

The combination of these psychosocial stressors and functional limitations can increase the likelihood of emotional adjustment difficulties for children and adolescents with JRDs (Rapoff, 2000). For example, youth with JIA are significantly more likely to have a depressive disorder than healthy youth (Mullick et al., 2005). Moreover, a recent meta-analysis examining the psychological functioning of youth with JIA found that these children exhibited an increased risk for adjustment difficulties and internalizing symptoms (i.e., depressive symptoms) (LeBovidge et al., 2003). Furthermore, youth who report higher levels of pain have been shown to also display poorer adjustment as well as poorer quality of life compared to healthy youth (Sallfor, Fasth, & Hallberg, 2002; Sawyer et al., 2004; 2005). Accordingly, depressive symptomatology appears to be a significant concern for children with JRDs.

One of the most robust findings across pediatric chronic illnesses is that mothers caring for children with chronic illnesses are especially at risk for the development of depressive symptoms (Kashikar-Zuck et al., 2008). Numerous studies have reported clinically elevated levels of depression in mothers of children with chronic illnesses, ranging from 22% to 33% (Driscoll et al., 2010; Jaser et al., 2007; Weissman et al., 2006; Weissman, Warner, Wickramaratne, Moreau, & Olfson, 1997). Specific to JRDs, studies have shown that mothers report significantly higher levels of emotional distress than mothers of healthy children (Manuel, 2001). Fathers of children with JRDs also indicate

higher levels of emotional distress compared to those with healthy children (McNeill, 2004).

Rooted in multivariate adjustment models of chronic illness (Thompson & Gustafson, 1996), it is widely recognized that child and parent adjustment issues do not exist independently; rather, there is a clear transactional relationship between parental and child functioning (e.g., Chaney et al., 1997; Gil, Williams, Thompson, & Kinney, 1991; Thompson, Gustafson, Hamlett, & Spock, 1992; Thompson, Zeman, Fanurik, & Sirotkin-Roses, 1992; Timko, Baumgartner, Moos, & Miller, 1993; von Weiss et al., 2002). Given the pervasive depressive symptomatology seen in this population, recent studies have examined the parent-child adjustment process in an attempt to delineate specific mechanisms by which parental distress may exert an effect on depression in children with JRDs. For instance, Wagner et al. (2003) demonstrated that high levels of parental distress in combination with higher levels of child-reported illness intrusiveness (i.e., perceived illness interference with activities) predicted increased depressive symptoms. Similarly, the combined effect of increased parental distress and elevated levels of child-reported illness uncertainty have also been shown to predict depressive symptoms in children with JRDs (White, 2005).

Importantly, extant studies examining the association between parent distress and child depression in chronic illness populations have utilized global or multidimensional measures of general parent distress (e.g., Symptom Checklist – 90 (SCL-90); Derogatis, 1983; Brief Symptom Inventory (BSI); Derogatis, 1993) rather than specific measures of depression. Utilizing general measures of distress in these types of investigations may be problematic for several reasons. General measures of distress tap a broad and

heterogeneous group of symptoms pertaining to negative mood or emotional distress rather than depression-specific symptoms, and these symptoms may be more reflective of the stressors associated with chronic health conditions rather than depression per se (Fisher, 2007). Previous factor analysis of the nine-factor structure of the BSI suggests varying degrees of usefulness of the respective nine scales. In a factor analysis of a large sample of mixed psychiatric patients a six-factor solution was yielded, providing only partial support for the proposed structure of the BSI. Items from the depression scale defined a single factor, although items from other scales contributed to the factor (Greenblatt, 2002). These findings suggest that the BSI may indeed contribute to the assessment of some distinct aspects of symptomatology but does not adequately or solely measure general distress.

The purpose of re-examining existing data utilizing DSM-IV specific criteria for depressive symptoms speaks to the issue of targeting more precise mechanisms (or symptoms) that are present in the parent-child transactional adjustment relationship. Extant literature regarding this transactional relationship utilizes general measures of distress rather than domain specific indices of symptomatology, yet these results are readily interpreted as measuring specific symptomatology (i.e., Driscoll et al., 2010; Imayama, et al., 2011). Extrapolating items on a general measure of distress, such as the BSI, that map directly onto DSM-IV criteria for depressive symptoms clarifies what symptoms are being measured within this given population, allowing for more thorough and sound interpretations of what specific symptomatology is contributing to the parent-child transactional relationship. This re-examination, whether successful or unsuccessful, has several potential implications. Successful replication of previous findings using

depression-specific indices of distress will lead towards a better understanding of both global and specific indices of symptoms of parental adjustment. Specifically, it will help delineate specific features of youth and parent adjustment that are most influential in the transactional adjustment process. Although utilizing measures of general distress allows for greater sensitivity in detecting potential parent-child adjustment links, it results in decreased specificity regarding the nature of the parent-child adjustment link. Investigations that examine domain-specific indices of parental adjustment (i.e., depression) are needed to delineate specific features of parent adjustment that are most influential in determining depression in children with chronic illnesses (see Chaney et al., 1997). The importance of properly identifying the presence of symptoms facilitates subsequent treatment planning and resources necessary for reducing those symptoms. In order for treatment to occur, diagnoses need to be identified and global measures of general distress do not allow for specific diagnoses of DSM-IV disorders. Although several evidenced-based treatments for adult depression exist (e.g., Behavioral Activation, Cognitive Behavioral Treatment; Dobson et al., 2008; Martell, 2009), similar interventions for general distress do not. Thus, an additional implication for successful re-examination lies in more defined targets of psychosocial interventions and empirically driven treatments for parent depressive symptoms. This is an important implication because depressive symptoms have much more serious consequences (i.e. suicide, self-harming behaviors) than distress which further supports the need for more defined targets of psychosocial interventions and empirically driven treatments. If more precise concordance between parent and child depressive symptoms were established, increased efforts toward empirically driven treatments for parent depressive symptoms may result.

Successful re-examination of this data may also suggest that global measures of distress are sufficient in depicting depressive symptoms in parents of children with JRDs suggesting that the ways in which symptoms are currently measured through global measures of distress is satisfactory. Perhaps such failure to successfully replicate existing results may arise from symptoms interacting in measures of general distress (i.e., tripartite models; Dia et al., 2010). An interaction of symptoms may suggest that parents of chronically ill children have a plethora of symptoms that arise due to the chronic condition itself. In this case, more attention still needs to be paid to these parents and would further indicate the need for more defined targets of psychosocial interventions and empirically driven treatments for parents of youth with chronic illnesses, such as JRDs. Moreover, such unsuccessful re-examination may indicate that contemporary conceptualizations of general distress support the utilization of general distress measures, and this conceptualization may indeed be most relevant and sufficient.

The goal of the present paper is to provide an overview of the physical and emotional challenges faced by children with JRDs and their families, with particular emphasis on the transactional nature of the parent-child adjustment relation. Results of a study are then presented that examined the relation between parent depressive symptoms and child depressive symptoms in a sample of children and adolescents with JRDs. Specifically, data from an investigation by Wagner et al. (2003) were re-examined to determine whether the parent distress-child depressive symptom association observed in the original study could be observed using only depression-specific items from the original parent distress measure (BSI).

CHAPTER II

REVIEW OF THE LITERATURE

Juvenile Rheumatic Diseases: An Overview

Juvenile Rheumatic Disease (JRD) represents a group of chronic heterogeneous autoimmune disorders that cause persistent inflammation of the joints, restriction in functional ability, and intermittent pain (Cassidy & Petty, 2005). JRDs consist of four disease subtypes: juvenile idiopathic arthritis (JIA), systemic lupus erythematosus (SLE), juvenile spondylarthropathy (JAS), and juvenile dermatomyositis (JDMA). JRDs, as a group, possess discrete clinical characteristics, such as analogous arthritic features, inflammation of the gastrointestinal tract, and muscle weakness. Specifically, JIA is characterized by synovitis (i.e., inflammation of the synovial joint membrane); SLE is marked by systemic inflammation, blood vessel abnormalities, and immune complex disposition; peripheral arthritis is common in JAS along with initial effects occurring in the spine and then most commonly in the hips; and JDMA effects connective tissues characterized by colitis of the skin, muscle, and gastrointestinal tract (Cassidy & Petty, 2005).Development of any of the subtypes of JRDs occur during adolescence; however, polyarticular disease or spondyloarthropathy tend to occur most often in the teenage years (Rapoff, 2009).

JIA is the most prevalent chronic childhood illness and most commonly diagnosed JRD, affecting as many as 150 per 100,000 children in the U.S. (Cassidy & Petty, 2005). The etiology of JIA is unknown; however, variables such as genetic predisposition, environmental triggers, and immune reactivity have been identified as possible pathways. Criteria for classification of JIA includes an onset of symptoms before the age of 16 (25% of onset occurring within adolescence), arthritic features, such as swelling or effusion, or the presence of two or more of the following symptoms in one or more joints: limited range of motion, tenderness or pain on motion, or increased heat. Further criteria for a diagnosis of JIA is the duration of disease lasting six weeks or longer as well as onset of the specific JIA type diagnosed within the first six months. JIA consists of three subtypes; polyarticular (40% of JIA diagnoses), systemic disease (10% of JIA diagnoses), and oligoarticular (40-50% of JIA diagnoses), in which the categorization is defined according to the symptomatology in the first six months (Cassidy & Petty, 2005). Early and accurate diagnosis is essential for positive health outcomes in order to appropriately control the arthritic features and manifestations, as well as to prevent complications such as impairment in vision, gait abnormalities, and leg-length discrepancies (Rapoff & Lindsley, 2009).

Symptoms of JIA are differentiated by subtype. Polyarticular disease is the most frequently diagnosed JIA in adolescence and is diagnosed by the involvement of symptoms in more than four joints (typically hands, wrists, hips, knees, ankles, and neck). As many as 25% of youth diagnosed with polyarticular disease have an increased risk for more severe disease as indicated by a positive rheumatic factor test. Aggressive long-term treatment is often required to control symptoms and prevent disease

progression (Rapoff & Lindsley, 2009). As many as 50% of adolescents diagnosed with polyarticular disease experience a persistence disease course into their adult years (Wallace & Levinson, 1991). Long-term risks include recurrently active disease, destruction of joints, osteoporosis, residual growth asymmetries, and side effects of medication (Cassidy & Petty, 2005).

Systemic disease is diagnosed by the presence of a characteristic rash or high cyclic fevers in conjunction with arthritis. Although often associated with arthritis, non-articular manifestations such as lymph node inflammation (lymphadenopathy), inflammation of the pericardium or sac enclosing the heart (pericarditis), enlargement of the liver and spleen (hepatosplenomegaly) are often also present. Notably, pericarditis can be life-threatening resulting in frequent and long-term hospital admittances. Unlike polyarticular disease, systemic disease is not usually diagnosed in adolescence (Rapoff & Lindsley, 2009). As joint symptoms endure and develop, systemic systems subside. This subtype has proven to be the most difficult to treat with the most severe disease involvement affecting mobility and dexterity occur most often in the hands, wrists, hips, and neck. Up to 25% of those with systemic disease have a poor prognosis with recurrently vigorous and poorly responsive disease (Cassidy & Petty, 2005).

Systemic lupus erythematosus (SLE) is an episodic, multisystem, autoimmune disease characterized by the presence of antinuclear antibodies and widespread inflammation of the blood vessels and connective tissues (Cassidy & Petty, 2005). Presenting symptoms of SLE often include rashes, arthritis, and fever (Cassidy & Petty, 2005). SLE affects between 12 and 50 per 100,000 adults in the United States and accounts for approximately 4.5% of patients with a pediatric rheumatic disease (Cassidy

& Petty, 2005). Rarely diagnosed in children less than five years of age, SLE is most frequently diagnosed in adolescents, and girls are affected 4.5 times more frequently than boys (Cassidy, Sullivan, Petty & Ragsdale, 1977). In addition, a high prevalence and disease severity has been noted in non-white races, such as Native American and African American (Sutcliffe, Clarke, Gordon, Farewell, & Isenberg, 1999).

Juvenile spondylarthropathies affects the joints of the axial skeleton as well as the peripheral joints, and can be broken down into several different subtypes. One major sub-type, juvenile ankylosing spondylitis (JAS**),** is characterized by symptoms such as limited spine motion, pain in the spine, asymmetry in the lower extremities, and peripheral arthritis. JAS is frequently accompanied by enthesitis and antinuclear antibodies, and has a firm genetic basis. Present in one to seven percent of children with a rheumatic disease, JAS occurs most often in boys (seven to one) and the average age of onset is greater than ten years (Ansell, 1980).

The last subtype of the JRD, juvenile dermatomyositis (JDM), is a multisystem disease characterized by acute and chronic inflammation of striated muscle, skin, and gastrointestinal tract (Cassidy & Petty, 2005). Although no reliable data on the prevalence rates of JDM is available, incidence rates in the United States are approximately .5 per 100,000 (Medsger, Dawson, & Masi, 1970). Children with JDM typically experience substantial functional disability as the major presenting symptom is muscle weakness and tenderness, specifically in the limb-girdle muscles, anterior neck flexors and abdominal muscles (Cassidy & Petty, 2005). Additional symptoms may include arthritis (65% of children with JDM), discoloration of the eyelids with periorbital

edema, and a scaly rash over their knuckles. More common in girls, the onset of JDM most often occurs between ages ten and fourteen (Cassidy & Petty, 2005).

Medical Management of JRDs

The goals of treatment for JRDs are to repress inflammation and prevent complications such as joint deformity, visual impairments, and/or growth irregularities (Lovell, Giannini, & Brewer, 1984). Youth with active arthritis or ongoing active treatment need to be seen regularly by their physician, typically every 3 to 6 months (Cassidy & Petty, 2005). Disease management has been shown to be relatively effective for children with JRDs due to the currently available medication.

Specific treatment regimens are dependent on the maturity level of the adolescent and severity of the diagnosis with the average duration of treatment ranging from 4-6 weeks (Lovell, Giannini, & Brewer, 1984). Medications that reduce inflammation and fever as well as relieve pain are typically prescribed with non-steroidal inflammatory agents (NSAIDs) being the standard therapy (Rapoff & Lindsley, 2009). Although NSAIDS provide symptomatic relief, they do not influence the underlying disease process in any way. In the event of a NSAIDs ineffective course, disease-modifying antirheumatic drugs (DMARDs) are prescribed. Moreover, strong anti-inflammatory drugs, such as gluticosteroids, may be recommended although there can be adverse side effects, such as growth suppression, osteoporosis, Cushing's syndrome, and suppression of the immune system (Cassidy & Petty, 2005). Young children with a JRD diagnosis are often prescribed naproxen or ibuprofen while older children diagnosed with a JRD are often prescribed longer acting, daily medications, such as nabumetibe, prioxicam, COX-2 inhibitor, or celecoxib (Cassidy & Petty, 2005).

Treatment is often dependent upon disease type as each disease type can respond differently to medications and the variability of symptoms requires different treatment regimens. For pauciarticular disease, NSAIDs are typically prescribed (Rapoff & Lindlsey, 2009). For unresponsive joints, intra-articular corticosteroids are prescribed with the potential for additional regimens of second-line agents, such as sulfasalzaine or hydroxychloroquine which have been shown to be effective when added to NSAIDs (Cassidy & Petty, 2005). Treatment for systemic disease typically includes disease-modifying anti-rheumatic drugs (DMARDs) early in the disease course, which take weeks to months to be effective. In cases of severe disease, pericarditis, or macrophage activation syndrome, daily corticosteroids may be prescribed in addition to a prescribed DMARD, such as hydroxychloroquine or methotrexate (Cassidy & Petty, 2009). If eye involvement is present corticosteroids eye drops and dilating agents are often prescribed (Rapoff & Lindsley, 2009). Treatment for polyarticular disease typically involves initial therapy of NSAIDs with additional DMARDs, such as sulfasalzaine, methotrexate, or hydroxychloroquine, to treat a period of unresponsive disease that can last from weeks to months. Short-term corticosteroids are often utilized in small doses to control symptoms during a transition period (Cassidy & Petty, 2009). Although experimental and clinical data demonstrate the efficacy of NSAIDs, methotrexate, and glucocorticoids, further research is needed to determine if differences occur across different genetic or ethnic components (Helliwell & Ibrahim, 2003).

Treatment geared towards the physical components of JRDs is also necessary. Most often, children are encouraged to learn and understand their treatment regimens, maintain adherence to all treatment regimens, and maintain a physically active lifestyle

(Cassidy & Petty, 2005). Physical therapy is often prescribed in order to maintain physical activity (Rhodes, 1991). In addition to physical therapy, various splints are utilized to maintain correct positioning of joints and relieve chronic pain (Cassidy & Petty, 2005). Daily massages, warm baths, and/or electric blankets may be prescribed as a source of treatment for children who experience stiffness and/or pain (Lehman, 1993). Specifically, Field and colleagues (1997) reported that 15 minute massages once a day for a period of 30 days decreased pain in mild to moderate cases of JIA.

Lovell (1997) included an additional aspect of treatment beyond physical and pharmacological treatment for JIA. Due to the pervasive nature of the disease course and comorbid adjustment problems for children with JIA, Lovell highly suggested the need for a comprehensive treatment program comprised of a multidisciplinary medical team as an additional resource and treatment element. This treatment program provides parents with training workshops and written materials on how to facilitate healthy adjustment in various aspects of their children's lives (i.e. academic, emotional, and physical adjustment). In addition to this comprehensive treatment program, eliciting positive self-image and health family dynamics can be important to aid in successful treatment plans.

Although a cure for JRDs does not exist, spontaneous remissions can occur (Cassidy & Petty, 2005). During these times of remission, rheumatologists focus on achieving disease control. Conversely, during periods of flare, increased disease activity and subsequent exacerbated symptoms, such as pain, muscle weakness, and fatigue can occur (Schanberg, Anthony, Gil, & Maurin, 2003). Unfortunately optimal treatment for JRDs continues to be unclear. One thing that does remain clear is the need for regular rheumatology appointments for children with active JRDs, typically every three to six

months to maintain disease control. In review of the literature on treatment regimens and treatment management, there is much knowledge to be acquired regarding optimal disease management and treatment outcomes for children with JRDs.

Multivariate Models of Children's Adjustment

A hallmark characteristic of JRDs is the unpredictable, episodic course that requires affected youth to engage in extensive disease management aimed at improving range of motion, controlling pain and inflammation, and maintaining muscle strength and function to facilitate typical physical development (Cassidy & Petty, 2005). These functional limitations present as considerable psychosocial stressors that can exacerbate adjustment-related issues for children with JRDs. The psychosocial impact of JRDs has been examined extensively, indicating that youth with JRDs are at increased risk for a number of psychosocial adjustment problems, such as internalizing disorders (Ryan et al., 2010). Youth with JRDs report school difficulties and fears for the future (Rapoff & Lindsley, 2009), poorer quality of life than their healthy peers (Sawyer et al., 2004), and substantial psychological adjustment difficulties (LeBovidge, Lavinge, Donenberg, & Miller, 2003). The combination of these psychosocial stressors and functional limitations can increase the likelihood of emotional adjustment difficulties for children and adolescents with JRDs (Rapoff, 2000).

Recent multivariate adjustment models have demonstrated, however, that child adjustment does not occur in isolation; rather, adjustment is conceptualized as a dynamic process involving multiple facets. Specifically, Thompson & Gustafson (1996) demonstrated the variability of adjustment to chronic conditions that occurs across different disease states which has resulted in a focus on identifying the range of variables

that play a role in psychological adjustment. Theories regarding transactional models of the adjustment process have been examined to clarify some of this ambiguity. Transactional stress and coping models within an ecological-systems theory perspective illustrate the processes that are associated with both good and poor adjustment to chronic illnesses.

As discussed previously, chronic conditions present a number of stressors to which families must adapt. Family processes mediate the illness-outcome relationship above and beyond illness parameters (i.e. severity of disease) and demographic variables (i.e., SES, sex, age) (Thompson et al., 1993). Three forms of meditational processes are included in this model: the cognitive processes of appraisals of stress (Lazarus & Folkman, 1984), efficacy (Bandura, 1977); coping methods (Folkman & Lazarus, 1997); and family functioning (Thompson et al., 1989). Multivariate transactional stress and coping models have demonstrated that considerable amounts of variance in child adjustment can be explained by the influence of maternal adjustment. Overall, the literature regarding adjustment in childhood chronic illness suggests that multifaceted behavioral and/or emotional transactions occur between family members and that these transactions are central to the psychological adjustment process. In order to delineate more specifically the transactional nature of child-parent adjustment, more attention needs to be given to the role of paternal variables in this process.

Extensive pediatric psychology literature postulates that caring for a chronically ill child is both demanding and stressful (Chaney & Peterson, 1989). Parents of chronically ill children are faced with accepting that their child has a condition that has no known cure, as well as the possibility that their child may often experience pain,

emotional distress, and limited social interactions. In addition to these stressors, parents are faced with the management of complex treatment regimens involving a range of medication, physical therapies, avoidance of health-risk behaviors, and frequent hospital visits (Barlow et al., 2002). However, research has indicated that families of children with JRD report high levels of family cohesion and expressiveness and low levels of family conflict. Parent-child interactions were examined in a group of children and adolescents with JRDs, fibromyalgia, and healthy controls and their parents while participating in a pain-inducing task. Among the groups, no significant difference was found for parent-child interactions when controlling for pain and across groups parents provided more encouraging and positive statements when their child reflected any pain related to the task (Reid, McGrath, & Lang, 2005).

Despite this overall positive picture of parents of children with JRDs, increased familial burden and parental distress are quite prevalent. Mothers of children with JRDs report significantly higher levels of emotional distress than a similar group of mothers of healthy children (Manuel, 2001). These mothers of children with JRDs also reported that higher daily hassles and illness-related stressors predicted greater emotional distress (Manuel, 2001). Fathers of children with JRDs have also been shown to report high levels of emotional distress (McNeill, 2004). Furthermore, parental psychological distress has been shown to indirectly affect child physical health outcomes through its influence on treatment adherence (Chaney & Peterson, 1989). Although parents of chronically ill children are generally at increased risk for psychological distress, a number of cognitive variables, such as children's perceived illness intrusiveness (Wagner et al., 2003) and

illness uncertainty (White et al., 2005) have the potential to increase or decrease the impact of parent adjustment on children adjustment difficulties.

Given the depressive symptomatology seen in this population of youth, recent studies have examined the parent-child adjustment process in an attempt to delineate specific mechanisms by which parental distress may exert an effect on depression in children with JRDs. For instance, Wagner et al. (2003) demonstrated in a sample of 45 children with JRDs and their parents, that high levels of parental distress in combination with higher levels of child-reported illness intrusiveness (i.e., perceived illness interference with activities) predicted increased depressive symptoms in children. Similarly, the combined effect of increased parental distress and elevated levels of child-reported illness uncertainty have also been shown to predict depressive symptoms in a sample of 50 children with JRDs and their parents (White, 2005).

Global vs. Domain-Specific Indices of Distress

Interestingly, some studies have demonstrated that children with JRDs do not experience significantly greater levels of distress compared to their healthy peers (Noll et al., 2000); however, the presence of daily mood symptoms appears to impact daily functioning (Schanberg at al., 2000). For example, symptoms such as fatigue, stiffness, and activity interference have been shown to significantly impact the daily functioning of youth with JRDs (Schanberg et al., 2000), suggesting that mood-related cognitive appraisals, such as control over illness (e.g., "There is nothing I can do to alleviate my stiffness") and general pessimistic attributions (e.g., "If I cannot do this activity, then I cannot do any activities") may be vital to the day-to-day functioning of children with JRDs (Wagner et al., 2007). Furthermore, youth with JRDs may be particularly

susceptible to the effects of depressive symptoms, particularly in the presence of both disease-related and unrelated stress (LeBovidge, Lavigne, & Miller, 2005). These findings further suggest the need for domain-specific indices of depressive symptoms because global measures of distress are less sensitive to these specific symptoms. LeBovidge and colleagues (2003) suggested that a closer examination of specific anxiety and depression symptoms may provide more clarity/information about the emotional experiences of children with JRDs than would global assessments of internalizing or externalizing disorders.

Most studies of chronically ill youth have heeded LeBovidge's (2003) suggestion and focus on domain specific measures of child psychological adjustment (i.e. depression, anxiety). Unfortunately, assessment of parent distress in this population has not followed suit. Measurement of parent distress is variable between studies, and it is not always apparent whether each method similarly assesses depression or whether different methods uniformly classify patients (Fisher et al., 2007). Several studies have concluded significant findings of parental distress on child health and psychological outcomes using global measures of distress. For instance, Andrews et al. (2009) reported that parent-reported intrusiveness of their child's illness demonstrated a significant effect on distress for all 52 parents of children with JRDs in their sample. Furthermore, in a sample of parents of children at varying stages of a cancer diagnosis, parental distress was assessed using a multi-dimensional scale of disease-related distress (Parental Psychosocial Distress in Childhood Cancer-PPDC) (Boman, Lindahl, & Bjork, 2003). The PPDC was subsequently utilized to identify parents at particular risk for suffering long-term adjustment consequences.

A number of the most widely used general distress measures (e.g., Brief Symptom Inventory; BSI, Derogatis, 1993) do not directly address diagnostic criteria for depression as defined by the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR; APA, 2000); rather, they consist of a list of emotional symptoms that are endorsed by the reporter as either present or absent within a given time period (Fisher, 2007). Furthermore, measures of general distress have been shown to be more reflective of the stressors associated with other interrelated chronic health conditions and socioeconomic factors rather than depression specific items. Most importantly, approximately 70% of patients who were not clinically depressed but scored at a clinical level on a general measure of distress displayed significant deficits in behavioral and biological markers, deficits often considered to be a function of clinical depression (Fisher, 2007). These findings illustrate that general measures of distress tap a broad and heterogeneous group of symptoms pertaining to negative mood or emotional distress rather than depressive affect or clinical depression. However, this creates a gap in the current literature regarding consistency in measurement of psychological constructs across parents and children.

To illustrate, utilizing measures of general distress are problematic for two primary reasons. First, although such an approach allows for greater sensitivity in detecting potential parent-child adjustment links, it results in decreased specificity regarding the nature of the parent-child adjustment link. Second, evidenced-based treatments for general distress do not exist. Future examinations of both global and domain specific indices of parental adjustment will help to delineate specific features of youth and parent adjustment that are most influential in transactional adjustment (Chaney

et al., 1997). Studying more specific parent variables allows for more defined targets for psychological interventions (Streisand, Rodrigue, Houck, Graham-Pole, & Berlant, 2000). If more precise concordance between parent and child depressive symptoms were established, increased efforts toward empirically driven treatments for parent depressive symptoms may result.

CHAPTER III

PRESENT STUDY

Based on the preceding review of the literature, it is apparent that children diagnosed with a JRD may be particularly at risk for adjustment related issues. Previous literature has indicated that parents of children with JRDs may experience increased levels of depressive symptoms, putting children of depressed parents at an increased risk for developing similar depressive symptoms. The robust relationship between parental depressive symptoms and child depressive symptoms has been demonstrated numerous times within the pediatric chronic illness literature, specifically through transactional stress and coping models. Overall, the literature regarding adjustment in childhood chronic illness suggests that multifaceted behavioral and/or emotional transactions occur between family members and that these transactions are central to the psychological adjustment process. However, to delineate more specifically the transactional nature of parent-child adjustment, more attention is needed in research regarding parent variables. Furthermore, more attention is needed regarding measurement of these constructs.

Findings regarding youth with JRDs being particularly susceptible to the effects of depressive symptoms, particularly in the presence of both disease-related and unrelated stress suggest the need for domain specific indices of depressive symptoms because global measure of distress are less sensitive to these specific symptoms. As suggested by previous literature, a closer examination of specific anxiety and depressive symptoms

may provide more clarity and information about the emotional experiences of children with JRDs than would global assessments of internalizing or externalizing disorders. Most studies of chronically ill youth have heeded these suggestions and focus on domain specific measures of child psychological adjustment (i.e. depression, anxiety). Unfortunately, assessment of parent distress in this population has not followed suit. Measurement of parent distress is variable between studies and it's not always apparent whether each method similarly assesses depression or whether different methods uniformly classify patients. Some of the most widely used depression measures, such as the Brief Symptom Inventory and SCL-90, do not directly address diagnostic criteria as defined by the Diagnostic and Statistical Manual-Fourth Edition. Rather, they consist of a list of emotional symptoms that are endorsed by the reporter as either present or absent within a given time period. Measures of general distress have been shown to be more reflective of the stressors associated with other interrelated chronic health conditions and socioeconomic factors rather than depression specific items. This illustrates that general distress taps a broad and heterogeneous group of symptoms pertaining to negative mood rather than clinical depression. This creates a gap in the literature that the present study seeks to address.

The purpose of the present study was to examine the relation between parent depressive symptoms and child depressive symptoms in a sample of children and adolescents with JRDs. Specifically, it was hypothesized that re-examination of data from a study by Wagner et al. (2003) would reveal that the parent distress-child depressive symptom associations observed in the original study would be observed using only depression-specific items from the original parent distress measure (BSI). Additionally, it

was hypothesized that the moderating role for perceived illness intrusiveness in the relation between parental distress and child depressive symptoms would be confirmed using only depression-specific items from the original parent distress measure (BSI).

CHAPTER IV

METHODOLOGY

Archival data from Wagner et al. (2003) were re-analyzed in an attempt to replicate their findings using exclusively DSM-IV Major Depression criteria items as the measure of parent distress. Specifically, utilizing only items from the Brief Symptom Index (BSI) that map onto specific DSM depression symptoms, the current study represents an attempt to replicate previous findings indicating a moderating role for children's perceived illness intrusiveness in the relation between parent distress and child depressive symptoms (i.e., Wagner, 2003).

Participants and Procedure

Participants were recruited from a pediatric rheumatology clinic in a large teaching hospital in the Midwest region of the United States. Participants were recruited by a graduate student research assistant through one of two ways dependent upon accessibility. Eligible participants who were attending the Rheumatology clinic for an appointment were given study packets for both parent and child to complete and return via postage paid mail. Eligible participants who were not scheduled for upcoming appointments in the clinic were recruited by telephone and study packets were mailed to the participants and returned via paid postage mail. Participants were given $10.00 for study participation.

Sample

Participants were 45 children and adolescents (29 females, 16 males) between the ages of 9 and 17 (M=13.66, SD=2.42) with a diagnosis of a JRD (juvenile rheumatoid arthritis=27, systemic lupus erythematosus =11, juvenile dermatomyositis =5, juvenile ankylosing spondylitis =2) and their parents. Majority of youths were Caucasian (47%), followed by Native American (27%), Hispanic American (11%), African American (7%) and Asian American (2%).

Measures

Brief Symptom Inventory (BSI; Derogatis, 1993). In the original Wagner et al. (2003) study, this 53-item self report questionnaire was used to assess global psychological adjustment. Respondents rated the degree to which they have felt distressed in the past week, ranging from 1 (not a lot distressed) to 4 (extremely distressed). The BSI contains nine primary symptom dimensions; somatization, obsessive-compulsive, interpersonal sensitivity, depression, anxiety, hostility, phobic anxiety, paranoid ideation, and psychoticism and an additional scale for additional items. The global severity index (GSI) is the average distress score and was utilized to represent global parental distress in the Wagner et al. (2003) study. The BSI has demonstrated high internal consistency (α=.71-.85; Derogatis, 1993) as well as a Cronbach's alpha of .97 (Cronbach, 1951).

Depression Scale. As shown in Table 1, only six items from the original BSI comprise the depression subscale established by Derogatis and Melizaratos (1983). The 13-item measure of depression developed for this study contains an additional seven

items from the BSI that also map onto DSM-IV Major Depression criteria. The revised Depression scale used in the present study was developed by a Ph.D. advisor and four graduate level clinical psychology doctoral students by selecting items from the BSI that represent depression symptoms from the DSM-IV diagnostic nomenclature. These thirteen DSM-IV depression-specific BSI items were summed to comprise the primary measure of parent depressive symptoms. In the present sample, internal consistency for the thirteen-item Depression scale (DS) was high (α=.91).

Children's Depression Inventory (CDI; Kovacs, 1992). The CDI is a 27-item self-report instrument for children ages 7-17 that assesses depressive symptoms present during the past two weeks. Each item on the CDI comprises a group of three statements that collectively measure the severity of a single depressive symptom. An overall index score is calculated by summing the 27-items. The CDI demonstrated high internal consistency (α=.91). Furthermore, the CDI has been shown to be a valid outcome measure with previous JRD samples (Hagglund, Vieth, Sadler, Johnson, & Hewett, 2000).

Illness Intrusiveness Scale-Child (IIS-C). The IIS-C is a 12-item measure that assesses the degree to which children perceive their illness as interfering with their ability to engage in a variety of activities (i.e. school, social, family). Previous psychometric data for the IIS-C are not available due to the fact that it was adapted from the 13-item adult illness intrusiveness measure. However, data from adult RA and lupus samples indicate that internal consistency estimates for the original IIS range from .87 to .94. Test-retest reliability indexes range from .79 to .85 over a 6-week period, and support has been provided for its construct validity (Devins et al., 2001; Devins & Edworthy, 2000;

Edworthy, Domazet, Talavera, & Devins, 1998). Internal consistency on the IIS-C in this sample was high (α=.84). Moreover, the IIS-C did not correlate significantly with children's self-reported functional disability (*r*=.23) which provides support for the independent nature of perceived disability and illness intrusiveness.

The Juvenile Arthritis Functional Assessment Report- Child (*JAFAR-C*; Howe et al., 1991) is a 23-item measure completed by children to provide subjective estimates of their functional ability. Respondents rate how often they are able to perform 23 daily tasks (e.g. buttoning a shirt, getting in and out of bed) on a 3-point Liker scale, ranging from 0 (*all the time*) to 2 (*almost never*). Higher sum scores on the JAFAR-C indicate greater disability (*M*=6.46; *SD*=6.46, range 0-27 for the present sample). The JAFAR-C has demonstrated good construct validity and acceptable internal consistency for both the child-report (.85) and the parent-report (.93) version of the scale (Howe et al., 1991). Cronbach's alpha in the present study was .92.

Physician-rated Functional Disability (PRFD; Hochbarg et al., 1992). Physician-rated functional disability was assessed as an index for disease activity. The pediatric rheumatologist classified participants immediately following their appointment into one of four functional ability classes, ranging from Class I (limited to no disability in vocational and self-care activities) to Class IV (severe disability in vocational and self-care activities). Physician rating was based on several aspects of overall functioning such as parent or child self report, joint involvement, disease symptoms, and laboratory data. The PRFD has been shown to be a valid indicator of functioning disability in JRD populations (Baildam, Holt, Conway, & Morton, 1995; Gerhardt et al., 2003; Hochberg et

al., 1992). The overall classification for this sample was low, which suggests that this sample did not display or experience significant functional disability.

CHAPTER V

RESULTS

Primary Analyses

To re-examine the potential moderator effect of illness intrusiveness in the parent distress-child depressive symptomatology relationship, a hierarchal regression equation was constructed identical to that of the original study (Wagner et al., 2003). Demographic (gender, age) and disease variables (disease duration, PRFD, JAFAR-C) were entered on steps 1 and 2 of the regression. On step 3 of the equation, parent depressive symptoms (DS) and child illness intrusiveness (IIS-C) variables and a parent depressive symptoms X child illness intrusiveness interaction terms (DS X IIS-C) were entered. The DS and IIS-C variables were first centered to reduce multicolinearity within the interaction term (Aiken & West, 1991). Similar to Wagner et al. (2003), the interaction of parent depressive symptoms and child illness intrusiveness contributed additional variance to child depressive symptoms beyond the influence of demographic and disease variables and the main effects of parent depressive symptoms and child illness intrusiveness, t (44) = 2.269, p = .03 (see Table 3). Thus, children's perceived illness intrusiveness did moderate the association between parent depressive symptoms and child depressive symptoms.

Post hoc Probes

Post hoc probes were conducted to further examine the significant moderator effect of illness intrusiveness on the parent-child adjustment relationship (Holmbeck, 2002). First, conditional moderator variables were computed for low illness intrusiveness (Lo-IIS) and high illness intrusiveness (Hi-IIS). Two new interaction terms were then computed from these conditional variables. Separate regression analyses were conducted in which demographic and disease covariates were entered on steps 1 and 2. On step 3 of the first equation, Hi-IIS, DS, and the Hi-IIS X DS interaction terms were simultaneously entered. In step 3 of the second equation, Lo-IIS, DS, and the Lo-IIS X DS interaction terms were simultaneously entered.

Results revealed that the simple slope for the DS regression line under Lo-IIS conditions was significant, t (1) = -2.43, p = .001; the simple slope for the DS regression line under Hi-IIS condition was also significant, t (1) = 3.54, p = .02 (see Figure 1). Specifically, the influence of parent depressive symptoms on child depressive symptoms was enhanced under conditions of high perceived child-reported illness intrusiveness. Under conditions of low perceived child-reported illness intrusiveness, parent depressive symptoms were related to child depressive symptoms.

Exploratory Analyses

Four separate partial correlations controlling for demographic (age, gender) and disease (JAFAR-C, PRFD, disease duration) covariates were calculated to examine the performance of the DS scale developed for this study relative to other BSI dimensions in predicting children's depressive symptoms on the CDI. The analyses examined the following BSI scales: (1) the 13-item DSM-IV specific depressive symptoms scale (DS); (2) the original 6-item depression subscale of the BSI (Derogatis, 1993); (3) the original

BSI measure including all 53 items (BSI; Derogatis, 1993) (see Appendix B for all 53 items; and (4) the 40-items remaining from the original BSI not included on the 13-item DS scale (see Table 4). Further, *r* to *z* transformations revealed no differences among the four measures, indicating that the 13-item DS measure developed for this study was as reliable in the prediction of child depressive symptoms as the original 53-item measure, as well the other combinations of scale items.

CHAPTER VI

DISCUSSION

The current study examined the relation between parent depressive symptoms and child depressive symptoms in a sample of children and adolescents with JRDs. In order to delineate more specifically this parent-child relationship, re-examination of an investigation by Wagner et al. (2003) was conducted to determine whether the parent distress-child depressive symptom association observed in this study can be replicated using depression-specific items from the original parent distress measure (BSI). Consistent with previous literature (Chaney et al., 1997; Gil, Williams, Thompson, & Kinney, 1991; Mullins et al., 1995; Thompson, Gil, Burbach, Keith, & Kenny, 1993a,b; von Weiss et al., 2002; Williamson, Walters & Shaffer, 200) results revealed a significant association between increased parent depressive symptoms and children's depressive symptoms, again demonstrating the transactional nature of child adjustment in pediatric chronic illness. Additionally, and consistent with previous literature, children's perceptions of illness intrusiveness were shown to play a significant role in child depressive symptoms, beyond the influence of parental depressive symptoms (Manuel, 2001; McNeill, 2004). More importantly, extrapolating depression specific indices as defined by the DSM-IV from a measure of global distress was found to be as reliable in the prediction of childhood depressive symptoms compared to other variations of the general distress measure. Thus, findings of the present study indicated that global

measures of distress may indeed contribute to the assessment of some distinct aspects of symptomatology, but do not adequately or solely measure general distress.

Because this study measured depression specific indices rather than general distress, we have reason to believe that previous literature reporting a significant relationship between parent distress and children's depressive symptoms through global measures of distress is actually measuring predominantly parent depressive symptomology. Thus, findings of the present study indicated that domain specific indices of measurement may be more pragmatic for determining parent-child adjustment associations. The present paper extrapolated items from the BSI in order to more specifically target depressive symptoms as set forth by the DSM-IV to determine whether or not the BSI measures general distress or depressive symptoms. Results indicated that Wagner et al.'s original findings that child perceived illness intrusiveness moderated the relationship of parent distress and child depressive symptoms could be successfully replicated utilizing depression specific items from the BSI measure instead of utilizing the BSI as a global measure of distress. In extrapolating items from the BSI that map directly onto DSM-IV criteria for depressive symptoms, the same transactional relationship was found. Any initial concerns regarding issues of power in the original BSI depression scale (6 items) versus the depression symptoms measure utilized in this study (13 items) are put to rest due to the result of the 13 item measure correlating at a higher level than the original BSI measure of 53 items and the left-over non-depression items extrapolated from the original BSI of 40 items. Therefore, results of the current paper and its new measure can be interpreted without issues regarding measurement validity.

In general, the present results re-emphasizes the importance of examining children's cognitive appraisals in adjustment to pediatric chronic illness, particularly within a parent-child transactional context, and provide further evidence for one potential route by which parent and child variables combine to influence child emotional adjustment (i.e., Wagner et al., 2003). More specifically, the present results emphasize the potential problematic measurement of domains within the field as evidenced by the successful re-examination of published work utilizing more precise measurement. In successfully yielding the same results previously reported by Wagner et al. (2003) with the utilization of a new and more precise measure of a specific construct (i.e. depressive symptoms as defined by the DSM-IV as opposed to global distress as set forth by the BSI) more reliable measurement of the parent-child transactional adjustment relationship is established. As a result, more reliable measurement sets the stage for more valid measurement within this parent-child transactional adjustment relationship.

To date, several studies regarding the parent-child transactional adjustment relationship utilize global measures of distress rather than domain specific indices of symptomatology (i.e. Driscoll et al., 2011; Imayama et al., 2011), yet readily interpret these global measures of distress as measuring specific symptomatology. Although utilizing measures of general distress allows for greater sensitivity in detecting potential parent-child adjustment links, it results in decreased specificity regarding the nature of the parent-child adjustment link. Conversely, a growing body of literature indicates the importance of delineating specific features of youth and parent adjustment that are most influential in the transactional adjustment process (Chaney et al., 1997). Indeed, the current results target which specific mechanisms (i.e. depressive symptoms) that are

present in this parent-child transactional adjustment relationship. Furthermore, these data suggest that the BSI may indeed contribute to the assessment of distinct aspects of depressive symptomatology rather than global measurement of distress.

Our data, unlike previous studies of global measures of distress (Wagner et al., 2003; White et al., 2003; Ryan et al., 2010), are more consistent with transactional models of parent and child adjustment (e.g. Thompson & Gustafson, 1996), and suggest that parental depressive symptoms constitute one specific mechanism that influence child depressive symptoms. These findings lead towards a better understanding of both global and specific indices of symptoms of parental adjustment, specifically explaining precise features of youth and parent adjustment that are most influential in the transactional adjustment process. The importance of properly identifying these specific symptoms facilitates subsequent treatment planning and resources for reducing those symptoms. In order for treatment to occur for children and adolescents with chronic illnesses, specific diagnoses need to be identified. The measure of parental depressive symptoms in this study allows for such diagnostic features. Moreover, such ability to diagnose specific disorders through such precise measurement allows for more defined targets of psychosocial interventions and empirically driven treatments for parent depressive symptoms. Global measures of general distress simply do not allow for specific diagnoses of DMS-IV disorders, and thus do not allow for specific diagnostic features necessary for treatment to occur.

The results of the current study offer a number of clinical and research implications. First, these results argue for early screening of both parental and child depressive symptoms soon after diagnosis. Indeed, parents and youth may benefit from

brief, evidence-based psychosocial interventions that address adaptive coping mechanisms. These interventions may consist of traditional cognitive behavioral therapy or may also include interventions created for family and youth with a chronic illness, such as Behavioral Family Systems Therapy (Wysocki et al., 2007). Furthermore, our findings suggest that both parent and child depressive symptoms should be a key aspect to monitor throughout the child's developmental process. If more precise concordance between parent and child depressive symptoms were established, increased efforts toward empirically driven treatment for parent depressive symptoms may result. Going forward, researchers should consider utilizing domain specific measurement in order to report more precise measurement overall. General measures of global constructs should not be entirely ignored, however, it is imperative that researchers are cognizant of the interpretations of such measures and when discussing such results should interpret carefully. In particular, when discussing results of the BSI, researchers should be cognizant that the BSI measures depressive symptoms rather than global distress. Furthermore, researchers should understand that existing studies in the literature regarding the BSI really demonstrate that the best interpretation using these general measures of adjustment are really demonstrating the measurement of depressive symptoms.

The current study should be interpreted in light of several limitations. First, because CDI, BSI, and IIS-C are self report measures, the observed relations may have been due to shared method variance. However, our inclusion of multiple informants allows for the provision of unique and essential information about different aspects of functioning of both children and parents (Holmbeck, 2002). Second, extensive

demographic information was not collected from parent participants. Therefore, some demographic (i.e. parental psychiatric history, access to care, and familial resources) data that potentially could have aided in interpretation of the current findings were unavailable.

Despite the limitations of the present study, the findings demonstrate the importance of addressing domain specific measurement of symptomatology rather than global measures of general distress in youth with chronic illnesses and their parents. Future research should re-examine valid studies with domain specific indices to provide further support for the importance of more precise measurement. Further, this would potentially afford to better explain the parent-child transactional relationship in eliciting which specific symptoms are present in this relationship. Additionally, future studies need to investigate the correspondence between disease-related and disease-unrelated events as to how they may relate to depressive symptoms in order to generalize these findings to the general child clinical literature as a whole.

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FIGURES & TABLES

Figure 1. *Child's perceived illness intrusiveness as a moderator between the parent depressive symptoms and child depressive symptoms*

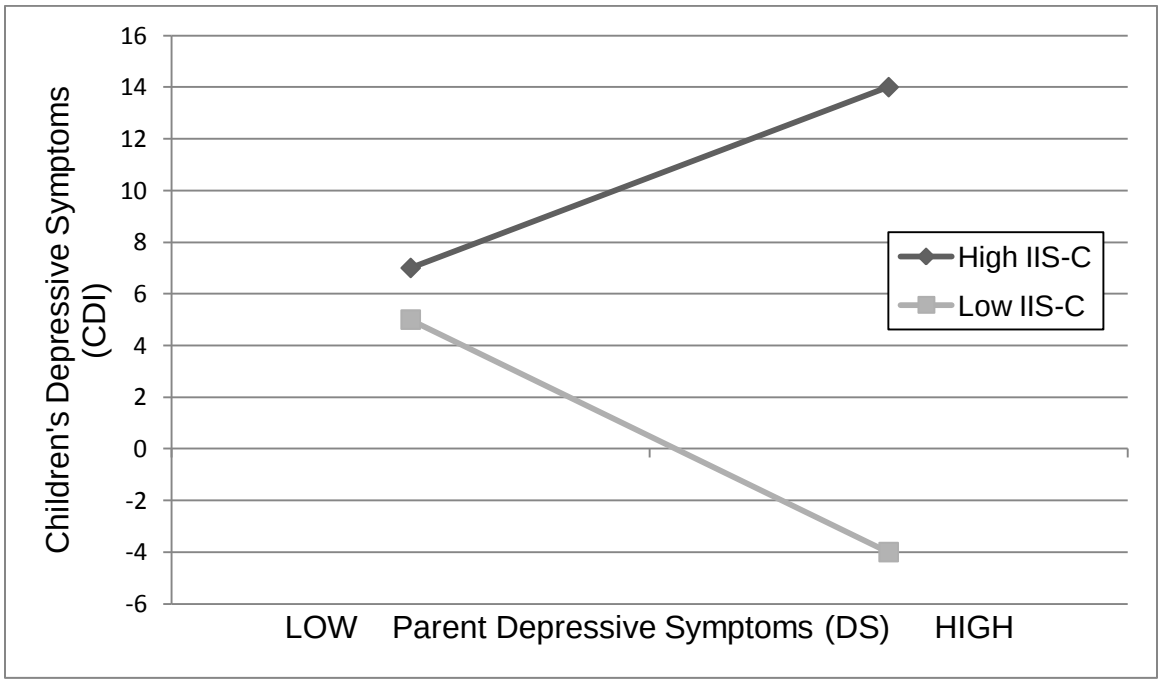

Table 1. *Brief Symptom Inventory Depression Sub-Scale vs. DSM-IV Specific Depressive Symptoms Scale*

Brief Symptom Inventory – Depression Subscale

9. Thoughts of ending your life
16. Feeling lonely
17. Feeling blue
18. Feeling no interest in things
35. Feeling hopeless about the future
50. Feelings of worthlessness

DSM-IV Specific Depressive Symptoms Scale (DS)

9. Thoughts of ending your life
11. Poor appetite
16. Feeling lonely
17. Feeling blue
18. Feeling no interest in things
25. Trouble falling asleep
27. Difficult making decisions
35. Feeling hopeless about the future
36. Trouble concentrating
39. Thoughts of death or dying
49. Feeling so restless you couldn't sit still
50. Feelings of worthlessness
51. Feelings of guilt

Table 2. *Hierarchical Regression Analyses of Children's Depression Inventory*

Step	Variable	*b*	*t* for Within-Step Predictors	R^2 Change for Step	Cumulative R^2	*F* Change for Step
1	Child's gender	-.03	-.28	.24	.24	2.475*
	Child's age	.11	1.17			
	JAFAR-C	.156	1.57			
	Disease duration	-.14	-1.57			
	PRFD	-.21	-2.23*			
2	DS	.37	2.71**	.49	.73	21.487***
	IIS-C	.66	5.94***			
3	DS x IIS-C	.49	3.85***			

Note. PRFD = Physician-Rated Functional Disability; DS = DSM-IV Depressive Symptoms; IIS-C = Illness Intrusiveness Scale-Child form; JAFAR-C = Juvenile Arthritis Functional Assessment Report – Child form.
$^{*} = p < .05$. $^{**} = p < .01$. $^{***} = p < .001$.

Table 4. *Partial Correlations of Four Variations of Parent Depressive Symptoms Measures with Child Depression (CDI)*

Measure	**Partial Correlations**
DSM-IV depressive symptoms (13 items)	.458*
Original BSI depression sub-scale (6 items)	.381**
Original BSI (53 items)	.435*
Remaining items on BSI after considering DSM-IV criteria (40 items)	.418*

* $p < .05$
** $p < .01$

APPENDICES

APPENDIX A

PROVIDER QUESTIONAIRE

1. Patient's name:_____

2. Patient's diagnosis (if multiple diagnoses, please list the rheumatic illness first; please indicate if patient is seropositive or ANA-positive)

   _____

   _____

   _____

3. When was the patient diagnosed with the above rheumatic illness?

   Date of diagnosis: _____

4. What is the patient's current medication regimen?

   _____ _____
   _____ _____
   _____ _____

5. Currently, how active is the patient's illness?

1	2	3	4
Clinical Remission (off meds 12 mo)	Clinical Remission (on medication)	Inactive Disease	Active Disease

Based on the patient's physical exam, please classify him/her into one of the following four classes:

Class I	**Class II**	**Class III**	**Class IV**
Completely able to perform usual activities of daily living (self-care, vocational, and avocational)	Able to perform usual self-care and vocational activities, but limited in avocational activities	Able to perform usual self-care activities, but limited in vocational and avocational activities	Limited ability to perform usual self-care, vocational and avocational activities

APPENDIX B

BRIEF SYMPTOM INVENTORY (BSI)

INSTRUCTIONS:
On the next page is a list of problems people sometimes have. Please read each one carefully, and blacken the circle that best describes HOW MUCH THAT PROBLEM HAS
DISTRESSED OR BOTHERED YOU DURING THE PAST 7 DAYS INCLUDING TODAY. Blacken
the circle for only one number for each problem and do not skip any items. If you change your mind, erase your first mark carefully. Read the example before beginning,
and if you have any questions please ask them now.

Not at all	A little bit	Moderately	Quite a bit	Extremely	Example How much were you distressed by:
0	1	2	3	4	Bodyaches

Not at all	A little bit	Moderately	Quite a bit	Extremely	How much were you distressed by:
0	1	2	3	4	Nervousness or shakiness inside
0	1	2	3	4	Faintness or dizziness
0	1	2	3	4	The idea that someone else can control your thoughts
0	1	2	3	4	Feeling others are to blame for most of your troubles
0	1	2	3	4	Trouble remembering things
0	1	2	3	4	Feelings easily annoyed or irritated
0	1	2	3	4	Pains in heart or chest
0	1	2	3	4	Feeling afraid in open spaces or on the streets
0	1	2	3	4	Thoughts of ending your life
0	1	2	3	4	Feeling that most people cannot be trusted
0	1	2	3	4	Poor appetite
0	1	2	3	4	Suddenly scared for no reason
0	1	2	3	4	Temper outbursts that you could not control
0	1	2	3	4	Feeling lonely even when you are with people
0	1	2	3	4	Feeling blocked in getting things done
0	1	2	3	4	Feeling lonely
0	1	2	3	4	Feeling blue
0	1	2	3	4	Feeling no interest in things
0	1	2	3	4	Feeling fearful
0	1	2	3	4	Your feelings being easily hurt
0	1	2	3	4	Feeling that people are unfriendly or dislike you
0	1	2	3	4	Feeling inferior to others
0	1	2	3	4	Nausea or upset stomach
0	1	2	3	4	Feeling that you are watched or talked about by others
0	1	2	3	4	Trouble falling asleep
0	1	2	3	4	Having to check and double-check what you do
0	1	2	3	4	Difficult making decisions
0	1	2	3	4	Feeling afraid to travel on buses, subways, or trains
0	1	2	3	4	Trouble getting your breath
0	1	2	3	4	Hot or cold spells

0	1	2	3	4	Having to avoid certain things, places, or activities because they frighten you
0	1	2	3	4	Your mind going blank
0	1	2	3	4	Numbness or tingling in parts of your body
0	1	2	3	4	The idea that you should be punished for you sins
0	1	2	3	4	Feeling hopeless about the future
0	1	2	3	4	Trouble concentrating
0	1	2	3	4	Feeling weak in parts of your body
0	1	2	3	4	Feeling tense or keyed up
0	1	2	3	4	Thoughts of death or dying
0	1	2	3	4	Having urges to beat, injure, or harm someone
0	1	2	3	4	Having urges to break or smash things
0	1	2	3	4	Feeling very self-conscious with others
0	1	2	3	4	Feeling uneasy in crowds, such as shopping or at a movie
0	1	2	3	4	Never feeling close to another person
0	1	2	3	4	Spells of terror or panic
0	1	2	3	4	Getting into frequent arguments
0	1	2	3	4	Feeling nervous when you are left alone
0	1	2	3	4	Others not giving you proper credit for your achievements
0	1	2	3	4	Feeling so restless you couldn’t sit still
0	1	2	3	4	Feelings of worthlessness
0	1	2	3	4	Feeling that people will take advantage of you if you let them
0	1	2	3	4	Feelings of guilt
0	1	2	3	4	The idea that something is wrong with your mind

APPENDIX C

CHILDREN'S DEPRESSION INVENTORY

This form lists feelings and ideas that kids sometimes have. From each group of feelings and ideas, pick one sentence that describes you best for the past two weeks. After you pick a sentence from one group, go on to the next group.

There is no right or wrong answer. Just pick the sentence that best describes the way you have been recently. Put a mark like this "X" in the box next to the sentence that you pick.

Here is an example of how this form works. Try it. Put a mark next to the sentence that describes you best.

EXAMPLE: _____ I read books all the time
_____ I read books once in a while
_____ I never read books.

_____
_____

1. _____ I am sad once in a while
_____ I am sad many times
_____ I am sad all the time

2. _____ Nothing will work out for me
_____ I am not sure if things will work out for me
_____ Things will work out for me O.K.

3. _____ I do most things O.K.
_____ I do many things wrong
_____ I do everything wrong

4. _____ I have fun in many things
_____ I have fun in some things
_____ Nothing is fun at all

5. _____ I am bad all the time
_____ I am bad many times
_____ I am bad once in a while

6. _____ I think about bad things happening to me once in a while
_____ I worry that bad things will happen to me
_____ I am sure that terrible things will happen to me

7. _____ I hate myself
_____ I do not like myself
_____ I like myself

8. _____ All bad things are my fault
_____ Many bad things are my fault
_____ Bad things are not usually my fault

9. _____ I do not think about killing myself
_____ I think about killing myself but I would not do it
_____ I want to kill myself

10. _____ I feel like crying every day
_____ I feel like crying many days
_____ I feel like crying once in a while

11. _____ Things bother me all the time
_____ Things bother me many times
_____ Things bother me once in a while

12. _____ I like being with people
_____ I do not like being with people many times
_____ I do not want to be with people at all

13. _____ I cannot make up my mind about things
_____ It is hard to make up my mind about things
_____ I make up my mind about things easily

14. _____ I look O.K.
_____ There are some bad things about my looks
_____ I look ugly

15. _____ I have to push myself all the time to do my school work
_____ I have to push myself many times to do my school work
_____ Doing school work is not a big problem

16. _____ I have trouble sleeping every night
_____ I have trouble sleeping many nights
_____ I sleep pretty well

17. _____ I am tired once in a while
_____ I am tired many days
_____ I am tired all the time

18. _____ Most days I do not feel like eating
_____ Many days I do not feel like eating
_____ I eat pretty well

19. _____ I do not worry about aches and pains
_____ I worry about aches and pains many times
_____ I worry about aches and pains all the time

20. _____ I do not feel alone
_____ I feel alone many times
_____ I feel alone all the time

21. _____ I never have any fun at school
_____ I have fun at school only once in a while
_____ I have fun at school many times

22. _____ I have plenty of friends
_____ I have some friends but I wish I had more
_____ I do not have any friends

23. _____ My school work is all right
_____ My school work is not as good as before
_____ I do very badly in subject I used to be good in

24. _____ I can never be as good as other kids
_____ I can be as good as other kids if I want to
_____ I am just as good as other kids

25. _____ Nobody really loves me
_____ I am not sure if anybody loves me
_____ I am sure that somebody loves me

26. _____ I usually do what I am told
_____ I do not do what I am told most times
_____ I never do what I am told

27. _____ I get along with people
_____ I get into fights many times
_____ I get into fights all the time

THE END

APPENDIX D

ILLNESS INTRUSIVENESS SCALE-CHILD (IIS-C)

INSTRUCTIONS: Please rate how much your illness or its treatment "interferes with" (or keeps you from doing) the activities listed below and circle a number to the right of that item. If an item does not apply to you, then circle the "X" next to that item.

How much does your illness or its treatment interfere with:

	Does not Apply to me			A Little				A Lot
1) School or work	X		1 2	3	4	5	6	7
2) Activities outside of school or work (such as: camp, scouts, or community organizations)		X		1 2	3	4	5	6 7
3) Physical activities (such as: Swimming/baseball/soccer)		X		1 2	3	4	5	6 7
4) Other activities (such as: video games/board games)		X		1 2	3	4	5	6 7
5) Managing money		X		1 2	3	4	5	6 7
6) Relationships with your family		X		1 2	3	4	5	6 7
7) Relationships with your Friends		X		1 2	3	4	5	6 7
8) Relationships with your boyfriend or girlfriend		X		1 2	3	4	5	6 7
9) Being yourself	X	1 2	3	4	5	6	7	
10) Going to church	X	1 2	3	4	5	6	7	

11) Overall health	X	1 2	3	4	5	6	7
12) Eating a healthy diet	X	1 2	3	4	5	6	7

APPENDIX E

IRB APPROVAL FORM

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Oklahoma State University
Institutional Review Board

Protocol Expires: 2/10/2005

Date: Thursday, February 12, 2004 IRB Application No AS00104

Proposal Title: PSYCHOLOGICAL COMORBIDITY IN JUVENILE RHEUMATOID DISEASES: A COMPARISON OF AMERICAN INDIANS AND CAUCASIANS.

Principal Investigator(s):

Nicole Andrews
215 North Murray
Stillwater, OK 74078

Janelle Wagner
215 N. Murray
Stillwater, OK 74078

James Jarvis
OUHSC
Oklahoma City, OK 73104

Molly White
407 N. Murray
Stillwater, OK 74078

John M. Chaney
215 N. Murray
Stillwater, OK 74078

Reviewed and Processed as: Expedited (Spec Pop)

Approval Status Recommended by Reviewer(s): Approved

Dear PI :

Your IRB application referenced above has been approved for one calendar year. Please make note of the expiration date indicated above. It is the judgment of the reviewers that the rights and welfare of individuals who may be asked to participate in this study will be respected, and that the research will be conducted in a manner consistent with the IRB requirements as outlined in section 45 CFR 46.

As Principal Investigator, it is your responsibility to do the following:

1. Conduct this study exactly as it has been approved. Any modifications to the research protocol must be submitted with the appropriate signatures for IRB approval.
2. Submit a request for continuation if the study extends beyond the approval period of one calendar year. This continuation must receive IRB review and approval before the research can continue.
3. Report any adverse events to the IRB Chair promptly. Adverse events are those which are unanticipated and impact the subjects during the course of this research; and
4. Notify the IRB office in writing when your research project is complete.

Please note that approved projects are subject to monitoring by the IRB. If you have questions about the IRB procedures or need any assistance from the Board, please contact me in 415 Whitehurst (phone: 405-744-5700, colson@okstate.edu).

Sincerely,

Carol Olson

Carol Olson, Chair
Institutional Review Board

VITA

Margaret S. Bonner

Candidate for the Degree of

Master of Science

Thesis: A RE-EXAMINATION OF PARENT-CHILD ADJUSTMENT IN JUVENILE RHEUAMTIC DISEASE USING DEPRESSION SPECIFIC INDICES OF PARENT DITRESS

Major Field: Psychology

Education: Completed the requirements for the Master of Science in Psychology at Oklahoma State University, Stillwater, Oklahoma in December, 2011.

Received Bachelor of Science degree in Psychology from University of Cincinnati, Cincinnati, Ohio in 2008

Professional Memberships:
Psychological Association (APA) Division 54, Society of Pediatric Psychology, Oklahoma Psychology Association (OPA)

Experience: Graduate Student Research Assistant
Parent and Child Adjustment to Juvenile Rheumatic Disease
Oklahoma University Health and Sciences Center and Oklahoma State

Publications:

Drotar, D. & **Bonner, M.S.** (2009). Influences on adherence to pediatric asthma treatment: A review of correlates and predictors. *Journal of Developmental and Behavioral Pediatrics*, 30, 574-582.

Drotar, D., Crawford, P., **Bonner, M.S.** (2010). Collaborative decision-making and promoting treatment adherence in pediatric chronic illness. *Patient Intelligence, 2*, 1-7.

Pai, A.H., Ingerski, L.M., Perazzo, L., Ramey, C., **Bonner, M.S.**, Goebel, J. (2011). Preparing for transition? The allocation of oral medication regimen tasks in adolescents with renal transplants. *Pediatric Transplantation, 15,* 9-16.

Fedele, D.A., Ramsey, R.R., Ryan, J.L., **Bonner, M.S.**, Mullins, L.L., Jarvis, J.N., & Chaney, J.L. (2011). The association of illness uncertainty to parent and youth adjustment in juvenile rheumatic diseases: Effect of youth age. *Journal of Developmental and Behavioral Pediatrics, 32,* 361-367.

Fedele, D.A., Ryan, J.L., Ramsey, R.R., Grant, D.M., **Bonner, M.S.**, Stermer, S.P., Chaney, J.M., Jarvis, J.N. (under review). Utility of Illness Intrusiveness Scale in Parents. *Rehabilitation Psychology*.

Name: Margaret Bonner Date of Degree: December, 2011

Institution: Oklahoma State University Location: Stillwater, Oklahoma

Title of Study: A RE-EXAMINATION OF PARENT-CHILD ADJUSTMENT IN JUVENILE RHEUAMTIC DISEASE USING DEPRESSION SPECIFIC INDICES OF PARENT DITRESS

Pages in Study: 67 Candidate for the Degree of Master of Science

Major Field: Clinical Psychology

Objective: To re-analyze archival data in an attempt to replicate previous findings using exclusively DSM-IV Major Depression criteria items as a measure of parent distress. Furthermore, to replicate the moderating role of cognitive appraisal variables (perceived illness intrusiveness) in both the relation between parental distress and child depressive symptoms. **Method:** Forty-five youth and their parents in the original study (age 9-17) were recruited from a pediatric rheumatology clinic in a large children's hospital in the Midwest. Parents completed the Brief Symptom Inventory (BSI); youth completed the Child Depression Inventory (CDI) and the Illness Intrusiveness Scale. The primary rheumatologist provided diagnostic and disease severity information (i.e., (physician-rated functional disability) following a routine medical visit. **Results:** Thirteen depression-specific BSI items that mapped onto DSM-IV criteria for major depression were summed to comprise the primary parent measure of depressive symptoms. Results revealed a significant association between increased parent depressive symptoms and children's depressive symptoms. The interaction of parent depressive symptoms and child illness intrusiveness contributed additional variance to child depressive symptoms beyond the influence of demographic and disease variables and the main effects of parent depressive symptoms and child illness intrusiveness. **Conclusion:** Extrapolating depression specific indices as defined by the DSM-IV from a measure of global distress was found to be as reliable in the prediction of childhood depressive symptoms compared to other variations of the general distress measure.

ADVISER'S APPROVAL: Dr. John M. Chaney