# THE CONTRIBUTION OF PARENTAL ADJUSTMENT AND CHILDREN'S PERCEIVED ILLNESS INTRUSIVENESS TO CHILD DEPRESSION IN JUVENILE RHEUMATIC DISEASES

By

JANELLE LEE WAGNER

Bachelor of Arts

Wake Forest University

Winston-Salem, North Carolina

1998

Submitted to the Faculty of the
Graduate College of the
Oklahoma State University
in partial fulfillment of
the requirements for
the Degree of
MASTER OF SCIENCE
May, 2002

THE CONTRIBUTION OF PARENTAL ADJUSTMENT

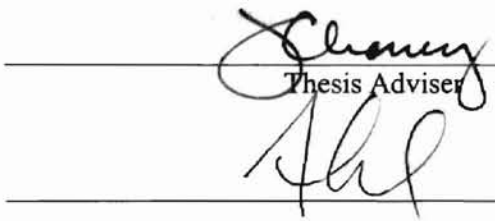
AND CHILDREN'S PERCEIVED ILLNESS

INTRUSIVENESS TO CHILD

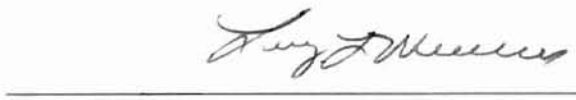
DEPRESSION IN JUVENILE

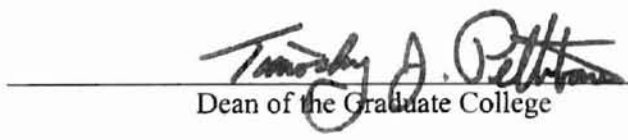
RHEUMATIC DISEASES

Thesis Approved:



Thesis Adviser





Dean of the Graduate College

ACKNOWLEDGEMENTS

I would like to thank my major advisor, Dr. John Chaney, for his mentorship, expertise, and encouragement on this project. I am sincerely grateful for his invaluable assistance. I would also like to express my appreciation for my other committee members, Dr. Larry Mullins, and Dr. Frank Collins. Their suggestions and discussions were quite helpful and thought provoking. In addition, I would like to express my gratitude to Dr. James Jarvis who was so generous to provide access to his rheumatology clinic and to offer his expertise.

I would also like to thank Molly White, Kevin Hommel, and Mike Mc Laughlin for their dedication to the lab and assistance with data collection. I am especially thankful to Kevin Hommel for his advice and to Molly White for her support.

Finally, I would like to express my appreciation to my loving family. My sincere gratitude goes to my husband, Jared, for his patience and encouragement. His faith in me meant more than I could ever express, and I will forever be thankful to him. The faith and support of my parents, Ken and Lois Stern, and brother, Aaron, were also invaluable to me.

TABLE OF CONTENTS

## LIST OF TABLES AND FIGURES

# CHAPTER I

## INTRODUCTION

### Description and Epidemiology of Juvenile Rheumatic Diseases (JRD)

The Juvenile Rheumatic Diseases (JRD) represent a heterogeneous group of chronic disorders, including juvenile rheumatoid arthritis, systemic lupus erthematosus, the juvenile spondylarthropathies, and juvenile dermatomyositis. These diseases are characterized by intermittent and sometimes chronic episodes of joint swelling and pain, which can restrict ability to perform daily activities and can be associated with psychosocial maladjustment (Vandvik, 1990; David et al., 1994).

Specifically, juvenile rheumatoid arthritis (JRA) is an autoimmune disorder that affects approximately 65,000 to 70,000 children in the United States, making it one of the most common chronic childhood illnesses. Distinctive characteristics of JRA include persistent inflammation of joints, restricted functional ability, and pain (Singsen, 1993). The origin of JRA is unknown; however, there is support for various immunological and environmental factors. These factors, including viruses, bacteria, nutrition, and toxins, are thought to possibly trigger the disease or maintain its process in predisposed individuals (Albert, Woo, & Glass, 1990). The onset of inflammatory arthritis typically occurs before age 16 (Kewman, Warschausky, & Engel, 1995), and JRA is more common in girls than boys; however, both sex and age ratios differ across the three subtypes of JRA: systemic, polyarticular, and pauciarticular (Singsen, 1993).

Systemic JRA can develop at any age, affects approximately 10% of children with JRA, and is equally common in boys and girls. Children with this subtype of JRA often

experience spiked fevers and pink rashes in the late afternoon and evening. About fifty percent of these children will have more than one systemic attack, which may last from days to months and is unexpected. In addition, 50% of children with systemic JRA will have severe, chronic arthritis, which continues after a remission of systemic symptoms (Singsen, 1993).

The onset of polyarticular JRA occurs in about 40% of children with JRA and consists of arthritis in at least five joints. Seventy-five percent of these patients have symmetric joint involvement. Children with this subtype of JRA often present with weight loss, low-grade fever, anemia, and growth retardation. Polyarticular JRA affects girls three times more than boys and may begin at any age (Singsen, 1993).

Pauciarticular JRA is characterized by arthritis in four or fewer joints and occurs in up to 50% of children with JRA. In one half of children with pauciarticular JRA, only one joint is involved, most commonly the knee (Singsen, 1993). This type of JRA usually occurs before the age of 10, and boys are affected five times more than girls (Kewman et al., 1995).

Systemic lupus erythematosus (SLE), a rheumatic disease characterized by a butterfly rash, arthritis, and arthralgias, involves the production of antibodies to components of the cell nucleus and is manifested by inflammation, blood vessel abnormalities, and immune complex disposition. Females are more commonly affected than males by a ratio of 4 to 3.1. Children with SLE may experience photosensitivity, fever, lymphadenopathy, nephritis, and arthritis. However, unlike JRA, arthritis in patients with SLE is not destructive to the bone. There may be central nervous system

involvement and subtle cognitive disturbances, and pulmonary symptoms can be found in 19-36% of cases. Skin lesions may spread to mucous membranes and other tissues of the body. In addition, almost all children with SLE have some form of renal disease. Indeed, the most common causes of death are infection and renal failure. Fortunately, the prognosis for children diagnosed with SLE has improved (White, 1993).

Another class of juvenile rheumatic diseases, the juvenile spondylarthropathies, occur more often in boys than girls. Symptoms develop from late childhood to early adolescence and frequently include asymmetry in the lower extremities and large joint arthritis. A subtype of the spondylarthropathies, juvenile ankylosing spondylitis (JAS) may be present in 10% of children with arthritis and is characterized by back pain and stiffness. The spine is first affected, and peripheral arthritis is common, with the hips being most often affected. About one fourth of children will exhibit polyarticular arthritis (Singsen, 1993). Due to the systemic nature of the disease, the eyes and heart are often affected, and inflammatory bowel disease is common. The course of JAS is generally favorable but is characterized by unexpected remissions and exacerbations (Khan, 1993).

Juvenile dermatomyositis (JDMA) is a disease of the connective tissues characterized by vasculitis of the skin, muscle, and the gastrointestinal tract. JDMA is more common in girls and occurs most often in children ages five to 14. Genetics and infectious agents are hypothesized to contribute to onset. Patients with JDMA commonly present with a rash displayed as a heliotrope discoloration of the eye lids. In addition, as many as 50% of children with JDMA having abnormal electrocardiograms will develop myocarditis. The majority of patients with JDMA present with muscle weakness and

tenderness, and as many as 20% of children with JDMA have arthritis. Thus, JDMA represents a disease characterized by substantial functional disability. However, the prognosis is good with less than seven percent mortality (White, 1993).

## Psychosocial Factors and Adjustment

The relationship of psychosocial variables to adjustment in juvenile rheumatic disease (JRD) has been widely examined. For example, in a sample of children with JRA, 63% demonstrated difficulty in psychological functioning, and 51% met criteria for at least one DSM-III diagnosis (Vandvik, 1990). Similarly, children with severe JRA have demonstrated increased levels of anxiety, depression, and other psychological problems in comparison to those with mild or inactive JRA and healthy controls (Billings, Moos, Miller, & Gottlieb, 1987). In addition, Varni, Wilcox, Hanson, and Brik (1988) found that psychological adjustment, combined with family environment, chronic pain, and disease activity was a significant predictor of functional disability (including activities of daily living, activity involvement, school functioning, and social functioning). Finally, research has demonstrated the long-term presence of psychological distress. David and colleagues (1994) found that 21% of JRA patients were clinically depressed 10-39 years after disease onset, and depression and anxiety levels increased with severity of disability.

Researchers have also examined the psychological adjustment in patients with systemic lupus erythematosus (SLE). A study comparing outpatients with SLE to a psychiatric group found no trends towards significant psychiatric disturbances in the SLE group (Mitchell & Thompson, 1990). Further, Mitchell and Thompson suggest that SLE

patients appear to be equivalent to patients with other chronic medical disease with respect to psychological adaptation. On the other hand, in a review of studies examining the psychological and psychiatric aspects of SLE, Chaney and Youll (1994) indicate that the clinical course and disease management of SLE contains many obstacles for the patient. In addition, they document the lack of well-controlled research on psychological aspects of SLE. Finally, Cornwell and Schmitt (1990) demonstrated that SLE and its treatments may have profound effects on adolescents' perceptions of their body images. Thus, it appears that patients with SLE do have psychological disturbances related to their illness.

Given evidence that 1.) children with JRD are at increased risk for psychological maladjustment (Vandvik, 1990; David et al, 1994), and 2.) disease variables often do not account for a significant amount of variance in psychological adjustment (Bennett, 1994), it is necessary to search for other intervening variables that contribute to adjustment.

## Illness Intrusiveness

Because disease features (i.e., pain and disability) provide only a limited explanation for depression in individuals with chronic diseases (Parker & Wright, 1995; Zautra, Burleson, Matt, Roth, & Burrows, 1994), current research has focused on the role of cognitive appraisal mechanisms in the relationship between disease variables and depression. For example, increased illness uncertainty has been shown to be associated with a significant increase in depressive symptomotology (Mullins, Chaney, Pace, & Hartman, 1997; Mullins, Chaney, Balderson, & Hommel, 2000). Further, a negative attributional style has also been shown to be significantly related poorer psychological

adjustment (Mullins, et al., 1997). Another cognitive appraisal that appears to have particular relevance to adjustment in JRD is illness intrusiveness and is defined as: the objective and perceived intrusiveness of an illness hypothetically derived from "illness induced barriers" which may restrict a patient from engaging in activities and interests valuable to him/her (Devins, et al. 1983-84). In other words, illness intrusiveness is an underlying dimension, comprised of disruptions produced by the illness that require the reduction or elimination of involvement in valued activities and interests (Devins, 1989). Devins (1991) suggests that illness related disruptions can be direct (i.e., physiological effects, treatment regimen) or indirect (i.e., disruptions in family and friend relationships).

It is important to note that perceived control and illness intrusiveness are not synonymous, but are conceptually related. Devins et al. (1983-84) computed partial correlations, controlling for perceived control, between perceived intrusiveness and positive and negative mood, and vice versa. They found that in patients with end-stage renal disease, increased levels of illness intrusiveness and decreased levels of perceived control were independently correlated with self-report positive and negative moods.

In addition, in adult patients with rheumatoid arthritis (RA), illness intrusiveness was significantly related to RA induced physical disabilities and was also correlated with depressive symptoms, after controlling for physical disability (Devins, Edworthy, Gutherie, & Martin, 1992). In this study, illness intrusiveness was demonstrated to be significantly related to depression across age; however, this effect was greater among younger patients. Unfortunately, despite research findings like these suggesting a

differential age impact, the research literature on illness intrusiveness has neglected children, including those with juvenile rheumatic diseases.

## Transactional Stress and Coping Model

Given the psychological components and physical pain and disability that often accompany chronic childhood illnesses, it is not surprising that family members' coping styles and behaviors affect children's adjustment. Both children and their families are faced with the tasks of disease management and psychological and social adjustment. A transactional stress and coping model (Thompson, 1985) combined with an ecological systems theory perspective (Bronfrenbrenner, 1977) states that chronic illness is viewed as a potential stressor for the individual as well as the family to which everyone must adapt. The outcome of adjustment to the illness is a function of biomedical, developmental, and psychosocial processes.

Studies have shown that parents' coping behavior can affect children's adjustment to the disease, beyond the influence of demographic and disease factors (Gil, Williams, Thompson, & Kinney, 1991; Thompson, Gustafson, Hamlett, & Spock, 1992; Chaney et al., 1997). In addition, Ennett and colleagues (1991) found significant differences in the magnitude of JRA disease impact as reported by mothers and children. Specifically, mothers rated children's perceived competence more negatively than children rated themselves. However, much of the research in this area has been limited to children with cystic fibrosis and sickle cell disease, and has focused on parent adjustment and child adjustment via parent report.

## Outline of Thesis

Existing research has failed to examine transactional patterns of adjustment as well as the influence of illness of intrusiveness on child adjustment in patients with JRD. Therefore, it is the aim of present study to examine the relationship of parental reports of psychological distress and the psychological adjustment (measured by children's reports of depression) in children with rheumatic diseases. In addition, this study examines the predictive utility of children's perceptions of illness intrusiveness in determining children's psychological adjustment. To accomplish this, a comprehensive review of the JRD literature is presented. First, a review of the literature associated with both psychological and medical treatment of JRD is presented. Second, literature examining psychological comorbidity and the relationship between psychological variables and disease outcome in JRD is reviewed. Then, the psychological construct of illness intrusiveness and its relationship to psychological adjustment in chronic illness are discussed. Next, the theory of transactional stress and coping and its utility in examining psychological adjustment in children with chronic illness and their families is presented. Finally, a study is described that examines [1)] the predictive utility of parental psychological adjustment in determining children's psychological adjustment (child-report depressive symptoms), [2)] the relationship of children's perceptions of illness intrusiveness and children's reports of depression, and [3)] potential mediator/moderator relationships between illness intrusiveness and parental adjustment in determining levels of child depression in a sample of children and adolescents with juvenile rheumatic diseases.

# CHAPTER II

# REVIEW OF THE LITERATURE

## Treatment Issues in JRD

### Medical Treatment

The JRD are a group of diseases characterized by a variable and unpredictable disease course. In fact, the variable nature of these diseases often leads into uncertainty in physicians, which impedes their ability to make a diagnosis at the early stages of symptom presentation. Therefore, symptoms may go undiagnosed for months or even years before a child is given a diagnosis. Unfortunately, this time lapse suggests that a patient may be displaying more severe symptoms by the time a diagnosis is given, and thus, the disease may have progressed to a later stage. Further, the similar symptoms of the JRD often make a differential diagnosis difficult (Fischbach, 1991). Given the reality that uncertainty often delays diagnosis and thus treatment, once a diagnosis is made, adherence to the treatment regime is quite salient.

In a review of medical treatment for juvenile rheumatoid arthritis, Singsen (1993) states that due to the perceived alarming nature of the diagnosis of JRA, parents, children, and teachers should be educated on the disease process. In addition, the primary goals of treating JRA should be relief of symptoms because there is no cure for the disease. For those in the early stages of the illness, maintenance of joint range of motion and muscle strength are the focus; whereas, rehabilitation should be the focus for those in later disease stages. Singsen (1993) notes that diagnosis and assessment of responses to

treatment should include evaluation of age appropriate functional abilities, assessment of movement, and parental information about changes in the child's activity.

Aspirin is the single most effective and least expensive anti-inflammatory medication in the treatment of JRA. However, many children are now treated with ibuprofen, tolmentin, naproxen, and fenoprofen because of the threat of Reye's syndrome in children who use aspirin. Use of these nonsteriodal anti-inflammatory drugs (NSAIDs) should be continued for 12-18 months after symptoms have disappeared. If aspirin or the NSAIDs are ineffective, intramuscular gold therapy, methotrexate, or systemic corticosteriods can be used. However, corticosteriods have adverse side effects and are usually used only if other treatments have failed.

Singsen (1993) states that children should be encouraged to remain as physically active as possible, and to be independent and responsible for adhering to the treatment if age appropriate. For example, many children experience morning stiffness and can initiate symptom relief by taking warm baths or using electric blankets. However, parents, relatives, caregivers, schools, etc. must adopt the treatment plan and actively participate. In addition, psychological or vocational programs are beneficial to help the child and his/her family cope with the disease and make necessary adjustments (Singsen, 1993).

Treatment for other juvenile rheumatic diseases is similar to that of JRA. Parent and child education on the disease is important. NSAIDs, corticosteriods, methotrexate, in addition to antimalarials may be used for patients with lupus. Lupus patients often experience photosensitivity and should be instructed to limit sun exposure. In addition,

infections are common; therefore, physicians should be attentive to fever symptoms, etc. (Kippel, 1993). Treatment of ankylosing spondylitis should include physical activity as permitted, attention to development, including in the school setting (e.g., cognitive and social), and physical treatments. Aspirin and ibuprofen are commonly used, with other drugs added for difficult cases (Singsen, 1993). Finally, the focus of treatment on patients with JDMA is to improve muscle strength and reduce swelling. Physical therapy is incorporated, and sometimes methotrexate is prescribed (White, 1993).

Psychological Treatment

Singsen (1993) states that psychological and vocational counseling are beneficial for JRA patients, especially those who are in adolescence. While medical treatment serves its purpose in maintenance of the disease, research has shown that psychosocial treatments are also important in helping the patient adhere to drug regimens, manage pain, and make psychosocial adjustments. For example, to increase compliance, token economy systems have been employed and found to be effective (Rapoff, Lindlsey, & Christophersen, 1984); self-monitoring and verbal feedback also increased the likelihood that patients would take their medications (Rapoff, Purviance, & Lindsley, 1988; Pieper, Rapoff, Purviance, & Lindsley, 1989).

Cognitive behavioral treatments (CBT) for patients with JRA have been empirically supported. For example, a reduction in pain intensity was seen after children and parents were introduced to muscle relaxation, guided imagery, and meditative breathing (Walco, Varni, & Ilowite, 1992; Lavigne, Ross, Berry, & Hayford, 1992). Other cognitive behavioral treatments have included active participation in treatment

decisions and skills that enhance and maintain self-efficacy (Loscalzo, 1996). In addition CBT has reduced depressive symptoms and stress in individuals with rheumatoid arthritis, improved the quality and quantity of sleep, and increased self-efficacy (O'Leary, Shoor, Lorig, & Holman, 1988).

Social support is another area of interest for psychotherapeutic approaches in the treatment of childhood chronic illnesses. Wallander and Varni (1989) demonstrated that children with high social support from family and friends showed significantly better adjustment when compared to those who had low social support. However, patients are not the only ones who can benefit from social support. For example, a social support program, which paired mothers of young adult JRA patients with mothers of children recently diagnosed with JRA, showed decreases in the number of reported mental health symptoms in mothers compared to controls (Ireys, Sills, Kolodner, & Walsh, 1996). Further, arthritis camps have become popular and are beneficial to children with JRA by improving emotional functioning and caregiver strain (Hagglund et al., 1996). Children who attend these camps have also shown improvements in self-concept, with effects maintained for at least 6 months (Stefl, Shear, & Levinson, 1989).

## Psychological Comorbidity

Due to the unpredictable course and chronic nature of juvenile rheumatic diseases, it is not surprising that children as well as parents experience emotional difficulties. Research supports that individuals who have chronic illnesses are at increased risk for depression, anxiety, and lower self-esteem (Ireys, Werthamer-Larsson, Kolodner, & Gross, 1994; Patterson, 1988; Chaney et al., 1996, 1999; Bennett, 1994).

Bennett (1994) presented a meta-analysis and review of depression in children with chronic medical problems. Across 60 studies, the duration of the illnesses was unrelated to depression, no relationship between age and depression among children was found, and no gender differences in depression among children were revealed. Lavigne and Faier-Routman (1993) also conducted a meta-analysis on the literature regarding adjustment to chronic illness in childhood. These authors reviewed 38 studies that included a host of chronic illnesses, including JRA. Results of this review suggest that disease severity, family adjustment/support/cohesion, self-concept, coping, IQ, prognosis, and functional ability contribute to adjustment.

Parent Adjustment

Parents must also adjust to their child's illness and may be impacted by the disease in ways similar to their children. Specifically, parents of children diagnosed with JRA may experience internal psychological maladjustment. For example, parents of children with JRA have demonstrated increased guilt, anxiety, anger, frustration, helplessness, powerlessness, and isolation (Barlow, Harrison, & Shaw, 1998). In addition, Barlow and colleagues (1998) found that inadequate support and lack of knowledge compromised parents' coping abilities. Further parents report considerable helplessness in their ability to control the disease, and thus perceived competence and self-esteem are negatively impacted (Patterson, 1988).

Research suggests that some parents cope with the impact of the disease by internalizing behavior. For example, mothers of children with recent onset of rheumatic disease exhibited increases in state anxiety, which was associated with the number of

affected joints in the children (Vandvik & Eckblad, 1991). Further, Timko, Stovel, and Moos (1992) found that children's pain, psychosocial difficulties, and functional disability contributed to poorer psychological functioning among parents. In addition, a longitudinal investigation found that parents' distress and depressed mood were predictive of poorer adjustment of children with juvenile rheumatic disease over a four-year period (Timko, Baumgartner, Moos, & Miller, 1993). In support of the findings of Timko and colleagues, Frank and colleagues (1998) found that maternal depression and parental distress were associated with child behavior problems. Thus, research supports the existence of psychological maladjustment in parents of children with chronic illness and suggests a relationship between the psychosocial outcomes of parents and children. However, extant studies examining the relationship between parent and child adjustment comprise only a small contribution to the JRD literature.

Child Adjustment

Research suggests that psychological symptomatology in adults with chronic illness may be a result of the perceived uncontrollability of the negative aspects of the disease (Andersen & Lyon, 1987; Chaney et al., 1996; Frank, Chaney, Clay, & Kay, 1991). It is presumed that this lack of control produces increases in anxiety and depression, and research on juvenile rheumatic diseases has supported those results found in chronic illness studies in general. For example, Vandvik (1990) found that half of children with rheumatic disease met criteria for a psychiatric diagnosis; 64% demonstrated at least mild maladjustment. In support of Vandvik's findings, David and colleagues (1994) found that 21% of a sample of 43 JRA patients were clinically

depressed; the rate of depression and anxiety increased with the degree of disability. In addition, Timko, Stovel, Baumgartner, and Moos (1995) found that experience with acute negative events was related to increased depressive symptomatology and dysfunctional behavior in children with rheumatic disease. Further, Ennett and colleagues (1991) found that children with a more negative disease experience reported diminished perceptions of competence. Thus, it seems that children with JRA may be more likely to internalize psychological difficulties more than they externalize them (Daltroy et al., 1992). Finally, it appears that psychological dysfunction is related to reported physical symptoms, including pain. In a sample of 78 JRA patients, children's psychological distress was a significant predictor of greater reported pain, controlling for the influence of disease factors (Ross et al., 1993). Thus, it is apparent that children with rheumatic diseases are likely to experience psychosocial difficulties that impact various areas of functioning.

## Illness Intrusiveness

The emotional impact of a chronic illness is complex; therefore, one would be naive to assume that there exists a single or direct explanation for psychological outcome. One factor that conceptually appears particularly salient to JRD but has not been empirically examined is illness intrusiveness. Illness intrusiveness can be defined as an underlying psychological dimension derived from illness "barriers" which can impede chronically ill patients from pursuing valued interests and activities (Devins, 1983). Illness intrusiveness is hypothetically manifested by illness-related disruptions in continued activity involvement. These illness features can necessitate a reduction in

valued activities, introduce new considerations (i.e., arrange recreational activities so that they conform to treatment schedules), and make participation in these activities more difficult (Devins, 1989).

Devins, Edworthy, Gutherie, and Martin (1992) posit that illness intrusiveness affects psychological well-being and distress through two separate mechanisms: 1) the availability of positive and rewarding experiences is greatly reduced; therefore, decreases in psychological well-being and increases in distress are observed, and 2) compromised personal control over important outcomes. Further Devins and colleagues (1992) introduce three constructs related to illness intrusiveness: burden of the illness, functional deficits, and physical disabilities. They argue that the burden of illness impacts functional deficits (i.e., limitations to sensory systems, such as inflammation of joints), which impact physical disability (i.e., limitations to performance of complex functions such as decrease in muscle strength or flexibility). This process presumably contributes to illness intrusiveness, and thus impacts psychosocial well-being and distress. Intrusiveness has been studied by examining the various life domains, such as work, family, marriage, recreation, etc., that are affected. In particular, one study with end-stage renal disease (ESRD) patients found that physical well-being and work/finances were significantly affected by intrusiveness (Devins, Mandin, et al, 1990). Similarly, a study with RA patients found that work/finances, health/diet, and recreational/social relationships were significantly disrupted (Devins, Edworthy, Gutherie, et al., 1992).

Much of the research on illness intrusiveness, primarily conducted with ESRD and multiple sclerosis (MS) patients, has demonstrated a relationship of illness

intrusiveness and psychological maladjustment. In patients with ESRD, an increase in negative moods and a decrease in positive moods have been associated with low control and high perceived intrusiveness (Devins et al, 1986-87). In addition, high perceived intrusiveness has been associated with increased depression, decreased life satisfaction, decreased positive affect and self-esteem, and increased pessimism and illness-related concerns, after statistically controlling for the influence of demographic variables (Devins, Mandin et al, 1990). Further, Devins, Armstrong and colleagues (1990) found that intrusiveness can affect self-reporting of physical symptoms. These authors demonstrated that increased reported pain in ESRD patients was associated with increased intrusiveness, suggesting that recurrent pain problems affect patients' quality of life by contributing to increased perceptions of illness intrusiveness. In summary, increased illness intrusiveness in patients with ESRD appears to be associated with comorbid conditions, such as depression and pain problems, etc., treatment factors, and psychological (e.g., stigma of the disease, intrusion into life domains) and social (e.g., age) factors (Devins, 1994).

As previously mentioned, illness intrusiveness has been studied in patients with MS and psychological well-being has been shown to correlate significantly with high personal control and low intrusiveness (Devins et al., 1993). Similarly, Devins and colleagues (1996) found that psychological well-being decreased with increased illness intrusiveness. Interestingly, illness intrusiveness increased more sharply in the younger patients in this study. These results are supported by research demonstrating that the severity of depressive symptoms increases more sharply in younger RA patients when

illness intrusiveness increases (Devins, Edworthy, Gutherie, et al., 1992). Thus, it appears that illness intrusiveness affects younger patients to a greater extent than it affects older patients. Perhaps, this differential age impact is due to expectancies toward disability and disengagement from valued activities. Older individuals may expect their activities to be hindered just as a function of growing older; whereas, younger individuals may not expect to lose participation in activities at that stage in their lives.

Research examining illness intrusiveness in patients with rheumatic diseases is limited. In fact, only two known studies (Devins, Edworthy, Gutherie et al., 1992; Devins, Edworthy, Paul et al., 1992) have demonstrated the effects of illness intrusiveness on psychological adjustment in patients with RA. Illness intrusiveness in patients with RA was significantly correlated with depressive symptoms, RA-induced physical disabilities, and age (Devins, Edworthy, Gutherie, et al, 1992). Further, Devins, Edworthy, Paul, and colleagues (1992) hypothesized that restless sleep contributes to increases in illness intrusiveness. Indeed, they found that individuals with RA, ESRD, and MS who experienced restless sleep reported significantly higher illness intrusiveness than those who did not. Although these findings are significant, the existence of only two studies examining illness intrusiveness in patients with rheumatic disease necessitates further research. Unfortunately, despite existing results which reveal the differential age impact of intrusiveness, with younger patients reporting sharper increases in depression with increased illness intrusiveness, research has failed to examine illness intrusiveness in children and adolescents with JRD.

## Transactional Stress and Coping Model

A considerable body of research indicates that chronic illness is a significant stressor for both children and their families. Further, the process of coping involves the use of several types of resources, including cognitive processes and social support. Due to the long-term and sometimes severe nature of childhood chronic illnesses, these resources may be insufficiently developed or unavailable (Thompson, 1981). Thus, both children affected by the disease and their parents have substantial barriers to overcome. Subsequently, parents' coping behavior affects the child's adjustment and vice versa. Thompson and colleagues (Thompson, Gustafson, George, & Spock, 1994; Thomspon, Gil, Burbach, Keith, & Kinney, 1993a, 1993b) have developed a transactional stress and coping model to examine these relationships between psychosocial outcomes of parents and children.

This transactional stress and coping model, which incorporates an ecological systems theory (Bronfrenbrenner, 1977) and Lazarus and Folkman's (1984) theory of stress, appraisal, and coping, views chronic illness as a stressor to which the individual and family must adapt. Bronfrenbrenner's ecology of human development focuses on the ongoing accommodation of an individual to the changing environment, in the immediate context as well as the larger social context. Inherent in this theory is the idea that an individual is continuously influenced by his/her environment. Specifically, Bronfrenbrenner hypothesized a relationship between the stress and symptoms of family members (i.e., child's environment) and the psychological adjustment of children.

Lazarus and Folkman's (1984) theory of stress and coping focuses on the cognitive aspects of coping. In other words, how one responds to possible stress is dependent upon how one appraises the situation and perceives available resources. The model proposed by Thompson et al. (1993a), posits that the illness-outcome relationship is not direct but is a function of the relationships between the illness, demographics, and child and parental adaptation processes. Guided by the work of Lazarus and Folkman, Thompson and colleagues (1993a) chose three adaptational processes: [1] cognitive processes of appraisal of stress and expectancy of efficacy and health locus of control, [2] coping methods, and [3] social support with respect to family functioning.

Research has supported the transactional stress and coping model in explaining the psychological adjustment of children with chronic illnesses and their parents. For example, Kronenberger and Thompson (1990) found that chronically ill children with behavior problems have less supportive and more conflict-oriented families; thus, the child's environment impacts psychosocial outcome. In addition, Varni, Wilcox, Hanson (1988) found that family and social support (by mother report) was a significant predictor of child psychological adjustment (i.e., internalizing and externalizing behaviors) in children with JRA, even after controlling for disease activity. Therefore, the family can be viewed as a mediating variable, which provides the environment in which the child can find (or not find) the needed resources to facilitate coping with a chronic illness (Varni et al., 1988).

Research has demonstrated that mothers' adjustment to their children's chronic illness is related to a variety of factors. Mullins and colleagues (1991) found that income

and disease severity in children with diabetes did not predict maternal adaptation. However, family life stress was a significant predictor of maternal anxiety and hostility but not depression. In another study, better adjustment in mothers of children with spina bifida was related to better marital quality and support and a less controlling family environment (Kronenberger & Thompson, 1992). However, research with mothers of children with sickle cell disease and cystic fibrosis has shown that maternal adjustment was not related to illness severity (Thompson et al., 1993a; Thompson, Gustafson, et al., 1992a). Thus, maternal adjustment appears to be related to social support and family stress but not to disease severity.

Research supports the hypothesis that parents' adjustment and coping behavior affects children's psychosocial outcome. In a study with sickle cell patients, parents high in coping attempts had children with fewer reductions in household and social activities and fewer calls/visits to the physician, beyond that accounted for by age and frequency of painful episodes. Further, increased parental coping attempts were associated with decreased negative thinking in children (Gil, Williams, Thompson, & Kinney, 1991). Indeed, research has shown that parental psychological maladjustment is related to behavior problems in children. For example, Thompson, Gustafson, and colleagues (1992a) found that maternal anxiety accounted for a 10-16% increase in internalizing (i.e., depression) and externalizing (i.e., hostility and aggression) behavior problems (by mothers' report) in children with cystic fibrosis. Further, maternal anxiety was also strongly related to child adjustment as evidenced by child-report. Most research has examined maternal adjustment; however, one study in particular revealed a relationship

between fathers' distress and their children's adjustment. Specifically, increases in father's distress over time contributed significant amounts of variance to poorer children's adjustment after controlling for demographic and disease parameters (Chaney et al., 1997).

Support for these findings is offered by a study with muscular dystrophy patients indicating that parent-appraisal of stress, use of palliative coping methods (i.e., emotion focused, avoidant, self-blaming), and level of family conflict accounted for 58% of the variance in children's general distress, 50% in depressive symptoms, and 31% in anxiety symptoms (Thompson, Zeman, Fanurik, Sirotkin-Roses, 1992). In addition, Mullins and colleagues (1995) demonstrated a significant association between maternal depression and increased depression in children with insulin-dependent diabetes mellitus. Another study examining children with sickle cell disease found that maternal anxiety added a 16% increment in mother-reported internalizing behaviors and a 33% increment in mother-reported externalizing behaviors after illness and demographic variables were controlled (Thompson, et al., 1993b). Further, research supports the lack of significant changes over a one-year period in child-reported symptoms and mother-reported internal behavior problems in children with cystic fibrosis (Thompson, Gustafson, George, Spock, 1994). These results suggest that transactional patterns of stress and coping are evident in families of children with chronic illness and are maintained over time.

As previously mentioned, most of the research on transactional patterns of coping and stress in children with chronic illnesses and their parents has focused on children with cystic fibrosis and sickle cell disease. Therefore, it is imperative that researchers

examine the possible transactions in other childhood chronic illnesses. Bennett (1994) suggests that previous findings provide support for a disease specific model of adjustment. In addition, Thompson and colleagues (1998) explain that their use of a "modified categorical approach" because illnesses differ in terms of stresses and presentation to the family, such as onset, type and severity of symptoms, treatment regimens, and life expectancy. Thus, it appears that there may be important differences in the processes associated with psychological adjustment as a function of illness type.

Another limitation in the existing body of literature involves examining child adjustment by mother report almost exclusively. For example, parents of chronically ill children rated them as having greater depressive symptoms compared to controls than did the children themselves (Bennett, 1994); thus, Bennett argues for the necessity of future research to compare parent and child perceptions. Further, in a study of children with JRA, Ennett and colleagues (1994) found a significant differential impact of the disease as reported by mothers and children. Children reported more daily problems, and mothers reported a greater impact on the family. In addition, mothers rated children's perceived competence more negatively than children rated themselves. Indeed, due to the evidence of discrepancy between parent and child-report and the reliability of child-report methodology in assessing child adjustment, there is a need for child adjustment to be measured by child report (Gil et al., 1991). Further, Kronenberger and Thompson (1992) argue for child-report of adjustment because the nature of the definition of coping involves appraisal, which necessitates the inclusion of self-report measures. Finally, by using child-report, Thompson, Gustafson, George, & Spock (1994) provided evidence

that maternal adjustment affects child adjustment, rather than simply maternal perceptions of the child's behavior. Thus, by using child-report, more distinct conclusions can be made about the relationship between parental and child psychosocial outcomes.

## Summary

Juvenile rheumatic diseases, including JRA, lupus, ankylosing spondylitis, and JDMA are chronic illnesses which involve inflammation, disability, and arthritis. These illnesses have unpredictable courses involving remissions and unexpected exacerbations. Thus, children with JRD often undergo complex treatments and are physically restricted from participating in valued activities. Consequently, children and their parents may develop psychological comborbidity (Vandvik, 1990; David, 1994; Barlow et al., 1998).

Because of common physical activity restrictions or reductions in children with JRD, it is important to examine perceptions of illness intrusiveness and concomitant psychological adjustment. Research has shown that high perceived intrusiveness is associated with depression and numerous other psychological components (Devins, Mandin, et al., 1990). Further, illness intrusiveness is greater in young patients, suggesting that perhaps illness intrusiveness is a more salient factor for younger individuals (Devins et al., 1996). However, research has failed to examine intrusiveness in chronically ill children overall, particularly children with JRD.

Children with JRD and their parents are faced with adapting to and coping with their illness. Research suggests that children's coping behavior influences parents' psychological adjustment and vice versa (Thompson, Zeman, et al., 1992; Chaney et al.,

1997; Gil et al., 1991). Thompson and colleagues (1993a, b) developed a transactional stress and coping model to explain this mutual experience and transmission of stress between parents and children. For example, maternal anxiety has been shown to account for increased internal and external behavior problems in children with chronic illnesses (Thompson, Gustafson, et al., 1992b; Thompson et al., 1993b). Unfortunately, the extant research fails to consistently provide disease-specific transactional relationships between parent and child adjustment outcomes. Further, research examining transactional patterns in JRD is quite limited.

# CHAPTER III

## STATEMENT OF PURPOSE

Based on the preceding review of literature examining adjustment in children with Juvenile Rheumatic Diseases (JRD), it is evident that children with JRD are at increased risk for psychological maladjustment (Vandvik, 1990; David et al., 1994; Timko et al., 1995). Further, research has shown that disease variables often do not account for a significant amount of variance in psychological adjustment (Bennett, 1994); these findings necessitate the search for other intervening variables that contribute to adjustment. Because JRD impose a number of restrictions on children's behavior, it is important to examine the extent to which the disease places limitations on activities and how these perceived limitations affect psychological well-being. Illness intrusiveness was discussed as a cognitive appraisal mechanism that appears to accurately capture this process, and one which may have particular relevance to the experience of JRD. Indeed, research has revealed relationships between illness intrusiveness and depression, life satisfaction, and pessimism across a variety of adult illness groups (Devins, Mandin, et al., 1990; Devins, Edworthy, Gutherie, et al., 1992). Unfortunately, however, illness intrusiveness has not been examined in pediatric chronically ill populations.

The literature on pediatric chronic illnesses also reveals that a portion of children's adjustment to chronic illness is related to parents' levels of adjustment (Thompson, Gustafson, et al., 1994; Thompson, Gil, et al., 1993a, 1993b). Thompson and colleagues' transactional stress and coping model highlights the importance of

examining parental adjustment in empirical investigations of childhood adjustment to illness.

Given these noted findings in the extant literature, the purpose of the present study was threefold: 1.) to examine the contribution of parents' psychological adjustment to children's report of depression, controlling for disease and demographic variables, 2.) to examine the independent contribution of children's perceptions of illness intrusiveness to children's report of depression, controlling for the influence of parents' psychological adjustment, and 3.) to examine potential mediator and/or moderator relationships between illness intrusiveness and parental distress in determining levels of child depression in a sample of children with JRD.

## Primary Hypotheses

### Hypothesis 1

Consistent with a transactional stress and coping conceptualization of adjustment, it was hypothesized that parental distress, as measured by the Brief Symptom Inventory (BSI) would contribute significantly to child self-report of depression (CDI), after controlling for demographic and disease variables.

### Hypothesis 2

It was anticipated that child-reported illness intrusiveness (IIS-C) would contribute significant incremental variance to self-reported depression (CDI), beyond that accounted for by parent adjustment on the BSI and demographic and disease variables.

Research Question 1

Because parental distress may lead to increased perceptions of negative impact (i.e., perceived intrusiveness) of JRD resulting in greater depression in children, illness intrusiveness was examined as a potential mediator in the parent adjustment-child adjustment relationship. To determine whether illness intrusiveness mediates this relationship, several criteria must be satisfied (Baron & Kenny, 1986):

1.) The predictor variable (BSI) must be associated with the outcome variable (CDI),

2.) The predictor variable (BSI) must be associated with the proposed mediator (IIS-C),

3.) The relationship between the predictor and the outcome variables must be no longer significant after accounting for the influence of the mediator, and

4.) The relationship between the mediator and the outcome variable must remain significant after accounting for the influence of the predictor.

Research Question 2

Alternatively, it may be that the combined influence of greater parental distress **and** illness intrusiveness enhances either the magnitude or direction of the effects these variables have on child adjustment, beyond their independent direct effects. The existence of a moderator relationship between parental distress and illness intrusiveness

in determining child adjustment requires that the interaction of parental distress (as measured by the BSI) and illness intrusiveness (as measured by the IIS-C) contributes incremental unique variance to child adjustment, beyond the influence of the main effects of these variables.

# CHAPTER IV

# METHOD

## Participants

Participants were 40 (26 females; 14 males) children and adolescents between the ages of nine and 21 ($\underline{M}$ = 14.4; $\underline{SD}$ = 2.92), who had been diagnosed with juvenile rheumatoid arthritis (JRA; $\underline{N}$ = 24), lupus ($\underline{N}$ = 9), juvenile dermatomyositis (JDMA; $\underline{N}$ = 4), or juvenile ankylosing spondylitis (JAS; $\underline{N}$ = 3) and their parents. The majority of child participants were Caucasian, followed by Native American, African American, Hispanic, Biracial, and Asian (see Table 1 for complete descriptive statistics).

Participants were recruited from the pediatric rheumatology clinics at Children's Hospital of Oklahoma. Inclusion criteria for participation included the following: 1) diagnosis of one of the above-mentioned illnesses and between the ages of nine and 21, and 2) the duration of the child's symptoms had been at least one year. Illness duration was calculated by subtracting the date of diagnosis from the date of participation and ranged from 0.04 years to 14.59 years ($\underline{M}$ = 2.69; $\underline{SD}$ = 2.86). Therefore, some patients in the sample had been diagnosed for less than one year but had had active symptoms for more than a year, and thus still qualified for the present study. Exclusion criteria were as follows: 1) the child had comorbid cognitive deficits (e.g., mental retardation), and 2) the child had a comborbid chronic illness. The primary rheumatologist verified the inclusion criteria before eligible participants were contacted. Participants were compensated monetarily with $10.00 per family.

## Instruments

### Physician-Report Measures

Provider Questionnaire. This questionnaire was designed to obtain information from the physician regarding patient diagnosis, date of diagnosis, and current medications. Current disease severity was assessed by a single question using a 7-point Likert scale, with a rating of one signifying "disease not active or in remission" and a rating of seven indicating "severe." In addition, as a measure of functional disability, the physician classified patients into one of four functional classes, with Class I representing limited to no disability in vocational and self-care activities, and Class IV representing severe disability in these same activities (e.g., Hochberg, et al., 1992). The data for the present study indicate a low level of physician-rated disease severity and functional disability (see Table 1). As this present study was part of a larger project, the Provider Questionnaire assesses several other domains; however, for the purposes of this present study, only the above-mentioned variables were utilized (see Appendix A). The rheumatologist completed the provider questionnaire once the study packets were returned to the researchers.

### Parent-Report Measures

The Brief Symptom Inventory. (BSI; Derogatis & Melisaratos, 1983) is a 53-item questionnaire that assesses global psychological adjustment (see Appendix B). Respondents rated the degree to which they were distressed by each psychological symptom in the past seven days. Rating was done on a Likert scale, ranging from 1 (not

a lot) to 4 (extremely), and a global severity index (GSI) was measured by taking the sum of the scores and dividing by 53 to obtain an average score. In the present sample, the mean score for the GSI was 0.48, and approximately 32% of the sample obtained clinically elevated GSI scores. The BSI has been previously found to have acceptable internal consistency; alpha coefficients range from .71 to .85 (Derogatis & Melisaratos, 1983). Chronbach's alpha for this sample was also found to be high ($\alpha$=.92).

Patient-Report Measures

Background Information Questionnaire. This questionnaire was created to obtain the following information: age, gender, ethnicity, and many other variables assessed on a seven point Likert scale. However, for the purpose of this present study, only the variables of age, gender, and ethnicity were utilized (see Appendix C).

The Children's Depression Inventory (CDI; Kovacs, 1983; 1992) is a 27-item scale that measures depressive symptoms over the previous two weeks (see Appendix D). Each of the items on the CDI includes three statements that combine to measure the severity of a depressive symptom on a 0 to 2 scale. Scores were derived by summing the 27 items for an overall index, with a higher score indicating more severe depression. Raw scores can be converted to T-scores, and a T-score of 66 or greater is considered clinically elevated. The average CDI score for the present sample was equivalent to a T-score of 50, indicating that the present sample was fairly well adjusted with respect to depression. The CDI has been shown to be a reliable scale, with internal consistencies ranging from .71 to .89, and has been shown to be a valid measure of depressive

symptomatology in children. Chronbach's alpha for the present sample was high ($\alpha$=.92).

The Illness Intrusiveness Scale-Child (IIS-C) is a 12-item measure that assesses the degree to which patients feel that their illness interferes with their ability to perform daily tasks (see Appendix E). This form was developed from the original IIS (Devins et al., 1983), which contained 13 items. Specifically, items on the child form were created by revising the questions on the adult form to provide a more age-appropriate questionnaire. Each of the items was summed to yield a measure of total intrusiveness. Children were asked to respond on a scale from 0 (does not apply to me) to 7 (a lot); therefore, higher scores indicate greater intrusiveness. Internal consistency estimates for the original IIS range from .80 to .88 in end-stage renal disease patients, with a test-retest reliability index of .79 over a six-week period (Devins et al., 1990). Internal consistency for the present sample was also found to be high ($\alpha$=.86). Additional studies have indicated that the original IIS is significantly related to reported difficulties in daily activities (Devins, Mandin et al., 1990), and there are significant differences in the level of intrusiveness depending on the type of illness (Devins et al., 1993).

The Juvenile Arthritis Functional Assessment Report-Child (JAFAR-C; Howe et al., 1991) was completed by patients to provide information about subjective perceptions of functional ability (see Appendix F). The JAFAR-C is a 23-item measure designed specifically to assess functional ability in JRD patients. Respondents rated how often they should be able to perform 23 daily tasks (e.g., button shirt, get into bed) on a three point Likert scale, ranging from 0 (all the time) to 2 (almost never). Therefore, a higher

score indicates greater disability, and the amount of functional disability is represented by the sum of the items. The range of possible averages is from 0 to 2, and the average for the present sample indicates minimal disability (see Table 1). The JAFAR has demonstrated good internal reliability coefficients for child-report (.85) and parent-report (.93) and construct validity (Howe et al., 1991). Previous studies have shown the JAFAR-C to have high internal consistency (.93) (Howe et al., 1991). Chronbach's alpha for the present study was also high ($\alpha$=.91).

## Procedure

Eligible participants were recruited one of two ways. Some participants, who were not scheduled for upcoming appointments in the rheumatology clinic, were sent a letter explaining the study; a postage-paid postcard was enclosed for them to return if they were interested in participating. If a family indicated they were willing to participate, a packet was then sent with the following information enclosed: parental consent form and BSI for the parent to complete, and the assent form, IIS-C, CDI, JAFAR-C, and Background Information Questionnaire for the child to complete. Once participants mailed the completed packet back to the investigators, they received the $10 compensation for their participation. Other patients were recruited in the rheumatology clinic. They were approached during a scheduled visit with the rheumatologist and told about the study. If they were willing to participate, patients and their parents were asked to fill out the packets while in the clinic or were asked to take them home and return them via postage-paid mail. If the packet was completed in the rheumatology clinic, the family

was compensated with $10; if the packet was returned via mail, the $10 compensation was mailed to the family.

No significant differences were observed across disease ($F = 0.11$, $p > .05$) or psychosocial ($F = 2.86$, $p > .05$) variables for participants recruited by mails versus those recruited in the clinic.

# CHAPTER V

# RESULTS

## Preliminary Analyses

Preliminary analyses were conducted to rule out effects of ethnicity and disease subtype on key variables. Several one-way multivariate analyses of variance (MANOVAs) revealed no significant effects for ethnicity (Caucasian vs. Non-Caucasian) on disease variables (physician-rated disease severity, physician-rated disability, JAFAR-C, and illness duration; all $p$'s > .05) or psychosocial variables (IIS-C, CDI, BSI; all $p$'s > .05). Similarly, several one-way MANOVAs revealed no significant effects for disease subtype on disease variables (physician-rated disease severity, physician-rated disability, JAFAR-C; all $p$'s > .05) or psychosocial variables (IIS-C, CDI, BSI; all $p$'s > .05). Thus, further analyses were performed collapsing across ethnicity and disease subtype.

## Selection of Covariates

Covariates utilized in the present study were selected based on theoretical rationale and on findings in the extant literature. Except for age and BSI (see Table 2), no significant associations were observed for demographic and disease variables with the psychosocial measures. However, they were included in the regression analyses to provide for a more conservative test of anticipated relationships among variables and to control for potential shared variance among variables, which could influence the contributions of key predictor variables (i.e., IIS-C and BSI) to child depression. Also, previous research has demonstrated significant age effects on depression and illness

intrusiveness in patients with rheumatoid arthritis (RA; e.g., Devins et al., 1992). In addition, extant research suggests a significant relationship between gender and depression in RA populations (e.g., Hommel, Wagner, Chaney, & Mullins, 1998).

## Primary Analyses

### Hypothesis 1

It was anticipated that parent distress (as measured by the BSI) would contribute significant variance to child depression (as measured by the CDI) beyond the influence of demographic and disease variables. To examine this hypothesis, partial correlations were calculated between parent BSI and child CDI measures, controlling for demographic and disease variables. Results revealed a significant association ($pr = .49$, $p < .01$), indicating that parent BSI accounted for 21% of the variance in CDI depression (see Table 2).

### Hypothesis 2

It was anticipated that child-reported illness intrusiveness (IIS-C) would contribute significant incremental variance to self-reported depression (CDI), beyond that accounted for by parent adjustment on the BSI and demographic and disease variables. This hypothesis was tested utilizing a hierarchical multiple regression procedure, in which age and gender were entered on Step 1 of the equation, followed by entry of physician-rated disease severity and functional ability, JAFAR-C, and illness duration on Step 2. On Step 3, the BSI and IIS-C were entered simultaneously (see Table 3). Thus, the regression equation was hierarchical between steps and stepwise within steps (Cohen & Cohen, 1983). The equation revealed a significant main effect for child reported

illness intrusiveness on child depression ($t = 3.98$, $p < .001$), after controlling for parental distress, accounting for 22% of the variance in depression (see Table 3).

Research Question 1

Because parental distress may contribute to increased perceptions of the negative impact (i.e., perceived intrusiveness) of JRD resulting in greater depression in children, illness intrusiveness was examined as a potential mediator in the parent adjustment-child adjustment relationship. Initial zero-order and partial correlations (controlling for age, gender, and disease variables) were conducted to examine associations among the key variables as a preliminary step in determining the existence of a mediator relationship. As shown in Table 2, parental distress (BSI; i.e., predictor variable) was significantly associated with illness intrusiveness (i.e., potential mediator; $r = .39$, $p < .05$), and both parental distress ($pr = .49$, $p < .001$) and illness intrusiveness ($pr = .64$, $p < .001$) were significantly related to children's depression (i.e., outcome variable). However, multiple regression analyses revealed that the contribution of parental distress to child depression remained significant in the presence of the hypothesized mediator, illness intrusiveness ($t = 2.40$, $p < .05$). Thus, as parental distress and child illness intrusiveness exerted independent effects on child depression, illness intrusiveness failed to meet criteria for mediation (e.g., Baron & Kenny, 1986).

Research Question 2

It was also examined whether the combined influence of greater parental distress **and** illness intrusiveness would enhance either the magnitude or direction of the effects

these variables have on adjustment, beyond their independent direct effects. The existence of a moderator relationship between parental distress and illness intrusiveness in determining child adjustment would require the interaction of parental distress (as measured by the BSI) and illness intrusiveness (as measured by the IIS-C) to contribute incremental unique variance to child adjustment, beyond the influence of the main effects of these variables. To test for the potential moderator effect of illness intrusiveness on the parent distress-child depression relationship, on Step 4 of the regression model, a parental distress X child illness intrusiveness interaction term was entered (see Table 3). The interaction of parental distress and child illness intrusiveness was significant ($F$ change = 5.50, $p < .05$), contributing 7% of the variance in child depression beyond the influence of demographic and disease variables and the main effects of child illness intrusiveness and parental distress. The positive beta indicates that the combined influence of parental distress and child illness intrusiveness predicted a significant increase in levels of child depression. Specifically, although parental distress and illness intrusiveness exerted main effects on depression, the influence of parental distress on child depression was enhanced under conditions of greater perceived child-reported illness intrusiveness (see Figure 1).

# CHAPTER VI

# DISCUSSION

## Conclusions

The present study examined transactional patterns of adjustment in children with juvenile rheumatic diseases and their parents. Two specific hypotheses were proposed: 1) increased parental distress would be significantly associated with child depression; and, 2) children's perceived illness intrusiveness would be significantly associated with child-reported depression, beyond the influence of parental distress. Consistent with the hypotheses, partial correlations revealed that increased parental distress was significantly associated with an increase in child depression. This relationship was observed after controlling for demographic and disease variables. In addition, regression analyses revealed that child illness intrusiveness was a significant predictor for child depression, after controlling for parent distress and disease and demographic variables. Specifically, increased self-report intrusiveness was significantly associated with increased self-report depression, after controlling for the influence of parent-reported distress.

Two research questions were also proposed to examine child illness intrusiveness as a potential mediator and/or moderator in the parent-child distress relationship. Results of the regression analyses indicated that both child illness intrusiveness and parent distress exerted independent main effects on child depression. Thus, illness intrusiveness did not serve as a mediator in the parental distress-child depression relationship. Examination of a moderator effect for illness intrusiveness on the parental distress-child

depression relationship indicated a significant parental distress X child illness intrusiveness interaction effect on child depression. This significant interaction revealed that the effects of parental distress on child depression were enhanced under conditions of increased child perceived illness intrusiveness.

As has been shown in a number of studies, transactional patterns of adjustment are crucial relationships to examine in chronic illness populations. Indeed, children's adjustment to chronic illness is influenced by parental adjustment, and those children whose parents have adaptive coping styles and social support also have better psychological adjustment to their disease (Gil et al., 1991; Thompson et al., 1992). Results of the present study provide additional support for transactional patterns of adjustment. The results also strengthen the existing body of literature by demonstrating this transactional relationship between parent and child adjustment in a previously understudied population (i.e., juvenile rheumatic diseases) and by utilizing child self-report measures instead of the exclusive reliance on parent-report measures of child adjustment frequently seen in the pediatric chronic illness literature.

Previous research has revealed the necessity of examining cognitive appraisals (Mullins et al., 1997) and their potential mediating/moderating influences (Peyrot, 1996) within a transactional model when providing an explanation for psychological adjustment in individuals with chronic illness. In the present study, illness intrusiveness appears to have particular relevance to the explanation of child depression in JRD. As Devins, Edworthy, Gutherie and colleagues (1992) hypothesize: illness intrusiveness may affect psychological well-being and distress through greatly reducing the availability of positive

and rewarding life experiences. Indeed, the awareness of disease interference with these positive experiences constitutes the subjective perception of illness intrusiveness.

Although the independent significant effects of child illness intrusiveness and parental distress on child depression are both meaningful, the combined influence of parental distress and child illness intrusiveness on child depression warrants a detailed discussion. Thompson and colleagues (1993a, 1993b, 1994) have hypothesized and provided support for the mediating/moderating influence of cognitive appraisals on psychological adjustment in chronically ill populations. Their transactional stress and coping model hypothesizes that parental and child adaptational processes (i.e., coping styles, family support) are influential variables in psychological outcome. In the present study, the influence of parental distress on child depression was enhanced under conditions of greater child illness intrusiveness, highlighting the transactional nature of parent and child adjustment.

The moderating effect of child intrusiveness on the parent distress-child depression relationship observed in the present study provides an interesting explanation for child adjustment to chronic illness. To illustrate, measures of intrusiveness (Devins et. al, 1983) assess the extent to which the disease interferes with the child's perceived functioning across several domains, including family (parent-child) relationships. Wallander and Varni (1989) demonstrated that children who rated the quality of perceived family support as higher showed significantly better adjustment when compared to those characterized by low family support. In addition, these findings were replicated by Varni, Wilcox, & Hanson (1992), who proposed that the family provides an

environment in which children can (or cannot) find the resources needed to cope with their chronic disease. Thus, the present data may suggest that when parents are distressed, children may perceive a decreased availability of parental support due to parents feeling overwhelmed by the emotional and/or functional challenges of having a chronically ill child. Children who are already feeling emotionally distressed as a function of their illness and look to their parents for support may experience even greater levels of distress (e.g., depression) when that support is not available.

Theoretical support for this explanation can be found in Lewinsohn's theory of depression (1974a and b), which states that depression is due to a low rate of response-contingent positive reinforcement. Lewinsohn further states that a low rate of reinforcement exists if only a few events are reinforcing, few reinforcers are available in the environment, and/or the individual infrequently makes those responses that would be reinforced. In the context of the present study, one can speculate that some children with JRD may perceive few opportunities for response-contingent positive reinforcement as a function of their illness (i.e., greater illness intrusiveness). Further, as a result of their children's JRD, some parents are emotionally taxed and consequently, less available to their children for support. Thus, children who view their illness as intrusive and simultaneously do not receive sufficient response-contingent reinforcement in the form of parental support may experience greater levels of depression.

At a more general level, Lewinsohn's theory may serve as a useful model for our understanding of the relationship between intrusiveness and depression in chronic illness populations. In support of Lewinsohn's theory, Devins, Edworthy, Gutherie et. al (1992)

highlight the reduction of rewarding experiences as a mechanism through which illness intrusiveness affects psychological well-being. Further, Katz (1995) has demonstrated an association between depressive symptoms in individuals with rheumatoid arthritis and performance of fewer valued activities. In another study, Katz and Yelin (1994) found that those individuals with rheumatoid arthritis who were depressed rated more activities as important but actually performed fewer valued activities. Therefore, it appears that individuals with a chronic illness who are depressed engage in fewer valued activities, and the potential for perceived absence of this response-contingent reinforcement can be explained in terms of illness intrusiveness.

## Strengths and Limitations

There are several strengths to the present study, including the utilization of both parent and child-report measures. Previous research in the pediatric chronic illness literature has almost exclusively examined child adjustment by mother report. Such a practice can be problematic because studies have demonstrated a discrepancy between parent and child report of child distress (Ennett et al., 1994; Bennett, 1994). Therefore, the present study provides a more accurate report of subjective distress and cognitive appraisals by utilizing self-report measures for children. In addition, the present study strengthens the existing body of literature that focuses on transactional patterns. For example, Bennett (1994) argues for a disease specific approach to illness because illnesses differ in terms of stresses and presentation to the family. Previous to the present study, transactional patterns between children with JRD and their families had not yet been extensively examined.

The findings of this study must be qualified by several limitations. One limitation involves the use of self-report inventories, which may have resulted in spurious correlations due to shared method variance and not to actual associations between the variables under study. This concern is attenuated somewhat by the utilization of both child and parent self-report measures. In addition, the correlational nature of this study does not permit the examination of causal relationships between variables. In other words, although illness intrusiveness was conceptualized as a predictor of depression in the regression analyses, there is no way of determining if intrusiveness was causally antecedent to depression. It may well have been the case that a certain subgroup of children were experiencing elevated levels of depression, independent of illness intrusiveness, and the children's depression resulted in a general pessimistic cognitive set, influencing appraisals of the degree to which their illness interferes with their lifestyle. Further, interpretation and generalization of these results remain limited because of the inclusion of a relatively small, self-selected sample of individuals. For example, it is possible that the present sample of children with JRD and their parents felt significantly distressed and thus chose to participate in this study. This self-selection bias may have resulted in a more homogeneous sample characterized by elevations in parental distress, child depression, and child illness intrusiveness. Unfortunately, although 85-90% of patients agreed to participate in the study, the procedure for data collection did not allow for comparisons of potential differences between those patients with JRD who participated and those who did not. Finally, study variables were collapsed across disease subgroup. Specifically, children with JRA represented the majority of

participants, while children with JAS and JDMA were underrepresented; however, preliminary analyses indicated no significant differences between disease subtypes across all variables.

Unfortunately, the scope of this study did not allow for further examination of other specific response-contingent reinforcers that may be absent in the environments of children with JRD. Future research should focus on these potential reinforcers, with implications for why they are not present and/or their association with intrusiveness and depression in children with JRD. Therefore, in the future, studies should focus on the mechanisms by which intrusiveness increases depression. In addition, future longitudinal studies could examine long-term effects of increased illness intrusiveness and parental distress on child depression.

## Clinical Implications

Finally, the results of this present study provide support for specific clinical interventions. Given that response-contingent reinforcement appears to be a critical factor in determining psychological outcome in children and adolescents with JRD, clinical interventions should focus on increasing participation in valued activities, particularly social and family relationships. Further, Devins (1989) suggests the importance of family support and the invaluable social and emotional resources families can provide to or potentially withhold from chronically ill patients. Therefore, transactional patterns of adjustment and the apparent saliency of social and family support with regards to illness intrusiveness in JRD provide the following implication for psychological treatment: the provision of support for parents of children with JRD.

Social and family support for parents can provide a buffer for stress and reduce distress (Lazarus and Folkman, 1984), thus allowing parents to be more available to their children for support. Indeed, a social support program, which paired mothers of young adult JRA patients with mothers of children recently diagnosed with JRA, showed decreases in the number of reported mental health symptoms compared to controls (Ireys, Sills, Kolodner, & Walsh, 1996).

## Future Research

The findings of the present study suggest the necessity for further research, which would examine the relationship of social and family support to perceived illness intrusiveness as well as examine possible differential psychological adjustment in families receiving social interventions and those not receiving interventions.

# REFERENCES

Albert, E., Woo, P., & Glass, D.N. (1990). Immunogenetic aspects. In P. Woo, P.H. White, & B.M. Ansell (Eds.), *Pediatric rheumatology update* (pp. 6-20). New York: Oxford University Press.

Anderson, S.M., & Lyon, J.E. (1987). Anticipating undesired outcomes: The role of outcome certainty in the onset of depressive affect. *Journal of Experimental Social Psychology, 23*, 428-443.

Barlow, J., Harrison, K., & Shaw, K. (1998). The experience of parenting in the context of juvenile chronic arthritis. *Clinical Child Psychology and Psychiatry, 3*(3), 445-463.

Baron, R.M. & Kenny, D.A. (1986). The moderator-mediator variable distinction in the social psychological research: conceptual, strategic, and statistical considerations. *Journal of Personality and Social Psychology, 51*(5), 1173-1182.

Bennett, D.S. (1994). Depression among children with chronic medical problems: A meta-analysis. *Journal of Pediatric Psychology, 19*(2), 149-169.

Billings, A.G., Moos, R.H., Miller, J.J., & Gottlieb, J.E. (1987). Psychosocial adaptation in juvenile rheumatic disease: A controlled evaluation. *Health Psychology, 6*(4), 343-359.

Binik, Y.M., Chowanec, G.D., Devins, G.M. (1990). Marital role strain, illness instrusiveness, and their impact on marital and individual adjustment in end-stage renal disease. *Psychology and Health, 4*, 245-257.

Bronfenbrenner, U. (1977). Toward an experimental ecology of human development.

*American Psychologist, 32*(7), 513-529.

Chaney, J.M., Mullins, L.L., Frank, R.G., Peterson, L. Mace, L.D., Kashani, J.H., & Goldstein, D.L. (1997). Transactional patterns of child, mother, and father adjustment in Insulin-dependent diabetes mellitus: A prospective study. *Journal of Pediatric Psychology, 2*(20), 229-244.

Chaney, J.M., Mullins, L.L., Urtesky, D.L., Doppler, M.J., Palmer, W.R., Wess, S.J., Klein, H.S., Doud, D.K., & Reiss, M.J. (1996). Attributional style and depression in rheumatoid arthritis: The moderating role of perceived illness control. *Rehabilitation Psychology, 3*, 205-223.

Chaney, J.M., Mullins, L.L., Urtesky, D.L., Pace, T.M., Werden, D., Hartman, V.L. (1999). An experimental examination of learned helplessness in older adolescents and young adults with long-standing asthma. *Journal of Pediatric Psychology, 24*(3), 259-270.

Chaney, J.M, & Youll, L.K. (1994). Systemic lupus erythematosus: Psychological issues. In R. A. Olson, L.L. Mullins, J.B. Gillman, & J.M. Chaney (Eds.), *The sourcebook of pediatric psychology* (pp. 167-176). Boston: Allyn and Bacon.

Chronbach, L. (1951). Coefficient alpha and the internal structure of tests. *Psychometrika*, 16, 297-334.

Cohen, S., & Cohen, P. (1983). *Applied multiple regression/correlation anaylsis for the behavioral sciences* (2nd ed). Hillsdale, NJ: Lawrence Erlbaum.

Cornwell, C., & Schmitt, M. (1990). Perceived health status, self-esteem, and body

image in women with rheumatoid arthritis or systemic lupus erythematosus. *Research in Nursing & Health, 13*, 99-107.

Daltroy, L.H., Larson, M.G., Eaton, H.M., Partridge, A.J., Pless, I.B., Rogers, M.P., & Liang, M.H. (1992). Psychosocial adjustment in juvenile arthritis. *Journal of Pediatric Psychology, 17*(3), 277-289.

David, J., Cooper. C., Hickey, L., Lloyd, J., Dore, C., McCullough, C., & Woo, P. (1994). The functional and psychological outcomes of juvenile chronic arthritis in young adulthood. *British Journal of Rheumatology, 33*(9), 876-881.

Derogatis, L.R., & Melisaratos, N. (1983). The Brief symptom inventory: An introductory report. *Psychological Medicine, 13*(3), 595-605.

Devins, G.M. (1989). Enhancing personal control and minimizing illness intrusiveness. In N.G. Kutner, D.D. Cardenas, & J.D. Bower (Eds.), *Maximizing rehabilitation in chronic renal disease* (pp. 109-136). New York: PMA Publishing.

Devins, G.M. (1991). Illness intrusiveness and the psychosocial impact of end-stage renal disease. *Loss Grief Care, 5*, 83-99.

Devins, G.M. (1994). Illness intrusiveness and the psychosocial impact of lifestyle disruptions in chronic life-threatening disease. *Advances in Renal Replacement Therapy, 1*(3), 251-263.

Devins, G.M., Armstrong, S.J., Mandin, H., Paul, L.C., Hons, R.B., Burgess, E.D., Taub, K., Schorr, S., Letourneau, P.K., & Buckle, S. (1990). Recurrent pain, illness intrusiveness, and quality of life in end-stage renal disease. *Pain, 42*, 279-285.

Devins, G.M., Binik, Y.M., Hutchinson, T.A., Hollomby, D.J., Barre, P.E., & Guttmann,

R.D. (1983-84). The emotional impact of end-stage renal disease: Importance of patients' perceptions of intrusiveness and control. *International Journal of Psychiatry in Medicine, 13*(4), 327-343.

Devins, G.M., Binik, Y.M., Mandin, H., Burgess, ED., Taub, K., Letourneau, P.K., Buckle, S., Low, G.L. (1986-87). Denial as a defense against depression in end stage renal disease: An empirical test. *International Journal of Psychiatry in Medicine, 16*(2), 151-162.

Devins, G.M., Edworthy, S.M., Gutherie, N.G., & Martin, L. (1992). Illness intrusiveness in Rheumatoid arthritis: Differential impact on depressive symptoms over the adult lifespan. *Journal of Rheumatology, 19*, 709-715.

Devins, G.M., Edworthy, S.M., Paul, L.C., Mandin, H., Selend, T.P., Klein, G., Costell, C.G., & Shapiro, C.M. (1992). Restless sleep, illness intrusiveness, and depressive symptoms in three chronic illness conditions: Rheumatoid arthritis, end-stage renal disease, and multiple sclerosis. *Journal of Psychosomatic Research, 37*(2), 1-8.

Devins, D.M., Mandin, H., Beanlands, H., Paul, L.C. (1997). Psychosocial impact of illness intrusiveness moderated by self-concept and age in end-stage renal disease. *Health Psychology, 16*(6), 529-538.

Devins, G.M., Mandin, H., Paul, L.C., Hons, R.B., Burgess, E.D., Klassen, J., Taub, K., Schorr, S., Letourneau, P.K., & Buckle, S. (1990). Illness intrusiveness and quality of life in end-stage renal disease: Comparison and stability across treatment modalities. *Health Psychology, 9*(2), 117-142.

Devins, G.M., Seland, T.P., Klein, G., Edworthy, S.M., & Saary, M.J. (1993). Stability and determinants of psychosocial well being in multiple sclerosis. *Rehabilitation Psychology, 38*, 11-26.

Devins, G.M., Styra, R.S., O'Connor, P.O., Gray, T., Seland, T.P., Klein, G.M., & Shapiro, C.M. (1996). Psychosocial impact of illness intrusiveness moderated by age in multiple sclerosis. *Psychology, Health & Medicine, 1*(2), 179-191.

Ennett, S.T., DeVellis, B.M., Earp, J.A., Kredich, D., Warren, R.W., & Wilhem, C.L. (1991). Disease experience and psychosocial adjustment in children with Juvenile rheumatoid arthritis: Children's versus mother's reports. *Journal of Pediatric Psychology, 16*(5), 557-568.

Fifield, J., Tennen, H., Reisine, S., & McQuillian, J. (1998). Depression and the long-term risk of pain, fatigue, and disability in patients with rheumatoid arthritis. *Arthritis and Rheumatism, 41*(10), 1851-1857.

Frank, R., Chaney, J., Clay, D., & Kay, D. (1991). Depression in rheumatoid arthritis: A re-evaluation. *Rehabilitation Psychology, 36*, 219-230.

Frank, R.G., Hagglund, K.J., Schopp, L.H., Thayer, J.F., Vieth, A.Z., Cassidy, J.T., Goldstein, D.E., Beck, N.C., Clay, D.L., Hewett, J.E., Johnson, J.C., Chaney, J.M., & Kashani, J.H. (1998). Disease and family contributors to adaptation in juvenile rheumatoid arthritis and juvenile diabetes. *Arthritis Care and Research, 11*(3), 166-176.

Gil, K.M., Williams, D.A., Thompson, R.J., & Kinney, T.R. (1991). Sickle cell disease in

children and adolescents: The relation of child and parent pain coping strategies to adjustment. *Journal of Pediatric Psychology, 16*(5), 643-663.

Hagglund, K.J., Doyle, N.M, Clay, D.L., Frank, R.G., Johnson, J.C., & Pressly, T.A. (1996). A family retreat as a comprehensive intervention for children with arthritis and their families. *Arthritis Care and Research, 9*(1), 35-41.

Hamlett, K.W., Pellegrini, D.S., & Katz, K.S. (1992). Childhood chronic illness as a family stressor. *Journal of Pediatric Psychology, 17*(1), 33-47.

Hochberg, M.C., Chang, R.W., Dwosh, I., Lindsey, S. Pincus, T. Wolfe, F. (1992). The American College of Rheumatology 1991 revised criteria for the classification of global functional status in rheumatoid arthritis. *Arthritis and Rheumatism, 35*(5), 498-502.

Holm, M.B., Rogers, J.C., & Kwoh, C.K. (1998). Predictors of functional disability in patients with rheumatoid arthritis. *Arthritis Care and Research, 11*(5), 346-355.

Hommel, K.A., Chaney, J.M., Mullins, L.L., Palmer, Wees, & Klein. (1998). Relative contributions of attributional style and arthritis helplessness to depression in rheumatoid arthritis: a longitudinal investigation. *International Journal of Rehabilitation and Health, 4*(1), 59-67.

Hommel, K.A., Wagner, J.L., Chaney, J.M., Mullins, L.L. (1998). Gender-specific effects of depression on functional disability in rheumatoid arthritis: A prospective study. *International Journal of Rehabilitation and Health, 4*(3), 183-191.

Howe, S., Levinson, J., Shear, E., Hartner, S., McGirr, G., Schulte, M., & Lovell, D.

(1991). Development of a disability measurement tool for juvenile rheumatoid arthritis. *Arthritis and Rheumatism, 34*(7), 873-880.

Ireys, H.T., Sills, E.M., Kolondner, K.B., & Walsh, B.B. (1996). A social support intervention for parents of children with juvenile rheumatoid arthritis: Results of a randomized trial. *Journal of Pediatric Psychology, 21*(5), 633-641.

Ireys, H.T., Werthhamer-Larsson, L.A., Kolodner, K.B., & Gross, S.S. (1994). Mental health of young adults with chronic illness: The mediating effect of perceived impact. *Journal of Pediatric Psychology, 19*(2), 205-222.

Kahn, M.A. (1993). Seronegative spondylarthropathies: Ankylosing spondylitis. In H.R. Schumacher, Jr., J. H. Klippel, & W.J. Koopman (Eds.), *Primer on the rheumatic diseases: Tenth edition* (pp. 171-174). Atlanta, GA: Arthritis Foundation.

Katz, P.P. (1995). The Impact of rheumatoid arthritis on life activities. *Arthritis Care and Research, 8*(4), 272-278.

Katz, P.P, & Yelin, E.H. (1994). Life activities of persons with rheumatoid arthritis with and without depressive symptoms. *Arthritis Care and Research, 7*(2), 69-77.

Kewman, D.G., Warschausky, S.A., & Engel, L. (1995). Juvenile rheumatoid arthritis and neuromuscular conditions: Scoliosis, spinal cord injury, and muscular dystrophy. In Roberts, M.C. (Eds.), *Handbook of pediatric psychology: Second edition* (pp. 384-402). New York, NY: The Guildford Press.

Kippel, J.H. (1993). Systemic lupus erythematosus: Treatment. In H.R. Schumacher, Jr., J. H. Klippel, & W.J. Koopman (Eds.), *Primer on the rheumatic diseases: Tenth edition* (pp. 112-115). Atlanta, GA: Arthritis Foundation.

Kovacs, M. (1983). *The Children's Depression Inventory: A self-rated depression scale for school-aged youngsters*. Unpublished manuscript, University of Pittsburgh School of Medicine.

Kovacs, M. (1992). *Children's Depression Inventory Manual*. Toronto, Ontario: Multi-Health Systems, Inc.

Kronenberger, W.G., Thompson, R.J. (1990). Dimensions of family functioning in families with chronically ill children: A higher order factor analysis of the Family Environmental Scale. *Journal of Clinical Child Psychology, Special Issue: The Stresses of Parenting, 19*(4), 380-388.

Kronenberger, W.G., Thompson, R.J. (1992). Psychological adaptation of mothers of children with spina bifida: Association with dimensions of social relationships. *Journal of Pediatric Psychology, 17*(1), 1-14.

Lavigne, J.V. & Faier-Routman, J. (1993). Correlates of psychological adjustment to pediatric physical disorders: A meta-analytic review and comparison with existing models. *Journal of Developmental and Behavioral Pediatrics, 14*(2), 117-123.

Lavigne, J.V., Ross, C.K., Berry, S.L., Hayford, J.R. (1992). Evaluation of a psychological treatment package for treating pain in juvenile rheumatoid arthritis. *Arthritis Care and Research, 5*(2), 101-110.

Lazarus, R.S., & Folkman, S. (1984). *Stress, appraisal, and coping*. New York: Springer.

Lewinsohn, P.M. (1974a). A behavioral approach to depression. In R.J. Riedman &

M.M. Katz (Eds.), *The psychology of depression: Contemporary theory and research*. Washington, D.C.: V.H. Winston.

Lewinsohn, P.M. (1974b). Clinical and theoretical aspects of depression. In K.S. Calhoun, H.E. Adams, K.M. Mitchell (Eds.), *Innovative treatment methods in psychopathology*. New York: Wiley.

Lorish, C.D., Abraham, N., Austin, J., Bradley, L.A., & Alarcon, G.S. (1991). Disease and psychosocial factors related to physical functioning in rheumatoid arthritis. *The Journal of Rheumatology, 18*(8), 1150-1157.

Mitchell, W.D., Thompson, T.L. (1990). Psychiatric distress in systemic lupus erythematosus outpatients. *Psychsomatics, 31*(3), 293-300.

Mullins, L.L, Chaney, J.M., Balderson, B., & Hommel, K.A. (2000). The relationship of illness uncertainty, illness intrusiveness, and asthma severity to depression in young adults with long-standing asthma. *International Journal of Rehabilitation and Health, 5*(3), 177-186.

Mullins, L.L., Chaney, J.M., Hartman V.L., Olson, R.A., Youll, L.K., Reyes, S., & Blackett, P. (1995). Child and maternal adaptation to cystic fibrosis and Insulin-Dependent Diabetes Mellitus: Differential patterns across disease states. *Journal of Pediatric Psychology, 20*, 2, 173-186.

Mullins, L.L., Olson, R.A., Reyes, S. Bernardy, N., Huszti, H.C., Volk, R.J. (1991). Risk and resistance factors in the adaptation of mothers of children with cystic fibrosis. *Journal of Pediatric Psychology, 16*(6), 701-715.

Mullins, L.L., Chaney, J.M., Pace, & Hartman, V.L. (1997). Illness uncertainty,

attributional style, and psychological adjustment in older adolescents and young adults with asthma. *Journal of Pediatric Psychology, 22*(6), 871-880.

O'Leary, A., Shoor, S., Lorig, L., & Holman, H.R. (1988). A cognitive-behavioral treatment for rheumatoid arthritis. *Health Psychology, 7*(6), 527-544.

Parker, J.C., & Wright, G.E. (1995). The importance of depression for pain and disability in rheumatoid arthritis. *Arthritis Care and Research Special Issue: A feminist clinician's guide to the memory debate, 8*(4), 279-283.

Patterson, J.M. (1988). Chronic illness in children and the impact on families. In C.S. Chilman, E.W., Nunnally, & F.M. Cox (Eds.), *Chronic illness and disability* (pp.69-107). Newbury Park, CA: Sage Publications.

Peyrot, M. (1996). Causal analysis: Theory and application. *Journal of Pediatric Psychology, 21*, 3-24.

Pieper, K.B., Rapoff, M.A., Purviance, M.R., & Lindsley, C.B. (1989). Improving compliance with prednisone therapy in pediatric patients with rheumatic disease. *Arthritis Care and Research, 2*(4), 132-135.

Rapoff, M.A., Lindsley, C.B., & Christophersen, E.R. (1984). Improving compliance with medical regimens: Case study of juvenile rheumatoid arthritis. *Archives of Psychiatric Medicine and Rehabilitation, 65*(5), 267-269.

Rapoff, M.A., Purviance, M.R., & Lindsley, C.B. (1988). Educational and behavioral strategies for improving medication compliance in juvenile rheumatoid arthritis. *Archives of Physical Medicine and Rehabilitation, 69*, 437-441.

Ross, C.K., Lavigne, J.V., Hayford, J.R., Berry, S.L., Sinacore, J.M., & Pachman, L.M.

(1993). Psychological factors affecting reported pain in juvenile rheumatoid arthritis. *Journal of Pediatric Psychology, 18*(5), 561-573.

Singsen, B.H. (1993). Pediatric rheumatic diseases. In H.R. Schumacher, Jr., J. H. Klippel, & W.J. Koopman (Eds.), *Primer on the rheumatic diseases: Tenth edition* (pp. 171-174). Atlanta, GA: Arthritis Foundation.

Smith, T., Christensen, A., Peck, J., & Ward, J. (1994). Cognitive distortion, helplessness, and depressed mood in rheumatoid arthritis: A four-year longitudinal analysis. *Health Psychology, 13*, 213-217.

Stefl, M.E., Shear, E.S., & Levinson, J.E. (1989). Summer camps for juveniles with rheumatic disease: Do they make a difference? *Arthritis Care and Research, 2*(1) 10-15.

Thompson, R.J., (1985). Coping with the stress of chronic childhood illness. In A.N. O'Quinn (Ed.), *Management of chronic disorders of childhood* (pp.11-41). Boston: G.K. Hall.

Thompson, R.J, Gil, K.M., Burbach, D.J., Keith, B.R., & Kinney, T.R. (1993a). Psychological adjustment of mothers of children and adolescents with sickle cell disease: The role of stress, coping methods, and family functioning. *Journal of Pediatric Psychology, 18*(5), 549-559.

Thompson, R.J, Gil, K.M., Burbach, D.J., Keith, B.R., & Kinney, T.R. (1993b). Role of child and maternal processes in the psychological adjustment of children with sickle cell disease. *Journal of Consulting and Clinical Psychology, 61*(3), 468-474.

Thompson, R.J., Gil, K.M., Gustafson, K.E., George, L.K., Keith, B.R., Spock, A., & Kinney, T.R. (1994). Stability and change in the psychological adjustment of mothers of children and adolescents with cystic fibrosis and sickle cell disease. *Journal of Pediatric Psychology, 19*(2), 171-188.

Thompson, R.J., Gil, K.M., Keith, B.R, Gustafson, K.E., George, L.K, & Kinney, T.R. (1994). Psychological adjustment of children with sickle cell disease: Stability and change over a 10-month period. *Journal of Consulting and Clinical Psychology, 62*(4), 856-860.

Thompson, R.J., Gustafson, K.E., George, L.K., & Spock, A. (1994). Change over a 12-month period in the psychological adjustment of children and adolescents with cystic fibrosis. *Journal of Pediatric Psychology, 19*(2), 189-203.

Thompson, R.J., Gustafson, K.E., Gil, K.M., Godfrey, J., & Bennett-Murphy, L.M. (1998). Illness specific patterns of psychological adjustment and cognitive adaptational processes in children with cystic fibrosis and sickle cell disease. *Journal of Clinical Psychology, 54*(1), 121-128.

Thompson, R.J., Gustafson, K.E., Gil, K.M, Kinney, T.R., Spock, A. (1999). Change in the psychological adjustment of children with cystic fibrosis or sickle cell disease and their mothers. *Journal of Clinical Psychology in Medical Settings, 6*(4), 373-392.

Thompson, R.J., Gustafson, K.E., Hamlett, K.W., & Spock, A. (1992a). Stress, coping, and family functioning in the psychological adjustment of mothers of children and

adolescents with cystic fibrosis. *Journal of Pediatric Psychology, Special Issue: Theory-Driven Research in Pediatric Psychology, 17*(5), 573-585.

Thompson, R.J., Gustafson, K.E., Hamlett, K.W., & Spock, A. (1992b). Psychological adjustment of children with cystic fibrosis: The role of child cognitive processes and maternal adjustment. *Journal of Pediatric Psychology, 17*(6), 741-755.

Thompson, R.J., Zeman, J.L, Fanurik, D., Sirotkin-Roses, M. (1992). The role of parent stress and coping and family functioning in parent and child adjustment to Dechenne muscular dystrophy. *Journal of Clinical Psychology, 48*(1), 11-19.

Timko, C., Baumgartner, M., Moos, R.H., & Miller, J.J. (1993). Parental risk and resistance factors among children with juvenile rheumatic disease: A four-year predictive study. *Journal of Behavioral Medicine, 16*(6), 571-588.

Timko, C., Stove, K.W., Baumgartner, M., & Moos, R.H. (1995). Acute and chronic stressors, social resources, and functioning among adolescents with juvenile rheumatic disease. *Journal of Research on Adolescence, 5*(3), 361-385.

Timko, C., Stove, K.W., & Moos, R.H. (1992). Functioning among mothers and fathers of children with juvenile rheumatic disease: A longitudinal study. *Journal of Pediatric Psychology, 17*(6), 705-724.

Vandvik, I.H., (1990). Mental health and psychosocial functioning in children with recent onset of rheumatic disease. *Journal of Child Psychology and Psychiatry, 31*(6), 961-971.

Vandvik, I.H., Eckblad, G. (1991). Mothers of children with recent onset of rheumatic disease. *Journal of Child Psychology and Psychiatry, 31*(6), 961-971.

Varni, J.W., Wilcox, K.T., Hanson, V. & Brik, R. (1988). Chronic musculoskeletal pain and functional status in juvenile rheumatoid arthritis: An empirical model. *Pain, 32*(1), 1-7.

Varni, J.W., Wilcox, K.T., & Hanson, V. (1988). Mediating effects of family social support on child psychological adjustment in juvenile rheumatoid arthritis. *Health Psychology, 7*(5), 421-431.

Walco, G.A., Varni, J.W., Ilowite, N.T. (1992). Cognitive-behavioral pain management in children with juvenile rheumatoid arthritis. *Pediatrics, 89*, 1975-1077.

Wallander, J.L., & Varni, J.W. (1989). Social support and adjustment in chronically ill and handicapped children. *American Journal of Community Psychology, 17*(2), 185-201.

White, P. (1993). Other pediatric rheumatic diseases. In H.R. Schumacher, Jr., J. H. Klippel, & W.J. Koopman (Eds.), *Primer on the rheumatic diseases: Tenth edition* (pp. 176-181). Atlanta, GA: Arthritis Foundation.

Zautra, A.J., Burleson, M.H., Matt, K.S., Roth, S., & Burrows (1994). Interpersonal stress, depression, and disease activity in rheumatoid arthritis and osteoarthritis patients. *Health Psychology, 13*(2), 139-148.

Table 1.

Disease, demographic, and psychosocial variables

| **Variables** | Frequency | M | % | SD | Range |
|---|---|---|---|---|---|
| Child's Gender | | | | | |
| Male | 14 | | 35% | | |
| Female | 26 | | 65% | | |
| Child's Ethnicity | | | | | |
| Caucasian | 19 | | 47.5% | | |
| Native American | 09 | | 22.5% | | |
| African American | 04 | | 10% | | |
| Hispanic | 03 | | 7.5% | | |
| Asian | 01 | | 2.5% | | |
| Biracial | 04 | | 10% | | |
| Child's Age (years) | | 14.4 | | (2.92) | 9-21 |
| Diagnosis | | | | | |
| JRA | 24 | | 60% | | |
| Lupus | 09 | | 22.5% | | |
| JDMA | 04 | | 10% | | |
| JAS | 03 | | 7.5% | | |
| Illness Duration (years) | | 2.69 | | (2.86) | .04-14.6 |
| PR Disease Severity | | 3.08 | | (1.65) | 1-7 |
| PR Functional Disability | | 1.57 | | (0.71) | 1-3 |
| JAFAR-C | | 4.31 | | (5.36) | 0-23 |
| BSI | | 0.48 | | (0.43) | 0-1.85 |
| IIS-C | | 21.1 | | (14.26) | 0-63 |
| CDI | | 8.65 | | (8.40) | 0-44 |

Table 2.

Zero-order and partial correlations for study variables.

| **Variables** | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
|---|---|---|---|---|---|---|---|---|---|
| 1. Child's Age | _ | | | | | | | | |
| 2. Child's Gender | | _ | | | | | | | |
| 3. PRDS | .05 | .03 | _ | | | | | | |
| 4. JAFAR-C | .07 | -.26 | .42** | _ | | | | | |
| 5. PRFD | -.03 | .08 | .66** | .43** | _ | | | | |
| 6. Illness Duration | .02 | .20 | -.18 | -.14 | .06 | _ | | | |
| 7. IIS-C | .29 | -.20 | .29 | .18 | .18 | -.12 | _ | | (.64**) |
| 8. BSI | .33* | -.10 | .12 | .21 | .06 | -.04 | .39* | _ | (.49**) |
| 9. CDI | .25 | -.01 | -.11 | -.03 | -.13 | -.20 | .58** | .50** | _ |

Note. PRDS = Physician-rated disease severity; JAFAR-C = Juvenile Arthritis Functional Assessment Report-Child Form; PRFD = Physician-rated functional disability; Duration = Illness duration (in years); IIS-C = Illness Intrusiveness Scale-Child Form; BSI = Brief Symptom Inventory; CDI = Children's Depression Inventory. Partial correlations, controlling for age, gender, PRDS, JAFAR-C, PRFD, Illness Duration, appear above the diagonal (in parentheses).

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

Table 3.

Hierarchical regression analyses of Children's Depression Inventory.

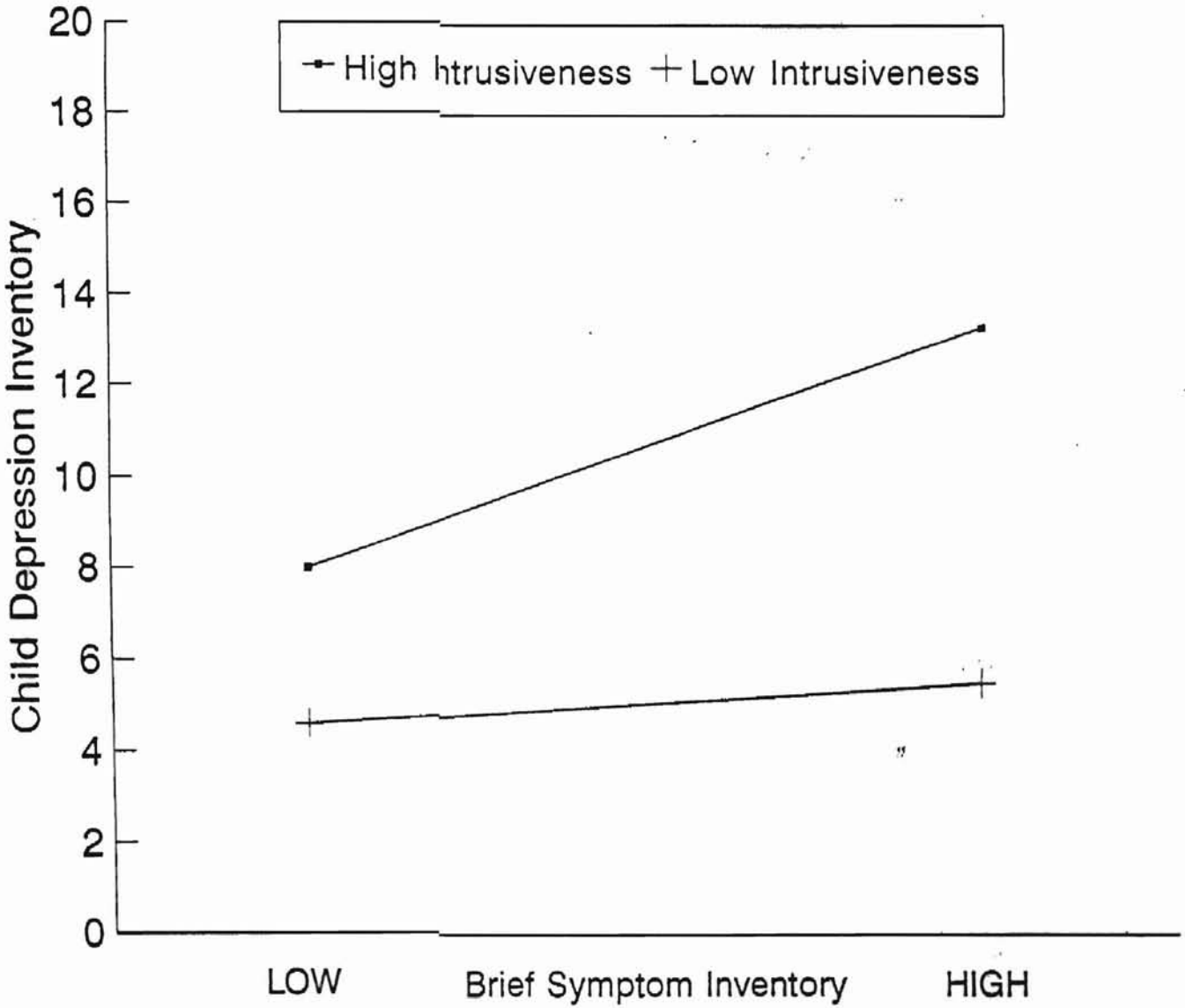
| Step | Variable | β | t for within-step predictors | $R^2$ Change for step | Cumulative $R^2$ | F Change for step |
|---|---|---|---|---|---|---|
| 1 | Gender | -.03 | -.17 | .06 | .06 | 1.21 |
| | Age | .25 | 1.55 | | | |
| 2 | PRDS | -.17 | -.72 | .07 | .13 | .67 |
| | JAFAR-C | .01 | .04 | | | |
| | PRFD | -.01 | -.04 | | | |
| | Duration | -.25 | -1.41 | | | |
| 3 | BSI | .32 | 2.40* | .43 | .57 | 15.49*** |
| | IIS-C | .56 | 3.98*** | | | |
| 4 | BSI X IIS-C | .82 | 2.35* | .07 | .63 | 5.50* |

Note: PDRS = Physician-rated disease severity; JAFAR-C = Juvenile Arthritis Functional Assessment Report-Child; PRFD = Physician-rated functional disability; Duration = Illness duration (in years); BSI = Brief Symptom Inventory; IIS-C = Illness Intrusiveness Scale-Child Form.

*$p < .05$. **$p < .01$. ***$p < .001$

Figure 1

Interaction of Parental Distress and Child Illness Intrusiveness on Child Depression.


High Intrusiveness
Low Intrusiveness
Child Depression Inventory
20
18
16
14
12
10
8
6
4
2
0
LOW
Brief Symptom Inventory
HIGH

# APPENDIX A

## Provider Questionnaire

1. Patient's name: _____

2. Patient's Diagnosis (if multiple diagnoses, please list 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 | 5 | 6 | 7 |
|---|---|---|---|---|---|---|
| Not Active or In Remission | | Mild | | Moderate | | Severe |

6. Compared to other patients, how well does this patient adhere to his/her treatment regimen?

| 1 | 2 | 3 | 4 | 5 | 6 | 7 |
|---|---|---|---|---|---|---|
| Adheres Very Poorly | | Worse than Most Patients | | Better than Most Patients | | Adheres Extremely Well |

7. Compared to other patients, how well does this patient cope with his/her illness?

| 1 | 2 | 3 | 4 | 5 | 6 | 7 |
|---|---|---|---|---|---|---|
| Copes Very Poorly | | Worse than Most Patients | | Better than Most Patients | | Copes Extremely Well |

# 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.

EXAMPLE

| Not at All | A little Bit | Moderately | Quite a Bit | Extremely | HOW MUCH WERE YOU DISTRESSED BY: |
|---|---|---|---|---|---|
| 0 | 1 | 2 | 3 | 4 | Bodyaches |

| | | 0 | 1 | 2 | 3 | 4 | HOW MUCH WERE YOU DISTRESSED BY: |
|---|---|---|---|---|---|---|---|
| 1 | | 0 | 1 | 2 | 3 | 4 | Nervousness or shakiness inside |
| 2 | | 0 | 1 | 2 | 3 | 4 | Faintness or dizziness |
| 3 | | 0 | 1 | 2 | 3 | 4 | The idea that someone else can control your thoughts |
| 4 | | 0 | 1 | 2 | 3 | 4 | Feeling others are to blame for most of your troubles |
| 5 | | 0 | 1 | 2 | 3 | 4 | Trouble remembering things |
| 6 | | 0 | 1 | 2 | 3 | 4 | Feeling easily annoyed or irritated |
| 7 | | 0 | 1 | 2 | 3 | 4 | Pains in heart or chest |
| 8 | | 0 | 1 | 2 | 3 | 4 | Feeling afraid in open spaces or on the streets |
| 9 | | 0 | 1 | 2 | 3 | 4 | Thoughts of ending your life |
| 10 | | 0 | 1 | 2 | 3 | 4 | Feeling that most people cannot be trusted |
| 11 | | 0 | 1 | 2 | 3 | 4 | Poor appetite |
| 12 | | 0 | 1 | 2 | 3 | 4 | Suddenly scared for no reason |
| 13 | | 0 | 1 | 2 | 3 | 4 | Temper outbursts that you could not control |
| 14 | | 0 | 1 | 2 | 3 | 4 | Feeling lonely even when you are with people |
| 15 | | 0 | 1 | 2 | 3 | 4 | Feeling blocked in getting things done |
| 16 | | 0 | 1 | 2 | 3 | 4 | Feeling lonely |
| 17 | | 0 | 1 | 2 | 3 | 4 | Feeling blue |
| 18 | | 0 | 1 | 2 | 3 | 4 | Feeling no interest in things |
| 19 | | 0 | 1 | 2 | 3 | 4 | Feeling fearful |
| 20 | | 0 | 1 | 2 | 3 | 4 | Your feelings being easily hurt |
| 21 | | 0 | 1 | 2 | 3 | 4 | Feeling that people are unfriendly or dislike you |
| 22 | | 0 | 1 | 2 | 3 | 4 | Feeling inferior to others |
| 23 | | 0 | 1 | 2 | 3 | 4 | Nausea or upset stomach |
| 24 | | 0 | 1 | 2 | 3 | 4 | Feeling that you were watched or talked about by others |
| 25 | | 0 | 1 | 2 | 3 | 4 | Trouble falling asleep |
| 26 | | 0 | 1 | 2 | 3 | 4 | Having to check and double-check what you do |
| 27 | | 0 | 1 | 2 | 3 | 4 | Difficulty making decisions |
| 28 | | 0 | 1 | 2 | 3 | 4 | Feeling afraid to travel on buses, subways, or trains |
| 29 | | 0 | 1 | 2 | 3 | 4 | Trouble getting your breath |
| 30 | | 0 | 1 | 2 | 3 | 4 | Hot or cold spells |
| 31 | | 0 | 1 | 2 | 3 | 4 | Having to avoid certain things, places, or activities because they frighten you |
| 32 | | 0 | 1 | 2 | 3 | 4 | Your mind going blank |
| 33 | | 0 | 1 | 2 | 3 | 4 | Numbness or tingling in parts of your body |
| 34 | | 0 | 1 | 2 | 3 | 4 | The idea that you should be punished for your sins |
| 35 | | 0 | 1 | 2 | 3 | 4 | Feeling hopeless about the future |
| 36 | | 0 | 1 | 2 | 3 | 4 | Trouble concentrating |
| 37 | | 0 | 1 | 2 | 3 | 4 | Feeling weak in parts of your body |
| 38 | | 0 | 1 | 2 | 3 | 4 | Feeling tense or keyed up |
| 39 | | 0 | 1 | 2 | 3 | 4 | Thoughts of death or dying |
| 40 | | 0 | 1 | 2 | 3 | 4 | Having urges to beat, injure, or harm someone |
| 41 | | 0 | 1 | 2 | 3 | 4 | Having urges to break or smash things |
| 42 | | 0 | 1 | 2 | 3 | 4 | Feeling very self-conscious with others |
| 43 | | 0 | 1 | 2 | 3 | 4 | Feeling uneasy in crowds, such as shopping or at a movie |
| 44 | | 0 | 1 | 2 | 3 | 4 | Never feeling close to another person |
| 45 | | 0 | 1 | 2 | 3 | 4 | Spells of terror or panic |
| 46 | | 0 | 1 | 2 | 3 | 4 | Getting into frequent arguments |
| 47 | | 0 | 1 | 2 | 3 | 4 | Feeling nervous when you are left alone |
| 48 | | 0 | 1 | 2 | 3 | 4 | Others not giving you proper credit for your achievements |
| 49 | | 0 | 1 | 2 | 3 | 4 | Feeling so restless you couldn't sit still |
| 50 | | 0 | 1 | 2 | 3 | 4 | Feelings of worthlessness |
| 51 | | 0 | 1 | 2 | 3 | 4 | Feeling that people will take advantage of you if you let them |
| 52 | | 0 | 1 | 2 | 3 | 4 | Feelings of guilt |
| 53 | | 0 | 1 | 2 | 3 | 4 | The idea that something is wrong with your mind |

# APPENDIX C

## Background Information Questionnaire

1. Age: _____

2. Gender: M (1) F (2)

3. Ethnicity:
   1 Caucasian
   2 African American
   3 Native American
   4 Hispanic
   5 Asian
   6 Biracial; Specify: _____
   7 Other; Specify: _____

4. Highest level of education attained:
   1 Elementary School
   2 Middle School
   3 High School
   4 Some College; Specify number of years: _____

5. Marital Status:
   1 Never married
   2 Married
   3 Divorced
   4 Cohabitation (living with partner)
   5 Widowed
   6 Other: _____

6. Parent's Occupation: Father: _____ Mother: _____

7. Parent's highest level of education:

   Father:
   1 Middle School
   2 High School
   3 Some College; Specify number of years: _____
   4 College Degree
   5 Post-Graduate Degree

   Mother:
   1 Middle School
   2 High School
   3 Some College; Specify number of years: _____
   4 College Degree
   5 Post-Graduate Degree

8. Living Arrangement:
   1 Live alone
   2 Live with both parents
   3 Live with one parent; Specify which parent: _____
   4 Other; Specify: _____

9. Are you currently taking any psychoactive medication (e.g., antidepressants, anti-anxiety)?

   Yes (1) No (2)

10. Have you ever received any type of psychological counseling/therapy? Yes 1 No 2

11. Have you ever received counseling directly related to your JRD? Yes 1 No 2

12. Please indicate the number of visits to your physician due to your JRD in the past 6 months: _____

13. How severe do you think your JRD has been in the past year?

| 1 | 2 | 3 | 4 | 5 | 6 | 7 |
|---|---|---|---|---|---|---|
| Not Active or In Remission | | Mild | | Moderate | | Severe |

14. How much control do you think **you** have over the **daily symptoms** of your JRD?

| 1 | 2 | 3 | 4 | 5 | 6 | 7 |
|---|---|---|---|---|---|---|
| No Control | | A Little Control | | A Great Deal Of Control | | Complete Control |

15. How much control do you think your **physician** has over the **daily symptoms** of your JRD?

| 1 | 2 | 3 | 4 | 5 | 6 | 7 |
|---|---|---|---|---|---|---|
| No Control | | A Little Control | | A Great Deal Of Control | | Complete Control |

16. How much control do you think **you** have over the **long-term course** of your JRD?

| 1 | 2 | 3 | 4 | 5 | 6 | 7 |
|---|---|---|---|---|---|---|
| No Control | | A Little Control | | A Great Deal Of Control | | Complete Control |

17. How much control do you think your **physician** has over the **long-term course** of your JRD?

| 1 | 2 | 3 | 4 | 5 | 6 | 7 |
|---|---|---|---|---|---|---|
| No Control | | A Little Control | | A Great Deal Of Control | | Complete Control |

18. How important to you is the ability to perform, by yourself, activities of daily living such as dressing yourself?

| 1 | 2 | 3 | 4 | 5 | 6 | 7 |
|---|---|---|---|---|---|---|
| Not at all Important | | A Little Important | | Somewhat Important | | Very Important |

19. Currently, how active are the symptoms of your JRD?

| 1 | 2 | 3 | 4 | 5 | 6 | 7 |
|---|---|---|---|---|---|---|
| Not Active or In Remission | | Mild | | Moderate | | Severe |

20. Please indicate the number of school and/or work days you have missed in the last 6 months: _____

# APPENDIX D

## Children's Depression Inventory (CDI)

Kids sometimes have different feelings and ideas.

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

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

Remember, pick out the sentence that describes your feelings and ideas in the PAST TWO WEEKS.

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 in not a big problem

16. _____ I have trouble sleeping every night

_____ I have trouble sleeping may 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 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 subjects 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

THANK YOU FOR FILLING OUT THIS FORM

# APPENDIX E

## Illness Intrusiveness Scale-Child Form (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 activites (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 within 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 F

## Juvenile Arthritis Functional Assessment Report for Children (JAFAR-C)

Below are some questions about some things that have to be done to eat, get dressed, and go to school. Please tell us how well you've been able to do these things during the past week by placing a check mark under the column that describes your ability. For example, if you were asked, "Over the past week, have you been able to brush your hair by yourself: All of the time, Just some of the time, of Almost never?", you would place a check mark under the column labeled "All of the time" if you were able to do this everyday. For the following questions, please tell us how often you have been able to perform each of the following activities:

| | All the time | Sometimes | Almost Never |
|---|---|---|---|
| 1. Take shirt off hanger | _____ | _____ | _____ |
| 2. Button shirt | _____ | _____ | _____ |
| 3. Pull on sweater over head | _____ | _____ | _____ |
| 4. Turn on water faucet | _____ | _____ | _____ |
| 5. Climb into bathtub | _____ | _____ | _____ |
| 6. Dry back with towel | _____ | _____ | _____ |
| 7. Wash face with washcloth | _____ | _____ | _____ |
| 8. Tie shoelaces | _____ | _____ | _____ |
| 9. Pull on socks | _____ | _____ | _____ |
| 10. Brush teeth | _____ | _____ | _____ |
| 11. Stand up from chair without using arms | _____ | _____ | _____ |
| 12. Get into bed | _____ | _____ | _____ |
| 13. Cut food with knife and fork | _____ | _____ | _____ |
| 14. Life empty glass to mouth | _____ | _____ | _____ |
| 15. Reopen previously opened food jar | _____ | _____ | _____ |
| 16. Walk 50 feet without help | _____ | _____ | _____ |
| 17. Walk up 5 steps | _____ | _____ | _____ |
| 18. Stand up on tiptoes | _____ | _____ | _____ |
| 19. Reach above head | _____ | _____ | _____ |
| 20. Get out of bed | _____ | _____ | _____ |

| | | | |
|---|---|---|---|
| 21. Pick up something from floor from standing position | _____ | _____ | _____ |
| 22. Push open door after turning knob | _____ | _____ | _____ |
| 23. Turn head and look over shoulder | _____ | _____ | _____ |

# APPENDIX H

## IRB Approval Form

# Oklahoma State University
# Institutional Review Board

Protocol Expires: 1/21/03

Date : Tuesday, January 22, 2002 IRB Application No AS00104

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

Principal Investigator(s) :

Janelle Wagner
407 N. Murray
Stillwater, OK 74078

James Jarvis
407 N Murray
Stillwater, OK 74078

Molly White
407 N. Murray
Stillwater, OK 74078

John Chaney
407 N Murray
Stillwater, OK 74078

Reviewed and Expedited (Spec Pop) **Continuation**

Approval Status Recommended by Reviewer(s) : Approved

---

Signature : Carol Olson

Carol Olson, Director of University Research Complian

Tuesday, January 22, 2002
Date

Approvals are valid for one calendar year, after which time a request for continuation must be submitted. Any modifications to the research project approved by the IRB must be submitted for approval with the advisor's signature. The IRB office MUST be notified in writing when a project is complete. Approved projects are subject to monitoring by the IRB. Expedited and exempt projects may be reviewed by the full Institutional Review Board.

# APPENDIX I

## Informed Consent and Assent Forms

Consent Form

I, _____(name of participant's parent/legal guardian), voluntarily consent to allow my child to participate in the investigation of psychological factors and juvenile rheumatic diseases (JRD).

**PURPOSE OF STUDY** The purpose of the study is to examine psychological factors associated with JRD disease processes.

**DESCIUPTION OF RESEARCH PROCEDURES:** The research requires the completion of several paper-and-pencil measures in the Pediatric Rheumatology Clinic at the Children's Hospital of Oklahoma that address psychological factors and perceptions of life events, both in general and with respect to JRA. Some items on the questionnaires contain sensitive issues (e.g., depression, relationships, etc.).

**COSTS:** There are no costs to your child for participation in this study.

**POSSIBLE RISKS:** There is virtually no risk associated with completing questionnaires. It is possible that your child may experience some negative emotions during the completion of the questionnaires, but these will be short-lived and have no long-term effects.

**RIGHT TO REFUESE OR WITHDRAWAL:** My child's participation is voluntary; there is no penalty for refusal to participate, and my child is free to withdraw his/her consent and participation in this project at any time without penalty, after notifying the project director.

**BENEFITS**: Although my child's participation may not necessarily be personally beneficial to my child, the information derived from this project may have important implications for others who have JRD. The information gained may contribute to a better understanding of the cognitive/emotional functioning and overall treatment of individuals with JRD.

**COMPENSATION AND INJURY:** I understand that my child and I will receive $10.00 compensation in the form of gift certificates for approximately one hour of participation, and there is no risk of injury as a result of this study.

**SUBJECT ASSURANCES:** Any data collected as part of my child's participation in this experiment will he treated as confidential and will receive a code number so that they will remain confidential. In no case will any use be made of these data other than as research results. If data from my child's participation are ever displayed, my child's identity w'ill remain confidential.

I may contact Dr. John Chaney, Oklahoma State University, Psychology Department, 215 North Murray Hall, Stillwater, Oklahoma 74078, at (405) 744-5703 should I wish further information about the research. I may also contact the Institutional Review Board (IRB) executive assistant, Sharon Bacher, Oklahoma State University, 203 Whilehurst, Stillwater, Oklahoma 74078, (405) 744-5700. Should any problems arise during the course of the study, I may take them to Dr. Maureen Sullivan, Psychology Department Head, Oklahoma State University, Department of Psychology, 215 North Murray Hall, Stillwater, OK 74078, at (405) 744-027

I have read and fully understand the consent form, and the option to receive a copy of this consent form has been given to me. I sign it freely and voluntarily.

Date: _____ Time: _____ (A.M./P.M.)

Signed: _____

(Signature of participant's parent/legal guardian)

Witness(es) if required: _____

I certify that I have personally explained all elements of this form to the subject before requesting the subject to sign it

Signed: _____

(Project director or his/her authorized representative)

Assent Form

By signing this form, you are saying that you volunteer to participate in the following study on feelings and juvenile rheumatoid disease (JRD). For this study you will complete several questionnaires. No harm will come to you as a result of participating in this study, however, you are free to stop at any time during your participation in the study. Although the information that you provide will not benefit you directly, other individuals with RA and related medical conditions will likely benefit through better overall treatment of their disease. Your name will not be used after you complete these questionnaires. This means that the information you provide will not be made public in any way, and only you and the experimenter will know what answers you provide on the questionnaires.

Signed:_____
(Signature of participant)

Date: _____ Time:_____ (A.M./P.M.)

Witness(es) if required: _____

I certify that I have explained all elements of this form to the participant before requesting them to sign it.

Signed: _____

7

# VITA

Janelle L. Wagner

Candidate for the Degree of

Master of Science

Thesis: CONTRIBUTION OF PARENTAL ADJUSTMENT AND CHILDREN'S PERCEIVED ILLNESS INTRUSIVENESS TO CHILD DEPRESSION IN JUVENILE RHEUMATIC DISEASES

Major Field: Psychology

Biographical

Education: Graduated from Stillwater High School, Stillwater, OK, in May 1994; Received Bachelor of Arts degree in Psychology and graduated Summa Cum Laude with a minor in Religion and Honors in Psychology from Wake Forest University, Winston-Salem, NC in May 1998; Completed the requirements for the Master of Science degree with a major in Clinical Psychology at Oklahoma State University in May 2002.

Experience: Clinical practica experience through Oklahoma State University Psychological Services Center, August 1999 to present; clinical practica experience through the Center for Child Abuse and Neglect and Consultation Liaison Services at the University of Oklahoma Health Sciences Center, June 2001 to present; Instructor of Introductory Psychology, August 2000 to June 2001; Teaching Assistant, August 1999 to May 2001 and August 2001 to present; research associate in the Health Psychology Research Lab under John Chaney, Ph.D. in the Department of Psychology at Oklahoma State University, August 1999 to present; research assistant at the Attention Deficit Program under C. Keith Conners, Ph.D., in the Department of Psychiatry at Duke University Medical Center, September 1998 to June 1999; research tutor in the Fast Track Program under Dr. John Coie, Ph.D., in the Department of Psychology at Duke University, September 1998 to February 1999; honors research project under Deborah Best, Ph.D., in the Department of Psychology at Wake Forest University

Professional Affiliations: American Psychological Association (APA), APA Division 54-Society of Pediatric Psychology, APA Graduate Student Association, Association for the Advancement of Behavior Therapy, Oklahoma State University Psychology Graduate Student Association