# TRANSACTIONAL PATTERNS OF PARENT AND CHILD ADJUSTMENT IN JUVENILE RHEUMATIC DISEASES: THE ROLE OF ILLNESS UNCERTAINTY

By

MOLLY MARIE WHITE

Bachelor of Science

Kansas State University

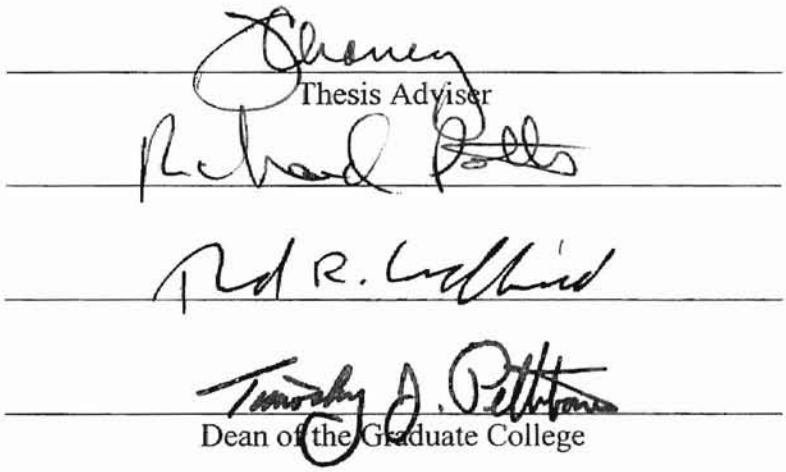
Manhattan, Kansas

2000

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
August, 2002

TRANSACTIONAL PATTERNS OF PARENT AND CHILD ADJUSTMENT IN JUVENILE RHEUMATIC DISEASES: THE ROLE OF ILLNESS UNCERTAINTY

Thesis Approved:



Thesis Adviser

Dean of the Graduate College

## ACKNOWLEDGMENTS

I wish to express my sincere appreciation to my major advisor, Dr. John M. Chaney for his support, inspiration, intellect, and guidance. I want to also thank Dr. Chaney for providing me with the opportunity to expand my research experiences and knowledge, while encouraging and pushing me to venture beyond my comfort zone. I also wish to express my appreciation to my other committee members, Dr. Thad Leffingwell and Dr. Richard Potts, whose assistance, guidance, and encouragement are also valued. My appreciation extends to Dr. Jim Jarvis, who provided the opportunity to work with him in his clinic and collect research data from his patients.

Additionally, I want to express my gratitude to those who provided suggestions, support, and additional guidance for this study. In particular, I wish to convey my sincere appreciation to both Janelle Wagner and Jill Van Pelt for not only their suggestions to this project, but also for their friendship and support.

Finally, I wish to convey my special gratitude and appreciation to my family, Pres, Marikay, Joel, Melody, and Seth White for not only their encouragement and support through this project, but also for their understanding, love, and support through these past few years.

TABLE OF CONTENTS

Chapter Page

## NOMENCLALTURE

| | |
|---|---|
| JRD | juvenile rheumatic disease |
| JRA | juvenile rheumatic arthritis |
| SLE | systemic lupus erythematosus |
| SA | juvenile spondyloarthropathies |
| JDM | juvenile dermatomyositis |
| JAFAR-P | Juvenile Arthritis Functional Assessment Report-Physician |
| BSI | Brief Symptom Inventory |
| JAFAR-C | Juvenile Arthritis Functional Assessment Report-Child |
| CDI | Child Depression Inventory |
| MUIS-C | Mishel Uncertainty in Illness Scale-Child |
| IV | Independent variable |
| DV | Dependent variable |
| ANOVA | one way analysis of variance |

# CHAPTER I

# INTRODUCTION

## Epidemiology of Juvenile Rheumatic Diseases (JRD)

Juvenile rheumatic diseases (JRD) are a heterogeneous group of autoinflammatory diseases characterized by a variable, unpredictable disease course, and disabling nature. The most common JRD are juvenile rheumatoid arthritis (JRA), systemic lupus erythematosus (SLE), juvenile spondyloarthropathies (SA), and juvenile dermatomyositis (JDM). Diagnositic criteria include the presence of swelling or effusion of one or more joints for at least six weeks and in addition, two or more of the following must be present: limitation of motion, pain, heat, or tenderness (Brewer et al., 1977).

Juvenile rheumatoid arthritis (JRA) is not only the most common childhood arthritis, but also one of the most common childhood illnesses. It is estimated that in the United States there are 70,000 to 250,000 active and inactive cases of JRA in children less than sixteen years of age, girls being affected twice as often as boys (Cassidy & Nelson, 1988; Lovell, & Walco, 1989; Schanberg et al., 2000). In addition, approximately 35,000 to 50,000 individuals over the age of sixteen in the United States have active JRA (Lovell & Walco, 1989). Juvenile rheumatic arthritis is an autoimmune disorder characterized by inflammation of the joints, pain, fatigue, morning stiffness, restricted movement, and functional impairment (Cassidy & Petty, 1995; Schanberg et.

al, 2000). More specifically, the synovium, which is the protective lining of the joint, becomes inflamed and causes the membrane to thicken and increase the production of synovial fluid, which increases the pressure on the joint. The inflammation, which does not subside when it should, causes tissue damage. It is unknown why the inflammation takes on such a destructive nature. The onset of JRA is typically before age 16 and can be as early as six months of age. Individuals with JRA have arthritis in one or more joints, which is defined as swelling or effusion, or the presence of two or more of the following symptoms: limited range of motion, tenderness or pain during motion, or increased heat. In addition, the duration of the symptoms must persist longer than six weeks and other forms of juvenile arthritis must be excluded. Lastly, the type of disease classification must be made during the first six months of onset between the three JRA subtypes: systemic, polyarticular, and pauciarticular (Cassidy, Levinson, Brewer, 1989).

Systemic JRA can develop at any age, but most commonly occurs from 1 to 6 years of age, and affects 10% - 20% of children diagnosed with JRA equally affecting boys and girls (Kewman, Warschausky, & Engel, 1995). This subtype is characterized by daily or twice daily intermittent fever spikes (>101 F) with frequent shaking chills, and pink rheumatoid rashes, which may occur anywhere on the body and typically arise late in the day. Systemic JRA may include inflammation around the heart, increases in white blood cells and platelets, and enlargement of other internal organs (e.g., liver and spleen). In addition, the arthritis affects large and small joints (e.g., knees, wrists, hands, ankles, feet, elbows, cervical spine, jaw, shoulders) (Wedgewood & Schaller, 1977).

Polyarticular JRA occurs in about 40% of children with JRA, can occur at any age, and affects girls three times more than boys (Kewman, Warschausky, & Engel,

1995). This subtype can be described as the presence of arthritis in five or more joints and onset of symptomology peaks at 1 to 3 years of age. Children with this disease often experience fatigue, anorexia, protein-caloric malnutrition, anemia, growth retardation, delays in sexual maturation, and osteopenia. In addition, systemic features may occur; however, this is uncommon. Similar to individuals with systemic JRA, children with polyarticular JRA experience the affects of the arthritis in both the large and small joints of the body (Kewman, Warschausky, & Engel, 1995).

Pauciarticular JRA is characterized by arthritis in four or fewer joints and occurs in approximately 50% of children with JRA. In general, children show symptoms between one to three years of age, boys are affected five times more than girls, and the arthritis usually involves larger joints (e.g., knee, hip) (Kewman, Warschausky, & Engel, 1995). Pauciarticular JRA is divided into two categories: early onset (one to five years of age) and late onset. In early onset, girls are four times more likely to be affected than boys, and 30-50% experience inflammation of the inner eye, which can result in severe, irreversible eye changes including loss of vision. Later onset pauciarticular JRA is more common in boys than in females, and it is less likely for the occurrence of chronic eye complications (Lovell, 1996).

Systemic lupus erythematosus (SLE) is a rheumatic disease characterized by muscle pain, weakness, fatigue, anorexia, morning stiffness, swelling, and limited range of motion; however, deformity and erosion of the bone is uncommon. The only specific clinical sign is a butterfly rash, which occurs over the child's facial cheeks and bridge of nose. In addition, ulcers may occur on the palate and in the nose, as well as temporary hair loss. It is estimated that 10% of patients seen in pediatric rheumatology have SLE,

which is usually diagnosed in adolescence and is five times more common in girls than in boys. Disease involvement may include some combination of the renal, pulmonary, cardiovascular, gastrointestinal, and endocrine systems. It is estimated that about half the children diagnosed with SLE will experience some central nervous system effects during the course of their illness (Chaney & Youll, 1994). The prognosis for SLE has improved, but there is evidence that renal disease occurs in 60-90% of children with SLE. The most common causes of death in childhood lupus are infection, cerebritis, pancreatisis, and pulmonary hemorrhage (Emery, 1986).

Juvenile spondyloarthropathies (SA) is another class of juvenile rheumatic diseases affecting 10-15% of children diagnosed with a JRD (Schaller, 1983). It is less common in children than JRA, occurs more often in boys than girls, and is diagnosed before the age of 16. Children usually experience episodic arthritis versus chronic, and the lower extremities are much more commonly affected (Lovell, 1996).

Juvenile dermatomyositis (JDM) is characterized as acute and chronic nonsuppurative inflammation of striated muscle, skin, and gastrointestinal tract. More generally, JDM is a disease of the connective tissue, which occurs in approximately 1 in 200,000 individuals in the United States. Onset is usually between five and 14 years of age and occurs more frequently in girls. The cause is unknown; however, infectious agents have long been believed to play a role. Children with JDM usually present with heliotrope discoloration of the eyelids, scaly rash, muscle weakness, fatigue, malaise, and fever. In addition, 25-50% of children with JDM develop calcinosis, which are subcutaneous calcium deposits, and can result in physical disability. The most frequently detected cardiac abnormalities are nonspecific electrocardiogram changes and murmurs.

## Psychological Factors

The relationship between psychological variables and juvenile rheumatic diseases has been widely examined. It is believed that individuals with JRA may be more susceptible to psychological complications due to the characteristics of the disease: experiences of pain, physical deformity, disability, and chronicity. In addition, Patterson and Blum (1996) indicate uncertain prognosis, invisible condition, chronic pain, and a remitting course as additional risk factors for psychological distress. David and colleagues (1994) found that 21% of JRA patients were clinically depressed and that these rates tended to increase with the degree of disease severity. In particular, patients perceived arthritis as creating the most problems in the areas of employment and home, over the ability to form social relationships. Research has also indicated that in a sample of children with JRA, 51% met criteria for one or more DSM-III diagnoses, and 64% showed some difficulty in psychosocial functioning (Vandvik, 1990). Lovell (1996) found that more than 30% of JRA patients had significant limitations after 10 or more years follow-up. In addition, a study which compared children with severe rheumatic diseases to both a group of children with milder or inactive forms of rheumatic diseases and a control group consisting of healthy children found that the children with severe rheumatic disease experienced significantly more physical and psychological problems than the other two groups (Billings, Moos, Miller, & Gottlieb, 1987). Pless (1984) found that children with chronic illness have an estimated 1.5 to 3 times great risk of experiencing significant psychological or social problems during childhood than that of healthy peers.

Researchers have also examined the psychological adjustment of children diagnosed with systemic lupus erythematosus (SLE). Given that SLE has variable clinical presentations and an unpredictable cause, it is common that both the patient and family feel despair and frustration from the initial diagnosis and treatment uncertainties associated with SLE (Chaney & Youll, 1994). Mitchell and Thompson (1990) compared three different outpatient groups. One was comprised of children diagnosed with SLE, another group included children experiencing a general medical condition, and finally a psychiatric group. Results indicated that children diagnosed with SLE and children coping with a general medical condition experienced similar symptoms and stressors. Overall, results showed no differences between SLE and other chronic medical diseases.

In general, it appears children with JRD are at greater risk for adjustment problems. However, disease variables alone do not account for the observed variance in psychological adjustment (Bennett, 1994; Pless, 1984). In other words, children with similar levels of pain and disease severity often demonstrate varying levels of adjustment problems, including depression and anxiety (Ennet, DeVellis, Earp, Kredich, Warron, & Wilhelm, 1991). These findings suggest that not merely the disease, but the manner in which children perceive the disease may make significant contributions to psychological adjustment.

## Cognitive Appraisal: Illness Uncertainty

Research has begun to examine cognitive appraisal mechanisms in the adjustment process in pediatric chronic illnesses. One cognitive appraisal variable that has received a good deal of attention and appears to have particular relevance to the adjustment process

in JRD is illness uncertainty (Mullins, Chaney, Balderson, & Hommel, 2000; Mullins, Chaney, Pace, & Hartman, 1997). Illness uncertainty is defined as a cognitive state created when an event cannot be adequately structured or categorized because of a lack of sufficient cues (Mishel, 1984). More specifically, a situation is judged as uncertain when the decision maker is unable to assign definite values to objects and events and/or is unable to accurately predict the outcome (Mishel, 1983). To illustrate, because JRD are such highly variable and unpredictable illnesses, greater perceived uncertainty about illness management and outcome are both highly likely and may constitute a significant stressor contributing to individuals' negative perceptions of their illness and to increased emotional distress. Moreover, repeated exposure to such behavior-outcome noncontingency may result in less effective problem-solving and greater depression (e.g., Chaney, Mullins, Urtesky, Pace, Werden, & Harman, 1999). Mishel's (1988) model of illness uncertainty suggests that individuals attempt to organize and make sense of illness experiences which are: 1) inherently ambiguous, 2) complex, 3) providing insufficient information, or 4) inaccurately predicting outcomes. Under these conditions illness uncertainty may result. In other words, individuals may develop a sense of uncertainty about future outcomes as a function of the ambiguous contingencies (i.e., adherence-improvement) frequently inherent in the clinical course of JRD. Moreover, there appears to be a relationship between perceived uncertainty and mood disturbance, emotional distress, and anxiety (Bennett, 1994; Mast, 1995).

As stated previously, events and objects can be described as being uncertain if they are vague, ambiguous, unpredictable, unfamiliar, inconsistent, or lacking information, which can lead to the inability to determine meaning of illness-related

events (Mishel, 1988). Specifically applied to a medical setting, some common events that can be described as uncertain include words used by the medical staff, knowing one's diagnosis or seriousness, and knowing the anticipated amount and occurrence of pain and discomfort from treatment. Mishel and Braden (1987) found that the experience of uncertainty changes across the disease course. For example, during the diagnosis stage, uncertainty centers on the ambiguity of the illness. Later during the treatment stage, uncertainty is expressed through the complexity of the treatment, and during the stabilization stage, uncertainty is centered on the unpredictability of the outcome. In addition, Cohen (1995) stresses the significance of the changes of uncertainty, which occur during the remission stage. Uncertainty at this time focuses on the question of whether or not, or when, the illness will resurface.

Prior research has demonstrated significant relationships between the experience of uncertainty and one's ability to cope with a chronic illness. For example, uncertainty has been shown to be a significant intervening variable in the relationship between social support and adjustment (Mishel and Braden, 1987). In addition, Mishel (1984) found a strong relationship between uncertainty and stress. Braden and Lynn's study (as sited in Mishel & Braden, 1988) examined uncertainty in individuals diagnosed with rheumatic arthritis. Results indicated that the lack of a consistent symptom pattern was the greatest predictability of uncertainty. Uncertainty has also been associated with elevated anxiety levels in caretakers of persons with systemic lupus (King, 1983).

Further, although no known studies have examined the role of children's perceived illness uncertainty in adjustment to JRD, studies have demonstrated that perceived illness uncertainty/unpredictability is reliably associated with emotional

difficulties across a number of pediatric chronic medical conditions (Mullins et al., 1997; Mullins, Chaney, Hartman, Albin, Miles, & Roberson, 1995; Ireys, Werthamer-Larsson, Kolodner, & Gross, 1994). Because many features of illness uncertainty (e.g., ambiguity, predicting outcomes) are likely in JRD and can be addressed through clinical intervention, there appears to be a need for examining the role of this cognitive appraisal variable in children's adjustment to JRD.

## Transactional Stress and Coping Model

Chronic illness, given its psychological, painful, and disabling nature, is often viewed as a potential stressor to which both the child and family system endeavor to adapt (Thompson, 1985). In general, a number of studies have documented the potential influence of illness on children and other family members (e.g., Chaney & Peterson, 1989; Eiser & Havermans, 1992; Hamlett, Pellegrini, & Katz, 1992; Pless, 1984). More specifically, research by Compas and colleagues (1989) indicated that psychological adjustment of chronically ill children was affected by levels of stress and symptoms experienced by other family members. In general, the transactional stress and coping perspective takes into consideration the biomedical, developmental, behavioral, and psychosocial parameters, and how these parameters influence stress and adjustment in the child and parents.

Studies have indicated that children's ability to manage pain is likely influenced by their parents' level of distress (Peterson, 1989; Ross, Lavigne, Hayford, Berry, Sinacore, & Pachman, 1993; Siegel & Smith, 1989). In addition, a study comprised of a sample of children diagnosed with sickle cell disease, found that parent's coping strategy

accounted for significant proportions of variance in child's activity level, visits/calls to physician, and psychological distress (Gil, Williams, Thompson, and Kinney, 1991). Similar transactional relationships have been demonstrated in other disease populations. For example Thompson and colleagues (1992c) examined children diagnosed with Duchenne Muscular Dystrophy and found that 57% of the parents reported themselves as having poor psychological adjustment. Parent distress accounted for 19% of the variance in children's internalizing behavior problems and 16% of the variance in externalizing behavior problems. Chaney and colleagues (1997) found similar transactional relationships in the families of children diagnosed with insulin-dependent diabetes mellitus.

Unfortunately, the research examining parent-child transactional relationships has neglected to examine this process in children diagnosed with juvenile rheumatic diseases. Additionally, many of the studies (Daltroy et al., 1992; Wallander, Varni, Babani, Baris, & Wilcox, 1988; & Varni, Wilcox, & Hanson, 1988) have relied exclusively on parent-report measures of both parent and child adjustment. Beyond these limitations, it is clear that parent and child distress are interrelated, but it is currently unclear the specific processes by which these emotional transactions occur.

## Outline of Thesis

The present paper examines the relationship between parental psychological distress and children's psychological adjustment (i.e., depression) in children with juvenile rheumatic disease. Special emphasis is placed on the potential influence of children's perceived illness uncertainty in the parent-child adjustment relationship.

A study is proposed that will utilize Baron and Kenny's (1986) cognitive mediation perspective (see also Holmbeck, 1997) in examining both the direct and indirect (i.e., mediation and moderation) contributions of parent and child variables to child adjustment. Specifically, the study will examine the predictive utility of both parental psychological distress and child illness uncertainty in determining children's psychological adjustment in a sample of children with juvenile rheumatic disease.

To accomplish this, a review of the current literature is presented, examining potential parent and child psychological variables related to children's adjustment to JRD. Specific attention is given to the examination of the cognitive appraisal mechanism of illness uncertainty and how this construct may play an important role in the JRD disease process. Additionally, the transactional stress and coping model of adjustment is discussed regarding its utility in examining parent and child variables contributing to children with JRD.

# CHAPTER II

# REVIEW OF THE LITERATURE

## Treatment Issues in JRD

Currently there is no known causal agent for JRD. Vandvik (1990) stresses that the occurrences of these diseases are multifactorial, including genetic, immunological, and infectious triggers. In addition to the triggers proposed by Vandvik, Schanberg and colleagues (2000) propose trauma, psychological stress and mood as additional prompts to the causes of JRD. Conflicting research has resulted from examining the role of psychological stress as a causal agent for the onset of JRA. Specifically, two studies examined multiple sets of monozygotic twins and found prior to the onset of the disease, the twin who was diagnosed with JRA experienced increased psychological distress (Jacox, Meyerowitz, & Hess, 1966; Meyerowitz, Jacox, & Hess, 1968). Later research done by Vandvik and Eckblad (1991) indicated that there was no relation between psychosocial background factors and both disease parameters and disease severity.

Treatment goals for JRA include attempting to control inflammation, prevent joint deformities, maximize functioning, as well as increase and amplify psychosocial adjustment. There are multiple methods for intervention, including medications and utilizing resources of medical specialists. Specifically, some medication commonly utilized to treat JRA include: nonsteriodal anti-inflammatory drugs, gold

hydroxychloroquine, antimalarial drugs, D-penicillamine, sulfasalazine, methotrexate, intravenous immunoglobulins, monoclonal antibody treatments, and corticosteroids (Kewman, Warschausky, & Engel, 1995). Some medical specialists and resources, which are commonly utilized in treatment, are physical therapists, occupational therapists, psychological treatment, and orthopedic surgery.

## Psychological Comorbidity

### Parental Distress

Findings have demonstrated that parents who have children with chronic illnesses have increased stress, psychosocial problems, and adjustment difficulties. A recent study examining the mothers of 92 children diagnosed with JRA found that the sample of mothers reported higher levels of psychological symptoms than a normative group (Manuel, 2001). More specifically, greater illness-related and daily hassles were significantly related to elevated levels of psychological distress reported by the mothers. Other researchers found similar results when examining a sample of mothers having children diagnosed with JRD. Specifically, findings indicated that in a sample of 84 mothers of children diagnosed with JRD, 50% of the mothers indicated psychiatric levels of distress during the first hospitalization admission of their child (Vandvik & Eckblad, 1991). Additionally, Thompson and colleagues (1992b) found in a sample of 68 mothers of children diagnosed with cystic fibrosis that 34% of the mothers reported poor adjustment. Additionally, 21% of the mothers fell in the clinical range for depression and 18% for anxiety.

Other research has focused on not only the mother's psychological adjustment to the child's illness, but also the father's functioning. Specifically, Timko and colleagues (1992) found that mothers reported more depression than fathers and that mothers were at a greater risk for stress-related psychopathology. Conditions that appeared to buffer or lessen psychological distress experienced by the parents included having more family resources and family support.

Child Distress

As previously emphasized, chronic medial problems affect 9 to 14% of children in the United States (Bennett, 1994; Frank et al., 1988). Past research has emphasized the increased risk for children diagnosed with a chronic illness to experience psychological distress (Frank, et al., 1988; Lavigne & Faier-Routman, 1993). Specifically, Pless (1984) found through parent report that children with a chronic illness are 1.5 to 3 times more likely to experience significant psychological or social problems during childhood when compared to healthy peers. Research has indicated that children diagnosed with a chronic illness tend to be more vulnerable to internalizing problems (anxiety, depression, withdrawal, somatic complaints) versus externalizing difficulties (Bennett, 1994; Lavigne & Faier-Routman, 1993). In addition a study examining 106 parents of children diagnosed with a chronic illness, found that 72% of the families indicated chronic family difficulties, 50% of the children received a psychiatric diagnosis, and 64% of the children were reported to be experiencing psychosocial distress (Vandvik, 1990).

A meta-analysis, which reviewed sixty studies examining the relationship between depression and chronic illness in adolescents, concluded that 9% of children

suffering from a chronic illness also met criteria for a major depressive disorder or an unspecified depressive disorder. This percentage is higher than what is typical for a community sample. Specifically, it is estimated that 1 to 5% of children and adolescents in a typical community sample meet criteria for either a major depressive disorder or an unspecified depressive disorder (Bennett, 1994).

In addition to the daily stressors faced by all children, children with a chronic illness are exposed to additional stressful. For example, Siegel and Smith (1989) emphasized that children suffering from a chronic illness must address feeling different from their peers, the reality of no longer having a healthy body, as well as deal with either perceived or real threats to one's life. In addition, research has shown that children with a chronic illness must also address their physical limitations, the difficulties in adhering to treatment regimens, increased frequency of school absences, limited opportunities for socialization, feelings of helplessness, and increased dependency on others (Bennett, 1994). Additional stressful issues that may result in depression include the disruption of future plans, fantasies, and dreams (Anderson & Lyon, 1987; Lazarus & Folkman, 1984). Specific to children diagnosed with a JRD, children must confront their physical disability, the feelings of isolation from their peers, their increased dependency on their family, the uncertainty about the future, and the difficulties with the maintenance of a complicated medical regimen (Schanberg et al., 2000).

Research specifically focusing on children with JRD has found similar relationships between disease experiences and depression. David and colleagues (1994) found in a sample of 43 patients with polyarticular JRA that 21% were experiencing moderate to severe depression. Specifically, results indicated that there was a significant

linear trend between depression (measured by the BDI), disability (examined by the Steinbrocker classification of functional capacity), and Katz's index of activities of daily living. Additionally, children with JRA who reported more negative disease experience indicated that they felt less competent about their athletic skills, less well liked by their peers, less physically attractive, and had a diminished self-worth (Ennett et al., 1991). In addition, a study which compared children with severe rheumatic diseases (n=43) to both a group of children with milder or inactive forms (n=52) of rheumatic diseases and a control group consisting of healthy children (n=93) found through parent report that the children with severe rheumatic disease experienced significantly more physical and psychological problems than the other two groups. Specifically, 53% of the children in the severe group, 24% in the mild/inactive group, and 16% in the control group indicated that they experienced anxiety. A similar distribution resulted across the three groups when asked about feeling sad or blue: 68%, 44%, and 34 %, respectively (Billings et al., 1987).

Schanberg and colleagues (2000) examined 12 children diagnosed with a JRD across 7 days by utilizing a daily diary, which assessed mood, stressful events, and symptoms on a daily basis. Results indicated that more negative daily moods and more daily stressful events significantly predicted increased reports of fatigue, stiffness, and decreases in daily activities. Additionally, negative mood was found to be positively correlated with reported pain.

Joyce and colleagues (1989) examined a sample of 50 children with systemic lupus erythmatosus and found a relationship between clinical disease activity and health status, which the researchers defined as a composite of physical, functional, and

psychosocial variables. Specifically, they found a significant relationship between depression and the physical manifestations of SLE disease activity. In addition, the sample identified difficulties with pain, depression, anxiety, physical activity, and social activity. This study not only examined the relationship between depression and disease activity, but also evaluated whether psychosocial elements are components of disease activity or whether these elements vary independently.

Research has indicated that the psychosocial difficulties these children must address are not solely explained by disease severity. A review of JRA literature indicated that in addition to illness severity, functional loss, children's perceptions of JRA, child self-concept, parents' level of psychological disturbance, family stressors, problems, and social support may be related to psychosocial adjustment in children with JRA (Jaworski, 1993; Jacox, Meyerowitz, & Hess, 1993). In addition, findings from a sample of 38 children diagnosed with JRA indicated that children's reports of their disease experience were directly related to their adjustment independent of their disease status. Specifically, their perception of the burden placed on the family, the day-to-day experiences, and whether or not the disease made them feel different from their peers related to their adjustment (Ennett et al., 1991). Other researchers found in a sample of children with JRA that 57% of the variation in functional status was predicted by children's internalizing and externalizing problems, family relationships, pain, and disease activity (Varni, Wilcox, & Hanson, 1988). Similarly in a sample of 270 mothers with chronically ill and handicapped children, findings indicated that these children displayed significantly more internalizing and externalizing behavior problems, as well as lower levels of social skills than a normative sample (Wallander et al., 1988).

Research has also examined samples of children diagnosed with JRA to their siblings (Timko, Stovel, Moos, Miller, 1992). Findings indicate that the children diagnosed with JRA are involved in fewer extracurricular activities than their siblings, and that these activities include events with peers and family. Additionally, the children diagnosed with JRA viewed themselves as less popular and less attractive than their siblings. Overall, these findings add further support to the idea that children diagnosed with JRA have greater difficulties across psychological, social, and family domains.

Overall, findings stress the importance to consider variables other then disease severity. Specifically, children's perceptions of a disease appear to be related to their psychological adjustment, independent of disease status. In addition, Lavigne and Faier-Routman (1993) emphasize the importance of focusing on life stressors, parent/family variables, and child variables since they currently appear to have the greatest predictive ability in relation to the child's psychosocial adjustment.

## Illness Uncertainty

Because disease variables alone do not account for the observed variance in psychological adjustment (Bennett, 1994; Pless, 1984), research has begun to examine psychological mechanisms in the adjustment process in pediatric chronic illnesses, specifically cognitive appraisals. One cognitive appraisal variable, which has received a good deal of attention and appears to have an important role in the adjustment to chronic medical conditions, is illness uncertainty (Mishel, 1984; Mishel & Sorensen, 1991). This cognitive appraisal variable appears to have particular relevance to the adjustment process in JRD because as a group they are highly variable and unpredictable illnesses.

Subsequently, greater perceived uncertainty about illness management and outcome are both highly likely and may constitute a significant stressor contributing to individuals' negative perceptions of their illness and to increased emotional distress. Repeated exposure to such behavior-outcome noncontingency in chronic illness has been shown to result in less effective problem-solving and greater depression (e.g., Chaney et al., 1999).

Mishel's (1988, 1990) model of illness uncertainty suggests that when individuals attempt to organize and make sense of illness experiences which are: (a) inherently ambiguous, (b) complex, (c) providing insufficient information, or (d) inaccurately predicting outcomes, illness uncertainty may result. In other words, individuals may develop a sense of uncertainty about future outcomes as a function of the ambiguous contingencies (i.e., adherence-improvement) frequently inherent in the clinical course of JRD. Moreover, there appears to be a strong relationship between uncertainty and mood disturbance, emotional distress, and anxiety (Bennett, 1994; Mast, 1995).

Illness uncertainty is defined as a cognitive state created when an event cannot be adequately structured or categorized because of a lack of sufficient cues (Mishel, 1984). In other words, the decision-maker is unable to assign definite values to objects and events and/or is unable to accurately predict outcomes. Research has demonstrated the relevance of illness uncertainty in the adjustment process in JRD (Mullins et al., 1997; 2000). Additionally, researchers have suggested that better adjustment is related to perceived control over the daily aspects of disease management (Chaney et al., 1996).

Illness uncertainty can result if the patient does not form an appropriate cognitive schema for illness events. Specifically, Mishel (1988) proposed that symptom pattern, event familiarity, and event congruence provide the stimuli or needed information to

reduce uncertainty. Symptom pattern refers to the degree to which the symptoms are perceived has having a pattern. If a pattern is not detected, for example by examining the intensity, frequency, location or duration of the symptoms, these symptoms cannot be utilized to accurately appraise the disease experience. Event familiarity takes into consideration the degree to which the events are consistent or contain familiar cues. Lastly, event congruence refers to the consistency between the expected and actual disease experience. In general, for an illness-related event to be recognized and classified, the stimulus must be precise, recognizable, reliable, complete, and limited in number with clear boundaries in regards to both temporal and physical contexts (Mishel, 1988).

Previously stated, Mishel's (1988) model of illness uncertainty suggests that individuals attempt to assign meaning, or organize and make sense of the following illness experiences: (a) ambiguity concerning the state of the illness, (b) complexity regarding treatment and the system of care, (c) lack of information about diagnosis and seriousness, or (d) unpredictability of prognosis and disease course. Three possibilities, which can result in a situation being viewed as uncertain, include: the event is not recognized, or in other words is unfamiliar, the event may be familiar but is not classified, or the event is familiar but classified incorrectly.

Mishel's theory of illness uncertainty identifies two mediating processes between uncertainty and emotional distress. Specifically, mastery is seen as a mediator between illness uncertainty and appraisal. Mastery is defined as a situationally based personality variable that produces specific self-control expectations based on the evaluation of the particular event characteristics. When uncertainty is negatively related to mastery, mastery will be reduced and an enhanced sense of danger will result. In other words,

when the sense of mastery has been reduced, the personal resources to manage the situation have also decreased, which can result in a diminished sense of control (Braden, 1990; Mishel & Sorenson, 1991; Siegel & Smith, 1989). Alternatively, under conditions of heightened mastery an enhanced sense of opportunity results. This portion of the theory is consistent with Rosenbaums's (1988) view of mastery. Specifically, this theory emphasizes that it is difficult to identify advantageous behaviors when a situation is vague and poorly defined, in other words a state of increased uncertainty.

The other intervening factor in the illness uncertainty theory is coping, which is believed to influence the relationship between appraisal (danger or opportunity) and adjustment. When uncertainty is seen as a danger and one believes he or she can do little to alter a situation, emotion-focused coping strategies are expected to be utilized resulting in emotional distress. Conversely, when uncertainty is seen as an opportunity and one feels the situation is manageable, it is expected that problem focused coping strategies will be utilized which will decrease emotional distress (Mishel & Braden, 1988; Mishel & Sorenson, 1991).

The uncertainty theory emphasizes the idea that uncertain events are often appraised as being stressful (Mishel, 1984). Specifically, uncertainty results from the cognitive appraisal of an event, which either has an unclear outcome or the cues are insufficient, unfamiliar, contradictory, or too numerous to come to a conclusion (Lazarus & Folkman, 1984). Additionally, research has indicated that the degree of stress experienced depends on the child's appraisal of the situation. Specifically, the amount of stress encountered will depend on what degree the child views the event as a challenge, as a threat to one's well being, and the amount of loss or harm already occurred (Siegel &

Smith, 1989). Lazarus and Folkman (1984) further point out the possibility that personal factors may affect the appraisal of the event more than the objective features of the situation. Further, uncertainty events are believed to be stressful because the outcome is unclear, which inhibits coping responses and causes difficulty in assigning meaning to the events. Coping is defined as "constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person" (Lazarus & Folkman, 1984).

Specific to the disease experience, illnesses with remissions and exacerbations, as well as unpredictable and inconsistent symptomology result in a greater experience of ambiguity about the status of the illness and therefore, more psychological distress (Fritz, Williams & Amyon, 1988; Jessop & Stein, 1988; Mishel & Braden, 1988; Pless, 1984). Research has also indicated that the credibility of authority, or in this case the primary physician, was the major precursor factor influencing the level of uncertainty in a sample of 61 women receiving treatment for gynecological cancer. In addition, social support in the form of affirmation, symptom pattern, and assigning meaning and having familiarity to the events accounted for significant variance in uncertainty (Mishel & Braden, 1988). Individuals who are unable to form a schema about their illness events are believed to experience greater uncertainty since acquiring a schema can provide interpretations of the illness, treatment, and hospitalization (Padilla, Mishel, & Grant, 1992).

Prior research across a number of chronic medical conditions has supported the presence of a relationship between the cognitive appraisal variable of uncertainty and the emotional difficulties experienced by a patient. Braden (1990) examined a sample of 396 individuals diagnosed with either rheumatic arthritis or an arthritis-related condition.

Results demonstrated that increased illness severity was related to increased uncertainty, which was further associated with reduced quality of life. Further, uncertainty is reduced in the patients who actively seek out information from a health care provider. These results are further supported by the finding that individuals who are more knowledgeable about one's disorder were found to be less depressed. In addition, some findings supported that when individuals are informed of the disease designation uncertainty is reduced (Horner, 1997; Kvist, Rajantie, Kvist, & Siimes, 1991); however, Christman (1990) emphasizes that even though the diagnosis may be certain, questions and uncertainties remain in regards to treatment options and efficacy. In fact, other studies have found contrary results indicating that uncertainty actually increases at the time of diagnosis (Cohen, 1993).

In a sample of 100 women (age=20 to 81) receiving treatment for gynecological cancer, uncertainty was found to be significantly associated with the appraisal of either danger or opportunity, which predicted the degree of mastery. Specifically, increased states of uncertainty correlated with decreases in mastery, which intensified the degree of danger and decreased the sense of opportunity (Mishel, Padilla, Grant, & Sorenson, 1991). Further research completed on a similar sample underscored the importance of examining the impact of illness uncertainty on patients' quality of life (Padilla, Mishel, & Grant, 1992). Research examining young adults with a chronic illness found that the unpredictability of symptoms was correlated with more psychological symptoms, and that one-third of the sample were in risk for mental health problems (Ireys, Werthamer-Larsson, Kolodner, & Gross, 1994). Another study, which examined older adolescents and young adults diagnosed with asthma, found similar findings in that there was a

significant relationship between illness uncertainty and levels of psychological distress. Specifically, as illness uncertainty increased, levels of reported psychological distress also increased. (Mullins, Chaney, Balderson, Hommel, 2000). Uncertainty has also been found to relate to an individual's causal attributional style. Particularly, studies have demonstrated that both increases in illness uncertainty and increases in stable negative attributions (Mullins, Chaney, Pace, & Harman, 1997), as well as both stable and global (Mullins et al., 1995) attributional styles are related to poorer adjustment.

The relationship of illness uncertainty, hope, disease severity, and adjustment has also been examined. Specifically, in a sample of adults receiving external beam radiotherapy for cancer treatment, illness uncertainty, hope, and symptom severity were all found to account for significant variations in adjustment, with illness uncertainty explaining the greatest amount of variation. Additionally this study further concluded that there was no evidence that uncertainty had any positive or beneficial effects on the sample (Christman, 1990). An additional study also found hope to be negatively correlated with uncertainty (Mishel, Hostetter, King, & Graham, 1984). Overall, these finding add further support that illness uncertainty may be stressful and influence coping and adjustment in illness and treatment.

Studies have also examined the effects of illness uncertainty in the family unit. For example, in a sample of children admitted to a pediatric intensive care unit, parental uncertainty accounted for 36% of the variance in parental anxiety (Mintun, 1984). Cohen (1995) conducted a five-year longitudinal study on 10 families having a child with a chronic, life-threatening disease and examined these families under sustained uncertainty. In particular, this study examined seven commonly occurring events, which were found

to increase parental anxiety by triggering an awareness of the uncertainty concerning the illness. Specifically the triggers found to intensify parental awareness of uncertainty were the following: routine medical appointments, body variability (crying, changes in appetite or energy level), key words and provocative questions (words such as high risk, remission), changes in therapeutic regimen, evidence of negative outcomes, new developmental demands of the child, and nighttime (Cohen, 1995). Additional research has examined the relationship between maternal uncertainty and stress, coping, and adaptation in 40 mothers of children with unplanned admissions to a pediatric intensive care unit. Findings have demonstrated a positive association between illness severity and maternal uncertainty and a negative association between family cohesion and maternal uncertainty (Tomlinson, Krischbaum, Harbaugh, & Anderson, 1996). These findings suggest that under conditions of maternal uncertainty, stress can interfere with coping and child management.

## Transactional Stress and Coping Model

Stress is defined as a situation "in which environmental demands, internal demands, or both tax or exceed the adaptive resources of an individual, social system, or tissue system" (Monat & Lazarus, 1977, pg. 3). It is widely recognized that a chronic illness meets this definition and that both the individual and family system attempt to adjust. Some common experiences faced by the family include home based treatment for the child, heightened concerns with bodily functions, medication monitoring, special diets, limitations in activities, hospitalizations, and financial burdens (Thompson, 1985). Interestingly, some families cope with the chronic illness unscathed; where as other

families are at an increased risk for psychosocial problems. It is important to determine the differences between families, which seem to adjust with little or no distress, from those families who experience psychosocial problems.

One model, which attempts to examine the ways in which stress is transferred across the system, is the transactional stress and coping model proposed by Thompson (Thompson, 1985). This theory, which took an ecological-systems theory perspective (Bronfrenbrenner, 1977), was guided by the cognitive stress and coping model (Lazarus & Folkman, 1984), expectations of efficacy (Bandura, 1977) and locus of control (Rotter, 1954), coping methods (Felton & Revenson, 1984), and family functioning (Daniels, Moos, Billings, & Miller, 1987). Thompson and colleagues (1992a) proposed that the level of adjustment to an illness is a function of transactions of biomedical, developmental, behavioral, and psychosocial processes. Within this perspective, the psychological adjustment of the child is influenced by the experience of the family. Specifically, beyond the disease variables (type of illness, complications, frequency of painful episodes) and demographic parameters (SES, and child's gender and age), the illness-outcome relationship is believed to be influenced by individual and family processes (Thompson et al., 1992a).

Some possible familial intervening processes include: cognitive processes, methods of coping, and family functioning. Cognitive processes consist of the appraisal of the stress (daily hassles, illness tasks) and expectations (efficacy and health locus of control). Methods of coping consist of palliative (regulation of emotional states associated with stress) and adaptive mechanisms, where as family functioning includes the degree of support, conflict, or control the family system maintains. The child

intervening variables include cognitive processes and individual methods of coping (specifically with the pain). Some cognitive processes include the child's expectations in regards to one's self-esteem and health locus of control. Specifically for this study, the part of the transactional model, which will be of central focus, examines children's cognitive appraisals as intervening variables in the parental adjustment/child adjustment relationship (Thompson, et al., 1993a; Thompson et al., 1993b; Thompson, et al, 1999).

Currently, a great deal of the research examining the transactional stress and coping model resulted from focusing on children with sickle cell disease or cystic fibrosis. Findings across numerous studies indicated that maternal distress, in particular, accounted for a large amount of the variance in child adjustment to a chronic illness. Specifically, Thompson and colleagues (1992a) examined a sample of 45 children diagnosed with cystic fibrosis, and found that 60% of the children demonstrated poor adjustment according to maternal report and 62% meet criteria for a DSM-III diagnoses according to self report. Additionally, the maternal psychological adjustment, which was measured by level of anxiety, accounted for 68% of the variance in children's psychosocial adjustment. Thompson and colleagues (1993b) found similar results when examining a sample of children diagnosed with sickle cell disease. Specifically, 64% of the children were identified as having poor adjustment by maternal report, and 50% met criteria for a DSM-III diagnosis according to child report. Results indicated that maternal anxiety accounted for 16% of the variance in internalizing problems and 33% of the variance in externalizing problems reported by the child. Similarly, additional researchers examined 95 mothers of children in four different conditions: cystic fibrosis, diabetes, mental retardation, and well. Results found that maternal depression was associated with

higher levels of reported child behavior problems (Walker, Ortiz-Valdes, & Newbrough, 1988).

Research has also examined variables within the family, specifically coping mechanisms and appraisals, which impact parental adjustment and in turn influences the relationship of child adjustment and illness-outcome. Research with children diagnosed with Duchenne Muscular Dystrophy indicated that 57% of the parents reported poor adjustment. Specifically, parents who reported poorer adjustment also reported higher levels of stress, lower levels of family support, and higher levels of family conflict than parents who were found to have good adjustment (Thompson et al., 1992c). Additionally, parental distress measured by GSI from the SCL-90-R, accounted for 19% and 16% of the variance in internalizing and externalizing behavior problems, respectively. Similar findings resulted when researchers examined 109 chronically ill children and their families. Findings supported the transactional model, which indicates a relationship between family environment and child adjustment. Specifically, in this sample of children 4 to 14 years of age, children with behavior problems indicated having less supportive and more conflicted families (Kronenberger & Thompson, 1990).

Other research conducted by Thompson and colleagues (1993a) demonstrated similar findings. In a sample of 78 mothers with children diagnosed with sickle cell disease, 36% of the mothers were found to have poor adjustment. These mothers reported increased levels of daily stress, utilization of palliative coping more frequently, and less family support. Specifically, maternal adjustment was related to a number of psychosocial processes: palliative coping (30%), daily hassles (13%), and control in family (3%). Results indicated that 46% of the variance in maternal adjustment was

accounted for by these psychosocial variables, supporting the idea of intervening processes in the transactional stress and coping model. Additionally, Chaney and colleagues (1997) conducted a longitudinal study and examined transactional patterns of child, mother, and father adjustment in a sample of children diagnosed with insulin-dependent diabetes mellitus. Results indicated the level of distress reported by the father at time one was positively associated with the child's level of distress one year later.

Minimal research has examined the transactional stress and coping model in children diagnosed with juvenile rheumatic disease. One study, examining 165 children with JRD found that maternal depression was strongly associated with more psychosocial problems in children (Timko, Stovel, Moos, & Miller, 1992). Specifically, findings indicated that when mothers were more depressed, their children were less socially integrated in school. Conversely, children of mothers who reported having a sense of mastery, reported less distress and more social interactions. Frank and colleagues (1997) found similar results in a sample of children classified as either JRA, IDDM, or healthy. Findings indicated that reports of mother's depression and parental distress were significantly related to child behavioral problems.

Based on this review of the literature it is apparent that children diagnosed with JRD show an increased risk for experiencing emotional problems. Research has also demonstrated that child cognitive appraisals influence their own adjustment. Additionally, it has been demonstrated in a number of studies across several chronic illness populations that parental distress is associated with child distress. However, it is unclear what the mechanisms are by which the parent-child transmission of distress occurs. One variable that may provide a link between parent and child adjustment is

illness uncertainty. Specifically, because of the variable and unpredictable nature of JRD, greater uncertainty about the illness management-disease outcome process may be experienced. Thus, illness uncertainty may constitute an additional source of stress for the child, resulting in greater negative perceptions about the illness. The resulting heightened susceptibility to adjustment difficulties may provide the occasion for parent variables to further impact children's emotional distress.

# CHAPTER III

## THE PRESENT STUDY

Juvenile rheumatic diseases are characterized by a variable, unpredictable disease course, and physical disability including joint inflammation and pain, and functional impairment (Cassidy & Petty, 1995; Schanberg et al., 2000). It is believed that individuals with JRD may be more susceptible to psychological complications due to the characteristics of the disease: experiences of pain, physical deformity, disability, and chronicity, as well as the uncertain prognosis, invisible condition, chronic pain, and remitting course.

In general, it appears that children with JRD are at greater risk for adjustment problems. However, research has shown that disease variables alone do not sufficiently account for the observed variance in child distress (Bennett, 1994; Pless, 1984). In other words, children with the same physical symptoms may experience varying levels of adjustment problems (i.e., depression, anxiety). These findings suggest that not merely the disease, but the manner in which the child perceives the disease may make significant contributions to psychological adjustment. One possible cognitive appraisal mechanism relevant to the adjustment processes in JRD is illness uncertainty. Given the highly unpredictable and variable disease course of JRD, greater uncertainty and, ultimately, increased emotional adjustment problems may result from inconsistent disease management-outcome contingencies.

It is also the case that child adjustment does not occur in a vacuum, independent of parental influences (Chaney et al., 1997; Frank et al., 1998; Thompson et al., 1992a; Thompson, et al., 1993a; Thompson et a., 1993b; Thompson, et al, 1999). However, no appreciable research has examined potential mechanisms by which parent distress influences child adjustment in pediatric chronic illnesses. Thus, although the transactional stress and coping model stipulates that chronic illness is a potential stressor to which both the child and family system endeavor to adapt, more precise information regarding the means by which parent-child emotional transactions take place is not known.

The present study is designed to extend existing JRD research by: 1) examining the influence of parent distress on child adjustment; 2) examining the direct effects of illness uncertainty on depression; and 3) examining the potential mediating and/or moderating role of children's perceived illness uncertainty in the parent-child adjustment relationship in JRD.

# CHAPTER IV

# METHOD

## Participants and Procedure

Participants for this study were 40 (26 girls; 14 boys) children and adolescents between the ages of 9 and 21 years ($M = 14.4$, $SD = 2.92$), who had been diagnosed with juvenile rheumatoid disease; more specifically this included: juvenile rheumatoid arthritis (JRA; $n = 24$), systemic lupus erythematosus (SLE; $n = 9$), juvenile dermatomyositis (JDM; $n = 4$), and juvenile spondyloarthropathies (SA; $n = 3$). The majority of the children were Caucasian ($n = 19$), followed by Native American ($n = 9$), African American ($n = 4$), Biracial ($n = 4$), Hispanic ($n = 3$), and Asian ($n = 1$).

Participants were recruited through the Pediatric Rheumatology Clinic at the Children's Hospital of Oklahoma in Oklahoma City, Oklahoma. Institutional review board (IRB) approval for the protection of human participants was obtained, and written informed consent and assent were obtained from each participant, parent, or legal guardian (Appendixes C, D, and E). The inclusion criteria consisted of patients who were between the ages of 9 and 21, were diagnosed with a JRD, and the duration of symptoms had been at least one year. Illness duration, which was calculated by subtracting the date of diagnosis from the date of participation, ranged from 0.04 to 14.59 years ($M = 2.71$, $SD = 2.85$). Although some patients in the sample had been diagnosed for less than one

year, they still qualified for the study given they had had active symptoms for at least one year. Children were excluded if they had comorbid cognitive deficits and/or a comorbid chronic illness. The pediatric rheumatologist verified the inclusion criteria before participants were contacted for solicitation.

At a scheduled physician visit, the rheumatologist conducted a semistandardized physical examination on all study participants. This examination included joint count measurements assessing the number of joints that were painful, tender, and stiff, range of motion, and other physiological indices such as erythrocyte sedimentation rate (ESR). The rheumatologist provided physical disability ratings upon completion of the physical examination. Following the examination, participants and parents were given a questionnaire packet. Participants then mailed back their packets in a postage-paid envelope. Participants were compensated monetarily with $10.00 per family.

## Instruments

### Physician-report Measures

The rheumatologist completed a Provider Questionnaire (Appendix F), which was designed to obtain patient disease information from the physician regarding diagnosis, date of diagnosis, current medications, disease severity, and functional disability. The physician rated the patients' functional disability by classifying the patients into one of four functional classes, ranging from Class I (representing limited to no disability in vocational and self-care activities) to Class IV (representing severe disability in these

same activities) (e.g., Hochberg et al., 1992). The data for the present study suggested a relatively low level of functional disability ($M = 1.58$; $SD = .71$ ).

Parent-report Measures

The Brief Symptom Inventory (BSI; Derogatis & Melisaratos, 1983; Appendix G) is a 53-item questionnaire, which assesses global psychological adjustment in adults. Individuals rate the degree to which they were distressed in the past seven days by each psychological symptom. Respondents rate their distress on a 4-point Likert scale, ranging from 1 (not a lot) to 4 (extremely). A global severity index (GSI) was obtained by taking the sum of the scores and dividing by the number of total items (53). In the present sample, the mean GSI score was 0.48. The BSI has been previously found to have acceptable internal consistency; alpha coefficients range from .71 to .85 (Derogatis & Melisaratos, 1983). Cronbach's (1951) alpha for this sample was high ($\alpha = .95$).

Child-report Measures

A Background Information Questionnaire (Appendix H) was created to obtain information regarding patient's age, gender, and ethnicity.

The Juvenile Arthritis Functional Assessment Report -Child (JAFAR-C; Howe et al., 1991; Appendix I) form was completed by patients to provide information regarding subjective perceptions of functional ability. The JARAR is a 23-item measure of functional ability designed specifically for assessment of patients with JRD. Respondents rated how often they could 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. The sum of the items represents the amount of functional disability the patient demonstrates. The JAFAR has demonstrated good internal consistency coefficients for both child-report (.85) and parent-report (.93) and good construct validity (Howe et al., 1991). Baildam and colleagues (1995) found in a study of 29 children with JRA (age=7 to 16) that the JAFAR-C correlated with other measure of disease severity, including the functional class, joint counts, and measures of pain and stiffness; therefore, supporting the use of this measure to monitor disease activity, as well as patients' responses to treatment. Cronbach's alpha for the present study was high ($\alpha = .91$).

The Children's Depression Inventory (CDI; Kovacs, 1979; 1992; Appendix J) is a 27-item instrument that assesses depressive symptomatology in children over the previous two weeks. Each of the items on the CDI is a group of three statements that combine to measure the severity of a single depressive symptom on a 0 to 2 scale. Scores were derived by summing the 27 items for an overall index of depressive symptomatology. The CDI has been shown to be a reliable (internal consistencies ranging from .71 to .89) and valid measure of depressive symptomatology in children. Cronbach's alpha for the present study was high ($\alpha = .91$).

The Mishel Uncertainty in Illness Scale-Child (MUIS-C; Appendix K) is a 23-item scale that asks respondents to rate items on a five-point scale that illustrates the four components of illness uncertainty: ambiguity, uncertainty, lack of information, and unpredictability. A single composite score is derived from the MUIS-C. Higher composite scores reflect greater illness uncertainty. Research has found the MUIS-C to be a reliable and valid measure of illness uncertainty across a number of chronic illness

conditions (e.g., Mishel & Braden, 1988; Mullins et al., 1995). Cronbach's (1951) alpha for this sample was high ($\alpha = .86$).

## Hypotheses

### Primary Hypotheses

Hypothesis 1. Consistent with the transactional stress and coping model, it was anticipated that parental adjustment (as measured by the BSI) would contribute significant variance to child adjustment (as measured by the CDI) after controlling for demographic and disease variables.

Hypothesis 2. It was anticipated that child illness uncertainty (as measured by the MUIS-C) would contribute unique variance to child adjustment (as measured by the CDI) after controlling for demographic and disease variables.

### Research Questions

Research Question 1. Because increased levels of parental distress may contribute to increased perceptions of illness uncertainty and ultimately greater child distress, illness uncertainty was examined as a potential mediator in the parent distress-child distress relationship. These analyses were guided by Baron and Kenny's (1986) cognitive mediation perspective (see also Holmbeck, 1997) (see Figure 1). To determine whether illness uncertainty mediated this parental-child adjustment relationship, several criteria must have be satisfied:

1. Regress the DV (CDI) on the IV (BSI)
2. Regress (DV) CDI on potential mediator (MUIS-C)

3. Regress the potential mediator (MUIS-C) on the IV (BSI).

4. Regress simultaneously the DV (CDI) on both the IV (BSI) and the mediator (MUIS-C)

Research Question 2. Because varying levels of illness uncertainty may increase or decrease the likelihood that parents' distress will influence children's adjustment, illness uncertainty was examined as a potential moderator in the parent distress-child adjustment relationship. Statistical analyses was guided by Baron and Kenny's (1986) cognitive moderation perspective (see also Holmbeck, 1997) (see Figure2). The determination of illness uncertainty as a moderator in the parent-child adjustment relationship involved:

1. Regressing the DV (CDI) on both the IV (BSI) and the potential moderator (MUIS-C)

2. Regressing the interaction term or product of the IV (BSI) and the moderator (MUIS-C) on the DV (CDI)

# CHAPTER V

# RESULTS

## Analyses

### Preliminary Analyses

Several one way analysis of variance (ANOVA) tests were conducted to test for potential effects of ethnicity (Caucasian vs. non-Caucasian), recruitment method (mail vs. clinic), or disease subtype (JRA vs. non-JRA) on child depression. Results yielded no significant differences in child reported depression as a function of ethnicity (Caucasian vs. non-Caucasian) ($F(1,39) = .34, p = .56$). A second ANOVA revealed no significant differences in child depression as a function of recruitment method (mail vs. clinic) ($F(1,39) = .22, p = .64$). A third ANOVA indicated significant differences in child depression as a function of disease subtype (JRA vs. Non-JRA) ($F(1, 39) = 4.83, p < .04$). Given no significant effects across ethnicity or recruitment method on child depression variables, these variables were not included in subsequent analyses; however, because of the significant effect for disease subtype on child depression, disease subtype was utilized as a covariate in the primary analyses.

Additional covariates utilized in this study were chosen based on theoretical rationale and on findings in the literature. Because prior research has indicated that children diagnosed with JRD are at increased risk for depression due in part to the

physical characteristics of the disease (David, 1994; Vandvik, 1990), physician rated functional ability and child ratings of functional ability were included in the analyses. Additionally, significant variability was observed in both age and disease duration in the sample. Further, previous research has indicated differences in illness appraisals across cognitive developmental stages (Berry, Hayford, Ross, Pachman, & Lavinge, 1993). Thus, age and disease duration were included as covariates in the primary analyses. Lastly, because previous research has demonstrated differences in depression between males and females in rheumatoid arthritis populations (e.g., Hommel, Wagner, Chaney, & Mullins, 1998), gender was also covaried in the primary analyses. Even though no significant correlations were found between these variables and CDI depression (dependent variable), disease variables, age, and gender were included in the analyses to provide a more conservative test of anticipated relationships. Zero-order correlations are presented in Table 2.



Primary Analyses

Hypothesis 1. Consistent with the transactional stress and coping model, it was anticipated that parental adjustment (as measured by the BSI) would contribute significant variance to child depression (as measured by the CDI) after controlling for demographic and disease variables. A hierarchical regression equation was constructed to test this hypothesis by first entering demographic variables (age and gender) and disease subtype on Step 1. Disease variables (disease years, physician rated functional ability, and child JAFAR ratings) were entered on Step 2. On Step 3 of the regression, the BSI was entered. Results revealed a significant effect for the BSI on CDI depression ($F(1,32)$

= 7.21, $p < .05$) after controlling for demographic and disease variables, indicating parental distress was significantly associated with child depression (see Table 3). Hypothesis 1 was supported by the data.

Hypothesis 2. It was anticipated that child illness uncertainty (MUIS-C) would contribute unique variance to child depression (CDI) after controlling for demographic and disease variables. To test the second hypothesis, a similar regression analysis was conducted to examine the unique contribution of child perceived illness uncertainty (as measured by the MUIS-C) to child adjustment (CDI) after controlling for demographic and disease variables. Specifically, a regression equation was constructed with demographic variables (age and gender) and disease subtype entered on Step 1 and disease variables (disease years, physician rated functional ability, and child JAFAR ratings) entered on Step 2. On Step 3 of the regression, the MUIS-C was entered. Results revealed no significant effect for child perceived illness uncertainty on CDI depression ($F(1,32) = .01$, $p = .92$) (See Table 3). Thus, Hypothesis 2 was not supported by the present data.

## Research Questions

Research Question 1. Because increased levels of parental distress may contribute to increased perceptions of illness uncertainty and ultimately increased child depression, illness uncertainty was examined as a potential mediator in the parent distress-child adjustment relationship. To determine whether illness uncertainty mediated the observed parent-child depression relationship, several criteria had to be satisfied (see Baron and Kenny, 1986; Holmbeck, 1997): (1) the predictor variable (BSI) must be significantly

associated with the outcome variable (CDI), (2) the potential mediator (MUIS-C) must be significantly related to the outcome variable (CDI), (3) the predictor variable (BSI) must be significantly correlated with the potential mediator (MUIS-C), and (4) when the predictor (BSI) and mediator (MUIS-C) are entered simultaneously, the previously significant relationship between the predictor (BSI) and outcome (CDI) must no longer be significant.

Primary analysis testing Hypothesis 1 revealed a significant effect for BSI on CDI ($F(1,32) = 7.21, p < .05$) after controlling for demographic and disease variables (see Table 3). Thus, criterion one was demonstrated by the significant association between parental distress (predictor) and child depression (outcome).

The second criterion for mediation required a significant association between child perceived illness uncertainty (potential mediator) and child depression (outcome). Results testing for Hypothesis 2 failed to reveal a significant effect for child perceived illness uncertainty ($F(1,32) = .01, p = .92$) on child depression, after controlling for demographic and disease variables. Consequently, no further analyses were conducted examining the mediating role of illness uncertainty. Results did not support child perceived illness uncertainty as a mediator in the parent distress-child depression relationship.

Research Question 2. Because varying levels of illness uncertainty may increase or decrease the likelihood that parents' distress will influence children's adjustment, illness uncertainty was examined as a potential moderator in the parent distress-child adjustment relationship. To determine whether illness uncertainty moderated the parent-child adjustment relationship, the BSI x MUIS-C interaction term must be significantly

associated with the CDI, after controlling for BSI and MUIS-C main effects (see Baron and Kenny, 1986; Holmbeck, 1997).

A hierarchical regression equation was constructed to test moderation. On step 1 of the equation, demographic variables (age and gender) and disease subtype were entered, and on step 2 disease variables (disease years, physician rated functional ability, and child JAFAR ratings) were entered into the equation. On step 3, the BSI, MUIS-C and the BSI x MUIS-C interaction term were entered simultaneously. Results revealed a significant BSI x MUIS-C interaction effect on CDI depression ($B = .39$, $SE = .13$, $p < .01$), accounting for an additional 16% of incremental variance (see Table 3). Results support MUIS-C as a moderator in the parent-child adjustment relationship, suggesting illness uncertainty enhances the magnitude or direction of the relationship between parental distress and child depression.

Post-hoc Analysis

Guided by Holmbeck (2002), analyses were conducted to further examine the significance of the interaction between parental distress and child perceived illness uncertainty on child depression. Specifically, post-hoc probes examined whether the simple slopes (slopes of the regression lines) of BSI distress were significantly different from zero under high versus low levels of MUIS-C uncertainty. In order to gain this information, a series of statistical tests were conducted to compute the simple slopes. Initially, the BSI (predictor) and MUIS-C (moderator) were centered by subtracting the grand mean from the value of each participant [($BSI_{Centered}$ = BSI - .48); ($MUIS\text{-}C_{Centered}$ = MUIS-C – 65.23)]. Centering of the variables was completed to reduce multicollinearity

between the predictor and interaction terms. Next, two new conditional moderators (HIMUIS-C and LOMUIS-C) were constructed to examine the conditional effects of the BSI (predictor) on the CDI (outcome). The conditional moderator terms were computed by adding and subtracting the standard deviation [HIMUIS-C = MUIS-C – (.18.55); LOMUIS-C = MUIS-C – (-18.55)]. Following, two new interaction variables were created, which incorporated each of the new conditional variables (i.e., HIMUIS-C X BSI; and LOMUIS-C X BSI).

Once these new variables were created, two separate post-hoc regressions were conducted, each including the BSI main effect, one of the conditional MUIS-C variables (HIMUIS-C or LOMUIS-C), and the interaction of the BSI and the conditional MUIS-C variable (HIMUIS-C X BSI or LOMUIS-C X BSI) (see Table 4). The first regression equation examines the conditional effects of BSI (predictor) on CDI (outcome) under conditions of high uncertainty. Specifically, on step 1 of the equation, demographic variables (age and gender) and disease subtype were entered, and on step 2 disease variables (disease years, physician rated functional ability, and child JAFAR ratings) were entered into the equation. On step 3, the $BSI_{Centered}$, HIMUIS-C, and HIMUISC X BSI interaction term were entered simultaneously. Results revealed a significant HIMUIS-C X BSI interaction effect on CDI depression ($t(1) = 4.34$, $p < .001$), indicating a significant effect on child depression when MUIS-C was 1 SD above the mean.

A similar hierarchical regression was constructed to formulate the slope for the low MUIS-C condition. On step 1, demographic variables (age and gender) and disease subtype were entered, and on step 2 disease variables (disease years, physician rated functional ability, and child JAFAR ratings) were entered into the equation. On step 3,

the $BSI_{Centered}$, LOMUIS-C, and LOMUISC X BSI interaction term were entered simultaneously. Results revealed no significant effect on CDI depression ($t(1) = .65$, $p = .52$), indicating no significant effect on child depression when MUIS-C is 1 SD below the mean.

Equations for the regression lines were constructed to facilitate the plotting of the regression lines. Following are the regression equations for high MUIS-C (1 *SD* above the mean) and low MUIS-C (1 *SD* below the mean), respectively:

$$CDI_{est} = .015\ (HIMUISC) + 16.75\ (BSI) + .39\ (HIMUISCXBSI) + 2.75$$

$$CDI_{est} = .015\ (LOMUISC) + 2.19\ (BSI) + .39\ (LOMUISCXBSI) + 2.18$$

The regression lines were then plotted by substituting high BSI (*SD* = .44) and low BSI (*SD* = -.44) into each equation. (see Figure 3).

# CHAPTER VI

# DISCUSSION

The purpose of the present study was to examine the transactional nature the association between parental distress and child psychological adjustment in a sample of children diagnosed with juvenile rheumatic disease. Further, because it is unclear the mechanisms by which such transactions occur, this study was also designed to examine the potential intervening role of child perceived illness uncertainty in the parent distress-child depression process. In general, results are consistent with Thompson's transactional stress and coping model of adjustment (Thompson et al., 1992a, 1993a) and provide support for a growing body of literature demonstrating the important role of parent distress in child adjustment to chronic illness (e.g., Chaney et al., 1997; Frank et al., 1998).

The main effect of parental distress on child adjustment was qualified by results indicating a significant interaction between child perceived illness uncertainty and parental reports of distress. Thus, although no main effect was observed for child perceived illness uncertainty on child depression, results indicated that illness uncertainty is still an important variable in the experience of children with JRD. Specifically, child perceived illness uncertainty was found to function as a moderator in the parent distress-child depression relationship, indicating that illness uncertainty enhances the magnitude of this relationship. In other words, when illness uncertainty was present, parental distress

was found to have a greater impact on child adjustment. The enhanced relationship between parent distress and child depression under conditions of increased child perceived illness uncertainty provides one possible explanation of the specific mechanisms by which parent distress impacts child depression.

Additional post-hoc probes indicates that not only was the relationship between parental distress and child depression enhanced under conditions of increased uncertainty, at low levels of child perceived illness uncertainty, the relationship between parental distress and child depression was nonsignificant, indicating that this relationship was attenuated. In essence results indicate that not only was the effect of parent distress on child depression enhanced under conditions of high child perceived illness uncertainty, but that at decreased levels of illness uncertainty, parent distress was unrelated to child depression. Results suggest that lower levels of illness uncertainty may serve to buffer the influence of parent distress on child depression.

It is important to note that these findings do not provide causal explanations of the direction by which the variables are related. In other words, although parent distress was conceptualized as accounting for significant variance in child depression, results from the present study cannot verify the direction of the relationship. It is possible that increases in child depression actually precede increases in parental distress. The present results simply demonstrate that under increased levels of child perceived illness uncertainty the relationship between parent distress and child depression is enhanced and under conditions of low illness uncertainty, this relationship is attenuated.

In general, the results support previous findings that parent distress is associated with children's adjustment and levels of depression. Additionally, the present study

examined the role of a cognitive appraisal mechanism, illness uncertainty, and found under levels of high child perceived illness uncertainty, the relationship between parental distress and child adjustment was enhanced, and under low levels of illness uncertainty, this relationship was no longer present. This study highlights the importance of not only examining the main effects of variables, but also examining the interrelationships between variables.

## Treatment Implications

Results of the present study have several important treatment implications. Although the present findings do not provide causal explanations for the directions by which the behavioral transactions occur between the parent and child, the finding that increased levels of parental distress was related to increased child reported depression suggests the need to focus on examining both parent and child variables in the adjustment process. Specifically, results indicate that distress is communicated throughout the family system, which suggests interventions should focus on alleviating both parent distress and child depression.

Social and family support appear to be promising variables to address in reducing parent distress (e.g., Lazarus and Folkman, 1984). One recent study demonstrated that a social support intervention for mothers of children with JRA revealed that the availability of support was associated with decreases in mental health symptomology (Ireys, Sills, Kolodner, & Walsh, 1996). In addition to increasing supportive outlets for parents who have children diagnosed with JRD, other interventions targeted at decreasing distress throughout the family system include examining parental coping mechanisms, levels of daily stress, and levels of family conflict. Previous research has indicated that poor

maternal adjustment is associated with higher levels of daily stress, lower levels of family supportiveness, and higher levels of family conflict (Thompson, 1992a; 1993b). Again, these finding emphasize the importance of social support for families who have children diagnosed with a chronic illness.

Results of the present study also suggest the importance of interventions that focus on decreasing child perceived illness uncertainty. This appears particularly important, yet challenging given the fact that illness uncertainty appears to be an inherent component of JRD. From the outset, a great deal of uncertainty is involved in making an accurate diagnosis and timely referral to a rheumatology specialist. It can take several referrals and repeated doctor visits before a diagnosis of JRD is confirmed. In fact, systemic lupus has been referred to as the "great imitator" and "great imposter" because early manifestations of the disease mimics other disorders (Kinahsi, 1983, p.19). Additionally, the diagnosis of JRA is made clinically given there is no medical test which can confirm its presence (Wedgewood & Schaller, 1977). It is also the case that the treatment regimen is surrounded by a great deal of uncertainty given there is no standard treatment protocol for JRD (Lovell, 1996). Treatment can range from taking an anti-inflammatory (e.g., aspirin) to enduring injections. With respect to disease outcome, there is no cure for JRD, but long-term survival is now more likely; however, the details of what long-term survival looks like is not certain (Lovell, 1996).

Because uncertainty appears to be an inherent component of all aspects of JRD and is associated with multiple facets of the chronic illness experience, including hospitalizations, diagnosis, treatment regimen, and treatment outcome (Mishel, 1984), interventions should focus on communicating to the patient more realistic expectations

regarding the variable and unpredictable disease course, treatment, and outcome of JRD (Mullins et al., 1995). This could help guide the family's assumptions about the disease and health care experiences (Horner, 1997).

Further, previous studies have demonstrated that increased illness uncertainty is associated with perceptions of low illness control, depressive symptomology (Edwards & Weary, 1998), and lack of social support (Mishel & Braden, 1987). These results, along with those of the present study, indicate the importance for both psychological and medical interventions to assist in giving the child a sense of control over his/her disease experience. In addition, interventions should be directed at providing social support for the child, which has demonstrated to be associated with decreased psychological distress and decreased reports of perceived illness uncertainty in adult populations (Mishel & Braden, 1987).

In general, these findings suggest that interventions targeted to increase adjustment to juvenile rheumatic disease should be aimed at decreasing child perceived illness uncertainty and parental distress.

## Methodological Considerations

It is important to consider the present findings in light of several methodological limitations. First, objective measures of disease severity, such as erythrocyte sedimentation rate (ESR), joint counts, and radiographs were not utilized to examine disease outcome. However, because the focus of this study was on the influence of subjective illness perceptions on adjustment, measures were selected that reflected the illness experience of JRD rather than objective indices of disease outcome. Illness

process variables (e.g., JAFAR-C) were utilized in the study to capture the subjective experience of JRD, which are more closely related to psychological outcome (Howe et al., 1991). Additionally, ratings of disease severity and disability were obtained from the pediatric rheumatologist, which provided clinical indices of current disease status.

Next, because self-report inventories were utilized exclusively, associations between the variables under study may have partially resulted from spurious correlations due to shared method variance and not due to the predicted associations between the variables under study (Coyne and Gotlib, 1983). This concern is somewhat attenuated by the utilization of independent responses from child and parent self-report measures. Additionally, the nonsignificant correlation between child self-report measures (MUIS-C and CDI) provides an added degree of confidence that the observed significant associations were not due simply to method variance.

Interpretation of results needs to take into account two issues related to the wide age range of participants in this sample. First, the depression measure utilized in the study (CDI) was designed for children between the ages of 7 and 17 (Kovacs, 1992). Because the study sample included children that fell outside this range, it is possible that the present findings may not accurately capture the experience of depression for children completing this measure (i.e., those older than 17). This concern is somewhat minimized in that age and CDI were found to be unrelated and the fact that internal consistency on the CDI was quite high (.91). Perhaps a more important issue is that the present sample included children that potentially represented three cognitive developmental stages (e.g., preoperational, concrete operations, and formal operations; Piaget, 1952) as well as, large differences in experienced based development. Research has demonstrated that children's

perceived control and accurate understanding of the cause and treatment of their illness show a clear developmental progression as children mature (e.g., Berry et al., 1993; Bibace & Walsh, 1980; Campbell, 1975; Redpath & Rodgers, 1984). Thus, there is the real possibility that, despite findings consistent with hypotheses the results may not capture developmental differences that exist in parent-child adjustment relationships in chronic illness.

Additionally, the interpretation and generalization of the results to the larger JRD population is limited given the participants were recruited from only one clinic, housed in a teaching hospital setting. It is possible that the sample does not represent the larger population of children with JRD who do not attend these types of clinics. Additionally, because no comparisons could be made between participants and non-participants, there is the potential for a self-selection bias on psychological and/or disease variables, which could have resulted in a more homogenous sample of children than if every family had agreed to participate. However, the sample utilized to derive the conclusions did represent the broader JRD population in terms of the characteristic 2:1 female to male gender ratio (26 female, 14 male). Further, the sample was comprised of participants representing a wide range of ethnic groups (48% Caucasian, 22% Native American, 10% African American, 10% Biracial, 8% Hispanic, and 2% Asian), compared to other studies that were comprised of predominantly Caucasian participants (e.g., Ireys, et al., 1994; Kronenberger & Thompson, 1992; Thompson, 1994b).

Despite these limitations, this study adds to the literature in two ways. First, the present findings highlight the importance of extending statistical analysis beyond main effect examinations of the data and exploring the interrelationships among variables

associated with adjustment (Holmbeck, 2002). Had the analyses not proceeded beyond examining the main effects, conclusions and interpretations of the data would have been incomplete. Specifically, the main conclusion of the study would have been that illness uncertainty is not an important variable influencing the experience of depression in children with JRD. However, by examining the indirect nature of relationships among variables, illness uncertainty was found to play a role in child depression by enhancing the relationship between parent distress and child depression.

Additionally, the present study examined the relationships between parent and child influences on child adjustment. Previous research utilizing transactional stress and coping models, has mainly focused on the relationship between parent cognitive variables and parent adjustment (Kronenberger & Thompson, 1990; Thompson et al., 1992b; Thompson et al., 1993a). The few studies examining parent-child adjustment relationships have relied on parent reports of child adjustment (Thompson et al., 1992c) or have neglected child cognitive appraisal mechanisms in the process (Thompson et al., 1994a; Thompson et al., 1994b). The present study examined the interrelationship between parent and child variables, utilized a self-report child measure of adjustment, and examined child cognitive appraisals as an intervening variable in the parent-child adjustment relationship.

## Recommendations for Future Research

Recommendations for future research include examining a JRD population comprised of larger sample sizes, ideally from multiple sites. This would allow for a more heterogeneous representation of the JRD population. Additionally, it would be

beneficial to examine these variables longitudinally, which may help better explain long-term adjustment in children diagnosed with JRD. Specifically, research should examine how parental distress, child distress, illness uncertainty, and other possible child cognitive appraisal variables impact child adjustment to disease over time. Additionally, these variables should be examined longitudinally with respect to their influence on disease outcome (e.g., treatment adherence, functional ability, etc). Finally, future studies should take into consideration the different developmental levels of participants. This could be done either by assessing for developmental level or by restricting analyses to specific age ranges (e.g., 9-12, 13-16) so that results more accurately reflect age-specific developmental processes. This would also allow for comparisons of potential parent-child adjustment relationships across developmental stages.

Overall, the present study adds to a growing body of literature demonstrating the utility of transactional stress and coping approaches to child adjustment in pediatric chronic illness populations. Further, results provide support for examining child cognitive appraisal mechanisms as intervening variables in the parent-child adjustment process. The identification of child illness uncertainty as an important variable to child adjustment in JRD provides additional insights into the complex relationship between parent and child adjustment, which may translate into more effective psychological interventions to reduce psychological comorbidity and enhance the overall treatment for children and adolescents with JRD and their families.

# REFERENCES

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.

Baron, R.M. & Kenny, D.A. (1986). The moderator-mediator variable distinction in social psychological research: Conceptual, strategic, and statistical considerations. *Journal of Personality and SocialPsychology, 51*(6), 1173-1182.

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

Berry, S.L., Hayford, J.R., Ross, C.K., Pachman, L.M., & Lavigne, J.V. (1993). Conceptions of illness by children with juvenile rheumatoid arthritis: A cognitive developmental approach. *Journal of Pediatric Psychology, 18*(1), 83-97.

Bibace, R. & Walsh, M.E. (1980). Development of children's concepts of illness. *Pediatrics, 66*(6), 912-17.

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.

Braden, C.J. (1990). A test of the self-help model: Learned response to chronic illness experience. *Nursing Research, 39*(1), 41-47.

Braden, C.J. & Lynn, M. (1987, October 1). *Antecedents to and out-comes of uncertainty experienced in chronic illness*. Paper presented at Nursing Advances in Health: Models, Methods, and Applications, ANA Council of Nursing Researchers, International Nursing Research Conference, Washington, D.C.

Brewer, E.J., Bass, J., Baum, J., Cassidy, J.T, Fink, C., Jacobs, J., et al. (1977). Current proposed revision of juvenile rheumatoid arthritis criteria. *Arthritis and Rheumatism, 20,* 195-199.

Bronfenbrenner, U. (1977). Toward an experimental ecology of human development. *American Psychologist, 32*(7), 513-530.

Campbell, J.D. (1975). Illness is a point of view: The development of children's concepts of illness. *Child Development, 46,* 92-100.

Cassidy, J.T., Levinson, J.E., & Brewer, E.J. (1989). The development of classification criteria for children with juvenile rheumatoid arthritis. *Bulletin on Rheumatic Diseases, 38*(6), 1-7.

Cassidy, J.T., & Nelson, A.M. (1988). The frequency of juvenile arthritis. *Journal of Rheumatology, 15,* 535-536.

Cassidy, J.T., & Petty, J.T. (1995). The frequency of juvenile arthritis. *The Journal of Rheumatology, 15*(4), 535-536.

Chaney, J.M., Mullins, L.L., Frank, R.G., Peterson, L., Mace, L.D., Kashani, J.H., et al. (1997). Transactional patterns of child, mother, and father adjustment in insulin-dependent diabetes mellitus: a prospective study. *Journal of Pediatric Psychology, 22*(2), 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., & Peterson, L. (1989). Family variables and disease management in juvenile rheumatoid arthritis. *Journal of Pediatric Psychology, 14*(3), 389-403.

Chaney, J.M. & Youll, L.K. (1994). Systemic lupus erythmemaosus: Psychological issues. In R.A. Olsen, L.L. Mullins, J.B. Gibson, & J.M. Chaney (Eds). *The Sourcebook of Pediatric Psychology* (167-176). Boston, MA: Allyn & Bacon.

Christman, N.J. (1990). Uncertainty and adjustment during radiotherapy. *Nursing Research, 39*(1), 17-20.

Cohen, M.H. (1993). The unknown and the unknowable-managing sustained uncertainty. *Western Journal of Nursing Research, 15*(1), 77-96.

Cohen, M.H. (1995). The triggers of heightened parental uncertainty in chronic, life-threatening childhood illness. *Qualitative Health Research, 5*(1), 63-77.

Compas, B.E., Howell, D.C., Phares, V., Williams, R.A., & Leadoux, N. (1989). Parent and child stress and symptoms: An integrative analysis. *Developmental Psychology, 25*(4), 550-559.

Coyne, J. & Gotlib, I. (1983). The role of cognition in depression: A critical review. *Psychological Bulletin, 94*, 472-505.

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

Daltroy, L.H., Larson, M.G., Eaton, H.M., Patridge, A.J., Pless, I.B., Rodgers, M.P., et al. (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., et al. (1994). The functional and psychological outcomes of juvenile chronic arthritis in young adulthood. *British Journal of Rheumatology, 33*, 876-881.

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

Edwards, J.A. & Weary, G. (1998). Antecedents of causal uncertainty and perceived control: A prospective study. *European Journal of Personality, 12,* 135-148.

Eiser, C. & Havermans, T. (1992). Mothers and fathers coping with chronic childhood disease. *Psychology and Health, 7*, 249-257.

Emery, H. (1986). Clinical aspects of systemic lupus erythematosus in childhood. *Pediatric Rheumatology, 33*(5), 1177-1190.

Ennett, S.T., DeVillis, B.M., Earp, J.A., Kredich, D., Warren, R.W., & Wilhelm, 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*, 557-568.

Frank, R.G., Beck, N.C., Parker, J.C., Kanshani, J.H., Elliott, T.R., Haut, A.E., et al. (1988). Depression in rheumatoid arthritis. *The Journal of Rheumatology, 15*(6), 920-925.

Frank, R.G., Hagglund, K.J., Schopp, L.H., Thayer, J.F., Vieth, A.Z., Cassidy, J.T., et al. (1997). Disease and family contributors to adaptation in juvenile rheumatoid arthritis and juvenile diabetes. *Arthritis Care and Research, 11*(3), 166-176.

Fritz, G., William, J., & Amylon, M. (1988). After treatment ends: Psychosocial sequelae in pediatric cancer survivors. *American Journal of Orthopsychiatry, 58*, 552-561.

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.

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.

Holmbeck, G.N. (1997). Toward terminological, conceptual, and statistical clarity in the study of mediators and moderators: Examples from the child-clinical and pediatric psychology literatures. *Journal of Consulting and Clinical Psychology, 65*(4), 599-610.

Holmbeck, G.N. (2002). Post-hoc probing of significant moderational and mediational effects in studies of pediatric populations. *Journal of Pediatric Psychology, 27*(1), 87-96.

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.

Horner, S.D. (1997). Uncertainty in mothers' care for their ill children. *Journal of Advanced Nursing, 26,* 658-663.

Howe, S., Levinson, J., Shear, E., Hartner, S., McGirr, G., Schulte, M., et al. (1991). Development of a disability measurement tool for juvenile rheumatoid arthritis: The Juvenile Arthritis Functional Assessment Report for children and their parents. *Arthritis and Rheumatism, 34*(7) 873-880.

Ireys, H.T., Sills, E.M., Kolodner, 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., Werthamer-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.

Jacox, R.F., Meyerowitz, S., & Hess, W.D. (1966). A genetic, clinical, and psychological study of nine sets of monozygotic twins, discordant for rheumatic arthritis. *Manitoba Medical Review, 46*(8), 522-523.

Jaworski, T.M. (1993). Juvenile rheumatoid arthritis: Pain-related and psychological aspects and their relevance for assessment and treatment. *Arthritis Care and Research, 6*(4), 187-196.

Jessop, D., & Stein, R. (1985). Uncertainty and its relation to the psychological correlates of chronic illness in children. *Social Science and Medicine, 20,* 552-561.

Joyce, J., Berkebile, C., Hastings, C., Yarboro, C., & Yocum, D. (1989). Health status and disease activity in systemic lupus erythematosus. *Arthritis Care & Research, 2*(2), 65-69.

Kewman, D.G., Warschausky, S.A., & Engel, L. (1995). Juvenile rheumatoid arthritis and neuromuscular conditions: Scoliosis, spinal cord injury, and muscular dystrophy. In M.C. Roberts (Ed). *Handbook of Pediatric Psychology: 2nd Edition* (384-402). New York, NY: The Guilford Press.

Kinash, R. (1983). Systemic lupus erythematosus: The psychological dimension. *Canada's Mental Health,* 19-22.

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 environment scale. *Journal of Clinical Child Psychology, 19*(4), 380-388.

Kvist, S.B.M., Rajantie, J., Kvist, M., & Siimes, M.A. (1991). Aggression: The dominant psychological response in children with malignant diseases. *Psychological Reports, 68,* 1139-1150.

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

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

Lovell, D.J. (1996). Juvenile rheumatoid arthritis and juvenile spondyloarthropatheis. *Primer on Rheumatic Diseases*. 393-398.

Lovell, D.J., & Walco, G.A. 1989. Pain associated with juvenile rheumatoid arthritis. *Pediatric Clinics in North America, 36,* 1015-1027.

Manuel, J.G. (2001). Risk and resistance factors in the adaptation in mothers of children with juvenile rheumatoid arthritis. *Journal of Pediatric Psychology, 26*(4), 237-246.

Mast, E.M. (1995). Adult uncertainty in illness: A critical review of research. *Scholarly Inquiry for Nursing Practice: An International Journal, 9*(1), 3-23.

Meyerowitz, S., Jacox, R.F., & Hess, D. W. (1968). Monozygotic twins discordant for rheumatic arthritis: A genetic, clinical, and psychological study of eight sets. *Arthritis and Rheumatism, 11*(1), 1-21.

Mintun, M. (1984). *Measurement of parental uncertainty in PICU*. Unpublished master's thesis, University of Kansas Health Sciences, Kansas City, Kansas.

Mishel, M.H. (1983). Parents' perceptions of uncertainty concerning their hospitalization child. *Nursing Research,32*(6), 324-330.

Mishel, M.H. (1984). Perceived uncertainty and stress in illness. *Research Nursing and Health, 7,* 163-171.

Mishel, M.H. (1988). Uncertainty in illness. *Image: Journal of Nursing Scholarship, 20*(4), 225-232.

Mishel, M.H. (1990). Reconceptualization of the uncertainty in illness theory. *Journal of Nursing Scholarship, 22*(4), 256-262.

Mishel, M.H. & Braden, C. (1987). Uncertainty: A mediator between support and adjustment. *Western Journal of Nursing Research, 9*(1), 43-57.

Mishel, M.H., & Braden, C. (1988). Finding meaning: Antecedents of uncertainty in illness. *Nursing Research, 37*, 98-127.

Mishel, M.H., Hostetter, T., King, B., & Graham, V. (1984). Predictors of psychosocial adjustment in patients newly diagnosed with gynecological cancer. *Cancer Nursing, 7,* 291-299.

Mishel, M.H., Padilla, G., Grant, M., & Sorenson, D.S. (1991). Uncertainty in illness theory: A replication of the mediating effects of mastery and coping. *Nursing Research, 40*(4), 236- 240.

Mishel, M.H., & Sorenson, D.S. (1991). Uncertainty in gynecological cancer: A test of the mediating functions of mastery and coping. *Nursing Research, 40*(3), 167-171.

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

Monat, A., & Lazarus, R.S. (1977). *Stress and coping: an anthology*. New York, NY: Columbia University Press.

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, L., Albin, K., Miles, B., & Roberson, S. (1995). Cognitive and affective features of postpolio syndrome: Illness uncertainty, attributional style, and adaptation. *International Journal of Rehabilitation and Health, 4*(1), 211-222.

Mullins, LL, Chaney, J.M, Pace, T.M. & 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.

Padialla, G.V., Mishel, M.H & Grant, M.M. (1992). Uncertainty, appraisal, and quality of life. *Quality of Life Research, 1,* 155-165.

Patterson, J. & Blum, R.W. (1996). Risk and resilience among children and youth with disabilities. *Archives of Pediatrics and Adolescents, 150,* 692-698.

Peterson, L. (1989). Coping by children undergoing stressful medical procedures: Some conceptual, methodological, and therapeutic issues. *Journal of Consulting and Clinical Psychology, 57*(3), 380-387.

Pless, B.I. (1984). Clinical assessment: Physical and psychological functioning. *Pediatric Clinics in North America, 31*(1), 33-45.

Redpath, C.C. & Rogers, C.S. (1984). Healthy young children's concepts of hospitals, medical personnel, operations, and illness. *Journal of Pediatric Psychology, 9*(1), 29-39.

Rosenbaum, M. (1988). Learned resourcefulness, stress, and self-regulation. In S. Fisher and J. Reaser (Eds), *Handbook of Life Stress, Cognition, and Health* (483-495). New York, NY: J. Wiley & Sons.

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.

Schanberg, L.E., Sandstrom, M.J., Starr, K., Gil, K.M., Lefebvre, J.C., Keffe, F.J., et al. (2000). The relationship of daily mood and stressful events to symptoms in juvenile rheumatic disease. *Arthritis Care and Research, 13*(1), 33-41.

Siegel, J.L, & Smith, K.E. (1989). Children's strategies for coping with pain. *Pediatrician, 16,* 110-118.

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

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., et al. (1994a). 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., Gustafson, K.E., George, L.K., & Spock, A. (1994b). Change over a 12-month period in the psychological adjustment of children and adolescents with cystic fibrosis. *Journal of Pediatric Psychology Special Issue: Chronic illness, 19*(2), 189-203.

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). 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., Gustafson, K.E., Hamlett, K.W., & Spock A. (1992b). Stress, coping, and family functioning in the psychological adjustment of mothers of children and adolescents with cystic fibrosis. *Journal of Pediatric Psychology, 17*(5), 573-585.

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

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

Timko, C., Stovel, K.W., Moos, R.H., & Miller, J.J. (1992). A longitudinal study of risk and resistance factors among children with juvenile rheumatic disease. *Journal of Clinical Child Psychology, 21*(2), 132-142.

Tomlinson, P.S., Krischbaum, M., Harbaugh, B., & Anderson, K.H. (1996). The influence of illness severity and family resources on maternal uncertainty during critical pediatric hospitalization. *American Journal of Critical Care, 5*(2), 140-146.

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.

Vandvick, I.H., & Eckblad, G. (1991). Mothers of children with recent onset of rheumatic disease: Associations between maternal distress, psychosocial variables, and the disease of the children. *Journal of Developmental and Behavioral Pediatrics, 12*(2), 84-91.

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.

Walker, L.S., Ortiz-Valdes, J.A., & Newbrough, J.R. (1988). The role of maternal employment and depression in the psychological adjustment of chronically ill, mentally retarded, and well children. *Journal of Pediatric Psychology, 14*(3), 357-370.

Wallander, J.L., Varni, J.W., Babani, L., Banis, H.T., & Wilcox, K.T. (1988). Children with chronic physical disorders: Maternal reports of their psychological adjustment. *Journal of Pediatric Psychology, 13*(2), 197-212.

Wedgewood, R.J. & Schaller, J.G. (1977). The pediatric arthritides. *Hospital Practice.* June 1977, 83-97.

# APPENDIXES

# APPENDIX A

## TABLES

Table 1

Descriptive Statistics for Demographic, Psychosocial, and Disease-Related Variables

| Variable | M | SD | Range |
|---|---|---|---|
| Age | 14.4 | 2.92 | 9 - 21 |
| Disease Years | 2.71 | 2.85 | .04 – 14.59 |
| Functional Ability | 1.58 | .71 | 1 – 3 |
| JAFAR-C | 4.31 | 5.76 | 0 – 23 |
| Parental Distress (BSI) | .48 | .44 | 0 – 1.85 |
| Illness Uncertainty – Child (MUIS-C) | 65.23 | 18.55 | 32 – 104 |
| Depression (CDI) | 8.65 | 8.40 | 0 – 44 |

Note. JAFARC = The Juvenile Arthritis Functional Assessment Report-Child; BSI = Brief Symptom Inventory; MUIS-C = Mishel Uncertainty in Illness Scale-Child form.

Table 2

Zero-order Correlations for Study Variables

| | 1 | 2 | 3 | 4 | 5 | 6 |
|---|---|---|---|---|---|---|
| 1. Age | | | | | | |
| 2. Disease Duration | -.001 | | | | | |
| 3. JAFAR-C | .07 | -.14 | | | | |
| 4. Functional Class | -.03 | .05 | .43** | | | |
| 5. BSI | .33* | -.04 | .21 | .06 | | |
| 6. MUIS-C | .10 | -.37* | .08 | .002 | .01 | |
| 7. CDI | .25 | -.21 | -.03 | -.13 | .50** | .13 |

Note. JAFARC = The Juvenile Arthritis Functional Assessment Report-Child; BSI = Brief Symptom Inventory; MUIS-C = Mishel Uncertainty in Illness Scale-Child form; CDI = Child Depression Inventory.

* $p < .05$

** $p < .01$

Table 3

Hierarchical Multiple Regression Analyses

| Step | Variables | *t* for within step predictors | $R^2$ Change for Step | F Change |
|---|---|---|---|---|
| | EQUATION 1 | | | |
| 1 | Age | 1.21 | .15 | 2.08 |
| | Gender | -.09 | | |
| | Disease Subtype | 1.91 | | |
| 2 | Disease Years | -1.40 | .07 | .98 |
| | JAFARC | .58 | | |
| | Functional Class | -.79 | | |
| 3 | BSI | 2.69* | .14 | 7.21* |
| | EQUATION 2 | | | |
| 3 | MUISC | .01 | .00 | .01 |
| | EQUATION 3 | | | |
| 3 | BSI | -1.95 | .30 | 6.28** |
| | MUISC | -2.00 | | |
| | BSIXMUISC | 3.14** | | |

Note. JAFARC = The Juvenile Arthritis Functional Assessment Report-Child; BSI = Brief Symptom Inventory; MUIS-C = Mishel Uncertainty in Illness Scale-Child form.

* $p < .05$

** $p < .01$

Table 4

Post-hoc Hierarchical Multiple Regression Analyses

| Step | Variables | *t* for within step predictors | $R^2$ Change for Step | F Change |
|---|---|---|---|---|
| | EQUATION 1 | | | |
| 1 | Age | 1.21 | .15 | 2.08 |
| | Gender | -.09 | | |
| | Disease Subtype | 1.91 | | |
| 2 | Disease Years | -1.4 | .07 | .98 |
| | JAFARC | .58 | | |
| | Functional Class | -.79 | | |
| 3 | $BSI_{Centered}$ | 4.34** | .30 | 6.28** |
| | HIMUISC | .24 | | |
| | HIMUISC X BSI | 3.14** | | |
| | EQUATION 2 | | | |
| 3 | $BSI_{Centered}$ | .65 | .30 | 6.28** |
| | LOMUISC | .24 | | |
| | LOMUISC X BSI | 3.14** | | |

Note. JAFARC = The Juvenile Arthritis Functional Assessment Report-Child; BSI = Brief Symptom Inventory; MUIS-C = Mishel Uncertainty in Illness Scale-Child form.

* $p < .05$

** $p < .01$

# APPENDIX B

## FIGURES

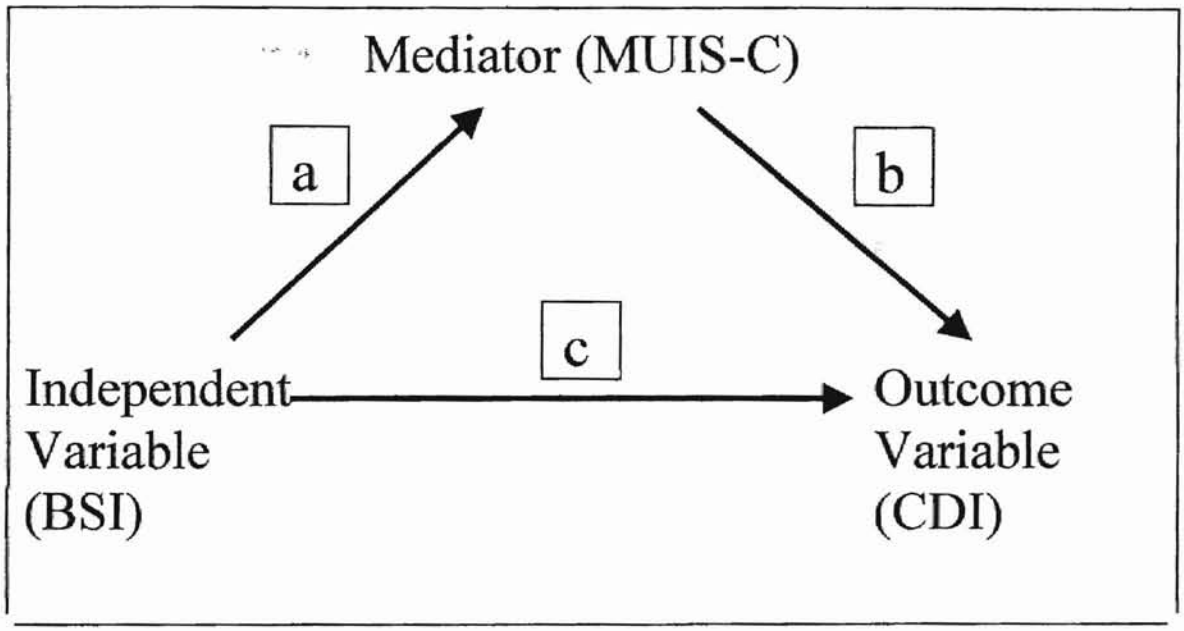



Figure 1. Mediational Model

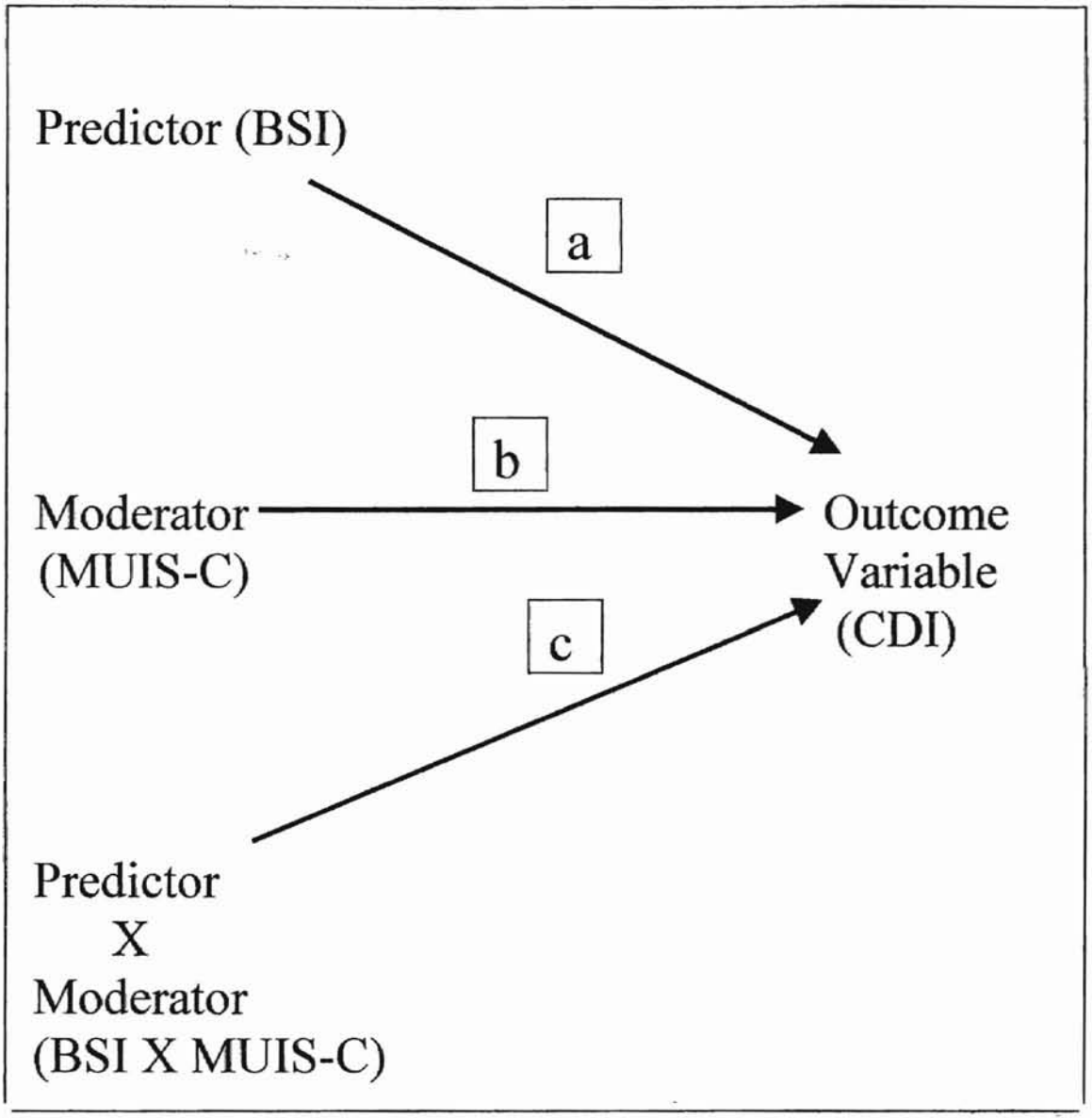



Figure 2. Moderator Model

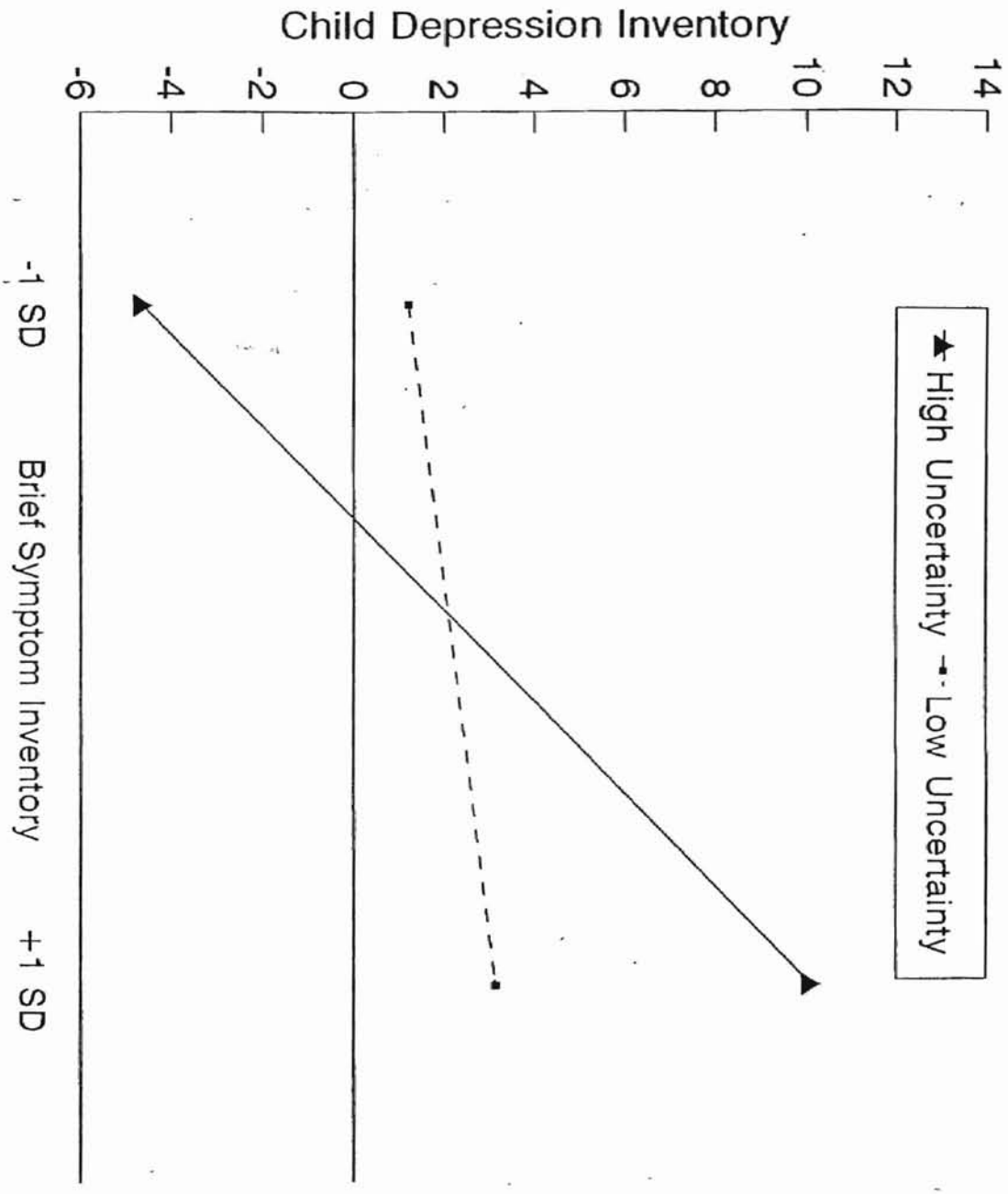



Figure 3. BSIXMUIS-C Interaction

# APPENDIX C

## INSTITUTIONAL REVIEW BOARD 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 D

# 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.

**DESCRIPTION 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 be 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 will 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 Whitehurst, 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) 744-6027.

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)

# APPENDIX E

# 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 JRA 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:_____

# APPENDIX F

# 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 G

# BRIEF SYMPTOM INVENTORY

# BSI®

## *Brief Symptom Inventory™*

Leonard R. Derogatis, PhD

Last Name First MI

ID Number

Age Gender Test Date

DIRECTIONS:

1. Print your name, identification number, age, gender, and testing date in the area on the left side of this page.
2. Use a lead pencil only and make a dark mark when responding to the items on page 3.
3. If you want to change an answer, erase it carefully and then fill in your new choice.
4. Do not make any marks outside the circles.

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

| | NOT AT ALL | A LITTLE BIT | MODERATELY | QUITE A BIT | EXTREMELY | 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 are 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 H

## BACKGROUND INFORMATION QUESTIONNAIRE

1. Age: _____

2. Gender: M F
   1 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: _____

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

9. 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

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

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

| Yes | No |
|---|---|
| 1 | 2 |

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

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

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

15. 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 |

16. 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 |

17. 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 |

18. 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 |

19. 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 |

20. 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 |

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

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

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

# APPENDIX I

## THE 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 you hair by yourself: All of the time, Just some of the time, or Almost never?", you would place a check mark under the column labeled "All the time" if you were able to do this every day. 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. Lift 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 J

# CHILD DEPRESSION INVENTORY

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

REMEMBER, DESCRIBE HOW YOU HAVE BEEN IN THE PAST TWO WEEKS.

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 K

## MISHEL UNCERTAINTY IN ILLNESS SCALE CHILD FORM

Instructions: Please read each statement. Take your time and think about each statement. Then circle the answer that says how you feel today. If a statement says how you feel, then circle "very true" or "true." If a statement does not say how you feel, then circle "false" or "very false." If you are not sure how you feel about a statement, then circle "unsure." Please circle one answer for each statement.

1. I don't know what is wrong with me.

Very True True Unsure False Very False

2. I have a lot of questions about my illness and I don't know what the answers are.

Very True True Unsure False Very False

3. I don't know if my illness is getting better or worse.

Very True True Unsure False Very False

4. I don't know how bad my pain will be.

Very True True Unsure False Very False

5. The things they tell me about my illness confuse me.

Very True True Unsure False Very False

6. I don't know why I have to do each of the treatments.

Very True True Unsure False Very False

7. I don't know why some days I feel worse.

Very True True Unsure False Very False

8. I understand everything they tell me about my illness.

Very True True Unsure False Very False

9. The doctors say things to me that could mean a lot of different things.

Very True True Unsure False Very False

10. My treatment is to hard to figure out.

Very True True Unsure False Very False

11. It is hard to know if the treatments or medicine I am getting are helping me get better.

Very True True Unsure False Very False

12. Because I don't know what's going to happen with my illness, I cannot plan for the future.

Very True True Unsure False Very False

13. I never know how I will feel, I have good days and bad days.

Very True True Unsure False Very False

14. Everybody seems to have different ideas about what is wrong with me.

Very True True Unsure False Very False

15. I am not always sure what is going to happen to me.

Very True True Unsure False Very False

16. The results of my tests go back and forth between good and bad.

Very True True Unsure False Very False

17. They do not know if the treatment will work.

Very True True Unsure False Very False

18. Because of my treatment, I never know what I can do and cannot do.

Very True True Unsure False Very False

19. I know they will not find anything else wrong with me.

Very True True Unsure False Very False

20. I know the treatment I am getting will work and make me better.

Very True True Unsure False Very False

21. They have not told me what is wrong with me.

Very True True Unsure False Very False

22. I know how bad my illness is.

Very True True Unsure False Very False

23. The doctors and nurses explain things so I can understand.

Very True True Unsure False Very False

VITA 2

Molly Marie White

Candidate for the Degree of

Master of Science

Thesis: TRANSACTIONAL PATTERNS OF PARENT AND CHILD ADJUSTMENT IN JUVENILE RHEUMATIC DISEASES: THE ROLE OF ILLNESS UNCERTAINTY

Major Field: Psychology

Biographical:

Education: Graduated from Emporia High School, Emporia, Kansas in May 1996; received Bachelor of Science degree in Psychology from Kansas State University, Manhattan, Kansas in May 2000. Completed the requirements for the Master of Science degree with a major in Psychology at Oklahoma State University in August 2002.

Experience: Research assistant, Department of Psychology, Perception Lab, Kansas State University, Manhattan, KS, Supervisor: John Uhlarik, Ph.D.; Research assistant, Department of Psychology, Child Research Lab, Kansas State University, Manhattan, KS, Supervisor: Mark Barnett, Ph.D.; Research Assistant, Department of Psychology, Health Psychology Lab, Oklahoma State University, Stillwater, OK, Supervisor: John M. Chaney, Ph.D.

Professional Memberships: Brain Injury Association of Oklahoma, American Psychological Association (APA), APA Division 54: Society of Pediatric Psychology, APA Division 22: Rehabilitation Psychology, APA Division 38: Health Psychology, APA Division 45: Society for the Psychological Study of Ethnic Minority Issues, Southwestern Psychological Association, Association for the Advancement of Behavior Therapy, Oklahoma Psychological Association, American Psychological Association of Graduate Students, Mortar Board National Senior Honor Society, Psi Chi National Honor Society.