TRANSACTIONAL PATTERNS OF DEPRESSION, ILLNESS UNCERTAINTY, AND ILLNESS INTRUSIVENESS IN PARENTS OF CHILDREN AND ADOLESCENTS WITH JUVENILE RHEUMATIC DISEASE

By

MICHAEL STUART MCLAUGHLIN

Bachelor of Science
Oklahoma State University
Stillwater, Oklahoma
1996

Master of Science
Oklahoma State University
Stillwater, Oklahoma
2000

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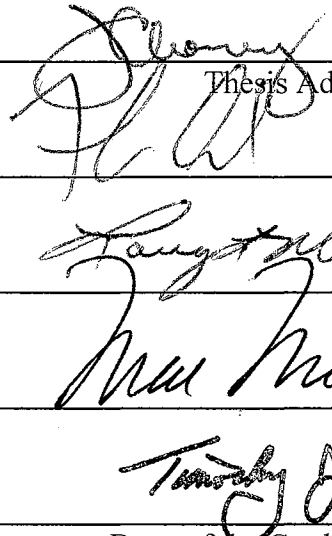

Thesis Adviser

Dean of the Graduate College

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CHAPTER I

INTRODUCTION

Description and Epidemiology of Juvenile Rheumatic Diseases (JRD)

The Juvenile Rheumatic Diseases (JRD) include juvenile rheumatoid arthritis (JRA), systemic lupus erthematosus (SLE), the juvenile spondylarthropathies, and juvenile dermatomyositis (JDMA). These conditions constitute a heterogeneous class of chronic illness that share common elements. Specifically, they are characterized by chronic and/or intermittent episodes of joint inflammation, swelling, and pain that can cause functional impairment, restrict performance of daily living activities, and can be associated with poor psychosocial adjustment (David et al., 1994; Vandvik, 1990).

Juvenile rheumatoid arthritis (JRA) is an autoimmune disorder that affects approximately 70,000 children and adolescents in the United States, and is one of the most common chronic childhood diseases (Singsen, 1993). The disease is characterized by persistent inflammation of the synovial tissue, causing pain, swelling, stiffness, restricted functional ability (Singsen, 1993), and in severe cases leads to deformity in one or more affected joints (Rennebohm, 1995). Onset of JRA typically occurs before age 16 (Kewman, Warschausky, & Engel, 1995) and may range from infancy through adolescence (Rennebohm, 1995). Various environmental factors (e.g., viruses, bacteria,

nutrition, toxins) have been suggested as potential triggers for disease onset in predisposed individuals (Albert, Woo, & Glass, 1990), however, the root cause of the inflammatory immune response is not known. JRA generally affects girls more often than boys, however, age and sex ratios vary across the three subtypes of JRA: systemic, polyarticular, and pauciarticular (Singsen, 1993).

Systemic JRA may develop at any age during childhood and comprises nearly 10% of JRA cases, affecting boys about as equally as girls. Children with systemic JRA often experience fever spikes associated with rashes, that generally occur in the late afternoon or evening. Around one-half of these patients go on to have multiple systemic episodes, which often occur unexpectedly even after several years of remission, and may last from days to months in duration. Further, approximately 50% of children diagnosed with systemic JRA will eventually develop severe, chronic polyarthritis which persists long after the systemic symptoms have abated (Singsen, 1993).

Polyarticular JRA onset similarly may develop at any time during childhood and comprises approximately 40% of JRA cases; girls are affected about three times more often than boys. This subtype of JRA is characterized by low-grade fever, weight loss, malaise, anemia, and growth retardation. These patients develop arthritis in five or more joints, and 75% of children with polyarticular JRA present with symmetric joint involvement (Singsen, 1993).

Pauciarticular JRA typically occurs before age 10, with boys affected up to five times more often than girls. This disease subtype is characterized by inflammatory arthritis in four or fewer joints and comprises approximately 50% of JRA cases. In half of

children diagnosed with this subtype of JRA, only one joint is involved, most commonly the knee (Singsen, 1993).

Systemic lupus erythematosus (SLE) is a rheumatic disease involving chronic autoimmune dysfunction. It differentially affects girls to boys at a ratio of approximately four to three. Emery (1986) suggests that approximately 10% of patients who are seen in pediatric clinics have SLE. The inflammatory immune response of SLE can negatively influence a much wider spectrum of bodily systems than JRA [including joints, organs (e.g., kidneys, heart, lungs), muscles, bones, central nervous system, etc.]. Although the number and types of possible symptoms associated with SLE may be broad (depending upon the site of the inflammatory attack), common symptoms include photosensitivity, butterfly rash, chronic fatigue, arthritis, chest pain, and fever (Rennebohm, 1995). Unlike JRA, the arthritis associated with SLE is typically intermittent, mild, and does no irreversible damage to the joint tissue or bone. Approximately 75% of patients with SLE develop nephritis (kidney inflammation) of varying severity, which is usually a symptomless condition. However, severe lupus nephritis may lead to renal failure or renal death (Rennebohm, 1995).

There is significant variability in the disease severity and symptom presentation of SLE. Children with mild SLE may only experience mild arthritis and fatigue, without inflammation of other internal organs. These types of patients often only require mild anti-inflammatory drugs and may experience a gradual remission of symptoms after several years. However, individuals with more severe forms of the SLE can develop life-threatening diseases centered around various affected organs, requiring much more aggressive drug treatment. When patients with severe forms of SLE die from the disease,

it is generally due to a secondary infection that can result from the aggressive immunosuppresive drug treatments used (Rennebohm, 1995).

Another sub-group of juvenile rheumatic diseases, the spondylarthropathies, occur more often in boys than in girls. A relative lack of clear diagnostic criteria makes diagnosis of this class of rheumatic disease problematic. However, these diseases frequently occur in children with a positive family history, suggesting possible genetic disease factors. One type of spondylarthopathy, juvenile ankylosing spondylytis (JAS), comprises up to 10% of childhood arthritis cases (Singsen, 1993). Onset of JAS typically occurs from late childhood to adolescence, and is characterized initially by peripheral arthritis which may then spread to the back. JAS often develops in the lower extremities, particularly the hip joints. Approximately one-fourth of children with JAS will experience polyarticular arthritis, and approximately one-fourth will have axial or sacroiliac symptoms at onset (Singsen, 1993). Due to the systemic nature of the disease, JAS often affects the eyes and heart, and inflammatory bowel disease is commonly seen. The prognosis for JAS is generally favorable, but may be characterized by unexpected remissions of physical symptoms (Kahn, 1993).

Juvenile dermatomyositis (JDMA) is another inflammatory connective tissue disease characterized by vasculitis of the skin, muscle, and gastrointestinal tract. JDMA occurs more often in girls than boys, and onset commonly occurs between five and 14 years of age. The etiology of the disease is yet unknown, but similar to JRA, genetic and infectious factors (e.g., viruses) are considered to play significant roles in disease onset (Singsen, 1993). Common symptoms of JDMA include proximal muscle weakness, which makes some physical activities difficult (e.g., running, climbing stairs), and a

characteristic rash that may include a heliotrope discoloration of the eyelids similar to that seen in SLE.

Adjustment and Psychosocial Factors

The association between psychosocial variables and adjustment in juvenile rheumatic disease (JRD) has been extensively examined. For example, in a sample of children with JRA, 63% demonstrated difficulty in psychological functioning, and 51% met criteria for at least one DSM-III diagnosis (Vandvik, 1990). In a similar study, healthy controls (i.e., children with mild or inactive rheumatic disease) were compared with children with severe JRA (Billings, Moos, Miller, & Gottlieb, 1987) and children with severe JRA demonstrated increased levels of anxiety, depression, and other types of psychological distress. Lastly, research has supported that living with a chronic illness like JRA for long-term periods of time, results in psychological maladjustment. David and colleagues (1994), found that 21% of individuals who had lived with JRA for extended periods of their lives (i.e., 10 to 39 years) experienced clinical depression, and the rate of depression and anxiety increased with the severity of their functional disability.

Psychological adjustment has also been examined in patients diagnosed with systemic lupus erythematosus (SLE), resulting in some mixed findings. Mitchell and Thompson (1990) suggest that SLE patients receiving outpatient treatment appear similar to individuals with other types of chronic disease regarding their psychological adjustment. However, when these patients were compared with a psychiatric group no trends toward significant psychological disturbance in the SLE group emerged. Alternately, in a review of studies investigating psychological adjustment in SLE, Chaney

and Youll (1994) document the scarcity of well-controlled research examining these issues. Additionally, Chaney and Youll suggest that the disease course and clinical treatment of SLE involves numerous difficult obstacles. Lastly, Cornwell and Schmitt (1990) demonstrated that SLE and its treatments may have profound effects on adolescents' perceptions of their body image. Thus, it appears that patients with SLE do experience psychological disturbances related to the illness, but more well-controlled studies are needed.

Uncertainty in Chronic Illness

When individuals or families experience an illness event, often they are faced with a situation that is defined by its own ambiguity. In such situations people may actively assign meaning to the experience in an attempt to lessen ambiguity and make coherent sense of the experience. Mishel (1988) suggested that illness uncertainty may result from attempts to make sense of an illness experience if: 1) the experience is inherently ambiguous or complex, 2) the individual lacks sufficient information, or 3) an outcome cannot be accurately predicted. Originally this model was constructed to explain uncertainty associated with *acute* illness events (Mishel, 1988), however, Mishel (1990) later reconceptualized the model to explain illness uncertainty in chronic illness situations.

Mast (1995) has suggested that the extant uncertainty literature has effectively demonstrated an influence of illness uncertainty on psychological adjustment in adults who experience an illness event. Specifically, individuals may experience greater emotional difficulty when uncertain situations are interpreted as dangerous to the

individual (Mast, 1995). Additionally, there appears to be a strong relationship between uncertainty and mood disturbance, emotional distress, and anxiety (Bennett, 1993; Braden, 1990; Christmen et al., 1988; Hawthorne & Hixon, 1994). However, it is unlikely that illness uncertainty influences psychological adjustment in a vacuum. Some inconsistencies between the uncertainty model and existing research suggest that additional illness-related variables may contribute a mediating influence to psychological functioning.

Illness Intrusiveness

Research has demonstrated that children or adolescents with chronic illness are at risk for dysfunction from both the disease itself, and psychosocial problems which may develop as a result of the disease (e.g., Billings, Moos, Miller & Gottlieb, 1987; Timko, Stovel, Moos, & Miller, 1992). Thus, examining factors that contribute to, or detract from, the adjustment of chronically ill patients is important to providing effective care to patients and families. One psychological construct that has received increasing attention in the literature is illness intrusiveness. Devins and colleagues (1983) described illness intrusiveness as the degree to which an illness and/or treatment for an illness interferes with an individual carrying out his/her normal daily life activities. This interference may impede daily activities directly (e.g., due to physical or physiological limitations resulting from the disease course or treatment), or it may manifest itself indirectly (e.g., by disrupting normal relationship patterns or family roles). For example, a child with systemic JRA who is experiencing significant physical symptoms of joint pain and swelling, and who restricts valued physical activities (e.g., active play with friends) to

avoid exacerbating their symptoms would likely perceive high illness intrusiveness. In situations such as the previous example, or when the response to treatment at times appears non-contingent with expected outcomes, patients may perceive that they have little control over their illness. Although perceived illness intrusiveness is not synonymous with perceived control, these constructs likely share some conceptual overlap.

The relationship between perceived illness intrusiveness and positive and negative mood has been examined extensively in patients diagnosed with end-stage renal disease (ESRD) (e.g., Devins et al., 1983-84). For these patients, increased levels of illness intrusiveness and decreased levels of perceived personal control of disease factors were independently associated with self-reported positive and negative moods. This suggests that illness intrusiveness does indeed exert an influence on affective functioning.

In another study on adult patients with rheumatoid arthritis (RA), illness intrusiveness was found to be significantly related to both physical disability and depressive symptoms (after controlling for physical disability) (Devins, Edworthy, Gutherie, & Martin,1992). Interestingly, whereas illness intrusiveness was significantly related to depression across all ages in this adult RA sample, illness intrusiveness had a greater impact on depression in younger patients. Despite these research findings suggesting a differential influence of illness intrusiveness by age, few studies of illness intrusiveness have focused on children, and none have examined the influence of illness intrusiveness on families of children with juvenile rheumatic disease.

The Transactional Stress and Coping Model

Given the psychological concomitants, physical pain, and functional disability that often accompany chronic childhood illnesses, it is not surprising that family members' coping styles and behaviors are believed to influence children's adjustment. Both children and their families are faced with the tasks of disease management and psychological and social adjustment. Thompson's (1985) transactional stress and coping model, operating from an ecological systems theory perspective (Brofrenbrenner, 1977), suggests that chronic illness may be viewed as a chronic stressor for the patient as well as the family, and that successful adjustment requires all members to adapt. Thus, the outcome of illness adjustment becomes a function of a multidimensional process (i.e., the family system seeks to adapt to various biomedical, developmental, and psychosocial factors).

Studies have shown that parents' coping behavior can affect children's adjustment to disease, beyond the influence of demographic and disease factors (Chaney et al., 1997; Gil, Williams, Thomson, & Kinney, 1991; Thompson, Gustafson, Hamlett, & Spock, 1992). In addition, Ennett and colleagues (1991) found significant differences in the magnitude of JRA disease impact as reported by mothers and children. Specifically, mothers rated children's perceived competence more negatively than children rated themselves. It is clear that adjustment is a reciprocal process among family members, however, the precise manner in which these transactions take place deserves closer examination.

This paper examines the roles of parent perceived illness intrusiveness (i.e., the degree to which their child's illness intrudes on their own lives) and illness uncertainty

(i.e., ambiguity experienced by parents arising from the inability to determine the meaning of illness-related events involving their child), in determining psychological adjustment in parents of children with chronic rheumatic disease. Further, this paper examines the role of child adjustment in determining parental adjustment to the chronic illness. To this end, a comprehensive review of the literature is presented in the following pages.

First, a review of the literature addressing the medical and psychological treatment of JRD is presented. Next, literature focused on the connection between disease variables and disease outcome in JRD will be reviewed. Third, the psychological constructs of illness uncertainty and illness intrusiveness and their relationship to psychological adjustment in chronic illness will be discussed. Then, the theory of transactional stress and coping and its conceptual implications for psychological adjustment in parents of children with chronic illness and their families will be examined. Finally, a study is described that examined the predictive utility of parents' perceived illness intrusiveness and illness uncertainty in determining their own psychological adjustment in a sample of parents of children with chronic juvenile rheumatic disease.

CHAPTER II

REVIEW OF LITERATURE

Treatment Issues in Juvenile Rheumatic Arthritis

Traditional Medical Treatment

Singsen (1993) provides an overview of the primary medical treatment considerations for patients with various forms of juvenile rheumatic arthritis (JRA). One of the first steps in providing effective care for patients with JRA is to apply a comprehensive treatment approach directed at educating the patient, family, community, and the health care team. This also includes educating schools, coaches, therapists, or any other extra-curricular organizations in which the child participates. Medical treatment of JRA is focused primarily on the management of the physical symptoms, since there are no definitive cures for this class of diseases (McCracken, 1991). Singsen (1993) suggests that early in the course of the disease the most immediate treatment goals should address symptom relief, maintenance of joint range of motion, and maintenance of muscle strength; whereas later in the disease course, efforts at rehabilitation should guide medical treatment.

Treatment of inflammatory symptoms with aspirin is the most effective and least expensive medication treatment available to patients with JRA. However, due to the risk

of Reye's syndrome associated with aspirin use in children, many JRA patients are treated with nonsteroidal anti-inflammatory (NSAID) drugs (e.g., ibuprofen, tolmetin, naproxen, or fenoprofen). Because the physical symptoms associated with JRA may unexpectedly return following brief remissions, it is usually recommended that patients continue taking anti-inflammatory drugs up to a year-and-a-half after overt manifestations of the disease disappear. Intramuscular gold salt treatments or oral methotrexate therapy can also be used if NSAID therapy is ineffective or only partially effective after several months of treatment. Cases of severe polyarthritis or systemic arthritis may warrant the use of systemic corticosteroids. However, due to adverse side affects associated with these drugs, their application is usually reserved for when other drug treatments have failed.

Success in the medical treatment for JRA depends largely on the patient becoming invested in their own course of treatment and adopting changes to their daily routine. These children should be encouraged to be self-reliant in their maintenance of an age-appropriate treatment plan. Allowing for some basic accommodations in treating daily symptoms can help children with JRA to lead active, functional and independent lives. For example, morning stiffness associated with arthritis may be relieved through warm baths or through the use of electric blankets. Also, Singsen (1993) suggests that encouraging JRA patients to remain physically active in the face of these arthritis symptoms is helpful, because inactivity ultimately contributes to prolonged stiffness, joint pain, and functional disability. Lastly, vocational or psychological counseling may benefit children and adolescents with JRA (and their families) by helping them cope effectively with the affective sequela arising from the experience of a chronic debilitating illness.

Medical treatment options for other forms of juvenile rheumatic disease are similar to those directed at treating JRA. Appropriate child and parent education about the disease is important. Systemic lupus erythematosus (SLE) patients are often treated with NSAIDs, corticosteroids, methotrexate for arthritis symptoms, or antimalarial drug treatments for fever symptoms. Because of the photosensitivity that individuals with SLE often experience, these patients should be instructed to limit their sun exposure as well. Kippel (1993) suggests that physicians must be mindful of fever symptoms, because of the likelihood of infections associated with SLE. Like JRA, treatment of spondylarthropathies involves maintenance of physical activity as permitted, with attention to cognitive and social development throughout the disease course. Aspirin and ibuprofen are commonly used anti-inflammatory agents, with alternate drugs available for more difficult cases (Singsen, 1993). Lastly, treatments for patients with juvenile dermatomyositis (JDMA) focus on reduction of joint swelling and improving muscle strength. Adjunctive application of physical therapy is often warranted, and methotrexate is occasionally prescribed (White, 1993).

Psychological Treatment

Psychological intervention or therapy, as well as vocational counseling have been suggested as beneficial for JRA patients, particularly for adolescents (Singsen, 1993), as it may contribute to improving functional outcome. Some research has demonstrated that psychological treatments may be effective in helping the patient maintain medication compliance, manage their pain, or improve psychosocial functioning. For example, Rapoff, Lindsley, and Christopherson (1984) effectively applied a token economy

paradigm to increase medication compliance. Other methods that have increased the probability of medication compliance have been self-monitoring programs and verbal feedback (Pieper, Rapoff, Purviance, & Lindsley, 1989; Rapoff, Purviance, & Lindsley, 1988).

Cognitive behavioral treatments (CBT) for patients with JRA have also been found to be empirically supported. Lozcalzo (1996) actively involved JRA patients in their own treatment decisions and taught skills to enhance and maintain perceptions of self-efficacy. Other methods have included relaxation training, where a reduction in the child's pain intensity was demonstrated following training of parents and children in muscle relaxation skills (Walco, Varni, & Ilowite, 1992). Guided imagery, and meditative breathing techniques have also been successfully applied to JRA (Lavigne, Ross, Berry, & Hayford,1992).

Psychotherapeutic approaches directed at improving social support have been used in treatment of childhood chronic illnesses. Wallander and Varni (1989) found that children who received high social support from family and friends evidenced better psychological adjustment when compared to children with low social support. Patients are not the only individuals who can benefit from increased social support. One social support program paired mothers of young adult JRA patients with mothers of children with recently diagnosed JRA. The mothers of newly diagnosed JRA evidenced a decrease in number of reported mental health symptoms compared to controls (Ireys, Sills, Kolodner, & Walsh, 1996). Considering that illness uncertainty increases in circumstances of little information about the stressor, the effectiveness of this type of support group is understandable. Another method to increase social support has been

through arthritis camps, which are beneficial to JRA patients through improving emotional functioning while also easing caregiver strain (Hagglund et al., 1996). Children who attend these camps maintained moderate-term changes (at least six months) in self-concept improvements.

Uncertainty in Chronic Illness

Illness uncertainty is broadly described as resulting from patients experiencing difficulty understanding, or assigning meaning to illness events. This construct was originally formulated by Mishel (1988, 1990) to describe the uncertainty resulting from discrete, acute illness events. Illness uncertainty is thought to be more likely when illness events are ambiguous, very complex, when the individual lacks pertinent information, or when outcomes cannot be adequately predicted. According to Mishel (1988), when patients believe that they can mitigate their uncertainty, they will often utilize coping strategies that are problem-focused (e.g., seeking information, reappraising the situation more positively) as a means of reducing their uncertainty and thereby reducing the emotional reactivity associated with uncertainty. Alternately, when uncertainty *is preferred* (e.g., as when intermittent chronic illness is in remission, and could recur), or when problem-focused strategies fail, patients may form illusory self-enhancing beliefs supporting their mastery over threatening symptoms (Mishel, 1988). These emotion-focused coping strategies (e.g., wishful thinking, cognitive distancing) help maintain a positive appraisal of the event. In this way, Mishel (1988) views coping strategies as having a mediating effect between uncertainty appraisal and psychosocial adjustment.

The psychological construct of uncertainty in *chronic illness* developed as a reconceptualization of the illness uncertainty model first described by Mishel (1988). Mishel (1990) reformulated the model to account for the different type of experience that individuals with chronic illness often have (i.e., illness experiences that result in more continuous and/or unpredictable uncertainty). She theorized that individuals who have this type of illness experience may gradually revise their views of the world and themselves such that uncertainty takes on a more normative status, and they eventually come to view uncertainty less as a threat and more as an opportunity for personal growth. This new model stresses a shift in focus toward adaptive change over time, when the uncertainty experience becomes prolonged. Mishel (1990) describes this adaptive process as one in which the uncertainty itself is a the catalyst for reorganization of the self. Specifically, as the duration of uncertainty increases, an increased sense of disorganization and instability develops. Previous cognitive schema are no longer adequate for assigning meaning to experiences, and slowly the uncertainty itself becomes integrated into the individual's self-schema (i.e, through accommodation, assimilation, and approximation). Subsequent illness uncertainty becomes less distressing because the individual now has a more conditional cognitive framework with which they may interpret events. Mishel (1990) suggests that this adaptive change may be protracted when the following situations occur: 1) when supportive resources do not support a probabilistic world view, 2) when the person processing the uncertainty is a caretaker of others (i.e., which may lead to a delayed response to the uncertainty), 3) when the person experiencing the uncertainty is lacking in social resources, or, 4) when health care

professionals seek predictability and certainty in treatment (when it may be inherently absent).

The influence of illness uncertainty on psychological functioning has been well documented in adults who experience an illness event (Mast, 1995). Components of Mishel's original illness uncertainty theory have been widely supported (Bennett, 1993; Christman et al., 1988; Mishel & Braden, 1988; Warrington & Gottlieb, 1987; Wineman et al., 1993). Additionally, antecedent factors (e.g., personal factors, social supports, illness situation variables), appear to impact the experience of uncertainty (Mishel & Braden, 1987; 1988). Specifically, increased social support, increased familiarity with illness-specific events, and increased feelings of personal control tend to reduce perceptions of uncertainty (Mishel & Braden, 1988). When perceived uncertainty is high, events are more likely to be labeled as threats, resulting in greater reliance on emotion-focused coping strategies (Mishel & Sorenson, 1991; Webster & Christman, 1988). Similarly, lower illness uncertainty has been associated with problem-focused coping, whereas higher illness uncertainty was associated with more emotion-focused coping (Mishel, et al., 1991). Further, individuals may experience more emotional difficulties when uncertain situations are appraised as a danger (Mast, 1995). This finding is congruent with several studies which demonstrated a strong association between uncertainty and emotional distress, mood disturbance, and anxiety (Bennett, 1993; Braden, 1990; Christman et al., 1988; Hawthorne & Hixon, 1994).

In summary, individuals tend to experience greater illness uncertainty during illness events when those events are perceived as ambiguous, extremely complex, when the individual is lacking sufficient information, or when they cannot predict an outcome.

Additionally, individuals are more likely to experience uncertainty when there is less consistency in the symptom pattern of the illness, or when they perceive incongruence between what they had expected and the event itself (e.g., a treatment does not result in expected improvement) (Mishel, 1988, 1990). Lastly, greater illness uncertainty has been shown to be associated with poorer psychological adjustment (e.g., Bennett, 1993; Braden, 1990). It should be noted, however, that some inconsistencies between the extant literature and Mishel's (1988, 1990) uncertainty in illness model seems to implicate additional unknown variables which may mediate the influence between uncertainty and psychological adjustment.

Illness Intrusiveness

Another psychological construct that has been considered a fundamental determinant of the psychosocial impact of chronic illness has been that of illness intrusiveness (Devins, 1989, 1991). Illness intrusiveness is described as the degree to which an illness and/or its treatments may interfere with an individual's normal and valued life activities (Devins et al., 1983). This interference may be direct, when the physiological effects of the disease process or elements of the treatment regimen limit a patient's ability to maintain active participation in their preferred activities. Illness intrusiveness may also manifest itself *indirectly*, through the disruption of normal relationship patterns with friends and family members. For example, family roles and responsibilities may begin to shift as the chronically ill individual becomes to be viewed as "helpless" in the face of their illness, when they may have been considered a very independent or capable person prior to disease onset (Devins et al., 1990). Thus, illness

intrusiveness as a construct may be considered as having its foundation in illness "barriers" that hinder chronically ill patients from pursuing valued interests and activities (Devins et al., 1983). It has been suggested that illness intrusiveness influences psychological distress through two distinct mechanisms, namely: 1) through the reduction of the availability of positive and rewarding experiences, and 2) by compromising the degree to which an individual may exercise personal control over important outcomes (Devins & Seland, 1987; Devins et al., 1992).

Research has supported the influence of perceived illness intrusiveness on psychological adjustment with several different chronic diseases. Specifically, increased levels of illness intrusiveness has been significantly correlated with increased depressive symptomatology (Devins, 1989; Devins et al., 1983, 1986, 1990a, 1990b, 1992a, 1992b). This effect has been observed even after controlling for relevant functional (e.g., functional disability), demographic (e.g., age), medical (illness severity), and contextual variables (stressful life events), suggesting a robust role of illness intrusiveness in psychological functioning. In addition, illness intrusiveness has been significantly related to several other indices of psychological well being, including self-esteem, positive and negative mood, marital role strain and adjustment, life satisfaction, mood disturbance, pessimism, and global symptoms of psychopathology (Devins, 1989; Devins et al., 1983, 1990, 1992a, 1992b). Devins and colleagues (1993) suggest that these relationships remain consistent across other socioeconomic factors such as education, marital status, and gender.

Patient report of illness intrusiveness has been shown to vary with treatment modalities, which vary in the degree of relative lifestyle disruption (i.e., the greater the

lifestyle disruption, the greater the perceived intrusiveness). Additionally, patient report of illness intrusiveness have been validated with illness intrusiveness appraisals of significant others (e.g., family members, friends, healthcare professionals) (Binik et al., 1990; Devins et al., 1983, 1990). Variability in illness intrusiveness across types of chronic illness is attributed to disease-specific differences in symptom presentation, and variability in the degree of lifestyle disruption due to these symptoms and the associated treatment regimes (Devins et al., 1993). For example, because physical disability is thought to be an important factor in determining perceived illness intrusiveness, individuals with more physically disabling conditions (e.g., rheumatoid arthritis or multiple sclerosis) tend to experience significantly greater illness intrusiveness into physical domains like recreational pursuits (Devins et al., 1993).

The illness intrusiveness construct has conceptual relevance to juvenile rheumatic disease (JRD), and it likely represents a significant determinant of psychosocial outcome in individuals with these forms of chronic illness. As previously mentioned, the various symptom constellations of JRD may include: chronic joint pain often resulting in physical disability, decreased muscle strength and flexibility, and fatigue (leading to disease imposed limitation of activity), to name a few examples. The disease course of JRD can be quite variable, often characterized by unpredictable symptom flares and symptom remissions. When one also considers JRD treatment factors such as: complicated treatment regimes, dependence upon healthcare professionals, and economic stresses related to long-term treatment, it becomes clear that perceived illness intrusiveness may play a significant role in psychological functioning for these individuals.

Devins and colleagues (1993) compared several types of chronic disease [e.g., end-stage renal disease (ESRD), rheumatoid arthritis (RA), and multiple sclerosis (MS)], and found that patients with rheumatoid arthritis (RA) experienced moderate intrusiveness in the domain of diet, which is conceptually congruent with medication regimes used in the treatment of RA. Additionally, patients often reported disruption of appetite and taste due to their medication. RA patients also experienced significantly greater intrusiveness into physical domains (e.g., sports participation) than did individuals with conditions involving less physical disability like ESRD.

In a study examining the potential varying psychosocial impacts of illness intrusiveness across age in adults with rhueumatoid arthritis (RA), Devins and colleagues (1992) described the chronic and often permanent damage to the joints that these individuals experience as a disease-specific "burden of illness." In their view, burden of illness, along with physical disability and functional deficits, are significant contributors to perceived illness intrusiveness, and thus, psychological distress. Specifically, burden of illness is thought to impact functional deficits (e.g., limitations to sensory systems, such as joint inflammation), which in turn contribute to physical disability (e.g., decrease in muscle strength and flexibility limiting performance of complex functions). Devins and colleagues (1992) found that illness intrusiveness in RA was moderate, but that the intrusiveness was apparent in many different domains of functioning. Specifically, the life domains of work and finances, health and diet, and recreation and social relations were disrupted by RA to the greatest extent. Illness intrusiveness was significantly associated with depressive symptomatology across all adult age groups, however, interestingly younger individuals experienced higher levels of depressive symptoms due to illness

intrusiveness than older individuals. Thus, these results suggest that illness intrusiveness may exert more influence on the psychological adjustment of younger adult patients than older adult patients.

Although the significant impact of illness intrusiveness has been demonstrated in patients with rheumatic disease, studies examining the construct with this population are scant. Additional empirical research is needed to better understand how factors specific to rheumatic disease, its disease course, symptom presentation, and treatment regimes may (through illness intrusiveness) affect psychological well being. Further, despite findings that young adult patients may experience greater psychological maladjustment due to illness intrusiveness than older adult patients, research has failed to examine the potential role that illness intrusiveness has in the psychological adjustment of individuals from pediatric populations with JRD.

Transactional Stress and Coping Model

A considerable amount of research demonstrates that the experience of chronic illness represents a significant stressor for both ill children and their families. Additionally, the coping process relies on the presence of several types of resources (e.g., social and cognitive processes). Because of the drawn out, and at times severe nature of childhood chronic illness, these resources may be absent or insufficiently developed to allow to effective coping (Thompson, 1981). To conceptualize how children with chronic illness and their families attempt to adapt to the myriad unique stressors that accompany the experience of dealing with a childhood chronic illness, Thompson (1985) proposed a transactional stress and coping model, within an ecological systems theory framework

(Brofenbrenner, 1977). From this perspective, the illness-outcome relationship is influenced by the transactions between members of the system, and biomedical, psychosocial, and developmental processes (Thompson, Gustafson, Hamlett, & Spock, 1992). Thompson (1981) suggests that caring for a chronically ill child involves families coping with unique psychosocial, economic, educational, and medical related stressors, and that these require adaptation by all family members. Further, Thompson (1981) posits that the effectiveness of this coping has a significant bearing on the psychological adjustment of the patient, as well as for every family member. Thus, the transactional stress and coping model provides a framework to understand the coping process as one which is complex and multidimensional, rather than simple and linear.

The ecological-systems theory perspective proposes that psychological adjustment of children is influenced by levels of symptoms and stress manifested by other family members (Thompson, Gustafson, Hamlett, & Spock, 1992). Specifically, there is evidence that parental depressive symptoms play a significant role in behavioral and emotional problems in children (e.g., Compas, Howell, Phares, Williams, & Guinta, 1989; Daniels, Moos, Billings, & Miller, 1987). Other research has demonstrated that parent's coping behavior can affect children's adjustment to the disease, beyond the influence of demographic and disease factors (Chaney et al., 1997; Gil, Williams, Thomson, & Kinney, 1991; Thompson, Gustafson, Hamlett, & Spock, 1992). Given the psychological concomitants, physical pain, and functional disability that often accompany chronic childhood illness, it is understandable that coping styles and behaviors of family members affect adjustment of the ill-child and of the family itself. Caregivers, ill

children, and healthy siblings are all confronted with the tasks of disease management, and psychological and social adjustment.

It has been suggested that a lack of congruency between report modalities may present specific challenges for researchers examining potential transactional processes in childhood chronic illnesses. Specifically, Ennett and colleagues (1991) found significant differences in the magnitude of JRA disease impact ratings as reported by mothers and children. In this study, mothers rated children's perceived competence more negatively than children rated themselves. This finding emphasizes the need to gather information regarding patient functioning from several sources (e.g., child/patient, caregiver, physician), and also underscores the difficulties inherent to collecting data that is both well controlled, and yet does conceptual justice to the multidimensional model of transactional stress and coping. Most of the research in this area, however, has been limited to examining parent adjustment and child adjustment via child report on populations of children with sickle cell disease and cystic fibrosis.

One possible solution to address this difficulty would be to examine adjustment in one member of the transactional system, while controlling for levels of adjustment in other key members. Some researchers have applied this approach by focusing on the bidirectional influences between ill child and family system (e.g., Chaney & Peterson, 1989; Kazak, 1989; Whitt, 1984), or by focusing on the portions of the system with the greatest breadth of behavioral and psychological interchange (e.g., primary caregiver and chronically ill child). Indeed, many reasonable research questions may not have the goal of quantifying *all* aspects of Thompson's (1985) transactional system at once, but may still provide valuable information about family adjustment variables with chronic illness.

However, the relationships of influence between psychosocial variables and adjustment among family members of an ill-child system have been well supported by empirical data (e.g., Chaney et al., 1997) and cannot be disregarded if future research is to contribute meaningful parts to the larger conceptual whole.

CHAPTER III

THE PRESENT STUDY

Juvenile rheumatic diseases such as JRA, lupus, JAS, and JDMA are forms of pediatric chronic illness which share some common symptomatological characteristics. Although these each have somewhat different symptom constellations, prevalence ratios, and vary in age of onset, all are autoimmune disorders that involve inflammation, functional disability, and arthritis. Additionally, these childhood diseases are characterized by a progressive disease course that is often long-standing, frequently unpredictable, distinguished by unexpected symptom flares and remissions, and variable in response to medical treatment (within each disease). As a result, these children and their families may be at increased risk for psychological comorbidity (Barlow et al., 1998; David, 1994; Vandvik, 1990).

One area of research examining the psychological concomitants of chronic illness has focused on the construct of uncertainty in illness. In general, high levels of illness uncertainty has been associated with poorer psychological adjustment (e.g., Bennett, 1993; Braden, 1990; Christman et al., 1988). Additionally, the very conditions which are conceptualized as contributing to illness uncertainty [i.e., 1) when events are perceived as ambiguous, 2) when events are very complex, 3) when the individual is lacking sufficient information, or 4) when the individual cannot predict an outcome] may be found in the

type of non-contingent situations which often characterize the course and treatment of JRD.

Arthritis is a common factor that these rheumatic conditions share, and the resulting symptoms of pain, joint swelling and stiffness, and functional disability often causes patients to restrict and reduce physical activities which they value. Because of this, the role that perceived illness intrusiveness [i.e., the degree to which an illness and/or its treatments interfere with an individual's important normal life activities (Devins et al., 1983)] plays in subsequent psychological adjustment of the child and their family cannot be overlooked. Research has shown that high levels of illness intrusiveness is associated with greater depressive symptomatology, and other manifestations of psychological maladjustment (Devins et al., 1990). However, the extant research has not extensively examined this construct in chronically ill pediatric populations. Noteably, there is some limited evidence that suggests that illness intrusiveness may have a more powerful effect in younger patients (Devins et al., 1996).

These psychological constructs associated with the chronic illness experience do not simply manifest themselves in the psychological isolation of a single individual. One useful framework for conceptualizing how families of children with chronic illness attempt to cope with disease variables, and illness uncertainty and intrusiveness is Thompson's (1985) transactional stress and coping model, which is grounded in ecological systems theory (Brofenbrenner, 1977). Research focused on adjustment in childhood chronic illness has demonstrated that complex emotional and behavioral transactions occur within the family system (and between the family system and the environment) which have important implications for the psychological adjustment and

coping process. These transactions are viewed as bidirectional, with child and parent adjustment variables mutually influencing each other (e.g., Compas, Howell, Phares, Williams, & Guinta, 1989; Daniels, Moos, Billings, & Miller, 1987; Thompson, Gustafson, Hamlett, & Spock, 1992) beyond the influence of demographic and disease factors (Gil, Williams, Thomson, & Kinney, 1991). These relationships of psychosocial influence and adjustment among family members of an ill-child system are well supported and should be accounted for in any controlled investigation of these phenomena.

The purposes of the present study were threefold: 1) to examine the influence of child adjustment in determining parent adjustment, 2) to examine the independent influence of parent perceived illness uncertainty and illness intrusiveness in determining parent adjustment, and 3) to examine potential mediator and/or moderator relationships between illness uncertainty and illness intrusiveness in determining parent adjustment.

CHAPTER IV

METHOD

Participants

Participants were 45 (28 female; 17 male) children and adolescents between the ages of nine and 21 (M = 14.51; SD = 2.91), who had been diagnosed with juvenile rheumatoid arthritis (JRA; N = 28), lupus (SLE; N = 9), juvenile dermatomyositis (JDMA; N =5), or juvenile ankylosing spondylitis (JAS; N = 3) and their parents or primary caregiver. The majority of child participants were Caucasian, followed by Native American, African American, Biracial, Hispanic, and Asian participants (see Appendix H, Table 1 for detailed descriptive statistics).

Participants were recruited from the pediatric rheumatology clinic at Children's Hospital of Oklahoma. Inclusion criteria for participation included the following: 1) diagnosis of one of the above-mentioned illnesses, 2) age between nine and 21 years, and 3) the child had been symptomatic for one of the above-mentioned illnesses for a duration of at least six months. Illness duration was calculated by subtracting the date of diagnosis from the date of participation and ranged from 0.04 years to 15.74 years (M = 2.99; SD = 3.36). Therefore, some patients in the sample had been diagnosed for less than six months, but had experienced active symptoms for longer than six months, and thus still qualified for the present study. Exclusion criteria were as follows: 1) the child had

comorbid cognitive deficits (e.g., mental retardation), and/or the child had a comorbid chronic illness. The primary rheumatologist verified the inclusion criteria before eligible participants were contacted for recruitment. Participants received monetary compensation of $10.00 per family for participating in the study.

Instruments

Physician-Report Measures

Provider Questionnaire. This questionnaire was developed for the present study to acquire information from the rheumatologist regarding patient diagnosis, date of diagnosis, disease status, and current medication (see Appendix A). Current disease severity was assessed by a single question using a 7-point Likert scale, with a rating of one representing "disease not active or in remission" and a rating of seven representing "severe." The Provider Questionnaire also asked the physician to rate functional disability by classifying participants into one of four functional classes.

Parent-Report Measures

Juvenile Arthritis Functional Assessment Report-Parent (JAFAR-P; Howe et al., 1991). The JAFAR-P was completed by the parent or caregiver and consists of 23-items designed to assess parent/caregiver perceptions of functional ability in the JRD patient (see Appendix B). Respondents rated how often their child is able to perform 23 daily tasks (e.g., button shirt, get into bed) on a three point Likert scale, ranging from 0 (all the time) to 2 (almost never). Thus, endorsement of functional disability across a range of

daily activities indicate greater perceived functional disability, and the amount of perceived functional disability is represented by a sum of all items. The JAFAR has demonstrated good internal reliability coefficients for child-report (.85) and parent-report (.93) and construct validity (Howe et al., 1991). Chronbach's alpha for this sample was found to be high as well (α=.94).

Brief Symptom Inventory (BSI; Derogatis, 1993). The BSI is a 53-itemscale that assesses global psychological adjustment (see Appendix C). Respondents rate the degree to which they are distressed by each psychological symptom using a 5-point Likert scale ranging from 0 (not at all) to 4 (extremely). The sum of the items indicates the level of global distress the respondent is experiencing. The BSI was used in the present study to assess psychological functioning of the caregiver. The BSI has been found to have sufficient internal consistency with alpha coefficients ranging across dimensions from .71 to .85 (Derogatis & Melisaratos, 1983). Chronbach's alpha for the present study was also high (α=.96).

Mishel Uncertainty in Illness Scale-Parent (MUIS-P; Mishel et al., 1988). The MUIS-P is a 31-item scale that asks respondents to rate items on a five-point scale that depicts the four components of illness uncertainty, namely: ambiguity, uncertainty, lack of information, and unpredictability (see Appendix D). The MUIS yields a single component score, with higher scores reflecting greater illness uncertainty. Previous studies have shown the MUIS to be a reliable and valid measure of illness uncertainty across a number of chronic disease states (e.g., Mishel & Braden, 1988; Mullins et al., 1995). Chronbach's alpha for this sample was high (α=.86).

Illness Intrusiveness Scale-Parent (IIS-P; Devins et al., 1983). This 13-item scale assesses the degree to which parents or caregivers feel that their child's illness interferes with their (parent's or caregiver's) ability to perform various life activities (e.g., work, health, diet) (see Appendix E). This form of the measure was developed from the original IIS. Respondents rate the extent that their child's illness interferes with their ability to perform as well as they would like to across the various life activities using a 7-point Likert scale ranging from 1 (a little) to 7 (a lot). Items are summed to yield a total score ranging from 13 to 91, with higher scores indicating greater illness intrusiveness. Devins and colleagues (1993) have found significant differences in the level of intrusiveness reported depending on the type of illness. Internal consistency estimates range from .80 to .88 in end stage renal disease patients, with high test-retest reliability over a six-week interval ($r = .79$). Additional studies indicate that the IIS significantly correlates with collateral ratings by nephrology treatment staff, and by friends and family members (Devins, 1983). Further, the IIS is significantly related to reported difficulties in a variety of daily activities (Devins et al., 1990). Chronbach's alpha for this sample was high (α=.95).

Patient-Report Measures

Background Information Questionnaire. This questionnaire was developed for the present study to obtain the following information: age, gender, ethnicity, education level, marital status, parents' occupation and education level, living arrangement, psychoactive medication information, history of psychotherapy, JRA-related therapy, health care utilization, and interference of the disease with school/work (see Appendix F).

Children's Depression Inventory (CDI; Kovacs, 1979; 1992). The CDI is a 27-item instrument used to assess depressive symptomatology in children (see Appendix G). Each item on the CDI is a set of three statements combined to measure the severity of a single depressive symptom. Respondents select one of the three statements which best describes their feelings or ideas during the previous two week period. Responses are scored on a scale ranging from 0 to 2, with 0 indicating less severity and 2 indicating greater severity. An index of overall depressive symptomatology is derived by summing the scores of the 27 individual items. The CDI has been shown to be a reliable (i.e., internal consistencies ranging from .71 to .89) and valid measure of depressive symptomatology in children. Chronbach's alpha for this sample was also high (α=.91).

Procedure

Eligible participants were recruited in one of two ways. Some participants were recruited directly in the rheumatology clinic. These individuals and their caregivers were approached and informed about the study during a regularly scheduled visit with the rheumatologist. If families were willing to participate, the patient and their caregiver were asked to complete the study packet of questionnaires either during their time in the clinic or take the packet home to complete and return via postage-paid mail. Study packets included: 1) Parental forms of: written consent, JAFAR-P, BSI, MUIS-P, IIS-P, and 2) Patient forms of: written assent, Background Information Questionnaire, and CDI. Families that completed the packet during their clinic visit were then compensated with $10; if the completed packet was returned via mail the $10 compensation was mailed to the family.

Other patients who were not scheduled for an upcoming appointment in the rheumatology clinic were recruited via mail solicitation. A letter explaining the study was sent with an enclosed postage-paid postcard, which they could then return to indicate their interest in participating in the study. If a family indicated that they were willing to participate a study packet consisting of the above-mentioned materials was mailed for them to complete. When the completed packet was returned via postage-paid mail, the family was sent the $10 compensation. Once completed packets were received in the clinic or through the mail, the rheumatologist was asked to complete the provider questionnaire to obtain disease severity and functional disability information.

CHAPTER V

RESULTS

Preliminary Analyses

Preliminary analyses were performed to rule out effects of ethnicity and disease subtype on study variables. Several one-way multivariate analyses of variance (MANOVAs) revealed no significant effects for ethnicity (Caucasian vs. Non-Caucasian) on disease variables [physician-rated disability, parent-rated functional disability (JAFAR-P), and illness duration (in years); all p's > .05] or psychosocial variables [parent adjustment (BSI), parent-rated illness uncertainty (MUIS-P), parent-rated illness intrusiveness (IIS-P), and child depression (CDI); all p's > .05]. Similarly, several one-way MANOVAs revealed no significant effects for disease subtype (JRA, SLE, JAS, or JDMA) on disease variables (physician-rated disability, JAFAR-P, and illness duration; all p's > .05) or psychosocial variables (parent adjustment, parent-rated illness uncertainty, parent-rated illness intrusiveness, and child depression; all p's > .05). Thus, ethnicity and disease subtype variables were collapsed in all subsequent analyses. Additional preliminary analyses were performed to rule out effects of mode of recruitment (i.e., recruitment in the rheumatology clinic versus through the mail), on disease (physician-rated functional disability, JAFAR-P, and illness duration) and psychosocial (BSI, MUIS-P, IIS-P, and CDI) variables. Several one-way multivariate

analyses of variance (MANOVAs) revealed significant differences between recruitment groups on parent adjustment (as measured by the BSI), ($F = 5.22$, $p < .05$), and on parent-rated functional disability of their child, ($F = 6.86$, $p < .05$), such that mail-recruited parents reported greater distress and higher functional disability in their child than clinic-recruited parents; all other p's were not significant. Recruitment method was included as a covariate in subsequent analyses to control for these differences.

Other covariates were selected based on additional preliminary analyses, theoretical rationale, and findings in the extant literature. As seen in Table 2 (Appendix H), child age was significantly associated with parent distress and illness intrusiveness ($r = .40$, $p < .01$) and ($r = .38$, $p < .05$), respectively; and parent-rated functional disability of the child was correlated with both parent distress and illness intrusiveness ($r = .41$, $p < .01$), and ($r = .54$, $p < .001$), respectively. No other significant associations between demographic or disease variables with the psychosocial measures emerged. However, because of the unequal gender distribution and wide range in disease duration, these variables were included in the regression analyses to provide for a more conservative test of anticipated relationships among variables. Also, physician and parent ratings of disability were included to control for the influence of objective and subjective disease activity. Inclusion of these variables was also intended to control for shared variance among variables that could influence the contributions of key predictor variables to parent adjustment. This rationale is supported by previous research that showed significant effects of age on illness intrusiveness and depression in patients with rheumatoid arthritis (RA; Devins et al., 1992). Extant literature also suggests a significant relationship

between patient gender and depression in RA populations (e.g., Hommel, Wagner, Chaney & Mullins, 1998).

Primary Analysis

Hypothesis 1. It was predicted that child distress (CDI) would contribute significant variance to parent distress (BSI) beyond the influence of demographic (age and gender) and disease (physician-rated disability, JAFAR-P, and illness duration) variables. To examine this hypothesis, a partial correlation was calculated between child distress and parent distress measures, controlling for demographic and disease variables. Recruitment method was also controlled for due to the results of the preliminary analyses. Results revealed a significant association between child distress (CDI) and parent distress (BSI) ($pr = .44$, $p < .01$), indicating that child distress accounted for 19% of the variance in parent distress (see Table 2, Appendix H).

Hypothesis 2. It was also predicted that both parent-reported illness uncertainty (MUIS-P) and parent-reported illness intrusiveness (IIS-P) would contribute significant incremental variance to parental distress (BSI), beyond that accounted for by demographic, disease, and child adjustment variables. This hypothesis was tested using a hierarchical multiple regression procedure, in which demographic variables of age and gender, and recruitment method were entered on Step 1 of the equation. Then, disease variables of physician-rated functional disability (PRFD), illness duration (in years), and parent-rated functional disability of the child (JAFAR-P) were entered on Step 2. Psychosocial variables of child depression (CDI), parent-rated illness uncertainty

(MUIS-P), and parent-rated illness intrusiveness (IIS-P) were entered on Step 3 of the equation (see Table 3, Appendix H). The equation revealed significant main effects for age ($t = 2.53$, $p < .05$), recruitment method ($t = -2.05$, $p < .05$), parent-rated functional disability of the child ($t = 2.42$. $p < .05$), and child depression ($t = 2.36$, $p < .05$) in determining parent adjustment. No significant main effects for parent-reported illness uncertainty (MUIS-P) or parent-reported illness intrusiveness (IIS-P) were found (see Table 3, Appendix H).

Research Questions

Research Question One. As a preliminary step in determining the existence of a potential mediator relationship of illness intrusiveness in the illness uncertainty-adjustment relationship, initial zero-order correlations and partial correlations (controlling for age, gender, recruitment method, and disease variables) were performed to examine the relationships among these key variables. In order for illness intrusiveness to serve as a mediator in the illness uncertainty-adjustment relationship, the following conditions must be met (Baron & Kenny, 1986):

1) Parent-rated illness uncertainty (MUIS-P), (the predictor variable), must be significantly associated with parental distress (BSI), (the outcome variable),

2) Parent-rated illness uncertainty (MUIS-P), (the predictor variable), must also be significantly associated with parent-rated illness intrusiveness (IIS-P), (the potential mediator),

3) The relationship between parent-rated illness uncertainty (MUIS-P), (the predictor variable), and parental distress (BSI), (the outcome variable) must no longer be significant after accounting for the influence of parent-rated illness intrusiveness (IIS-P), (the potential mediator), and.

4) The relationship between parent-rated illness intrusiveness (IIS-P), (the potential mediator), and parental distress (BSI), (the outcome variable) must remain significant after accounting for the influence of parent-rated illness uncertainty (MUIS-P), (the predictor variable).

As noted in Table 2 (Appendix H), parent-rated illness uncertainty (MUIS-P) was significantly associated with parental adjustment (BSI), (pr = .33, p <.05), after controlling for demographic, recruitment, and disease variables (fulfilling criterion one for mediation, above). Second, parent-rated illness uncertainty (MUIS-P) *was not* significantly associated with parent-rated illness intrusiveness (IIS-P), (pr = .15, ns) after controlling for demographic, recruitment, and disease variables (*failing* to fulfill criterion two for mediation, above). As a result, no additional mediation analyses were performed. Thus for the present study, illness intrusiveness failed to meet criteria for mediation (e.g., Baron & Kenny, 1986) in the illness uncertainty-parent adjustment relationship.

Research Question Two. The combined effect of parent-rated illness uncertainty (MUIS-P) *and* parent-rated illness intrusiveness (IIS-P) was also examined to determine whether the interaction between these variables exerted a combined influence on parental adjustment beyond any independent direct effects. For this moderating relationship to exist between illness uncertainty and illness intrusiveness in determining parental

adjustment, the interaction between illness uncertainty and illness intrusiveness must contribute unique incremental variance to parental adjustment over and above the influence of the main effects of these variables. To test for this potential moderator effect, a regression equation was constructed identical to the one used to test Hypothesis one, except that an illness uncertainty X illness intrusiveness interaction term was entered on Step 4 of the regression model (see Table 3, Appendix H). The interaction of illness uncertainty and illness intrusiveness *was not* significant (F change = .03, ns). However, the addition of this interaction term to the regression equation did not substantially reduce the predictive value of the equation. Thus, in the present study no moderating relationship existed between illness uncertainty and illness intrusiveness in determining parental adjustment.

Supplementary Analyses

Because illness uncertainty and illness intrusiveness were not found to contribute significant incremental variance to parent distress either independently or through their interaction (as had been predicted), some supplementary exploratory analyses were conducted in an attempt to clarify the relationships between the study variables. It was possible that child depression served as a moderator in the relationship between parent-rated illness uncertainty and parent adjustment, and/or between parent-rated illness intrusiveness and parent adjustment. To examine these potential interactions, two separate hierarchical multiple regression equations were constructed.

The first regression equation tested for a potential interaction between child depression and parent-rated illness uncertainty on parent adjustment. On Steps 1 and 2,

demographic, recruitment, and disease variables were entered as a block (i.e., identical Steps to those used in the regression for Hypothesis two). Then, in order to account for any variance in parent adjustment directly attributable to child depression or parent-rated illness uncertainty, CDI and MUIS-P were included separately on Step 3. Lastly, a CDI X MUIS-P interaction term was entered on Step 4 of the regression model. There was no significant interaction between child depression and parent-rated illness uncertainty in determining parent adjustment (F change for step = .82 , ns).

Similarly, the second regression equation tested for a potential interaction between child depression and parent-rated illness intrusiveness on parent adjustment by entering the same variables as above in Steps 1 and 2. Then, CDI and IIS-P were entered on Step 3 to account for any variance in parent distress directly attributable to child depression and parent-rated illness intrusiveness. Finally, on Step 4, a CDI X IIS-P interaction term was entered. There was no significant interaction between child depression and parent-rated illness intrusiveness in determining parent adjustment (F change for step = .40 , ns). Thus, in the present study, no moderating relationship existed between child depression and either parent-rated illness uncertainty or parent-rated illness intrusiveness in determining parent adjustment.

CHAPTER VI

DISCUSSION

The present study examined transactional patterns of adjustment in parents of children diagnosed with juvenile rheumatic disease. The juvenile rheumatic diseases (JRA, Lupus, JAS and JDMA) are pediatric chronic illness characterized by a long-standing, progressive, and frequently unpredictable disease course, punctuated by unexpected symptom flares and equally unexpected remissions. Children with these diseases show variable response to medical treatment (within each disease type, and within individuals over time), making them and their families vulnerable to potential psychological comorbidity (Vanvik, 1990; David, 1994; Barlow et al., 1998). Two primary hypotheses were proposed: 1) increased distress in the chronically ill child would be significantly associated with poorer parental adjustment, beyond the influence of demographic and disease variables, and 2) increased perceived illness uncertainty and illness intrusiveness by the parent of the chronically ill child would be significantly associated with poorer parental adjustment, beyond the influence of demographic, disease, and child distress variables. Consistent with the first hypothesis, multiple regression analyses revealed that increased distress in the chronically ill child was significantly associated with poorer parental adjustment. This relationship was observed after controlling for demographic, recruitment, and disease variables. However, the

second hypothesis that parent perceived illness uncertainty and illness intrusiveness would significantly predict parental adjustment was not supported.

Two research questions were also proposed to examine whether parent-perceived illness intrusiveness acts as a potential mediator in the uncertainty-adjustment relationship of the parent, or alternatively, if a moderator relationship exists between parent illness uncertainty and illness intrusiveness in determining parent distress. Parent-perceived illness intrusiveness was not found to serve as a mediator on the illness uncertainty-adjustment relationship of the parent. Additionally, the combined effect of illness uncertainty and illness intrusiveness was not found to exert a moderating effect on parental adjustment. An interpretation and discussion of these results follows.

Psychological adjustment in children with chronic illness and their parent-caregivers is considered to be influenced by multiple psychosocial factors, over and above objective measures of disease severity and demographic variables (Thompson et al., 1992). Research on childhood chronic illness has demonstrated that complex emotional and behavioral transactions occur within the ill-child family system, and between that system and the environment (e.g., the treating physician). These transactions have implications for coping and psychological adjustment for individuals within the family system, they are viewed as bi-directional, and child and parent adjustment variables are considered to mutually influence each other (e.g., Compas, Howell, Phares, Williams, & Guinta, 1989; Daniels, Moos, Billings, & Miller, 1987; Thompson, Gustafson, Hamlett, & Spock, 1992) beyond the influence of demographic and disease factors (Gil, Williams, Thomson, & Kinney, 1991). Thus, from both the individual and the systemic perspective, coping with and adjustment to living with chronic illness becomes a complex, dynamic,

and multidimensional process, influenced by various unique disease, psychosocial, and family process variables (Thompson et at., 1992).

Results from the present study provide support for the growing literature on the transactional nature of adjustment in pediatric chronic illness. Specifically, these results elaborate the nature of this transactional adjustment relationship between caregiver and child in a relatively unstudied childhood chronic illness population (i.e., children diagnosed with juvenile rheumatic disease). It has been suggested that a disease-specific approach to investigation is warranted, given the degree of variability that exists between different forms of chronic disease such as physical symptoms, disease course, and response to treatment (Bennet, 1994). Previous research in the pediatric chronic illness literature has largely relied on measures of mother-reported child adjustment, which may be problematic given the potential for discrepancy between parent and child report of child adjustment and distress (Bennet, 1994; Ennett et al., 1994). The results of the present study further help expand the extant transactional adjustment literature by examining multiple sources of patient functioning information (i.e., child, parent and physician report), as opposed to dependence on parent-report measures of child adjustment frequently seen in the pediatric chronic illness literature. This multimodal inclusion of subjective child report of distress and physician report of functional disability, in addition to parent reported measures, may provide for a clearer depiction of the transactional process.

Although the association between cognitive appraisal processes and stress are well established (e.g., Lazarus & Folkman, 1984) and should be considered as potential mediating or moderating influences (Peyrot, 1996) on psychological adjustment, parent-

perceived illness uncertainty and illness intrusiveness *were not* significant predictors of parent adjustment as was hypothesized. In the extant literature, these cognitive appraisal factors have been shown to exert a robust effect on measures of psychosocial adjustment and adaptation to a variety of chronic illness conditions (e.g., Devins, 1992; Mullins et al., 1997). The unexpected lack of incremental predictive power of illness uncertainty and illness intrusiveness on parent adjustment in the present study warrants further discussion.

Mishel (1990) suggests that the role served by illness uncertainty in influencing adjustment may need to be reconceptualized in chronic illness conditions, particularly when the disease course and treatment response is serially unpredictable. Over time with prolonged a uncertainty experience, individuals may revise their world view such that unpredictability takes on a normative status. In this way, the impact of illness uncertainty on psychological adjustment may diminish over time because the uncertain situation is perceived less as a threat, and because adaptive forms of coping may develop in response to the prolonged uncertainty. Patients in the present study were fourteen and a half years old on average, and they had been living and coping with their juvenile rheumatic disease for an average of approximately three years. This may have been a sufficiently long duration to allow the parents to develop effective copying strategies and such that uncertainty was no longer significantly distressing together.

The influence of patient-perceived illness intrusiveness on psychological adjustment beyond the effects of disease variables has been well supported with several chronic diseases (e.g., Devins, 1989; Devins et al., 1983, 1986). Devins and colleagues (1992) suggest that individuals with chronic illness conditions that result in greater physical and/or functional disability (e.g., rheumatoid arthritis, multiple sclerosis)

experience significant illness intrusiveness into physical domains (e.g., recreational pursuits). Further, in adults with rheumatoid arthritis, illness intrusiveness has been found to be associated with depressive symptomatology (Devins, 1992), with a greater influence of illness intrusiveness on psychological adjustment experienced by younger adult patients than older patients. However, unlike the present study, these studies document the degree of perceived intrusiveness imposed by their illness on adjustment, not the degree of intrusiveness imposed by their child's illness.

In the present study, the measure of illness intrusiveness in the parent of child patients indicates the degree that their child's chronic illness interferes with their (the parent's) ability to perform as well as they would prefer within various life domains (e.g., work, health, family relationships). Potentially, as with illness uncertainty, parents of ill children in the present study had sufficient time (i.e., average illness duration of three years) to integrate JRD disease factors and treatment activities (e.g., warm baths in the early morning to ease joint pain and inflammation) into their lifestyle, thus diminishing their perceived level of illness intrusiveness (Devins, 1992). Interestingly, the positive correlation between patient age and both parent-rated illness intrusiveness and parent distress suggests that developmental stage may further complicate the relationships between study variables. Specifically, illness intrusiveness may exert greater influence in parent distress when superimposed on the typical challenge of adolescence. In this way, the daily task demands of disease management could interact with the daily task demands of adolescence to negatively impact parent adjustment.

Because physical and functional disability are implicated in severity of illness intrusiveness (e.g., Devins et al., 1992), lower functional disability in this JRD sample

may have contributed to decreased impact on parent adjustment due to illness intrusiveness. Mean physician rated functional disability for patients in the present study was near the low end of the classification scale (i.e., with an average rating between "completely able to perform all activities of daily living" and "able to perform usual self-care and vocational activities, but limited in avocational activities"). Parent-rated functional disability showed a similar floor effect, where the mean score was 5.24 on a scale ranging from 0 to 46 (where higher scores reflect greater functional disability). Lastly, the lack of significant mediating or moderating effect of illness intrusiveness on parental adjustment may indicate that illness intrusiveness as a construct is not as influential when the rater is not the chronically ill individual.

It is possible that cognitive appraisal variables are simply not as consequential in determining parent adjustment as how their chronically ill child is coping on a daily basis. In other words, when the ill child is distressed, this becomes the predominant determinant of parent adjustment, overriding all other appraisal variables. Inversely, whe the ill child is coping effectively and experiencing less distress, parents experience less distress and thus may be less susceptible to the negative impact of such cognitive appraisal mechanisms.

The relatively low level of distress evidenced in the present sample may also have implications for these mixed findings. The Global Severity Index (GSI) represents the average of ratings of perceived distress for 53 psychological symptoms (where 0 = "not at all," 1 = "a little bit," 2 = "moderately," 3 = "quite a bit," and 4 = "extremely" distressed by the symptom). The mean GSI score for this sample was 0.54, indicating that, on average, parents rated specific psychological symptoms in a range between "not at all"

distressing to "a little bit" distressing. This average level of global distress would not typically be considered clinically significant. This finding could suggest a possible floor effect of the dependent variable, with the restricted range of responses resulting in decreased variability of the dependent measure. Thus, there may have been a reduced probability of detecting significant relationships between study variables, had they existed. Other studies of families with a chronically ill child have qualified parent adjustment with a variety of broad measures of distress (e.g., the Symptom Checklist-90-Revised, the Impact on the Family Scale, and the Psychiatric Symptom Index), making direct comparisons difficult. However, unlike the present sample, most of these studies have consistently found that parents self-report clinically significant psychological distress (or levels approaching clinical significance) in the context of caring for their ill child (e.g., Chaney et al., 1997; Manuel, 2001; Tompson et at., 1993, 1994).

This restricted range of perceived distress may actually be representative of parental experience in the face of adjustment over time to the prolonged illness uncertainty and intrusiveness that conceptually results from the unpredictable disease course and treatment response of JRD. As Mishel (1990) suggests, extended experience of illness uncertainty in the context of chronic illness conditions may result in an evolution of the meaning of the uncertainty, such that it becomes a less potent stressor. The mean illness duration (three years) may have allowed caregiving parents the processing time for these psychosocial factors to become somewhat of a "normative standard." If this were true, then it is likely that parents of more recently diagnosed JRD patients would experience greater distress than parents in the study sample due to a greater influence of illness uncertainty and illness intrusiveness, however the findings

from the present study cannot clarify this possibility. Although the implications may be that the present sample was comprised of relatively well-adjusted parents of chronically ill children, these findings do not negate the potential value of examining these constructs with less well-adjusted parents and children.

The findings of the present study must be qualified by several limitations. Because the present study relied on the use of self-report inventories, it is possible that significant findings resulted from shared method variance rather than from actual associations between variables; however, the use of child and parent report measures and lack of association observed between parent self-report measures should mitigate this likelihood. Additionally, the correlational nature of the present study precludes determining the direction of the relationships between study variables. For example, although child distress was conceptualized as accounting for significant variance in parent distress, results from the present study cannot confirm whether or not increases in child distress causally *precede* parent distress. It is possible that parent adjustment determines child adjustment or that child adjustment is independent of parent adjustment and is influenced by some unmeasured variable. This variable could then be responsible for the variance in parent distress.

Finally, these findings may not generalize well to the larger population of individuals with juvenile rheumatic disease because this study relied on a relatively small sample of individuals who self selected for participation. The relatively low levels of distress endoresed by parents in this sample suggest that they may have done so because they were relatively *free* from distress (again, perhaps the extended illness duration of the sample allowed time for coping and adjustment). In this view, families that chose not to

participate may have been too overwhelmed from coping with their child's illness to consider giving up the time involved in participation, or participation might have represented increased exposure to the very stimuli that are currently distressing to them (e.g., questions about the functional disability of their child, or thoughts and feelings associated with their care for the child), and thus was avoided. Unfortunately, comparisons to examine differences between study participants and non-participants were not possible due to the nature of recruitment and data collection procedures, and issues of confidentiality. However, most eligible patients and families (91%) that were approached agreed to participate in the study, lessening the possibility that a substantially differently presenting segment of the JRD population was under-sampled.

In summary, the present study supports the growing literature on the transactional nature of stress and coping within the context of childhood chronic illness. Specifically, these findings refine the conceptualization of the ill-child and caregiver system with a relatively understudied chronic illness population (i.e., juvenile rheumatic disease). However, the incongruities of some of these findings (i.e., specifically of the role of illness uncertainty and illness intrusiveness in determining caregiver adjustment) with previous literature on other types of chronic illness raises additional questions about this population, and warrant closer examination. The findings of the present study suggest the necessity for further research on these psychosocial variables with this chronic illness population to determine if illness uncertainty and illness intrusiveness are meaningful predictors of caregiver distress under different conditions than were present in this study (i.e., when the child's condition has been more recently diagnosed, under conditions of greater disease severity, or with younger chronically ill patients). Additionally, future

research should incorporate measures of coping and adaptive behavior of families, to determine how these factors impact changes in parent adjustment, and in the contextual meaning of illness uncertainty and illness intrusiveness over time.

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APPENDIXES

APPENDIX A

PROVIDER QUESTIONNAIRE

Subject # _____
Date: _____

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

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

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

APPENDIX B

JUVENILE ARTHRITIS FUNCTIONAL ASSESSMENT

REPORT-PARENT (JAFAR-P)

The Juvenile Arthritis Functional Assessment Report for Parents (JAFAR-P)

Over the past week, how often has your child been able to perform each of the activities in the list below?

	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 C

BRIEF SYMPTOM INVENTORY (BSI)

Subject _____

Brief Symptom Inventory (BSI)

INSTRUCTIONS:

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

EXAMPLE

HOW MUCH WERE YOU DISTRESSED BY:		NOT AT ALL	A LITTLE BIT	MODERATELY	QUITE A BIT	EXTREMELY
1. Bodyaches	1	0	1	2	3	4

HOW MUCH WERE YOU DISTRESSED BY:		NOT AT ALL	A LITTLE BIT	MODERATELY	QUITE A BIT	EXTREMELY
1. Nervousness or shakiness inside	1	0	1	2	3	4
2. Faintness or dizziness	2	0	1	2	3	4
3. The idea that someone else can control your thoughts	3	0	1	2	3	4
4. Feeling others are to blame for most of your troubles	4	0	1	2	3	4
5. Trouble remembering things	5	0	1	2	3	4
6. Feeling easily annoyed or irritated	6	0	1	2	3	4
7. Pains in heart or chest	7	0	1	2	3	4
8. Feeling afraid in open spaces or on the streets	8	0	1	2	3	4
9. Thoughts of ending your life	9	0	1	2	3	4
10. Feeling that most people cannot be trusted	10	0	1	2	3	4
11. Poor appetite	11	0	1	2	3	4
12. Suddenly scared for no reason	12	0	1	2	3	4
13. Temper outbursts that you could not control	13	0	1	2	3	4
14. Feeling lonely even when you are with people	14	0	1	2	3	4
15. Feeling blocked in getting things done	15	0	1	2	3	4
16. Feeling lonely	16	0	1	2	3	4
17. Feeling blue	17	0	1	2	3	4
18. Feeling no interest in things	18	0	1	2	3	4
19. Feeling fearful	19	0	1	2	3	4
20. Your feelings being easily hurt	20	0	1	2	3	4
21. Feeling that people are unfriendly or dislike you	21	0	1	2	3	4
22. Feeling inferior to others	22	0	1	2	3	4

******Please Continue on the Next Page******

BSI (continued)

HOW MUCH WERE YOU DISTRESSED BY:		NOT AT ALL	A LITTLE BIT	MODERATELY	QUITE A BIT	EXTREMELY
23. Nausea or upset stomach	23	0	1	2	3	4
24. Feeling that you are watched or talked about by others	24	0	1	2	3	4
25. Trouble falling asleep	25	0	1	2	3	4
26. Having to check and double check what you do	26	0	1	2	3	4
27. Difficulty making decisions	27	0	1	2	3	4
28. Feeling afraid to travel on buses, subways, or trains	28	0	1	2	3	4
29. Trouble getting your breath	29	0	1	2	3	4
30. Hot or cold spells	30	0	1	2	3	4
31. Having to avoid certain things, places, or activities because they frighten you	31	0	1	2	3	4
32. Your mind going blank	32	0	1	2	3	4
33. Numbness or tingling in parts of your body	33	0	1	2	3	4
34. The idea that you should be punished for your sins	34	0	1	2	3	4
35. Feeling hopeless about the future	35	0	1	2	3	4
36. Trouble concentrating	36	0	1	2	3	4
37. Feeling weak in parts of your body	37	0	1	2	3	4
38. Feeling tense or keyed up	38	0	1	2	3	4
39. Thoughts of death or dying	39	0	1	2	3	4
40. Having urges to beat, injure, or harm someone	40	0	1	2	3	4
41. Having urges to break or smash things	41	0	1	2	3	4
42. Feeling very self-conscious with others	42	0	1	2	3	4
43. Feeling uneasy in crowds, such as shopping or at a movie	43	0	1	2	3	4
44. Never feeling close to another person	44	0	1	2	3	4
45. Spells of terror or panic	45	0	1	2	3	4
46. Getting into frequent arguments	46	0	1	2	3	4
47. Feeling nervous when you are left alone	47	0	1	2	3	4
48. Others not giving you proper credit for your achievements	48	0	1	2	3	4
49. Feeling so restless you couldn't sit still	49	0	1	2	3	4
50. Feelings of worthlessness	50	0	1	2	3	4
51. Feeling that people will take advantage of you if you let them	51	0	1	2	3	4
52. Feelings of guilt	52	0	1	2	3	4
53. The idea that something is wrong with your mind	53	0	1	2	3	4

******Please Turn Over and Complete on Reverse******

APPENDIX D

MISHEL UNCERTAINTY IN ILLNESS

SCALE-PARENT (MUIS-P)

MISHEL UNCERTAINTY IN ILLNESS SCALE--PARENT/CHILD FORM

Instructions: Please read each statement. Take your time and think about what each statement says. Then place an "X" under the column that most closely measures how you are feeling about your child TODAY. If you agree with a statement, then you would mark under either "Strongly Agree" or "Agree." If you disagree with a statement, then mark under either "Strongly Disagree" or "Disagree." If you are undecided about how you feel about your child, then mark under "Undecided" for that statement. Please respond to every statement.

1. I don't know what is wrong with my child.

Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
____	____	____	____	____

2. I have a lot of questions without answers.

Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
____	____	____	____	____

3. I am unsure if my child's illness is getting better or worse.

Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
____	____	____	____	____

4. It is unclear how bad my child's pain will be.

Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
____	____	____	____	____

5. The explanations they give about my child seem hazy to me.

Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
____	____	____	____	____

6. The purpose of each treatment for my child is clear to me.

Strongly Agree (1)	Agree (2)	Undecided (3)	Disagree (4)	Strongly Disagree (5)
____	____	____	____	____

7. I do not know when to expect things will be done to my child.

Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
____	____	____	____	____

. My child's symptoms continue to change unpredictably.

Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
____	____	____	____	____

. I understand everything explained to me.

Strongly Agree (1)	Agree (2)	Undecided (3)	Disagree (4)	Strongly Disagree (5)
____	____	____	____	____

. The doctors say things to me that could have many meanings.

Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
____	____	____	____	____

. I can predict how long my child's illness will last.

Strongly Agree (1)	Agree (2)	Undecided (3)	Disagree (4)	Strongly Disagree (5)
____	____	____	____	____

. My child's treatment is too complex to figure out.

Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
____	____	____	____	____

3. It is difficult to know if the treatments or medications my child is getting are helping.

Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
____	____	____	____	____

4. There are so many different types of staff, it's unclear who is responsible for what.

Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
____	____	____	____	____

5. Because of the unpredictability of my child's illness, I cannot plan for the future.

Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
____	____	____	____	____

6. The course of my child's illness keeps changing. He/she has good and bad days.

Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
____	____	____	____	____

7. It's vague to me how I will manage the care of my child after he/she leaves the hospital.

Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
____	____	____	____	____

8. It is not clear what is going to happen to my child.

Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
____	____	____	____	____

9. I usually know if my child is going to have a good or bad day.

Strongly Agree (1)	Agree (2)	Undecided (3)	Disagree (4)	Strongly Disagree (5)
____	____	____	____	____

10. The results of my child's tests are inconsistent.

Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
____	____	____	____	____

11. The effectiveness of the treatment is undetermined.

Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
____	____	____	____	____

22. It is difficult to determine how long it will be before I can care for my child by myself

Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
____	____	____	____	____

23. I can generally predict the course of my child's illness.

Strongly Agree (1)	Agree (2)	Undecided (3)	Disagree (4)	Strongly Disagree (5)
____	____	____	____	____

24. Because of the treatment, what my child can do and cannot do keeps changing.

Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
____	____	____	____	____

25. I'm certain they will not find anything else wrong with my child.

Strongly Agree (1)	Agree (2)	Undecided (3)	Disagree (4)	Strongly Disagree (5)
____	____	____	____	____

26. They have not given my child a specific diagnosis.

Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
____	____	____	____	____

27. My child's physical distress is predictable, I know when it is going to get better or worse.

Strongly Agree (1)	Agree (2)	Undecided (3)	Disagree (4)	Strongly Disagree (5)
____	____	____	____	____

28. My child's diagnosis is definite and will not change.

Strongly Agree (1)	Agree (2)	Undecided (3)	Disagree (4)	Strongly Disagree (5)
____	____	____	____	____

29. I can depend on the nurses to be there when I need them.

Strongly Agree (1)	Agree (2)	Undecided (3)	Disagree (4)	Strongly Disagree (5)
____	____	____	____	____

30. The seriousness of my child's illness has been determined.

Strongly Agree (1)	Agree (2)	Undecided (3)	Disagree (4)	Strongly Disagree (5)
____	____	____	____	____

31. The doctors and nurses use everyday language so I can understand what they are saying.

Strongly Agree (1)	Agree (2)	Undecided (3)	Disagree (4)	Strongly Disagree (5)
____	____	____	____	____

APPENDIX E

ILLNESS INTRUSIVENESS SCALE-PARENT (IIS-P)

IIS-Parent

For each of the items below, rate the extent to which your child's illness "interferes with" your ability to perform as well as you would like to. (Circle the Number for each item.)

	A Little						A Lot
1. Work	1	2	3	4	5	6	7
2. Active recreation (e.g., golf, tennis)	1	2	3	4	5	6	7
3. Passive recreation (e.g., playing cards)	1	2	3	4	5	6	7
4. Financial status	1	2	3	4	5	6	7
5. Relationship with your spouse/lover	1	2	3	4	5	6	7
6. Sex Life	1	2	3	4	5	6	7
7. Relationships with your family	1	2	3	4	5	6	7
8. Relationships with other persons	1	2	3	4	5	6	7
9. Self-expression/ self-improvement	1	2	3	4	5	6	7
10. Religious expression	1	2	3	4	5	6	7
11. Community/civic involvement	1	2	3	4	5	6	7
12. Health	1	2	3	4	5	6	7
13. Diet	1	2	3	4	5	6	7

APPENDIX F

BACKGROUND INFORMATION QUESTIONNAIRE

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	No
1	2

13. Have you ever received counseling directly related to your Juvenile Rheumatic Disease (JRD) (includes juvenile rheumatoid arthritis (JRA), systemic lupus erythematosus (SLE), juvenile spolndylarthropathies, juvenile dermatomyositis (JDMA))

Yes	No
1	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 G

CHILDREN'S DEPRESSION INVENTORY (CDI)

Feelings Questionnaire

(CDI)

Kids sometimes have different feelings and ideas.

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

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

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

EXAMPLE:

____	I read books all the time.
_X_	I read books once in a while.
____	I never read books.

Remember, pick out the sentences 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 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

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

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

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

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

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

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

21. _____ I never have 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

8. _____ All bad things are my fault

_____ Many bad things are my fault

_____ Bad things are not usually my fault

9. _____ I do not think about killing myself

_____ I think about killing myself but I would not do it

_____ I want to kill myself

10. _____ I feel like crying every day

_____ I feel like crying many days

_____ I feel like crying once in a while

11. _____ Things bother me all the time

_____ Things bother me many times

_____ Things bother me once in a while

12. _____ I like being with people

_____ I do not like being with people many times

_____ I do not want to be with people at all

13. _____ I cannot make up my mind about things

_____ It is hard to make up my mind about things

_____ I make up my mind about things easily

14. _____ I look O.K.

_____ There are some bad things about my looks

_____ I look ugly

15. _____ I have to push myself all the time to do my school work

_____ I have to push myself many times to do my school work

_____ Doing school work is not a big problem

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

APPENDIX H

TABLES

Table 1

Demographic, Disease, and Psychosocial Variables

Variables	Frequency	M	%	SD
Child's Gender				
Male	17		38%	
Female	28		62%	
Child's Ethnicity				
Caucasian	23		51%	
Native American	10		22%	
African American	4		8%	
Biracial	4		8%	
Hispanic	3		7%	
Asian	1		2%	
Child's Age (years)		14.5		(2.91)
Diagnosis				
JRA	28		62%	
Lupus	9		20%	
JDMA	5		11%	
JAS	3		7%	
Illness Duration (years)		2.99		(3.36)
PR Functional Disability		1.56		(0.69)
JAFAR-P		5.24		(7.00)
BSI		0.54		(0.49)
MUIS-P		76.96		(14.09)
IIS-P		24.88		(16.63)
CDI		9.09		(8.45)

Note. PR = Physician-rated; JAFAR-P = Juvenile Arthritis Functional Assessment Report-Parent Form; BSI = Brief Symptom Inventory; MUIS-P = Mishel Uncertainty in Illness Scale-Parent Form; IIS-P = Illness Intrusiveness-Parent Form; CDI = Children's Depression Inventory.

Table 2

Zero-Order and Partial Correlations for Study Variables

Variables	1	2	3	4	5	6	7	8	9	10
1. Child's Age	_									
2. Child's Gender	-.01	_								
3. Recruitment	-.16	-.23	_							
4. Illness Duration	.02	.07	.11	_						
5. PRFD	-.03	.10	-.10	-.06	_					
6. JAFAR-P	.10	.18	-.37**	.06	.42**	_				
7. BSI	.40**	-.02	-.33*	.13	.03	.41**	_	(.33*)		(.44**)
8. MUIS-P	.18	.08	-.14	-.05	-.06	.21	.41**	_	(.15)	
9. IIS-P	.38*	.18	-.23	.01	.11	.54***	.43**	.29*	_	
10. CDI	.25	.04	-.13	-.19	-.14	.18	.48***	.37**	.47***	_

Note. PRFD = Physician-rated functional disability; JAFAR-P = Juvenile Arthritis Functional Assessment Report-Parent Form; BSI = Brief Symptom Inventory; MUIS-P = Mishel Uncertainty in Illness Scale-Parent Form; IIS-P = Illness Intrusiveness Scale-Parent Form; CDI = Children's Depression Inventory. Partial correlations, controlling for age, gender, recruitment method, PRFD, Illness Duration, and JAFAR-P appear above the diagonal (in parentheses).

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

Table 3

Hierarchical Regression Analyses of Brief Symptom Inventory

Step	Variable	β	t for within-step predictors	R^2 Change for step	Cumulative R^2	F Change for step
1	Gender	-.09	-.62	.24	.24	4.25*
	Age	.35	2.53*			
	Recruitment Method	-.29	-2.05*			
2	PRFD	-.12	-.86	.13	.36	2.52
	Illness Duration	.13	.95			
	JAFAR-P	.38	2.42*			
3	CDI	.35	2.36*	.16	.52	3.76*
	MUIS-P	.19	1.49			
	IIS-P	-.03	-.20			
4	MUIS-P X IIS-P	-.17	-.18	.00	.52	.03

Note: PRFD = Physician-rated functional disability; Illness Duration (in years); JAFAR-P = Juvenile Arthritis Functional Assessment Report-Parent; CDI = Child Depression Inventory; MUIS-P = Mishel Uncertainty in Illness Scale-Parent; IIS-P = Illness Intrusiveness Scale-Parent Form.
*$p < .05$. **$p < .01$.

APPENDIX I

INSTITUTIONAL REVIEW BOARD

APPROVAL FORM

Oklahoma State University
Institutional Review Board

Protocol Expires: 1/21/03

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

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

Principal Investigator(s) :

Janelle Wagner
407 N. Murray
Stillwater, OK 74078

James Jarvis
407 N Murray
Stillwater, OK 74078

Molly White
407 N. Murray
Stillwater, OK 74078

John Chaney
407 N Murray
Stillwater, OK 74078

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

Approval Status Recommended by Reviewer(s) : Approved

Signature : Carol Olson

Carol Olson, Director of University Research Complian

Tuesday, January 22, 2002
Date

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

VITA 2

Michael Stuart McLaughlin

Candidate for the Degree of

Doctor of Philosophy

Thesis: TRANSACTIONAL PATTERNS OF DEPRESSION, ILLNESS UNCERTAINTY, AND ILLNESS INTRUSIVENESS IN PARENTS OF CHILDREN AND ADOLESCENTS WITH JUVENILE RHEUMATIC DISEASE

Major Field: Psychology

Biographical:

Personal Data: Born in Gardiner, Maine, On April 6, 1967, the son of Dennis and Marjorie McLaughlin

Education: Graduated from Stillwater High School, Stillwater, Oklahoma in May 1985; received Bachelor of Science degree in Forestry and Wildlife Management from Mississippi State University, Starkville, Mississippi, and Bachelor of Science degree in Psychology from Oklahoma State University, Stillwater, Oklahoma, in May 1990 and May 1996, respectively. Received Master of Science degree in Psychology from Oklahoma State University in May, 2002. Completed the requirements for the Doctor of Philosophy degree with a major in Clinical Psychology at Oklahoma State University in August, 2002.

Experience: Raised in Stillwater, Oklahoma; employed by the U.S. Forest Service Bude, Mississippi; Graduate teaching assistant and associate director of the psychological services center for the Oklahoma State University, Department of Psychology; Predoctoral clinical psychology intern at the Togus Veterans Affairs Medical and Regional Office Center, 2001-2002.

Professional Membership: American Psychological Association, Association for the Advancement of Behavior Therapy, Southwestern Psychological Association, American Psychological Association of Graduate Students, Oklahoma Psychological Association, Oklahoma Psychological Society, OSU Psychology Graduate Student Association.