THE RELATIONSHIP BETWEEN PARENTAL ILLNESS UNCERTAINTY, CHILD ILLNESS UNCERTAINTY AND PARENTAL DISTRESS IN THE JUVENILE RHEUMATIC DISEASES

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TABLE OF CONTENTS

Chapter Page

LIST OF TABLES

Table Page

CHAPTER I

INTRODUCTION

Juvenile Rheumatic Diseases: An Overview

Juvenile Rheumatic Diseases (JRD) are a heterogeneous group of autoimmune diseases which are some of the most common in childhood. A meta-analysis of practitioner and clinic- based studies found that 132 per 100,000 children were affected by juvenile idiopathic arthritis (Oen & Cheang, 1996). Juvenile rheumatoid arthritis (JRA) is the most common form of J with an estimated prevalence of between 30,000 and 50,000 adolescents each year (Lawrence et al., 1998). Other common forms of JRD include systemic lupus erythematosus (SLE), juvenile ankylosing spondylitis (JAS), and juvenile dermatomyositis (JDMA). Although not typically thought of as a fatal group of diseases, JRA has a mortality rate of 0.4% to 2%, which is about three times the rate for the general population in the United States (Hashkes, & Laxer, 2008). While JRDs are comprised of over 100 different disorders, all include the absence of a known etiology, unpredictable pain flare ups, musculoskeletal symptoms and inflammatory issues which may lead to physical limitations and medical problems (Nabors, Iobst, Weisman, Precht, Chiu, & Brunner, 2007; Minden, 2006).

JRDs are classified as chronic diseases, which can be defined in multiple ways,

including Sperry's (2006) definition as an objective and definable process "marked by periods of exacerbation and remission as well as progressive degeneration" (p.6). Chronic illness is further defined by Sperry as a subjective experience of a chronic disease. In the context of JRDs, most children do not achieve full remission and thus the disease remains an ever present burden on the child and family throughout the individual's lifetime. It has been shown that having a child with a chronic disease can impact family cohesion, maternal social support, parental mental health, child mental health, and child social and academic functioning (Dewey & Crawford, 2007; Frank et al., 1998; Helgeson, Janicki, Lerner, & Barbarin, 2003; Sandstrom & Schanberg, 2004). Thus, these children and their parents can be considered at risk for potential negative adjustment outcomes.

The relationship between JRDs and psychosocial adjustment has been widely researched. A recent meta-analysis comparing children with JRDs to controls found a higher prevalence of internalizing problems in children with JRDs and called for more studies looking at specific psychosocial variables that may impact adjustment (LeBovidge, Lavigne, Donenberg & Miller, 2003). A high level of support from parents, the school system, and peers has been shown to also impact adjustment. Nabors and colleagues (2007) found positive family functioning reduced the need for support from teachers, classmates and school nurses, however, Von Weiss et al (2002) found high levels of support from parents and classmates were related to better adjustment. Additionally, high levels of JRD-related pain have been associated with increased depressive symptoms (Sandstrom & Schanberg, 2004), negative daily mood (Schanberg et al., 2000), worse family functioning, and negative attitude towards their illness (Iobst, Nabors, Brunner, & Precht, 2007). The experience of pain and difficulty with physical

activity has been shown to impact peer rejection, ability to focus in school and involvement in afterschool activities which, in combination, negatively impacts the child's psychosocial functioning at school and self esteem (Degotardi, Revenson, & Ilowite, 1999, Sandstrom & Schanberg, 2004).

In accordance with the transactional stress and coping model, parental distress has consistently been shown to be associated with children's psychosocial adjustment. Mothers of children with JRDs report higher levels of depression (Frank et al., 1998), decreased quality of life (Bruns, Hilário, Jennings, Silva & Natour, 2008), and increased guilt and anxiety (Barlow, Harrison, & Shaw, 1998). Other researchers have found normal levels of functioning in the areas of parental distress, family functioning, and social support (Gerhardt et al., 2003, Press, Neumann, Uziel, Bolotin, & Buskila, 2002). Various studies have shown that while some mothers and fathers exhibit mild distress, with scores falling within the normal range of functioning (Frank et al., 1998; Timko et al., 1992), it is still important to examine variables which may be impacting negative adjustment outcomes. A variety of cognitive appraisals variables, including the construct of illness uncertainty, have been linked with psychosocial distress in both parents of chronically ill children (Stewart & Mishel, 2000) as well as their children (Mullins et al., 1997). As such, illness uncertainty will be the primary variable of interest in the current thesis.

A variety of cognitive appraisal variables linked to JRDs have been studied in the past to gain further insight into psychosocial adjustment and psychological distress of both children and parents, particularly given that adjustment outcomes have not been fully explained by disease presence, course, or severity (e.g., level of pain, physical

impairment) (Bruns et al., 2008, Frank et al., 1998, Sawyer, Whitham, Roberton, Taplin, & Varni et al., 2004, Vandvik, Hoyeraal, & Fagertun, 1989). Negative attitude towards illness has been associated with children reporting a poorer attitude toward their illness, less positive illness perceptions and poorer family functioning (Iobst et al., 2007) and a positive attitude was a protective factor against the impact of psychosocial stress (LeBovidge et al., 2005). Wagner et al. (2003) showed an association between illness intrusiveness and child depressive symptomatology, lending further support to the transactional stress and coping model of illness. Illness uncertainty is a cognitive appraisal variable which has received relatively little attention in the context of JRDs. Illness uncertainty has been defined as a cognitive experience elicited in situations in which the meaning of illness-related events is unclear and outcomes are unpredictable due to a lack of sufficient information or cues (Mishel, 1990). In an analysis of uncertainty in childhood illness literature, Stewart & Mishel (2000) identified the most commonly reported result of parental uncertainty as psychological distress. Additionally, while a small body of research exists on children's attitude towards juvenile rheumatic disease (e.g., Iobst et al., 2007) and illness intrusiveness (e.g., Wagner et al., 2003), only one study has examined the role of child illness uncertainty (White et al., 2005). White and colleagues found parental distress had a greater impact on child depressive symptoms when children exhibited increased levels of perceived illness uncertainty.

The Current Thesis

Existing research has yet to examine the association between parental illness uncertainty and child illness uncertainty from a transactional perspective in families with

JRDs. It is therefore the aim of this study to examine the relationship between parent-reported illness uncertainty and child-reported uncertainty in children with JRDs. Additionally, the role of parental distress, as measured by the Brief Symptom Inventory (BSI), will be examined to see if this variable acts as a moderator between parent and child uncertainty. In the sections to follow, a comprehensive review of the literature will be conducted. First, an overview of medical and psychological treatment for JRDs will be presented. Second, the psychological adjustment difficulties and psychological comorbidity of both parents and children with JRDs will be reviewed. Next, information regarding cognitive appraisal mechanisms, including illness uncertainty, and their impact on both parents of and children who have chronic illness will be covered. Fourth, the transactional stress and coping model will be briefly reviewed as a theoretical framework to better understand the impact of chronic illness on children and their families. Lastly, the current study aims will be presented, including an examination of: 1) the association between parental illness uncertainty and child illness uncertainty and 2) the moderating role of parental distress in the association of parent illness uncertainty and child illness uncertainty.

CHAPTER II

REVIEW OF LITERATURE

Epidemiology of Juvenile Rheumatic Diseases

All JRDs are characterized by disease onset before a child turns 16, with a peak in diagnosis at ages 1-3 and 8-12 years. It is further characterized by persistent arthritis in one or more joints for a minimum of six weeks and exclusion of other causes of arthritis (Reiter-Purtill, Gerhardt, Vannatta, Passo & Noll, 2003).The most common presentation of JRD includes inflammation of the synovial membrane of a joint (synovitis), joint stiffness, limitation of motion, pain during motion, joint warmth, gait disturbance, fatigue, and vision problems. Although complaints of pain may accompany JRD as it does in adult rheumatoid arthritis, children will, at times, not express joint pain (arthralgias) upon onset. Thus, joint swelling, stiffness and rash can be important early indicators of JRD (McGhee, Burks, Sheckels, & Jarvis, 2002).

Although the medical etiology of JRDs is not fully understood, genetics, immune reactivity, and infectious and environmental factors appear to play a role. Siblings of children with JRD are 15 to 30 times more likely than the general population to develop JRD (Prahalad, O'Brien, Fraser, Mineau, Pratt, et al., 2004). It is believed that the genetic background of the child will also factor into determining the severity of the disease, although additional research is called for to determine the exact association (Woo, 2008).

Specific genes and proteins (e.g., T cells and S100 proteins in the serum) in the body continue to be analyzed in order to determine which may be linked to JRD development (Macaubus et al., 2009) though no single microorganism has been identified as the cause of JRD. Additionally, many children with JRD have a previous respiratory infections, though the exact relationship has yet to be determined (Woo, 2008). The yet undetermined etiology of JRDs may play a factor in the illness uncertainty reported by parents and children with JRDs (White, Chaney, Mullins, Wagner, Hommel, Andrews & Jarvis, 2005). As JRD is a chronic illness, its course varies and is marked by a series of flare-ups and remissions which may vary from mild to severely restrictive. The specific subtype of JRA, which is identified over approximately the first six months of medical care, impacts the presentation and severity of symptoms.

Juvenile idiopathic arthritis (JIA) is the most common classification of JRD and one of the most common childhood illnesses in the United States. The term JIA is now used almost interchangeably with JRDs and is used to describe seven subtypes of JRDs: systemic JIA, olioarticular JIA, rheumatoid factor-negative polyarticular JIA, rheumatoid factor-positive polyarticular JIA, enthesitis-related arthritis, psoriatic arthritis and undifferentiated JIA (Petty, Southwood, Manners, Baum, Glass, Goldberg et al., 2004). Although the term JIA is now being used in some of the literature to refer to JRDs, this paper will continue in the tradition of using the term "JRD."

Systemic-onset juvenile rheumatoid arthritis (JRA) affects one or more joints and is preceded by fever for a minimum of 2 weeks lasting for at least 3 consecutive days. Systemic-onset JRA is most often diagnosed between the ages of 5 and 10-years-old and boys and girls are equally affected. In all cases of systemic-onset, JRA, arthralgia is

present. Additionally, the child must exhibit at least one of the following symptoms: evanescent erythematous rash, lymph node enlargement, hepatomegaly and serositis. Systemic-onset JRA impacts between 2%-17% of children with JRA and is the most difficult subtype to treat. The joints of the hands, hips and neck are most commonly involved and the child may experience a reduction in dexterity and mobility (Lovell, 2008; Rapoff, Lindsley, Karlson, 2009).

Oligoarticular (Pauciarticular) JRA (oJRA) affects one to four joints during the first six months, usually the knees or ankles. Arthritis must be present for six weeks in order to make a diagnosis. This subtype occurs in 24-58% of children with JRA. oJRA has two subtypes which are categorized by the total number of joints affected over the lifespan of the disease. Persistent oligoarthritis affects no more than four joints total. Extended oligoarthritis affects more than four joints after the first six months of the disease. Within these subgroups, two gender distinctions can be made in regards to other possible complications. Some younger females may test positive for antinuclear antibodies (ANA) and thus have a risk of developing eye problems (uveitis) which occur in 30-50% of those with oJRA. Some older boys will have a long-term risk of arthritis in the axial skeleton, hips and back (Lovell, 2008; Rapoff et al., 2009).

Polyarticular JRA (pJRA) involves five or more joints during the first six months and occurs in about 12-40% of cases. It is more common in females than males (Lovell, 2008). The joints in the neck, hands, wrists, hips, knees and ankles are most commonly affected by synovitis. Weight loss, anemia, growth retardation and low-grade fever may be present. While the disease can begin at any age, if it begins when a child is very young his or her mandibular growth center may be impacted resulting in facial asymmetry. A

positive rheumatoid factor may designate a more serious course of the disease (Rapoff et al., 2009).

Systemic lupus erthematosus (SLE) presents in children as fever, rash, fatigue, weight loss, arthralgias and synovitis (Kaufman, 1986). Females are affected at four times the rate of males and ethnic minorities also have higher prevalence rates (White, 1993). Genetic predisposition, viral infection and a poor immune system interact to cause SLE though no primary cause is known (Kaufman, 1986). SLE is characterized by autoantibodies which attack self-antigens and result in synovitis, inflammation of organs, blood vessel abnormalities and immune system dysregulation. Increased production of ANA results in immune complex formation and tissue damage. Hematologic abnormalities such as thrombocytonpenia, leucopenia, lymohocytopenia, and hemolytic anemia may occur. In the past thirty years, the outcome prognosis and survival rates of SLE have drastically improved because of earlier recognition and more advanced treatment methods and medications (González, Hernández, Olguín, Miranda, Lira, Toso, et al., 2005).

Medical Treatment of JRDs

Aspirin is the most consistently used anti-inflammatory drug to initially treat JRDs, primarily due to its' ease of administration, availability, and low cost. However, the need to administer aspirin three times per day, the possible influence on serum transaminases levels and other liver function tests, and association with Reye syndrome have made it less popular. Nonsteroidal anti-inflammatory drugs (NSAIDs) are often used in treatment with Naproxen or ibuprofen as the first choice with young children.

Adolescents often use oral, once-a-day NSAIDs such as nambutome, prioxicam or celicoxib. Approximately 50% of patients show symptom relief within the first two weeks and the remainder during the first eight weeks of use (Jordan & McDonagh, 2006). NSAIDs should continue to be used 12 to 18 months after symptoms have disappeared, which can result in considerable problems with adherence during this time. Approximately 25%-33% of children with JIA, usually those with oJIA, respond well to NSAIDs (Hashikes & Laxer, 2005). As NSAIDs do not directly modify the disease, they are mainly used to treat pain, joint stiffness and fever. A possible side effect of NSAIDs is gastrointestinal (GI) distress, which may also lead to adherence problems. However, GI distress can usually be avoided by administration of medication with food.

If a child is unresponsive or minimally responsive to NSAIDs, disease-modifying anti-rheumatic drugs (DMARDs) are used (Hashkes & Laxker, 2008). Methotrexate (MTX) is a common DMARD that acts by inhibiting the metabolism of folic acid. MTX use is discontinued when possible because of many associated side effects, including anemia, neutropenia, increased risk of bruising, nausea, dermatitis and diarrhea (Jordan & McDonagh, 2006). A meta-analysis by Hashkes and Laxer (2005) found MTX to be most widely used with children who have polyarthritis, most effective with oJIA, and ineffective with systemic JIA. While NSAIDs should be administered with food, MTX should be given on an empty stomach as food decreases its bioavailability. High dosage treatments (above 12mg/m^2) should be administered intravenously. To decrease associated nausea, ulcers in the mouth and liver enzyme abnormalities, folic acid should be given orally 24 hours after administration. Nausea and GI side effects are common but

can be dampened by MTX administration before bedtime, intravenous (versus oral) administration, and using antiemetics (Hashkes & Laxker, 2008).

Intra-articular (IA) corticoseteroid injections may be used short-term during the beginning of treatment as DMARDs may not be effective for many months. Corticosteroids are long-acting steroids that result in increased mobility and decreased pain and stiffness. Although IA corticosteroids provide quick relief to the child, they must be administered in a doctor's office and multi-injection visits often necessitate sedation for younger children. The most common sedatives are Ketalar or Propofol and these may be paired with Fentanyl to reduce associated pain (Padeh & Passwell, 1998). Triamcinolone hexacertonide is administered intra-articularlly and dosage varies by severity of inflammation and size of joint. Corticosteroids can be administered orally or intravenously for higher doses, which have been especially effective for children with oJIA. Padeh & Passwell (1998) reported that 82% of treated children had a full remission of synovitis, with remission lasting more than 6 months post injection. These children also evidenced decreased pain and increased movement, and 40% were arthritis-free in that joint for over two years. Intra-articular injections beginning soon after diagnosis of oJIA have been shown to reduce leg length discrepancies which may lead to improved movement over time (Hashkes & Laxer, 2005).

Prednisone doses of 1 mg daily have also proven successful for treating SLE (Kaufman, 1986). While beneficial, use of IA corticosteroids should be avoided if possible because of serious side effects including toxicity, acne, cataracts, growth retardation, Cushings disease, osteoporosis, fractures, obesity and hypertension (Kaufman, 1986; Rapoff et al., 2009). Additionally, patients with SLE who have received

doses over 20 mg/day have developed a cushingoid appearance including bloated faces, weight gain, easy bruising, and abdominal, breast, thigh and upper arm striae which disappear with reduced dosage (Kaufman, 1986).

Anterior uveitis, a type of eye disease that causes swelling and pain in the middle portion of the eye, occurs in between 5% to 50% of children with JRA and can include problems with cataracts, glaucoma and band keratopathy. Risk factors for uveitis include diagnosis prior to age six, oJIA, and ANA positivity (Lindsley, 2005). Girls under the age of 8 with positive ANA and oJIA are at the greatest risk (Jordan & McDonagh, 2006). Anterior uveitis is assessed by an ophthalmologist using a slit lamp examination and can be treated with topical Methotrexate drops. If drops are not initially effective, subtenon corticosteroid injections may be implemented in the treatment plan. School performance should be monitored as uveitis can cause difficulties in seeing classroom boards and focusing on reading in textbooks.

Children with JRAs may have growth abnormalities related to poor nutritional status and low muscle mass. NSAIDs and MTX can cause loss of appetite whereas corticosteroid may lead to weight gain, hypertention, bone loss and calcium and vitamin D deficiencies. Thus nutrition, protein and weight should be monitored during clinic visits and nutritional supplements may be used as a part of treatment (Hashkes & Laxer, 2008; Lindsley, 2009).

Physical therapy is a central aspect in treatment of JRDs and assists in controlling pain, improving range of motion and muscle strength, preventing limb deformities and minimizing or preventing loss of functioning, and ensuring normal growth and development (Cakmak & Bolukbas, 2005). Children with JRDs often hold their joints in

positions that are most comfortable for them, and often do not initiate enough movement. Subsequently, they develop weakness and compensatory contractures around inflamed joints. Physical therapy includes guided range of motion and strengthening exercises, splints, serial casting as well as positioning to steady joints and straighten joint deformities (Akikusa & Allen, 2002). Heat treatment, cold treatment, massage and therapeutic exercises can be delivered in therapy but must also be implemented in home-based programs. When used on the knees and feet, these methods can improve gait, decrease pain while walking, and minimize pressure to reduce calluses. Occupational therapy for the wrists, hand and fingers can aid in improving efficiency at daily activities such as eating, writing and washing. Although primarily used with children who have JIA, physical therapy is also used with juvenile dermatomyositis, scleroderma and SLE. Parents often allow, and at times encourage, children to avoid physical activity, especially if it is paired with pain complaints (Gerhardt et al., 2003). Exercise should be encouraged as it has been shown to decrease joint symptoms and improve affect. Klepper (1999) found a decrease in an articular severity index and joint count and an increase in aerobic endurance after an 8-week weight-bearing, physical conditioning program.

Chronic pain is a hallmark characteristic of arthritis, though the majority of young children report little or no pain. However, for those children who do experience significant pain, a decrease in quality of life is often observed (Sawyer, Whitham, Roberton, Taplin, Varni, & Baghurst, 2004). Pain is often a result of the heat caused by the rubbing of joint fibers during synovitis and continues due to sensitization in affected joints. It is important to have an accurate understanding of the child's pain experience, as pain has been linked to increased anxiety, depressive symptoms, negative mood,

emotional distress, poorer attitude about illness, decrease in quality of school work, and difficulty concentrating in school (Iobst et al., 2007; Nabors et al., 2007; Rapoff et al., 2009; Sandstrom & Schanberg, 2004). Additionally, pain has been associated with externalizing behaviors, malpositioning of affected joints, and avoidance of physical and social activities. Such behaviors have been shown to be maladaptive and should be discouraged by parents through reinforcement of positive coping strategies and enforcement of rules such as school attendance and physical therapy exercise adherence (reference here). When conducting psychosocial interventions including pain management, the "gate-control theory" can be used to conceptualize the sensory, affective and evaluative components of the pain experience and how they may possibly influence disease activity (Smith & Dalen, 2007). As poor coping skills have been associated with higher levels of pain, pain coping strategies should be taught during therapy and should continue to be assessed using tools such as the Pain Coping Questionnaire (Reid, Gilbert, McGrath, 1998). Cognitive refocusing on activities which distract the child from pain and a posttraumatic growth perspective have both been shown to be superior to emotion-focused avoidance (catastrophizing) and cognitive self instruction (wishful thinking) (Rapoff, Lindsley, & Karlson, 2009; Smith & Dalen, 2007). Additionally, cognitive behavioral techniques such as progressive muscle relaxation, guided imagery, and meditative breathing have been shown to be helpful when pain impacts academic performance, extracurricular participation and interpersonal interactions (Walco, Varni, & Ilowite, 1992).

Psychological Treatment of JRD-Associated Problems

In the following section, the research regarding the psychological treatment of children with a chronic illness will be briefly reviewed. Psychological treatment has been shown to be successful in multiple domains. Treatment options will be discussed in the following order: treatment adherence, self-care behaviors, and parenting strategies and support.

Treatment adherence is a significant problem across multiple chronic illness groups, with research demonstrating decreases in adherence occurring with the duration of the illness (Rapoff, 1999). It is therefore important to educate families about the nature of their treatment regimen early after diagnosis. In the context of the Health Belief Model, education about the short and long-term benefits of following a treatment regimen has been shown to improve adherence (Rosenstock, Strecher, & Becker, 1988). Decreasing uncertainty about disease management and course begins with the pediatric rheumatologist educating parents and children during doctors visits. Akikusa & Allen (2002) recommend four steps to improving education about JRDs: a separate educational session, exploration of patient/family beliefs and misconceptions about JRDs, selection of the least complex treatment regimen, and careful discussion about medications. Although education has been shown to be effective, Rapoff (1999) found a combination of education and behavioral strategies produce the highest levels of compliance. Additionally, he found a clinic-based, nurse-administered behavioral and educational program prevented a drop in adherence over time to nonsteroidal anti-inflammatory medications in children with JRDs (Rapoff, Belmont, Lindsley, Olson, Morris, & Padur, 2002).The inclusion of a psychological component in addition to education (e.g., relaxation, biofeedback, cognitive-behavioral therapy) was supported in a meta-analysis

of 25 studies with rheumatoid arthritis patients. Significant improvements in coping, pain, functional disability, depression and self-efficacy were found, with improvements remaining in coping, tender joints and depression at an 8.5 month follow-up (Astin, Beckner, Soeken, Hochberg, & Berman, 2002).

Self-care behaviors have been linked to family functioning, the psychological health of parents and children, and coping strategies utilized. In order to assure optimal treatment adherence, teaching coping skills and thereby enhancing psychological adjustment should be considered. Moos (2002) posited a general stress and coping framework that can be used to understand the adaptation of adolescents with chronic illnesses. He posited a transactional chronic illness model that mapped reciprocal feedback among the context of the illness, the adolescent's coping, and the adolescent's adaptation. Moos stated it is important to study the process of both coping and crisis resolution, as well as the link between parent and child coping behavior and parental resources and child adjustment. Maladaptive coping skills have been routinely associated with poorer psychological and physical health. Specifically, catastophizing has been related to increased pain, functional disability and depression in those with rheumatoid arthritis (Keefe, Brown, Wallston & Caldwell, 1989) and avoidance coping has been associated with impulsive outbursts and adjustment problems in children with JRDs (Degotardi et al., 1999). While the effectiveness of coping strategies depends on the child's cognitive-developmental and situation, approach coping skills have been shown to be the most beneficial overall (Thompson & Gustafson, 1997). Approach coping skills center around seeking information rather than avoiding information, and have been associated with less distress in relation to stressful medical procedures (Blout, Davis,

Powers & Roberts, 1991). Coping skills education is especially important as youth with JRDs have been found to use a wider variety of coping skills than control youth (Harris, Newcomb & Gewanter, 1991).

Parental treatment regimen and emotional support of children with chronic illness has been shown to be beneficial for both the ill child and the parents. In a study by Berg and colleagues (2007), collaborative coping, or the teamwork approach, was associated with less depressive symptoms and more positive emotion in children with type 1 diabetes and their mothers. Collaborative coping included appraising each other as being actively involved in brainstorming and negotiating about stressful events related to the illness. While parents of children with chronic illness have been shown to be more hands on, the greatest benefits have been seen when a balance is achieved through collaborative disease management and the sharing of control.

When parents feel they have mastery over their child's disease, they exhibit more positive, supportive parenting. Children with JRDs reported less distress and more social integration when their mothers had a sense of mastery (Timko, Stovel, Moos, & Miller, 1992). Similar results have been found in families of children with epilepsy. Increased parental encouragement of child autonomy and parental support are associated with decreases in behavior problems (Austin, Dunn, Johnson, & Perkins, 2004) and internalizing problems (Sbarra, Rimm-Kaufman, & Pianta, 2002). Parental control may be beneficial in its emphasis on disease management but too much control may also reduce expressiveness and independence (Moos, 2002). In a recent literature review of family factors and psychopathology, the authors opined that overprotectiveness itself may not be a negative parenting factor, but that its level should be appropriate with the

developmental stage of the child (Rodenburg, Meijer, Deković & Aldenkemp, 2005). Further, the support of parents and siblings has been shown to reduce both internalizing and externalizing behavior problems in children with JRA (Timko, et al., 1995, Varni, Wilcox, & Hanson, 1988). Adjustment to JRDs, including less illness worry, less appearance worry, and higher self-esteem, can be improved by reducing family conflict and increasing family cohesion through communication (Helgeson, Janicki, Lerner, and Barbarin, 2003). Additionally, support from friends, teachers and peers is associated with fewer adjustment problems, depressive symptoms (von Weiss et al., 2002), lower psychological distress and higher self-esteem (Varni, Katz, Colegrove, & Dolgin, 1994, Varni, & Setoguchi, 1996).

Psychological Comorbidity

Parent Adjustment.

Children are not the only individuals affected by their chronic illness; the transactional stress and coping model posits parent's psychosocial health is also influenced by their children's chronic illness. The major aim of past research has been to document parental adaptation; however, more research now includes the manner in which parental attitudes, psychological distress and functioning influence child adjustment (Kazak, Rourke, & Navsaria, 2009; White et al., 2005). As it has been shown that parental adjustment and family system variables have more predictive power regarding child adaptation and adjustment than disease factors or illness severity, it is critical to continue to look at variables influencing parental adjustment (Cohen, 1999; Frank et al., 1998).

In general, parents of chronically ill children have reported greater use of psychological services (Cadman, Rosenbaum, Boyle, & Offord, 1991), more depression (Frank et al., 1998), greater stress, and less martial satisfaction (Katz, 2002) than those of healthy children. In a survey of 1,800 families, Cadman and colleagues (1991) found mental health treatment was 2-3 times more commonly utilized by parents of chronically ill children than by parents of healthy children. Utilization of health services not only takes time away from self-care, care of family and employment obligations but it takes a monetary toll on families who are already carrying additional medical expenses related to the JRD. Risk factors for parent's psychological distress include daily hassles stress (Manuel, 2001), higher levels of physical limitations (Lustig, Ireys, Sills & Walsh, 1996), child behavior problems (Frank et al., 1998), social impairment, and perceived higher level of distress and burden (Mullick, Nahar, & Naq, 2005).

Parents of children with juvenile rheumatoid arthritis and juvenile diabetes report higher levels of depressive symptoms, compared to parents of control children, which have been linked with increased burden of care, loss of social activities and their own physical health problems (Frank et al., 1998). Wallander (1993) found that mothers of children with sickle cell disease frequently met criteria for major depressive disorder (21%), and other affective disorders, with 34% meeting criteria for at least two disorders. Parental distress has been found to be related to distress in children with cancer (Robinson, Gerdardt, Vannatta, & Noll, 2007), spina bifida (Friedman, Holmbeck, Jandasek, Zuckerman, & Abad, 2004), and juvenile rheumatic disease (Timko et al., 1992). In further support of the transactional nature of chronic illness, the presence of parental psychological distress has been linked with child adjustment problems.

The experiences of families are not always maladaptive, and some researchers have demonstrated that functioning of JRD families may similar to control families in terms of quality of life (Press et al., 2002), parental distress, family functioning, social support (Gerhardt et al., 2003), and perceived competence (Harris, Newcomb, & Gewanter, 1991). Family cohesiveness (Dewey & Crawford, 2007), cooperation, participation of family members in caring for the chronically ill child (Katz, 2002), positive maternal appraisal of the illness, high level of maternal education (Manuel, 2001), a sense of maternal mastery about the illness, and more social integration (Timko, Stovel, Moos, & Miller, 1992) have been associated with better parental and family functioning. It is thus important to examine variables which predict adjustment of specific family members as well as specific characteristics of varibles which may act as either risk or resistance variables.

Child Adjustment. In general, children with a chronic illness have a risk for adjustment problems that is 1.5 to 3 times higher than their healthy peers (Pless, 1984). A meta-analysis looking at the psychological adjustment of children and adolescents with chronic arthritis by LeBovidge and colleagues (2003) showed they were at a 13% to 45% increased risk for internalizing symptoms compared to controls. In another study of individuals with JRA, 21% of the children with JRA were clinically depressed, with the level of depression and anxiety increasing with the degree of disability (David, Cooper, Hickey, Lloyd, Dore, McCullough, et al., 1994). Children with juvenile rheumatic disease have been shown to have higher rates of depression when they experience pain, peer rejection and problematic social behavior (Sandstrom & Schanberg, 2004). As such,

social support and school adjustment can be key factors in child psychosocial functioning.

A child who has JRD can have serious impairment in the amount of classroom activities in which they are able to participate. Gym class activity and after-school sports can be impacted by joint pain, stiffness and growth retardation. When a child with a JRD is able to participate in physical activity, he or she has more difficulty participating and may not feel adults within the school make accommodations to allow for their full participation (Nabors et al., 2007).

Compounding the negative influence of physical difficulty in participation is the possible dissatisfaction with physical appearance caused by leg braces and swollen joints. The decrease in participation with peers during activity can separate children with JRDs from their healthy peers and negatively impact the amount of social support felt from other school children during a time that is already ripe with difficulties related to self confidence and self-esteem (Degotardi et al., 1999). Additionally, the chronic pain has been shown to impede the child's ability to focus in school and influence the quality of their school work. Von Weiss et al. (2002) reported that children with JIA who had more support from classmates and parents were better adjusted than those without high levels.

Social support is fostered through good peer relationships, which can only occur with the allowance of autonomy from the parents. It has been shown that parents of chronically ill children may unknowingly discourage autonomy by being overprotective and overly directive (e.g., Power, Dahlquist, Thompson, & Warren, 2003; Thomasgaard, Shonkoff, Metz, & Edelbrock, 1995). Mothers exhibited increased worry about general

health and joint injury, specifically, and did not allow them to play more physically rigorous games whereas fathers reported increased difficulty punishing their children who had a JRD (Gerhardt, Vannatta, McKellop, Taylor, Passo et al., 2003). Parents may generalize their child's need for assistance with JRD related activities to other areas of his or her life including, for example, cognitive tasks that are not going to be influenced by the physical difficulties of JRDs (Power et al., 2003). Psychosocial functioning is improved when children with JRDs are supported yet given a developmentally appropriate level of autonomy.

In summary, psychosocial functioning of chronically ill children and their family members can be impacted by the presence of a chronic illness. However, psychosocial functioning and illness course and severity are not the only predictors of parental and child adjustment. Research has also indicated that cognitive appraisal variables are consistent and sometimes robust predictors of adjustment across chronic illnesses.

Illness Uncertainty

The role of cognitive appraisal variables has been examined across child chronic illnesses, yet much work needs to be done in order to fully understand their impact on the experiences of both parents and children. One such variable that has received considerable attention is that of illness uncertainty (e.g., Hommel, Chaney, Wagner, White, Hoff, & Mullins, 2003; Mullins, et al., 1997; White et al., 2005). Illness uncertainty has been defined as a cognitive experience elicited in situations in which the meaning of illness-related events is unclear and outcomes are unpredictable due to a lack of sufficient information or cues (Mishel, 1990). Mishel posited that illness uncertainty is

comprised of four components: perceived ambiguity regarding the state of the illness, complexity regarding treatment, lack of information about the seriousness of the illness and prognosis, and perceived unpredictability of the illness course (Mishel, 1984). Additionally, she stated that stress and uncertainty are related not through the appraisal of an event as stressful but by the vagueness, lack of clarity and lack of information surrounding the event. JRDs are certainly appropriate to examine in the context of illness uncertainty, as they are characterized by a highly variable and unpredictable illness course (Akikusa & Allen, 2002, Jordan & McDonagh, 2006).

Cognitive attributions, including illness uncertainty, have been shown to be salient variables when aspects of an illness are ambiguous or variable. Mullins and colleagues examined the role of illness uncertainty and causal attributions in older adolescents and young adults with asthma and found both increased illness uncertainty and increased stable attributions for negative events were associated with poorer psychological health ((Mullins, Chaney, Balderson & Hommel, 2000, Mullins, Chaney, Pace, & Hartman, 1997). Similar findings were shown in individuals with multiple sclerosis (Mullins, Cote, Fuemmeler, Jean, Beatty, & Paul, 2001). In another study with older adolescents with asthma, illness uncertainty was again associated with anxiety and but not with depression (Hommel, et al., 2003). In an analysis of uncertainty in childhood illness literature, Stewart & Mishel (2000) identified the most commonly reported consequence of heightened parental uncertainty was psychological distress. When looking at longitudinal psychological distress in parents of chronically ill children, general distress can be predicted by initial illness uncertainty above and beyond the variance attributed to child illness duration and initial psychological distress in parents of

children with type 1 diabetes mellitus (Carpentier et al., 2006). Illness uncertainty thus continues to be an important factor to consider when analyzing cognitive appraisal variables in order to fully understand the course of parent and caregiver mental health. Additionally, it has been shown that a reduction in illness uncertainty has been linked to better mental health outcomes. By examining illness uncertainty in the initial stages of treatment and identifying methods to reduce this cognitive attribution, a preventative approach to care can be utilized.

In addition to the impact of illness uncertainty on parents and caregivers, psychological distress has been shown to be associated with increased illness uncertainty in children with chronic illness. In a study by Neville (1998), 30% of the total variance in psychological distress of children with cancer could be predicted by uncertainty. Distress has also been seen in youth with asthma (Mullins et al., 1997), type 1 diabetes (Hoff, Mullins, Chaney, Hartman, & Domek, 2002) and JRDs (White et al., 2005). To date, research has failed to adequately incorporate illness uncertainty into the transactional model and to study its impact on multiple family members. White and colleagues (2005) found parental distress had a greater impact on child depressive symptoms when children exhibited increased illness uncertainty. Additionally, they found there was a significant interaction effect of high child illness uncertainty and parental distress on child depression scores. However, they did not find an interaction effect when child illness uncertainty scores were low. To build on the research of White and colleagues, the relationship of parental illness uncertainty on the illness uncertainty experienced by children with JRDs needs to be explored. Additionally, there has been no research that looks at the direct effect of parental illness uncertainty on child illness uncertainty in the

JRD population. To build on the existing research on illness uncertainty, examination of this link in this disease specific population will be completed. To better place the current research in context, the Transactional Stress and Coping Model will be briefly reviewed.

Transactional Stress and Coping Model

The transactional stress and coping model (TSC; Thompson, Gustafson,Hamlett, & Spock, 1992) conceptualizes chronic illnesses as stressors within an ecological-systems-theory perspective (Bronfrenbrenner, 1977). The interaction of illness and parental adaptational processes, including methods of coping, stress processing, and family functioning, is related to the health status and psychological well being of the child In this model, chronic illness is viewed as a potential stressor, and the family system subsequently responds to the stressor in adaptive or maladaptive ways. The ecological-systems-theory provides the basis for inclusion of demographic factors (child gender and age, family SES), illness parameters (type and severity), and both child and family functioning in the TSC model.

Within the TSC model, child and parent adaptational processes are viewed as both separate and, yet ultimately, interacting. Three types of psychosocial mediational processes are outlined for mother's adaptation: 1) cognitive appraisal-stress surrounding daily hassles and illness tasks, expectations of efficacy and health locus of control; 2) coping methods (palliative or adaptive); and 3) family functioning (supportive, conflicted or controlling). Child psychosocial mediational processes are expectations of self-esteem, health locus of control, and methods of coping (Thompson & Gustafson, 1994).

The model has been used by Thompson and numerous other researchers to study the link between parent and child adjustment in a wide variety of chronic diseases (e.g.,

Carpentier, et al.; Frank et al., 1998). Cognitive appraisals by both the parents and child have been shown to influence levels of distress and adjustment in both individual and family functioning. In families with children who have juvenile rheumatic arthritis, family conflict has been found to be related to greater adjustment difficulties, whereas family cohesion (supportive functioning) has been associated with fewer adjustment difficulties (Helgeson, Janicki, Lerner &Berberin, 2003). Even when controlling for disease factors, family and social support continued to be a significant predictor of psychological adjustment in children with JRA, per maternal report (Varni, Wilcox, & Hanson, 1988). Furthermore, Dewey and Crawford (2007) found higher levels of both maternal and paternal psychological distress were associated with lower family cohesion.

A parent's psychological functioning is often impacted by the reality that their child is living a different life than they had pictured, a phenomenon sometimes referred to as "chronic sorrow" (Kokkonen, Kokkonen, & Moilanen, 2001). Parents are attuned to their child's interpersonal and psychological difficulties and can feel overwhelmed by their own expectations about their effectiveness in helping their children cope and managing their child's illness. Higher levels of maternal reported stress have been associated with poorer child adjustment when factoring out illness and demographic parameters (e.g., Thompson, Gil, Keith, Gustafson, George, & Kinney, 1994). In the context of JRDs, Wagner and colleagues (2003) demonstrated that both parental distress and illness intrusiveness impacted child depression. Additionally, they found that children's perceptions of illness intrusiveness were significant predictors of child depressive symptomatology. Thus, the TSC model certainly appears to be a model relevant to the experience of families of a child with a JRD.

When examining the possible relationship of child uncertainty to child distress, it is appropriate to do so from a transactional stress and coping model framework. Previous research has evaluated the influence of cognitive appraisals, including illness uncertainty, on children who have a chronic illness (Andrews, Chaney, Mullins, Wagner, Hommel, & Jarvis, 2007; Carpentier et al., 2007; Mullins, et al., 2007). Mullins and colleagues (2007) viewed illness uncertainty as a person-environment interaction between the objective experience of chronic illness and an individual's cognitive appraisal of their subjective experience of the events. Previous studies have shown illness uncertainty to be connected with parental and child adjustment to cancer (Grootenhuis & Last, 1997), asthma (Mullins, et al., 1997; Van Pelt, Mullins, Carpentier, & Wolf-Christensen, 2006) and Type 1 Diabetes (Carpentier, Mullins, Chaney, & Wagner, 2006). In the present study, the impact of parental distress on both parental and child illness uncertainty will be examined in order to better understand the relationship of parental uncertainty to child uncertainty in the context of pediatric rheumatic disease.

CHAPTER III

METHODOLOGY

Participants and Procedure

Participants were 61 (41 females; 20 males) children and adolescents between the ages of nine and 21 (M = 14.42; SD = 2.88), who had been diagnosed with juvenile rheumatoid arthritis (JRA; N = 35), systemic lupus erythematosus (SLE; N = 14), juvenile ankylosing spondylitis (JAS; N = 4), and juvenile dermatomyositis (JDMA; N = 7), and their parents. The majority of child participants were Caucasian (45.9%), followed by Native American (26.2%), African American (9.8%), Hispanic (9.8%), Biracial (6.6%), and Asian (1.6%) (See Table 1 for complete descriptive statistics). Participants were recruited from a pediatric rheumatology clinic in the Southwestern United States. Institutional Review Board approval was granted and written informed assent and consent were obtained from each participant, parent or legal guardian. Inclusion criteria for eligibility included the following: 1) diagnosis of JRA, SLE, JAS or JDMA, 2) between the ages of 9 and 21, 3) no other comorbid cognitive deficits or chronic illness, and 4) duration of symptoms for at least one year. Participants met illness duration criteria if they had active symptoms for at least one year, therefore some participants were included who did not have a formal diagnosis for one full year. Illness duration was calculated by subtracting the date of diagnosis from the date of data

collection 0.04 years to 15.73 years (M = 2.57; SD = 3.24). Inclusionary criteria were verified through rheumatologist and self report. Each participant family was compensated monetarily with $10.00.

Eligible participants were identified by the rheumatologist and then contacted by a research assistant. While the majority of participants were recruited in the clinic, those who were not scheduled for upcoming appointments were contacted via telephone. Packets for the study were disseminated during a clinic visit or were sent to the family in the mail. The packets were either completed in the clinic or sent back to the research assistant in a pre-paid postage envelope. Study packets included a background information questionnaire, a parental consent form, a child assent form, a BSI for the parent to complete, and a JAFAR-C, CDI, and CUIS for the child to complete. As this study was part of a larger study, other psychosocial measures were included in the packet that will not be covered in the scope of this manuscript. Participant families were $10 in monetary compensation once their completed packet was received.

Measures

Physician-Report Measures

Provider Questionnaire. The provider questionnaire was completed by the rheumatologist once the researchers had received a completed packet. It included information about diagnosis (type, date), current medications, disease severity and functional class. Disease severity was assessed using a 7-point Likert scale, ranging from 1 (*disease not active or in remission*) to 7 (*severe*). The Steinbrocker revised criteria for the classification of global functional status in rheumatoid arthritis was used to assess for

functional disability. Research has shown the criteria to be a valid measurement for this population (Adib, Silman, Thompson, 2005; Hochberg et al., 1992). Patients were categorized into one of four classes, wherein Class I denoted no disruption in ability to perform daily activities and Class IV denoted limitations in ability to perform usual daily self-care, vocational and avocational activities (Hochberg et al., 1992). Data collection was previously completed as part of a larger research project on JRDs conducted at OUHSC, as such, variables not pertinent to the current research study were not included in this manuscript.

Parent-Report Measures

Background Information Questionnaire. The questionnaire was used to gather information about age, gender, ethnicity, and other demographic variables. The present study will only utilize the data about age, gender, and ethnicity.

Brief Symptom Inventory. (BSI; Derogatis & Melisaratos, 1983). The parents completed the BSI, a 53-item questionnaire used to assess global psychological functioning in nine domains (e.g., somatization, depression). Respondents rate the degree of their distress over the past 7 days using a Likert scale, ranging from 0 (*not a lot*) to 4 (*extremely*). The global severity index (GSI) and the Depression scale will be looked at to determine level of distress. It has been used in previous studies with the pediatric chronic illness population (Andrews et al., 2007; Canning, Harris, & Kelleher, 1996; Pai et al., 2006; Wagner et al., 2003; White et al., 2005) and has been shown to have good internal consistency with alpha coefficients ranging from 0.71 to 0.85 (Derogatis & Melisaratos, 1983) Cronbach's alpha for the present sample was found to be high (α=.96).

Mishel Uncertainty in Illness Scale – Community Form. (MUIS-C, Mishel & Braden, 1988). The MUIS-C is a 23-item questionnaire which assesses the four components of illness uncertainty: ambiguity, uncertainty, lack of information, and unpredictability. Respondents rate their illness uncertainty on a 5-point Likert scale ranging from 1 (*very true*) to 5 (*very false*). A total sum score is calculated with higher scores reflecting greater illness uncertainty. The MUIS-C has been used with chronic illness populations in the past (e.g., Carpentier et al., 2007; Van Pelt et al., 2006) and reliability coefficients for the MUIS-C have been high, ranging from .74 to .92 (Mishel, 1997). Cronbach's alpha for this sample was also found to be high (α=.88).

Child- Report Measures

Children's Uncertainty in Illness Scale (CUIS; Mullins & Hartman, 1995). The CUIS is a 23-item self-report measure used to address four components of children's perceived uncertainty regarding their illness: ambiguity, lack of clarity, lack of information, and unpredictability. The items included in this version have been adapted from the Mishel's (1983) original Uncertainty in Illness Scale – Community Form adult version in order to be developmentally appropriate. Participants rate items (e.g., "My treatment is hard for me") on a 1-5 Likert scale, ranging from 1 (*very true*) to 5 (*very false*). A total sum score is calculated with higher scores reflecting greater illness uncertainty. The CUIS has good internal consistency reliabilities, with alphas ranging from 0.88 to 0.89, and has been used with pediatric chronic illness populations in the past). Chronbach's alpha for the present sample was also found to be high (α=.85).

Statement of Purpose

Based on the preceding literature review, it appears that children with JRDs are at an increased risk for negative psychological adjustment outcomes (David et al., 1994; LeBovidge et al., 2003). As disease variables do not fully account for the level of distress in children with JRDs (Cohen, 1999; Frank et al., 1998), it is necessary to further examine other variables which may play a role in adjustment. The cognitive appraisal variable of illness uncertainty has been consistently associated with psychological distress in chronically ill children (Hoff et al., 2002; Mullins et al., 1997; Neville, 1998). It is a variable that is uniquely appropriate for understanding the impact of the unpredictability of JRD flare-ups (e.g. changes in pain, joint mobility). A previous study which examined the impact of illness uncertainty on children with JRDs found parental distress (GSI) had a main effect on child depressive symptoms (CDI). Also, they found an interaction effect of parental distress and child illness uncertainty (CUIS) which accounted for 6% of the variance between disease factors, demographics and the main effect (White et al., 2005). Additionally, they found no significant impact of child uncertainty (CUIS) on child depressive symptoms (CDI). Unfortunately, the study by White and colleagues is the only study to date which looks at the role of child illness uncertainty in JRD. Clearly, parental psychological functioning impacts the psychological adjustment of their chronically ill child (Friedman et al., 2004; Robinson et al., 2007; & Timko et al., 1992). Based on the transactional stress and coping model outlines previously, it is appropriate to further elucidate the association between parental adjustment and child adjustment to JRDs and build on the study previously completed by White and colleagues.

Based on the current knowledge of parental and child illness uncertainty and adjustment to JRDs, the purpose of this study was twofold. It first examined the relationship of parental uncertainty to child uncertainty after controlling for disease and demographic variables. Second, it examined the possible moderating role of parental distress on the relationship between parental illness uncertainty and child illness uncertainty.

Primary Hypotheses:

Hypothesis 1: It was hypothesized that parental illness uncertainty (MUIS) would be significantly associated with child illness uncertainty (CUIS), after controlling for disease and demographic variables.

Hypothesis 2: In line with the transactional stress and coping conceptualization of family adjustment, it was hypothesized that parental distress (BSI) would moderate the relationship between parent illness uncertainty (MUIS) and child illness uncertainty (CUIS).

CHAPTER IV

FINDINGS

Overview of analyses

The following statistical procedures were conducted to address the specific hypotheses of this study. Descriptive statistics were first conducted to examine possible covariates.

Hypothesis 1: It was hypothesized that parental illness uncertainty (MUIS) would be significantly associated with child illness uncertainty (CUIS), after controlling for disease and demographic variables. It was anticipated that parental illness uncertainty would contribute significant variance to child illness uncertainty beyond the influence of demographic and disease variables.

Hypothesis 2: In line with the transactional stress and coping conceptualization of family adjustment, it was hypothesized that parental distress (BSI) would moderate the relationship between parent illness uncertainty (MUIS) and child illness uncertainty (CUIS). The existence of a moderator relationship between parental distress and illness uncertainty would require the interaction of parental distress (as measured by the BSI) and illness uncertainty to contribute incremental unique variance to child illness uncertainty, beyond the influence of the main effects of these variables.

Preliminary Analyses

Preliminary analyses were run to rule out the possible effects of demographic variables and disease subtype on key variables. Several one-way multivariate analysis of variance (MANOVAs) were conducted to examine the potential effects of demographic variables and disease subtype on child illness uncertainty (CUIS). There were no significant differences of demographic variables on disease variables (physician-rated disease severity, physician-rated disability, JAFAR-P, and illness duration; all p's > .05) or psychosocial variables (MUIS-C, CUIS, BSI; all p's > .05). Additionally, there was no effect of disease subtype on disease variables (physician-rated disease severity, physician-rated disability, JAFAR-P, and illness duration; all p's > .05) or psychosocial variables (CUIS, MUIS-C, BSI, all p's > .05).

An examination of the correlation matrix indicated that there was a significant positive partial correlation between parental illness uncertainty and parental psychological distress (pr = .36, p < .01). In addition, there was a significant positive correlation between child illness uncertainty and subjective physician-reported disease severity (pr = .26, p < .05). Subjective physician-reported functional disability was also positively correlated with subjective physician-reported disease severity (pr = .60, p < .01). The parents assessment of child daily functioning (JAFAR-P) was significantly positively correlated with subjective physician-reported functional disability (pr = .35, p < .01) and physician-reported disease severity (pr = .30, p < .05). Lastly, ethnicity was significantly negatively correlated with age (pr = -.34, p <. 05).

Selection of Covariates

Demographic and disease variables were included as covariates based on theoretical rationale, preliminary findings, and findings in the extant literature (age, gender, ethnicity, physician rated functional severity, physician rated functional disability, JAFAR-P and illness duration). Disease and demographic variables were included in order to provide for a more conservative test of the hypothesized relationships among variables and to control for possible shared variance. While the relationship is not always consistent, child disease severity has been shown to impact parental health in the past, and it was thus included as a covariate in this study (e.g., Bruns et al., 2008).

Primary Analyses

Hypothesis 1: A hierarchical regression equation was constructed to test the hypothesis that parental illness uncertainty (as measured by MUIS-C) would contribute significant variance to child illness uncertainty (as measured by the CUIS). Demographic variables were entered on Step 1 and disease variables were entered on Step 2. Parental illness uncertainty (MUIS-C) was entered on Step 3. Results revealed no significant effect of MUIS-C on CUIS, $F(1, 50) = 1.04$, $p = 0.42$ (see Table 2).

Hypothesis 2: It was also anticipated that parental distress (BSI) would act as a moderator in the relationship between parental illness uncertainty (MUIS-C) and child illness uncertainty (CUIS) and contribute unique variance to CUIS, beyond the main effects of these variables. A hierarchical multiple regression equation was constructed in which demographic variables were entered on Step 1 and disease variables were entered on Step 2. Parent illness uncertainty (MUIS-C) and child illness uncertainty were then

centered to reduce multicolliniarity (Slinker, B.K., & Glantz, S., 2008). The main effects of parent psychological distress (BSI) and parental illness uncertainty (MUIS-C) were entered on Step 3. On Step 4, a Parent Distress X Parent Illness Uncertainty (BSI X MUIS-C) interaction term was entered. Results revealed no significant BSI X MUIS-C interaction (F change = 0.01, p = .48).

CHAPTER V

CONCLUSION

The present study examined the transactional nature of adjustment in children with juvenile rheumatic diseases and their parents. Two specific hypotheses were proposed: 1) parental illness uncertainty and child illness uncertainty would be significantly related to each other, and, 2) parental distress would moderate the relationship between parental and child illness uncertainty. Contrary to the hypotheses, hierarchical multiple regression analyses revealed that parental illness uncertainty was not significantly associated with child illness uncertainty after controlling for disease variables. In addition, a second hierarchical regression analyses revealed that parental distress did not function as a moderator in the parent-child illness uncertainty relationship.

It has been shown in numerous studies on child chronic illness that there is a transactional pattern of adjustment within the family of the ill child. However, results of this study were not consistent with Thompson's transaction stress and coping model of adjustment (Thompson et al., 1992). A number of possible explanations exist for such findings. First, it is possible that the current study did not have enough power to demonstrate the effect of parental uncertainty on child uncertainty. Second, it is also possible that there was not enough variability in our sample's experience of illness

uncertainty to demonstrate an impact. Lastly, it may be that in the context of JRDs, illness uncertainty is a variable that does not directly impact child illness uncertainty and that some unmeasured construct is a mediator or moderator that exists in the relationship

Although the non-significant findings do not lend support to a significant relationship between parent and child illness uncertainty the bivariate correlations did reveal a positive relationship between parent and child illness uncertainty. A post hoc power analysis conducted using G Power showed the power for the current study was .78 when using a small effect size (Faul, Erdfelder, Buchner, & Lang, 2009). It is possible that parental illness uncertainty alone does not have a large enough effect on child illness uncertainty independent of other variables. Future studies would do well to target more restricted age groups and more specific (high versus low) illness uncertainty groups.

Another possible explanation for these discrepant findings may be a function of what appears to be an average level of illness uncertainty expressed by parents ($\underline{M}$ = 69.64, $\underline{SD}$ = 14.98). The level of illness uncertainty in the current study falls within the range of parental illness uncertainty reported by parents of children with cancer ($\underline{M}$ = 80.05, $\underline{SD}$ = 14.94, Lin, Yeh, & Mishel, 2010, $\underline{M}$ = 60.20, $\underline{SD}$ = 14.50, Santacroce, 2002) and type 1 diabetes mellitus ($\underline{M}$ = 63.47, $\underline{SD}$ = 13.42, Carpentier et al., 2006). Though speculative, it is possible that higher levels of parental uncertainty are necessary in order to make a significant contribution to child illness uncertainty. However, these findings are somewhat consistent with the results from Mullins and colleagues (2007), who found that the parent's perceived child vulnerability did not predict illness uncertainty in children with Type 1 diabetes or asthma, although it was significant for adolescents. In addition, in a study on pediatric transplant recipients, Steele and colleagues (2009) found

youth-reported illness uncertainty was not significantly associated with parent-reported internalizing symptoms after controlling for both demographic factors and parent uncertainty. They did, however, find youth uncertainty was related to overall parent psychosocial functioning. Although this study examined both child and parent illness uncertainty, the impact of parent IU on child IU was not included in the analyses. Thus, research on the relationships between parent and child illness uncertainty and parent psychosocial functioning remains inconclusive, thus warranting future studies in these areas.

As demonstrated in the present study, parental illness uncertainty was significantly related to psychological distress in parents of children with JRDs. Prior studies have also supported the link between parent illness uncertainty and psychological distress. Steele and colleagues (2009) showed a significant association between increased parental illness uncertainty and parent-reported psychological distress in parents of youth recipients of liver and kidney transplantations. Additionally, a literature review by Stewart & Mishel (2000) supported the association between illness uncertainty and psychological distress in parents of children with a chronic illness (Stewart & Mishel, 2000). Importantly, Carpentier and colleagues (2006) found longitudinal psychological distress in parents of chronically ill children could be predicted by initial illness uncertainty above and beyond the variance attributed to child illness duration and initial parental psychological distress. While there is a growing body of literature on the relationship between illness uncertainty and psychological distress, further examination of uncertainty and distress in parents of children with JRDs is necessary.

Parental psychological distress, while related to parental illness uncertainty, did not act as a moderator in the relationship between parent and child uncertainty. While previous research has shown parental distress to be associated with poorer child adjustment in JRDs (Timko et al., 1992) and other chronic illnesses (e.g., Thompson, Gil, Keith, Gustafson, George, & Kinney, 1994), the results of this study suggest it may not be associated with the cognitive appraisal variable of child illness uncertainty. White and colleagues (2005) found an interaction effect of parental distress and child illness uncertainty (CUIS) which accounted for 6% of the variance between disease factors, demographics and child depression scores. Thus, it is possible that parental psychological distress may impact upon similar distress mechanisms in children but not have an impact on their cognitive experience of unclear or unpredictable illness-related events (Mishel, 1990). Further examination of the parental distress-child outcome relationship is necessary to better understand the transactional nature of the family's cognitive appraisal of chronic illness.

Strengths and Limitations

There are several strengths to the present study, including being theoretically-driven, and the use of both parent- and child-report measures of illness uncertainty. The majority of studies on child adjustment to chronic illness have used only parent report data (almost exclusively mother report). However, there are multiple weaknesses in the present study. The small sample size resulted in low power, which may have resulted in the inability to detect the effects of parental illness uncertainty and distress, and thus a type I error. Small sample size can be an inherent difficulty in conducting research with chronic illness groups and in the future a larger sample size would be beneficial.

Additionally, the results are correlational in nature and thus no causal conclusions can be made. Longitudinal research would be helpful in order to determine causality and the direction of the relationships. Lastly, the current research used a global severity index of psychological distress (BSI), a measure that has been previously utilized in assessing adjustment in parents of chronically ill children (Andrews et al., 2007; Canning, Harris, & Kelleher, 1996; Pai et al., 2006; Wagner et al., 2003; White et al., 2005). However, in the future it may be beneficial to use a measure that highlights more specific aspects of distress (e.g., depression, anxiety) to further determine any possible relationship to illness uncertainty.

Clinical Implications and Future Research

Previous research has demonstrated the effect of parental distress on child depression symptoms is enhanced when child illness uncertainty is high (White et al., 2005). Clinically, it would still seem important to address issues related to illness uncertainty as parental illness uncertainty and parental-reported psychological distress are associated in the present study. Akikusa & Allen (2002) recommend four steps to improving education about JRDs: a separate educational session, exploration of patient/family beliefs and misconceptions about JRDs, selection of the least complex treatment regimen, and careful discussion about medications. Basic education about JRDs continues to be recommended and supported by the present findings. It would be beneficial to add this educational component to treatment and compare results to a treatment as usual group. In such an experimental design, the longitudinal relationship between parental and child illness uncertainty and parental and child distress could be examined with greater control.

The current study was the first to show a significant relationship between physician-rated disease severity and child illness uncertainty. As previous research on the impact of illness severity in other chronic diseases has been mixed (Bruns et al., 2008, Frank et al., 1998, Sawyer, Whitham, Roberton, Taplin, & Varni et al., 2004, Vandvik, Hoyeraal, & Fagertun, 1989), the present finding helps elucidate the impact of this disease factor on illness uncertainty in the JRD population. Early identification of those children with severe JRDs may be helpful in reducing illness uncertainty, which has been previously associated with poorer child psychological adjustment (Hoff et al., 2002, Mullins et al., 1997, Neville, 1998). Importantly, the majority of past research has focused on educational interventions for adults and parents (e.g., Carpentier et al., 2006, Gil et al., 2006, Holm et al., 2008, Hommel et al., 2003). While it continues to remain important to address parental illness uncertainty, the present study highlights the lack of a relationship between parental and child illness uncertainty. It appears that interventions aimed at reducing parent illness uncertainty will not directly impact child illness uncertainty. Future studies should take into consideration the unique nature of child illness uncertainty and specifically target this cognitive appraisal variable.

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APPPENDICES

APPENEDIX A

TABLES

Table 1. Disease, demographic and psychosocial variables

Variables	Frequency	M	%	SD
Child's Gender				
Male	20		33%	
Female	41		67%	
Child's Ethnicity				
Caucasian	28		46%	
African American	6		10%	
Native American	16		26%	
Hispanic	6		10%	
Asian	1		1.5%	
Biracial	4		6.5%	
Child's Age (years)		14.42		(2.88)
Diagnosis				
JRA	35		58%	
Lupus	14		23%	
JAS	4		6.5%	
JDMA	7		11.5%	
Illness Duration (years)		2.12		(3.20)
PR Functional Disability		1.53		(0.65)
PF Functional Severity		3.19		(1.76)
JAFAR-P		5.09		(6.67)
BSI		1.97		(0.50)
MUIS-C		69.64		(14.98)
CUIS		68.05		(18.00)

Note. PR = Physician-rated; JAFAR-P = Juvenile Arthritis Functional Assessment Report; BSI = Brief Symptom Inventory; MUIS-C: Illness Uncertainty, parent form; CUIS: Illness Uncertainty, child form

Table 2. Zero-order correlations for Study Variables

Variables	1	2	3	4	5	6	7	8	9	10
1. Age	_									
2. Ethnicity	-.34**	_								
3. Gender	.01	.02	-							
4. Duration	.03	.04	.04	_						
5. PRFD	-.04	-.01	.02	-.03	_					
6. PRDS	-.09	.22	-.11	-.18	.60**	_				
7. JAFAR-P	.04	-.16	.09	.07	.35**	.30*	-			
8. BSI	.25	-.09	.06	.05	-.03	.07	.31*	-		
9. CUIS	.03	.05	-.05	-.22	.01	.26*	.03	-.07	_	
10. MUIS-C	.11	.12	.12	-.22	-.22	-.00	.13	.36**	.18	_

PRDS = Physician-rated disease severity; JAFAR-C = Juvenile Arthritis Functional Assessment Report-Parent Form; PRFD = Physician-rated functional disability; Duration = Illness duration (in years); BSI = Brief Symptom Inventory; MUIS-C = Illness Uncertainty, parent form; CUIS: Illness Uncertainty, child form. Partial correlations, controlling for PRDS, JAFAR-P, PRFD, Duration, appear above the diagonal (in parentheses). *$p < .05$. **$p < .01$.

Table 3. Hierarchical Regression Analyses of Children's Illness Uncertainty (CUIS)

Step	Variable	β	t for within-step predictors	R^2 Change for step	Cumulative R^2	F Change for step
1	Gender	-.05	-.05	.01	.01	.15
	Age	.06	.06			
	Ethnicity	.08	.08			
2	PRDS	.37	2.02	.12	.13	1.17
	JAFAR-P	-.01	.05			
	PRFD	-.22	-1.28			
	Duration	-.16	-1.01			
3	MUIS-C	.04	.15	.01	.14	.40
	BSI	.10	.40			
4	BSI X MUIS-C	-.76	-.71	.01	.15	.51

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

APPENDIX B

INSTITUTIONAL REVIEW BOARD FORM

Oklahoma State University
Institutional Review Board

Protocol Expires: 1/21/03

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

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

Principal Investigator(s) :

Janelle Wagner
407 N. Murray
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John Chaney
407 N Murray
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Reviewed and Expedited (Spec Pop) **Continuation**

Approval Status Recommended by Reviewer(s) : Approved

Signature: Carol Olson

Carol Olson, Director of University Research Complian

Tuesday, January 22, 2002
Date

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

APPENDIX C

CONSENT FORM

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

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

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

COST: There are no costs to your child for participating in this study.

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

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

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

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

SUBJECT ASSURANCES: Any data collected as part of my child's participation in this experiment will be treated as confidential and will received a code number so that they will remain confidential. In no case will any use be made of these data other than as research results. If data from my child's participation is ever displayed, my child's identity will remain confidential.
I may contact Dr. John M. Chaney, Oklahoma State University, Psychology Department, 215 North Murray Hall, Stillwater, Oklahoma 74078, at (405) 744-5703 should I wish further information about the research. I may also contact the Institutional Review Board (IRB) executive assistant, Sharon Bacher, Oklahoma State University, 203 Whitehurst, Stillwater, Oklahoma 74078, (405) 744-5700. Should any problems arise during the course of the study I may take them to Dr. Maureen Sullivan, Psychological Department Head, Oklahoma State University, Department of Psychology, 215 North Murray Hall, Stillwater, Oklahoma, 74078, at (405) 744-6027.

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

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

Signed:_____
(Signature of participant's parent/legal guardian)

Witness(es) if required: _____

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

Signed_____
(Project director or his/her authorized representative)

APPENDIX D

ASSENT FORM

Assent Form

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

Signed: _____
(Signature of participant)

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

Witness(es) if required: _____

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

Signed: _____

APPENDIX E

PROVIDER QUESTIONNAIRE

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?

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

7. Compared to the 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, & avocational)	Able to perform usual self-care and vocational activities, but limited in avocational	Able to perform usual self-care activities, but limited in avocational activities	Limited ability to perform usual self-care, vocational and avocational activities

APPENDIX F

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 educational attained: 1 Elementary School
2 Middle School
3 High School
4 Some College; Specify number of years:_____

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

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

7. Parent's Highest level of education:

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

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

9. Are you currently taking any psychoactive medication (e.g., antidepressants, anti-anxiety)?
Yes No
1 2

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

VITA

Ashley Nicole Junghans

Candidate for the Degree of

Master of Science

Thesis: THE RELATIONSHIP BETWEEN PARENTAL ILLNESS UNCERTAINTY AND PARENTAL DISTRESS IN THE JUVENILE RHEUMATIC DISEASES

Major Field: Clinical Psychology

Biographical:

Education: Graduated from Breck School in Golden Valley, Minnesota in June, 2001; received Bachelor of Arts in Psychology from DePaul University, Chicago, Illinois in December 2005.Completed the requirements for Master of Science degree in Psychology from Oklahoma State University, Stillwater, Oklahoma in December 2005.

Experience: Research assistant, Department of Psychology, Youth Tobacco Access Project, DePaul University, Chicago, IL, Supervisor: Leonard A. Jason, Ph.D.; Research assistant, Department of Psychology, Clinical Neuropsychology Lab, Oklahoma State University, Stillwater, OK, Supervisor: Jared P. Dempsey, Ph.D.; Research assistant, Department of Psychology, Pediatric Psychology Lab, Oklahoma State University, Stillwater, OK, Supervisor: Larry L. Mullins, Ph.D.

Professional Memberships: American Psychological Association (APA), American Psychological Association of Graduate Students, APA Division 54: Society of Pediatric Psychology, APA Division 52: International Psychology, APA Division 8: Society for Personality and Social Psychology, Society for Psychophysiological Research, Psi Chi National Honor Society.

Name: Ashley Nicole Junghans Date of Degree: December, 2010

Institution: Oklahoma State University Location: Stillwater, Oklahoma

Title of Study: THE RELATIONSHIP BETWEEN PARENTAL ILLNESS UNCERTAINTY, CHILD ILLNESS UNCERTAINTY AND PARENTAL DISTRESS IN THE JUVENILE RHEUMATIC DISEASES

Pages in Study: 78 Candidate for the Degree of Master of Science

Major Field: Clinical Psychology

Scope and Method of Study: The present study attempted to examine the relationship between parent and child illness uncertainty, as well as the possible moderating variable of parental distress, in families with juvenile rheumatic diseases (JRD). Participants were 61(41 females; 20 males) children and adolescents between the ages of nine and 21 (M = 14.42; SD = 2.88) and their parents. Participants were recruited through the Pediatric Rheumatology Clinic at the University of Oklahoma Health Sciences Center in Oklahoma City, Oklahoma. The pediatric rheumatologist completed a Provider Questionnaire which included information regarding diagnosis duration, severity, and functional ability. Parents completed a background information questionnaire, the Brief Symptom Inventory (BSI, Derogatis & Melisaratos, 1983) and the Mishel Uncertainty in Illness Scale – Community Form (MUIS-C, Mishel & Braden, 1988). Children completed the Children's Uncertainty in Illness Scale (CUIS, Mullins & Hartman, 1995).

Findings and Conclusions: Results of the present study showed parental illness uncertainty was not related to child illness uncertainty. Additionally, while parental distress was related to parent illness uncertainty, it was not related to child illness uncertainty. Importantly, physician-rated illness severity was associated with child illness uncertainty. These findings suggest the need to examine different models for child illness uncertainty and parent illness uncertainty in JRDs, as no relationship was found between the two. Additionally, because child illness uncertainty was related to illness severity, clinical interventions should focus on providing educational interventions for children, as well as parents, especially those children with severe JRDs.

ADVISER'S APPROVAL: Dr. Larry L. Mullins