DIFFERENTIAL EFFECT OF ILLNESS INTRUSIVENESS ON ADJUSTMENT AMONG NATIVE AND CAUCASIAN PARENTS OF CHILDREN WITH JUVENILE RHEUMATIC DISEASE

By

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CHAPTER 1

INTRODUCTION

Juvenile rheumatic diseases (JRD) are one of the more common chronic illnesses of childhood. Currently, 65,000-70,000 children are affected by juvenile rheumatoid arthritis (JRA; Lovell, 1997); that diagnosis alone affects as many children as does juvenile diabetes (Cassidy & Petty, 2001). Within this group, there are three subtypes reflecting the level of joint involvement—pauciarticular, polyarticular, and systemic. Among the general population, the pauciarticular subtype is most prevalent (Lovell, 1997). However, JRA comprises only around half of JRD cases; systemic lupus erythematosus (SLE), juvenile dermatomyositis (JDM), and juvenile spondyloarthropathies (JSA) represent the majority of the remaining, though less common, JRD diagnoses. Although differences in presentation exist between the various diagnoses, they are characterized by a variety of similar symptoms, including connective tissue inflammation, pain, restricted ability, and a chronic course (Vandvik & Hoyeraal, 1993).

The vast majority of research on children with JRD has focused on Caucasian populations and largely ignores ethnic minority groups, particularly Native Americans. Further, although evidence suggests that symptomatology and other clinical outcomes vary across ethnic groups, ethnic group membership itself may not be responsible for these differences. Within Native American populations, for example, disease subtype,

residence, access to appropriate health care, and living conditions appear to have higher predictive value in determining clinical outcomes (Oen et al., 2003). The importance of research focusing on Native populations is highlighted by the prevalence of rheumatic disease among Native people. For example, among the Chippewa and Blackfeet tribes, prevalence rates of adult rheumatoid arthritis are five times the rate observed in Caucasian populations (Peschken & Esdaile, 1999). It is also important to note that in addition to higher prevalence rates, the various subtypes of rheumatic disease are distributed differently among Native people. Whereas pauciarticular JRA is more common among Caucasian groups, polyarticular is the most common disease subtype among Native children. Further, one particular subtype of juvenile spondyloarthropathy (JSA) is also seen more frequently in Native children than in the general population (Oen & Cheang, 1996). Research examining the physical manifestations of JRD in Native children is limited—however, even fewer studies exist that examine psychological outcomes for Native American children with JRD and their parents.

Across the diagnoses encompassed by JRD, psychological maladjustment among children has been researched extensively, perhaps due to the highly variable and pervasive nature of these diseases and their treatment. Although considerable research has focused on child adjustment to chronic illness, parental adjustment is equally important. Thompson et al. (1993 a, b) have highlighted the complex interplay between parental distress and child maladjustment in pediatric chronically ill populations. In addition to affecting children's psychological adjustment, parent distress can lead to poorer physical outcomes indirectly by influencing treatment compliance (Chaney & Peterson, 1989). Indeed, parent distress appears to be a more important determinant of

child maladjustment and future outcomes than disease factors (Chaney et al., 1997; Frank et al., 1998). Similarly, disease severity is less important in predicting parent distress than subjective ratings of illness by the parent. These subjective ratings are particularly salient when they are tied to parents' perceptions of their role as care provider (Walker, Ford & Donald, 1987).

Further, nearly two-thirds of parents of children with JRD report moderate to severe familial difficulties such as conflict and a lack of sufficient support (Vandvik, Hoyerhaal & Fagertun, 1989). Similar results have been found in longitudinal studies (i.e., Kupst & Schulman, 1988; Wallander et al., 1989), where disease variables were significantly poorer predictors of parental difficulties than level of social support, marital difficulties, and other environmental variables. These effects appear to be more pronounced in mothers than fathers. For example, a study of parents of children diagnosed with cystic fibrosis found that fathers' distress levels were similar to those of the general population, whereas mothers' distress levels were significantly higher (Nagy & Ungerer, 1990). Other studies (e.g., Dahlquist et al., 1993), however, found elevated symptoms of anxiety for both mothers and fathers. Regardless, parents of chronically ill children generally report more emotional distress than parents of healthy children.

Parental adjustment is not only deeply tied to child outcomes, but clearly constitutes an important area of investigation apart from child adjustment issues. Similar to child adjustment to illness, parental adjustment is likewise highly variable and determined by a host of variables, including both disease and demographic parameters. Indeed, Manuel et al. (2001) have pointed out that parents of chronically ill children face a host of stressors that involve both illness-specific and illness-unrelated challenges. To

further complicate matters, stressors can also comprise factors related to ethnic or racial minority status.

Interestingly, although major theoretical models of adjustment to illness (e.g., Wallander et al., 1989; Thompson et al., 1994) include variables such as demographic and socio-ecological factors, relatively few studies have examined the influence of racial minority status on parental adjustment in pediatric chronic illness. This lack of relevant research is somewhat surprising in light of recent theoretical models that consider racial minority status as a specific vulnerability factor for experiencing increased stress and illness (Clark et al., 1999).

Although the precise mechanisms by which racial minority status leads to increased stress are unclear, there are a host of potential sources. Racial minority status may be directly related to stress as a result of discrimination, prejudice, negative stereotypes, and acculturation pressures (Contrada et al., 2000; Franklin & Boyd-Franklin, 2000; Robinson-Zanartu, 1996; Schulz, Israel, Williams, Parker & Becker, 2000). Alternatively, racial minority status may be an indirect source of stress through structural barriers that prevent minority group members from obtaining available resources including access to quality health care (Yeates et al., 2002). Indeed, parents of children with JRD who have less access to key resources report increased stress and symptoms of depression (Timko, Stovel, & Moos, 1992). It is important to point out that the bulk of the data suggest that the link between racial minority status and outcomes is largely independent of socioeconomic status (e.g., Gibbons, Gerrard, Cleveland, Wills & Brady, 2004).

Despite the importance of child illness parameters and socio-demographic variables in parent adjustment to pediatric illness, these variables account for a small portion of the variance in parent psychological adjustment (Chaney et al., 1997). Much like child adjustment to illness, parent adjustment is presumed to be multi-determined by a host of variables, including cognitive appraisal processes. Except for a few studies (e.g., Lustig, Ireys, Sills & Walsh, 1996), cognitive appraisals have been largely overlooked in investigations of parent adjustment to childhood chronic illness.

Because of the significant level of physical impairment and lifestyle disruptions associated with JRD, one cognitive appraisal variable that appears particularly relevant to parent adjustment in JRD is *illness intrusiveness*. Briefly, illness intrusiveness is conceptualized as a generalized cognitive schema representing perceived "illness-induced barriers" across a wide array of life domains (Devins et al., 1983-84; p. 329). Illness intrusiveness is related to perceived disability, but it is considered conceptually distinct. To illustrate, perceived disability as it is traditionally assessed in the rheumatic diseases represents the degree to which routine activities of daily living such as walking, dressing, etc., are restricted. Illness intrusiveness captures the extent to which perceived illness restrictions (including but not limited to disability) preclude involvement in and/or access to disease-unrelated activities (e.g., family activities, social relationships, leisure activities). Illness intrusiveness theory suggests that the resulting decrease in rewarding activities is largely responsible for adjustment difficulties.

Because JRD often involve a significant decrease in children's activity levels (Henderson et al., 1995), the role of parents' perceptions of interference with routine activities due to illness may take on particular importance. Although there are no known

studies documenting the relationship between parents' perceived intrusiveness of their child's illness and parent adjustment, there is evidence in the adult and child rheumatic literature suggesting the salience of illness intrusiveness in the adjustment process. For example, research on adults with rheumatoid arthritis (RA) indicates that the extent to which individuals perceive their own illness as interfering with disease-unrelated activities is associated with significant increases in depressive symptoms and decreased overall quality of life (Devins et al., 1992). Importantly, these associations were more relevant for younger individuals with RA, which may indicate that the effects of lifestyle disruptions due to illness may be more pronounced when they are inconsistent with normal developmental expectation regarding reductions in activity level. This would certainly have implications for youth with JRD and their parents. Indeed, high levels of child-reported illness intrusiveness have been shown to increase the effect of parent distress on child depression (Wagner et al., 2003). However, extant literature has failed to examine the extent to which parental global distress is influenced by parent perceptions of the intrusiveness of their child's illness.

Although research on how that relationship might play out differently across ethnic groups is quite limited, increased lifestyle disruptions in illness-unrelated areas of functioning have been observed for Native American children. Andrews et al. (2004) found that Native children with JRD missed significantly more days of school compared to a Caucasian cohort, thus suggesting that the degree of illness-induced disruptions (i.e., illness intrusiveness) may be particularly relevant for ethnic minority families. This study, however, did not address parents' perceptions of these daily disruptions or any subsequent parental distress.

The present study attempts to address these limitations in the extant literature by examining the potentially different patterns in the association between illness intrusiveness and global distress among parents of Native American and Caucasian children with JRD. To fulfill this aim, a review of the current literature in the area is presented. This review will encompass a discussion of the factors affecting the distress of parents of children who have been diagnosed with a JRD; this includes cognitive, disease and treatment variables. Finally, a study is described that examines the illness intrusiveness-parental distress relationship among both Caucasian and Native American parents of children and adolescents diagnosed with a JRD. In other words, the potential moderating role of ethnicity on the illness intrusiveness-parental distress relationship is examined. More specifically, it is hypothesized that the illness intrusiveness-parent distress relationship will be significant for both ethnic groups. However, for parents of Native American children with JRD, this association will be significantly greater compared to the Caucasian group.

CHAPTER II

REVIEW OF THE LITERATURE

Medical and Clinical Issues in JRD

Issues Associated with Diagnosis

The Juvenile Rheumatic Diseases (JRD) consist of juvenile rheumatoid arthritis (JRA), systemic lupus erythematosus (SLE), juvenile spondyloarthropathies, and juvenile dermatomyositis (JDMA), and are a series of autoimmune disorders characterized by a highly similar presentation. These symptoms, including connective tissue inflammation, pain, restricted ability, and a chronic course (Vandvik & Hoyeraal, 1993), make differential diagnosis difficult. Unfamiliarity on the part of medical staff often results in delays in both treatment and referrals to specialists, which are associated with poorer long-term outcomes. Further compounding this problem, even for specialists, JRD are highly unpredictable and unstable—symptoms that suggest a diagnosis of JRA immediately after symptom onset may later be more congruent with another rheumatic diagnosis once more specific disease markers appear (Cassidy & Petty, 2001). Thus, attaining an accurate diagnosis may really be due to a process of elimination (Vandvik & Hoyeraal, 1993; Cassidy & Petty, 1990), concluding far after the onset of significant symptoms; even then, misdiagnosis is common. This seems to be especially true for JRA, where 22% of diagnosed children received a replacement diagnosis within ten years (Flato, Aasland, Vinje & Forre, 1998). Even after obtaining an accurate diagnosis and treatment plan, symptoms may persist and even worsen despite parents' best efforts to the contrary (Young, 1992). Thus, the process of diagnosis and eventual treatment is frequently highly distressing for parents of children diagnosed with a JRD.

Disease Subtypes

Juvenile rheumatoid arthritis (JRA) is the most commonly diagnosed JRD, and ranks as one of more prevalent chronic childhood illnesses. Distinctive characteristics of JRA include persistent inflammation of joints, restricted functional ability, and pain (Lovell, 1997). Growth is commonly delayed across the disease course, and is due to either corticosteriod use or the presence of progressive symptomatology. Normal development can be anticipated during periods of remission; however, permanent delay in growth and development of secondary characteristics may be seen. Regardless of disease severity and growth delays, some atrophy of the muscles around affected joints is common (Cassidy & Petty, 2001). Generally, onset of inflammatory symptoms occurs prior to age 16 (Kewman, Warschausky, & Engel, 1995), with increases in prevalence at ages 2, 8, and 12 (Cassidy & Petty, 2001), thus illustrating the potential damage to a child's growth. In addition, JRA is more common in girls than boys; however, incidence by gender and age is different for the pauciarticular, polyarticular, and systemic subtypes (Lovell, 1997).

Pauciarticular JRA consists of involvement in fewer than five joints and is the most common subtype among the general population. Occurring in up to 50% of children with JRA (Lovell, 1997), onset is typically before age 10. Gender differences are prominent, as with many rheumatoid diagnoses, with boys affected five times more than girls (Kewman et al., 1995). Large joints are most frequently affected irrespective of gender; knee involvement is most common among children with only one arthritic joint (Lovell, 1997). Arthritis is typically the only disease manifestation—growth retardation,

subcutaneous nodules (painless nodules often on the heel or elbow) and cardiac involvement are usually absent for this subtype (Cassidy & Petty, 2001).

The next most common subtype, polyarticular JRA, is present in approximately 40% of children diagnosed with JRA. Consisting of arthritis in at least five joints, most children have over 20 joints involved, and 75% of these children show symmetric involvement. Early symptoms often include weight loss or failure to make expected gains, low-grade fever, anemia, and growth retardation. Onset is not age-specific, but is three times as common among girls as among boys (Lovell, 1997). Later onset, however, is associated with a more adult symptom pattern of rheumatoid arthritis among rheumatoid factor seropositive girls (Cassidy & Petty, 2001). In addition to the presence of subcutaneous nodules, this late onset is usually indicative of a poor disease course consisting of progressive and deforming disease activity (Calabro, Marchesano & Parrino, 1989).

The onset of systemic JRA is independent of both age and gender, and affects around 10% of children with JRA. This subtype is characterized by attacks of spiked fevers and pink rashes late in the day. These attacks are highly unpredictable, both in onset and in length; half of the children diagnosed with systemic arthritis will have more than one attack. During a remission of these classic systemic symptoms, half of the diagnosed children show symptoms of severe arthritis as well (Lovell, 1997). Complications in severe cases commonly include lymphatic, cardiac, liver, and spleen involvement, as well as uveitis (Cassidy & Petty, 2001).

The other diagnoses contained under the JRD umbrella, although intrinsically different than JRA, frequently contain an arthritic component, thus complicating

diagnosis. Systemic lupus erythematosus (SLE) involves abnormal production of antibodies to components of cell nuclei, which causes inflammation, blood vessel abnormalities, and immune changes. It is characterized by a butterfly rash, arthritis, and arthralgias. Unlike JRA, however, arthritis in children with SLE does not destroy the affected bone (Lehman, 1997). Onset primarily occurs in adolescence (Cassidy & Petty, 2001), with girls accounting for more diagnoses by a ratio of 4 to 3.1. Additional symptoms may include nephritis, diffuse tissue lesions, photosensitivity, fever and lymphadenopathy (Lehman, 1997). In more severe cases, complications may include cardiac, gastrointestinal, renal, and vascular difficulties (Cassidy & Petty, 2001), and significant nervous system involvement is present in 19% to 36% of children diagnosed with SLE. Although uncommon, fatalities among SLE patients are usually due to renal failure or general infection (Lehman, 1997).

The juvenile spondylarthropathies are a class of diagnoses, with juvenile ankylosing spondylitis (JAS) as the most common subtype. JAS occurs more often in boys than girls, with onset in late childhood or adolescence (Cassidy & Petty, 2001). Characteristic, although nonspecific, symptoms include large joint arthritis, with asymmetry in the lower extremities. JAS is present in 10% of children with arthritis; common symptoms include back pain and stiffness. Onset typically involves the spine, with peripheral arthritis frequently following—the hips are most often affected. Peripheral involvement extends to polyarticular arthritis in 25% of patients (Lovell, 1997). Although JAS follows a highly unpredictable course of remissions and flares, prognosis is usually good; however, if complications arise, they are typically of cardiac or gastrointestinal nature (Khan, 1993).

Juvenile dermatomyositis (JDMA) is a disease of the connective tissues characterized by diffuse vasculitis. Affected areas may include the skin, muscle, and gastrointestinal system. Initial symptoms frequently consist of tenderness, fever and a rash on the eyelids, as well as muscle weakness. Additionally, one-fifth of children diagnosed with JDMA have arthritic symptoms, and cardiac symptoms leading to myocarditis are not uncommon. Onset is most frequent among girls from ages five to fourteen, and appears to be precipitated by genetics and infections (Lehman, 1997).

Long-term Prognosis

JRD are, by their very nature, chronic diseases with potential symptoms and effects lasting into adulthood. Adults previously diagnosed with JRA show greater mortality compared with the population at large, as well as increased limitations to their functioning such as pain, and energy level. In addition to these general health issues, 65.9% reported current arthritic symptoms (Peterson et al., 1997). Perhaps illustrating the unpredictable nature of JRD, however, over half of patients with JRA were in remission a decade later (Flato, Aasland, Vinje & Forre, 1998). Fatalities due to JRA are fortunately rare, and are usually due to cardiac or renal complications. Mortality rates are from 2-4% (Cassidy & Petty, 2001), and are mostly among children diagnosed with systemic arthritis (Petty, 1999). These data are encouraging; however, there is no way to predict specific outcome for children diagnosed with a JRD, as the course is so unreliable (Vandvik & Hoyeraal, 1993).

Ethnicity and Clinical Presentation

The vast majority of research on the clinical presentation, prevalence and potential biological markers of JRD primarily focuses on Caucasian children; however, it

appears that differences in symptomatology are present between ethnic groups. Research on minority children is extremely limited, however, and is mostly restricted to JRA rather than JRD as a whole. With respect to prevalence, ethnic differences are not present for JRA. However, the proportion of Native American children diagnosed with polyarticular JRA is significantly higher than among Caucasian children, and the proportion of children diagnosed with pauciarticular arthritis is significantly lower. These studies found that race (defined as Native American, East Indian, Caucasian, or other) explained nearly half of the variability in the proportion of patients with these particular onset types; there were no differences found for systemic JRA (Oen & Cheang, 1996).

Native Americans with juvenile or adult rheumatic disease cannot be viewed as a homogenous group, however, due to significant tribal and group differences in clinical presentation. When researching rheumatic disease, common subtypes are dramatically different by tribal group. For example, the most prominent expression of RD among the Choctaw is scleroderma, whereas among the Kiowa, RA is the most common RD diagnosis (Scofield, Fogle, Rhoades & Harley, 1996; Arnett et al., 1996). Prevalence rates for RA range from five times as high to approximately the same among Caucasian populations in North America (Peschken & Esdaile, 1999).

With respect to Native Americans in Oklahoma, mean annual incidence of RA is approximately 4/100,000—this is low in comparison to other Indian Health Services areas (Acers & Acers-Wam, 1994). This group primarily includes Cherokee, Creek, Choctaw, Chickasaw, Seminole, Kiowa, Shawnee, Comanche, and Osage individuals. Thus, the presentation of JRD and RD is radically different depending on geographical

location and variance in tribal affiliation; however, genetic markers are likely responsible for the prevalence of rheumatoid disease in Native Americans across the United States.

Interest in the genetic markers associated with RD largely focuses on human leukocyte antigen (HLA-DR) genes and their myriad subtypes, which are located in the major histocompatibility complex (MHC; Firestein, 2003). The susceptibility epitope sequence is an amino acid chain found in multiple subtypes that may help the HLA-DR gene to bind peptides with arthritogenic properties. These subtypes, especially when the patient is homozygous, increase the risk of systemic and progressive symptoms reflective of a severe disease course (Weyand, Hicok, Conn & Goronzy, 1992).

Additionally, HLA-DR may help to initiate a poor immune response to disease activity, by failing to bind peptides that are arthritogenic pathogens (Zanelli, Breedveld & de Vries, 2000). According to Weyand et al., the HLA genes may help to isolate a highly heterogeneous disease population into homogenous subsets; the vast majority of these will likely be based on race. This is illustrated by the high prevalence of the susceptibility epitope among Native Americans both diagnosed and undiagnosed with a RD, especially the Chippewa and other Native American groups (including all major Oklahoma tribal groups; see Peschken & Esdaile, 1999, for a review).

Issues Associated with Treatment

Pharmacological treatment among children with JRD is highly similar to adult RD, although careful attention to side effects is necessary. This is the most prevalent and efficient method of treating JRD, although physical therapy, maintaining a normal activity level, and symptom management techniques such as the use of electric blankets to decrease morning stiffness may be helpful (Rhodes, 1991). Use of non-steroidal anti-

inflammatory medications such as aspirin, ibuprofen, tolmentin, naproxen, and fenoprofen is common, effective, and well tolerated. These medications are popular in part because of the speed of their effect—most children show symptom reduction within a month. Use of aspirin is declining, however, due to the risk of severe disease complications such as Reye's syndrome. If this inexpensive option does not reduce symptoms, such as with more severe cases of polyarticular or systemic arthritis, intramuscular gold therapy or corticosteroids such as prednisone may be used. Oral administration of corticosteroids results in fewer side effects, as frequent injections can damage cartilage within the joint. Treatment options outside of the NSAIDS are problematic, not only because of the severity of their side effects, but also because symptoms are reduced slowly—methotrexate, for example, takes 3-6 months to achieve its maximum effectiveness. As such, these drugs are primarily used with children diagnosed with severe polyarticular or systemic arthritis (Lovell, 1997).

Socio-emotional Issues in Pediatric Chronic Illness

Parent Adjustment

Although considerable research has focused on child adjustment to chronic illness, parental adjustment is equally important. Thompson et al. (1993 a, b) have highlighted the complex interplay between parental distress and subsequent child maladjustment among chronically ill children. Cross-sectional (Daniels, Moos, Billings & Miller, 1987) as well as longitudinal (Timko, Stovel & Moos, 1992a; Timko, Stovel & Moos, 1992b; Timko, Baumgartner, Moos & Miller, 1993) results based in JRD populations highlight the lasting importance of parent variables in determining child adjustment. Indeed, parent distress actually seems to be a more important determinant of

child maladjustment and psychosocial outcomes than disease-related variables, especially for mothers (e.g., Chaney, Mullins, Frank, Peterson, Mace, Kashani & Goldstein, 1997; Frank et al., 1998). Likewise, objective disease severity is less important in predicting parents' distress than subjective ratings of illness severity by the parent, particularly when parents perceive their child's illness as negatively influencing their ability to parent (Walker, Ford & Donald, 1987).

Compared to research on children's adjustment to illness, far less research has been conducted examining parents' adjustment to their child's illness. The data that do exist suggest that, in general, parents of children diagnosed with chronic illnesses are at greater risk for a host of psychological difficulties compared to the general population. For example, Timko, Stovel & Moos (1992a) found that among a sample of 165 children diagnosed with JRD and their parents, levels of depression, drinking problems, and negative life events remained stable over a period of one year.

Further, Landolt et al. (2002) examined adjustment in a sample of parents of 38 children diagnosed with Type 1 diabetes. Half of mothers and 40% of fathers displayed clinical or subclinical symptoms of posttraumatic stress; nearly 25% of parents displayed symptoms that met full DSM-IV criteria for Posttraumatic Stress Disorder. Additionally, Dahlquist et al. (1993) found that, among 134 parents of children recently diagnosed with cancer, 25% of mothers and 28% of fathers reported significant marital distress, which was predicted by general emotional distress, anxiety, and maladaptive coping mechanisms.

Similarly, Chaney et al. (1997) found that 50% of fathers and 33% of mothers demonstrated significant adjustment difficulties in a sample of 48 children diagnosed

with Type 1 diabetes and their parents. These levels of distress remained consistent over a one-year period; indeed, only 25% of both mothers and fathers demonstrated changes in psychological symptoms as measured by the SCL-90-R.

Further, Thompson et al. (1994) found that in two longitudinal studies of mothers of children diagnosed with sickle cell disease or cystic fibrosis, a moderate level of maternal distress was found in both samples. Further, both studies found moderate stability in maternal adjustment over time. The first study, with a sample of 57 mothers of children diagnosed with cystic fibrosis, found that the rate of poor maternal adjustment decreased between time 1 and time 2. However, those mothers with stable poor adjustment reported more daily stress and familial conflict than the other mothers in the sample. The second study, with a sample of 60 mothers of children diagnosed with sickle cell disease, also found that the amount of poor maternal adjustment decreased over time. Further, those mothers also reported more daily stress, but also reported higher levels of illness-related stressors and lower levels of family support.

More recently, Sloper et al. (2000) found that, among a sample of 68 mothers and 58 fathers of children diagnosed with cancer, significant levels of distress were present for both parents over time. Variables predictive of parental distress differed by gender, however, with mothers being influenced by appraisals of illness-related strain, family cohesion, and coping strategies. Although fathers' distress was similarly influenced by these appraisals, cohesion, employment concerns and frequency of hospital admission variables were also important determinants of fathers' distress.

In addition to differences in adjustment between parents of chronically ill and healthy children, multiple studies have found significant differences between mothers and

fathers (e.g., Chaney et al., 1997). For example, Timko, Stovel & Moos (1992b) found that levels of depressive symptoms among the parents of 111 children diagnosed with JRD were significantly higher for mothers than for fathers over time; however, the same stress and coping factors were important for both. These variables included family resources, family dysfunction, and illness-related coping.

In another study, Bristol et al. (1988), found that mothers of developmentally disabled sons reported more familial difficulties and symptoms of depression than fathers; this finding extended to control families with a non-disabled child. In a more recent example, Nagy and Ungerer (1990) found that, among 37 sets of parents of children diagnosed with cystic fibrosis, fathers' distress levels were similar to those of the general population, whereas mothers' distress levels were significantly higher—a common finding. In this study, paternal support buffered mothers from illness-related stress.

Although the majority of studies have found poorer adjustment for parents, multiple studies have found that parents of chronically ill children do not report added signs of distress beyond those seen in the general population. For example, Cadman, Rosenbaum, Boyle, and Offord (1991) found that among a sample of 1869 households, parents of chronically ill children experienced small elevations in symptoms such as negative maternal affect. Overall, however, there were no significant differences between parents of chronically ill and healthy children. Similarly, in a sample of parents of 64 children diagnosed with JRA, Gerhardt et al. (2003) found no differences in distress between these families and matched controls. Daltroy et al. (1992) also found comparable distress levels for mothers of 102 children diagnosed with arthritis and those

seen among the general population. Further, depressed mood scores for the Daltroy et al. sample were significantly lower than normative data for psychiatric outpatients.

Despite a few exceptions (e.g., Cadman et al., 1991; Gerhardt et al., 2003), it is apparent that parents of children diagnosed with a chronic illness are generally at an increased risk for psychological difficulties; however, there appear to be extenuating factors that increase or decrease the potential for emotional and adjustment problems. Thus, adjustment difficulties do not seem to be inevitable, but instead seem to be related to a number of evaluative variables, such as perceived stress, illness impact, and other cognitive factors (e.g., Sharpe, Brown, Thompson & Eckman, 1994).

Factors Affecting Parent Adjustment

Cognitive Appraisals. Many studies have found that a variety of cognitive appraisal variables are key determinants of adjustment for parents of chronically ill children. For example, in a sample of 53 mothers of children ages two to eleven diagnosed with JRA, Lustig, Ireys, Sills, and Walsh (1996) found that both biological and functional severity aspects of the disease contributed to the mothers' level of distress. Importantly, however, the effects of disease variables on maternal distress were not direct, and were partially mediated by maternal appraisals of the extent to which the child's illness impacted the functioning of the family as a whole. In other words, despite the direct effects of child illness on maternal adjustment, this relationship was mediated by the perceived impact of the illness.

The influence of maternal appraisals extends to perceived level of stress. For example, Thompson et al. (1994) found that, among two longitudinal samples totaling 117 mothers of children diagnosed with either cystic fibrosis or sickle cell disease, ratings

of daily stress differentiated mothers with varying levels of adjustment. Independent of initial maternal adjustment as measured by the Symptom Checklist 90-Revised (SCL-90-R; Derogatis, 1983), maternal levels of daily stress were predictive of maternal adjustment at the one-year follow-up. Additionally, mothers demonstrating poorer adjustment also endorsed greater levels of illness-related stress.

Further, Manuel (2001) found that, among a sample of 92 mothers of children diagnosed with JRA, mothers' perceived control (as measured by the Multidimensional Health Locus of Control Scale; Wallston, Wallston, & Devellis, 1978) over their child's illness was associated with lower parent distress. This relationship remained significant even when illness-related stress was high. Thus, appraisal style acted as a moderator between stress and psychological symptomatology. Similarly, Sloper (2000) found that, among a sample of 68 mothers and 58 fathers of children diagnosed with cancer, both subjective appraisals of the child's illness and their perceived ability to handle associated stressors (as described by Thompson et al., 1992) were predictive of parent distress.

These studies suggest that, much like child adjustment to illness, parent adjustment is regulated in a complex manner—this includes child, demographic, family, and other systemic variables, including the parents' cognitive appraisal processes. Despite this, research on parents' cognitions in response to their child's illness is relatively scarce.

Illness Intrusiveness. Because of the significant level of physical impairment and subsequent limitations that frequently accompany a JRD diagnosis (Henderson et al., 1995), one cognitive appraisal variable that seems to be particularly salient to parents of children diagnosed with a JRD is *illness intrusiveness*. On the surface, illness

intrusiveness appears to be highly similar to perceived disability due to illness. Devins et al. (1983) state that although illness intrusiveness includes perceived disability due to illness, illness intrusiveness represents a broader concept that attempts to capture perceptions of the extent to which participating in daily, non-disease related activities such as church and school attendance are restricted due to the disease and its effects. This is illustrated by Devins and colleagues' characterization of illness intrusiveness as consisting of wide-ranging and generalized "illness-induced barriers" (1983, p. 329).

These barriers are hypothetically linked to increased maladjustment and depressive symptoms both by reducing positive, reinforcing experiences, and by decreasing perceived control over important personal outcomes (Devins, Edworthy, Guthrie, & Martin, 1992). Thus, it is not the disease itself that determines the intrusiveness of the illness; rather, it is the individual's subjective appraisal of how the disease interferes with the person's life across multiple domains that constitutes illness intrusiveness and subsequent distress (Devins, Seland, Klein, Edworthy, & Saary, 1993).

Indeed, among a sample of 78 adults diagnosed with multiple sclerosis, Mullins et al. (2001) found that illness intrusiveness related to illness outcomes exerted an effect on adjustment (as measured by the SCL-90-R; Derogatis, 1993). This effect was found to be independent of physical difficulties, as well as demographic variables. Further, the relationship between illness intrusiveness and adjustment was mediated by illness-related uncertainty.

Further, Franche et al. (2004) found that, among a sample of 81 men and 67 women who had experienced a cardiac event, depression as assessed during the initial hospitalization predicted illness intrusiveness one year later. These results were

influenced by perceived social support. Thus, illness intrusiveness and depressive symptoms influence each other over time within the patient's social and emotional context.

In addition to its direct influence on distress, illness intrusiveness also has indirect effects in combination with patients' perceived psychosocial resources and other cognitive variables. For example, Devins, Stam, and Koopmans (1994) found that among a sample of 51 cancer patients who had recently undergone a laryngectomy, the combined influence of illness intrusiveness and perceived stigma associated with the illness had a significant effect on psychosocial well being. More specifically, highly stigmatized self-perceptions enhanced the impact of illness intrusiveness on maladjustment. Further, among a sample of 90 adult recipients of a bone marrow transplant, individuals who endorsed increased illness intrusiveness also demonstrated a significantly greater tendency to incorporate the transplant patient identity into their self-definition (Beanlands et al., 2003). This finding was heightened when patients perceived higher levels of hopelessness, helplessness, and distress.

Similarly, Devins et al. (1997) found that increased illness intrusiveness led to increases in distress among a sample of 101 renal transplant and dialysis patients. This relationship was moderated by self-concept; individuals whose self-concept was largely defined by their illness and who reported greater illness intrusiveness exhibited increases in distress.

Further, among a sample of 110 adults from ages 24-78 diagnosed with rheumatoid arthritis, Devins, Edworthy, Guthrie, and Martin (1992) found an interaction between age and illness intrusiveness in predicting depression. Specifically, increases in

illness intrusiveness were associated with greater increases in depressive symptoms for younger patients. The authors suggested that perceived intrusiveness resulted in less opportunity for rewarding events, which led to greater depression and lower quality of life. For younger patients, this decrease in physical capacity and rewarding events is in direct contrast to normal developmental expectations; this is vastly different than for older patients who are more likely to perceive that the physical limitations due to their illness are more appropriate for their age (Rolland, 1987). It seems that this incongruity would be even more devastating for pediatric patients and their caregivers given the expectations and activity levels of same-age peers.

Indeed, among pediatric populations, the effects of illness intrusiveness seem to be particularly relevant when a family is faced with a highly unpredictable illness that does not necessarily reward their efforts to treat and alleviate symptoms. Thus, parents of chronically ill children must cope with stressors that are directly tied to their children's illness or indirectly related through the barriers created by that illness. In addition, daily stressors that are entirely separate from the child's illness may be present (Manuel et al., 2001). Results from a sample of 92 mothers of children diagnosed with JRA showed that disease variables were not significant predictors of maternal distress; rather, daily stress was the strongest predictor, followed by illness-related stressors. It is likely that the additive effect of typical parenting stress and illness-related stressors lead to greater overall distress among parents of children diagnosed with a chronic illness.

Despite the importance of parents' adjustment, existing research on illness intrusiveness in pediatric chronic illness has targeted the relationship between children's perceptions of intrusiveness and their own adjustment. For example, Wagner et al.

(2003) found that children's perceived illness moderated the relationship between parent and child distress among a sample of 45 children ages 9-17 diagnosed with JRD. Thus, children's heightened illness intrusiveness increased the impact of parent distress on child depressive symptoms. Although illness intrusiveness appears to play an important role in child adjustment to JRD, current research has not addressed parent's perceptions of the intrusiveness of their child's illness and its impact on parental distress.

Ethnicity. Currently, there is little research on the relationship between cognitive variables and distress among minority groups of children diagnosed with a chronic illness; this is especially true with Native American populations. In the case of JRD, the paucity of research is especially concerning given the high prevalence of particular types of JRD and the current interest in genetic factors associated with rheumatic diseases among Native Americans. Although there is considerable research into biomedical variables, little research regarding the direct and indirect effects of ethnicity on coping exists; this problem extends beyond Native American populations to minority groups in general.

The lack of research on minority populations in the area of chronic illness is particularly salient when considering the work of Clark and colleagues (1999), who suggest that minority status in and of itself should be considered a marker for increased risk for high levels of stress and illness. There are at least two ways in which ethnic minority status may function—direct and indirect. One direct way this may be manifested is frustration that arises due to a lack of familiarity and culturally sensitive rapport with medical staff (Abdullah, 1995), as well as a lack of culturally specific definitions of illness and health (Baker, 1997).

For example, Kramer, Harker, and Wong (2002) found that, among a sample of 56 adult Native Americans, of whom 45 were currently experiencing joint pain and 11 were not, symptoms were communicated to medical staff in a minimal, subtle manner. Specifically, these authors found that although individuals experiencing chronic pain in multiple joints had consulted a physician when their self-care strategies failed; their pain remained under-treated. The authors concluded that this was largely due to the subtle and indirect ways the Native participants reported their symptoms. As a result, the level of pharmacological intervention was less than expected given their actual level of pain.

It might also be the case that ethnic minority status influences stress and illness indirectly through decreased ability to meet basic needs and lowered access to health care resources. For example, Plant and Sachs-Ericsson (2004) found that, among a sample of 4,700 adult participants in the Colorado Social Health Survey, members of minority ethnic groups reported higher rates of depressive symptoms. However, this relationship was mediated by difficulties in meeting basic needs; minority group members reported more difficulties in meeting their basic needs, which was associated with higher rates of depression.

In addition, Mayberry, Mili and Ofili (2000) note that overall, members of minority groups are less likely to have access to quality healthcare; further, members of minority groups are less likely to have a regular healthcare provider, insurance, and preventive treatment (e.g., patient education, immunization). This is particularly true for pediatric populations. As one example, African American children are more likely to visit the emergency room as a result of their asthma episodes, and less likely to make scheduled visits to a primary care provider. Here, and in other areas, it appears that the

cost of routine care is partially involved in decision making by members of minority groups.

Wallander et al. (1989) lent insight into this process when they found that, among a sample of 153 chronically ill children and their families, chronically ill and/or disabled children were more resistant to psychological maladjustment in the presence of greater "utilitarian" and socio-emotional family resources. Utilitarian resources were defined by family income and the educational background of the mother, whereas socio-emotional resources included the level of family cohesion, expressiveness, conflict, organization, and control. Thus, greater resources within a systemic context, both for parents and for the family as a whole, were found to provide a resilience factor for chronically ill children.

The absence of familial resources appears to be especially relevant for minority parents of children diagnosed with a chronic illness. For example, Farmer et al. (2004) found that, among a sample of 83 chronically ill children and their parents, minority families reported higher levels of unmet needs across the categories of information, social support, community services, family functioning, financial needs, and explaining their child's condition to others. Although overall group differences were found, ethnic discrepancies were particularly acute with respect to community services such as dental and health care.

However, despite evidence suggesting that the absence of basic resources are detrimental to parents struggling to cope with their child's diagnosis and treatment, extant literature has largely failed to examine the ways in which a paucity of resources might be expressed among minority groups. This lack of research is even more glaring given the

lifestyle disruptions in illness unrelated areas such as school that are visible for Native American children, in addition to the JRD-specific issues that affect particular ethnic groups. Indeed, Andrews et al. (2004) found that among a sample of 40 Native American and Caucasian children diagnosed with a JRD, the Native American children missed significantly more days of school. This suggests that Native American families may be more vulnerable to the social and academic impact of chronic illness.

These differences in school absenteeism, and by extension, coping in general, may be attributable to a variety of variables. Differences between ethnic groups may incorporate differing educational and socioeconomic status, (as suggested by Devins et al., 2000), or any number of socio-cultural factors, such as cultural attitudes towards Western medicine and illness. Additionally, parental support and low levels of parental stress seem to act as a buffer against the indirect effects of JRD (VonWeiss et al., 2002). Decreased compliance with treatment regimens has been observed among parents who perceive a high number of stressors in their lives (Chaney & Peterson, 1989).

It is likely that a combination of these disease-related and disease-unrelated variables increases the collective stress on families. When experiencing significant cultural stress in combination with the issues inherent to a chronic illness, these parents may be more likely to experience increased social and environmental difficulties. These issues have a family-wide impact, as parent adjustment has additionally been found to have an impact on the psychosocial well being of healthy siblings of chronically ill children (e.g., Jaworski, 1993). Also, Kroll and colleagues have noted that the manner in which JRA and its treatment are perceived and experienced may differ by ethnic group, which may create barriers to treatment adherence (1999).

Importantly, Yeates et al. (2002) found that among a multiracial sample of 91 children with a traumatic brain injury (TBI) and 55 children with orthopedic injuries, parental stress was independent of socioeconomic status. At follow-up, the negative consequences perceived by the parents of children diagnosed with a TBI were more pronounced for African American parents than Caucasian parents. Ethnicity, therefore, acted as a moderator between the effects of a TBI and parental distress. If minority status is a risk factor for increased level of stress, as suggested by Clark et al. (1999), studies such as this should elaborate on how minority status alters perceptions and coping strategies within pediatric chronic illness—a little-investigated area of research.

Summary. Parents of chronically ill children are affected by a wide variety of variables from both disease and demographic-related domains (Manuel et al., 2001). However, because these variables account for a small portion of the variance in parent adjustment, it is necessary to examine cognitive variables as well. These variables include perceived control, daily stress, and other cognitive appraisals. One such variable that seems particularly relevant to parent adjustment in JRD is illness intrusiveness, which is a general perception of "illness-induced barriers" to daily activities (Devins et al., 1983-84; p. 329). As such, this variable is believed to contribute to increased maladjustment in illnesses like JRD because both parents and children experience distress as a result of the corresponding decrease in rewarding activities.

Although there have been studies investigating the prevalence of various pediatric chronic illnesses among minority groups, research on the impact of those illnesses is limited. This paucity of research is especially acute with respect to the differential role of cognitive appraisal variables. Illness intrusiveness, however, may be of particular interest

among minority groups because of the challenges, such as a lack of basic social resources, that minority parents are already facing. Indeed, Clark and colleagues (1999) state that minority status should be considered a marker of increased risk for high levels of stress and illness; further, Farmer et al. (2004) have found that minority families report that fewer of their needs (e.g., information, social support, community services, family functioning, financial needs, and explaining their child's condition to others) are being met. However, research regarding these potential ethnic differences and their expression is scarce.

CHAPTER III

THE PRESENT STUDY

Based on the preceding review of the literature, it is apparent that children diagnosed with a juvenile rheumatic disease and their families face a variety of challenges across multiple domains. Parent adjustment, for example, is presumed to be multi-determined by a host of variables, including cognitive appraisal processes. Except for a few studies (e.g., Lustig, Ireys, Sills & Walsh, 1996), however, cognitive appraisals have been largely overlooked in investigations of parent adjustment to childhood chronic illness.

One such cognitive appraisal variable, illness intrusiveness, appears to be particularly relevant to the illness process in rheumatic diseases, especially in ethnic minority groups (Devins & Edworthy, 2000). However, the vast majority of research on illness intrusiveness has focused exclusively on children's perceptions of intrusiveness and its relation to child adjustment—extant literature has largely ignored parents' intrusiveness perceptions as a determinant of their own distress levels. Because parent adjustment influences children's adjustment to chronic illness, such information could prove useful in developing interventions to modify parents' illness perceptions, their adjustment, and ultimately, children's adjustment.

Also conspicuously absent in the pediatric chronic illness literature are investigations examining potential differences in the manner in which cognitive appraisals influence adjustment across ethnic minority groups. This is of particular importance in light of the added stressors faced by minority parents; these stressors can include discrimination, prejudice, negative stereotypes, and acculturation pressures (e.g.,

Contrada et al., 2000), in addition to indirect factors such as reduced access to health care (Mayberry, Mili, and Ofili, 2000).

There is currently little research, however, into how ethnic minority status affects the operation of cognitive appraisal variables in adjustment to chronic illness. Further, there is limited research into how parent perceptions of the intrusiveness of their child's illness alter their own level of distress. The present study attempted to address these limitations in the literature by investigating the association between parent-reported illness intrusiveness and parent distress in a sample of Native American and Caucasian children with JRD. Specifically, the present study examined the potential moderating influence of ethnicity on the relationship between parent-reported illness intrusiveness and parent distress.

Primary Hypotheses

Hypothesis 1. It was anticipated that greater parents' perceived illness intrusiveness on the IIS-P would be related to lower parent adjustment as measured by the GSI for both parents of Native American and Caucasian children. It was hypothesized that this relationship would remain after controlling for demographic and disease variables.

Hypothesis 2. The association between illness intrusiveness on the IIS-P and parent adjustment on the GSI was expected to be significantly greater for Native American participants in comparison to the Caucasian group. Thus, it was expected that ethnic group membership would moderate the relationship between parent perception of illness intrusiveness and global parent adjustment, such that illness intrusiveness would be more closely related to parent adjustment in the Native American sample of parents compared to the Caucasian sample.

CHAPTER IV

METHODS

Participants and Procedures

Participants were 40 parents (24 Native American, 16 Caucasian) of children who had been diagnosed with JRA (*N* = 24), SLE (*N* = 7), JSA (*N* = 3), or JDM (*N* = 6). The families were recruited from the pediatric rheumatology clinic at Children's Hospital of Oklahoma at the University of Oklahoma Health Sciences Center. Inclusion criteria included the following: 1) diagnosis of one of the above-mentioned illnesses, 2) living at home and between the ages of nine and 19, 3) self-reported Caucasian or Native American ethnicity, and 4) the duration of the child's symptoms had been at least one year, irrespective of the time of diagnosis. Illness duration, however, was defined as the subtraction of the date of diagnosis from the date of participation, and ranged from .00 – 15.73 years. For complete information regarding disease, demographic, and psychosocial variables, see tables 1 and 2. Exclusion criteria consisted of: 1) the child had comorbid cognitive deficits such as mental retardation, 2) the child had a comorbid chronic illness, and 3) either the child or the parent were non-fluent English speakers. The primary rheumatologist verified the inclusion criteria before eligible participants were contacted.

Eligible participants were recruited in either of the two following ways. The majority of participants were recruited during a routine visit to the rheumatology clinic (N = 27). If the family chose to participate, parents completed a questionnaire packet. This packet was either returned to the clinic or to researchers via postage-paid mail. Participants not scheduled for upcoming appointments in the rheumatology clinic were contacted by phone and the packet was sent by mail (N = 13). These families had previously met the researchers prior to telephone contact. Parent psychological

adjustment did not differ as a function of recruitment method F (1, 38) = .69, p = 41. Once participants returned the completed packet, they received $10 compensation in the form of a gift card.

Instruments

Parent-Report

The *Brief Symptom Inventory* (BSI; Derogatis, 1993) is a 53-item questionnaire that assesses overall psychological adjustment (see Appendix A). Respondents rated the degree to which they were distressed by each psychological symptom over the past week. Rating was done on a Likert scale, where responses ranged from 1 (not a lot) to 4 (extremely). The global severity index (GSI) is the average score of the items and was used as the measure of parent distress. The BSI has been previously found to have acceptable internal consistency; alpha coefficients range from .71 to .85 (Derogatis, 1993). For this study, Cronbach's alpha was .97.

The *Illness Intrusiveness Scale–Parent* (IIS-P) The IIS-P used in the present study was adapted from the original IIS (Devins et al., 1983). For this study, the original 13 items remain the same; directions were changed from *"rate the extent to which your illness..."* to *"rate the extent to which your child's illness interferes with your ability to perform as well as you would like to"*. The IIS-P is a 13-item measure that assesses the degree to which parents perceive their child's illness as interfering with their own ability to engage in activities across a variety of life domains, such as work, relationships, and recreation (see Appendix B). Parents were asked to respond on a scale from 1 (*affects performance a little)* to 7 (*affects performance a lot).* Items were summed to achieve a total intrusiveness score, with higher scores indicating greater levels of illness intrusiveness. Data from adult RA and lupus samples reflecting intrusiveness of adults'

own illness symptoms indicate that internal consistency estimates range from .87 to .94 and test-retest reliability indexes range from .79 to .85 (Devins & Edworthy, 2000). In the present sample, Cronbach's alpha was slightly lower, at .78.

The *Juvenile Arthritis Functional Assessment Report–Parent* (JAFAR-P; Howe et al., 1991) is a 23-item parent rating intended to cover a variety of subjective estimates of their child's functional ability (see Appendix C). Questions address the frequency that their child is able to perform specific tasks related to daily functioning, such as reaching above their head, button a shirt, and brush their own teeth. Responses were made on a three-point Likert scale, where 0 refers to being able to perform the task *all the time,* and 2 refers to being able to perform the task *almost never*. Responses were summed, so that higher scores on the JAFAR-P indicate a perception of greater disability. The JAFAR has demonstrated good construct validity and acceptable internal consistency for the parent-report (.93) version of the scale (Howe et al., 1991). Again, Cronbach's alpha was slightly lower at .74.

Physician-Report

Provider Questionnaire. This questionnaire was designed to obtain information from the physician regarding patient diagnosis, date of diagnosis, and current rheumatologist-prescribed medications (see Appendix D). As a measure of functional disability, the physician classified participants into one of four functional classes, with Class I representing limited to no disability in everyday self-care activities, and Class IV representing severe disability in these same activities (Hochberg et al., 1992).

CHAPTER V

RESULTS

Preliminary Analyses and Selection of Covariates

Selection and entry of demographic and disease covariates were guided by multivariate models of adjustment to chronic illness (e.g., Thompson et al., 1993a), as well as by significant relationships between the covariates and the criterion variable. First, bivariate correlations were conducted to identify any significant relationships between key demographic and disease variables and GSI parent distress. Mean comparisons were also utilized to test for differences in GSI across demographic and disease variables.

Zero-order correlations revealed no significant relationships for GSI on demographic (maternal and paternal education, gender) or disease (duration, parent and physician-perceived disability) variables. Further, one-way analyses of variance (ANOVA) revealed no significant gender or diagnosis differences for GSI.

Although diagnosis, parent-related disability and physician-rated disability (i.e., functional class) did not demonstrate a direct relationship to scores on the GSI, these variables were included as covariates to provide a more conservative test in accordance with extant literature. Further, although age did not demonstrate a direct relationship, previous research on adults with RA (Devins et al., 1992) suggests that age can influence adjustment in an indirect way through its interaction with illness intrusiveness. Due to this finding in the extant literature, as well as the large age range present in this sample, age was included as a covariate to account for the potential indirect effect of age on parent distress in the presence of perceived illness intrusiveness.

Primary Analyses

Hypothesis 1. It was anticipated that greater parents' perceived illness intrusiveness on the IIS-P would be related to lower parent adjustment as measured by the GSI for both parents of Native American and Caucasian children. Further, it was predicted that this relationship would remain after controlling for demographic and disease variables. To investigate this hypothesis, a regression equation was constructed in which age, diagnosis, functional class, and JAFAR-P were entered as step 1. On Step 2, parent report of illness intrusiveness (IIS-P) was entered. Results revealed a significant main effect of IIS-P on GSI F (1, 34) = 4.58, p = .04. The positive F value supported Hypothesis 1 by demonstrating the direct relationship between illness intrusiveness and parent distress for the entire sample.

Hypothesis 2. The association between illness intrusiveness on the IIS-P and parent adjustment on the GSI was expected to be significantly greater for Native American participants in comparison to the Caucasian group. Thus, it was expected that ethnic group membership would moderate the relationship between parent perception of illness intrusiveness and global parent adjustment, such that illness intrusiveness would be more closely related to parent adjustment in the Native American sample of parents compared to the Caucasian sample. To investigate this hypothesis, a regression equation was constructed in which age, diagnosis, functional class, and JAFAR-P were entered as a block on Step 1. On Step 2, ethnicity and parent report of illness intrusiveness (IIS-P) were entered. On Step 3, the interaction term of ethnicity x IIS-P was entered. Results revealed a significant ethnicity x IIS-P interaction, which accounted for an additional 19% of incremental variance in parental distress F (1, 32) = 12.31, p = .001. The

significant interaction indicates that ethnic group membership moderated the relationship between parent perception of illness intrusiveness and global parent adjustment in the predicted direction. Specifically, illness intrusiveness was more closely related to parent adjustment among the Native American parents than among the Caucasian parents.

Post-hoc Probes

As suggested by Holmbeck (2002), post-hoc probes were conducted to determine the nature of the significant interaction found in the primary analyses. Prior to any analyses, however, IIS-P was centered by subtracting the sample mean from each individual IIS-P raw score (CIIS-P). Conditional moderator variables were then created for the original dichotomous ethnicity variable; GROUP A had Caucasian coded as 1 and Native American coded as 0. GROUP B was computed by subtracting one from all GROUP A values; i.e., GROUP B had Caucasian coded as 0 and Native American coded as –1. Two new interaction terms were then created by multiplying each GROUP variable by centered illness intrusiveness.

One equation was computed to generate the slope for the GROUP A condition (Native American = 0), and the other was computed to generate the slope for the GROUP B condition (Caucasian = 0). As in the primary analyses, age, diagnosis, functional class, and JAFAR-P were entered as a block on Step 1. For the purposes of interpretation, both the main effects and interaction term were entered simultaneously on Step 2. Therefore, GROUP A, CIIS-P, and the GROUP A x CIIS-P interaction were simultaneously entered for equation one. The second step for equation 2 consisted of GROUP B, CIIS-P, and the GROUP B x CIIS-P interaction. The following two equations were then generated by substituting zero for the conditional ethnicity variables:

Equation one (Native American):

GSI = .22 (age) + .08 (DX) -.08 (PRFD) + .31 (JAFAR-P) + 1.18 (CIIS-P) + .23

Equation two (Caucasian):

GSI = .203 (age) + .08 (DX) - .02 (PRFD) + .12 (JAFAR-P) + .15 (CIIS-P) - .31

Significance tests indicated that the simple slope for the regression line for equation one was significant, t (1) = 4.44, p = .001; the simple slope for equation two was nonsignificant, t (1) = .94, p = .35. Thus, the post-hoc test provided support for Hypothesis 2; namely that illness intrusiveness was significantly associated with parent distress for the Native American sample, but was unrelated to parent distress in the Caucasian sample.

CHAPTER VI

DISCUSSION

The present study was designed to address two key limitations in the extant literature on adjustment to pediatric chronic illness. First, despite findings in the pediatric psychology literature indicating that parents of chronically ill children are at increased risk for emotional adjustment problems such as anxiety (e.g., Dahlquist et al., 1993) and familial conflict (e.g., Vandvik, Hoyerhaal & Fagertun, 1989), little is known about the precise mechanisms responsible for this. Some data indicate that a variety of variables, including children's adjustment, influence parent adjustment (Thompson et al., 1993 a, b); other data suggest that parents' perception of their child's illness and its management are a major contributor to parent adjustment issues. Specifically, there is evidence to suggest that parents' perceptions of the impact of their child's illness can have negative effects on parents' adjustment (Walker, Ford, & Donald, 1987). However, there are little empirical data to support this. Because there is a paucity of research into how parent distress levels are affected by perceptions of their child's illness, the present study was designed to investigate this issue in the context of illness intrusiveness. This variable, which represents perceived "illness-induced barriers" across a wide array of life domains (Devins et al., 1983; p. 329), was examined in the present study because JRD often involve a significant decrease in children's activity levels (Henderson et al., 1995). Because of this, the role of parents' perceptions of interference with routine activities due to illness assumes particular importance.

Another shortcoming in the literature is the lack of data addressing adjustment issues among ethnic minority children with chronic illnesses. For example, in an analysis

of seventy-one articles regarding empirically supported treatments for pediatric asthma, cancer, diabetes and obesity, Clay and colleagues (2002) noted that less than one-third even reported the ethnicity of participants. More importantly, even fewer (6%) examined ethnic minority or cultural status as a primary variable associated with psychological outcome. Compared to the multitude of variables associated with adjustment that have been examined over the past 20 years in the childhood chronic illness literature, little is known about the potential differential effect of racial minority status on the cognitive appraisal-adjustment relationship in parents of these children. Stressors facing minority parents can include discrimination, prejudice, negative stereotypes, and acculturation pressures (e.g., Contrada et al., 2000), in addition to factors such as reduced access to health care (Mayberry et al., 2000). It seems likely that the added presence of these potential stressors would increase the risk of poor adjustment among minority parents of children diagnosed with a chronic illness. Further, studies on how ethnic minority status affects the operation of specific cognitive appraisal variables, such as illness intrusiveness, in adjustment to chronic illness are extremely rare, especially with respect to Native American populations.

To address these issues, two hypotheses were proposed for this study: first, that greater parents' perceived illness intrusiveness on the IIS-P would be related to greater parental distress as measured by the GSI for both parents of Native American and Caucasian children. Second, it was expected that ethnic group membership would moderate the relationship between parent perception of illness intrusiveness and global parent adjustment; specifically, that illness intrusiveness would be more closely related to

parent adjustment in the Native American sample of parents compared to the Caucasian sample.

Results of the primary analyses were consistent with the first hypothesis; namely, the present study found that greater parents' perceived illness intrusiveness on the IIS-P was related to lower parent adjustment as measured by the GSI across both ethnic groups. Studies on parent adjustment to chronic illness largely suggest that these parents are at risk for increased distress and symptoms of depression (for exceptions, see Cadman et al., 1991; Gerhardt et al., 2003) and that adjustment difficulties are affected by a host of cognitive processes, including perceived illness impact (e.g., Sharpe, Brown, Thompson & Eckman, 1994).

Illness intrusiveness appears to be especially devastating when a family is faced with a highly unpredictable illness that does not necessarily reward their efforts to treat and alleviate symptoms, as is the case for JRD. Thus, parents of chronically ill children must cope with stressors that are either directly tied to their children's illness or indirectly related through the barriers created by that illness. These illness-induced barriers are hypothesized to increase maladjustment by reducing positive, reinforcing experiences, and by decreasing perceived control over important personal outcomes (Devins, Edworthy, Guthrie, & Martin, 1992).

This appears to be similar to Lewinsohn and Atwood's reinforcement theory of depression, which states that depression is "initiated and maintained by prolonged reductions of positive social reinforcement" (p. 171; 1969). Although the concept of a direct, exclusive relationship between positive events and depression has been largely unsupported (e.g., Hammen & Glass, 1975; Wener & Rehm, 1975), Sweeney and

colleagues (1982) suggest that an indirect relationship may be present. They hypothesize that cognitive variables such as perceived uncontrollability may mediate the relationship between insufficient pleasurable events and depression. Thus, although a direct relationship between decreased positive reinforcement and adjustment may be difficult to ascertain, the reinforcement theory of depression may still apply to JRD adjustment in the context of decreased controllability. In other words, the unpredictable nature of JRD may influence parents' perceptions of controllability for disease-unrelated activities, such that not only is the child's disease seen as imposing barriers to accessing activities across a number of family life domains, but they become seen as uncontrollable or unchangeable barriers as well. Perhaps future studies should investigate the specific interplay between perceived uncontrollability and illness intrusiveness in studies of adjustment to chronic illness.

The reinforcement explanation may also help to understand the results of the second primary hypothesis, namely that ethnic status acted as a moderator in the illness intrusiveness-parent distress relationship. More specifically, illness intrusiveness was related to parent adjustment in the Native American sample of parents, but not in the Caucasian sample. Results are consistent with a reinforcement interpretation in which minority families are already experiencing a reduced level of reinforcement due to the direct or indirect effects of racial minority status. For example, Native American families in our sample may be experiencing difficulties in acquiring adequate resources, including information, social support, community services and financial support.

Although speculative, it may be that perceived illness-induced barriers had a greater impact on Native American parents as a function of an existing vulnerability due

to factors associated with belonging to a disadvantaged group. In other words, the effect of illness intrusiveness in this group is linked to increased maladjustment and depressive symptoms in part, by reducing positive, reinforcing experiences (Devins et al, 1992). This effect may have been more prominent because fewer reinforcing experiences and contexts were available to the Native American families irrespective of the illness itself. Indeed, Native American families may be provided with fewer opportunities for reinforcement due to a lack of adequate care or other limitations.

More direct barriers to adequate care may also help account for the relationship between IIS-P and GSI found among the Native American sample. For example, Kramer, Harker, and Wong (2002) found that although Native Americans with RA had consulted a physician, their pain remained under-treated due to culturally specific, indirect ways of reporting pain. Similar results have been observed within the context of JRA; the ways in which illness and its treatment are perceived and experienced may differ by ethnic group, which may create barriers to treatment adherence (Kroll et al., 1999). This issue is compounded by a lack of familiarity and culturally sensitive rapport with medical staff across minority groups in healthcare settings (Abdullah, 1995). Thus, in addition to decreased illness-independent opportunities for reinforcement, Native American families may be experiencing fewer instances of reinforcement even within health-related settings. The Native American families in this sample may have been more vulnerable than Caucasian families because of this cumulative lack of positive experiences.

This study is a demonstration of the importance of examining the effect of ethnic minority status on adjustment in pediatric chronic illness. Results of the primary analyses

showed that ethnic group membership moderated the relationship between parent perceptions of illness intrusiveness and global parent adjustment. Specifically, illness intrusiveness was found to related to parent adjustment only among the Native American parents. Had race not been examined, the results would have suggested that illness intrusiveness significantly impacted parent adjustment for the entire sample. Although not explicitly stated, it was anticipated that the post-hoc tests would reveal a significant increase in maladjustment across both ethnic groups. Thus, it was anticipated that there would be a significant relationship between illness intrusiveness and adjustment for both Caucasian and Native American parents, but that the influence of intrusiveness on adjustment would be greater for the Native American participants.

The lack of a relationship between illness intrusiveness and parent adjustment for the Caucasian sample is somewhat puzzling. These non-significant results of intrusiveness on adjustment could simply be an artifact of the small sample available for this project, and the positive effect for the Native American families may have been robust enough to transcend the sample limitations present in this study. Alternatively, it may have been that the Caucasian parents in the current sample did not demonstrate a wide enough range of distress, and were a fairly well-adjusted group. Although there were no significant group differences in distress, the difference in GSI between Native American and Caucasian parents approached significance (See Table 2). Thus, it may have been the case that Native American parents in this sample were more distressed, and consequently, elevations in negative cognitive appraisals (i.e., IIS-P) were observed. Likewise, the decreased distress in the Caucasian group may have resulted in the absence of such a relationship. Regardless, this study illustrates the need for future studies to

include ethnicity as a primary variable in investigations of parent adjustment to pediatric chronic illness.

Strengths and Limitations

The present study has several strengths; although it has been suggested that illness intrusiveness would be particularly relevant to the illness process in rheumatic diseases, especially in ethnic minority groups (Devins & Edworthy, 2000), little research has been conducted on illness intrusiveness and cognitive appraisals in general. This study addresses a major gap in extant literature, for minority groups in general, and specifically for Native Americans, who are proportionally underrepresented in psychological research as a whole.

Further, this study represents the only investigation of parent perceptions of the intrusiveness of their child's illness. Given the importance of parent adjustment in pediatric physical and psychological outcomes (Thompson et al., 1993 a, b), it seems that an analysis of parent-reported illness intrusiveness would represent a valuable addition to the current intrusiveness literature. Indeed, parent distress appears to be a more important determinant of child maladjustment and future outcomes than objective disease factors (Chaney et al., 1997; Frank et al., 1998).

An associated strength of the study is the inclusion of both objective, physician-rated disease severity and subjective, parent-rated perceptions of disease severity. Inclusion of both variables is theoretically important because objective disease severity is less important in predicting parent distress than subjective ratings of illness by the parent. Especial importance is attached to these subjective ratings when they are tied to parents' perceptions of their role as care provider (Walker, Ford & Donald, 1987). Indeed as

Ravelli and colleagues (1997) note, objective and subjective ratings of functional ability are independently related to outcomes.

However, this study also has multiple limitations as well. With respect to the design of the study itself, self-report inventories were used exclusively to assess both parent adjustment and cognitive appraisals. Thus, the significant association observed between illness intrusiveness (IIS-P) and adjustment (GSI) may have been due to shared method variance and not to the directional relationships predicted in the hypotheses. However, the fact that parent-reported perceptions of illness intrusiveness did not demonstrate a significant relationship with parent adjustment among the Caucasian sample lessens concerns that shared method variance was responsible for the observed relationships in the Native American sample.

A further limitation involves the small sample size used in this study. A small sample may misrepresent relationships between predictor and criterion variables across the study by including a narrow, group of patients' families. Families experiencing more distress may have chosen to take part in this study, creating a selection bias. Certainly, generalizability and power are limited for this study.

The generalizability of any study investigating adjustment among Native Americans is lowered by the heterogeneity of American Indians as a whole, especially with a small, localized sample. For example, evidence has shown that specific tribal groups share a more severe and debilitating disease course (Peschken & Esdaile, 1999); however, such results may primarily be due to SES and residence on a reservation (Oen et al, 2002). This sample was not reservation-based, and certainly does not reflect the breadth of disease activity, social resources, or cultural issues present among Native

American groups across the United States. However, adjustment among Native American parents of chronically ill children is an under-researched issue irrespective of the tribal origins of the sample.

A final issue related to the size of the sample concerns the prevalence of particular subtypes of JRD. Specific diagnoses were almost universally underrepresented, with JRA comprising over half of the sample. Ethnic differences in disease subtypes, therefore, were entirely obscured. As Oen and Cheang (1996) note, ethnic differences are not present for JRA, but prevalence of the subtypes of JRA differ dramatically. With respect to this study, it seems that systematic differences involving ethnicity and diagnosis and their effect on parental distress might not be recognized.

Future Studies

Many of these issues could be addressed by future studies. For example, further projects in this area should incorporate more subjects from a wider range of geographical areas and socioeconomic groups in order to increase generalizability. More specifically, Native American participants should be recruited from both reservation and non-reservation-based tribal groups. Further, a larger sample would likely include more representative proportions of diagnoses instead of being overloaded on children diagnosed with JRA; this would increase generalizability across the population of families of children diagnosed with a JRD.

Increasing generalizability could also be achieved by designing the study to decrease selection bias among the participants. This issue could be addressed by designing the study so that it would be possible to compare potential differences between participating and non-participating families. Further design changes could incorporate a

variety of methods of assessment could be utilized, rather than solely relying on parent-report measures. The incorporation of structured interviews, for example, would alleviate concerns regarding shared method variance.

In conclusion, the findings of the present study highlight the importance of parental perceptions of the intrusiveness of their child's illness with respect to parent distress; in addition, the study illustrates the increased risk facing parents of Native American children diagnosed with a JRD.

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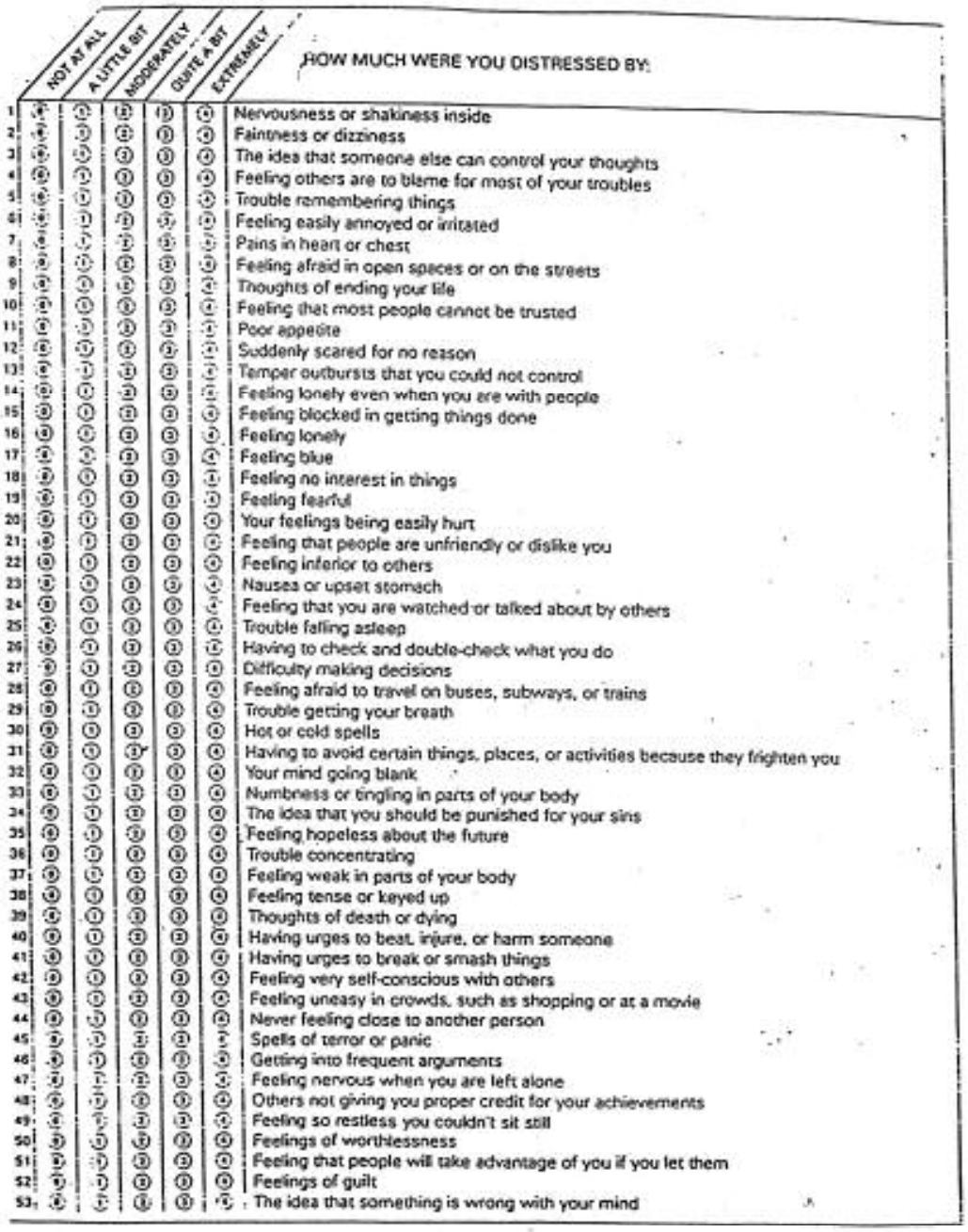
Appendix A

Brief Symptom Inventory (BSI)



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

Appendix B

Illness Intrusiveness Scale–Parent (IIS-P)

IIS-Parent Name_____

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 C

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 D

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, & 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 E

IRB Approval Form

Oklahoma State University
Institutional Review Board

Protocol Expires: 2/10/2005

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

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

Principal Investigator(s):

Nicole Andrews
215 North Murray
Stillwater, OK 74078

Janelle Wagner
215 N. Murray
Stillwater, OK 74078

James Jarvis
OUHSC
Oklahoma City, OK 73104

Molly White
407 N. Murray
Stillwater, OK 74078

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

Reviewed and Processed as: Expedited (Spec Pop)

Approval Status Recommended by Reviewer(s): Approved

Dear PI :

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

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

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

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

Sincerely,

Carol Olson

Carol Olson, Chair
Institutional Review Board

Appendix F

University of Oklahoma Health Sciences Center
Dr. James N. Jarvis

- Consent Form

This is a research study being conducted at the University of Oklahoma Health Sciences Center. Research studies involve only individuals who choose to participate. Please take your time to make your decision. Discuss this with your family and friends. You are being asked to take part in this study because your child has a diagnosis of a juvenile rheumatic disease.

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).

WHY IS THIS STUDY BEING DONE?
The purpose of the study is to examine psychological factors associated with JRD disease processes.

HOW MANY PEOPLE WILL TAKE PART IN THIS STUDY?
About 100 children and caregivers will participate in this study.

WHAT IS INVOLVED IN THIS STUDY?
The research requires the completion of several paper-and-pencil measures in the Pediatric Rheumatology Clinic at the Children's Hospital of Oklahoma that address psychological factors and perceptions of life events, both in general and with respect to JRD. Some items on the questionnaires contain sensitive issues (e.g., depression, relationships, etc.)
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.

WHAT ARE THE RISKS OF THE STUDY?
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.

WHAT ARE THE BENEFITS OF TAKING PART IN THE STUDY?
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.

WHAT ABOUT CONFIDENTIALITY?
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. You will be asked to sign a separate authorization form for use or sharing of your protected health information.

WHAT ARE THE COSTS?
There are no costs to your child for participation in this study.

WILL I BE PAID FOR PARTICIAPATING IN THIS STUDY?
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.

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.

Signed:_____ Date:_____ Time_____(A.M./P.M.)
(Signature of participant's parent/legal guardian)

Child's Assent_____ 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)

APPROVED
JUL 3 1 2003
OUHSC IRB

APPROVAL EXPIRES
JUN 3 0 2004
OUHSC IRB

Table 1.

Disease and Demographic Variables: Frequencies

Variables	Native American Frequency (%)	Caucasian Frequency (%)	Total Sample Frequency (%)
Child's Gender			
Male	4 (25.0%)	11 (45.8%)	15 (37.5%)
Female	12 (75.0%)	13 (54.2%)	25 (62.5%)
Diagnosis			
JRA	8 (50.0%)	16 (66.7%)	24 (60.0%)
SLE	3 (18.8%)	4 (16.7%)	7 (17.5%)
JDMA	3 (18.8%)	3 (12.5%)	6 (15.0%)
JAS	2 (12.5%)	1 (4.2%)	3 (7.5%)
Mother's Education			
Middle School	1 (6.3%)	2 (8.6%)	3 (7.5%)
High School	7 (43.8%)	7 (29.2%)	14 (35.0%)
Some College	4 (25.0%)	10 (41.7%)	14 (35.0%)
College Degree	3 (18.8%)	3 (12.5%)	6 (15.0%)
Post-graduate Degree	1 (6.3%)	1 (4.3%)	2 (5.0%)
Unknown	0 (0%)	1 (4.3%)	1 (2.5%)
Father's Education			
Middle School	2 (12.5%)	2 (8.3%)	4 (10.0%)
High School	6 (37.5%)	10 (41.7%)	16 (40.0%)
Some College	5 (31.3%)	4 (16.7%)	9 (22.5%)
College Degree	2 (12.5%)	3 (12.5%)	5 (12.5%)
Post-graduate Degree	1 (6.3%)	1 (4.3%)	2 (5.0%)
Unknown	0 (0%)	4 (0%)	4 (10.0%)

Table 2.

Disease, Demographic, and Psychosocial Variables: Means

	Native American		Caucasian	
Variables	M (SD)	Range	M (SD)	Range
Child's Age	13.94 (2.82)	9-19	14.33 (2.35)	9-18
Illness Duration (years)	3.17 (4.18)	0-14.59	2.46 (3.38)	.4-15.73
PRFD	1.50 (0.63)	1-3	1.42 (0.58)	1-3
JAFAR-P	5.33 (4.95)	0-18	3.89 (5.42)	0-18
IIS-P	22.06 (10.80)	12-48	22.03 (14.87)	12-67
GSI*	0.80 (.79)	.13-3.13	0.47 (0.42)	0-1.51

	Total Sample	
Variables	M (SD)	Range
Child's Age	14.18 (2.52)	9-19
Illness Duration (years)	2.75 (3.68)	0-15.73
PRFD	1.45 (.60)	1-3
JAFAR-P	4.45 (5.23)	0-18
IIS-P	22.04 (13.29)	12-67
GSI	0.60 (.60)	.00-3.13

Note: PRFD = Physician-rated functional disability; JAFAR-P = Juvenile Arthritis Functional Assessment Report; IIS-P = Illness Intrusiveness Scale – Parent; GSI = Global Severity Index.

* $p = .10$

Table 3.

Hierarchical Regression Analyses of Parent-Reported Illness Intrusiveness on GSI

Step	Variable	β	t	R^2 Change	Cumulative R^2	F Change
1	Age	.22	1.36	.12	.12	1.21
	Diagnosis	.08	.50			
	PRFD	-.79	- .45			
	JAFAR-P	.31	1.78			
2	IIS-P	.36	2.14*	.11	.23	4.58*

Note: PRFD = Physician-rated functional disability; JAFAR-P = Juvenile Arthritis Functional Assessment Report; IIS-P = Illness Intrusiveness Scale – Parent; GSI = Global Severity Index.

* $p = .04$

Table 4.

Hierarchical Regression Analyses of Parent-Reported Illness Intrusiveness on GSI as moderated by Ethnicity

Step	Variable	β	t	R^2 Change	Cumulative R^2	F Change
1	Age	.22	1.36	.12	.12	1.21
	Diagnosis	.08	.50			
	PRFD	-.79	- .45			
	JAFAR-P	.31	1.78			
2	Ethnicity	.31	1.99	.19	.32	4.48*
	IIS-P	.39	2.38*			
3	IIS-P X Ethnicity	1.29	3.51**	.19	.51	12.31**

Note: PRFD = Physician-rated functional disability; JAFAR-P = Juvenile Arthritis Functional Assessment Report; IIS-P = Illness Intrusiveness Scale – Parent; GSI = Global Severity Index.

* $p = .03$ ** $p = .001$

VITA

Nicole R. Andrews

Candidate for the Degree of

Master of Science

Thesis: DIFFERENTIAL EFFECT OF ILLNESS INTRUSIVENESS ON ADJUSTMENT AMONG NATIVE AND CAUCASIAN PARENTS OF CHILDREN WITH JUVENILE RHEUMATIC DISEASE

Major Field: Psychology

Biographical

Education: Graduated from Putnam City West High School, Oklahoma City, OK, May, 1999; Received Bachelor of Science degree in Psychology and graduated Magna Cum Laude from the University of Oklahoma, Norman, OK, July, 2002; Completed the requirements for the Master of Science degree with a major in Psychology at Oklahoma State University, July, 2005.

Experience: Clinical practica experience through OSU Psychological Services Center, August 2002-July 2005; Clinical practica experience through the A Better Chance (ABC) clinic at University of Oklahoma Health Science Center, June 2004-July 2005; Instructor of Introductory Psychology, August 2003-June 2004; Teaching Assistant, August 2002-June 2003; Research Assistant in Dr. John Chaney's Health Psychology Research Lab at OSU, August 2002-July 2005; Outcome Evaluator at the Infant Parenting Program at the University of Oklahoma Health Sciences Center; Undergraduate honors psychology research at the University of Oklahoma, August 2001-May 2002.