Brief Report: Illness Intrusiveness and Adjustment among Native American and Caucasian Parents of Children with Juvenile Rheumatic Diseases

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Objective To investigate cognitive appraisal–adjustment relationships in Native American (NA) and Caucasian parents of children diagnosed with juvenile rheumatic diseases. Methods NA (n = 16) and Caucasian (n = 24) parents completed measures of disease status, illness intrusiveness, and adjustment; the rheumatologist provided estimates of disease severity. Results Hierarchical regression analysis revealed a moderating effect for racial group membership on the illness intrusiveness–parent adjustment relationship. Specifically, parent-perceived illness intrusiveness was more closely related to poorer adjustment among NA parents relative to Caucasian parents. Post hoc tests indicated that illness intrusiveness was significantly associated with poorer adjustment in NA parents, but was unrelated to parent adjustment in the Caucasian sample. Conclusions Results highlight the importance of examining racial group differences in cognitive appraisal–adjustment outcome relationships. Results are discussed with respect to the need for incorporating cultural issues into pediatric chronic illness research and treatment.

Key words illness intrusiveness; juvenile rheumatic disease (JRD); Native Americans; parent adjustment.

Juvenile rheumatic diseases (JRDs) are among the more common childhood chronic illnesses, and include juvenile rheumatoid arthritis (JRA), systemic lupus erythematosus (SLE), juvenile dermatomyositis (JDM), and juvenile spondyloarthropathies (JSA). Although distinct in presentation, JRDs have connective tissue involvement, pain, restricted ability, and a chronic, unpredictable course that may last into adulthood (Cassidy & Petty, 2001).

Parent adjustment to JRD has received less attention than child adjustment, even though nearly two-thirds of parents report moderate-to-severe difficulties (Vandvik, Hoyerhaal, & Fagertun, 1989). Aside from the transactional link between parent adjustment and child outcomes (e.g., Thompson, Gil, Burbach, Keith, & Kinney, 1993), parent adjustment constitutes an important area of investigation in and of itself (e.g., Gerhardt et al., 2003). Similar to children’s adjustment, parent adjustment is highly variable and determined by a host of both disease and cognitive appraisal factors (e.g., Manuel, 2001).

Studies conducted on JRD populations focus almost exclusively on Caucasian children, even though JRDs among Native American (NA) children are characterized by greater clinical variability. For example, in certain parts of the US, NA prevalence rates of JRA mirror those for Caucasian populations; however, rates may be 2–5 times higher in other geographic regions (Peschken & Esdaile, 1999). Equally intriguing are findings demonstrating both inordinately high rates of certain JRD subtypes in NA children (i.e., JDM; JSA) and the absence of others (i.e., pauci-articular JRA) (Jarvis, Solomon, & Menifee, 2000).

The limited research examining physical manifestations of JRD in NA children is eclipsed by the virtual absence of data regarding parent and child psychological...
outcomes. Despite the inclusion of demographic factors in major models of adjustment to pediatric illness (e.g., Thompson et al., 1993), studies have largely failed to examine the influence of race on variables related to adjustment. To illustrate, in an analysis of 71 articles describing empirically supported treatments for adjustment across a variety of pediatric conditions, Clay, Mordhorst, and Lehn (2002) noted that less than one-third of the studies reported participants’ race. Still fewer (6%) examined race as either a primary or moderating variable associated with psychological outcome. In sum, very little is known about differences in the adjustment process among racially diverse JRD populations, especially NAs.

Although the mechanisms by which race may influence adjustment are unclear, there are a number of potential sources. Racial status may directly relate to adjustment as a function of discrimination, prejudice, and acculturation pressures (e.g., Conrada, Ashmore, & Gary, 2000), or indirectly through structural impediments to accessing valuable resources, including quality health care (Yeates, Taylor, & Woodrome, 2002). This may be particularly relevant for NA parents who often face significant barriers that limit their access to subspecialty care (Jarvis & Cleland, 2003).

Parents of chronically ill children often experience significant lifestyle disruptions (Kazak et al., 2006). Because NA parents may already experience significant structural barriers in the environment, the extent to which their child’s illness is perceived as interfering with the implementation of daily routines may contribute to adjustment. One variable that appears to capture this process is illness intrusiveness, a generalized cognitive schema conceptualized as the extent to which illness restrictions (including, but not limited to disability) are seen as precluding involvement in and/or access to disease-unrelated activities (Devins, Edworthy, Guthrie, & Martin, 1992). Illness intrusiveness theory suggests that the decrease in available rewarding activities resulting from perceived illness-induced barriers contributes to adjustment difficulties.

Although no known studies document the relationship between parents’ perceived intrusiveness of their child’s illness and parent adjustment, there is evidence in both the adult and child arthritis literature on the role of illness intrusiveness in the adjustment process (e.g., Devins et al., 1992; Wagner et al., 2003). Moreover, illness intrusiveness has been shown to explain race-related adjustment differences in adult rheumatic illness populations (e.g., Devins & Edworthy, 2000).

In the present study, we report data examining the illness intrusiveness—adjustment relation in a sample of NA and Caucasian parents of children with JRD. It was anticipated that greater parent-perceived illness intrusiveness would be related to poorer parent adjustment in both NA and Caucasian groups. Further, it was anticipated that racial group membership would moderate the relationship, such that illness intrusiveness would be more closely related to poorer parent adjustment in the NA sample of parents compared with the Caucasian sample.

Method
Participants and Procedure
Participants were 40 primary caregivers [16 NA, 24 Caucasian American (CA)] of children aged 9–19 years (M = 14.2 years, SD = 2.5) who had been diagnosed with JRA (N = 24), SLE (N = 7), JSA (N = 3), or JDM (N = 6) and attended a pediatric rheumatology clinic at a large children’s hospital in the southwestern US. Primary caregivers were primarily biological mothers (98%). Institutional Review Board (IRB) approval was granted, and written informed consent and assent were obtained from each participant. All participants were living at home with their parents and had experienced JRD symptoms for at least 1 year (M = 2.75 years, SD = 3.68). Eligible participants were recruited either during a routine clinic visit (N = 27) or by phone (N = 13); all families who were recruited agreed to participate in the study. Parents completed measures of socioeconomic status (SES; Hollingshead, 1975), psychological adjustment, illness appraisal, and perceived child disability in the clinic or returned questionnaire packets via postage-paid mail. Upon completion, participants were compensated with a $10 gift card. Parent adjustment did not differ as a function of recruitment method F(1, 38) = .69, p = .41.

Measures
The Brief Symptom Inventory (BSI; Derogatis, 1993) is a 53-item questionnaire that assesses global psychological adjustment. Respondents rated on a 5-point scale (1 = not at all; 5 = extremely) the degree to which they were distressed by each psychological symptom over the past week. The global severity index (GSI) is the summary score and was used as the primary dependent measure of parent distress. The BSI has been previously found to have acceptable internal consistency: α-coefficients range from .71 to .85 (Derogatis, 1993). For this study, Cronbach’s-α was .97.
The Illness Intrusiveness Scale–Parent (IIS-P) is a 13-item measure that assesses the degree to which parents perceived 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 on a 7-point scale. Higher sum scores reflect increased perceived illness intrusiveness. The IIS-P was adapted from the original Illness Intrusiveness Scale designed to measure adults’ perceptions of their own illness. Acceptable internal consistency (.87 to .94) and test–retest reliability estimates (.79 to .85) on the original IIS have been demonstrated in adult rheumatic illness populations (Devins & Edworthy, 2000; Devins et al., 1992). In the present sample, Cronbach’s-α was .78.

The Juvenile Arthritis Functional Assessment Report–Parent (JAFAR-P; Howe et al., 1991) is a 23-item measure that assesses parents’ subjective estimates of their child’s ability to perform tasks related to daily functioning (e.g., dressing, walking) from 0 (all the time) to 2 (almost never); higher scores indicated greater perceived child 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). Cronbach’s-α in the present study was .74.

The Physician-Rated Functional Disability (PRFD) estimates were provided by the pediatric rheumatologist following a routine visit. Participants were classified into one of four categories, ranging from Class I (limited to no disability) to Class IV (severe disability) (cf. Hochberg et al., 1992). This measure has been shown to be a valid indicator of functional disability in JRDs (e.g., Gerhardt et al., 2003) and was significantly correlated with parent-rated JAFAR-P scores in the present sample, r = .39, p = .02.

**Results**

Selection of covariates for the analysis on GSI parent distress was guided by multivariate models of adjustment to chronic illness (e.g., Thompson et al., 1993; see Table I for descriptive statistics on study measures). A hierarchical regression equation was constructed in which age, disease subtype, functional disability, JAFAR-P, and SES were entered on Step 1. On Step 2, parent illness intrusiveness (IIS-P) and race were entered. The interaction term of IIS-P × race was entered on Step 3. Results revealed a significant main effect of IIS-P on GSI scores, t = 4.58, p = .03. This was qualified by a significant IIS-P × race interaction, which accounted for an additional 19% of incremental variance in distress, F (1, 32) = 12.31, p = .001 (Table II, Figure 1). Thus, racial group membership moderated the relationship between parents’ perceived illness intrusiveness and parent adjustment, such that higher illness intrusiveness was more closely related to poorer adjustment among NA parents relative to CA parents.

Post hoc probes (e.g., Holmbeck, 2002) were conducted to determine the nature of the significant

| Table I. Descriptive Statistics for Disease, Demographic, and Psychosocial Variables |
|-----------------|--------|-----------------|--------|-----------------|
| Variables       | M (SD) | Range           | M (SD) | Range           |
| Child’s age     | 13.94  | (2.82)          | 9–19   | 14.33           | (2.35)          | 9–18   |
| Illness duration| 3.17   | (4.18)          | 0–14.59| 2.46            | (3.38)          | 0–15.75|
| 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   |
| SES             | 36.40  | (18.06)         | 6–60   | 38.45           | (11.07)         | 12–56  |
| 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 |

**Table II. Hierarchical Regression Analysis of Illness Intrusiveness × Race Interaction on Parent Distress**

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<td>21</td>
<td>12.12**</td>
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Note: *CA = 1; NA = 2.
*p = .05; **p = .002.
interaction found in the primary analysis. Results indicated that the simple slope for the NA regression line was significant, $p = .001$; the simple slope for the CA regression line was nonsignificant, $p = .35$. Thus, post hoc tests indicated that illness intrusiveness was significantly associated with distress for NA parents, but was unrelated to parent distress in the CA sample.

Discussion

The present study examined race as a moderator in the illness intrusiveness–parent adjustment association among NA and Caucasian parents of children with JRDs. Although our findings are preliminary, results indicated that racial group membership moderated the relation between parents’ perceived illness intrusiveness and adjustment. Illness intrusiveness was more closely related to poorer adjustment outcomes in NA parents, after controlling for the influence of both demographic and illness parameters. Interestingly, post hoc tests indicated that illness intrusiveness was not related to adjustment for Caucasian parents. Thus, findings revealed that NA parents in our sample who reported higher levels of illness intrusiveness were also experiencing higher levels of psychological distress.

Although the present results do not allow for the identification of specific mechanisms by which NA parents experience such intrusiveness, they do suggest that illness-related burdens faced by these parents may exacerbate existing social and economic circumstances—resulting in increased emotional distress. Additional research is clearly needed to examine specific barriers and obstacles that NA families experience, including those related to cultural constraints and potential problems in accessing adequate health care resources (e.g., Jarvis & Cleland, 2003).

Results of the present study should be interpreted in light of a number of limitations. First, our sample size was quite limited; replication with much larger samples is paramount. Further, because data were gathered only at one site, results may not be generalizable to other geographic areas. Multisite studies targeting NA families of children with JRDs across various regions and tribes are necessary to establish the reliability of these findings. Also, the exclusive use of self-report measures to assess psychological distress and perceived illness intrusiveness introduces method variance as a concern. Finally, additional research is warranted that examines illness intrusiveness–adjustment associations in both NA and Caucasian youth with JRDs, whose experience of their disease and cognitive appraisals may be quite different from those of their parents. Indeed, Wagner et al. (2003) have demonstrated that child report of illness intrusiveness moderates the relationship between parent adjustment and child adjustment outcomes in children with JRDs.

These limitations notwithstanding, the present study is among the first to examine race as a moderator in the cognitive appraisal–adjustment relation among parents of chronically ill children. Certainly, it is the only known study to evaluate the nature of this association among parents of NA youth with JRDs. From a clinical perspective, pediatric psychologists should be sensitive to the fact that additional risk factors may well exist for NA parents of children with JRDs, and attempts should be made to identify culturally appropriate interventions and resources for these parents.

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References


