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Utility of the Illness Intrusiveness Scale in Parents of Children Diagnosed With Juvenile Rheumatic Diseases

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Objective: To examine the factor structure and convergent validity of the Illness Intrusiveness Scale—Parent Version in mother and fathers of children and adolescents ages 7 to 18 (M = 13.56 years, SD = 2.67) diagnosed with a juvenile rheumatic disease. ***Design:*** Parents of 122 children and adolescents (82 girls, 40 boys) completed the Illness Intrusiveness Scale—Parent Version, and both parents and children and adolescents completed measures of functional disability, general distress, and illness uncertainty. An exploratory factor analysis was conducted on the Illness Intrusiveness Scale—Parent Version to identify the factor structure. The factors were then compared with parent- and child-report measures of functional disability, general distress, and uncertainty. Finally, analyses were conducted to determine whether the magnitude of the correlations was significantly different between factors for parents and children and adolescents. ***Results:*** The Illness Intrusiveness Scale—Parent Version was found to have a two-factor structure. The Relationships/Personal Development factor contained items related to self-fulfillment and interactions with others, and the Instrumental factor contained items related to health and work. These factors were found to have good internal consistency and were significantly correlated with measures of parent-reported functional disability and parent- and youth-reported distress and uncertainty. The magnitude of these correlations was also found to differ depending on informant and outcome measure. ***Conclusion:*** The Illness Intrusiveness Scale—Parent Version appears to be a valid measure for use in parents of children with juvenile rheumatic disease.

Keywords: juvenile rheumatic disease, adjustment, functional status, stress and coping

Impact and Implications

• The current study is the first to examine the psychometric properties of the Illness Intrusiveness Scale—Parent Version.

• Results demonstrate that the Illness Intrusiveness Scale—Parent Version is a valid measure of perceived illness intrusiveness in parents of children and adolescents diagnosed with juvenile rheumatic diseases.

• Based on the results of the current study, clinicians can use the Illness Intrusiveness Scale—Parent Version to determine the differential relation of illness intrusiveness to areas of self-fulfillment and interactions with others or areas of health and work.

• Given the relation between parental perceptions of illness intrusiveness and psychological adjustment, clinicians and physicians are encouraged to screen for this construct during patient visits.

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Introduction

Juvenile rheumatic diseases (JRDs), one of the most common pediatric chronic conditions, are a group of autoimmune disorders characterized by an unpredictable course that includes intermittent symptom flares, including decreased mobility, joint and muscle inflammation, and pain (Cassidy, Petty, Laxer, & Lindsley, 2010). Episodic and recurrent disease flares may be associated with joint abnormalities and physical limitations, resulting in significant life disruptions for the child and parents. Thus, a diagnosis of a JRD, like other pediatric chronic illnesses, is not a single, discrete event. Rather, for both the parents and the affected child the diagnosis is only the beginning of a compilation of illness-related events that occur over an extended period of time (Felner, Farber, & Primavera, 1983; Mazur, 2008). Examples of disruptions for children and their families include excessive school or work absences, missing social activities, and devoting more time or assistance to helping children with JRDs complete daily tasks compared with their healthy peers or siblings (Sandstrom & Schanberg, 2004; Verbrugge & Juarez, 2006). Beyond lifestyle disruptions, it is well documented that children and adolescents with JRDs are also at an

increased risk for psychological adjustment difficulties, including anxiety and depression (LeBovidge, Lavigne, Donenberg, & Miller, 2003).

Pediatric psychology theorists of stress and coping have elucidated the bidirectional nature of stressful life events surrounding a chronic illness. Kazak, Segal-Andrews, and Johnson's (1995) social–ecological model states that parent and child adjustment to a chronic illness is closely tied and is a result of the complex interaction among parent, child, illness, and demographic factors. As such, these researchers state that parent adjustment can exert a significant effect on subsequent child adjustment (e.g., Ryan et al., 2010). Research has suggested this theory to be correct, with both cross-sectional and longitudinal studies across multiple chronic illness populations, including youth with JRDs, demonstrating the robust association between parent adjustment and child and adolescent adjustment difficulties (e.g., Chaney et al., 1997; Mullins & Chaney, 2001; Thompson, Gustafson, Gil, Kinney, & Spock, 1999; Wagner et al., 2003). Moreover, parenting factors associated with caring for a child with a chronic illness (e.g., caregiver demand, parenting stress) have been found to be associated with adjustment difficulties in children and adolescents (Ryan et al., 2010; Wolfe-Christensen et al., 2010).

Recent studies have begun to examine a host of cognitive appraisal variables in an effort to delineate specific factors associated with adjustment to a pediatric chronic illness (e.g., Andrews et al., 2009; Carpentier, Mullins, Wolfe-Christensen, & Chaney, 2008; Colletti et al., 2008; Ryan et al., 2010). Illness intrusiveness is one specific parent cognitive appraisal variable that appears to have particular relevance to adjustment in JRD populations. Briefly, illness intrusiveness is characterized as a subjective appraisal of the extent to which both illness-specific factors (e.g., degree of pain, functional limitations, and visible deformities) and treatment factors (e.g., side effects and time required for treatment) are perceived as interfering with an individual's lifestyle, activities, or interests (Devins, 1994, 2010). Illness intrusiveness is thought to contribute to poor psychological adjustment through a combination of (a) limiting positively reinforcing outcomes associated with participation in meaningful activities and (b) reducing perceptions of control by limiting one's ability to achieve positive outcomes and/or reduce the potential for negative ones (Devins, 1994; Devins, Seland, Klein, Edworthy, & Saary, 1993). Extensive support exists for the association between perceptions of illness intrusiveness and psychological adjustment across a variety of illness groups, including adults with cancer (Mah, Bezjak, Loblaw, Gotowiec, & Devins, 2011), multiple sclerosis (Mullins et al., 2001), end-stage renal disease (Binik, Chowanec, & Devins, 1990), and rheumatoid arthritis (Devins, Edworthy, Guthrie, & Martin, 1992; Devins et al., 2009).

Parental perceptions of illness intrusiveness in parents of children and adolescents diagnosed with JRDs may be a particularly important cognitive appraisal mechanism to examine. For these parents, the role of caregiver is a long-term endeavor and a potentially chronic stressor as children with JRDs often require extensive home health care, with parents often serving as primary medical caregivers. Furthermore, this role is accompanied by new, complex responsibilities, such as administering medication, maintaining regular medical appointments, promoting behaviors aimed at decreasing symptoms, and helping to manage chronic pain (Cassidy et al., 2010). Managing their child's illness, in addition to general parenting responsibilities, may intrude on parents' ability to engage in and perceive a sense of gratification from personally meaningful activities.

In accordance with multivariate models of stress and coping (e.g., Kazak et al., 1995), it also stands to reason that parents' sense of control over their efforts to engage in positively reinforcing activities may be thwarted by perceptions of intrusiveness imposed by their child's chronic illness, thereby affecting their psychological adjustment. Indeed, in the only study to our knowledge to examine this construct in JRDs, it was found that increased parental perceptions of illness intrusiveness were significantly associated with increased global distress among parents of children diagnosed with JRDs and was marginally related in parents of adolescents (Andrews et al., 2009).

To date, the psychometric properties of the Illness Intrusiveness Scale—Parent Version (IIS–P) have not been examined. The purpose of the current study was to examine the utility of this measure assessing illness intrusiveness among parents of children with JRDs. The goals of the current study were to (a) examine the factor structure of the IIS–P using exploratory factor analysis in parents of children and adolescents with JRDs and (b) examine convergent validity by determining whether the factors are associated with relevant measures of psychological adjustment. Specifically, parent measures included the Brief Symptom Inventory, Parental Perceptions of Uncertainty Scale, Juvenile Arthritis Functional Assessment Report—Parent, and child and adolescent measures included the Children's Depression Inventory, Children's Uncertainty in Illness Scale, and the Juvenile Arthritis Functional Assessment Report—Child. Based on the Kazak and colleagues (1995) social–ecological model, we hypothesized that all factors of the IIS–P would be significantly correlated with each of the parent- and child-report outcome measures.

Method

Participants and Procedure

Participants were 122 children and adolescents (82 girls, 40 boys) ranging in age from 7 to 18 years old ($M = 13.56$ years, $SD = 2.67$) and their parents. This gender ratio is not surprising given that girls are nearly twice as likely to be diagnosed with juvenile idiopathic arthritis, the most commonly diagnosed JRD (Cassidy et al., 2010). See Table 1 for a summary of parent and child demographic information. Notably, parent demographic information was collected on only a subset of the parents in this sample.

Participants were recruited from a pediatric rheumatology clinic in a large teaching hospital in the midwestern United States. Hospital and university institutional review board approval was obtained. Inclusion criteria included that the family identify English as their primary language and that the child or adolescent have (a) a physician-confirmed diagnosis of a JRD, (b) illness duration of at least 1 year, and (c) no evidence of cognitive deficits or comorbid chronic illness. After verification of inclusion criteria, a graduate research assistant approached the family in the clinic. The study was described to participants, and consent/assent was obtained in conformity with institutional review board standards. Children and adolescents completed measures assessing depressive symptoms, uncertainty, and self-perceptions of functional

Table 1
Family Demographics of Children and Adolescents With Juvenile Rheumatic Diseases

Variable	Statistic
Child sex, *n* (%)	
Female	82 (67.2)
Male	40 (32.8)
Family ethnicity, *n* (%)	
Caucasian	67 (54.9)
Hispanic	19 (15.6)
Native American	18 (14.8)
African American	7 (5.7)
Other	7 (5.7)
Asian	3 (2.5)
Not reported	1 (0.8)
Child diagnosis, *n* (%)	
Juvenile idiopathic arthritis	79 (64.8)
Systemic lupus erthematosus	16 (13.1)
Juvenile dermatomyositis	12 (9.8)
Juvenile ankylosing spondylitis	7 (5.7)
Other rheumatic diseases	7 (5.7)
Not reported	1 (0.8)
Mean (*SD*) child age (years)	13.56 (2.67)
≤12 years old, *n* (%)	41 (33.6)
≥13 years old, *n* (%)	81 (66.4)
Mean (*SD*) illness duration (years)	3.39 (3.53)
Mother education level, *n* (%)	
Middle school	3 (2.5)
High school	43 (35.2)
Some college	38 (31.1)
College degree	31 (25.4)
Postgraduate degree	3 (2.5)
Not reported	4 (3.3)
Father education level, *n* (%)	
Middle school	8 (6.6)
High school	44 (36.1)
Some college	29 (23.8)
College degree	24 (19.7)
Postgraduate degree	7 (5.7)
Not reported	10 (8.2)
Family living arrangement, *n* (%)	
Two-parent home	71 (58.2)
One-parent home	41 (33.6)
Other	9 (7.4)
Not reported	1 (0.8)

ability, and parent participants completed a measure of their child or adolescent's functional ability, personal distress, uncertainty, and intrusiveness associated with their child or adolescent's JRD. Graduate research assistants were available to answer questions or read measures to younger children in the clinic. Participants who were not able to complete the measures during their clinic visit were allowed to return their packets via mail. Parents were financially compensated on completion.

Measures

Illness Intrusiveness Scale–Parent Version. The IIS–P measures parental perceptions of the extent to which their child or adolescent's illness and its treatment interfere with 13 life domains: health, diet, work, active recreation (e.g., sports), passive recreation (e.g., reading), financial situation, relationship with spouse, sex life, family relationships, other social relationships, self-expression or self-improvement, religious expression, and community and civic involvement. Although the IIS–P uses the same 7-point scale with answer choices ranging from *not very much* to *very much* and identical response items as the Illness Intrusiveness Ratings Scale (Devins et al., 1983), the directions have been altered to instruct that the parent complete the form with the intrusiveness of their child or adolescent's illness in mind. The original Illness Intrusiveness Ratings Scale has been purported to have a three-factor structure that is invariant across sexes (Devins et al., 2001; Mah et al., 2011). The first factor, Relationships and Personal Development, contained the active recreation, passive recreation, family relationships, other social relationships, self-expression or self-improvement, religious expression, and community and civic involvement items. The relationship with spouse and sex life items loaded on a factor titled Intimacy, and the financial situation, health, and work items made up the Instrumental factor. The original Illness Intrusiveness Ratings Scale has demonstrated good psychometric properties among various chronic illnesses (Devins et al., 2001). Cronbach's alpha for IIS–P in the current study was .93.

Brief Symptom Inventory. The Brief Symptom Inventory (Derogatis, 1993) is a 53-item measure that assesses global psychological adjustment. Parents rate the degree to which they have been distressed by psychological symptoms within the past week using a 4-point scale ranging from *not at all* to *extremely*. The Global Severity Index, an average of all items, was used as the indicator of parental distress in the current study. The Brief Symptom Inventory has previously demonstrated acceptable psychometric properties (Derogatis, 1993). Cronbach's alpha for the current study was .97.

Parental Perceptions of Uncertainty Scale. The Parental Perceptions of Uncertainty Scale (Mishel, 1983) is a 31-item measure that assesses parental uncertainty in regard to their child or adolescent's illness and treatment. Parents respond via a 5-point scale ranging from *strongly agree* to *strongly disagree*. Answers on the Parental Perceptions of Uncertainty Scale are summed to create a total caregiver uncertainty score, with higher scores indicating greater parental uncertainty. The Parental Perceptions of Uncertainty Scale has been shown to have high internal reliability ($\alpha = .91$) in previous studies (Mishel, 1983). Cronbach's alpha for the current sample was .90.

Juvenile Arthritis Functional Assessment Report—Parent. The Juvenile Arthritis Functional Assessment Report—Parent (Howe et al., 1991) is a 23-item measure that assesses parental estimates of their child or adolescent's functional ability. Parents rate how often their child or adolescent is able to perform 23 daily tasks (e.g., getting into bed) on a 3-point Likert scale with answer choices ranging from *all the time* to *almost never*. Answers are summed to create a total score, with higher scores indicating poorer perceived functional ability. The Juvenile Arthritis Functional Assessment Report—Parent has demonstrated good psychometric properties in previous studies (Howe et al., 1991). Cronbach's alpha for the current study was .96.

Children's Depression Inventory. The Children's Depression Inventory (Kovacs, 2003) is a 27-item self-report scale of child and adolescent depressive symptoms. Respondents are asked to rate their symptoms over the previous 2 weeks on a 3-point scale. Higher total scores indicate more severe depressive symptoms. The Children's Depression Inventory has been shown to be

a reliable and valid measure of child and adolescent depression (Kovacs, 2003). Cronbach's alpha for the current study was .90.

Children's Uncertainty in Illness Scale. The Children's Uncertainty in Illness Scale (Mullins & Hartman, 1995) is a 16-item questionnaire that measures a child or adolescent's perceived uncertainty regarding the course, treatment, and prognosis of the illness. The Children's Uncertainty in Illness Scale uses a 5-point rating scale with answer choices ranging from *very false* to *very true*, with higher total scores indicating greater illness uncertainty. The Children's Uncertainty in Illness Scale has shown good to excellent internal reliability (Pai et al., 2007). Cronbach's alpha for the current study was .92.

Juvenile Arthritis Functional Assessment Report—Child. The Juvenile Arthritis Functional Assessment Report—Child (Howe et al., 1991) is a 23-item measure that assesses a child or adolescent's subjective estimates of functional ability. The Juvenile Arthritis Functional Assessment Report—Child is identical to the parent version in regard to items and scaling. Likewise, the Juvenile Arthritis Functional Assessment Report—Child has demonstrated good psychometric properties in previous studies (Howe et al., 1991). Cronbach's alpha for the current study was .97.

Results

Overview of Analyses

Descriptive analyses were conducted to examine the pattern of IIS–P total scores and family demographic variables (see Table 2). An exploratory factor analysis using principal axis factor analysis was then conducted on the IIS–P to identify the underlying structure. Prior to conducting the exploratory factor analysis, we examined the correlation matrices for each measure for appropriateness through Bartlett's test of sphericity and the Kaiser–Meyer–Olkin statistic. The eigenvalue >1 criterion (Kaiser, 1960), scree plot, and a parallel analysis were used to estimate the number of factors, although all potential solutions were inspected for theoretical interpretability and parsimony (Floyd & Widaman, 1995; Horn, 1965; Lance, Butts, & Michels, 2006). One hundred random data sets were used to generate mean eigenvalues of the same rank as the original data set for the parallel analysis. Eigenvalues were retained if the eigenvalue from the original data set exceeded the generated eigenvalue from the random data set (O'Connor, 2000).

The exploratory factor analysis was first conducted with direct oblimin rotation ($\delta = 0$) to determine whether factor correlations were substantially correlated ($>.30$). However, if factor correlations were negligible, orthogonal solutions were considered acceptable. A salient factor loading cutoff of $\geq .40$ was implemented and secondary loadings above .40 and items within .10 of the highest loading were prohibited (Gorsuch, 1983). Items with substantial factor loadings were then summed to create subscales. These factors were then examined for internal consistency.

The factors were correlated with both parent- and child-report measures to test convergent validity. Furthermore, analyses were conducted to determine whether the magnitude of the correlations was significantly different between factors following the guidelines proposed by Meng, Rosenthal, and Rubin (1992).

Table 2
Descriptive Analyses of the Illness Intrusiveness Scale—Parent Version

Variable	Range	*M* (*SD*)
Child sex		
Female	13–75	22.97 (14.90)
Male	13–68	21.05 (12.44)
Family ethnicity		
Caucasian	13–59	19.61 (10.10)
Hispanic	13–49	22.26 (10.08)
Native American	13–72	26.06 (18.74)
African American	13–66	34.00 (26.27)
Other	13–75	31.43 (22.20)
Asian	13–19	16.00 (3.00)
Child diagnosis		
Juvenile idiopathic arthritis	13–75	20.58 (12.83)
Systemic lupus erthematosus	13–66	28.94 (18.78)
Juvenile dermatomyositis	13–59	28.41 (16.99)
Juvenile ankylosing spondylitis	13–35	17.86 (8.09)
Other rheumatic diseases	13–48	21.71 (12.05)
Child age (years)		
$\leq$12 years old	13–75	22.02 (16.63)
$\geq$13 years old	13–61	22.51 (12.71)
Mother education level		
Middle school	34–50	43.33 (8.33)
High school	13–68	19.77 (12.80)
Some college	13–72	22.66 (14.48)
College degree	13–75	23.77 (14.88)
Postgraduate degree	13–49	25.00 (20.78)
Father education level		
Middle school	13–49	24.76 (15.75)
High school	13–66	20.73 (12.53)
Some college	13–68	24.24 (14.84)
College degree	13–75	22.92 (15.55)
Postgraduate degree	13–43	19.29 (10.84)
Family living arrangement		
Two-parent home	13–75	20.84 (13.20)
One-parent home	13–66	25.17 (14.54)

Exploratory Factor Analysis of the Illness Intrusiveness Scale—Parent

Examination of the scree plot and parallel analysis from the initial factor analysis resulted in inspection of the two- and three-factor solutions for theoretical interpretability (Floyd & Widaman, 1995). A direct oblimin rotation ($\delta = 0$) indicated that the factors were substantially correlated (.30 or greater) in both solutions, indicating that an oblique solution was desirable. The three-factor solution yielded a factor that included heterogeneous item content and was therefore not theoretically defensible (e.g., the sex, health, and active recreation items loading on the same factor). The two-factor solution appeared parsimonious and accounted for 60.60% of the total variance after rotation. Based on the Devins et al. (2001) factor analysis of the original Illness Intrusiveness Ratings Scale, Factor 1 was termed Relationships/Personal Development and Factor 2 was termed Instrumental. All items demonstrated substantial loadings. Furthermore, Cronbach's alphas for the Relationship/Personal Developmental and Instrumental factors were .92 and .85, respectively (see Table 3).

Table 3
Factor Analysis of the Illness Intrusiveness Scale—Parent Version

	Factor		
	Relationships/ Personal Development	Instrumental	
Item	P (S)	P (S)	h^2
1. Work	.13 (.53)	**.58** (.66)	.45
2. Active recreation (e.g., golf, tennis)	**.64** (.72)	.12 (.57)	.53
3. Passive recreation (e.g., playing cards)	**.92** (.84)	−.12 (.52)	.71
4. Financial status	.09 (.57)	**.69** (.75)	.57
5. Relationship with your spouse/lover	**.78** (.79)	.01 (.55)	.62
6. Sex life	**.48** (.54)	.08 (.41)	.29
7. Relationships with your family	**.67** (.82)	.22 (.68)	.69
8. Relationships with other persons	**.69** (.86)	.24 (.72)	.77
9. Self-expression/self-improvement	**.72** (.85)	.18 (.68)	.73
10. Religious expression	**.71** (.66)	−.06 (.43)	.44
11. Community/civic involvement	**.85** (.79)	−.08 (.51)	.62
12. Health	−.12 (.58)	**1.00** (.92)	.85
13. Diet	.11 (.60)	**.70** (.78)	.61
Initial eigenvalues	7.39	1.22	
Sum of squared loadings	7.02	0.86	
Percentage of variance after rotation	54.02	6.58	
Internal consistency	.92	.85	

Note. P = pattern coefficient; S = structure coefficient; h^2 = communalities. Items in boldface represent substantial factor loadings. Internal consistency value is based on items with substantial factor loadings only. Instructions for the questionnaire are as follows: 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.

Relation of the Illness Intrusiveness Scale—Parent Version to Parent and Child/Adolescent Outcome Measures

Bivariate correlations revealed significant correlations for both the Relationships/Personal Development and Instrumental factors (see Table 4). Specifically, the Relationships/Personal Development factor was significantly correlated with the Brief Symptom Inventory, Parental Perceptions of Uncertainty Scale, Juvenile Arthritis Functional Assessment Report—Parent, Children's Depression Inventory, and Child's Uncertainty in Illness Scale such that higher scores on this factor were related to higher scores on the parent- and youth-report outcome measures. Similarly, the Instrumental factor was significantly correlated with the Brief Symptom Inventory, Parental Perceptions of Uncertainty Scale, Juvenile Arthritis Functional Assessment Report—Parent, and Children's Depression Inventory such that higher scores on the Instrumental factor were related to greater scores on the outcome measures. Notably, neither factor was significantly correlated with the Juvenile Arthritis Functional Assessment Report—Child, although the Relationship/Personal Development factor evidenced a significant trend, $r(121) = .17$, $p = .057$.

Between-Factors Comparisons

Comparison of the correlation coefficients across factors revealed a significant difference for the Parental Perceptions of Uncertainty Scale, such that the Instrumental factor was significantly more correlated with the Parental Perceptions of Uncertainty Scale than the Relationship/Personal Development factor ($z = 1.90$, $p = .029$). Alternatively, the Relationships/Personal Development factor evidenced a significant trend of being more correlated with the Child's Uncertainty in Illness Scale than the Instrumental factor ($z = 1.60$, $p = .055$). Although neither factor evidenced a significant bivariate correlation with the Juvenile Arthritis Functional Assessment Report—Children's, the Relationships/Personal Development factor was significantly more correlated with the Juvenile Arthritis Functional Assessment Report—Children's than the Instrumental factor ($z = 2.11$, $p = .017$). All other correlations did not differ significantly across factors.

Discussion

The purpose of the current study was to examine the utility of the IIS–P in a sample of parents and children and adolescents with JRDs by using an exploratory factor analysis to evaluate the factor structure of the IIS–P. In addition, we sought to investigate the convergent validity of the factors by comparing them with common parent- and child- report outcome measures. Although the

Table 4
Correlations of the Illness Intrusiveness Scale—Parent Version With Parent and Child Measures

Measure	1	2	3	4	5	6	7	8
1. Relationships/Personal Development factor		.70***	.52***	.38***	.22*	.34***	.20*	.17
2. Instrumental factor			.51***	.50***	.19*	.30**	.09	.02
3. BSI				.31**	.15	.39***	.20*	.12
4. PPUS					.23*	.29**	.08	.19
5. JAFAR–P						.06	.09	.57***
6. CDI							.26**	.19*
7. CUIS								.20*
8. JAFAR–C								

Note. BSI = Brief Symptom Inventory; PPUS = Parental Perceptions of Uncertainty Scale; JAFAR–P = Juvenile Arthritis Functional Assessment Report—Parent; CDI = Children's Depression Inventory; CUIS = Children's Illness Uncertainty Scale; JAFAR–C = Juvenile Arthritis Functional Assessment Report—Child.
* $p < .05$. ** $p \leq .01$. *** $p \leq .001$.

adult self-report Illness Intrusiveness Ratings Scale has demonstrated good psychometric properties, including reliability, validity, and factor invariance across sexes (Devins et al., 2001; Mah et al., 2011), no studies have examined the psychometric properties of a measure of parental perceptions of illness intrusiveness as a function of their child's pediatric chronic illness.

Results from the current study indicated that the IIS–P has a two-factor structure for parents of youth with JRDs. Specifically, nine of the 13 items loaded onto a factor termed Relationships/Personal Development. This factor contained items that appeared to tap perceived illness intrusiveness in interactions with others (e.g., family members, spouse, and friends) and self-improvement activities (e.g., recreation, community involvement). The second factor, termed Instrumental, contained the remaining four items, which appeared to measure mandatory or necessary activities (e.g., work and diet). Both of the factors were found to have good internal reliability.

It is noteworthy that the final factor structure of the IIS–P differs somewhat from that of the Illness Intrusiveness Ratings Scale (Devins et al., 2001). As previously reported, the Illness Intrusiveness Ratings Scale has a three-factor structure, with a Relationships and Personal Development factor similar to that found in the current study, and an Intimacy factor comprising the sex life and relationship with spouse items. Furthermore, the Instrumental factor of the Illness Intrusiveness Ratings Scale does not contain the diet item, as it failed to evidence a substantial loading. Differences in the factor structure between the Illness Intrusiveness Ratings Scale and IIS–P could occur because individuals are completing this measure as parents of children and adolescents with a chronic illness rather than adults with a medical condition. In this regard, it is possible that parents conceptualize illness interference in a more straightforward manner, as evidenced by the two-factor structure of the IIS–P. Therefore, it may be that adults who are directly affected by a medical condition may indeed experience a different set of challenges to their relationship with their significant others, thereby creating challenges to maintaining intimacy.

Partially consistent with hypotheses, the IIS–P evidenced a significant relationship with the majority of both parent- and child-report outcome measures, indicating that it is an externally valid measure. These results appear to fit well with Kazak and colleagues' (1995) social–ecological model, which describes psychosocial adjustment to be a multisystemic process in which factors associated with the child or adolescent's illness (e.g., diagnosis and severity) impact both the parent's and child or adolescent's ability to cope and adjust. Indeed, parent's perceived illness intrusiveness in activities of daily living, such as relationships with others, self-improvement activities, and instrumental activities, was found to be related to global parent distress and child depressive symptoms. In addition, the IIS–P factors also demonstrated significant associations with parent and child perceptions of illness uncertainty, both of which are constructs previously shown to be related to parent and child and adolescent adjustment (Mullins et al., 2001; Wagner et al., 2003; White et al., 2005). Taken together, for both parents and children or adolescents diagnosed with a JRD, these findings suggest that parental perceptions of illness intrusiveness not only impede on everyday activities, but are also related to levels of distress and perceptions of illness uncertainty.

In examining the correlations between the IIS–P factors and the parent- and child- report outcome measures, the current study directly points to differences between parental perceptions of illness interference and child-reported estimates of functional disability. Although previous research with JRDs has demonstrated large differences in estimates of pain and disability between parents and children and adolescents (Palermo, Zebracki, Cox, Newman, & Singer, 2004), it appears that parental perceptions of illness intrusiveness also may not be directly related to their child or adolescent's level of disability. In other words, parental perceptions of the extent to which their child or adolescent's illness impacts their own life domains may exist independently from the level of functional disability the child or adolescent reports. This finding clearly demonstrates the need to use a multimethod, multiinformant paradigm to gather information from both the parent and child or adolescent when measuring functional disability and the interference it may exert on the family system.

Finally, although the IIS–P factors were similarly correlated with most of the outcome measures, comparisons revealed that the Relationships/Personal Development factor was more highly correlated with the Parental Perception of Uncertainty Scale than the Instrumental factor, whereas a trend in the opposite direction was found for the Child's Uncertainty in Illness Scale. These findings demonstrate that, depending on the informant (i.e., parent vs. child or adolescent), different components of parental perceptions of intrusiveness are related to uncertainty. Parental levels of uncertainty appear to be more related to perceived intrusiveness in activities such as work, finances, and health. Alternatively, child and adolescent levels of uncertainty are linked to perceived intrusiveness in items that loaded on the Relationships/Personal Development factor such as recreation, relationships with family, spouses, and others, sex, self and religious expression, and community involvement. Although speculative, these findings may suggest that, depending on the child or adolescent's age, uncertainty is either directly or indirectly communicated to them by their parents. Based on previous research, it is possible that uncertainty is indirectly communicated to children and adolescents through developmentally inappropriate parenting practices such as elevated levels of overprotection (Mullins et al., 2007).

The current study should be considered within the context of several limitations. First, the current sample was primarily Caucasian, thereby limiting the generalizability of the findings to other races. The current sample of JRDs represents a group of chronic heterogeneous autoimmune disorders that, as a group, shares analogous arthritic features; however, it is important to note that each subtype possesses discrete clinical characteristics. The results of the current study may therefore not reflect valid differences in the relative intrusiveness related to each subtype of JRD. Parents and children and adolescents completed multiple self-report questionnaires. Therefore, it is possible that the results reflect common rater bias or shared method variance. Unlike studies using single-informant methods, however, both parent and child and adolescent informants were used in an attempt to attenuate this concern (e.g., Treutler & Epkins, 2003). Children and adolescents ranged from 7 to 18 years of age, which limited the ability to examine whether the factor structure of the IIS–P varies across developmental periods. Likewise, this broad age range did not allow for investigation of how child or adolescent age may impact the convergent validity of the IIS–P factors. Lastly, extensive demographic information

about the parents of the child or adolescent with a JRD, including the sex and age of the parents, was not available for the entire sample.

Future directions should include replication of the current study, with particular attention being paid to potentially relevant dimensions such as disease subtype, severity of illness, illness duration, and parent demographic information. Because child and adolescent age has been shown to potentially impact perceptions of illness intrusiveness (Andrews et al., 2009), it is particularly important that future studies aim to determine whether the factor structure of the IIS–P is invariant across different child and adolescent ages or developmental levels. Although not a central focus of the article, descriptive analyses suggest that parental perceptions of illness intrusiveness are, on average, higher for ethnic minority groups, particularly African Americans and Native Americans. Future studies should examine ethnic and cultural factors (e.g., equality or autonomy among in-group members; Devins et al., 2009) potentially associated with parental perceptions of illness intrusiveness to increase awareness and address any barriers to positive adjustment outcomes. Furthermore, examining the psychometric properties of the IIS–P in other pediatric populations will help delineate the impact of illness intrusiveness to other childhood chronic medical conditions. Longitudinal research designs are also needed to examine whether the factor structure of the IIS–P remains stable across parents over time, as developmental differences may occur.

The findings of the current study clearly demonstrate that parents may perceive their child or adolescent's JRD as interfering with two correlated, but distinct, indices of activities of daily living that tap their relationships with others/self-improvement and mandatory/necessary activities (e.g., work). Researchers and clinicians interested in examining perceptions of illness interference and the toll that they may take on activities of daily living would be encouraged to use this measure in JRD populations. The current study also demonstrates that two distinct factors of the IIS–P may be used to delineate specific intrusiveness patterns that could be the focus of discussion for pediatricians or clinicians in a clinical context. Collectively, these findings fit well with the Kazak and colleagues (1995) social–ecological theory by demonstrating that parent and child adjustment are closely linked. Furthermore, the current study demonstrates that the IIS–P has utility with parents of children and adolescents with JRDs.

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