Examination of parent–child adjustment in juvenile rheumatic diseases using depression-specific indices of parent and youth functioning

Margaret S Bonner, Rachelle R Ramsey, and Jamie L Ryan
Oklahoma State University, USA

David A Fedele
University of Florida, USA

Larry L Mullins
Oklahoma State University, USA

Janelle L Wagner
Medical University of South Carolina, USA

James N Jarvis
State University of New York at Buffalo, USA

John M Chaney
Oklahoma State University, USA

Abstract
Studies demonstrate a link between parental distress, youth illness appraisals, and depression symptoms in youth with juvenile rheumatic diseases. However, the exclusive use of broadband (i.e. general) measures of parental distress in these studies has resulted in conceptual and clinical imprecision regarding the parent–child adjustment process. Our aim was to reanalyze previously published data (i.e. Wagner et al., 2003) using a depression-specific scale derived from the general adult distress measure in the original study. Parents completed the Brief Symptom Inventory (BSI), youth completed the Child Depression Inventory (CDI), and the Illness Intrusiveness Scale (IIS-C). Thirteen Diagnostic and Statistical Manual of Mental Disorders (Fourth Edition)
depression-specific items from the BSI comprised the parent measure of Depressive Symptoms Scale (DS). Consistent with Wagner et al. (2003), adult DS scores were associated with youth CDI scores. However, youth illness appraisals had unique effects on the parent–child depression relation. Elevated youth perceptions of illness intrusiveness amplified the negative effect of parent depressive symptoms on youth depressive symptoms; decreased illness intrusiveness buffered the negative effect of parent depression. The empirical and clinical implications of assessing parent and youth adjustment in a domain-specific manner are discussed.

**Keywords**
Depressive symptoms, illness intrusiveness, juvenile rheumatic diseases, parent–child interaction

Juvenile rheumatic diseases (JRDs) represent a group of chronic autoimmune disorders that share many clinical characteristics, such as persistent inflammation, restrictions in functional ability, and intermittent pain (Cassidy et al., 2010). Not surprisingly, the combination of functional limitations and extensive disease management efforts associated with illness and disability can increase the likelihood of emotional adjustment difficulties for both youth and their parents (Carter, 1998; Kashikar-Zuck et al., 2008; LeBovidge et al., 2003; McCann et al., 2012; Mullick et al., 2005; Sawyer et al., 2004; Whiting, 2013). Furthermore, multivariate transactional investigations of youth adjustment to pediatric chronic illness indicate that parent and youth emotional distress do not operate independently (e.g. Robinson et al., 2007). In fact, studies of youth with JRDs demonstrate a direct link between parental distress and child emotional functioning, particularly depressive symptomatology (e.g. Ryan et al., 2010).

However, unlike studies examining parent influences on child depression in healthy populations (Goodman, 2007), comparable investigations in the JRD literature typically utilize broadband (i.e. general) measures of parental distress to test this association rather than depression-specific indices of adult emotional functioning (e.g. Ramsey et al., 2013; Ryan et al., 2010; White et al., 2005). Exclusive reliance on general measures of adult distress to examine the association between parent functioning and child depression symptoms presents a number of conceptual and clinical challenges. First, such an approach obscures both conceptual and empirical precision because it does not allow researchers to delineate specific features of parental distress (e.g. depression symptoms) that may be salient determinants of child depression symptoms. From a clinical perspective, the chief concern is that data emanating from existing studies do not help to identify potentially relevant parent symptoms/symptom clusters related to child depression that would inform targeting empirically supported treatment resources for parents of youth with JRDs.

This lack of clarity is further complicated when we consider the complex interplay between parental distress and child illness appraisals in determining depression in youth with JRDs (e.g. White et al., 2005). For example, youth with chronic medical conditions often face a number of physical and functional limitations that can lead them to perceive their illness as interfering with a host of routine activities, even disease-unrelated activities (e.g. peer interactions, school events, and social activities; Adams et al., 2002; Stinson et al., 2012). These perceived illness intrusions are problematic when they become sufficiently generalized to a wide array of interests and result in decreased involvement in enjoyable activities and, subsequently, a limited range of available opportunities for positive reinforcement from the environment. This sequence is thought to set the stage for increased risk of youth depressive symptoms, especially in the presence of increased
parental distress. Indeed, in a sample of youth with JRDs, Wagner and colleagues (2003) found that general parental distress as measured by the Brief Symptom Inventory (BSI; Derogatis, 1993) was associated with child depressive symptoms, but only among youth who also perceived that their illness significantly restricted their participation in a wide array of life domains.

Thus, it is evident that parent emotional functioning is related to child depression symptoms in youth with JRDs, and that this relation is moderated by certain child illness appraisals. However, extant empirical investigations of these associations yield data that are difficult to interpret, both conceptually and clinically. In other words, whereas existing studies utilizing general measures of adult distress reliably demonstrate sensitivity in detecting parent–child adjustment associations, the use of general distress measures in these studies does not provide specificity regarding the precise nature of this relation. The primary aim of the present study was to address whether domain-specific measurement of both parent and youth emotional functioning (i.e., depression symptoms) could reveal more precise data regarding the nature of the relation between parental distress, youth illness appraisals, and youth depressive symptoms in JRD. Specifically, we reanalyzed previously published data from Wagner and colleagues (2003). However, we employed a depression-specific index of parent emotional functioning that was derived from the general distress measure (BSI) used in the original study to examine youth illness appraisals as a moderator in the parent–child adjustment relation.

**Method**

**Participants and procedure**

Participants in the Wagner et al. (2003) study were 45 children and adolescents (29 females) between the ages of 9 and 17 years ($M = 13.66, SD = 2.42$) with a diagnosis of a JRD (juvenile idiopathic arthritis, $n = 27$; systemic lupus erythematosus, $n = 11$; juvenile dermatomyositis, $n = 5$; and juvenile ankylosing spondylitis, $n = 2$) and their parents. The majority of youth lived with both parents and self-identified as Caucasian (42%), followed by Native American (29%), Hispanic American (12%), African American (8%), Biracial (7%), and Asian American (2%). Consent and participation rates were not reported in the original publication and are not reported here.

Participants were recruited from a pediatric rheumatology clinic in a large teaching hospital in the Midwest region of the United States. Participants were recruited by graduate student research assistants through one of two ways. Eligible participants who were attending the rheumatology clinic for an appointment were given study packets for both parent and child to complete and return via postage paid mail ($n = 29$). Potential participants who were not scheduled for an upcoming appointment in the clinic were recruited by telephone and study packets were mailed to them and returned via paid postage mail ($n = 16$). Consent and participation rates were 74% for those recruited in the clinic and 97% for those recruited by telephone. Once study packets were received, participants were compensated $10 for their participation.

**Measures**

**Brief Symptom Inventory.** Parents rated the degree to which they have felt distressed by 53 symptom items in the past week, ranging from 1 (*not a lot*) to 4 (*extremely*). The Depressive Symptoms Scale (DS) used in the present study was developed by an expert in the psychosocial functioning of youth with JRD (JMC) and four graduate level clinical psychology doctoral students by selecting items from the BSI (Derogatis, 1993) that represent *Diagnostic and Statistical Manual of Mental*
Disorders (Fourth Edition; *DSM-IV*) depression symptoms. These 13 *DSM-IV* depression-specific BSI items were summed to comprise the DS, which was the primary measure of parent depressive symptoms in the present study (see Table 1).

This approach was favored over factor analysis for a couple of reasons. First, the sample size ($N = 45$) was insufficient to reliably factor analyze questionnaire data. Furthermore, previous analysis of the structure of the BSI indicates varying degrees of usefulness of the respective nine scales, including the depression scale. For example, Greenblatt and Landsberger (2002) found a six-factor solution for the BSI, and the resulting depression factor included items from other scales that are not considered *DSM-IV* depression symptoms. Internal reliability for the BSI reported in the original study was .97 (Wagner et al., 2003). Internal consistency for the 13-item DS developed for this study was also high ($\alpha = .91$).

**Children’s Depression Inventory.** The Children’s Depression Inventory (CDI; Kovacs, 2003) is a 27-item self-report instrument for children aged 7–17 years that assesses depressive symptoms during the past two weeks. Each item on the CDI comprises a group of three statements that collectively measure the severity of a single depressive symptom. An overall severity score is calculated by summing the 27 items. The CDI has been shown to be a reliable and valid outcome measure with previous JRD samples (Hagglund et al., 2000; White et al., 2005). The CDI demonstrated good internal consistency ($\alpha = .91$) (Wagner et al., 2003).

**Illness Intrusiveness Scale-Child.** The Illness Intrusiveness Scale-Child (IIS-C; Wagner et al., 2003) is a 12-item measure in which children rate (on a 7-point Likert scale) the degree to which they perceive their illness as interfering with their ability to engage in a variety of activities (i.e. school, social, family). Data from JRD samples reveal internal consistency estimates for the IIS-C of .92 (Andrews et al., 2009). Internal consistency for the IIS-C as previously reported in the present sample was .84 (Wagner et al., 2003).

### Table 1. Comparison of brief symptom Inventory Depression Subscale items versus brief symptom inventory *DSM-IV* DS items.

<table>
<thead>
<tr>
<th>Brief Symptom Inventory Depression Subscale</th>
<th>Brief Symptom Inventory Depressive Symptoms Scale (DS)</th>
</tr>
</thead>
<tbody>
<tr>
<td>9. Thoughts of ending your life</td>
<td>9. Thoughts of ending your life</td>
</tr>
<tr>
<td>35. Feeling hopeless about the future</td>
<td>18. Feeling no interest in things</td>
</tr>
<tr>
<td>50. Feelings of worthlessness</td>
<td>25. Trouble falling asleep</td>
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<tr>
<td></td>
<td>27. Difficult making decisions</td>
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<tr>
<td></td>
<td>35. Feeling hopeless about the future</td>
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<td></td>
<td>36. Trouble concentrating</td>
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<td></td>
<td>39. Thoughts of death or dying</td>
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<tr>
<td></td>
<td>49. Feeling so restless you couldn’t sit still</td>
</tr>
<tr>
<td></td>
<td>50. Feelings of worthlessness</td>
</tr>
<tr>
<td></td>
<td>51. Feelings of guilt</td>
</tr>
</tbody>
</table>

*DSM-IV*: *Diagnostic and Statistical Manual of Mental Disorders* (Fourth Edition); DS: Depressive Symptoms Scale.
The Juvenile Arthritis Functional Assessment Report-Child. The Juvenile Arthritis Functional Assessment Report-Child (JAFAR-C; Howe et al., 1991) is a 23-item measure completed by children to provide subjective estimates of their functional ability. Respondents rate how often they are able to perform 23 daily tasks (e.g. buttoning a shirt, getting in and out of bed) on a 3-point Likert scale, ranging from 0 (all the time) to 2 (almost never). Higher sum scores on the JAFAR-C indicate greater functional disability ($M = 6.46; SD = 6.46$). The JAFAR-C has demonstrated good construct validity and internal consistency (Howe et al., 1991). Cronbach’s alpha reported for the present sample was .92 (Wagner et al., 2003).

Physician-Rated Functional Disability. Physician-Rated Functional Disability (PRFD; Hochberg et al., 1992) was assessed as an index of disease activity. Following a routine medical visit, the pediatric rheumatologist classified participants into one of the four functional ability classes, ranging from Class I (limited to no disability in vocational and self-care activities) to Class IV (severe disability in vocational and self-care activities). The PRFD has been shown to be a valid indicator of functioning disability in JRD populations (Hochberg et al., 1992). The overall classification for this sample was low ($M = 1.5, SD = .61$) (Wagner et al., 2003), suggesting relatively minimal functional disability.

Results

Preliminary analyses

Three separate partial correlations controlling for demographic (age, gender) and disease (JAFAR-C, PRFD, disease duration) covariates were calculated to examine the association between the CDI and DS compared with conventional BSI dimensions (i.e. the Global Severity Index (GSI) and the Depression subscale from Derogatis, 1993). Analyses revealed comparable associations between the CDI and the DS ($pr = .46, p < .05$), the GSI ($pr = .44, p < .05$), and the Depression subscale ($pr = .38, p < .05$). Furthermore, $r$ to $z$ transformations revealed no significant differences among the three partial correlations (all $ps > .05$). Preliminary results indicated that the 13-item DS measure developed for this study was as reliably associated with CDI symptoms as the GSI scale used in the original Wagner et al. (2003) study and the standardized BSI Depression subscale.

Primary analyses

We constructed a hierarchal regression equation similar to Wagner et al. (2003), except that the DS measure served as the dependent variable instead of the global symptom index (GSI) used in the original study to test illness intrusiveness as a moderator in the parent–child distress relation. Demographic (i.e. gender, age) and disease variables (i.e. disease duration, PRFD, JAFAR-C) were entered on steps 1 and 2 of the hierarchal regression. Parent depressive symptoms (DS), child illness intrusiveness (IIS-C), and the DS $\times$ IIS-C interaction terms were entered on step 3. Both the DS and IIS-C were centered to reduce multicollinearity (Aiken and West, 1991).

Similar to Wagner et al. (2003), both the DS and the IIS-C demonstrated direct associations with CDI depressive symptoms beyond the influence of demographic and disease variables; furthermore, the interaction of DS and IIS-C contributed significant incremental variance to CDI scores, $r(44) = 2.27, p = .03$. Thus, regression results revealed that children’s perceived illness intrusiveness moderated the association between parent and youth depression symptoms.
Post hoc probes

Post hoc probes were conducted to examine the relation between parent and youth depressive symptoms under high and low levels of youth’s perceived illness intrusiveness. First, conditional moderator variables were computed for low illness intrusiveness (Lo-IIS) and high illness intrusiveness (Hi-IIS). Two new interaction terms were then computed from these conditional variables (i.e. Lo-IIS x DS, Hi-IIS x DS). Separate regression analyses were conducted in which demographic and disease covariates were entered on steps 1 and 2 in both the equations. On step 3 of the first equation, Hi-IIS, DS, and the Hi-IIS x DS interaction terms were simultaneously entered. Similarly, on step 3 of the second equation, Lo-IIS, DS, and the Lo-IIS x DS interaction terms were simultaneously entered (see Holmbeck, 2002).

Consistent with Wagner et al. (2003), results revealed a significant positive slope for the DS regression line under Hi-IIS conditions, $t(1) = 3.54, p = .02$. In contrast to Wagner et al. (2003), post hoc results revealed a significant negative slope for the DS regression line under Lo-IIS conditions, $t(1) = -2.43, p = .001$. Thus, we replicated Wagner et al.’s (2003) primary findings that, regardless of youth illness appraisals, youth depressive symptoms were functionally equivalent when parent depressive symptoms were low. Furthermore, elevated parent depressive symptoms were associated with upward variations in youth depressive symptoms in the presence of higher levels of youth perceived illness intrusiveness. Unlike Wagner et al. (2003), however, we found that elevated parent depressive symptoms were associated with decreased youth depressive symptoms in the presence of low perceived illness intrusiveness. This unique finding indicated that more favorable illness perceptions buffered youth against the negative influence of parent depressive symptoms (see Figure 1).

Discussion

The present study was designed to examine more precisely the nature of the relation between parental distress, youth illness appraisals, and youth depression symptoms in a sample of youth.
with JRDs. We reanalyzed data from a previously published investigation by Wagner and colleagues (2003) utilizing a depression-specific scale that was derived from the general adult distress measure (BSI) used in the original study. Consistent with Wagner et al. (2003), results indicated that youth depressive symptoms varied as a function of both parent depressive symptoms and youth illness appraisals. Specifically, when parents reported few depressive symptoms, youth depressive symptoms were indistinguishable regardless of high or low illness intrusiveness appraisals. As parent depressive symptoms increased, youth depressive symptoms increased for those who reported elevated levels of illness intrusiveness.

Importantly, however, our reexamination using a depression-specific index of parent functioning yielded unique findings regarding the role of youth perceived illness intrusiveness. Specifically, while Wagner et al. (2003) observed no effect for low illness intrusiveness on the parent–child adjustment association, our data indicated that decreased youth appraisals of illness intrusiveness played an advantageous role and buffered youth against the negative downstream effect of depression-specific parent emotional distress. Thus, the present data suggest that when parent and youth distress are examined in a domain-concordant manner (i.e. depression), elevated perceptions of illness intrusiveness amplify the impact of parental distress on youth depressive symptoms; decreased illness intrusiveness significantly minimizes it. Taken together, results of the original study and our reexamination suggest that increased youth appraisals of illness intrusiveness interact with both general and depression-specific parental distress to produce elevations in youth depressive symptoms. However, decreased illness intrusiveness appraisals mitigate the negative effects of elevated parental distress on youth depressive symptoms only when parental distress is assessed in a depression-specific manner.

The unique findings from our investigation have important clinical implications for adjustment outcomes in youth with JRDs. Foremost, the protective function observed for decreased illness intrusiveness against the negative impact of parent depression-specific symptoms highlights the paramount importance of addressing maladaptive youth illness appraisals and screening for depressive symptoms. Elsewhere, Wagner and Smith (2007) and Wagner and colleagues (2010) have demonstrated the feasibility of conducting routine screening in pediatric clinics as well as the benefits of brief self-management interventions that enhance cognitive and behavioral skills. Our findings also suggest that clinicians may need to be particularly vigilant to the potential for youth adjustment problems if parent reports of distress are characterized by predominantly depression-related symptoms. Our findings support emerging research highlighting the importance of directly targeting clinical interventions toward parental distress associated with illness and disability (Resch et al., 2012; Ryan et al., 2010; Tifferet et al., 2011). Evidence suggests that these interventions not only improve parent emotional functioning (Mullins et al., 2012), but also have beneficial downstream effects on child adjustment outcomes (Fedele et al., 2013).

The current study should be interpreted in light of several limitations. First, all the measures utilized in the original investigation were self-report instruments, raising the possibility that the observed associations may have been artificially inflated due to shared method variance (e.g. Podsakoff et al., 2003). However, because data came from multiple informants, our analyses did allow for the examination of information regarding emotional functioning gathered independently from both youth and parents. Also, the vast majority of our sample (88%) was mothers, which precludes the generalizability of our interpretations to fathers of youth with JRDs. Although reports in the literature suggest that maternal and paternal variables may differentially impact youth adjustment to illness (Chaney et al., 1997; McNeill, 2004; Pelchant et al., 2003, 2007; Tifferet et al., 2011), there were simply too few fathers in the current sample to reliably examine these potential effects.
Clearly, there is a need for similar studies on fathers of youth with JRDs to determine whether similar domain-concordant adjustment relations exist. Finally, the DS measure of parent depressive symptoms developed for the present study was not subjected to rigorous psychometric evaluation to establish its validity, normative information, or severity thresholds. Keeping this in mind, however, our primary interest was to examine the manner in which youth depressive symptoms varied as a function of youth illness appraisals and varying levels of parent depressive symptoms, not threshold or diagnostic levels of depression. Although preliminary evidence for the reliability and validity of the DS measure was demonstrated in the present study, the inclusion of standardized measures of adult depressive symptoms (e.g. Beck Depression Inventory; Beck et al., 1996) in future studies of parent–child depression associations in youth with JRDs would alleviate these psychometric concerns.

Despite these considerations, our findings emphasize the importance of examining the influence of parental distress on youth adjustment to chronic illnesses like JRDs. The present results also serve as a reminder of the complex interplay between parental distress and child illness appraisals in determining youth adjustment outcomes. The unique findings of our study point to the need for considering domain-concordant indices of parent and child emotional distress in future studies, both for elucidating the complexities of the parent–child adjustment relation and for guiding appropriate treatment resources for youth with JRDs and their parents. Our results do not advocate for the discontinued use of general measures of parent emotional functioning; however, it is imperative that researchers are cognizant of the limitations and potential exceptions to interpreting such results. Domain-specific measurement approaches may provide for more precise identification of adjustment dimensions (e.g. anxiety, depression) that have particular relevance for specific pediatric illness populations.

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**References**


