Parent Pain Responses as Predictors of Daily Activities and Mood in Children with Juvenile Idiopathic Arthritis: The Utility of Electronic Diaries

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Abstract
The present study used electronic diaries to examine how parent responses to their child’s pain predict daily adjustment of children with juvenile idiopathic arthritis (JIA). Nine school-aged children with JIA along with one of their parents completed thrice-daily assessments of pain-related variables, activity participation, and mood using handheld computers (Palm® pilots) for 14 days, yielding a potential of 42 child and parent assessments for each dyad. Children provided information on current pain level, mood, and participation in social, physical, and school activities. Parents independently rated their own mood as well as their behavioral responses to their child’s pain at the same time points using a separate handheld computer. Results of multilevel modeling analyses demonstrated that use of “protective” pain responses by parents significantly predicted decreases in child activity and positive mood, with an even stronger inverse relationship between protective pain response and positive mood observed in children with higher than average disease severity. Protective pain responses were not found to be significantly predictive of daily negative mood in children. The use of “distracting” responses by parents significantly predicted less child activity restrictions but only in children having higher disease severity. There also was an unexpected trend in which parent use of more distracting pain responses tended to be associated with lower child positive mood. These preliminary findings suggest the importance of the parent in influencing adjustment in children with JIA and lend support to the incorporation of parents into comprehensive pain management approaches. The potential benefits of using electronic daily diaries as a strategy to examine pain and adjustment in children with JIA pain are discussed. J Pain Symptom Manage 2010;39:579–590. © 2010 U.S. Cancer Pain Relief Committee. Published by Elsevier Inc. All rights reserved.

Key Words
Children, juvenile arthritis, pain, parent, electronic diary

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Introduction

Despite significant advances in medical treatments for children with juvenile idiopathic arthritis (JIA), persistent pain is a common complaint. Pain has been shown to be a primary determinant of the physical, emotional, and social functioning in these children. Disease variables such as the level of inflammation do not fully explain the extent to which pain affects function and adjustment in children with JIA; thus, treatments that solely target disease activity may be inadequate to optimize health outcomes. The biobehavioral model of pain adds to our understanding of impairment in children with JIA by emphasizing factors in addition to disease variables, such as emotional and social influences.

Studies based on samples of children with idiopathic chronic pain conditions have increasingly recognized the important role of the family context. In particular, parent responses to a child’s pain may partially explain the extent to which pain affects the child’s physical, emotional, and social well-being. Specifically, in children with chronic headache and chronic abdominal pain, parent responses characterized by high levels of attention or vigilance to pain, as well as responses that convey permission to avoid daily responsibilities because of pain (i.e., protective responses), have been associated with greater functional disability such as reduced social and physical activities. Conversely, responses that promote active coping efforts and refocus the child’s attention away from pain sensations (i.e., distracting responses) decrease functional disability, such as school absenteeism.

These findings are consistent with social learning theories that emphasize how responses to pain can lead to pain-related disability. Parent variables also are relevant in predicting the health status of children with JIA. For example, studies have shown that parental emotional distress, the extent to which the parent perceives his or her child as vulnerable and prone to developing medical problems, and the parent’s own history of chronic pain are each associated with the physical and psychological adjustments of the child. However, research on children with JIA has not yet fully explored how parent pain responses relate to physical, emotional, and social aspects of the child’s daily life.

Prior studies evaluating the influence of parent responses to children’s pain are limited by cross-sectional design (i.e., single-point assessment) and reliance on paper-and-pencil measures that examine the usual or typical parent response patterns. This methodology assumes that parent pain responses, children’s functional ability, and their association are relatively consistent over time. However, previous studies challenge this assumption, showing that caregivers of children with chronic arthritis interact differently with the child depending on the child’s current pain level and other disease symptoms. An additional limitation to cross-sectional methodology is that retrospective recall of pain and associated symptoms is often inaccurate. Consequently, an innovative approach is needed to study how day-to-day variations in parent responses to pain predict changes in functioning in children with JIA.

The purpose of the present study was to examine the relationship between parents’ pain responses and the daily activity (i.e., physical, social, academic, and emotional functioning) of children with JIA using handheld computers (Palm® pilots). The use of handheld computers to collect data from participants within and across days, referred to as “computerized ecological momentary assessment,” allows for in-the-moment tracking of pain and pain responses over time. We hypothesized the following: 1) greater use of “distracting” parental pain responses (responses that promote active coping and self-management of pain in children) will predict less reduction in daily physical, academic, and social activities and less adverse effects on children’s daily mood; 2) greater use of “protective” parental pain responses (responses that promote passive or avoidant coping and reinforce illness behaviors in children) will predict greater reductions in daily activities and greater adverse effects on children’s daily mood; and 3) relationships observed in Hypotheses 1 and 2 will not be significantly affected by child’s daily pain intensity levels or disease severity.

Methods

Participants

Participants were recruited during routine follow-up visits at the Pediatric Rheumatology
Clinic at Duke University Medical Center over a three-month recruitment interval. The target sample size for this study was 10 dyads and was based on an estimate of the number of dyads that could be recruited within the specified time interval, given available resources. Fifteen consecutive families were approached before obtaining the target sample size of 10 dyads. Families that declined participation cited time constraints as the primary reason. Technical problems in retrieving data from one of the electronic diary devices resulted in the loss of one child-parent dyad’s data, leaving a final usable sample of nine dyads.

Of the final nine child participants, eight were female; seven self-identified as Caucasian (with the remaining two self-identifying as African American); and the average age was 12.3 years (standard deviation [SD] = 3.4 years, range 8–16 years). All child participants were diagnosed with JIA by a pediatric rheumatologist based on criteria established by the International League Against Rheumatism. All child participants had polyarticular arthritis; seven had polyarticular JIA, and two had spondyloarthropathy. Disease severity ratings based on physician assessment at the initial study visit were as follows: two patients in remission, three patients with mild disease severity, three patients with moderate disease severity, and one patient with severe disease severity. Seven children were on methotrexate, and two were on an anti-tumor necrosis factor agent. Five children in the sample also were taking scheduled nonsteroidal anti-inflammatory drugs.

Of the final nine parents, eight were the biological mothers and one was the biological father. Average age of the parent participants was 40 years (SD = 6 years, range 31–58 years). Five of the parents were married, three were divorced, and one was widowed. Combined family income ranged from less than $10,000 to $130,000, with an average of $80,000.

Procedure

Consecutive patients between the ages of 8 and 16 years with a diagnosis of JIA were pre-screened by clinic staff using clinic schedules. Children and their primary caregiver were approached by a research assistant immediately following their clinic visit. The intent and requirements of the study were explained to the family by the research assistant. Those interested in participating completed parental permission and child assent forms approved by the Institutional Review Board of Duke University Medical Center.

After providing permission and assent, both the child and parent were independently trained in using Palm® pilots (Model m505). Both the child and parent were given their own Palm® pilot to use for the study. The Palm® pilots were programmed to signal an auditory alarm three times per day (morning, afternoon, and evening) at times individually tailored to the dyad’s daily schedule. Times were programmed to maximize the chances that the parent and child would have had recent interaction. The morning assessment was scheduled just after awakening and before school or work, when the child and parent would likely be together. The afternoon assessment was scheduled for an after-school time, and the evening assessment was scheduled before bedtime. Repeat alarms continued to go off at 30-second intervals for an additional two minutes if responses to the diary questions were not initiated. If no responses were entered within 30 minutes of the alarm, the assessment was no longer available to complete until the next scheduled assessment point. Following training and the completion of sample diary entries, parents and children took the Palm® pilots home and independently completed questions at the programmed times for the next 14 days (42 occasions per dyad, or a possible 378 observations across the nine dyads). All data were time- and date-stamped and uploaded to a database on return of the devices at the end of the study.

Child Electronic Diary Measures

Pain. At each assessment, children were asked whether they were currently in pain (without the source of pain being specified) and if so, how intense their current pain was. Pain intensity was measured on a 50 mm electronic visual analog scale (converted to a 0–100 continuous scale for analyses) with anchors “no pain” and “worst pain possible.” Electronic visual analog scales have been previously validated in pediatric populations and are comparable to their paper-based counterparts.

Mood. Using a modified version of the 10-item Positive and Negative Affect Schedule for Children (PANAS-C), children also were
asked to rate the extent to which they were currently feeling a given affective descriptor such as “excited” or “upset” using a five-point rating scale ranging from “very slightly or not at all” to “extremely.” The measure yields two modestly correlated scales (positive and negative affect). Both the positive and negative affect scales were used as indices of emotional functioning in the present study. Between-person internal consistency estimates (Cronbach’s alphas calculated on each patient’s item scores aggregated across days) were 0.96 for positive affect and 0.77 for negative affect.

Activity Interference. The level of current activity interference was assessed using 11 items adapted from the Child Activity Limitations Questionnaire.25,26 Children were asked to rate the extent to which they were currently reducing their involvement in social activities (e.g., activities with friends and family, group or club activities, hobbies), physical activities (e.g., sports, walking, lifting or carrying things, chores), and academic activities (e.g., writing, doing schoolwork, participating in school). Consistent with prior diary studies in children with arthritis,27 response categories were decreased from the original measure to a three-point scale (reducing the activity “not at all,” “a little,” or “a lot”) to facilitate repeated responding via an electronic diary. An extra category of “not applicable” was added for the school items. Responses were summed at each assessment point and within each category (social, physical, and academic). Responses of “a little” or “a lot” were then combined to compute the percentage that children reported cutting back on overall activities and to compute the percentages of activity reductions within the social, physical, and academic domains. Between-person internal consistency estimates (Cronbach’s alphas averaged across patients and days) for the total scale was 0.95. The social and physical items yielded sufficient internal consistency (0.86 and 0.85, respectively) to warrant subscale analyses, whereas the academic items did not (Cronbach’s alpha of 0.35) in part because of low variability on the items, (i.e., in 98% of instances, children reported no reduction in school attendance or schoolwork). Thus, the academic subscale was not evaluated separately in analyses, but academic items were still included for analyses involving total scale scores.

Parent Electronic Diary Measures

Interaction with Child. At each assessment, parents were first asked whether they were presently with their child to gauge the number of assessments when parents and children were together.

Mood. Parents were then asked to rate their own current mood using the PANAS.28 The adult PANAS is a 20-item scale that includes descriptors of both positive and negative affects. Participants indicate the degree to which they experienced a given affect that day using a response scale of 1 (“very slightly or not at all”) to 5 (“extremely”). Raw scores for negatively valenced descriptors are averaged to comprise an index of negative affect, and scores for positively valenced descriptors are averaged to comprise an index of positive affect. Many studies, including daily diary studies,29 have used this instrument and demonstrated internal consistency and validity. Between-person internal consistency estimates for the present study were 0.97 for positive affect and 0.85 for negative affect.

Caregiver Responses to Child Pain. Caregiver pain responses were assessed using 14 items adapted from the Adult Responses to Children’s Symptoms Questionnaire (ARCS).9,30 The ARCS assesses three categories of caregiver behavioral responses to child pain: protective responses, discouraging or minimizing responses, and distracting or monitoring responses. Protective responses are responses that either positively reinforce pain complaints through increased parental presence or attention or negatively reinforce pain complaints through permission to escape or avoid unwanted roles or responsibilities. Discouraging responses are responses that either are overtly negative (e.g., expressing anger or frustration about the child’s pain complaint) or imply lack of concern or support. Distracting or monitoring responses comprise responses that monitor the child’s level of pain through inquiry or facilitate distraction away from pain sensations through strategies such as involvement in activities. For the present study, parents were asked to indicate whether they used a specific response since they last completed an electronic diary entry. For analyses,
responses were summed within each category of the original scale to derive separate subscale scores for protective, discouraging or minimizing responses, and distracting or monitoring responses. The between-person internal consistency estimates (Cronbach’s alphas averaged across parents and days) were 0.81 for protective responses and 0.83 for distracting or monitoring responses. Discouraging or minimizing pain responses were reported on very few occasions that a separate subscale could not be validly computed. Thus, only two subscales (protective responses and distracting or monitoring responses) were used for the analyses.

Sample Characteristics
Data on child demographics (date of birth, gender, race, and grade in school) and parent demographics (age, marital status, and combined family income) were collected for descriptive purposes via a brief questionnaire. Disease subtype and medication data were obtained from the electronic medical record. All children were classified along a four-point disease severity scale ranging from “in remission” (1) to “severe” (4) by the same pediatric rheumatologist based on most recent joint count and erythrocyte sedimentation rate.31

Analyses
Descriptive analyses were conducted on each of the daily measures and summarized using daily means, variances, and frequency distributions. Multilevel modeling was used for primary analyses to account for repeated measurements (referred to as “Level 1 units”) nested within each child-parent dyad (referred to as “Level 2 units”). This form of analyses is regarded as being the most accurate for the type of data furnished by computerized ecological momentary assessment.32,33 The type of multilevel model used for primary analyses is often referred to as a two-level “intercepts and slopes as outcomes” model, with randomly varying intercepts and nonrandomly varying slopes.34,35 To test our hypotheses, the number of distracting and protective pain responses endorsed by parents at a given time was separately specified as “Level 1” predictor variables; child activity interference, positive affect, and negative affect scores were separately specified as “Level 1” outcome variables. The relationship between a given predictor variable and an outcome variable was then estimated for each child by a Level 1 slope coefficient while adjusting for any effects of pain intensity. These Level 1 slope coefficients were then evaluated as outcome variables at Level 2 to determine the statistical significance of the average slope coefficients for this sample (Hypotheses 1 and 2) and the extent to which these average slope coefficients changed because of the child’s level of disease severity (Hypothesis 3) (see Appendix for further explanation). Hierarchical linear modeling software36 was used to furnish maximum likelihood estimates of the model parameters.

To test for changes in responses that may occur simply as a function of completing multiple assessments over time (e.g., “reactivity effects”), temporal trends in the reporting of parent pain response subscales and child functioning subscales were evaluated (i.e., by specifying “day” as a sole Level 1 predictor variable and specifying parent pain response subscales or child functioning subscales as the Level 1 outcome variable). Unconditional means (i.e., intercept only models at Level 1 and Level 2) were fit before proceeding with our primary analyses. The unconditional means model permits an evaluation of the proportion of total variance in child functioning and parent responses attributable to individual differences (the “intraclass correlation coefficient”).

Results
Descriptive Statistics
Table 1 presents descriptive statistics on the daily child and parent measures. The parent response rate was 93% of days (7% missing responses, ranging from 0% to 50%), and the child response rate was 87.5% of days (12.5% missing response, ranging from 0% to 36%). Parents reported being present with their child for 74% of the assessments with no systematic association between presence with child and time of assessment (morning, afternoon, and evening), \( \chi^2(2), n = 350, P = 0.81 \). Most (80%) of the children in the sample reported that they would prefer to use electronic diaries relative to completing questions on paper. Those who said that they would prefer paper questionnaires stated that they did not like the imposed time limit for completing questions on the
electronic diary. Other suggestions included having a belt clip for the Palm®/C210 pilots, reducing the redundancy of completing the same questions at each time point during the day, and providing an option to change the times at which assessments were programmed to be completed following the baseline study visit.

Children reported reducing anywhere between 0% and 82% of total activities at any given assessment, with the area of most activity reductions being in the physical domain (M = 25.5%, SD = 38.4%). Parents reported using at least one protective response to their child’s pain on 100% of assessments, at least one distracting or monitoring response to their child’s pain on 46% of assessments, and at least one discouraging or minimizing responses to their child’s pain on 6% of assessments.

The total percentage of child activity reductions and scores on the parent pain response scales (protective responses and distracting or monitoring responses) did not significantly change as a function of more experience with the diaries alone across days, t(8) = 0.21–1.33, P = 0.20–0.83, suggesting no significant reactivity effects. Intraclass correlation coefficients (interpreted as an estimate of the proportion of total variability in the given variable that can be accounted for by “baseline” differences between dyads) were 0.89 for total activity reduction percentage, 0.77 for parent distracting or monitoring responses, and 0.72 for parent protective responses.

**Multilevel Analyses**

**Parent Protective Pain Responses on Child Activity Reduction and Mood.** The first set of models evaluated the association of parent protective pain responses on child activity reductions and mood (controlling for pain intensity at the given moment). These results are summarized in Table 2. As predicted, greater use of protective pain responses at a given moment was significantly associated with greater total child activity reductions, t(324) = 3.43, P < 0.01. Disease severity did not significantly modify this relationship, although there was a trend suggesting a more pronounced association of protective pain responses on reductions in activities for children with higher disease severity, t(324) = 1.65, P = 0.10. When examining activity domains separately, greater use of protective pain responses significantly predicted greater reductions in social activities, t(324) = 3.52, P < 0.01, and physical activities, t(324) = 2.35, P = 0.02. Also as predicted, greater use of protective pain responses at a given moment significantly predicted lower child positive mood, t(324) = −3.54, P < 0.01. Disease severity unexpectedly moderated this relationship, suggesting a more pronounced adverse effect of protective pain responses on child positive mood for children with higher disease severity, t(324) = −3.31, P < 0.01. Parent protective responses had no significant effect on child negative mood, t(324) = −0.91, P = 0.36, and disease severity did not modify this relationship, t(324) = 1.15, P = 0.25.

**Parent Distracting and Monitoring Pain Responses on Child Activity Reduction and Mood.** The second set of models evaluated the effect of parent distracting and monitoring pain responses on child activity reductions and

### Table 1

<table>
<thead>
<tr>
<th>Variable</th>
<th>Possible Response Scale</th>
<th>Mean (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pain intensity</td>
<td>0–100</td>
<td>28.3 (11.7)</td>
</tr>
<tr>
<td>Percentage of total activities reduced</td>
<td>0–100</td>
<td>21.3 (29)</td>
</tr>
<tr>
<td>Percentage of physical activities reduced</td>
<td>0–100</td>
<td>29.4 (38.8)</td>
</tr>
<tr>
<td>Percentage of social activities reduced</td>
<td>0–100</td>
<td>25.5 (38.4)</td>
</tr>
<tr>
<td>Percentage of school activities reduced</td>
<td>0–100</td>
<td>4.8 (12.6)</td>
</tr>
<tr>
<td>Child positive affect</td>
<td>1–5</td>
<td>3.8 (0.9)</td>
</tr>
<tr>
<td>Child negative affect</td>
<td>1–5</td>
<td>1.2 (0.3)</td>
</tr>
<tr>
<td>Parent protective pain responses</td>
<td>0–6</td>
<td>3.0 (2.0)</td>
</tr>
<tr>
<td>Parent distracting or monitoring pain responses</td>
<td>0–3</td>
<td>1.0 (1.1)</td>
</tr>
<tr>
<td>Parent discouraging or minimizing pain responses</td>
<td>0–2</td>
<td>0.0 (0.2)</td>
</tr>
<tr>
<td>Parent positive affect</td>
<td>1–5</td>
<td>3.6 (0.8)</td>
</tr>
<tr>
<td>Parent negative affect</td>
<td>1–5</td>
<td>1.1 (0.3)</td>
</tr>
</tbody>
</table>

*These values represent medians instead of means for easier interpretation because the median is a possible value for a dyad, whereas the mean (which would contain decimal values and suggest a “fraction of a pain response”) is not.
### Table 2

Summary of Multilevel Findings for Parent Pain Responses on Child’s Activity Reductions and Mood

<table>
<thead>
<tr>
<th>Predictor Variables</th>
<th>Total Activity Reduction</th>
<th>Social Activity Reduction</th>
<th>Physical Activity Reduction</th>
<th>Positive Affect</th>
<th>Negative Affect</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>$b \pm SE$</td>
<td>$t$</td>
<td>$b \pm SE$</td>
<td>$t$</td>
<td>$b \pm SE$</td>
</tr>
<tr>
<td>Level 2 intercepts</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Protective responses</td>
<td>$1.63 \pm 0.48$, SE 3.43</td>
<td>$2.44 \pm 0.69$, SE 3.52</td>
<td>$1.51 \pm 0.64$, SE 2.35</td>
<td>$-0.74 \pm 0.21$, SE $-3.54^*$</td>
<td>$-0.96 \pm 0.06$, SE $-0.91$</td>
</tr>
<tr>
<td>Distracting responses</td>
<td>$1.45 \pm 0.91$, SE 1.59</td>
<td>$1.73 \pm 1.32$, SE 1.31</td>
<td>$2.02 \pm 1.23$, SE 1.64</td>
<td>$-0.67 \pm 0.41$, SE $-1.65^*$</td>
<td>$-0.03 \pm 0.12$, SE $-0.28$</td>
</tr>
<tr>
<td>Level 2 slopes</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Protective responses $\times$ disease severity</td>
<td>$0.95 \pm 0.50$, SE 1.65</td>
<td>$0.94 \pm 0.73$, SE 1.28</td>
<td>$0.86 \pm 0.68$, SE 1.26</td>
<td>$-0.72 \pm 0.22$, SE $-3.31^*$</td>
<td>$0.96 \pm 0.05$, SE 1.15</td>
</tr>
<tr>
<td>Distracting responses $\times$ disease severity</td>
<td>$-3.23 \pm 1.09$, SE $-2.98^*$</td>
<td>$-5.87 \pm 1.57$, SE $-3.73^*$</td>
<td>$-2.26 \pm 1.16$, SE $-1.95^*$</td>
<td>$-1.36 \pm 0.47$, SE $-2.86^*$</td>
<td>$0.04 \pm 0.11$, SE 0.38</td>
</tr>
</tbody>
</table>

Values following "$\pm$" are estimated standard errors (SEs) associated with the regression coefficient. "$b$" coefficients for the "Level 2 intercepts" represent the estimated average Level 1 slope (i.e., the estimated average change in the given outcome variable associated with each additional endorsed parent pain response in that parent pain response category, while holding daily pain intensity constant at average levels at Level 1 and baseline disease severity constant at average levels at Level 2). "$t$" coefficients for the "Level 2 slopes" represent the estimated change in the corresponding Level 2 intercepts associated with dyads in which the child is one unit away from the mean of the sample on disease severity.

$P<0.05$.

$P<0.10$.

Exploratory analyses first evaluated whether parent pain responses (i.e., protective, or...
Discussion

Using electronic diary methods, this study evaluated the association between parents’ responses to their child’s arthritis pain and the functional consequences for the child. Results indicated substantial variation in the extent of activity reductions reported by a child at any given time, ranging from no social, physical, or academic activity cutbacks to cutting back on nearly all activities that were reported on. Large variations in parents’ reports of how they responded to their child’s pain also were observed, but parents reported most frequently using protective responses and almost never using discouraging or minimizing responses. Greater use of protective responses by parents at a given time was found to be associated with significantly more child activity reductions in all areas and lower child positive mood. Greater use of distracting and monitoring responses by parents was found to be significantly associated with fewer activity reductions and lower positive mood but only for children with more severe disease.

The significant findings about parent pain responses are consistent with prior studies using other chronic pain samples. Prior studies have shown that protective pain responses result in increased school absenteeism and reduced social and physical activities possibly because children learn to cope with pain in more passive ways through escape or avoidance and primarily rely on caregivers for coping, in turn often leading to poorer functional outcomes. Given these relationships, it is especially important to understand the role of protective responses in children with JIA. During flare-ups, some parents may have a tendency to protect their child and encourage avoidance of activities. The results of the present study suggest, however, that the extent to which parents choose to use protective responses is not significantly dependent on the child’s level of disease activity as rated by a pediatric rheumatologist and that such responses overall might actually lead to greater daily reductions in the child’s physical and social activities as well as less positive mood. Thus, health care providers may be able to improve child health outcomes by teaching parents more effective responses to their child’s pain. In addition, educating parents about the relationships between parent pain responses and their child’s mood and participation in activities may improve child quality of life.

Although in the present study we were unable to identify parent pain responses that universally seemed to promote positive child outcomes, distracting responses were associated with maintenance of involvement in activities, at least in those children rated as having moderate to severe disease. Parents of children with greater disease severity also used significantly more distracting responses relative to parents of children with lower disease severity. This is interesting in light of a prior experimental study of parent-child interactions in
children with JIA. In that study, parents of children with greater disease severity were more directive of their children’s behavior and more likely to set structure and rules than parents of children with less severe arthritis or no chronic disease. In the present study, greater use of distracting responses by parents was associated with positive activity outcomes for children with more severe disease. This may suggest that at higher levels of disease severity, parents may become more directive in offering suggestions of distraction, and this may help these children maintain their activities despite the severity of symptoms. However, greater use of distracting parent responses also predicted lower positive mood in children with more severe arthritis. Given that positive mood in this study was based on descriptors that largely connote arousal (e.g., “excited,” “joyful”), perhaps greater activity engagement in children with more severe disease was more draining or difficult. Indeed, a post hoc evaluation of correlations between mean scores on a computed index of positive emotions high in “arousal” and total activity involvement showed that this relationship was strong and positive for children lower in disease severity (suggesting that more activity involvement is expectedly associated with having more arousing positive emotions for these children) but became weaker and in the opposite direction for children in the sample with higher disease severity (suggesting that more activity involvement is associated with having less arousing positive emotions in these children). Causality clearly cannot be assumed with such an analysis, but it suggests the potential importance of disease severity as a moderator when considering clinical recommendations. Parent responses that lead to more activity engagement may inadvertently result in lower positive mood for children with more active disease. Alternatively, perhaps distracting parent responses were more directive or demanding for children with higher disease severity such that these children might “passively” comply with engaging in more activities but would not experience enjoyment and an increase in positive mood. Clearly, more study is indicated to make recommendations to parents about how to respond to their children with arthritis in a way that facilitates both optimal activity and mood outcomes.

This study is the first, to our knowledge, to use electronic diary methodology to simultaneously capture both child and parent data, and this novel methodology seemed to yield clinically relevant data worthy of further exploration. Electronic diary methodology has several advantages for studying variables that fluctuate in meaningful ways over time by offering improved response validity, reduced recall bias, and relative ease of use when tracking variables at multiple times within and across days. Although the sample used in the present study was relatively small, the number of observations analyzed per child was 42, thus helping to offset the usual limitations of small samples. Similar to prior studies using electronic diaries to study pain in children with arthritis, the results of the present study suggest relatively good completion rates on the electronic diaries allowed us to track elements of the daily social context in the child’s environment, whereas past studies have generally been more experimentally contrived. In all but one case, no technical problems arose in using the electronic diaries. In the one instance of technical problems, the data were completely lost. Future studies might use continual wireless upload to a Web-based server to prevent significant data loss.

There are several limitations of the present study. Although we obtained multiple assessments over time on each parent-child dyad, the small sample size affects confidence in generalizing any observed associations to the larger population of children with idiopathic arthritis and also may have resulted in insufficient power to detect small to moderate effects. Related to this, there was an underrepresentation of children rated as having severe disease such that the findings regarding the moderating effect of disease severity need to be interpreted cautiously. Also, the primary data were self-report and may have been influenced by social desirability effects, resulting in parents almost never endorsing negative pain responses and both child and parents rarely endorsing negative emotions. The design of the study also did not permit statements about
causal effects, and it is quite likely that there are bidirectional relationships between parent pain responses and the functional limitations observed in children with arthritis. Additionally, we did not capture responses from people other than the primary caregiver (which in all but one dyad was the biological mother) or events at school. Future studies evaluating parent responses to pain should consider deliberately recruiting fathers or other family members as well to determine if different patterns of findings emerge relative to those observed with mothers (e.g., have mother-child dyads complete daily assessments for one week followed by father-child dyads the next week).

In conclusion, data from the present study suggest that use of electronic diaries offers a novel, valid, and potentially clinically useful method of improving our understanding of how parent responses affect the daily physical, social, academic, and emotional functioning of children with JIA. Future studies are needed to further explore child or family moderators (such as child disease severity and caregiver education) of the extent to which specific parent responses to children’s pain influence their emotional adjustment and involvement in age-appropriate activities. Information from such studies could then be used to develop individually tailored interventions to optimize parent responses that could work in concert with medical treatments to improve child health outcomes.

References


Appendix

Explanatory Notes

At Level 1 (comprising variables measured repetitively at specific “t” time points), activity interference scores (total, social, and physical) and negative and positive affect index scores for individual children ("i") were specified as outcome variables in separate models. Parent protective or distracting/monitoring pain response index scores were separately specified as Level 1 predictor variables, with child pain intensity as a control variable in these models (centered on each child’s pain intensity mean such that Level 1 intercept coefficients could be interpreted as the expected value of the given outcome variable during times of typical levels of pain intensity for the child in the dyad). Specifically, Level 1 models were specified as follows: outcome = p*0 + p*1(pain - pain) + p*2(parent responses) + e. The Level 1 intercept coefficient (p*0i representing the estimated mean values on the given outcome variable adjusted for dyad differences in parent pain responses and child pain intensity) was then modeled at Level 2 as a function of the estimated overall mean outcome value plus a random effect (representing unaccounted for
dyad differences in the given outcome variable): \( \pi_{0i} = \beta_{00} + \epsilon_{0i} \). These intercept coefficients assisted with the interpretation of slope effects but were not integral to the hypotheses specified. The Level 1 slope coefficient \( \pi_{1i} \) (representing the estimated relationship between pain intensity and the given outcome variable) was modeled at Level 2 only as a function of the average relationship for the sample: \( \pi_{1i} = \beta_{1i} \); this value also was not part of the specific hypotheses evaluated for this study but was necessary for the specification of the model. The Level 1 slope coefficient \( \pi_{2i} \) (representing the average association between parent pain responses and the given outcome variable adjusted for differences in child pain intensity) was modeled at Level 2 as a function of the estimated average association for the sample (the Level 2 intercept \( \beta_{20} \) in these models) plus any incremental differences in this association resulting from differences in child disease severity (the Level 2 slope \( \beta_{21} \) in these models), with disease severity centered on the grand mean: \( \pi_{2i} = \beta_{20} + \beta_{21} (\text{severity}_i - \bar{\text{severity}}) \). The primary study hypotheses pertained to the evaluation of the statistical significance associated with the Level 2 intercepts \( \beta_{20} \) (i.e., the average relationship for this sample between parent pain responses and outcomes holding constant pain intensity and disease severity) and slopes \( \beta_{21} \) (i.e., whether the sample average relationship between parent pain responses and outcomes shifted in magnitude or direction as a function of child disease severity).