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Author manuscript *Disabil Rehabil.* Author manuscript; available in PMC 2020 March 01.

Published in final edited form as: *Disabil Rehabil.* 2019 March ; 41(6): 641–648. doi:10.1080/09638288.2017.1400594.

## The Role of Perceived Family Social Support and Parental Solicitous Responses in Adjustment to Bothersome Pain in Young People with Physical Disabilities

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## Abstract

**Purpose:** Family social support and parental solicitous responses have been hypothesized to play an important role in pediatric pain. However, research testing the hypothesized associations between these social domains and measures of adjustment to pain in youths with disabilities and chronic pain is nonexistent.

**Methods:** 111 youths with physical disabilities and bothersome pain were interviewed and asked to complete measures of average pain intensity, pain interference, family social support, parent solicitous responding and catastrophizing.

**Results:** Children's perceptions of pain-related solicitous responses from their parent/guardian were associated both with more pain interference and greater pain-related catastrophizing; perceived social support was negatively associated with pain interference.

**Conclusions:** The findings provide new information regarding the role that psychosocial factors have in predicting function and adjustment, and have important implications as to how youth with physical disabilities with pain might be most effectively treated.

## Keywords

Chronic pain; Youths; Adjustment; Social suport; Parents solicitous responses

Declarations of interest:

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The authors declare no financial or other relationships that might lead to a conflict of interest related to this study.

## INTRODUCTION

Chronic pain is a significant problem worldwide (1–3). It can interfere with people's lives (4,5) and diminish quality of life (6,7), including among individuals with physical disabilities (8–11). Experts understand chronic pain as a biopsychosocial phenomenon, and research has demonstrated that psychosocial factors can contribute to adjustment to chronic pain (12,13). For example, family factors have been shown to be associated with functioning in adults with chronic pain (14–16). Spouse solicitous responses – which can be defined as reactions that are usually meant to be supportive, such as encouragement to rest – to patient pain behaviors is one factor that has demonstrated consistent positive associations with a patient's pain and physical dysfunction in adults with chronic pain (e.g., (17–19)). For example, frequently attending to a person's pain behaviors – providing him or her positive pain behavior-contingent attention – or encouraging the person to stop doing something that might be viewed as unpleasant when the person displays pain behavior, can positively reinforce those pain behaviors. This can inadvertently contribute to the maintenance of pain and disability by facilitating the physical deconditioning of the person (i.e., loss of strength, flexibility and/or endurance).

Social factors have also been shown to influence children and adolescents' adjustment to pain (20–22). For example, parent's modeling of pain behavior as well as their solicitous responses to their child's pain behaviors have both been shown to be associated with greater child dysfunction and disability (23–27). While direct effects of parent responses to their children's levels of pain and function have been identified, it is possible that there are factors which may moderate these associations. For example, Logan and Scharff (28), in a study with a sample of children with recurrent abdominal pain or migraine headaches, found that the family environment moderated the relationship between pain and functional disability; specifically, the risk of poor functioning in response to chronic pain was reported only in disruptive family environments, but not in the more adaptive ones. Similarly, Peterson and Palermo (26) in a sample of 215 children between 8 to 16 years with a diagnosis of headache, juvenile idiopathic arthritis or sickle cell disease, found that a child's psychological distress influenced the impact of his or her parental solicitous responses on the child functional disability.

The research on the role of psychosocial factors in functioning of individuals with chronic pain has recently been expanded to include individuals with physical disabilities. A review of research in this area concluded that, in adults with physical disabilities, general social support (i.e., the perception and/or actual provision of assistance from other people) is consistently associated with *better* outcomes, whereas pain-contingent responses, mostly as indicated by solicitous spouse or significant other reactions to pain behaviors, tended to be associated with *poorer* outcomes (e.g., higher pain intensity, worst psychological function) (29).

Although there is information about the role that psychosocial factors may play in the adjustment of youth with chronic pain as a primary problem, briefly summarized above, to the best of our knowledge, there are no studies about the role of perceived family social support or parental solicitous responses in the adjustment to chronic pain in young people

with physical disabilities. Also, it is possible that age might influence how psychosocial factors contribute to function in youth with chronic pain. Thus, given that age-related development may play a role, it is possible that the role of family support in adjustment to chronic pain may vary as a function of the patient's age. For example, it is possible that parent responses to their children's pain may play a larger role in younger children than in adolescents (given that adolescents are moving towards greater independence). For example, Walker and Zeman (22), in a study with 151 schoolchildren in grades 2 to 12, reported a significant association between age and parental reactions, but in a different hypothesized direction; that is, preadolescents and adolescents reported significantly more maternal reinforcement (the authors called it "encouragement") of illness behavior. This result did not emerge with respect to paternal reactions. However, in a study of the development of a new questionnaire to measure parents' reactions to their children pain behaviors, Huguet and colleagues (23) reported a non-significant association between parents' responses and their children's age. Similarly, in a study of the type of maternal responses to children's abdominal pain symptoms, Langer and colleagues (30) found that age was not predictive of maternal response. Therefore, the relationship between different types of parental responses and age is far from clear, subsequently warranting further research.

Given these considerations, the aim of this study was to improve our understanding of the role that family social support (i.e., and parental solicitous responses play in the adjustment of young people with disabilities who also have bothersome pain. Based on previous research with adults, we hypothesized that, in a sample of young people with physical disabilities and bothersome pain, we would find significant and negative associations between a measure of family social support and measures of pain interference and catastrophizing thoughts related to pain. In addition, we hypothesized significant and positive associations between a measure of parental solicitous responding and measures of pain interference and pain-related catastrophizing. Given the wide variability in the ages of the individuals participating in this study (from 8 to 21 years old), the study also allowed for an examination of the possible moderating effects of age on the associations examined. We therefore examined the possible moderating effects of age in exploratory analyses.

## 2. METHODS

## 2.1. Participants

The participants in this study came from a sample of young people with physical disabilities who participated in an interview survey study. They were recruited from different sources using a variety of strategies, including mailings from clinics, word of mouth, and contacts with a summer camp sponsored by the Muscular Dystrophy Association (USA). To be eligible for the study, the youths needed to have one of five diagnoses associated with physical disability: spinal cord injury, spina bifida, limb deficiency, cerebral palsy or neuromuscular disease. They also needed to have: (1) a chronological age between 8 and 21 years; (2) the capacity to communicate in English; and (3) no more than mild cognitive impairment as determined by a brief telephone screening with the parent/guardian and a minimum passing score of 17 (out of 25) on a modified mini-mental Status Examination (MMSE; (31)). Although the MMSE was not initially developed to screen for cognitive

dysfunction in children, it has been used by other researchers to assess cognitive dysfunction in children as young as seven years old (62). A total of 185 youths were interviewed.

Participants provided either written informed assent (if they were minors) or consent (in the case of adult participants, or parents of a minor participant). Permission to conduct the study was obtained by the Institutional Review Board at Children's Hospital and Regional Medical Center in Seattle.

To be included in the current analyses, the participants needed to endorse having experienced a bothersome pain in the three months prior to the interview and provided responses to the measures used in the current analyses (see Measures section). A paper has been published using data from this interview survey, but it sought to answer different questions from the ones that are the focus of the current study (32). A total of 111 youths met the study criteria (60% of those interviewed)

In this study, youths of a wide age range participated. We preferred to not limit participants to children (i.e., those younger than 18 years old or younger), because many pediatric specialists continue to treat patients that they have a history of treating even after they become 18 years old, particularly in the cases of patients with uncommon medical conditions, including the diagnoses that served as inclusion criteria for this particular sample. Perhaps because many specialists continue treating patients into their early 20s, pediatric researchers often include participants who are 18 years old or older in their studies (33–36).

#### Procedures

#### Measures

**Demographic/Descriptive Variables.:** The parents of the participants in the original study were administered a structured interview that requested information about the child's medical diagnosis, sex and age.

Average Pain Intensity.: Participants reported their average pain intensity during the past week on a 0–10 numeric rating scale, where 0 meant "*No pain*" and 10 meant "*Pain as bad as it could be*". Ratings from this self-report measure have been found to be valid and reliable (37–39) even when used with children as young as 6 years of age (40), and with youths with physical disabilities (41).

**Pain Interference.:** We used a modified version of the Brief Pain Inventory (BPI; (42,43) to assess pain interference. The modifications to the original questionnaire were as follows: (1) we changed the item requesting information about "normal work" to request information about "school, work, or chores", in order for the item to be a more age appropriate; (2) we added three items to increase the content validity of the measure (these included items assessed pain interference with "social activities", "recreational activities" and "self-care (taking care of your daily needs]"; and (3) revised the "interference with walking" item to ask about "interference with mobility (ability to get around]" which made it possible for all of the participants to respond to this item, including those who were not able to ambulate independently. Previous studies using this modified version of the questionnaire have shown

**Family social support.:** Participants' perceived social support from family was assessed using 4 items from the Multidimensional Scale of Perceived Social Support (MSPSS; (45)). Although the original MSPSS has 12 items (4 items related to family, 4 related to friends and 4 related to the support of a significant other), in this study we used only those that assessed perceived social support from the family. Respondents were asked to rate their level of agreement with each statement on a 7-point Likert scale (1 = "Very strongly disagree" to 7 = "Very strongly agree"). Scores could therefore range from 4 to 28, with higher scores indicating a higher level of perceived social support from the family. Previous studies with the MSPSS have shown good internal consistency values (Cronbach's alpha of .88 for the global score (45)), and that it provides valid and reliable scores when used with youths with physical disabilities (46). The Cronbach's alpha in our sample was .87.

**Parent/Guardian Solicitous Responding.:** Perceived solicitous responses from the participant's parent/guardian was assessed using the 6 items of the West Haven-Yale Multidimensional Pain Inventory Solicitous scale (WHYMPI; (47)). Participants were asked to indicate how often their parents/guardians responded to them by doing any of the responses/actions described in the 6 items/statements, on a 0 ("*Never*") to 6 ("*Very often*") scale. The internal stability (alpha coefficient = .78) and test-retest stability (correlation coefficient = .89) have both shown to be high in the original scale development study (47). Moreover, the scale has consistently demonstrated predictive validity through its relationships to pain severity and disability among persons with chronic pain (47–50). Although the WHYMPI was developed and validated among adult samples, the items are not complex (e.g., "Gets me something to eat" reading level = grade 2.8), making it a likely measure easily understandable by young people. Previous studies using the WHYMPI have shown that it provides valid and reliable scores when used with youths (51). The Cronbach's alpha in our sample was .81, indicating good reliability, and consistent with the idea that participants were able to understand the items.

**Pain-Related Catastrophizing.:** The child version of the Pain Catastrophizing Scale (PCS-C) used here was developed before the availability of the Crombez and colleagues' (52) pediatric version of the PCS. The version that we used included 12 items that assessed how often respondents have certain thoughts or feelings when they are experiencing pain, using a 3-point Likert scale ranging from 0 ("*No, not at all*") to 2 ("*Yes, I think this all the time*"). The PCS-C consists of Helplessness, Magnification, and Rumination subscales, and is scored by averaging individual items into subscores ranging from 0 to 2. The modified version of the PCS used in the current study – which is similar to that developed by Crombez and colleagues (52) – consists of items from the PCS rephrased for simplified language for use with a younger population. Also, one item from the adult PCS – "*I anxiously want the pain to go away*" – was not adaptive for inclusion, because the authors determined that this item reflects an emotional response (anxiety/motivation) and not a catastrophizing belief. Previous studies using this modified version of the questionnaire have

shown that it provides valid and reliable scores when used with youths with physical disabilities (53). The Cronbach's alpha for the PCS-C in our sample was .81.

#### **Data Analyses**

We first computed descriptive statistics to describe the sample with respect to age, sex, and medical diagnosis. Next, we examined the data to ensure that the assumptions for the planned regression analyses were met. After confirming the absence of significant skewness, kurtosis, outliers, heteroscedasticity, and multicollinearity for any predictor or criterion variable (parameters: skewness < 2.0, kurtosis < 2.0, visual inspection of scatterplot of residuals, variance inflation factors < 10.0 (54)), we computed zero order correlations among the key predictor (family support, solicitous support) and criterion (pain interference, catastrophizing) variables. We then performed two regression analyses to evaluate the relative importance of family support and parent/guardian solicitous responses as predictors of pain interference and pain-related catastrophizing in the youth sample. In these analyses, we first entered demographic variables (sex and age, with age centered) in step 1, and then average pain intensity in step 2, to control for their potential confounding effects. In step 3, we entered the primary predictors (perceived family support and solicitous responses, both centered) to determine the extent to which they contributed to the prediction of the criterion variables over and above the demographic variables and pain intensity. Finally, in order to explore the potential moderating effects of the child's age on the associations between the psychosocial factors and the criterion variables, we then entered terms representing the Age X Family Support and Age X Solicitous Responding interactions in Step 4. In the event that significant interaction effects emerged, we planned to perform a median split of age and compute the zero order associations between the psychological factor and criterion variable involved.

## RESULTS

#### Description of the study sample

The majority of the study sample were white (78%) males (57%); a plurality of the sample had a diagnosis of cerebral palsy (34%). The average age of the participants was 14.4 years (SD = 3.29; range = 8 - 21). On the extreme ranges, sixteen (14%) of the participants were pre-pubescent (10 years old or younger), and fourteen (12%) were 19–21 years old. Additional descriptive information about the study sample and the study variables is presented in Table 1.

#### Assumptions testing

As shown by skewness and kurtosis statistics, the distributions of the study variables were adequately normal for the planned regression analyses (skewness range = -1.05 to 1.46, kurtosis range, -1.07 to 1.32). Furthermore, all of the variance inflation factor values were below the standard cutoff value of 10 (ranging from 1.07 to 1.42), indicating that multicollinearity would not be a problem thus not biasing the findings (54).

#### Zero order correlations among the predictor and criterion variables

Table 2 presents the zero order Pearson correlation coefficients between the study predictor and criterion variables. As can be seen, the strongest association (r = .46, p < .001) was between solicitous responding and perceived social support. Moderate positive associations were found between solicitous responding and catastrophizing (r = .31, p < .01) and catastrophizing and pain interference (r = .37, p < .001). Solicitous responding evidenced a very weak (and nonsignificant) association with pain interference, and perceived support from the family evidenced a very weak (and nonsignificant) association with catastrophizing.

## Predicting pain interference

The results of the regression analyses predicting pain interference are presented in Table 3. As can be seen, the block containing the control variables of sex and age made a significant contribution to the prediction of pain interference, with this effect being mostly related to sex. A t-test comparing pain interference between boys and girls indicated that girls reported significantly more pain interference (Mean = 2.26, SD = 2.10) than boys (Mean = 1.40, SD = 1.40; t(109) = 2.58, p < .05). As would be expected, average pain intensity also made a significant contribution to pain interference, accounting for 34% of the variance in the explained variable. The block of predictors including both family support and parent/ guardian solicitous responding also made a significant contribution of 3%. The effect size  $(f^2)$  associated with this contribution was .05, which represents a small effect.(55) An examination of the beta weights indicated that both predictors contributed independently (i.e., while controlling for the other) to this effect, although in the opposite direction and consistent with the study hypotheses; greater perceived family support was associated with less pain interference, while more parent/guardian solicitous responding was associated with more pain interference. No significant interactions involving age emerged in the regression analyses predicting pain interference.

#### Predicting pain-related catastrophizing

The results of the regression analyses predicting pain-related catastrophizing are also presented in Table 3. In these analyses, neither the demographic variables nor average pain intensity were significantly associated with catastrophizing. However, the block including family support and solicitous responding did make a significant contribution, explaining 11% of the variance. The effect size ( $f^2$ ) associated with this contribution was .13, which represents a medium effect.(55) In the third step, only parent/guardian solicitous responding, and not general family support, made a significant independent contribution, with more solicitous responding associated with more pain-related catastrophizing in the youth sample. However, a significant Age X Family Support interaction was found in step 4. Following this step, the direct effect of family support became statistically significant (and the direct effect of solicitous responding remained significant). The correlational analyses performed to help understand the significant interaction indicated that among participants who were 14 years old or younger, family support was associated positively, but not statistically significantly, with catastrophizing (r = .24, p = .071). Among participants who were 15 years old or older,

family support was associated negatively, but not statistically significantly, with catastrophizing (r = -.23, p = .097).

## DISCUSSION

The aim of this work was to evaluate the hypothesized associations between family social support and parental solicitous responses with both pain interference and catastrophizing in a sample of young people with disabilities and bothersome pain. This study provides new and important findings that have significant theoretical and practical implications that could help to understand and manage function in these patients.

Consistent with the findings from other research on chronic pain in children and adolescents, average pain intensity was a significant predictor of pain interference (7,56). To the extent that the finding with respect to pain intensity is found to be a causal association – a conclusion that would appear to be intuitive but would also need to be examined using longitudinal or experimental research – this finding suggests that clinical interventions which effectively targeted pain intensity could also be expected to reduce pain-related interference with function, and therefore to potentially prevent further disability.

Moreover, and as hypothesized, we found that psychosocial factors significantly contributed to the explanation of both pain interference and catastrophizing. Although the effect sizes associated with social support as a predictor were small to medium, they are generally consistent with the findings examining the associations between perceived social support from significant others and function in adults with chronic pain (17–19), as well as studies examining the associations between perceived social support from parents and function in youth presenting with pain as a primary problem (21,57). However, this is, to the best of our knowledge, the first study to report this for youth with physical disabilities and chronic pain.

Although we found that perceptions of more general (i.e., not pain-contingent) support from the family was associated with less pain interference, consistent with the idea of this support is generally helpful in this population, the role that perceived social support may play in catastrophizing appears to be more complicated. First, the hypothesized negative associations between perceived social support and the criterion variables which were supported in the multivariate regression analyses did not emerge for the prediction of catastrophizing in the univariate analyses. A reasonable explanation for this pattern of results would be the possibility that general perceptions of social support may reflect both paincontingent support (i.e., solicitous responses) and non-pain-contingent support (i.e., the provision of support regardless of pain levels). This possibility is supported by the strong univariate association (r = .46, about 21% of overlap in variance) between perceived family support and solicitous responses. However, once the "negative" aspect of support (solicitous responses) is controlled for, the effects of the residual (presumably the "positive" benefits of social support) can be observed, as represented by the unique and statistically significant contribution of perceived social support to the prediction of catastrophizing in the regression analysis.

A second complexity regarding the role of perceived social support as a predictor of catastrophizing emerged in an age moderation effect, with the hypothesized negative association between family support and catastrophizing emerging for older participants only. Younger participants evidenced a *positive* association between perceived family support and catastrophizing. This is the first time, to our knowledge, that the differences in the role that family (i.e., parents) support plays in youths with disabilities and chronic pain as a function of age has been examined empirically. The findings suggest that responses which are perceived as supportive by younger children may be less useful for them (at least with respect to the prediction of catastrophizing; no moderation effect emerged in the prediction of pain interference) than for older participants. Future research is needed to determine if this age moderation effect is reliable.

The results with respect to solicitous responses were more consistent than those with respect to family support, were not moderated by age, and were entirely consistent with the study hypotheses. Specifically, we found that youth's perceptions of solicitous responses from their parent/guardian to the youth's pain behaviors were associated both with more pain interference and greater pain-related catastrophizing. Solicitous responses are displayed more often when a child with pain is experiencing more pain intensity or displaying more pain behaviors (37). Based on the operant model, such responses are hypothesized to reinforce pain behaviors and increase pain reports, contributing over time to greater disability (58). Our findings regarding parental solicitous responding are therefore consistent with the operant model.

If replicated, these findings suggest the possibility that youth with disabilities and pain could potentially benefit from treatments based on the operant model; that is, treatments that would teach parents and family members to pay less attention to the youth's pain and pain behaviors, and instead respond more positively to the youth's "well behaviors." The positive associations found here between general social support and lower levels of pain interference emphasize the potential benefits of this approach. In other words, when discouraging parents from providing pain-contingent solicitous responding, they should not at the same time be discouraged from providing ongoing support unrelated to pain (59,60). Overall, the findings from this study indicate that research to examine the potential benefits of family (or at least parent) training in operant principles on pain interference and catastrophizing in children with physical disabilities is warranted.

There are a number of limitations of this study that should be considered when interpreting the results. First, although the overall sample size of the study was relatively large (when compared to the sample sizes used in other studies of pain in youth with disabilities; as these other studies have had sample sizes ranging 40 to 80 participants (53,61)) and appropriate for the analyses conducted, participants had five different disability diagnoses and had a wide age-range. We cannot determine whether the results would have been different had the group been less heterogeneous. However, the fact that the findings are generally consistent with those from studies in adults with chronic pain (as well as adults with disabilities and chronic pain) suggests that they would be reliable across different diagnostic groups. Nevertheless, it would be useful for future researchers to examine further the possibility that there are differences in the associations found as a function of diagnostic group. Another

issue to consider is the large variability in age in the study. On the positive side, broad age range allowed us to evaluate age as a possible moderator of the associations between the predictors and criterion variables. However, children as young as 8 years old clearly differ in important ways from young adults who are 21 years old. Future researchers should consider these differences and how psychosocial factors may play different roles in the lives of young people as a function of age and developmental level. Our finding of an age moderation effect provides further support for such research. Another limitation is that our sample was one of convenience. It is possible, therefore, that the sample may not be representative of the population of youth who have the diagnoses studied. Relatedly, because we did not have any demographic or other information from potential participants we were unable to contact or who declined participation, we were not able to perform analyses to determine if there were systematic differences between participants and nonparticipants. Furthermore, although in our analysis we adjusted for pain intensity to control for its potential confounding effect, we were not able to do the same for the level of disability or assistance required for basic activities of daily living (we did not have measures of these). It is possible that these variables that were not controlled might have influenced the results. These limitations provide additional support for the importance of replicating the current findings to help determine their reliability and generalizability.

Despite the limitations, this study provides important new information regarding the associations between psychosocial factors and function in youth with physical disabilities and bothersome pain. They are consistent with the idea that it matters how parents respond to their children with disabilities who have pain, and raise the possibility that interventions which target these responses may result in significant benefits for the children. Research to examine this possibility is warranted.

#### Acknowledgments

Support for the study upon which the findings reported here are based was provided by Grant P01 HD033988 from the National Center for Medical Rehabilitation Research, National Institute of Child Health and Human Development, National Institutes of Health. JM's work is supported by Fundación Española del Dolor, the Institució Catalana de Recerca i Estudis Avançats (ICREA-Acadèmia), Fundación Grünenthal, and from grants provided from Obra Social de Caixabank, Universitat Rovira i Virgili (PFR program), RecerCaixa, the Spanish Ministry of Innovation (MINECO; PSI2015–70966-P; PSI2016–82004-REDT), the European Regional Development Fund (ERDF), and the Fundació La Marató de TV3. RV's work is supported by a Beatriu de Pinós Postdoctoral Fellowship (2014 BP-A 00009) granted by the Agency for Administration of University and Research Grants (AGAUR).

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## IMPLICATIONS FOR REHABILITATION

- Little is known about the role of perceived family social support or parental solicitous responses in the adjustment to chronic pain in young people with physical disabilities.
- This study provides new and important findings that have significant theoretical and practical implications that could help to understand and manage function in these patients.
- Results show that it matters how parents respond to their children with disabilities who have pain, and raise the possibility that interventions which target these responses may result in significant benefits for the children.

#### Table 1

Description of the study sample (N = 111).

Variable	Percent	Ν	Mean (SD)	Range
Age, years		111	14.41 (3.29)	8 - 21
Sex				
Boys	57%	63		
Girls	43%	48		
Ethnicity/Race*				
White	78%	81		
Asian	13%	14		
Native American/Pacific Islander	4%	4		
Black	4%	4		
Hispanic	4%	4		
Other	2%	2		
Diagnosis				
Cerebral Palsy	34%	38		
Limb Deficiency	6%	7		
Spina Bifida	24%	27		
Neuromuscular Disease	25%	28		
Spinal Cord Injury Cerebral Palsy &	8%	9		
Limb Deficiency	2%	2		
Average pain intensity			3.14 (2.45)	0 - 10
Pain interference			1.77 (1.78)	0 - 8.5
Family social support			23.89 (4.50)	4 - 28
Parental/Guardian Solicitous				
Responding			3.38 (1.54)	0-6
Pain-related catastrophizing			8.33 (4.26)	0 – 19

\*Race/Ethnicity information was missing for 2 (1.8%) participants

#### Table 2.

Zero order Pearson correlation coefficients between the study predictor and criterion variables.

Variable	Family support	Solicitous responding	Pain interference	
Solicitous responding	.46***			
Pain interference	21*	.08		
Catastrophizing	.02	.31**	.37 ***	

<sup>\*</sup>p < .05

\*\* p<.01

\*\*\* p<.001

#### Table 3.

Multiple regression analyses results predicting pain interference and pain-related catastrophizing from measures of perceived family support and parental/guardian solicitous responding, controlling for age, sex, and average pain intensity.

Step and variable	Total $R^2$	$R^2$ change	F change	$\boldsymbol{\beta}$ to enter	Final <b>β</b>
Crite	rion variable	e: Pain Interfe	rence		
1. Control variables	.07	.07	3.73*		
Sex				.24*	.15
Age (centered)				.08	.02
2. Average pain intensity	.41	.34	62.17***	.60 ***	.55 ***
3. Predictors	.44	.03	3.12*		
Family support (centered)				18*	20*
Solicitous responding (centered)				.19*	.20*
4. Interactions					
Age X Family Support				08	08
Age X Solicitous Responding				.02	.02
Criterion v	ariable:Pain	-Related Catas	strophizing		
1. Control variables	.02	.02	0.83		
Sex				.12	.13
Age (centered)				03	02
2. Average pain intensity	.04	.03	2.95	.17	.10
3. Predictors	.15	.11	6.84 **		
Family support (centered)				12	20
Solicitous responding (centered)				.38**	.42 ***
4. Interactions	.22	.07	4.54*		
Age X Family Support				24*	24*
Age X Solicitous Responding				07	.07

\* p<.05

\*\* p<.01

> \*\*\* p<.001