

## **DIFFERENCES IN PARENTAL RESPONSE TO PAIN BETWEEN WHITE AND HISPANIC PARENTS OF PEDIATRIC ONCOLOGY PATIENTS**

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Parental response to children's pain has emerged as a prominent factor associated with certain pain outcomes including the duration of children's functional disability. Studies have shown that solicitous, or protective, parental responses are strongly linked to increases in children's depression, functional disability, and school absences. No study to date has focused on ethnic differences in parental response, especially in a pediatric oncology setting. In this study, parental responses were compared between English-speaking non-Hispanic White, English-speaking Hispanic, and Spanish-speaking Hispanic parents of children with cancer. 275 families of children with cancer participated in the study. Parents provided data regarding the frequency and manner in which they respond to their child's pain. They also responded to questions regarding their perception of their child's health-related quality of life. The results showed no significant difference in solicitous responses across the three groups. However, Spanish-speaking Hispanics reported engaging their child in activities (i.e. school, family, etc.) the least of all the groups. In addition, parental responses that promote pain coping were negatively associated with parental perception of child's health-related quality of life. The threat to life that cancer poses to children may provoke their parents to respond in all kinds of ways. Thus, the relationship between parental response and child functioning in an oncology population may be more complex than those of chronic pain populations. Further research on parental responses in cancer populations is needed to develop interventions to improve parental distress and enhance quality of life.

Recently, the role that parents play in the pediatric chronic pain experience has gained considerable attention (Palermo and Chambers 2005; Claar et al 2008; Claar et al 2010). The role of parental responses to children's pain behaviors has become an important mediator of children's pain-related disability. Parental responses and behaviors influence the development and maintenance of child pain behavior (Claar et al 2010). Social learning theory (Bandura 1977)

has been used as the primary theoretical framework to explain this phenomenon (Walker and Zeman 1992; Chambers et al 2002; Claar et al 2010). In the context of children's pain behaviors, social learning theory applies two distinct learning mechanisms, parental modeling and parental reinforcement (Chambers et al 2002). This model suggests that parental responses to children's pain reinforce the child's perception and expression of pain (Chambers et al 2002; Claar et al 2010).

The importance of understanding the influence of parental responses has resulted in the development of several measures modeled after the West Haven-Yale Multidimensional Pain Inventory (Kerns et al 1985). These measures have identified three distinct categories of responses; solicitous, distracting, and punishing (Walker and Zeman 1992, Wall et al 1997, Van Slyke and Walker, 2006). Solicitous parental responses to pain behaviors include giving the child special attention when they complain of pain or excusing the child from responsibilities when in pain (Claar et al 2010). Distracting responses refer to parental efforts to engage their child in activities that focus their attention away from pain (Van Slyke and Walker, 2006; Kerns et al 1985). Punishing parental responses involve criticisms and negative affect towards their child's pain behaviors (Kerns et al 1985). More recent conceptualization of parental responses include protective, minimizing, and encouraging/monitoring (Claar et al 2010; Van Slyke and Walker, 2006).

Early studies showed that solicitous, or protective, parental responses to pain behaviors were associated with increased child reports of symptoms and disability (Whitehead et al 1994; Walker and Zeman 1992). Recent studies have linked protective parental responses to more frequent school absences, increased child depression, and greater health care utilization (Claar et al 2010; Palermo and Chambers 2005; Walker et al 2002). Some studies also suggest that

parental minimization is linked to increased child depression and somatic symptoms (Claar et al 2008; Van Slyke and Walker, 2006). Children in the aforementioned studies presented with recurring abdominal pain, chronic headache/migraines, juvenile rheumatoid arthritis, acute illnesses (i.e. colds), chronic musculoskeletal pain, and diffuse pain. No study to date, however, has focused on parental influences on children's pain-related disability within the pediatric oncology population.

More than 12,000 children are diagnosed with cancer each year (Cancer Facts & Figures 2012) and at advanced stages of disease 89% of these patients report experiencing pain (Sirkia et al 1998). Due to the aggressiveness of treatment protocols, children treated with chemotherapy often experience painful conditions, including mucositis, infection, and peripheral neuropathy (Van Cleve et al 2004). Children are also subjected to repeated painful procedures, such as lumbar punctures, bone marrow aspirations, and venipunctures (Zeltzer 1994). Uncontrolled pain can have major consequences for the care of children. Sleep deprivation, fatigue, emotional despair, and a sense of helplessness may result from unrelieved pain (Mercadante 2004). Due to the advancements in cancer care, children spend less time at the hospital and more time at home (Hendershot et al 2005). In the home setting, pain management in children is dependent on the ability of parents to recognize and assess pain and on their decision to treat it or not (Yaster and Nichols, 2001).

There is also a lack of research focusing on parental responses to child's pain and the differences seen across various ethnic groups. The behavioral and emotional responses to pain are mediated by cultural perceptions, expectations, and past experiences, which are known to differ among ethnic groups (Shavers, Bakos, and Sheppard, 2010; Weissman, Gordon, and Bidar-Sielaff, 2004). This suggests that the perception, expression, and control of pain are

culture-specific (Good et al 1992; Shavers et al 2010). Thus, parental responses, beliefs, and standards, which influence a child's expression of pain and selection of coping strategies, may differ across cultural groups (Kankkunen et al 2009). Investigators must consider these variations when developing interventions for improving parental home pain management.

In the U.S., growth in the Hispanic population accounted for over half of the nation's growth (56%) from 2000 to 2010. Among children ages 17 and younger, there were 17 million Latinos, representing 23% of this age group, a 6% increase since 2000 (Pew Research Center 2011). Due to the prevalence of the Hispanic population in the U.S., it is necessary to study the pain management attitudes and behaviors of Hispanic parents in order to help improve pediatric quality of life. For Hispanics, stoicism tends to be an accepted and expected response to pain (Villarruel 1995; Juarez et al 1998; Jacob et al 2008). Hispanic individuals may perceive enduring and hiding pain as a personal strength (Juarez et al 1998). Consequently, Hispanic patients underreport and underrate pain when questioned about it (Jacob et al 2008; Calvillo and Flaskerud 1991). Due to this pattern of assessment and perception of pain, Hispanic parents may display more minimizing responses to pain.

Previous studies involving children with chronic pain have investigated the role that parental responses play in regards to child functional disability and the results suggest that parents indeed play a significant role (Palermo and Chambers 2005; Claar et al 2008; Claar et al 2010). Recent research has documented that both protective and minimizing parental response to children's pain is strongly associated with child depression and increased child functional disability (Palermo and Chambers 2005; Claar et al 2008). No study thus far has focused on the interactions between parental response and parental pain management in the pediatric oncology population. There is also a lack of research focusing on the differences of parental responses

across various cultural groups. The rapid increase within the Hispanic population in the United States suggests the importance of incorporating this cultural group in clinical research.

Therefore, this study is designed to supplement the growing body of literature focusing on the outcomes of parental responses to children's pain by highlighting the relationship between parental responses to child's pain and parental pain management within an English- and Spanish-speaking pediatric oncology population. It is hypothesized that Hispanic parents, honoring their cultural beliefs of self-control and stoicism, will present less solicitous responses towards their child's pain behaviors compared to Caucasian parents.

## **MATERIALS AND METHODS**

*All experiments were carried out in accordance with the Institutional Review Board at the University of California, Irvine, and were consistent with Federal guidelines.*

### **Participants**

A total of 275 families with children with cancer participated in the study. Families were 38.8% English-speaking non-Hispanic White, 28.1% English-speaking Hispanic, and 33.1% Spanish-speaking Hispanic. The majority of children were diagnosed with leukemias (45.8%), followed by central nervous system tumors (18.9%), lymphomas (13.1%), and sarcomas (10.5%). The remaining 11.6% were categorized as "other", which included cancers such as germ cell tumor and Wilm's tumor. The majority of the respondents were mothers (84.8%), followed by fathers (13.1%), grandmothers (1.5%), and siblings (0.6%).

### **Procedures**

Families of children of with chronic illness were recruited in person during a scheduled visit in the Cancer Institute or Outpatient Infusion Center located at CHOC Children's Hospital. Parents had the option of completing the study packets while in the waiting room during their

child's appointment or completing them at home and mailing the completed surveys.

Additionally, parents had the option of filling out the packets in English or Spanish and they provided written consent prior to participating.

## **Measures**

*Demographics.* Parents were asked to provide baseline demographic information including gender, race and ethnicity, parents' education, occupation, age and family income. Regarding ethnicity and culture, the demographics form asks for information including cities and countries of parents' previous residence, languages spoken in the home, and parents' and children's primary and secondary languages.

*Parental Response to Pain Questionnaire (PRPQ-R).* The PRPQ-R is a 23-item scale that is derived from two previously developed and validated measures, the Illness Behavior Encouragement Scale (Walker & Zeman, 1992) and the Parent Response to Pain Scale (Wall et al. 1997). The PRPQ-R measures both occurrence and frequency of parental behaviors by asking parents to indicate how they have responded to their child's pain. The stem for each item is, "When my child was in pain:" Responses are rated on a 5-point Likert-type scale ranging from "Rarely/Never" (1) to "Almost Always/Always" (5). The PRPQ-R is composed of four subscales: Solicitous (e.g. "I spent more time with my child"), Secondary Gain (e.g. "I avoided conflict with my child because it might make the pain worse"), Promote Pain Coping (e.g. "I encouraged my child to use relaxation, guided imagery, or self-hypnosis"), and Promote Activity (i.e. "I gently pushed my child to participate in normal daily activities").

*Pediatric Quality of Life Inventory (PedsQL).* The PedsQL is a 23-item scale that measures health related quality of life. The scale is divided into four categories: Physical, Emotional,

Social, and School. Responses are rated on a 5-point Likert-type scale ranging from “Never” (0) to “Almost Always” (4). Higher scores indicate a better health related quality of life.

*Pediatric Quality of Life – Cancer Module.* This inventory is comprised of 27 items and contains 8 categories: Pain, Hurt, Nausea, Procedural Anxiety, Treatment Anxiety, Cognitive Problems, Perceived Physical Appearance, and Communication. This inventory is scored using a 5-point Likert-type scale ranging from “Never” (0) to “Almost Always” (4). Higher scores indicate better health related quality of life.

### **Statistical Analysis**

SPSS version 20 was used to analyze descriptive statistics for the whole sample and conduct tests of group differences between English-speaking non-Hispanic White, English-speaking Hispanic, and Spanish-speaking Hispanic parents. To analyze for differences between categorical variables (i.e. ethnicity, language spoken) in regards to their relationship with parental response, analysis of variance (ANOVA) tests were conducted on the PRPQ-R subscales as the dependent variable. Pearson product correlations were used to measure the association between PRPQ subscales and Pediatric and Cancer Quality of Life total responses.

## **RESULTS**

### **Differences in Parental Response to Children’s Pain**

In the total sample, ANOVA indicated that the differences in Solicitous responses were not significant ( $p = 0.646$ ) between the groups. Differences in Secondary Gain responses ( $p = 0.158$ ) and Promote Pain Coping responses ( $p = 0.334$ ) were not significant as well. However, ANOVA revealed a significant difference ( $p = 0.008$ ) in Promote Activity responses between the groups (Table 1). Further analysis with Fisher’s least significant difference (LSD) revealed that Spanish-speaking Hispanics were scoring significantly less on the Promote Activity subscale

when compared to English-speaking non-Hispanic White ( $p = 0.002$ ) and English-speaking Hispanic ( $p = 0.024$ ). English-speaking Hispanics and English-speaking non-Hispanic White parents displayed no significant differences when compared with each other ( $p = 0.478$ ).

Participants' scores on the Secondary Gain, Promote Pain Coping, and Promote Activity generally followed normal distributions however Solicitous scores were heavily skewed. Table 1 presents the mean values for each subscale across the different groups. Because solicitous responses did not follow a normal distribution, a Kruskal-Wallis test was performed to analyze the median differences between the groups. Results revealed differences at the trend level in solicitous responses ( $p = 0.062$ ) between the groups.

**Table 1.** PRPQ-R subscale descriptive statistics

PRPQ-R Subscale (Range)	English-speaking non-Hispanic White	English-speaking Hispanic	Spanish-speaking Hispanic	ANOVA $p$ -value
Solicitous (7-35) [mean $\pm$ SD]	30.9 $\pm$ 3.2	31.1 $\pm$ 3.2	31.5 $\pm$ 4.5	0.646
Secondary Gain (5-25) [mean $\pm$ SD]	15.8 $\pm$ 4.4	14.8 $\pm$ 4.7	14.3 $\pm$ 5.4	0.158
Promote Pain Coping (5-25) [mean $\pm$ SD]	13.9 $\pm$ 5.0	13.7 $\pm$ 5.1	14.9 $\pm$ 5.1	0.334
Promote Activity (6-30) [mean $\pm$ SD]	17.2 $\pm$ 4.6	16.7 $\pm$ 4.4	14.8 $\pm$ 4.9	0.008

### Relationship Between Parental Response and Children's Quality of Life

Bivariate correlations were performed to determine if there were any relationships between total PRPQ-R subscale and total parent PedsQL and Cancer Module scores (Table 2). Significant correlations were only found between the Promote Pain Coping subscale and PedsQL  $r(139) = -0.26, p < 0.01$  and Cancer Module  $r(138) = -0.22, p < 0.05$ .



**Table 2.** Correlations with PRPQ-R subscales and Parent Quality of Life for all three groups combined.

Variable	Sollicitous	Secondary Gain	Promote Pain Coping	Promote Activity	Total Parent PedsQL	Total Parent Cancer Module
Sollicitous	1	0.390**	0.355**	0.027	-0.086	-0.098
Secondary Gain		1	0.268**	-0.044	-0.108	-0.132
Promote Pain Coping			1	0.353**	-0.256**	-0.222*
Promote Activity				1	-0.161	-0.133
Parent PedsQL					1	0.740**
Parent Cancer Module						1

\*\* = Correlation is significant at the 0.01 level; \* = Correlation is significant at the 0.05 level

## DISCUSSION

This purpose of this study was to determine if there are differences in parental response to children's pain within an oncology population between Hispanic and White parents. Since some Hispanic individuals predominantly speak English while others can only speak Spanish, participants were categorized by both ethnicity and primary language spoken. This classification resulted in three groups; English-speaking non-Hispanic White, English-speaking Hispanic, and Spanish-speaking Hispanic.

Overall, there appeared to be no differences in solicitous responses between the groups. Unexpectedly, both Hispanic groups reported slightly higher average solicitous scores than White parents. This was not as originally hypothesized; however the differences were minimal and did not show any significance. This pattern contradicts previous notions that Hispanic individuals promote stoic responses to pain. Additionally, parents were scoring much higher on the Solicitous subscale than any other subscale of the PRPQ-R. Parental uncertainty may be a possible explanation for the high solicitous scores. Regardless of culture and ethnicity, a

diagnosis of childhood cancer in the family causes various emotional reactions. Consequently, parents of children with cancer may experience uncertainty as an extreme vulnerability that can intensify parental distress (Santacrose 2002). Thus, parents may try to cope with their uncertainty by displaying more solicitous responses to their child's illness-related pain. Future research will determine if parental uncertainty can mediate parental response to children's pain in a pediatric cancer setting. Overall, Hispanic and White parents seemed to respond solicitously with similar frequency to their child's illness-related pain.

Analyses showed the lowest endorsement of Promote Activity responses in the Spanish-speaking Hispanic group. These parents may not want to overwhelm their child by asking them to participate in extraneous activities. They may also believe that participation in physical and social activities may exacerbate their child's pain symptoms. Further testing is needed to validate these speculations. This study did not include any methods of identifying why parents chose to respond in the manner in which they did. Thus, further investigations will benefit from supplementing parental response scales with measures that illustrate the reasoning behind parents' choices of response.

Interestingly, Pearson correlations showed a negative association between Promote Pain Coping scores and parent overall and cancer-related quality of life. This implies that even though parents perceive to be promoting adaptive coping, they may actually be promoting illness behavior. It may also be that the child's worsening quality of life prompts any and all parental responses and that the relationships between parental response and child functioning are not linear. Further research should explore this pattern to attain more conclusive results.

In conclusion, the study demonstrated no distinct differences in parental solicitous responses to children's chronic illness related pain. The uncertainty parents feel regarding their

child's illness trajectory may attenuate cultural beliefs on pain coping. The perceived threat to life that these illnesses pose on their children may also cause parents to respond in this manner. Significant differences were only observed for the Promote Activity subscale of the PRPQ-R. Spanish-speaking Hispanic parents were reporting the lowest scores, implying that these individuals are not engaging their child in activities that may be beneficial to their child's overall health. Lastly, parental quality of life for all three groups is negatively associated with the total Promote Pain Coping subscale scores. Parents may not be properly promoting adaptive coping which can lead to unrelieved pain experienced by their children, which in turn may be aggravating parental distress. With more studies exploring parental response to children's pain within an oncology population, investigators may create interventions that can promote adaptive coping and ameliorate parental distress.

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