

**PROBLEM-SOLVING AND MATERNAL DISTRESS AT THE TIME OF CHILD'S  
CANCER DIAGNOSIS: ENGLISH VERSUS SPANISH-SPEAKING MOTHERS**

by

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Abstract

In the United States, cancer is the leading cause of death by disease among children; approximately 9500 new cases of were diagnosed in 2006 among children under 19 years of age. Among these children it was estimated that 1850 of these cases were Hispanic children. Survival rates have sharply risen over the past 25 years and now more than 75% of children diagnosed with cancer in the US are alive 5 years after diagnosis. This increase in childhood survival rates have exposed a need for increased understanding of parental functioning following their child's cancer diagnosis. While a majority of parents report increased distress following a traumatic event such as a child's cancer diagnosis, the aim of this study was to investigate distress and problem-solving skills between English (N=253) and monolingual Spanish-speaking (N=44) mothers. Data for this study was extracted from a pre-existing data set from a large intervention study on maternal problem-solving skills training and participants were mothers who were recruited within 2 to 16 weeks following their child's cancer diagnosis. Compared with English-speaking mothers, monolingual Spanish-speaking mothers reported greater distress and poorer problem-solving skills at baseline, but only one distress measure (IES-R) was significant after controlling for maternal education.

The findings from this exploratory analysis are significant to public health because it is important to assess psychosocial adjustment following traumatic events, such as a child's cancer

diagnosis, among the fastest growing minority population in the United States. It is also important to determine the contribution of socio-cultural characteristics to parental adjustment for minority populations. A better understanding of these socio-cultural differences in family adjustment to traumatic events has the potential to create interventions to improve the quality of life for families.

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## **PREFACE**

I would like to acknowledge my family and friends, especially my parents Jim and Mary Pilsner, for all of their love, support, and encouragement throughout the years. My family has provided me with an immeasurable example on the importance of education, a strong work ethic, and to never give up on my dreams. I would not be where I am today without their sincere support, patience, and reminder to embrace every opportunity and not be discouraged by change.

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## 1.0 INTRODUCTION

In the United States, cancer is the leading cause of death by disease among children; approximately 9500 new cases were diagnosed in 2006 among children under 19 years of age (National Cancer Institute, 2007). Survival rates have sharply risen over the past 25 years. More than 75% of children diagnosed with cancer in the US are alive 5 years after diagnosis, compared to approximately 60% in the mid-1970s (SEER Cancer Statistics Review, 2007). These improvements in survival rates are the result of increasingly complex treatments that place high demands on children and their families. Given the improved mortality, but with more intense therapy, there is a need for increased understanding of the psychological impact of these experiences. One specific domain of interest has been parental functioning following a child's diagnosis with cancer (Fuemmeler, Mullins, Van Pelt, Carpentier, & Parkhurst, 2005).

Of the approximate 9500 United States children diagnosed with cancer in 2006, it was estimated that 1850 of these children were Hispanic. Unfortunately in the United States, these children have a lower 5-year survival rate than Caucasian children (SEER Cancer Statistics Review, 2007). Perceptions of the traditional United States medical system, their child's illness, and perceived trauma may be influenced by cultural factors and could be very different among Spanish-speaking mothers than English-speaking mothers following a cancer diagnosis. For example, asking direct questions to the physician about sensitive topics may be perceived as disrespectful; Hispanic patients and parents may show respect by avoiding eye contact with

health care providers; Hispanic patients expect the provider to look directly at them even when talking through an interpreter. These examples, as well as cultural challenges, such as the underutilization of the extended family system between patients and providers, have the potential to create greater distress for Hispanic parents. Many Latino groups have a “fatalistic” view about their health and illness and many believe that both are beyond their control, or “what will be, will be” (*está para pasar*). Instead of taking this as a positive learning experience and working with the family in a culturally-appropriate manner, many clinicians may interpret this belief as hopeless although the potential to affect the care and relationship between the family and oncologist ((Munet-Vilaro, 2004). Another common experience among Latino families dealing with a cancer diagnosis is the resignation and acceptance to the pain brought on by the intense treatments; often children and parents will express a concern with the pain but might not strongly advocate for a pharmacological measure to control the pain (Munet-Vilaro, 2004). Additionally, families with limited experience with the traditional United States healthcare system are not accustomed to taking part in the decision-making process in their child’s treatment management and may perceive asking for clarification on treatment options as disrespectful. According to Munet-Vilaro (2004), confusion also arises among Latino families when the oncology team obtains permission to treat their child. The family does not understand the idea of giving consent since they believe that the doctors “are the experts” and that it should be their decision how to treat their child. These factors illustrate the importance and the contribution of socio-cultural characteristics to parental adjustment and the importance of pursuing this area of research.

Studies of parental adjustment to childhood cancer have documented increased levels of emotional distress, most frequently elevated anxiety and depression (Barrera et al., 2004; R. B.

Noll, Gartstein, Hawkins, Vannatta, & et al., 1995; Overholser & Fritz, 1990; Sloper, 2000; Steele, Dreyer, & Phipps, 2004). Additionally, there are reports of parents experiencing posttraumatic stress disorder (Best, Streisand, Catania, & Kazak, 2001; A. E. Kazak & Barakat, 1997). The literature supports the contention that mothers of children diagnosed with cancer represent a group prone to high levels of emotional distress and that the period shortly after their child's diagnosis and at the start of treatment may be particularly stressful and traumatic (Dolgin et al., 2007; Sawyer, Antoniou, Toogood, Rice, & Baghurst, 2000; Wallander et al., 1989). Being faced with a cancer diagnosis is a traumatic event and often times when children are diagnosed, their treatment begins very rapidly and families do not always have time to process the overload of information. The way that a mother copes with a traumatic event has the potential to affect their child's reaction to the event, especially because mothers play a pivotal role in family functioning. For example, positive maternal coping styles can actually buffer children's reactions to traumatic events.

Culture refers to the values, beliefs, traditions, symbols, language, and social organization that are meaningful and affect a group's way of life (Munet-Vilaro, 2004). Cultural beliefs are used to make judgments, guide actions, and support decisions. Behaviors which are based on cultural beliefs become more apparent when faced with illness such as cancer. People draw from their cultural values when faced with an event such as a major illness to help conceptualize, explain, and respond to the situation. How an individual responds to caring for a child with cancer is significantly influenced by the individual's culture and their environment (Munet-Vilaro, 2004).

Distress is a universal human experience which occurs across cultures and at all ages, but the expression of distress, the cognitions, and the causes vary with age and across cultures.

Understanding cultural manifestations of distress and cognitions about this concept can facilitate assessment and treatment of ethnic minorities as well as demonstrate the role of culture on perceptions of illness and well-being (Arcia, Castillo, & Fernandez, 2004). The ability to problem-solve is also an important framework to investigate since problem-solving may help to ameliorate difficulties following a trauma by equipping the individual with a new way of approaching the situation. Little is known about whether the experience for caring for a child with a cancer differs for caregivers from different racial or ethnic backgrounds. A particular focus of this paper is to examine the psychological impact for Spanish-speaking mothers compared to English-speaking mothers who are co-residing with a child recently (2-16 weeks) diagnosed with cancer. I am particularly interested in whether there are differences in the psychological reactions between these groups of mothers of children with cancer.

For the purpose of this paper the terms "Hispanic" and "Latino" are used interchangeably to refer to individuals in the United States who have come or have ancestry from Mexico, Puerto Rico, Dominican Republic, Cuba, El Salvador, Nicaragua, Columbia, Venezuela, Ecuador, Honduras, and other Latino American countries. There is a trend for some groups to prefer one term over the other, but neither term is accepted by all groups. These terms refer to an ethnic group whose origins and culture vary dramatically, and are comprised of ethnic subgroups not necessarily related to their nationality.

Family cohesion, support, and functioning have been shown to be important to Latina mothers and Latino families are more likely than non-Latino white families to care for a child with a disability in the home (Magana, Schwartz, Rubert, & Szapocznik, 2006). Despite the acculturation process, traditional values within the Latino culture emphasize *la familia*, *respecto*, *personalismo*, and *confianza*. Although many Latino families living in the United States are

socioeconomically disadvantaged and lack empowerment, family provides a great deal of emotional strength and social support and treatment decisions reflect a high level of respect for the entire family. This being known, there is no current research that focuses on whether Latino and other minority populations are at greater risk for distress when their child is diagnosed with cancer.

The literature does provide insight on Latino emotional well-being in regards to childhood disabilities. One study provided evidence that having more family problems was significantly related to higher depressive symptoms for both Latina and white mothers; however, there was a significantly stronger relationship between family problems and depressive symptoms for Latina mothers (Magana & Smith, 2006). Perceptions that one's family is unified and cohesive appear to be associated with better emotional well-being for patients and their Hispanic family members dealing with schizophrenia, but not for whites (Weisman, Rosales, Kymalainen, & Armesto, 2005). Other research has shown that mothers of Mexican-descent who were caring for children with disabilities had relatively high levels of depressive symptoms compared to a sample consisting of Mexican-American mothers without disabilities (Shapiro & Tittle, 1990) .

Lopez et al. (1997) found that Hispanic mothers of children with mental retardation reported higher levels of depressive symptoms than did their Hispanic counterparts with typically developing children. Research suggests that family structure, family norms, and social support systems are protective factors against developing psychiatric disorders (Holman, Silver, & Waitzkin, 2000; Vega, Kolody, & Valle, 1987). However, as Latino families immigrate to the United States and begin to acculturate into the mainstream American culture, their traditional cultural norms become less important, they may become vulnerable to developing psychiatric

symptoms and there appears to be a worsening of psychiatric health among this population (Holman et al., 2000).

Immigrant mothers with limited English fluency have difficulty communicating and understanding complex medical systems and treatments and may be more likely to experience their child's situation as severe and life-threatening even when reassured otherwise. Perceptions of the traditional United States medical system can also pose as a challenge for these mothers, especially when it comes to navigating the system, participation in clinical trials, or requesting supplemental support services following diagnosis. Even without an ill child, the difficult process of acculturation experienced by immigrant families is associated with the loss of supportive family, social, and cultural relationships; higher levels of poverty; interrupted maternal education; and increased emotional demands and distress. These life experiences have also been found to exacerbate the perceived stress of a child's illness (Sahler et al., 2005).

These data can inform future interventions to address the unique needs and aspects of the most rapidly growing minority group in the United States. While research has focused on family functioning in the months following diagnosis and treatment (A. E. Kazak & Barakat, 1997) (Anne E. Kazak et al., 2001; Wijnberg-Williams, Kamps, Klip, & Hoekstra-Weebers, 2006), few studies have examined parental distress at the time of cancer diagnosis; there are no published studies examining differences in distress associated with cultural background.

One of the first studies to examine usual psychological care (UPC) versus problem-solving skills treatment (PSST) among mothers of children recently diagnosed with cancer (Sahler et al., 2005). One of the objectives of that study was to examine particular problems experienced by the Hispanic population in the context of caring for a child with a catastrophic illness (Sahler et al., 2005). Research has shown that newly immigrated Spanish-speaking



mothers of pediatric cancer patients are at an increased risk for traumatic stress reactions associated with their child's illness (Hart, Katz, Stuber, Morpew, & Lopez, 2000; Sahler et al., 2005).

The purpose of this study is to (1) investigate maternal distress and (2) problem-solving skills of English and Spanish-speaking mothers at the time of their child's cancer diagnosis. Since several factors exist which place high demands on mothers with limited English fluency who have a child diagnosed with cancer, I hypothesized that independent of socioeconomic status, Spanish-speaking mothers will report greater distress and therefore poorer problem-solving skills than English-speaking mothers.

## **2.0 METHOD**

The study is a secondary analysis of pre-existing data of a randomized clinical trial funded by the National Cancer Institute. Baseline assessment data and demographic information from this clinical trial was analyzed to explore 1) distress and 2) problem-solving skills for both monolingual Spanish-speaking and English-speaking mothers of a child newly diagnosed cancer. For the purpose of this paper, newly diagnosed cancer is defined as 2-16 weeks after diagnosis. Institutional review board (IRB) approval for the original study was obtained at each participating site as well as from the University of Pittsburgh IRB for this secondary data analysis (See Appendix A for University of Pittsburgh IRB approval letter).

## 2.1 PARTICIPANTS

Participants from the initial clinical trial where these data originated were recruited from seven national pediatric cancer sites in the United States and one site in Israel (Rambam Medical Center, Petach Tikvah, Israel). For the purpose of this paper, the data from the seven United States sites will be utilized. The participants were recruited from the population of mothers of children newly diagnosed with any form of cancer/brain tumor at the following seven sites: Children's Hospital, Los Angeles, California; Children's Hospital and Medical Center, Cincinnati, Ohio; Children's Hospital and Health Center, San Diego, California; University of Texas/M.D. Anderson Cancer Center, Houston, Texas; St. Jude Children's Research Hospital, Memphis, Tennessee; Oregon Health and Science University Medical Center, Portland, Oregon; and Golisano Children's Hospital at Strong, University of Rochester Medical Center, Rochester, New York.

Eligibility criteria for the initial study included having a child diagnosed with cancer 2-16 weeks before contact by the research team, the ability to speak and read English or Spanish, and residence within a 50-mile radius of the participating center. Monolingual Mexican-Spanish-speaking mothers were preferentially recruited until they comprised 20% of the total sample. Four of the seven United States sites had participants who were monolingual Spanish-speaking: Children's Hospital Los Angeles; Children's Hospital and Health Center San Diego; M.D. Anderson Cancer Center; and Oregon Health and Science University Medical Center; however, 50% of the Spanish-speaking mothers were from Children's Hospital Los Angeles.

## **2.2 DATA COLLECTION PROCEDURE**

Potential participants received a written description of the intervention and its goals. Mothers who agreed to participate were consented into the research study as approved by the institutional review board of the center at which her child was receiving care. Once baseline assessments (demographic questionnaires, four measures of distress, and one measure of problem-solving ability) were completed by all of the mothers, they were stratified by site then centrally randomized into one of two groups: (1) problem-solving skills training (PSST), a cognitive-behavioral intervention based on problem-solving therapy and usual psychosocial care (UPC), or (2) usual psychosocial care (UPC) only. (Appendix C) Any mother in the UPC group was also offered to participate in PSST after she completed the final assessment. Additionally, each participant received a stipend of \$100 when the final assessment was complete.

## 2.3 OUTCOME MEASURES

In addition to demographic questionnaires, the following measures were administered at baseline to all mothers, either in English or Spanish depending on the mother's choice of primary language (For English questionnaires see Appendix B). The Profile of Mood States (POMS), Beck Depression Inventory-II (BDI-II), and Impact of Event Scale-Revised (IES-R) were the baseline assessments used to operationalize distress and the Social Problem Solving Inventory-Revised (SPSI-R) was the baseline assessment to operationalize problem-solving skills. For the purposes of this study, I analyzed these baseline measures and compared mean scores between English and monolingual Spanish-speaking mothers.

### 2.3.1 Profile of Mood States (POMS)

The POMS (McNair, Lorr, & Droppleman, 1992) is a 65-item inventory of positive and negative adjectives used to describe feelings and fluctuating affective states over a one-week period. Participants responded to each item by endorsing it on a 5-point likert scale ranging from 1 (not at all) to 5 (extremely). The scale produces 7 factor-based subscales (tension/anxiety, depression/dejection, anger/hostility, fatigue, confusion, vigor, and friendliness) of which all were included except friendliness. To obtain scores for such mood subscale, the sum of the responses is obtained for the adjective defining the factor and all items are keyed in the same direction with the exception of "Relaxed" in the Tension-Anxiety Scale and "Efficient" in the Confusion Scale which both receive negative weights in calculating the scores. The subscale scores are combined to produce a total POMS score, or Total Mood Disturbance Score, by summing the scores with Vigor weighted negatively) on the six primary mood factors. (McNair

et al., 1992) If Vigor is high and the other scales are low, it is then possible to receive a negative overall Total Mood Disturbance Scores. A higher total POMS score reflects greater mood disturbance (negative affectivity).

The POMS is widely used and has acceptable test-retest reliability ( $r = .65-.74$ ) and high levels of concurrent validity with related scales. The internal consistencies of the POMS are highly satisfactory, near .90 or above (McNair et al., 1992). The POMS has been used to measure mood disturbance caused by the physical and psychological effects of cancer (McNair et al., 1992). The use of the POMS has been successful in determining association of beliefs and attributions with adjustment to cancer. In general, these studies seem to indicate that POMS profiles often demonstrate higher levels of Depression, Tension-Anxiety, Fatigue, Confusion-Bewilderment and Total Mood Disturbance (Holland et al., 1986; Spiegel, Bloom, & Yalom, 1981; Taylor, Lichtman, & Wood, 1984; Taylor et al., 1985). The POMS has also been used in parents of children with chronic illness to assess substantial stress symptoms and mood disturbance (Daltroy et al., 1992; Minor, Carlson, Mackenzie, Zernicke, & Jones, 2006).

### **2.3.2 Beck Depression Inventory-II (BDI-II)**

The BDI-II (Beck, Steer, Ball, Ciervo, & Kabat, 1997) is a 21-item self-report measure which assesses the cognitive, affective, and behavioral components of depressive symptoms in adults and adolescents aged thirteen years and older (Beck et al., 1997). The BDI-II is widely used for both clinical and research purposes for addressing the severity of depression in diagnosed patients and for possible depression in normal populations (Piotrowski, Sherry, & Keller, 1985). The BDI-II has good internal consistency (.92 and above) and test-retest reliability (0.93). It also provides secondary measures of PSST treatment efficacy.

To obtain a score for the BDI-II, the ratings are summed for the 21 items. Each item is rated on a 4-point scale ranging from 0 to 3 and the maximum total score is 63 (Beck et al., 1997). Scoring is then broken up into four categories: minimal (0-13), mild (14-19), moderate (20-28), and severe (29-63) depression. The BDI-II has been widely used to assess depression and anxiety levels in mothers of children with cancer, chronic illness, and disabilities (Allen, Newman, & Souhami, 1997; Baki et al., 2004; Boles et al., 2005; Mulhern, Fairclough, Smith, & Douglas, 1992; Solomon, Goodlin-Jones, & Anders, 2004).

### **2.3.3 Impact of Event Scale-Revised (IES-R)**

The IES-R (Weiss & Marmar, 1997) assesses perceived posttraumatic stress as a component of negative affectivity. The IES-R is a 22-item self-report measure which includes three subscales (intrusion, avoidance, and hyperarousa) that assesses posttraumatic stress during the preceding week experienced in response to a specific event. The total IES-R score is the sum of the three subscales. The IES-R has been widely used to measure posttraumatic stress symptoms associated with significant events, such as a cancer diagnosis (Sahler et al., 2005). The IES-R has acceptable internal consistency reliability of the intrusion, avoidance, and hyperarousal subscales (.91, .84, .90 respectively) (Weiss & Marmar, 1997). Like the SPSI-R, the IES-R provides a secondary measure of PSST treatment efficacy. The IES-R has been used to assess posttraumatic stress symptoms among mothers following their child's cancer diagnosis (Norberg & Boman, 2007) and is sensitive to what it is supposed to measure in the study population.

### **2.3.4 Social Problem-Solving Inventory-Revised (SPSI-R)**

The SPSI-R is a 52-item instrument measuring five dimensions of problem solving (D'Zurilla & Nezu, 1990). Respondents endorse statements by rating them on a 5-point scale ranging from 1 (not at all true) to 5 (extremely true). The SPSI-R distinguishes between problem orientation (positive or negative) and problem solving (rational or characterized by impulsivity-carelessness or avoidance). The sum of (+) problem orientation and rational problem solving is termed constructive problem solving; sum of (-) problem solving (NPO), impulsivity-carelessness style, and avoidance style (AS) is termed dysfunctional problem solving. The total score (0-20) is the weighted average of the five subscores. A higher total score indicates better problem-solving skills. The SPSI-R provides a measure of problem-solving skill. The SPSI-R is internally consistent with alpha coefficients ranging from .80 to .95 across the five sub-scales. Test-retest estimates range from .72 to .88 across scales (among sample 1) and .68 to .91 among a second sample. The SPSI-R is concurrently valid, having the ability to distinguish between groups, and has a strong correlation with other problem-solving measures. The SPSI-R is also predictively valid and has significant correlations with measures of stress, anxiety, depression, etc. The SPSI-R has demonstrated effectiveness in assessing problem-solving orientation among mothers of children undergoing treatment (Hoekstra-Weebers, Jaspers, Kamps, & Klip, 1998) . (Hoekstra-Weebers, et al., 1998) (Nelson, Gleaves, & Nuss, 2003).



### **3.0 PROCEDURE**

During the clinical trial, most measures were administered three times: (1) baseline, prior to randomization (T1); (2) at the end of the PSST intervention, or 10-12 weeks after T1 for controls (T2); and (3) 6 months after T1 (T3). Demographics were assessed at baseline. For the purpose of this paper, only the baseline (T1) assessment for distress and problem solving along with the demographic questionnaire will be evaluated and the results will be compared between English-speaking mothers and monolingual Spanish-speaking mothers. The POMS, BDI-II, and IES-R were the initial baseline assessments used to report distress and the Social Problem Solving Inventory-Revised (SPSI-R) was the baseline assessment to report problem-solving skills.

### 3.1 METHODS

Two statistical methods were used to evaluate differences in mean scores between English and monolingual Spanish-speaking mothers. Two-tailed  $t$ -tests ( $\alpha = .05$ ) were used to evaluate differences in POMS, BDI-II, and IES-R, and SPSSI-R scores (including any subscales). Additionally, an analysis of covariance (ANCOVA) was used as a secondary measure to determine significance after consideration of potentially confounding demographic variables (i.e. maternal education). All statistical analyses were done using SPSS/16 software.

Cross-tabulation and chi square tests were used to detect demographic differences between English and Spanish-speaking mothers and whether these differences were significant.

A power analysis, which was conducted using GPOWER (Faul & Erdfelder, 1992), determined that a sample size of 140 would be necessary to detect a medium effect size ( $d = .5$ ) at a reasonable level of power (.9) for a one-tailed  $t$ -test. A power analysis determined that a sample size of 172 would be necessary to detect a medium effect size ( $d = .5$ ) at a reasonable level of power (.9) for a two-tailed  $t$ -test. Since the sample size was 297 mothers, two-tailed  $t$ -test was used for this analysis.

## **4.0 RESULTS**

### **4.1 PARTICIPANTS AND DEMOGRAPHICS**

#### **4.1.1 Participants**

A total of 430 mothers were enrolled in the clinical trial (213 UPC, 217 PSST); however, only a portion of this sample was used for this secondary analysis. This data set also included a sample of Hebrew-speaking mothers from a pediatric cancer site in Israel; however, they were not included in this analysis since I was only investigating potential difference between English and Spanish-speaking mothers. Baseline data from 297 mothers that included 253 English-speaking and 44 monolingual Spanish-speaking mothers was used.

Approximately 25% of mothers approached across the eight pediatric cancer sites refused participation. There are no data specifying the refusal rate by language spoken. The most frequent reasons for refusal given were lack of time/too busy/schedule problems (47%), feeling overwhelmed (14%), and not interested (19%). There were no major differences in age or type of cancer between the children of the mothers who participated in the clinical trial and those who refused; however, there was a difference between these two groups in the time from diagnosis. The mothers who participated were randomized into their intervention group an average of 9.3 weeks after diagnosis and those mothers who refused did so an average of 6.0 weeks after

diagnosis. This high (approximately 50%) refusal rate among mothers initially approached to join the clinical trial within 2 to 4 weeks of their child's diagnosis led to a midstudy decision to delay all recruitment efforts for at least 4 weeks after diagnosis. Initial recruitment was often delayed for 6 weeks or more, extending the window to 16 weeks (Sahler et al., 2005).

Completion of all baseline assessments also added an average of 1 week since diagnosis.

#### **4.1.2 Demographics**

Table 1 illustrates the demographic characteristics of the English and monolingual Spanish-Speaking mothers and includes age, maternal education, marital status, race/ethnicity, number of children, and age of child at diagnosis.

Differences in maternal education were significant ( $p < 0.05$ ) between the two groups with the English-speaking mothers having a significantly higher level of education. There was also a significant difference in marital status between the English and Spanish-speaking mothers. It was noted that 28 (11.2%) Hispanic mothers were “primarily English-speaking” (i.e. all study materials were administered in English) although they also chose Hispanic as their ethnic category. This observation led me to perform an additional analysis in order to see if these potentially bilingual mothers were more similar to the English or Spanish-speaking mothers. Lastly, the significant difference in maternal education between the two groups of mothers prompted a further analysis to control for education.

**Table 1: Demographic Differences**

<b>Variable</b>	<b>English-Speaking (N=253)</b>	<b>Monolingual Spanish-Speaking (N=44)</b>	<b>Significance* (<math>\alpha = .05</math>)</b>
Mean Age (Years)	36	35	NS
Education (%)	-	-	.000
<High School	3 (1.2%)	22 (55.4%)	-
High School	89 (35.2%)	15 (35.7%)	-
Postsecondary	125 (49.4%)	4 (9.5%)	-
Graduate School	33 (13%)	1 (2.4%)	-
Marital Status (%)	-	-	NS
Single	22 (8.7%)	3 (6.8%)	-
Married	188 (74.3%)	29 (65.9%)	-
Divorced/Separated	26 (10.3%)	2 (4.5%)	-
Unmarried, Living with Partner	9 (5.5%)	8 (18.2%)	-
Widowed	2 (0.8%)	0 (%)	-
Ethnicity/Race (%)	-	-	.000
American Indian/AN	6 (2.4%)	0	-
Asian/Pacific Islander	5 (2%)	0	-
Black, not Hispanic	20 (8%)	0	-
Caucasian	189 (75.6%)	0	-
Hispanic	28 (11.2%)	43 (100%)	-
Other/Unknown	2 (0.8%)	0	-
Number of Children	2.4 (2)	2.7 (3)	NS
Age of Child-Diagnosis	5.48	7.7	NS

\* Chi square tests were used to test significance

## 4.2 MEAN DIFFERENCES IN SCORES

### 4.2.1 Distress

Mean baseline assessment scores were compared between English and monolingual Spanish-speaking mothers for the POMS, BDI-II, and IES-R by using a two-tailed t-test of significance. (Table 2) Although the POMS Total Mood Disturbance scores were not significantly different between the two groups of mothers ( $p=.205$ ), two of the six subscales (depression and anger) produced significant results. Spanish-speaking mothers had higher scores on the depression (17.2 versus 13.1) and anger subscales (12.3 versus 8.8) than the English-speaking mothers ( $p= .043$  and  $.013$  respectively) suggesting greater mood disturbance and negative affectivity.

The IES-R total score was significantly different between the two groups of mothers; Spanish-speaking mothers reported higher scores (43.2 versus 27.2), indicated greater perceived posttraumatic stress ( $p= .000$ ). The IES-R Avoidance and Hyperarousal subscales of the IES-R were also significantly different, with Spanish-speaking mothers showing more distress; however, the IES-Intrusion subscale was not significant ( $p= .000$  and  $.018$  respectively). Lastly, no significant mean score difference existed between both groups of mothers on the BDI-II.

When controlling for maternal education between the English and Spanish-speaking groups, mean score differences were no longer significant on the measures mentioned above, with the exception being the IES-R. (Table 2) The IES-R Total and Avoidance and Hyperarousal subscales remained significant ( $p= .000$ ,  $.018$ ,  $.004$  respectively), with the IES-R Intrusion subscale approaching significance ( $p=.056$ ). This difference emphasizes the

importance of taking demographic variables into account when comparing groups that may vary greatly on education or socioeconomic status.

#### **4.2.2 Problem-solving skills**

Mean score differences were compared between English and monolingual Spanish-speaking mothers for the SPSI-R by using a two-tailed t-test of significance. (Table 2) Problem Solving Skills Results show a significant baseline difference in the SPSI-R, with the English-speaking mothers having a higher score and indicating better problem solving skills (14.1 versus 12.9;  $p = .004$ ).

After controlling for education, the mean score differences on the SPSI-R between English and monolingual Spanish-speaking mothers were no longer significant. (Table 2)

**Table 2: Mean Score Differences**

Variable	English-Speaking (N=253)		Monolingual Spanish-Speaking (N=44)		Significance ( $\alpha = .05$ )	
	<i>Mean</i>	<i>SD</i>	<i>Mean</i>	<i>SD</i>	<i>t-test</i>	<i>ANCOVA*</i>
POMS (Total Score)	42.2	38.8	50.3	38.7	.205	NS
POMS Tension	13.1	7.8	14.9	7.9	.171	NS
POMS Depression	13.1	12.1	17.2	12.4	.043	NS
POMS Anger	8.8	8.4	12.3	10.0	.013	NS
POMS Fatigue	11.3	6.8	9.6	6.7	.116	NS
POMS Confusion	9.1	5.3	10.6	5.2	.095	NS
POMS Vigor	18.9	6.2	17.9	4.4	.317	NS
BDI-II	13.8	9.3	15.9	8.6	.151	NS
IES-R (Total Score)	27.2	16.0	43.2	20.3	.000	.000
IES-R (Avoidance)	7.7	5.9	15.4	8.2	.000	.000
IES-R (Intrusion)	11.7	6.6	14.3	7.3	.018	.056 (Approaching Significance)
IES-R (Hyperarousal)	7.8	6.1	13.4	6.9	.000	.000
SPSI-R	14.1	2.5	12.9	2.0	.004	NS

\* ANCOVA controlled for maternal education

\*\* Higher scores indicate healthier functioning for SPSI-R; lower scores indicate healthier functioning for all other measures



### 4.3 POST-HOC ANALYSIS

In order to further delineate and explain differences between the English and monolingual Spanish-speaking mothers in this study, a post-hoc analysis was completed.

According to the data, 28 (11.2%) Hispanic mothers were primarily English-speaking, thus they received all study materials and assessments in English. Although the primary research question is based on language differences, it is possible that these families, although bilingual, primarily speak Spanish at home and are not a true representation of predominantly English-speaking families. To account for a possible covariate, all statistical tests were run including these 28 mothers and not including these mothers; however, no significant differences were found between mean scores when controlling for this factor.

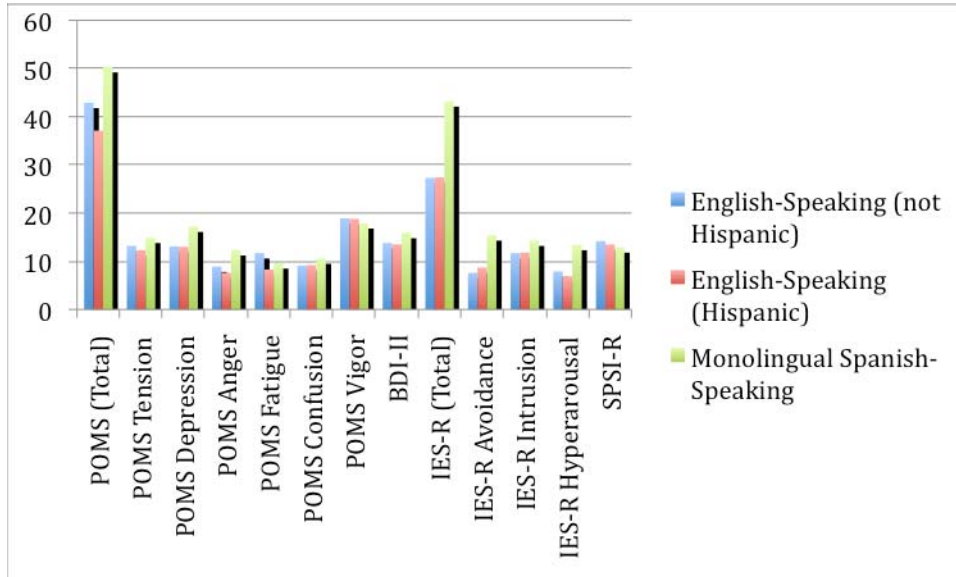
Table 3 illustrates mean scores for the distress and problem-solving measures among these 28 Hispanic, English-speaking mothers. When comparing these scores to non-Hispanic English-speaking mothers and monolingual Spanish-speaking mothers, it was revealed that their scores tend to be more like the non-Hispanic English-speaking mothers for all of the measures except POMS fatigue. (Figure 1) Although the difference was minimal, the Hispanic and non-Hispanic English-speaking mothers were also similar on their SPSI-R scores. The largest discrepancy between both English-speaking groups and the monolingual Spanish-speaking mothers existed on the IES-R total score, which was the assessment that remained significant even after controlling for education. Scores for this measure were almost identical between both non-Hispanic and Hispanic English-speaking groups of mothers (27.2 and 27.4 respectively).

Figure 2 illustrates maternal education differences between the three groups of mothers: (1) English-speaking, non Hispanic, (2) English-speaking, Hispanic, and (3) Monolingual

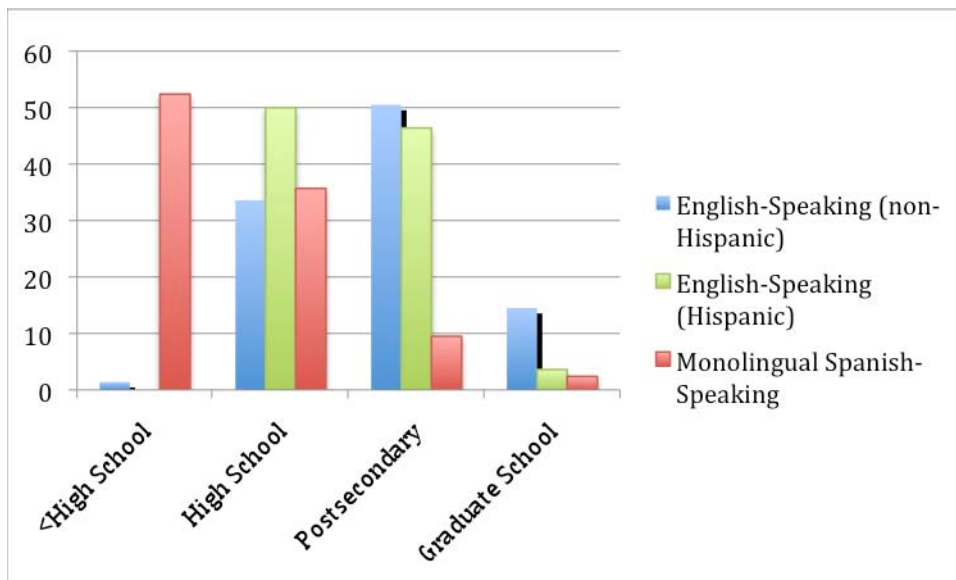
Spanish-speaking. As with the mean scores of the assessments, the education levels between the two English-speaking groups of mothers were most similar.

**Table 3: Mean Score Differences in non-Hispanic English-Speaking mothers**

Variable	English-Speaking Hispanic Mothers (N=28)	
	<i>Mean Score</i>	<i>Standard Deviation</i>
POMS (Total Score)	37.1	41.7
POMS Tension	12.3	7.9
POMS Depression	13.0	14.9
POMS Anger	7.6	8.4
POMS Fatigue	8.3	6.6
POMS Confusion	9.2	6.1
POMS Vigor	18.8	5.4
BDI-II	13.5	9.6
IES-R (Total Score)	27.4	17.2
IES-R (Avoidance)	8.7	7.3
IES-R (Intrusion)	11.8	6.7
IES-R (Hyperarousal)	6.9	5.6
SPSI-R	13.5	2.6



**Figure 1: Mean Score Differences**



**Figure 2: Maternal Education Differences**

## **5.0 DISCUSSION**

### **5.1 SYNTHESIS OF THEMES AND FINDINGS**

The results of this secondary data analysis demonstrate the differences between English and monolingual Spanish-speaking mothers following their child's cancer diagnosis. The overall picture is of statistical significance between the groups in the IES-R total score and IES-R subscores for avoidance, intrusion (approaching significance), and hyperarousal. Although there were no major differences for distress and problem-solving once I controlled for maternal education, these findings should still be considered within the framework of family based supportive care that is culturally competent for minority youth and families. This is an area worthy of further research that includes the inclusion of a larger Latino and minority sample, stronger measures of distress and problem-solving, a measure of acculturation, and a more precise measure of demographic data.

Monolingual Spanish-speaking mothers had a significantly lower education level than English-speaking mothers; therefore, maternal education was controlled for when running the data analysis. Studies have shown that Spanish-speaking mothers with limited English proficiency and formal education are more likely to have depressive symptomatology. One study found Latina immigrants to be more than twice likely to have greater depression than women with adequate literacy when seeking prenatal care services (Bennett, Culhane, McCollum,

Mathew, & Elo, 2007). Another study explored parental characteristics in understanding distress suffered by parents of children with disabilities (Harrison & Sofronoff, 2002). Results concluded that maternal education was controlled in the analysis due to significant association with psychological distress. Coping styles can also be affected by maternal education and Tseng and Chou (Tseng & Chou, 2006) investigated maternal distress and found an association between coping behavior and education. Results from this study demonstrated that mean score differences for the program-solving measure (SPSI-R) were only significant before controlling for maternal education; this reveals how results can considerably change when looking at two remarkably different groups. Not only should the association between low literacy and distress be considered when working with vulnerable populations and when designed health services, but also when analyzing data in order to obtain the most accurate results.

Facing a child's cancer diagnosis is no doubtably a traumatic event and often times treatment begins immediately following diagnosis and the family has to make adjustments to schedules and daily life activities very quickly. Despite common belief, children are quite resilient and it is not the children that are suffering from depressive symptoms, but rather the mothers (or primary caretaker). We know that mothers are at high-risk for depressive symptomology; however, the literature does not include any studies investigating the psychological impact of these experiences in minority populations. Although once education was controlled for in this study the results were no longer significant, previous studies (Sahler et al., 2005) found that Spanish-speaking mothers know significantly less about their child's cancer and fared better over time when exposed to problem-solving skills training. Based on what we know about this population and their difficulties with navigating the traditional U.S. medical system, it was surprising that the differences were so small between the English and monolingual

Spanish-speaking mothers. It is possible that this is due to the fact that several Latino groups are not accustomed to taking part in their child's treatment decisions. The doctors are considered the "experts" and it is viewed disrespectful to ask questions, make suggestions, or be involved in any treatment procedures. Once these families immigrate to the United States, they are not aware of the traditional norms of the medical system, informed consent, and that they are expected to be involved in their child's treatment options. This change in culture within the healthcare system has the potential to create great distress for these mothers; however, I believe there are some major limitations in the collection of data for this study which did not fully portray an accurate picture of psychosocial functioning.

## **5.2 LIMITATIONS**

A major limitation is the potential lack of cultural relevance of the psychosocial assessments used to measure distress and problem-solving. Although these assessments were translated and back-translated from English to Spanish, I am not convinced that these assessments are necessarily the best judge of distress when working across certain populations, especially since these measures were not normed with primarily Latina mothers. It is a realistic possibility that some of the assessment questions may have lost relevance once translated to Spanish.

The data set used for this study also did not include some key components which could have illustrated patterns, for example a correlation between acculturation and distress. It would have been very interesting to analyze if length of time in the United States increased or decreased the mothers' level of distress following their child's cancer diagnosis.

Additionally, the original research study only collected baseline data quantitatively by use of surveys. If mothers lacked literacy skills or were not accustomed to completing surveys, it is possible that qualitative data collection would have painted a very different picture of the distress and problem-solving ability of these mothers. Qualitative data analysis is a superb method used to capture attitudes, perceptions, and beliefs that quantitative surveys are not always able to reveal. Qualitative methods that might be beneficial in future investigation of this population would be focus groups, in-depth interviews, and qualitative surveys. Other creative techniques might also be employed to help increase involvement and participation, such as using photo voice. Photo voice (or “fotonovellas”), would be the most beneficial with this population because it was and remains a popular form of literature in Central and South America. This method attempts to increase learner involvement in the development of assessment materials, and most importantly, offers a vehicle for appropriately gearing materials to the culture, ethnicity, race, gender, language, and class status of the learners. The dialogue, drawn directly from the people’s speech can also be naturally geared to literacy needs (Rudd & Comings, 1994).

Another limitation in this data set was the unequal size of the groups of mothers: English-speaking (N=253) and monolingual Spanish-speaking (N=44). Due to the higher incidence of childhood cancer among Caucasians, it is easier to recruit this population of mothers; however, efforts should be made in the future to oversample for a higher percentage of Spanish-speaking families. In addition, due to the age of the data (1999-2000) when the demographic survey asked the ethnicity of the respondent, it did not differentiate between race and ethnicity categories as was done starting with the 2000 census. For example, since Hispanic is an ethnicity (and not a race per the 2000 census) these mothers were not able to chose “Caucasian” or “African American” as race and “Hispanic” as ethnicity. In future data collection, the race and ethnicity

categories must be adjusted to better differentiate between racial and ethnic categories and investigate similarities/differences between groups more accurately.

### **5.3 RECOMMENDATIONS AND CONCLUSION**

The findings from this study as well as further research have significant implications for public health professionals. Not only is it important to determine the contribution of socio-cultural characteristics to parental adjustment to a cancer diagnosis, but this area of research has the potential to translate findings to family functioning and adjustment following any traumatic event in order to create better models of care. A better understanding of socio-cultural differences in family adjustment to traumatic events has the potential to create interventions to improve the quality of life for families.

Future research following a child's cancer diagnosis should also concentrate on how cultural-competent care affects the use of health-related services among families, how populations view both their physical and mental health status, and how they seek and utilize care services. A child's cancer diagnosis can lead to months, if not years, of healthcare professionals working very closely with families. Although each family represents their own culture, independent of race, ethnicity, or language, health care providers must take steps forward to become confident to work across cultures. It is impossible to become culturally "competent" in every culture; however, providers should make the effort to move from sensitivity and awareness to action and learn traditional social norms and beliefs among the populations they are predominantly treating.



**APPENDIX A: IRB APPROVAL LETTER**



# University of Pittsburgh

## *Institutional Review Board*

3500 Fifth Avenue  
Ground Level  
Pittsburgh, PA 15213  
(412) 383-1480  
(412) 383-1508 (fax)  
<http://www.irb.pitt.edu>

### **Memorandum**

TO: [ROBERT NOLL](#), PhD  
FROM: [SUE BEERS](#), PhD, Vice Chair  
DATE: 3/6/2008  
IRB#: PRO08010123  
SUBJECT: Problem-Solving and Maternal Distress at the Time of Child's Cancer  
Diagnosis in English Versus Spanish-Speaking Families

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The above-referenced project has been reviewed by the Institutional Review Board. Based on the information provided, this project meets all the necessary criteria for an exemption, and is hereby designated as "exempt" under section 45 CFR 46.101(b)(4).

Please note the following information:

- If any modifications are made to this project, please contact the IRB Office to ensure it continues to meet the exempt category.
- Upon completion of your project, be sure to finalize the project by submitting a termination request.

**Please be advised that your research study may be audited periodically by the University of Pittsburgh Research Conduct and Compliance Office.**

## **APPENDIX B: BACKGROUND OF UPC VERSUS PSST**

*From Sahler, et al., 2005:*

At pediatric cancer centers, usual psychosocial care (UPC) is provided by members of a multidisciplinary team to address psychosocial concerns of children with cancer and any family members who might be affected (R. Noll & Kazak, 1997). Although UPC differs by site, it normally involves a comprehensive initial assessment performed by a mental health professional completed within a few days of the child's cancer diagnosis. Psychological, psychiatric, social work, or additional interventions are also provided or recommended if necessary (Sahler et al., 2005). The PSST intervention group received UPC in addition to eight 1-hour individual sessions conducted according to a detailed protocol (Varni, Sahler, Mulhern, Copeland, & Noll, 1999).

In the original clinical trial, PSST was offered a generic coping skill applicable to a range of challenges which commonly arise during childhood cancer treatment (Sahler et al., 2005). PSST, as used here, had two main purposes. First, it increased the mother's engagement to issues relevant to her and her family since issues were chosen that were of specific interest to her. Second, it allowed the mother and interventionist to review the appropriateness of solutions if circumstances changed over time (Sahler et al., 2005). The PSST intervention utilized the acronym "Bright IDEAS". *Bright* signified optimism about solving problems. The letters I (identify the problem), D (determine the options), E (evaluate options and choose the best), A (act), and S (see if it worked) signify the five essential steps of problem solving (D'Zurilla & Nezu, 1990). Instructional materials included: treatment manual, a pocket-sized Bright IDEAS logo refrigerator magnet, and trigger cartoons to help guard against negative automatic thoughts (Sahler et al., 2005).

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