THE EFFECTS OF PARENTAL LANGUAGE ON CHILDREN'S ILLNESS UNCERTAINTY

Guzman, Brenda
Department of Anesthesiology & Perioperative Care

Fortier, Michelle, PhD

This study explored the effects of parental language and ethnicity on children's illness uncertainty. Illness Uncertainty is defined as a cognitive experience elicited in situations in which the meaning of illness-related events is unclear and outcomes are unpredictable, which can lead to poor psychological functioning. The children's uncertainty in illness scale (CUIS) measures the child's perceived uncertainty about their illness. Literature supports the idea that direct communication with children about their illness in a developmentally appropriate manner is important in minimizing illness uncertainty. However, when language barriers between healthcare providers and parents exist, children may experience illness uncertainty. A total of 127 parent-child dyads were recruited from the Cancer Institute at Children's Hospital of Orange County (CHOC). Parents completed a demographics questionnaire and children completed measures of illness uncertainty. All participants completed quality of life measures. One-way analysis of variance (ANOVA) revealed significant group differences in children's illness uncertainty among three ethnic/language groups: Spanish-speaking Hispanic, English-speaking Hispanic, and English-speaking non-Hispanic White ($F(2, 124) = 3.29$, $p = .04$). Follow-up, post-hoc analyses revealed that children of Spanish-Speaking Hispanic parents reported greater illness uncertainty compared to children of English-Speaking non-Hispanic Whites ($p=.01$). No other pairwise comparisons revealed group differences (p's = ns). When parental education and income were entered as covariates for a follow up analysis of covariance (ANCOVA), the overall model was no longer significant. Results of this study suggest race/ethnicity and socioeconomic status may impact child uncertainty in illness, but future research is needed to understand the mechanism of impact.

Illness Uncertainty is defined as a cognitive experience elicited in situations in which the meaning of illness-related events is unclear and outcomes are unpredictable (Mishel, 1990). Studies of adults with myocardial infarction, multiple sclerosis, and cancer have shown that patients with high levels of illness uncertainty are at increased risk of poorly adapting to their illness or developing psychological distress (Mullins et al., 2007; Pai et al., 2007). Similarly, parents of children with a wide variety of chronic health conditions have expressed high levels of uncertainty about their children's illnesses (Maikranz et al 2007; Stewart & Mishel, 2000). Parental uncertainty is also a prominent predictor of adjustment outcomes among parents of

children with chronic illness such as type-1 diabetes, cancer, and asthma (Pai et al., 2007; Stewart & Mishel, 2000) and has been correlated with increased psychological distress, including anxiety, depression, and even post-traumatic stress symptoms (Mullins et al., 2007; Stewart & Mishel, 2000).

Recent studies have confirmed that children also experience illness uncertainty regarding their treatment, symptoms, possibility of recurrence, and their ability to participate in daily activities (Pai et al., 2007; Stewart & Mishel, 2000). Analogous to adults, illness uncertainty is associated with anxiety, depressive symptoms, and general psychological distress in children with chronic illnesses (Mullins et al., 2007; Pai et al., 2007). Additionally, the literature shows that a child with decreased psychological functioning may be less likely to adhere to treatment (Maikranz et al 2007). Furthermore, child illness uncertainty has been shown to be a predictor of quality of life in children with cancer (Fortier, (in press)).

According to the American Cancer Society, 10,400 children under the age of 15 were diagnosed with cancer in 2007 (Garcia et al., 2007). Illness uncertainty is common and children who are older, have parents with higher illness uncertainty, have lower cancer knowledge, and are newly diagnosed with cancer report higher illness uncertainty (Stewart & Mishel, 2000). Uncertainty in children with cancer has been associated with psychological distress and poor social support (Stewart & Mishel, 2000). Communication has been thought to play a key role in resolving and managing uncertainty in illness (Babrow et al 1998).

The United States (U.S.) Census Bureau reported that 37 million people speak Spanish at home and only roughly over half speak English with varying proficiencies (Shin & Bruno, 2003). Because of the growing Spanish speaking population in the U.S., it is imperative to understand how parental ethnicity/language may affect illness uncertainty in children. Children rely heavily on their parents for information about their illness and if parents struggle to clarify important aspects of the child's illness due to language barriers, it is likely that children will develop illness uncertainty. Therefore, in this study, we explore the possibility of parental language and ethnicity as a predictor of child uncertainty of illness. Based on this body of

research, it was hypothesized that children of Spanish-speaking parents would report greater illness uncertainty compared to children of English-speaking parents. Moreover, it was hypothesized that parental ethnicity and language would impact the relationship between children's illness uncertainty and quality of life.

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

As a part of a larger study examining pain and pain management in children with cancer, a total of 127 parent-child dyads were recruited from the Outpatient Infusion Center (OPI) and/or Cancer Institute at Children's Hospital of Orange County (CHOC Children's). Spanish-and English-speaking parents were included. All participating children were between the ages of 8-18 and were diagnosed with various types of cancer. Children with developmental delays were not eligible to participate in this study.

Measures

Demographic Baseline Form (parent self-report) The demographic baseline packet assessed a wide variety of information including child age and parental ethnicity, language, education, and income.

Children's Uncertainty in Illness Scale (CUIS) (Pai et al., 2007) The CUIS measures children's perceived uncertainty about the course, prognosis, and treatment of their illness. It assesses their perceived ambiguity and unpredictability about their condition and the lack of information (e.g. "I have a lot of questions about my illness," "I don't know what the answers are.") This 23-item measure is rated on a five-point Likert-type scale ranging from 1=*very true* to 5=*very false.* Greater scores are indicative of higher uncertainty. The validity of the CUIS has been tested and has demonstrated good internal consistency (Pai et al., 2007). Studies have shown an association between CUIS and child depressive symptoms (Pai et al., 2007).

Pediatric Quality of Life Inventory, Parent and Child Report (PedsQL) *(Varni et al 2002)*. The PedsQL is a 23-item scale that measures health related quality of life (HRQOL) in four categories (physical, emotional, social, and school). This measure is appropriate for children between the ages of 2-18 that are healthy or have acute/chronic illnesses, and it is rated on a 5-point Likert-type scale ranging from 0=never to 4=almost always, where lower scores suggest a lower HRQOL. Those who can self-report have shown an internal consistency reliability of .88 for the total scale score. Parent reports have demonstrated a higher internal consistency reliability of .90 to .93.

Pediatric Quality of Life Inventory-Cancer Module, Parent and Child Report (Varni et al., 2001). The PedsQL Cancer Module is a 27-item measure used to help further understand the how cancer affects a child's health related quality of life (HRQOL). The scale is composed of 8 categories, which include pain and hurt, nausea, procedural anxiety, treatment anxiety, cognitive problems, perceived physical appearance, and communication. Analogous to the PedsQL, the 5-point Likert scale ranges from 0=never to 4=almost always where lower scores signify a lower HRQOL. The internal consistency reliability for this measure is .72 and .87 for the child self-report and parent, respectively.

Procedures

Potential participants were identified through CHOC Children's Outpatient Infusion Center or Cancer Institute. Electronic medical records were reviewed and evaluated for eligibility. Eligible subjects were mailed a letter of introduction, which included detailed information about the study, expectations, contact information, and eligibility requirements. Two weeks after mailing the letter of introduction, potential participants were contacted to address questions and concerns and invite participation. Parents and children who agreed to participate were notified that they would receive a research packet with questionnaires. Once the research packet was completed, participants mailed them back in prepaid envelopes or returned them during their regularly scheduled visit to the Outpatient Infusion Center or Cancer Institute.

Statistical Analysis

All analyses were conducted using IBM SPSS 21.0. A one-way analysis of variance (ANOVA) was executed to test for significant differences in child age, parental education, and income between the 3 ethnic/language groups. ANOVA was conducted to examine potential differences between mean child uncertainty in illness (CUIS) scores and parental language/ethnicity. Follow-up, pairwise comparisons were conducted to determine where the differences between the groups were. Additionally, to control for confounding variables a follow-up analyses of covariance (ANCOVA) was conducted to look for differences in illness uncertainty after controlling for significant differences in group demographics. Finally, Pearson product-moment correlations were used to measure associations between child uncertainty and quality of life (QOL) between the groups.

RESULTS

Participant Demographics

ANOVA demonstrated significant group differences in parental education (F(2, 277)= 104.50, $p<.001$) and income (F(2, 247)=95.46, $p<.001$) between the three groups (Table 1). A post hoc least significant difference (LSD) test showed that English-speaking non-Hispanic White parents reported significantly higher income ($p<.001$) and greater years of education ($p<.001$) compared to English-speaking Hispanic parents. In addition, Spanish-speaking Hispanic parents reported significantly lower income ($p<.001$) and less years of education ($p<.001$) compared to English-speaking Hispanic parents and English-speaking White parents.

Table 1. Means for child age, parental education, and income

	English Speaking Non- Hispanic White Parents (M ± SD)	English Speaking Hispanic Parents (M ± SD)	Spanish Speaking Hispanic Parents (M ± SD)	Significance (p)
Child Age (yrs)	10.80 ± 5.32	10.70 ± 4.67	10.27 ± 4.67	0.71
Parental Education (yrs)	16.02 ± 2.34	13.62 ± 2.43	10.36 ± 3.42	<.001

Income (range)	$51,000 to 80,000	$31,000 to 50,000	$11,000 to 20,000	<.001

Ethnic/Language Differences in Children's Illness Uncertainty

ANOVA revealed significant group differences in children's illness uncertainty among the 3 groups ($F(2, 124)=3.29$, $p=.04$; Table 2). Follow-up, post-hoc analyses revealed that children of Spanish-speaking Hispanic parents reported greater illness uncertainty compared to children of English-speaking non-Hispanic White parents ($p=.012$). No other pairwise comparisons revealed group differences (ps=ns).

Table 2. Differences in mean Child Uncertainty in Illness Scale scores between the groups.

	English Speaking non-Hispanic White Parents M ± SD	English Speaking Hispanic Parents M ± SD	Spanish Speaking Hispanic Parents M ± SD
Child Uncertainty in Illness Scale	51.19 ± 12.89	55.24 ± 14.29	58.74 ± 14.72

Because group differences were found in education and income, both variables were entered as covariables in a follow-up analysis of covariance (ANCOVA). The overall model was not significant ($F(4,84)=1.962$, $p=.108$); and neither ethnicity/language nor the covariates were significant predictors of children's illness uncertainty (Table 3).

Table 3. Analysis of covariance for parental income and education

Source	SS	df	MS	F	p
Income	32.45	1	32.45	.177	.675
Education	152.98	1	152.98	.834	.364
Ethnicity/Language	268.061	2	134.03	.731	.485
Error	15405.43	84	183.34		
Total	286,840.00	89			

Ethnic/Language Differences in the Relationship between Children's Illness Uncertainty and Quality of Life

Pearson product-moment correlations showed that parental-reported cancer-specific quality of life was strongly and negatively correlated with child uncertainty in English-speaking non-Hispanic White parents and Spanish-speaking Hispanic parents, but not in English-speaking

Hispanic parents (Table 3). Illness uncertainty scores were all negatively correlated with quality of life, regardless of parental language/ethnicity.

Table 4. Correlations between child and parental quality of life (QOL) and child uncertainty in illness scale (CUIS) score when divided by ethnicity/language.

	Child Generic QOL	Child Cancer module	Parent Generic QOL	Parent Cancer module
CUIS score- English speaking Non Hispanic White parents	-.54**	-.51**	-.35*	-.48**
CUIS score- English speaking Hispanic parents	-.44*	-.56*	-.30	-.32
CUIS score- Spanish speaking Hispanic parents	-.48*	-.65**	-.28	-.55**

* Correlation is significant at the p<0.05 level
** Correlation is significant at the p<0.01 level

DISCUSSION

The purpose of this study was to determine whether parental ethnicity and language were significantly related to illness uncertainty in children diagnosed with cancer. Although initial differences in children's uncertainty were found between English-speaking non-Hispanic White parents and Spanish-speaking Hispanic parents, such that children of Spanish-speaking parents reported higher illness uncertainty, these differences no longer persisted after controlling for education and income. These findings suggest that the relationship between ethnicity/language, socioeconomic status (SES), and children's illness uncertainty is complex and warrants further investigation. The percentage of non-Hispanic White mothers with a bachelor's degree in 2008 was three times that of Hispanic mothers (Aud et al 2010). Previous research has suggested that lower education may lead to increased uncertainty as a result of higher perceived complexity regarding treatment and the system of care. Conversely, greater education may lead to the ability to quickly modify illness uncertainty and the ability to construct meaning for events. Overall, those with less education experience uncertainty for longer periods of time than

7

individuals with more education (Mishel, 1988). In this model it is possible that parental education is affecting child illness uncertainty scores. However, further research is needed to better understand the mechanisms behind these findings.

Literature supports the idea that direct communication with children about their illness, prognosis, and treatment in a developmentally appropriate manner is important in minimizing illness uncertainty (Barlow et al 1998). However, when language barriers between parents and healthcare providers exist, it may be difficult for parents to understand their child's illness. In turn, it will be unlikely for parents to minimize the child's perceived ambiguity and unpredictability about their condition through communication or explanation of their illness. Additionally, research suggests that language and SES can affect illness uncertainty. A small sample size in this study may have been the reason why significant results were not obtained. It is also possible that important variables were not taken into account, and therefore not included in the model. Variables, such as acculturation, may play an important role in illness uncertainty by affecting how a parent is able to understand and navigate the healthcare system.

Previous studies have shown that child illness uncertainty is a predictor of quality of life (Fortier, (in press)). In this study, associations between child and parent quality of life and children's uncertainty in illness scores differed by ethnicity/language. Stronger negative correlations between CUIS scores and quality of life were observed in Spanish-speaking Hispanic parents compared to English-speaking Hispanic parents or non-Hispanic White parents.   The increase in correlation strength follows a similar pattern to the differences in child illness uncertainty among the three ethnic groups observed. Stronger correlation between CUIS scores and QOL in the Spanish-speaking group compared to the English-speaking non-Hispanic White group may suggest that language and ethnicity are important components in understanding children's illness uncertainty and its relationship with health-related quality of life. However, there may be other significant contributions to children's uncertainty other than language/ethnicity, which explains why these variables alone do not predict uncertainty when controlling for education and income. Parental cancer module correlation scores were also more

strongly correlated among Spanish-speaking Hispanic parents than in English-speaking White parents. However, no significant correlation was observed in English-speaking Hispanic parents. This is likely due to a much smaller sample size than that of non-Hispanic White parents. A future study with a larger sample size may be able to find a correlation between parental cancer module scores as well.

The relationship between children's illness uncertainty and language/ethnicity is complex and should be further explored. It is possible that child uncertainty is impacted by a combination of language, cultural, and SES factors that may not have been adequately included in the current study. However, language remains an important tool in reducing illness uncertainty through communication. As a result, it is important that healthcare providers adequately explain illness related information to parents. Furthermore, it may be beneficial if healthcare providers provided children with more information, which may help reduce uncertainty due to ambiguity and unpredictability about their illness. Integration of these practices into pediatric care may help improve health related quality of life in both parents and children.   In conclusion, future research should focus on identifying mechanisms through which ethnic and language differences may affect child illness uncertainty.

LITERATURE CITED

Aud, Susan, Fox, Mary Ann, & KewalRamani, Angelina. (2010). Status and trends in the education of racial and ethnic groups.

Babrow, Austin S, Kasch, Chris R, & Ford, Leigh A. (1998). The many meanings of uncertainty in illness: Toward a systematic accounting. *Health Communication, 10*(1), 1-23.

Fortier, M.A., Batista, M.L., Wahi, A., Kain, A., Strom, S., & Sender, L.S. . ((in press)). Illness uncertainty and quality of life in children with cancer. *J Pediatr Hematol Oncol 2013.*

Garcia, M, Jemal, AWECMHYSRTMJ, Ward, EM, Center, MM, Hao, Y, Siegel, RL, & Thun, MJ. (2007).Global cancer facts & figures 2007. *Atlanta, GA: American Cancer Society, 1*(3)

Maikranz, Julie M. Steele, Ric G. Dreyer, Meredith L. Stratman, Aaron C. Bovaird, James A. (2007). The relationship of hope and illness-related uncertainty to emotional adjustment and adherence among pediatric renal and liver transplant recipients. *Journal of Pediatric Psychology, 32*(5), 571-581.

Mishel, Merle (1988). Uncertainty in illness. *Journal of Nursing Scholarship, 20*(4), 225-232.

Mishel, Merle (1990). Reconceptualization of the Uncertainty in Illness Theory. *Journal of Nursing Scholarship, 22*(4), 256-262. doi: 10.1111/j.1547-5069.1990.tb00225.x

Mullins, Larry L, Wolfe-Christensen, Cortney, Pai, Ahna L Hoff, Carpentier, Melissa Y, Gillaspy, Stephen, Cheek, Jeff, & Page, Melanie. (2007). The relationship of parental overprotection, perceived child vulnerability, and parenting stress to uncertainty in youth with chronic illness. *Journal of Pediatric Psychology, 32*(8), 973-982.

Pai, Ahna LH, Mullins, Larry L, Drotar, Dennis, Burant, Christopher, Wagner, Janelle, & Chaney, John M. (2007). Exploratory and confirmatory factor analysis of the child uncertainty in illness scale among children with chronic illness. *Journal of Pediatric Psychology, 32*(3), 288-296.

Shin, Hyon B, & Bruno, Rosalind. (2003). Language Use and English-Speaking Ability: 2000. Census 2000 Brief.

Stewart, Janet L, & Mishel, Merle H. (2000). Uncertainty in childhood illness: A synthesis of the parent and child literature. *Research and theory for nursing practice, 14*(4), 299-319.

Varni, James W., Burwinkle, Tasha M., Katz, Ernest R., Meeske, Kathy, & Dickinson, Paige. (2002). The PedsQL™ in pediatric cancer. *Cancer, 94*(7), 2090-2106. doi: 10.1002/cncr.10428

Varni, James W., Seid, Michael, & Kurtin, Paul S. (2001). PedsQL(TM) 4.0: Reliability and Validity of the Pediatric Quality of Life Inventory(TM) Version 4.0 Generic Core Scales in Healthy and Patient Populations. *Medical care, 39*(8), 800-812.