Does Decisional Conflict Differ Across Race and Ethnicity Groups? A Study of Parents Whose Children Have a Life-Threatening Illness

Caprice Knapp, PhD,¹ Melanie Sberna-Hinojosa, PhD,¹ Jacqueline Baron-Lee, PhD,¹
Charlotte Curtis, RN,² and I-Chan Huang, PhD¹

Abstract

Objective: Children with life-threatening illnesses and their families may face a myriad of medical decisions in their lifetimes. Oftentimes these complicated medical decisions cause disagreements among patients, families, and providers about what is the best course of action. Although no evidence exists, it is possible that conflict may affect subgroups of the population differently. This study aims to investigate how decisional conflict varies among racial and ethnic subgroups.

Sample: Two hundred sixty-six surveys were completed with parents whose children have a life-threatening illness. All children lived in Florida and were enrolled in the Medicaid program. The Decisional Conflict Scale, overall and broken down into its five distinct subscales, was used to assess parental decision-making. Descriptive, bivariate, and multivariate analyses were conducted. Subgroup analyses were conducted on Latino respondents.

Results: Our bivariate results suggest that minority parents report less Effective Decision Making ($p < 0.05$) and report less Support in Decision Making ($p < 0.05$) compared to white, non-Hispanic parents. For the subgroup analysis, we found that those who identify as Mexican American and Central/South American report having greater Uncertainty in Choosing Options ($p < 0.05$) and less Values Clarity ($p < 0.05$) as compared to Puerto Rican or Cuban Americans. Results from the multivariate analyses suggest that those whose primary language is not English are associated with greater Uncertainty in Choosing Options ($p < 0.05$). Values Clarity was lower for children who were diagnosed with their life-threatening condition at birth ($p < 0.05$) as compared to children diagnosed at a later time.

Conclusions: Our study is the first to describe racial and ethnic differences in decisional conflict of parents of children with life-threatening illnesses. Significant differences exist by race, ethnicity, language spoken, and diagnosis time across several subdomains of decisional conflict. These differences are important to address when creating clinical care plans, engaging in shared decision-making, and creating interventions to alleviate decisional conflict.

Introduction

MEDICAL DECISION MAKING among children with life-threatening illnesses begins at the first contact with the health care system and continues until the end of life. These medical decisions vary in frequency, magnitude, and impact. In the past few decades, health care providers have focused more attention on improving patient-provider interactions through sharing in decision making.¹⁻⁴ Shared decision-making is defined as health professionals and pa-

tients taking steps to participate in making decisions by expressing their preferences, sharing information, negotiating, and coming to a mutually agreed-upon decision.^{5,6} Measures of decisional conflict are often used when examining shared decision making as these constructs are integrally related. Shared decision-making may be compromised when there is conflict in making medical decisions.⁷

The Institute of Medicine recommends that shared decision-making, in the form of care plans that are individualized and responsive to needs and preferences, be an integral part of

¹Department of Health Outcomes and Policy, University of Florida, Gainesville, Florida.

²Florida Department of Health, Children's Medical Services Network Division, Tallahassee, Florida.

Accepted November 26, 2013.

physical and mental health care.⁸ The Maternal and Child Health Bureau has named shared decision-making one of the six core measures of the care for children with special health care needs including life-threatening illness.⁹ Naturally, some medical decisions are more difficult to make and may cause internal and external conflict. Moreover, it may also be difficult to strategize about how to implement interventions designed to reduce decisional conflict across different subgroups of the population.

Feelings of conflict related to treatment decisions among patients and caregivers may emerge when there is clinical equipoise related to treatment, when patients and caregivers are uninformed about treatment options, or when treatments carry significant side effects.⁶ Decisional conflict has been defined as “personal uncertainty about which course of action to take when choice among competing options involves risk, regret, or challenge to personal life values.”¹⁰

A recent national study found that as many as one-half of patients experienced some kind of conflict and preferred to leave final treatment decisions to the physician.¹¹ Interestingly, Black and Hispanic patients were more likely to defer final decisions to providers and women were more likely to choose involvement in treatment decisions.¹² Racial and ethnic minority patients may prefer to delegate decisions to physicians because of their expectations of the physician-patient relationship, literacy/language barriers, self-efficacy in health care, or physician expectations of patients.^{10,11}

Little is known about the decision-making experiences of families whose children have life-threatening illnesses. Moreover, children with life-threatening illnesses are unique, as they have a range of illnesses from rare to complex chronic and all are at risk of dying before they reach adulthood. As a result, their families are faced with many health care decisions related to treatment and end of life care in which decisional conflict may arise. For example, families may have to decide when to stop curative treatment and to begin palliative care or if they should pursue both concurrently. Lyon and colleagues¹² studied advanced planning of 38 adolescents with HIV.

Educational sessions were conducted with the goal of reducing decisional conflict. Adolescents in the intervention felt better about their decisions.¹² A study by Knapp and colleagues¹³ compared the performance of two decisional conflict scales with 266 parents of children with life-threatening illnesses. Results from the study suggest that the Decisional Conflict Scale (DCS) is a valid and reliable instrument for this population.¹³ Although these studies are insightful, they only provide a paucity of information on parents of children with life-threatening illnesses and they do not indicate how decisional conflict varies across racial and ethnic subgroups. Without an understanding of how decisional conflict differs by patient or family characteristics, it is difficult to strategize about how to implement interventions designed to reduce decisional conflict in particular populations.

Our study addresses these key gaps in the existing literature. Our objective is to investigate how decisional conflict differs among low income, racially and ethnically diverse families of children with life-threatening illnesses and examine additional factors that contribute to decisional conflict in this population. We hypothesize that minority individuals will have greater decisional conflict, that decisional conflict will vary across subgroups of minorities, and that additional

factors, such as time of diagnosis with a life-threatening illness, will be associated with greater decisional conflict.

Sample and Methods

Sample

Our study commenced in 2007, a time for great change for policies toward children with life-threatening illnesses living in Florida. Florida had received federal approval in 2005 to begin the nation's first publicly funded palliative care program that would offer services to children concurrently with curative care. Florida created guidelines of diagnoses for admission and those were used to identify children eligible for this study.¹⁴ The reader is referred to Knapp et al.¹⁴ for a list of diagnoses codes that are eligible for Florida's pediatric palliative care program. All of the children in our study were eligible for Medicaid.

Medicaid administrative data were queried to identify children who had diagnoses that would make them eligible for the palliative care program. All children in the study were aged 1 to 18 years. Children younger than 1 and those older than 18 were excluded from the study because they are not eligible for the Medicaid program in Florida and thus not part of the dataset used for this study. Telephone surveys were conducted in English and Spanish between November 2007 and April 2008. The University of Florida's Institutional Review Board approved this study.

Measures

To measure decisional conflict and its components, the DCS was used.¹⁵ Additional measures not discussed in this article were also used in the survey as part of a larger study. The DCS consists of 16 items that measure 5 domains relevant to decision making: Uncertainty in Choosing Options (e.g., unclear and unsure about best choices, difficult decisions to make); Informed Choices (e.g., knowledge of options, benefits, risks, and side effects); Values Clarity (e.g., clarity on benefits, risks and side effects most important to patient); Support in Decision Making (e.g., having advice and support from others without pressure); and Effective Decision Making (e.g., perception of having made an informed choice/decision important to patient, expectation to stick with decision). The response categories for each item are “strongly disagree,” “disagree,” “neither agree nor disagree,” “agree,” and “strongly agree.” The domain scores are calculated by summing item scores in a specific domain and then linearly transforming them to a 0–100 scale, with 0 for the lowest decision conflict and 100 for the highest. For the subscales, higher scores indicate worse outcomes.¹⁶

Gender of child, age of child, and parents' rating of child's health (ranging from “Excellent” to “Poor”) are included in the analysis. Additional factors, including primary language in the home, parent/caregiver's relationship to the child (parent or nonparent), marital status of parent/caregiver, household type (single-parent household, two-parent household), educational level of parent/caregiver, and age of parent/caregiver were also used in the analyses.

The impact a child's illness has on the family was measured using the Impact on Family (IOF) scale.^{17–20} The IOF was developed to measure the impact of children's illnesses on families, but has also been used with families of children

with life-threatening illnesses.^{13,14} The scale includes 15 items assessing various aspects of family stress and strain in various settings. Response categories for individual items are “strongly disagree,” “disagree,” “agree,” and “strongly agree.” Items are scored from 1 to 4, with 4 for indicating the greatest impact. The total IOF score is calculated by summing the item scores. Low scores indicate no or low impact on family and higher scores indicate high impact on family. Missing data were not imputed or computed for this study.

Analyses

Descriptive analyses were performed to summarize the characteristics of the sample and estimate the mean, median, and standard deviation of the DCS. One-way analysis of variance tests (ANOVA) and Tukey *post hoc* tests were performed as part of the bivariate analyses. Multivariate logistic regression analyses were also conducted to determine the association between the additional patient and family characteristics and the total DCS score, as well as the scores of the five DCS domains. The distribution of each of the five subscales and the total DCS were bimodal with subjects clustering at 0 (no decisional conflict) and 25 (mild decisional conflict). We decided to use 25 as a cut point for logistic regression analyses so that we modeled mild to no decisional conflict (DCS = 1) compared to moderate to high decisional conflict (DCS = 0). Thus, coefficients for the logistic regressions conducted represent the likelihood of having moderate to high decisional conflict.

Results

Nine hundred thirty-six parents were selected from the group of children with life-limiting illnesses and 489 of the potential respondents were unable to be reached due to invalid contact information. Overall, 266 surveys were completed and the response rate was 54.4%. Table 1 displays the descriptive characteristics of our sample. White parents/caregivers made up 43.3% of the sample followed by Latino parents (31.1%) and black parents (25.6%). Of the parents/caregivers who were Latino, 23.1% identified as Mexican American, 29.5% as Puerto Rican, 14.1% as Cuban American, and 33.3% as a combination of South American, Central American, and/or other Hispanic/Latino descent. Male children made up 55.3% of the sample and 80.8% spoke English as their primary language. Eighty percent of the caregivers answering the survey were parents of the children for whom they were answering questions and 48.5% were married. Fifty-two percent of children lived in two-parent households and 57.3% of parents held a high school diploma or less. The average age of the parent/caregiver was 43.1 years and the average age of the child was 11.5 years.

The DCS was used as our main outcome variable but was also broken out into five subscales. Cronbach α tests were used to evaluate reliability for the overall DCS ($\alpha=0.967$) and for the five subscales; Uncertainty in Choosing Options $\alpha=0.849$, Informed Choices $\alpha=0.917$, Values Clarity $\alpha=0.884$, Support in Decision Making $\alpha=0.862$, and Effective Decision Making $\alpha=0.898$.

Table 2 displays bivariate ANOVA tests for differences in decisional conflict subscales by race and Latino pan-ethnicity subgroup. The columns in the table display the average scores for each DCS subscale and the overall DCS score. The first

three columns compare the decisional conflict reported by black, white, and Latino parents/caregivers. There were no significant differences in the overall DCS score. Within the Effective Decision Making subscale, however, whites reported more Effective Decision Making compared to Black and Latino parents ($p<0.05$). Similarly, whites reported more Support in Decision Making compared to black and Latino parents ($p<0.05$). The next columns in the table show an ANOVA test for differences among Latino parents only. The results indicate that across each of the five DCS subscales, parents who identify as Mexican Americans, Puerto Rican, Cuban American, and Central/South American differ in decisional conflict. In the overall DCS, Mexican American parents had higher levels of overall decisional conflict compared to Puerto Rican and Cuban American Latinos ($p<0.01$), but Mexican Americans were similar to Central and South Americans. This pattern also emerges across each of the five DCS subscales.

Table 3 displays the results of the multivariate logistic regression analysis for the overall DCS and each of the five DCS subscales. Odds ratios produced represent the log likelihood of having moderate to high levels of overall decisional conflict (or subscale) relative to those with low or mild levels when adjusting for additional factors including race/ethnicity, age, household type, educational status, gender, language spoken in the home, child health, onset of child's health condition, and impact on family. Results show that several of these different family characteristics predict decisional conflict across the five subscales. The likelihood of having greater Values Clarity was significantly higher for among children who were born with their life-threatening illness compared to parents of children whose condition developed later (odds ratio [OR]=0.25, 95% confidence interval [CI] 0.09, 0.72). The likelihood of worse Effective Decision Making was also significantly higher (OR=3.55 95% CI 1.13, 11.10) among single-parent families. In addition, likelihood of decreased Support in Decision Making (OR=4.89 95% CI 1.10, 21.74) and increased Uncertainty in Choosing Options (OR=5.16 95% CI 1.42, 18.79) was significantly higher among families that spoke Spanish or another language in the home compared to families that primarily spoke English in the home.

Table 4 displays the results of a second logistic regression analysis for each of the five decisional conflict subscales. In this analysis, we selected only Latino parents/caregivers in order to compare them by pan-ethnic Latino subgroup to understand the differences by ethnicity. The likelihood of greater Values Clarity (OR=0.03, 95% CI 0.00, 0.68) was significantly higher among Puerto Rican parents compared to Mexican American parents. In addition, Puerto Rican parent also had significantly less Uncertainty in Choosing Options (OR=0.08, 95% CI .01, .098) compared to parents who identify as Mexican American.

When accounting for other factors in addition to ethnicity, results show that Effective Decision Making was significantly worse among parents/caregivers reporting a more negative impact of the child's illness on the family (noted by the IOF scale) (OR=2.18, 95% CI 1.07, 4.44). In addition, the likelihood of having worse Support in Decision Making was significantly higher among parents of children who had their life-threatening illness at birth compared to those whose child developed it later in life (OR=7.53, 95% CI 1.02, 55.59).

TABLE 1. DESCRIPTIVE STATISTICS OF SAMPLE

	<i>Percent or mean</i>	<i>SD</i>	<i>Median</i>	<i>n</i>
Caregiver race				
Latino	31.1%			79
White	43.3%			110
Black	25.6%			65
Caregiver Latino ethnicity				
Mexican American	23.1%			18
Puerto Rican	29.5%			23
Cuban American	14.1%			11
South American, Central American & Other Hispanic/Latino	33.3%			26
Gender of child				
Male	55.3%			147
Female	44.7%			119
Caregiver primary language				
English	80.8%			212
Spanish/Other	19.3%			54
Marital status of caregiver				
Married/common law	48.5%			129
Divorced/separated	24.1%			64
Widowed	2.3%			6
Single	25.2%			67
Household type				
Single-parent household	47.5%			125
Two-parent household	52.2%			138
Caregiver education				
Less than high school	18.9%			50
High school diploma/GED	38.5%			102
Some college	29.8%			79
College degree	12.8%			34
Diagnosis time				
Diagnosed at birth	40.9%			97
Diagnosed later	59.1%			140
Child health				
Excellent	12.9%			34
Very Good	17.1%			45
Good	37.6%			99
Fair	21.7%			57
Poor	10.6%			28
Family impact (range, 0–60)	36.7	8.3	37	263
Age				
Age of child	11.5	5.5	12	262
Age of caregiver	43.1	11.4	42	265
Decisional Conflict Scale (range, 0–100)				
Values Clarity	20.7	17.4	25	262
Effective Decision Making	18.6	14.2	25	261
Informed Choices	22.3	18.9	25	262
Support in Decision Making	20.8	17.8	25	261
Uncertainty in Choosing Options	23.7	18.0	25	258
Overall Scale	20.9	15.5	25	257

SD, standard deviation.

Discussion

Our study aimed to investigate how decisional conflict differs among racially and ethnically diverse families of children with life-threatening illnesses enrolled in Medicaid and to examine the factors that contribute to decisional conflict in this population. Results from our study extend the literature on children with life-threatening illnesses and the decisional conflict literature in the following ways.

First, results from the unadjusted bivariate analyses provide support of our hypothesis that minority individuals would have greater decisional conflict than Whites. Black and Latino parents report worse outcomes in the areas of Effective Decision Making and Support in Decision Making compared to Whites. Conflict in decision making among minorities, especially in cases of life-limiting illnesses may often be related to mistrust among physicians and the medical community. Mistrust among non-whites has been a historical

TABLE 2. ONE-WAY ANALYSIS OF VARIANCE COMPARING MEANS FOR DECISION CONFLICT SUBSCALES BY RACE AND ETHNICITY

Decisional Conflict Subscale	All races						Latino pan-ethnic subgroups												p value
	Black		White		Latino		p value	Mexican		Puerto Rican		Cuban		Central/South American					
	Mean	SD	Mean	SD	Mean	SD		Mean	SD	Mean	SD	Mean	SD						
Values Clarity	23.3	17.2	17.5	15.9	21.1	18.1	0.069	32.9	17.9	15.9	13.5	17.4	11.5	25.7	25.7	0.007			
Effective Decision Making	20.4	12.1	15.8	13.6	19.8	15.3	0.044	23.9	9.2	15.8	12.3	16.3	11.9	23.7	12.5	0.043			
Informed Choices	23.4	16.4	19.3	16.8	23.6	21.3	0.193	31.5	14.7	14.9	14.4	20.5	14.1	26.6	17.0	0.006			
Support in Decision Making	23.6	19.6	17.3	14.7	21.8	18.0	0.037	34.7	20.1	16.3	13.9	16.7	11.8	25.2	23.1	0.012			
Uncertainty in Choosing Options	25.0	15.6	21.1	16.6	24.1	19.9	0.272	31.9	10.7	19.6	14.3	19.7	10.1	27.8	19.5	0.041			
Overall Scale	22.5	13.9	18.0	14.2	21.8	16.7	0.086	30.8	10.9	16.4	11.9	17.0	10.9	24.8	15.4	0.004			

Note: Decisional Conflict Scale range: 0–100. Higher scores denote greater conflict.
SD, standard deviation.

presence since the time of the Tuskegee experiments which ended in the 1970s. A volume of evidence suggests that decisional conflict for minorities is rooted in mistrust and miscommunication.^{22,23} Issues related to mistrust and its impact on decisional conflict are particularly relevant given the evidence of racial disparities in health care.²⁴

Results from both the unadjusted and adjusted subgroup analyses show that parents who identify as Mexican and Central/South Americans had higher levels of decisional conflict compared to all other Latino subgroups. Potential reasons for the differences found in this analysis may center on immigration patterns, patterns of citizenship, or socioeconomic status²⁵ although there is little research in this area. Compared to Puerto Rican and Cuban Americans, Mexican and Central/South Americans are recent arrivals with language barriers who work in jobs that put them at the lower levels of income strata. This variability might be the reason why there is more decisional conflict among these pan-ethnic groups, particularly the Mexican Americans in our study. In comparison, many Cuban Americans immigrated to the United States more than 30 years ago seeking political asylum. Cuban immigrants tended to have higher education levels and resources putting them in a different socioeconomic status than Mexican Americans. Puerto Ricans are American citizens by birth and many are taught to speak English in school, which may explain why their experiences are different from Mexican Americans. Puerto Ricans will be more familiar with the American health care system than the other Latino subgroups. The socio-historical context of immigration might explain the lower levels of decisional conflict of Puerto Ricans versus Mexican Americans but further research is warranted.

Results from the multivariate analyses adjusted for race, age, household type, educational status, gender, language, child health, onset of life-threatening illness, and impact on family, suggest that English not being the primary language negatively impacts uncertainty and support in decision making. This could be related to the lack of cultural competency in the current health care system. Competencies range from making sure translators are available and that materials are printed in various languages to providers understanding how to communicate in a culturally sensitive manner with patients and their families.²⁶ Although making changes to promote cultural sensitivity might be costly, doing so is particularly important due to changing demographics in the United States. According to the 2010 U.S. Census, Latinos make up 16% of the U.S. population and that number is likely to continue to grow because the United States is the world's leading destination for immigrants.²⁷ The health care system will continue to grapple with determining the most cost-efficient way to provide care to non-English speakers and in turn grapple with how to make decision making a key component of care provision.

Beyond our findings on race and ethnicity, we found that decisional conflict in the fully adjusted models was related to whether a child had the life-threatening illness at birth or whether they developed a life-threatening illness later in life. Parents whose children were diagnosed with a life-threatening condition at birth may have experiential learning as compared to parents whose children have newer diagnoses. Experiential learning through reflection and active experimentation might temper conflict as opposed to the informational-based learning

TABLE 3. LOGISTIC REGRESSION FOR DECISIONAL CONFLICT SCALE AND SUBSCALES

	Values clarity			Effective decision making			Informed choices			Support in decision making			Uncertainty in choosing options			Overall scale		
	OR	Upper	Lower	OR	Upper	Lower	OR	Upper	Lower	OR	Upper	Lower	OR	Upper	Lower	OR	Upper	Lower
Caregiver race																		
White	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Black	2.10	9.296	0.48	1.97	8.78	0.44	2.03	7.74	0.53	3.40	16.10	0.72	2.06	8.00	0.53	2.50	8.19	0.77
Latino	0.65	2.84	0.15	0.52	2.45	0.11	0.76	2.82	0.20	2.51	11.57	0.54	2.49	8.99	0.69	1.95	6.02	0.63
Caregiver age	1.01	1.047	0.97	0.95	1.00	0.90	0.98	1.03	0.94	1.00	1.04	0.97	0.97	1.01	0.94	0.92	1.02	0.96
Household type																		
Two Parent Household	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Single Parent Household	1.46	3.67	0.58	3.55	11.10	1.13	1.56	3.80	0.64	2.30	5.50	0.97	2.09	4.57	0.96	1.75	3.51	0.88
Parent educational status																		
Less than HS	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
HS graduate	1.67	6.89	0.40	0.93	5.66	0.15	0.60	2.14	0.17	0.76	2.41	0.24	1.39	4.46	0.43	0.84	2.18	0.32
Some College	2.01	8.65	0.47	3.58	20.25	0.63	1.37	4.73	0.40	1.18	3.90	0.36	2.73	8.97	0.83	12.31	3.31	0.46
College Grad or More	2.32	12.31	0.44	3.19	22.63	0.45	1.76	7.28	0.43	0.86	4.04	0.18	1.74	7.22	0.42	1.04	3.54	0.30
Gender																		
Female	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Male	2.22	5.59	0.88	1.70	4.74	0.61	1.36	3.18	0.58	1.66	3.77	0.73	1.83	3.84	0.87	1.85	3.61	0.94
Language spoken in home																		
English Spoken as Main Language	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Spanish or Other Language	1.76	7.61	0.41	1.25	6.05	0.26	1.18	4.59	0.30	4.89	21.74	1.10	5.16	18.79	1.42	2.11	6.77	0.66
Parent reports of child general health																		
Child in Excellent, Very Good or Good Health	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Child in Fair or Poor Health	0.60	1.60	0.23	0.98	2.80	0.34	1.00	2.50	0.40	1.28	3.00	0.55	1.16	2.52	0.53	1.06	2.18	0.52
Development of health condition																		
Child Developed Condition After Birth	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Child Had Condition At Birth	0.25	0.72	0.09	1.34	3.68	0.49	0.43	1.09	0.17	1.03	2.32	0.46	0.78	1.64	0.37	0.70	1.39	0.36
Impact on family scale																		
Constant	1.03	1.09	0.97	1.03	1.10	0.96	1.04	1.10	0.98	1.02	1.08	0.97	1.02	1.07	0.98	1.03	1.07	0.99
	0.02			0.05			0.06			0.01			0.04			0.05		

OR, odds ratio; Upper, upper limit of 95% confidence interval; Lower, lower limit of 95% confidence interval.

TABLE 4. LOGISTIC REGRESSION DECISIONAL CONFLICT AND SUBSCALES BY LATINO ETHNIC SUBGROUPS

	Decisional clarity			Decisional effectiveness			Informed decision making			Supported decision making			Decisional uncertainty			DCS total scale		
	OR	Upper	Lower	OR	Upper	Lower	OR	Upper	Lower	OR	Upper	Lower	OR	Upper	Lower	OR	Upper	Lower
Race/ethnicity																		
Mexican	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Puerto Rican	0.03	0.00	0.68	241.61	0.07	813114.82	0.16	0.01	2.19	0.13	0.01	2.24	0.08	0.01	0.98	0.01	0.00	0.21
Cuban	0.00	0.00	-	0.00	0.00	-	0.24	0.01	6.21	0.00	0.00	-	0.00	0.00	-	0.00	0.00	-
Central/South American	0.14	0.01	2.46	670.84	0.12	3860741.14	0.79	0.08	6.88	0.32	0.03	3.32	0.11	0.01	1.08	0.05	0.00	0.67
Parent's age	0.97	0.87	1.08	0.47	0.20	1.07	1.00	0.91	1.10	1.00	0.91	1.10	0.95	0.87	1.05	0.98	0.89	1.08
Household type																		
Two Parent Household	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Single Parent Household	4.92	0.51	47.40	13.46	0.11	1615.12	0.63	0.09	4.57	5.93	0.75	46.76	3.54	0.60	20.82	5.11	0.58	45.16
Parent's educational status																		
Less than HS	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
HS graduate	7.19	0.64	80.44	0.00	0.00	3.59	1.37	0.22	8.57	1.77	0.22	14.08	3.58	0.45	28.31	1.94	0.25	15.29
Some College	0.00	0.00	0.00	0.00	0.00	9.55	0.00	0.00	0.00	4.57	0.11	186.33	1.75	0.06	50.92	0.00	0.00	-
College Grad or More	21.54	0.71	655.54	0.93	0.00	1002.50	12.68	0.10	16.52	1.83	0.07	45.50	6.11	0.36	102.99	7.07	0.36	140.42
Gender																		
Female	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Male	1.04	0.15	7.40	2.09	0.01	429.69	0.73	0.13	4.21	0.87	0.13	5.89	0.56	0.11	2.97	0.48	0.07	3.19
Language spoken in home																		
English Spoken as Main Language	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Spanish or Other Language	2.57	0.28	23.72	664.76	0.31	1438223.03	0.67	0.10	4.36	7.82	0.59	104.49	8.28	0.98	70.01	2.32	0.26	21.03
Parent reports of child general health																		
Child in Excellent, Very Good or Good Health	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Child in Fair or Poor Health	1.35	0.20	9.35	0.00	0.00	5.56	1.30	0.23	7.29	2.40	0.34	16.90	1.09	0.21	5.73	2.03	0.27	15.03
Development of health condition																		
Child Developed Condition After Birth	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Child Had Condition At Birth	0.21	0.03	1.58	1.56	0.01	496.61	0.64	0.13	3.23	7.53	1.02	55.59	1.68	0.34	8.25	2.86	0.43	18.86
Impact on family scale																		
Constant	1.12	0.97	1.30	2.18	1.07	4.44	1.11	0.99	1.24	1.08	0.93	1.25	1.12	0.97	1.28	1.05	0.91	1.20
	0.00			0.00			0.01						0.01			0.19		

OR, odds ratio; Upper, upper limit of 95% confidence interval; Lower, lower limit of 95% confidence interval.

likely to be received in the clinical setting.²⁸ These results have direct implications on intervention development as parents might need to practice decision making in order to decrease decisional conflict.

We also found that single-parent households had more conflict compared to two-parent households across one domain. Perhaps being able to talk through medical decisions with someone else provides decision makers a different perspective. Future research would benefit from the investigation of how the discussion of medical decisions impacts decisional conflict.

Every study has limitations and ours is no exception. Our response rate was 54.4% and we have no information about nonresponders. While this number is in alignment with other surveys of the Medicaid population²⁹ it may introduce bias related to excluded responders. In addition, defining which children have life-threatening illnesses is always challenging. Different methodologies have been used such as screeners on surveys or looking through diagnosis codes, and we chose to identify children through a list of agreed upon list of diagnosis codes. It is possible that some children were missed because a combination of less severe diagnoses made them appropriate for palliative care programs. For example, one child with dwarfism and severe allergies was deemed eligible for the program. Third, our choice of the DCS was based on its past performance with this population. Other decisional tools exist and might be valid with this population as well. Also, this study was conducted in Florida, a state that two-thirds of Cubans in the United States call home.³⁰ It has been more than 30 years since the first wave of Cuban immigrants began to arrive in Florida and the subsequent accommodations made in the health care system are likely to be different from other locals not facing this unique immigration pattern. Finally, our study asked about decision making in general. We did not predicate this study on specific decisions, such as the decision to enroll in a palliative care program or even create an advance directive. Specifying the decision might yield different results both across and within subgroups.

Identifying group differences in decisional conflict may help understand the processes by which shared decisions are made in clinic settings. Understanding the scope and extent to which there is conflict in the medical decision making process will help advance policy and practice related to patient centered care and culturally appropriate care. Despite the limitations of our study, we contribute important information to advance the evidence of understudied racial and ethnic differences in decisional conflict. Future research should be focused on understanding the reasons behind decisional conflict for particular pan-ethnic Latino groups such as Mexican Americans and pilot testing interventions that can be used to ameliorate this conflict.

Author Disclosure Statement

No competing financial interests exist.

References

1. Brody D: The patient's role in clinical decision making. *Ann Intern Med* 1980;93:718–722.
2. Levenstein J, McCracken E, McWhinney I, Stewart M, Brown J: The patient-centered clinical method: A model for the doctor-patient interaction in family medicine. *Fam Pract* 1986;3:24–30.
3. McWhinney I: Why we need a new clinical method. *Scand J Prim Health Care* 1993;11:3–7.
4. Brown J, Stewart M, McCracken E, McWhinney I: The patient centered clinical method: Definition and application. *Fam Pract* 1986;3:75–79.
5. Charles C, Gafni A, Whelan T: Decision making in the physician-patient encounter: Revisiting the shared treatment decision making model. *Soc Sci Med* 1999;49:651–661.
6. DHHS: Shared Decision Making in Mental Health Care: Practice, Research and Future Directions: Substance Abuse and Mental Health Services Administration; 2011, SMA-09-4371.
7. Michael JB: Health decision aids to facilitate shared decision making in office practice. *Ann Intern Med* 2002;136:127–135.
8. Institute of Medicine: *Improving the Quality of Health Care for Mental and Substance Use Conditions: Quality Chasm Series*. Washington, D.C.: The National Academies Press, 2006.
9. McPherson MG, Weissman G, Strickland B, van Dyck PC, Blumberg SJ, Newacheck P: Implementing community-based systems of services for children and youths with special health care needs: How well are we doing? *Pediatrics* 2004;113(Suppl 4):1538–1544.
10. LeBlanc A, Kenny DA, O'Connor AM, Legare F: Decisional conflict in patients and their physicians: A dyadic approach to shared decision making. *Med Decis Making* 2009;29:61–68.
11. Levinson W, Kao A, Kuby A, Thisted RA: Not all patients want to participate in decision making: A national study of public preferences. *J Gen Intern Med* 2005;20:531–535.
12. Lyon ME, Garvie PA, Briggs L, He J, McCarter R, D'Angelo LJ: Development, feasibility, and acceptability of the Family/Adolescent-Centered (FACE) Advance Care Planning intervention for adolescents with HIV. *J Palliat Med* 2009;12:363–372.
13. Knapp C, Huang I, Madden V, Vadaparampil S, Quinn G, Shenkman E: An evaluation of two decision making scales for children with life-limiting illnesses. *Palliat Med* 2009;23:518–525.
14. Knapp C, Madden V, Curtis C, Sloyer P, Huang I, Thompson L, Shenkman E: Partners in care: together for kids: Florida's model of pediatric palliative care. *J Palliat Med* 2008;11:1212–1219.
15. O'Connor AM: Validation of a decisional conflict scale. *Med Decis Making* 1995;15:25–30.
16. O'Connor AM: User Manual—Decisional Conflict Scale. 1993 [updated 2010]. www.ohri.ca/decisionaid (Last accessed March 21, 2014).
17. Stein REK, Jessop DJ: The impact on family scale revisited: Further psychometric data. *Dev Behav Pediatr* 2003;24:9–16.
18. Stein RE, Reissman CK: The development of an impact on family scale: Preliminary findings. *Med Care* 1980;18:465–472.
19. Hinojosa M, Knapp C, Madden V, Huang IC, Sloyer P, Shenkman E: Caring for children with life-threatening illnesses: Impact on white, African American, and Latino families. *J Pediatr Nurs* 2012;27:500–507.
20. Dehn LB, Korn-Merker E, Pfafflin M, Ravens-Sieberer U, May TW: The impact an family scale: Psychometric analysis

- of long and short forms in parents of children with epilepsy. *Epilepsy Beh* 2014;32:21–24.
21. Stewart MA: Effective physician-patient communication and health outcomes: A review. *Can Med Assoc J* 1995; 152:1423–1433.
 22. Cooper-Patrick L, Gallo JJ, Gonzales JJ, Vu HT, Powe NR, Nelson C, Ford DE: Race, gender, and partnership in the patient–physician relationship. *JAMA* 1999;282:583–589.
 23. Peek ME, Gorawara-Bhat R, Quinn MT, Odoms-Young A, Wilson SC, Chin MH: Patient trust in physicians and shared decision-making among African-Americans with diabetes. *Health Commun* 2013;28:616–623.
 24. Etchason J, Armour B, Ofli E, Rust G, Mayberry R, Sanders L, Pitts MM: Racial and ethnic disparities in health care. *JAMA* 2001;285:883.
 25. Marshall PA, Koenig BA, Grifhorst P, van Ewijk M: Ethical issues in immigrant health care and clinical research. In: Loue S (ed): *Handbook of Immigrant Health*. New York: Plenum Press; 1998, pp. 203–226.
 26. McPhatter AR: Cultural competence in child welfare: What is it? How do we achieve it? What happens without it? In: Jackson S, Brissett-Chapman S (eds): *Serving African American Children: Child Welfare Perspectives*. Piscataway, NJ: Transaction Publishers; 1999, pp. 251.
 27. Pew Research Center, Pew Hispanic Center Report: A Nation of Immigrants A Portrait of the 40 Million, Including 11 Million Unauthorized. January 29, 2013. www.pewhispanic.org/2013/01/29/a-nation-of-immigrants/ (Last accessed March 21, 2014).
 28. Kolb D, Boyatzis R, Mainemelis C: *Experiential Learning Theory: Previous Research and New Directions*. August 31, 1999.
 29. Knapp C, Madden V, Wang H, Curtis C, Sloyer P, Shenkman E: Spirituality of parents whose children are enrolled in a pediatric palliative care program. *J Palliat Med* 2011;14: 437–443.
 30. Pew Research Center, Pew Hispanic Center Fact Sheet: Cubans in the United States. August 25, 2006. <http://pewhispanic.org/files/factsheets/23.pdf> (Last accessed March 15, 2013).

Address correspondence to:
 Caprice Knapp, PhD
 1329 SW 16th Street
 Room 5130
 Gainesville, FL 32610
 E-mail: caprice1@ufl.edu