# Individual Adjustment, Parental Functioning, and Perceived Social Support in Hispanic and Non-Hispanic White Mothers and Fathers of Children With Spina Bifida

Katie A. Devine, <sup>1</sup> PhD, Christina E. Holbein, <sup>2</sup> BS, Alexandra M. Psihogios, <sup>2</sup> BA, Christina M. Amaro, <sup>2</sup> BS, and Grayson N. Holmbeck, <sup>2</sup> PhD <sup>1</sup> University of Rochester Medical Center and <sup>2</sup> Loyola University Chicago

All correspondence concerning this article should be addressed to Grayson N. Holmbeck, Department of Psychology, Loyola University Chicago, 1032 W. Sheridan Rd., Chicago, IL 60660, USA. E-mail: gholmbe@luc.edu

Received July 1, 2011; revisions received September 2, 2011; accepted September 8, 2011

**Objective** To compare Hispanic and non-Hispanic White mothers and fathers of children with spina bifida on measures of individual adjustment, parental functioning, and perceived social support. **Method** Mothers (29 Hispanic, 79 non-Hispanic White) and fathers (26 Hispanic, 68 non-Hispanic White) completed questionnaires regarding psychological distress, parental functioning, and perceived social support. **Results** Mothers and fathers reported similar individual adjustment across groups. Hispanic mothers reported lower levels of parenting satisfaction, competence as a parent, and social support, as well as higher perceptions of child vulnerability. Hispanic fathers reported lower levels of parenting satisfaction and higher perceptions of child vulnerability. Effect sizes were reduced when socioeconomic status was included as a covariate. **Conclusions** Hispanic parents, particularly mothers, are at risk for lower feelings of satisfaction and competence as parents. More research is needed to understand cultural factors related to these differences.

Key words Hispanic; parental adjustment; parenting stress; social support; spina bifida.

#### Introduction

Spina bifida is a congenital birth defect involving the central nervous system that is associated with a broad range of challenges and responsibilities for children and parents. It is caused by an incomplete closing of the spinal cord in early gestation and occurs in approximately 3 out of every 10,000 live births (National Birth Defects Prevention Network, 2010). Spina bifida can result in impaired mobility, neurological deficits, frequent surgeries, and bowel and urinary difficulties. Parents of youth with spina bifida are at risk for increased levels of stress and psychological symptoms, reduced social support, and an intrusive parenting style (Holmbeck et al., 1997; Holmbeck, Coakley, Hommeyer, Shapera, & Westhoven, 2002; Sawin et al., 2003; Vermaes, Gerris, & Janssens, 2007). However, little attention has been paid to parental

adaptation to spina bifida across different cultural populations (Holmbeck & Devine, 2010). Parents may adjust to their children's chronic health problems in different ways due to cultural factors such as religion, language, and relationships with providers, family, friends, and community members (Smith, Freeman, Neville-Jan, Mizokawa, & Adams, 2010). The present study addressed this gap in the literature by examining differences in individual adjustment, parental functioning, and perceived social support between Hispanic<sup>1</sup> and non-Hispanic White parents of children with spina bifida.

Meta-analyses have shown that spina bifida has a medium to large effect on parental functioning, with the

<sup>1</sup>We recognize that some individuals prefer "Hispanic" while others prefer "Latino/Latina." We will use the term Hispanic throughout this article.

largest effect on mothers (Vermaes, Janssens, Bosman, & Gerris, 2005). Parents have reported more psychosocial stress and lower parental satisfaction than parents of typically developing children (Holmbeck et al., 1997). While both parents are affected by their child's spina bifida, mothers and fathers adapt to the challenges differently. For example, mothers of children with spina bifida (but not fathers) have reported lower perceived competence, greater social isolation, and less adaptability to change compared with mothers of typically developing youth, while fathers of children with spina bifida (but not mothers) have reported more severe psychological symptoms compared with fathers of typically developing youth (Holmbeck et al., 1997). Thus, it is critical to examine mothers' and fathers' functioning separately.

Parents of youth with chronic health problems such as spina bifida face unique challenges, including the management of the child's medical regimen, stress related to the child's health status, and uncertainty regarding the child's current and future independence (Mullins et al., 2007). The impact of these obstacles on parent functioning is important to understand, as family functioning directly contributes to outcomes of the child with the condition (Davidson & Cardemil, 2009; Hsin, La Greca, Valenzuela, Moine, & Delamater, 2010). Parents' adjustment and functioning can be conceptualized using Bronfenbrenner's (1979) social-ecological model. Typically, the child is placed in the center of the model, with concentric circles representing influential systems (e.g., family, peer, school, community, and culture) drawn outward from most immediate to more distal levels of influence (Kazak, Rourke, & Navasaria, 2009). According to the social-ecological model, child adjustment is directly influenced by parental adjustment and indirectly influenced by multiple factors that affect parental adjustment and parenting behaviors. Here, we focus on three aspects of functioning: parents' individual adjustment, parental functioning, and parents' perceived social support. We define parents' individual adjustment as their psychological adjustment and parental functioning as their parenting-specific functioning.

Although parents' functioning in families of children with spina bifida has previously been studied, little is known about the specific impact the disability has on families from various cultural backgrounds. It is especially important to focus on Hispanic families because prevalence rates of spina bifida are the highest for Hispanic families (Boulet et al., 2008; Williams, Rasmussen, Flores, Kirby, & Edmonds, 2005). Furthermore, Hispanic families are also the fastest growing ethnic group in the United States (U.S. Census Bureau, 2011). Despite high prevalence rates

and a growing population, Hispanic families of youth with spina bifida remain largely unstudied. One study of neuropsychological functioning found that Hispanic children with low socioecomonic status (SES) had lower verbal IQ (Swartwout, Garnaat, Myszka, Fletcher, & Dennis, 2010), suggesting an increased risk for poorer outcomes in this group. However, that study did not examine psychosocial functioning. Moreover, Spanish-speaking Hispanic families have reported greater unmet needs related to their children's health conditions than non-Hispanic White families, suggesting that Spanish-speaking parents may be particularly affected by their children's condition (Inkelas, Raghavan, Larson, Kuo, & Ortega, 2007). Language barriers can adversely affect access to care, quality of care, health outcomes, and perceived social support for Spanish-speaking families (Bailey et al., 1999; Munet-Vilaró, 2004; Timmins, 2002). We sought to compare the functioning of Hispanic parents and non-Hispanic White parents of youth with spina bifida to better understand parental adjustment in this under-studied ethnic group.

In terms of parents' individual adjustment, parents of youth with chronic health conditions such as spina bifida tend to experience significant stress and internalizing symptoms (Vermaes et al., 2007). Similar findings have been documented in Hispanic populations, with Hispanic parents of children with chronic conditions reporting lower morale, more depressive symptoms, and higher rates of clinical depression than non-Hispanic parents (Blacher & McIntyre, 2006; Blacher, Lopez, Shaprio, & Fusco, 1997). Some researchers have suggested that Hispanic parents may view the child's disability as a reflection of their own personal failings, resulting in feelings of guilt, hopelessness, and anxiety (Mardiros, 1989).

Additionally, spina bifida affects specific aspects of parental functioning, including parental satisfaction, intrusiveness, and perceived vulnerability of the child with the health concern. Satisfaction with parenting experiences and abilities is lower among parents of children with spina bifida than among parents of typically developing youth (Holmbeck et al., 1997). Parents of children with chronic conditions can be intrusive at times, providing their children with more structure and fewer opportunities to develop independence skills (Holmbeck et al., 2002; Sawin et al., 2003; Vermaes et al., 2007). This wellintentioned support often fails and has been coined "miscarried helping" (Anderson & Coyne, 1991). Excessive helping may be due to perceptions that children with chronic conditions are more susceptible to harm (Mullins et al., 2007). Most of the research to date has been limited to English speaking, non-Hispanic White families. Some qualitative work suggests that Hispanic parents of children with developmental disabilities emphasize the role of family and a sheltered home-based life, as opposed to independence, during the transition from childhood to young adulthood (Rueda, Monzo, Shapiro, Gomez, & Blacher, 2005). More research is needed to identify parental functioning concerns that are unique to Hispanic families.

Regardless of ethnicity, a large social support network of family and friends is associated with better parental adjustment to a child's chronic health issues (e.g., Barakat & Linney, 1992; Vermaes et al., 2005). Some research suggests that Hispanic families have larger, denser networks of social support than Anglo American families (Schaffner & Wagner, 1996).

This study aimed to evaluate differences in individual adjustment, parental functioning, and perceived social support between Hispanic and non-Hispanic White mothers and fathers of children with spina bifida. We hypothesized that Hispanic mothers and fathers would report more psychological distress, lower parenting satisfaction, lower perceived competence, greater social isolation, greater perceived vulnerability of their child with spina bifida, more protectiveness over their child, and more support from family but not friends compared with non-Hispanic White parents. We did not anticipate any group differences in role restriction.

# Methods Participants

Participants were part of a larger longitudinal study examining family, psychosocial, and neurocognitive functioning among children with spina bifida (Devine, Holmbeck, Gayes, & Purnell, 2011). Families of children with spina bifida were recruited from four hospitals and a statewide spina bifida association in the Midwest. Inclusion criteria consisted of: (a) diagnosis of spina bifida (types included myelomeningocele, lipomeningocele, and myelocystocele); (b) age 8-15 years; (c) ability to speak and read English or Spanish; (d) involvement of at least one primary caregiver; and (e) residence within 300 miles of lab to allow for home visits for data collection. During recruitment, 246 families were approached. Of the original 246 families, 163 agreed to participate; however, 21 of those families could not be contacted or later declined, and 2 families did not actually meet inclusion criteria. The final sample of participants included 140 families of children with spina bifida (53.6% female; M age = 11.40). Of these 140 children,53.3% were Caucasian, 27.9% were Hispanic, 12.9% were African American, and 5.7% were of another ethnicity. We oversampled Hispanic families to better study this population of children with spina bifida. The families who declined participation did not differ from those who accepted participation with respect to type of spina bifida (myelomeningocele vs. other),  $\chi^2$  (1) = 0.0002, ns, shunt status,  $\chi^2$  (1) = 0.003, ns, or occurrence of shunt infections,  $\chi^2$  (1) = 1.08, ns.

Of the 140 families, we limited our analyses to parents who reported ethnicity of Hispanic or non-Hispanic White. Of the 108 mothers included, 29 (26.9%) were Hispanic and 79 (73.1%) were non-Hispanic White. Of the 94 fathers included, 26 (27.7%) were Hispanic and 68 (72.3%) were non-Hispanic White. Parent and child demographic information is presented in Table I. There were no significant differences between Hispanic and non-Hispanic families across most domains, with the exceptions of family SES, t(101) = 7.29, p < .001, and child IQ, t(97) = 3.99, p < .001. Hispanic children had lower family SES and IQ scores, similar to previous studies (Swartwout et al., 2010). Within the Hispanic sample, 16 mothers (55.1%) and 15 fathers (57.7%) were born in Mexico, 6 mothers (20.7%) and 6 fathers (23.1%) were born in the United States, 3 mothers (10.3%) and 1 father (3.8%) were born in Ecuador, 1 mother (3.5%) and 1 father (3.8%) were born in Uruguay, 1 mother (3.5%) was born in Ireland, and 2 mothers (6.9%) and 2 fathers (7.7%) did not report their country of birth. Thirty-two families (22.9% of our total sample) reported that the primary language spoken at home was Spanish.

#### Procedure

This study was approved by university and hospital Institutional Review Boards. Data were collected by trained undergraduate and graduate student research assistants during two home visits that each lasted approximately three hours. For visits where families primarily spoke Spanish in the home, at least one RA was bilingual. Informed consent from parents and assent from children were obtained prior to the start of the first visit. Parents completed releases of information to allow for data collection from medical charts, teachers, and health professionals.

The larger study involved child, parent, teacher, health professional, and peer questionnaires, child neuropsychological testing, videotaped family interaction tasks, and videotaped peer interaction tasks. Questionnaires available only in English were adapted for Spanish speakers using forward and back translation by a translation team (the same team as in Swartwout et al., 2010). For this study, only parent-completed questionnaire data were employed. Families received monetary compensation (\$150) and gifts (t-shirts and pens) for participation.

Table I. Demographic Information

	Hispanic n = 32 children, 29 mothers, 26 fathers	Non-Hispanic White $n = 71$ children, 79 mothers, 68 fathers		
Child age, M (SD) <sup>a</sup>	11.97 (2.38)	11.38 (2.35)		
Child sex, a n (%)				
Male	14 (43.8)	35 (49.3)		
Female	18 (56.3)	36 (50.7)		
FSIQ M (SD) <sup>a</sup>	76.97 (16.09)	93.12 (19.75)*		
Type of spina bifida, a n (%)				
Myelomeningocele	28 (87.5)	57 (80.3)		
Other	4 (12.5)	9 (12.7)		
Lesion level, <sup>a</sup> n (%)				
Sacral	7 (21.9)	12 (16.9)		
Lumbar	17 (53.1)	48 (67.6)		
Thoracic	6 (18.8)	9 (12.7)		
Missing	2 (6.3)	2 (2.8)		
Hydrocephalus present, a n (%)	25 (78.1)	51 (71.8)		
Mother age M (SD)	38.69 (6.93)	41.53 (6.69)		
Father age M (SD)	41.54 (7.45)	43.22 (6.70)		
Family SES <sup>a</sup>	26.09 (12.43)	46.57 (13.52)*		
Mother marital status, n (%)				
Married/partnered	24 (82.8)	70 (88.6)		
Divorced/separated/single	5 (17.2)	9 (11.4)		
Father marital status, n (%)				
Married/partnered	26 (100)	66 (97.1)		
Divorced/separated/single	0 (0)	2 (2.9)		

Note. FSIQ = full scale intelligence quotient from WASI;

#### **Individual Measures**

#### Demographics

Parents of children with spina bifida completed a questionnaire assessing a variety of demographic factors, including relationship to child, marital status, ethnicity, education, employment status, income, child age, and child ethnicity. The Hollingshead Four Factor Index of socioeconomic status was used to assess SES based on parents' education and occupation (Hollingshead, 1975). Higher scores indicated higher SES.

#### Individual Parental Adjustment

The Symptom Checklist-Revised (SCL-90-R; Derogatis, Rickels, & Rock, 1976) was used to assess psychological symptoms in parents. Parents rated each item on a 4-point scale ranging from 0 (not at all distressed) to 4 (extremely distressed) for symptoms experienced over the past week. The SCL-90-R comprised nine symptom subscales and three overall indices. The Global Severity Index (GSI) is calculated as the average severity response across all

items. The GSI demonstrated high levels of internal consistency for this sample (Cronbach's  $\alpha$  = .98 for Hispanic mothers, .95 for Hispanic fathers, .97 for non-Hispanic mothers, and .95 for non-Hispanic fathers).

## **Parental Functioning Measures**

## Parental Satisfaction

Parents completed the 12-item Parenting Satisfaction scale (PS; Hill, Holmbeck, Marlow, Green, and Lynch, 1985; Holmbeck et al., 1997) assessing how parents feel about parenthood (e.g., how satisfying being a parent is). The PS demonstrated adequate internal consistency for Hispanic mothers ( $\alpha$ =.61) and fathers ( $\alpha$ =.72) and for non-Hispanic mothers ( $\alpha$ =.78) and fathers ( $\alpha$ =.66).

#### **Parenting Stress**

The Parenting Stress Index (PSI; Abidin, 1990) was used as a measure of parenting stress. This study used three subscales: restriction of role, perceived parental competence, and social isolation. The validity of using single subscales has been demonstrated (Abidin, 1990). Cronbach's  $\alpha$  coefficients were adequate to good for all subscales (range = .60 to .86), with the exception of the perceived parental competence subscale for Hispanic fathers ( $\alpha$  = .41). Given the low internal consistency for Hispanic fathers, we interpreted results using this subscale cautiously.

#### Perceived Child Vulnerability

The 16-item Vulnerable Child Scale-Parent report (VCS-P; Perrin, West, & Culley, 1989) was used to assess parents' concerns about their children's health. The present study employed a 15-item version of this measure (the item "I sometimes worry that my child will die" was dropped due to its negative nature and the possibility of interfering with rapport). This measure demonstrated high internal consistency among Hispanic mothers ( $\alpha$  = .84) and fathers ( $\alpha$  = .87) and non-Hispanic mothers ( $\alpha$  = .76) and fathers ( $\alpha$  = .81). It was scored so that higher scores indicate greater perceptions of vulnerability.

#### Parental Protectiveness

The Parent Protection Scale (PPS; Thomasgard, Metz, Edelbrock, & Shonkoff, 1995) is a 25-item scale that assesses parenting behavior across the subscales of supervision, dependence, separation problems, and control. The total PPS score was used. The PPS demonstrated adequate internal consistency for Hispanic mothers ( $\alpha$  = .63) and fathers ( $\alpha$  = .76) and non-Hispanic mothers ( $\alpha$  = .76) and fathers ( $\alpha$  = .77).

<sup>&</sup>lt;sup>a</sup>Differences between groups tested based on maternal report of child's ethnicity. \*p < .001.

#### Perceived Social Support

The Perceived Social Support Scale (PSS; Procidano & Heller, 1983) consists of two 20-item scales representing perceived social support available from family members (PSS-FA) and friends (PSS-FR). Both scales are considered global measures of perceived social support with items reflecting emotional, informational, feedback, and reciprocal supports. The PSS-FA demonstrated adequate internal consistency for all groups,  $\alpha = .69$  to .94. The PSS-FR scale demonstrated good internal consistency for mothers,  $\alpha = .92$  for Hispanic and .67 for non-Hispanic White mothers. The PSS-FR demonstrated good internal consistency for non-Hispanic White fathers,  $\alpha = .91$ . Cronbach's α could not be calculated for Hispanic fathers because the majority of participants (85%) answered "I don't know" for at least one question, and "I don't know" was treated as missing. A participant is dropped from the  $\alpha$  analysis when one or more answers are missing.

#### Child Measures

#### Child Intelligence

The Wechsler Abbreviated Scale of Intelligence (WASI; Wechsler, 1999) is a well-validated measure of child intelligence, with a normative mean of 100 and standard deviation of 15. The vocabulary and matrix reasoning subtests were administered, and an estimated full scale IQ (FSIQ) was computed.

#### **Medical Information**

Information regarding the type of spina bifida, lesion level, hydrocephalus status, and other medical data were abstracted from medical records. Parents also completed questionnaires regarding their child's health status.

## **Data Analysis**

Analyses were conducted separately for mothers and fathers. Group differences (Hispanic vs. non-Hispanic White) were assessed via univariate analysis of covariance (ANCOVA) for parents' individual adjustment and two multivariate analyses of covariance (MANCOVAs) with univariate follow-up analyses for parental functioning (six dependent variables—parenting satisfaction, role restriction, sense of competence as a parent, social isolation, perceived child vulnerability, and parental protectiveness) and perceived social support (two dependent variables-family support and friend support). Child age and estimated FSIQ were used as covariates in all analyses. The pre-existing SES differences between our Hispanic and non-Hispanic White families are meaningful, as SES and ethnicity are intertwined (Heller, Markwardt, Rowitz, & Farber, 1994). Removing the variance in outcomes due to SES would also remove shared variance in the group variable (Hispanic vs. non-Hispanic White) that is associated with the dependent variables (Miller & Chapman, 2001); in other words, such covariate analyses can distort the nature of the group variable. Therefore, we present the analyses with and without SES included as a covariate. The inclusion of SES as a covariate attempts to answer the question of whether group differences would exist if the two groups were not different in SES, though the meaningfulness of this question could be debated (Miller & Chapman, 2001). Effect sizes are presented as Cohen's *d*, with correction for unequal sample sizes (Rosnow, Rosenthal, & Rubin, 2000). Cohen's *d* is interpreted as .2 indicating a small effect, .5 a medium effect, and .8 a large effect (Cohen, 1992).

## Results Individual Adjustment

Unadjusted means and standard deviations are presented by group for mothers in Table II and for fathers in Table III. For mothers, there were no significant differences in parental adjustment by group when SES was not included as a covariate, F(1, 95) = 2,11, p > .05, d = .33, or when SES was included, F(1, 94) = 0.08, p > .05, d = .06. The results were similar for fathers: without SES, F(1, 82) = 0.54, p > .05, d = .18, and with SES, F(1, 80) = 0.76, p > .05, d = .22.

## **Parental Functioning**

Again, unadjusted means and standard deviations for mothers and fathers are presented in Tables II and III, respectively. For mothers, there was a main effect for group in the multivariate analysis of parental functioning when SES was not included as a covariate, F(6, 90) = 5.76, p < .001, and when SES was included, F(6, 89) = 3.13, p < .01. Follow-up univariate analyses without SES as a covariate indicated that Hispanic mothers reported lower parenting satisfaction, F(1, 95) = 5.89, p < .05, d = .56, lower sense of competence as a parent, F(1,95) = 9.16, p < .01, d = .70, and more severe perceptions of child vulnerability, F(1, 95) = 14.51, p < .001, d = .88. Follow-up univariate analyses with SES included as a covariate followed a similar pattern in terms of statistical significance, but effect sizes were lower, d = .47 for parenting satisfaction, .56 for sense of competence as a parent, and .49 for perceived child vulnerability. In general, effects were small to medium for most domains, with a medium to large effect size for perceived child vulnerability.

Table II. Individual Adjustment, Parental Functioning, and Perceived Social Support in Hispanic and Non-Hispanic White Mothers

	Hispanic		Without SES			With SES as covariate		
	M (SD)		Difference (95% CI)	F	d	Difference (95% CI)	F	d
Individual adjustment								
Psychological Symptoms	0.40 (0.48)	0.30 (0.28)	0.12 (-0.04 to 0.28)	F(1, 95) = 2.11	.33	0.03 (-0.16 to 0.21)	F(1, 94) = 0.08	.06
Parental functioning				F(6, 90) = 5.76***			F(6, 89) = 3.13**	
Parenting Satisfaction	3.18 (0.46)	3.38 (0.36)	-0.23 (-0.41 to -0.04)	F(1, 95) = 5.89*	.56	-0.22 (-0.43  to  -0.01)	F(1, 94) = 4.13*	.47
Role restriction	2.89 (0.82)	2.62 (0.69)	0.28 (-0.07 to 0.62)	F(1, 95) = 2.58	.37	0.10 (-0.28 to 0.49)	F(1, 94) = 0.28	.12
Perceived Competence	3.65 (0.51)	3.95 (0.40)	-0.31 (-0.51 to -0.11)	F(1, 95) = 9.16**	.70	-0.28 (-0.51  to  -0.05)	F(1, 94) = 5.79*	.56
Social isolation	2.35 (0.84)	2.20 (0.60)	0.16 (-0.15 to 0.48)	F(1, 95) = 1.05	.24	0.01 (-0.35 to 0.37)	F(1, 94) = 0.01	.02
Perceived child	2.22 (0.55)	1.80 (0.37)	0.38 (0.18 to 0.58)	F(1, 95) = 14.51***	.88	0.23 (0.01 to 0.45)	F(1, 94) = 4.44*	.49
Vulnerability								
Parental Protectiveness	1.18 (0.33)	1.18 (0.26)	-0.04 (-0.16 to 0.07)	F(1, 95) = 0.52	.17	-0.05 (-0.18 to 0.08)	F(1, 94) = 0.52	.17
Perceived social support				F(2, 91) = 5.17**			F(2, 90) = 0.93	
Family support	14.08 (4.96)	16.82 (3.73)	-2.93 (-4.91 to -0.95)	F(1, 92) = 8.64**	.70	-1.36 (-3.50 to 0.77)	F(1, 91) = 1.60	.30
Friend support	12.92 (4.79)	15.75 (3.95)	-2.75 (-4.77 to -0.73)	F(1, 92) = 7.28**	.64	-1.18 (-3.37 to 1.00)	F(1, 91) = 1.15	.26

Note. Unadjusted means and standard deviations are reported. Difference scores reflect adjusted means. Child age and IQ are covariates in all analyses. \*p < .05, \*\*p < .01, \*\*\*p < .001.

Table III. Individual Adjustment, Parental Functioning, and Perceived Social Support in Hispanic and Non-Hispanic White Fathers

	•	٠,		'		1			
	Hispanic <i>M (SD)</i>	Non-Hispanic White <i>M (SD)</i>	Without SES			With SES as covariate			
			Difference (95% CI)	F	d	Difference (95% CI)	F	d	
Individual adjustment									
Psychological symptoms	0.24 (0.22)	0.28 (0.25)	-0.05 (-0.17 to 0.08)	F(1, 82) = 0.54	.18	-0.07 (-0.21 to 0.08)	F(1, 80) = 0.76	.22	
Parental functioning				F(6, 73) = 2.78*			F(6, 71) = 1.38		
Parenting satisfaction	2.92 (0.69)	3.30 (0.34)	-0.36 (-0.59 to -0.12)	F(1, 78) = 9.28**	.78	-0.32 (-0.60 to -0.04)	F(1, 76) = 5.24*	.60	
Role restriction	2.52 (0.45)	2.47 (0.59)	-0.04 (-0.33 to 0.24)	F(1, 78) = 0.09	.08	0.10 (-0.23 to 0.44)	F(1, 76) = 0.36	.16	
Perceived competence	3.93 (0.52)	3.98 (0.44)	0.01 (-0.23 to 0.25)	F(1, 78) = 0.01	.02	-0.04 (-0.33 to 0.25)	F(1, 76) = 0.08	.07	
Social isolation	2.22 (0.64)	2.38 (0.56)	-0.20 (-0.51 to 0.11)	F(1, 78) = 1.68	.33	-0.13 (-0.49 to 0.23)	F(1, 76) = 0.53	.19	
Perceived child Vulnerability	2.11 (0.53)	1.82 (0.39)	0.26 (0.03 to 0.48)	F(1, 78) = 5.09*	.58	0.07 (-0.19 to 0.33)	F(1, 76) = 0.32	.15	
Parental protectiveness	1.19 (0.33)	1.06 (0.27)	0.04 (-0.09 to 0.18)	F(1, 78) = 0.43	.17	0.09 (-0.07 to 0.25)	F(1, 76) = 1.25	.29	
Perceived social support				F(2, 74) = 0.33			F(2, 72) = 0.28		
Family support	15.42 (4.41)	16.38 (4.51)	-0.50 (-2.92 to 1.92)	F(1, 75) = 0.17	.11	-0.48 (-3.36 to 2.39)	F(1, 73) = 0.11	.09	
Friend support	12.63 (4.90)	13.93 (4.79)	-1.08 (-3.71 to 1.55)	F(1, 75) = 0.67	.22	-1.16 (-4.29 to 1.96)	F(1, 73) = 0.55	.21	

Note. Unadjusted means and standard deviations are reported. Difference scores reflect adjusted means. Child age and IQ are covariates in all analyses. \*p < .05, \*\*p < .01, \*\*\*p < .001.

For fathers, there was a main effect for group in the multivariate analysis of parental functioning when SES was not included as a covariate, F(6, 73) = 2.78, p < .05, but not when SES was included, F(6, 71) = 1.38, p > .05. Follow-up univariate analyses without SES as a covariate indicated that Hispanic fathers reported lower parenting satisfaction, F(1, 78) = 9.28, p < .01, d = .78, and more severe perceptions of child vulnerability, F(1, 78) = 5.09, p < .05, d = .57. Although the multivariate test including SES as a covariate was not significant, we conducted follow-up univariate analyses to compare with the analyses not including SES. Only parenting satisfaction was significant, F(1, 76) = 5.24, p < .05, d = .60, though the effect size was slightly reduced. In general, effects were negligible

to small for most domains, with a medium to large effect observed for parenting satisfaction.

## **Perceived Social Support**

For mothers, there was a main effect for group in the multivariate analysis of perceived social support when SES was not included as a covariate, F(2, 91) = 5.17, p < .01, but not when SES was included, F(2, 90) = 0.93, p > .05 (see Table II). Follow-up univariate analyses without SES as a covariate indicated that, contrary to our hypothesis, Hispanic mothers reported lower levels of support from family, F(1, 92) = 8.64, p < .01, d = .70, and lower levels of support from friends, F(1, 92) = 7.28, p < .01, d = .64. Again, although the multivariate test including SES as a

covariate was not significant, we conducted follow-up univariate analyses to compare with the analyses not including SES. There were no significant group differences for family or friend support, and effect sizes were reduced, d=.30 for family and d=.26 for friend. Thus, effect sizes were medium for analyses without SES and small when SES was included. There was not a significant main effect for group for fathers with or without SES as a covariate (see Table III).

#### **Discussion**

In this study, we documented a number of differences in parental functioning between Hispanic and non-Hispanic White mothers and fathers of children with spina bifida. In line with our hypotheses, Hispanic mothers and fathers reported lower levels of parental satisfaction and greater perceptions of child vulnerability (though the latter finding did not hold for fathers when SES was included as a covariate). Hispanic mothers also reported a lower sense of competence as parents. Contrary to our hypotheses, we did not find any significant differences in individual adjustment or parental protectiveness between Hispanic and non-Hispanic White parents. Further, we found that Hispanic mothers reported lower levels of perceived social support from both family and friends (when SES was not included as a covariate), while no differences in perceived social support were found among fathers.

Interestingly, about half of the differences found between groups were robust when SES was included as a covariate, and the other half were greatly reduced. Specifically, regardless of the inclusion of SES, Hispanic mothers reported lower perceptions of competence as a parent and higher perceptions of their child's vulnerability, while Hispanic fathers reported lower levels of parenting satisfaction. Mothers' higher sense of child vulnerability and lower sense of self-competence fit with the idea that some Hispanic parents view their child's disability as a reflection of their own failings (Mardiros, 1989). Alternatively, parents who perceive their child to be highly vulnerable may engage in increased supervision of the child and take greater responsibility for the child's daily activities, leading to increased caregiver burden and reduced feelings of satisfaction and competence as a parent.

Previous work comparing mothers and fathers of youth with spina bifida to parents of typically developing youth found robust group differences on the parenting variables and varying patterns of differences for mothers and fathers (Holmbeck et al., 1997). Our results showed a similar pattern, with the most robust differences between

Hispanic and non-Hispanic White families found on parenting variables and different patterns of results for mothers and fathers. Together with previous work, these results suggest that Hispanic parents, especially mothers, may be at risk for lower perceived competence as a parent, which could negatively impact individual and familial functioning. Moreover, since low SES has been associated with increased risk for psychosocial problems, poorer family functioning, and less adaptive coping strategies (Barakat & Linney, 1995; Holmbeck et al., 2002), there appears to be a cumulative effect in low SES, ethnic minority families. These analyses showed that removing variance associated with SES reduced the effect size of group, but for many of the parenting variables, the effect was robust regardless. Since ethnicity and SES were confounded in our sample, interpreting the effect without SES as a covariate gives a more realistic picture of the differences between groups, such that we cannot disentangle the influence of SES and ethnicity (Miller & Chapman, 2001). Further, these group differences are only a starting point; more research is needed to understand what cultural factors influence parenting variables in Hispanic families.

Clinically, our results suggest that Hispanic mothers, in particular, may feel incompetent and worry about the vulnerability of their children. These issues may have implications for teaching independence skills to children with spina bifida. Clinicians working with families need to be sensitive to relevant cultural issues, such as parents' wishes for independence, as some Hispanic families may emphasize independence skills within the context of living with the family rather than living independently (Rueda et al., 2005; Smith et al., 2010). Acculturation needs to be considered, as children who are more acculturated than their parents may have increased conflict regarding autonomy. Research on culturally sensitive family-based interventions has shown the potential for increased retention but also some reduced positive outcomes (Kumpfer et al., 2002). Particularly for families from low SES backgrounds, increasing access to evidence-based treatments in their spoken language is an important first step. Our results also suggest that Hispanic mothers from low SES backgrounds are at risk for reduced social support, consistent with previous reports of Hispanic families with higher SES having more available social support (Griffith & Villavicencio, 1985). Connecting Hispanic families from low SES backgrounds with general or spina bifida-specific community-based organizations may help provide greater social support. We recommend increased outreach efforts by community-based organizations such as the Spina Bifida Association to provide parenting resources and support to these families.

Finally, our results suggest that Hispanic fathers have lower parenting satisfaction, signifying a need for further communication with fathers regarding their parenting needs. Although past research showed large divides in the responsibility of care for children with chronic health conditions, fathers are increasingly involved in routine care of the child even if unable to participate in appointments that conflict with their work schedules. Clinicians may need to use alternative methods for communicating with fathers, such as phone calls or emails. Further, since fathers tend to rely on their partners for support (Saloviita, Italinna, & Leinonen, 2003), interventions targeting mother–father dyads may be useful.

Although our study had several strengths, including our focus on Hispanic families and inclusion of fathers, there were also several limitations. Despite over-enrollment of Hispanic families, our sample size was still relatively small. We also recognize that although our analyses assume the Hispanic group to be homogeneous, wide differences exist among individuals within the group in terms of country of origin, cultural practices, and acculturation. More than half of our Hispanic group was Mexican-American, consistent with population trends, and results may be more representative of that group. Finally, the perceived competence subscale from the PSI demonstrated poor internal consistency in our sample of Hispanic fathers, suggesting that the measure was not capturing one construct as intended. Although most Hispanic fathers answered enough questions to score the Perceived Social Support Scale—Friends, the large number of missing responses precluded our ability to conduct a reliability analysis on this scale. This may suggest that something in this measure was not adequately culturally adapted for Hispanic fathers. These issues highlight the need to evaluate the validity of measures in this population.

Further research is needed to understand why parental functioning differs between Hispanic and non-Hispanic White families. Multisite studies and data-pooling from various studies can help increase sample sizes. Larger sample sizes may allow researchers to tease out the effects of SES. Recruiting a large number of Hispanic families would also allow for examination of SES within one cultural sample. Additionally, including a comparison group of Hispanic families with typically developing youth may help clarify the relationships between ethnicity, SES, spina bifida, and parental functioning. To understand differences among Hispanic families, we need to expand our assessments to include acculturation and relevant cultural factors. Qualitative work may be helpful in identifying constructs that are important to Hispanic parents' competence

and satisfaction. We also need to expand our assessments, focusing on strengths in addition to potential problems.

## Funding

The National Institute of Child Health and Human Development (RO1 HD048629) and the March of Dimes Birth Defects Foundation (12-FY01-0098); this study is part of an ongoing, longitudinal study.

Conflicts of interest: None declared.

#### References

- Abidin, R. R. (1990). Parenting stress index—manual (3rd ed.). Charlottesville, VA: Pediatric Psychology Press.
- Anderson, B. J., & Coyne, J. C. (1991). "Miscarried helping" in the families of children and adolescents with chronic diseases. In J. H. Johnson, & S. B. Johnson (Eds.), *Advances in child health psychology* (pp. 167–177). Gainesville, FL: University of Florida Press.
- Bailey, D. B., Skinner, D., Correa, V., Arcia, E., Reyes-Blanes, M. E., Rodriguez, P., ... Skinner, M. (1999).
  Needs and supports reported by Latino families of young children with developmental disabilities.
  American Journal on Mental Retardation, 104, 437–451.
- Barakat, L. P., & Linney, J. A. (1992). Children with physical handicaps and their mothers: The interrelation of social support, maternal adjustment, and child adjustment. *Journal of Pediatric Psychology*, 17, 725–739.
- Barakat, L. P., & Linney, J. A. (1995). Optimism, appraisals, and coping in the adjustment of mothers and their children with spina bifida. *Journal of Child and Family Studies*, 4, 303–320.
- Blacher, J., Lopez, S., Shapiro, J., & Fusco, J. (1997). Contributions to depression in latina mothers with and without children with retardation: Implications for caregiving. Family Relations, 46, 325–334.
- Blacher, J., & McIntyre, L. L. (2006). Syndrome specificity and behavioural disorders in young adults with intellectual disability: Cultural differences in family impact. *Journal of Intellectual Disability Research*, 50, 184–198.
- Boulet, S. L., Yang, Q., Mai, C., Kirby, R. S., Collins, J. S., Robbins, J. M., ... Mulinare, J. (2008). Trends in postfortification prevalence of spina bifida and anencephaly in the United States. *Birth Defects Research (Part A)*, 82, 527–532.

- Bronfenbrenner, U. (1979). *The ecology of human development*. Cambridge, MA: Harvard University Press.
- Cohen, J. (1992). A power primer. *Psychological Bulletin*, 112, 155–159.
- Davidson, T. M., & Cardemil, E. V. (2009). Parent–child communication and parental involvement in latino adolescents. *Journal of Early Adolescence*, 29, 99–121.
- Derogatis, L. R., Rickels, K., & Rock, A. F. (1976). The SCL-90 and the MMPI: A step in the validation of a new self-report scale. *British Journal of Psychiatry*, 128, 280–289.
- Devine, K. A., Holmbeck, G. N., Gayes, L., & Purnell, J. Q. (2011). Friendships of children and adolescents with spina bifida: Social adjustment, social performance, and social skills. *Journal of Pediatric Psychology*, doi:10.1093/jpepsy/JSR075
- Griffith, J., & Villavicencio, S. (1985). Relationships among acculturation, sociodemographics characteristics and social support in Mexican American adults. Hispanic Journal of Behavioral Sciences, 7, 75–92.
- Heller, T., Markwardt, R., Rowitz, L., & Farber, B. (1994). Adaptation of Hispanic families to a member with mental retardation. *American Journal on Mental Retardation*, 99, 289–300.
- Hill, J. P., Holmbeck, G. N., Marlow, L., Green, T. M., & Lynch, M. E. (1985). Pubertal status and parent–child relations in families of seventh-grade boys. *Journal of Early Adolescence*, 5, 31–44.
- Hollingshead, A. B. (1975). Four factor index of social status. New Haven, CT: Yale University Press.
- Holmbeck, G. N., Coakley, R. M., Hommeyer, J. S.,
  Shapera, W. S., & Westhoven, V. C. (2002).
  Observed and perceived dyadic and systemic functioning in families of preadolescents with spina bifida. *Journal of Pediatric Psychology*, 27, 177–189.
- Holmbeck, G. N., & Devine, K. A. (2010). Psychosocial and family functioning in spina bifida. *Developmental Disabilities Research Reviews*, 16, 40–46.
- Holmbeck, G. N., Gorey-Ferguson, L., Hudson, T.,
  Seefeldt, T., Shapera, W., Turner, T., & Uhler, J.
  (1997). Maternal, paternal, and marital functioning in families of preadolescents with spina bifida.
  Journal of Pediatric Psychology, 22, 167–181.
- Hsin, O., La Greca, A., Valenzuela, J., Moine, C. T., & Delamater, A. (2010). Adherence and glycemic control among Hispanic youth with type 1 diabetes: Role of family involvement and acculturation. *Journal of Pediatric Psychology*, 35, 156–166.
- Inkelas, M., Raghavan, R., Larson, K., Kuo, A. A., & Ortega, A. N. (2007). Unmet mental health need and access to services for children with special

- health care needs and their families. *Ambulatory Pediatrics*, 7, 431–438.
- Kazak, A. E., Rourke, M. T., & Navasaria, N. (2009).
  Families and other systems in pediatric psychology.
  In M. C. Roberts, & R. G. Steele (Eds.), Handbook of pediatric psychology (4th ed., pp. 656–671). New York: Guilford Press.
- Kumpfer, K. L., Alvarado, R., Smith, P., & Bellamy, N. (2002). Cultural sensitivity and adaptation in family-based prevention interventions. *Prevention Science*, 3, 241–246.
- Mardiros, M. (1989). Conception of childhood disability among Mexican-American parents. *Medical Anthropology*, 12, 55–68.
- Miller, G. A., & Chapman, J. P. (2001). Misunderstandings analysis of covariance. *Journal of Abnormal Psychology*, 110, 40–48.
- Mullins, L. L., Wolfe-Christensen, C., Pai, A. L. H., Carpentier, M. Y., Gillaspy, S., Cheek, J., & Page, M. (2007). The relationship of parental overprotection, perceived child vulnerability, and parenting stress to uncertainty in youth with chronic illness. *Journal of Pediatric Psychology*, 32, 973–982.
- Munet-Vilaró, F. (2004). Delivery of culturally competent care to children with cancer and their families—The Latino experience. *Journal of Pediatric Oncology Nursing*, 21, 155.
- National Birth Defects Prevention Network (2010).

  Prevalence of spina bifida and anencephaly before and after folic acid fortification, NBDPN Neural Tube Defect Ascertainment Project; 1995–2006. Retrieved from http://www.nbdpn.org/current/2010pdf/NTD% 20fact%20sheet%2001-10%20for%20website.pdf
- Perrin, E., West, P., & Culley, B. (1989). Is my child normal yet? Correlates of vulnerability. *Pediatrics*, 83, 355–363.
- Procidano, M. E., & Heller, K. (1983). Measures of perceived social support from friends and from family: Three validation studies. *American Journal of Community Psychology*, 11, 24.
- Rosnow, R. L., Rosenthal, R., & Rubin, D. B. (2000). Contrasts and correlations in effect-size estimation. *Psychological Science*, 11, 446.
- Rueda, R., Monzo, L., Shapiro, J., Gomez, J., & Blacher, J. (2005). Cultural models of transition: Latina mothers of young adults with developmental disabilities. *Exceptional Children*, 71, 401–414.
- Saloviita, T., Italinna, M., & Leinonen, E. (2003). Explaining the parental stress of fathers and mothers caring for a child with intellectual disability: A

- double ABCX model. *Journal of Intellectual Disability Research*, 47, 300–312.
- Sawin, K. J., Bellin, M. H., Roux, G., Buran, C., Brei, T. J., & Fastenau, P. S. (2003). The experience of parenting an adolescent with spina bifida. *Rehabilitation Nursing*, 28, 173–185.
- Schaffner, D. M., & Wagner, R. W. (1996). American and anglo single mothers: The influence of ethnicity, generation, and socioeconomic status on social support networks. *Hispanic Journal of Behavioral Sciences*, 18, 74–86.
- Smith, K., Freeman, K. A., Neville-Jan, A., Mizokawa, S., & Adams, E. (2010). Cultural considerations in the care of children with spina bifida. *Pediatric Clinics of North America*, 57, 1027–1040.
- Swartwout, M. D., Garnaat, S. L., Myszka, K. A., Fletcher, J. M., & Dennis, M. (2010). Associations of ethnicity and SES with IQ and achievement in spina bifida meningomyelocele. *Journal of Pediatric Psychology*, 35, 927–936.
- Thomasgard, M., Metz, W. P., Edelbrock, C., & Shonkoff, J. (1995). Parent-child relationship disorders: Part I. Parental overprotection and the development of the parent protection scale. *Journal of Developmental and Behavioral Pediatrics*, 16, 244–250.

- Timmins, C. L. (2002). The impact of language barriers on the health care of Latinos in the United States: A review of the literature and guidelines for practice. *The Journal of Midwifery & Women's Health*, 47, 80–96.
- U.S. Census Bureau (2011). 2010 census shows nation's hispanic population grew four times faster than total U.S. population. Retrieved from http://2010.census.gov/news/releases/operations/cb11-cn146.html
- Vermaes, I. P. R., Gerris, J. R. M., & Janssens, J. M. A. M. (2007). Parents' social adjustment in families of children with spina bifida: A theory-driven review. *Journal of Pediatric Psychology*, 32, 1214–1226.
- Vermaes, I. P. R., Janssens, J. M. A. M., Bosman, A. M. T., & Gerris, J. R. M. (2005). Parents' psychological adjustment in families of children with spina bifida: A meta-analysis. BMC Pediatrics, 5, 32–44.
- Wechsler, D. (1999). WASI: Wechsler abbreviated scale of intelligence manual. San Antonio, TX: Harcourt Assessment, Inc.
- Williams, L. J., Rasmussen, S. A., Flores, A., Kirby, R. S., & Edmonds, L. D. (2005). Decline in the prevalence of spina bifida and anencephaly by race/ethnicity: 1995–2002. *Pediatrics*, 116, 580–586.