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Understanding the Family Impact of Autism Spectrum Disorder in a Racially and Ethnically Diverse Sample: Findings from the National Survey of Children with Special Health Care Needs

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Abstract

Objectives Caregivers of children with autism spectrum disorder (ASD) experience stress at greater rates than caregivers of other children with developmental conditions. Little is known about how families from different racial and ethnic backgrounds report family impact beyond individual stressors associated with caregiving. This paper aims to examine differences in family impact variables among caregivers of ASD children from different racial/ethnic backgrounds. *Methods* Using data from the 2005–2006 and 2009–2010 National Survey of Children with Special Health Care Needs, this retrospective, cross-sectional study examined family impact among caregivers of children with ASD. Family impact was defined as financial impact, time spent caregiving, and work impact variables and evaluated in five racial/ethnicity groups: white, non-Hispanic; any race, English-speaking Hispanic; any race, Spanish-speaking Hispanic; black, non-Hispanic; and other race, non-Hispanic respondents ($n=5115$). Multivariate logistic regression was used to analyze the association of race and ethnicity with family impact variables while controlling for child and family covariates. *Results* Significant differences were found between race/ethnicity groups of caregivers on financial spending of more than \$500 per year on care and providing more than 11 h a week on direct child care. No significant differences were observed in job impact variables between race/ethnicity groups. *Conclusions for Practice* Racial/ethnic differences exist in providing and spending more on direct care, but they do not necessarily represent disparities. More research is needed to fully understand if family impact is affected by cultural differences in care provided for children with ASD.

Keywords Autism spectrum disorder · Family caregiver · Racial/ethnic health disparities

Significance

What is already known on this subject? Caregivers of all racial/ethnic backgrounds that care for children with ASD experience family impact associated with the child's condition. *What this study adds?* This study adds evidence that financial and time caregiving impact differs between racial/ethnic groups within a U.S. population-based sample of respondents who care for children with ASD.

Introduction

Raising a child with autism spectrum disorder (ASD) has a substantial influence on family caregivers' emotional and physical health and wellbeing. Caregivers of children with ASD experience significantly higher levels of parenting stress and are more likely to be diagnosed with depression

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compared to parents of children with other developmental disabilities or parents of children without ASD (Cohrs and Leslie 2017; Hayes and Watson 2013). Changes in caregiver's physical health are described in the literature. For example, when compared with mothers of typically-developing children of similar age, mothers of adolescents and adults with ASD showed down-regulation of cortisol activity, a biological marker of stress (Seltzer et al. 2010). Other studies show increased levels of pro-inflammatory cytokines (Lovell et al. 2012) and higher levels of blood pressure (Gallagher and Whiteley 2012) in caregivers of children with ASD, suggesting increased risk for poor physical health in this population.

Although a caregiver's psychological and physical health may impact their family, other indicators may also significantly contribute to a family's overall well-being such as financial, time, and work-related variables. Research investigating the financial impact of caring for a child with ASD has found that families of children with ASD earned 28% less than families of children with no health conditions (Cidav et al. 2012). Additionally, these families spend more per year than families of children without ASD on health care, education, ASD-related therapies, family-coordinated services, and caregiving time (Lavelle et al. 2014). Little research has evaluated these financial, time, and work impacts in families of different racial and ethnic backgrounds.

Empirical evidence shows racial and ethnic disparities in the early identification and care of children with ASD. For example, compared to white, non-Hispanic children, racial and ethnic minority children are evaluated for and diagnosed with ASD significantly later (Christensen et al. 2016; Fountain et al. 2011; Magaña et al. 2013), receive fewer ASD-related specialty or educational services (Magaña et al. 2016), and are significantly more likely to have greater unmet service needs (Magaña et al. 2013). Given that families of children with ASD in general are more likely to spend additional costs on their children's education, specialized therapies, and coordinating care (Lavelle et al. 2014), the family impact may be even greater in families of certain racial and ethnic backgrounds. Examining differences in financial, time, and work-related family impact among families of different racial and ethnic backgrounds is a necessary precursor to understand strategies for supporting racially and ethnically diverse families of children with ASD, and remains an important and understudied area.

McManus et al. (2011) presented a conceptual model that explained family impact in terms of financial burden and time providing and coordinating care in families of children with developmental disabilities, including those with ASD. McManus and colleagues found a significant relationship between unmet health care needs and financial burden and time spent providing and coordinating care for children with developmental disabilities. Existing literature, however, rarely addresses culture and the possible role that race and/or ethnicity (as a proxy for culture) might contribute towards family impact. Indeed, McManus and colleagues (2011) found that race/ethnicity was associated indirectly with caregiver burden, but did not explore specific minority groups. Our study aimed to extend this model to evaluate differences in reported racial/ethnic minority caregiver impact variables. The purpose of our study was to identify differences in caregiver reported family impact, as quantified by financial, work, and time variables, among caregivers of children with ASD in a racially/ethnically diverse, population-based sample.

Methods

The study was exempted by the first author's institutional review board before data analysis. We obtained public use files from the 2005–2006 and 2009–2010 National Survey of Children with Special Health Care Needs (NS-CSHCN) (Centers for Disease Control and Prevention [CDC] 2013) to conduct this retrospective, cross-sectional design study. Data preparation details are provided in other study publications (e.g., Benevides et al. 2016). Briefly, these population-based surveys collected information about household demographic characteristics, respondent characteristics, and respondent perception of the impact of a child with special healthcare need's condition on the family, among other things (Blumberg et al. 2008; Bramlett et al. 2014). We used non-imputed variables from the screening, household, and main interview datasets.

Sampling methods for these surveys are described in CDC publications for each survey year (Blumberg et al. 2008; Bramlett et al. 2014). Telephone surveys were conducted with respondents familiar with the child with special health care needs; we use the term 'caregivers' throughout this article since not all were parents. Survey changes were made between the survey years (CDC 2013). Changes affecting our analyses were the inclusion of mobile/cell-phone users in 2009–2010 and ascertainment of 'autism spectrum disorder.' These changes to the survey methods are discussed below.

The larger NS-CSHCN was comprised of 364,841 and 372,698 households with children under the age of 18 years who were screened for the 2005–06 and 2009–10 surveys, respectively. The screening process identified whether a CSHCN lived at the residence (Blumberg et al. 2008; Bramlett et al. 2014). Caregivers of screened CSHCN were invited to participate in the main interview survey, which was used to define the analytic sample. The full analytical sample for each survey year included 40,723 (2005–2006) and 40,242 (2009–2010) CSHCN.

Respondents on the main interview survey were asked yes/no questions about conditions commonly seen in childhood, including ASD. Caregivers identified children with ASD in 2005–2006 ($n = 2123$) and 2009–2010 ($n = 3055$) by answering 'yes' to the following questions: 'to the best of your knowledge, does [child] have autism or autism spectrum disorder?' (2005–06), or in 2009–2010: 'does [child] *currently* have autism or an autism spectrum disorder?'. Our study focus on the subpopulation in which respondents indicated the CSHCN had an autism spectrum disorder (n = 5178 across both survey years), of whom $n = 5115$ had complete race and ethnicity data and comprised our analytic sample.

Variables

Family Impact

Outcome variables in this study were selected based on McManus et al.'s (2011) conceptual framework, and represent financial, time spent caregiving, and work-related demands. The survey questions from the NS-CSHCN used to elicit these data are presented in Table 1, as is our rationale for variable coding. Only one variable was restricted in sample size (hours providing direct care), because this variable included only those caregivers who reported providing direct care at home ($n = 2425$).

Race and Ethnicity

Our primary independent variable was the race and ethnicity of the child, which the original survey categorized as white, black, American Indian, Alaska Native, Asian, Native Hawaiian, Pacific Islander, and other. The 2005–2006 NS-CSHSN provided race in four categories, which in the ASD sample included: White-only, Black-only, Multiple, and Other. In 2009–2010, the NS-CSHSN survey provides the race variable in three categories: White-only, Black-only, and Other. Due to differences in these two survey years in reporting 'Multiple' races, we were unable to examine biracial groups, however, the number of 'Multiple' race individuals in 2005 was small (n = 86) for our ASD sample and unlikely would have been able to be examined due to small sample. Ethnicity in the original survey was reported based on two categories (non-Hispanic or Hispanic/Latino/Spanish origin).

We created a single variable for race-ethnicity for purposes of our study which used five categories to examine differences in family impact variables: (1) white, non-Hispanic; (2) any race, English-speaking Hispanic; (3) any race, Spanish-speaking Hispanic; (4) black, non-Hispanic; and (5) other race, non-Hispanic. We collapsed several of these groups in some strata due to small sample sizes. Moreover, the method of coding for the race/ethnicity variable (i.e., the other race, non-Hispanic group, which includes individuals who identify as biracial or with some of the categories listed in the original survey) is similar to that seen in other studies that used the NS-CSHCN to examine their research foci (Lin et al. 2017; Ross et al. 2018). Additionally, we created two Hispanic groups based on language spoken at home because differences in prevalence and functional needs of children have been found for primarily English-speaking Hispanic families versus primarily Spanish-speaking Hispanic families (Mandell et al. 2009). While the method of parsing out the Hispanic group by the language of predominance has not been widely studied, past literature by Mandell and colleagues (2009) suggests language may be a variable of interest.

Child and Family Covariates

Child and family covariates which we controlled for during analysis included: child age (continuous), gender, child insurance status (private, public, private and public, other, uninsured), household income operationalized as federal poverty level (FPL; < 200% FPL, 200–400% FPL, > 400% FPL), caregiver education (less than high school, high school graduate, more than high school), and child need characteristics (functional limitation as assessed with the question, 'since [child's] birth, how often have your child's [medical, behavioral, or other health conditions] affected [his/her] ability to do things other children [his/her] age do?' and the possible answers never, sometimes, frequently, always) (CDC 2013). Geographical location was operationalized as urban or non-urban using metropolitan statistical area status as classified in the NS-CSHCN (Blumberg et al. 2008; Bramlett et al. 2014; CDC 2013). Metropolitan statistical area status was suppressed for cases living in states with either few rural (< 500,000 persons) or few urban (> 500,000 persons) locations (Blumberg et al. 2008; Bramlett et al. 2014; CDC 2013). To retain as many individuals as possible for analysis, respondents living in states with few metropolitan statistical areas were classified 'non-urban,' and respondents living in states with many metropolitan statistical areas were classified 'urban' (Dusing et al. 2004).

Statistical Analysis

Data within each survey year were merged in SAS, and after modification of variables in each survey year to ensure appropriate harmonization of variable names and values across survey years, the main analytic files were concatenated in Stata. Data analysis was done in Stata version 14.1 (StataCorp, LP, College Station, TX). All analyses reported below used the provided population weights in NS-CSHCN documentation (Bramlett et al. 2014) according to Stata's svy procedures and used appropriate subpop option to

Table 1 Family impact constructs and outcome variables. Source: Wording of the questions came directly from the National Survey for Children with Special Healthcare Needs 2005–2006 and 2009–2010, available from: http://www.cdc.gov/nchs/slaits/cshcn.htm

Construct and variable	Question from original National Survey for Children with Special Health Care Needs	Modification of original variable for analysis	Coding for use in logistic regression models
Caregiving hours			
Hours spent providing direct care	Among caregivers reporting providing care at home we used the variable: "How many hours per week do you or other family members spend providing direct health care at home for [child]?" *Responses were reported in exact hours*	The median number of hours was 6, and we coded those who had the greatest burden of time—the top 25% of caregivers reporting providing 11 or more hours of care per week	< 11 h 11 or more hours
Hours spent arranging care	"How many hours per week do you or other family members spend arranging or coordinating care for [child]?" *Responses were reported in exact hours*	The median number of hours was 2, and we coded those who had the greatest burden of time—the top 25% of caregivers reporting providing 5 or more hours of coordination per week	< 5 h 5 or more hours
Job impact			
Stopped work due to child	"Have you or other family members stopped working because of [child's] health conditions?"		No Yes
Cut hours at work due to child	"Have you or other family members cut down on the hours you work because of [child's] health conditions?"		No Yes
Financial impact			
Caregiver perceived financial problems due to child	"Have [child's] health conditions caused financial problems for your family?"		No Yes
Spending on child's care	"During the past 12 months, would you say that your family paid more than $500, 250–500, less than 250, or nothing for [child's] care?"	This ordinal variable was recoded into a dichotomous variable. Approximately 53% of the ASD sample had spent less than $500 per year, and responses were dichotomized using that level of spending	$500 or less More than $500

ensure adequate weighting for the subpopulation of ASD while accounting for the entire sample. Bivariate comparison of the proportion of caregivers responding to a particular family impact variable from each race/ethnicity group was evaluated with Pearson Chi square statistics. Multivariate logistic regressions were used to examine associations of race/ethnicity with family impact variables, and compared a base model with models that included child covariates, enabling family covariates, and child function categorical variables (all models not shown). Models were examined for specification errors, multicollinearity, and goodness of fit; the best regression models are reported.

To address missingness in the sample, 'Refused' and 'Don't Know' responses were coded as missing. Because the primary dependent variable was race/ethnicity, any caregivers without a response ($n = 63$) were excluded from analysis. Missingness in our sample was low (< 1%) for all other covariates except federal poverty level. For this variable, 8.3% of the respondents had missing data (n = 415), but missingness did not differ between race/ethnicity groups. Listwise deletion was used for managing missingness due to the large sample and random nature of missingness. Planned regression analyses used an alpha value of $p \leq 0.05$ to minimize type I error; all regression analyses and analyses of p values and confidence intervals accounted for the complex survey design.

Results

Caregivers of children with ASD ($n = 5115$) reported on child and family level characteristics, including impact variables. Of these, 71.8% ($n = 3717$) were white, non-Hispanic, 8% ($n = 408$) were Hispanic, English-Speaking, 3% ($n = 130$) were Hispanic, Spanish speaking, 8% ($n = 418$) were black, non-Hispanic, and 9% ($n = 442$) were other race,

Table 2 Child and family characteristics by race and ethnicity category

	White, non-Hispanic ($n = 3717$)	Any race, Hispanic, English speaking ($n = 408$)	Any race, Hispanic, Spanish speaking ($n = 130$)	Black, non-Hispanic ($n = 418$)	Other race, non-Hispanic ($n = 442$)	p
	% [95% CI]	% [95% CI]	% [95% CI]	% [95% CI]	% [95% CI]	
Age (mean years)	10.0 [9.8, 10.2]	8.8 [8.2, 9.6]	7.8 [6.7, 9.0]	9.8 [9.2, 10.4]	9.9 [9.4, 10.5]	< 0.001
Male	80.0 [77.7, 82.1]	81.1 [73.6, 86.9]	78.8 [66.6, 87.3]	76.4 [70.0, 81.8]	81.8 [74.6, 87.4]	0.76
% Federal Poverty Level						< 0.001
< 200% FPL	34.1 [31.4, 36.8]	48.1 [39.8, 56.5]	76.7 [60.8, 87.5]	67.3 [60.6, 73.3]	36.9 [27.7, 47.3]	
200–400% FPL	35.1 [32.4, 38.0]	31.4 [24.2, 39.6]	20.1 [10.0, 36.5]	18.2 [13.8, 23.7]	31.8 [20.1, 46.3]	
> 400% FPL	30.8 [28.4, 33.3]	20.5 [14.5, 28.2]	3.2 [0.8, 11.6]	14.5 [10.3, 19.9]	31.3 [21.6, 43.1]	
Child's insurance status						< 0.001
Private	54.0 [51.2, 56.7]	39.9 [32.4, 47.8]	19.1 [11.2, 30.7]	21.4 [16.7, 26.9]	39.6 [30.3, 49.6]	
Public	24.8 [22.5, 27.3]	36.4 [29.0, 44.4]	51.0 [38.5, 63.3]	55.2 [48.4, 61.7]	37.5 [26.3, 50.1]	
Private and public	16.1 [14.1, 18.3]	17.5 [11.8, 25.1]	14.9 [7.8, 26.7]	17.8 [13.2, 23.6]	16.8 [9.3, 28.5]	
Other insurance	2.9 [2.2, 3.8]	3.0 [1.2, 7.3]	5.5 [0.8, 29.4]	2.3 [1.1, 4.6]	1.7 [0.6, 4.7]	
Uninsured	2.2 [1.7, 2.9]	3.3 [1.6, 6.7]	9.5 [4.5, 19.1]	3.4 [1.7, 6.7]	4.5 [2.0, 9.6]	
Household MSA status						< 0.001
Urban	79.9 [77.7, 81.9]	91.3 [87.4, 94.0]	97.5 [94.8, 98.8]	87.9 [82.8, 91.6]	85.3 [78.2, 90.3]	
Household education[a]						< 0.001
Less than high school	4.2 [3.0, 6.0]	12.8 [7.5, 21.0]	29.4 [19.7, 41.3]	11.5 [7.8, 16.5]	4.8 [2.6, 8.7]	
High school graduate	16.8 [14.7, 19.1]	22.5 [16.3, 30.1]	33.8 [22.4, 47.5]	27.8 [21.7, 34.9]	13.1 [8.1, 20.5]	
More than high school	79.0 [76.4, 81.4]	64.7 [56.2, 72.4]	36.8 [25.8, 49.4]	60.7 [53.7, 67.4]	82.1 [74.3, 88.0]	
Child's condition impact on function						0.04
Never	5.5 [4.5, 6.7]	6.1 [2.9, 12.6]	1.9 [0.6, 5.6]	8.2 [5.1, 13.0]	5.7 [2.5, 12.2]	
Sometimes	28.0 [25.5, 30.6]	26.1 [20.2, 32.9]	24.4 [15.6, 36.0]	36.4 [30.2, 43.1]	23.7 [16.9, 32.2]	
Usually	19.9 [17.8, 22.1]	19.5 [13.8, 26.9]	14.8 [7.8, 26.3]	9.3 [6.7, 12.8]	19.5 [13.8, 26.8]	
Always	46.7 [44.0, 49.4]	48.3 [40.3, 56.3]	58.9 [46.3, 70.4]	46.1 [39.4, 53.0]	51.1 [40.1, 62.1]	

Data source: Centers for Disease Control and Prevention, National Center for Health Statistics, National Survey of Children with Special Health Care Needs, 2005–2006 and 2009–2010

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ASD autism spectrum disorder, *CI* confidence interval, FPL household federal poverty level

[a] Indicates highest level of education of anyone in the child's household

non-Hispanic. Table 2 displays demographic characteristics of children and families. The average child's age was 9.8 years (95% confidence interval 9.60–9.97), and children were primarily male (79.79%). A greater percentage of children from Hispanic English-speaking (36.36%), Hispanic Spanish-speaking (50.97%) and black (55.16%) groups had public insurance coverage, compared to white non-Hispanic (24.83%). Hispanic, Spanish-speaking children had higher rates of uninsured status (9.5%) compared to all other children (2.9%). More caregivers from white, non-Hispanic (78.9%) and other race, non-Hispanic (81.0%) groups had 'greater than a high-school' education as compared to Hispanic, English-speaking (64.5%), Hispanic, Spanish-speaking (36.0%), or black non-Hispanic (60.1%) caregivers.

Bivariate comparisons between different race/ethnicity groups are displayed in Table 3. Overall, there were no significant differences in any of the two job impact variables between different race/ethnicity groups. However, there were significant differences in time and financial variables between groups. Hispanic English-speaking caregivers reported spending significantly more time providing direct care for their child with ASD than white, non-Hispanic caregivers. Specifically, nearly 59% of these Hispanic caregivers reported spending more than 11 h a week providing direct care for their child, as compared to 36% of white, non-Hispanic caregivers. Financially, there were significant differences between groups in the proportion of caregivers reporting spending more than $500 per year on their child's care, with white non-Hispanic (50.3%) and English-speaking Hispanic caregivers (42.2%) reporting spending more than $500/year significantly more frequently than Spanish-speaking Hispanic caregivers (15.7%), black, non-Hispanic caregivers (24.7%), and caregivers of other racial/ethnic backgrounds (31.1%) (Table 3).

In logistic regression models adjusted for characteristics of the child and family (Table 4), English-speaking Hispanic caregivers were two times more likely (OR = 2.01, 95% CI 1.14–3.55) to report spending 11 or more hours caring for their child as compared to white, non-Hispanic caregivers. Because logistic models revealed that all race/ethnicity

Table 3 Reported family impact among caregivers of children with ASD of different racial and ethnic backgrounds

	White, non-Hispanic (n = 3717)	Any race, Hispanic, English speaking (n = 408)	Any race, Hispanic, Spanish speaking (n = 130)	Black, non-Hispanic (n = 418)	Other race, non-Hispanic (n = 442)	Total (n = 5115)	*p*
	% [95% CI]	% [95% CI]	% [95% CI]	% [95% CI]	% [95% CI]	% [95% CI]	
Caregiving hours							
Spends 11 or more hours providing direct care per week[a]	35.9 [32.17, 39.90]	58.6 [46.89, 69.46]	55.6 [35.09, 74.32]	39.5 [29.65, 50.19]	43.2 [24.23, 64.34]	39.8 [36.08, 43.55]	0.04
Spends 5 or more hours arranging care per week	26.1 [23.60, 28.70]	34.1 [26.55, 42.56]	29.8 [18.99, 43.35]	28.79 [22.85, 35.56]	25.77 [18.86, 34.15]	27.31 [25.18, 29.54]	0.32
Job impact							
Stopped work due to child	36.07 [33.51, 38.72]	42.8 [34.97, 50.96]	53.5 [41.06, 65.49]	35.8 [29.49, 42.65]	40.4 [29.27, 52.62]	37.8 [35.47, 40.2]	0.09
Cut hours at work due to child	36.4 [33.79, 39.09]	41.1 [33.29, 49.39]	49.1 [36.89, 61.47]	34.8 [28.53, 41.64]	33.5 [22.55, 46.57]	36.94 [34.59, 39.36]	0.30
Financial impact							
Caregiver perceived financial problems due to child's condition	41.3 [38.64, 44.03]	43.5 [35.7, 51.53]	33.7 [23.41, 45.79]	36.6 [30.25, 43.45]	45.8 [34.39, 57.58]	41.0 [38.65, 43.46]	0.42
Spent > $500 in past year on child's care	50.3 [47.56, 53.01]	42.2 [34.28, 50.48]	15.7 [8.975, 26.11]	24.7 [19.17, 31.19]	31.1 [23.64, 39.71]	43.3 [40.98, 45.64]	< 0.0001

Data Sources: Centers for Disease Control and Prevention, National Center for Health Statistics, National Survey of Children with Special Health Care Needs, 2005–2006, and National Survey of Children with Special Health Care Needs, 2009–2010

[a] Total sample size for this question (*n* = 2425) reflects only caregivers reporting providing any care at home

Table 4 Adjusted[a] Likelihood of reporting caregiver impact among caregivers of children with autism spectrum disorder

	Spent > 11 h/week providing direct care	Spent > 5 h/week arranging care	Stopped work due to child	Cut hours at work due to child	Caregiver perceived financial problems due to child	Spent >$500/ year on child's care
	OR [95% CI of OR]	OR [95% CI of OR]	OR [95% CI of OR]	OR [95% CI of OR]	OR [95% CI of OR]	OR [95% CI of OR]
White, non-Hispanic	1.00	1.00	1.00	1.00	1.00	1.00
Any race, Hispanic, English speaking	2.01* [1.14, 3.55]	1.32 [0.87, 1.99]	1.08 [0.75, 1.54]	1.07 [0.74, 1.53]	1.05 [0.73, 1.52]	0.92 [0.62, 1.37]
Any race, Hispanic, Spanish speaking	1.24 [0.45, 3.38]	0.93 [0.46, 1.85]	1.37 [0.74, 2.52]	1.39 [0.75, 2.56]	0.67 [0.36, 1.24]	0.28* [0.13, 0.59]
Black, non-Hispanic	0.98 [0.53, 1.82]	1.05 [0.70, 1.58]	0.74 [0.51, 1.06]	0.93 [0.65, 1.32]	0.91 [0.63, 1.30]	0.55* [0.36, 0.85]
Other race, non-Hispanic	1.14 [0.50, 2.59]	0.83 [0.52, 1.32]	1.04 [0.63, 1.69]	0.83 [0.51, 1.38]	1.09 [0.68, 1.73]	0.43* [0.29, 0.65]

Data Sources: Centers for Disease Control and Prevention, National Center for Health Statistics, National Survey of Children with Special Health Care Needs, 2005–2006, and National Survey of Children with Special Health Care Needs, 2009–2010

* $p < 0.05$

[a] Logistic regressions of family impact with white, non-Hispanic as the indicator variable adjusted for year of survey, cell-phone sample status, child age, child gender, Federal Poverty Level, metropolitan statistical area, child type of health insurance, caregiver education level, caregiver reported functional level of the child. All regressions accounted for the complex sample design

categories other than white, non-Hispanic were less likely to spend less than $500 (Table 4), we conducted analyses to ease interpretation by changing the indicator variable. These models reveal that white non-Hispanic caregivers were significantly more likely to spend $500 or more on their child's care than black non-Hispanic (OR = 1.80, 95% CI 1.18–2.80), Spanish-speaking Hispanic (OR = 3.60, CI 1.69–7.64), and caregivers of other racial/ethnic backgrounds (OR = 2.32, CI 1.55–3.49).

Although the intent of our analysis was not to examine co-variates in the regression models, only child's functional abilities variable consistently predicted greater family impact across all regression models. Caregivers with children whose functional abilities were 'Always' impacted by their autism reported significantly greater caregiver burden than other caregivers. Because this variable was included in all models, all racial/ethnic differences were adjusted for functional impact.

Discussion

Our results suggest that racial and ethnic differences are not restricted to service access among children with ASD, but likely exist when examining family impact variables as well. Although caregiver perception of financial burden did not significantly differ between the race/ethnicity groups, on average across all racial/ethnic groups, 41% of all caregivers reported experiencing some financial impact in the past year in caring for their child with ASD. In addition, families of children with ASD reported they stopped or cut work hours due to care for their child ranged from 35.8% in black, non-Hispanic families to 53.8% from Hispanic, Spanish speaking families. Our results extend findings in family impact as identified by Cidav et al. (2012), who found that maternal caregivers of children with ASD reported greater financial burden and were less likely to work or work fewer hours per week due to spending more time caring for their child with ASD compared to mothers of children with no health limitation. Lavelle et al. (2014) also reported that costs for care among children with ASD are generally higher than for children without ASD. The unique contribution of this study is that financial and time caregiving impact differs between racial/ethnic groups within a U.S. population-based sample of respondents who care for children with ASD.

Although the perception of financial burden did not differ across racial/ethnic groups, we found that significantly greater rates of caregivers from white, non-Hispanic and English-speaking Hispanic backgrounds reported spending more than $500 a year on their child with ASD as compared to other groups. Our results from adjusted analyses suggest that differences in reported spending existed after adjusting for socio-demographic variables. While this study had no way to determine reasons or choices for caregiver reported spending, possible reasons why caregivers may or may not spend money on a child's care include access to care and knowledge of services or resources (Liptak et al. 2008; Magaña et al. 2013).

In addition to financial differences, we found differences in time spent caregiving. English-speaking Hispanic caregivers were significantly more likely to report spending 11 or more hours a week providing direct care for their child than other racial/ethnic groups. In contrast, families of different racial and ethnic backgrounds did not differ in time spent coordinating their child's care. Thus, we found differences in providing *direct care*, rather than in coordinating care, between groups. One possible reason is that the variable for direct care only included caregivers who indicated they provided direct care at home (about half of the original sample, n = 2451). However, about 50% of each race/ethnicity group reported providing any care at home, but the proportion of those providing greater number of hours was significantly greater among English-speaking Hispanic caregivers. Further clarity is needed to determine whether caregivers who reported spending greater than 11 h a week were compelled to engage in this level of caregiving due to lack of finances or lack of other support, or whether the caregiver chose to engage in caregiving based on preference, cultural expectations, or family norms. Familism, direct caregiving to the person with illness by family members, is an important cultural value of Hispanic families with individuals who have intellectual disabilities (Magaña 1999). Future work should aim to examine the perceptions of caregivers from racial and ethnic families related to time spent providing care for their child with ASD.

Of interest is that we found differences between English-speaking Hispanic and Spanish-speaking Hispanic caregivers on spending for child's care. This finding is similar to the qualitative differences explored in medical care seeking behaviors (Collado et al. 2016) and sociocultural factors noted in the literature. Flower et al. (2017) specifically noted that these differences do not seem to be a sequela of ethnicity, but rather linguistic differences. Similarly, Torres-Harding et al. (2008) found that language and cultural factors seemed to contribute to differences in their study on fatigue and stress in Spanish- and English-speaking Hispanics. The differences between these groups are valuable for further study, given that Hispanics comprise a most rapidly growing and dispersing ethnic group (Nathenson et al. 2016). Although much of the literature groups 'Hispanic/Latino' together, as highlighted by The U.S. Department of Health and Human Services Surgeon General's report of 2001, a wide degree of variation among subgroups within the Hispanic population exist, and future investigation into caregiver preferences for spending time and money are relevant.

While the findings of our study showed racial and ethnic differences in providing direct care for a child with ASD and spending more for care, they do not represent disparities. Spending money and time providing care may be culturally-driven constructs which reflect familial values and priorities when providing support to a child with a special health care need (Bishop et al. 2007; Dyches et al. 2004). With other demographic variables controlled for, these findings suggest the need to support caregivers in their preferred methods of providing care. In a qualitative study, DeGrace (2004) identified that families spent significant time in managing the day-to-day experience of parenting, and that this time spent was more about addressing child needs than in establishing family cohesion. Although this is likely the case for many (if not all) parents of children with ASD, understanding the nuanced differences of the time spent caregiving among racially and ethnically diverse families is an important next step in understanding the experience of caregiving for a child with ASD. Caregivers may require support in the form of childcare services or respite care, which allow them time away; they may also need resources and supports to be provided at home to meet their child's needs. Existing legislation allows for states to provide self-directed services through Medicaid (Centers for Medicare and Medicaid Services n.d.). This type of legislation may be helpful for families who wish to select services that most appropriately meet their family's needs and is aligned with the idea that different caregivers prefer to provide support to their child through various approaches (Warfield et al. 2014). Training providers to support family choice is another method for ensuring that families understand the options available to meet their needs.

Providers should ensure effective communication with caregivers of children with ASD when discussing available intervention and community resources, to ensure that caregivers from different backgrounds can engage in caregiving activities in preferred ways—either through providing direct care, spending money on treatment, or stopping work. Policymakers may help to target specific dimensions of caregiver experience by developing policies to provide culturally competent and family-centered supports, emphasizing social supports, and increasing access to care and specialized services for families in need. These could include availability of services and funds which are spent in accordance with the preferences of the family, rather than as prescribed by a case manager or required by a system of care. Although some available support for aligning services with family need has been somewhat available to caregivers, the evidence suggests that generally, caregivers are not given the support they need to make decisions about services (Galpin et al. 2017). Our research suggests that the impact of caregiving may differ among families of different racial/ethnic backgrounds, and consideration for family preferences should be addressed in a culturally sensitive manner.

Limitations

With any survey design research, limitations exist in our ability to understand the extent to which respondents accurately answered survey questions and the limitations presented due to self-report. Interpretative differences in the meaning of the questions may exist and possibly impacted the caregiver's answers. Secondary data analysis is not collected with a specific purpose in mind. Thus, we were unable to include other variables which could differentiate family impact in the groups we examined. Additionally, our classification of racial and ethnic groups artificially creates categories, which may not allow us to fully understand the complexities of caregiving among people from different cultural backgrounds. Importantly, this study is not causal and cannot infer the direction of effects (e.g., whether time spent caregiving affects financial spending or vice versa).

Conclusion

To the best of our knowledge, this study is the first to analyze differences in racial/ethnic family impact among caregivers of children with ASD. Our findings further extend previous research in this area by demonstrating the family impact associated with caring for a child with a developmental disability, and more specifically the differences in racial/ethnic minorities in time spent caregiving and in financial spending. Additional qualitative investigation into the cultural experience of caregiving and caregiver impact among those raising a child with ASD is warranted. Developing and providing more culturally-appropriate interventions to ensure services are aligned with caregiver preferences in spending time and money are necessary.

Author Contributions All authors contributed to the supervision and design of the study equally. TB developed methodology, conducted and interpreted analyses, and contributed to the writing of the article. JL, NN, and JLF conducted the literature review, participated in interpretation of results and implications, and contributed to the writing of the article.

Compliance with Ethical Standards

Ethical Statement This study was deemed exempt from the first author's institutional review board, and all research for this manuscript was conducted in accord with prevailing ethical principles.

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