


Parental Stress in Families of Children With Autism and Other Developmental Disabilities

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Abstract

The level of parental stress in families of children with autism and other developmental disabilities and its association with child comorbid symptoms was studied in an ethnically diverse population, in a cross-sectional study with structured interview. The sample included 50 families of children with autism and 50 families of children with other developmental disabilities, matched by age/gender. Interview included Parenting Stress Index–Short Form, Gastrointestinal Questionnaire, Child Sleep Habits Questionnaire, and Aberrant Behavior Checklist. In this ethnically diverse sample, parental stress was significantly higher for the autism group and for non-Hispanic and US-born mothers. In both study groups, parental stress was related to child irritability. Parental stress was also related to gastrointestinal problems in the autism group and to sleep difficulties in the developmental disabilities group. Targeting child irritability may be particularly important in reducing parental stress for families of children with autism and other developmental disabilities.

Keywords

parental stress, autism spectrum disorder, developmental disabilities, children, irritability

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Autism spectrum disorders are characterized by developmental deficits in socialization and communication and the presence of restricted, repetitive behaviors or circumscribed interests.^{1,2} Besides the core features, children with autism spectrum disorder frequently present comorbid behavioral difficulties that interfere with their functioning. The diagnosis of an autism spectrum disorder can have a tremendous effect on a family, and it has been well documented that parents of children with autism often face significant emotional strains, changes in lifestyle, and economic hardship associated with caring for their children. Across studies, relative to parents of children with typical development or with other developmental disabilities, parents of children with autism have reported higher levels of parental stress.³⁻⁷ Reported stressors have included child's maladaptive behaviors⁸⁻¹⁰ and sleeping problems.^{11,12} Because most studies in the literature are based on samples consisting predominantly of white, middle-class parents,¹³ little is known about parenting stress among racial and ethnic minority groups.¹⁴ However, autism spectrum disorders are reported to occur in all racial, ethnic, and socioeconomic groups,¹⁵ and given the nondiscriminatory nature of the diagnosis, more information on subpopulations within the autism spectrum disorder community is needed to better understand the ramifications of the diagnosis and to optimize individualized approaches to therapeutic intervention. Specifically, information about parental stress in families of children

with autism spectrum disorder in ethnic minority groups is sparse. Given the role of pediatricians and other health care practitioners in coordinating care and resources for these families, an understanding of the impact on family function would be of particular importance. We previously studied families of diverse ethnic backgrounds, with a majority of Hispanic and African American families,¹⁶ and observed that families of children with autism spectrum disorder reported higher levels of parental stress than families of children with other developmental disabilities. To expand knowledge of parental stress and its association with potential stressors in autism spectrum disorder, this study examines associations between comorbid symptoms and level of parental stress in a group of children with autism spectrum disorder

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and a group of children with other developmental disabilities, primarily in Hispanic and African American inner city families. Comorbid symptoms included gastrointestinal, sleeping problems and behavioral difficulties. Our hypothesis was that parental stress will be reported by families of children with autism who present comorbid symptoms.

Methods

Population and Recruitment

This study was conducted as part of a larger project that examined the use of complementary and alternative medicine in children with autism spectrum disorder.¹⁶ Children eligible for the study included those aged 2 to 18 years with autism spectrum disorder followed by the developmental pediatrics program of the Albert Einstein College of Medicine, the Children's Evaluation and Rehabilitation Center of the Kennedy Center. Subjects were recruited between February 2007 and February 2010. The comparison group consisted of children with other developmental disabilities who were recruited from the same site, matched for age and gender to the group with autism spectrum disorder. Subjects in the comparison group were matched to subjects with autism spectrum disorder by age (± 6 months) because of the wide age range of the group with autism spectrum disorder. They were matched by gender because of the predominance of males in the group with autism spectrum disorder.

Informed consent and, when appropriate, assent were obtained in all cases. Both English and Spanish speaking families were included.

The study design and procedures were approved by the institutional review board of the Albert Einstein College of Medicine.

Inclusion and Exclusion Criteria

Cases. Eligible cases were children with autism spectrum disorder between 2 and 18 years of age who were followed at this center. The diagnosis of autism spectrum disorder was made by a multidisciplinary team based on the *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV-TR)*, criteria for autistic disorder.¹ Inclusion also required a score of 30 or more on the Childhood Autism Rating Scale.¹⁷ Excluded were children with known genetic syndromes such as trisomy 21, tuberous sclerosis, Rett disorder, and other known static or progressive neurologic conditions.

Comparison group with developmental disabilities. Participants were 50 children matched with the group with autism spectrum disorder for age and gender, with other major developmental disabilities, including intellectual disability, cerebral palsy, and global developmental delay. The diagnoses were made by a multidisciplinary team, using the appropriate diagnostic algorithm. Exclusions were the same as for the group with autism spectrum disorder. The children with developmental disabilities were required to have a total Childhood Autism Rating Scale score of 20 or less to avoid including children with some autistic features. Thus, children with total Childhood Autism Rating Scale scores of 21 to 29 were not eligible for either study group.

Procedures

The structured interview was conducted in either English or Spanish. A developmental history was obtained from the parent and from review of the medical record. Descriptive data such as demographics, other

developmental diagnoses, time since diagnosis, use of medication, and other possible confounders, such as level of maternal education, were collected from interviews of the parent and child. Level of functioning was determined from a review of the available medical and educational records. Ethnicity was determined based on maternal self-report.

The structured interview included one questionnaire to assess parental stress, the Parenting Stress Index–Short Form,¹⁸ and three questionnaires to examine child comorbid symptoms, the Gastrointestinal Questionnaire,¹⁹ the Children's Sleep Habits Questionnaire,²⁰ and the Aberrant Behavior Checklist.²¹

Measure of parent stress. The Parenting Stress Index–Short Form¹⁸ was used to measure parental stress associated with child and parent-child relationship. It includes 36 items generally rated on a 5-point scale of agreement and yields a Total Stress score and three subscale scores: Parental Distress, Parent-Child Dysfunctional Interaction, and Difficult Child. This scale has been used extensively in families of children with developmental disabilities,^{22,23} including families of children with autism spectrum disorder¹³ and Spanish-speaking families.²⁴ Parental stress was analyzed as total parent stress score and relative to a prespecified clinical threshold, defined as percentile scores above the 90th percentile in the total score.²⁵

Measures of comorbid symptoms. The Gastrointestinal Questionnaire is a structured interview based on a Clinical Diagnostic Questionnaire for Pediatric Functional Gastrointestinal Disorders.²⁶ This short version allows for the identification of lifetime and ongoing gastrointestinal and feeding problems, including prior diagnosis of food allergy, food and types of selectivity, vomiting, abdominal pain, characteristics of the bowel movements, and constipation. This questionnaire has been used in previous research studies with similar population and autism spectrum disorder.¹⁹

Sleep disturbances were examined using the abbreviated version of the parent-report Children's Sleep Habits Questionnaire,²⁰ which includes 33 items rated on a 3-point scale. Sleeping difficulties were defined as a total overall score >41 . This tool has been used as a screening for sleeping abnormalities in preschool and school-age children, and it has been used in previous research work in children with autism spectrum disorder.²⁷

The Aberrant Behavior Checklist²¹ is a 58-item symptom checklist for assessing problem behaviors of children and adults with low cognitive functioning and yields subscales of (1) Irritability, Agitation; (2) Lethargy, Social Withdrawal; (3) Stereotypic Behavior; (4) Hyperactivity, Noncompliance; and (5) Inappropriate Speech. This instrument has been widely used in the developmental disabilities literature.

Analysis

The primary analysis compared the children in the autism spectrum disorder group and the group with other developmental disabilities using paired analysis, since the groups were matched. Categorical data were analyzed using the McNemar test, and continuous variables were analyzed with paired *t* tests. Analysis within each group included chi-square and independent samples *t* test or nonparametrics. Univariate and multivariate logistic regression analyses were used to assess the relation of parental stress to the developmental diagnosis and child comorbid symptoms with adjustment for demographics. The results were expressed in odds ratio with a confidence interval of 95%. Statistical significance was defined as *P* values of less than .05, with 2-tailed tests used throughout. All analyses were performed using SPSS software (SPSS, Inc, Chicago, IL).

Table 1. Demographics, Clinical Characteristics and Parental Stress for Children by 2 Groups of Development.

Demographic/clinical characteristics	ASD N=50	DD N=50	p ^a
Child's characteristics			
Mean current age (year \pm SD)	8.8 \pm 3	9.2 \pm 3	.5 ^b
Mean age at diagnosis (year \pm SD)	3.8 \pm 2	1.6 \pm 2	<.001 ^b
Time since diagnosis (year \pm SD)	4 \pm 3	7.4 \pm 4	<.001 ^b
Gender male/female	47/3	47/3	1
Other developmental problems in the child n (%)	27 (54)	32 (64)	.4
Attention deficit/hyperactivity disorder	10 (20)	3 (6)	.09
Food allergies, n (%)	7 (14)	7 (14)	1
Gastrointestinal problems, ^c n (%)	33 (66)	20 (40)	.04
Food selectivity, n (%)	37 (74)	31 (62)	.2
Sleeping problems, ^d n (%)	39 (78)	17 (34)	<.001
Seizure disorder, n (%)	2 (4)	10 (20)	.09
Behavioral problems, ^e n (%)	41 (82)	12 (24)	<.001
Irritability score (ABC)	61 \pm 7	54 \pm 7	<.001
No. children on medication, n (%)	26 (52)	27 (54)	1
Medication for behavior, n (%) ^f	18 (36)	6 (12)	.01
Antiepileptical medication, n (%)	2 (4)	10 (20)	.09
More than one medication, n (%)	8 (16)	2 (4)	.1
Maternal characteristics			
Race/ethnic groups, n (%)			1 ^g
White	11 (22)	1 (2)	
Hispanic	21 (42)	30 (60)	
African American	12 (24)	19 (38)	
Other	6 (12)	0	
Mother born in the US, n (%)	32 (64)	18 (36)	.009
Bilingual household (Spanish-English), n (%)	16 (32)	23 (46)	.1
Current maternal age (year \pm SD)	38 \pm 7	38 \pm 9	.8 ^b
Maternal age at birth (year \pm SD)	29 \pm 8	29 \pm 6	.9 ^b
Maternal education, n (%)			.002 ^c
<High school	8 (16)	17 (34)	
High school	11 (22)	18 (36)	
Some college	18 (36)	8 (16)	
College 4+ y	13 (26)	5 (10)	
Other child in the family with DD, n (%)	15 (30)	11 (22)	.4
Parental stress			
	ASD (N=49)	DD (N=50)	
Parental Stress, ^h n (%)	22 (45)	11 (22)	0.05
Total Stress Index (mean \pm SD)	89 \pm 24	72 \pm 29	0.003 ^b
Parental distress	31 \pm 10	24 \pm 10	0.02 ^b
Parent-child dysfunctional interaction	26 \pm 8	22 \pm 7	0.01 ^b
Difficult child	31 \pm 9	26 \pm 10	0.006 ^b

ASD: Autism Spectrum Disorder; DD: children with other developmental disability, including global developmental delay/intellectual deficiency and cerebral palsy
 ABC: Aberrant Behavior Checklist.

^aMcNemar test.

^bPaired t test.

^cGastrointestinal problems, one or more symptoms, including frequent abdominal pain, frequent vomiting, chronic constipation and abnormal stool pattern.

Wilcoxon rank sum test.

^dSleeping problems defined as Total Overall Score Children Sleep Habits Questionnaire²⁰ >41.

^eBehavioral problems were defined as 2 or more item >85th percentile in the Aberrant Behavior Checklist.²¹

^fIncludes stimulant medication and antipsychotic medication.

^gWilcoxon rank sum test.

^hParental Stress was defined as scores above the 90th percentile in the Parenting Stress Index-Total.¹⁸

Results

Population Characteristics

The demographic characteristics and relevant symptoms of the children in both groups are summarized in Table 1. As expected in a sample of children with autism spectrum

disorder, the majority were boys. The primary diagnoses for children in the group with developmental disabilities were cerebral palsy (n = 28, 56%) and intellectual disability/global developmental delays (n = 22, 44%). Of the 50 children with autism spectrum disorder, 25 presented with low cognitive functioning. The racial/ethnic distribution is similar to the

Table 2. Demographics by 2 Groups of Development and Parental Stress.

	ASD			DD			Total		
	Stress ^b (n = 22)	No stress (n = 27)	P ^a	Stress ^b (n = 11)	No stress (n = 39)	P ^a	Stress ^b (n = 33)	No stress (n = 66)	P ^a
Current age (y), M ± SD	9.7 ± 4	8.6 ± 3	.6 ^c	9.7 ± 3	9.1 ± 4	.5 ^c	9.2 ± 3	8.9 ± 3	.5 ^c
Age at diagnosis (y), M ± SD	3.5 ± 3	4.1 ± 2	.4 ^c	2.5 ± 2	1.3 ± 1	.1 ^c	3.1 ± 3	2.4 ± 2	.3 ^c
Time since diagnosis (y), M ± SD	5 ± 3	4.4 ± 3	.4 ^c	7 ± 4	7.8 ± 4	.6 ^c	5.7 ± 4	6.4 ± 4	.3 ^c
Mother born in the US, n (%)	15 (68)	16 (59)	.5	4 (36)	14 (36)	1	19 (57)	30 (45)	.2
Maternal age (y), M ± SD	39 ± 7	37 ± 7	.5 ^c	39 ± 12	38 ± 9	.8 ^c	39 ± 8	38 ± 8	.4 ^c
Latino mother, n (%)	6 (27)	15 (56)	.04	7 (63)	23 (59)	.7	13 (39)	38 (57)	.08
Maternal education ^d	14 (63)	17 (63)	1	2 (18)	11 (30)	.7	16 (48)	28 (44)	.6
Bilingual household	6 (27)	10 (37)	.5	6 (54)	17 (44)	.7	12 (36)	27 (41)	.8
Other child in the family with DD, n (%)	6 (27)	9 (33)	.7	3 (27)	8 (20)	.6	9 (27)	17 (26)	1

Abbreviations: ADHD, attention-deficit hyperactivity disorder; ASD, autism spectrum disorder; DD, children with other developmental disability, including global developmental delay/intellectual deficiency and cerebral palsy; M, mean; SD, standard deviation.

^aChi-square test.

^bParental Stress was defined as scores above the 90th percentile in the Parenting Stress Index–Total.¹⁸

^cNonparametric Mann-Whitney test.

^dSome College or above versus rest.

distribution described previously in the Bronx²⁸ where this study was done. Although the children were matched for age and gender, there were some differences in other demographic characteristics of the groups. In particular, for the group with autism spectrum disorder, the level of maternal education was higher and more mothers were born in the United States compared to the group with developmental disabilities. In addition, as reported previously,¹⁶ families of children with autism spectrum disorder reported more comorbid symptoms than families of children with other developmental disabilities (Table 1), including more behavioral problems (82% vs 24%, $P < .001$). Also, children with autism spectrum disorder were more likely to be taking medication to address behavioral difficulties (36% vs 12%, $P = .01$) than children with other developmental disabilities.

Parental stress in families of children with autism spectrum disorder and with other developmental disabilities.

The Parenting Stress Index–Short Form was completed by 49 families of children with autism spectrum disorder and 50 families of children with other developmental disabilities. Almost half of the families of children with autism spectrum disorder (45%) reported significant levels of parental stress, defined as scores above the 90th percentile in the Parenting Stress Index–Total Scale, compared to less than a quarter (22%) of the families of children with other developmental disabilities (see Table 1). Families of children with autism spectrum disorder had significantly higher Total scale scores as well as significantly higher subscale scores (see Table 1).

Parental Stress Related to Demographics

Across groups, there were differences in the level of parental stress by maternal ethnicity and maternal country of birth (United States vs other), as measured by the Parenting Stress Index–Total Scale. Latino mothers reported lower total stress scores

(Parenting Stress Index–Total Score 75 ± 23 vs 86 ± 25 , $P = .02$). Similarly, mothers born outside of the United States reported lower total stress scores (Parenting Stress Index–Total Score 86 ± 24 vs 75 ± 24 , $P = .02$). There were no differences by age of the child or age at diagnosis/time since diagnosis, bilingual household, maternal age, or level of maternal education across or within groups or whether there was another child with developmental disabilities (see Table 2). Examination of within-group differences showed that Latino mothers of children with autism spectrum disorder were less likely to report significant stress (28% vs 58%, $P = .04$) (see Table 2).

Parental stress related to child characteristics

Gastrointestinal problems. Across groups, parental stress was not associated with gastrointestinal problems (38% vs 27%, $P = .2$) or overall food selectivity (34% vs 31%, $P = .7$) or food allergies (50% vs 30%, $P = .2$) (see Table 3). However, within the group with autism spectrum disorder, parental stress was related to gastrointestinal problems and food allergies (Table 3). Parents who reported higher levels of stress were more likely to report 1 or more gastrointestinal symptoms, including frequent abdominal pain, frequent vomiting, chronic constipation, and abnormal stool pattern (78% vs 48%, $P = .03$) (Table 3). No association was reported with overall food selectivity in this group. Within the group of children with other developmental disabilities, there was no association with gastrointestinal symptoms or food selectivity or food allergies (Table 3).

Sleeping problems. Across groups, parental stress was more common in children with sleeping problems (44% vs 20%, $P = .02$) (Table 3). In the group with autism spectrum disorder, there was no association between parental stress and sleeping difficulties (77% vs 78%, $P = .1$) whereas parents of children with other developmental disabilities who reported higher levels of stress were more likely to report sleeping problems in the child (66% vs 20%, $P = .004$).

Table 3. Child Comorbid Symptoms and Behavioral Difficulties by 2 Groups of Development and Parental Stress.

	ASD			DD			Total		
	Stress ^b (n = 22)	No stress (n = 27)	P ^a	Stress ^b (n = 11)	No stress (n = 39)	P ^a	Stress ^b (n = 33)	No stress (n = 66)	P ^a
Child's comorbid symptoms, n (%)									
Any GI symptom ^c	17 (78)	13 (48)	.03	3 (28)	17 (45)	.3	20 (60)	20 (33)	.2
Food selectivity	16 (72)	20 (74)	.1	10 (66)	21 (60)	.8	26 (79)	41 (62)	.7
Food allergies	6 (27)	1 (4)	.03	2 (13)	5 (14)	1	8 (24)	6 (9)	.2
Sleeping problems ^d	17 (77)	21 (78)	.1	10 (66)	7 (20)	.004	27 (81)	28 (42)	<.001
Behavioral problems, ^e n (%)	21 (95)	19 (70)	.03	7 (64)	5 (13)	.002	28 (84)	24 (36)	<.001
Irritability ^f	17 (77)	9 (35)	.004	6 (55)	4 (10)	.004	23 (70)	13 (20)	<.001
Lethargy ^f	13 (59)	6 (23)	.01	3 (27)	2 (5)	.06	16 (48)	8 (12)	<.001
Stereotyped behaviors ^f	18 (82)	15 (58)	.1	3 (27)	2 (5)	.06	21 (63)	17 (26)	<.001
Hyperactivity ^f	14 (64)	11 (42)	.1	5 (45)	5 (13)	.03	19 (57)	16 (24)	.003
Inappropriate speech ^f	14 (64)	20 (77)	.3	7 (64)	5 (13)	.002	21 (63)	25 (38)	.04
Medication for behavioral problems, n (%)	7 (32)	11 (4)	.5	2 (18)	4 (10)	.6	9 (27)	15 (23)	.6
More than 1 medication, n (%)	3 (14)	5 (18)	.7	0	2 (5)	1	3 (9)	7 (11)	1
ADHD, n (%)	3 (14)	7 (26)	.4	0	3 (100)	1	3 (9)	10 (15)	.5
Seizure disorder, n (%)	1 (4)	1 (4)	1	1 (9)	9 (23)	.4	2 (6)	10 (15)	.3

Abbreviations: ADHD, attention-deficit hyperactivity disorder; ASD, autism spectrum disorder; DD, children with other developmental disability, including global developmental delay/intellectual deficiency and cerebral palsy; GI, gastrointestinal.

^aChi-square test.

^bParental stress was defined as scores above the 90th percentile in the Parenting Stress Index-Total.¹⁸

^cGastrointestinal problems, 1 or more symptoms, including frequent abdominal pain, frequent vomiting, chronic constipation and abnormal stool pattern.

^dSleeping problems were defined as a total overall score >41 in the Children Sleep Habits Questionnaire.²⁰

^eBehavioral problems were defined as 2 or more items >85th percentile in the Aberrant Behavior Checklist.²¹

^fScores >85th percentile in the Aberrant Behavior Checklist.²¹

Behavioral problems. Across and within groups, parents who reported higher levels of stress reported more behavioral difficulties defined as 2 or more items >85th percentile in the Aberrant Behavior Checklist²¹ (see Table 3). Overall, parents who reported more stress also reported that the child was irritable (70% vs 20%, $P < .001$) and were more likely to present other behavioral problems, including hyperactivity (57% vs 24%, $P = .003$), stereotyped behaviors (64% vs 26%, $P < .001$), lethargy (48% vs 12%, $P < .001$), and inappropriate speech (64% vs 41%, $P = .04$). In the group of children with autism spectrum disorder, parental stress was associated with irritability and lethargy (see Table 3), whereas in the group of children with other developmental disabilities, parental stress was related to irritability, hyperactivity, and inappropriate speech (see Table 3). There was no association in either group between parental stress and another developmental diagnosis such as attention-deficit hyperactivity disorder (ADHD), seizure disorders, or whether the child was taking medications to address behavioral issues.

Irritability and other comorbidities. Of the behavioral problems measured by the Aberrant Behavior Checklist, only irritability was associated with significant differences in parental stress across study groups and within each study group. This result was explored by analysis of the association between irritability and other comorbid symptoms (see Table 4). Overall, children with sleeping problems were more irritable (78% vs 43%, $P < .001$). In the group of children with autism spectrum disorder, those with gastrointestinal problems were more irritable,

whereas in the group of children with other developmental disabilities, those with sleeping problems were more irritable.

Multivariate Analysis

Multivariate logistic regression analysis was performed (Table 5) to assess the association of parental stress with developmental diagnosis (autism spectrum disorder vs other developmental disabilities), irritability (as the only behavioral factor associated with significant differences in parental stress for both groups), and sleeping and gastrointestinal problems, adjusting for potential confounders (selected on the basis of significant differences between the groups), including ethnic group, level of maternal education, and time since diagnosis. Because the number of Caucasians was low, we compared Latino families versus others. In the univariate analysis done in the 99 children, parental stress was associated with autism spectrum disorder. However, the association did not persist when child comorbid symptoms, including irritability, were analyzed simultaneously. The results of the univariate and multivariate analyses indicate that, when combining both groups, parental stress is associated with irritability and sleeping problems.

Discussion

The results of this study indicate that in an ethnically diverse population, at least 45% of families of children with autism spectrum disorder report significant parental stress compared

Table 4. Child Comorbid Symptoms by 2 groups of Development and Irritability.^a

Child Comorbid Symptoms	ASD			DD			Total		
	Irritable ^c (n = 26)	Not irritable (n = 23)	<i>P</i> ^b	Irritable (n = 10)	Not irritable (n = 40)	<i>P</i> ^b	Irritable (n = 33)	Not irritable (n = 63)	<i>P</i> ^b
Any GI symptom ^d	23 (88)	10 (43)	.04	4 (40)	16 (40)	.1	27 (75)	26 (42)	.1
Food selectivity	21 (80)	16 (70)	.5	7 (70)	24 (60)	.7	28 (78)	40 (63)	.1
Food allergies	3 (11)	4 (17)	.6	1 (10)	6 (15)	.1	4 (11)	10 (15)	.5
Sleeping problems ^e	21 (80)	17 (74)	.7	7 (70)	10 (25)	.02	28 (78)	27 (43)	<.001
Seizure disorder	1 (4)	2 (9)	.5	0	10 (25)	.1	1 (3)	12 (19)	.2

Abbreviations: ADHD, attention-deficit hyperactivity disorder; ASD, autism spectrum disorder; DD, children with other developmental disability, including global developmental delay/intellectual deficiency and cerebral palsy; GI, gastrointestinal.

^aValues are n (%).

^bChi-square test.

^cScores >85th percentile in the Aberrant Behavior Checklist.²¹

^dGastrointestinal problems, 1 or more symptoms, including frequent abdominal pain, frequent vomiting, chronic constipation, and abnormal stool pattern.

^eSleeping problems were defined as a total overall score >41 in the Children Sleep Habits Questionnaire.²⁰

Table 5. Factors Associated with Parental Stress (Logistic Regression Model).

Dependent Variable: Parental Stress ^a					
Independent variable	Unadjusted OR	95% CI	Adjusted OR ^b	95% CI	<i>P</i>
Autism spectrum disorder	2.8	1.2-6.9	1.07	0.2-4.2	.9
Age of the child	1.02	0.9-1.1	1.2	0.9-1.5	.1
Time since diagnosis	0.9	0.8-1.06	0.8	0.6-1.07	.1
Maternal education	1.1	0.7-1.5	0.6	0.3-1.2	.2
Latino mother vs rest	0.4	0.2-1.1	0.2	0.04-0.8	.03
Mother US born	1.6	1.7-3.7	0.6	0.1-2.3	.5
Irritability score ^c	1.1	1.06-1.2	1.1	1.02-1.1	.01
Sleeping problems ^d	3.01	1.2-7.4	3.4	0.8-12.9	.07
Gastrointestinal problems ^e	2.7	0.8-9	3.1	0.7-12.9	.1

Abbreviations: CI, confidence interval; OR, odds ratio.

^aParental Stress was defined as scores above the 90th percentile in the Parenting Stress Index–Total.¹⁸

^bLogistic Regression Model–Omnibus Test of Model Coefficients: $\chi^2 = 26.9$; degree of freedom = 9; *P* = .001.

^cIrritability score from the Aberrant Behavior Checklist.²¹

^dSleeping problems were defined as a total overall score >41 in the Children Sleep Habits Questionnaire.²⁰

^eGastrointestinal problems, 1 or more symptoms, including frequent abdominal pain, frequent vomiting, chronic constipation, and abnormal stool pattern.

to 22% of families of children with other developmental disabilities. Across groups, parental stress was related to child comorbid symptoms, including sleep and behavioral difficulties. Of problematic behaviors identified by the Aberrant Behavior Checklist, irritability specifically was associated with significant differences in reported stress for both groups.

The level of parent stress observed for the group of families of children with autism spectrum disorder are similar to the rates described in a number of other studies of parental stress in autism⁶ and lower than that reported in one study based on a predominantly Caucasian and higher socioeconomic status population.¹³ The rates observed for the group of children with other developmental disabilities are similar to the rates described in other studies of parental stress in children with cerebral palsy.²²

As previously reported, prior studies have identified child maladaptive behaviors as potential stressors^{8,9,13} and reported that the effect of a child's behavioral difficulties was independent of the developmental diagnosis. In this study, among the

maladaptive behaviors identified by the Aberrant Behavior Checklist, irritability specifically was found to be a major factor for parental stress, beyond developmental diagnosis, other comorbid symptoms, and demographics. This finding is key, as it suggests that treatment addressing irritability specifically in these children may have a particular impact on the level of parental stress. Providers of children with autism spectrum disorder or other developmental disabilities with behavioral difficulties, and irritability specifically, should be aware that these families may be experiencing clinical parental stress, which needs to be addressed.

Families of children with a diagnosis of autism spectrum disorder and with other comorbid symptoms, such as gastrointestinal symptoms, were more likely to report higher levels of stress. There have been reports of higher levels of parental stress in children with typical development with gastrointestinal problems, related to behavioral feeding problems.²⁹ That our results do not indicate this association in the group of children with other developmental disabilities may be related to the

lower number of patients with gastrointestinal problems in our sample. Gastrointestinal problems did not contribute uniquely to parental stress in the multivariate analysis, and the results suggest that its effects are related to the confounder effect of irritability. Child's diagnosis of autism spectrum disorder is associated with increased risk of parental stress, as well as with increased behavioral difficulties and gastrointestinal problems,³⁰ in children with autism spectrum disorder and gastrointestinal problems³⁰ and it is possible that the effect of gastrointestinal symptoms in parental stress is actually due to an associated behavioral dysfunction.

Parental stress was also associated with food allergies in the group of families of children with autism spectrum disorder. This finding has also been reported in the literature in children with typical development.³¹ Interestingly, we did not see differences in parental stress associated with overall food selectivity in either group. This lack of association may reflect a ceiling effect since food selectivity was very common in both groups, reported in 74% of the children with autism spectrum disorder and 62% of children with other developmental disabilities.

As reported previously in the literature, sleeping difficulties affected parental stress overall but, surprisingly, in the group with autism spectrum disorder, parents who reported more sleep problems did not report higher levels of stress. The lack of association with sleeping difficulties is probably related to a ceiling effect since sleeping problems are very prevalent in the group of children with autism spectrum disorder, reported by 78% of the current sample (with 78% in high stress group and 77% in less stress group), and a larger sample may be needed to look at this association. Sleeping difficulties did have an effect on families of children with other developmental disabilities, and results are similar to previous reports.^{11,12} The results of the multivariate analysis suggested that sleeping problems are related to parental stress when child diagnosis and other comorbid symptoms are controlled for.

Other factors previously associated with parental stress in autism were age of the child,¹³ with parents reporting higher levels of stress when their child was older. In this study, there was no association with age or time since the child was diagnosed or other characteristics of the family, such as the presence of other children in the family with developmental problems.

Although children in the two groups were matched by age and gender and were drawn from the same patient population, there were differences in their demographic characteristics. In the current study, non-Hispanic families and parents born in the United States reported higher stress. Reasons for the lower perceived stress and implied higher resilience for immigrant families and Hispanic families need to be investigated. Research on Latino families who have a child with a developmental disability, and autism in particular, is limited. In previous studies, Latino mothers of children with developmental disabilities presented lower levels of psychological distress and higher levels of psychological well-being and were more likely to report more satisfaction with coresidence with their child with autism.³² These differences, reported in

the literature and observed in the current study, may be related to cultural factors, which are not explored in this paper but which need further study. In contrast to previous studies,¹³ parental stress was not related to the level of maternal education. A larger sample with heterogeneous socioeconomic status and maternal education is needed.

There are a number of difficulties in assessing parental stress. All the data in this study relating to stress and comorbid symptoms are based on maternal report. We were examining self-perceived or experienced stress, and thus the use of self-report questionnaires was appropriate, but biomarkers of stress and confirmation of medical or psychiatric conditions may be helpful in future studies.³³ Another limitation is the relatively small size of our samples. However, the results do indicate the association of parental stress with behavioral problems, and child irritability specifically, in families of children with developmental disabilities, including autism spectrum disorder, in an ethnically diverse/minority population. Providing more targeted support on these behavioral issues, specifically irritability and sleep, may help reduce parental stress in families of children with developmental disabilities, including autism. Addressing parental stress should be an integral part of comprehensive care for the families of all children, especially those with any developmental disability, and it should be addressed by all members of the medical team, from primary care to specialist.

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Author Contributions

All the authors contributed to the conception, design, interpretation of data and critical review, revisions, and approval of the final manuscript. MVM conducted the analysis and prepared the initial draft.

Declaration of Conflicting Interests

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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Ethical Approval

The study was approved by the Committee of Clinical Investigation of Albert Einstein College of Medicine (IRB: 2007-371).

References

1. *Diagnostic and Statistical Manual of Mental Disorders*. 4th ed, text rev. Washington, DC: American Psychiatric Association; 2000.
2. Rapin I. Autism. *N Engl J Med*. 1997;337:97-104.
3. Baker-Ericzén MJ, Brookman-Frazee L, Stahmer A. Stress levels and adaptability in parents of toddlers with and without autism spectrum disorders. *Res Pract Persons Severe Disabil*. 2005;30:194-204.
4. Bouma R, Schweitzer R. The impact of chronic childhood illness on family stress: a comparison between autism and cystic fibrosis. *J Clin Psychol*. 1990;46:722-730.
5. Estes A, Munson J, Dawson G, et al. Parenting stress and psychological functioning among mothers of preschool children with autism and developmental delay. *Autism*. 2009;13:375-387.
6. Davis NO, Carter AS. Parenting stress in mothers and fathers of toddlers with autism spectrum disorders: associations with child characteristics. *J Autism Dev Disord*. 2008;38:1278-1291.
7. Hastings RP, Johnson E. Stress in UK families conducting intensive home-based behavioral intervention for their young child with autism. *J Autism Dev Disord*. 2001;31:327-336.
8. Hastings RP. Child behaviour problems and partner mental health as correlates of stress in mothers and fathers of children with autism. *J Intellect Disabil Res*. 2003;47:231-237.
9. Hodapp RM, Dykens EM, Masino LL. Families of children with Prader-Willi syndrome: stress-support and relations to child characteristics. *J Autism Dev Disord*. 1997;27:11-24.
10. Tervo RC. Developmental and behavior problems predict parenting stress in young children with global delay. *J Child Neurol*. 2012;27:291-296.
11. Honomichl RD, Goodlin-Jones BL, Burnham M, et al. Sleep patterns of children with pervasive developmental disorders. *J Autism Dev Disord*. 2002;32:553-561.
12. Quine L. Sleep problems in children with mental handicap. *J Ment Defic Res*. 1991;35:269-290.
13. Rivard M, Terroux A, Parent-Boursier C, Mercier C. Determinants of stress in parents of children with autism spectrum disorders. *J Autism Dev Disord*. 2014;44:1609-1620.
14. Cardoso JB, Padilla YC, Sampson M. Racial and ethnic variation in the predictors of maternal parenting stress. *J Soc Serv Res*. 2010;36:429-444.
15. Jarquin VG, Wiggins LD, Schieve LA, Van Naarden-Braun K. Racial disparities in community identification of autism spectrum disorders over time; Metropolitan Atlanta, Georgia, 2000-2006. *J Dev Behav Pediatr*. 2011;32:179-187.
16. Valicenti-McDermott M, Burrows B, Bernstein L, et al. Use of complementary and alternative medicine in children with autism and other developmental disabilities: associations with ethnicity, child comorbid symptoms, and parental stress. *J Child Neurol*. 2014;29:360-367.
17. Schopler E, Reichler RJ, Renner BR. *The Childhood Autism Rating Scale (CARS)*. Los Angeles: Western Psychological Services; 1988.
18. Abidin RR. *Parenting Stress Index*. 3rd ed. Odessa: Psychological Assessment Resource; 1995.
19. Valicenti-McDermott M, McVicar K, Rapin I, et al. Frequency of gastrointestinal symptoms in children with autistic spectrum disorders and association with family history of autoimmune disease. *J Dev Behav Pediatr*. 2006;27(2 suppl):S128-S136.
20. Owens JA, Spirito A, McGuinn M. The Children's Sleep Habits Questionnaire (CSHQ): psychometric properties of a survey instrument for school-aged children. *Sleep*. 2000;23:1043-1051.
21. Aman MG, Singh NN, Stewart AW, Field CJ. The aberrant behavior checklist: a behavior rating scale for the assessment of treatment effects. *Am J Ment Defic*. 1985;89:485-491.
22. Parkes J, Caravale B, Marcelli M, et al. Parenting stress and children with cerebral palsy: a European cross-sectional survey. *Dev Med Child Neurol*. 2011;53:815-821.
23. Webster RI, Majnemer A, Platt RW, Shevell MI. Child health and parental stress in school-age children with a preschool diagnosis of developmental delay. *J Child Neurol*. 2008;23:32-38.
24. Solis ML, Abidin RR. The Spanish version Parenting Stress Index. *J Clin Child Psychol*. 1991;20:372-378.
25. Abidin R. Parenting Stress Index: a measure of the parent-child system. In: Zalaquett C, Wood R, eds. *Evaluating Stress: A Book of Resources*. Lanham, MD: Scarecrow Press, Inc; 1997: 277-291.
26. Rasquin-Weber A, Hyman PE, Cucchiara S, et al. Childhood functional gastrointestinal disorders. *Gut*. 1999;45(suppl II):II60YII68.
27. Malow BA, Marzec ML, McGrew SG, et al. Characterizing sleep in children with autism spectrum disorders: a multidimensional approach. *Sleep*. 2006;29:1563-1571.
28. Valicenti-McDermott M, Hottinger K, Seijo R, Shulman L. Age at diagnosis of autism spectrum disorders. *J Pediatr*. 2012;161(3): 554-556.
29. Wu YP, Franciosi JP, Rothenberg ME, Hommel KA. Behavioral feeding problems and parenting stress in eosinophilic gastrointestinal disorders in children. *Pediatr Allergy Immunol*. 2012;23: 730-735.
30. Mazefsky CA, Schreiber DR, Olin TM, Minshew NJ. The association between emotional and behavioral problems and gastrointestinal symptoms among children with high-functioning autism. *Autism*. 2013;18:493-501.
31. King RM, Knibb RC, Hourihane JO. Impact of peanut allergy on quality of life, stress and anxiety in the family. *Allergy*. 2009;64: 461-468.
32. Magaña S, Smith MJ. Psychological distress and well-being of Latina and non-Latina White mothers of youth and adults with an autism spectrum disorder: cultural attitudes towards coresidence status. *Am J Orthopsychiatry*. 2006;76:346-357.
33. Foody C, James JE, Leader G. Parenting stress, salivary biomarkers, and ambulatory blood pressure: a comparison between mothers and fathers of children with autism spectrum disorders. *J Autism Dev Disord*. 2015;45:1084-1095.