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Race influences parent report of concerns about symptoms of autism spectrum disorder

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Abstract

Racial differences in parent report of concerns about their child's development to healthcare providers may contribute to delayed autism spectrum disorder diagnoses in Black children. We tested the hypotheses that compared to White parents, Black parents of children with autism spectrum disorder would report fewer concerns about autism symptoms and would be more likely to report concerns about disruptive behaviors. A sample of 18- to 40-month-old toddlers (*N* = 174) with autism spectrum disorder and their parent participated. After screening positive for autism spectrum disorder risk, but prior to a diagnostic evaluation, parents completed free-response questions soliciting concerns about their child's development. Parent responses were coded for the presence or the absence of 10 possible concerns, which were grouped into autism concerns (e.g. social and restricted and repetitive behavior concerns) or non-autism concerns (e.g. general developmental and disruptive behavior concerns). Compared to White parents, Black parents reported significantly fewer autism concerns and fewer social and restricted and repetitive behavior concerns. However, Black parents did not report significantly fewer non-autism concerns. Race did not influence parent report of disruptive behavior concerns. Lower reporting of autism concerns by Black parents may impact providers' abilities to identify children who need further screening or evaluation.

Keywords

autism, autism spectrum disorder, child development, diagnostic disparities, parent concerns, race and ethnicity

Introduction

Although the majority of parents of children with autism spectrum disorder (ASD) report concerns about their child's development during the first 2 years of the child's life (Herlihy et al., 2013; Richards et al., 2016; Zuckerman et al., 2015), the median age of diagnosis is after the child's fourth birthday (CDC, 2016). Early detection of ASD facilitates early intervention, which is associated with better outcomes (Anderson et al., 2014; Linstead et al., 2016; MacDonald et al., 2014; Orinstein et al., 2014; Smith et al., 2015; Vivanti et al., 2016). Despite progress in using standardized screening to identify children at risk for ASD (Pierce et al., 2011; Robins et al., 2014), Black children are diagnosed with ASD at older ages than White children and children of other races (Mandell et al., 2007, 2002, 2009; Valicenti-McDermottet al., 2012). To date, little research has been devoted to elucidating potential reasons for such diagnostic disparity. The purpose of this study is to offer insight into delayed ASD diagnosis for Black children by examining whether concerns that parents communicated to healthcare providers about their child's development prior to diagnosis differed as a function of race.

Diagnostic disparity in Black children with ASD

In light of the implications of delayed or missed diagnosis, it is crucial to address ASD diagnostic disparity in Black children. Although the ASD phenotype is not thought to

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differ by race, studies have found that Black children had a lower incidence of documented ASD diagnoses than White children (Kogan et al., 2009; Mandell et al., 2009; Valicenti-McDermottet et al., 2012). Compared to White peers, Black children were diagnosed with ASD 1.4 years later (Mandell et al., 2002), required threefold more specialty care visits and spent 8 months longer in mental health treatment prior to receiving a diagnosis (Mandell et al., 2007). One study found significantly fewer documented mild-to-moderate ASD diagnoses among Black than White children 5 years and older, suggesting potential under-identification of older Black children with mild-to-moderate ASD (Jo et al., 2015). Many possible causes of such diagnostic disparity have been proposed, including unequal access to healthcare (Liptak et al., 2008; Montes and Halterman, 2011), clinician prejudice (Institute of Medicine, 2002; Mandell et al., 2002), and parent interpretation and report of symptoms to healthcare providers (Barton et al., 2012b; Mandell et al., 2007).

Mandell et al. (2007) found that Black children were nearly twice as likely as children of other races to be misdiagnosed with conduct disorders and oppositional defiant disorders prior to an ASD diagnosis. They posited that Black parents may relate concerns about their child's development to healthcare providers in ways that deemphasize ASD symptoms and emphasize disruptive behaviors, which may sway clinicians from considering ASD and other diagnoses. An important next step is to directly test the hypotheses that prior to receiving an ASD diagnosis, Black parents report fewer ASD symptom–specific concerns about their child than White parents and that Black parents are more likely to report concerns about disruptive behaviors.

Parent concerns about child development

Parent report of concerns about their child's behaviors and development to healthcare providers often initiates referrals for evaluation of ASD and other developmental delays. Although the American Academy of Pediatrics (AAP) recommends ASD-specific screening during well-child visits at 18 and 24 months (Johnson and Myers, 2007), ASD screening is not widely utilized (Sices, 2007) to initiate further evaluation of a child. Indeed, recent estimates of compliance rates for ASD-specific screenings were only 42.9% (Zuckerman et al., 2013) and 55% (Daniels and Mandell, 2013). Thus, caregivers' reports of concerns to providers, including communicating about delayed or otherwise non-typical behaviors, is critical as these voiced concerns likely trigger referrals.

Studies have found that parent concerns accurately reflect delays and predict diagnoses. For instance, greater parent concerns about their child's development have been found to be related to lower scores on cognitive and language measures (McMahon et al., 2007) and higher scores on ASD severity measures (Richards et al., 2016) in toddlers at risk for ASD. In this same study, Richards et al. (2016) found that although parents of children with and without an ASD diagnosis did not differ in the mean number of concerns about their child's development prior to their child being evaluated, parents of children diagnosed with ASD were more likely to report concerns specific to ASD criteria than parents of children without ASD, demonstrating specificity in parent concerns. By the time a child is 12 months old, parent concerns about ASD symptoms are predictive of later ASD diagnosis (Ozonoff et al., 2009). Given the demonstrated utility of parent concerns, it is important to examine how parents' characteristics may influence the extent and/or content of their reported concerns. For example, parents of lower socioeconomic status (SES) reported fewer concerns about their child's development than parents of higher SES (Sun et al., 2014), and parents of boys reported concerns about their child's development later than parents of girls (Horovitz et al., 2012).

Racial and ethnic differences in parent concerns

Parent race/ethnicity is one understudied factor that may influence the extent or content of parent report of concerns about their child's development. The only known study examining differences in concerns among Black and White parents of toddlers with ASD (Jang et al., 2014) found no effect of race on the age at which parents reported that they first became concerned about their child's development. Yet, race and ethnicity may be more relevant to the extent and content of parent concerns. For example, parents of preschool children in Singapore reported significant concerns about their child's development at much higher rates than American and Australian parents (Kiing et al., 2012), suggesting potentially different thresholds for perceiving and reporting concerns among different cultures. Similarly, Hispanic mothers reported significantly fewer concerns specific to ASD criteria than non-Hispanic mothers, despite the fact that ultimately, Hispanic children diagnosed with ASD demonstrated greater ASD severity than the non-Hispanic children diagnosed with ASD (Blacher et al., 2014). Moreover, when faced with similar symptom presentations in children with ASD, parents from distinct cultural backgrounds may emphasize different symptoms depending on the cultural importance of a particular delayed skill (Mandell and Novak, 2005). For example, in studies of parents of children with ASD, American and Japanese parents reported that they were first concerned about delayed speech (De Giacomo and Fombonne, 1998; Ohta et al., 1987), whereas urban Indian parents reported that they were primarily concerned about their child's impaired social functioning (Daley, 2004), which may reflect the emphasis placed on social relatedness and conformity in traditional Indian culture.

Studies finding differences in parent report and perceptions of attention-deficit/hyperactivity disorder (ADHD) between Black and White parents may offer additional insight into differences in concerns among Black and White parents of children with ASD. One study found that Black parents of children at risk for ADHD were less likely to endorse several specific symptoms than parents of White children with comparable levels of hyperactivity (Hillemeier et al., 2007). Fewer reported ADHD symptoms by Black parents may in part reflect less parental knowledge about the disorder; indeed, one study found that when compared to White parents, Black parents reported that they had less knowledge about ADHD (Bussing et al., 2007, 2012). Moreover, when attributing the cause of their child's ADHD symptoms, Black parents were four times more likely to label their child as "bad" and three times less likely to use a genetic label for the symptoms than White parents (Bussing et al., 1998). Similarly, parents of Black girls with ADHD were particularly likely to characterize their child as a "misbehaving child" (Bussing et al., 2005).

Taken together, this research suggests potential underreporting of ADHD symptoms and interpretations of children's ADHD symptoms as disruptive behavior among Black parents; this phenomenon may extend to other neurodevelopmental disorders, such as ASD. In a qualitative study, Black families of children with ASD reported a belief that there were gaps in knowledge about ASD in the Black community (Burkett et al., 2015), which may lead to underreporting ASD concerns to healthcare providers. Moreover, Black parents may emphasize children's disruptive behaviors to healthcare providers and/or misinterpret children's ASD symptoms as indicators of disruptive behavior problems. Indeed, disruptive behaviors may be particularly salient to Black parents. Black parents have been found to endorse stricter discipline practices (e.g. non-abusive physical punishment; Ibanez et al., 2006; Ispa and Halgunseth, 2004; Kelley et al., 1992), which may reflect efforts to respond to less neighborhood safety (Barajas-Gonzalez and Brooks-Gunn, 2014) and/or protect children from experiences of racism, prejudice, and discrimination (Thomas and Dettlaff, 2011). Like ADHD, ASD symptoms may be easily interpreted as "bad behavior." For example, a child may not comply with a parent's instructions or directives due to delayed receptive language, lack of concern for pleasing the parent reflecting social deficits, or the interference of restricted and repetitive behaviors (RRBs).

Study hypotheses

In summary, although missed and delayed diagnoses are well documented in Black children with ASD, less is known about factors that may contribute to diagnostic disparities such as parent report of concerns about their child's development. The purpose of this study was to investigate racial differences in parent report of concerns about their child's behavior to healthcare providers before their child received an ASD diagnosis. Prior to children's participation in a diagnostic evaluation—but after showing risk on an ASD screening tool—parents answered free-response questions in which they indicated concerns about their child's behavior and development. Researchers coded parent responses into categories of concerns specific to ASD diagnostic criteria as well as other, non-ASD concerns. The hypotheses were that compared to White parents, Black parents would (1) report fewer ASD concerns, but not non-ASD concerns; (2) be less likely than White parents to report a concern within each individual category of ASD concerns (speech/communication, RRB, social deficits, and directly naming autism/ASD as a concern); and (3) be more likely to report a disruptive behavior concern.

Method

Participants

Participants were from two multi-site studies validating the Modified Checklist for Autism in Toddlers (–Revised), with Follow-Up (M-CHAT(-R)/F; Chlebowski et al., 2013; Robins et al., 2014). Parents completed the M-CHAT(-R; Robins et al., 1999, 2009) during toddler well-child visits at participating pediatricians' offices. Consistent with the larger studies, participants from both study sites (metro-Atlanta, Connecticut) were examined in this study. Researchers called families of children who screened positive for risk of ASD and completed the M-CHAT(-R) Follow-Up to obtain additional information regarding the at-risk responses on the initial questionnaire. If the child screened positive on the Follow-Up, the family was offered a free diagnostic evaluation (3.24% of the screened sample). Parents were told that their responses on the screener indicated risk for developmental delay in their child and that an evaluation would be beneficial; ASD was not explicitly mentioned. The majority of children who screened positive (62.2%) completed the evaluation. In the larger study, families with less maternal education were less likely to complete the evaluation after screening positive; race did not significantly predict evaluation completion (Khowaja et al., 2015). Parents completed a history questionnaire eliciting parent concerns about their child's development prior to the evaluation.

Children were excluded from the larger studies if they (1) had an ASD diagnosis prior to screening or (2) had sensory or motor disabilities that prevented completion of the evaluation. Criteria for inclusion in this study were (1) diagnosed with ASD; (2) completion of the history questionnaire, in English, by the child's parent; (3) the parent respondent of the history questionnaire self-reported a race of either White or Black; and (4) the parent respondent self-reported their level of education.

The current sample included 174 toddlers (autistic disorder ($n=98$), pervasive developmental disorder not otherwise

Table 1. Demographic variables.

	Percent or mean (*SD*)		
	Overall sample (*N* = 174)	Atlanta site (*n* = 105)	Connecticut site (*n* = 69)
Child variables			
Sex (male)	71.8%	70.5%^{a}	73.9%^{a}
Sex (female)	28.2%	29.5%^{a}	26.1%^{a}
Age (months)	25.77 (4.77)	26.24 (4.64)^{a}	25.06 (4.93)^{a}
Race (White)	60.9%	47.6%^{a}	81.2%^{b}
Race (Black)	39.1%	44.8%^{a}	14.5%^{b}
Parent variables			
Sex (mothers)	93.7%	92.4%^{a}	95.7%^{a}
Sex (fathers)	6.3%	7.6%^{a}	4.3%^{a}
Education (years[1])	14.25 (2.49)	14.69 (2.60)^{a}	13.59 (2.18)^{b}
Race (White)	66.7%	54.3%^{a}	82.6%^{b}
Race (Black)	33.3%	44.8%^{a}	13.0%^{b}

SD: standard deviation.

Means/percentages in each row with differing superscripts are significantly different from each other ($p \leq 0.05$).

[1] Self-reported education level was converted to years of education, capped at 18 years to indicate graduate degree (some high school = 10, high school degree = 12, some college = 14, college degree = 16, and graduate degree = 18).

specified (PDD-NOS; *n*=76)) according to the *Diagnostic and Statistical Manual of Mental Disorders* (4th ed., text rev.; DSM-IV-TR; American Psychiatric Association, 2000) and their parents who completed the history form. The sample is a subset of that reported in Richards et al. (2016) and was used in this study to answer a novel question regarding racial differences in parent concerns; see Table 1 for demographics. Regarding parents, 116 self-identified as non-Hispanic White ("White," 66.7%), whereas 58 self-identified as non-Hispanic Black ("Black," 33.3%). Parents identified their child's race; 106 were identified as White (60.9%), 57 as Black (32.8%), 9 as Biracial (4.3%), 1 as Asian (0.6%), and 1 child's race was not reported (0.6%).

Diagnosis

The evaluation measured cognitive, adaptive, motor and language functioning, and ASD symptomatology. Measures included the Mullen Scales of Early Learning (MSEL; Mullen, 1995), the Vineland Adaptive Behavior Scales-II (VABS-II; Sparrow and Cicchetti, 1985; Sparrow et al., 2005), Autism Diagnostic Observation Schedule (2nd edition; ADOS-II; Lord et al., 2012, 1999), the Toddler Autism Symptom Interview (TASI; Barton et al., 2012a), and the Childhood Autism Rating Scales (2nd edition; CARS-II; Schopler et al., 1980, 2010). A licensed clinician made the diagnosis, integrating all available information using DSM-IV criteria for any ASD.

Measures

History questionnaire. Parents completed a history questionnaire with multiple-choice and free-response questions related to demographics, family history, pre- and perinatal history, medical history, developmental milestones and behavioral details, and parent concerns (Herlihy et al., 2013; Richards et al., 2016). Parents' free responses to three items that probed for concerns were coded for this study: "Please briefly list any concerns/worries you have about how the child has been developing (walking, speaking, playing) or behaving," "Concerns about your child's development," and "What were the first things that made you concerned about your child's development?"

Coding of parent concerns. The coding scheme, reported in Richards et al. (2016) and adapted from Ozonoff et al. (2009), classified responses to the three concern questions from the history questionnaire into 10 different concern categories (Table 2). This study's concern categories differed from those used by Richards et al. (2016) in that a disruptive behavior concern category was separated from other behavioral/temperament concerns. The disruptive behavior category reflected conduct and oppositional symptoms that are developmentally relevant to toddlers such as aggression, anger, and noncompliance to discipline.

The 10 individual concern categories were grouped into two broad concern categories for analysis based on previous research (Ozonoff et al., 2009; Richards et al., 2016). The ASD concern category was composed of the sum of concerns specific to DSM-IV diagnostic criteria for ASD: speech/communication, social, RRB, and the autism label (i.e. the parent directly named "autism/ASD" as a concern) categories (range: 0–4). The non-ASD concern category was composed of the sum of concerns falling in the remaining categories: motor (excluding repetitive motor behaviors), behavioral/temperament,

Table 2. Coded categories of parent concerns.

Concern	Description	Example
ASD concerns		
Speech/communication	Related to production and comprehension of speech; gestures; reciprocity	"Doesn't speak"
Restricted and repetitive behavior	Restricted and repetitive behaviors in sensory, motor, or object use	"Flaps her arms"
Social	Social interest; social attention; play; reciprocity	"Doesn't interact with other children"
Autism label	Directly named autism	"Worried about ASD"
Non-ASD concerns		
Motor	Motor difficulties; clumsiness	"Balance, frequent falls"
Behavior/temperament	Related to temperament (inattention, shyness); related to behavior (activity level, self-injurious behavior)	"Has a short attention span"
Medical/regulatory	Medical condition; related to a regulatory behavior (sleeping, toileting)	"Not sleeping through the night"
General developmental	General development concerns	"Worried about general development"
Feeding/eating	Related to feeding/eating	"Picky eater"
Disruptive behavior	Tantrums, aggression, anger, noncompliance	"Aggressive toward other children"

ASD: autism spectrum disorder.

medical/regulatory, general developmental, feeding/eating and disruptive behavior concerns (range: 0–6). If the parent described more than one type of concern, all relevant categories were coded.

Coding was completed by two trained researchers who were blind to child diagnosis and demographic characteristics. Cohen's kappa values of 0.70 or higher were achieved for all concern categories. Discrepancies were resolved by consulting with a team of experts and joint consensus was used.

ADOS Calibrated Severity Scores. Calibrated Severity Scores (ADOS-CSS) were calculated to compare ASD symptoms across ADOS modules (Gotham et al., 2009; Hus et al., 2014). These variables were used as covariates in the tests of hypotheses to control for the possibility that racial differences in parent concerns about symptoms of ASD are due to racial differences in symptom severity in our sample. This study uses the overall CSS (Overall-CSS), the CSS for the Social Affect domain (SA-CSS), and the CSS for the RRB domain (RRB-CSS). Higher scores indicate greater severity (range: 1–10).

Procedure

All parents provided informed consent. Prior to the evaluation (but after learning that the child was at risk for developmental delay based on screening), parents completed the history questionnaire. Parents and children then completed the diagnostic evaluation. Institutional Review Boards at Georgia State University and the University of Connecticut (H05185 and H12139) approved all data collection procedures.

Data analytic plan

Two separate analyses of covariance (ANCOVAs) were conducted to examine the effect of parent race on ASD concerns and non-ASD concerns. Five logistic regression analyses were conducted to examine the effect of race on each of the four individual categories of ASD concerns and the disruptive behavior concerns category.

Results

Preliminary analyses

Overall, White parents ($M=14.55$, $SD=2.22$) had more years of education than Black parents ($M=13.66$, $SD=2.91$; $t(91.16)=2.07$, $p=0.04$, $\sigma^2=0.04$). Higher numbers of Black parents ($\chi^2(1)=18.27$, $p<0.001$) and Black children ($\chi^2(1)=21.95$, $p<0.001$) came from the Atlanta versus the Connecticut site, and Atlanta parents had more years of education ($M=14.69$, $SD=2.60$) than Connecticut parents ($M=13.59$, $SD=2.18$; $t(161.79)=2.99$, $p<0.001$, $\eta^2=0.05$).

Correlations and *t*-tests between MSEL and Vineland standard scores and study variables were examined, considering the higher prevalence of ASD with intellectual disability (ID) in Black than White children (CDC, 2016). Lower MSEL scores were associated with lower Vineland scores ($r=0.65$, $p<0.001$). Black children had lower MSEL scores ($M=55.28$, $SD=8.23$) than White children ($M=63.85$, $SD=14.42$; $t(147.95)=-4.64$, $p<0.001$, $\eta^2=0.13$). Black children also had lower Vineland scores ($M=73.89$, $SD=9.37$) than White children ($M=80.48$, $SD=10.48$; $t(95)=-3.26$, $p=0.002$, $\eta^2=0.10$). Lower SES was associated with lower MSEL ($r=0.19$, $p=0.02$) and Vineland scores ($r=0.27$, $p=0.01$). Importantly, neither MSEL nor

Table 3. Correlations among continuous variables.

Variables	1.	2.	3.	4.	5.	6.	7.	8.	9.
1. Child age									
2. Parent respondent's education	–0.02								
3. MSEL composite score	–0.06	0.19*							
4. VABS-II composite score	–0.17	0.27**	0.65**						
5. ADOS-CSS	0.27**	–0.16*	–0.33**	–0.27**					
6. ADOS SA severity score	0.19*	–0.16*	–0.30**	–0.25**	0.90**				
7. ADOS RRB severity score	0.25**	–0.06	–0.29**	–0.24*	0.69**	0.44**			
8. Total ASD concerns	0.02	0.17*	0.02	0.07	0.02	–0.01	0.10		
9. Total non-ASD concerns	0.04	–0.02	0.10	–0.17	–0.10	–0.08	–0.02	0.06	
10. Total concerns	0.04	0.09	0.09	–0.08	–0.06	–0.07	0.05	0.68**	0.77**

MSEL: Mullen Scales of Early Learning; VABS-II: Vineland Adaptive Behavior Scales-II; ADOS: Autism Diagnostic Observation Schedule; CSS: Calibrated Severity Score; SA: Social Affect; RRB: restricted and repetitive behavior; ASD: autism spectrum disorder.
*$p < 0.05$, **$p < 0.01$.

Vineland scores were related to any outcome variable (i.e. either broad concern category or any specific concern category), suggesting that they do not need to be included as covariates in tests of the hypotheses. Furthermore, researchers have cautioned against using variables such as IQ as covariates when they are attributes of a particular neurodevelopmental disorder and therefore cannot be separated from the disorder's effects (Dennis et al., 2009).

Correlations between ADOS-CSS scores and parent and child demographic variables indicated that fewer years of parental education were associated with higher Overall-CSS and SA-CSS, but not RRB-CSS (Table 3). Older children had greater severity scores on all three CSS variables than younger children. Lower MSEL and Vineland scores were related to greater severity scores on all three CSS variables. Neither the overall-CSS nor the RRB-CSS differed significantly between children of Black and White parents. However, children of Black parents ($M=6.89$, $SD=1.94$) had significantly greater SA-CSS than children of White parents ($M=6.24$, $SD=1.73$; $t(160)=2.21$, $p=0.03$, $\eta^2=0.03$).

We also tested whether child and parent demographic variables or study site were related to outcome variables. More parental years of education were significantly and positively correlated with more ASD concerns ($r=0.17$, $p=0.03$). Connecticut parents ($M=1.12$, $SD=0.95$) reported significantly more non-ASD concerns than Atlanta parents ($M=0.80$, $SD=0.85$; $t(172)=-2.29$, $p=0.02$, $\eta^2=0.03$). A greater proportion of parents of boys than girls reported an autism label concern ($\chi^2(1)=4.16$, $p=0.04$). A greater proportion of parents from Connecticut than Atlanta reported a disruptive behavior concern ($\chi^2(1)=4.94$, $p=0.03$). As a result of these analyses, child sex was included as a covariate in analyses of the autism label concern variable, and study site was included as a covariate in analyses of the non-ASD concerns and disruptive behavior concern variables. Education of the parent respondent, a common proxy for SES, was included as a covariate in all analyses. Finally, the overall-CSS was included as a covariate in analyses of the ASD concern and non-ASD concern variables, and the SA-CSS was included as a covariate in the analysis of the social concern variable and the RRB-CSS was included as a covariate in the analysis of the RRB concern variable.

White parents ($M=2.52$, $SD=1.32$) endorsed a greater number of distinct categories of concerns about their children's development (i.e. the sum of all 10 individual concern categories) than Black parents ($M=1.97$, $SD=0.92$; $t(153.87)=-3.27$, $p<0.001$, $\eta^2=0.06$). Across parents, concerns about speech/communication were the most common concern (Table 4), followed by motor and social concerns. The pattern was similar when examining parent concerns by race. For White parents, speech concerns were the most common, followed by social and motor concerns. For Black parents, speech concerns were the most common, followed by motor concerns as second most common and social and medical concerns as third most common.

Tests of study hypotheses

ASD concerns. There was a statistically significant effect of race on the total number of ASD concerns ($F(1{,}167)=10.04$, $p<0.001$, partial $\eta^2=0.06$). Black parents had significantly fewer ASD concerns than White parents ($M_{diff}=0.42$, $SE=0.13$).

Non-ASD concerns. There was not a statistically significant effect of race on the number of non-ASD concerns ($F(1{,}167)=1.19$, $p=0.28$, partial $\eta^2=0.007$).

Individual categories of ASD concerns. Figure 1 displays the percent endorsement of each individual category of ASD concerns by parent race. Race significantly affected the likelihood that parents would report a social concern ($\chi^2(3)=8.217$, $p=0.04$ (Table 5)). White parents had 2.61 times (95% confidence interval (CI): 1.17, 5.831)

Table 4. Descriptive statistics of CSS severity and concern variables: frequencies, means, and standard deviations.

	Percent or mean (*SD*)		
	Overall sample (*N* = 174)	Black (*n* = 58)	White (*n* = 116)
MSEL standard score	60.83 (13.53)	55.28 (8.23)	63.85 (14.42)
VABS standard score	77.42 (10.42)	73.89 (9.37)	80.48 (10.48)
ADOS-CSS	6.38 (2.02)	6.60 (2.07)	6.27 (2.00)
ADOS SA severity score	6.49 (1.79)	6.95 (1.86)	6.26 (1.72)
ADOS RRB severity score	6.54 (2.45)	6.37 (2.46)	6.63 (2.44)
ASD concerns (% yes)			
Speech/communication	87.4%	82.8%	89.7%
RRB	19.0%	6.9%	25.0%
Social	29.3%	17.2%	35.3%
Autism label	5.7%	5.2%	6.0%
Total ASD concerns[a]	1.41 (0.77)	1.12 (0.70)	1.56 (0.77)
Non-ASD concerns (% yes)			
Motor	31.0%	31.0%	31.0%
Behavior/temperament	13.2%	5.2%	17.2%
Medical/regulatory	12.6%	17.2%	10.3%
General developmental	12.1%	10.3%	11.9%
Feeding/eating	11.5%	12.1%	11.2%
Disruptive behavior	12.1%	8.6%	13.8%
Total non-ASD concerns[b]	0.93 (0.90)	0.84 (0.77)	0.97 (0.96)

MSEL: Mullen Scales of Early Learning; VABS-II: Vineland Adaptive Behavior Scales-II; ADOS: Autism Diagnostic Observation Schedule; CSS: Calibrated Severity Score; RRB: restricted and repetitive behavior; ASD: autism spectrum disorder; *SD*: standard deviation.
[a] Sum of ASD concern categories (range = 0–4).
[b] Sum of non-ASD concern categories (range = 0–6).

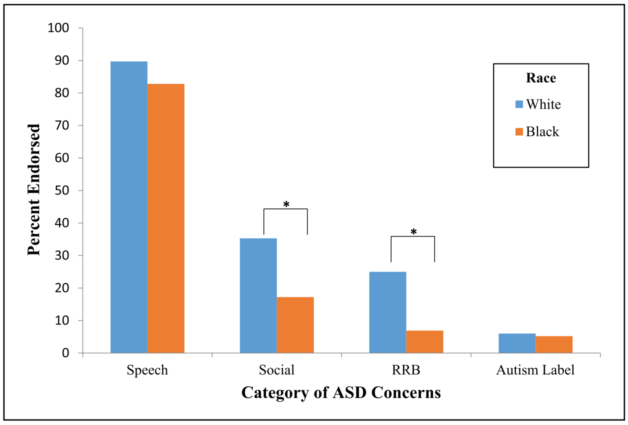

Figure 1. Percent endorsement of ASD-specific concerns by race (*$p \leqslant 0.05$).
RRB: restricted and repetitive behavior.

the odds of reporting a social concern than Black parents. Race also significantly affected the likelihood that parents would report a RRB concern ($\chi^2(3) = 11.35$, $p = 0.01$ (Table 6)). White parents had 4.12 times (95% CI: 1.36, 12.46) the odds of reporting a RRB concern than Black parents. Race did not significantly predict the likelihood that parents would report a speech/communication ($\chi^2(2) = 1.61, p = 0.45$) or autism label ($\chi^2(2) = 1.59$, $p = 0.45$) concern.

Disruptive behavior concerns. Race did not significantly affect the likelihood that parents would report a disruptive behavior concern ($\chi^2(3) = 5.02, p = 0.17$).

Discussion

This study found racial differences in the concerns that parents reported to healthcare providers about children's behaviors before children received an ASD diagnosis. Black parents reported fewer concerns about their child's ASD-specific behaviors than White parents. Specifically, Black parents were less likely than White parents to report concerns about two ASD symptoms—social and RRB—in their child with ASD. Importantly, these differences cannot be explained by lower ASD symptom severity in Black children; in fact, Black parents were less likely to report a social concern than White parents even though their children's SA symptoms were significantly more severe than the children of White parents. Consistent with findings of higher prevalence of ASD with ID in Black than White children (CDC, 2016), Black children had lower scores on measures of cognitive and adaptive functioning; however, neither measure was related to parent concerns, suggesting that racial differences in parent concerns cannot be explained by perceived or actual deficits in children's cognitive and adaptive abilities. As expected, race did not impact the number of non-ASD concerns that parents

Table 5. Logistic regression predicting likelihood of reporting social concerns based on parent race, parent education, and SA-CSS.

	B	*SE*	Wald	*df*	*p*	Odds ratio	95% CI for odds ratio	
							Lower	Upper
Parent education	0.08	0.07	1.28	1	0.26	1.09	0.94	1.25
SA severity	0.10	0.10	1.01	1	0.32	1.11	0.91	1.34
Parent race	0.96	0.41	5.50	1	0.02	2.61	1.17	5.83
Constant	–3.39	1.37	6.15	1	0.01	0.03		

SA-CSS: Calibrated Severity Score for the Social Affect domain; *SE*: standard error; CI: confidence interval.
Race is for White parents compared to Black parents.

Table 6. Logistic regression predicting likelihood of reporting RRB concerns based on parent race, parent education, and RRB-CSS.

	B	*SE*	Wald	*df*	*p*	Odds ratio	95% CI for odds ratio	
							Lower	Upper
Parent education	0.13	0.09	2.12	1	0.15	1.14	0.96	1.18
RRB severity	0.01	0.08	0.003	1	0.95	1.01	0.85	1.18
Parent race	1.42	0.57	6.29	1	0.01	4.12	1.36	12.46
Constant	–4.43	1.52	8.47	1	0.004	0.01		

RRB: restricted and repetitive behavior; CSS: Calibrated Severity Score; *SE*: standard error; CI: confidence interval.
Race is for White parents compared to Black parents.

reported, suggesting that the effect was specific to concerns about ASD symptoms. Contrary to expectations, there were no racial differences in parents' disruptive behavior concerns.

Consistent with previous research (De Giacomo and Fombonne, 1998; Hess and Landa, 2012; Ozonoff et al., 2009), concerns about speech/communication were most common across both Black and White parents. Social difficulties, typically the second most common parent concern (Hess and Landa, 2012; Young et al., 2003), were slightly less common than motor concerns in our sample. White and Black parents differed in their second and third most commonly reported concerns, suggesting some racial differences in the most frequently reported parent concerns about children's development. These differences appear primarily driven by differences in social concerns; 35.3% of White parents reported social concerns compared to 17.2% of Black parents.

Previous studies have demonstrated decreased help-seeking patterns (e.g. seeking services; amount of information shared with providers) in Black individuals, even after controlling for insurance and SES (Dobalian and Rivers, 2008; McMiller and Weisz, 1996). In a qualitative study, Black families of children with ASD described incidents in which they felt that providers did not listen or take action in response to their concerns about their child's development (Burkett et al., 2015); these experiences may contribute to families reporting fewer concerns to providers. However, in the current sample, there were no racial differences in the number of non-ASD concerns reported by parents, suggesting that under-reporting is specific to ASD symptoms among Black parents of children with ASD and does not simply reflect reduced help-seeking or distrust of healthcare providers. One factor that may explain report of fewer ASD concerns by Black parents of children diagnosed with ASD is less knowledge of the disorder, perhaps particularly less knowledge about social and RRB symptoms. Indeed, some Black parents of children with ASD have expressed the belief that they have less knowledge of and access to information about ASD than White parents (Burkett et al., 2015). In the same study, Black parents of children with ASD reported that they rarely reached out to other families affected by ASD and knew few other Black families with a child with ASD. Thus, cultural norms surrounding discussion of ASD within Black communities may also impact parents' knowledge about the disorder. Parents of different cultural backgrounds may also have different expectations or interpretations of a child's behavior, which may affect their report of concerns. For instance, there may be differences between White and Black parents in perceptions of whether ASD-specific behaviors indicate serious delays and are important to disclose to providers; indeed, thresholds of determining whether certain behaviors are problematic vary as a function of culture (Weisz and Weiss, 1991; Weisz et al., 1988).

Most critically, the findings have important clinical implications. While the use of screening tools has improved (Arunyanart et al., 2012), pediatricians still rely heavily on parent report of concerns to trigger referrals for evaluations. Parent under-reporting of concerns specific to ASD symptoms may contribute to providers missing symptoms of ASD and may thus influence their decisions about whether to administer ASD-specific screeners and/or make referrals for diagnostic evaluations. Reduced reporting of children's ASD symptoms by Black parents may contribute to providers disproportionately missing symptoms in Black children and thus may contribute to missed or delayed diagnosis. Lesser reporting of ASD concerns by Black parents may be particularly detrimental in combination with clinician factors such as prejudices and statistical discrimination that likely also contribute to diagnostic disparities in Black children (Institute of Medicine, 2002). Reassuring and/or passive provider responses to parent concerns (e.g. stating that nothing was wrong or that the child might "grow out of it") may also contribute to delays between a parent's first conversation with the provider and the child's ASD diagnosis (Zuckerman et al., 2015). Future studies examining potential differences in the extent of passive provider responses based on the child's race may provide additional valuable insight into diagnostic disparity for Black children with ASD.

In this study, Black parents were less likely than White parents to report concerns about their child's social deficits and RRBs. These symptoms are more specific features of ASD in very young children than speech/communication concerns, which are also characteristic of other early childhood disorders such as global developmental delay and developmental language delay (Ventola et al., 2007). Thus, not reporting concerns about these particular symptoms may be especially problematic in that it may hinder providers from adequately considering ASD in Black children. The current findings may inform recommendations to pediatricians aimed at garnering crucial information from parents including culturally sensitive interviewing techniques and underscore the importance of increasing the use of ASD-specific screening instruments that explicitly probe for ASD symptoms and rely less heavily on parents' knowledge of problematic behaviors.

It has been theorized that Black parents may emphasize children's disruptive behaviors to healthcare providers (Mandell et al., 2007), which may contribute to the over diagnosis of disruptive behavior disorders in Black children with ASD. There was not a racial difference in parent report of concerns about their children's disruptive behaviors in our sample; in contrast, disruptive behaviors were reported by parents of children with ASD regardless of racial identity and at rates similar to report of other non-ASD symptoms. The study by Mandell et al. (2007) examined older children (mean 6.7 years at their first specialty provider visit); future research should examine whether children's disruptive behaviors become increasingly salient to, and reported by Black parents, with children's increasing age. Although determining reasons for over-diagnosis of conduct disorder in Black children with ASD is beyond the scope of this study, this study findings suggest that future research should also investigate factors other than parent report of symptoms, such as clinicians' biased interpretation of symptoms as disruptive behavior, in Black children with ASD.

Limitations and future research

One limitation is that the sample was highly educated and the majority of parents had completed college. Future research should increase participation of participants with fewer years of formal education, perhaps through over-sampling from community clinics, to increase the generalizability of the findings. Researchers should investigate whether Black parents' report of fewer ASD concerns than White parents is related to limited access to knowledge about the disorder, particularly the social deficits and RRB that are characteristic of ASD. Evidence of less knowledge of social and RRB symptoms could inform interventions aimed to increase Black parents' knowledge of warning signs of ASD, such as the Autism Speaks "Maybe" ad campaign (Autism Speaks, 2013). Such findings may also inform interventions to help parents articulate concerns about such symptoms to healthcare providers. Research should also investigate whether potentially different thresholds of perceiving ASD concerns exist between White and Black parents. Finally, studies should examine whether Black parents' report of fewer ASD concerns is predictive of children's misdiagnosis or delayed diagnosis. In spite of limitations, this study provides evidence for the need to account for racial differences that impact the diagnostic process for children and provides a framework for novel investigations of factors that account for diagnostic disparity in Black children with ASD.

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Declaration of conflicting interests

Diana Robins is co-owner of M-CHAT LLC, which licenses use of the M-CHAT in electronic products. However, data used in this study were collected using the free version of the M-CHAT and no royalties are associated with this study.

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