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Short Report: Do early caregiver concerns differentiate girls with Autism Spectrum Disorders?

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Introduction

Autism spectrum disorders (ASD) are increasingly being diagnosed, and caregivers are more aware of potential signs of ASD due to increased public and media attention. Recognizing initial caregiver concerns may aid in earlier detection, thus facilitating earlier enrollment in early intervention services (Hess & Landa, 2012). Caregiver concerns likely precede an ASD diagnosis; it is unclear if specific types of concerns may be specific to children with ASD versus another developmental condition. While previous studies have gathered parent-report data from high-risk samples (e.g., Sacrey et al., 2015, Zwaigenbaum et al., 2009) or used retrospective reports (Gaspar de Alba & Bodfish, 2011; Guinchat et al., 2012), caregiver concerns preceding a diagnosis of ASD in a large community based sample remain unexamined. Therefore, this study investigated the extent to which caregiver concerns differed among boys and girls with an eventual diagnosis of ASD versus those with other developmental conditions in a community-based sample aged 12 months to 11 years 11 months.

Early studies of caregiver concerns used retrospective methods to examine parent recollection of child age when concerns were first noted, as well as specific concerns that were identified prior to a diagnostic evaluation (e.g., Young et al., 2004; Hess and Landa (2012) Gaspar de Alba and Bodfish, 2011). However, parent recall after diagnostic evaluation poses limitations as the diagnostic process may impact parents' perceptions of their initial concerns after the fact. As a result, further research examined caregiver concerns prior to a diagnostic evaluation (Ozonoff et al., 2009). Overall, these studies support the potential clinical utility of caregiver concerns to aid in identifying children with ASD.

The role of gender, as it may impact parents' first concerns and early identification, remains largely unexplored. Specifically, there may be gender differences in child age at which concerns first arise and the specific patterns of behavior that trigger first concerns. Higher functioning girls with ASD may be identified later versus boys and average time between initial caregiver concern and diagnosis of ASD may be slightly longer for girls (Begeer, Mandell, Wijnker-Holmes, Venderbosch, Rem, Stekelenburg & Koot, 2013). However, one study showed that the average age of parent concerns was significantly younger for girls with ASD, although parent concerns are significantly earlier for children with ASD versus

those with another developmental disability (DD) (Horovitz, Matson, Turygin & Beighley, 2012). Importantly, research aimed at understanding specific parental concerns that differ by gender and diagnostic group (i.e., ASD, DD) may result in earlier identification of children at-risk. If young girls with ASD do not show similar patterns of behavior that are concerning to parents, early identification efforts for females may need to focus on other areas of child development.

Overall, the literature points to the value of caregiver concerns as they relate to earlier identification of children with potential ASD and DD. To date, however, little research has specifically tested how caregiver concerns prior to a diagnosis of ASD may differ between males and females. Additionally, little is known about how gender differences may play a role in the early differentiation of children with ASD versus another DD. The current study aimed to address these gaps in the literature by examining caregivers' primary concerns prior to a diagnostic evaluation among children referred to a medical university-based clinic for neurodevelopmental disabilities. We addressed the following:

1. To what extent do four groups of children (i.e., males with DD, females with DD, males with ASD, females with ASD) differ on ASD Related Concerns and General Developmental Concerns?
2. To what extent do specific caregiver concerns differ between children in the four groups?

Methods

Participants

Participants were drawn from a university-based medical center in a large metropolitan area (n=699), ages 12 months to 11 years, 11 months, including: females with ASD (n=63) males with ASD (n=320), females with DD (n=76) and males with DD (n=240). Participant numbers in the overall sample align with current prevalence rates of a 5:1 ratio of boys diagnosed with ASD as compared to girls (CDC, 2013). Although the chronological age (CA) among groups in the larger sample was not significantly different at time of diagnosis, questions around parental concerns are largely related to CA and cognitive ability. To address research questions, therefore, we matched participants based on our sample of girls with ASD on CA and cognitive ability. We used the fuzzy case-control extension of SPSS; maximum CA difference was set at 3 months and IQ difference was set at 10 points. Participant characteristics of the final sample (n=242) are shown in Table 1.

Measures

Prior to diagnostic evaluation, caregivers completed intake paperwork that included a variety of questions about behavior and developmental history. Caregivers were asked to identify their highest three concerns about their child. These concerns were then coded, using a modification of Ozonoff et al. (2009) into the following domains of concern: 1) Externalizing Behaviors; 2) Cognitive Development; 3) Medical; 4) Motor; 5) Speech/Communication; 6) Social Interaction; 7) Stereotyped Behavior; 8) Sensory Aversions/Preferences; and 9) Internalizing Behaviors. Coders reached 89% reliability; 20% of the data

was coded for reliability. Caregiver concerns were coded as binary variables (present/not present).

The diagnostic process included administration of standardized assessment measures, behavioral reports, a review of medical history and a clinical diagnostic interview. A developmental hierarchy of cognitive measures (selected based on age and language ability) was used to determine cognitive ability, including: Bayley Scales of Infant and Toddler Development—third ed. (BSID-III; Bayley, 2005), Kauffman Assessment Battery for Children—second ed. (KABC-II; Kaufman & Kaufman, 2004a), Wechsler Preschool and Primary Scale of Intelligence—third ed. (WPPSI-III; Wechsler, 2002), Wechsler Intelligence Scale for Children—fourth ed. (WISC-IV; Wechsler, 2003), Psychoeducational Profile—third ed. (PEP-3; Schopler, Lansing, Reichler, & Marcus, 2005), and Kaufman Brief Intelligence Test—second ed. (KBIT-2; Kaufman & Kaufman, 2004b). Cognitive measures were available for a subset of our sample (see Table 1).

The ASD diagnostic evaluation included administration of the Autism Diagnostic Observation Schedule (ADOS) along with either the Childhood Autism Rating Scale (CARS-2; Schopler, Van Bourgondien, Wellman, & Love, 2010) or the Autism Diagnostic Interview—revised (ADI-R; Le Couteur, Lord, & Rutter, 2006) and unstructured observation. The ADOS and ADI-R administration and scoring were completed by clinically trained team members; all teams included at least one member with ADOS or ADI-R research training.

Data Analysis

To calculate concern scores, we used scores adapted from Ozonoff et al. (2009) which included: *ASD Related Concerns* (sensory, speech, social, stereotyped behavior) and *General Developmental Concerns* (motor, medical, internalizing, externalizing, general development). To account for differences in number of items in concern categories, we used mean scores in analyses. We used analysis of variance (ANOVA) to examine the potential impact of cognitive ability on concerns across groups. For research question 1, we used ANOVA with Bonferonni follow up comparisons to examine differences in caregiver concerns across groups. For research question 2, we first used descriptive statistics to examine the highest endorsement category of concerns. We then used multinomial regression to determine the extent to which specific caregiver concerns predicted diagnostic/gender category (i.e., male DD, female DD, male ASD, female ASD).

Results

ASD Related and General Developmental Concerns across Groups

The number of available cases with cognitive scores across groups did not significantly differ ($X^2 [135] = 138.71, p=.396$). ANOVA results showed that the available cognitive scores between groups were not significantly different $F(3,105)=.440, p=.725$. Therefore, cognitive ability was not included in subsequent analyses. We used ANOVA to determine differences in ASD Related Concern and General Developmental Concern scores between groups. Results showed that there was not a significant main effect for ASD Related

Concern Scores [$F(3,238)=2.326, p=.075$]; however, there were significant differences in General Developmental Concern Scores [$F(3,238)=4.910, p<.01$]. We then used Bonferonni follow up comparisons. In General Developmental Concern Scores, boys and girls with ASD were not significantly different (ASD boys mean=.683; ASD girls mean=.730). Boys and girls with ASD significantly differed from girls with DD ($p<.05$) (mean=1.127) but not from boys with DD (mean=.952). Girls with DD had the highest number of General Developmental Concerns as compared to all other groups ($p<.01$). Overall, girls with ASD were only significantly different from girls with DD on general developmental concerns. While not statistically significant, results suggest that males with ASD had a higher number of ASD Related Concerns than females with ASD, males with DD, and females with DD ($p=.075$).

Specific Concerns that Differentiated all Groups

To address research question 2, we examined if there were individual concerns that may differ by group. We used multinomial regression to examine the predictive value of each binary concern category (i.e., Sensory, Speech, Social, Stereotyped Behavior, Motor, Medical, Internalizing, Externalizing, Cognitive Development) on group (i.e., male DD, female DD, male ASD, female ASD). Results showed an overall significant model [$\chi^2=47.54 (30), p<.01$; Cox and Snell=.178; Nagelkerke=.190]. Concerns that had significant predictive value included Social Interaction ($\chi^2=18.04 [3], p<.001$), Externalizing Behavior ($\chi^2=9.035 [3], p<.05$), and Medical/Regulatory concerns ($\chi^2=7.823[3], p=.05$).

As compared to girls with ASD, boys with ASD were more likely to have Social Interaction concerns (Exp[B]=3.183, 95% CI: 1.447–7.007, $p<.01$). Boys with ASD had a higher likelihood of showing Social Interaction concerns as compared girls with DD (Exp[B]=4.269, 95% CI: 1.750–10.412, $p<.01$) and boys with DD (Exp[B]=4.510, 95% CI: 1.940–10.486, $p<.01$). Girls with DD were more likely to have Externalizing Behavior concerns as compared to girls with ASD (Exp[B]=3.056, 95% CI: 1.329–7.025, $p<.01$). Girls with ASD did not have any significant differences in concerns from boys with DD. As compared to boys with ASD, girls with DD were more likely to have externalizing concerns (Exp[B]=2.809, 95% CI: .1.197–6.589, $p<.05$). Boys and girls with DD did not significantly differ on any concerns. Boys with DD were more likely than boys with ASD to show Cognitive Development concerns (Exp[B]=2.733, 95% CI: 1.110–6.730, $p<.05$). As compared to boys with ASD, girls with DD are more likely to show Medical/Regulatory concerns (Exp[B]=4.783, 95% CI: 1.388–16.479, $p<.01$) (Refer to Figure 2).

Discussion

Gender differences in developmental trajectories among children with ASD versus those with DD remain largely unexplored. To ensure that our diagnostic and gender groups aligned on CA and cognitive ability, we used a matching procedure based on the characteristics of our sample of girls with ASD. Findings showed that ASD Related Concerns did not significantly differ between groups; instead, boys and girls with DD had higher General Developmental Concerns than those with ASD. Overall ASD Related Concerns (i.e., Social

Interaction, Speech, Stereotyped Behavior, Sensory Behaviors) were not significantly different between boys and girls with ASD from those with DD.

Specific caregiver concerns may help uncover differences between the development of boys and girls with ASD versus DD. Boys with ASD had higher social interaction concerns than other groups, which suggests that girls with ASD may not show pronounced social interaction difficulties. Girls with DD showed increased Externalizing Concerns, while boys with DD showed a high rate Cognitive Development concerns as compared to boys with ASD and girls with DD. Interestingly, girls with ASD did not significantly differ from boys with DD on type of caregiver concerns. While earlier studies suggest females with ASD are more cognitively impaired than males with ASD (Lord, Schopler, & Revicki, 1982), some studies speculate higher functioning girls may be ‘missed’ (Lai et al., 2014). Our findings suggest that girls with ASD have the potential to be ‘missed’ due to a lack of differentiating factors that align with ASD Related or General Developmental Concerns. It may be that young girls with ASD have particular characteristics that remain unnoticed in everyday family routines. While social interaction difficulties differentiated boys with ASD from all other groups, this is not salient for females with ASD in our sample suggesting either more subtle social difficulties and potentially that highly salient concerns (such as medical or externalizing behaviors) are required for referral. While some studies show that girls with ASD show increased internalizing behaviors (e.g., Solomon et al., 2012), such behaviors may not be concerning for parents early in children’s development. A limitation of the current study was a lack of cognitive scores for all participants. Future research may examine the role of cognitive level as well as how parent concerns align with standardized measures of functioning in children based on gender differences.

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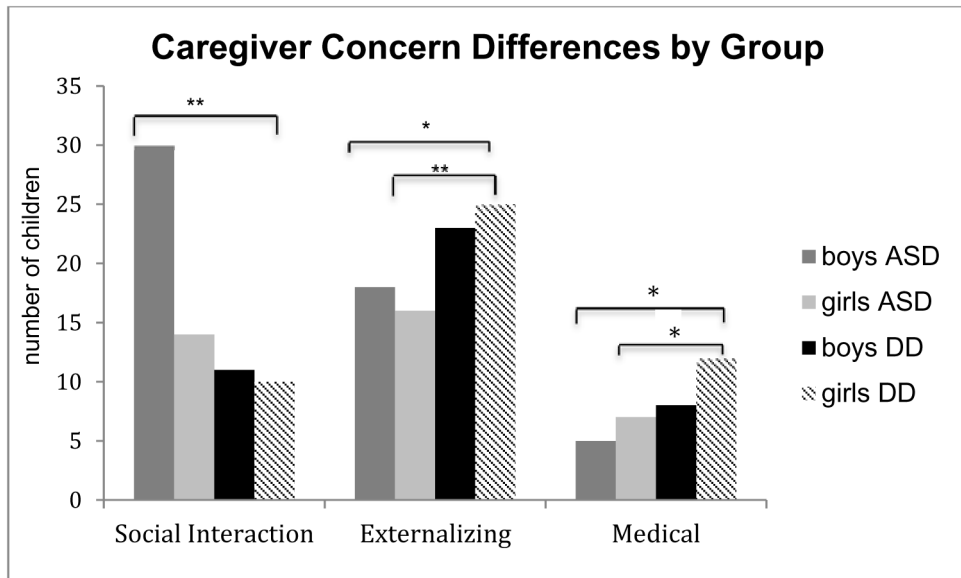


Figure 1.
 Follow up Comparisons by Group
 * $p < .05$, ** $p < .01$

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Table 1

Participant Characteristics

group	n	CA mean (SD) range	% with IQ score	IQ mean (SD) range
	63	72.14 (34.81) 24–143	44.4	87.75 (22.98) 48–132
ASD girls				
	63	69.52 (35.29) 21–140	47.6	82.66 (17.52) 46–112
ASD boys				
	62	71.34 (32.44) 23–141	40.3	85.48 (14.52) 65–138
DD girls				
	54	71.34 (34.23) 21–140	43.0	83.39 (15.94) 55–115
DD boys				

Note: IQ are standardized with a mean of 100 and a standard deviation of 15.