The relationship between ethnicity and age of first concern in toddlers with autism spectrum disorder

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ABSTRACT

The current study examined the relationship between ethnicity and the age at which parents first become concerned about their children’s development in 1478 toddlers with autism spectrum disorder (ASD) and atypical development. Based on the current findings, there were no racial/ethnic differences in age of parent’s first concerns. Caregivers of toddlers with ASD first developed concerns around the same time independent of which ethnic groups they belong to. In addition, the age of caregivers’ first concerns was significantly younger for those with ASD compared to those who are atypically developing without an ASD diagnosis. Implications regarding these findings are discussed.

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Autism spectrum disorder (ASD) is a common, neurodevelopmental disorder characterized by qualitative deficits in social communication as well as the presence of restricted, repetitive, and stereotyped patterns of behavior, interests or activities (Fodstad, Matson, Hess, & Neal, 2009; Horovitz & Matson, 2010; Matson, Bojsioli, Hess, & Wilkins, 2010; Matson, Kozlowski, Hattier, Horovitz, & Sipes, 2012; Matson, Mahan, Hess, Fodstad, & Neal, 2010). In addition to core deficits, individuals with ASD often evince a range of associated symptoms such as cognitive impairment, deficits in adaptive functioning, and feeding and sleep difficulties (Kozlowski, Matson, Belva, & Rieske, 2012; Krakowiak, Goodlin-Jones, Hertz-Picciotto, Croen, & Hansen, 2012; Matson, Hattier, & Belva, 2012; Matson & Shoemaker, 2009). Additionally, challenging behaviors commonly co-occur and are problematic (Matson, Hess, & Bojsioli, 2010; Matson & Rivet, 2008). Because individuals with ASD are affected across the lifespan and often need continued services into adulthood (Howlin, Mawhood, & Rutter, 2000; Matson, Dempsey, & Fodstad, 2009; Matson, Rivet, Fodstad, Dempsey, & Bojsioli, 2009), ASD can be a very emotionally and economically taxing condition for those afflicted and their caregivers.

ASD was once considered a relatively rare condition with original prevalence rates estimated at one in 2500 individuals (Matson & Kozlowski, 2011). Conversely, epidemiological studies from the early 2000s indicated that ASD prevalence estimates were closer to one in 150 individuals (Center for Disease Control [CDC], 2007; Inglese & Elder, 2009). Today, estimated prevalence rates are higher than ever; ASD affects approximately one in 88 children in the United States (CDC, 2012). Further, ASD has previously been thought to predominantly affect non-Hispanic white children (CDC, 2007); however, the rate of ASD in all ethnicity/race has increased dramatically since earlier studies. Compared to prevalence rates published in 2007, there has been a 70% increase in ASD among non-Hispanic white children, a 91% increase among non-Hispanic black children, and a 110% increase among Hispanic children (CDC, 2012).

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One of many factors that may be contributing to the growing prevalence of ASD is increased awareness of the condition in the general and professional populations. Increased awareness of the symptoms of ASD may lead to earlier and improved detection in young children (Matson & Kozlowski, 2011). Although the onset of symptoms primarily occurs in affected individuals before 30 months of age, typical diagnosis of ASD is made at 3 or 4 years old (Matson, Wilkins, & Gonzalez, 2008). However, researchers suggest reliable diagnosis of ASD can be made as early as 2 years old (Horovitz, Matson, Turygin, & Beighley, 2012; Matson, Gonzalez, Wilkins, & Rivet, 2008). With growing prevalence rates as well as the widespread and lifelong impairments associated with ASD, early evaluation and diagnosis is imperative (Matson, Gonzales, & Wilkins, 2008).

Caregiver detection of symptoms at a young age is imperative in ensuring early diagnosis and early treatment. Researchers indicate that parents of children with ASD report first having concerns around 13 months of age (Kozlowski, Matson, Horovitz, Worley & Neal, 2011). Because earlier detection of symptoms is correlated with earlier age of which parents’ seek evaluation (Kozlowski et al., 2011), research into the factors related to parental symptom recognition is of importance. Child gender has been associated with earlier parental detection of delays; parents of female children report earlier concerns (Horovitz et al., 2012). However, little is known about the influence of child ethnicity on parent’s first detection of symptoms. Therefore, the current study seeks to explore the relationship of child ethnicity to age of first concern. Previous researchers looked at the relationship between child ethnicity and child age at diagnosis and found that African American and Hispanic children received an autism diagnosis at older ages than Caucasian children (Mandell, Listerud, Levy, & Pinto-Martin, 2002; Mandell et al., 2009). Based on results of these studies, it is hypothesized that child’s age of parent’s first concern and ethnicity will be significantly different. More specifically, it is hypothesized that the mean age of Caucasian parents’ first concerns will be earlier than those of non-Caucasian parents.

1. Methods

1.1. Participants

A total of 1478 toddlers (1034 male and 444 female) were included in the current study. Participants ranged in age from 17 to 37 months (M = 25.79, SD = 4.72) at the time of assessment. Based upon informant report, the ethnicity of the participants included Caucasian (n = 799), African-American (n = 552), and other ethnicity including Hispanic and Asian (n = 127). Because the number of participants who were not Caucasians or African-Americans was small, those of Hispanic, Asian, and other ethnicity were collapsed into one group; however, uneven distribution of race of our sample is representative of the Louisiana population. Participants were assessed as a part of their inclusion in the state of Louisiana’s Early Steps, an early intervention program provided by the Individuals with Disabilities Education Act, Part C.

Following assessment, participants were separated into one of two diagnostic groups: ASD groups who met diagnostic criteria (n = 255) and Atypical development (n = 1223). Participants in the Atypical development group were not diagnosed with an ASD but were identified as being developmentally delayed or were reported to have a disorder such as Down Syndrome, seizure disorder, sickle cell anemia, premature birth, and microcephaly. Diagnostic decisions were made based upon results of the Modified Checklist for Autism in Toddlers (M-CHAT; Robins, Fein, Barton, & Green, 2001), the Battelle Developmental Inventory, Second Edition (BDI-2; Newborg, 2005), diagnostic criteria from the Diagnostic and Statistical Manual of Mental Disorders, 5th Edition (DSM-5; American Psychiatric Association, 2013), and clinical judgment. Clinical diagnosis was made by a licensed clinical psychologist with over three decades of experience in working with individuals with developmental disabilities. Complete demographic information can be found in Table 1.

1.2. Measures

Modified Checklist for Autism in Toddlers (M-CHAT; Robins et al., 2001). The M-CHAT is a brief assessment designed for use by specialists and pediatricians when ASD is suspected. A total of 23 items are administered to parents and caregivers to assess the individual’s behavior, social skills, and communication. Additional evaluation is recommended if a parent endorses “no” for three or more total items or two critical items. Diagnostic specificity (.99) and specificity (.87) are reported

Table 1
Demographic characteristics per race and diagnostic group (n = 1478).

<table>
<thead>
<tr>
<th></th>
<th>ASD</th>
<th>Non ASD</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>African-American (n = 112)</td>
<td>Caucasian (n = 121)</td>
</tr>
<tr>
<td>Age M (SD)</td>
<td>26.45 (4.5)</td>
<td>25.88 (4.47)</td>
</tr>
<tr>
<td>Gender %</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>70.50%</td>
<td>71.90%</td>
</tr>
<tr>
<td>Female</td>
<td>29.50%</td>
<td>28.10%</td>
</tr>
</tbody>
</table>

*Note: Age is denoted in months.*
**Table 2**
First age of parental concern means (standard deviations) by race.

<table>
<thead>
<tr>
<th></th>
<th>African-American (n = 840)</th>
<th>Caucasian (n = 1174)</th>
<th>Other (n = 183)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean</td>
<td>12.78 (8.88)</td>
<td>13.21 (8.56)</td>
<td>12.31 (9.47)</td>
</tr>
</tbody>
</table>

**Table 3**
First age of parental concern means (standard deviations) by diagnostic group.

<table>
<thead>
<tr>
<th></th>
<th>ASD (n = 255)</th>
<th>Atypically developing (n = 1223)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean</td>
<td>12.05 (8.48)*</td>
<td>13.16 (8.81)*</td>
</tr>
</tbody>
</table>

*Denotes significant difference found between groups.

to be high. Overall, the M-CHAT demonstrates good internal reliability (.85) and internal reliability for the critical items is reported to be .83 (Robins et al., 2001; Tables 2 and 3).

Battelle Developmental Inventory, Second Edition (BDI-2; Newborg, 2005). The BDI-2 is designed to assess children from birth to 7 years 11 months for delay in five domains of childhood development (i.e., personal/social, adaptive, motor, communication, and cognitive). The BDI-2 consists of 450 items that are scored based upon direct observation and informant response. For most items, the examiner may choose from one of three examination methods to best allow item completion. Item endorsement includes a 3-point scale ranging from “no ability in this skill” (0), to “ability in this skill” (2). A developmental quotient (DQ) based upon item endorsement is calculated for each individual domain and for the Total Score. Content and criterion validity of the BDI-2 has been observed in multiple populations (e.g., developmental delays, motor delays, speech and/or language delays, premature birth, and ASD). The BDI-2 was observed to be moderately correlated with the Vineland Adaptive Behaviors Scale-2nd edition (Bliss, 2007). Internal consistency for the computed total score is reported to be between .98 and .99 (Newborg, 2005). Test–retest reliability for the BDI-2 was observed to be above .80 for the individual domains and total scores (Newborg, 2005).

Baby and Infant Screen for Children with Autism Traits (BISCUIT) Demographic Form (Matson, Bojsjoli, & Wilkins, 2007). The BISCUIT is a battery of assessments designed to assess for ASD symptoms, comorbid symptoms, and problem behaviors in infants and toddlers. The larger assessment battery also includes a Demographic Form in order to gain relevant information such as age, race, ethnicity, weight, and height (Matson et al., 2007). In addition to demographic information the form includes additional questions to be read aloud to the informant by a qualified professional. This section includes background information such as age of first concern and the specific concern, relevant medical history, child’s age for each developmental milestone, and additional family information.

### 1.3. Procedure

The present study was approved by the institutional review board of a state university in the southern United States and the Office for Citizens with Developmental Disabilities for Louisiana. All parents or caregivers provided informed consent prior to their inclusion in the current study. Parents or caregivers were administered a battery of assessments as part of their participation in the EarlySteps program. Diagnostic measures (i.e., BISCUIT, BDI-2, and M-CHAT) were administered by certified or licensed practitioners in fields such as early childhood development, speech/language pathology, special education, social work, and psychology. Raters held a minimum of a bachelor level degree and received additional training in assessment administration.

### 1.4. Statistical analyses

First, a priori analyses were conducted to determine if the groups vary significantly on any of the diagnostic variables (i.e., age, gender). Chi square tests were conducted to determine potential differences among groups in gender of the participants. A priori Chi Square test indicated that groups did not significantly differ for gender, \( \chi^2 (2) = 2.41, p > .05 \). An Analysis of Variance (ANOVA) was conducted to determine potential group differences in age. The assumption of homogeneity of variances was not violated, as assessed by Levene’s Test of Homogeneity of Variance (\( p = .47 \)). An ANOVA did not reveal any differences between groups on age, \( F(2, 1475) = 2.12, p > .05 \). Following analyses of demographic data, a two-way, between subjects Analysis of Covariance (ANCOVA) was conducted to investigate differences in age of first concern among different ethnic groups. Child’s ethnicity and diagnostic group were entered as independent variables, age of parents’ first concerns was entered as the dependent variable, and age at assessment was entered as a covariate. Age at assessment was entered as a covariate because previous literature showed significant relationship between age of parents’ first concerns and age at assessment (e.g., Horovitz et al., 2012; Kozlowski et al., 2011). Our sample also confirmed this significant relationship, \( r = .24, p < .001 \).
2. Results

An ANCOVA was run to determine the effect of different ethnicity on child’s age of parents’ first reported concern after controlling for age at assessment. There was a linear relationship between age at assessment and child’s age of parent’s first concern for each level of independent variables, as assessed by visual inspection of a scatterplot (see Figs. 1 and 2). There was homogeneity of regression slopes as the interaction term was not statistically significant, $F(2, 1471) = 1.04, p = .35$; $F(1, 1471) = 1.97, p = .16$. There was homoscedasticity and homogeneity of variances, as assessed by visual inspection of a scatterplot and Levene’s test of homogeneity of variance ($p = .153$), respectively (see Fig. 3). After adjustment for age at assessment, there was no statistically significant difference in the child’s age of parent’s first concern between different ethnicity, $F(2, 1471) = .57, p = .57$, partial $\eta^2 = .001$. The mean age (months) of parent’s first concerns for African-American children, Caucasian children, and other ethnicity including Hispanic and Asian were 12.8, 13.2, 12.3, respectively.

A significant main effect was found for diagnostic group, $F(1, 1471) = 4.05, p < .05$, partial $\eta^2 = .003$, such that parents’ first concerns for those with ASD were younger ($M = 12.05, SD = 8.48$) than for those without an ASD diagnosis ($M = 13.16, SD = 8.81$).

The covariate, age at assessment, was also significant, $F(1, 1471) = 90.03 p < .001$. The interaction of race and diagnostic group was not significant, $F(2, 1471) = .41, p = .66$, partial $\eta^2 = .058$.

3. Discussion

The core symptoms of ASD and its associated conditions such as challenging behavior and comorbid disorders may affect quality of life of those afflicted with ASD; they may experience lifelong deficits in social, cognitive, and adaptive skills (Matson, Dempsey, & Fodstad, 2009a, 2009b; Matson, Mayville, Lott, Bielecki, & Logan, 2003). Given the lifelong nature of ASD, it is critical to identify the condition as early as possible in order to effectively treat it (LoVullo & Matson, 2009; Matson, Rieske, & Tureck, 2011; Poon, 2012; Smith & Matson, 2010a, 2010b, 2010c). EIBI is considered the most well-established treatment for ASD; EIBI involves the use of operant conditioning techniques (i.e., applied behavior analysis) to target behavioral deficits and excesses in children with ASD. EIBI has been shown to improve the core symptoms of ASD and proves most effective when treatment is intensive (20–40 h/week) and administered directly to the child over a long period of time (Howard, Sparkman, Cohen, Green, & Stanislaw, 2005; Matson, Tureck, Turygin, Beighley, & Rieske, 2012; Matson, Gonzalez, Wilkins, & Rivet, 2008; Matson, Gonzales, & Wilkins, 2008). Previous researchers have found that EIBI is effective in improving cognitive, social, and adaptive skills and decreasing autism severity and challenging behaviors in children with ASD (Dawson et al., 2010; Eikeseth, Klintwall, Jahr, & Karlsson, 2012; Eikeseth, Smith, Jahr, & Eldevik, 2007; Fava et al., 2011;
Fig. 2. Assumption of linearity for all groups of the independent variable, diagnosis.

Fig. 3. Assumption of homoscedasticity: Scatterplot of the standardized residuals against the predicted values.
Fernell et al., 2011; Granpeesheh, Tarbox, & Dixon, 2009; Howard et al., 2005; Makrygianni & Reed, 2010; Matson & Wilkins, 2009; Peters-Scheffer, Didden, Korzilius, & Matson, 2012; Virues-Ortega, 2010).

Further highlighting the importance of EIBI, a number of researchers have demonstrated that the best treatment outcomes result from earlier intervention (Howard et al., 2005; Horovitz et al., 2012). Many researchers examined age at intervention and treatment outcome and found that they were positively related. For example, Fenske, Zalenski, Krantz, and McClannahan (1985) found that children’s age at intervention entry was strongly related to positive treatment outcome, which was measured by continued residence with family and attendance at public school. Harris and HANDLEMAN (2000) found that younger children with higher IQ at time of admission to a behavioral treatment had better educational placement than older children with lower IQ. Granpeesheh, Dixon, Tarbox, Kaplan, and Wilke (2009) also found that younger children with ASD showed greater treatment outcome compared to older children and discussed that it becomes more challenging to address deficits as the gap between chronological and developmental age increases (Howard et al., 2005). Results of these studies emphasize the importance of early detection and intervention in autism.

Due to inconsistent methodology of most of the EIBI studies, researchers can come to different conclusions about factors that affect the effectiveness of EIBI (Matson & Smith, 2008). Without a doubt, additional research with more consistent measurement methods is needed to learn more about the true value of EIBI; however, despite the shortcomings of EIBI studies, EIBI still is one of the few evidence-based treatment for individuals with ASD and is the pre-eminent intervention for young children. Then, early detection of autism symptom is essential for faster ASD diagnoses to ensure treatment as early as possible (Fernell & Gillberg, 2010; Giannoni & Kass, 2010).

In the current study, we found that parents of children with ASD developed their first concerns earlier compared to parents of atypically developing children without an ASD. Caregivers of this sample reported that they first recognized their children’s developmental problems around 12–13 months of age. This finding is in agreement with previous studies (Chawarska et al., 2007; Kozlowski et al., 2011). Early recognition of autism was also detected in home videotapes of 1-year old children; those with ASD evinced significantly fewer social and joint attention behaviors (e.g., pointing, showing objects, looking at others, responding to name) than the control group (Osterling & Dawson, 1994). The earlier recognition than other studies (Baghdadli, Picot, Pascal, Pry, & Aussilloux, 2003; De Giacomo & Fombonne, 1998) may be explained by increased awareness and better understanding of ASD.

More importantly, no racial differences were found in age of parent’s first concerns. In other words, caregivers reported their first concerns of their children’s development around the same time independent of their races. The finding of the current study is of interest because racial/ethnic disparities exist in receipt of autism diagnoses despite the fact that race/ethnicity was not a factor of symptom recognition. For example, researchers found significant racial/ethnic disparities in autism diagnosis; African American and Hispanic children received an autism diagnosis at older ages than Caucasian children (CDC, 2006; Mandell et al., 2002, 2009). Mandell et al. (2002) found that on average, Caucasian children received autism diagnoses at 6.3 years of age, African American children at 7.9 years of age, and Hispanic children at 8.8 years of age. Furthermore, researchers found racial disparities in autism treatment. Feinberg, Silverstein, Donahue, and Bliss (2011) found that African American children at 24 months were five times less likely to receive early intervention than Caucasian children. Magana and colleagues also found racial disparities in quality of care; African American and Latino children with autism faced greater difficulties in receiving high-quality health care than Caucasian children did (Magana, Parish, Rose, Timberlake, & Swaine, 2012).

Limitation of the current study is unequal group sizes. Also, participants of Hispanic and Asian ethnicity were grouped together due to the small Asian and Hispanic population in Louisiana. Uneven group sizes are representative of the current population of Louisiana. However, with unequal group sizes, caution must be applied, as the findings might not generalize well to the population. Asian groups and Hispanic groups may have different views so the fact that they were grouped in one group may not reflect their true views. Future research should include more equal sample groups to ensure that results of the current study are meaningful.

Generally, there is an overall delay in diagnosis. A 13-month delay between evaluation and autism diagnosis has been reported (Wiggins, Biao, & Rice, 2006); they reported that their sample children were initially evaluated at a mean age of 48 months but were not diagnosed with ASD until a mean age of 61 months. Many studies including the current study showed that autism symptoms arise as early as 12 months. Clinicians need to pay particular attention when evaluating infants and toddlers and look for subtle behaviors such as attentiveness and responsiveness (Matson, Gonzalez, & Wilkins, 2009). Furthermore, more research is needed to examine racial/ethnic disparities in autism diagnosis and treatment (Matson & LoVullo, 2009). Researchers and clinicians should better understand culture differences on health issues (i.e., different perspectives on disability/disorder, help-seeking, and support/advocacy). More research, support, and education are needed to eliminate racial/ethnic/gender differences in autism diagnosis and treatment in order to maximize positive outcomes for all affected children (Rivet & Matson, 2011).

References


