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To cite this article: Abigail Issarraras, Johnny L. Matson, Maya Matheis & Claire O. Burns (2018): Differences in Developmental Concerns of Young Children with Autism Spectrum Disorder Across Racial/Ethnic Groups, Developmental Neurorehabilitation, DOI: 10.1080/17518423.2018.1504828

To link to this article: https://doi.org/10.1080/17518423.2018.1504828

Published online: 06 Aug 2018.
Differences in Developmental Concerns of Young Children with Autism Spectrum Disorder Across Racial/Ethnic Groups

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ABSTRACT

Purpose: Parents/caregivers of children with autism spectrum disorder (ASD) have varying types of initial concerns regarding their child’s development, which may be culturally bound to parents’ perceptions of their child’s development. This study investigated differences in the types of initial developmental concerns reported by parents or caregivers of different racial/ethnic groups with children in an early intervention program.

Method: This study examined the frequency of endorsement of different types of concerns in African American, Caucasian, and Hispanic families.

Results: No significant differences between racial/ethnic groups were found in the endorsement of concerns related to communication, language/speech, motor, problem behavior, sensory, feeding, prematurity, attention, adaptive functioning, and medical conditions. Racial/ethnic groups differed significantly in their endorsement for social concerns.

Conclusion: Racial/ethnic group differences were confirmed regarding initial developmental concerns related to social behavior, which may be due to cultural beliefs. The implications of these findings on early identification are discussed.

Autism spectrum disorder (ASD) is a neurodevelopmental disorder characterized by impairments in social communication and patterns of restricted and repetitive behaviors.1,2 According to the most recent reports from the Autism and Developmental Disabilities Monitoring (ADDM) Network, 1 in 59 children are diagnosed with autism spectrum disorder in the United States.3 Early identification and intervention are critical for children with ASD, as both early identification and beginning early intensive behavioral interventions (EIBI) before the age of three are associated with improved long-term individual and family outcomes.4-6 The lifetime costs associated with treating an individual with ASD, estimated to be over $1 million in the United States,7 may be lessened if children are able to access intervention programs earlier in their development to improve communication, adaptive behavior, and other important skills.

Parents and caregivers of children with ASD report concerns about their child’s development early in childhood, with the average age of first concerns found to range from 14 to 19 months.8-11 Findings indicate that parents of children with ASD report significantly earlier concerns as well as more concerns about their child’s development compared to parents of children with other forms of atypical development.12-14 In fact, Zuckerman and colleagues found that children with ASD had younger ages of both initial parental concerns (2.1 years) and initial discussion of concerns with a provider (2.3 years) compared to children with intellectual disability or other developmental delays.14 Despite early parental concerns and increasing evidence for the stability of ASD diagnosis given as young as 18 months,15,16 the ADDM estimates the current median age of diagnosis at 52 months.3 An ASD diagnosis can be delayed up to three years after initial presentation of concerns to a health care provider.14

The gap from initial concern to diagnosis widens when researchers examine differences across racial and ethnic groups. Though the 2018 report from the ADDM also notes that the discrepancies between the prevalence of ASD in Caucasian children compared to African American and Hispanic children has decreased, African American and Hispanic children are still diagnosed later than Caucasian children.17,18 A study by Mandell and colleagues found that while the mean age of diagnosis is 6.3 years for Caucasian children, this increases to 7.9 years in African American children and to 8.8 years in Hispanic children.18 The delays experienced by minority children do not appear to be due to differences in age of developmental concern, as studies have not found a significant relationship between race/ethnicity and age of parental first concern.11,19 Racial/ethnic disparities in ASD diagnosis are likely related to the greater difficulties children from racial/ethnic minority groups experience in accessing and receiving quality health care,20-22 increased risk of misdiagnosis among minority groups,23-25 and factors related to lower socioeconomic status.26,27

Additionally, while the timing of developmental concerns may not vary across racial/ethnic groups, it is possible that they may vary in their nature and/or intensity, which may impact the timing of ASD diagnosis. Although the most commonly reported developmental concerns for children

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later diagnosed with ASD are delays in communication and language, parents frequently report developmental concerns unrelated to core features of ASD, such as motor problems, medical issues, and challenging behaviors. Parental concerns that are more general or not specific to autism were found to be related to earlier age of concern but later diagnosis. The nature of parental concerns can also impact the sensitivity of certain diagnostic instruments, particularly those like the Autism Diagnostic Interview-Revised (ADI-R) which rely heavily on parental report.

It is possible that parents or caregivers of children with ASD from different ethnic/racial groups have varying types of initial developmental concerns regarding their child’s development that they bring to initial screenings and evaluations, impacting the assessment process. These differences may be culturally bound to parents or caregivers’ perceptions of their child’s development, which could contribute to the delay many children from minority backgrounds face regarding an early ASD diagnosis. To investigate the possible relationship between initial developmental concerns and ethnicity, this study explores the types of initial developmental concerns reported by parents or caregivers with children in an early intervention program. The current study hypothesizes that racial group differences exist in the types of initial developmental concerns brought to an initial evaluation.

Method

Participants

Participants in this study were young children enrolled in EarlySteps, Louisiana’s statewide early intervention program under the Individuals with Disabilities Education Act, Part C. Children are eligible for EarlySteps if they have a developmental disability or are at risk for a developmental delay (e.g., due to a medical condition) and are under three years of age. Therefore, all participants in this sample were considered atypically developing and may not be representative of the general population.

All data were extracted from a pre-existing dataset provided for research purposes. Data were collected from 2008 to 2016 and included 17,838 individuals. From this original sample, 1,357 individuals were found to meet Diagnostic and Statistical Manual of Mental Disorders (DSM-5) ASD diagnostic criteria based on clinical record review by a licensed clinical psychologist with over 30 years of experience in the field. These cases were selected for participation. Classifications were made by the clinical psychologist in accordance with diagnostic criteria from the DSM-5 based on a comprehensive review of records and clinical judgement. This process is consistent with previously described methodology utilized in research studies.

Data on racial/ethnic background were missing for 125 individuals, while another 27 individuals did not report any initial developmental concerns; therefore, these participants were removed from the final sample. A total of 1,205 participants were included in the final sample. Demographic information is presented in Table 1. Participants’ age ranged from 13–39 months at the time of assessment, with a mean age of 25.96 months (SD = 4.58). The final sample was 75.4% male and 24.2% female; data on gender were not available for four participants from the final sample. Based on their reported racial background, the final sample was 45.6% African American, 45.1% Caucasian, and 3.8% Hispanic. The racial breakdown of the sample differs from the state of Louisiana, which is 32.6% African American, 59.0% Caucasian, and 5.2% Hispanic. This discrepancy is likely due to the early intervention sample, as minorities are often over-represented in such programs that serve families of low socioeconomic status.

| Table 1. Participant demographics, age at first concern, and ASD symptom severity. |
|---------------------------------|-----------------|-----------------|-----------------|-----------------|-----------------|
| Variable                        | African American (N = 549) | Caucasian (N = 610) | Hispanic (N = 46) | Total (n = 1205) |
|                                 | M (SD)           | M (SD)           | M (SD)           | M (SD)           | F Value         |
| Age in months                   |                  |                  |                  |                  |                 |
| At first concern                | 14.09 (8.04)     | 13.94 (7.92)     | 14.43 (7.13)     | 14.03 (7.94)     | 0.087           |
| At assessment                   | 26.18 (4.46)     | 25.76 (4.63)     | 26.00 (5.11)     | 25.96 (4.58)     | 1.218           |
| BISCUIT-Part 1 Total Score      | 52.95 (19.7)     | 51.88 (20.41)    | 46.98 (18.39)    | 52.18 (20.03)    | 2.03            |
| Gender                          |                  |                  |                  |                  |                 |
| Male                            | 408 (74.3%)      | 468 (76.7%)      | 33 (71.7%)       | 909 (75.4%)      |                 |
| Female                          | 140 (25.5%)      | 139 (22.8%)      | 13 (28.3%)       | 292 (24.2%)      |                 |
| Not specified                   | 1 (0.2%)         | 3 (0.5%)         | 0                | 4 (0.3%)         |                 |

Note: *** p < .001, ** p < .01, * p < .05

Measures

The Baby and Infant Screen for Children with Autism Traits, Part 1 (BISCUIT-Part 1) is a 62-item informant-report measure that assesses ASD symptoms across socialization/nonverbal communication, repetitive behavior/restricted interests, and communication in children 17 to 37 months of age. Parents or caregivers rate each item on a 3-point Likert scale (i.e., 0 corresponds to not different from same aged peers; 1 indicates somewhat different; 2 denotes very different). Previous research has indicated that the BISCUIT-Part 1 has an estimated internal reliability of .87 and correct classification rate of .89. Further, it has been shown to have adequate convergent (i.e., with the Modified Checklist for Autism in Toddlers and the Battelle
Developmental Inventory, Second Edition [BDI-2] Personal-Social domain) and divergent (i.e., with the BDI-2 Adaptive and Motor domains) validity.36

The BISCUIT-Part 1 includes a demographic form which collects information regarding the demographics (e.g., age, gender, ethnicity), developmental milestones, medical history, concerns regarding development, and family history. Parents or caregivers of participants completed this form as part of a larger assessment battery. The demographic form was used to gather information for the current study regarding the child’s ethnicity and the parents or caregivers’ initial concerns regarding their development or behavior.

Procedure

The use of EarlySteps records for research was approved by the Louisiana State University Institutional Review Board and the State of Louisiana’s Department of Health. Personal identifiers (e.g., name, date of birth) were removed from the records by the State of Louisiana’s Office for Citizens with Developmental Disabilities prior to receipt of the database by Louisiana State University. As the data were obtained from a secondary de-identified database, the Institutional Review Board determined that informed consent was not required.

All participants were administered an assessment battery that included the BISCUIT-Part 1 demographic form and the BDI-2 as part of an EarlySteps assessment. Parents or caregivers had the option to complete the BISCUIT-Part 1 as an ASD screener. Parents/caregivers who preferred not to receive an ASD screen signed a refusal form indicating their preference, and were not included in the present study. Service providers with appropriate degrees and certifications or licenses in related fields administered the assessment. These providers included speech therapists, occupational therapists, speech language pathologists, and special instruction educators, among others, all of whom had training in administering the EarlySteps battery. Service providers administered the BISCUIT-Part 1, including the demographic form, orally to parents and caregivers. The purpose of this procedure was to allow providers the opportunity to answer questions or provide clarification as necessary.

Statistical analyses

Statistical analyses were run using SPSS Statistics Software (Version 24). A priori bivariate analyses were conducted to test whether groups differed significantly on demographic variables (i.e., age and gender). A chi-square test was used to test any potential differences in the gender breakdown among racial/ethnic groups (i.e., African American, Caucasian, Hispanic), while analysis of variance (ANOVA) was used to determine whether groups differed in either age at time of evaluation, age of initial developmental concern, or in regards to ASD symptom severity. Chi-square tests were run between groups and each type of initial developmental concern to examine any potential differences across ethnicities. The initial developmental concerns considered in this study included: general/overall concerns, communication, motor, problem behavior, social, feeding, sensory, weight, prematurity, attention, adaptive functioning, and medical. If more than one initial developmental concern was reported by the parent or caregiver, all initial concerns were included in the analyses.

Results

An a priori chi-square test did not indicate any significant differences in gender across groups, $\chi^2(2) = 1.50$, $p > .05$. Additionally, an ANOVA did not reveal any significant differences in the mean age at the time of assessment across ethnicities, $F(2, 1201) = 1.22$, $p > .05$. An ANOVA was also conducted to determine whether groups differed in mean age of initial developmental concern, which did not reveal any significant differences in age of initial developmental concern across racial groups, $F(2, 895) = 0.09$, $p > .05$. The BISCUIT-Part 1 total score was used as a measure of autism symptom severity. An ANOVA did not reveal significant differences in scores of symptom severity across racial groups, $F(2, 1201) = 2.03$, $p > .05$.

To examine the relationships between ethnicity and type of initial developmental concern, chi-square tests were run between groups and each type of concern (Table 2). There were no significant differences between racial/ethnic groups in the frequency of endorsement of initial developmental concerns related to communication, motor, problem behavior, feeding, sensory, weight, prematurity, attention, adaptive functioning, and medical ($p > .05$). Racial/ethnic groups differed significantly in their rates of endorsement for social concerns (Figure 1; $\chi^2 = 18.91$, $p < .001$). Post hoc analysis was conducted to examine the standardized residuals to further understand the association between endorsement of social concerns and racial/ethnic group membership.37,38 Critical values of $\pm 1.96$ ($p < .05$), $\pm 2.58$ ($p < .01$), $\pm 3.29$ ($p < .001$) were used.37 Standardized residuals were statistically significant for endorsement of social concerns in the Caucasian group ($z = 2.7\alpha$, $p < .01$) and the African American group ($z = -2.4$, $p < .05$), indicating that more parents/caregivers in the Caucasian group and fewer parents/caregivers in the African American group endorsed social concerns than would be expected.

<table>
<thead>
<tr>
<th>Type of Concern</th>
<th>Total ($n = 1205$)</th>
<th>African American ($N = 549$)</th>
<th>Caucasian ($N = 610$)</th>
<th>Hispanic ($N = 46$)</th>
<th>$\chi^2$</th>
</tr>
</thead>
<tbody>
<tr>
<td>General/Overall</td>
<td>14.3</td>
<td>12.6</td>
<td>16.2</td>
<td>8.7</td>
<td>4.38</td>
</tr>
<tr>
<td>Communication</td>
<td>70.5</td>
<td>72.9</td>
<td>67.9</td>
<td>78.3</td>
<td>4.84</td>
</tr>
<tr>
<td>Motor</td>
<td>13.6</td>
<td>15.1</td>
<td>11.8</td>
<td>19.6</td>
<td>4.14</td>
</tr>
<tr>
<td>Problem behavior</td>
<td>23.9</td>
<td>25.3</td>
<td>23.0</td>
<td>19.6</td>
<td>1.39</td>
</tr>
<tr>
<td>Social</td>
<td>14.2</td>
<td>10.4</td>
<td>18.4</td>
<td>4.3</td>
<td>***18.91</td>
</tr>
<tr>
<td>Feeding</td>
<td>4.8</td>
<td>3.8</td>
<td>5.7</td>
<td>4.3</td>
<td>2.33</td>
</tr>
<tr>
<td>Sensory</td>
<td>1.3</td>
<td>1.3</td>
<td>1.5</td>
<td>0.0</td>
<td>0.73</td>
</tr>
<tr>
<td>Weight</td>
<td>0.7</td>
<td>0.5</td>
<td>0.8</td>
<td>0.0</td>
<td>0.66</td>
</tr>
<tr>
<td>Prematurity</td>
<td>0.9</td>
<td>0.9</td>
<td>1.0</td>
<td>0.0</td>
<td>0.46</td>
</tr>
<tr>
<td>Attention</td>
<td>1.5</td>
<td>1.1</td>
<td>2.0</td>
<td>0.0</td>
<td>2.23</td>
</tr>
<tr>
<td>Adaptive</td>
<td>1.7</td>
<td>1.8</td>
<td>1.8</td>
<td>0.0</td>
<td>0.85</td>
</tr>
<tr>
<td>Medical</td>
<td>5.5</td>
<td>6.6</td>
<td>4.6</td>
<td>4.3</td>
<td>2.28</td>
</tr>
</tbody>
</table>

Note: *** $p < .001$, ** $p < .01$, * $p < .05$; highest frequency in each row is in bold.
Overall, the most commonly reported initial developmental concerns were related to communication, regardless of ethnicity. For Caucasian families, 67.9% endorsed communication concerns; in African American families, 72.9% endorsed communication concerns. Hispanic families endorsed the largest percentage of communication concerns (78.3%).

Discussion

Parent and caregiver’s initial concerns about their child’s development are an important component of the ASD assessment process, as often parent or caregivers’ initial concerns prompt families to seek out further assessment. The types of initial developmental concerns can influence aspects of the diagnostic assessment that rely significantly on parental report, such as initial conversations with healthcare providers, formal parent interviews, and even the sensitivity of certain diagnostic tools.\textsuperscript{14,28,30} Parents and caregivers also frequently report initial developmental concerns unspecific to ASD symptomology, which may influence delays in ASD diagnosis, regardless of the child’s demographic background (i.e., race/ethnicity, socioeconomic status, geographic region). Because researchers have reported further disparities in the age of ASD diagnosis across racial/ethnic groups, it is critical for both researchers and clinicians to understand factors that contribute to these differences.\textsuperscript{18,26}

The current study investigated whether types of initial developmental concerns reported by parents or caregivers of children who met diagnostic criteria for ASD differed across racial/ethnic groups. Results indicated that the most frequently endorsed initial developmental concerns for all children in the sample, regardless of race/ethnicity, were concerns related to communication (70.5%) and problem behavior (23.9%). When separated by racial/ethnic groups, the most frequently endorsed initial developmental concern was also communication, as 72.9% of African American families, 67.9% of Caucasian families, and 78.3% of Hispanic families reported communication concerns (Table 2). As hypothesized, some racial/ethnic group differences were confirmed regarding initial developmental concerns related to social behaviors (Figure 1). Regarding social behavior, 18.4% of Caucasian families reported this as an initial developmental concern, compared to only 10.4% of African American families and 4.3% of Hispanic families; post-hoc analyses indicated greater endorsement of social concerns in Caucasian families compared to African American and Hispanic families.

These results highlight important issues for families seeking an ASD diagnosis. As stated previously, caregiver report influences specificity of certain ASD diagnostic tools \textsuperscript{30}, however, initial developmental concerns can also impact treatment planning, as interventions are often based on parent or caregiver goals for treatment when children are as young as the early intervention sample utilized in this study. Current estimates describe significant differences in ASD prevalence across racial/ethnic groups, with ASD having a 20% higher prevalence among non-Hispanic white children than non-Hispanic black children and a 50% higher prevalence among non-Hispanic white children than Hispanic children.\textsuperscript{39} These low rates of diagnosis in Hispanic families have been thought to be related to socioeconomic status, though evidence from a large Hispanic community in Texas has found that other socio-cultural factors may impact low rates of ASD diagnosis.\textsuperscript{40} Nearly 80% of Hispanic families in this study reported initial developmental concerns related to communication. For children from Hispanic backgrounds, speech and language delays may be assumed to be due to issues related to a bilingual home environment. Considering that only 4.3% of Hispanic families and 10.4% of African American families reported initial developmental concerns related to socialization, a core symptom of ASD, while 18.4% of Caucasian families reported socialization concerns, it is possible that developmental concerns related to socialization contribute towards differences in rates of ASD identification across ethnic groups, as well. A study by Ratto, Reznick, and Turner-Brown found that Latina mothers in this study demonstrated less awareness of general developmental milestones and of ASD
specifically. Consistent with previous research on the types of initial developmental concerns reported by parents/caregivers and consistent with the results of this study, Latina mothers were more likely to report concerns related to their child’s temperament and problem behavior. For minority families, developmental concerns may be related to other behaviors (e.g., language, feeding) or more general concerns not directly associated with ASD symptomology. Understanding whether this speaks to less awareness of ASD in minority communities or differing cultural expectations of children’s behavior could elucidate these differences found across racial/ethnic groups.

Initial developmental concerns are important for both parents/caregivers and professionals throughout the assessment process. As initial developmental concerns may prompt help-seeking behavior, it is important for pediatricians and other health professionals working with families from diverse backgrounds to validate caregiver developmental concerns in the early steps of the assessment process. Furthermore, health professionals may need to probe for ASD symptomology more specifically with minority families, providing additional examples and information for families who have concerns about their child’s development. It is possible that different cultural beliefs regarding typical child behavior may direct parents or caregivers to focus on different aspects of their child’s development. Though ASD symptomology may be present, the relative importance of different symptoms to the assessment process may prompt parents or caregivers from different racial/ethnic groups to highlight different initial developmental concerns. Future research should aim to understand how a healthcare provider’s cultural competency impacts parental report of concerns, as this information could be useful in the training of providers who interact with families from various cultural, ethnic, socioeconomic, and other diverse backgrounds.

The current study presents several limitations which are important to note when interpreting results. First, the study relied solely on caregiver report of initial developmental concerns, which introduces the possibility of recall bias. However, due to the fact that the data were collected from an early intervention sample (i.e., children are younger than 36 months), recall bias effects are likely minimal. Another limitation relates to collapsing the types of initial developmental concerns into such broad categories, which may overlook slight but meaningful differences in parent or caregiver report. Additionally, the sample was taken from an early intervention program for children with developmental delays in a very specific geographic region of the country, and as such may not be representative of the entire U.S. population. However, the sample studied is diverse and provided the researchers with an opportunity to explore these nuances in types of concerns in populations often underrepresented in research samples. A broader limitation in this study regards the conflation of race and ethnic categories and their use as independent variables, as well as the use of these categories as a proxy for culture. This is an issue that has been raised within the area of multicultural research and the field of psychology. This methodology is certainly not ideal but was necessary given the constraints of available demographic data, underscoring the need for such information to be collected with more nuance in future research. Despite these limitations, these findings represent a preliminary step towards a better understanding of how parent/caregiver initial developmental concerns may vary across ethnic and cultural groups. Future research should elucidate the cultural differences within the Hispanic group, which is culturally heterogeneous, as well as within other ethnic groups.

Further research is necessary to examine factors that impact the formation of developmental concerns. Likewise, greater understanding of specific cultural beliefs related to child development, the influence of socioeconomic status and parent or caregiver education level on developmental concerns, exploration of the cultural biases of healthcare providers, and other factors that may impact the assessment process are all crucial to understanding the experience of minority families in receiving an ASD diagnosis.

Disclosure Statement
Deann Matson, Dr. Johnny Matson’s wife, is the sole owner of the Baby and Infant Screen for Children with autism Traits (BISCUIT), which is sold by her company.

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References


