Factors related to parental age of first concern in toddlers with autism spectrum disorder

Maya Matheis, Johnny L. Matson, Claire O. Burns, Xinrui Jiang, W. Jason Peters, Michael Moore, Kaitlin A. de Back & Jasper Estabillo

To cite this article: Maya Matheis, Johnny L. Matson, Claire O. Burns, Xinrui Jiang, W. Jason Peters, Michael Moore, Kaitlin A. de Back & Jasper Estabillo (2016): Factors related to parental age of first concern in toddlers with autism spectrum disorder, Developmental Neurorehabilitation, DOI: 10.1080/17518423.2016.1211186

To link to this article: http://dx.doi.org/10.1080/17518423.2016.1211186

Published online: 11 Aug 2016.
Autism spectrum disorder (ASD) is a prevalent neurodevelopmental disorder characterized by deficits in social communication and restricted/repetitive behavior patterns that can result in lifelong impairments. Although children can be diagnosed with ASD as early as 18 months of age, the majority of children in the United States do not receive a diagnosis before the age of 5 years. Early diagnosis for ASD is critical as it enables the child and the family to access early interventions. The age at which parents or caregivers first develop concerns about their child’s development has been shown to be correlated with the age of ASD diagnosis.

Evidence suggests that early behavioral interventions for ASD are related to substantial improvement in social behavior, intellectual ability, adaptive behavior, symptom severity, and challenging behaviors. Higher rates of improvement in these domains are associated with a younger age at intervention initiation. In particular, early intensive behavioral intervention (EIBI) for preschool-aged children has been demonstrated to be evidence-based, with research indicating significant improvements in IQ and adaptive behavior.

With this emphasis on early identification of ASD, research has focused on the first concerns of parents of children with ASD. Previous reports of mean age of first concern (AOC) for children with ASD range from 17 to 19.6 months. Deficits in communication and language have consistently been reported as the most frequent and reliable first concerns of parents of children with ASD, while concerns related to other typical social and behavioral deficits characteristic of ASD individuals are not frequently reported.

At 12 months of age, parents of children with ASD were found to have significantly more concerns about their child’s development when compared to parents of children with other delays. Children with ASD were also found to have earlier AOC compared to atypical developing children without ASD. Earlier AOC has been linked to comorbid intellectual disability, presence of medical problems, and deficits in speech and social adaptation. Ethnicity and geographic factors have not been found to be related to AOC, while research on gender and birth order has had mixed results.

To further explore and extend the findings of previous research on AOC, this study aimed to answer the following questions: First, what is the average age of first concerns among parents and caregivers of toddlers with ASD? Second, what types of first concerns are the most common among parents and caregivers of toddlers with ASD? And third, what factors predict earlier age of the first concern for toddlers with ASD?

Methods

Data for this study were obtained from EarlySteps, the early intervention program of the state of Louisiana, via the Louisiana State Office for Citizens with Developmental Disabilities (OCDD). EarlySteps provides services to qualifying children from birth to 36 months of age with a developmental delay or medical condition likely to result in a developmental delay under the Individuals with Disabilities Education Act, Part C, a United States federal law.
Participants and sample

Participants from this study were sampled from a version of the EarlySteps database provided for research purposes. The original sample (n = 9348) included infants and toddlers screened for ASD by EarlySteps between February 2008 and October 2015. Children who met criteria for ASD were selected for participation in the study based on a diagnostic algorithm applied by a clinician with over 20 years of experience in assessing ASD (n = 1244). Data on both AOC and the type of first concern were missing for 18 cases, which were removed from the sample. The final sample for analysis included 1226 participants who all had information available on types of first concerns, and for whom 895 had data on AOC. Characteristics of the sample are reported in Table 1. The age participants at the time of assessment ranged from 13 to 39 months, with an average of 26.01 months (SD = 4.65). The majority of the sample was male (75.6%). With regard to ethnicity, 45.8% of the sample was white, 41.8% was African American, and 10.1% were of other ethnicity. Additionally, 19.5% of participants had a family member with ASD. The demographics of this sample differed slightly from the demographics of the State of Louisiana as a whole (i.e., approximately 63.4% white and 32.5% African American), but in a pattern that is consistent with the fact that the EarlySteps program tends to service low socioeconomic status families.

Measures

Battelle developmental inventory, second edition (BDI-2)

The BDI-2 is a developmental assessment for early childhood developmental milestones across five domains: personal/social, adaptive, motor, communication, and cognitive. Designed for use with children from birth through the age of 7 years 11 months, the BDI-2 is administered using a combination of caregiver interviews, structured activities, and behavior observation in the natural environment. Items are scored as “0” (did not demonstrate ability in this skill), “1” (emerging skill), or “2” (ability in this skill). A developmental quotient (DQ) is calculated for each subdomain and combined to form a total DQ on a standardized scale. The criterion and content validity of the BDI-2 has been observed in multiple populations, including children with developmental delays, motor delays, speech and/or language delays, and ASD. A moderate correlation has been found between the BDI-2 and the Vineland Adaptive Behavior Scale – 2nd Edition. The BDI-2 has been demonstrated to have excellent internal consistency for the total computed score and test–retest reliability above 0.80 for each of the individual subdomains and the total score.

Baby and infant screen for children with autism traits – part 1 (BISCUIT: Part 1)

The BISCUIT is a comprehensive assessment of symptoms of ASD, comorbid symptoms, and challenging behaviors designed for use with infants and toddlers. The BISCUIT: Part 1 measures levels of ASD symptoms and is used as a screening measure for ASD within the EarlySteps program. The BISCUIT: Part 1 is administered to caregivers who use a 3-point Likert scale to compare their child to typically developing children of the same age on 62 items: 0 (not different; no impairment), 1 (somewhat different; mild impairment), or 2 (very different; severe impairment). The measure also includes a Demographic Form that collects relevant demographic information, including AOC, types of first concern, gender, age, ethnicity, relevant medical history, information about developmental milestones, and family history of ASD. The BISCUIT: Part 1 has been demonstrated to have an overall classification rate of 0.88 and good internal reliability. 

Procedure

Screening and diagnosis

Children enrolled in EarlySteps have the option of undergoing an ASD screening at each assessment time point alongside other standard tests and services administered as part of EarlySteps services, including the BDI-2. ASD screenings consist of the BISCUIT: Part 1, which is conducted in a one-on-one interview with a parent or caregiver. De-identified data from the BISCUIT: Part 1 and the BDI-2 were shared for research purposes. Diagnostic classifications regarding ASD were made for research purposes for all participants by a licensed clinical psychologist with over 20 years of experience using an algorithm for ASD that mapped data from the BISCUIT: Part 1 and BDI-2 onto DSM-5 ASD symptom criteria. The sample for the current study was comprised of children screened for ASD by EarlySteps using the BISCUIT: Part 1 who were determined to meet DSM-5 criteria for ASD.

Testers and test administration

All assessments were conducted in the child’s home or other private setting. Test administrators were EarlySteps service providers, each of whom held an appropriate degree and certification or licensure, including those in the fields of special education, social work, occupational therapy, speech therapy, physical therapy, speech–language pathology, and psychology. Each test administrator was trained and experienced in administering the BDI-2 as well as the BISCUIT: Part 1.

Ethical considerations

The Louisiana State University Institutional Review Board and the State of Louisiana’s Department of Health and Hospitals Institutional Review Board have approved the use of data from EarlySteps for research purposes. All procedures were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. Personal identifiers of EarlySteps participants, including name and date of birth, were removed from the database by OCDD before receipt.

Variables

Age of first concerns (AOC)

AOC was defined as the age of a child at which the parent or caregiver first developed concerns about his or her development. These data are based upon caregiver report and is measured continuously in months. Data on AOC, obtained
from the BISCUIT: Part 1 Demographic Form, were missing at random for approximately 27% of the sample. Listwise deletion for cases without data available for AOC was used in all analyses involving this variable as there were no found differences between participants with or without these data.

**Types of first concern**

Caregivers reported on the types of first concerns regarding their child’s development as part of the BISCUIT: Part 1 demographics section. Respondents had the option of listing more than one type of concern. Responses were recoded dichotomously into the following categories (0 = concern not present, 1 = concern): general development, communication, language/speech, motor, problem behavior, social, feeding, sensory, weight, prematurity, attention, adaptive functioning, and related to a medical condition. All concerns not falling into one of these categories were recoded into the category of other concerns. The categories of communication and language/speech were differentiated due to the high occurrence of both categories. In regard to the differentiation between the two, concerns reported with the precise term “communication” were coded as such, and those that referenced language, speech, word-use, or articulation were coded as language/speech concerns.

**ASD symptom severity**

The total score from the BISCUIT: Part 1 was used as an indication of ASD symptom severity.

**Developmental delay**

Data on developmental delay were obtained from the BDI-2 based on DQ total score. A participant’s total DQ score was recoded dichotomously (0 = no developmental delay, 1 = developmental delay) using the cutoff criteria recommended by the measure, which specifies that standardized scores two standard deviations below the mean (standardized scores ≤ 70) indicates developmental delay.

**Gender**

Data on a child’s gender were obtained from the BISCUIT: Part 1 demographics section. Male gender was used as the reference category (0 = male, 1 = female).
**Age at screening**

The participant’s age in months at time of screening was included in the analysis as a continuous variable.

**Ethnicity**

Data on a child’s ethnicity were obtained from the BISCUIT: Part 1 demographic section. Response categories included African American, Caucasian, Hispanic, and other. Because of the small percentage of participants coded as Hispanic, the “Hispanic” category was collapsed with “other.” These data were recoded into dummy variables for white (0 = non-white, 1 = white), African American (0 = non-African American, 1 = African American), and other (0 = non-other, 1 = other).

**Birth weight**

The child’s birth weight, measured in pounds, was obtained via caregiver report as part of the BISCUIT: Part 1 demographics section.

**Previous existing diagnoses**

Information about existing medical and developmental diagnoses was collected as part of the BISCUIT: Part 1 demographics section based on caregiver report. The following diagnoses were coded dichotomously (0 = diagnosis not present, 1 = diagnosis): ASD, premature birth, global developmental delay (GDD), Down syndrome, seizure disorder, hearing difficulties, vision difficulties, cerebral palsy, chronic ear infections, gastrointestinal disorders, allergies, asthma, and intellectual disabilities. All other diagnoses not falling into one of these diagnostic categories were recoded into the following categories: (1) other medical diagnosis, or (2) other genetic disorder.

**Family member with ASD**

Caregivers were asked to list any known family members with ASD or whom had been suspected as having ASD as part of the BISCUIT: Part 1 demographics section. This variable was recoded dichotomously (0 = no family members with ASD, 1 = family member(s) with ASD).

**Data analysis**

Statistical analyses were performed using SPSS Statistics (Version 22). Univariate analyses were conducted to describe sample characteristics and perform variable diagnostics and to report the mean age of first concern among participants. Bivariate analyses, including Pearson’s correlation and independent t-tests, were conducted to describe the relationships of the variables being investigated. Multiple regression was conducted to determine the predictive influence of independent variables on the dependent variable, AOC.

**Results**

**Descriptive results**

Table 1 reports on characteristics of the sample as well as descriptive statistics for all variables used in analysis. The mean AOC was found to be 13.97 months (SD = 7.86). Figure 1 depicts a histogram of AOC among the sample, which shows that the most frequent AOC were 12 (16.87%), 18 (15.08%), 24 (12.29%), and 0 (11.51%) months of age. The most common type of first concern among the sample was speech/language (38.7%), followed by communication (33.9%) and problem behavior (24.0%).

**Bivariate results**

Bivariate analysis results between AOC and independent variables are presented in Table 1. Independent t-tests and one-way analysis of variance (ANOVA) were conducted to examine the differences in AOC in categorical groups, while Pearson’s correlation was used to examine the relationship between AOC and continuous independent variables. Total BISCUIT: Part 1 score had a small negative correlation with AOC, r(894) = −.19, p < .001, as did age at screening, r(894) = −.27, p < .001. Birth weight, r(827) = .22, p < .001, had a small positive correlation with AOC. The difference in AOC between males and females was significant, t(889) = −2.83, p < .01, with females having a younger AOC (M = 12.65, SD = 8.19) compared to males (M = 14.38, SD = 7.72). Children with developmental delay (BDI DQ ≤ 70) had significantly lower AOC than children who did not, t(878) = −3.70, p < .001. There was not a significant difference in AOC between ethnic groups, nor between children with family members with ASD and those without.

Children with first concerns in the categories of communication, t(884) = 5.98, p < .001, speech/language, t(884) = 6.87, p < .001, problem behavior, t(884) = 3.18, p < .01, and social, t(884) = 2.76 p < .01, were found to have significantly later AOC than children without these concerns. Conversely, children with first concerns related to general development, t(884) = −8.08, p < .001, motor, t(884) = −7.42 p < .001, feeding, t(884) = −2.61, p < .01, weight, t(884) = −3.20, p < .001, prematurity, t(883) = −4.72, p < .001, and related to a medical condition, t(884) = −7.33, p < .001 were found to be have significantly earlier AOC than those without these concerns. The type of first concerns with the highest mean AOC were communication (M = 16.26, SD = 6.34), speech/language (M = 16.20, SD = 6.91), and problem behavior (M = 15.57, SD = 7.43), whereas prematurity (M = 2.45, SD = 5.03), weight...
A multiple regression model was created using AOC as the dependent variable regressed on the variables found to be significantly related to AOC in bivariate analysis as covariates. The categories of concerns related to prematurity and medical conditions were excluded from the model, despite being significantly related to AOC, due to their relationship with previous medical diagnostic categories. Table 2 presents the full list of predictor variables included in the model, as well as model results. Assumptions for multiple regression analysis were found to be met for the model. The model was found to significantly predict AOC, F(21, 803) = 23.70, p < .001, and explain 37% of the variance in AOC, R² = 0.39; adjusted R² = 0.37.

Gender, birth weight, and developmental delay were not found to significantly predict AOC when all other variables were controlled for within the model. Age at screening, b = .39, t = 7.84, p < .001, and total BISCUIT: Part 1 score, b = −0.05, t = −4.04, p < .001 were significant predictors of AOC, with older age at screening associated with later AOC and higher severity level scores associated with earlier AOC. Concerns related to general development, b = −1.56, t = −2.03, p < .05, and motor, b = −3.83, t = −5.93, p < .001, were found to be significant predictors of earlier AOC. Conversely, concerns related to communication, b = 4.03, t = −2.03, p < .001, language/speech, b = 4.32, t = 7.58, p < .001, were significant predictors of later AOC, with results indicating that children with initial parental concerns related to communication or speech/language have an AOC approximately 4 months later than those with other first concerns.

Previous diagnosis of premature birth, b = −3.54, t = −4.01, p < .001, seizures, b = −4.26, cerebral palsy, b = −4.39, t = −2.51, p < .05, t = −3.62, p < .001, other genetic disorder, b = −3.58, t = −2.98, p < .001, or other medical diagnosis, b = −1.93, t = −2.98, p < .01, significantly predicted AOC. Results indicated that AOC was 3.54 months earlier for children with premature birth, 4.26 months earlier for children with seizures, 4.39 months earlier for children with cerebral palsy, 3.58 months earlier for children with other genetic disorders, and 2.98 months earlier for those with other medical diagnoses compared to children with different first concerns.

### Table 2. Results of multiple regression analysis of factors related to age of first concerns (n = 803).

<table>
<thead>
<tr>
<th>Predictor</th>
<th>b (95% CI)</th>
<th>SE</th>
<th>t</th>
<th>p Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Constant</td>
<td>3.60 (−0.68, 7.28)</td>
<td>1.87</td>
<td>1.92</td>
<td>.055</td>
</tr>
<tr>
<td>Age at screening</td>
<td>.39 (.29, .49)</td>
<td>.05</td>
<td>7.84</td>
<td>.000***</td>
</tr>
<tr>
<td>Birth weight (in pounds)</td>
<td>.24 (−.05, .52)</td>
<td>.15</td>
<td>1.60</td>
<td>.109</td>
</tr>
<tr>
<td>Severity level (BISCUIT total score)</td>
<td>−.05, (−.07, −.03)</td>
<td>.01</td>
<td>−.40</td>
<td>.004***</td>
</tr>
<tr>
<td>Developmental delay (BDI DQ)</td>
<td>.12 (−.84, 1.08)</td>
<td>.49</td>
<td>−.25</td>
<td>.805</td>
</tr>
</tbody>
</table>

Note. Adjusted R² = 0.37, F(21, 803) = 23.70, p < 0.001.  
**p < .001; *p < .01; *p < .05.

### Discussion

Early identification of ASD has become increasingly important with the accumulation of evidence demonstrating the efficacy of early behavioral interventions on improving outcomes for individuals with ASD. Early recognition of atypical development by parents and caregivers has been found to be related to earlier ASD diagnosis, which in turn increases access to services and supports for families. The current study examined the AOC of parents and caregivers of toddlers with ASD as well as factors related to AOC, with the hope of informing ASD screening practices.

The average AOC among the sample of children ranging in age from 13 to 39 months was 13.97 months. The average AOC of the current study was younger than has been found in previous research, which may be related to the young age range of the sample and the fact that the sample was obtained from a statewide early intervention program targeting children with developmental delays. The most frequently reported AOC were 24, 18, 12, and 0 months of age. The high rates of caregiver reported concerns at 0 months are likely related to prematurity or conditions present at birth, whereas high rates of concerns at 24, 18, and 12 months may be due to these being recognizable age markers typically associated with common developmental milestone periods.

The most frequently reported concerns were those related to speech/language, communication, and problem behaviors. These results are not surprising, given that delays in language development and deficits in communication may be related to the social communication diagnostic feature of ASD and that challenging behaviors occur at high rates amongst children.
with ASD. These findings are consistent with previous studies that have identified language and communication deficits, as well as challenging behaviors as some of the most frequently reported first concerns of parents of children with ASD.

Multivariate analysis revealed several significant predictors of AOC, including age at screening, with younger ages at screening predicting younger AOC, and severity level, with higher total BISCUIT: Part I scores predicting younger AOC. Interestingly, although significant differences in AOC between males and females were found in initial analysis in line with previous research, gender was not a significant predictor of AOC when other variables were controlled for within the model. The presence of developmental delay was also not found to be a significant predictor of AOC.

The categories of first concern that were found to significantly predict AOC were general development, communication, language/speech, and motor. Concerns related to general development and motor skills predicted earlier AOC. This is consistent with previous evidence indicating that early motor delays are associated with increased risk for ASD in young children. Conversely, children with first concerns related to communication and language/speech were found to have AOCs approximately 4 months later than children with different initial concerns. This may be due to the fact that verbal and nonverbal communication emerges later in development than features related to the other concerns, such as motor, feeding, and medical conditions. For instance, speech typically emerges after multiple significant motor milestones (e.g., rolling over, crawling), so it follows that abnormal motor development would be identified prior to communication concerns. Certain concerns are more likely to appear during infancy, while deficits in communication or social skills may be more apparent at later developmental stages.

It is also possible that parents are more likely to recognize physical symptoms, such as a motor skill deficit or feeding difficulty, than delays in receptive or expressive communication. Additionally, some of the symptoms characteristic of social deficits, such as eye contact and recognizing the emotions of others, could be considered subtler and may be more difficult for parents to recognize in young children. Considering that social demands increase with age, some social deficits may become more pronounced as children get older and may not recognizable at such young ages. Thus, in addition to the varying developmental stages for each of these factors, the saliency of symptoms may also impact the age of first concern. Previous research has found that despite later AOC, children of parents who reported concerns specifically related to ASD symptom domains were diagnosed with ASD earlier than those with concerns about general development. As a result, the relative delay in concerns related to language/speech and communication compared to other concern areas may not necessarily indicate a delay in ASD diagnosis.

Relatedly, the results of the current study suggest that children with co-occurring medical disorders have earlier AOC than those without medical conditions. Previous diagnoses in the categories of premature birth, seizures, cerebral palsy, other genetic disorder, and other medical diagnoses were found to significantly predict earlier AOC. Premature birth has previously been linked to earlier AOC, as have other medical conditions. ASD has been demonstrated to co-occur at high rates with other developmental and medical disorders. Kielinen and colleagues found that medical or genetic disorders (e.g., tuberous sclerosis, Down syndrome, fragile X syndrome, epilepsy, hydrocephalus, cerebral palsy) existed in 12.3% of children with ASD. Similarly, Chakrabarti and Fombonne found that 9.3% of children with some sort of pervasive developmental disorder have an associate medical condition.

While these results pertaining to AOC are consistent with several previous studies, alternative evidence suggests that children with medical disorders tend to have a later age of diagnosis of ASD. This contrast may be due to the fact that the medical condition is the primary concern of the caregivers and physicians, and so autism symptoms may go unnoticed. Caregivers may also assume that any developmental delays could be attributed to the medical concern and not be recognized as indicative of an ASD.

Early intervention for children with ASD has been shown to be one of the most important factors for prognosis, and recent research indicates that younger children show greater responsiveness to treatment than children who begin treatment at an older age. It is therefore crucial for children with ASD to receive a diagnosis as early as possible so that they can begin receiving services. Evidence exists that screening in children at 18–24 months can assist in early detection. It is important for physicians in primary care settings to conduct routine screenings and provide adequate information to caregivers so that they can recognize early signs of developmental delay.

Several limitations should be considered when interpreting the results of this study. As the sample was obtained from one statewide early intervention program, the generalization of the findings may be limited. Data related to age of first concern were based on caregiver report, which may be subject to recall error or bias. Additionally, the use of a diagnostic algorithm to classify participants according to DSM-5 ASD criteria is not comparable to a clinical diagnosis obtained from a comprehensive assessment for ASD. That being said, the large sample size of young children as well as the ethnic diversity of the sample are major strengths that should also be considered.

Further research is needed to elucidate the relationship between the age of first concerns (and subsequent diagnosis) and the types of concerns. Specifically, future studies should focus on the association between co-occurring medical diagnoses and ASD. It was beyond the scope of the current study to evaluate different categories of medical conditions, but additional research is necessary to understand the impact of the severity levels of health issues.

In addition to further investigation of medical conditions in children with ASD, subsequent research should also focus on identifying factors that influence age of first concern, as these affect the age of diagnosis. The finding that concerns that tend to be associated with the social communication impairments characteristic of ASD (i.e., communication, language, social skills) are recognized later than other concerns may indicate that better education of parents and increased public awareness of autism symptoms may lead to these symptoms being
identified sooner. The current study has significant implications for age of diagnosis, since a better understanding of the relationship between age of first concerns and the type of concern may help inform policies for early screenings and facilitate earlier identification and diagnosis.

**Declaration of interest**

Deann Matson, Dr. Johnny Matson’s wife, is the sole owner of the Baby and Infant Screen for Children with autism Traits (BISCUIT) and sells the scale.

**References**


