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BRIEF COMMUNICATION

Barriers to early identification of autism in Brazil

Sabrina H. Ribeiro,[1] Cristiane S. de Paula,[1,2] Daniela Bordini,[1] Jair J. Mari,[1] Sheila C. Caetano[1]

[1]*Ambulatório de Cognição Social Marcos Tomanik Mercadante (TEAMM), Departamento de Psiquiatria, Universidade Federal de São Paulo (UNIFESP), São Paulo, SP, Brazil.* [2]*Programa de Pós-Graduação em Distúrbios do Desenvolvimento, Universidade Presbiteriana Mackenzie, São Paulo, SP, Brazil.*

Objective: Parents of children with autism spectrum disorders (ASD) seem to perceive that their child's development is not following the normal pattern as early as the first year of life. However, ASD children may not receive a diagnosis until they are of preschool age, especially in low- and middle-income countries. The objective of this study was to evaluate the pathway between initial parental concerns about atypical child development and ASD diagnosis in Brazil.
Methods: Nineteen mothers whose children had been diagnosed with ASD participated and were interviewed. The ASD group consisted of two girls and 17 boys, with a mean age of 93.0 months (SD 48.4 months; range 39-197 months).
Results: Mothers had their first concerns regarding ASD when children were 23.6±11.6 months old, but formal diagnosis occurred at a mean ± SD age of 59.6±40.5 months, corresponding to a 3-year delay. Most mothers felt discouraged to address their concerns due to negative experiences with health professionals.
Conclusion: In Brazil, mothers perceived the first signs of ASD in their children at an age similar to that reported in other countries, but the diagnosis of ASD seemed to be delayed. Consistent with the literature, mothers reported negative experiences with health professionals during the pathway to achieving ASD diagnosis.

Keywords: Autism spectrum disorder; parental identification; delayed diagnosis; low-and middle-income countries

Introduction

Atypicality in the core domains of social communication and social interaction, as well as the presence of repetitive behaviors between the ages of 12 and 24 months, have been proposed as markers for early identification of autism spectrum disorders (ASD).[1]

Parents seem to perceive that their child's development is not following the normal pattern as early as in the child's first year of life.[2] However, children with ASD often do not receive a diagnosis until they are of preschool age, especially in low-and-middle-income countries (LMICs).[3]

Later ASD diagnosis has been associated with family income, ethnicity, child impairment, clinical presentation, and parental concern about initial symptoms.[4] For example, children who live in poverty tend to be diagnosed at an older age.[3]

Research about the ASD diagnosis process in LMICs is still scarce. In Vietnam, the mean (standard deviation [SD]) age at first diagnosis was 30.6 (15.4) months.[5] In Venezuela, most children were diagnosed in the preschool years.[6] A review of early ASD identification in LMICs showed that parental concerns started when children were on average 21-24 months old, while age at diagnosis ranged from 45-57 months old.[7] The mean age at ASD diagnosis was very similar across LMICs, but older than in high-income countries.[7] To the best of our knowledge, there are no data about age at ASD diagnosis in Brazil.

The aim of this study was to evaluate the pathway between initial parental concerns about atypical child development and ASD diagnosis in a LMIC, Brazil, through direct in-depth interviews with parents.

Methods

We invited 19 mothers (mean ± SD age, 37.2±5.6 years; range, 29-49 years) whose children had been diagnosed with ASD to complete in-depth interviews. The ASD children were two girls and 17 boys, with a mean ± SD age of 93.0±48.4 months (range, 39-197 months) at interview time. Most of the families were middle-class, according to the Brazilian Association of Market Research Companies criteria, 2012 version (Associação Brasileira de Empresas de Pesquisa, http://www.abep.org/criterio-brasil).

All children were recruited from a specialty clinic for ASD at Universidade Federal de São Paulo (UNIFESP), Brazil. ASD diagnosis was ascertained by our team of specialists, based on DSM-IV criteria.[8] We also used the Autism Behavior Checklist (ABC)[9] (cutoff $\geqslant$ 47) and Autism Screening Questionnaire Scales (ASQ) (cutoff $>$ 15).[10]

Correspondence: Sabrina Helena Bandini Ribeiro, Rua Borges Lagoa, 570, 5º andar, CEP 04038-000, São Paulo, SP, Brazil.
E-mail: sabandini2@yahoo.com.br
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The semi-structured interview was based on Mandell's semi-structured questionnaire and adapted to Brazil by our team.[3] The main topics of the interview were: first concerns, when the diagnosis was established, and attitudes towards those concerns. Examples of questions were: "How old was your child when you first suspected of any strange or atypical behavior?," "What were the first signs or symptoms of ASD that you noticed?," "After observing these early signs, how long did you take to ask for professional advice?," and "Who was the first professional or first service you talked to about these signs?." Interviews were recorded in shorthand by a clinical psychologist (SHR).

The study was approved by UNIFESP ethics committee. Statistical analyses were performed in SPSS for Windows version 14, and a two-tailed significance level of 5% ($p < 0.05$) was set. Means, standard deviations, and percentages were calculated.

Results

Mothers were asked to recall their first three concerns about atypical development of their child. These concerns were: delay in verbal speech; failure to respond to his/her name; and lack of eye contact and agitation.

Mothers' first concerns occurred when children were 23.6±11.6 months old (range, 2-48 months), but a formal diagnosis of ASD was established only at a mean ± SD age of 59.6±40.5 months (range, 24-192 months), which corresponds to an average diagnostic delay of 36 months. Notably, 68.4% of mothers had their first suspicion of atypical development before their children were 2 years old (Figure 1).

Most mothers (79%) sought help within 3 months of first suspicion. Mothers mentioned their concerns first to pediatricians (84.2%) or specialists (15.8%, mainly pediatric neurologists). Only one-third (36.9%) of the children first seen by a pediatrician were further evaluated or referred for suspicion of atypical development. Mothers who had their concerns dismissed were told by their pediatricians: "children should not be compared to each other," and "boys have a slower development rate or are more agitated than girls." Most mothers described their interactions with the pediatrician as negative experiences (56.3%), as they felt discouraged to express their concerns again.

Discussion

Most mothers first became concerned about atypical development before their children were 2 years old, but children were diagnosed with ASD at a mean age of 5 years old. This delay between first parental concern and formal diagnosis of ASD is similar to that reported in other countries,[3,5,7,11-14] including LMICs.[5,7] Moreover, greater parental concern about initial symptoms seems to be associated with earlier ASD diagnosis in high-income countries,[4] and that could be the case in LMIC as well.[15]

In our sample, the first parental concerns were signs that have been consistently described as potential markers of ASD in the first years of life,[3] but most mothers had their concerns dismissed by pediatricians. They described their dismissal as negative experiences (56.3%), and felt discouraged to express their concerns again. As a result, they attributed an important impact on delay in diagnosis to these experiences. This is in agreement with previous studies.[12,15]

One could suppose that pediatrician-mother interactions may lead to the delay of formal ASD diagnosis by three main mechanisms: 1) by disregarding spontaneously reported symptoms, pediatricians may prevent parents from coming forth with later concerns that are more specific to ASD diagnosis; 2) by not investigating symptoms that have low specificity but high sensitivity to child psychopathology, such as agitation; and 3) by not asking about the child's development and specific symptoms related to ASD.

The World Health Organization emphasizes that LMICs should have an early ASD detection program.[11] Likewise, the Brazilian Academy of Pediatrics also promotes the importance of early diagnosis, and the Brazilian Ministry of Health has released guidelines for ASD diagnosis. Nevertheless, in most Brazilian public health facilities,

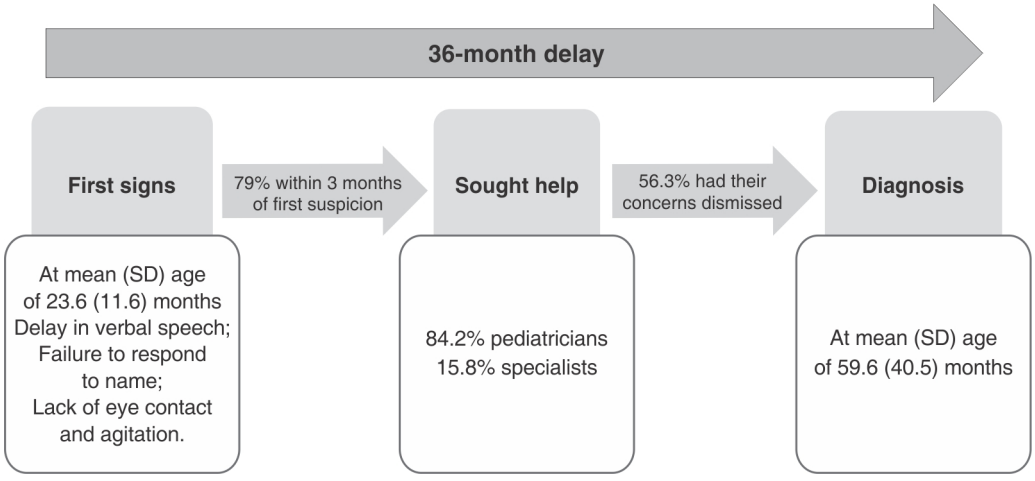

Figure 1 Pathway between first signs of autism spectrum disorder and its diagnosis in Brazil. SD = standard deviation.

validated protocols or screening algorithms for early ASD detection have not been implemented.

Limitations of this study include the small sample size and potential selection bias, as the sample was collected at a tertiary university hospital. Reporting bias may also be a concern, since this was a cross-sectional study.

In conclusion, in the current Brazilian scenario, parents seem to perceive the first signs of ASD at an age similar to that reported worldwide, but the diagnosis of ASD appears to be delayed.

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Disclosure

The authors report no conflicts of interest.

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