Autism diagnosis: Relation among contextual, family and child factors

Regina Basso Zanon[1]
Universidade Federal do Rio Grande do Sul, RS, Brasil

Bárbara Backes
Universidade Federal do Rio Grande do Sul, RS, Brasil

Cleonice Alves Bosa
Universidade Federal do Rio Grande do Sul, RS, Brasil

Abstract: While recognizing that some difficulties that characterize the Autistic Spectrum Disorder (ASD) can be identified in early infancy, study results show that many children are not diagnosed before school age, which may delay their entry in early intervention programs, as well as specific parental guidance. This study aimed to investigate the age the ASD diagnosis is reached in Brazilian participants and their relationship with the contextual, family and child variables. We conducted a cross-sectional and correlational study, based on data collected in a survey (online) and involving 136 parents of individuals with ASD. Among the main findings, the moderate and positive correlation between the variables child's age and age of completion of the ASD diagnosis stands out. The implications of the results and the methodological limitations of the study were discussed.

Keywords: autism; diagnosis; survey; child; family.

DIAGNÓSTICO DO AUTISMO: RELAÇÃO ENTRE FATORES CONTEXTUAIS, FAMILIARES E DA CRIANÇA

Resumo: Embora se reconheça que algumas dificuldades que caracterizam o Transtorno do Espectro Autista (TEA) possam ser identificadas ainda na primeira infância, os resultados dos estudos mostram que muitas crianças não são diagnosticadas antes do período escolar, podendo retardar o ingresso delas em programas de intervenção precoce, assim como a orientação parental específica. O presente estudo objetivou investigar a idade de realização do diagnóstico do TEA em participantes brasileiros e a sua relação com variáveis contextuais, familiares e da criança. O estudo é de natureza transversal e correlacional, sendo realizado com base em dados coletados em uma *survey* (on-line) e envolvendo 136 pais de indivíduos com TEA. Entre os principais achados, destaca-se a correlação moderada e positiva encontrada entre as variáveis idade do filho e idade da realização diagnóstico do TEA. As implicações dos resultados e as limitações metodológicas do estudo foram discutidas.

Palavras-chave: autismo; diagnóstico; survey; criança; family.

DIAGNÓSTICO DEL AUTISMO: RELACIÓN ENTRE FACTORES CONTEXTUALES, FAMILIARES Y DEL HIJO

Resumen: Las dificultades que caracterizan el trastorno del espectro autista (TEA) se pueden identificar en la primera infancia, pero los resultados de los estudios muestran

[1] **Mailing address:** Regina Basso Zanon, Instituto de Psicologia, Universidade Federal do Rio Grande do Sul, Rua Ramiro Barcelos, 2600, 90035-003 – Porto Alegre, RS, Brasil. Phone: +55 51 3308-5261. *E-mail:* rebzanon@gmail.com.

que muchos niños no son diagnosticados antes de la edad escolar, lo que puede retrasar su entrada en programas de intervención temprana, así como la orientación de los padres. Este estudio tuvo como objetivo investigar la edad de finalización de diagnóstico de TEA en los participantes de Brasil y su relación con las variables contextuales, de la familia y del niño. Este estudio tuvo como objetivo investigar la relación entre las variables de los niños, familiares y contextuales y la edad de finalización del diagnóstico de TEA en participantes brasileños. Se realizó un estudio transversal y correlacional, basado en datos colectados en un survey (*online*). Los participantes fueron 136 padres de individuos con TEA. Entre los principales resultados se destaca la correlación moderada y positiva entre las variables edad del niño y edad de finalización del diagnóstico de TEA. Se discuten las implicaciones de los resultados y las limitaciones metodológicas del estudio.

Palabras clave: autismo; diagnóstico; survey; niño; familia.

Introduction

Autism Spectrum Disorder (ASD) is defined by early problems in socio-communicative development and the presence of repetitive and stereotyped behaviors (*American Psychiatric Association* [APA], 2013). Despite acknowledging that some difficulties characteristic of ASD can be identified in early childhood, the study results show that many children are not diagnosed before school age (Daniels & Mandell, 2013; Noterdaeme & Hutzelmeyer-Nickels, 2010), which can delay the child's entry in intervention programs and specific parental guidance. In this respect, in a literature review about the Age of Diagnosis (AOD) of ASD, Daniels and Mandell (2013) found disparities among the findings of the 42 studies analyzed. It should be mentioned that, in the study cited, the children's mean age of diagnosis of ASD ranged between 32 and 111 months. The authors concluded that different factors can influence this age, which can be related to the characteristics of the child (e.g. severity of the atypical behaviors), the family (e.g. socioeconomic level) and the health context (e.g. health service characteristics), as reported next.

Until date, many studies have found negative correlations between the number and severity of the specific ASD symptoms and the AOD (Wiggins, Baio, & Rice, 2006; Perryman, 2009). In addition, some studies have demonstrated that the language regression history also seems to drive the accomplishment of the early diagnosis (Rosenberg et al., 2011; Valicenti-McDermott, Hottinger, Seijo, & Shulman, 2012). Despite the lack of a consensus on the definition of language regression, in operational terms, it tends to be defined as the loss of the communicative use of three to five words (except for "*papa*" and "*mama*") for more than three months, a phenomenon that affects between 20 and 30% of the children with this diagnosis (Backes, Zanon, & Bosa, 2013). To give an example, Rosenberg et al. (2011), in a survey based on the data of 6,214 children with ASD, diagnosed in the USA between 1994 and 2010, found significant associations between a moderate or severe regression history in socio-communicative skills, presented before the age of three years, according to parental reports, and the accomplishment of the early diagnosis. Similarly, Valicenti-McDermott et al. (2012), in a study involving 399 children, found that the mean AAD of the group of children with a language regression history was significantly lower

than in the group with ASD and without regression, corresponding to 34 and 40 months, respectively.

Most studies have found no significant association between the Gender variable and the AAD (Noterdaeme & Hutzelmeyer-Nickels, 2010; Rosenberg et al., 2011). It should be highlighted, however, that the findings of the study by Goin-Kochel et al. (2006) demonstrated that boys tend to be diagnosed earlier when compared to girls. On the other hand, Wiggins et al. (2006) found that girls tend to receive the ASD diagnosis earlier. Similarly, most studies found no significant associations between the child's ethnic origin and the AAD of ASD (Goin-Kochel et al., 2006; Wiggins et al., 2006; Perryman, 2009; Adelman, 2010). It is highlighted, however, that some studies have demonstrated that black African-American children tend to be diagnosed later than white children generally are (Rosenberg et al., 2011; Valicenti-McDermott et al., 2012). In contrast, in a study by Mandell, Morales and Xie (2010), it was demonstrated that white children tend to be diagnosed with ASD later than children of other racial groups. These controversial data lead us to think that other aspects than ethnic origin can exert influence, such as the way a certain condition is defined and assessed in a given culture for example. Therefore, it is relevant to develop studies involving participants from different cultures and ethnic origins.

What the socioeconomic level is concerned, the literature review showed us that some studies found not association between this variable and the AAD of ASD (Adelman, 2010; Noterdaeme & Hutzelmeyer-Nickels, 2010; Perryman, 2009; Valicenti-McDermott et al., 2012). On the other hand, in the research by Goin-Kochel et al., (2006) it was demonstrated that families with a higher family income tend to receive their child's ASD diagnosis earlier than families of low purchasing power, probably due to their fast access to specialized services, beyond each family's private and the contextual barriers (e.g. financial).

What the birth order is concerned, while some researchers found no associations between this variable and the AAD (Twyman et al., 2009; Valicenti-McDermott et al., 2012), others demonstrated that children who were the couple's first child tended to receive the diagnosis later (e.g. Rosenberg et al., 2011), perhaps due to the parents' limited experience and knowledge on the developmental milestones, among other factors. In addition, Adelman (2010) found that the presence of an older sibling with ASD in the family significantly anticipated the accomplishment of this diagnosis in the siblings. On the other hand, Twyman et al. (2009) found no association between these variables. Studies have also demonstrated that parents' higher education level is significantly related with the early diagnosis of ASD (e.g. Rosenberg et al., 2011). It is highlighted that these variables (presence of an older sibling with or without ASD diagnosis and parental level of education) can reflect the parents' greater knowledge on typical and atypical development, which justifies their anticipatory influence on the AAD.

Concerning the nature of the early signs of ASD that are identified, some studies have found that parents' initial concerns with symptoms that are not specific to ASD (Adelman, 2010) tend to retard their child's age at diagnosis. On the other hand, parents who are initially concerned with social development difficulties or atypical behaviors specific to ASD received the diagnosis earlier (Twyman et al., 2009). In addition, Perryman (2009) found important associations between the parents' beliefs on the nature of their child's early symptoms, measured using the *Attributions of Autism Symptom* (AOAS; Perryman, 2009), and the accomplishment of the ASD diagnosis. To give an example, parents who attributed the early signs of the disorder to motives non-specific of this condition (e.g. they thought that their child was disobedient, had a difficult personality, was spoiled) tended to receive the ASD diagnosis later.

Concerning the variables related to the contextual characteristics, studies demonstrated that the fact that the parents see a large number of health professionals during their search for a diagnosis also contributes to delay it (e. g., Goin-Kochel et al., 2006). Similarly, Adelman (2010) found that children who changed pediatricians in the first five years of life received the diagnosis later than children who did not do so. On the other hand, the same author demonstrated that the fact that, during the assessment process, the pediatricians asked the parents questions to screen for specific signs of ASD significantly influenced the age at diagnosis, anticipating it.

It should be highlighted that, in Brazil, no study has been executed thus far to specifically investigate the variables related to the AAD of ASD. Nevertheless, we imagine that different aspects specific to our culture can equally interfere in this process, mainly when considering the reality of our health context (e.g. lack of qualified professionals for the early identification of ASD, difficulties to get access to the services), and the low sociocultural and educational level of the population. We presume that the situation of children with ASD and their families may be even more difficult in Brazil than in North American or European countries, where the findings of most studies on the theme originate. It is acknowledged that a very small part of our population is diagnosed before the age of three years, in most cases being restricted to the large centers where specialists in the area exist. Therefore, we presume that families of low socioeconomic level living in small interior cities have very limited ways of getting access to specialized professional guidance. By the way, in general, there is a lack of qualified health professionals to identify and assess signs of alert for ASD in Brazil (Favero-Nunes & Santos, 2010).

Based on this justification, the objective in this study was to extend the international findings by investigating the AAD of ASD in Brazilian children and its relation with contextual, family and child variables. We also aimed to examine the relation between the AAD and the occurrence of language regression, and between AAD and a pediatric consult focused on assessing signs of alert for the disorder, besides further health aspects. We expect that the child's birth order, socioeconomic level and the

number of signs of alert to ASD the parents identify are related with the AAD, in a negative correlation (i.e. the higher the coefficients of these variables, the lower the AAD). On the other hand, we expect that the age of recognition of early signs of ASD and the child's age correlate with the AAD, but in a positive correlation (i.e. the lower the coefficients of these variables, the lower the AAD).

Method

Design

This cross-sectional and correlational study was developed based on data collected in an online survey, as part of a larger project entitled "The search for the diagnosis and treatment of children with autism: the influence of coping and social support on parents' stress levels". This project received approval from the Research Ethics Committee at the Psychology Institute of *Universidade Federal do Rio Grande do Sul*, in compliance with Resolution 466 from December 12th 2012, in 03/2013, under protocol 27134314.8.0000.5334.

Participants

The participants were 136 parents of children diagnosed with ASD, accomplished by a physician independent from this study, in accordance with parental reports. The parents were primarily contacted through Brazilian institutions working with children with ASD, as well as associations of parents of individuals with this disorder. The participants came from the five Brazilian regions. Parents (father or mother) of individuals with ASD were included, of different age ranges and who lived with their child while seeking the diagnosis and treatment for their child. If the parents were married or lived in a fixed relationship, we asked only one caregiver to complete the forms, this choice being at their discretion.

Instruments

A *Form with Sociodemographic Data and Data about the child with ASD and his/ her family* was used, elaborated particularly for this study to characterize the sample, confirm the criteria to include the participants in this study and investigate the following variables: birth order, parental education level, presence of oral language regression. The *Investigation Questionnaire of the Diagnostic Process of Autism Spectrum Disorder*, also elaborated particularly for this project, was used to investigate the age at the diagnosis of ASD, the age the early signs of ASD were recognized, the number of professionals in the same specialty seen before the formal diagnosis was reached; and whether specific questions were asked about the signs of ASD during the first medical assessment. The *Modified Checklist for Autism in Toddlers* (M-CHAT) (Robins, Fein, Barton & Green, 2001) was used to characterize the signs of alert for ASD, assessed when the child was between 18 and 24 months of age. The M-CHAT has been

translated and adapted for Brazilian Portuguese and validity scores have been presented for the Brazilian sample, with a satisfactory Cronbach's alpha (0.95) for the total scale score (Castro-Souza, 2011). In this study, the M-CHAT version with the items written in the past tense was used (available in Castro-Souza, 2011).

Results

Sample characteristics

The participants came from 19 Brazilian states, mostly living in Rio Grande do Sul (25%, $n = 34$), São Paulo (22.8%, $n = 31$) and Rio de Janeiro (8.8%, $n = 12$). Most participants lived in the state capital (61.8%, $n = 94$) and the respondents' mean age was 39.25 years (SD=8.02). What the socioeconomic level is concerned, according to the 2012 Brazil Criterion, most respondents fit into categories B1 (31.5%; $n=43$), B2 (22.8%; $n=31$) and A2 (22.1%; $n = 30$). Specifically concerning education, most parents held a post-graduate (36.8%, $n=50$) or higher education degree (26.5%, N=36). Concerning their children with ASD, it was observed that 87.5% ($n = 119$) were male, with a mean age of 9.8 years ($n=10.08$). Most children (60.3%, $n=82$) were the couple's first child and had no other associated impairment (87.5; $n = 119$). In addition, it was observed that most children presented no oral language regression (69.9%, $n = 95$).

Variables associated with the age at diagnosis of ASD

In the group studied, the average age at diagnosis of ASD was 60.14 months (SD=36.56), ranging between 16 and 204 months. The visual exploration of this variable through the histogram and box-plot showed that the data were not normally distributed but presented a positively asymmetric distribution. In addition, several outliers were observed that justify the high standard deviation. The result of the Kolmogorov-Smirnov test for one sample showed a non-normal data distribution, with KS=2.34 and $p<0.05$, therefore indicating the rejection of the null hypothesis of normality. In view of the present research objective, we decided not to exclude the outliers, assume the non-homogeneity of the data and apply a non-parametric test.

Initially, the correlations between the continuous and ordinal variables were tested by means of Spearman's rho, with a significance level of 0.05. To interpret the magnitude of the correlations, the following classification of the correlation coefficients was adopted: <0.4 (weak correlation); between >0.4 and <0.5 (moderate correlation); and >0.5 (strong correlation) (Hulley et al., 2003). The results of the correlations are displayed in Table 1. A moderate correlation was found between the variables Age at diagnosis and Chronological age of the child (r=0.49; p<0.05) and weak correlations between the variables Signs of autism (i.e. number of signs reported in the M-CHAT) and Age of Recognition of Early Signs of Autism (r=0.38; p<0.05), as well as between the Age of recognition of the early signs and the Child's chronological age (r=0.16; p<0.05). In this study, the early signs of ASD were identified when the child was, on average, 22.9 months old (SD=12.69).

Table 1. Correlation among the child, family and context variables based on Spearman's Rho test (N=136)

		Birth Order	ARES	AAD	Signs of Autism	Child's Age	SEL
Birth Order	Coefficient	1.000	.005	-.010	-.082	.045	-.076
	Sig.	.	.475	.453	.172	.300	.188
ARES	Coefficient	.005	1.000	.141	.384**	.156*	.061
	Sig.	.475	.	.051	.000	.035	.241
AAD	Coefficient	-.010	.141	1.000	.018	.489**	-.065
	Sig.	.453	.051	.	.419	.000	.225
Signs of Autism	Coefficient	-.082	.384**	.018	1.000	.106	.105
	Sig.	.172	.000	.419	.	.110	.113
Age of Child	Coefficient	.045	.156*	.489**	.106	1.000	.045
	Sig.	.300	.035	.000	.110	.	.302
SEL	Coefficient	-.076	.061	-.065	.105	.045	1.000
	Sig.	.188	.241	.225	.113	.302	.

Obs. AAD = Age at Diagnosis; ARES = Age of Recognition of Early Signs of Autism; SEL = Socioeconomic Level (Brazil Criterion); *= Correlation significant at 0.05 (one-tailed); **= Correlation significant at 0.01 (one-tailed).

What the nominal variables are concerned, with parents' answers in the dichotomous form, a difference was found between the mean AAD of ASD in the groups of children (1) with and without a history of oral language regression and (2) who underwent a specific assessment of the signs of ASD or not during the medical assessment with the first professional seen. The results of the Kruskal Wallis test for independent sample showed no statistically significant difference in the mean age of the ASD diagnosis between the children with and without oral language regression (p=0.87), nor between the children who went through a specific assessment to screen for ASD signs (p=0.59). It should be reminded that the mean AAD of the ASD in the group with regression corresponded to 56.63 months (SD =38.7), against 58 months (SD = 40.3) in the group without regression. The mean AAD in the group that underwent specific medical assessment for ASD was 54/79 (SD=35.4), against 58.14 (SD=40.6) in the group that underwent no such assessment. In the group under analysis, only 25.7% was satisfied with the diagnostic assessment executed and, when considering the group of caregivers who felt dissatisfied with their child's assessment (74.2%; *n*=101), 36% (*n*=49) reported having changed professionals for this reason.

Discussion

This study aimed to investigate whether different variables (related to the child, the family and the health context) are correlated with the AAD of ASD in Brazil. The results

of the analyses performed showed that, against the initial expectations, the only aspect that seemed to be associated with this variable was the child's age, in a moderate and positive correlation. This means that, the younger the child, the earlier (s)he received the diagnosis in accordance with parental reports. This information makes us think that, at least in populations with the same characteristics as in this study (e.g. high education level), the AAD of ASD seems to change over time. In this regard, it should be noted that, in recent years, there has been an increase in the number of actions promoted for the early identification of the signs of alert to the disorder, such as government programs, the work of NGOs from groups of families and academic research (e.g. Brasil, 2014; Zanon, Backes, & Bosa, 2014). It is worth mentioning, however, that the AAD of ASD in the group of Brazilian children investigated seems to be late when compared to other countries. For example, a study conducted in the United States involving 399 children aged one to six years found that the diagnosis was reached when the child was on average 38 months old (Valicenti-McDermott et al., 2012). In the present study, it was found that Brazilian children, whose parents volunteered to participate in this study, tend to be diagnosed when they are about five years old (i.e., M = 60.14, SD = 36.56 months). Considering that the first signs of ASD were identified when the child was, on average, 22.9 months old (SD = 12.69), an interval of approximately three years was noticed between the first concerns and the formal confirmation of the diagnosis. It should be emphasized that the recognition of the risk signs for ASD and the early diagnosis of the disorder is important because it permits the child's access to intervention programs, which in turn can promote significant gains in the development of these disorders. These gains are due to the cortical immaturity of the age group, which makes the development of skills quite malleable in this period. It is known that the development of the prefrontal cortex begins in early childhood, progressing rapidly in pre-school age, and more slowly through adolescence. This gradual and slow evolution makes it particularly sensitive to external influences (Pellicano, 2012).

In general, the mean age of recognition of the early signs of ASD found in the present study corroborates earlier studies on the subject. For example, retrospective surveys, based on parental reports, demonstrate that the early signs of ASD are identified between 12 and 24 months, most often by caregivers themselves, with difficulties in socio-communicative development being the most frequently reported signs (Zanon et al., 2014).

Furthermore, the number of ASD alerts signs identified between the ages of 18 and 24 months correlated, albeit weakly, with the age of recognition of the early signs of ASD. This aspect also approximates the findings reported in the international literature (Wiggins et al., 2006; Perryman, 2009). For example, Perryman (2009), in a survey involving 168 American children, found that the severity of the symptoms characteristic of ASD was associated with the early diagnosis of the disorder.

On the other hand, the socioeconomic status of the parents, the presence of oral language regression, the birth order of the child and the performance of a specific

evaluation of signs of ASD by the first professional consulted were aspects that in this study did not seem to be related to the AAD of ASD. Although these findings are different from those initially expected, it is acknowledged that some of them corroborate international studies, while others may be understood based on the characteristics of the participants, the context the study was developed in and the methodological limitations. In a study involving parents of 654 American children, Adelman (2010) also found no influence of the variables annual income and educational level at the age of diagnosis of ASD. As for the presence of oral language regression in the child, this has been identified in some studies as a potential early indicator of ASD because it occurs significantly more frequently in children with this disorder and because it is an important alert sign (Zanon et al., 2014). Considering that in the present study, however, a long period was observed between the first parental concerns and the formalization of the diagnosis, involving family mobilization and diagnostic investigation, it is assumed that, in this group of participants, regression of oral language may be related more with the ARES variable than with the AAD. In addition, although developmental regression in ASD affects a significant portion of children with this disorder (Backes et al., 2013), the lack of knowledge about this phenomenon can provide an explanation for the fact that the variables presence of regression and AAD were not related in this present study. Further analysis would be required to confirm these hypotheses though.

On the other hand, the results regarding the variables (1) the performance of a specific diagnostic evaluation for ASD by the professional and (2) IRD may have resulted from methodological limitations of this study, being influenced, for example, by the heterogeneity of the group of parents who volunteered to participate in this study (e.g. socioeconomic status, place of residence and education level) and the characteristics of their children (e.g. some with associated disabilities), as well as the manner in which the variables were investigated (i.e. through self-administered and exclusively online tools) and the small sample size.

Knowledge about the aspects that interfere in the AAD of ASD is certainly important and can serve as an alert for the professionals who work with small children and their families, considering that, in Brazil, this diagnosis is still late. It is worth mentioning that, although it is acknowledged that receiving a diagnosis of ASD is initially difficult and shocking for parents, many families report a relief reaction, since the diagnosis itself, when performed properly and in an interdisciplinary way, helps them to understand why the child presents atypical behaviors (Favero-Nunes & Santos, 2010; Osborne & Reed, 2008). In fact, some parents reported that, before they received the diagnosis, they felt guilty about the child's behaviors, even considering themselves "bad parents" (Osborne & Reed, 2008). On this issue, Semensato (2013), based on a theoretical model on the role of narrative in physician-patient communication, explains that "hearing a name" for what the child presents seems to help parents construct new meanings for the behavior of the child, assisting in what he believes to be

the parental elaboration of the diagnosis. Thus, the way the diagnosis is communicated by the professionals and is elaborated by the parents seems to influence the next steps taken by the family in the search for treatment.

The results of this study, although in part contrary to the initial expectations and the international findings, offer important contributions: a) Brazilian children tend to be diagnosed when they are about five years old; B) there is an interval of approximately three years between the first signs of alert identified by the parents and the formal confirmation of the diagnosis, pointing to the urgent need to reduce this time due to the implications of early intervention for child development. Concerning the contrary results and the initial expectations, it is important that future studies be developed, using specific tools to measure each of the variables investigated, as well as involving larger and probabilistic samples that, in turn, may influence the normality of the distribution, thus permitting the use of parametric and statistically more robust tests.

It is also considered that the data collection modality adopted in this study (exclusively on-line) may have influenced the constitution of the sample (e.g. educational and sociocultural level) and this bias, consequently affecting the research findings. Despite the increase in Internet use, a large part of the Brazilian population still does not have an electronic address and / or does not participate in the groups and communities in which the research link was disclosed. In addition, we recognize limitations related to the non-measuring of variables that may influence infant development, in addition to the characteristic signs of ASD, such as intellectual disability that can anticipate the diagnosis of the disorder (Norterdaeme & Hutzelmeyer-Nickels, 2010). The fact that parents from different Brazilian regions voluntarily contributed to the study of a topic that has not yet been investigated in the country, however, adds value to its findings. Thus, at the same time as this study is valued, it should be noted that all data presented here are preliminary and cannot be generalized.

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