Timing of Parents' Concerns Related to ASD and its Diagnosis: A Mediation Analysis.

Dunia Garrido, Gloria Carballo, Jonet Artis, Rocio Garcia-Retamero

Abstract

Parents are the first to indicate concerns about their child's development in up to 80% of children with autism spectrum disorders (ASD). They often notice symptoms related to ASD around the first two years, but the average age of diagnosis is 3.5 years old. This study examined the relationships between parents' early concerns and the time lag between suspicion and diagnosis. Forty-eight Spanish-speaking families were enrolled in this study. Parents were asked about early signs that made them think that their child could possibly have ASD. Mediation analyses showed that the child's age at suspicion mediated between sibling status and the time lag between suspicion and a formal diagnosis. Having another child with typical development accelerated parents' detection of ASD signs. The number of social-communication concerns that parents detected mediated this relationship. Parents who reported more social-communication concerns perceived these signs earlier, but have to cope with a longer time lag until diagnosis than those who reported more concerns related to restrictive and repetitive behaviors and interests, or other developmental concerns. Moreover, this relationship between concerns of ASD and the diagnoses was explained by the child's age. Training pediatricians on how to respond to parent questions and concerns could reduce the time lag between parents' concerns and diagnosis of ASD.

Keywords: Autism spectrum disorders; parents; signal detection; diagnosis

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An early diagnosis of autism spectrum disorder (ASD) is a critical need in psychology due to the significant role it plays in early intervention of ASD. Although the prevalence of ASD is currently estimated at around 1.5% of the general population, the average age of diagnosis in Europe is not until 3.5 years old (Developmental Disabilities Monitoring Network Surveillance Year 2010 Principal Investigators, & Centers for Disease Control and Prevention, 2014; Salomone, Charman, McConachie & Warreyn, 2016). Given that an early diagnosis allows for early intervention and therefore, may lead to better outcome, there are continual efforts to provide earlier diagnosis. Diagnosing ASD is challenging and the current diagnostic criteria are related to impairments in social interaction and communication, and restricted interests and repetitive behaviors (APA, 2013). These symptoms are usually not detected until the first two years of life. The purpose of this study was to examine the association between parents' early concerns related to ASD's criteria and age at diagnosis and to estimate to what extent socio-demographic variables could predict and/or mediate the time lag between early concerns and diagnosis.

In the absence of early biological markers for ASD, the early diagnosis of ASD is closely related to the recognition of the behavioral signs and symptoms of ASD. These signs and symptoms are present early in life and usually are detected by parents (Barbaro & Dissanayake, 2009; Guinchat et al., 2012). In Spain, parents are the first to

see signs in up to 79 % of children with ASD at 18 months (Fortea-Sevilla, Escandell-Bermúdez, & Castro-Sánchez, 2013), but these early concerns are not specific to ASD.

The first signs of ASD generally become visible prior to 36 months of life (Guinchat et al., 2012); furthermore, some studies found that between 30-50% of early concerns related to ASD are expressed around 12 months of life, and 80-90% by 24 months (Volkmar, Chawarska, & Klin, 2008). In Spain, although parents may be aware of some signs early, often their child does not receive a diagnosis until 37 months of life (Díaz-Atienza, García-Pablos, & Martín-Romera, 2004; Salomone et al., 2016), and the time lag between early concerns and a formal ASD diagnosis is close to 13 months (Fortea-Sevilla et al., 2013).

The time that it takes for children to receive a diagnosis after initial concerns are expressed by parents can be influenced by the manner in which pediatricians elicit and answer parents' developmental concerns (Zuckerman, Lindly, & Sinche, 2015). Parents and pediatricians may find it difficult to differentiate ASD from other developmental disorders at an early stage (Monteiro et al., 2015). This is due to the similarity of symptoms of ASD to symptoms of other developmental disorders (e.g., speech and language disorders or general developmental delay). The wide heterogeneity of ASD and the similarity of symptoms between different disorders could generate a delay in diagnosis of ASD because pediatricians have a wait-and-see attitude (Daniels & Mandell, 2014; Klin, Klaiman, & Jones, 2015).

Language delay and communication difficulties are two of the initial ASD-related concerns frequently reported by parents (Meek, Robinson, & Jahromi, 2012). These symptoms have been associated with early detection, but also with a later

diagnosis (Volkmar et al., 2008; Zwaigenbaum, Bryson, Rogers, Roberts, Brian, & Szatmari, 2005). Other features directly related to ASD diagnosis have been delays in reaching developmental milestones (e.g. speech and language delay), slower rate of development, loss of previously acquired skills (e.g. speech regression) (Kishore & Basu, 2011; Mishaal, Ben-Itzchak, & Zachor, 2014), less frequent instances of smiling, orienting, and vocalizing to people (Maestro et al., 2005), lack of joint attention (Kishore & Basu, 2011), poor eye contact, lack of play and interaction, and hand flapping and toe walking (Mandell, Novak, & Zubritsky, 2005). Concerns related to repetitive behaviors often emerge later, and are often reported for children with other developmental disorders too (Mooney, Gray, & Tonge, 2006).

Beside these early difficulties, several factors have been shown to influence age of early concerns specifically related to ASD. For instance, having another child without ASD has been associated with an early detection and diagnosis, as parents could compare the development of the child at risk of ASD with their child with typical development (TD) (Fountain, King, & Bearman, 2011; Herlihy, Knoch, Vibert, & Fein 2015; Mishaal et al. 2014; Rosenberg, Landa, Law, Stuart, & Law (2011). In general, higher maternal education would be associated with more knowledge of child development. Shattuck et al. (2009) showed that a lower level of maternal education and younger maternal age were associated with older children's ages for early concerns related to ASD. However, Mishaal et al. (2014) did not find significant correlations between parental age and educational attainment and age of ASD diagnosis. Furthermore, the gender of children with ASD has been another variable of scientific interest that might have an impact on the age in which children are diagnosed. Some

studies have found no differences between gender and the age of diagnosis (Begeer et al., 2013; Fountain et al., 2011). Nevertheless, parents may expect more social behavior from girls, and encourage them to act more socially, which could delay detection.

There is no clear consensus about which features are more important in the earlier detection of ASD and which variables have a significant impact on the time lag between type of parents' early concerns and the diagnosis of ASD. It is important to consider features that improve clinical practice in eliciting these concerns and as a result, help to improve the early diagnosis of ASD. In addition, an early and accurate diagnosis helps parents cope with the stress related to the disorder (Pozo & Sarria, 2014). Thus, this retrospective study investigates the association between parents' early concerns related to ASD symptom criteria and age at diagnosis. In particular, we investigated to what extent socio-demographic variables (i.e., type of parents' early concerns, parental level of education, parental age, child's age, sibling status, and child's gender) predict the time lag between early concerns and diagnosis.

Method

Participants

A total of 48 families from Granada (Spain) of a child with ASD (range: 4.1-10.1 years old) were enrolled in this study. All parents signed the informed written consent before participation, and The Ethics Committee of the University of Granada approved the methodology of the study. Inclusion criterion for each child was having an ASD diagnosis based on DSM-TR-IV (APA, 2000) and ADI-R (Le Couteur, Lord, & Rutter, 2003) or ADOS-G (Lord, Rutter, DiLavore, & Risi; 2002). The diagnosis was confirmed by an independent tester with the Guilliam Autism Rating Scales (GARS;

Guilliam, 2004). In additioin, one of our purposes was to investigate whether having an

older sibling with typical development could have delayed or accelerated parents'

doubts. As a reuslt, an additional inclusion criterion was that for the children with older

siblings, the older siblings must be deemed typically developing in order to be included

in this analysis

Parents were interviewed and they completed an open-ended questionnaire

measuring several aspects related to detection of ASD and diagnosis. This kind of

questionnaire enabled us to obtain more spontaneous information and to run both

qualitative and quantitative analyses (Chamak, Bonniau, Oudaya, & Ehrenberg, 2011;

Guinchat et al., 2012). Families were asked (1) about early concerns that made them

think that their child could have ASD, (2) what was their child's age when these signs

were detected, and (3) when the child received the diagnosis of ASD.

Coding procedure and analysis

We focused on parents' early concerns about ASD. The coding procedure

consisted of breaking down early concerns into 2 fields related to two domains from

DSM-5 (APA, 2013): (1) social communication (SC), and (2) restrictive and repetitive

behaviors and interests (RRBI). Moreover, because many parents usually reported

concerns that were not specific to autism criteria (Guinchat et al., 2012), we included a

third category (3) other concerns non-specific to ASD (OC). The operational definitions

of what variables were considered as SC, RRBI, or OC are mentioned in Table 2. Two

independent coders identified the three different types of concerns. Mean percentage

agreement (based on Cohen's Kappa inter-rater agreement measurement) was over 95%

for all symptoms. Disagreements were resolved through discussion.

INSERT TABLE 1 ABOUT HERE

Data analyses

All statistical analyses were performed using Statistica 13 software. To evaluate relationships between the two outcome variables (i.e., child's age at suspicion, and time lag between suspicion and diagnosis) and four predictor variables (i.e., sibling status, SC, RRBI, and OC) bivariate Pearson correlations were conducted. To determine the influence of each predictor, we run several multiple regression analyses. Furthermore, to examine potential meditational effects, path analyses were computed. Parental age, education, and child's gender were entered as covariates. We consulted the bootstrapping method with bias-corrected confidence estimates to test our results. The 95% confidence interval of the indirect effect was obtained with 5000 bootstrap samples.

Results

Forty-eight families were enrolled in this study. Descriptive statistics for all study variables are presented in Table 1. From the whole sample, 12.5% (n=6) reported child's age at diagnosis less or equal to 24 months; 54.2% (n=26) reported child's age at diagnosis between 25 and 35 months; the remain 33.3% (n=16) reported child's age at diagnosis longer than 36 months.

INSERT TABLE 2 ABOUT HERE

Bivariate Pearson correlations are presented in Table 3. Correlations between parents' early concerns (i.e., SC, RRBI, and OC), parental level of education, parental age, child's age at suspicion, time lag between suspicion and diagnosis, sibling status, and child's gender were computed. We focused on two of these variables: child's age at

suspicion and time lag between suspicion and diagnosis. Younger child's age at suspicion was related to more number of SC reported by parents (p<.05), longer time lag between suspicion and diagnosis (*p*<.001), and having an older sibling with typical development (*p*<.001). Additionally, longer time lag between suspicion and diagnosis was positively related to having an older sibling with typical development (*p*<.05).

INSERT TABLE 3 ABOUT HERE

We then conducted two multiple linear regression analyses with outcomes child's age at suspicion, and time lag between suspicion and diagnosis respectively. The results of these regressions are presented in Table 4, including standardized regression coefficients for each predictor.

Child's age at suspicion. This model accounted for 56% of the total variance, $F(4,42) = 15.612$, *p*<.001. From all potential predictors, the number of SC and having an older sibling with typical development were the statistically significant variables (*p*<.005, and *p*<.001 respectively).

Time lag between suspicion and diagnosis. This model accounted for 35% of the total variance, $F(5,41) = 5.896$, *p*<.001. In this model, from all potential predictors, child's age at suspicion was the only statistically significant variable (*p*<.05).

INSERT TABLE 4 ABOUT HERE

Path analysis. To describe a comprehensive model, we carried out path analyses. We tested a path model that was based on the regression analyses and was consistent with the actual timeline of events (i.e., that having an older sibling with typical development influences the potential signs noticed by parents, which can in turn influence their suspicions of ASD, and finally the diagnosis).

The number of SC was related to child's age at suspicion, suggesting that it could be a potential mediator of the relationship between sibling status and the child's age at suspicion (see Figure 1). To test this possibility, we estimated indirect effect on number of SC via child's age at suspicion (see Table 5). The results showed that there was a significant indirect effect of number of SC on child's age at suspicion via sibling status (95% confidence interval excluding 0).

Regarding the second model, child's age at suspicion was related to time lag between suspicion and diagnosis, suggesting that it could be a potential mediator of the relationship between sibling status and the time lag between suspicion and diagnosis. To test this possibility, we estimated indirect effect on child's age at suspicion via time lag between suspicion and diagnosis. The results showed that there was a significant indirect effect of child's age at suspicion on time lag between suspicion and diagnosis through sibling status (95% confidence interval excluding 0). Moreover, results showed another significant indirect effect of SC on child's age at suspicion through sibling status.

INSERT FIGURE 1 ABOUT HERE

INSERT TABLE 5 ABOUT HERE

Discussion

To our knowledge, this is the first study that includes several variables to develop a mediation model between parents' early concerns, sibling status, child's age, and time lag between suspicion and diagnosis. Our study suggests that some variables are mediating over others that could explain the period of time between the suspicion and the diagnosis of ASD.

First, our results indicated that if the child with ASD has an older sibling with typical development, this precipitates parents' detection, as other authors have found (see for example, Herlihy et al., 2015; Mishaal et al., 2014). This can be explained by the fact that those parents who have another child, can compare the development of their child with ASD with a typical development, and can detect these signs earlier. This relationship is partially mediated by the type of concerns noted by parents. If we include SC, RRBI, and OC concerns in our model as predictors, the strength of the association between sibling status and child's age at suspicion decreases. Moreover, as previously has been found by Volkmar et al. (2008) and Zwaigenbaum et al. (2005), concerns related to SC and language hasten the suspicion of ASD. This can be explained by the fact that SC concerns such as smiling and orienting to others or speaking are detected earlier by parents because they appear before than those symptoms related to RRBI, such as interest in toys, resistance to change, stereotypic behaviors, or motor delay (Herlihy et al., 2015). On the other hand, our results did not find statistically significant other concerns such as RRBI, OC, or socio-demographic variables that were included in the model (e.g. parental level of education, parental age, and child's gender). One possible explanation might be that our sample showed similar levels of education and parental age.

Second, we found that the child's age at suspicion is a mediator between parents' early concerns and time lag between suspicion and diagnosis. This mediation can be explained by the fact that the age of suspicion is crucial in the ASD diagnosis. We need to keep in mind that these children have been diagnosed through DSM-IV-TR (APA, 2000), in which it was stated that the onset of ASD must be prior to 3 years of age, but

the diagnosis was not usually made until 3 years of age (Díaz-Atienza et al., 2004). This further explains why pediatricians decided to wait until children were 3 years old. Pediatricians may have understood that every child had their own pace of development and some of the early concerns could be related to other disorders (such as specific language disorder). So, it seems that parents may help their child receive a diagnosis earlier by relaying their concerns to their pediatricians but because every child has his/ her own rate of development, pediatricians chose to wait and see (Klin et al., 2015).

Finally, we found a relationship between sibling status and time lag between suspicion and diagnosis. Our results are partially consistent with those obtained by Fountain et al. (2011), Herlihy et al. (2015), and Rosenberg et al. (2011), because having another child without ASD was associated with an early detection. Surprisingly, our results showed that having another child make longer the time lag between suspicion and diagnosis. However, this relationship was totally mediated by the time when ASD was suspected and parental concerns (i.e., SC, RRBI, and OC). We found that the earlier the age of suspicion, the more time lag between the suspicion and the diagnosis of ASD they have to wait. This explanation sheds light on the previous association. This would explain why children who have older siblings have to endure longer wait times in order to receive an ASD diagnosis.

This study has several limitations. First, by using an open-ended questionnaire there is a possibility of parental recall bias and parents' limited knowledge about ASD. Nevertheless, this approach is an efficient way to collect the most spontaneous concerns and retrospective parental information has been widely used as a source of information about ASD (Barbaro & Dissanayake, 2009). In that sense, we encourage future research

to observe if parents report the same kind of concerns by comparing different procedures, such as a checklist and an open-ended questionnaire. Second, our sample consists of families with a high level of parental education, so we have not been able to assess whether educational level affects their ability to detect ASD signs. Third, due the fact that our parental sample belonged to the same age cohort, we could not evaluate this variable. It would be interesting to study possible differences between the signs detected by parents from different age cohorts. Maybe younger parents would detect more signs because of the huge amount of information about ASD available nowadays.

Clinical implications

We conclude that there are some variables related to the time lag between parents' early concerns and diagnosis of ASD. These relationships are not linear, but mediating variables are included. Parents who detected signs earlier reported more concerns related to SC than those who detected ASD later. Moreover, parents earlier detected ASD signs if their child had an older sibling with typical development. However, when they shared their concerns with the pediatrician, they often received the advice of wait and see. This could mean that pediatricians should give more attention to these signs and this also underscores the importance of promoting awareness about early signs of ASD.

Our study and others (Daniels & Mandell, 2014; Guinchat et al., 2012) have shown that a significant delay exists between the moment when parents first become concerned about their child's development and the moment when their child receive a formal ASD diagnosis. We consider that training pediatricians on how to respond to parents' questions or concerns might enhance their response to parents' concerns and

consequently, decrease the time until diagnosis of children with ASD. One potential response includes promoting parents' informed decisions and advising them to contact a specialist as soon as concerns arise.

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Table 1. First signs related to ASD reported by parents

Categories	Parents' early concerns about ASD
SC	Does not talk; impression of deafness; no language; language appeared later; language regression; language comprehension problems; no response to name; no reaction to social solicitation; no response to demands or questions; lacks social engagement; no joint attention; would not share games with peers (social reciprocity); dislikes being cuddle (social avoidance); no pointing; no eye contact; no gaze; no imitation.
RRBI	No interest in toys and games; only interest in strange and specific objects; resistant to change; stereotypies; strange behaviour; hand-flapping; temper tantrums; walks on tiptoes; scared by certain noises; places hands over ears.
OC	Cries all the time; delayed walking; sleeping problems (routines); feeding problems (selectivity); screams for no reason; hyperactivity.

SC= Social communication signs
RRBI= Restrictive and repetitive behaviors and interest signs
OC= Other developmental concerns non-specific to ASD

Table 2. Socio-demographic variables from families with a child with ASD

Families with a child with ASD	
N	48
Child's gender (Male)	34 (71%)
Child's age at suspicion [a] (SD)	22.58 (.96)
SC (SD)	3.17 (1.22)
RRBI (SD)	1.25 (1.27)
OC (SD)	.75 (.86)
Time lag between suspicion and diagnosis [a] (SD)	9.29 (.91)
Age of Diagnosis [a] (SD)	32.25 (1.10)
Parental age [b] (SD)	35.42 (.64)
High Parental education [c]	41 (85%)
Sibling status [d]	22 (46%)

Note: [a] months, [b] years, [c] post-secondary and university education, [d] having an older sibling with typical development.
SC= Social communication signs
RRBI= Restrictive and repetitive behaviors and interest signs
OC= Other developmental concerns non-specific to ASD

Table 3. Correlations coefficients values between symptoms related to ASD, and variables related to parents and children.

Variables	1	2	3	4	5	6	7	8	9
1. SC signs	−								
2. RRBI signs	-.09	−							
3. OC signs	-.12	.06	−						
4. Parental level of education	-.14	-.25	.09	−					
5. Parental age	.01	.16	.08	-.0	−				
6. Child's age at suspicion		.27	.16	-.2	.04	−			
7. Time lag between suspicion	.18	-.13	-.2	-.1	-.0	-.62	−		
8. Sibling status	.12	-.07		.15	.03	-.68	.	−	
9. Child's gender	-.16	.13	.03			.16	-.18	-.2	−

$*p<0.05; **p<0.01$

SC= Number of social communication signs

RRBI= Number of restrictive and repetitive behaviors and interests signs

OC= Other developmental concerns non-specific to ASD

Table 4. Regression analyses to determine the influence of each predictor on child's age at suspicion and time lag between suspicion and diagnosis.

| | Outcomes | | | | | |
| | Child's age at suspicion | | | Time lag between suspicion and diagnosis | | |
	β	SE	*p*	β	SE	*p*
Child's age at suspicion	-	-	-	-.53*	.18	.007
SC	-.28*	.55	.008	-.06	.47	.640
RRBI	.17	.52	.104	.01	.62	.991
OC	.09	.77	.368	-.17	.90	.176
Sibling Status	-.62**	1.00	<.001	.06	1.61	.724

* *p*<.01, **p*<.001

SC= Number of social communication signs

RRBI= Number of restrictive and repetitive behaviors and interests signs

OC= Other developmental concerns non-specific to ASD

Table 5. Estimated indirect effects from sibling status via path analysis

	Outcomes					
	Child's age at suspicion			Time lag between suspicion and diagnosis		
	95% CI			95% CI		
	Coeff	Lower	Upper	Coeff	Lower	Upper
Child's age at suspicion	-	-	-	3.199	.098	6.810
SC	-.320	-1.363	-.257	-.016	-.744	.435
RRBI	-.119	-1.122	.383	-.007	-.435	.346
OC	-.026	-.647	.211	.043	-.422	.853

SC= Number of social communication signs

RRBI= Number of restrictive and repetitive behaviors and interests signs

OC= Other developmental concerns non-specific to ASD

Figure 1. Results from mediation analyses
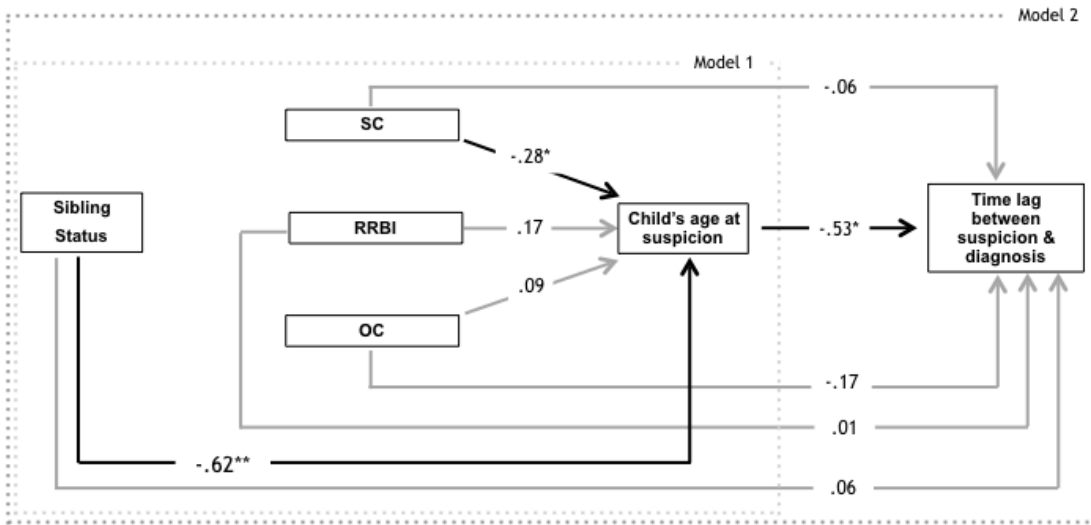
Note: Coefficients are standardized β. Only significant paths are displayed with black lines.

* p<.01, **p<.001

SC=Number of social communication signs RRBI= Number of restrictive and repetitive behaviors and interests signs OC= Other developmental concerns non-specific to ASD