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# Parents-perceived and self-perceived anxiety in children with autism spectrum disorder

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Autism spectrum disorders (ASD) are characterized by a series of deficits in social interaction and communication and restricted, repetitive, and stereotyped behavior patterns. In addition, a high percentage of ADS is associated with anxiety disorders. The goal of this study is to assess the perception of anxiety in a group of children and adolescents with ASD and the anxiety their parents think their children have, through the Screen for Child Anxiety Related Emotional Disorder (SCARED). Participants were 38 children and 38 parents, one for each child or adolescent. The results indicate that parental perception of anxiety is always higher than that of their children in all factors, and this difference is significant in the factors of generalized anxiety, social phobia, and anxiety in general. The correlations between the children and parents' scores were high and significant in the factors of generalized anxiety, separation anxiety, and social phobia. The size of the sample and the lack of girls are mentioned as a limitation of the study.

Key words: Autism spectrum disorder, anxiety, inter-evaluator agreement, self-report.

# INTRODUCTION

It is well known that children with developmental disorders have a higher risk of presenting symptoms of anxiety than typically developing children. White et al. (2009) performed a review, finding that between 11 and 84% of young people with ASD presented some deterioration due to symptoms of anxiety. This disparity of results is probably due to differences in sample size and the anxiety measurement employed. *The Statistical Manual for Mental Disorders-fifth edition* (DSM-5; American Psychiatric Association [APA], 2013) includes social anxiety as one of the characteristics of ASD. Recent research has shown that children with ASD often have clinically significant symptoms of anxiety (van Steensel et

al., 2011). These authors estimated that 16.6% of persons with ASD under 18 years of age present anxiety, and between 30 and 50% are diagnosed with at least one anxiety disorder. They also showed that the most common anxiety disorder was specific phobia (30%), followed by obsessive-compulsive disorder (17%), social anxiety (17%), and generalized anxiety (15%). Costello et al. (2005) suggest that children with ASD are twice as likely to suffer from anxiety as typically developing children.

Few studies have used the information gathered through parents' reports of the anxiety that their children suffer. Thus, Magiati et al. (2014), using the Spence

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Children's Anxiety Scale - Parent Version (SCAS-P; Spence, 1997) and the Child Self-Report (SCAS-C, Spence, 1998), found agreement between caregivers and children about the anxiety symptoms displayed by the latter. Similar results were found in several studies (Li et al., 2011; Nauta et al., 2004; Whiteside and Brown, 2008) performed in Australia, Hong Kong, and the United States, using the same instrument, with normally developing young people with and without anxiety disorders. They are also consistent with those obtained by Blakeley-Smith et al. (2012) using the SCARED in samples of youth with ASD.

However, other studies (Renno and Wood, 2013) report that the agreement between parents' reports and the self-reports of their children with ASD tend to be fairly weak compared to normal population with anxiety (van Steensel et al., 2012). These authors also conclude that parents tend to report higher anxiety than their children do (Castro et al., 2015). The results seem to vary depending on the instrument used to measure anxiety. In a thorough review of the research in the past 23 years on anxiety in children and adolescents with ASD, Kreiser and White (2014) confirm that the measures used to evaluate anxiety in ASD have shown internal consistency.

Although significant differences in age and gender have been found in typically developing children with regard to anxiety disorders (Costello et al., 2005), these variables have rarely been examined in population with ASD. The results are contradictory because some studies indicate higher anxiety symptoms in older children compared with voung children (Lecavalier, 2006), whereas others have not found them (Meyer et al., 2006). The types of anxiety disorder and their severity were found to be similar in children with ASD and in anxious children, but specific phobias were more frequent among children with ASD. In both groups, the children scored lower on separation anxiety disorder than their parents reported (van Steensel et al., 2012). In general, young people with ASD have difficulties to reflect on themselves and to identify and express their emotions (Baron-Cohen, 2002; Baron-Cohen et al., 1985; Losh and Capps, 2006; Quay and LaGreca, 1986) and therefore, researchers are reluctant to rely on young people's self-reports to meaningfully identify anxiety symptoms (Bellini, 2006; Chalfant et al., 2007; Reaven et al., 2009; Sofronoff et al., 2005; Wood et al., 2009). Some authors even advice caution because they found discrepancies between children's self-reports and reports issued by the parents in interviews (Mazefsky et al., 2011). Studies relating cognitive ability and anxiety in ASD have mostly focused on only children with "high functioning" autism, or on Asperger syndrome (White et al., 2009). Brereton et al. (2002) concluded that children with high functioning autism and Asperger syndrome have increased risk of developing symptoms of anxiety than those with a low performance level. In several studies, it was concluded that there were more anxiety symptoms in high functioning children than in children

with an IQ below 70 (Mazurek and Kanne, 2010; Sukhodolsky et al., 2008; Weisbrot et al., 2005). However, according to the meta-analysis of van Steensel et al. (2011), anxiety disorders were more common in participants with a lower IQ. These inconsistent findings regarding anxiety and IQ may be attributable to the problems posed by the assessment of anxiety in children with low intellectual functioning (Hallett et al., 2013). According to these authors, people with an IQ of 70 or higher score significantly higher in anxiety than people with intellectual disabilities, suggesting that, even taking into account the more visible aspects of anxiety, children with high intellectual functioning present more anxiety than children with a lower IQ.

Given that undiagnosed or misdiagnosed anxiety disorders can increase anxiety symptomatology and thereby affect children's daily lives, producing important deterioration, interest in the assessment of symptoms of anxiety in children with ASD is growing (Merlo et al., 2005). In terms of intervention, cognitive-behavioral treatment has reduced anxiety (Reaven et al., 2009). These results are promising, especially given high rates of comorbidity between ASD and anxiety (Attwood, 2005; Bellini, 2004). They are also consistent with the results of other studies that are beginning to show the applicability of these techniques in people with ASD (Attwood, 2005; Chalfant et al., 2007; Sofronoff et al., 2005; Sze and Wood, 2007).

# **METHOD**

### **Participants**

The inclusion criteria for the study were: a) chronological age between 7 and 18 years; (b) confirmed diagnosis of ASD through the Autism Diagnosis Interview Revised (ADIR) (Rutter et al., 2003/2006) and the Autism Diagnostic Observation Schedule (ADOS) (Lord et al., 1999/2008); (c) language and speech assessed by means of the ADOS, Modules 3 and 4; and d) verbal IQ equal to or above 70 measured with the Wechsler Intelligence Scales -IV (Weschler, 1974/2005).

Participants were 38 children who met these inclusion criteria, of whom 36 are boys and 2 are girls (Table 1). The mean age is 12.15 years (SD = 2.86, age range 8 to 17). One parent of each child participated, 38 in total, 22 fathers and 16 mothers. The parents' mean age was 45.74 years (SD = 5.25, age range of 37 to 58).

# Instrument

The SCARED in its 41-item version (Birmaher et al., 1999) is a self-report developed to assess a wide range of symptoms of anxiety in children from the general population, according to the *DSM-IV-TR* (APA, 2000). It is considered to be one of the best tools to discriminate anxiety from other disorders (Silverman and Ollendick, 2005). It was selected because it is short (41 items), there had been several prior versions that were improved, and it is completed on a Likert-type response format—which matches the learning style of people with ASD—, and there were psychometric data of its properties (Blakeley-Smith et al., 2012). It was adapted to the Spanish population by Domènech-Llabería (2002). In most

Table 1. Distribution of participants.

Participants	Mean age	Gender	N	%
Children	12.15	Boys	36	94.7
Children	12.15	Girls	2	5.3
Parents	45.74	Fathers	22	57.9

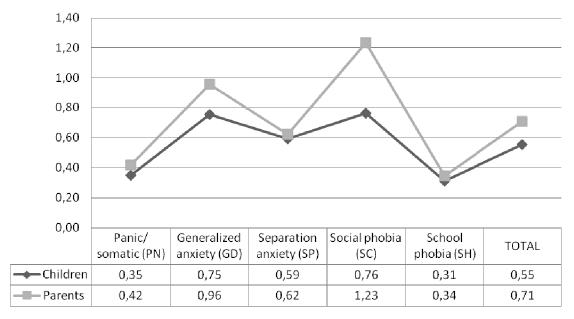


Figure 1. Means by factors as a function of participants.

adaptations, an internal five-factor structure was found, like the original version, with good convergent and divergent validity (Birmaher et al., 1999): Panic/Somatic, Generalized Anxiety, Separation Anxiety, Social Phobia, and School Phobia. In all the studies, the psychometric properties of the four scales related to the anxiety disorders of the DSM-IV-TR are high (Hale et al., 2011), but School Phobia produces controversial results (Doval et al., 2011). The parent-child versions are identical in content, differing only in the use of the phrase "your child". Lecavalier et al. (2014) found partial support in their study for the use of the SCARED as a measure of anxiety in high-functioning children with ASD. According to Stern et al. (2014), it is a valid and clinically useful tool to assess anxiety in children and adolescents and the outcome of their subsequent treatment. Each item rates the frequency of each symptom over the past three months on a scale ranging from 0 to 2 points. The total score ranges from 0 to 82. A total score greater than 25 indicates clinically significant anxiety.

# Design and procedure

Information was collected in two ways. The families were invited to participate in a briefing of the Asperger Association of the Canary Islands (ASPERCAN) about the study to be carried out, where they signed their consent. The SCARED for parents and children was distributed, to be filled in separately. We also visited a Medical Center specializing in ASD and informed the families, one by one, of the study, distributing the questionnaires and the informed

consent form. In both cases, the families handed in questionnaires after a few days.

# **RESULTS**

Figure 1 shows the mean scores (transferred to a single scale ranging from 0 to 2) of each of the factors of the SCARED, grouped by participants. As observed, the lines representing each group of participants are parallel, with the parents' perception of anxiety always being higher than that of their children.

We calculated symptom prevalence from the cut-off points for each factor and for the total score (Table 2). In the Total Anxiety factor, 34.2% of the children were above the cut-off point ( $\geq$  25) compared with 68.4% of the parents. The Panic/Somatic factor showed that 23.7% of the children and 36.8% of the parents were above the cut-off point ( $\geq$  7). In the Generalized Anxiety factor, 31.6% of the children and 52.6% of the parents were above the cut-off point ( $\geq$  9). In Separation Anxiety, one half of the children and one half of the parents were both above the cut-off point ( $\geq$  5). In Social Phobia, 26.3% of the children and 65.8% of the parents were above the

**Table 2.** Percentage of participants above the cut-off point of each factor.

SCARED factors	Children%	Parents%
Panic/somatic (PN)	23.7	36.8
Generalized anxiety (GAD)	31.6	52.6
Separation anxiety (SP)	50.0	50.0
Social phobia (SC)	26.3	65.8
School phobia (SH)	13.2	26.3
Total	34.2	68.4

**Table 3.** Mean difference between children and parents by factors.

SCARED factors	Children	Parents	t	р
Panic/somatic (PN)	4.50	5.42	965	.341
Generalized anxiety (GAD)	6.79	8.61	-2.531	.016
Separation anxiety (SP)	4.74	4.97	470	.641
Social phobia (SC)	5.34	8.63	-4.923	.000
School phobia (SH)	1.24	1.37	360	.721
Total	22.61	29.00	-2.511	.017

cut-off point (≥ 8). Lastly, in School Phobia, 13.2% of the children and 26.3% of the parents were above the cut-off point (≥ 3). Table 3 shows the mean difference between the children and parents. The differences in the Total Anxiety score were significant (p < .017). The parents obtained a total mean score of 29.00 versus the children's total mean score of 22.61. There were also a significant differences between children and parents in the factor of Generalized Anxiety (p < .016), where the parents obtained a mean score of 8.61 versus the children's mean score of 6.79, and in Social Phobia (p < .000), where the parents obtained a mean score of 8.63 versus the children's mean score of 5.34. In the remaining factors, no significant differences were found, although the parents' perception of anxiety was always higher than that of their children.

Analysis of the correlations between factors (Table 4) revealed differences in the number of significant correlations as a function of the type of participant (children or parents).

The Panic/Somatic factor had significant correlations with the rest of the factors, especially in the children, where the correlations ranged from r=.581 with Generalized Anxiety to r=.484 with School Phobia. In the case of parents, the correlations ranged from r=.620 with Separation Anxiety to r=.293 with Social Phobia. In addition to the above-mentioned correlation with the panic/somatic factor, generalized anxiety had significant correlations with the remaining factors both in children and parents. In the case of the children, the correlations ranged from r=.660 with Separation Anxiety to r=.246 with school phobia. In the case of the parents, the

correlations ranged from r = .319 with Social Phobia to r = .074 with School Phobia.

Separation anxiety significantly correlated with social phobia and school phobia both in children and parents, in addition to its association with Panic/somatic and Generalized Anxiety. In the specific case of children, the correlations varied from r = .422 with social anxiety to r = .234 with school phobia. In the case of parents, the correlations varied from r = .418 with school phobia to r = .254 with social phobia.

Lastly, social phobia had significant correlations with school phobia in children (r = .336), besides with the aforementioned factors. In the case of the parents' reports, no correlations between this factor and school phobia was found (r = .166)

Table 5 shows the correlations between the factors assessed by the SCARED and the participants' age. Although there was only one significant correlation, it can be observed that both in children and parents, the scores on the different factors correlated slightly and positively with age (except for one factor), such that higher age corresponded to more perception of anxiety, and vice versa. The only significant age-related correlation was with the Panic/Somatic factor (r=. 405) in children.

Lastly, Table 6 presents the correlation in each factor between parents and children. The correlation was high and significant in the factors of Generalized Anxiety (r = .547), Separation Anxiety (r = .560), and Social Phobia (r = .484). The correlation was positive but nonsignificant in the Panic/Somatic factor (r = .179) and the Total factor (r = .319). There was no correlation in School Phobia (r = .007).

# **DISCUSSION AND CONCLUSION**

Given that the prevalence of anxiety in children with ASD is now recognized as a major public health problem (Simonoff et al., 2008), additional information about the assessment of these symptoms is needed. This study represents an important step in the consideration of selfreports of children with ASD and for the analysis of the possible agreement between parents and their children regarding perception of anxiety symptoms. The results of this study suggest that such parent-child agreement is limited. In all the factors, the anxiety levels perceived by the parents in their children are higher than those manifested by the children themselves. These differences were significant in the total score of Anxiety, the Generalized Anxiety factor, and the factor of Social Phobia. In the remaining factors, no significant differences were found, although the parents' perception of anxiety was always higher than that of their children. Based on the cut-off points for each factor, the prevalence of symptoms shows that in all the factors, the percentage of parents above the cut-off point is always greater than the percentage of children above this point except for the

**Table 4.** Correlations between the SCARED factors by participants and gender.

		Generalized anxiety (GAD)	Separation anxiety (SP)	Social phobia (SC)	School phobia (SH)
Children	Panic/somatic	.581**	.536**	.525**	.484**
Parents	(PN)	.315	.620**	.293	.573**
Children		Satur (CAD)	.492**	.660**	.246
Parents	Generalized anxi	lety (GAD)	.309	.319	.074
Children		.t. (OD)		.422**	.234
Parents Separation Anxiet	ety (SP)		.254	.418**	
Children C. L. B. L.		0)			.336*
Parents	Social Phobia (SC)				.166

<sup>\*</sup>p < .05 (two-tailed). \*\*p < .01 (two-tailed).

Table 5. Correlations between SCARED factors and the participants' age and gender.

		Panic/Somatic (PN)	Generalized Anxiety (GAD)	Separation Anxiety (SP)	Social Phobia (SC)	School Phobia (SH)	Total
Children	٨٥٥	.405**	.267	.018	.273	.069	.312
Parents	Age	.002	.223	102	.117	.091	.100

<sup>\*\*</sup>p <.01 (two-tailed).

**Table 6.** Correlations between children's and parents' factors of the SCARED.

SCARED factors	Parents-children correlation	р
Panic/Somatic (PN)	.179	.281
Generalized Anxiety (GAD)	.547	.000
Separation Anxiety (SP)	.560	.000
Social Phobia (SC)	.484	.002
School Phobia (SH)	.007	.965
Total	.319	.051

factor of Separation Anxiety which has the same percentages. There are notable differences in the factors of Social Phobia and Total Anxiety, where the percentage of parents above the cut-off point is twice that of the children above this cutoff point. Although parent-child agreement tends to be lower in the group of ASD, the correlations were nonsignificant in the group of children with anxiety disorders (van Steensel et al., 2012). These findings support the notion of Reaven et al. (2012) that the potential problems associated with the use of self-reports in children with ASD may be the same as those of samples without ASD. In our study, the correlations between children and parents' scores are high and significant in the factors of Generalized Anxiety, Separation Anxiety, and Social Phobia. The correlation is

positive but nonsignificant in the Panic/Somatic factor and the Total Anxiety factor. There is no correlation between parents and children in the School Phobia factor. This study has several limitations that must be taken into account. First, little is known about the psychometric properties of anxiety measured in samples of children with ASD (White and Roberson-Nay, 2009). It is not yet clear whether anxiety measures designed for typical populations are reliable for all children with ASD, and hence, more studies are necessary. Generalization of the results of this study is limited by the relatively small sample, and because the girls are in a minority, even for people with ASD. However, we could justify the size and sex of the sample because the population with ASD without intellectual disabilities is still a minority, like girls

with ASD; in fact, girls with ASD with associated intellectual disabilities are more numerous than children.

Although anxiety disorders are characterized both by homotypal continuity (prediction of the disorder by the same disorder) and heterotypal continuity (prediction of the disorder by another disorder), certain anxiety disorders appear to covary more than others (Gregory et al., 2007). The Panic/Somatic and Separation Anxiety factors display a close developmental relationship, called the separation anxiety hypothesis (Klein, 1964; Silove et al., 1996). The two factors share common physiological disturbances, such as somatic symptoms (Pine et al., 2005; Slattery et al., 2002).

In our study, multiple significant correlations were found in the children between all the factors of the SCARED except for the factor of School Phobia, which does not correlate significantly with the factors of Generalized Anxiety, Separation Anxiety, and Social Phobia. In the case of parents, fewer significant correlations between factors are observed than those found in the children. The factors of Social Phobia and Generalized Anxiety have the fewest significant interactions with the other factors.

The correlations between age and the different factors measured by the SCARED are low or very low both in children and in parents. There was only one significant and high correlation in children with the Panic/Somatic factor. Similarly, other authors (Birmaher et al., 1997; Compton et al., 2000; Essau et al., 2002; Hale et al., 2005; Ogliari et al., 2006; Su et al., 2008) point out that although the Separation Anxiety decreases as adolescents mature, other anxiety disorders increase with age.

As mentioned in the introduction, anxiety disorders are one of the most common concurrent conditions and can be an important factor, as they interfere significantly with school and social adaptation (Leyfer et al., 2006). Anxiety is sometimes associated with an increase in aggression and it reduces participative relations in social activities (Selles and Storch, 2012). Cognitive-behavioral treatments considered the most effective psychosocial interventions (Fortea et al., 2008; Walkup et al., 2008). These individuals should be treated as soon as possible (Narbona and Crespo, 2012), focusing on the areas of altered development (Martos and Llorente, 2013), while involving the parents in the establishment of the goals to be achieved (Lord and Bishop, 2010). Family schools are also important because improvements have been observed in the reduction of parents' stress, as well as in their perception of their responses to their children's behavior and, significantly, in their assessment of the quality of the time shared by parents and siblings (Ayuda et al., 2012). Therefore, and taking into account that the visual channel is preferred for information processing of people with ASD, we should make use of augmentative communication systems combining speech with visual supports (Fortea et al., 2015).

# **Conflict of Interests**

The authors have not declared any conflict of interests.

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