



In the eye of the beholder: Reports of autism symptoms by Anglo and Latino mothers



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ARTICLE INFO

Article history:

Received 2 May 2014

Received in revised form 27 August 2014

Accepted 29 August 2014

Keywords:

Autism spectrum disorder

Latino families

Screening

Ethnicity

Culture

Parent report

Diagnosis

ABSTRACT

Latino children with autism spectrum disorder (ASD) are under-identified and under-diagnosed. Children suspected of ASD (28 Anglo and 55 Latino) were assessed via the Autism Diagnostic Observation Schedule (ADOS) and the mother Intake Form. A subsample of 40 children were assessed with the Autism Disagnostic Interview-Revised (ADI-R). The primary objective was to determine whether Anglo and Latino mothers differed in their symptom reports, and whether their children differed in the professional classifications. Anglo mothers reported significantly more developmental concerns and ASD symptoms than Latino mothers, yet Latino children meeting diagnostic criteria for autism on the ADOS obtained higher ASD severity scores than Anglo children. The authors set forth three possible explanations for such discrepancies between parents and professionals in perceptions and reporting of autism symptoms: (1) Latino mothers are not as aware of the symptoms, and thus do not report them; and (2) Latino mothers are aware of general developmental delay but not as concerned as Anglo mothers until social communication deficits become more apparent. (3) Latino mothers' parenting practices and cultural beliefs about child-rearing might mask both the ASD symptomatology exhibited by their children and their recognition of it.

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1. Introduction

Well-documented ethnic and racial disparities exist in the diagnosis and treatment of many physical and mental health disorders (Begeer, El Bouk, Boussaid, Terwogt, & Koot, 2009; Mandell, Listerud, Levy, & Pinto-Martin, 2002; Mandell & Novak, 2005; Smedley, Stith, & Nelson, 2002), yet recent evidence examining the prevalence of ASD among socioculturally diverse children is inconclusive. Recent studies have shown few, if any systematic differences in the prevalence of ASD among socioeconomic and ethnically diverse children (Centers for Disease Control, 2006; Mandell, Novak, & Zubritsky, 2005).

For Latino families, however, consistent findings have shown that they are less likely than White children to be diagnosed with an ASD (Kogan et al., 2009; Liptak et al., 2008; Mandell et al., 2009; Palmer, Walker, Mandell, Bayles, & Miller, 2010). In their analysis of over 1000 Texas school districts, Palmer and colleagues (2010) used school district records of autism to

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examine the prevalence of ASD in Latino children. They found that non-Latino children were two to three times more likely to be diagnosed with an ASD than the Latino children in the same district. According to Palmer and colleagues, socioeconomic status did not explain the lower prevalence of autism among Latino children in their sample. Thus, they questioned whether there was a systematic under-diagnosis of ASD in Latino children, or whether there were certain protective factors associated with being Latino that may have prevented these children from being diagnosed (Palmer et al., 2010). Another study based on parent report only, found less dramatic, but similar results. Kogan and colleagues (2009) found that the ASD estimate for Latino children was only slightly lower than the estimate for non-Latino White children. The differences in reporters may have contributed to the difference in prevalence for these two studies. Palmer and colleagues used school district records which presumably came from psychologists' diagnostic reports (although this was not clear in the study).

1.1. Cultural beliefs about child development and disability

Previous research has established that cultural groups vary in their beliefs about child development and disability (Skinner & Weisner, 2007). For Latino families, research has shown that parents have distinct beliefs about what developmental skills they expect for their children and when those skills should be mastered. For example, Gannotti and colleagues, studying Puerto Rican children with disabilities and their families found that parents expected their children to meet certain developmental milestones (e.g., drinking from a cup) much later than did Anglo parents (Gannotti, Handwerker, Groce, & Cruz, 2001). On the other hand, Arcia, Reyes-Blanes, and Vazquez-Montilla (2000) examined whether Latino parents' values and expectations for their children (e.g., to be respectful, to exhibit proper comportment) was evident in a sample of children with a disability. They found that these parents expected their children to exhibit the same behaviors as their typically developing peers: to be respectful, and responsible, to have a sense of right and wrong, to be close to their families, and to be curious (*preguntón*) (Arcia et al., 2000).

Related to diagnosis, cultural beliefs may influence parents' interpretation of symptoms pertaining to the disability. For example, in a qualitative study by García and colleagues (2000), interviews of Mexican heritage mothers who cared for children with language delays found that the mothers did not believe their child had communication disorders, as they did not expect their children to understand language or speak until age 3. Because they were not concerned about their child's emergent language development in relation to certain developmental milestones, they were not concerned about their child's communication difficulties (García, Pérez, & Ortiz, 2000); this lack of concern might preclude parents from seeking a diagnosis.

Service providers also may hold cultural beliefs that contribute to their interpretation of ASD symptoms and promote the under-diagnosis of ASD in children from socioculturally diverse backgrounds. For example, the communication deficits associated with ASD could be interpreted as a lack of proficiency in English, and the social deficits associated with ASD could be interpreted as the inability to adapt to US norms and culture (Reijneveld, Harland, Brugman, Verhulst, & Verloove-Vanhorick, 2005). Screening and diagnostic procedures for ASD in socioculturally diverse groups could be complicated by the social and communication deficits associated with ASD or by the child's ethnic and/or racial background. A recent study (Begeer et al., 2009) examined pediatricians' assessments of ASD among socioculturally diverse children (e.g., Moroccan, Turkish) and found that when pediatricians used their clinical judgment to assess for ASD, the socioculturally diverse children were under-represented as compared to the European (Dutch) children. However, when the same pediatricians used a structured measure to assess for ASD, the effect of ethnicity disappeared. An older study examining the same phenomenon with school psychologists and child psychiatrists found the same results (Cuccaro et al., 1996), suggesting that when clinicians put their own cultural beliefs aside and utilize a standardized protocol to assess for ASD, there will be less bias and more objective diagnoses.

1.2. Autism diagnosis and Latino children

Evidence exists for a universal set of symptoms associated with autism, and there is reliability in the diagnosis of ASD and the differences in subtypes (American Psychological Association, 2000, 2013; Fombonne et al., 2004; Hill et al., 2001). The Autism Diagnostic Observation Schedule (ADOS), often in combination with the Autism Diagnostic Interview-Revised (ADI-R), comprise the gold standard instrument in the assessment and diagnosis of ASD (Risi et al., 2006). The ADOS is a clinician-led, standardized observation tool used to detect qualitative abnormalities in communication, social reciprocity, and restrictive, repetitive, or stereotyped patterns of behavior (Lord, Rutter, DiLavore, & Risi, 2008). The ADI-R is a standardized, semi-structured, investigator-led interview for caregivers of children with autism (Le Couteur, Lord, & Rutter, 2003).

Although these tools have been translated into Spanish using traditional back-translation methods (Vrancic et al., 2002), the Spanish versions of these measures have not been validated with Spanish-speaking populations, and there is emerging evidence of cultural inequivalence among these assessments (Overton, Fielding, & Garcia de Alba, 2007; Magaña & Smith, 2006, 2013). Overton and colleagues (2007) studied a group of Latino children ($n = 28$) and found inconsistencies in diagnosis between the ADOS and the ADI-R. Children who exhibited greater deficits in social reciprocity on the ADOS did not have the same significant social deficits according to the ADI-R. Parents were under-reporting their children's social skills deficits (Overton et al., 2007).

A more recent study by Magaña and colleagues (2013) compared ADI-R scores in Latino adolescents to a matched group of non-Latino White adolescents. They found no significant differences between the two groups on the Social Reciprocity and

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