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Challenges of case identification and diagnosis of Autism Spectrum Disorders in China: A critical review of procedures, assessment, and diagnostic criteria

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ABSTRACT

The estimated prevalence of Autism Spectrum Disorders (ASD) in China has been consistently lower than most of the studies in the West. The current article addressed several challenges in identifying and diagnosing ASD in mainland China. The underestimated prevalence may due to a variety of reasons, including inconsistencies in screening and diagnostic procedures, variations in translated instruments, and discrepancies between diagnostic criteria. This review provides insight into ASD assessment and diagnosis in the Chinese population and discusses strategies for the further advancement of ASD identification and intervention in mainland China.

1. Introduction

A recent estimate of worldwide prevalence of Autism Spectrum Disorders (ASD) is 6.2 per 1000 children, with a higher rate in boys than girls (Elsabbagh et al., 2012). Available studies from Northern European countries (e.g., United Kingdom, Iceland, Denmark, and Sweden) report their prevalence rates ranging from 3.0 to 11.6 per 1000 children (Elsabbagh et al., 2012). In the United States, the most recent estimate of ASD prevalence is around 14.7 per 1000 children (about 1 in 68 or 1.5%; Christensen et al., 2016). In South America (e.g., Venezuela, Caribbean, and Argentina), ASD prevalence is estimated to be 1.3 to 3.9 per 1000 children (Lejarraga et al., 2008; Montiel-Nava et al., 2008; van Balkom et al., 2009). In Asia, the prevalence of ASD ranges from 2.8 to 9.4 per 1000 in Japan (Kawamura, Takahashi, & Ishii, 2008) and a surprisingly high rate from 19.1 to 33.7 per 1000 in South Korean among children ages 7 to 12 years old (Kim et al., 2011). It is important to note that the great variability of prevalence rates across studies

Abbreviations: ABC, Autism Behavior Checklist; ADI-R, Autism Diagnostic Interview-Revised; ADOS, Autism Diagnostic Observation Schedule; APA, American Psychiatric Association; ASD, Autism Spectrum Disorder; ASQ, Autism Spectrum Quotient; CABS, Clancy Autism Behavior Scale (CABS); CARS, Childhood Autism Rating Scale; CAST, Childhood Autism Spectrum Test; CCMD, Chinese Classification of Mental Disorders; CHAT, Checklist for Autism in Toddlers; DSM, Diagnostic and Statistical Manual of Mental Disorders; DSM-5, Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition; DSM-IV, Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition; DSM-IV-TR, Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision; ICD, International Classification of Diseases; ICD-10, International Classification of Diseases, Tenth Edition; IEP, Individualized education program; PEP, Psychoeducational Profile; PDD-NOS, Pervasive Developmental Disorder, Not Otherwise Specified; SCQ, Social Communication Questionnaire; SRS, Social Responsiveness Scale; VABS, Vineland Adaptive Behavior Scales

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may be influenced by the study methods, the measures used for assessing ASD characteristics, the targeted populations (e.g., toddlers, school-age children, or adolescents), and the criteria used for determining ASD. Furthermore, the recruitment approaches (e.g., investigating prevalence rates in underdiagnosed community-based populations versus among clinic-based samples) can significantly impact the estimated prevalence. When interpreting the differences in prevalence rates across studies, it is critical to understand the potential impact of these factors (extensive review in Elsabbagh et al., 2012).

Compared to the prevalence rates reported by other countries, epidemiological studies in mainland China have consistently reported lower estimates. One study based on a national sample from the Second China National Survey on Disability reported a prevalence rate of 2.38 per 1000 in mainland China (primarily based on clinician's diagnosis; Li, Chen, Song, Du, & Zheng, 2011). A systematic review of the available reports in mainland China, Hong Kong, and Taiwan suggests that the prevalence of autistic disorder (as defined in DSM-IV) is about 1.18 per 1000, and the prevalence of ASD (including autistic disorder, Asperger's disorder, and PDD-NOS) is about 2.66 per 1000 in the Chinese population (Sun et al., 2013). Another review of comparing the prevalence of ASD (i.e., autistic disorder, Asperger's disorder, and PDD-NOS in DSM-IV) in Chinese populations reported that the prevalence of ASD in Hong Kong and Taiwan ranged from 0.28 to 2.95 per 1000, whereas the estimate in mainland China ranged from 0.238 to 1.1 per 1000 children (primarily based on screening measures and clincial diagnoses; Feng et al., 2013). Furthermore, one study in Tianjin, China indicated that the prevalence of ASD was 2.75 per 1000 among toddlers between 18–36 months old (based on parent-reports; Huang et al., 2014). The estimated prevalence of undiagnosed ASD in school-age children (i.e., aged 6–12) is 11.9 per 1000 in mainland China based on a community sample of 737 students in Beijing [diagnosis using the Autism Diagnostic Observation Schedule (ADOS; Lord et al., 2000) and the Autism Diagnostic Interview-Revised (ADI; Rutter, LeCouteur, & Lord, 2003); Sun et al., 2015] Although some of the differences in rates reported in different studies could, to some extent, be explained by differences in methodology, such as recruitment methods, sampling population, and/or diagnostic procedures, rates reported in China are consistently lower, indicating challenges in identifying ASD which may also explain the low rates.

The current paper addresses the challenges in identifying and diagnosing ASD in mainland China. Specifically, it focuses on the inconsistencies in current diagnostic procedures, the changes in psychometric properties of Chinese-translated instruments, and the discrepancies in the diagnostic criteria between the Chinese Classification of Mental Disorders (CCMD) (Chinese Society of Psychiatry, 2001) and two widely used systems [i.e., the International Classification of Diseases (ICD) (World Health Organization, 1993) and American Psychiatric Associations Diagnostic and Statistical Manual of Mental Disorders (DSM) (American Psychiatric Association, 2000, 2013)]. Finally, strategies to enhance early detection and diagnosis of ASD in the Chinese population are discussed.

2. Screening and diagnostic procedures

A two-phase diagnostic procedure is commonly used in the United States, including a screening phase and a diagnostic evaluation phase with a multidisciplinary approach (Chawarska, Klin, & Volkmar, 2008). The American Academy of Pediatrics (Plauche Johnson, Myers, & The Conuncil on Children with Disabilities, 2007) recommends formal screenings in pediatric primary care facilities as early as 18 months of age. This phase typically involves the use of parent-report questionnaires to identify children at risk for ASD (National Research Council (U.S.). Committee on Educational Interventions for Children with Autism (2001)). When individuals screen positive for ASD symptoms on these questionnaires, they are referred to specialty clinics for a comprehensive evaluation by a multidisciplinary team.

In many other countries, utilizing this two-phase diagnostic procedure for ASD is not feasible due to cost, patient volumes, visit duration, and lack of formal training (e.g., Pinto-Martin, Dunkle, Earls, Fliedner, & Landes, 2005). The identification of developmental disorders, including ASD, often relies on the universal medical or developmental checkups with primary health care professionals. Therefore, primary care nurses and pediatricians play significant roles in the early identification of ASD. To address the issue of feasibility, a "developmental surveillance" program has been launched in Australia (Barbaro, Ridgway, & Dissanayake, 2011). Any early signs of ASD are monitored together with the developmental milestones when the practitioner is in contact with the child during routine medical checkups. During these visits, trained practitioners observe the child and ask about parent concerns related to the child's development. Studies revealed that the "developmental surveillance" program can identify individuals with ASD as early as 12 months of age in community settings (e.g., Barbaro & Dissanayake, 2013; Barbaro et al., 2011). Therefore, the "developmental surveillance" program is strongly recommended in Australia to enhance the early identification of ASD (Barbaro & Dissanayake, 2013; Barbaro et al., 2011).

2.1. Screening procedures

Similar to many other countries, there are regular physical and developmental checkups at local clinics (e.g., local community hospitals as well as health care centers for women and children) in mainland China. Unfortunately, ASD and neurodevelopmental screenings are not part of standard practice in pediatric primary care settings. Physicians and pediatricians at this level are often not trained to perform these types of screenings and are often unfamiliar with the symptoms of ASD (Duan et al., 2015; Huang, Jia, & Wheeler, 2013). As a result, early detection of ASD relies mostly on parents' awareness of symptoms and persistence in obtaining the appropriate services. It has been reported that parent education level is significantly related to the early detection of ASD in mainland China (Zhou et al., 2014). If parents fail to report behavioral difficulties associated with ASD, their children are typically overlooked by professionals.

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