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Final DSM-5 under-identifies mild Autism Spectrum Disorder: Agreement between the DSM-5, CARS, CASD, and clinical diagnoses

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ABSTRACT

Agreement between the final DSM-5 ASD criteria, Childhood Autism Rating Scale (CARS), and Checklist for Autism Spectrum Disorder (CASD) was assessed in 143 children with ASD and other disorders (e.g., ADHD, intellectual disability, and oppositional defiant disorder). Diagnostic agreement between the CARS and CASD was high (94%), but their agreement with the DSM-5 was lower (84% and 88%). Agreement between the DSM-5 and both the CARS and CASD increased to 94% and diagnostic accuracy increased from 92% to 96% when one less DSM-5 social communication and interaction symptom was required for a diagnosis. Children with ASD not meeting DSM-5 criteria most often did not have criterion A2 (deficits in nonverbal social communication). Total scores on the DSM-5, CASD, and CARS were far higher for children with mild ASD (formerly PDDNOS) than no ASD, indicating that these children are clearly on the autism spectrum and are quite different from children with other disorders. However, only one child with mild ASD was identified by the DSM-5. This study and 11 others show that the DSM-5 under-identifies children with ASD, particularly children at the mild end of the spectrum. This can be rectified by requiring one less social communication and interaction symptom for a diagnosis.

1. Introduction

1.1. Proposed 2012 DSM-5 criteria and validity studies

According to 11 studies, the proposed 2012 DSM-5 Autism Spectrum Disorder (ASD) criteria under-identifies children with ASD, particularly those with mild ASD or pervasive developmental disorder not otherwise specified (Barton, Robins, Jashar, Brennan, & Fein, 2013; Frazier et al., 2012; Gibbs, Aldridge, Chandler, Witzlsperger, & Smith, 2012; Huerta, Bishop, Duncan, Hus, & Lord, 2012; Matson, Belva, Horovitz, Kozlowski, & Bamburg, 2012; Matson, Hattier, & Williams, 2012; Matson, Kozlowski, Hattier, Horovitz, & Sipes, 2012; Mayes, Black, & Tierney, 2013; McPartland, Reichow, & Volkmar, 2012; Worley & Matson, 2012; Young & Rodi, 2013). Together, these studies included individuals of all ages (toddlers through adults), levels of functioning (severe intellectual disability to gifted), and degree of ASD (PDDNOS to severe autism). An important finding was that individuals who had a clinical diagnosis of ASD but did not meet the proposed DSM-5 criteria had

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significant autism symptoms on autism severity measures and when compared with clinical and normal controls (Matson, Belva, et al., 2012; Matson, Hattier, et al., 2012; Matson, Kozlowski et al., 2012; Mayes et al., 2013; Worley & Matson, 2012). The majority consensus was that the proposed DSM-5 ASD criteria should be relaxed. Three studies (Frazier et al., 2012; Matson, Hattier, et al., 2012; Mayes et al., 2013) showed that by simply requiring one less symptom for a DSM-5 diagnosis, fewer individuals with ASD were missed (increasing sensitivity by 12%, 14% and 16%, respectively), specificity was minimally decreased (by 2%, 0%, and 3%, respectively), and diagnostic agreement between the proposed DSM-5 and the DSM-IV improved.

1.2. Final 2013 DSM-5 criteria

The final DSM-5 ASD criteria (American Psychiatric Association, 2013, pp. 50–54) differ from the initial 2012 proposed criteria, potentially increasing the likelihood of an ASD diagnosis, as well as agreement with established autism tests. Major changes are: (1) specifically stating at the beginning of the diagnostic criteria that the symptoms are manifested "currently or by history" so that symptoms are scored based on life-time occurrence, (2) stating that examples in the criteria "are illustrative, not exhaustive" and providing additional examples not included in the initial criteria, (3) replacing "and" with "or" in a few places so that all symptoms are not required (e.g., as in "difficulties in sharing imaginative play or in making friends"), (4) relaxing the wording of some symptoms (e.g., "total lack of initiation of social interaction" is replaced with "failure to initiate or respond to social interactions"), (5) emphasizing the importance of peer relationships (replacing "absence of interest in people" with "absence of interest in peers"), (6) adding to Criterion C that symptoms "may be masked by learned strategies later in life," and (7) providing several additional examples of symptoms. These include: (A1) "deficits in...the ability to engage with others and share thoughts and feelings" and "difficulties processing and responding to complex social cues (e.g., when and how to join a conversation, what not to say)," (A2) "absent, reduced, or atypical use of ...facial expressions, body orientation, or speech intonation," (A3) "inappropriate approaches that seem aggressive or disruptive," "insistence on playing by very fixed rules," and "preference for...interacting with much younger or older people," (B1) "use of 'you' when referring to self," (B2) "difficulties with transitions," "rigid thinking patterns," "insistence on adherence to rules," "repetitive questioning," and "pacing a perimeter," and (B4) "excessive food restrictions."

2. Purpose

The purpose of our study is to determine diagnostic agreement between the final 2013 DSM-5 ASD criteria, clinical diagnoses, and scores on two autism measures with established validity and reliability, the Childhood Autism Rating Scale (CARS, Schopler, Reichler, & Renner, 1986; Schopler, Van Bourgondien, Wellman, & Love, 2010) and the Checklist for Autism Spectrum Disorder (CASD, Mayes, 2012). Both the CARS and CASD include symptoms falling under the DSM-5 social communication and interaction domain and the restricted and repetitive behaviors and interests domain, including the sensory symptoms which are a new addition to the DSM. The DSM-5 encourages the use of standardized measures and states "standardized behavioral diagnostic instruments with good psychometric properties, including caregiver interviews, questionnaires and clinical observation measures, are available and can improve reliability of diagnosis over time and across clinicians" (American Psychiatric Association, 2013, p. 55). We believe this is the first study using the final 2013 DSM-5 criteria and not the proposed criteria. Most previous studies retrospectively matched proposed DSM-5 symptoms with existing scores on autism measures. This technique is problematic because of poor agreement between experts on matching symptoms using some measures, such as the ADI-R and ADOS, and because the DSM-5 has symptoms which are not found on some of the measures used in previous studies (Barton et al., 2013). In contrast, our study is prospective and the DSM-5, CARS, and CASD were concurrently scored by clinicians during the diagnostic evaluations.

3. Methods

3.1. Sample

Participants are consecutive referrals evaluated after publication of the DSM-5 for possible ASD in the independent clinics of three licensed PhD psychologists, one board certified child psychiatrist, and one board certified developmental pediatrician, all with extensive ASD training and clinical experience. The 143 children are 1–18 years of age (*M* 7.3, *SD* 4.2). IQs range from 30 to 138 (*M* 87.8, *SD* 25.4) and were obtained primarily from the Wechsler scales or Bayley Mental Scale. Males comprise 65.0% of the sample, 87.4% are white, and 41.3% have a parent with a professional or managerial occupation. Diagnostic evaluations included an interview with the parent (and the child if able) about early history and current symptoms; a review of early intervention, school, and medical records; scores on behavior and autism rating scales completed by parents and, in most cases, also by teachers or child care providers; and clinical observations of the child. Ninety-nine children were diagnosed by one of the five clinicians with ASD. Of these, 89 had autism (formerly Autistic Disorder) and 10 had mild ASD (formerly PDDNOS). The 44 remaining children had other disorders (ADHD, intellectual disability, learning disability, oppositional defiant disorder, anxiety disorder, language disorder, depression, psychosis, and/or reactive attachment disorder). The three diagnostic groups did not differ significantly in age ($F = 0.0$, $p = .97$) or IQ ($F = 1.2$, $p = .30$)