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Comparability of DSM-IV and DSM-5 ASD Research Samples

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Abstract

DSM-5 criteria for ASD have been criticized for being too restrictive, especially for more cognitively-able individuals. It is unclear, however, if high-functioning individuals deemed eligible for research via standardized diagnostic assessments would meet DSM-5 criteria. This study investigated the impact of DSM-5 on the diagnostic status of 498 high-functioning participants with ASD research diagnoses. The percent of participants satisfying all DSM-5-requirements varied significantly with reliance on data from the *Autism Diagnostic Observation Schedule* (ADOS; 33%) versus *Autism Diagnostic Interview-Revised* (ADI-R; 83%), highlighting the impact of diagnostic methodology on ability to document DSM-5 symptoms. Utilizing combined ADOS/ADI-R data, 93% of participants met DSM-5 criteria, which suggests likely continuity between DSM-IV and DSM-5 research samples characterized with these instruments in combination.

Keywords

Autism; Diagnosis; Assessment; DSM-5; Autism Diagnostic Observation Schedule (ADOS); Autism Diagnostic Interview (ADI)

The proposal for the Fifth Edition of the *Diagnostic and Statistical Manual* (DSM-5; American Psychiatry Association 2012) involves significant changes to the criteria for autism and related disorders (<http://DSM5.org>). Excellent specificity has been found with these criteria (e.g. Frazier et al. 2011; Mattila et al. 2011; McPartland et al. 2012). However, multiple reports indicate that 60% or fewer of those with DSM-IV ASD diagnoses would satisfy DSM-5 criteria, and thus many concerns have been raised about the new criteria being too restrictive (e.g. Gibbs et al. 2012; McPartland et al. 2012; Matson et al. 2012a, 2012b; Worley & Matson 2012). Sensitivity has been especially low for individuals diagnosed with Asperger's disorder or PDD-NOS and those with normative cognitive function and better developed verbal abilities (e.g. Matilla et al. 2011; McPartland et al. 2012).

It is unclear, however, if verbal, cognitively-able individuals who have been research participants in past or current studies would fare similarly with DSM-5 criteria. In addition to having a clinical diagnosis, research participants are generally held to an even higher burden of proof that they have an ASD in order to ensure comparability across studies and

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validity of findings. Typically, a clinical diagnosis of ASD needs to be supported by a standardized assessment and verified by expert clinical opinion in order to sufficiently document the diagnosis prior to participation. An implication of this approach is that some individuals with the mildest ASD presentations may be excluded from traditional studies utilizing this approach and thus these studies may not reflect the entire clinical population. However, a significant advantage is consistent diagnostic categorization of ASD across studies despite heterogeneity in symptom presentation (Rutter 2012). This is essential in order to be certain that participants in ASD studies do in fact have an ASD and in order to enable comparison of findings across studies.

There are many ASD diagnostic tools available (Matson, Nebel-Schwalm, & Matson, 2007), and a variety of measures are used in research. Perhaps the most commonly used measures to document diagnosis in research studies are the Autism Diagnostic Observation Schedule (ADOS; Lord et al. 1999) and the Autism Diagnostic Interview – Revised (ADI-R; Rutter et al. 2003), which are required measures for all National Institutes of Health-funded autism program projects. Although there are limitations in the use of these measures clinically (e.g. time, level of required training, and significant cost of materials; Matson et al., 2007), combined use of these measures together with clinical judgment produces a rigorous and consistent diagnosis (Risi et al, 2006). However, given that the diagnostic algorithms for the ADOS and ADI-R were designed to maximize sensitivity and specificity based on DSM-IV, it is not clear if research participants whose ASD diagnoses were confirmed with these measures would have the symptoms required by DSM-5.

If individuals with ASD who met this commonly used and relatively stringent criteria to participate in research (e.g. clinical diagnosis of an ASD, expert opinion confirming diagnosis, and meeting ADOS, and ADI-R cut-offs) do not meet DSM-5 criteria, that would be of great concern and thus needs to be investigated. Further, understanding whether participants from published research studies would meet the proposed DSM-5 criteria is critical to understanding how comparable studies collected under DSM-5 will be to prior research. Thus, this study sought to better understand if concerns about DSM-5 criteria extend to verbal, cognitively-able research participants who were subjected to intensive diagnostic verification before entering into research. We developed an algorithm for mapping ADOS and ADI-R items onto the DSM-5. We then applied these DSM-5 ADOS/ADI-R algorithms to a large sample of research participants with ASD to determine whether there was evidence for the symptoms required by DSM-5 based on information from the ADOS alone, ADI-R alone, or a combination of the ADOS/ADI in this sample.

Method

Participants

This study included 498 participants with ASD. Participant ages ranged from 5- to 61-years-old, with a mean age of 21.8 (SD = 6). The majority of participants were male (82%; n = 419). The mean Full Scale IQ was 105 (SD = 16), with a range of 69 to 141 based on a Wechsler intelligence test (Wechsler, 1991, 1997, 2011).

Participants were prior research participants who had completed Module 3 or 4 of the ADOS and the ADI-R. The focus on Modules 3 and 4, which are for verbally fluent individuals, was chosen given concerns about the DSM-5 being too restrictive for higher-functioning individuals with ASD. Most participants had been diagnosed with several different subcategorical ASDs over time (e.g., PDD-NOS, Asperger's disorder, and high-functioning autism by different clinicians). Due to this inconsistency in subcategorical diagnosis, present analyses focused on individuals with any ASD diagnosis at the time of evaluation rather than separating by specific ASD diagnosis. All participants had a clinical diagnosis of an

ASD which was confirmed by expert clinical opinion and supported by standard DSM-IV-based cut-offs on the ADOS (at least ASD) and ADI-R. The ADOS and ADI-R were administered by diagnosticians who had completed ADOS and ADI-R research training and certification (e.g. ability to administer in standardized fashion, and established at least 80% or 90% agreement in scoring of the ADOS and ADI-R respectively with the test developers or their certified independent trainers). The ADOS and ADI-R were administered by different individuals to ensure unbiased diagnostic confirmation. Some participants had only ADOS or only ADI-R data; therefore sample sizes varied slightly by analysis (see Tables 1 and 2).

Measures

Autism Diagnostic Observation Schedule (ADOS) (Lord et al. 1999, 2000)—The ADOS is a semi-structured observational assessment that provides an opportunity to rate communication, social interaction, imagination/creativity, and stereotyped behaviors. Scores include: 0-no evidence of abnormality, 1-mild abnormality or slightly unusual behavior, 2-definitely abnormal behavior, and 3-definitely abnormal behavior that interferes with the assessment or that cannot be coded for quality due to lack of the behavior. All relevant algorithm and non-algorithm items from modules 3 and 4 were used in the analyses.

Autism Diagnostic Interview-Revised (ADI-R) (Rutter et al. 2003; Rutter et al. 2002)—The ADI-R is a semi-structured caregiver interview covering information needed for assessing ASD. The diagnostic algorithm items are coded for behavior at 4.0-5.0 years of age (ADI-R-defined as the most abnormal period) for all but three social and communication items (exceptions are scored for different age ranges or ever), and ever for repetitive behavior items. As with the ADOS, each question is scored from 0 to 3. Some participants were administered earlier versions of the ADI (LeCouteur et al. 1989); items were matched to ADI-R algorithm items for all analyses. To retain the greatest number of participants for each analysis, only relevant items from the ADI-R diagnostic algorithm were utilized. In the final analysis only, which focused on who satisfied full DSM-5 criteria using combined ADOS/ADI-R information, additional non-algorithm repetitive behavior items were included.

Procedure

The first three authors (three licensed clinical psychologists, all with research-level reliability in administration of the ADOS and ADI-R and extensive clinical experience with these measures) assigned the ADOS and ADI-R items to the DSM-5 criteria (January 2011 revision of proposed criteria). Symptom mapping was completed separately by ADOS module and the ADI-R, with each item only assigned to one DSM-5 criterion. A certified trainer for the ADOS and ADI-R reviewed the ADOS/ADI-R mapping. Final item assignments are available from the first author by request.

Consistent with standard ADOS/ADI-R procedure, all scores of 3 were converted to 2, resulting in a range for each item of 0-2. The range of possible total scores for each criterion and measure differed based on the number of items loading onto that particular criterion. In order to consider there to be evidence of a DSM-5 required symptom, a cut-off of 2 points was chosen (which could be either two scores of 1 or a score of 2 on a single item). Symptom-level results were accumulated to determine whether participants demonstrated the complete breadth of symptoms required of DSM-5. McNemar's test of change was applied to determine whether frequencies differed by source.

Results

There was adequate sampling of A1 and A2 criteria, with nearly all participants satisfying A1 and A2 for all three measures (see Table 1). As noted by the lower possible ranges, the ADOS provided fewer opportunities to score items related to A3 (friendship/relationships) and the B categories (repetitive behaviors). Approximately 75% had evidence of A3 criteria based on the ADOS, but nearly all participants satisfied A3 criteria based on ADI-R data. Across all measures, the means and medians for A criteria were well above the threshold. The rates of repetitive behavior symptoms varied, and were more susceptible to not meeting the criterion given only having one item assessing many of the B domains on the ADOS (thus a score of 2 on a single item would have been required). The ADI-R captured higher rates of repetitive behaviors, with the means and medians at or above the cut-off for all but B4 (sensory).

Based on the ADI-R, 97.5% had evidence of impairment for all three A criteria, but positive rates dropped to approximately 75% based on the ADOS. The majority of participants (84%) had evidence of two different types of repetitive behaviors (B criterion) based on the ADI-R. However, based on the ADOS, 29% (module 4) and 41% (module 3) demonstrated clear (2-point) evidence of at least two repetitive behaviors (module B).

Significantly fewer participants had evidence of abnormalities consistent with full DSM-5 ASD criterion (all three A criterion and at least 2 B criterion) based on the ADOS alone (~33% averaged across each module) compared to the ADI-R alone (83%) ($p < .0001$). Utilizing combined ADOS and ADI-R data (e.g., pooling across either measure to determine if a symptom had been reported or observed), ~87.5% of participants had evidence in all required domains, which significantly differed ($p < .05$) from rates based on the ADI-R alone (83%). When including ADI-R items of repetitive behaviors that are not part of the current ADI-R diagnostic algorithm in conjunction with ADOS data, 93% ($p < .0001$) of participants were found to have evidence of some abnormality across the domains required for DSM-5 criteria.

Discussion

In an effort to understand the impact of DSM-5 on the composition of ASD research samples, this study investigated whether a large sample of research participants collected under current DSM definitions would meet DSM-5 criteria based on evidence from the ADOS and ADI. There was a discrepancy in the proportion of individuals meeting diagnostic criteria based on clinical observation versus interview, with the ADOS alone resulting in a lower proportion of individuals meeting criteria than the ADI-R alone (33% and 83%, respectively). However, utilizing information from the ADI-R alone or the ADOS and ADI-R in combination, nearly all participants (93%) had evidence of symptoms in all required domains. These results demonstrate that, for the most part, the symptoms proposed for ASD in DSM-5 are evident among prior verbal research participants, indicating likely continuity between DSM-IV and DSM-5 research samples characterized with these instruments in combination.

Our results highlight a discrepancy between the ADOS and ADI-R in ability to capture DSM-5 symptoms. When only data from the ADOS was considered, which did not provide as many opportunities to observe or rate symptoms of interest, less than half of participants met criteria. Poorer sensitivity when only one measure is utilized has also been noted with regard to the ADOS and ADI-R as applied to DSM-IV with standard ADOS/ADI-R cut-offs (Mazefsky & Oswald 2006; Risi et al. 2006). However, our results indicate that

incorporation of collateral information about the individual becomes even more essential with DSM-5.

Aspects of the new criteria, especially the greater emphasis on repetitive behaviors and the requirement of impaired friendships/relationships, provide additional challenges to assessment. Repetitive behaviors are difficult to observe and elicit in a 45 minute (or even longer) observation (Lord et al. 2000). Further, even if some repetitive behaviors are observed, a full range of repetitive behaviors may not be demonstrated. In addition, given that the current proposal for DSM-5 requires the presence of two different types of repetitive behaviors across a person's lifetime, but not necessarily presently, historical information becomes essential. Second, while observational measures provide important opportunities to observe deficits in nonverbal communication and social-emotional reciprocity, a brief observation does not allow one to gauge success or facility in developing interpersonal relationships. Limited insight into the nature of social relationships also impairs ability to accurately self-report the status of relationships (Bauminger et al. 2004).

Moving forward, new or modified assessments will be required to capture the range of repetitive behaviors more highly integrated into DSM-5 criteria. In addition, coding of repetitive behaviors on measures such as the ADOS will require additional differentiation, recording facets of repetitive behavior rather than a summary score. Similarly, it will be important to determine how to accurately assess success with interpersonal relationships and how impaired friendship would manifest in very young children in whom this developmental achievement is not expected. There is also a need to determine feasible strategies for tapping the breadth of DSM-5 symptoms in clinical practices with time-limited assessments and in settings without the expertise and financial resources required to support the ADOS and ADI-R (Matson et al., 2007). Finally, it is important to note that the percentage of participants demonstrating sufficient repetitive behaviors (two different types) increased when non-algorithm ADI-R repetitive behavior items were considered. This again highlights that thorough probing of repetitive behaviors will be required moving forward so that these symptoms are not missed.

Some limitations should be considered when interpreting our findings. We did not explore specificity of the criteria and instead focused on whether the DSM-5 symptoms were present in a sample of prior research subjects (more akin to sensitivity). Our approach differed from a clinical evaluation, as clinicians rarely rely on merely counting symptoms to determine if criteria were met. This is also not how ADOS and ADI-R cut-offs were created, and it is possible that a certain cut-off and combination of ADOS items would have better sensitivity for DSM-5 than we found. However, this was a valid way in which to determine if there was evidence of the symptoms that will likely be required by DSM-5, which enabled us to address our primary question regarding suspected comparability of research samples collected under DSM-5 versus previous versions. This study was based on a particular sample of verbal individuals, and these results would only generalize to similarly characterized samples. Given that our samples were characterized in a manner similar to many other research studies, we hope that the results would generalize to other similarly characterized samples of verbal and more cognitively-able research participants. However, our results do not speak to whether the breadth of required DSM-5 symptoms are present among less cognitively able individuals or those who have a clinical diagnosis of ASD but would not be eligible for research based on these measures. An increasing body of research continues to highlight concerns regarding the restrictiveness of DSM-5 ASD criteria, especially for certain subgroups such as very young or mild children (e.g. Gibbs et al. 2012; McPartland et al. 2012; Matson et al. 2012a, 2012b; Worley & Matson 2012), who were not the focus of our study. Finally, we did not assess two proposed DSM-5 criteria: "Symptoms must be present in early childhood; and Symptoms together limit and impair everyday

functioning.” Given that participants had DSM-IV ASD diagnoses, which require symptoms by the age of 3 and the same requirement for impairment, we assume these criteria were satisfied.

Despite these limitations, these data support the presence of the proposed DSM-5 symptoms in a sample of high-functioning individuals with ASD and indicate probable comparability between past and future research studies that determined eligibility with combined administration of the ADOS and ADI-R. The likelihood of meeting threshold for a diagnosis would vary based on the depth, quantity and type of information collected, and therefore may differ in various clinic and research settings. This study addresses only one potential implication of the changing diagnostic criteria for a particular subset of the population, and multiple studies including participants with a variety of presentations and ages will be needed in order to fully understand the impact of DSM-5 on ASD.

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Table 1
Patterns of ADOS and ADI scores by DSM-5 diagnostic criteria domains

DSM-5 criteria	ADOS Module 3	ADOS Module 4	ADI-R
A1. Deficits in social-emotional reciprocity	Possible range: 0-14 N=194 Observed range: 1-14 Mean: 7.94 Median: 8.00 Mode: 7.0 %/n 2: 99.5%/193	Possible range: 0-16 N=238 Observed range: 0-16 Mean: 8.71 Median: 8.00 Mode: 8.00 %/n 2: 99.2%/236	Possible range: 0-14 N=498 Observed range: 0-14 Mean: 10.87 Median: 12.00 Mode: 14.00 %/n 2: 99.2%/494
A2. Deficits in nonverbal communicative behaviors used for social interaction	Possible range: 0-8 N=193 Observed range: 1-7 Mean: 3.67 Median: 4.00 Mode: 4.0 %/n 2: 93.3%/180	Possible range: 0-10 N=247 Actual range: 0-8 Mean: 4.96 Median: 5.00 Mode: 5.00 %/n 2: 98.4%/243	Possible range: 0-18 N=497 Observed range: 0-18 Mean: 10.97 Median: 11.00 Mode: 13.00 %/n 2: 98.4%/489
A3. Deficits in developing and maintaining relationships, appropriate to developmental level	Possible range: 0-4 N=195 Observed range: 0-4 Mean: 2.05 Median: 2.00 Mode: 2.0 %/n 2: 74.4%/145	Possible range: 0-4 N=247 Observed range: 0-4 Mean: 2.05 Median: 2.00 Mode: 2.00 %/n 2: 76.5%/189	Possible range: 0-20 N=488 Observed range: 1-7 Mean: 3.67 Median: 4.00 Mode: 4.0 %/n 2: 98.4%/480
B1. Stereotyped or repetitive speech, motor movements, or use of objects;	Possible range: 0-6 N=193 Observed range: 0-6 Mean: 1.75 Median: 2.00 Mode: 1.00 %/n 2: 51.3%/99	Possible range: 0-6 N=247 Observed range: 0-4 Mean: 1.51 Median: 1.00 Mode: 1.00 %/n 2: 44.9%/111	Possible range: 0-10 N=498 Observed range: 0-10 Mean: 4.62 Median: 5.00 Mode: 4.00 %/n 2: 90.0%/480
B2. Excessive adherence to routines, ritualized patterns of verbal or nonverbal behavior, or excessive resistance to change	Possible range: 0-2 N=195 Observed range: 0-2 Mean: 0.77 Median: 1.00 Mode: 0.00 %/n 2: 20.0%/39	Possible range: 0-2 N=247 Observed range: 0-2 Mean: 0.61 Median: 0.00 Mode: 0.00 %/n 2: 14.6%/36	Possible range: 0-4 N=498 Observed range: 0-4 Mean: 1.65 Median: 2 Mode: 2 %/n 2: 55.4%/276
B3. Highly restricted, fixated interests that are abnormal in intensity or focus	Possible range: 0-2 N=195 Observed range: 0-2 Mean: 0.87	Possible range: 0-2 N=247 Observed range: 0-2 Mean: 0.82	Possible range: 0-4 N=498 Observed range: 0-4 Mean: 2.19

DSM-5 criteria	ADOS Module 3	ADOS Module 4	ADI-R
	Median: 1.00	Median: 1.00	Median: 2
	Mode: 0.00	Mode: 0.00	Mode: 2
	%/n 2: 26.7%/52	%/n 2: 24.3%/60	%/n 2: 79.5%/396
B4. Hyper-or hypo-reactivity to sensory input or unusual interest in sensory aspects of Environment	Possible range: 0-2	Possible range: 0-2	Possible range: 0-2
	N=195	N = 247	N=498
	Observed range: 0-2	Observed range: 0-2	Observed range: 0-2
	Mean: 0.78	Mean: 0.45	Mean:0.81
	Median: 1.00	Median: 0.00	Median: 1.00
	Mode: 0.00	Mode: 0.00	Mode:1.00
	%/n 2: 26.2%/51	%/n 2: 14.2%/35	%/n 2: 17.5%/87

Table 2
Percent with evidence of DSM-5 Criteria based on ADOS and ADI Alone and ADOS-ADI Combined

DSM-5 Requirement		ADOS Module 3	ADOS Module 4	ADI-R
Must Meet each A Criterion				
Total N		193	238	488
0		0.0 (0)	0.0 (0)	0.2 (1)
Number of A Criteria with 2 points % (n)	1	3.1 (6)	1.3 (3)	1.2 (6)
	2	26.4 (51)	23.1 (55)	1.0 (5)
	3	70.5 (136)	75.6 (180)	97.5 (476)
Must Have At Least 2 of B1-B4				
Total N				
0		31.1 (60)	38.5 (95)	1.6 (8)
Number of B Criteria with 2 points % (n)	1	28.0 (54)	32.8 (81)	14.5 (72)
	2	27.5 (53)	21.9(54)	33.9 (169)
	3	11.9 (23)	6.4 (15)	40.0 (199)
	4	1.6 (3)	0.8 (2)	10.0 (50)
Full DSM-5 Criteria (Meets All A Criteria & At Least 2 B Criteria) - ADOS or ADI alone				
Total N		192	238	488
% (n)	No	59.1 (114)	76.1 (181)	17.4 (85)
	Yes	40.9 (79)	23.9 (57)	82.6 (269)
Full DSM-5 Criteria (Meets All A Criteria & At Least 2 B Criteria) - ADOS and ADI Together				
Total N		171	174	
% (n)	No	10.5 (18)	14.4 (25)	
	Yes	89.5 ¹ (153)	85.6 ² (149)	

Note. Shaded rows are consistent with DSM-5 requirements.

¹When non-algorithm ADI items for repetitive behaviors were included, this increased to 100% (n = 127);

²When non-algorithm ADI items for repetitive behaviors were included, this increased to 92.7% (n = 140).