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Disagreement between assessment of ASD utilizing the ADOS-2 and DSM-5 – A preliminary study

Abstract

This study compares the classification of ASD using ADOS-2 with diagnoses using DSM-5 among children between 8 and 10 years old. Case series data were used on four children who were referred with suspected autism, and as a result a discrepancy was found between the ADOS-2 assessment and the overall diagnosis.

Initial findings indicated that age, additional diagnoses, and over-reliance on observation may bias the ADOS-2 classification. In particular, children who were diagnosed with other disorders that share symptoms with ASD exhibit behaviors that may bias the ADOS-2 classification as it relies on observed behavior without considering the underlying cause. This discrepancy points to the importance of utilizing and integrating multiple sources of information in the process of establishing an ASD diagnosis, and suggests a need for specialized clinical training in diagnosing autism and other related co-morbid conditions in children aged 8–10.

This preliminary data calls for further research into the area, especially due to the current over-reliance on the ADOS-2 in clinical practice and research.

Keywords: ASD, ADHD, diagnosis, ADOS-2, DSM-5, school-age children

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Zróżnicowanie diagnozy ASD ze względu na wykorzystanie ADOS-2 i DSM-5 – badania wstępne

Streszczenie

Niniejsze badanie dotyczy zróżnicowania diagnozy ASD ze względu na zastosowane narzędzia diagnostyczne. Dane uzyskane przy pomocy dwu narzędzi diagnostycznych – ADOS-2 i DSM-5 od czworga dzieci z podejrzeniem autyzmu w wieku od 8 do 10 lat zostały porównane pod kątem zgodności uzyskanych przy ich pomocy wyników.

W wyniku analizy stwierdzono zróżnicowanie wyników ze względu na zastosowane narzędzia. Wstępne ustalenia wskazywały, że wiek oraz dodatkowo zdiagnozowane zaburzenia współwystępujące i nadmierna koncentracja na obserwacji mogą zniekształcić wyniki ADOS -2. W szczególności u dzieci ze zdiagnozowanymi innymi zaburzeniami objawiającymi się poprzez zachowania podobne do autystycznych, diagnoza uzyskana przy pomocy ADOS-2, może być zniekształcona, gdyż nie uwzględnia podstawowej przyczyny zaburzeń. Rozbieżność ta wskazuje na konieczność wykorzystania i połączenia wielu źródeł informacji w procesie diagnozowania ASD, a także sugeruje potrzebę specjalistycznego szkolenia klinicystów w zakresie diagnostyki autyzmu i innych współistniejących schorzeń u dzieci w wieku 8–10 lat.

Te wstępne wyniki są obiecujące, lecz wymagają dalszego empirycznego potwierdzenia, szczególnie ze względu na częste obecnie wykorzystywanie ADOS-2 w praktyce klinicznej i badaniach.

Słowa kluczowe: ASD, ADHD, diagnoza, ADOS-2, DSM-5, dzieci z wieku szkolnym

Introduction

The current estimations by the Centers for Disease Control and Prevention (CDC) is that 1 in 59 children aged 8 are diagnosed with ASD (Palinkas, Mendon, & Hamilton, 2019) compared with 4–16 in every 10,000 in DSM-IV (APA, 1991). In recent years, an increase in the prevalence of Autistic Spectrum Disorder (ASD) has raised questions regarding the accuracy of the methodology of clinical diagnoses and assessment of ASD. A standard approach to assessment which accurately employs relevant and psychometrically sound measures is of critical importance to avoid both the under-diagnosis and over-diagnosis of ASD (Ozonoff, Goodlin-Jones, & Solomon, 2005).

Different assessment strategies can be used to help diagnose ASD in accordance with the DSM-5 (APA, 2013) criteria. In this paper, the focus is on a classification instrument that is considered to be one of the most reliable and valid tools – the Autism Diagnostic Observation Schedule, second edition (ADOS-2); (Lord et al., 2012). Some of the challenges involved in establishing an ASD diagnosis will also be presented in this paper.

ASD Overlap with Other Neurodevelopmental Disorders

Researchers have discussed the considerable overlap between ASD symptoms and those of other neurodevelopmental disorders such as ADHD, learning disorders, tic

disorders, and developmental coordination disorders (DCD) also known as dyspraxia (O'Brien & Pearson, 2004), as well as conduct disorders (CD), and oppositional defiant disorders (ODD), (Siponmaa, Kristiansson, Jonson, Nyden, & Gillberg, 2001). Clinical experience and empirical literature suggest that children with ASD and children with ADHD have shared communication and social difficulties, thereby further complicating the diagnostic process (Mayes, Calhoun, Mayes, & Molitoris, 2012). Similarly, the presence of ADHD symptoms in individuals with autism is quite high, while children with ADHD may also exhibit autistic traits/behaviors (Miranda-Casas, Baixauli-Fortea, Colomer-Diago, & Roselló-Miranda, 2013).

Grzadzinski and colleagues (2011) described a subgroup of children with ADHD who had elevated core ASD traits that were not accounted for by ADHD or behavioral symptoms. Similarities were also seen in the neurological profiles of ADHD and ASD individuals in pragmatic language and theory of mind tests (Leitner, 2014). In a later study, Grzadzinski, Dick, Lord and Somer Bishop (2016) underscored the need to recognize that social problems are not specific to ASD. In another research study, Mayes et al. (2012) found that the core symptoms of ADHD, such as inattention and impulsivity, are present in autism, and that attentional features of autism and ADHD have similar underlying neuropsychological deficits such as executive functions deficits. In contrast, they found that autistic symptoms are not common in ADHD.

Diagnosing ASD Based on Information from a Variety of Sources

Experts on autism have provided detailed criteria for best practices in the assessment of ASD (Penner, Anagnostou, Andoni, & Ungar, 2018). The assessment should rely on two main sources of information: (1) caregivers' description of the course of development and of current behavior patterns, and (2) direct observation of the behavior (e.g., Ozonoff, Goodlin-Jones, & Solomon, 2005). Although doubts have been expressed in the past regarding parental reports of their children's symptoms of autism, previous studies support their validity (Daniels et al., 2012). For example, parent estimates of autism prevalence from 2003 to 2012 were highly concordant with professionals' estimates from the same time period. Increases in the prevalence of parent-reported ASD continued through 2011-2012. Diagnoses of children with previously unidentified ASD, especially children aged 6–13, account for much of the recent increase in ASD cases (Blumberg et al., 2013). Backed up by this plethora of research, guidelines for the assessment of autism emphasize the importance of using multiple sources such as parents, teachers, psychologists and physicians, as well as direct observation (Penner et al., 2018).

Research

The purpose of presented research was to examine the practices of ASD assessment by exploring children who are classified differently on the ADOS-2 and the DSM-5;

namely, children aged 8–10 who are classified as ASD on ADOS-2, while eventually not receiving an ASD diagnosis in a comprehensive assessment.

Method

Participants

In the current study, four cases that were referred to Marot Center at the Tel Aviv Sourasky Medical Center during an eight-month period are compared. The four children, whose characteristics is give in table 1, were referred with complaints of communication and social difficulties, and suspected of having autism.

Table 1. Sample characteristics

Cases	**Case 1**	**Case 2**	**Case 3**	**Case 4**
Age	8(6)	10(0)	9(0)	8(0)
Reason for referral	Suspected ASD[a]	Suspected ASD[a]	Suspected ASD[a]	Suspected ASD[a]
Previous diagnoses	ADHD[b]	ADHD[b]	ADHD[b]	ADHD[b]
	LD[c]	LaD[d]	LD[c]	
	LaD[d]	Tourette		

[a] Autism Spectrum Disorder, [b] Attention Deficit Hyperactivity Disorder, [c] Learning Disability, [d] Language Disability

Instruments

All the cases were evaluated by certified child and adolescent neurologists, psychiatrists, and psychologists. The children were evaluated by clinical observation, ADOS-2, and DSM-5. According to ADOS-2, they were classified as being on the autistic spectrum or with autism. Conversely, none of these children met the criteria for ASD according to DSM-5. The following three assessment tools were used to gain the research aim.

The Autism Diagnostic Observation Schedule, second edition (ADOS-2)

ADOS-2 is one of the most widely used measuring tools, and is considered to be the "gold standard" in assessing ASD symptoms for research and clinical purposes, particularly when combined with a comprehensive clinical assessment (de Bildt et al., 2004; Grzadzinski et al., 2016). The information used in ADOS-2 is collected through direct observation (Grzadzinski et al., 2016). The ADOS-2 diagnostic algorithm yields a total score in two domains: Social Affect (communication and reciprocal social interaction), and Restricted and Repetitive Behavior. Items such as conversation, use of gestures, facial expressions when facing others, quality of social response, and stereotyped/idiosyncratic use of words or phrases, are

scored. ADOS-2 classifies these scores into Autism and Autistic Spectrum categories (Lord et al., 2012). Items are scored on a 0–3 scale, with higher scores indicating greater impairment.

The Childhood Autism Spectrum Test (CAST)

CAST is a screening instrument for detecting potential cases of ASD in 4–11-year-old children. CAST is designed to address the difficulty in identifying children who have subtler or milder symptoms and are often missed until primary school (Kamio et al., 2007; Sun et al., 2014; Williams et al., 2005). CAST was used in this research to provide further validity to the DSM-5 and ADOS-2 results, and outline their social communication difficulties in another way.

Diagnostic and Statistical Manual of Mental Disorders – 5th Edition (DSM-5)

DSM-5 (APA, 2013) is the most widely used way for diagnosing ASD. It uses a 5-criteria list with the first two criteria including lists of symptoms. Criterion A lists three symptoms of persistent deficits in social communication and social interaction, all of which are required for a diagnosis. Criterion B includes 4 symptoms of restricted, repetitive patterns of behavior (RRBs), 2 of which are required to make a diagnosis. The DSM-5 is considered by many to be the final authority on the diagnosis of autism (Nemeroff et al., 2013).

Results

A summary of the evaluation data of the four cases is presented in Table 2.

Table 2. Diagnosis of four cases using four sources of information (overall DSM-5 previous diagnosis, ADOS-2, DSM-5 and CAST parental-report questionnaire)

Cases	**Case 1**	**Case 2**	**Case 3**	**Case 4**
Age	8(6)	10(0)	9(0)	8(0)
Reason for referral	Suspected ASD[a]	Suspected ASD[a]	Suspected ASD[a]	Suspected ASD[a]
Previous diagnoses	ADHD[b]	ADHD[b]	ADHD[b]	ADHD[b]
	LD[c]	LaD[d]	LD[c]	
	LaD[d]	Tourette		
*ADOS-2 Classification	ASD[a] (7)	ASD[a] (8)	Autism (13)	Autism (9)
DSM-5 Diagnosis	No ASD[a]	No ASD[a]	No ASD[a]	No ASD[a]
**CAST (Parent report)	12	18	17	21

[a] Autism Spectrum Disorder, [b] Attention Deficit Hyperactivity Disorder, [c] Learning Disability, [d] Language Disability

*ADOS-2 cutoff score for ASD- 7–8, 9 for Autism, ** CAST Cutoff score for social communication disorders-15

These data present the diagnoses of the cases using four sources of information – other professionals' impression, the ADOS-2, the DSM-5 and the CAST self-report questionnaire (Scott et al., 2002). Notably, none of the case studies met the criteria for a DSM-5 diagnosis of ASD. Conversely, three of the four cases were above the cut-off score for ASD conditions according to CAST, and they were all on the autistic spectrum according to ADOS-2. The findings presented in Table 1 demonstrate that, in all four cases, there had been previous diagnoses that had confounded the ADOS-2 classification but not the overall DSM-5 diagnoses. The CAST results were such that three of the four cases were above the cut-off for social communication disorders, further supporting the discrepancy between a comprehensive assessment that relies on multiple sources compared with a single screening tool. Both CAST and ADOS-2 rely on behavioral observations, and that can partially explain the similarities in the results, even though one relies on professionals' observations while the other relies on parental observations.

Description of the ADOS-2 Social Affect (SA) and Restricted and Repetitive Behavior (RRB) domains, as well as the overall score of the four cases, are presented in Table 3.

Table 3. Description of four cases using ADOS-2 scores

Cases	**ADOS-2 Items**	**Case 1**	**Case 2**	**Case 3**	**Case 4**
Social Affect (SA)					
Communication					
Reporting of Events	A-7	1	0	1	0
Conversation	A-8	2	0	2	0
Descriptive, Conventional, Instrumental or Informational Gestures	A-9	0	0	1	1
Reciprocal Social Interaction					
Unusual Eye Contact	B-1	0	2	2	0
Facial Expression Directed to Examiner	B-2	0	1	1	2
Shared Enjoyment in Interaction	B-4	0	1	1	1
Quality of Social Overtures	B-7	1	1	1	1
Quality of Social Response	B-9	1	1	1	1
Amount of Reciprocal Social Communication	B-10	0	1	1	1
Overall Quality of Rapport	B-11	1	0	1	2
SA Total		6	7	12	9
Restricted and Repetitive Behavior (RRB)					
Stereotyped/idiosyncratic Use of Words or Phrases	A-4	0	0	1	0
Unusual Sensory Interest in Play Material/Person	D-1	1	0	0	0

Hand and Finger and Other Complex Mannerisms	D-2	0	0	0	0
Excessive Interest in Unusual or Highly Specific Topics/Objects or Repetitive Behaviors	D-1	0	1	0	0
RRB Total		1	1	1	0
Overall Score (SA+RRB)		7	8	13	9
Comparison score		4	5	8	6
Level of autism spectrum-related symptoms		Low	Moderate	High	Moderate

Analyses of the ADOS-2 algorithms for each of the cases demonstrate interesting patterns. Scores were no higher than minimal (1) in all cases on items A-7, A-9, B-4, B-7, B-9, B-10, D-2, and D-4. For all four children, the RRB Total Score (the sum of the restricted and repetitive behavior items scores) was "no evidence" to "minimal" (scores 0 or 1). Additional diagnoses such as learning disorders and Tourette's are presented as well; notably, all four cases had been diagnosed with ADHD before the present evaluation.

Discussion

The paper focuses on four cases, all of which were referred following a suspicion of ASD, classified as being on the autistic spectrum or with autism by ADOS-2 (Lord et al., 2012). Utilizing the DSM-5, however, none were diagnosed with ASD. Our analysis indicates three sources for the discrepancies between ADOS classification and overall DSM-5 diagnosis: 1) age, 2) additional diagnoses, and 3) sources of information.

Age

The children in this study were all referred at a relatively late age (mean= 8.88). ADOS-2 is divided into several modules according to linguistic level and not necessarily age. School-age children may experience the effects of coping with longstanding difficulties (e.g., learning disabilities) which may cause them to withdraw, be anxious or feel helplessness. When the children undergoing the assessment are older, they may have experienced many more failures in social situations and not try as hard as younger children to compensate for their difficulties. This may lead them to present less favourably on the ADOS-2, which is not taken into account since the ADOS-2 is based on behavioral observations.

Additional Diagnoses

Another source of disparity relates to the characteristics and limitations of the assessment tool when used with relatively older children who have additional disorders. Since ADOS-2 is based only on behaviors observed during the administration of the test (Lord et al., 2012), socially awkward behaviors rooted in other diagnoses

may be coded as indicating autism. Moreover, since the ADOS-2 is observation-based and does not code the source of difficulty ("you score what you see"), it may produce false positives when additional diagnoses are involved. For example, a child coping with ADHD may receive a high score (indicating ASD) on item B7 – Quality of Social Overtures and item B9 – Quality of social responses. In such cases high scores would not necessarily indicate ASD, but may stem from the child's impulsivity.

Similarly, children or adolescents with depressive symptoms or social anxiety may be characterized with poor eye contact and poor facial expressions (B1 – Unusual Eye Contact, B2 – Facial Expressions directed to the Examiner), lack of enjoyment in interaction (B4 – Shared Enjoyment in Interaction), and limited ability to share their experiences with others (B7 – Reporting of Events, B8 – Conversation). There is ample research to suggest that depression and social anxiety are characterized by poor eye contact and difficulty sharing one's experience with others (e.g., Schneier, Rodebaugh, Blanco, Lewin, & Liebowitz, 2011; Kashdan & Breen, 2008; Fiquer et al., 2018).

Sources of Information

ADOS-2 is a classification tool based on interaction with the child, while the diagnostic process as a whole relies on multiple measures, teacher and parent reports. These sources are integrated with a skilled clinicians' understanding of the child's behaviors during a session. The difference between children's representations by each of these sources may lead to conflicting perceptions. Accordingly, in cases 2, 3 and 4, the parents believed their children to have ASD (as shown by the CAST parental-report questionnaire or parental interviews), while the skilled clinicians classified the children as not having ASD using the comprehensive DSM-5 evaluation. Moreover, all the cases were evaluated following another clinician's referral or parent's suspicion of the child having ASD which was eventually discarded.

Conclusions

The study points to disparities between ADOS-2 classification and DSM-5 diagnoses in children ages 8–10, with additional diagnoses. This can be highly relevant to both clinical practice and research, as in the latter the ADOS-2 is often used as a single source for validating the diagnosis. The ADOS-2 is highly valuable as it allows adding an observational scale to the diagnostic process. Nonetheless, these preliminary findings point to the confounding influence of age and additional diagnoses, and highlight the importance of considering specific biases in this regard. In clinical diagnostic assessments, it is common practice not to rely on a single diagnostic method, and research findings suggest that the combination of different measures is vital (Weeks, 2013). This study points to the importance of skilled clinicians integrating all diagnostic data with special attention to the overlapping symptoms between ADHD and ASD, further emphasizing the recommendation made by Kamp-Becker and colleagues (2018) that the unique challenges of diagnosing ASD in ages 8–10 be addressed only in centers specializing in autism.

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