Analysis of Tools for Diagnosing Autism Spectrum Disorder in the Indian Context

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Abstract

Autism Spectrum Disorder (ASD) is a neuro developmental condition with highly varied manifestations and poses a diagnostic challenge. The prevalence of ASD has increased in a highly populated and demographically 'young' country like India. However, prevalence rates are varied due to differences in measurement methods. Moreover, caregivers tend to delay reporting for developmental concerns as compared to physical health problems. The current analysis focuses on two common diagnostic tools used in India for ASD i.e. the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders and the Indian Scale for Assessment of Autism; and compares these methods with the revised Autism Diagnostic Interview. The analysis describes strengths and limitations of each of these tools and provides recommendations for their use in outpatient clinical practice.

Keywords: Autism Spectrum Disorder; Diagnosis; Analysis; India, DSM-5; ADI-R; ISAA

Abbreviations: ASD: Autism Spectrum Disorder; ISAA: Indian Scale for Assessment of Autism; ADI: Autism Diagnostic Interview

Introduction

Autism Spectrum Disorder (ASD) is a neuro developmental condition with highly varied manifestations and poses a diagnostic challenge. First, as per the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5), the current definition of ASD broadly includes features of previously known conditions such as 'classic autism' (or Kanner's autism), childhood disintegrative disorder, pervasive developmental disorder-not otherwise specified, as well as Asperger syndrome [1].

Although individuals with ASD have persistent deficits in social communication and interaction, as well as restricted and/or repetitive be saviors, the clinical features are part of a 'spectrum' i.e. each individual has different degrees of impairment, marked by combination of symptoms of varying severity [2]. Second, the etiological approach to diagnosing ASD (unlike several other physical or mental health conditions) is impractical. Genetic risk factors have been implicated to cause ASD [3], as also intake of valproic acid and thalidomide in pregnancy [4,5], in addition to routine perinatal complications [6], increased parental age [7] and birth defects associated with dysfunction of the central nervous system [8]. Definitive evidence on implicating these risk factors as causative agents has not been established. Third, in the Indian

context, caregivers tend to delay reporting of developmental concerns, as compared to physical health problems [9]. Thus, initial evaluation or diagnostic impression of ASD needs to be comprehensive and individualized to the child's needs – and not merely sensitive in detecting the condition. This is decisive in framing the goals and strategies of an intervention program.

Finally, from an epidemiological perspective, the prevalence of ASD has increased in a highly populated and demographically 'young' country like India. However, prevalence rates are varied due to differences in measurement tools [10-12]. Studies have reported prevalence of 1 in 65 children (2-9 years of age, 4000 households), 1 in 500 children (1-9 years of age, 5000 households) and 1 in 1000 children (1-10 years of age, 11,000 children) in different regions of India. These differences have failed to define the burden of ASD in the Indian context. Thus, we need a discussion on strengths and challenges of diagnostic tools for high-prevalence developmental disorders like ASD, to have a standardized evaluation approach.

The current analysis focuses on two common diagnostic tools used in India for ASD i.e. the DSM-5 and the Indian Scale for Assessment of Autism (ISAA); and compares these methods with the revised Autism Diagnostic Interview (ADI-R).

Diagnosis of ASD in India

A diagnostic tool needs to be culturally relevant, with optimum sensitivity and specificity. The assessment should exert minimum demand on professionals, in terms of their required training to use the tool. It should be feasible to administer in a clinic setting, based on time and costs. Finally, it should be comprehensive i.e. covering maximum aspects of the developmental-behavioral profile of ASD (Table 1) provides an overview of DSM-5 [1,2,13,14], ISAA [2,15,16] and ADI-R [17-19].

Analysis of strengths and weaknesses of diagnostic tools:

DSM-5: The strengths of DSM-5 include: (1) DSM-5 provides 'specifies' in addition to the diagnostic impression and level of severity. The specifies include accompanying language impairment; intellectual impairment; associated medical or genetic conditions or environmental factors; associated neuro developmental, mental or behavioral disorders and catatonia. Thus, DSM-5 creates scope to identify associated conditions along with the primary diagnosis.(2) DSM-5 provides severity level for each criterion (e.g. severity of deficits in social interaction and communication). (3) DSM-5 can be most rapidly administered, out of the three diagnostic tools.

Following are the limitations of DSM-5: 1) All previously defined disorders related to Autism have been grouped under 'ASD', which not only reduces the sensitivity (Table 1) particularly in younger children, but also limits the clinician to fully understand the (former) clinical sub-types (e.g. pervasive developmental disorder-not otherwise specified, Asperger's Disorder, Rett syndrome, childhood disintegrative disorder, etc.). This limits the individualization of an intervention plan to the child's needs. 2) DSM-5 does not specify the age-range for emergence of symptoms. It states that 'symptoms may not be fully manifest until social demands exceed capacity' [20].

Table 1: Overview of DSM-5, ISAA and ADI-R.

Parameter	DSM-5	ISAA	ADI-R
What does it include?	Assessment of clinical features based on pre-defined criteria	Standardized, semi-structured, individually administered interview	Standardized, semi-structured investigator-based interview
Test items derived from	Fourth edition of DSM-text revision (DSM-4 TR) and ICD-10	ADI, DSM-4 TR, ICD-10	ADI, DSM-4 TR, ICD-10
Year (released in)	2013	2015-2016	2003
Organization	American Psychiatric Association, USA	National Institute for Mentally Handicapped, India	Western Psychological Services, USA*
Type of assessment	Clinical Observation and Parental reporting	Clinical Observation and Parental Reporting	Clinical Observation and Parental reporting
Age group of subjects	2 years and above	3 years and above	2 years and above
Time to administer (clinically observed)	15-20 minutes	20-30 minutes	2 hours (approx)
Normative Sample	933	1123	226
Cost	$ 127	Free	$ 261
Training level of the professional	Clinical Psychologists	Clinical Psychologists, Social Workers and Special Educators	Clinical Professionals trained in ADI-R
Reliability and validity	Sensitivity- 25%-76 %# Specificity- 94.9%	Sensitivity – 93.3 % Specificity- 97.4 %	Sensitivity - 92 % Specificity- 89 %
Scoring	Criteria based	5 point rating scale	4 point rating scale

*The ADI-R is published by the Western Psychological Services, and is currently available through the Australia Council of Educational Research (ACER). ADI-R is available to professionals with accredited training in psychology, health sciences, counselling, education, medicine and other specialist areas. # DSM-5 has variable sensitivity based on diagnostic sub-groups of ASD (e.g. 76% for autistic disorder but 25% for Asperger's Disorder).

ISAA: The strengths of ISAA include: 1) ISAA scores symptoms through a five-point rating scale, which categorizes the symptom-frequency (i.e. rarely, sometimes, frequently, mostly and always). Percentages have been pre-assigned to these categories based on the validation processes implemented to prepare the scale [16]. Thus, the categorization improves the specificity of caregiver's reporting. 2) An important advantage of ISAA (and the rationale for its design) is its standardization and cultural relevance to the Indian population. 3) ISAA can be administered by professionals besides psychologists, which potentially widens its applicability in a high-prevalence region like India. 4) Along with observation and parental interview, ISAA also includes 'testing' i.e. the scale has recommended certain activities requiring clinic-based materials, which can be performed to elicit a response from the child suspected to have ASD [16]. Several of these materials are home-based. 5) ISAA provides disability certification based on scoring. It has been anecdotally observed that such a certification process, in-built within assessment techniques, has encouraged

parents to report for early intervention in other developed countries. However, evidence for the same is lacking in the Indian context. 6) ISAA has the highest specificity out of the three scales. 7) ISAA is free of cost and available in regional Indian languages.

The limitations are as follows: 1) Articulation of some items, in the 'Observation and Interview' section of ISAA is not adequately clear. This may necessitate the administrator to refer the manual during evaluation. Examples of few such items include: "(individual) has unusual vision", "has unusual memory of some kind", "engages in self-stimulating emotions", "shows exaggerated emotions" and "shows inappropriate emotional responses". 2) ISAA provides a summative diagnosis i.e. an overall score that categorizes the condition as 'no', 'mild', 'moderate' or 'severe' Autism. Thus, no specific severity levels have been provided for individual sub-domains (i.e. social relationship and reciprocity, emotional responsiveness, speech language and communication, behavior patterns, sensory aspects and cognitive component). 3) ISAA can only identify Autism in 3-9 year old children and certify disability of at least 40%. Further research is warranted to evaluate its diagnostic value in 2-3 year old children [21].

ADI-R: The strengths of ADI-R include: 1) ADI-R has the widest age-range out of the three scales. Two diagnostic algorithms are available for children 2 to less than 4 years of age, and 4 years and older. Moreover, new algorithms have been made for children 12-47 months of age and those with non-verbal mental age of 10 months, to increase its application [22]. 2) ADI-R provides a score-based severity level for each domain (unlike DSM-5 that provides a clinical judgment-based severity level). 3) ADI-R includes the most number of testing items - 93 items distributed across five sections i.e. introduction, communication, social development and play, repetitive and restricted behaviors and general behavior problems. Thus, due to its detailed nature (viz. items and severity levels), ADI-R provides the greatest breadth of information to locate the affected developmental domains in a child, for designing the most suitable intervention program. 4) ADI-R is a parent-friendly interview, since the questions are ordered in such a way that caregivers can inform positive aspects of the child's behavior, which reduces the discomfort of giving repeated answers on negative behaviors. 5) Most items are rated separately for 'current' behavior of the child; as well as the period in child's early life, during which the behavior in question was most atypical. Hence, the degree of detail is not only in the description of current symptoms, but also their emergence in early life, thus increasing credibility of the diagnostic impression. 6) ADI-R includes 'not-applicable' and 'not-known' codes for items (in contrast to DSM-5 and ISAA) which reduce the bias in scoring items that could be developmentally irrelevant.

In terms of limitations, ADI-R is the most expensive and time-consuming of the three tools, apart from the lack of cultural validation in the Indian context, and the fact that it needs specialized training, which may take at least two months to complete [23]. Moreover, in the Indian context, caregivers tend to focus more on physical health of the child, rather than mental health. Greater emphasis is placed on aspects like academic ability; while behaviors related to play and social interaction are often overlooked. Hence, responses generated by caregivers may not be appropriate [24].

Conclusion

The analysis compares three common tools for diagnosing ASD, in a context where screening alone may have little value, due to delayed identification of ASD and delayed reporting by caregivers. The authors propose that studies should be conducted to establish the specific indications where a DSM-5 or an ISAA will be more appropriate for diagnosis. Studies should also be conducted to validate ISAA in children younger than two years. In addition, there is a strong need to revise the articulation of some items in ISAA that may not be well understood. Moreover, since ISAA also involves testing, additional training maybe required for evaluation of certain domains, such as sensory aspects and cognitive component. In these cases, it will be more appropriate to modify some components of ISAA, so that professionals of different skill-sets can use the scale, for example – pediatricians, physicians, psychologists, special educators and medical social workers. In contrast, ADI-R mandates formal training and DSM-5 mandates administration only by psychologists.

ADI-R may not be suitable for routine use, given the time-constraints in developmental pediatric practice and the cultural incompatibility with the Indian context. With regard to the latter, however, it may be an assessment of choice for urban middle-income and upper-income families. Moreover, there are frequent situations where a child may have features of ASD but diagnostic criteria are not met in DSM-5. Such situations could arise in the use of ISAA as well. Hence, practitioners should take advantage of the detailed number of items and scoring strata in ADI-R, for evaluating such children. To that end, the therapy centre needs to have a trained professional who can administer ADI-R and has pre-tested the method with Indian parents in order to locate any items which need modification, based on cultural factors.

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