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RESEARCH ARTICLE

Diagnostic accuracy of AIIMS Modified INCLEN Diagnostic Tool (AIIMS Modified INDT–ASD) for diagnosis of Autism Spectrum Disorder

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Abstract:

Introduction: Autism spectrum disorder (ASD) is a neurodevelopmental condition with increasing prevalence over the years. The assessment tools validated for the diagnosis of ASD are based on the population in the West. We assessed the diagnostic accuracy of the AIIMS Modified INCLEN Diagnostic tool INDT-ASD against the Childhood Autism Rating Scale CARS-2 (ST) using DSM-V as the reference standard.

Methods: Children aged 2 to 9 years of age with suspected ASD, as identified by one or more of the red flags described by the American Academy of Neurology, were enrolled in the study. Those with cerebral palsy, global developmental delay, hearing impairment, and neurodegenerative disorders were excluded. CARS-2 (ST) and AIIMS modified INDT-ASD were done by two different professionals and the results were kept blinded. The DSM-V criteria were applied by a third professional to confirm the diagnosis.

Results: The study included 108 children. There was male predominance and the mean age of presentation was 36.9 months. AIIMS MODIFIED INDT-ASD was found to have a Sensitivity of 91.4%, a Specificity of 78.5%, a Positive predictive value of 89.2%, and a negative predictive value of 82.5%.

Conclusion: AIIMS Modified INCLEN INDT-ASD is a simple indigenous tool helpful in the diagnosis of ASD in the Indian population.

Keywords: Autism spectrum disorder, Childhood Autism Rating Scale, DSM-V criteria, INCLEN, neurodevelopmental

Introduction: Autism spectrum disorder (ASD) is a neurodevelopmental disorder with Core deficits in two domains namely social communication/ interaction and restrictive, repetitive patterns of behaviour, as defined by the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5) [1] The prevalence is estimated as 1 in 36 children by the Center for Disease Control and Prevention.[2]There is a scarcity of population prevalence studies in India for an estimate of children affected with Autism Spectrum. A study by Chauhan et al. found that the prevalence of Autism among Indian children aged 1 to 18 years was 0.09% in urban areas and 0.11% in rural areas. [3]There must be meticulous developmental surveillance to identify and diagnose autism at the earliest. As always known, early diagnosis opens the window of opportunity for early interventions and support for the child. There are some challenges to the diagnosis of ASD in limited-resource countries. Many of the tools that are validated for the assessment of ASD are based on the population in the West. Some of them include the Childhood Autism Rating Scale CARS-2 (ST), Autism Diagnostic Observation Scale (ADOS), and Autism Diagnostic Interview (ADI-R). They need certified training and are expensive to use in developing countries with limited resources. They may also not be culturally acceptable and are patented tools that are available only in English.

AIIMS Modified INCLEN INDT-ASD has been developed in India and used in wider parts of the country as a valuable aid for the assessment of Autism Spectrum Disorder.[4] It is closely mapped to DSM-V which is now being used for the diagnosis of ASD. The tool requires both history from the child's caregiver and direct observation of the child for some of the criteria. This has been standardized and validated against CARS-2 (ST).

Materials & Methods:

The study was conducted in a Child Development Unit in a tertiary care hospital in South India from October 2019 to June 2020. This was a prospective study to assess the diagnostic accuracy of AIIMS Modified INDT-ASD against CARS-2 (ST) using DSM-V as the reference standard. We also evaluated the sensitivity and specificity of AIIMS Modified INDT-ASD against theChildhood Autism Rating Scale CARS-2 (ST). The tool was originally validated for children in the age group of 1 to 14 years. Children with suspected ASD referred to our centre from 2 to 9 years of age alone were enrolled in the studydepending upon convenience sampling after informed consent. This included childrenwho had one or more of the red flags described by the American Academy of Neurology. These were no babbling or not using gestures like pointing by 1 year of age, not speaking meaningful words by 16 months, and two-word phrases by 2 years. Loss of language or social skills at any age in a child is another symptom to suspect ASD.[4] Children with comorbidities like Attention deficit hyperactivity disorder and cerebral palsy, global developmental delay, hearing impairment, and neurodegenerative disorders were excluded.

AIIMS Modified INDT-ASD has two sections, A and B. Section A has a total of 28 questions, including questions in both social interaction and communication (A1) and Repetitive and Restricted behaviours (A2). A1 is further divided into A1a, A1b, and A1c and contains questions for social-emotional reciprocity, non-verbal communication, and building relationships. A2 is divided into A2a, A2b, A2c, and A2d and has questions on repetitive behaviour, insistence on routines, restricted interests, and sensory symptoms., respectively. These are all derived from DSM-V criteria for ASD. Each question

has three responses- yes, no, and unsure. These questions have to be answered based on both the history of the primary caregiver and the observation of the child. In case of a discrepancy between the history and observation, an asterisk present on either one will indicate which should be considered to answer the question. The number of abnormal responses for the age should be calculated. Abnormal responses can be 'yes' or 'no' based on the question, and this will be indicated in the questionnaire. Section B is the scoring section which contains 9 questions to help make the diagnosis. Abnormal responses in all 3 subsections of A1 and at least 2 subsections of A2 are mandatory for a diagnosis of ASD. Along with this, symptoms onset in the early developmental period and symptoms impairing functioning are required to make a diagnosis. Healthcare professionals with appropriate training can administer this tool.

The Childhood Autism Rating Scale CARS-2 (ST) is a tool that helps to assess ASD. It can be used in children aged 2 years and above. It has 15 items which are scored based on observation and parental reports. The scoring is done on a 7-point scale from 1 to 4. The peculiarity, intensity, frequency, and duration of the child's behaviour must be kept in mind before scoring. Raw scores are added up and calculated. The scores are given in three categories based on the raw score. The child is said to have minimal to no symptoms of ASD if the score is 29.5 or below. If the score ranges from 30 to 36.5, the child has mild to moderate symptoms of ASD. If the score is above 36.5, the child has severe symptoms of ASD. [5]

CARS-2 (ST) was done by the psychologist, and AIIMS-modified INDT-ASD was done by the Developmental Paediatrician. The results were kept blind in a sealed envelope after scoring. DSM-V criteria were taken as the gold standard to confirm the diagnosis. The criteria were applied, and the diagnosis was confirmed by another Developmental Paediatrician. We enrolled 108 children with suspected ASD in our study. Considering the prevalence of ASD to be 1% in India, we calculated a sample size of 95 with a precision of 2% and a confidence interval of 95%. [6]

Results:

In our study, out of 108 children enrolled, the age range was from 25 months to 84 months of age. The mean age of presentation in our study was 36.9 months. There was male predominance in our study with a male-female ratio of 5.3:1. The commonest presenting complaint (referral concern) in our study was speech delay. Developmental / Intellectual Quotient –DQ / IQ were completed by the Bayley scale of Infant Development 3rd edition and Wechsler scales, respectively. We found (14.8%) as Average, (16.6% as below average, (37%) Mild delay, (12.9%) Moderate delay and around (18.5%) could not be tested.

CARS-2 (ST) was suggestive of ASD in 75 of the 108 children. AIIMS MODIFIED INDT-ASD administered was suggestive of ASD in 77 of the 108 children. Seven children diagnosed as ASD by CARS-2 (ST) were diagnosed as Not ASD by AIIMS MODIFIED INDT-ASD (false negatives). Similarly, 9 children diagnosed as ASD by AIIMS MODIFIED INDT-ASD were diagnosed as Not ASD by CARS-2 (ST) (false positives). Out of the 108 children, 24 were diagnosed as Not ASD by both CARS-2 (ST) and AIIMS MODIFIED INDT-ASD. DSM-V was suggestive of ASD only in the 75 children diagnosed with ASD by CARS-2 (ST).

ASD (n)		CARS-2 (ST) (comparable to DSM-V gold standard based on expert diagnosis)		TOTAL (n)
		No ASD (n)		
AIIMS MODIFIED INDT-ASD	ASD	68	9	77
	No ASD	7	24	31
TOTAL		75	33	108

AIIMS MODIFIED INDT-ASD was found to have a Sensitivity of 91.4%, a Specificity of 78.5%, a Positive predictive value of 89.2%, and a Negative predictive value of 82.5%.

Discussion:

In our study, 108 children with suspected Autism Spectrum Disorder from 2 to 9 years of age were enrolled. The mean age in our study was 36.9 months. There was a male predominance in our study (84%), similar to a study done by Juneja et al. with 71.4% boys [7]. Speech delay was the most common presenting complaint (87.9%) in our study, similar to a study done by Perera et al. [8]. From the results of our study, 77 children were diagnosed with ASD by the AIIMS Modified tool, but only 75 children were diagnosed as ASD by CARS-2 (ST). DSM-V was taken as the gold standard to make a definitive diagnosis. Only the 75 children diagnosed by CARS-2 (ST) were diagnosed with ASD by DSM-V.

Seven children were given a false negative diagnosis by AIIMS Modified INDT-ASD and nine children were given a false positive diagnosis of ASD when compared with CARS-2 (ST). 24 children were diagnosed as Not ASD by both CARS-2 (ST) and AIIMS Modified INDT-ASD. The seven children who were given a false negative diagnosis got a score of 30.5 and 30 by CARS-2 (ST) showing mild symptoms of ASD, which could possibly be the reason for their misdiagnosis by AIIMS Modified Tool. The nine children with false positive diagnoses of ASD were reanalyzed, and there was found to be a discrepancy between the history and observation. Five of the nine children were diagnosed with Social communication disorder, and the other four had Intellectual Impairment. They were given a false positive diagnosis of ASD, possibly because they had poor verbal and nonverbal communication.

The Sensitivity and specificity of AIIMS Modified INDT-ASD against CARS-2 (ST) were 91.4% and 78.5%, respectively. The Positive Predictive Value and Negative Predictive Value of the tool were 89.2% and 82.5% in our study. The development and validation of AIIMS-modified INDT-ASD was done by Gulati et al. in which the sensitivity and specificity of the tool were found to be 98.4% and 91.7%, respectively [4].

Indian Scale for Assessment of Autism (ISAA) is the tool that is mandated for certifying Autism as a disability according to the Government of

India guidelines. This is a detailed assessment tool consisting of 40 items, and it's based on observation, informant interviews as well as testing.[9] ISAA could, however, be used for certification of Disability due to ASD only in children aged 6 years and above, according to the guidelines by the National Trust (India) in 2016. A study by Mukherjee et al found that the specificity of ISAA is low when used for diagnosis of Autism in children aged 2-5 years. The specificity of ISAA in their study was found to be 28.9% in the 2 to 3 years age group, and 33.3% in the 3 to 5 years group. This, therefore, runs a risk of children being inaccurately labelled as ASD when ISAA is used for the younger age group[10]. In our study, we found the AIIMS Modified INDT-ASD tool to have higher specificity (78.5%) in the younger age group compared to the analysis with ISAA being administered in the same age group.

Some of the limitations of the AIIMS Modified INDT-ASD tool are that it is not externally validated for the Western population, and it could be challenging for children with ASD and good verbal skills. The relevant use of the tool in the Western population is that it could be used in referral triage by health visitors and schools. It can form part of the assessment pathway for Autism spectrum and, more importantly, can be used by doctors within the time constraints of Clinics.

Conclusion:

AIIMS Modified INDT-ASD is a simple, effective, user-friendly tool based on DSM V. This requires minimal training and is quick to administer. It can be a useful contribution to the ASD diagnostic pathway alongside other assessments. It is an indigenous tool developed to be culturally acceptable similar to the ISAA. Although validated for the Indian population, the tool can also be used in Western countries in primary care for triage, and in Asian minority populations as the questions are simple to comprehend.

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Conflicts of interest

There are no conflicts of interest.

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