# To assess the magnitude of autism spectrum disorder in Jharkhand by M-CHAT-R as a screening tool

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### **ABSTRACT**

Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder which is a clinically heterogenous condition with a wide range of etiological factors and causing significant public health burden. If diagnosed at an earlier age, early interventions can be started this leads to functional outcome of children with ASD with respect to social, behavior and occupational sphere. Therefore, early detection and intervention are widely recommended in these children. So screening of toddlers who were identified to be "at risk" can be diagnosed using screening questionnaires by interviewing parents. Overall with this study we can conclude that, toddlers identified to be "at risk" and those diagnosed with ASD were not uncommon and M-CHAT-R is a useful screening test for the identification of "at risk" toddlers for Autism Spectrum Disorder in Jharkhand.

Keywords: Autism, Jharkhan, toddller

# Introduction

Autism Spectrum Disorder (ASD) is a neurodevelpomental disorder with multiple causative factors and varied symptoms including impaired social communication, repetitive behavior and restricted interests causing significant burden on public health. ASD poses a great impact on the early childhood in the form of poor schooling and social interaction which later on continues to hamper adult productivity. This paper is relevant to practice to primary care physician as today there is an increase in the number of autistic children and its early detection and intervention will lead to better outcome of children.

The essential features of autism spectrum disorder (ASD) are persistent impairment in reciprocal social communication and interaction, and restricted, repetitive patterns of behavior or

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interests.<sup>[1]</sup> The diagnosis of ASD at an earlier age may lead to earlier intervention and, which typically includes behavioral, educational, and speech/language therapy.<sup>[1]</sup>

ASD is commonly seen during 2<sup>nd</sup> year of life but it can also present earlier than 12 months of age in case of severe developmental delay. The child with ASD can present initially with delayed language skill, odd and repetitive behavior along with lack of social interests.

The prevalence of ASD is nearly 1% worldwide, with males being more commonly affected than females. So early assessment with multidisciplinary approach is required for the early detection of ASD which will facilitate early intervention in such cases thereby improving their functional outcomes. It has been seen that with early diagnosis and management, there is a better developmental outcome in children with ASD (Eaves and Ho 2004<sup>[2]</sup>; Harris and Handleman 2000<sup>[3]</sup>). Thus, early screening using standardized developmental screening tests is essential to facilitate early diagnosis (American Academy of Pediatrics [AAP] 2006).

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There are various screening tools which are routinely used for screening children for ASD and the M-CHAT-R, i.e. Modified Checklist for Autism in Toddlers Revised is one of the screening tools which has a good specificity and sensitivity (Robins *et al.* 2009). <sup>[4]</sup> It is a questionnaire comprising a total of 20 questions which is freely available on the internet and downloadable in multiple languages. It has to be completed by parents or the caregiver and takes minimal time to complete and uses a simple scoring method based on yes/no items. It is conducted in children between age group of 16 to 30 months.

Presently, it has become important for the pediatricians to take responsibility for early screening and diagnoses of the children with ASD and also involve the parents in providing appropriate care for the children. This would include provision of comprehensive care with appropriate rehabilitational, educational, social and special services.

The problem of ASD is not only a medical problem but also a social problem. This needs to be tackled by the holistic coordination amongst clinicians, psychologists, medical social workers, social activists, politicians as well as family. The aim of the current study is not only to identify but try to develop a platform of coordinated approaches between the families of Autistic children and different types of caregivers.

# Aim of the Study

To assess the magnitude of Autism Spectrum Disorder in Jharkhand.

### **Material and Methods**

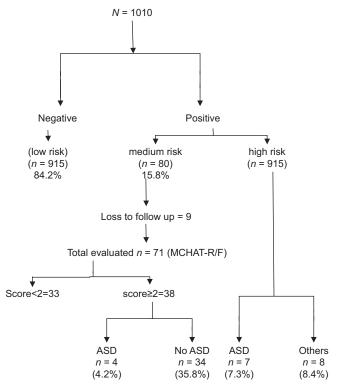
Present study was a cross sectional study conducted on 1010 patients who attended Pediatric OPD, RIMS, Ranchi from May'2019 to June'2020 and met the inclusion criteria. The inclusion criteria included children aged between 16 to 30 months with no prior diagnosis of ASD or developmental delay. Informed consent was taken by the parents prior to enrolment in the study. Among 1120 subjects 90% gave consent and 10% refused consent. The sample size was selected according to the number of patients in the age group of 16-30 months attending Pediatric OPD in 13 months period.

The study was conducted in 2 steps and M-CHAT-R was used as the screening tool to assess the risk of Autism Spectrum Disorder in the first step. The parents were asked to fill the questionnaire containing 20 items or were verbally asked in 2 languages (Hindi and English) according to the convenience of the parents. The children who screened positive for M-CHAT-R were divided into medium risk and high risk groups based on their M-CHAT-R score. Toddlers with medium risk were asked to follow up and reevaluated by M-CHAT-R/F; and those with high risk were evaluated by Diagnostic and Statistical Manual, Fifth Edition, (DSM-V)<sup>[5]</sup> criteria and INCLEN diagnostic tool for ASD.

# **Observation and Result**

A total of 1010 toddlers were surveyed in which 613 (60.7%) were males and 397 (39.3%) were females with male: female ratio 1.5:1 as shown in [Table 1]. Out of the 1010 toddlers screened, 915 were at low risk who scored 2 or less in M-CHAT-R; their parents were reassured and asked for regular follow up. The total number of toddlers screened positive were 95 out of which medium risk were 80 (84.2%) in number and high risk were 15 (15.8%) in number as shown in [Table 2]. Age wise distribution in relation to risk of autism is shown in [Table 3]. Table 4 showing distribution of age group in M-CHAT-R screen positive & negative groups. Among the total 80 medium risk toddlers, 9 were lost to follow up and 71 toddlers were assessed by M-CHAT-R/F. Out of the 71 medium risk toddlers evaluated, 33 scored <2 and the parents were reassured; and 38 scored ≥2 who were evaluated by DSM-5 criteria and INCLEN Diagnostic tool for ASD which showed 4 toddlers (4.2% of total screened positive) with ASD. After evaluation of 15 high risk toddlers 7 toddlers (7.3% of screen positive) showed features of ASD and 8 (8.4% of screen positive) were detected with other developmental disorders like speech delay, social anxiety and subthreshold autism symptoms not meeting the DSM-5 criteria.

Out of all the 95 screen positive ('at risk') toddlers, 40 (42.1%) were in the age group 16-20 months, 30 (31.6%) were in 21-25 months age group, and 25 (26.3%) were in age group 26-30 months as shown in [Table 4]. The result shows that there is insignificant association between age group and risk of ASD with P value 0.446.



**Figure 1:** Flow Chart representing the screening using M-CHAT-R in study population

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Out of the total 95 screen positive toddlers, 48 (50.5%) were between gestational age group of 24-30 weeks, 27 (28.4%) were between 31-36 weeks and 20 (21.1%) were between gestational age group of 37-42 weeks [Table 5]. There is a significant association between maternal gestational age and risk of ASD with P value < 0.001.

Out of all the 95 screen positive toddlers, 28 (29.5%) toddlers had a positive family history while 67 (70.5%) toddlers did not have any family history of ASD [Table 6]. The result shows that there is a significant association between family history and risk of ASD with P value < 0.001. Table 7 representing presence of ASD in various risk groups.

### Discussion

There has been increase in the prevalence of ASD in past years which has generated a considerable concern. In developing countries such as India, accurate and reliable estimates of autism prevalence at the national level are required to enable public health professionals and government policy makers to formulate strategies to meet the needs of the growing autism community. In this study we saw that M-CHAT-R is a simple screening tool using which we can easily suspect autism in growing children at a very early age and manage accordingly.

In this study, out of the total 1010 toddlers screened [Figure 1], 95 (9.4%) were screen positive comprising of medium risk and high risk toddlers as shown in [Table 4]. This result is similar to the study done by Chlebowski C *et al.* 2013<sup>[6]</sup> in which 9.1% of the 18,989 children screened by M-CHAT were screened positive. Recent studies like Joseph *et al.* 2021<sup>[7]</sup> and Yousef *et al.* 2021<sup>[8]</sup> shows that percentage of at-risk symptoms of autism was estimated to be 7.12% and 27.7%, respectively. However, an Indian study Ts J *et al.* 2017<sup>[9]</sup> showed that total toddlers identified to be 'at risk' for ASD were 5.5% using M-CHAT-R and 2.7% using "Best-Seven" of M-CHAT-R. Another community based Indian study Raina *et al.* 2015<sup>[10]</sup> using an indigenously validated tool ISAA showed only 0.9% screen positive toddlers. Other studies like Robins *et al.* 2014<sup>[4]</sup> and Ravi *et al.* 2016<sup>[11]</sup> showed 'at risk' toddlers to be 7.4% and 9.4%, respectively.

In the current study ratio of male: female who screened positive and were 'at risk' was found to be 2.2:1 as shown in [Table 2]. This result is in concordance to another study Toh *et al.* 2018<sup>[12]</sup> in which ratio of male: female who screen positive was 2.1:1. Another study, Guthrie *et al.* 2019<sup>[13]</sup> showed male: female ratio who screened positive was 1.3:1. Prevalence of ASD in the current observed population (n = 1010) was 1.08%. This result was lower as compared to study by Chlebowski *et al.* 2012<sup>[6]</sup> which showed that 4.8% (n = 18989) toddlers were diagnosed with ASD and Guthrie *et al.* 2019<sup>[13]</sup> which showed 2.2% (n = 23628) toddlers with ASD.

In the current study, out of all the 95 screen positive toddlers, 49 (51.6%) toddlers had a positive family history and out of 11 toddlers diagnosed as ASD, 6 (54.5%) had positive family history

as shown in [Table 6]. This result was similar to study done by Sandin *et al.* 2019<sup>[14]</sup> which showed that the individual risk of ASD and autistic disorder increased with increasing genetic relatedness. Heritability of ASD and autistic disorder were estimated to be approximately 50%. In another study done by Xie *et al.* 2019<sup>[15]</sup> showed that family history of ASD and neurological disorders is associated with increased risk of ASD.

In this study, 50.5% of the toddlers who screened positive ('at risk') had gestational age at birth between 24-30 weeks and there was a significant association between gestational age and risk of ASD as shown in [Table 5]. This indicates that prematurity is a risk factor for ASD. Persson *et al.* 2020<sup>[16]</sup> studied that the relative risk of ASD increased weekly as the date of delivery diverged from 40 weeks, both preterm and postterm, independently from sex and size for GA.

# Limitations of the study

The follow-up of low risk toddlers who scored ≤2 in M-CHAT could not be achieved 100%. Some of the toddlers who scored positive on the M-CHAT were also lost to follow-up. Such children who were not followed up may be at risk of developing

Table 1: Gender distribution in the study population			
GENDER	NUMBER	PERCENTAGE	
Male	613	60.7%	
Female	397	39.3%	

Table 2: Gender distribution of low risk, medium risk & high risk in study population using M-CHAT-R

SEX	LOW RISK	MEDIUM RISK	HIGH RISK	P
MALE	550	52	13	613
FEMALE	365	28	02	397
TOTAL	915	80	15	1010

Table 3: Table representing age distribution of toddlers among low risk, medium risk and high risk in study population

AGE	LOW RISK	MEDIUM RISK	HIGH RISK	TOTAL
16-20 mo	415	40	0	455
21-25 mo	270	25	5	300
26-30 mo	230	15	10	255
Total	915	80	15	1010

Table 4: Distribution of age group in M-CHAT-R screen positive & negative groups

Age (in	M-CHAT-R		
months)	Screen Negative	Screen Positive	
16-20	418 (45.7%)	37 (38.9%)	
21-24	268 (29.3%)	32 (33.7%)	
25-30	229 (25%)	26 (27.4%)	
Total	915	95	

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Table 5: Table representing distribution of gestational age among the study population

M-CH	IAT-R	
Negative	Positive	
56	48	
258	27	
601	20	
915	95	
	Negative  56 258 601	

Table 6: Table representing presence of family history among screen positive and negative in the study population

Family	M-CHAT-R negative	M-CHAT-R Positive	
History	Low risk	Medium risk	High risk
Present	13	21	07
Absent	902	59	08
Total	915	80	15

Table 7: Table representing presence of ASD in various risk groups

Risk Group	ASD present	ASD absent	P
Low Risk	0	915	915
Medium Risk	4	76	80
High Risk	7	8	15

ASD later causing delayed recognition of the condition thus hampering early management and leading to disability.

### Conclusion

Overall with this study we can conclude that, toddlers identified to be "at risk" and those diagnosed with ASD were not uncommon and M-CHAT-R is a useful screening test for the identification of "at risk" toddlers for Autism Spectrum Disorder in Jharkhand.

Since the developmental disorder is not generally taken care of by General Pediatrician, patients wander here and there to fend for themselves especially in Ranchi, Jharkhand. Being an old center for Psychiatric and Psychological diseases, these patients end up at Regional Institute of RINPAS/CIP. Being a center basically for Psychiatric disorders, doctors there are not trained for appropriate care and management of patients with developmental disorders. So, we need to develop a center of developmental disorder in the department of Pediatrics where these children can be screened, diagnosed, managed and followed up.

We propose to start an awareness program with the help of government and departments such as Health and Family Welfare, Social Welfare etc., to identify these children beforehand. This is a condition where parents need more support to improve the status of the children. So a broad program may be drawn for screening and detection of ASD to provide comprehensive care involving parents/caregiver, doctors, nurses and paramedics for long term improvement.

# Declaration of patient consent

The authors certify that they have obtained all appropriate patient consent forms. In the form the patient(s) has/have given his/her/their consent for his/her/their images and other clinical information to be reported in the journal. The patients understand that their names and initials will not be published and due efforts will be made to conceal their identity, but anonymity cannot be guaranteed.

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Nil.

### **Conflicts of interest**

There are no conflicts of interest.

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