MAK HILL Publications Research Journal of Medical Sciences

Research Article
doi: 10.36478/makrjms.2024.1.333.337

OPEN ACCESS

Key Words
Autism, community setting, prevalence, toddlers

Corresponding Author
Jaison Joseph,
Departments of Psychiatric Nursing, and Pediatrics, College of Nursing, Pt. B. D. Sharma University of Health Sciences, Rohtak, Haryana, India
jaisonjsph@yahoo.com

Received: 10 January 2024
Accepted: 20 February 2024
Published: 23 February 2024

Citation: Jaison Joseph, Deeksha Arora, Kusum Dangi, Manisha Deswal, Sudesh Kumari and Jaya Shankar Kaushik, 2024. Toddlers at Risk for Autism in a Semi-Urban Community of North India: A Cross-Sectional Study. Res. J. Med. Sci., 18: 333-337, doi: 10.36478/makrjms.2024.1.333.337

Toddlers at Risk for Autism in a Semi-Urban Community of North India: A Cross-Sectional Study

[1]Jaison Joseph, [2]Deeksha Arora, [3]Kusum Dangi, [4]Manisha Deswal, [5]Sudesh Kumari and [6]Jaya Shankar Kaushik
[1-6]Departments of Psychiatric Nursing and 1Pediatrics, College of Nursing, Pt. B. D. Sharma University of Health Sciences, Rohtak, Haryana, India

Abstract
The symptoms of autism manifest at an early age in children and are likely to results in lifelong disability. Early identification and institution of early intervention remain the mainstay in the management of autism. However, related community surveillance studies are limited in the literature. The present study was designed to assess the prevalence of "at risk for autism among children aged 18-36 months in a semi-urban community of Rohtak, Haryana, India. This cross-sectional study was conducted among 548 children. The eligible children were screened using the Hindi version of the Modified Checklist for Autism in Toddlers-Revised (M-CHAT-R). The prevalence of at-risk symptoms of autism was 0.55% and 6.57% as per M-CHAT-R score of >7 and >3-7, respectively. Most of the cases in the moderate-risk category were having M-CHAT-R score of 3–5 (n = 32, 82%). The study provides preliminary data on the prevalence of care giver-reported autism using the Hindi version of M-CHAT-R in a semi-urban community of North India. The Hindi version of M-CHAT-R could be a viable community surveillance tool for identifying toddlers at risk for autism in this setting.

INTRODUCTION

Autism spectrum disorders (ASDs) are characterized by impairment in reciprocal social interaction and social communication with the presence of restricted, repetitive patterns of behavior, interests, or activities[1].

Systematic reviews based on the epidemiological studies around the world revealed a varying global prevalence of ASD such as 20 per 10,000[2], 62 per 10,000[3] and 7.6 per 1000[4]. The reported prevalence of ASD in Asian countries is very low (14.8 per 10,000[5]) as compared to European countries (62 per 10,000)[3]. A recent systematic review on the ASD in children aged 0-18 years reported a pooled prevalence percentage of 0.09-0.11 in urban and rural Indian population[6]. The symptoms of autism manifest at an early age in children and are likely to results in lifelong disability. Early identification of symptoms of autism is essential for the initiation of early intervention strategies[7]. Lack of age-appropriate and culturally validated screening instruments, lack of awareness, lack of trained human resources the stigma associated with the diagnosis are significant hurdles to early diagnosis of autism[8]. The validated autism screening tools available in the Hindi language are the Modified Checklist for Autism in Toddlers-Revised (M-CHAT-R), autism spectrum quotient social communication disorder checklist[9]. Most of the reported studies on ASD are based on hospital-based data and community surveillance studies are limited. Hence, the present study was designed to assess the prevalence of at risk for autism among children aged 18-36 months in a semi-urban community of Rohtak, Haryana, India.

MATERIALS AND METHODS

A cross-sectional study was conducted among toddlers aged 18-36 months attending five government child care centers ("Anganwadi") and a primary health centerin a semi-urban area of Rohtak district, Haryana, India. The period of data collection was from June 1, 2018-June 22, 2018. The study settings were conveniently selected care givers of eligible children who were able to read and write the Hindi language and those who agree to give consent as per the information available on the participant information sheet were included. Those care givers available as per the registers of health centers were contacted those not responded after two visits or telephonic contact and individuals from locked houses and were excluded. Care givers were operationally defined as the caretaker or the parent who has the greatest responsibility for the daily care of the children. Ethical approval for the study was obtained from the Institutional Ethics Committee (IEC), Pt. B. D. SU. H. S. RTK (No. IEC/18/583).

The native vernacular language of the community is Hindi. We used the translated Hindi version of the M-CHAT-R developed by the National Centre for Autism India[10]. Four nurses with a postgraduate degree in psychiatric nursing were involved in the administration of M-CHAT-R who attended a 1-day state-level symposium on autism awareness and screening organized by Pt. B. D. Sharma UHS, Rohtak. The principal investigator provided an induction training on the administration of the Hindi version of M-CHAT-R based on the resources from the official website https://mchatscreen.com/. The nurses were trained by a pediatric neurologist on M-CHAT-R who provided screening linked services throughout the study.

The participant information sheet with the details of the study and informed consent forms were distributed to all the participants by the trained nurses. Besides, the M-CHAT-R form was distributed among mothers of eligible children. Mothers were encouraged to fill the form by themselves any difficulty in filling the form or understanding any question was clarified by the trained nurse. Mothers returned the filled form to the investigators. M-CHAT-R is a 20-item questionnaires total MCHAT-R score of 3 or higher was considered at risk for ASD, moderate risk: 3-7high risk: 8 and above[11]. Besides, seven questions from 20 items of M-CHAT-R that were considered to be best discriminative for ASD were compared among those who were screen positive and those who were screen negative. These items included questions 1, 2, 3, 7, 8, 910. A total score of two or higher was considered at risk for ASD[12].

The potential study participants were contacted as per the available information in the primary health center. In addition to that, a separate visit has been made to five Anganwadi centers to identify the study participants. In total, 1000 questionnaires were distributed and 871 questionnaires were returned, out of which 548 forms were included in the analysis. The exclusion was based on the following aspects: The incomplete forms in which missing responses in any of the items of M-CHAT-R (n = 51) and the forms that are not returned or with no responses (n = 401) were excluded. There are 39 M-CHAT-R-positive cases, in which 36 cases were in the moderate-risk category and 3 cases in the high-risk category. All screen-positive cases were invited for a screening linked referral by a pediatric neurologist. Unfortunately, all three children detected to be at high risk for autism refused for screening linked referral services owing to shift in the workplace in one two other parents had a belief that symptoms may resolve spontaneously over time. Owing to the apprehension of results, one child at moderate risk for ASD was consulted with the pediatric

neurologist and was detected to have cerebral palsy rather than ASD. However, the remaining parents do not express any concern about the moderate-risk score of M-CHAT-R. Fig. 1 explains the details of the recruitment procedure.

Statistical Analysis: Sociodemographics and clinical variables were expressed in frequency, the percentage for categorical variables as mean and standard deviation (SD) for continuous variables. Chi-square test was done to assess the relationship between Sociodemographics variables and scores of screening tools. Logistic regression analysis was used to predict the relationship between age groups, sex socioeconomic status (SES) as per at risk scores. All the analyses were done using SPSS 15.0 version.

RESULTS AND DISCUSSIONS

A total of 538 toddlers were enrolled in the study with 289 (52.7%) boys. The mean (SD) age of enrolled children was 28.66 (6.68) months. Most of them belonged to the age group of 28-36 months (n = 362; 66.05%) and middle SES (n = 345, 63%) as per the modified Kuppuswamy scale (Table 1). Of the 39 screen-positive cases identified, 36 toddlers (6.57%) were in moderate risk and 3 (0.55%) were in high risk. The prevalence of at-risk symptoms of autism was estimated at 0.55% and 6.57% with MCHAT-R score of >7 and >3, respectively. Most of the cases in the moderate-risk category were having M-CHAT-R score of 3-5 (n = 32, 82%).

There was no statistically significant association among screened positive cases of autism and selected sociodemographic variables such as age (P = 0.07), gender (P = 0.94)SES (P = 0.77). The response rate of the seven best discriminators of ASD as per M-CHAT-R was calculated and found that these items were significant for detecting the screen-positive cases. The association was statistically significant [P = 0.0001, (Table 2).

Our study revealed a prevalence rate of 0.55% at-risk symptoms of autism (M-CHAT-R score >7) among children aged 18–36 months in this setting. Previous studies using the M-CHAT-R as a screener in the community settings of India and Bangladesh reported at-risk rates of 1.3% and 1.24%, respectively[13,14].

Furthermore, a community-based study conducted at Northwest India used the Hindi version of the Indian Scale for Assessment of Autism and reported 0.1% of cases of autism in children aged 18-47 months[15]. However, a previous hospital-based study conducted in South India reported a higher rate of the at-risk score (9.4%, n = 33) as per M-CHAT-R[16]. The present study corroborates the results of earlier studies conducted in a community setting.

We used the Hindi version of M-CHAT-Rit was found to be an acceptable and feasible tool for screening autistic symptoms in this community setting. Nurses were involved in the M-CHAT-R administration none of the mothers reported any problems related to items in the translated Hindi version. Previous community surveillance studies for autism reported a higher rate of false screen-positive results for M-CHAT-R due to the problems associated with translation in the vernacular language[13,17]. Furthermore, the response rate of best discriminators of ASD as per M-CHAT-R revealed the use of these items as a short-form screener for early identification of ASD in the community setting. This is consistent with the findings of previous studies[18]. Care givers of children with high-risk scores in the present study were reluctant for further evaluation and consultation. This further invokes the need for psychosocial intervention to eradicate the stigma associated with autism[19].

The major strength of the study is that it is one of the studies that evaluated at risk symptoms of ASD among toddlers with the aid of a structured, developmentally appropriate translated instrument such as the MCHAT-R. We found a false-positive M-CHAT-R case upon further formal assessment. However, the results of the study relied on self-reported assessment and included those parents available as per the registers or during the time of home visit. We used the convenience sampling method the individuals from locked houses and those not contacted after two visits or telephonic contact were also excluded. Although efforts were carried out to confirm the diagnosis, parents of children with screened positive cases were reluctant for screening linked referral services due to logistic reasons.

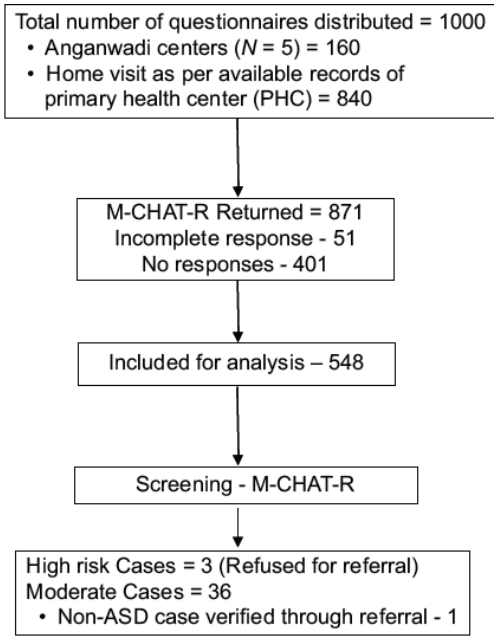

Fig. 1: Recruitment and screening procedure

Table 1: Sociodemographic profile of the study participants

Characteristics	n (%)
Age of children (months)	
18-27	215 (39.2)
28-36	333 (60)
Sex of children	
Boys	289 (52.7)
Girls	259 (47.2)
Socioeconomic status (Kuppuswamy scale)	
Upper (I)	043 (7.8)
Upper middle (II)	134 (24.5)
Lower middle (III)	211 (38.5)
Upper lower (IV)	138 (25.2)
Lower (V)	22 (4)

Table 2: Modified Checklist for Autism in Toddlers-Revised best discriminators' responses

		Total (n=548)		Screen-positive cases (n=39)		P(Chi-square
Item number	M-CHAT-R item description	No	Yes	No	Yes	test)
1	Follows point (e.g., follows directions towards any object such as animal, toys)	5	543	4	35	<0.0001
2	Doubt about deafness	537	11	31	8	<0.0001
3	Plays pretend or make-believe	46	502	19	20	<0.0001
7	Point to show (e.g., pointing aeroplane)	28	520	13	26	<0.0001
8	Interested in other children	16	532	11	28	<0.0001
9	Brings things to show	13	535	09	30	<0.0001
10	Responds to name	8	540	06	33	<0.0001

M-CHAT-R: Modified Checklist for Autism in Toddlers-Revised

CONCLUSION

The study provides preliminary data on the self-administered feasibility of the Hindi version of M-CHAT-R for screening autistic symptoms in a semi-urban community of North India. The M-CHAT-R best discriminator for ASD can be used as a short-form screener by nurses and other health-care professionals for early identification of autistic symptoms in this setting.

REFERENCES

1. Williams, J.G., 2005. Systematic review of prevalence studies of autism spectrum disorders. Arch. Dis. Childhood, 91: 8-15.
2. Elsabbagh, M., G. Divan, Y. Koh, Y.S. Kim and S. Kauchali et al., 2012. Global prevalence of autism and other pervasive developmental disorders. Autism Res., 5: 160-179.
3. Baxter, A.J., T.S. Brugha, H.E. Erskine, R.W. Scheurer, T. Vos and J.G. Scott, 2014. The epidemiology and global burden of autism spectrum disorders. Psycholo. Med., 45: 601-613.
4. Sun, X. and C. Allison, 2010. A review of the prevalence of autism spectrum disorder in asia. Res. Auti. Spect. Disord., 4: 156-167.
5. Singh, M., A. Chauhan, J. Sahu, N. Jaiswal and K. Kumar et al., 2019. Prevalence of autism spectrum disorder in Indian children: A systematic review and meta-analysis. Neurol. India, 67: 100-104.
6. Kleinman, J.M., D.L. Robins, P.E. Ventola, J. Pandey and H.C. Boorstein et al., 2007. The modified checklist for autism in toddlers: A follow-up study investigating the early detection of autism spectrum disorders. J. Autism Dev. Disord., 38: 827-839.
7. Mukherjee, S.B., M.K. Malhotra, S. Aneja, S. Chakraborty and S. Deshpande, 2015. Diagnostic accuracy of Indian scale for assessment of autism (isaa) in chidren aged 2–9 years. Indi. Pedias., 52: 212-216.
8. Rudra, A., S. Banerjee, N. Singhal, M. Barua, S. Mukerji and B. Chakrabarti, 2014. Translation and usability of autism screening and diagnostic tools for autism spectrum conditions in INdia. Auti. Res., 7: 598-607.
9. Robins, D.L., K. Casagrande, M. Barton, C.M.A. Chen, T. Dumont-Mathieu and D. Fein, 2013. Validation of the modified checklist for autism in toddlers, revised with follow-up (m-chat-r/f). Pediatrics., 133: 37-45.
10. Robins, D.L., J. Pandey, C. Chlebowski, K. Carr and J.L. Zaj,et al 2021. M-CHAT Best7: A new scoring algorithm improves positive predictive power of the M-CHAT. InProceedings of the symposium "Earlier Is Better and More Difficult: Opportunities and Challenges in Screening Children for an Autism Spectrum Disorder (ASD) in the General Population during the Second Year of Life" at the International Meeting for Autism Research.
11. TS, J., P. Jacob, S. Srinath, S.K. G and M. L et al., 2018. Toddlers at risk for autism spectrum disorders from kerala, India-a community based screening. Asi. J. Psychiatry., 31: 10-12.
12. Akhter, S., A.H.M.E. Hussain, J. Shefa, G.K. Kundu, F. Rahman and A. Biswas, 2018. Prevalence of autism spectrum disorder (asd) among the children aged 18-36 months in a rural community of Bangladesh: A cross sectional study. F1000Research., Vol. 7 .10.12688/f1000research.13563.1.

13. Raina, S., V. Kashyap, A. Bhardwaj, D. Kumar and V. Chander, 2015. Prevalence of autism spectrum disorders among children (1-10 years of age) - findings of a mid-term report from northwest India. J. Postgraduate Med., 61: 243-246.
14. Ravi, S., V. Chandrasekaran, S. Kattimani and M. Subramanian, 2016. Maternal and birth risk factors for children screening positive for autism spectrum disorders on m-chat-r. Asi. J. Psychiatry., 22: 17-21.
15. Perera, H., K. Wijewardena and R. Aluthwelage, 2009. Screening of 18-24-month-old children for autism in a semi-urban community in Sri Lanka. J. Trop. Pediatr.s, 55: 402-405.
16. Kamio, Y., H. Haraguchi, A. Stickley, K. Ogino, M. Ishitobi and H. Takahashi, 2015. Brief report: Best discriminators for identifying children with autism spectrum disorder at an 18-month health check-up in Japan. J. Auti. Dev. Disord., 45: 4147-4153.
17. Lodder, A., C. Papadopoulos and G. Randhawa, 2019. Stigma of living as an autism carer: a brief psycho-social support intervention (SOLACE). Stu. proto. random. cont. feasi. study., Vol. 5.