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AGE AT DIAGNOSIS OF AUTISM SPECTRUM DISORDER AND FACTORS ASSOCIATED WITH DELAY IN DIAGNOSIS - A STUDY FROM TAMIL NADU

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Abstract

Background: Autism spectrum disorder (ASD) is a major cause of childhood disability globally. Early diagnosis is critical for initiating timely interventions; however, many children experience significant diagnostic delays. This study aimed to determine the early clinical characteristics, age at diagnosis, and factors associated with delayed diagnosis of ASD in children. **Materials and Methods:** A cross-sectional descriptive study was conducted at the District Early Intervention Centre, Government Raja Mirasudar Hospital, Thanjavur Medical College from April to August 2023. Forty children diagnosed with ASD using the Indian Scale for the Assessment of Autism (ISAA) were included. A validated questionnaire collected socio-demographic data and treatment-seeking behaviour, including the timeline from symptom onset to diagnosis. **Result:** The study included 40 children (82.5% male) with a mean age at symptom recognition of 2.8 ± 1.1 years. Delayed speech was the most common initial symptom (35% of patients). The average age of formal diagnosis was 3.96 ± 1.4 years, with a mean delay of six months from symptom recognition to first consultation. Socioeconomic status ($p = 0.026$) significantly influenced the age at symptom recognition, while maternal education did not ($p = 0.372$). Many parents (40%) consulted multiple doctors before receiving a definitive diagnosis, which contributed to delays. The mean age at therapy initiation was 4.24 ± 1.2 years, hindered by financial constraints, distance to healthcare facilities, and parental responsibilities. **Conclusion:** Significant delays persist in ASD diagnosis due to multiple consultations, socioeconomic barriers, and lack of screening during routine paediatric visits. Integrating autism screening into immunization schedules and enhancing paediatricians' training can facilitate early identification and intervention.

INTRODUCTION

Autism spectrum disorders (ASD) are neurodevelopmental conditions characterised by impairments in social communication, social interaction, and restricted and repetitive patterns of behaviours, interests, or activities. The Centre for Disease Control (CDC) states that the prevalence of autism in 2016 was 18.5/1000 children,[1] while it was 16.8/1000 in 2014,[2] and 14.6/1000 in 2012, which clearly shows an alarming increasing trend.[3] These estimates are nearly 2.8 times (175%) higher than the first prevalence report by the CDC in 2000.[4]

The recent Global Burden of Disease (GBD) study in 2019 from 204 countries estimated the prevalence of ASD to be 28 million.[5] Though a systematic review of autism in India reported a prevalence rate of 12/10,000 to 14/10,000, which is relatively lower when compared to that of the United States, high-quality population-based epidemiological studies on ASD are needed to know the exact burden of this condition in India.[6] Early diagnosis has become increasingly important as research has shown positive outcomes with early, consistent, and appropriate intervention strategies tailored to the needs of the child and parents.[7]

Despite the increasing ability to identify the early signs of ASD and raise awareness about this condition, many children continue to remain undiagnosed until school age.[8] Our study aimed to identify the early clinical characteristics and age at

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diagnosis of children with autism spectrum disorder and to determine the factors associated with delayed diagnosis.

Aim

This study aimed to determine the early clinical characteristics and age at diagnosis of children with autism spectrum disorder and to determine the factors associated with delay in the diagnosis of autism spectrum disorder.

MATERIALS AND METHODS

This cross-sectional descriptive study included 40 children from the District Early Intervention Centre at the Government Raja Mirasudar Hospital of Thanjavur Medical College, Thanjavur, from April 2023 to August 2023. The institutional ethics committee approved the study and written informed consent was obtained from all parents.

Inclusion criteria

Parents of 40 children aged less than 12 years who were formally diagnosed with autism spectrum disorder by the Indian Scale for Assessment of Autism (ISAA) were included.

Exclusion criteria

Parents of children with genetic, neurological, or metabolic disorders were excluded from the study.

Methods

A self-designed questionnaire was developed to collect sociodemographic data and treatment-seeking behaviours of parents, focusing on the timeline from the initial appearance of autism symptoms to formal diagnosis. The questionnaire was created through a review of the existing literature, consultations with autism experts, and pilot testing with 10 parents of children with autism to evaluate clarity and relevance. Feedback from the pilot phase was incorporated to refine the wording, enhance comprehension, and ensure content validity.

Autism diagnoses were confirmed using the Indian Scale for Assessment of Autism (ISAA), a standardized diagnostic tool consisting of 40 items rated on a 5-point Likert scale (1 = rarely, 5 = always). These items assess six domains: social interactions, emotional responses, speech and communication, behaviour patterns, sensory responses, and cognitive functioning. The total ISAA scores range from 40 to 200, with higher scores reflecting greater symptom severity. According to the ISAA guidelines, scores below 70 indicate autism, scores of 70–106 indicate mild autism, 107–153 indicate moderate autism, and scores above 153 denote severe autism. Behavioural observations reported by parents were used to derive scores, adhering to the ISAA manual's protocol.

Statistical analysis

Data are presented as mean, standard deviation, frequency, and percentage. Continuous variables were compared using a one-way analysis ANOVA. Significance was defined as $P<0.05$, using a two-tailed test. Data analysis was performed using SPSS version 20 (IBM-SPSS Corp., Armonk, NY, USA).

RESULTS

Most of the children were male, with 33 (82.5%) males and 7 (17.5%) females. Most belong to the Hindu religion, with 30 (75%) Hindus, followed by six (15%) Christians and four (10%) Muslims. In terms of parental education, 14 (35%) fathers were graduates, 8 (20%) were professionals, 6 (15%) had a high school certificate, 6 (15%) had a middle school certificate, 4 (10%) had an intermediate/diploma, and 2 (5%) were illiterate. Among the mothers, 28 (70%) were graduates, 2 (5%) were professionals, 4 (10%) had a high school certificate, 4 (10%) had a middle school certificate, 1 (2.5%) had an intermediate/diploma, and 1 (2.5%) was illiterate.

Regarding occupation, 35 (87.5%) mothers were homemakers, 4 (10%) were employed, and 1 (2.5%) was deceased. Regarding status, 5 (12.5%) families had SES I, 17 (42.5%) had SES II, 11 (27.5%) had SES III, 5 (12.5%) had SES IV, and 2 (5%) had SES V. Almost all parents, 39 (97.5%), speak Tamil and one (2.5%) Urdu.

Family structure data showed that 20 (50%) families were nuclear, 16 (40%) were joint, and four (10%) were extended families. Regarding birth order, 25 (62.5%) children were first-born, 11 (27.5%) were second-born, and 4 (10%) were third-born. Overall, the data suggest that most children are firstborn males from Hindu, Tamil-speaking, nuclear families with educated parents, particularly mothers, who are mostly homemakers. Most families belonged to middle- and upper-middle-class socioeconomic groups [Table 1].

Table 1: Socio-demographic characteristics of the parents.

		Frequency (%)
Gender	Male	33 (82.5%)
	Female	7 (17.5%)
Religion	Hindu	30 (75%)
	Christian	6 (15%)
	Muslim	4 (10%)
Father's education	Professionals	8 (20%)
	Graduate	14 (35%)
	Intermediate/diploma	4 (10%)
	High school certificate	6 (15%)
	Middle school certificate	6 (15%)
	Illiterate	2 (5%)

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Mother's education	Professionals	2 (5%)
	Graduate	28 (70%)
	Intermediate/diploma	1 (2.5%)
	High school certificate	4 (10%)
	Middle school certificate	4 (10%)
	Illiterate	1(2.5%)
Mother's occupation	Homemaker	35 (87.5%)
	Employed	4 (10%)
	Expired	1 (2.5%)
SES status	I	5 (12.5%)
	II	17 (42.5%)
	III	11 (27.5%)
	IV	5 (12.5%)
	V	2 (5.0%)
Mother's tongue	Tamil	39 (97.5%)
	Urdu	1 (2.5%)
Type of family	Nuclear	20 (50%)
	Joint	16 (40%)
	Extended	4 (10%)
Birth order of the child	1st	25 (62.5%)
	2nd	11 (27.5%)
	3rd	4 (10%)

The most common issue seen in children is delayed speech, affecting 14 (35%) children. Hyperactivity and not responding to name calls were also quite common, each seen in seven (17.5%) children. Some children showed aloofness in four (10%) and poor eye contact in three (7.5%). A few made inappropriate sounds 2 (5%) or experienced seizures 2 (5%). The least common problem was loss of acquired speech, affecting only 1 (2.5%) [Table 2].

Table 2: Type of first symptoms noticed

	Frequency (%)
Delayed speech	14 (35%)
Hyperactivity	7 (17.5%)
Not responding to name calls	7 (17.5%)
Aloofness	4 (10%)
Poor eye contact	3 (7.5%)
Making inappropriate sounds	2 (5%)
Seizure	2 (5%)
Loss of acquired speech	1 (2.5%)

For SES status, the mean values range from 2.2±0.5 (SES I) to 4±2.8 (SES V), with a P-0.026, suggesting a significant difference among the groups. For the mother's education, the mean values range from 2.5±2.8 Profession to 3.8±1 (Others). A p-value of 0.372 indicates no significant difference among the education levels [Table 3].

Table 3: Comparison of age at noticing first symptom in children with socioeconomic status and mother's education

		Mean±SD	**P-value**
SES status	I	2.2±0.5	0.026
	II	3.1±0.8	
	III	2.3±0.9	
	IV	3.7±1	
	V	4±2.8	
Mother's education	Graduate	2.7±0.8	0.372
	High school certificate	3.2±0.8	
	Middle school certificate	3.5±1.7	
	Profession	2.5±2.8	
	Others	3.8±1	

DISCUSSION

This study describes the process of parental recognition of the first symptom of autism for the diagnosis of autism spectrum disorder. The male-to-female ratio in our study was 4.7:1. This condition was more commonly identified in boys, consistent with the findings of Zamora et al. Most parents achieved a higher education level. Despite 75% of the mothers being graduates, only 10% were currently employed, and many (35%) had to quit their jobs to take care of their child with ASD.[9]

Most children with ASD (62.5%) were first born to their parents, and in a significant proportion (40%), they were the only child to their parents. Most parents stated that they had decided not to have a second child for fear of recurrence in the next child and because they did not want the siblings overburdened with the responsibility of taking care of the child with ASD.[10]

The mean age at recognition of first symptoms in our

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study was 2.8 (1.1) years. In a study of 82 children from the UK, De Giacomo and Fombonne observed that the mean age of presentation of symptoms was 1.5 years, which was earlier compared to our study.[11] Mahapatra et al., in Indian research from Odisha, showed the average age of first parental concern to be 2.05(0.48) years.[10]

Delayed speech was the first symptom frequently noted in our study, which was following that reported by Daley TC, in which the most common symptom was delay in speech and language (44.9%) followed by social difficulties (44.5%).[12] Shrestha et al. cited that the most common symptom was delayed language (66%), followed by social difficulties (36%), abnormal repetitive behaviour (10%) and lack of eye contact (10%).[13] One child (2.5%) in our study was reported to have a loss of acquired speech, which has been highlighted by Lainhart et al. as regressive autism – a neurobiological subtype of autism.[14]

Only half of the study population did mothers notice the first symptom, whereas in the rest, it was noted by doctors, teachers, and others. Parents and family members not seeing the first symptom may be related to cultural factors and variable expectations regarding child development.[15] A study from Jordan stated that only a minority of parents had specific concerns about autism, indicating the need for increased awareness among the public.[16] There was no significant difference between the age of the first symptom noticed and the mother's education in our study. Samms-Vaughan et al. from Jamaica showed a statistically significant association between early noticing of symptoms and the higher educational status of the parent and higher SES.[17] Mandell et al. also observed statistical significance between the age of symptom recognition and income.[18]

This delay of six months in our study between the first symptom recognition and the first doctor consultation was attributed to denial of the diagnosis by the parents, cultural factors such as delayed language development in boys, family history of delayed language development, and certainty that it will settle with time. Most parents consulted multiple doctors before diagnosing autism. This 'doctor shopping' tendency was the contributing factor to the delay in diagnosis, as in the study done in Odisha.[10]

The first level of contact for most of the parents of children with ASD was the paediatricians, and that diagnosis of ASD was missed in our study indicating the need for training programs for autism. Masri et al. stated that a deficiency of knowledge among paediatricians about autistic symptoms and screening tools is a contributing factor to delay in diagnosis.[16] In a study from Nepal by Khunk et al., which included 54 paediatricians, only five were confident in recognizing children with autism.[19] The missed diagnosis of autism may have been due to clinicians overlooking ASD features, misattributing ASD symptoms to ADHD, and deferred diagnosis, as ambiguous symptoms do not become obvious until social demands exceed children's abilities. Several studies report that an initial diagnosis of ADHD/developmental delay precedes a conclusive diagnosis of ASD made later, which was also observed in our study.[20-22]

Table 4: Comparison of mean age at noticing of first symptom and mean age at diagnosis

Authors	Country year	Study population (Nos)	Mean age at noticing first symptom (years)	Mean age at diagnosis (years)
DeGiacomo et al.[11]	UK,1998	82	1.5 (0.7)	4.9
Daley TC,[12]	India, 2004	81	2.14 (1.0)	4.75
Samms-Vaughan et al,[17]	Jamaica, 2008	117	1.77 (0.9)	3.93(2.22)
Shrestha et al,[13]	Nepal, 2013	54	2.3 (1.2)	4.6
Jain et al,[24]	India, 2013	47	2	3.5
Our study	India, 2023	40	2.8 (1.1)	3.96 (1.4)

A quick autism screening tool should be integrated into sick and immunization visits to ensure early diagnosis.[23] Training healthcare personnel for developmental assessments is crucial, as no studies have explored autism screening during vaccination visits. The mean age at autism diagnosis in our study was 3.96 years. The mean age of confirmation of autism has been variably reported to be between 3.5 and 4.9 years in other studies.[11-13,17,24] [Table 4]. The mean age of initiation of therapy in our study after confirming autism was 4.24 (1.2) years. The reasons stated for the delay in the initiation of therapies were financial issues, distancing, health issues in the child, working parents, and caring for another child.

Limitations: The major limitation of our study is the small sample size. A larger sample drawn from different regions and socio-economic backgrounds, as well as both public and private hospitals, would have helped in more accurate reporting of clinical characteristics and a better understanding of awareness among public and medical professionals. The study was conducted in a district early intervention centre, so there is a potential for selection bias, and larger studies at the community level are warranted in the future.

CONCLUSION

This study provides insight into the acute need for awareness regarding autism among the public, the need for training of paediatricians and paramedical staff in screening and diagnosis of autism, and the inclusion of developmental screening in routine immunization schedules for early identification of autism.

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