Early Diagnosis and Intervention for Autism Spectrum Disorder: Need for Pediatrician–Child Psychiatrist Liaison

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ABSTRACT

Background: Early interventions in children with autism spectrum disorder (ASD) reduce progressive symptom development. Delay in diagnosis and initiation of ASD-specific interventions is observed across settings. This study aimed to assess the trends in time to diagnosis and treatment initiation in a tertiary care pediatric setting. **Methodology:** Families of children with ASD ($n = 50$) were assessed, and details regarding age at first symptom recognition, medical consultation, receiving the diagnosis, and initiation of treatment were collected, in addition to detailed clinical assessment. **Results:** About 70% of families met a pediatrician for initial concerns, and 20% received a diagnosis of ASD from the first-contact pediatrician. The mean age at initial symptom recognition was 22.22 ± 9.47 months, whereas the first consultation was 27.22 ± 10.83 months. The mean age at initiation of ASD-specific interventions was 36.58 ± 10.2 months, amounting to an overall delay of 14.38 months from initial symptom recognition to treatment initiation. The time delay in our study is found to be lesser compared with similar studies across settings. **Discussion:** Pediatricians have a significant role to play in early diagnosis and care of children with ASD in close liaison with child psychiatry teams. Improving awareness, routine screening, and prompt referral of children "at-risk" for ASD are imperative. Initiating ASD-specific interventions in pediatric or primary care settings is an effective alternative to curtail the delay in treatment initiation.

Key words: *Autism spectrum disorder, delay, early intervention, pediatric*

INTRODUCTION

Autism spectrum disorder (ASD) is a neurodevelopmental disorder characterized by persistent deficits in social interaction and communication and restricted, repetitive patterns of behavior, interests, or activities.[1] Recently, there has been an increasing worldwide prevalence of ASD, with an estimate of about 0.5%–1%,[2] and ASD is considered an issue of public health importance. The rising trends in prevalence are partly attributed

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to increasing awareness among medical professionals, community stakeholders, and, more importantly, parents; and better identification and prompt referral to experts for further management.[3]

Accumulating evidence suggests that early diagnosis and initiation of appropriate interventions in children with ASD result in an optimal outcome[4] and prevent progressive symptom development. Despite increasing awareness and earlier age at diagnosis, delay in initiation of specific interventions has been observed across settings. Indian studies have shown an average delay of 2 years from the point of the first consultation to treatment initiation.[5,6] Strategies such as streamlining the process of consultation and referral,[7] initiation of home-based interventions,[6,8] and changes in public health policies[9] have been proposed to curtail the delay.

As early detection often does not translate into early intervention, it is necessary to understand the reasons for treatment delay and formulate strategies to address the same. Studies in the Indian settings have been conducted in tertiary care child psychiatry and community settings. This study looked at the age at recognition, diagnosis of ASD, and initiation of specific interventions in a tertiary care pediatric setting, as pediatricians continue to be the first-contact medical professionals.

METHODOLOGY

The study was conducted in the Child Guidance Clinic (CGC) of a tertiary care center in South India. The CGC is housed in the Department of Pediatrics, runs in liaison with the child psychiatry team, and caters to about 200–300 children a month. Fifty children with a diagnosis of ASD according to DSM 5,[1] with a reliable informant (parent/grandparent), were consecutively recruited. Informed consent was obtained from parents. The study was approved by Institute Ethics Committee.

Primary caregivers, mostly the mothers, were interviewed using a semi-structured proforma for the sociodemographic profile, child's age at first symptom recognition, first symptom or developmental deviance of concern, age at first consultation, age at receiving the diagnosis of ASD, further consultations if any, and age at initiation of ASD-specific interventions. Details of the source of referral and referral diagnosis were collected. Parents were also asked about the reasons for the delay in treatment initiation. This was done in addition to diagnostic workup, comprehensive evaluation, and initiation of center-based and home-based interventions for these children.

Statistical analysis

All statistical analysis was carried out using SPSS version 19.0. Categorical variables are represented as frequencies and percentages. Continuous variables are represented as means and standard deviations. Correlation between the educational status of parents and age at first symptom, diagnosis, and treatment initiation was done using Pearson's correlation.

RESULTS

Of the 50 children, 84% were male, and 96% had the mother as the primary caregiver. About 22% and 38% of the families belonged to lower and middle socioeconomic status, respectively, whereas 40% belonged to higher socioeconomic status. About 45% of families belonged to the urban background, 20% of parents were professionals, while 64% of mothers were housewives. The mean age of the children was 41.46 ± 17.2 months. The average educational status of the primary caregiver as the number of years of schooling was 12.86 ± 3.8.

Figure 1 shows the average age at symptom recognition to diagnosis and treatment initiation. In our study, though the age at initial symptom recognition was at an average of 22.22 ± 9.47 months, age at first consultation was 27.22 ± 10.83 months, the time delay ranging from 0 to 40 months. The age at receiving the diagnosis of ASD was 32.4 ± 10.1 months, whereas the age at initiation of ASD-specific interventions was 36.58 ± 10.2 months, the time delay ranging from 0 to 60 months. This amounts to an overall mean delay of 14.38 months from the point of initial symptom recognition to treatment initiation.

Around 22% of the children were referred to the CGC by pediatricians, 8% and 2% by a speech therapist and occupational therapist, respectively, whereas 68% were self-referred. A total of 35 (70%) children received the diagnosis of ASD for the first time at our center. Of the remaining 30%, about 20% was diagnosed by pediatricians and 10% by speech and language therapist. Around 26% of children were referred with a diagnosis of attention deficit hyperactivity disorder,

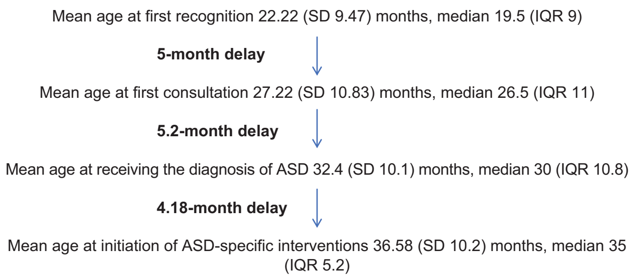

Figure 1: Age at recognition to treatment initiation

34% as suspected ASD, and 3% as expressive language delay, who on further evaluation received a diagnosis of ASD.

The reasons for the first consultation were speech delay in 48% and speech and social milestone regression in 4%. About 52% of families reported concerns such as poor eye contact, poor response to name call, and social interaction, whereas 6% reported motor stereotypies. About 30% of families had primary concerns about hyperactivity and 40% had primary concerns about epilepsy during their first consultation.

It is important to note that 70% of families chose to meet a pediatrician for their initial concerns, of which 20% received a diagnosis of ASD from their first-contact pediatrician. Around 40% of families had taken subsequent consultations and had met a median of 2 (interquartile range 2) professionals after receiving the first diagnosis. Subsequent consultations were obtained from other pediatricians, pediatric neurologists, ENT specialists, psychologists, and speech and occupational therapists. Approximately 40% of parents were in the phase of denial and hence took multiple consultations to seek reassurance. About 8% of parents had a false sense of security that “things would get better as the child grows up,” thus delaying treatment, and 4% reported that they were unaware that these are developmental deviances.

About 36% of families initiated ASD-specific interventions within the same month of receiving the diagnosis; an additional 12% initiated interventions within 2 months of diagnosis. There was no correlation between parental education and age of symptom recognition or the first consultation. However, there was a negative correlation between parental education and age at final diagnosis ($r = -0.282$, $P = 0.048$) and time delay in treatment initiation ($r = -0.323$, $P = 0.022$).

DISCUSSION

The delay in treatment initiation following diagnosis has been observed both in Indian and international settings.[5,10] A review of studies conducted over a period of 12 years reported that the mean age at diagnosis was 38–120 months, with a decreasing trend over time.[7] A community-based study in urban India found that the average age at initial symptom recognition was 24.1 months and parents waited at least 2 years from the point of first medical contact to the final diagnosis.[5] A tertiary care hospital-based study found that the mean age at first medical consultation in these children was 32.5 months, whereas age at initiation of disorder-specific treatment was 52.75 months.[6] A finding unique to our study is that age at diagnosis and treatment initiation is earlier by 1.5–2 years compared with studies within the same cultural context. It could be argued that these children first presented to the pediatric clinic. Prompt referral and close liaison with the child psychiatry team could have possibly led to an earlier initiation of interventions.

Pediatricians continue to remain the first-contact professionals in both primary and tertiary care settings.[11] It is recommended that first-contact medical professionals screen and refer children as early as possible whenever there is a concern of developmental deviance.[6] Routine screening for developmental deviance with instruments such as Trivandrum Development Screening Chart,[12] with particular emphasis on social milestones, and using specific screening tools for early detection of ASD like Modified Checklist for Autism in Toddlers – Revised[13] can facilitate early identification.

In resource-limited settings, there is a lack of a hierarchical referral system, compounded by lack of specialists. ASD-specific interventions are delivered in specialized centers in apex institutes and hospitals in urban areas. Alternately, initiating center-based interventions in pediatric or primary care settings are a further step forward to curtail delay in treatment initiation.[14]

In this study, children with various referral diagnoses were later identified to have ASD on detailed evaluation. This raises the importance of specifically looking for comorbid neurodevelopmental disorders in children presenting with developmental concerns. Presence of medical comorbidities and delay in motor development resulted in earliest consultations. Despite 50% of families having noticed deviances in social milestones, consultation was primarily delayed in the absence of medical comorbidities.

Irrespective of parental educational status, developmental concerns were noted at an earlier age. Parents with better educational status had spent lesser time seeking further consultations and initiated interventions earlier. Another aspect to delay in treatment initiation is parental stress in the early stages of receiving the diagnosis. Families of children with ASD undergo significant distress at personal and social levels.[15,16] This emphasizes the need for more awareness among parents,[9] clarifying misconceptions, and addressing parental stress from a cultural perspective.[8]

The small sample size and lack of use of structured interviews for diagnostic ascertainment are the limitations of the study.

CONCLUSION

Pediatricians have a significant role to play in the early diagnosis and care of children with ASD in close liaison with child psychiatry teams. Initiating specific interventions for ASD at the primary care or pediatric setting is an effective alternative to curtail delay in treatment initiation and improving outcomes as well as to address parental stress. Strengthening the CGCs in existing government teaching hospitals and District Early Intervention Centers would be effective to improve service delivery.

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Conflicts of interest
There are no conflicts of interest.

REFERENCES

1. Association AP. Diagnostic and Statistical Manual of Mental Disorders. 5th Revised Ed. Washington, DC: American Psychiatric Publishing; 2013. 991 p.
2. Elsabbagh M, Divan G, Koh Y-J, Kim YS, Kauchali S, Marcín C, *et al*. Global prevalence of autism and other pervasive developmental disorders. Autism Res 2012;5:160-79.
3. Wing L, Potter D. The epidemiology of autistic spectrum disorders: Is the prevalence rising? Ment Retard Dev Disabil Res Rev 2002;8:151-61.
4. Dawson G. Early behavioral intervention, brain plasticity, and the prevention of autism spectrum disorder. Dev Psychopathol 2008;20:775-803.
5. Daley TC. From symptom recognition to diagnosis: Children with autism in urban India. Soc Sci Med 2004;58:1323-335.
6. Preeti K, Srinath S, Seshadri SP, Girimaji SC, Kommu JVS. Lost time—Need for more awareness in early intervention of autism spectrum disorder. Asian J Psychiatry 2017;25:13-5.
7. Daniels AM, Mandell DS. Explaining differences in age at autism spectrum disorder diagnosis: A critical review. Autism 2014;18:583-97.
8. Srinath S, Jacob P. Challenges in parent-mediated training in autism spectrum disorder. Lancet Psychiatr 2016;3:93-5.
9. Wallace S, Fein D, Rosanoff M, Dawson G, Hossain S, Brennan L, *et al*. A global public health strategy for autism spectrum disorders. Autism Res 2012;5:211-7.
10. Rhoades RA, Scarpa A, Salley B. The importance of physician knowledge of autism spectrum disorder: Results of a parent survey. BMC Pediatr 2007;7:37.
11. Chakrabarti S. Early identification of autism. 2009.
12. Nair MK, George B, Philip E, Lekshmi MA, Haran JC, Sathy N. Trivandrum Developmental Screening Chart. Indian Pediatr 1991;28:869-72.
13. Robins DL, Casagrande K, Barton M, Chen CM, Dumont-Mathieu T, Fein D. Validation of the modified checklist for autism in toddlers, revised with follow-up (M-CHAT-R/F). Pediatrics 2014;133:37-45.
14. Harshini M, Preeti K. Autism Behavioural Interventional Research in low-resource settings: Overcoming prevailing challenges an Asian perspective. Asian J Psychiatry 2017;25:224-7.
15. Craig F, Operto FF, De Giacomo A, Margari L, Frolli A, Conson M, *et al*. Parenting stress among parents of children with Neurodevelopmental Disorders. Psychiatry Res 2016;242:121-9.
16. Desai MU, Divan G, Wertz FJ, Patel V. The discovery of autism: Indian parents' experiences of caring for their child with an autism spectrum disorder. Transcult Psychiatry 2012;49:613-37.