

# The Socio-Demographic and Clinical Profile of Individuals with Autism Spectrum Disorder in a Tertiary Care Teaching Hospital in South India

Original Article

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## Abstract

### BACKGROUND

Autism spectrum disorder (ASD) is a neuro-developmental disorder. There is a paucity of epidemiological data on ASD in India. This study is an attempt to understand the socio demographic and clinical characteristics of the individuals with ASD.

### METHODS

The case records were perused to extract the data.

### RESULTS

The study revealed that two third of individuals with ASD also have Intellectual Disability, more than half the mothers of individuals with ASD did not breastfeed beyond 12 months, about one third of individuals with ASD have not availed any kind of services. It takes around 6 years of age for the parents/ individuals with ASD to seek treatment help.

### CONCLUSION

Understanding the profile is essential for better treatment planning.

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**KEY WORDS:** Autism Spectrum Disorders, India, Clinical Profile

**RUNNING TITLE:** Profile of Individuals with Autism Spectrum Disorder

## INTRODUCTION

Autism spectrum disorder (ASD) is a neuro-developmental disorder. The individuals with ASD have the symptoms of persistent deficits in social communication and social interaction and have restricted repetitive patterns of behavior, interests or activities. These symptoms are present in the early developmental periods and it causes clinically significant impairment in social, occupational or other important areas of functioning in their lives.<sup>(1)</sup> The disorder has a huge impact not only on the individual but on the family as well. There has been an increase in the prevalence of ASD in India. ASD was once considered rare but now it has become apparent that it is a more common developmental disability than previously thought. The increased prevalence could be due to advanced parental age at conception and perinatal risks like prematurity and now high risk infant survival rate has also increased. There is a paucity of epidemiological data on ASD in India. Depending on the screening tools and the area surveyed, the estimated prevalence of ASD in India ranges from 0.15% to 1.01%.<sup>(2,3)</sup> The prevalence of ASD in the rural areas was 0.90%, while in the hilly regions it is 0.6%, in the urban areas it is 1.01%, in the tribal areas it is 0.1% and in coastal regions it is 0.61%.<sup>(3)</sup> As there is sparse information available on the clinical and social profile of the individuals with ASD, this study was carried to identify the demographic characteristics of individuals with ASD and factors associated with severity of ASD.

## MATERIALS AND METHODS

Case records of patients diagnosed with ASD in the period from April 2013 – July 2019 in the Department of Psychiatry of Chengalpattu Medical College Hospital were reviewed. The data related to the demographic

and diagnostic interview details and test results of Childhood autism rating scale (CARS), Vineland Social Maturity Scale (VSMS) and for the patients who were verbal, Binet-Kamat Test of Intelligence (BKT) results were extracted from the case records.

**Childhood autism rating scale (CARS):** CARS is a diagnostic instrument and it assesses the severity of autism. It has 15 items which addresses the different domains of ASD. Each of the items are rated from 1 to 4. The total score ranges from 15 to 60 and the cut off for the diagnosis of ASD is 30. The scores from 30 to 36.5 indicates mild to moderate autism and above that indicates severe autism.<sup>(4)</sup> The psychometric property of CARS has been well documented in Indian population.<sup>(5)</sup>

**Vineland Social Maturity Scale (VSMS):** VSMS is used to assess the social and adaptive functions and also the social competency of individuals. When standard intelligence tests cannot be administered due to impaired speech or poor cooperation VSMS is preferred. The VSMS has 8 domains: self-help general, self-help eating, self-help dressing, locomotion, communication, occupation, self-direction and socialisation. The social age is obtained.

**Binet-Kamat Test of Intelligence (BKT):** BKT is a modified version of Stanford Binet Scale and is used for measuring intelligence. It is an age scale and can be administered from 3 years of age. It includes both verbal and performance tests. It has both power and speed test. The intelligence quotient is obtained by dividing mental age by chronological age.

The data was analysed statistically using the SPSS 20. The frequency, mean, median, standard deviation and chi square were used. The level of significance was set at 0.05 level.

## RESULTS

**Table 1: Socio-Demographic Profile of Individuals with ASD**

Variable	N Frequency (%)
<b>Gender</b>	
Male	118 (86.1)
Female	19 (13.9)
<b>Marriage relationship of parents</b>	
Consanguineous	30 (21.2)
Non-consanguineous	107 (77.1)
Adopted	1 (0.7)
<b>Birth order</b>	
First	81 (59.1)
Second	45 (32.8)
Third	8 (05.8)
Sixth	1 (00.7)
<b>Father's Job</b>	
Agriculturist	5 (03.6)
Daily wager	9 (06.6)
Business	21 (15.3)
Private sector	80 (58.4)
Government sector	7 (05.1)
Self employed	12 (08.8)
Not available	3 (02.2)
<b>Mother's Job</b>	
Agriculturalist	3 (02.2)
Daily wager	2 (01.5)
Business	1 (00.7)
Private sector	13 (09.5)
Government sector	5 (03.6)
Homemaker	109 (79.6)
Not available	4 (02.9)

Table 1, shows the sociodemographic profile of the individuals with ASD, majority (86.1%) were males in the study. Nearly three fourth were born out of non-consanguineous union and 59.1% were first born. With regard to occupation of their parents, 58.4% of the fathers were working in the private sector and majority of the mothers were homemakers.

**Table 2: Clinical Profile**

<b>Variable</b>	<b>N (%)</b>	<b>Mean ± SD</b>
Autism with intellectual disability	87 (63.5)	
Autism without intellectual disability	16 (11.7)	
Global developmental delay	34 (24.8)	
Autism with speech impairment	124 (90.5)	
Autism without speech impairment	13 (09.5)	
<b>Severity of autism</b>		
Mild – moderate	123 (89.8)	
Severe	14 (10.2)	
CARS scores (Mean ±SD)		33.63 ± 02.97
Social age in months (Mean ± SD)		36.39 ± 14.43
IQ (Mean ± SD)		81.30 ± 16.79
Seizures	27 (19.7)	
On antiepileptic drugs	13 (08.8)	
Family h/o mental illness	23 (16.8)	

Table 2, shows the clinical profile, it has been found that nearly two third of the individuals in the study had intellectual disability and majority had speech impairment. Most of them who came for consultation had mild to moderate severity of autism. The mean CARS scores was 33.63 (SD 2.97), social age in months was 36.39 (SD 14.43) and intelligence quotient was 81 (SD16.79). One fifth had seizures wherein only small portions of the people were on regular AEDs. 16.8% had family history of mental illness.

**Table 3: Perinatal and Developmental Profile**

<b>Variable</b>	<b>N (%)</b>
<b>Place of Delivery</b>	
<i>Government public hospital</i>	74 (54.0)
<i>Private hospital</i>	60 (43.8)
<i>Home</i>	2 (01.5)
<i>Not available</i>	1 (00.7)
<b>Term of Delivery</b>	
<i>Full term</i>	122 (89.1)
<i>Pre term</i>	12 (08.8)
<i>Not available</i>	3 (02.1)
<b>Delivery Mode</b>	
<i>Natural birth</i>	64 (46.7)
<i>C section</i>	63 (46.0)
<i>Forceps/ instruments used</i>	7 (05.1)
<i>Not available</i>	3 (02.2)

<b>Birth Cry</b>	
<i>Immediate</i>	103 (75.2)
<i>Delayed</i>	31 (20.7)
<i>Not available</i>	3 (04.1)
<b>NICU</b>	
<i>Yes</i>	32 (23.4)
<i>No</i>	98 (71.5)
<i>Not available</i>	6 (05.1)
<b>Breast Fed</b>	
<i>Yes</i>	107 (78.1)
<i>No</i>	11 (08.0)
<i>Not available</i>	20 (13.9)
<b>Developmental Milestones</b>	
<i>Age appropriate</i>	1 (00.7)
<i>Delayed</i>	134 (97.8)
<i>Not available</i>	2 (01.5)
<b>Motor Milestones</b>	
<i>Age appropriate</i>	88 (64.2)
<i>Delayed</i>	47 (34.3)
<i>Not available</i>	2 (01.5)
<b>Speech Milestones</b>	
<i>Age appropriate</i>	1 (00.7)
<i>Delayed</i>	134 (97.8)
<i>Not available</i>	2 (01.5)

Table 3 shows the perinatal and developmental profile, nearly half the sample were born in government public hospital, majority were born full term, nearly half were caesarean section, two third had immediate birth cry, around one fourth were in the NICU and nearly three fourth was breast fed. Majority had delayed developmental milestones especially delayed speech milestones but only two third had delayed motor milestones.

**Table 4: Services**

<b>Variable</b>	<b>N(%)</b>	<b>Median (Range)</b>
<b>Receiving any services</b>		
<i>Yes</i>	83 (60.6)	
<i>No</i>	48 (35.0)	
<i>Not available</i>	4 (04.9)	
<b>Where are they receiving services</b>		
<i>Government sector</i>	15 (10.9)	
<i>Private sector</i>	70 (51.1)	
<i>Not taking any services</i>	48 (35.0)	
<i>Not available</i>	4 (03.0)	

<b>Services Received</b>		
<i>Medical</i>	2 (01.5)	
<i>Behaviour therapy, speech and occupational therapy</i>	1(00.7)	
<i>Special education</i>	1 (00.7)	
<i>Special education, speech &amp; occupationaltherapy</i>	60 (43.8)	
<i>Special education and speech therapy</i>	1 (00.7)	
<i>Speech therapy</i>	2 (01.5)	
<i>Speech and Occupational therapy</i>	7 (05.1)	
<i>Occupational therapy</i>	6 (04.3)	
<i>Physiotherapy</i>	1 (00.7)	
<i>Not receiving any services</i>	48 (35.0)	
<i>Not available</i>	8 (06.0)	
<b>Attended Play School</b>		
<i>Yes</i>	47 (34.3)	
<i>No</i>	78 (56.9)	
<i>Not available</i>	12 (08.8)	
<b>Disability Card</b>		
<i>Yes</i>	8 (05.8)	
<i>No</i>	129 (94.2)	
Age of first contact with Department		79 (58 – 113.9)
Child started school		36 (18 – 48)

Table 4 shows the details of the services that have been availed. It has been found that nearly half of the individuals were taking private services and one third attended play school. Two third were taking a combination therapy of special education, speech and occupational therapy. Only a very small group had disability card. The median age of first contact with the department was 79 months (Inter Quartile Range 58 – 113.9) and the child started schooling at a median age of 36 months (Range 18 – 48).

**Table 5: Relationship of Variables with Severity of Autism**

Variables	Severity of Autism		P – Value
	Mild/Moderate	Severe	
<b>Consanguinity</b>			
Consanguineous	28 (96.6)	1(3.4)	
Non-consanguineous	93 (87.7)	13 (12.3)	0.36
<b>Birth Order</b>			
1st	73 (90.1)	8 (9.9)	
2nd	41 (91.1)	4 (8.9)	0.03*
3rd	7 (87.5)	1 (12.5)	

<b>Place of Delivery</b>			
Government hospital/ PHC	62 (83.8)	12 (16.2)	
Private hospital	58 (96.7)	2 (3.3)	0.04*
Home	2 (100)	0 (0)	
<b>Term of Delivery</b>			
Full term	112 (91.8)	10 (8.2)	0.09
Pre term	9 (75)	3 (25)	
<b>Delivery Mode</b>			
Natural birth	56 (87.5)	8 (12.5)	
C section	60 (95.2)	3 (4.8)	0.07
Forceps/ instruments used	5 (71.4)	2 (28.6)	
<b>Birth Cry</b>			
Immediate	95 (92.2)	8 (7.8)	0.47
Delayed	25 (85.2)	4 (14.8)	
<b>NICU</b>			
Yes	26 (81.3)	6 (18.8)	0.02*
No	93 (94.9)	5 (5.1)	
<b>Breast Fed</b>			
Yes	98 (91.6)	9 (8.4)	0.08
No	8 (72.7)	3 (27.3)	
<b>Developmental Milestones</b>			
Age appropriate	1 (100)	0 (0)	0.90
Delayed	121 (90.3)	13 (9.7)	
<b>Motor Milestones</b>			
Age appropriate	81 (92)	7 (8)	0.27
Delayed	41 (87.2)	6 (12.8)	
<b>Speech Milestones</b>			
Age appropriate	0 (0)	1 (100)	0.09
Delayed	121 (91)	12 (9)	
<b>Mothers Feed</b>			
< 12 Months	72 (43)	14 (57)	0.00*
> 12 Months	51 (100)	0 (0)	

\*Significant

Table 5, shows that most of the individuals were of 1st birth order. Individuals with mild to moderate autism were more often born in government public hospital. Individuals with severe autism were significantly less likely to be breast fed than those with mild autism.

## DISCUSSION

This study has shown that 63.5% of individuals with ASD have intellectual disability which corresponds with the study by Bouras<sup>(6)</sup> where in their study they have found that nearly 70% of people with PDD also have ID. Majority also had speech impairment. The high prevalence of intellectual disability and speech impairment in the study could be as it is a tertiary care teaching hospital hence children with more disability are brought in by their parents for seeking treatment and also for availing governmental benefits.

The study shows that only 5.8% had disability card when they first made contact with the department while a huge proportion of individuals with ASD in the study have disability hence we need to think of efficient ways like conducting more awareness and screening camps in schools and communities to reduce this huge gap.

In the study males constituted the majority (86.1%) which is consistent with the studies of Fombonne<sup>(7) (8) (9)</sup> where the estimates of a male to female ratio is approximately 4.3:1. It has been found that 19.7% of the children in this study had seizures which has also been found in the study by Tuchman<sup>(10)</sup> where they found that the conservative estimate of epilepsy in autism is approximately 25%. Only 8.8% were on AED in the study. This shows the need to liaison with neurology department as the seizures has an overall impact on the individual and it needs to be controlled.

Nearly 43.8% in the study took combination therapy of special education, speech and occupational therapy and Subramanyam<sup>(11)</sup> has also recommended interdisciplinary therapy. In the study the mean age of the individual with ASD at the first contact with the department was 79 months, which is quite late, as children as young as 16 months can be screened for ASD<sup>(12)</sup> and clearly the value for early detection would help in supporting the family to obtain early

intervention which would help in effective cognitive and social learning and would also reduce the burnout for the family. Hence there is a need to focus on awareness and also on strengthening the pathways to help them avail services.

The majority of the 1st birth order (90.1) in the study had mild to moderate autism. This indicates that at the time when they came in for consultation they were first born, a follow up study can throw more light if the family decided to have another child and whether they underwent genetic counselling. It has been found that the majority of the individuals with mild to moderate autism were born in government public hospital. This could be because most of them belong to the LSES and mostly government public hospital is the preferred choice to deliver and to take treatment. Nearly half of the individuals with severe autism were breast fed less than 12 months. It would be interesting to explore this aspect and understand the mental health of the mother and also the impact of breastfeeding on improving the socialisation.

## CONCLUSION

Two third of individuals with ASD also have Intellectual Disability, more than half the mothers of individuals with ASD did not breastfeed beyond 12 months, about one third of individuals with ASD have not availed any kind of services. It takes arounds 6 years of age for the parents/ individuals with ASD to seek treatment help.

This study is an attempt to understand the socio demographic and clinical characteristics of the individuals with ASD. As there are limitations (hospital based study and perusal of records with missing data) a community based follow up would throw better clarity on overall clinical picture. That in turn will help in better policy making and awareness, early intervention and treatment protocol.

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