Section: Paediatrics

Original Research Article

ASSESMENT OF KNOWLEDGE, AWARENESS AND PERCEPTION OF AUTISM SPECTRUM DISORDERS IN PARENTS OF CHILDREN (0 TO 5 YEARS) ATTENDING TERTIARY CARE HOSPITAL

Kavitha.D[1], Indhumathi A.T.[2], Balaji.J[3]

[1]Assistant Professor, Department of Paediatrics, Institute of Child Health and Hospital for Children, Egmore, Tamilnadu, India.
[2]Assistant Professor, Department of Paediatrics, Institute of Child Health and Hospital for Children, Egmore, Tamilnadu, India.
[3]Assistant Professor, Department of Paediatrics, Institute of Child Health and Hospital for Children, Egmore, Tamilnadu, India.

Received : 10/08/2025
Received in revised form : 23/09/2025
Accepted : 13/10/2025

Keywords:
Autism spectrum disorder, Early recognition, Misconceptions, Parental awareness, Perception.

Corresponding Author:
Dr. Kavitha. D,
Email: kavisan1226@gmail.com

DOI: 10.47009/jamp.2025.7.5.216

Source of Support: Nil,
Conflict of Interest: None declared

Int J Acad Med Pharm
2025; 7 (5); 1145-1149

ABSTRACT

Background: Autism spectrum disorder (ASD) is a neurodevelopmental condition that affects communication, behaviour, and social interaction. Parental awareness is crucial for early recognition and timely interventions. This study assessed the knowledge, awareness, and perception of ASD among parents of young children in a tertiary care setting. **Materials and Methods:** A descriptive cross-sectional study was conducted among 200 parents of children aged 0–5 years who attended the outpatient department of a tertiary care hospital. Data were collected using a content-validated questionnaire assessing sociodemographic details, general knowledge, awareness of signs and symptoms, and perceptions related to stigma and diagnosis of the disease. Responses were analysed using frequencies and percentages to identify knowledge gaps and misconceptions. **Result:** Of the 200 parents, 51% were mothers and 49% were fathers, with most (33.7%) aged 26–30 years. Education levels varied, with 25.7% each completing SSLC and undergraduate degrees, while 3% were uneducated. Only 44.9% had heard of autism, 38% knew someone undergoing treatment, and 33.4% recognised the signs and symptoms. Misconceptions were common: 40% believed autism could not be detected before age four, 37% linked it to schizophrenia, 17.2% attributed it to vaccinations, and 47.6% thought most autistic children were mentally retarded. Regarding perceptions, 38% anticipated discrimination after diagnosis, 44.4% felt that ASD is often missed in practice, and 63% acknowledged a lack of parental awareness. **Conclusion:** Despite some positive perceptions, substantial gaps and misconceptions regarding ASD persist among parents of children with ASD. Integrating structured awareness interventions into routine paediatric and primary care services can help improve recognition, reduce stigma, and promote early intervention.

INTRODUCTION

Autism spectrum disorder (ASD) is a neurological and developmental disorder that affects how individuals interact with others, communicate, learn, and behave.[1] It is characterised by difficulties in social communication and interaction, such as limited eye contact, challenges with conversational reciprocity, difficulty in understanding others' perspectives, and trouble forming friendships.[2] Many individuals also exhibit restricted or repetitive behaviours, including echolalia, intense or overly focused interests, and resistance to routine changes. Sensory differences, such as heightened or reduced sensitivity to light, sound, or texture, along with sleep disturbances and irritability, are also common.[3] In spite of these challenges, people with ASD often possess unique abilities, such as strong memory, attention to detail, visual and auditory learning skills, and special abilities in areas such as mathematics, science, music, and art. These symptoms of ASD usually emerge in early childhood and are often apparent within the first two years of life.[1] ASD includes autistic disorder, pervasive developmental disorder, and Asperger's disorder.[4]

The exact cause of ASD remains unclear, but studies emphasise that a combination of genetic and environmental factors contributes to its development. Risk factors include having a sibling with ASD, older parents, certain genetic syndromes such as Down

ISSN (O): 2687-5365; ISSN (P): 2753-6556

syndrome and Fragile X syndrome, and being born with very low birth weight.[1] Early and accurate identification of ASD is critical because timely monitoring and intervention in the preschool years (including under age 3) are associated with improved developmental outcomes and access to supportive services.[5] Global surveillance and epidemiologic reports indicate that ASD has an increasing frequency, with variations in prevalence by geography, age, and surveillance method. ASD was ranked within the top ten causes of non-fatal health burden for people < 20 years of age.6 It is estimated that, globally, 1 in 100 children has autism; therefore, the World Health Organisation emphasises the need for population awareness, early detection, and community-level support to reduce delays in diagnosis and intervention.[7]

A study reports that there is a considerable gap in parental knowledge and their attitudes toward ASD that can hinder early diagnosis and effective management.[5] There a low to moderate levels of accurate understanding about ASD among the parents from low- and middle-income countries, along with mixed readiness to seek specialised care and beliefs about the causes and management.[8] Empirical surveys on parents of young children suggest the presence of misinformation about aetiology and treatment, inconsistent recognition of early signs, and an association between parental demographics and knowledge levels.[9] Additionally, the parents of these regions experience problems like delayed recognition, humiliation, and challenges in negotiating with health and educational systems after an ASD diagnosis.[10] Several studies have found that higher parental education, socioeconomic status, and prior exposure to information about ASD are associated with better knowledge and more positive attitudes.[9,11]

Understanding parental awareness is important, as it can help provide effective interventions and improve outcomes. Therefore, this study aimed to assess the knowledge and perception of ASD among parents of children under 5 years of age attending a tertiary care hospital and to determine the factors associated with adequate knowledge and positive attitude among them.

MATERIALS AND METHODS

This descriptive cross-sectional survey was conducted on 200 parents who came for regular checkups at the outpatient department of the Institute of Child Health and Hospital for Children, Chennai, for 6 months. The Institutional Ethics Committee approved the study, and written consent was obtained from all parents before inclusion.

Inclusion and Exclusion Criteria

Parents of children aged < 5 years who attended the outpatient department and provided informed consent were included in the study, while parents of children previously diagnosed with ASD were excluded.

Methods

Data were collected through a cross-sectional study targeting parents of children attending the outpatient department using a self-reported questionnaire administered to randomly selected parents. Since no standardised and validated awareness scale for autism exists, a questionnaire was developed specifically for this study based on a comprehensive literature review and expert consultations. The tool included socio-demographic details such as age, gender, education, family size, and presence of children with chronic health problems, and assessed parental knowledge of autism through 31 items covering general knowledge, clinical features, social effects, consequences, and curability. Data were presented in frequencies and percentages.

Sample size: The sample size was calculated using the formula $n = [Z2\alpha/2 * pq]/d2$, where $Z\alpha/2 = 1.96$, $p = 37.2\%$, $q = 62.8\%$, and $d = 7.4\%$. Thereby providing $n = 163.89$, which is rounded to 164. Because of the hospital-based design effect, $nfinal = 164*1.2$, providing 196.8, which was rounded to 200.

RESULTS

Of the 200 parents, almost all parents came as a pair (51% females and 49% males), and most parents were in the 26–30-year age group (33.7%), followed by ≤ 25 years (25.7%) and 31–35 years (23.8%). [Table 1]

Table 1: Distribution of age and gender

Categories		Count (%)
Gender	Female	103 (51%)
	Male	99 (49%)
Age (years)	≤ 25	52 (25.7%)
	26-30	67 (33.7%)
	31-35	47 (23.8%)
	36-40	25 (12.4%)
	> 40	9 (4.5%)

Footnotes: Data were presented in frequencies and percentages.

The majority of parents had completed the SSLC (25.7%) or an undergraduate degree (25.7%), followed by those with a diploma (16.3%), middle school education (11.9%), and higher secondary education (7.4%), while only 3% were uneducated. Regarding family size, more than half of the parents (54.5%) had families of four members, 37.1% had

ISSN (O): 2687-5365; ISSN (P): 2753-6556

three members, and 8.4% reported a family size of five. [Table 2]

Table 2: Distribution of educational status and family size

Categories		Count (%)
Educational status	Uneducated	6 (3%)
	Middle	23 (11.9%)
	SSLC	52 (25.7%)
	H.Sc	15 (7.4%)
	Diploma	33 (16.3%)
	UG degree	51 (25.7%)
	PG degree	10 (5%)
	Professional	10 (5%)
Family size (members)	3	75 (37.1%)
	4	108 (54.5%)
	5	17 (8.4%)

Footnotes: SSLC (Secondary School Leaving Certificate), H.Sc. (Higher Secondary Certificate), UG (undergraduate), PG (postgraduate). Data were presented in frequencies and percentages.

Among all the parents, less than half (44.9%) had heard of autism, and only 38% knew someone who had undergone treatment. 40% believed it was impossible to detect autism before age 4, 37% thought autistic children might develop schizophrenia, 17.2% thought vaccinations were attributed to autism, and 47.6% assumed most autistic children were mentally retarded. Only 33.4% of the parents reported awareness of the signs and symptoms of the disease. Regarding social interaction, 43.4% felt that autistic children maintained good eye contact, while 43.8% knew that they lacked interest in peer interaction. In terms of perception, 38% believed that a diagnosis could lead to discrimination, 44.4% felt that autism is often missed in general practice, and 63% acknowledged a lack of awareness among parents. [Table 3]

Table 3: Parents' awareness and perception of ASD

Questions		Yes	No	Don't know
Knowledge regarding autism	Have you ever heard of autism	89 (44.9%)	37 (18.7%)	73 (36.5%)
	Do you know anyone who is undergoing treatment for autism	76 (38%)	94 (47%)	30 (15%)
	It's impossible to tell if a child has autism before the age of four?	80 (40%)	60 (30%)	60 (30%)
	Do children with autism usually grow up to be adults with schizophrenia?	74 (37%)	38 (19%)	88 (44%)
	Are autistic children not affectionate?	43 (21%)	94 (47%)	63 (31.9%)
	Does autism exist only in childhood?	37 (18.4%)	104 (52%)	59 (29%)
	Do vaccinations contribute to autism?	34 (17.2%)	106 (53.2%)	60 (29.6%)
	Are most children with autism also mentally retarded?	97 (47.6%)	49 (23.9%)	57 (28.5%)
	Are you aware of the knowledge of signs and symptoms of autism?	68 (33.4%)	73 (36.3%)	59 (29.4%)
	Whether an autistic child looks at other children when interacting with them or makes good eye contact.	86 (43.4%)	62 (31.2%)	52 (25.4%)
	Whether an autistic child fails to show interest in other children or has no interest in interacting with other children?	88 (43.8%)	59 (29.6%)	53 (26.6%)
Perception concerning autism	Do you think that diagnosing a child with autism will lead to discrimination against the child?	76 (38%)	100 (50%)	24 (12%)
	Is autism undiagnosed or often missed in general practice?	89 (44.4%)	93 (46.5%)	17 (8.5%)
	Is there a lack of awareness regarding autism among parents?	126 (63%)	58 (29%)	60 (8%)

Footnotes: Data were presented in frequencies and percentages.

DISCUSSION

Autism spectrum disorder is a complex neurodevelopmental condition that affects social interaction, communication, and behaviour. Structured assessment of parental awareness helps in identifying and correcting the misconceptions, along with guiding targeted educational interventions. This study aimed to evaluate the knowledge, awareness, and perception of autism among parents of children under five years attending a tertiary care hospital.

The majority of the parents came as a pair (51% females and 49% males), and most parents were in the 26–30-year age group (33.7%), followed by ≤ 25 years (25.7%) and 31–35 years (23.8%). Similarly, Ruwaili et al. reported 50.5% male and 49.5% female parents, and the largest age group was 18 to 30 years old (52%), followed by 31 to 40 years old (30.2%).8 Asiri et al. observed that 54.7% males and 45.3% were females, while the most common age group was 40–49 years (32.1%), followed by 30–39 years (29.6%).[12] In contrast, Bhusal et al. reported that the majority of parents were mothers (76.92%), while only 23.08% of the fathers came for regular visits.[13] Thus, showing the difference in the age and enthusiasm for parent participation in the hospital visits across different regions.

The majority of parents had completed the SSLC (25.7%) or an undergraduate degree (25.7%), followed by those with a diploma (16.3%), middle

ISSN (O): 2687-5365; ISSN (P): 2753-6556

school education (11.9%), and higher secondary education (7.4%), while only 3% were uneducated. Regarding family size, more than half of the parents (54.5%) had families of four members, 37.1% had three members, and 8.4% reported a family size of five. In contrast, Sameea et al. reported that 48.4% of mothers were university-educated or above, 38.4% had up to a secondary school education, and 13.2% had up to a primary school education in Qatar.[14] Parikh et al. found that 53% of parents held a graduate degree, 40% were college graduates, and 6% had a high school education. They also noted that 73.50% of parents belonged to a joint family, while 26.50% were from a nuclear family.[15] Additionally, Wang et al. reported that mothers with a higher education had higher scores for their knowledge about autism compared to others.[16] Similarly, Ruwaili et al. emphasise that having a higher education is associated with the perception of parents towards ASD.[8] Therefore, this indicates that the education status of the parents varies with their geographical location, and most of the well-educated parents are from developed countries.

In our study, only 44% of parents had ever heard of autism, and only 36% correctly identified early signs and symptoms, while 17% believed vaccines were a cause, and 48% thought most autistic children were mentally retarded. Barik et al. reported comparable findings, where only 41% of respondents had heard of ASD and only 29% could identify the main symptoms.[17] Asiri et al. reported that 58.6% of parents had prior awareness, but only 16.4% correctly knew that most children with autism are not mentally retarded, and only 42% achieved a high knowledge score. 30.2% parents still believed that it's impossible to tell if a child has autism before the age of four.[12]

In our study, 35% of parents were worried that an ASD diagnosis could lead to discrimination. Similarly, Asiri et al. reported that 41% of parents agreed that stigma is a main barrier to management, particularly among families from conservative backgrounds.[12] In Odisha, 46% of parents felt that the fear of social judgment could limit the disclosure of a child's diagnosis.[17] Regarding prognosis, 52% of parents in our study believed that autistic children could not live independently as adults. This misconception was the same in China, where Wang et al. reported that 47% of parents assumed that autism children have poor long-term independence despite intervention.[16] Bhusal et al. reported that 63% of parents feel uncertain about their child's future.[13] Khateeb et al. reported that parents face difficulty while parenting ASD children due to intense social stigma and lack of awareness.[18]

In our study, 63% of parents acknowledged a lack of awareness about ASD and its characteristics. Similarly, few studies have reported that many parents lacked basic awareness about ASD, but a counselling session can clear most of their aetiology-related doubts and can significantly increase parental awareness.[15,19] Thus, most parents lack awareness regarding ASD, but parental education and proper counselling sessions can improve their knowledge and perception of autism.

Limitations: This study was conducted in a single tertiary care hospital with a small, hospital-based sample, which may not fully represent the broader community. In addition, the use of a self-developed questionnaire may limit comparability with other studies that used standardised tools. Recall and social desirability biases could also have influenced parental responses.

CONCLUSION

Many parents showed positive perceptions of autism, but their overall knowledge and awareness were limited, with misconceptions regarding aetiology, prognosis, and stigma, especially among male parents with a low level of education. Broader community-based and multicentric studies are required to validate these findings, and culturally sensitive educational programs are required to promote early diagnosis and intervention in children with ASD.

REFERENCES

1. Autism spectrum disorder. National Institute of Mental Health. https://www.nimh.nih.gov/health/publications/autism-spectrum-disorder. (accessed September 4, 2024).
2. Hodis B, Mughal S, Saadabadi A. Autism Spectrum Disorder. StatPearls 2025. https://www.ncbi.nlm.nih.gov/books/NBK525976/.
3. Alrehaili RA, ElKady RM, Alrehaili JA, Alreefi RM. Exploring early childhood autism spectrum disorders: A comprehensive review of diagnostic approaches in young children. Cureus 2023;15:e50111. https://doi.org/10.7759/cureus.50111.
4. Webb SJ, Jones EJH. Early identification of autism: Early characteristics, onset of symptoms, and diagnostic stability. Infants Young Child 2009;22:100–18. https://doi.org/10.1097/IYC.0b013e3181a02f7f.
5. Tsang LPM, How CH, Yeleswarapu SP, Wong CM. Autism spectrum disorder: early identification and management in primary care. Singapore Med J 2019;60:324–8. https://doi.org/10.11622/smedj.2019070.
6. Global Burden of Disease Study 2021 Autism Spectrum Collaborators. The global epidemiology and health burden of the autism spectrum: findings from the Global Burden of Disease Study 2021. Lancet Psychiatry 2025;12:111–21. https://doi.org/10.1016/S2215-0366(24)00363-8.
7. Autism. WHO int. https://www.who.int/news-room/fact-sheets/detail/autism-spectrum-disorders. (accessed September 4, 2024).
8. Ruwaili BF, Alrashdi BAT, Mallick A, Alruwaili TAM, Alanazi MF, Alruwaili HFS, et al. Knowledge, attitude, and perception towards autism spectrum disorders among parents in Sakaka, Al-Jouf Region, Saudi Arabia: A cross-sectional study. Healthcare (Basel) 2024;12:1596. https://doi.org/10.3390/healthcare12161596.
9. Parlak ME, Küçükkelepçe O, Öz E, Özbey MY, Kapici Y. Knowledge levels of mothers with children aged 0-6 about autism spectrum disorder. Eur Res J 2023;9:779–84. https://doi.org/10.18621/eurj.1223874.
10. 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. https://doi.org/10.1177/1363461512447139.

ISSN (O): 2687-5365; ISSN (P): 2753-6556

11. Shahid Khan M, Alamgir Kabir M, Mohammad Tareq S. Socio-economic status and autism spectrum disorder: A case-control study in Bangladesh. Prev Med Rep 2024;38:102614. https://doi.org/10.1016/j.pmedr.2024.102614.
12. Asiri AWM, Shati AA, Al-Qahtani SM, Al-Qahtani YA, Aldarami MS, Alamri FD, et al. Assessment of parental knowledge, awareness, and perception about autism spectrum disorders in Aseer region, southwestern Saudi Arabia. Int J Gen Med 2023;16:557–64. https://doi.org/10.2147/IJGM.S377521.
13. Bhusal I, Regmi A, Bajracharya SL. Perceived burden and coping strategies among parents of children with autism spectrum disorder attending in tertiary hospital, Kathmandu. PLOS Ment Health 2025;2:e0000254. https://doi.org/10.1371/journal.pmen.0000254.
14. Sameea AA, Abd El-Wahab EW, Osman SO. Mothers' awareness and knowledge of autism spectrum disorder (ASD): A multi-centre study in Qatar. Sage Open Pediatr 2025;12:30502225251348293. https://doi.org/10.1177/30502225251348293.
15. Parikh DD, Gediya DA, Prajapati DA, Parikh DA, Mehta MU, Shah DP. A study to determine the impact of short awareness module on the knowledge regarding autism among parents of children five years and younger. J Popul Ther Clin Pharmacol 2024;31:2031-40. https://doi.org/10.53555/jptcp.v31i6.6817.
16. Wang F, Lao U-C, Xing Y-P, Zhou P, Deng W-L, Wang Y, et al. Parents' knowledge and attitude and behavior toward autism: a survey of Chinese families having children with autism spectrum disorder. Transl Pediatr 2022;11:1445–57. https://doi.org/10.21037/tp-22-113.
17. Barik S, Sharma S, Pattanaik S, Patnaik L. A study on knowledge of autism spectrum disorders among a sample population of Odisha. J Datta Meghe Inst Med Sci Univ 2024;19:51–6. https://doi.org/10.4103/jdmimsu.jdmimsu_251_23.
18. Khateeb JM, Kaczmarek L, Hadidi MS. Parents' perceptions of raising children with autism spectrum disorders in the United States and Arab countries: A comparative review. Autism 2019;23:1645–54. https://doi.org/10.1177/1362361319833929.
19. Kapoor R, Pradhan MR. Awareness, challenges and coping strategies of the parents having children with Autism Spectrum Disorder (ASD) in Mumbai, India. Demogr India 2022;51:109-25. https://iasp.ac.in/uploads/journal/7.%20Awareness,%20Challenges%20and%20Coping%20Strategies%20of%20the%20Parents%20having%20Children%20with%20Autism%20Spectrum%20Disorder%20(ASD)%20in%20Mumbai,%20India-1669206682.pdf.

ISSN (O): 2687-5365; ISSN (P): 2753-6556