

Original Research Article

A descriptive study to assess the knowledge, attitude and perception about autism spectrum disorder in children among the mother(s) of age group 25 to 35 years in Bisrakh Community, Noida, U.P.

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ABSTRACT

Background: Autism spectrum disorder (ASD) is a neurodevelopmental condition characterized by difficulties in communication, social interaction, and behaviour, usually appearing during early childhood. In India, increasing numbers of children are being diagnosed with ASD, while limited awareness, inadequate services, and delayed diagnosis remain major concerns. This study aimed to assess knowledge, attitude, and perception regarding ASD among mothers aged 25-35 years in the Bisrakh Community, Noida, Uttar Pradesh.

Methods: Non-experimental descriptive research design was employed with 30 mothers' recruited by using non – probability convenient sampling. Data were collected using a 5-point Likert scale for perception and attitude assessment and a structured questionnaire for assessing knowledge.

Results: More than half of the mothers (53.33%) had poor knowledge regarding ASD, while 46.67% had average knowledge. None demonstrated good or excellent knowledge. Regarding perception, 43.32% of mothers agreed or strongly agreed with positive statements, while 40% disagreed or strongly disagreed and 16.66% were uncertain. Attitudes were mixed, with 43.34% reporting satisfaction, 20% remaining neutral, and 36.66% expressing dissatisfaction. Overall, the findings indicate a mixed attitude among mothers regarding ASD.

Conclusions: The study concludes that mothers in the Bisrakh Community had inadequate knowledge regarding Autism Spectrum Disorder (ASD), although most demonstrated a generally positive perception and a mixed attitude towards the disorder. These findings highlighted the need for targeted awareness and educational interventions to improve mothers' knowledge and promote more positive attitudes towards ASD, which may facilitate early identification and timely intervention for affected children.

Keywords: Autism spectrum disorder, Knowledge, Attitude, Perception

INTRODUCTION

Autism spectrum disorders (ASD) are neurodevelopmental disorders, meaning they are caused by abnormalities in the way the brain develops and works. It is a complex developmental condition characterized by challenges with social interaction, communication, and

restricted or repetitive behaviours.¹ The symptoms of autism usually manifest within the first three years of life, with some children displaying signs from birth, while others develop typically before experiencing a regression between 18 to 36 months.² Raising a child with autism presents significant challenges for parents, particularly when societal understanding of the condition is limited.³

Currently, ASD has rapidly growing global prevalence rates and is estimated to affect 98 per 10 000 children worldwide.⁴ Knowledge of ASD was studied in several population subgroups which basically showed that increased general awareness of ASDs has resulted in increasing numbers of children being diagnosed at young ages and has been associated with positive developmental outcomes.^{5,6} On the other hand, parent's lack of knowledge or awareness about ASD can delay their initial concern, therefore, seeking help and obtaining diagnoses are accordingly delayed.⁷

The prevalence rate is increasing in India every year because of lack of knowledge, considerable number of misconceptions about ASD, inadequate autism education and awareness campaigns, failure to recognize the disease, and failure to deliver multidisciplinary treatment in time. Moreover, in India, the health registries of ASD are not maintained meticulously.⁸

The reason for the increasing numbers could be due to the inclusion or diagnostic criteria modifying over time to be more inclusive and vast or because of increased risk factors being associated with the disorder itself. The alarming signs needed to be identified early. Parents of diagnosed autistic children complain of disturbed sleep pattern, resulting in overall drastic effects of daytime dysfunction, all this contributing to very high stress levels in parents/caregiver.⁹ There needs to be adequate awareness of autism disorder. The reason for individuals to be well informed is because family members of autistic children undergo great financial and mental burden and the more uninformed, they are, the greater the risk of misdiagnoses, thus making their child more difficult and resistant to therapy. Earlier recognition and diagnosis will help parents in devising a well-constructed and streamlined treatment plan, helping release stress, as they will be able to discuss and share their burden with the appropriate doctor and research a correct diagnosis.¹⁰

The level of parents' information affects the level of their practices. Improving the level of information and practices of parents improves the level of adaptation to the situation of children, reduces the level of anxiety and improves the care provided to children.¹¹ The current study aims to assess the mother's knowledge, attitude and perceptions about autism and its associated clinical features and effects among the mothers in a community setting.

METHODS

Research design and setting

A non-experimental descriptive research design was employed with 30 mothers' recruited by using non-probability convenient sampling. The study was conducted in a community setting in Jalalpur village, Bisrakh, Noida, Uttar Pradesh from September 2023 to May 2024. The data were collected using a 5-point Likert scale for

perception and attitude assessment and a structured questionnaire for assessing knowledge.

Population, sample and sampling

The target population comprised of mother's from Jalalpur village, Bisrakh Community. A sample of 30 mother's was selected using non probability convenient sampling.

Inclusion/exclusion criteria

Inclusion criteria typically included willingness to participate and able to freely communicate in Hindi and English, while mother's absent during data collection were excluded.

Instruments

Tools employed for data collection includes: Demographic proforma for obtaining age, religion, type of family, area of living, academic qualifications, occupation, family income, previous knowledge regarding ASD, knowing any child suffering from ASD.

Knowledge assessment consists of a structured questionnaire regarding ASD.

Perception assessment consists of a structured 16 item questionnaire based on a five-point Likert- scale ranging from strongly agree to strongly disagree assessing participants beliefs and perceptions regarding the causes, characteristics. Treatment and social implications of ASD.

Attitude was assessed using a structured 16 item questionnaire with responses recorded on a five-point Likert scale evaluating participants attitude regarding characteristics, diagnosis. Management and support of individuals with ASD.

Content validity of the tools was ensured by a panel of experts and necessary modifications were made based on feedback.

Data collection procedure

Formal written permissions were obtained from selected community in Bisrakh. Ethical approval was taken from the institutional ethics committee. Informed consent was taken from all participants, after explaining the purposes and procedure of the study. Participation was voluntary, and confidentiality, anonymity, and the right to withdraw at any point without academic penalty were assured. Structured questionnaire on knowledge, attitude and perceived barriers was collected from mother's present at the time of data collection.

Data analysis

Data was coded and entered on a spreadsheet and analysed using descriptive and inferential statistics. Frequencies,

percentages, mean, and standard deviations described demographic variables, knowledge, perception and attitude levels.

RESULTS

Sample characteristics

A total of 30 mothers participated in the study in which the majority were aged 26–30 years (56.66%), belonged to the Hindu religion (50%), resided in semi-urban areas (60%), and were housewives (50%). Most mothers were illiterate (40%), had a monthly family income of ₹10,000–30,000 (40%), and had three children (40%). Nuclear and joint families each accounted for 33.33% of the study participants.

Knowledge level regarding autism spectrum disorder

It revealed that 53.33% of mothers aged 25–35 years had poor knowledge regarding ASD, while 46.67% had average knowledge. None of the mothers demonstrated good (0%) or excellent (0%) knowledge regarding ASD. The overall mean knowledge score was 0.26, with a standard deviation of 0.44 and a median score of 0,

indicating that the majority of mothers had inadequate knowledge about ASD.

Perception regarding autism spectrum disorder

The finding showed that 26.66% of mothers agreed with positive statements regarding autism spectrum disorder, while 16.66% strongly agreed. In contrast, 20% of mothers disagreed, 20% strongly disagreed, and 16.66% were uncertain. The mean perception score was 3.42, with a median of 4, suggesting that the overall perception of mothers towards ASD was generally positive despite some uncertainty and disagreement.

Attitude regarding autism spectrum disorder

It indicated that 26.67% of mothers were very satisfied in their attitude regarding autism spectrum disorder, 16.67% were satisfied, and 20% were neither satisfied nor unsatisfied. Additionally, 16.66% were unsatisfied, while 20% were very unsatisfied. The mean attitude score was 2.10, with a standard deviation of 1.37 and a median score of 2, indicating that the overall attitude of mothers towards ASD was relatively neutral, with responses distributed across both positive and negative categories.

Table 1: Demographic data of study participants (n=30).

Demographic variables	Frequency (F)	Percentage (%)
Age (in years)		
20–25	2	6.66
26–30	17	56.66
31–35	11	36.66
Religion		
Hindu	15	50
Muslim	8	26.6
Christian	5	16.6
Others	2	6.66
Family type		
Nuclear	10	33.33
Joint	10	33.33
Extended	8	26.6
Single parent	2	6.66
Area of living		
Rural	2	6.66
Semi-urban	18	60
Urban	10	33.33
Academic qualification of mother		
Illiterate	12	40
Primary school	7	23.33
High school	6	20
Graduate	5	16.66
Occupation of mother		
House wife	15	50
Labor	8	26.66
Private employee	4	13.33
Government employee	3	10

Continued.

Demographic variables	Frequency (F)	Percentage (%)
Family income per month		
<10,000	5	16.66
10,000-30,000	12	40
30,000-50,000	8	26.66
>50,000	5	16.66
Number of children		
1	3	10
2	7	23.33
3	12	40
>3	8	26.66
Do you have any previous knowledge about ASD?		
Yes	10	33.33
No	20	66.7
Have you ever known any child suffering from ASD?		
Yes	2	6.66
No	28	93.37

Table 2: Distribution of knowledge scores regarding ASD among mothers (n=30).

Criteria for scores	Frequency (F)	Percentage (%)
Poor	16	53.33%
Average	14	46.67%
Good	0	00%
Excellent	0	00%

Table 3: Mean, median and standard deviation of knowledge scores regarding ASD among mothers (n=30).

Knowledge test	Maximum score	Mean	Median	Standard deviation
1	20	0.263333	0	0.440809

Table 4: Distribution of perception levels regarding ASD among mothers (n=30).

Criteria for scores	Frequency (F)	Percentage (%)
Strongly Agree (0-16)	5	16.66
Agree (17- 32)	8	26.67
Uncertain (33- 48)	5	16.67
Disagree (49- 64)	6	20
Strongly Disagree (64-80)	6	20

Table 5: Mean, median and standard deviation of perception scores regarding ASD among mothers (n=30).

Perception test	Maximum score	Mean	Median	Standard deviation
1	16	3.416667	4	1.486661

Table 6: Distribution of attitude levels regarding ASD among mothers (n=30).

Criteria for scores	Frequency (F)	Percentage (%)
Strongly agree	8	26.67%
Agree	5	16.67%
Neither agree nor disagree	6	20%
Disagree	5	16.66%
Strongly disagree	6	20%

Table 7: Mean, median and standard deviation of attitude scores regarding ASD among mothers (n=30).

Attitude test	Maximum score	Mean	Median	Standard deviation
1	16	2.1	2	1.374689185

DISCUSSION

The present study was conducted to assess the knowledge, perception, and attitude regarding ASD among mothers aged 25–35 years residing in the Bsirakh Community of Noida, Uttar Pradesh. The findings provide valuable insight into the demographic profile of the participants and their awareness and attitudes toward ASD, highlighting the need for community-based educational interventions. The demographic findings showed that most participants were young mothers from semi-urban areas. The study included mothers from diverse religious and family backgrounds, with many having low educational attainment, being homemakers, belonging to lower-middle income families, and having multiple children. These characteristics may have influenced their awareness and understanding of ASD.

The assessment of knowledge revealed that 53.33% of mothers had poor knowledge and 46.67% had average knowledge, while none demonstrated good or excellent knowledge. These findings indicate inadequate awareness regarding ASD among mothers, which may delay early recognition and intervention. Regarding perception, 26.66% of mothers agreed and 16.66% strongly agreed with positive statements regarding ASD, whereas 20% disagreed, 20% strongly disagreed, and 16.66% remained uncertain. The mean perception score (3.42) indicates an overall moderately positive perception despite limited knowledge. This suggests that mothers may be receptive to learning more about ASD through appropriate educational interventions. The attitude findings showed that 26.67% of mothers had a very positive attitude, 16.67% had a positive attitude, 20% were neutral, while 16.66% and 20% demonstrated negative and very negative attitudes, respectively. The mean attitude score (2.10) reflects a moderately favourable attitude with noticeable variability among participants. These differences may be attributed to variations in educational level, socioeconomic status, and exposure to information about ASD. A descriptive study involving 60 parents of children with autism found that more than three-quarters of parents had unsatisfactory knowledge and incompetent caregiving practices regarding autism. Parental knowledge was significantly associated with sociodemographic characteristics and positively related to caregiving practices, emphasizing the need for continuous parent education and training programs to improve autism care.¹²

A cross-sectional study among parents of children with autism in India found that 56.7% had good knowledge of autism and all participants demonstrated positive attitudes toward autistic children. Parental knowledge was

significantly associated with age and educational level, suggesting that sociodemographic factors influence autism-related understanding. These findings highlight the importance of parental education in enhancing awareness and fostering positive attitudes toward children with ASD.

A study in Qatar involving 600 mothers of children with ASD found that while 91.2% were aware of ASD, only 32.7% demonstrated good knowledge of its clinical features. The findings indicate that high awareness does not necessarily translate into adequate knowledge, underscoring the need for improved parent-focused education and support services.¹³

A Saudi Arabian study reported that fewer than half of parents had adequate knowledge of ASD, although most exhibited positive attitudes and perceptions. Knowledge, attitude, and perception were positively correlated, emphasizing the importance of parental education and awareness initiatives to improve ASD understanding.¹⁴

A cross-sectional study demonstrated that although parents generally had satisfactory perceptions of ASD, their knowledge of the disorder and its clinical features remained insufficient. Lower knowledge was particularly evident among fathers and parents with lower educational levels, supporting the need for targeted autism awareness programs.¹⁵ A descriptive study involving 120 parents of children with ASD found that parental knowledge remained inadequate despite generally positive attitudes and satisfactory caregiving practices. The study further demonstrated significant associations between parents' sociodemographic characteristics and their knowledge, attitudes, and practices, underscoring the need for tailored educational interventions to strengthen parental competence in ASD care.¹⁶

Overall, the findings demonstrate that although mothers showed moderately positive perceptions and attitudes towards children with ASD, their knowledge was inadequate. This highlights the need for structured awareness programmes, community health education, and nursing-led interventions to improve maternal knowledge, promote early identification of ASD, reduce misconceptions, and facilitate timely referral and management of affected children.

Limitations

The study was limited by its small sample size of 30 mothers, which may affect the generalizability of the findings. It was conducted in a single community Bsirakh, Noida, limiting its applicability to other settings. The findings were based on self-reported responses from mothers who were willing to participate, which may have

introduced response bias. Additionally, the limited time available for data collection restricted the scope of the study.

CONCLUSION

The study concludes that mothers had inadequate knowledge regarding ASD, although their perception and attitude towards children with ASD were generally moderate to positive. The findings highlight the need for structured health education and awareness programmes to improve mothers' understanding of ASD, promote early identification, reduce misconceptions, and facilitate timely intervention and appropriate care for affected children.

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