Journal of Population Therapeutics & Clinical Pharmacology

RESEARCH ARTICLE
DOI: 10.53555/jptcp.v31i6.6817

A STUDY TO DETERMINE THE IMPACT OF SHORT AWARENESS MODULE ON THE KNOWLEDGE REGARDING AUTISM AMONG PARENTS OF CHILDREN FIVE YEARS AND YOUNGER

Dr. Dhwani Parikh[1], **Dr. Alpesh Gediya**[2], **Dr. Aalapi Prajapati**[3], **Dr. Aatman Parikh**[4*], **Miss Urva Mehta**[5], **Dr. Priyanka Shah**[6]

[1]Third-year postgraduate resident, GCS Medical College, Hospital and Research Centre, Ahmedabad, Gujarat. Email id: dhwani883@gmail.com
[2]Professor, Department of Psychiatry GCS medical college, hospital and research Centre, Ahmedabad, Gujarat. Email id: alpeshgediya84@gmail.com
[3]Assistant Professor, Department of Psychiatry, GCS medical college, hospital and research Centre, Ahmedabad, Gujarat. Email id: aalapi3012@gmail.com
[4*]Assistant Professor, Department of Psychiatry, GCS medical college, hospital and research Centre, Ahmedabad, Gujarat. Email id: aatmanparikh1@gmail.com
[5]First-year MBBS student, GCS Medical College, Hospital and Research Centre, Ahmedabad, Gujarat. Email id: urvamehta2005@gmail.com
[6]Third-year postgraduate resident, GCS Medical College, Hospital and Research Centre, Ahmedabad, Gujarat. Email id: priyanka110796@gmail.com

***Corresponding Author: Dr. Aatman Parikh**
*Assistant Professor, Department of Psychiatry, GCS Medical College, Hospital and Research Centre, Ahmedabad, Gujarat.Email id: aatmanparikh1@gmail.com

ABSTRACT

Background: Autism spectrum disorder (ASD) presents significant challenges in social communication and behaviour impacting individuals globally. Despite its increasing prevalence, awareness among parents remains crucial for early identification and intervention.

Aim: This study aims to evaluate the impact of an awareness session on the knowledge of parents with children aged five or younger regarding ASD. It seeks to assess existing knowledge gaps and analyze the changes in parental understanding post-informative sessions.

Methods: A cross-sectional study involved 200 caregivers of children aged 2 to 5 years. Participants completed a pre-session questionnaire covering various domains of ASD knowledge. Subsequently, an autism awareness session was delivered by an experienced psychiatrist. Post-session, the same questionnaire was administered to assess changes in knowledge. A comparison between pre- and post-session data was conducted using the chi-square test.

Results: Sociodemographic analysis revealed predominant female participation, parental higher education qualification, and male predominance among children. Social media emerged as a primary source of ASD information. Post-session assessments demonstrated significant improvements ($p<0.05$) in parental knowledge across symptoms, behaviours, treatment, outcomes, and prognosis, highlighting the session's effectiveness.

Conclusion: This study emphasizes the vital role of parental awareness programs for autism, which can lead to a marked improvement in their knowledge of the condition. Recommendations include refining the assessment questionnaire and increasing awareness programs & video-based sessions for better impact.

Keywords: Autism Spectrum Disorder (ASD), Parental Awareness, Informative Session, Knowledge Assessment, Early Intervention.

INTRODUCTION:

The intricate interaction between genetics, brain function, cognition, emotions, and behaviour shapes neurodevelopment throughout one's life. When this complex process faces enduring disturbances due to genetic or environmental factors, it can result in neurodevelopmental disorders and disabilities. Neurodevelopmental disorders (NDDs) hinder the holistic realization of social and economic potential at various strata—individual, familial, communal, and national—impacting development across these intricate societal tiers.[1]

Autism spectrum disorder (ASD) represents a neurodevelopmental disorder marked by challenges in reciprocal social communication and a proclivity towards repetitive, stereotyped behavioural patterns, interests and activities. The global prevalence of autism, as estimated by the WHO, stands at approximately 1 in 500 individuals, with boys being four times more likely to be affected than girls. In India, where prevalence rates have increased from 1 in 10,000 children a decade ago to 3-4 per 1,000 live births, the incidence rate is roughly 1 in 90,666. This calculates to over 2 million people living with autism in India. Notably, the National Institute for the Mentally Handicapped in Secunderabad records approximately 100-125 new cases annually, signifying a notable rise compared to figures from five years prior. [2] The clinical spectrum of ASD presents a diverse array of manifestations, often encompassing a blend of delayed or immature behaviours alongside distinctive behavioural patterns. Early signs commonly involve challenges in joint attention, limited eye contact, a lack of social intent in communication, absence of imitative social play, and a fascination with sensory stimuli. These symptoms evolve and become more pronounced through motor stereotypies, object alignment, reduced peer interest, and difficulties in cooperative play. Conversely, some symptoms may manifest subtly, including conversational challenges, diminished empathy, the emergence of intensely focused interests, rigid cognitive styles and struggles in establishing reciprocal friendships.[3]

Cognitive difficulties are very common in such individuals. Some degree of intellectual disability is found in approximately 25–50% of Individuals. ASD symptoms may appear by 12 months, with severe signs seen a few months after that. Yet, some children show typical development until 18 to 24 months. The usual consensus is that ASD can be identified by the age of 2 years by expert professionals. [4]

Severely affected children often show early signs, including language delays, in preschool. While higher-functioning autistic children or those with Asperger's syndrome manifest behavioural traits at around 4 to 5 years, with subtler social issues surfacing later in childhood.[5]

The Diagnostic and Statistical Manual, fifth edition (DSM-5) defines two symptom areas necessary for a diagnosis of ASD: (1) persistent deficits in social communication and social interactions across multiple contexts (e.g., avoiding eye contact, unaware when people are talking) and (2) restricted, repetitive patterns of behaviour, interests or activities (e.g., trouble adapting to routine changes, unusual reactions to sensory stimuli). [6] The Indian Scale for Assessment of Autism (ISAA), developed by the National Institute for the Mentally Handicapped (NIMH) in 2009, is now widely utilized as a tool for diagnosing and measuring the severity of autism in India. Before the commencement of preschool or kindergarten, only parents have the most frequent interactions with their children. This proximity often positions parents as the primary observers of initial indicators of

autism spectrum disorder (ASD). However, they may lack awareness regarding these early cues, posing a challenge in identifying and seeking professional support. Theoretically, a parental understanding of ASD plays a pivotal role in the timely diagnosis and access to early intervention services for affected children. Equipped with knowledge about the signs and symptoms of ASD, parents can effectively communicate concerns to healthcare professionals at an early stage, potentially facilitating earlier diagnosis and thereby ensuring timely access to appropriate interventions for affected children. [4] This study endeavours to meticulously appraise parents' existing knowledge and awareness regarding autism spectrum disorder (ASD), aiming to pinpoint any voids in awareness and informational lacunae before introducing a structured informational session. It seeks to discern and compare the discernible enhancements in parents' knowledge concerning ASD, both pre and post-session. It also rectifies these gaps by elevating awareness and knowledge through the informational session. This accentuates the pivotal role of such sessions in enhancing parental knowledge of ASD.

MATERIALS AND METHODS:

A cross-sectional study, utilizing a questionnaire-based approach, was conducted among 200 caregivers of school-aged children between 2 and 5 years old from April 2023 to October 2023 after obtaining permission from the Institutional Ethics Committee. The study was conducted in 3 English medium schools in urban areas in Ahmedabad in groups of 100,50,50. Parents were recruited while they attended the Parents Teachers' meeting. Consent was obtained from schools and caregivers to scrutinize and assess their knowledge regarding autism. For this study, inclusion criteria stipulated were: (a) the participant should be at least 18 years of age, (b) should be a parent (including biological, adoptive or foster), (c) Age of index child should be 2-5 years. Exclusion criteria were: (a)Those who cannot comprehend English properly. For the first part of the form, comprehensive details like name, age, educational qualification, role with child, type of family, age and gender of the child, ever heard about ASD collected from the eligible participants after surpassing the above criteria.

After thoroughly reviewing similar studies, a 31 items based questionnaire -Autism Spectrum Knowledge Scale general population version was utilized for this study. [4,7] The scale is valid and reliable for evaluating the knowledge of autism amongst the general population. [8] This scale consists of 31 items focusing on five domains - (1) Etiology and Prevalence, (2) Symptoms and associated behaviours, (3) Assessment and Diagnosis, (4) Treatment and (5) Outcomes and Prognosis of ASD. Participants responded to the items as either True, False, or Don't Know. "Don't know" responses were calculated as Incorrect.

Following the questionnaire, an engaging and structured session lasting around 40 to 45 minutes was conducted. This session was meticulously crafted and carried out by an experienced psychiatrist to cover a wide array of topics related to ASD, like information regarding the frequency of ASD and its potential causative factors. Participants were enlightened about the various risk factors that might contribute to the development of ASD. A detailed overview of the diagnostic process for ASD was provided, shedding light on the criteria and methods used for assessment. Different treatment modalities and interventions available for individuals with ASD were discussed, emphasizing various approaches and their effectiveness. Insights were shared about the potential outcomes and prospects for individuals diagnosed with ASD, considering multiple interventions and support systems. Moreover, during this session, common myths and misconceptions surrounding autism were addressed and debunked, aiming to provide accurate information and dispel any misunderstandings.

Post-session, the same questionnaire was given to the participants who had initially filled it. Their responses were collected once again, enabling an assessment of any changes or enhancements in their understanding and knowledge regarding the various facets of ASD after the Informative session.

The study data analysis employed the trial version of SPSS (Statistical Packages for Social Sciences). Descriptive statistics were utilized to elucidate the demographic characteristics, while individual percentages were computed to portray demographic details. For each participant, the correct and incorrect responses across different domains were tallied, and a comparison between pre- and post-

session data was conducted using the chi-square test. A confidence interval of 95% ($p<0.05$) was applied to represent the statistical significance of the results.

RESULTS:

Table 1: Sociodemographic details of participants

DEMOGRAPHIC DETAILS	No.	%
Gender of parents		
Male	70	35%
female	130	65%
Age of parents		
25-29	55	27.50%
30-34	78	39%
35-39	56	28%
40-44	10	5%
>45	1	0.50%
Type of family		
Nuclear	53	26.50%
Joint	147	73.50%
Educational qualification		
High school	12	6%
Graduate	106	53%
College graduate	80	40.00%
Doctorate	2	1%
Gender of child		
Male	118	59%
female	82	41%

Sociodemographic details of the participants are shown in Table 1: The predominant gender among parents was female, totalling 130 individuals (65%). The highest proportion of participants belonged to the 30-34 age group, constituting 78 individuals (39%). Most of the participants, 147 individuals (73.50%) belonged to joint family. The majority of participants, 106 (53%), held a graduate degree, and the predominant gender of the child was male 118 (59%).

Out of 200 participants,128 individuals were aware of ASD. Among them, the largest group, comprising 92 individuals, came to know about ASD through social media platforms, as depicted in Figure 1.

Figure 1: Awareness of Autism Spectrum Disorder in Parents and its sources.

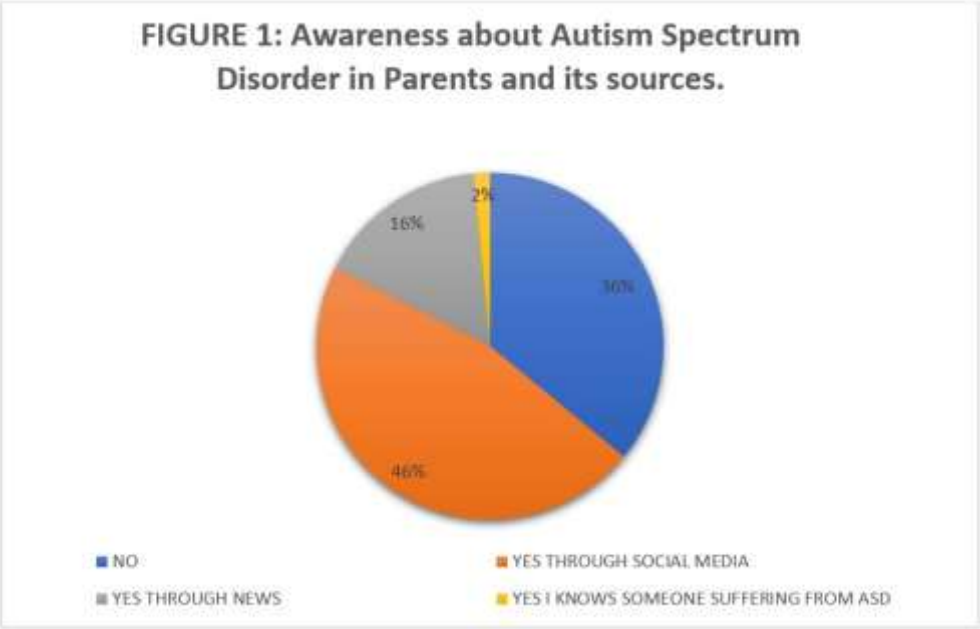

Table 2: Knowledge regarding Symptoms/Associated Behaviours

Sr.no	Questions	Before Session Response	After Session Correct Response	After Session Incorrect Response	P value
Symptoms and associated behaviours					
1	All individuals with autism spectrum disorder have low intellectual quotients (i.e., IQs)	Correct (38)	38	0	*<0.0001*
		Incorrect (162)	119	43	
2	Children with autism spectrum disorder may not play with toys the way they are intended	Correct (88)	88	0	*0.007*
		Incorrect (112)	103	9	
3	Individuals with autism spectrum disorder may have strict routines or rituals	Correct (66)	64	2	*0.002*
		Incorrect (134)	108	26	
4	Individuals with autism spectrum disorder have difficulties interacting socially with others	Correct (109)	109	0	*0.056*
		Incorrect (91)	88	3	
5	Some individuals with autism spectrum disorder may be uncoordinated or clumsy	Correct (16)	0	16	*0.768*
		Incorrect (184)	1	183	
6	Many individuals with autism spectrum disorder have difficulties expressing themselves	Correct (110)	110	0	*0.116*
		Incorrect (90)	88	2	
7		Correct	28	4	*0.001*

	Symptoms of autism spectrum disorder do not appear before the age of 2 years	(32)			
		Incorrect (168)	95	73	

In terms of symptoms of autism and its associated behaviours, a statistically significant improvement ($p<0.05$) was noted across the majority of questions post-session, as highlighted in Table 2.

Table 3: Knowledge regarding Treatment, Outcome and Prognosis

Sr.no	Questions	Before Session Response	After Session Correct Response	After Session Incorrect Response	P value
TREATMENT					
1	There are no beneficial treatments available for individuals with autism spectrum disorder.	Correct (86)	70	16	*0.003*
		Incorrect (114)	108	6	
2	Restricting certain foods (e.g., gluten) is an effective treatment for autism spectrum disorder.	Correct (41)	41	0	*0.003*
		Incorrect (159)	130	29	
3	Social skills training is an effective treatment for some individuals with autism spectrum disorder	Correct (116)	100	16	*0.232*
		Incorrect (84)	77	7	
4	Intellectual quotient (i.e., IQ) and age affect treatment success for children with autism spectrum disorder.	Correct (78)	78	0	*0.004*
		Incorrect (122)	110	12	
OUTCOME/PROGNOSIS					
1	Most individuals with autism spectrum disorder will never learn to speak.	Correct (81)	65	16	*0.721*
		Incorrect (119)	93	26	
2	Symptoms of autism spectrum disorder do not change throughout an individual's life	Correct (93)	68	25	*0.148*
		Incorrect (107)	68	39	
3	Autism spectrum disorder only affects children	Correct (33)	16	17	*0.309*
		Incorrect (167)	97	70	
4	Many individuals with autism spectrum disorder have difficulties living and working independently in adulthood	Correct (50)	49	1	*<0.00001*
		Incorrect (150)	105	45	
5	Up to 70% of individuals with autism spectrum disorder also	Correct (69)	69	0	*<0.00001*

	have an additional mental health diagnosis (e.g., anxiety).	Incorrect (131)	101	30	
6	Many children with autism spectrum disorder are at risk for academic difficulties.	Correct (77)	77	0	*<0.00001*
		Incorrect (123)	87	36	

In the domains regarding treatment, outcome and prognosis, a statistically significant improvement ($p<0.05$) was noted in most of the questions post-session, as highlighted in Table 3.

DISCUSSION:

In our study, more females participated than males, which is consistent with previous studies carried out in Lebanon, Saudi Arabia, and Karachi. [7,9,10] This could be attributed to increased maternal engagement with teachers & healthcare providers. Most of the participants were graduates. Also, the prevalent gender of the index child was male.

We found that a significant proportion of the study population (36%) was completely unaware of autism. Among those aware of autism, social media emerged as the dominant source of knowledge regarding ASD, surpassing other means like personal experiences and news. Our study shows findings similar to those of a survey by Conn et al. (2012), which revealed the significant contribution of Hollywood films in enhancing public awareness and education about autism spectrum disorders.[10] Moreover, an innovative approach utilizing mobile health technology to assess childhood autism in low-resource community settings in India has been an area of research.[11] However, amid its promising prospects, there is a mounting concern surrounding social media platforms due to the dissemination inaccurate or misleading health-related information. Consequently, individuals seeking information may discern and rely upon credible sources such as the World Health Organization (WHO) for accurate information.

In the domain of autism and associated behaviours, our study participants showed low scores on a pre-session questionnaire as many parents might have the misconception that all autistic children have low Intelligence Quotient (IQ). One of the factors responsible for this might be a lack of knowledge of varied and specific early neurodevelopmental disorders.

There was a significant increase in correct responses in all but one of the questions, and the majority showed statistically substantial improvement post-session.

The question that some autistic children might be uncoordinated or clumsy didn't show statistically significant improvement in correct scores post-session as the question might be a little confusing to many parents, and the question doesn't generalize clumsiness to all children with autism, which might put the answer further away from yes or no category into a grey area.

Regarding treatment, outcome and prognosis, there was a significant increase in correct responses across most questions after the session, indicating that this area might be most important to the parents. Firstly, there was a prevalent misconception that no beneficial treatments were available for individuals with ASD. However, the data demonstrated a significant shift in this belief after the session, with a notable increase in correct responses. This highlights the importance of education and awareness in debunking myths surrounding the efficacy of treatments for ASD. Another significant misconception identified in this survey was the belief that restricting certain foods, such as gluten, is an effective treatment for ASD. Despite limited scientific evidence supporting this claim, many participants endorsed this belief. However, the data showed a statistically significant decrease in incorrect responses after the session, suggesting a clear understanding regarding the dietary impact on autism post-session. The question regarding the importance of social skill training didn't show significant improvement, which might highlight the need for more insight into such training sessions.

Furthermore, the post-session increase in responses highlighted the significant insight regarding comorbid mental health diagnoses in individuals with ASD, with up to 70% of individuals also experiencing additional mental health issues such as anxiety. This underscores the importance of a comprehensive, multidisciplinary approach to treatment and support for individuals with ASD, addressing both core symptoms of ASD and associated mental health challenges. The question about autistic children having academic difficulties showed a significant positive shift in addressing the need for educational support and special interventions for individuals with ASD.

Overall, our study showed the positive impact of autism awareness sessions on parental knowledge, mirroring a similar study carried out in Kerala, which also revealed that the sample population gained 98-100% knowledge about social interaction difficulties, speech & language skills delays and motor developmental skills delay in children with autism after the awareness program.[12]

Autism shows various early neurodevelopmental signs such as atypical speech and language development, unusual social & emotional responses or delays in reaching developmental milestones, typically at 12 to 24 months of age. [13–15] Recent studies have shown that a diagnosis of autism can be reliably made between age 2 and 3 years.[5,16,17] The American Academy of Paediatrics (AAP) even recommends developmental and behavioural screening for all children at ages 9, 18 and 30 months and specifically for ASD at 18 and 24 months. [18]

Also, questions regarding unusual toy play and strict routines and behaviours showed statistical improvement post-session, which addressed the common misbelief of parents who might feel these 'lags' in development are a part of the normal range of behaviour and they might normalize with time as their child grows. A reason for this might be that parents seeking an autism diagnosis for their child often rely on advice from family and community members. Unfortunately, this reliance can sometimes dismiss their concerns, making it harder for them to get a diagnosis. Mothers, especially those without support from their partners and extended family cannot act on their worries about their child's development. This problem isn't unique and extends to Asian communities, particularly in Middle-Eastern cultures, where mothers feeling disempowered may prove to be a significant obstacle in seeking help for children with autism.[19,20]

CONCLUSION:

Our findings strongly support that education is pivotal in raising awareness, particularly evident in the positive outcomes observed following the awareness session. Specifically, the session has taught parents about Etiology & Prevalence, Symptoms of autism and its Associated behaviours, Diagnosis, Treatment, Outcome and Prognosis.

By gaining a deeper understanding of these issues through education, parents will be empowered to recognize potential signs of autism spectrum disorder (ASD) in their children and those around them at an early stage. This early identification is crucial for initiating timely interventions and support, which can significantly improve the long-term outcomes for individuals with ASD. Overall, the findings underscore the transformative impact that the awareness session brings, enabling parents to play a proactive role in the early identification and intervention of developmental challenges of ASD and facilitating the integration of individuals with ASD into society.

LIMITATIONS:

There are certain limitations and recommendations for this study. The study sample is limited, and the study's external validity can be strengthened by being conducted on a larger scale and in different religious, social, and educational settings. The Autism Spectrum Knowledge Scale General Version was developed in the United States, and it contains some questions that are not entirely relevant to Indian settings. Translating the scale into regional languages could facilitate its extensive use. We recommend conducting such periodic structured, informative sessions and health awareness campaigns in schools, which are the most accessible platforms for to and fro interactions between

teachers, children and parents. Conducting these sessions with graphical demonstrations and audio-visual information might be more impactful in raising awareness in the community.

Financial source of support: Nil

Conflict of interest: Nil

References:

1. Arora NK, Nair MKC, Gulati S, et al. Neurodevelopmental disorders in children aged 2-9 years: Population-based burden estimates across five regions in India. PLoS Med. 2018;15(7):e1002615.
2. Bhargava A. School Education of Children with Special Needs in India with a Perspective on the Initiatives for Children with Autism. http://www.iccwtnispcanarc.org/upload/pdf/1494590016school%20edcation%20special%20needs%20india.pdf
3. Johnson CP, Myers SM; American Academy of Pediatrics Council on Children With Disabilities. Identification and evaluation of children with autism spectrum disorders. Pediatrics. 2007;120(5):1183-1215.
4. Benallie, Kandice J., "Parent Knowledge of Autism Spectrum Disorder" (2019). All Graduate Theses and Dissertations, Spring 1920 to Summer 2023. 7693.
5. Baird G, Cass H, Slonims V. Diagnosis of autism. BMJ. 2003;327(7413):488-493.
6. American Psychiatric Association. Diagnostic and Statistical Manual of Mental Disorders. Fifth Edition. American Psychiatric Association; 2013.
7. Anwar MS, Tahir M, Nusrat K, Khan MR. Knowledge, Awareness, and Perceptions Regarding Autism Among Parents in Karachi, Pakistan. Cureus. 2018;10(9):e3299.
8. McClain MB, Harris B, Schwartz SE, Benallie KJ, Golson ME, Benney CM. Brief Report: Development and Validation of the Autism Spectrum Knowledge Scale General Population Version: Preliminary Analyses. J Autism Dev Disord. 2019;49(7):3007-3015.
9. AlAlmaei Asiri WM, Shati AA, Al-Qahtani SM, et al. Assessment of Parental Knowledge, Awareness, and Perception About Autism Spectrum Disorders in Aseer Region, Southwestern Saudi Arabia. Int J Gen Med. 2023;16:557-564.
10. Rouphael M, Gerges P, Andres C, Sacre Y, Bitar T, Hleihel W. Evaluation of the Lebanese Adults' Knowledge Regarding Autism Spectrum Disorder. Int J Environ Res Public Health. 2023;20(5):4622.
11. Dubey I, Bishain R, Dasgupta J, et al. Using mobile health technology to assess childhood autism in low-resource community settings in India: An innovation to address the detection gap. Autism. 2024;28(3):755-769.
12. George L, Sakeer S. Awareness about autism among parents. Int J Sci Res. 2015;4:151530.
13. Barbaro J, Dissanayake C. Autism spectrum disorders in infancy and toddlerhood: a review of the evidence on early signs, early identification tools, and early diagnosis. J Dev Behav Pediatr. 2009;30(5):447-459.
14. De Giacomo A, Fombonne E. Parental recognition of developmental abnormalities in autism. Eur Child Adolesc Psychiatry. 1998;7(3):131-136.
15. Short AB, Schopler E. Factors relating to age of onset in autism. J Autism Dev Disord. 1988;18(2):207-216.
16. Charman T, Baird G. Practitioner review: Diagnosis of autism spectrum disorder in 2- and 3-year-old children. J Child Psychol Psychiatry. 2002;43(3):289-305.
17. Stone WL, Lee EB, Ashford L, et al. Can autism be diagnosed accurately in children under 3 years?. J Child Psychol Psychiatry. 1999;40(2):219-226

18. CDC. Developmental Monitoring and Screening | CDC. Centers for Disease Control and Prevention. Published February 14, 2023. Accessed December 8, 2023. https://www.cdc.gov/ncbddd/childdevelopment/screening.html
19. Bhavnani S, Lockwood Estrin G, Arora R, et al. "I was Confused … and Still am" Barriers Impacting the Help-Seeking Pathway for an Autism Diagnosis in Urban North India: A Mixed Methods Study. J Autism Dev Disord. 2022;52(4):1778-1788.
20. Divan G, Vajaratkar V, Desai MU, Strik-Lievers L, Patel V. Challenges, coping strategies, and unmet needs of families with a child with autism spectrum disorder in Goa, India. Autism Res. 2012;5(3):190-200.