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Original Research Article

SOCIODEMOGRAPHIC AND CLINICAL PROFILE OF CHILDREN ON AUTISM SPECTRUM DISORDER FROM CHILD DEVELOPMENTAL CENTERS IN DELHI NCR.

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ABSTRACT

Background: Autism spectrum disorder (ASD) is a neurodevelopmental disorder. There is dearth of epidemiological data in India. This study aims to understand the sociodemographic and clinical profile of children with autism spectrum disorders.

Materials and Methods: Data was collected by Interviewing the parents of previously diagnosed children with ASD from 2-9 years of age using a semi-structured questionnaire. The children who were diagnosed by using INCLEN tool for ASD based on DSM-V criteria were included in the study. The data was collected from 5 multidisciplinary child developmental centers of Continua kids in Delhi NCR region. Descriptive statistical analysis of the data was conducted and presented in percentages/ frequencies.

Results: A total of 180 children diagnosed with ASD were included in the study. The findings revealed that children with sociodemographic profile including male gender, nuclear family, and high parental education are at higher risk of being diagnosed ASD. Several risk factors for autistic symptoms were studied including the mode of delivery, presence of exclusive breastfeeding, and early exposure to screen time. The clinical profile studied the severity of ASD symptoms and associated comorbidities sleep problems, behavioral problems and gastrointestinal symptoms in children with autism spectrum disorder.

Conclusion: Understanding the sociodemographic and clinical profile helps in better understanding of the need of early intervention services and planning of the same. Understanding the associated risk factor helps in better understanding of the preventable factors which can help with planning of the primordial and primary prevention.

Keywords: Autism spectrum disorders, India, risk factors, clinical Profile.

INTRODUCTION

Autism spectrum disorder is a neurodevelopmental disorder. Children with ASD are diagnosed based on the DSV diagnostic Criteria where they have deficits in social communication areas of development along with restricted, repetitive patterns of behaviour, activities or interest with or without sensory issues.[1] These symptoms cause significant impairment in occupational, social and everyday functioning of the child. There symptoms are present from the early childhood developmental years.[1] Despite the facts that symptoms of autism appear in the early years there is long delay in the diagnosis due to multiple factors like lack of awareness about early signs of autism contributing to the delay in seeking an evaluation, longer time taken by professionals and caregivers in the acknowledgement of the symptoms. There is paucity of reported epidemiological Indian data on the prevalence of autism spectrum disorder. As there is limited information available on the social demographic, risk factors and clinical profile of children on autism spectrum disorder available in Indian context, this study was conducted to identify

various sociodemographic characteristics, risk factors and clinical profile associated with ASD.

MATERIAL AND METHODS

Study is a descriptive prospective study conducted from July 2020 to August 2022 by the department of Community Medicine, HIMSR, New Delhi. The data was collected by Interviewing the parents of previously diagnosed children with ASD from 2-9 years of age. The data was collected from 5 multidisciplinary child developmental centers (Continua Kids) of Delhi NCR region. A semi structured questionnaire constituting of age, sex, family type, education of the head of the family was used to record the sociodemographic status of the children attending to these Child developmental clinics. The questionnaire also has questions around the course of pregnancy, childbirth, feeding, screen exposure, gestational age, family history of autism, family dynamics and the interventions that are being done. Standardized questioners like social responsiveness scale (SRS-2) were used to understand the severity of symptoms. Childhood sleep habit questionnaire- Abbreviated (CSHQ) was used to study the presence of sleep disturbances, Aberrant behavior checklist (ABC) for understanding the behavioral problems and Gastrointestinal index (GI Index) were used to study the presence of Gastrointestinal symptoms in children on autism to understand their clinical profile. (52, 53,54).

Inclusion Criteria

The children who were diagnosed by using INCLEN tool for ASD based on DSM-V criteria were included in the study.

Exclusion Criteria

Children less than 2 years and more than 9 years were not included in the study. Parents who did not confirm the diagnosis on INCLEN tool for ASD (based on DSM V Criteria of diagnosis) were excluded.

Ethical consideration

An approval from the ethics committee of the Jamia Hamdard University was obtained. A written consent was obtained from the parent/ Guardian before collecting the data and the study was carried out with child's complete anonymity and confidentiality of information. The data was collected after taking an informed written consent.

Statistical Analysis

The data collected was entered in Microsoft excel and SPSS version 25 was used to analyze the data. Categorical demographic variables were calculated in percentage, and for quantitative variables, means and standard deviation.

RESULTS

Distribution of Socio-demographic characteristics. [Table 1]

Total 180 children diagnosed with ASD in 2-9 years of age group were included in the study, of those most children were in 3-5 years of age group accounting to 58.33%, with 17.77 % being younger than 3 years and 23.88% were between 5-9years of age group. 77.22% were males nearly 3 times the females on ASD. About 79.44% families were living in nuclear family setting with only 20.55% were in joint family setting. A good 46.66% of the head of the family were post graduate by education, while 47.77% were graduates and only 5.55% of the head of the family were undergraduate and high school pass outs. None if the head of the family were found to be uneducated.

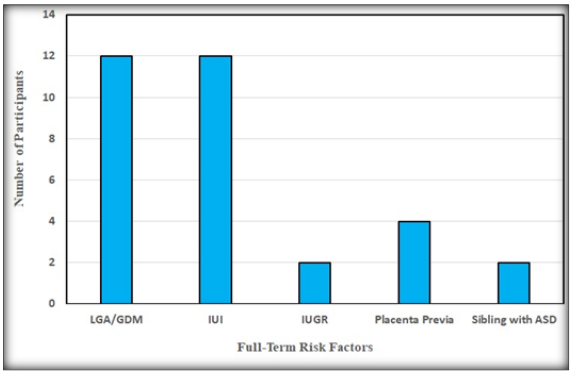

Figure 1: Distribution of ASD Participants based on Full-Term Risk Factors

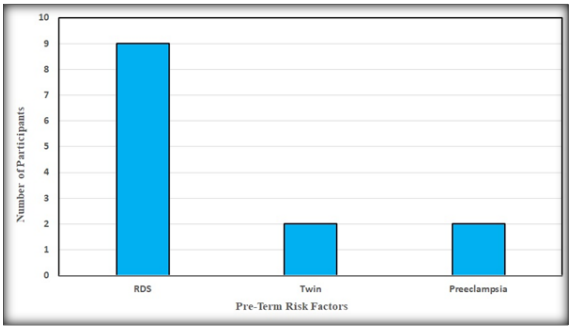

Figure 2: Distribution of ASD Participants based on Pre-Term Risk Factors

All children who justified the DSM V criteria of diagnosis were further confirmed by INCLEN Tool for ASD before including in the study.

Table 3 indicates that's 58.8 percent of the children diagnosed with ASD were having severe symptoms, 26.11 percent of the children has gastrointestinal disturbance, 50 precent had sleep disturbances and 59.4 percent had aberrant behavioral symptoms in the form of irritability, social withdrawal, stereotypic behaviors, hyperactivity and inappropriate speech.

Limitations

Subjects interviewed were those visiting the child developmental centers and control group for comparison was not there and the clinical information collected was limited. The data is from the metropolitan and rural population was not

included in the study thereby limiting the results to Urban population.

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Table 1: Socio-demographic Distribution of ASD Participants

Socio-Demographic Variables	Total N = 180(%)
Age groups	
Less than 3 years	32(17.77)
3-5 years	105(58.33)
Equal to and more than 5 Years to 9 years	43(23.88)
Gender	
Male	139(77.22)
Female	41(22.77)
Family Size	
Nuclear (Up-to 4 members)	143(79.44)
Joint Family (5 or greater than)	37(20.55)
Head of the Family Education	
12^{th}	10(5.55)
Graduate	86(47.77)
Postgraduate	84(46.66)

Table 2: Distribution of ASD Participants based on various Risk Factors

Factors	Total N=180 (%)
Mode of Delivery	
C Section	91(50.55)
NVD	89(49.44)
Breast fed/ Formula fed	
BF	81(45)
FF	25(13.88)
BF + FF	74(41.11)
Time and nature of complimentary feeds	
3-5 month	24(13.33)
6 and above months	156(86.66)
Hours of screen exposure (Before 2 years of age)	
Less than 2 hours	29(16.11)
2-5 hours	78(43.33)
6 hours and above	61(33.88)
No information available/ do not recall	12(6.66)
Hours of screen exposure (currently)	
Less than 2 hours	58(32.22)
2-5 hours	55(30.55)
6 hours and above	26(14.44)
None	41(22.77)
Diet	
Semisolid	17(9.44)
Solid	13(7.22)
Both	150(83.33)
Food Allergy /Special Diet	
Chewing difficulty	9(5)
Cow milk Allergy	1(0.2)
GFCF Diet	1(0.2)
None	169(93.88)
Intervention	
No Intervention	100(55.55)
Home based Intervention	9(5)
Special School	3(1.66)
1-6 hours/week	40(22.22)
7-12 hours/week	25(13.88)
13-18 hours/week	3(1.66)
Family Dysfunction	
Yes	16(8.88)
No	164(91.11)
Marital Discord	
Yes	13(7.22)
No	167 (92.77)
Gestational age	
PT	32(17.77)
FT	148(82.22)
Family History Of ASD	
No	155(86.11)
Sibling with ASD	14(7.77)
Uncle with ASD	11(6.11)

Table 3: Clinical Profile of children on ASD

SRS-2	N=180
Normal (59 and below)	7 (3.88)
Mild (60-65)	19(10.55)
Moderate (66-75)	48 (26.66)
Severe (76 and higher)	106 (58.88)
GI Index	
Less than 6	133(73.88)
6 and greater than 6	47(26.11)
CSHQ-Abbreviated	
Less than 57 (Below median)	83(46.11)
57 (Median)	07(3.8)
Greater than 57 (Above median)	90(50)
ABC	
Irritability	80 (44.44)
Social Withdrawal	105(58.33)
Stereotypic Behavior	121(67.22)
Hyperactive	102 (56.66)
Inappropriate speech	85 (47.22)
total	107 (59.44)

DISCUSSION

Over the last few decades, the prevalence of neurodevelopmental disorders has increased, such as Peck et al. reported a notable rise in the number of autism spectrum disorder (ASD) cases.[2] ASD is accompanied by various difficulties and deficits in communication abilities and social interactions.[1] Autistic children further display repetition of actions and interests which leads to the creation of fixed routines and patterns.[1] Elsabbagh noted that varying degrees of ASD worldwide has been reported by approximately 52 million individuals.[3] The World Health Organization (WHO) suggests that about one in every 100 children is affected by ASD.[4] The Centers for Disease Control and Prevention (CDC) estimated a prevalence rate of one in 44 children diagnosed with ASD, affecting children across all socio-economic, racial, and ethnic backgrounds.[5] Chiarotti and Venerosi estimated that 1% of the population in Asia, North America, and Europe are affected by ASD.[6] The development of autism symptoms has been explained by both genetic vulnerabilities and environmental influences in various studies. For instance, Froehlich-Santino et al. highlighted that genetic factors are thought to account for about 35-40% of ASD cases, whereas Tchaconas and Adesman emphasized that environmental aspects including prenatal, perinatal, and neonatal factors, are implicated in the remaining cases.[8]

The diagnosis and presentation of autistic symptoms have been attributed to some socio-demographic variables during the last few decades, including a child's gender, number of family members, and educational qualifications of parents or family head. First, a significant risk factor for ASD has consistently been the child's gender.[9] CDC estimated male to female ratio and reported values varying from 3.2:1 to 7.6:1.[10] The current study noted that the prevalence of ASD in males was 3.4 times more than females which falls within the range mentioned by CDC estimates. This prevalence has been supported by the existing literature. Recent studies such as conducted by Maenner et al. have shown a significant rise in ASD occurrences, with boys being four to five times more likely to be diagnosed than girls.[5] The analysis by Pinborough- Zimmerman et al. demonstrated that males have significantly higher risk of developing ASD than females.[11,12] Theoretical explanations of predominance of males observed in ASD cases have highlighted neurological and chromosomal differences.[13] but a definitive explanation has not yet been found. Khan et al. observed a strong association of the male gender with risk of developing ASD (70.6%) than healthy controls.[14] Therefore, the current study and the existing literature showed that males have a greater tendency to develop autistic symptoms than females.

Second, family size, particularly the distinction between nuclear families (with up to four members) and joint families (consisting of five or more members), emerges as a noteworthy socio-demographic factor in the context of ASD.[15] The prevalence and presentation of ASD may vary between these family types due to differing levels of support, resources, and environmental factors inherent in each setting. The current study observed that majority of autistic participants were brought up in nuclear families (79%) as compared to joint family setting (20%). Similar observations were obtained by Patra and Nath that more children with ASD (73.2%) lived in a nuclear family setup as compared to other autistic children.[16] They explained that the infant benefited from engagement with grandparents, uncles, and aunts as well as socialization with siblings and cousins in previous times when families lived together which made it easier for the special child to integrate into the society. The emergence of nuclear families in recent times may have contributed to the development of autistic tendencies in children, as it deprives them of all these exposures. The existing literature has reported that autistic children majorly belonged to nuclear families which estimates varying from

68.2%.[15] to 87%,[17] as compared to health controls. However, Khan et al. noted that the odds of developing ASD in children significantly reduced in nuclear family backgrounds as compared to joint families.[14] Faruk et al. indicated that a considerable number of autistic children (77.5%) belong to the nuclear family, while only 22.5% of children belonged to the joint family.[18] Overall, the data of the current study replicated similar outcomes of previous studies which highlight the fact that the dynamics within the family structures can significantly influence the identification, management, and overall experience of ASD.

Third, the educational level of the family head and parents is an important socio-demographic factor in ASD research.[11] This aspect is crucial as it may influence awareness, access to healthcare services, and attitudes towards ASD. Families with different educational backgrounds may exhibit varying levels of understanding and response to the disorder, potentially impacting the early detection and management of ASD in children. Van Meter et al. reported that autism has been linked to markers of higher education.[19] A positive association between maternal education and ASD symptoms have been reported by Pinborough- Zimmerman et al,[11] and this finding was supported by Bhasin and Schendel as they that noted higher parental education was significantly related to autistic symptoms.[20] Khan et al. depicted that the chances of developing ASD significantly reduced with higher educational levels of the fathers in Bangladesh (master and above) as compared to healthy control participants.[14] They further noted an insignificant inverse association of the chances of ASD with educational levels of the mothers in Bangladesh (master and above-level), whereas these odds were insignificantly increased with other educational levels. The evidence shows mixed results about how parental education level is associated with the chances of ASD. However, the current study presented the data that a majority of ASD participants belonged to the head of the family with graduate and above education (94.45%) as compared to those with high school graduate (5.55%). This may be attributed to higher level of awareness and early detection of ASD symptoms could be exhibited with higher levels of parental education which is suggested by most previous studies.

In exploring the risk factors of ASD, it is critical to consider a range of elements, including mode of delivery, infant feeding practices (breastfed or formula-fed), the timing and nature of complementary feeds (introduced at 3-6 months, or after 6 months), and screen exposure both before 2 years of age and currently. Additionally, familial aspects such as marital discord and the presence of a dysfunctional family environment are also pivotal. Each of these factors potentially contributes to the risk profile for ASD, shaping the understanding of its development and informing strategies for early detection and intervention.

First, a child's early and late life outcomes are significantly influenced by their mode of delivery. While there is no clear direct link between the technique of obstetric delivery and ASD, there is evidence to indicate that the two are related. Al-Zalabani et al. reported that the risk of ASD increased in children with caesarean section delivery.[21] Faruk et al. observed that the majority of autistic participants were delivered using caesarean section (73%), and some participants showed inadequate nutrition during pregnancy.[18] Curran et al. indicated that the odds of ASD were mildly increased in children delivered by caesarean section as compared to vaginal delivery (22). Galvan et al. studied Malaysian autistic children and reported that caesarean section was identified as one of the risk factors of ASD.[23] Gregory et al. noted that the risk of autistic symptoms was increased with induced labour or caesarean section.[24] Therefore, the existing evidence depicted that the mode of delivery significantly influences the probability of developing ASD. The current research observed that nearly 50.55% of the children on ASD were delivered by caesarean section which is more than 2 times the percentage of caesarean deliveries (21.5%) across India as per the National Family Health Survey-5(NFHS) (2019-2021), thus, adding to the existing pool of evidence that mode of delivery could influence the probability of developing ASD.

Second, the existing literature has noted a significant decrease in the probability of developing ASD symptoms in the presence of exclusive breastfeeding. Yong et al. suggested that the increase in the odds of ASD results from nutritional deficits in the child’s body due to feeding difficulties.[25] Kim et al. conducted cross-sectional research in Korea and reported that formula feeding was related to lower chances of developing ASD as compared to breastfeeding.[26] Huang et al. reported that partial or absence of breastfeeding was associated with increased likelihood of autistic symptoms as compared to exclusive breastfeeding.[27] Some researchers such as Tawfeeq et al. highlighted that breastfeeding may act as a protective factor against autistic symptoms,[28] whereas Say et al. did not show this association.[29] Findings by Jenabi et al. depicted that absence of breastfeeding acts as a risk factor for autistic symptoms.[30] Sabuncuoglu et al. highlighted that the infants receiving formula feeding showed significantly more ASD symptoms than those receiving breastfeeding.[31] Thus, the literature consistently demonstrated that breastfeeding is a protective factor against autistic symptoms. The data from current study indicates that only 45% of the children were exclusively breast feed which is nearly the same as the percentage of children being breast fed in India as per the NFHS (2019-2021) thus indicating no clear association between breast feeding and probability of developing ASD symptoms

Third, the timing and nature of complementary feeds (introduced at 3-6 months, or after 6 months) has been explored as one of the risk factors of ASD. The existing case-control studies on American.[32] and Indian,[33] children, and a birth cohort from Denmark,[34] depicted a significantly higher likelihood of ASD with shorter breastfeeding duration. In particular, Huang et al. suggested that there are higher chances of developing autistic symptoms with the absence of breastfeeding in newborns for the first six months of life.[27] The survey results by Shafai et al. illustrated that ASD diagnosis declined with the increase in the breastfeeding duration.[35] Furthermore, their statistical analysis suggested that breastfeeding for more than 1 year led to 6.67 times lower likelihood of being diagnosed with autism as compared to breastfeeding for less than 1 year. They mentioned that the probability of autism diagnosis was significantly related to breastfeeding for less than 6 months. Therefore, the timing and nature of feeds has been noted as a significant risk factor of autism diagnosis. In the current study, 86.66 percent of the child were breast fed for longer than 6 months as compared to the Indian data available where only 55 percent of the infants are breast fed past 6 months indicating there is no significant relationship between autism and duration of breast feeding.

Fourth, early exposure to screen time, specifically before the age of two, is increasingly scrutinized as a potential risk factor for autism diagnosis. Kushima et al. highlighted that this concern stems from the critical period of brain development occurring in these early years, where excessive screen time may impact social and cognitive development (36). Sarfraz et al. conducted a systematic review which explored the existing studies available on the relationship between risk of autism diagnosis and early screen time exposure.[37] They reported a significant positive association as the likelihood of ASD increased with higher screen exposure durations. They further indicated that this risk increased with earlier screen exposure. Hu et al. investigated the time spent by children using screen passively and actively.[38] The participants watched television and videos (passive screen time) for about 2.16 (SD = 1.03) hours, whereas they engaged in smartphones and computers (active screen time) for about 1.07 (SD = 0.90) hours. This indicated that the children being exposed to screens for about 60 to 120 minutes daily may result in autistic symptoms. Md Zaki Fadzil et al. highlighted an increased likelihood of developing autistic symptoms in those children who watch screens for more than three Hours.[39] However, Hill and colleagues demonstrated that the control participants who were not exposed to screens did not significantly differ from the ASD group.[40] Nonetheless, there is more support for the conclusion that early exposure to screen time could lead to higher chances of developing autistic symptoms. The current study indicates that 77.21 % of children were exposed to screentime at the time of enrolment in the study with 32.22% were watching screen for 0-2 hour, 30.55% were watching screen for 3-5 hours per day and 14.44% were having a current screen exposure of more than 6 hours a day.

The study also investigated the hours of screen exposure for the study subjects in their early childhood (less than 2 years) on basis of recall and the outcomes were alarming to the extent that 93.33% of children were exposed to screen watching time in their early toddler years with 16.11% children were on screen for 0-2 hours a day, while 43.33% were on screen time from 3-5 hours a day and 33.88 percent were watching screen for longer than 6 hours a day. The higher prevalence of screen exposure in late infancy and early toddler years in children being diagnosed with ASD indicates it is a risk factor which may be contributing to the development of autistic symptoms.

Fifth, marital discord is increasingly recognized as a potential risk factor for ASD. The quality of the marital relationship and the level of conflict within a family can significantly affect a child's emotional and psychological well-being. Bahri et al. reported that high levels of stress and discord in marital relationships may contribute to developmental challenges in children, potentially influencing the onset or severity of ASD.[41] Meadan et al. suggested that marital discord and stress could influence autistic children.[42] Expanding on the impact of marital discord as a risk factor for ASD, further research by Fitzgerald et al. indicated that the emotional climate of a household, shaped by the parents' relationship, plays a crucial role in a child's development.[43] The presence of persistent conflict and stress in the marital relationship not only disrupts a nurturing environment but also may indirectly affect the child's social and emotional growth. Thus, the studies observed an increased vulnerability or aggravation of existing autistic symptoms in these environments. However, the data from current study reported that majority ASD participants (92.77%) did not experience marital discord which is inconsistent with the evidence shown by previous studies. This discrepancy in findings could be attributed to differences in the populations studied, methodological variations, or the subjective nature of reporting marital discord. Additionally, the resilience of certain families or underreporting due to stigma might also explain the inconsistency.

The exposure to dysfunctional family setting is another crucial risk factor for autism diagnosis. Fitzgerald et al. highlighted that a stressful environment could be created due to instability, poor communication among family members, and lack of emotional support leading to the diagnosis and presentation of autistic symptoms.[43] Greenlee et al. conducted a literature review synthesis to examine how mother-father relationships and

family-level mechanisms such as household organization, communication, conflict, adaptability, routines, and cohesion impact the diagnosis and presentation of autistic symptoms.[44] Six primarily cross-sectional studies included in this review explored behavioural and emotional challenges in autistic children and reported mixed evidence. For example, Weiss et al. reported that these challenges in autistic children with comorbid intellectual disability are not influenced by better family functioning and family-level processes did not act as a protective factor against autistic symptoms.[45] In contrast, Kelly et al. identified that internalizing problems in autistic children were significantly correlated with family conflict.[45] Stoutjesdijk et al. reported that behavioural and emotional challenges in autistic children are negatively impacted by marital problems, poor family communication patterns, and low levels of familial support.[47] Baker et al. noted that difficulties experienced by autistic children during adolescence reduces with better family adaptability.[48] Thus, the existing evidence shows that positive outcomes for autistic children could be generated with healthy family level mechanisms. However, the data from current study noted that majority ASD participants (91.11%) did not experience family dysfunction which is incongruent with the findings shown by the existing literature. The divergence in findings may stem from underreporting due to stigma, variations in the assessment of family dysfunction, cultural differences affecting family dynamics, or the resilience and coping strategies of families. It is also possible that advancements in awareness and interventions have improved family functioning for many ASD participants.

The clinical profile of the children helps us to identify the severity of the ASD and associated comorbidities like gastrointestinal symptoms, sleep disturbances and various behavioral symptoms.

26 percent of the children with ASD reported gastrointestinal symptoms in the form of constipation, diarrhea, abdominal discomfort, vomiting, flatulence and foul-smelling stool reported by the parents and caregivers. These gastrointestinal symptoms have been reported to correlate to the various maladaptive behaviours in ASD children, such as irritability, social withdrawal, stereotypy, hyperactivity, and even language regression,[50] which emphasis on the need to find and treat these symptoms while managing the children on Autism spectrum disorder.

Sleep disturbance is a commonly known comorbidity in children on autism spectrum disorder. Previous research reports a prevalence of sleep problems in 32 to 71.5 % of children and adolescents with ASD.[51] In our study also 50% of the children were identified to have sleep disturbances which highlights the importance of taking history about sleep disturbances during a routine evaluation of a child with autism spectrum disorder and also emphasises the importance of managing disordered sleep which have potentially high improvement in the quality of life of these individuals and their families.

CONCLUSION

This research aimed to examine the sociodemographic and risk factor profiles of autistic children residing in metropolitan cities of North India. The descriptive analyses of the data offered various insights into the sociodemographic variables and identified potential protective factors against ASD, emphasizing the crucial impact of prenatal, perinatal, family dynamics, and environmental influences. These results contribute to the broader understanding of multifaceted etiology of ASD which offers useful data for researchers, policy developers, and healthcare professionals to formulate intervention approaches to alleviate risk factors and improve the well-being of autistic children and their caregivers. The clinical finding throws light on the severity of symptoms, aberrant behaviors and some of the commonly occurring comorbidities like Gastrointestinal disturbances and sleep disturbances. The findings highlight the importance and necessity of targeted early intervention services and the planning of primordial and primary prevention measures. Overall, these insights could be helpful in shaping future research and practice in the field of neurodevelopmental disorders.

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