

Perceptions of Autism Spectrum Disorder among People in a Remote Area of Bangladesh

Sultana N¹, Mawla MR², Khan NF³, Alam MR⁴, Karim MZ⁵, Haque N⁶DOI: <https://doi.org/10.3329/jafmc.v18i2.63999>**Abstract**

Introduction: Autism is a neurodevelopmental disorder which are manifested within two years of life. It exhibits difficulties in social interaction, verbal and nonverbal communication, as well as repetitive or constrained interests and actions. Autism has already posed significant burden in health sector in Bangladesh. That's why it is high time to address autism.

Objectives: To assess the factors affecting children with ASD and perception of rural people about it.

Methods: This cross sectional study was carried out from 01 January to 31 December, 2021 among 55 people of different unions of Bauphal Upazila of Patuakhali district.

Results: Majority of the autistic children are male (61.82%). In maximum cases, parents and family members were usually the first persons to identify (60%) the autistic symptoms. A good percentage (21.82%) respondents were ignorant about the cause of autism. Most (38.18%) of the children with autism were treated at government hospital. Maximum therapy received by the children is speech therapy (41.82%) and there is partial improvement (54.55%) of autism by applying therapy.

Conclusion: This study revealed that most of the parents of autistic child were unaware about its contributory factors and treatment. Even there is scarcity of trained or specialist health professionals. There are also false belief about autism that inhibit people to take proper treatment.

Recommendations: The government of Bangladesh should make an effort to aware population especially in rural areas as well as train physicians about its treatment and make proper treatment available in all government hospitals.

Key words: Autism, Neurodevelopment disorders, Genetic, Environmental factors.

Introduction

Autism is presently considered a serious health concern due to its increasing frequency and considerable effects on human functioning. Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder which usually first manifests in childhood and may last for entire life¹. It's severity levels ranging from low to high which is manifested by a number of behavioural characteristics². However, figure-1 has illustrated the triad impairments of autism.

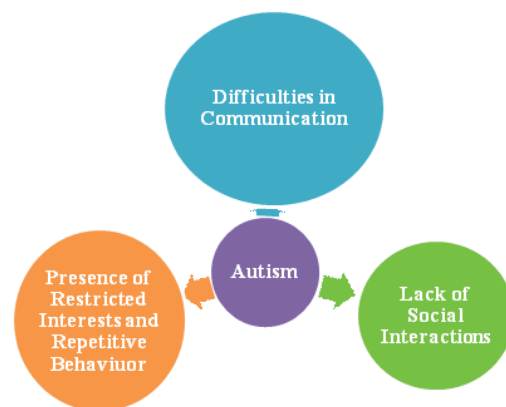


Figure-1: Triad impairments of Autism²

The most rapidly increasing significant developmental disorder is autism. Different studies exhibit that sign of autism can be detected as early as 1 year of child age³ and can be accurately identified by the age of two⁴. As per one study, the mean age of identification of autism is 1.8 years⁴. According to the World Health Organization (WHO), globally one child in 160 children has an ASD⁵. Though autism is under reported yet it poses substantial health issue in Bangladesh. In Bangladesh, 14 out of every 10,000 children had ASD in rural areas and 25 out of every 10,000 children in urban area⁵. Researchers are yet to prove the genuine single cause of autism. Researchers have anticipated that environmental, genetic, neurological and psychological factors can each have their own specific causes for autism as those may interfere with the brain's normal function^{3,6-8}. Besides that bad parenting⁷, parental ages⁹, pregnancy complications⁹ etc are also identified as causes of autism. So far, no definite medical treatment is available.

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Lack of awareness and proper knowledge on autism by both parents and physicians lead to late recognition and subsequently delay in suitable treatment. It necessitates significant amount of care not only from medical and educational sectors, but also from the society. However, the Government of Bangladesh (GoB) needs to make an endeavor to train physicians, nurses and medical assistants in mass scale on autism.

Materials and Methods

A cross sectional study carried out from 1st January to 31st December, 2021 where around 55 people participated, in Bauphal Upazila. Among those, 20 are the parents of autistic children, 15 are their relatives or their neighbours and 10 are local doctors, nurses and staffs. However, other psychological or neurological disorder and unwilling to participate in this survey are excluded. The survey was planned to assess perceptions of autism in a remote area of Bangladesh and factors related to it. Survey was undertaken randomly at four unions of Bauphal Upazilla under Patuakhali district in Barishal division (Figure-2). It has 14 Unions, 134 Mauzas, 146 villages. The study has purposively chosen four unions of the upazila namely Kalisuri, Bauphal, Nazirpur and Noamala. People of different background, age, gender, religious beliefs and educational background are also interviewed to get the real picture. A face-to-face interview was taken by using a semi-structured questionnaire.



Figure-2: Map of Survey Area

Results

Table-I shows the demographic characteristics of the respondents. However, majority (61.82%) male children are identified with autism (Figure-3). In most of the cases, parents and family members were usually the first persons to identified (60%) the child autistic symptoms which is followed by doctors (16.36%) (Table-II). A good percentage (21.82%) respondents are yet to know the prime cause of autism (Table-III). Both genetics and environmental factors (12.73%) and parental mistakes (12.73%) are considered as the prime cause of autism which is followed by parental age (10.91%) and consanguineous marriage (10.91%). Other causes are pregnancy complication, food nutrition, etc. Besides those, one peculiar result (09.09%) received from the survey that is black magic is one of the causes of autism (Table-III).

In majority cases (38.18%), children with ASD were treated in government hospital followed by traditional healers /homeopathy doctor 14(25.46%) (Table-IV). A significant percentage (41.82%) of children had been receiving speech therapy followed by occupational therapy (25.45%). More than half of the respondents (54.55%) said that there is partial improvement of autism by applying therapy (Table-IV). Maximum parents (38.18%) suffer stress problem followed by financial problem (29.09%) (Table-IV).

Table-I: Description of demographic characteristics of the respondents

Parameters		Randomly Selected Unions of Bauphal				Number of Respondents (%)
		Kalisuri	Bauphal	Nazirpur	Noamala	
Gender	Male	7	9	6	8	30 (54.55)
	Female	5	8	6	6	25 (45.45)
Age (years)	18 to 35	5	7	6	6	24 (43.64)
	36 to 50	3	7	4	4	18(32.72)
	≥ 51	3	4	3	3	13 (23.64)
Education	Up to primary Level	6	8	6	7	27 (49.09)
	SSC and HSC level	4	7	3	3	17(30.91)
	Graduate and above	2	4	2	3	11 (20.00)
Occupation	Farmers/Daily Labor	4	6	5	3	18 (32.73)
	Shopkeepers	3	5	3	4	15 (27.27)
	Business	1	2	1	2	06 (10.91)
	Service	3	5	5	3	16 (29.09)

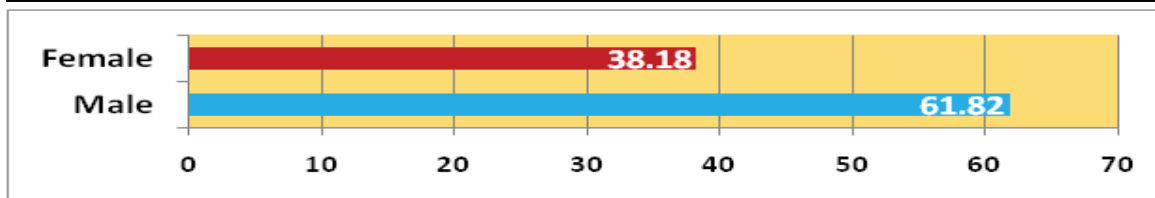


Figure-3: Gender base of autistic children in survey area (n=55)

Table-II: Identification of autistic children (n=55)

Identified by	Frequency	Percentage
Parents and Family Members	33	60.00
Relatives and Neighbor	06	10.91
Doctors	09	16.36
Teachers	05	09.09
Others	02	03.64
Total	55	100.00

Table-III: Tentative causes of autism, assumed by people (n=55)

Category	Frequency	Percentage
Increased age of Parents	06	10.91
Pregnancy	04	07.27
Parental mistakes	07	12.73
Vaccinations/ immunizations	05	09.09
Genetics and environmental factors	07	12.73
Black magic	05	09.09
Food Nutrition	03	05.45
Consanguineous marriage	06	10.91
No Comments/ Not answered	12	21.82
Total	55	100.00

Table-IV: Percentage distribution of place of treatment, type of therapy, level of improvement and parental problems of autistic children (n=55)

Parameters	n	%
Place of treatment received by autistic children		
Government hospital	21	38.18
Private Clinic/Hospital	10	18.18
Traditional Healers /Homeopathy	14	25.46
Prayer	06	10.91
Religious/ Spiritual Leader	04	07.27
Level of improvement by therapy		
No Improvement	10	18.18
Partially Improvement	30	54.55
Huge Improvement	15	27.27
Type of Therapy Received by Autistic Children		
Speech therapy	23	41.82
Occupational therapy	14	25.45
Physiotherapy	06	10.91
Medications	05	09.09
hydrotherapy	04	07.27
Other Therapy	03	05.46
Distribution of parental problems of autistic children		
Financial	16	29.09
Stress	21	38.18
Social Stigma	13	23.64
Divorce Problem	02	03.64
Other Problem	03	05.45

Discussion

This study exhibits higher percentages (approximately 61.82%) of male autistic children than female. This gender finding correlates with other studies also^{6,10,11}. Though there is a male dominance in identifying autism, but no conclusive explanation is yet to find in favor of male¹². Different studies portrayed that vulnerability of autism in case of males are four times more than that of females^{3,6}. According to one study, male to female autism ratio is nearly to 3:1 or 2:1¹¹.

This study represents that maximum parents or family members (60%) are first identifier about their children with autism. This study commensurate the result of another study where it is narrated that parents and family members are usually the first to notice autism's indications and symptoms⁴. Similar finding has been revealed by another author where mother noticed the absence of number of developmental concerns¹³. No conclusive evidence or specific cause could establish yet linking the onset of autism^{7,8,14}. However, genetic, environmental, biological factors etc are identified by different researchers for development of autism^{6-8,14}. Besides that, bad parenting^{7,15}, vaccinations^{7,16}, non-medical reasons^{2,16}, parental ages^{9,15}, pregnancy related cause⁹ etc are also identified as some causes of autism. A significant percentage of respondents demonstrated that there is lack of understanding and knowledge on autism in Bangladesh especially in rural areas. This result commensurate with other studies conducted at UK, USA and China^{17,18}.

A small percentage of respondents (09.09%) believed that vaccinations are the cause of autism in this study. Few respondents assumed receiving number of vaccinations in a month has made a different child. Similar finding was demonstrated by a researcher where vaccines especially measles, mumps, and rubella (MMR) was blamed for autism though later on, it was proved to be false^{16,19}. However, according to recent study, childhood vaccinations, particularly MR as well as mercury have no association with rise of autism¹⁹. Rather, vaccinations and mercury are contributory factors of autism which is regarded as myths^{16,19}.

Around 12.73% respondents of this study believe that autism is due to genetic and environmental factors. Similar results have received by other researchers also^{2,6,9,20,21}. According to recent studies, researchers revealed that dozens of genes are the contributing factors to autism²⁰. The majority of the risk for autism is explained by hereditary factors^{2,9}. Autism is not solely caused by genetics; environmental variables may also be important²⁰. From survey, it has evidence that consanguineous marriage among first cousin has the possibility of giving birth autistic child. Approximately 9.1% of all children with ASD parents had the history of consanguineous marriage. About 10.9% of parents in Dhaka research²¹ had a history of consanguineous marriage which is a nearly identical finding to the current study.

A very meager percentage of people (05.45%) in this study gave opinion on favor of poor nutrition. Though it is unlikely that malnutrition causes autism, but multivitamins therapies have been popular for a long time to treat the symptoms of autism⁹. The idea behind multivitamins therapy is that ASD symptoms may be linked to biochemical errors due to nutritional deficits. Again, there is evidence that some supplements, especially omega 3 fatty acid in fish oils can help to alleviate some symptoms of autism⁹. Studies show that multivitamins supplements are said to be beneficial for children with ASD, however there is currently no scientific evidence to back up this claim^{2,9}.

A good percentage of respondents (12.73%) argue that due to poor parenting, autism happens and parents who have not in mental peace and remain in stress, like to give birth of autistic children. People in rural areas believe that parents may be father or mother, have committed some immoral activities before or after the marriage²² and as a result, God punished them by giving an autistic children³. Further, parents, especially mother were always blamed for giving birth of an autistic child. But there no pragmatic evidence to be

believed that autism is caused by mothers²³. Still now, there is no clear evidence that parents are the cause of autism. Rather, parents play a pivotal role for caring and development of their children.

A considerable percentage of people (10.91%) in survey areas, have voted in favor of parental age as a cause of autism. There is evidence to support the idea that a father's age may be more crucial for a child's healthy birth. In this modern age, researchers revealed that advanced age of parents has close link with the elevation risk of autism^{9,15}. Again, the susceptibility to autism may be influenced probably by only the maternal¹⁵ or paternal ages¹⁵. Other studies represent that advanced maternal age has the greater risk of autism^{10,24}.

About 8% of people in survey areas, have mentioned pregnancy as a cause of autism. Few recent studies stated that pregnancy is a prime time for the brain development^{9,14}. Numerous studies have revealed that autistic children are experience with more pregnancy complicacies and birth risks than normal children^{9,14}. The immune system of the fetus can potentially obstruct the growth of its brain. Again, the potentiality of greater risk of ASD is likely to depend on adverse pregnancy and delivery outcomes¹⁴.

According to the current study, the majority of children (38.18%) were treated in government hospitals. It is to mention that there is no specialized physicians and related equipment available at Bauphal Upazilla Health Complex. According to a study in rural area in Bangladesh, still now parents of ASD rely on traditional healers⁹. They further belief that as autism is caused by evil spirits, there is nothing to do with drugs for treatment²⁶. A small percentage of rural especially elderly people believe that prayer will solve crisis and distress including autism. They utilize their faith upon God as a coping mechanism for raising children who have autism spectrum disorder¹⁹.

This study represents, maximum people (54.55%) have marked significant improvement of the children with ASD by using therapy though negligible number of respondents (18.18%) did not find any improvement. This study also correlates another study conducted in Bangladesh³. From a survey among 220 respondents depicted that more than 95% respondents are beneficial after autism treatments and 24% felt those advantages were life-changing²⁵.

In this study maximum respondents opined for speech therapy (41.82%) and occupational therapy (25.45%) as a significant step of treatment of their children. This

study is consonance with findings of other studies^{3,9}. Another survey conducted at urban areas of Bangladesh where it is shown that parents prefer to send their child to autistic institution rather than general hospital as in institution, children get training and treatment both for improvement⁶.

This study portrays 38.18% parents of autistic children suffer from stress. Further, financial burden (29.09%) and social stigma (23.64%) are also observed by significant percentages of respondents. This study has similar findings with other studies also^{6,27}. Children with ASD parents reported higher levels of tension, despair and nervousness compared to parents of typically developing children. Mother with ASD children demonstrated higher degrees of psychological anguish and parenting stress²⁷. The stigma is not solely focused on the child with autism, but the entire family²².

Bangladesh is regarded internationally as a leader for raising national awareness of autism and rehabilitation of people suffered from autism. In order to increase public understanding of autism, the Ministry of Primary and Mass Education developed a brief episode of the "Meena" cartoon and demonstrated in 158 sub-district levels^{5,28}. Autism was included in the curriculum for primary education. The "Physical Teaching, Health Science and Sports" book for grades nine and ten featured a chapter on autism and in every grade few basic information have been incorporated. However, under the umbrella of inclusive education, the government has developed a strategic action plan for children with autism, and as a result, all ASD students will be granted an additional 20 minutes during public examinations²⁸. The United General Assembly unanimously adopted "Resolution 67/82" from Bangladesh^{5,14,28}. Two significant acts have been passed in 2013 by the National Parliament of the GoB to safeguard the rights along with safety people with neuro-developmental disabilities, including ASD. The Disability Rights Law of 2013 is one law and the Neuro Developmental Disability Protection Trust Act of 2013 is another one^{5,14,28}.

The age limit for accessing the services has been raised to 40 years old by the GoB, who reserves 1% of all first- and second-class jobs, including BCS, for disabled and autistic individuals and 10% for class three and class four jobs for disabled and orphans. The majority of government primary schools outright denied accepting autistic children into their facilities. Therefore, preserving quota for their employment will be useless if the children do not receive at least a pleasant environment for their elementary education²⁹. Therefore, all must cooperate in order to support and encourage appropriate actions for autism affected families.

Conclusion

Though the exact cause of autism cannot be identified, but there are several factors are linked with autism like genetic, environment, parental age, poor parenting, pregnancy cases etc. However, understanding of autism, lack of awareness and shortage of specialized doctors along with cost are identified as main hurdle of treating autism. The GoB should make an effort to aware population especially in rural areas as well as train physicians on autism basic treatment and make available in all government hospitals.

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