Original Paper

Socio-demographic Characteristics and Related Factors Affecting Children with Autism Spectrum Disorder

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Abstract

Introduction: Autism Spectrum Disorder (ASD) is a neuro-developmental disorder characterized by social deficits, communicative difficulties and repetitive behaviors, with evidence of cognitive dysfunction. Approximately 1% of the world's population or 67 million are affected by autism. ASD is an emerging public health issue globally which is associated with a huge burden on the family, community and the nation.

Objective: To determine the socio-demographic characteristics and related factors affecting children with ASD to help the government and relevant organizations to take necessary steps to reduce burden of the families.

Materials and Methods: This cross-sectional study was carried out from July 2015 to June 2016 among 154 children with ASD. Data were collected by face-to-face interview with semi-structured questionnaire following systematic random sampling technique.

Results: Majority (73.4%) of the children were male and mean (±SD) age was 6.66±2.97 years. Most (88.8%) of the children were from urban areas with average monthly family income Tk. 41785.71±23936.45. Majority of the fathers (45.5%) and mothers (31.8%) had 'masters level'of education. Maximum (68.2%) children were from nuclear family and a few (9.1%) parents had a history of consanguineous marriage. Most (96.8%) of the children were initially treated by specialist doctors whereas, the majority (74.0%) were diagnosed in government hospitals. Most (89.6%) of the children were treated withspeech therapy.

Conclusion: Since ASD is a growing public health problem in Bangladesh, countrywide proper early diagnostic facilities, especially in peri-urban and rural areas, should be available to measure its actual burden in the country.

Key-words: Autism spectrum disorder (ASD), Special school, Therapy, Quality of life.

Introduction

Autism Spectrum Disorder (ASD) is a neuro-developmental disorder characterized by social deficits, communicative difficulties and repetitive behaviors with evidence of cognitive dysfunction[1]. Developmental disorders are a group of conditions with onset in infancy or childhood and characterized by impairment or delay in functions related to the central nervous system maturation. Individuals with ASD may have decreased general intellectual ability[2]. Recent research has clearly indicated the importance of early identification since early intensive treatment is associated with better long-term outcome[3].The identification of an ASD is difficult before the age of about 12 months but the diagnosis is ordinarily possible by the age of two years[4].

Autism is highly heritable; researchers suspect both environmental and genetic factors are responsible[5].The recurrence rate in siblings of children with autism is between 2% and 8%, increasing the risk of having a second child with autism nearly 50-fold over that in the general population[3]. ASD is typically diagnosed in children by the age of three where difficulties arerecognized in the area(s) of social interaction, language for communication, and/or restricted, repetitive and stereotyped patterns of behavior[6]. Autism now affects children worldwide, regardless of race, ethnicity or socioeconomic status[7].

Autism is the fastest-growing serious developmental disability and since 2002 through 2006 its growth rate was around 57 per cent[8]. As per WHO, approximately 1% of the world's population or 67 million are affected by autism[9]. At present, 1 in 68 United States (U.S) children have an ASD which is an increase from 1 in 88 of two years ago[10] and is growing

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at a rate of 10% to 30% per year[11]. The prevalence rate is 5 times more among boys (1 in 42) than among girls (1 in 189)[10]. Studies in Asia, Europe and North America have identified individuals with ASD with an average prevalence of about 1%. Prevalence rates in Western Europe, Canada and Australia are similar to those in the United States whereas rates but in Japan and China are somewhat higher[8].The prevalence of ASD in South Korea was estimated to be 2.64% and the male-to-female ratio[12] was 5.1:1. The prevalence rate of autism in India is 1 in 250 and currently, 10 million people are suffering in India. The government only recognized the disorder in 2001 untilthe 1980s, there were reports that Autism didn't exist in India[13].

According to the report of the Ministry of Social Welfare, Bangladesh, the total number of persons with ASD, could be as high as 1.4 million of whom only a few hundred have been diagnosed. One estimation is also that one child in 500 in Bangladesh has autism, meaning that the approximate number of children with ASD in Bangladesh is no less than 280,000. The general attitude towards autism is mostly negative and it is seen as a social barrier. Even today, autism is considered a God-given curse and children with ASD are taken as possessed by the Devil[14].

This study was conducted to determine the Socio-demographic characteristics and related factors affecting children with ASD which will subsequently help the government and relevant organizations to take necessary steps to provide economic and infrastructural support to reduce the burden of the families for the children with ASD.

Materials and Methods

This cross-sectional study was carried out from July 2015 to June 2016 among 154 children with ASD to find out the socio-demographic features and related factors of children with autism spectrum disorder. Data were collected from parents of all diagnosed children with ASD, attended to the selected two special schools and two specialized hospitals of Dhaka city during data collection period. All children with ASD between 3 to 18 years of age were included in the study but the seriously ill children due to co-morbidities were not included. Pre-testing of research instrument was done in a private autism school on 15 children with ASD. Informed consent was taken before the interview from the respondents' parents. Systematic random sampling technique was followed. Fifty three children were included from Institute of Paediatric Neurodisorder & Autism (IPNA), Bangabandhu Sheikh Mujib Medical University (BSMMU), Dhaka, 25 children from Shishu Bikash Kendro (SBK), Dhaka Shishu Hospital, Dhaka, 54 children were included from from Proyash, Institute of special education, Dhaka Cantonment and 22 children from Special school for Autism, Bangladesh Jatiyo Protibondhi Unnayan Foundation (JPUF), Mirpur, Dhaka. Analysis of data was done by "Statistical Package for Social Science" (SPSS) program in the computer.

Results

The distribution of children by socio-demographic characteristics shows that the mean (±SD) age of the children was 6.66±2.97 years. Majority of the children (73.4%) were male and male-female ratio was 2.76: 1. It was also found that most (88.8%) of the children were from urban areas. According to education level, majority (51.9%) children were in pre-primary level followed by 42(27.3%) in Early Childhood Development Program (ECDP), 28(18.2%) were illiterate and only 4(2.6%) were in the primary level of education. The study shows that maximum (68.2%) children were from nuclear family and maximum i.e 59.7% children were of the 1st child according to birth order (Table-I).

Table-I: Distribution of the children by socio-demographic characteristics (n=154)

Variables		Frequency	%
Age	3-5 years	71	46.1
	6-10 years	66	42.9
	11-16 years	17	11.0
	Statistics	Mean ± SD:6.66 ± 2.97 and Range: 3-16	
Sex	Male	113	73.4
	Female	41	26.6
Place of residence	Urban	136	88.3
	Peri-urban	7	4.5
	Rural	11	7.1
Education level	Illiterate	28	18.2
	ECDP	42	27.3
	Pre-primary	80	51.9
	Primary	4	2.6
Family Type	Nuclear	105	68.2
	Joint	49	31.8
Birth order	1st child	92	59.7
	2nd child	48	31.2
	3rd child	11	7.1
	4th child	3	1.9

According to socio-demographic characteristics of the parents, majority (54.5%) mother was of 16-26 years age group and the mean (±SD) of the age of mother was 26.79 ± 5.73 years. The study revealed that majority father (45.5%) and mother (31.8%) were educated up to master's level. Among all the children, maximum (67.5%) fathers were service holder, 9.1% parents had consanguineous marriage and the mean monthly family income was Tk. 41785.71 with standard deviation ± Tk. 23936.45 and majority (41.6%) family had monthly income Tk. 20001-40000 (Table-II).

Table-II: Distribution of the parents by socio-demographic characteristics (n=154)

Variables	Frequency	%
Age of mother at birth of the children		
16-26 years	84	54.5
27-40 years	70	45.5
Statistics	Mean ± SD: 26.79 ± 5.73 and Range: 16-40	
Educational qualification of father		
Primary	7	4.5
Secondary	14	9.1
Higher secondary	17	11.0
Graduate	46	29.9
Masters	70	45.5
Educational qualification of mother		
Primary	6	3.9
Secondary	30	19.5
Higher secondary	31	20.1
Graduate	38	24.7
Masters	49	31.8
Occupation of father		
Service	104	67.5
Business	47	30.5
Day laborer	3	1.9
Consanguineous marriage		
Yes	14	9.1
No	140	90.9
Monthly family income		
9000-20000 Tk	31	20.1
20001-40000 Tk	64	41.6
40001-60000 Tk	31	20.1
60001-100000 Tk	28	18.2
Statistics	Mean ± SD: 41785.71 ± 23936.45, Range: 9000-100000	

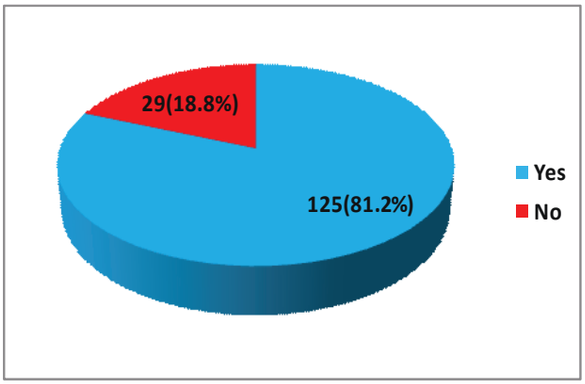

Fig-1: Distribution of the children by instant treatment seeking

Figure-1 shows that, out of 154 children, majority (81.2%) children received instant treatment after initial complaints of Autism Spectrum Disorder (ASD) .

Among 125 children, majority 121(96.8%) were treated initially by specialist doctors followed by special school 13(10.4%), MBBS doctors 8(6.4%) and homeopathy doctor 1(0.8%) (Table-III).

Table-III: Distribution of the children by the source of initial treatment (n=125)

Source of treatment	Frequency	%
Specialist doctor	121	96.8
Special School	13	10.4
MBBS doctor	8	6.4
Homeopathy doctor	1	0.8

Of all children, majority 114(74.0%) were diagnosed in government hospital followed by specialist doctors' chamber 19(12.3%), private hospital 13(8.4%) and private clinic 8(5.2%) (Table-IV).

Table-IV: Distribution of the children by place of diagnosis (n=154)

Place of diagnosis	Frequency	%
Government hospital	114	74.0
Specialist chamber	19	12.3
Private hospital	13	8.4
Private clinic	8	5.2
Total	**154**	**100.0**

According to the children's age at diagnosis of ASD, out of all, majority (50.0%) children were diagnosed at the age of 3-4 years followed by 66(42.9%) at 1-2 year and 11(7.1%) at 5-7 years. The mean (±SD) age of diagnosis was 2.86±1.17 years while the range was 1-7 years (Table-V).

Table-V: Distribution of the children by age at diagnosis (n=154)

Age	Frequency	%	Mean±SD	Range
1-2 years	66	42.9	2.86±1.17	1-7
3-4 years	77	50.0		
5-7 years	11	7.1		
Total	**154**	**100.0**		

Different types of therapy are the key interventions for the treatment of ASD children. Among all children, majority 115(74.7%) had received different types of therapy and 39(25.3%) did not receive any therapy (Fig-2).

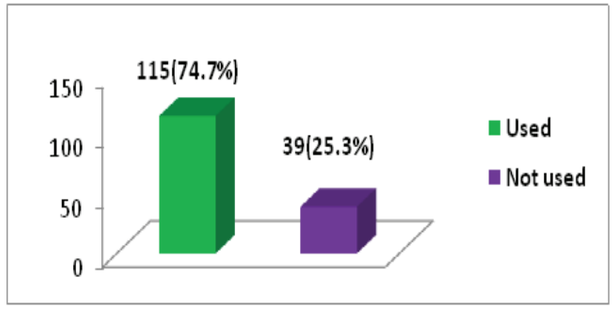

Fig-2: Distribution of the children by use of therapy (n=154)

Among 115 children, majority i.e. 103 (89.6%) had received speech therapy followed by occupational therapy 74(64.3%), physiotherapy 50(43.5%), psychotherapy 13(11.3%), music therapy 9(7.8%) and audio therapy 6(5.2%) (Table-VI).

Table-VI: Distribution of the children by types of therapy used (n=115)

Type of therapy	Frequency	%
Speech therapy	103	89.6
Occupational therapy	74	64.3
Physiotherapy	50	43.5
Psychotherapy	13	11.3
Music therapy	9	7.8
Audio therapy	6	5.2

Out of 115 children, majority (60.9%) had little improvement of the quality of life due to use of therapy followed by 40 (34.8%) had lot of improvement and 5(4.3%) had no improvement (Fig-3).

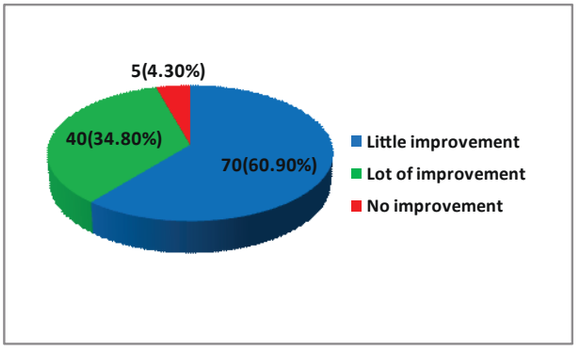

Fig-3: Distribution of children by the level of improvement of quality of life of the children following therapy (n=115).

Curriculums of special schools are designed to develop the children with ASD according to the individual ability plan (IAP). Of all, majority 122(79.2%) children attended special schools while 32(20.8%) didn't attend (Fig-4).

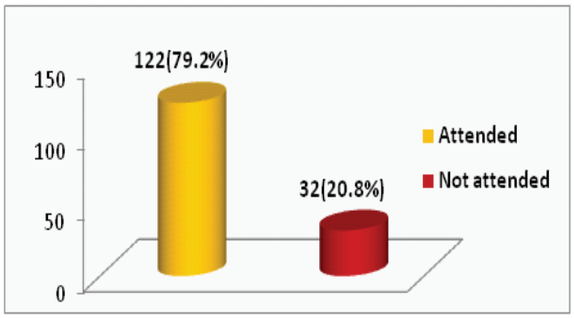

Fig-4: Distribution of the children by attendance of special schools (154).

The study showed that, out of 154 children, only 5(3.2%) siblings were suffering from ASD (Fig-5).

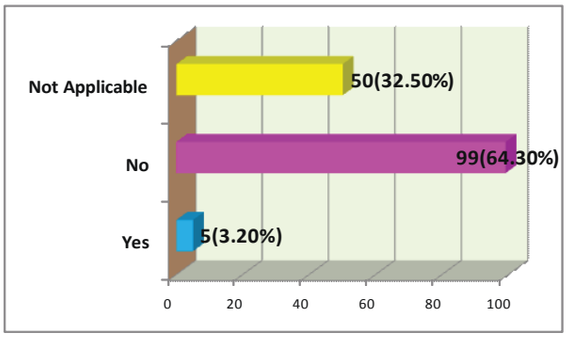

Fig-7: Distribution of the children by sibling suffering from ASD (n=154)

Discussion

ASD is a neurodevelopmental disorder and an emerging public health issue globally which is associated with a huge burden on the family, community and the nation. This study was conducted to find out the socio-demographic characteristics and related factors affecting children with ASD to help the government and relevant organizations to take necessary steps to reduce burden of the families. A total of 154 children with ASD were included in this study. The mean (±SD) age of children was 6.66±2.97 years, majority (73.4%) were male, male female ratio was 2.76:1, maximum (68.2%) children were from nuclear family and most (88.8%) from urban areas. The findings of the present study have almost similarity with findings of the studies conducted by Amr[15], Sun[16], Khanom[17] and Rahman[18]. According to birth order of the children, out of all, majority (59.7%) were 1st child. A study conducted in Dhaka City[19] revealed that the birth-order of the child was important as 58% of children were first born and 33% were second born (p value<0.001).

In the present study, majority (54.5%) mothers were of 16-26 years age group at birth of the child and 45.5% were of 27-40 years age group. The mean (±SD) of the age of mother was 26.79±5.73. A study conducted in Bangladesh[20] revealed that maximum (59.0%) mothers were of 31-40 age groups and the mean±SD (33.6±5.7). This variation is because in the present study age of mother was considered age at birth of the children. Regarding educational qualification of parents, majority (45.5%) father and majority (31.8%) mother were educated up to masters' level. A study conducted in Dhaka[19] revealed that maximum mothers (62.0%) were graduates. Again, maximum (67.5%) father were service holder, whereas majority (89.0%) mothers were housewives, which has similarity with the studies conducted by Nahar[20] and Khan[21].

Consanguineous marriage is thought to be one of the causes of developmental disorders. Off all the ASD children 9.1% parents had history of consanguineous marriage. A study conducted in Dhaka[19] showed 10.9% parents had history of consanguineous marriage, which is an almost similar finding with the present study. The study revealed that, majority (41.6%) family had monthly income 20001 – 40000 Tk. and the mean monthly family income was 41785.71 Tk. According to the Bangladesh Bureau of Statistics[22] total average monthly household income was Tk. 11479.00. In the present study monthly family income is more because per capita income of Bangladeshi people has increased and the present study was conducted in Dhaka city.

In the present study, most (81.2%) of the children received treatment instantly after initial complaints of ASD. Maximum (81.2%) children were treated instantly because now good numbers of the people are aware about ASD and its treatment facilities. The government of Bangladesh and few private organizations are continuing awareness program since last decades. Low socio-economic condition and stigma were the reasons for not to taking instant treatment. Maximum (96.8%) children were treated initially by specialist doctors because now specialist doctors are available in all levels of healthcare facilities mainly in district.

According to the present study, majority (74.0%) children were diagnosed in government hospitals because diagnostic facilities of ASD were available in tertiary level government hospitals and treatment costs in these government hospitals were also less than specialist chamber and private hospitals. Moreover, paediatric neurologist, psychologists, diagnostic and other facilities were available mainly in government hospitals.

In the study, half of the children were diagnosed at the age of 3-4 years and the mean (±SD) age of diagnosis was 2.86 ± 1.17 years. The identification of an ASD is difficult before the age of about 12 months but diagnosis is ordinarily possible by the age of two years[2]. A study was conducted by Sun[16] revealed that the mean age for diagnosis was 2.8 years old (range: 1.7, 6.8) which is similar with the present study. Among all the children, majority (74.7%) had used different types of therapy. Off the children (74.7%) who used therapy, most (89.6%) of them used speech therapy followed by occupational therapy (64.3%), physio therapy (43.5%). A study conducted in USA[6] and indicated that, speech therapy being the most common (87.3%) service for children diagnosed with autism followed by occupational therapy (67.5%). A survey was conducted in North Carolina, USA by Thomas[23] revealed, 83% of families used speech and language therapy, 64% of families used occupational therapy, 28% used social skills training and 11% used physical therapy. These results are almost consistent with the present study and few deviations are due to understanding, knowledge and socio-economic difference between Bangladesh and USA.

Regarding the improvement of quality of life of the children followed by use of therapy, among the children (74.7%) who used different types therapy, majority (95.7%) had improvement of quality of life. A qualitative research was conducted by Rahman[24] showed that overall all participants' children had a good change in socialization and most of the participant's children had a good change in play skills.

The primary goal of special schools is to enable the students to adapt to the environment and increase their learning ability. Curriculums of special schools are designed to develop the children according to the individual ability plan (IAP). Off all, majority (79.2%) children were attended special school. In 2003, Järbrink[25] conducted a pilot study in UK and found all of the children were either in a special school setting or had special support in a mainstream school.

Regarding siblings of ASD children, out of all, 3.2% siblings were suffering from ASD. A study was conducted in Dhaka[18] found that 8.7% siblings had autism. Another study was conducted by Barbaresi[3] stated that the recurrence rate in siblings of children with autism is between 2% and 8%, increasing the risk of having a second child with autism nearly 50-fold over that in the general population. These differences of results with the present study may be due to variation in time, place and condition of the studies.

Conclusion

Autism spectrum disorder is increasingly recognized as a major and growing public health problem in Bangladesh. It poses a huge socioeconomic burden to the families of the victims. Since ASD is a growing public health problem in the world and also in Bangladesh, countrywide proper early diagnostic facilities, especially in peri-urban and rural areas, should be available to measure its actual burden in the country. The study recommended undertaking cost-effective measures like subsidized or free of cost treatment, special education and therapy facilities to reduce the socio-economic burden of families for the children with ASD.

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