Original article:

Socio-demographic status of Children with Autism Spectrum Disorder and their Parents in Dhaka city

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Abstract:

Background: Autism spectrum disorder (ASD) has increased dramatically in the last two decades in the whole world. ASD hampers child's and their parent's quality of participation in everyday life. This study examined socio-demographic status of ASD children and their parents in Dhaka city, Bangladesh. Methodology: This is a descriptive type of crosssectional study. Total 44 parents of Autistic children were interviewed, excluding 9 non respondent parents. We collected data by using self-administered questionnaires. Data was analyzed in SPSS-16. Results: Majority (52.3%) ASD children were within 11-15 years. 75% of them had 2-4 siblings and 95.5% of them had no health insurance for themselves or their parents. About parents of ASD children, majority (34.1%) were between 41-50 years old, 90.9% of the participants were mother, 90.9% were married, 79.5% parent lives in a nuclear family, 75% of them were unemployed and most (29.5%) of them are with medium education (HSC). However, male female ratio of ASD children was 2.05:1 in our study. Conclusion: The findings from this study indicated that parents of children with ASD are with medium education. They are unemployed and with no medical insurance either for themselves or for their children. Again, abetter study design is needed in future to collect gender of all selected ASD population.

Keywords: ASD children, pParents of ASD children, Dhaka city

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Introduction:

Autism is a neurodevelopmental disorder with lack of social interaction, verbal and non-verbal communication and repetitive behavior. So, the term of 'autistic' sometimes referred to as 'autism spectrum disorder', ASD^{1,2,3}. It has the common symptoms such as impaired communication, difficulties in social interaction and individual patterns of behavior, poor sleep and motor skill (MS) deficits⁴. ASD is affecting almost 1% of the population⁵. In 2014, the Centers for Disease Control and Prevention's Autism and Developmental Disabilities Monitoring Network reported that approximately 1 in 68 children in the United States have an Autism Spectrum Disorder.

In the 1980s, autism prevalence was reported as 1 in 10,000. In the 1990s, prevalence rate was 1 in 2500 children and later 1 in 1000⁶. This may due to either communicable disease are on main focus at that time or in these last few decades ASD prevalence is actually increased. In Bangladesh 2013 pilot study, utilizing community health workers, has found prevalence of all kinds of neurodevelopmental disability is 7.1%. Whereas, for ASD, the study indicates a prevalence of 0.15% (3% in Dhaka city and 0.07% in rural area)⁶.

ASD hampers child's quality of participation in everyday life^{7,8}, which eventually hampers parent's physical, mental and social health. These children will often require specialized schooling

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and other community resources. Although the survival of these children may not be seriously affected, but they need treatments throughout their lifetime, and the cost to the public health care system wouldbe huge. When they reach adulthood, productivity is often lower than those with traditional developmental children. In that way the ASD child becomes a societal burden⁹. Boys (XY) are at higher risk for autism than girls (XX). The ratio of boys to girls varies from 2:1

Boys (XY) are at higher risk for autism than girls (XX). The ratio of boys to girls varies from 2:1 to 5:1, depending on the different studies¹⁰. There is a study onmale female ratio in Bangladesh, in which the ratio is 3.4:1¹¹.

Forall the management styles of ASD children and their caregiver within public health budget, it is important to know the target population very well. In Bangladesh, although there are some published data about ASD children, there are very few published data about socio-demographic statusof their parents. Therefore,in this study we aimed to focuson socio-demographic status of ASD children and their parents in Dhaka city of Bangladesh.

Methodology

In this study, we performed a descriptive type of cross sectional study. Ethical approval was taken from human ethical committee of State University of Bangladesh (SUB) before selection of special school. After that the clearance and written consent were received from secretary general of special school. Some special schools were selected by simple random sampling. Participants werealso selected by simple random sampling. All participants were parents of ASD children. All participants gave their written informed consent before fillingoutquestionnaires.

Parents of ASD diagnosed children were selected by simple random sampling. Total 53 parents were selected.9 of them were non-respondent.We interviewed with the parents of ASD diagnosed childrenin the special school, when they came to drop their child to school or to pick up their child. Most of our participants were used to selfadministered questionnaire. So, selfadministered questionnaire was used here to get better response. The completed questionnaires were collected, checked for completeness and clarity, and then were compiled. The data from the complete filled up questionnaires were analyzed by means of SPSS - 16 (Statistical Packages for Social Sciences) software program.

a) Distribution of ASD children by age

Child age	Frequency
below 5	7 (15.9%)
6-10	8 (18.2%)
11-15	23 (52.3%)
16-20	5 (11.4%)
above 21	1 (2.3%)
Total	44 (100%)

b) Number of children in the family including this one

Number of siblings	Frequency
One	9 (20.5%)
2-4	33 (75%)
above 4	2 (4.5%)
Total	44 (100%)

c) Frequency of medical insurance for the ASD children or their family

Medical Insurance	Frequency
Yes	2 (4.5%)
No	42 (95.5%)
Total	44 (100%)

Table 1 : Socio-demographic status of ASD children

Results

Almost half of the ASD children, 52.3% (n=23) were between 11-15 years of age (Table1a). Mean age of children was 11.68 ± 4.69 years, minimum 3 years and maximum 24 years. 75% (n=33) ASD children had 1-3 siblings (Table1b). Only 4.5% (n=2) of ASD children had medical insurance for themselves and/or for their family (Table1c).

Socio-demographic status of parents shows that,

a) Distribution of respondents by age

Age of the Participant	Frequency
21-30	9 (20.5%)
31-40	13 (29.5%)
41-50	15 (34.1%)
51-60	6 (13.6%)
Above 61	1 (2.3%)
Total	44 (100%)

b) Respondents relationship with child

Relation with child	Frequency
Father	4 (9.1%)
Mother	40 (90.9%)
Total	44 (100%)

c) Distribution of family types

Type of Family	Frequency
Joint	9 (20.5%)
Nuclear	35 (79.5%)
Total	44 (100%)

Table 2: Socio-demographic status of parents

a) Distribution of respondent's marital status

Marital Status	Frequency
Married	40 (90.9%)
Divorced	4 (9.1%)
Total	44 (100%)

b) Distribution of respondent's employment status

Employment status	Frequency
Employed	11 (25%)
Not Employed	33 (75%)
Total	44 (100%)

c) Distribution of participant's educational status

Educational status	Frequency
Below SSC	8 (18.2%)
SSC (10th gread)	8 (18.2%)
HSC (12th gread)	13 (29.5%)
Bachelor	9 (20.5%)
Above bachelor	6 (13.6%)
Total	44 (100%)

 Table 3:Distribution of respondents

among the total respondents, majority 34.1% (n=15)were between 41-50 years of age (Table 2a). Mean age of respondents was 40.91±9.53 years, minimum 22 years and maximum 62 years of age. 90.9% (n=40) were mothers and 9.1% (n=4) were fathers (Table 2b). We find that, 79.5% (n=35) respondents were from nuclear family, where 20.5% (n=9) were from joint family (Table 2c).

Table 3 shows that, 9.1% (n=4) of respondents were divorced (Table 3a). Besides these, 75% (n=33) of participants were not employed (Table 3b). Educational statusof parents shows that,29.5% (n=13) respondents were up to HSC. Again, 20.5% (n=9) respondents were passed bachelor degree (Honors degree). Where, below SSC and

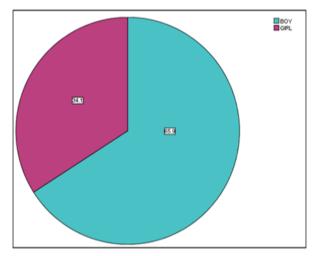


Fig. 1: Gender distribution of the ASD children

up to SSC is same, 18.2% (n=8). On the contrary, 13.4% respondents (n=6) were passed above bachelor degree (Table 3c).

We also analyzed gender distribution amongASD children. 65.9% (n= 29) ASD children were male (XY) and 34.1% (n= 15) ASD children were female (XX). However, in our study, the ratio of boys and girls of ASD children were 2.05:1.

Discussion

In this study, most of the ASD children (52.3%) were within 11-15 years, 75% of them had 2-4 siblings and 95.5% of them had no health insurance. Previous one study¹¹ in Bangladesh mentioned that, 32% (most of the children) of them were 7-9 years old, and only 18% were 10-14 years old. Our result was contradictory comparing with that case. And that study also mentioned that the autistic children were born (58%) as a first child. In our study we did not search the position of the children but the number of siblings, where greater part (75%) had 2-4 siblings, who are traditional

developmental child.

Regarding parents of ASD children, majority of parents (34.1%) were between 41-50 years old, 90.9% of them were mother, 90.9% were married, 79.5% lives in a nuclear family, 75% of them were unemployed and majority (29.5%) of them were with medium education (HSC). We compared this demographic status of parents with another study¹¹. According to that study, 87% of parents were from nuclear family, and we had 79.5% of nuclear family which was nearly consistent with their study. About this similarity, our observation is, they live in a nuclear family, because; either many of them came from periphery of the country to Dhaka city with the hope of better management and treatment of their child and live in a nuclear family. Or they are not getting any social or mental support to take care of their ASD child from their family members which influence them to become separate from their joint family (Table 2c). Again, in our study, majority of (29.5%) ASD parents had medium education (Table3c). In this survey, we found caregiver/parents of ASD childrenhave no medical insurance for their own or their special child; they are ignoring their own health (Table1c). Either they are not regularly checkup their own health. Or, if they are diagnosed ashypertension, diabetes, or any other manageable disease, they are not taking any medication or even any specialist's advice. They are doing this either they are spending their entire budget for their special child or they are depressed enough to take care of themselves. In future, since they are already financially burden without any job, this situation would create a social burden on them (Table3b).

Finally, the male female ratio in our study was 2.05:1, which is consistentwith all other studies^{10,11,12}.One study mentions that ASD is more frequent in boys than girls 12. Here, we found chromosomal dominance which is consistent with another study¹⁵. Our observation is, it may occur for two reasons. Firstly, female ASD children are more ignored by their family and are not registered in school or any government disability fund. So in the studies they might not be included. Again, when all study conducted, there is a huge number of non-respondents rate (in this study 9 out of 53, 16.98%). We even do not know the gender of the childrenof non-respondent's case. So there is a chance of false result of gender distribution. In both above possibilities, it needs social science interpretation and a better study design in future

to detect at least the gender of ASD child of non-respondent participants.

Conclusion

As it can be gleaned from the study, majority of ASD children were within puberty and they are growing up with 2-4 siblings. Caregivers are generally mothers who are at above their middle age. The larger part of parents lives in a nuclear family. Although, maximum of them were with medium education (HSC), unemployed and had no medical insurance for their ASD children or for themselves. However, like other studies, this study shows that, ASD is a male dominant neurological disorder. A better study design is suggested in future to collect at least gender information of the all selected ASD population.

Limitations of the study: The current study has small population of respondents. Large sample

size might give us more reliable information about ASD socio-demographic status.

Conflict of interest: None. Author's contribution:

FAB designed the study and collected data. ASMMHR and FAB performed data analysis. ASMMHR and MSI completed the final draft of this manuscript.

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