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 cross-sectional 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, a better study design is needed in future to collect gender of all selected ASD population.

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

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’, ASD¹⁻³. 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 life⁷⁻⁸, 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 would be huge. When they reach adulthood, productivity is often lower than those with traditional developmental children. In that way the ASD child becomes a societal burden. 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 studies. There is a study on male female ratio in Bangladesh, in which the ratio is 3.4:1.

For all 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 status of their parents. Therefore, in this study we aimed to focus on 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 were also selected by simple random sampling. All participants were parents of ASD children. All participants gave their written informed consent before filling out questionnaires.

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 children in 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 self-administered questionnaire. So, a self-administered 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.

### Results

Almost half of the ASD children, 52.3% (n=23) were between 11-15 years of age (Table 1a). 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 (Table 1b). Only 4.5% (n=2) of ASD children had medical insurance for themselves and/or for their family (Table 1c). Socio-demographic status of parents shows that,

#### Table 1: Socio-demographic status of ASD children

| 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%) |

#### Table 1: Socio-demographic status of ASD children

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

#### Table 1: Socio-demographic status of ASD children

| Medical Insurance | Frequency |
|-------------------|-----------|
| Yes               | 2 (4.5%)  |
| No                | 42 (95.5%)|
| Total             | 44 (100%) |
### Table 2: Socio-demographic status of parents

| 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%) |

### Table 3: Distribution of respondents

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

### Table 4: Distribution of respondent’s employment status

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

### Table 5: Distribution of participant’s educational status

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

**Table 2:** Socio-demographic status of parents  
**Table 3:** Distribution of respondents  
**Table 4:** Distribution of respondent’s employment status  
**Table 5:** Distribution of participant’s educational status
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 status of 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

devitational 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 study. 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 (Table 3c). In this survey, we found caregiver/parents of ASD children have no medical insurance for their own or their special child; they are ignoring their own health (Table 1c). Either they are not regularly checkup their own health. Or, if they are diagnosed as hypertension, 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 (Table 3b).

Finally, the male female ratio in our study was 2.05:1, which is consistent with all other studies. One study mentions that ASD is more frequent in boys than girls. Here, we found chromosomal dominance which is consistent with another study. 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 children of 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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