

Towards Sociology of Autism: A Case Study on the Parents of Autistic Children in Dhaka City

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Abstract

Autism that is a pervasive developmental disability is rapidly growing in our world today, being manifested as inability to develop normal social relationship and communication. The present study, hence, seeks to understand autism as a social problem and its consequences on society. With this regard, a total of 240 parents of autistic children were selected for collecting data from four autistic institutions of Dhaka city using quantitative technique like structured questionnaire. In order to validate the quantitative data, qualitative technique like FGD was also employed in the study. The study finds that most of the autistic children face language and communication problem (40.83 %). The most significant problem faced by autistic children in their daily life affairs is sleeping (28.33%). The study also shows that the parents of autistic children face various difficulties especially stress in their daily lives (47.08%). In addition, 90 percent respondents opine that they are neither supported by the structural or community level nor by NGOs in order that their autistic children cannot be labeled as a burden for society. The study concludes suggesting some recommendations through which autistic children can be considered to be asset instead of burden for society.

Keywords: Towards Sociology, Autism, Parents of Autistic Children

Background

Autism is a neurological, pervasive developmental disorder, which is still a mysterious and a complex disorder evident before 30 months of age, in which there is a profound and general failure to develop normal social relationships, together with delayed and deviant language development

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and the presence of ritualistic or compulsive phenomena. Leo Kanner, a former child psychologist at Johns Hopkins University, first introduced autism to medical literature in 1943 (Hill & Uta, 2003). All the epidemiological studies show a significantly greater number of boys than girls with autism. Male to female ratios vary from 2:1 (Giadella & Mabelle, 1989) to almost 3:1 (Steffenburg & Gillberg, 1986). The sex ratio seems to vary with ability: most girls with autism are at the lower end of the ability range, while at the more able end boys may outnumber girls 5:1 (Lord & Schopler, 1987) with male: female ratio of 4:1 (Hirtz, Thurman & Gwinn-hardy, 2007). Historically autism was considered a form of social withdrawal by vulnerable children from emotionally cold, rejecting, "refrigerator mothers" (Bettelheim, 1967; Kanner, 1943). Little is known about what causes autism, but some theories exist. Autism research reports suggest that autism is triggered by a virus or genetic disposition. Or autism may be caused by intrauterine, prenatal, or neonatal stress or trauma (Waldron, 2000). There is a growing concern that toxins and pollution in the environment can also lead to autism.

The number of people diagnosed with autism has increased dramatically since the 1980s in developed countries but some later in developing countries. In The United States of America autism is diagnosed in one in every 166 births (Autism Society of America, 2007). In the 1990s, in the United States of America, the autism increase was 172% (Autism Society of America, 2007). In the United Kingdom 38.9 in every 10 000 children are diagnosed with autism. Simplified, this is a ratio of 1 in 257 (The National Autistic Society, 2007). Autism affects one in 158 children under the age of six in South Africa (Autism Western Cape, 2007). Current prevalence rates of Autism are 1 in 160 children in Australia, 1 in 100 in United Kingdom and 1 in 91 in the United States. The prevalence rate of autism in India is 1 in 250 and currently 10 million people are suffering in India ("Report Casts Shadow," 2013). The government is going to count the number of autistic children in Bangladesh. About 10% of Bangladesh's people are challenged of those, 1% is estimated to be autistic, amounting to around 1.5 lakh people (Shegufta, 2012). There will be around 76,000 children with ASD under the age of five in Bangladesh if we consider prevalence rate of India

Sociologists are now thinking about the issue of autism. Perhaps as sociologists spend more time watching how children with autism are taught to navigate the social world and how socialization despite disability still determines. Sociologists are well positioned to weigh on

how autism is diagnosed and treated, and how families and other social institutions cope with the challenges associated with it. Though, sometimes, being reluctant to study biological and genetic disabilities, sociologists especially in Western Europe and Australia are beginning to make important contributions to both public and medical understandings of the conditions underlying autism and how to deal with them most effectively. But there has no dynamic sociological study conducted on autism in Bangladesh to overcome the problems of autistic children and challenging issues of parents to cope with society in difficult situation. The present study, hence, needs to analyze autism from sociological perspectives.

The study is conducted taking into account that autism affects girls and boys of all races and in all geographic regions and has a large impact on children, their families, communities and societies. People see autism as a problem due to their impairment of reciprocal social interaction e.g., appearing aloof and indifferent to others, not fully understanding the meaning of common gestures, facial expressions or tone of voice. (Frith, 1989) Difficulties in social understanding mean that the simplest interactions are fraught with problems. Inability to cope with change and the need to adhere to fixed routines and patterns of behavior can make every-day life threatening and disturbing (Howlin, 1991). The inability to engage in social play, to join in with the activities of their peer group, or to form close friendships are well documented (Schopler & Mesibov, 1983). Parents with autistic children have felt stigmatized in public situations such as supermarket or a shopping mall (Gray, 1993). Parents of autistic children are considered to be at a higher risk for depression, social isolation and marital discord. Some parents go through periods of disbelief, deep sadness and depression and self-blame and guilt whereas others experience helplessness, feelings of inadequacy, anger, shock and guilt (Gupta & Singhal, 2005). Social interaction problems are forming attachments and showing affection, parents of autistic children denied fundamental rewards of parenthood. Parents of children with autism face greater challenges than other parents (Laura, Schieve & Blumberg, 2007). Still, the most basic questions about autism and the broader implications they raise are the most intriguing to sociological readers and researchers.

Objective of the Study

The main objective of the study is to understand autism from sociological perspectives. To achieve this purpose, the study seeks to detail two questions:

- *Is autism a social problem?*
- *What are the consequences of autism on society?*

Autism: Sociological Understanding

Though classical sociologists were not concerned about theorizing on this particular area, autism as a public health problem can be explained from different sociological approaches: *Parsonian functionalism*, *Symbolic interactionism*, *Marxism*, *feminism* and *Foucauldianism*. Parsonian functionalism is centered on the role the sick person plays in society. This perspective requires the social responsibilities to cure the patient(s) in order that the equilibrium can be restored and the disequilibrium cannot be furthered due to the sick role. Symbolic interactionism seeks to understand how the assimilation between the different role players in the health and illness drama is constructed through the doctor-patient interaction. Marxist theory explains the concepts 'health' and 'illness' in connection with capitalism as a social organization, focusing on how health and illness are addressed by economic activity in capitalism (Nettleton, 1995). Feminist theory sees the illness and treatment of patients in terms of their gendered nature, where a medical treatment encompasses male domination over women's bodies and identities (Lesley, 1995). Foucauldian theory describes how the dominant medical discourse addresses normality (health) and deviance (sickness) and plays an important role in the management of individual bodies (Evans & Ellie, 2002).

Study Design and Methods

Study Population and Data Collection

The present study is based on mixed methods. Data have been collected from the study areas from April to May 2014. Quantitative technique like a structured questionnaire survey was used to collect data on the parents of children with autism. Also qualitative techniques like FGD and semi-structured questionnaire were conducted in order to authenticate quantitative data. The data of this study were collected from four autistic welfare institutions of Dhaka city: Shymoli (Society for Welfare of Autism Children), Mohammadpur (Autistic welfare Foundation), Lalmatia (School for Gifted Children) and Mirpur (Autistic Children's Welfare Foundation). A total of 240 parents of autistic children were selected based on simple random sampling by considering the fact that most of the parents face homogeneous societal problems for their autistic children. However, while collecting data some target respondents were found to be unavailable. In this situation, alternative respondents were selected in order that the overall sample size was achieved.

Data Analysis and Ethical Issues

After the completion of the fieldwork for the descriptive instrument, SPSS Version 20 was used to code data. Then descriptive statistical analyses were advanced by using tables. This study did not use any unethical means to collect information. Voluntary sharing of the respondents as well as confidentiality of their information was strictly maintained and to monitor any potential risks associated with participation in the study. While interviewing the respondents, force and coercion were avoided and their privacy was safeguarded.

Study Findings*Personal and family information of the respondents*

In total 240 parents of autistic children participated in our study. It focuses on the condition of autistic children and their family members. From the table-1, it is evident that most of the autistic children ages (65.00%) was ranged from 11 to 15 years.

Table-1: Information about autistic children

Autistic Children	N	%
Age (in year)		
<4	7	2.92
5-10	52	21.67
11-15	156	65.00
>16	25	10.42
Total	240	100.00
Gender		
Male	180	75.00
Female	60	25.00
Total	240	100.00
Religion		
Islam	225	93.75
Other	15	6.25
Total	240	100.00
First diagnosed age		
0-2	75	31.25
3-5	120	50.00
6-8	30	12.50
9-11	5	2.08
12-14	5	2.08
>15	5	2.08
Total	240	100.00

In terms of gender, most of the autistic children were found to be male (75.00%) where boys are at the level of high risk for ASD and most of the children were Muslim (93.75%). However, autism cannot be diagnosed at the time of birth. When the respondents were asked to

expose their first diagnoses age, 50.00 percent autistic children were found to be diagnosed at the age of 3 to 5 years.

From the table-2, it is seen that the majority of the respondents (68.75 %) were less than 35 years old. As reported by nearly 89.58 percent respondents, their monthly incomes exceeded Tk. 20,000, which clearly indicates that most of the autistic children were come of rich family. The study found above 90 percent of the respondents as literate. In terms of household goods, more than 85 percent of the respondents answered positively.

Table-2: Socio demographic features of the respondents

Socio demographic	N	%
Age		
<35	165	68.75
>35	75	31.25
Total	240	100.00
Household Income		
< 20,000	25	10.42
> 20,000	215	89.58
Total	240	100.00
Education		
Illiterate	20	8.33
Literate	220	91.67
Total	240	100.00
Household Goods		
Highly Priced	205	85.42
Normal	35	14.58
Total	240	100.00

Autism a social problem

Autistic children are unable to successfully communicate and interact with others. Children with ASD may have difficulty developing language skills and understanding what others say to them. They also may have difficulty communicating nonverbally, such as through hand gestures, eye contact, and facial expressions. Autism is not only a problem to the family members but also to the people of the society. It is one kind of life-long disease. Most of the people do not afford proper interaction with autistic children whereas they interact with other disease patients. They take autism as a curse of Allah. For these reason autism become as a problem to adapt her/him in society and most of the time family members feel stress for their children. In this study, some common problems of autistic children are found as evident from table-3.

Table-3: Percentage distribution about the Problems of autistic children

Problems	N	%
Common Problems		
Sensory integration dysfunction	24	10.00
Language & communication problem	98	40.83
Social development problem	95	39.58
Behavioral problem	23	9.58
Total	240	100.00
Daily life problems		
Sleeping problem	68	28.33
Toileting problem	48	20.00
Playing problem	48	20.00
Eating problem	76	31.67
Total	240	100.00
Social developmental problems		
Social cues	55	22.92
Sharing	43	17.92
Fail to develop peer relationship	76	31.67
Responsiveness	26	10.83
Lack of social or emotional reciprocity	40	16.67
Total	240	100.00

This data set shows that more than 40 percent of autistic children face language and communication problem followed by social developmental problem (39.58%), sensory integration dysfunction (10%) and behavioral problem (nearly 9%). In case of daily life affairs, they face some problems related to eating (31.67%), sleeping (28.33%) as well as both toileting and playing (20%). In addition, the autistic children face social problems where most of them (31.67 %) failed to develop peer relationship following some other problems which relate to social cues (22.92%), sharing with others (17.92%), social or emotional reciprocity (16.67%) and responsiveness (10.83%). These problems do upset the parents of autistics children. As an FGD participant puts it:

I cannot express my sorrows about how much problems I face everywhere due to my autistic child. That gives pain all the family members in every sphere. My child is discriminated in the society considering her as workless or fruitless. She is underestimated for inability to communicate with others. Consequently, society departs her from social activities. Thus, both my child and family members are being deviant from the mainstream socio-cultural practices and stigmatized by the different individuals of the society (32 Years Old Fatema Begum, Field Work, Dhaka).

How autism is addressed by society

It is found in the study that society addresses autism as a problem. 67.50% household members see it burden whereas merely 6.25 percent household members shows friendly behavior with them and 7.08 percent feel pity with autistic children. When relatives get together, nearly 60 percent parents do not willingly introduce their children with relatives. The study also finds that the attitude of the majority neighbors (48.33%) towards the autistic children were found to be very discriminatory while 14.58 percent regard them as the disgrace to the family, 23.76% see them as funny and merely 13.33% feel pity towards them. This study also finds that nearly 65 percent of autistic children face obstacle to move to their school, approximately 13 percent of them cannot get any help from their classmates (see table- 4).

Table-4: Autism addressed by society as problem

Autistic addressed by society	N	%
Attitude of other household members towards autistic children		
very bad	40	16.67
very good	6	2.50
Friendly	15	6.25
Burden on family	114	67.50
They feel pity	65	7.08
Total	240	100.00
Willingly introducing autistic children with relatives		
Yes	102	42.50
No	138	57.50
Total	240	100.00
Attitude of neighbors towards autistic children		
Disgrace to the family	35	14.58
They find funny	57	23.76
Nothing to do with them	0	0
Very discriminatory	116	48.33
They feel pity towards of them	32	13.33
Total	240	100.00
Obstacle to achieve education		
Obstacle to move to school	153	63.75
Non-cooperation by classmates	33	13.75
Lack of care by teachers	12	5.00
Others	42	17.50
Total	240	100.00

Autism and its Consequences on Family Members and Society

The table 5 shows that no parent was found without facing problems. For their autistic children, all the parents face numerous problems related to behavior, sleeping, community, eating and socialization. As FGD participants, for instance, put it:

Autistic children are treated as mad person in the society. When I take my child to a park, he behaves 'abnormally' and therefore people misbehave with them by labeling "mad" or "Psycho". This humiliation, rejection makes me feel bad. I feel humiliated, stigmatized and become isolated in social interaction because of my child. People didn't communicate, cooperate with me. In such progression, I found my autistic child a burden for me (25 Years Old Mily, Field Work, Dhaka).

Parents also face various difficulties in their lives such as stress as reported by almost 50 percent of them followed by other problems such as social discrimination (27.50%), sleeping problem (10.42%), financial problem (8.75%) and divorce for autistic child (6.25%). The similar trends of data have been reflected in the qualitative findings. As an FGD participant puts it:

I gave birth to a boy after two years of marriage. He was a good looking boy and my husband was pleased with me but when he knew about the illness (autism) of the boy, he began to misbehave with me. Sometimes he underwent battering. His family members started blaming me on baby's state. This matter finally ended up with a divorce (28 Years Old Rubi, Field Work, Dhaka).

The study also shows that parents cannot be freed from tension about their children even they feel uncertainty in future life of their children because their children cannot expose their names and cannot do normal eye-contact with others as reported by respectively 20.83 and 84.58 percent of the parents. 68.75 percent parents of autistic children informed that they could not join in various social or religious ceremonies for their autistic children due to their children's incapability of coping with new environment and of taking any food items in new places. When the teachers of the autistic schools were asked about their education, they unfortunately showed negative attitude towards the policy makers of our country, reporting the high cost of education in those schools. Almost 50 percent teachers reported this cost as to be ranged from Tk. 3000 to 3500 and nearly 40 percent said that the monthly expenditure for autistic children were Tk. 3500 to 4000. As reported by 70 percent of the parents, GOs' and NGOs' contribution to the betterment of autistic children were not sufficient. The similar trends of data have been reflected in the qualitative findings. As FGD participant, for instance, puts it:

“Despite the problems such as discrimination, deviation from the mainstream rituals, stigma and labeling as unproductive part of society, we did not observe significant measures and policies to be taken by GOs or NGOs through which autistic children can apply their inherent competencies and potentialities for contributing to the society. They also shared that they have exclusive potentialities in different areas like mathematics, painting, innovation etc. that the policy makers are not concerned.” (31 Years Old Rayhan, Field Work, Dhaka).

Table-5: Social consequences of autism on society

Social consequence	N	%
Problem faced by parents		
Yes	240	100.00
No	0	0.00
Total	240	100.0
Parental Problem		
Financial	21	8.75
Stress	113	47.08
Social stigma	66	27.50
Divorce problem	15	6.25
Sleeping problem	25	10.42
Total	240	100.00
Response his / her name		
Yes	190	79.17
No	50	20.83
Total	240	100.00
Normal eye- contact		
Yes	37	15.42
No	203	84.58
Total	240	100.00
Participation in social & religious ceremonies		
Yes	75	31.25
No	165	68.75
Total	240	100.00
Cost in institutions		
2500-3000	32	13.33
3000-3500	119	49.58
3500-4000	89	37.08
Total	240	100.00
Activities of GOs & NGOs		
Sufficient	24	10.00
Not sufficient	168	70.00
Don't know	48	20.00
Total	240	100.00

Conclusion

The objective of the present study was to understand autism as a social problem and its consequences on the family members and society as a whole. To achieve this purpose, the study employed both quantitative and qualitative techniques of data collection. The study finds that most of the autistic children face language and communication problem (40.83 %) followed by social developmental problem (39.58%), sensory integration dysfunction (10%) and behavioral problem (nearly 9%). Among significant problems faced by autistic children in their daily life affairs are sleeping problem (28.33%), toileting and playing problem (20%), eating problem (31.67%), problem of share with others (17.92%) and failure in developing peer relationship (31.67%). The study shows that the parents of autistic children face various difficulties in their daily lives such as stress (47.08%), victim of discrimination for social stigma from different facilities of societies (27.50%) and divorced by husband (6.25%). In addition, 90 percent respondents opine that they are neither supported by the structural or community level nor by NGOs in order that their autistic children cannot be labeled as a burden for society. The study concludes suggesting some recommendations through which autistic children can be considered to be asset instead of burden for society. *First* of all, the policy makers and the leaders from different sectors of the government should take the proper initiatives to flourish the competencies of autistics children through special educational programs and measures. *Secondly*, GoB should find out the comfortable job areas for autistic children and create opportunities for recruiting them accordingly. *Thirdly*, GoB also should take proper and quick steps in building up alternative care centers for them in the absence of their parents. *Fourthly*, sociologists of Bangladesh should conduct rigorous studies on the *Problems and Consequences of Autistic Children in Bangladesh* and move to the *Sociology of Autism to Medical Sociology*. *Finally*, the significant others should play important role in socializing both the present and future generations, raising the slogan “autistic children are not burden but asset for the society”.

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