

**Original article:**

**Mothers Initial Challenges Having Children with Autism Spectrum Disorders in Bangladesh**  
Tanjina Farhana Upoma<sup>1</sup>, Mst. Sabrina Moonajilin<sup>2</sup>, Md Estiar Rahman<sup>3</sup>, Most Zannatul Ferdous<sup>4</sup>

**Abstract:**

**Background:** Autism, one of the most widespread problems in the world, is rising alarmingly in Bangladesh day by day. Over the most decade autism has become one of the most visible and articulated social issues in Bangladesh. Besides, in our country, journey of a mother with a special child is a challenge. **Objectives:** To find out the experiences and challenges of mothers having children with ASDs. **Materials and Methods:** The study was based on case study method where 20 mothers were selected purposively from Dhaka division. Data was collected using an open ended questionnaire and in depth interviews. **Results:** In this study though majority of the mothers reported having a typical pregnancy with little or no complications. Majority of the mothers had no knowledge about autism before. The average age of children when they diagnosed was 2.9 years. In response to their initial reactions to diagnosis of their child, mothers reported the following emotional states: shock, depression, self-blamed, sadness. Prayer was a clear coping strategy for parents of an autistic child. Most of the mothers reported passing many days with depression and frustration. All the mothers were satisfied with the activities of the current special school. **Conclusion:** Mothers reported about their most challenging part of raising their autistic child were to manage their hyperactivity and social interaction. They realize a strong familial and social support are necessary as it was found as a key factor in adjusting and coping a mother to her challenging life with her autistic child.

**Keywords:** ASDs, mothers

*Bangladesh Journal of Medical Science Vol. 19 No. 02 April'20. Page : 268-272  
DOI: <https://doi.org/10.3329/bjms.v19i2.45006>*

**Introduction:**

Autism, a major concern in today's world, is a form of developmental delay. Autism is not a single disease, but a wide range of symptoms that is called Autism Spectrum Disorders (ASDs)<sup>1</sup>. ASDs also referred to as Pervasive Developmental Disorders (PDDs), are brain-based disorders with a strong genetic component. They are characterized by deficits in verbal and nonverbal communication, social interaction, as well as repetitive or restricted interests and behaviors<sup>2</sup>. According to estimates from CDC's Autism and Developmental Disabilities Monitoring (ADDM) Network, about 1 in 68 children has been

identified with ASD. ASD is about 4.5 times more common among boys (1 in 42) than among girls (1 in 189), making it more common than childhood cancer, juvenile diabetes and pediatric AIDS combined<sup>3</sup>.

At present, autism becomes a panic for the parents throughout the world. The number of autism affected children is increasing rapidly in the world<sup>4</sup>. It is also increasing in Bangladesh at an alarming rate. It's been estimated that 1% of the world's population, suffer from an ASD<sup>5</sup>. Unfortunately, in many developing countries like Bangladesh we have no data for how many children or adults suffer from this lifelong developmental neurological condition<sup>6</sup>. A recent

1. Tanjina Farhana Upoma, Public Health and Informatics, Jahangirnagar University.
2. Dr. Mst. Sabrina Moonajilin, Assistant Professor, Department of Public Health and Informatics, Jahangirnagar University, Bangladesh, email: [moonajilin@juniv.edu](mailto:moonajilin@juniv.edu)
3. Md Estiar Rahman, Public Health and Informatics, Jahangirnagar University.
4. Most Zannatul Ferdous, Lecturer, Department of Public Health, Hamdard University Bangladesh.

**Correspondence to:** Dr. Mst. Sabrina Moonajilin, Assistant Professor, Department of Public Health and Informatics, Jahangirnagar University, Bangladesh. E-mail: [moonajilin@juniv.edu](mailto:moonajilin@juniv.edu)

2013 pilot study in Bangladesh, utilizing community health workers, has found a prevalence of all kinds of neurodevelopment disability is 7.1% whereas, for ASD, the study indicates a prevalence of 0.15%<sup>7</sup> (3% in Dhaka city and 0.07% in the rural area).

Having a child with autism affects the entire family. Autism is such a developmental disability which has a great impact on the family's adaptation and functioning<sup>6</sup>. Parents of autistic children generally avoid social gathering and feel stigmatized in public places. There is a higher risk of anxiety, depression, social isolation and marital discord among parents. Social support is often lost due to the behaviors exhibited by the child with ASD<sup>8</sup>. Having a child with autism not only affects the parenting role, but more to the point defined how they live in their world<sup>9</sup>. A child with ASD restrict the family's ability to plan and pursue recreational and leisure interest, social and community interest and go on holidays and family excursions<sup>10</sup>. Career problems were also common with some parents, particularly mothers, denied any opportunity for outside employment due to their child disability<sup>11</sup>.

Raising a child is definitely a challenge for parents, especially for mothers. But mothers of children with developmental disabilities such as ASDs face additional obstacles and stressors<sup>12</sup>. Mothers have to redefine their journey of parenthood once their child is diagnosed with ASDs<sup>13</sup>. There were several possible reasons for the mothers' greater distress, including greater involvement in child raising, increased exposure to negative social reactions by outside and the absence of employment. Mothers reported their children with ASD needed significant attention, supervision and direction<sup>14</sup>. The sources of stress of mothers were exhausted, being the only person taking care of their child, financial constraints and negative attitude of people towards the child<sup>15</sup>. Religion and family values influence cultural perceptions of autism and the welfare of families<sup>16</sup>. The insensitivity of and negative comments made by the community members resulted in mothers feel shy for their children, which negatively influence their socioeconomic stability<sup>6</sup>.

Children with Autism are one of the marginalized groups in Bangladesh when in consideration to their education, health and social care and life opportunities<sup>17</sup>. Lack of resources for children with autism, such as qualified and trained teachers, appropriate infrastructure, teaching materials and assistive technology as well as the stigma

associated with disability act as barriers to special education and health care for special needs children. The stigma extends from neurodevelopment to neurocognitive disorders. Parents of low-income countries experience a social stigma of having a child with ASD. A study conducted by the National Institute of Mental Health of Bangladesh revealed that more than 50% rural people in the study had faith on traditional healers<sup>1</sup>. Moreover, they considered that the autism and other mental disorders were caused by ill spirits and required some measure other than medication<sup>18</sup>. Bangladesh is a South East Asian developing country with a moderate literacy rate where mental illness is considered as a burden for the country. There is a widespread tendency to stigmatize people with mental illness in the developing countries. The mentally ill people and families are victim of social deprivation, discrimination and injustice.

In this circumstance, this study conducted to determine the initial experiences and challenges of Bangladeshi mothers having children with ASDs.

## **Material and Methods**

### ***Study type:***

The study was customized with the qualitative research approach. Case study method was used.

### ***Study area:***

Dhaka district was selected as study area. Two autistic care institutions of Dhaka district were selected for the convenience of collecting data. One was 'BPF Kollyani Inclusive School' at Mirpur, Dhaka and another was 'Anandoshala' at Jahangirnagar University Community, *Savar, Dhaka*.

### ***Sample size and sampling techniques:***

As the study was conducted on the basis of case study, the sample size was 20 mothers having children with ASD and the sampling technique was 'purposive sampling'.

### ***Data collection tools:***

A guideline with open ended questionnaire was used in the data collection. A Questionnaire was finalized by pre testing. Mothers were first responding to questions that were attempted to gather demographic data such as name, gender of child, age of the mother and the child etc. Then, an open ended interview plan guided the interview to collect information related to the experiences and the challenges of the mothers.

### ***Data collection procedures:***

In depth interview and observation techniques were

applied to collect data. Mothers were interviewed individually, and only one investigator was present during each interview. These interviews were audio taped by tape recorder and noted down where necessary after taking permission from the participants. Each interview session was between 30-40 minutes.

#### ***Data Processing, Analysis and Interpretation:***

The recorded data were transcribed and edited to ensure accuracy of information. The main points of transcribed data were summarized and analyzed in narrative form in MS word.

#### ***Ethical considerations:***

Permission was taken from each participant by using the consent form. At the beginning of the data collection the researcher informed every participant about the ethical and confidential issues. They were informed that data would be used only for the research purpose and confidentiality would be maintained. Then the research participants were requested to sign a consent form which was emphasized the voluntary nature and the aims of the study.

#### **Results and discussion:**

The average age of mothers was 33.45 years. Almost all mothers lived in a nuclear family. Most of them belonged to a middle class society. Almost half of them came to Dhaka and Savar from nearest districts and villages as there were no treatment facilities and mainstream schools. This study showed that there are some relationships with pregnancy and delivery complications to have a child with autism. Though majority of the mothers said having no or typical complications during pregnancies, but some mothers were found to have critical complications during pregnancy and childbirth, which was supposed to be responsible for their child having autism. The Majority (70%) of the mothers gave birth to their children via cesarean section (CS). Among them one case was found to have post dated CS and the baby was not sound after delivery. Another case was found to have severe diarrhea during pregnancy and the mother was admitted in hospital for several days and was treated with high power antibiotic. Six mothers (30%) were found to have a vaginal delivery. Among them one had cervical incompetence during delivery. One had prolonged labor during delivery along with oligohydramnios. Another case was found that the new born got a head injury during normal home delivery at the village. Two cases were found to have premature child and were kept in intensive

care unit (ICU) for one month. There is a genetic role in the etiology of autism as one case was found that the mother had three maternal relatives who were autistic.

#### ***Challenges and experiences of diagnosis of children having autism spectrum disorders***

##### Knowledge about autism before diagnosis:

From majority of the mothers, it was found as a common voice that they had no knowledge about autism before their child's diagnosis. They first knew about autism from the neurologists, from therapists and from the teachers of the special schools. A very few mothers said that they had partial knowledge, but no exact knowledge about autism. All of them gathered their clear knowledge on autism after admitting their children to special schools. Some mothers said that they had doubts whether their child would be cured or not. After admitting them in special school they came to know that autism had no exact treatment and it never be cured. They were now fully informed about autism. This finding was quite different from the study of Koydemir & Tosun<sup>15</sup> where mothers indicated that they were not still fully informed about their child's conditions.

##### Types of abnormal behaviors first noticed:

The average age of the children when some abnormal behaviors first noticed was 1.7 years. Most of the mother expressed having some suppositions that something was different about their child. These were behavioral differences which were reinforced by comparing their child with other children of the same age. They reported that the use of comparison allowed them to notice differences. The most common abnormal behaviors that were first noticed to the mothers were- no speech (most common), poor or lack of eye contact, epilepsy, restlessness, walking delay, gradual loss of speech, lack of interaction, fascination with TV, babbling and not responding to their name. This finding was quite similar to the findings of a conducted in Jamaica in 2013<sup>19</sup> where mothers reported first noticing a number of different developmental concerns like language delay, lack of eye contact and unusual social interactions.

##### Uncertainty before the diagnosis:

There were some uncertainties among mothers about their child's problems. Almost all the mothers claimed that when they noticed some abnormalities in their children they discussed about it with other family members. But they did not take it seriously. Especially the mothers who noticed a speech delay

of their children, when they talked about it with other family members they said that it's not a problem, as many kids are late in talking. All these created some uncertainty and caused late diagnosis to their children. The average age of children when they diagnosed with autism was 2.9 years.

#### Situation around the diagnosis:

The majority of the parents first took their concerns to a child's pediatrician. Some of the pediatrician could not diagnose the problem. The pediatrician referred the child to a neurologist. The tests used for the diagnosis of autism were electroencephalogram (EEG) and computerized tomography (CT) scan. The neurologist suggested the mothers to admit their child to a mainstream school and gave them speech therapy and occupational therapy (OT). Medication was continued for the child who had epilepsy.

#### Initial reactions of mothers:

It was too difficult to express their feelings when they found out their children having autism. In response to their initial reactions to the diagnosis of their child, mothers reported the following emotional states: shock, depression, self-blamed, sadness, emotional emptiness. Some mothers had mental preparation as their child had some problems from the birth. The other mothers said that the news was an 'instant shock' for them. This finding is in accordance with the findings of Koydemir & Tosun conducted in 2009<sup>15</sup> where the emotional reactions of mothers included denial, shock, and severe grief and self-blamed.

#### Mental preparedness for facing all the situations:

Comparison was founded as a source of support for mental preparation. Most of the mothers stated that when they admitted their child to a special school, after seeing other children and their mothers, after sharing their sorrows with each other they became mentally prepared to handle the situation. Besides, their husband and family members helped them to be mentally strong. There were several mothers who reported that they personally made themselves prepared to handle their child as they did not get mental support from their husband and family. All of them kept faith in God; a deep Muslim faith in God, which seemed to provide parents with a great deal of comfort and consolation. It helped them to understand and accept the situation. Doig conducting a study among Bangladeshi parents reported prayer was a clear coping strategy for parents of an autistic child<sup>20</sup>.

#### Coping with all challenges:

Most of the mothers reported passing many days with depression and frustration. Almost all mothers reported that they were trying to cope up their life with their special child and going ahead as there was no other option without coping with the situation. They were always trying to make their child happy and by this way they tried to remain happy and stress free.

A research has emphasized that mothers included 'recognizing the joys' as a coping mechanism<sup>14</sup>. Satisfaction level varied according to the severity of their child's condition along with financial condition. All the mothers were satisfied with the activities of the special school. They all expressed with happy that their children loved the school too much and after admitting in this school they gradually improved.

Mothers reported about their most challenging part of raising their autistic child were to manage their hyperactivity and social interaction. They realized a strong family and social support are necessary as it was found as a key factor in adjusting and coping a mother to her challenging life with her autistic child.

#### Conclusion

In a poor country like Bangladesh, the life of a mother of an autistic child is very difficult. Sometimes they become detached from the society. Sudden news of their child diagnosis of autism can changed all of their hopes. All of their lives have to pass through compromising; sacrificing and adjustment. We can make their life easy by supporting them as much as possible.

#### Conflict of interest:

The authors declared no potential conflicts of interest with respect to the research, authorship, and publication of this article.

#### Authors Contributions:

Data gathering and idea owner of this study: Tanjina Farhana Upoma, M Sabrina Moonajilin

Study design: M Sabrina Moonajilin

Data gathering: Tanjina Farhana Upoma

Writing and submitting manuscript: Tanjina Farhana Upoma, M Sabrina Moonajilin, Md. Estiar Rahman, Most Zannatul Ferdous.

Editing and approval of final draft: M Sabrina Moonajilin, Md. Estiar Rahman, Most Zannatul Ferdous

## References:

1. NIMH (National Institute of Mental Health). NIMH » Autism Spectrum Disorder. 2018:1-8. <https://www.nimh.nih.gov/health/publications/autism-spectrum-disorder/index.shtml>.
2. Zander E. A Parent ' s Guide to Autism Spectrum Disorder. 2011:27.
3. Autism and Developmental Disabilities Monitoring (ADDM) Network | CDC. 2018. <https://www.cdc.gov/ncbddd/autism/addm.html>.
4. *Stress and the Autism Parent \_ Interactive Autism Network*.2017
5. World Health Organization (WHO). Autism spectrum disorders. 2016.
6. Preity S, Delwer M, Hawlader H, Akhter S, Abdullah AS, Biswas A. Views of the Parents of Autistic Children about Autism and Schools for Autistic Children : A Qualitative Study in Urban Bangladesh. *Int J Public Heal Res*. 2017;**5**(5):56-61.
7. CRI. *Global Autism Movement and Bangladesh | CRI*.; 2015. <http://cri.org.bd/2014/09/03/global-autism-movement-and-bangladesh/>.
8. Dzubay S. Parental Grief, Coping Strategies, and Challenges When a Child has Autism. *Month*. 2011.
9. Woodgate RL, Ateah C, Secco L. Living in a world of our own: The experience of parents who have a child with autism. *Qual Health Res*. 2008;**18**(8):1075-1083. doi:10.1177/1049732308320112
10. Dillenburger K, Keenan M, Doherty A, Byrne T, Gallagher S. Living with children diagnosed with autistic spectrum disorder: parental and professional views. *Br J Spec Educ*. 2010;**37**(1):13-23. doi:10.1111/j.1467-8578.2010.00455.x
11. Gray DE. Ten years on: A longitudinal study of families of children with autism. *J Intellect Dev Disabil*. 2002;**27**(3):215-222. doi:10.1080/1366825021000008639
12. Ogston PL, MacKintosh VH, Myers BJ. Hope and worry in mothers of children with an autism spectrum disorder or Down syndrome. *Res Autism Spectr Disord*. 2011;**5**(4):1378-1384. doi:10.1016/j.rasd.2011.01.020
13. Matenge B. An Exploration of the Lived Experiences of Mothers Raising Children with Autism. 2013.
14. Kuhaneck HM, Madonna S, Novak A, Pearson E. Effectiveness of interventions for children with autism spectrum disorder and their parents: A systematic review of family outcomes. *Am J Occup Ther*. 2015;**69**(5):1-14. doi:10.5014/ajot.2015.017855
15. Koydemir S, Tosun Ü. Impact of autistic children on the lives of mothers. *Procedia - Soc Behav Sci*. 2009;**1**(1):2534-2540. doi:10.1016/j.sbspro.2009.01.447
16. Gona. J., Newton. C., Rimba. K., Mapenzi. R, Kihara. M, Vijver. F. Challenges and coping strategies of parents of children with autism on the Kenyan coast. *Rural Remote Health*.2016;**16**(2):3517. <http://ovidsp.ovid.com/ovidweb.cgi?T=JS&PAGE=reference&D=emed17&NEWS=N&AN=616590576>.
17. Dr. Shaker Uddin Ahmed. *Situation Analysis of Autistic Children*.; 2017. <http://www.theindependentbd.com/printversion/details/40798>.
18. Rabbani, M., Helal, A., Mannan, M., Chowdhury, W. A., & Alam MF. Autism in Bangladesh Window for Stigma Removal. In: *2014 International Meeting for Autism Research*. ; 2014.
19. Mann AR. The experiences of mothers of children with autism in Jamaica: An exploratory study of their journey. *ProQuest Diss Theses*. 2013;(January):276. <http://scholarcommons.usf.edu/cgi/viewcontent.cgi?article=5919&context=etd>.
20. Doig S. An exploration of the experience of bangladeshi parents of children who have been diagnosed with an autistic spectrum disorder. *PQDT - UK Irel*. 2012;(May).