

Parenting Stress among Mothers of Children with Autism Spectrum Disorders in Proyash, Dhaka, Bangladesh

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Abstract: *The Autism Parenting Stress Index yields a wide range of stresses associated with parenting children with ASD. It concentrates on and highlights some of the key aspects of daily caregiving that are particularly difficult and stressful, such as behavioral and communicational problems. Indeed, the Index is apparently designed to tap into the more "stressful" aspects of ASD caregiving. The present study focuses on parents who were undergoing different level of stress when dealing with children with Autism Spectrum Disease. A total number of 111 parents of children with ASD, from Proyash, an Institute of special education and Research, Dhaka were purposefully selected for the study. In fact, 78.9% of the mothers displayed parenting stress that was clinically significant. This statistics really portrays the high psychological burden that not just these mothers, but likely other mothers too, have with parenting a child with ASD. And this is made even more salient when we consider the fact that the next main point discusses the dimensions and critical stressors that contribute to this parenting stress and also the disorder itself. The study's findings thus shed light on ways to seriously advocate for psychological and community-based support for the mothers of children with autism in Bangladesh. Access to adequate mental health resources, public knowledge about autism, and strong institutional support may do much to mitigate the stress that mothers in this context experience. This study adds to the scant literature on parenting stress associated with autism in South Asia, and it offers some important insights that are likely to be relevant to a range of individuals working to optimize family functioning in the context of autism.*

Keywords: *Parenting Stress; Mothers of Children with Autism; Autism Spectrum Disorder; Psychological Burden; Bangladesh.*

1. Introduction

Autism Spectrum Disorder (ASD) is a complex cognitive and neurobehavioral condition characterized by a triad of impairments in socialization, communication, and the presence of stereotypical and ritualistic behaviors (Hirtz et al., 2006; Mayers & Johnson, 2007). It is considered one of the most severe and pervasive chronic childhood disorders and is highly complex in its developmental manifestations (Nair, 2004). ASD primarily affects brain regions responsible for social behavior and communication skills (Carper & Courchesne, 2000). Children diagnosed with ASD often display restricted, repetitive, and ritualistic patterns of behavior, interests, and activities, along with significant social deficits, including impairments in verbal and non-verbal communication that hinder the development of reciprocal relationships (Hirtz et al., 2006; Mayers & Johnson, 2007). Autism is typically diagnosed within the first three years of life based on observable

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deficits in social reciprocity, language development, communication, and behavioral flexibility (Glasson et al., 2004; Mayers & Johnson, 2007).

Over the past several decades, the global prevalence of ASD has increased dramatically, with epidemiological research indicating a substantial rise since the late 1960s and 1970s (Nair, 2004; Schultz et al., 2006). International estimates suggest that ASD affects approximately 1% of the global population, with varying prevalence rates reported across different countries (Hirtz et al., 2006; Mayers & Johnson, 2007). Despite this increasing global prevalence, Bangladesh still lacks a comprehensive national epidemiological study on ASD (Rakib, n.d.).

Based on prevalence estimates from neighboring countries such as India, it has been suggested that a significant number of children under five years of age in Bangladesh may be living with ASD (Nair, 2004; Rakib, n.d.). National data also indicate a rising trend in diagnosed cases, as reflected in institutional reports from specialized centers in Bangladesh (Rakib, n.d.). A pilot study conducted in Bangladesh using community health workers reported an overall prevalence of neurodevelopmental disabilities of 7.1%, with a specific autism prevalence of 0.15% (Rakib, n.d.).

Consistent with global findings, ASD is more prevalent among boys than girls, with markedly higher rates observed in males (Hirtz et al., 2006). Beyond its clinical implications, ASD imposes substantial financial, emotional, and psychological burdens on families, with healthcare and related costs significantly higher for children with ASD compared to those without the condition (Mayers & Johnson, 2007).

Raising a child with ASD places considerable psychological and emotional strain on parents, particularly mothers who often serve as primary caregivers (Davis & Carter, 2008; Hastings et al., 2005). Parenting stress refers to the distress associated with the demands of the parenting role, and while some stress is normal, chronic or excessive stress can negatively affect parental well-being, self-efficacy, and family functioning (Keller & Honig, 2004; Whiteside-Mansell et al., 2007). Research consistently demonstrates that parents of children with ASD experience significantly higher levels of stress compared to parents of typically developing children or those with other disabilities (Abbeduto et al., 2004; Allik et al., 2006).

Elevated levels of anxiety, depression, and marital dissatisfaction have also been widely reported among parents of children with ASD (Blacher et al., 2010; Hastings et al., 2005). Furthermore, high parental stress may compromise the effectiveness of therapeutic interventions for children, emphasizing the importance of family-centered approaches that address both child and caregiver well-being (Dardas & Ahmad, 2013; Silva & Schalock, 2012b).

2. Method

The present study was designed to assess the level of parenting stress and its associated factors among mothers of children with ASD attending Proyash, an institute for special education and research located in Dhaka, Bangladesh. The specific objectives of the

study were to determine the level of stress experienced by these mothers, explore their socioeconomic status, identify the key factors associated with parenting stress, and gather parent-driven recommendations for improving the management of children with ASD. Proyash provides multidisciplinary services to children with special educational needs from Bangladesh and beyond and serves as a training and research center for the development of special education professionals and therapists. This institution was selected as the study site given its established role in serving the ASD population.

A quantitative research design was adopted for this study to accurately measure the proportion and level of parenting stress among mothers of children with ASD. The study population included all mothers of children with ASD who were attending Proyash during the period of data collection. A self-selected sampling technique was utilized to ensure the comfort and willingness of participants, recognizing that many parents may be reluctant to discuss their child’s disability. Mothers aged between 18 and 65 years, capable of providing informed written consent, were included in the study, while severely ill or debilitated mothers or those unable to provide consent were excluded.

Data collection was conducted using a pretested, semi-structured interview questionnaire comprising both open and close-ended questions. The questionnaire gathered information on socio-demographic and economic characteristics, as well as specific items designed to assess the level of parenting stress. To ensure a reliable assessment of parenting stress, the Autism Parenting Stress Index was utilized, a tool specifically developed to capture the unique stressors experienced by parents of children with ASD. The questionnaire also included sections where parents could provide recommendations for government and service providers to improve support systems and alleviate their challenges.

All data were analyzed using SPSS version 17. A pretest involving 30 participants was conducted to evaluate the reliability of the Autism Parenting Stress Index, with internal consistency assessed using Cronbach's alpha. This approach ensured that the data collection tools were both valid and reliable, providing a robust foundation for understanding the parenting stress experienced by mothers of children with ASD in the Bangladeshi context.

Table 1: Data Collection Tool: “Autism Parenting Stress Index”

Autism Parenting Stress Index						
	Not stressful	Sometimes creates stress	Often creates stress	Very stressful on a daily basis	So stressful sometimes we feel we can't cope	
Your child’s social development	0	1	2	3	5	

Your child's ability to communicate	0	1	2	3	5
Tantrums/meltdowns	0	1	2	3	5
Aggressive behavior (siblings, peers)	0	1	2	3	5
Self-harming behavior	0	1	2	3	5
Challenges with task switching	0	1	2	3	5
Sleep disturbance	0	1	2	3	5
Your child's dietary intake	0	1	2	3	5
Issues with bowel movement (constipation, diarrhea etc.)	0	1	2	3	5
Toilet training	0	1	2	3	5
Impaired parent-child attachment	0	1	2	3	5
Concern about your child's future social acceptance	0	1	2	3	5
Uncertainty about your child's future independence	0	1	2	3	5

3. Findings of the Study

We have collected data from 111 samples and analyzed those using SPSS vs 16. A pretest was done on 30 samples to check the internal consistency of our scale “Autism Parenting Stress Index” was found .869 which indicates a high level of internal consistency. Findings of study are given below. Our first specific objective was to determine the level of stress among the mothers of children with ASD. We found majority of the mothers were mildly stressed which is 45.9%. Severe stress found in only 5.3% cases and moderate stress level found in 11.3% cases and 21.1% mothers shows no significant stress.

Table 2: Stress level of Mothers of Children with ASD

	Stress Level	Frequency	Percent	Valid Percent	Cumulative Percent
Valid	No Stress	28	21.1	25.2	25.2
	Mild Stress	61	45.9	55.0	80.2
	Moderate Stress	15	11.3	13.5	93.7
	Severe Stress	7	5.3	6.3	100.0
	Total	111	83.5	100.0	

Mothers’ stress regarding child’s social development, we found 1.80% respondents reported no stress, 19.8% said sometimes creates stress, 56.80% reported often creates stress, 19.80% said very stressful and only 1.80% reported it as so stressful sometimes they feel they cannot cope. Regarding Child’s ability to communicate highest percentage seen as 39.60% said it often creates stress and the lowest percentage 1.80% reported very severe stress. Regarding Tantrum, 35.5% reported that they feel it stressful sometimes and 7.20% mothers said it as severe stressful. Regarding the child’s aggressive behavior 36.90% reported that it sometimes creates stress 7.20% reported that it is very stressful. Regarding the self injuries behavior 36% reported it is mildly stressful and only 3.60% reported it is severely stressful. 25.6% mothers said she feels mild stress and 5.40% feels severe stress regarding sleep problem. Moderate level of stress has seen among mothers regarding child’s diet, bowl problem. 26.60% mother reported that she feels severe stress regarding the concern for their child’s future and living independently.

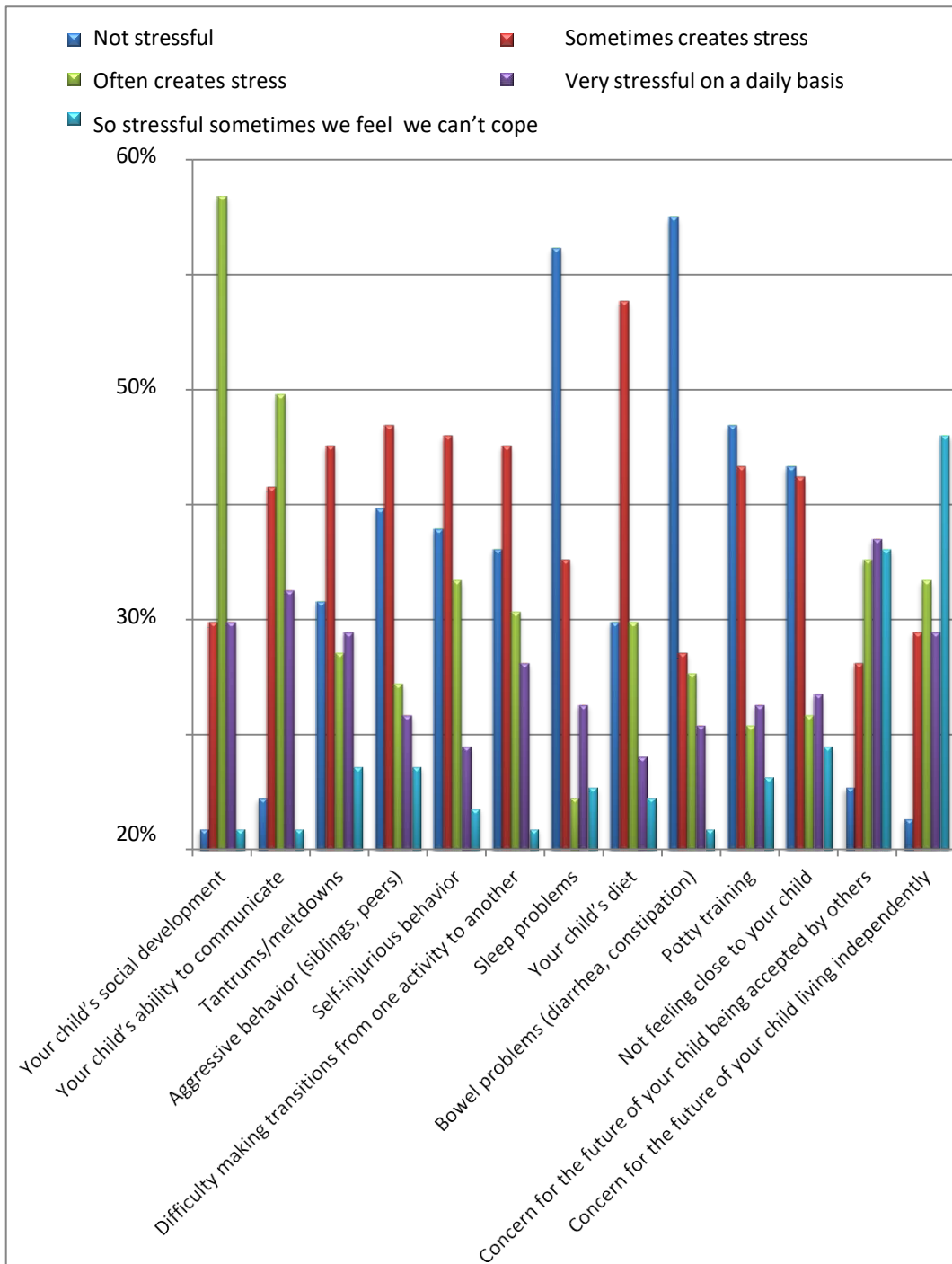


Figure 1: Stress level of Mothers of Children with ASD

Table 3: Distribution of Study participants by their Age

	Age Groups	Frequency	Percent	Valid Percent	Cumulative Percent
Valid	20-24	7	6.3	6.3	6.3
	25-29	16	14.4	14.4	20.7
	30-34	30	27.0	27.0	47.7
	35-39	36	32.4	32.4	80.2
	40-44	12	10.8	10.8	91.0
	45-49	8	7.2	7.2	98.2
	50-54	2	1.8	1.8	100.0
	Total	111	100.0	100.0	

Our second study objective was “To identify the socioeconomic status of the parents of children with ASD” among the mothers of children with ASD the percentage of age distribution were 6.3% in the age group 20-24, 14.4% in the age group 25-29, 27% among the age group 30-34, 32.4% among the age group 35-39 10.8% among the age group 40-44, 7.2 % among the age group 45-49 and 1.8% among 50-54 years. Among this group the highest percentage was seen as 32.4% in age group 35-39 years and lowest percentage seen in 1.8% among 50-54 years.

Among the mothers of ASD 95% were found married, 3% of them were widow and 2% were separated. Among the mothers of ASD babies, their educational level was quite satisfactory. Majority of the mothers 61.3% were found completed their Graduation. Lowest percentage seen as 1.8% completed their Primary and Secondary education.

Table 4: Distribution of Study participants by their “Educational level”

	Educational Level	Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Primary	2	1.8	1.8	1.8
	Secondary	2	1.8	1.8	3.6
	Higher Secondary	16	14.4	14.4	18.0

Graduate	68	61.3	61.3	79.3
Others	23	20.7	20.7	100.0
Total	111	100.0	100.0	

Table 5: Distribution of Study participants by their “Socio-economic Condition”

	Income Range	Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0-14999	5	4.5	4.5	4.5
	15000-29999	27	24.3	24.3	28.8
	30000-49999	23	20.7	20.7	49.5
	>=50000	29	26.1	26.1	75.7
	others	27	24.3	24.3	100.0
	Total	111	100.0	100.0	

Among the mothers of babies with ASD, their socio-economic condition was found good, 26.1% their monthly family income was more than 50,000 BDT, and only 5% shows their monthly family income was below 15000 BDT.

Most of the mothers' occupation was housewife which is 84.7% rests were working mother and the percentage is 15.3%. Our another specific objective was to identify the factors associated with stress among mothers of ASD babies, in this regard the respondents were asked about their physical activity they reported only 2.7% of them did regular physical exercise, high percentage 65% reported they do not do any kind of exercise and 32.3% said they do irregular physical exercise Percentage distribution of “Personality Types” among Mothers shows that majority 55% of them is mixed personality, 28.8 % were Introvert and 16.2 % are extrovert. Regarding the duration of marriage, we found most of their duration of marriage was above 10 years which is 46.8%, in 22.5% cases were found to have the duration of marriage was above 5 and 11.7% were below 5 years.

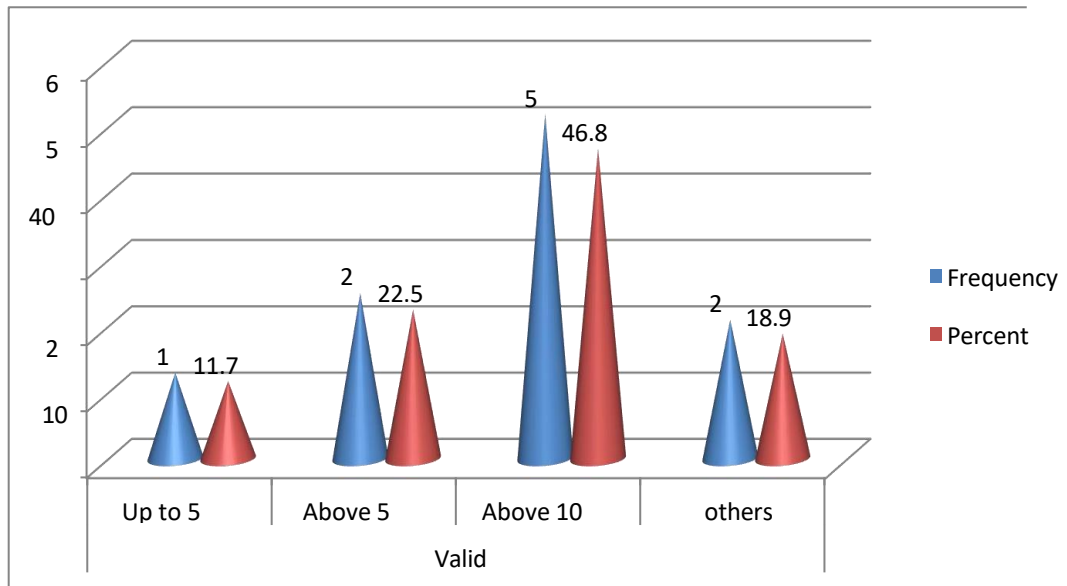


Figure 2: Distribution of Study Participants by their “Duration of Marriage”

3. Discussion

Parents of children diagnosed with Autism Spectrum Disorders (ASD) consistently report more stress than parents of typically developing children. Further, parents of children with ASD report more symptoms of anxiety and marital dissatisfaction than parents of children with other types of disabilities. Researchers purport that the treatment of children with ASD may be compromised when parents are experiencing overwhelming levels of stress, exhibiting symptoms of psychopathology (e.g., anxiety, depression), or having difficulty living with and rearing their child with ASD.

At our study, we found very high level of stress 78.9% among the mothers of children with ASD. Whereas in the study conducted in USA by Louisa Silva and Mark Schalok they found Overall, half (50.4%) of the parents of children with autism indicated that they were “stressed.” This compares to 7.1% of parents of typically developing children and 23.6% of parents of children with other developmental disabilities. They found stress for parents of children with autism was highest on items related to the ability of their child to communicate (77.6%) and acceptance of their child by others (72.2%). These parents were least stressed about feeling close to their child and their child’s self-injurious behavior (19.6%), though still one in five parents felt stress about these issues whereas at our study we found parenting stress on the ability of a child to communicate was highest (36.90%) reported it as mild stress and acceptance of their child by others (27.9%). We found highest level of stress regarding child’s social development which was 56.80% and for self-injuries behavior the percentage of parenting stress was 36%.

Another study done by Abdur Rakib 44.48% parents suffer from parenting stress in comparison to our study we found very high level of stress 78.9% among the mothers of

children with ASD. He found 28.89% parents suffer from social stigma whereas we found 78.1% mothers suffer from social stigmatization.

According to a study done in Northern India by Nishi Tripathi and Ashum Gupta, their major findings were most of the parents of children with ASD (81%) were in the clinical range of stress which is nearly similar to ours and they said that the level of severity was found significantly related with level of stress.

4. Conclusion

Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder that affects a person's ability to think, interact socially, and function in society. Such a disorder can hinder a person's ability to lead a fully independent and productive life. An autism diagnosis for a child, can be overwhelming and emotionally distressing. Often, it is a family crisis, especially when the diagnosis is unexpected and there is little to no support, no appropriate referrals, or clear guidance provided. This phase can be marked by intense psychological stress.

Results of the study suggest that the stress levels of mothers of children with autism spectrum disorder is significantly high. In particular, the higher stress level was perceived to be tightly linked to a lack of control regarding their child's social development, adjusting to social change, and a number of social behavior problems, including, attention-seeking and aggressive disobedience, dietary problems, and bowel difficulties. Reflecting on the child's future, especially with regard to social acceptance, adds to the already heavy burden of stress concerning the child's ability to live independently in adulthood.

These findings highlight the the parents of these children with autism spectrum disorder. These findings illustrate the need for support services aimed especially at the mentally disabled.

5. Recommendation

In Bangladesh, where autism awareness is still growing and specialized services are limited, it is essential to develop competent service providers who can effectively support individuals with autism, their families, and the wider community. Although Bangladesh Govt. has made significant progress towards ASD management, but it is still insufficient in comparison to demand. Adequate number of standard educational organization and treatment centers should be established for this special type of babies which must need to be affordable, available and also easily accessible. Moreover, majority of the mothers said that the most contributing factor for their elevated level of stress is social stigmatization and almost everyone thinks that creating mass-awareness may improve this condition. Therefore, creating proper sustainable training support programs for parents-particularly mothers- that offer training directly related to appropriate interactions with children with ASD is important. With the level of stress typically associated with the overwhelming experience of being a parent of a child with ASD, it is crucial that psychological counselling service and emotional support are provided to the parents. If

parents could effectively manage their own stress, need for development of coping strategies, and demands placed on their own mental health in general, it would be good for their whole selves and good for their child's developmental outcomes with ASD. Finally, the impact on society by increasing awareness and society accommodating to children with autism will be essential to provide parents and children with the holistic approach to work toward positive outcomes.

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