

Psychological Burden on Parents of Children with Autism Spectrum Disorder Attending in Tertiary Care Hospitals, Dhaka, Bangladesh

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ABSTRACT

Background & Objective: Autism Spectrum disorder (ASD) is a developmental disorder that requires constant care by family members. Meeting the continuous care demand of the affected children takes a lot of time and effort. Studies have shown that parents of children with ASD experience heightened stress. The present study was intended to investigate the level of stress or burden of parents of children with ASD and to identify different psychiatric disorders among them.

Methods: This cross-sectional study was conducted at Out Patient Department (OPD) of the Institute for Paediatric Neurodisorder and Autism (IPNA) in Bngobandhu Sheikh Mujib Medical University (BSMMU), Department of Psychiatry, BSMMU, Dhaka and Out-patient Department (Child Guidance Clinic), National Institute of Mental Health (NIMH), Sher-E-Bangla Nagar, Dhaka between January, 2015 to February, 2017. A total of 180 parents of children with ASD who voluntarily consented to participate in the study were included. Parents' burden was assessed with the help of Bangla version Zarit Burden Interview 20 tool, which verifies the burden on caregivers who take care of people with mental and physical disabilities. The level of burden was operationalized and measured on a 0-4 Likert scale using 22 questions.

Result: The mean age of the respondents (parents) was 36.2(range: 24-57) years with mothers being predominant (60%) in the sample. Nearly three-quarters (74.7%) of the mothers were housewife. The respondents on an average spent 60% of their time for caring their children. Thirty percent of the respondents had family history of mental illness. The mean duration of caring of children by the respondents was 6.1 years. In two-thirds of the respondents psychiatric disorders were also identified (15.6% were major depressive illness, 11.7% were dysthymic disorder, 8.9% panic disorder, 7.8% somatic symptoms disorder and 22% other disorders). About 44% of the respondents had moderate to severe burden, 35.6% mild to moderate burden and 16.1% severe burden. Younger parents were more likely to have moderate to severe and severe burden than their older counterparts ($p = 0.048$). Mothers tend to be associated with moderate to severe and severe burden more often than the fathers do ($p < 0.001$). Moderate to severe and severe burden demonstrated its significant presence among housewives than that among the other occupants ($p = 0.028$).

Conclusion: The study concluded that parents who provide care to their child with ASD invariably suffer from stress or burden and a substantial proportion of them experience moderate to severe or severe burden requiring support to cope with the burden. Younger parents, mothers, particularly housewives are more likely to suffer from moderate to severe and severe burden.

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INTRODUCTION:

Autism Spectrum Disorder (ASD) is a type of neurodevelopmental disorder affecting the mental, emotional, learning and memory of a person¹. It is the most enigmatic and restricting lifelong disability that is complex and typically appears during the first three years of life. According to the Diagnostic and Statistical Manual of Mental Disorders, ASD is characterized by pervasive and severe impairments in reciprocal social interaction and communication as well as repetitive and stereotyped patterns of behavior. Qualitative impairment of social interaction includes failure to develop peer relationships and impairment in the use of multiple nonverbal behaviors to regular social interaction².

Autism spectrum disorder is considered a growing concern all over the world; however, in different countries and at different time points, the prevalence of autism was reported differently. As per WHO, approximately 1% of the world population or 70 million, are affected by autism. The Autism and Developmental Disabilities Monitoring Network of Center for Disease Control and Prevention in 2014 reported that approximately 1 in 68 children in the United States has Autism Spectrum Disorder³. A recent study in India reported that the prevalence rate of autism is 1 in 250 children and currently 10 million people are suffering from the disease⁴. In, A study conducted in Bangladesh in 2005 explored the prevalence of psychiatric disorders among children aged between 5 and 10 in rural, urban and slum areas, where the prevalence of autism was found 0.2%.⁵ Another survey was done in 2009 to explore the prevalence of mental disorders, mental retardation, epilepsy and substance abuse in children, where the prevalence of ASD was 0.8%.⁶

Parents of children with autism bear a disproportionate share of the burden of caring for children with autism, such as managing a child's social, physical, emotional, and educational needs, which can cause anguish and despair⁷⁻⁹. Several studies in this field show that sources of parental depression and anxiety may be diverse, which among others, include children with behavioral problems, lack of appropriate professional support,

problems in relationship between the parents and professionals, social attitudes towards autistic people and difficulties to ensure the necessary services for children with ASD. Possible reasons for the increased distress include more time spent caring for a highly challenging child, reduced income associated with increased financial worries, increasing concern about the future, lack of services for adults with autism, and fears about what would happen to their children when parents would no longer be able to care for them.¹⁰ Caring for children with ASD increases the risk of psychiatric morbidity among care-givers compared to caring for children with other illnesses or children who are growing normally^{11,12}. By far, no study has yet been conducted to address such issues in the context of Bangladesh. The aim of the present study was, therefore, to identify the burden of the parents of children with ASD and their psychiatric morbidity. Moreover, it is intended to find the socio-demographic correlates of these disorders, which can be of great help in the clinical setting and in further planning for service delivery.

METHODS:

The present cross-sectional analytical study was conducted at Out Patient Department (OPD) of the Institute for Pediatric Neurodisorder and Autism (IPNA) in Bangabandhu Sheikh Mujib Medical University (BSMMU), Out Patient Department of Psychiatry, BSMMU and Out-patient Department (Child Guidance Clinic), National Institute of Mental Health (NIMH), Sher-E-Bangla Nagar, Dhaka over a period of 2 years from January 2015 to February 2017. A total of 180 parents of children with ASD were included in the study population.

A questionnaire developed after reviewing a number of literatures was divided into two sections. The first section of the questionnaire was comprised of personal information of both parents and children with ASD, including age, family structure, marital status, education, employment, monthly income, and duration of caregiving. The second section was designed to determine the levels of burden among autistic child's parents using the Zarit Burden Interview (ZBI)¹³ and psychiatric condition with the

help of Structured Clinical Interview of Axis 1 Disorder (CV) (SCID I Questionnaire)¹⁴. The ZBI was translated in Bangla and was validated by Rabin and colleagues¹⁵ of BSMMU, Bangladesh. The ZBI provides a comprehensive assessment of both objective and subjective burden. The 22 items were assessed on a 5-point Likert scale, ranging from 0 = 'never' to 4 = 'nearly always' with 1-rarely, 2-sometimes and 3-often in between them. These items inquired about caregiver's health, psychological wellbeing, finances, social life and the relationship between the caregiver and the impaired person. The individual scores indicate how much discomfort the occurrence of particular items causes. Individual item scores were then added up to give a total score ranging from 0 to 88, with higher scores indicating greater burden. Accordingly, integrated score 0-20 was considered as "little or no burden", score 21-40 "mild to moderate" burden, 41-60 "moderate to severe" and 61-88 "severe" burden. The purpose and importance of the study were first explained to the potential respondents and the questionnaire was given to them to fill in.

Collected data were processed analyzed using SPSS (Statistical Package for Social Sciences), version 16.0. The test statistics used to analyze the data were descriptive statistics, Chi-square (χ^2) and Unpaired t-Tests. The data presented on categorical scale were expressed as frequency with corresponding percentage and were compared between two groups of patients with different levels of burden (one group with moderate to severe & severe burden and another group with no or mild burden) using Chi-square (χ^2) Test, while the data presented on continuous scale were expressed as mean \pm SD and were compared between groups using Unpaired t-Test. The risk or odds of having the expected outcome (burden) was estimated using Odds Ratio (with 95% CI for Odds Ratio). The level of significance was set at 5% and $p < 0.05$ was considered significant.

RESULTS:

Over half (55.5%) of the respondents were 30-50 years old, followed by 22.8% less than 30 years and 21.7% 50 or > 50 years old with mean age of the

respondents being 36.2 ± 6.9 years (range: 24 – 57 years). Over 60% of the respondents were mother and the rest (38.3%) were father. Nearly half (46.1%) was housewife, 18.9% were businessmen and another 18.9% were service-holder. More than 40% had monthly family income of Taka > 30000, 36.1% Taka 20-30 thousands and 19.2% Taka 10-20 thousands. Approximately 80% of the respondents were living together with their spouses. About one-third (32.8%) was graduate and higher level educated and 24.4% primary, 17.2% secondary and 18.9% higher secondary level educated. In terms of type of family, 62.2% belonged to joint family with 58.3% having 5 – 6 family members. Nearly 40% of the respondents were the key providers in the family. Nearly 60% of the parents were giving consistent care to their autistic child for more than 5 years, and most of the parents (71.7%) spent more than 12 hours daily on caregiving. The mean duration of caring of children by the respondents was 6.1 years and the respondents on an average spent 60% of their time for caring their children (Table 1).

Of the psychiatric disorders identified among the care-giving parents, 15.6% were major depressive illness, 11.7% were dysthymic disorder, 8.9% panic disorder, 7.8% somatic symptoms disorder. Other disorders like social phobia, agora phobia and obsessive-compulsive disorder were seldom identified (Table II). In terms of level of burden, about 60% of the respondents had moderate to severe burden (43.9% moderate to severe and 16.1% severe burden) and 40% had no or mild to moderate burden (4.4% no/little burden and 35.6% mild to moderate burden) (Table III).

Parents with moderate to severe and severe burden were comparatively young than those with mild to moderate or no/little burden ($p = 0.048$). Mothers tend to be associated with moderate to severe and severe burden more often than the fathers do ($p < 0.001$). Moderate to severe and severe burden demonstrated its significant presence among housewives than that among the other occupants ($p = 0.028$). No other demographic features were found to be associated with parents' burden (Table IV).

Table I. Distribution of respondents by socio-demographic characteristics (n=180)

Socio-demographic characteristics	Frequency	Percentage
Age* (yrs)		
< 30	41	22.8
30 – 50	100	55.5
≥ 50	39	21.7
Relationship with child		
Father	81	45.0
Mother	99	55.0
Occupation		
Housewife	83	46.1
Businessman	34	18.9
Service	33	18.3
Farmer, laborer & others	30	16.7
Monthly income (BDT)		
<10000	6	3.3
10000 – 30000	100	55.5
>30000	74	41.1
Marital Status		
Married	142	78.9
Divorced	17	9.4
Widow/ widower	21	11.7
Education		
Illiterate	12	6.7
Primary	44	24.4
Secondary	31	17.2
Higher secondary	34	18.9
Graduate and above	59	32.8
Family type		
Nuclear	79	43.8
Joint	101	56.1
Family members		
3 – 4	60	33.3
5 – 6	105	58.3
7 or more	15	8.7
Duration of caregiving (years)#		
Less than 5 years	75	41.7
More than 5 years	105	58.3
Daily time spend for providing care (hours)**		
Less than 12 hours	51	28.3
More than 12 hours	129	71.7

*Mean age = (36.2 ± 6.9) years; range = (24 – 57) yrs;

#Mean duration of caregiving = (6.1 ± 2.0) yrs.

Table II. Distribution of respondents by psychiatric disorder identified (n=180)

Diagnoses	Frequency	Percentage
Nothing diagnosed of clinical significance	62	34.4
Major depressive disorder	28	15.6
Dysthymic disorder	21	11.7
Panic disorder	16	8.9
Somatic symptoms disorder	14	7.8
Generalized anxiety disorder	13	7.2
Obsessive compulsive disorder	6	3.3
Social phobia	7	3.9
Adjustment disorder	2	1.1
Agora phobia	7	3.9
Others (specific phobia, non-alcoholic substance dependence, alcohol dependence and cannabis abuse disorder)	4	2.2

Table III. Distribution of respondents by level of burden (n = 180)

Level of burden	Frequency	Percentage
Little or no burden	8	4.4
Mild to moderate	64	35.6
Moderate to severe	79	43.9
Severe	29	16.1

Table IV. Association between parents' burden and demographic features (n = 180)

Demographic features	Burden		p-value
	Moderate to severe & severe (n = 108)	No & Mild to moderate (n = 72)	
Age# (yrs)	35.4 ± 6.7	37.5 ± 7.0	0.048
Sex			
Mother	78(72.2)	33(45.8)	< 0.001
Father	30(27.8)	39(54.2)	
Education			
Illiterate & primary	37(34.3)	19(26.4)	0.264
Secondary & higher	71(65.7)	53(73.6)	
Income (Taka)			
≤300000	68(63.0)	38(52.8)	0.174
>300000	40(37.0)	34(47.2)	
Occupation			
Housewife	57(52.8)	26(36.1)	0.028
Others	51(47.2)	46(63.9)	
Religion			
Islam	80(74.1)	53(73.6)	0.945
Others	28(25.9)	19(26.4)	
Marital status			
Living together	82(75.9)	60(83.3)	0.233
Divorced or widow/er	26(24.1)	12(16.7)	
Type of family			
Nuclear	37(34.3)	31(43.1)	0.233
Joint	71(65.7)	41(56.9)	
Family size			
Small (3-4 members)	35(32.4)	25(34.7)	0.747
Large (>4 members)	73(67.6)	47(65.3)	

Data were analyzed using χ^2 Test. figures in the parentheses denote corresponding percentage.

#Data were analyzed using Unpaired t-Test and were presented as mean ± SD.

DISCUSSION:

Autism spectrum disorder is a neurodevelopmental disorder whose prevalence is quickly growing across the world. According to studies, parents of children with developmental disabilities suffer increased stress, fatigue, and weariness^{16,17}. Parenting children with ASD is more difficult than parenting children who are typically developing or have other developmental disorders¹⁸. More than 60% of our

respondents were mother which is somewhat low compared with Martins¹⁹ study where 80% of the respondents were mother. Nearly three-quarters (74.7%) of our mothers were housewife which indicates that mothers engaged in care-giving of their children with ASD (because the respondents on an average have to spent 60% of their time for caring their children) rarely have spare time to do outside job which compares well with the findings of Ute et al,²⁰ where the investigators found that mothers of autistic children had difficulty in pursuing their professional careers, due to excessive time demand for caring the child. In another study, however, half of the mothers worked outdoor and the remaining half worked as teachers, maids and industry workers.²¹

In the present study more than 95% of the parents of children with ASD had burden with 60% having moderate to severe or severe burden. A substantial proportion of care-giving parents (65%) had psychiatric disorders as well. Probably these disorders may have developed as a result of stress & burden they have to endure in order to take care of their children with ASD. These findings corroborate descriptions of the literature on impairments in quality of life of families of children with disorders of the autism spectrum disorders.^{22,23} The consequences and limitations on personal life of the caregiver comprises many situations, which may cause changes and impact on personal life, such as reduced time available, affected health, and also the necessity of changing many habits, in order to support the needs of the children.¹⁹ In a study conducted by Fox et al.²⁴, parents indicated that they refrained from participating in activities outside the home because their attention was constantly on their child with autism and because they felt that others did not understand their child's behavior problems. In another study, Bitsika and Sharpley²⁵ showed that nearly half of the parents with ASD children were severely anxious and nearly two-thirds were clinically depressed. Hirst²⁶ provides the most convincing evidence of mental health issue arising directly from caregiving. The study showed that those providing more intense care (20 hours or more

per week) were at twice the risk of psychological distress as non-caregivers and this effect is greater on women.

Arksey and his colleagues²⁷ in 2005 explored the relationship of informal caregiving and employment decisions based on a literature review and research with 80 caregivers from a range of occupations. They found an inverse relationship between the hours spend on caregiving and participation in paid employment (the more hours spent on caregiving, the less hour spent on paid work). Women were more likely to move from full time to part time paid employment than men, and co-resident caregivers were less likely to be in paid full-time employment. Caregiving nearly always arises out of a long-standing familial relationship. Being a primary caregiver means feeling responsible for that person's day to day wellbeing. People enter into caregiving for a mix of reasons including obligation and reciprocity.

Care-giving for a child with disability puts stress on the whole family system. Common family problems include increased marital stress, negative impact on family cohesiveness and relationships and drastically curtail social time for families resulting in isolation. Parental caregivers of children with high and complex needs struggle with balancing the needs of these children with the needs of their siblings. Siblings commonly complain of double standards, while parents report difficulty maintaining consistent parenting while operating with different expectations between the disabled and non-disabled children. Many children are ashamed of and embarrassed by their high need sibling. Parents need to manage the impact of behaviors of their high need child on the siblings. Marital relationships can also suffer due to stress and lack of quality time together. Many parents of disable children are separated or divorced from their partners, which in our study was 24.1%. Loss of social contact is a very common consequence of caregiving. This is particularly concerning as social support has been identified as protective against the strains of the role. Both mothers and fathers may be impacted by raising a child with significant needs. But, in particular mothers of children diagnosed with an ASD tend to do more caregiving, engage in less

leisure activities, and experience significantly more stressful events than mothers of typically developing children among other things.²⁸

Furthermore, as we investigated the association between parents' burden and demographic characteristics, most of the demographic variables were not found to influence the parents' level of burden. However, younger parents tend to be associated with moderate to severe and severe burden more often than their older counterparts ($p = 0.048$). Mothers were more likely to be associated with moderate to severe and severe burden than the fathers ($p < 0.001$). Mothers being housewives also had to bear burden significantly more than the other occupants ($p = 0.028$). Other demographic features like education, occupation, income, religion, marital status and type and size of family were not found to be associated with parents' burden. However, Misquiatti and colleagues²¹ did not find a single demographic variable to be associated with parents' burden, which may be due to too small sample size ($n = 20$). Thus, summarizing the findings of the present study and those compared and contrasted revealed how parents experience raising their children with ASD, and constitute an important element for planning interventions targeting children with ASDs and their families.

CONCLUSION:

The study concluded that parents who provide care to their child with ASD invariably suffer from stress or burden and a substantial proportion of them experience moderate to severe or severe burden requiring support to cope with. Nearly two-thirds of the parents had different types of psychiatric disorders as well. Although most of the demographic characteristics were not observed to be associated with parents' burden, younger parents, mothers, particularly housewives are more likely to be associated with moderate to severe and severe burden. Thus, the findings of this study suggest that caring for children with ASDs can overwhelm their parents with different types of burden. The burden of the parents of children with ASD and the factors which influence this burden constitutes an important element for planning interventions targeting children with ASDs and their parents together.

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