

Consequences of Family Financial Burden for the Children with Autism Spectrum Disorder

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Abstract

Background: Autism spectrum disorder (ASD) is a serious neurodevelopmental disorder that causes problems with thinking, reasoning, language, and interacting with others. Around one out of 160 children in the world suffer from autism spectrum disorder (ASD).

Objective: To investigate the consequence of the financial burden faced by families on children with ASD.

Methods: A cross-sectional study of 154 children with ASD was conducted from July 2015 to June 2016, using a systematic sampling technique, and data was collected using face-to-face interview method through semi-structured questionnaires.

Results: The monthly family income and overall treatment cost was Tk. 41785.71 ± 23936.45 and Tk. 23076.62 ± 15341.09 correspondingly. Consequences included impairment of professional life of parents (97.4%), mental stress (98.1%) and financial constraints (89.6%). About 52.2% families had financial restraints due to financial burden which were notably higher when compared with others ($p<0.05$). Additionally, medical expenses were higher in families with higher family income ($r=0.526$, $p<0.005$).

Conclusion: ASD is a complex problem that has significant financial impacts on victims' families and results in a variety of consequences for families, including poor work, stress, relationships with relatives, and financial constraints. ASD is a public health problem in Bangladesh and early diagnosis is essential to understand the actual burden in the country.

Keywords: Autism spectrum disorder, Consequences, Impairment of Professional life, Financial constraints.

Introduction

Autism spectrum disorders (ASD) can be defined as a group of highly disruptive neurodevelopmental disorders that cause problems with thinking, reasoning, language and interacting with others. Autism is becoming increasingly common in society and affects men more than women.¹ Abundant evidence suggests that early interventions beginning in childhood can substantially enhance the development, well-being, health and

overall quality of life of people with autism. Autistic children with ID who receive early access to evidence-based mental health interventions are better equipped to communicate their experiences and engage in community power.² The identification of ASD is difficult before the age of one year but diagnosis is generally possible by the age of 2 years.³ Autism is highly genetic and both hereditary and environmental factors may be responsible.⁴ Although there is no specific diagnosis, the recurrence rate in siblings of children with autism is up to 8% and the risk of having a second child increases approximately 50 times.²

Although there is little data in low- and middle-income nations, the World Health Organization (WHO) estimated that 0.76% of children globally had autism spectrum disorder (ASD) in 2010. It is estimated that there are 5.7 to 21.9 cases of autism spectrum disorder (ASD) for every 1,000 eight-year-old children in the United States.¹ The prevalence in Asia, Europe, and North America is estimated to be approximately 1%, with a prevalence similar to that in the United States. is similar. It is slightly higher in the United States but in Japan and China in Western Europe, Canada, and Australia. In recent years, cases have increased in Latin America, Asia, the Middle East and Africa.⁵ In India, the incidence is 1 in 250 and 10 million people currently suffer. The prevalence of autism spectrum disorder (ASD) in Bangladesh is 17 per 10,000 children; prevalence is higher in urban areas than in rural areas- 25/10,000 and 14/10,000 respectively. Most children with ASD occur in families with older parents (especially mothers) and higher income brackets.⁶

About 0.3% of all disability-adjusted life years are accounted for by ASD which places a heavy emotional and financial burden on families. It is difficult to care for these kids, especially when there is a lack of access to resources and assistance. Most individuals with this condition and their families around the world do not receive any assistance from the social or medical institutions.⁷ Due to the excessive demands on their time, energy, and finances, families raising these children experience a great deal of stress.²

Even though there isn't a recognized cure for autism, early intervention treatment programs can help control and improve the disease. In order to reduce or manage the symptoms of autism, therapy options may include dietary modifications,

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behavioral and educational interventions, complementary and alternative medicine or medication. However, these treatments can be costly.⁸ Students who have been diagnosed with ASD are eligible to receive special education services if their impairment or behaviors are hindering their academic progress.⁹

The economic consequence is referred to as the financial burden and families with ASD bear a heavy financial burden.³ The annual expenditure on autism in the United States amounts to over \$35 billion and this figure is projected to rise substantially in the coming years. Sadly, less than 5% of research funds are allocated to autism and many believe that there is currently no medical cure for autism.¹⁰ When compared to people without ASD, the costs of healthcare for persons with ASD can reach 45% greater.¹¹ The escalating expenses associated with medical diagnosis and treatment, childcare, specialized education and the loss of income for caregivers. The financial strain caused by ASD can lead to poverty and social isolation, particularly in developing countries like Bangladesh, due to the significant out-of-pocket expenses incurred.⁵

Materials and Methods

This cross-sectional study was conducted from July 2015 to June 2016 among 154 children with ASD to find out the consequences of financial burden. Parents of the diagnosed ASD children, aged between 3 to 18 years were included in the study, who attended two special schools and two specialized hospitals of Dhaka city during data collection period, but seriously ill children due to co-morbidities were not included. Systematic sampling technique was followed.

Results

The mean (\pm SD) age of children was 6.66 ± 2.97 years and the mean monthly family income was Tk. 41785.71 with standard deviation \pm Tk. 23936.45. Majority (41.6%) family had monthly income Tk. 20001-40000 (Table-I).

Table-I: Distribution of the children by socio-demographic characteristics (n=154)

	Variables	Frequency	Percentage
Age (years)	3-5	71	46.1
	6-10	66	42.9
	11-16	17	11.0
	Statistics	Mean \pm SD: 6.66 ± 2.97 , Range: 3-16	
Sex	Male	113	73.4
	Female	41	26.6
Type of family	Nuclear	105	68.2
	Joint	49	31.8
Monthly family income(Tk.)	9000-20000	31	20.1
	20001-40000	64	41.6
	40001-60000	31	20.1
	60001-100000	28	18.2
	Statistics	Mean \pm SD: 41785.7 ± 23936.45 Range: 9000-100000	

Regarding consequences of financial burden of family for the children with ASD, Out of all, 151(98.1%) families had mental stress, 97.4% of the parents had impaired professional life, 138(89.6%) families had financial constraints, 88(57.1%) and

52.6% families experienced social isolation and loss of position respectively. Whereas, majority, i.e., 79(51.3%) and 83.8% families had no effect on relationship with spouse and relatives respectively due to financial burden (Table-II).

Table-II: Distribution of the family by the consequences of financial burden (n=154)

Consequences of Financial Burden	Yes	No
Mental stress of the family	151(98.1%)	3(1.9%)
Impairment of professional life of parents	150(97.4%)	4(2.6%)
Financial constraint of the family	138(89.6%)	16(10.4%)
Social isolation of the family	88(57.1%)	66(42.9%)
Loss of social position of the family	81(52.6%)	73(47.4%)
Deterioration of relationship with spouse	25(16.2%)	129(83.8%)
Deterioration of relationship with relatives	75(48.7)	79(51.3%)

Among 151 families, majority, i.e. 110(72.8%) had severe mental stress followed by 35 (23.2%) had moderate stress and 6(4.0%) had mild mental stress (Figure-1).

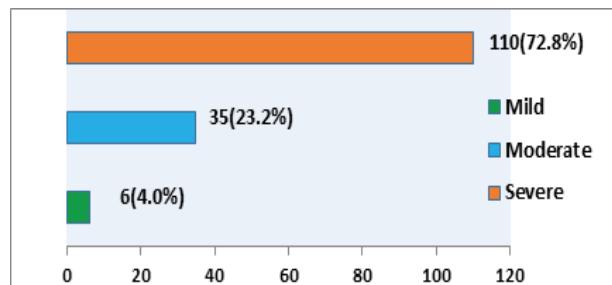


Figure-1: Distribution of the family by level of mental stress (n=151)

Out of 150, majority i.e. 140(93.3%) families only one parent was full time employed followed by 131(87.3%) had impaired of home activities, 40(26.7%) loss of emSployment of at least one parent, 12(8.0%) part time employment of one parent and 1(0.7%) both parents were part time employed (Table-III).

Table-III: Distribution of the family by nature of impairment of professional life (n=150)

Nature of impairment	Frequency	Percentage
One parent full time employed	140	93.3
Impairment of home activities	131	87.3
One parent loss of employment	40	26.7
One parent part time employed	12	8.0
Both parents part time employed	1	0.7

Among 138 families, majority, i.e. 66(47.8%) had severe financial constraints followed by moderate 50(36.2%) and mild financial constraints 22(15.9%) which is revealed in the following (Figure-2).

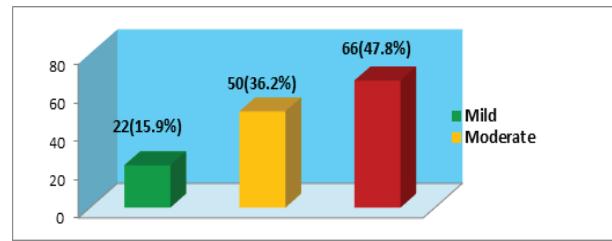


Figure-2: Distribution of the family by the nature of financial constraint (n=138)

Among all families majority i.e. 129(83.8%) spouses did not face any difficulties in relationship due to the children with ASD whereas 75(48.7%) families experienced deterioration of relation with relatives (Figure-3).

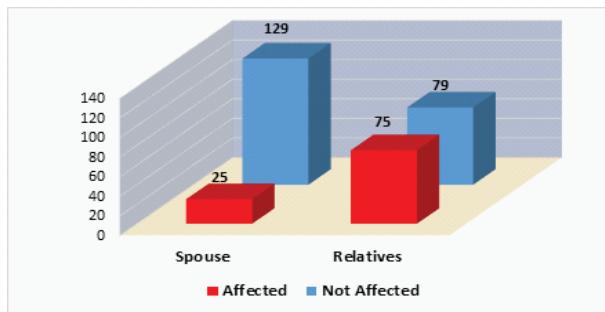


Figure-3: Distribution of the family by affect on relationship with spouse and relatives (n=154)

According to the financial constraint of the family as consequences of financial burden, out of 138, majority (52.2%) families incurred Tk. 20001-78700 as total cost, whereas 47.8% families incurred Tk. 5300-20000 as total cost, this difference of total cost by financial constraint of

family was statistically significant [$\chi^2=4.236$, $p<0.05$]. Again, maximum (50.7%) families had impaired professional life as consequences of financial burden and incurred Tk. 20001-78700 as total cost, majority (51.0%) families had mental stress as consequences of financial burden and incurred Tk. 5300-20000 as total cost, maximum (53.4%) families had social isolation as a consequences of financial burden and incurred Tk. 20001-78700 as total cost, majority (53.1%) families had loss of social position as consequences of financial burden and incurred Tk. 20001-78700 as total cost, maximum (53.3%) families relation with relatives was affected as a consequences of financial burden and incurred Tk. 5300-20000 as total cost and majority (56.0%) families relation with spouse was affected as a consequences of financial burden and incurred Tk. 5300-20000 as total cost, whereas, these difference of total cost by impaired professional life ($p>0.05$), mental stress ($p>0.05$), social isolation ($p>0.05$), loss of social position ($p>0.05$), affected relation with relatives ($p>0.05$) and spouse ($p>0.05$) as a consequences of financial burden were not statistically significant which is shown in (Table-III).

Table-IV: Association between total cost and consequences of financial burden

Consequences	n	Total cost (Tk.)		Significance
		5300-20000 f (%)	20001-78700 f (%)	
Impairment of professional life of parents	150	74 (49.3)	76 (50.7)	Fisher's Exact Test =4.001, df= 1, $p>0.05$
Mental stress of the family	151	77 (51.0)	74 (49.0)	Fisher's Exact Test =0.367, df= 1, $p>0.05$
Social isolation of the family	88	41 (46.6)	47 (53.4)	$\chi^2=1.353$, df= 1, $p>0.05$
Loss of social position of the family	81	38 (46.9)	43 (53.1)	$\chi^2=1.353$, df= 1, $p>0.05$
Financial constraint of the family	138	66 (47.8)	72 (52.2)	$\chi^2=4.236$, df= 1, $p<0.05$
Effect on relationship with relatives	75	40 (53.3)	35 (46.7)	$\chi^2=0.421$, df= 1, $p>0.05$
Effect on relationship with spouse	25	14 (56.0)	11 (44.0)	$\chi^2=0.342$, df= 1, $p>0.05$

The following Figure-4 results showing that, the correlation co-efficient r was 0.526 which means positive correlation among monthly income and total cost. Therefore, families (52.6%) with higher monthly income incurred higher total cost which was statistically significant [$r=0.526$, $p<0.05$].

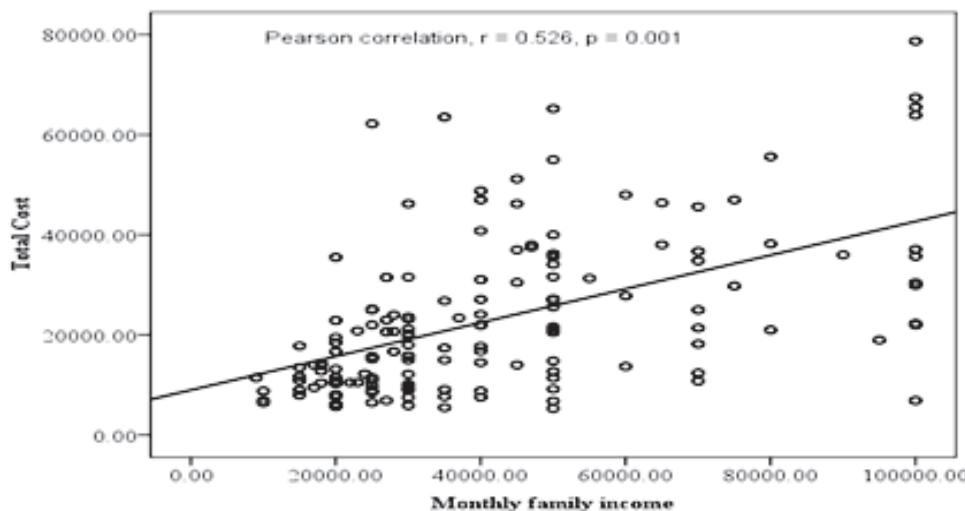


Figure-4: Correlation of total cost with monthly family income

Discussion

The objective of this study was to investigate the impact of family financial burden on children with autism. A total of 154 children, most of whom (46.1%) were between the ages of 3-5 and the average age of the children was 6.66, were included in this study. A 12-years study conducted in mainland China found that the average age was 4.6 years. This small difference is due to the good health and good education of people involved in treating children with autism in China's capital.¹²

The monthly income of the children of the majority of families (41.6%) is one thousand Tk. 20001-40000, average monthly household income is Tk. 41785.71. There is a significant relationship between household income and total debt ($r=0.526$, $p<0.005$). For families with higher incomes, all costs are higher and more significant. A study by Hasnain¹³ showed that the largest number of people (62%) come from families with a salary below \$365 (Tk.28500). In this study, since the per capita income of Bangladeshis has increased in the last year, their monthly household income is higher.

Among these, parents' jobs were lost in the largest proportion (97.4%). Among these, the majority of single-parent families (93.3%) work full-time. A cross-sectional study conducted by Nahar¹⁴ found that raising a child with an intellectual disability costs parents an average of 14% of their total household income. It is often difficult for both parents to work full time, meaning family income decreases while expenses increase. Because many parents must work full time to provide health insurance, full-time unemployment can be devastating and impact a family's finances. The findings are consistent with the current study.

Mental stress is one of the major consequences of family having children with ASD. Among them, 98.1% of families suffered from mental stress. Among the 151 families, the highest proportion (72.8%) suffered from mental stress. A study by Rakib¹⁵ shows that raising a child with autism is costly. Average families cannot afford to send their children with autism to private schools. Most parents (44.0%) experience stress and different problems with their children with autism. A report published by the Autism Association¹⁶ states that parents' stress comes from concerns about their child's future health. According to Naseef¹⁷, parents are under pressure to change goals and activities for their children diagnosed with autism and are forced to follow different plans for their children's education. All of these findings are nearly consistent with existing research.

Again, 57.1% of families are separated. According to the Autism Society¹⁶, parents refuse to take their children to visit friends or relatives, sometimes resulting in parents being isolated from friends, family and society. Qualitative study by Schaff et al¹⁸ shows that most parents are concerned that

their autistic child will destroy other people's belongings when they become deregulated. These results align with the current study. Most of the families (52.6%) experienced loss of their social position. A study conducted in Goa, India showed that due to conflicting responsibilities, parenting a kid with ASD can be extremely stressful for families. This frequently results in early social disengagement followed by reintegration into social networks.¹⁹

Financial constraints are one of the main consequences for families with children with special needs. 89.6 % of families experienced financial difficulties. Looking at the nature of financial constraints, 47.8% of people had severe financial constraints. The difference in total cost based on household financial constraints is significant statistically ($p<0.05$). A study by Rakib¹⁵ showed that the high cost of having an autistic child prevents middle-class families from accepting their autistic children into private schools, while most parents face different problems for autistic children. These findings are consistent with the current study. 48.7% of families are separated from their relatives due to financial problems. A study by Altieri and Kluge found that fathers reported losing their friends.²⁰

Regarding the impact of their relationship with their spouse, the majority of spouses (83.8%) did not face any difficulties in relationship, while 16.2% of their spouses' relationship is affected. A study conducted by Rakib¹⁶ in Dhaka, Bangladesh shows that most of the parents face different problems and 6% are facing the problem of divorce. Another study found that male parents of children diagnosed with ASD relied on their spouses to support the family. Additionally, fathers used the marriage process as support by discussing problems and establishing relationships.

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