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Financial Burden of Family for the Children with Autism Spectrum Disorder

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Abstract- Autism Spectrum Disorder (ASD) is the fastest growing serious developmental disorder characterized by social deficits, communicative difficulties, and repetitive behaviors. ASD is an emerging public health issue globally which is associated with huge financial burden to the family, community and the nation. The aim of this study was to assess the financial burden of family for the children with Autism spectrum Disorder. This cross-sectional study was carried out from July 2015 to June 2016 among 154 children with ASD to assess the financial burden of family. Data were collected by face-to-face interview with semi-structured questionnaire following systematic random sampling technique. Majority (73.4%) children were male and mean (±SD) age was 6.66 ± 2.97 years. Most (88.8%) of the children were from urban areas with average monthly family income Tk. 41785.71±23936.45. Average monthly direct cost of the children was Tk.17656.49 ± 9984.35, while indirect cost was Tk. 13462.90 ± 9713.54 and total treatment cost was Tk. 23076.62 ± 15341.09. Special education cost (Tk. 4871.00), cost of therapy (Tk. 4124.07) and travel cost (Tk. 3988.31) were the major types of direct cost, while loss of income (Tk.14570.18) was the chief indirect cost incurred by the families. The study found that majority (59.8%) of the children attended special schools were incurred Tk.20001-78700 as total treatment cost, which were statistically significant ($p<0.001$). Again, families with higher monthly family income incurred higher treatment cost ($r=0.526$, $p<0.05$). Difference between mean direct and indirect cost was found significant ($t=4.190$, $df=61$, $p<0.001$). According to the analysis of variance, mean difference of father's educational status among direct cost ($F=10.337$, $p<0.001$) and total treatment cost ($F=7.841$, $p<0.001$), which were statistically significant. The study revealed that maximum children with ASD were under five years, three-fourth were male. According to monthly family income, maximum family were in middle class. The study recommends cost effective interventions and financial safety-net measures to reduce the financial burden of families for the children with ASD.

Keywords- Autism spectrum disorder, financial burden, direct cost, indirect cost, Special education.

I. Introduction

AUTISM SPECTRUM DISORDER (ASD) is a neurodevelopmental disorder characterized by social deficits, communicative difficulties, and repetitive behaviors, with evidence of cognitive dysfunction [1]. Recent research has clearly specified the importance of early identification, since early intensive treatment is associated with better long-term outcome.

Early diagnosis of autism is very important because early intervention services are more effective in children with autism than other developmental disabilities [2]. Autism is highly heritable; researchers suspect both environmental and genetic factors are responsible [3]. ASD is typically diagnosed in children by the age of three [4]. Autism now affects children worldwide, regardless of race, ethnicity, or socioeconomic status [5]. Autism is the fastest growing serious developmental disability and since 2002 through 2006 its growth rate is around 57 per cent [6]. Approximately 1% of the world's population or 67 million are affected by autism [7]. At present, one in 68 United States (U.S) children have an ASD, which is an increase from 1 in 88 of two years ago [8], and is growing at a rate of 10% to 30% per year [9]. Prevalence rate is 5 times more among boys (1 in 42) than among girls (1 in 189) [8]. Studies in Asia, Europe, and North America have identified, individual with ASD with an average prevalence of about 1%. Prevalence rates in Western Europe, Canada, and Australia are similar to those in the United States, whereas, rates in Japan and China are somewhat higher.

The prevalence of ASDs in South Korea was estimated to be 2.64% and the male-to female ratios was 5.1:1 [10]. Again, every 2-6 children out of 1000 child in India have autism and the prevalence of autism in India is 1 in 250, however, currently 10 million people are suffering in India [11]. According to the report of the Ministry of Social Welfare, Bangladesh, the total number of persons with ASDs, could be as high as 1.4 million- of whom only a few hundred have been diagnosed. One estimation is also that one child in 500 in Bangladesh has autism, meaning that the approximate number of children with ASD in Bangladesh is no less than 280,000 [12]. This study will determine the financial burden of children with ASD, which will subsequently help the government and relevant organizations to take necessary steps to provide economic and infrastructural support to reduce financial burden of family for the children with ASD.

II. Materials and Methods

This cross-sectional study was carried out from July 2015 to June 2016 among 154 children with ASD to estimate financial burden of family for the children with autism spectrum disorder. Data were collected from parents of all diagnosed children with ASD, attended to the selected two special schools and two specialized hospitals of Dhaka city during data collection period. All children with ASD between 3 to 18 years of age were included in the study but the seriously ill

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children due to co-morbidities were not included in this study. Pre-testing of research instrument was done in a private autism school on 15 children with ASD. Informed consent of the respondents was taken before the interview. Systematic random sampling technique was followed. 53 children were included from Institute of Paediatric Neurodisorder & Autism (IPNA), Bangabandhu Sheikh Mujib Medical University (BSMMU), Dhaka, 25 children from Shishu Bikash Kendro (SBK), Shishu Hospital, Dhaka, 54 children were included from Proyash, Institute of special education, Dhaka cantonment, Dhaka and 22 children from Special school for Autism, Bangladesh Jatiyo Protibondhi Unnayan Foundation (JPUF), Dhaka. Analysis of data was done by "Statistical Package for Social Science" (SPSS) program in the computer.

III. Results

The distribution of children by socio-demographic characteristics shows that the mean (±SD) age of the children was 6.66 ± 2.97 years. Majority of the children (73.4%) were male and male female ratio was 2.76: 1. It was also found that, most (88.8%) of the children were from urban areas. The mean monthly family income was Tk. 41785.71 with standard deviation ± Tk. 23936.45 and the range was Tk. 9000-100000. Majority (41.6%) family had monthly income Tk. 20001-40000 (as shown in Table I).

TABLE I
Distribution of the Children by Socio-Demographic Characteristics (N=154)

Variables	Frequency	%
Age (years)		
3-5	71	46.1
6-10	66	42.9
11-16	17	11.0
Statistics	Mean ± SD: 6.66 ± 2.97	Range: 3-16
Sex		
Male	113	73.4
Female	41	26.6
Place of residence		
Urban	136	88.3
Peri-urban	7	4.5
Rural	11	7.1
Statistics	Mean ± SD: 5.08 ± 1.91	Range: 3-11
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 ± SD: 41785.71 ± 23936.45	Range: 9000-100000

Table II shows that out of 154 families, 119 had to pay consultation charges, among them, majority, i.e. 91.6% paid Tk. 200-1000 and the mean (±SD) of consultation cost was Tk. 489.08 ± 366.27. Out of all 126 families paid drug cost. Off them, maximum i.e. 55.6% spent Tk. 200-1000 for cost of drug and the mean (±SD) cost of drug was Tk. 1134.13 ± 877.28. Again, early and appropriate access to intervention therapy is known to improve a child's long-term outcome. According to cost of therapy, off 108 families, majority i.e. 70.4% spent Tk. 1000-5000 for cost of therapy and the mean (±SD) was Tk. 4124.07 ± 2890.26. Regarding cost of other health care services, 40 families paid charges, off them, maximum i.e. 80.0% spent Tk. 500-1000 for other healthcare services cost and the mean (±SD) was Tk. 850.00 ± 498.07. Out of all 66 families had to pay laboratory investigation charges. Off them, majority i.e. 80.3% spent Tk. 500-1000 for laboratory investigation cost and the mean (±SD) was Tk. 884.85 ± 659.66. All 154 families had to incur the travel cost, among them, majority i.e. 56.5% spent Tk. 1000-3000 as travel cost and the mean (±SD) was Tk. 3988.31 ± 2589.84. According to the direct medical cost, among all 154 families, majority i.e. 53.9% spent Tk. 1300-8000 for direct medical cost and the mean (±SD) of direct medical cost was Tk. 8786.36 ± 5256.52.

Table III shows that out of all, only 31 families paid childcare charges. Among them, maximum i.e. 77.4% spent Tk. 1000-5000 for childcare cost and the mean (±SD) childcare cost was Tk. 5000.00 ± 1807.39. Special education is needed for almost every child with ASD and incurs a substantial financial burden to the family. Among all, 100 families paid charges for special education. Off them, majority i.e. 56.0% spent Tk. 1000-5000 for special education cost and the mean (±SD) special education cost was Tk. 4871.00 ± 3276.96. Out of 152 families, majority i.e. 63.8% spent Tk. 1001-3000 for special aids and the mean (±SD) special aid cost was Tk. 1863.16 ± 1045.56. Among all the families, majority i.e. 72.7% spent Tk. 1001-3000 for cost of food the mean (±SD) food cost was Tk. 2705.84 ± 1104.49. Regarding direct non-medical cost, among all, majority i.e. 57.1% families spent Tk. 1500-8000 as direct non-medical cost and the mean (±SD) direct non-medical cost was Tk. 8870.13 ± 5657.20.

Loss of income is one of the main contributing factors for financial burden of the families ASD children. Off the all, 57 families described loss of income. Among them, majority i.e. 54.4% had monthly income loss of Tk. 3000-10000 and the mean (±SD) income loss was Tk. 14570.18 ± 9305.07. Out of 154, only 8 families had to pay unofficial payment. Among them, majority, i.e. 75.0% family spent Tk. 200-500 and the mean (±SD) unofficial payment was Tk. 525.00 ± 225.20. According to indirect cost, out of 62 families, majority i.e. 56.5% spent Tk. 400-10000 for indirect cost and the mean (±SD) indirect cost was Tk. 13462.90 ± 9713.54, which are shown in Table IV.

Among all the family, majority i.e. 80 (51.9%) spent Tk. 3800-15000 as direct cost followed by 50 (32.5%) spent Tk. 15001-30000 and 24 (15.6%) spent Tk. 30001-48700. The mean (±SD) direct cost was Tk. 17656.49 ± 9984.35 while the range of direct cost was Tk. 3800-48700 (as shown in Table V). According to Table VI the mean total cost was Tk. 23076.62 with standard deviation ± Tk. 15341.09 and the range was Tk. 5300-78700. Among the entire family, majority i.e. 78 (50.6%) spent Tk. 5300-20000 followed by 66 (42.9%) spent Tk. 20001-50000 and 10 (6.5%) spent Tk. 50001-78700.

Out of 122 children attended special school, majority (59.8%) families incurred Tk.20001-78700 as total cost,

whereas, among the children did not attended special school, most (90.6%) families incurred Tk. 5300-20000 as total cost. However, this difference in total cost by educational level of the children was statistically significant [$\chi 2=25.934$, $p<0.001$], which is shown in Table VII.

TABLE II
DISTRIBUTION OF THE FAMILY BY DIFFERENT TYPES OF DIRECT MEDICAL COST

Types of cost	n	Cost (Tk.)
Consultation cost	119	200-1000=91.6%, 1001-2000=8.4% Mean± SD: 489.08 ± 366.27 Range: 200-2000
Cost of drug	126	200-1000=55.6%, 1001-3200=44.4%, Mean± SD: 1134.13± 877.28 Range: 200-3200
Cost of therapy	108	1000-5000=70.4%, 5001-10000=29.6% Mean± SD: 4124.07± 2890.26 Range: 1000-10000
Cost of other healthcare services	40	500-1000=80.0%, 1001-2000=20.0% Mean± SD: 850.00± 498.07 Range: 500-2000
Laboratory investigation cost	66	500-1000=80.3%, 1001-3000=19.7% Mean± SD: 884.85 ± 659.66 Range: 500-3000
Travel cost	154	1000-3000=56.5%, 3001-6000=27.9%, 6001-10000=15.6% Mean± SD: 3988.31± 2589.84 Range: 1000-10000
Direct medical cost	154	1300-8000=53.9%, 8001-16000=35.7%, 16001-25700=10.4% Mean± SD: 8786.36± 5256.52 Range: 1300-25700

TABLE III
DISTRIBUTION OF THE FAMILY BY DIFFERENT TYPES OF DIRECT NON-MEDICAL COST

Types of cost	n	Cost (Tk.)
Childcare cost	31	1000-5000=77.4%, 5001-10000=22.6% Mean± SD: 5000.00 ± 1807.39 Range: 1000-10000
Special education cost	100	1000-5000=56.0%, 5001-12000=44.0% Mean± SD: 4871.00 ± 3276.96 Range: 1000-12000
Special aid cost	152	500-1000=26.3%, 1001-3000=63.8%, 3001-5000=9.9% Mean± SD: 1863.16 ± 1045.56 Range: 500-5000
Cost of food	154	500-1000=5.2%, 1001-3000=72.7%, 3001-5000=22.1% Mean± SD: 2705.84 ± 1104.49 Range: 1000-5000
Direct non-medical cost	154	1500-8000=57.1%, 8001-16000=30.5%, 16001-24000=12.3% Mean± SD: 8870.13 ± 5657.20 Range: 1500-24000

TABLE IV
DISTRIBUTION OF THE FAMILY BY DIFFERENT TYPES OF INDIRECT COST

Types of cost	n	Cost (Tk.)
Loss of income of parents	57	3000-10000=54.4%, 10001-20000=17.5%, 20001-30000=28.1% Mean± SD: 14570.18 ± 9305.07; Range: 3000-30000
Unofficial payment	8	200-500=75.0%, 501-1000=25.0% Mean± SD: 525.00 ± 225.20; Range: 200-1000
Indirect cost	62	400-10000=56.5%, 10001-20000=17.7%, 20001-30500=25.8% Mean± SD: 13462.90 ± 9713.54; Range: 400-30500

TABLE V
DISTRIBUTION OF THE FAMILY BY DIRECT COST (N=154)

Direct cost (Tk.)	Frequency	Percent
3800-15000	80	51.9
15001-30000	50	32.5
30001-48700	24	15.6
Total	**154**	**100.0**
Statistics	Mean ± SD: 17656.49 ± 9984.35	Range: 3800-48700

TABLE VI
DISTRIBUTION OF THE FAMILY BY TOTAL COST (N=154)

Total cost (Tk.)	Frequency	Percent
5300-20000	78	50.6
20001-50000	66	42.9
50001-78700	10	6.5
Total	**154**	**100.0**
Statistics	Mean ± SD: 23076.62 ± 15341.09	Range: 5300-787000

TABLE VII
ASSOCIATION BETWEEN TOTAL COST AND ATTENDED SPECIAL SCHOOL BY THE CHILDREN

Attended special school	Total Cost (Tk.)				Significance
	5300-20000 f (%)	20001-50000 f (%)	50001-78700 f (%)	Total f (%)	
Yes	49(40.2)	63(51.6)	10(8.2)	122(100.0)	$\chi 2=25.934$
No	29(90.6)	3(9.4)	0(0.0)	32(100.0)	df= 2
Total	78(50.6)	66(42.9)	10(6.5)	154(100.0)	$p<0.001$

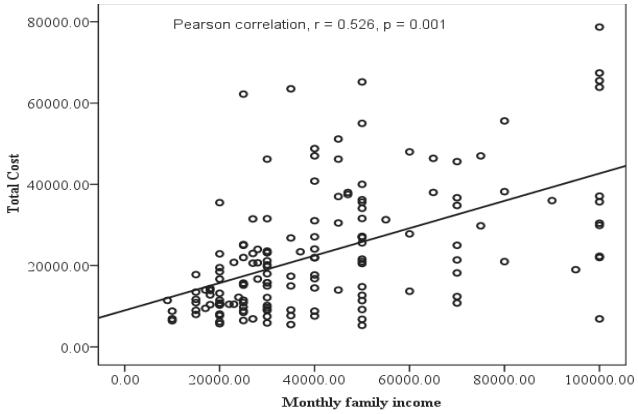

Fig. 1 Correlation of total cost with monthly family income

Fig. 1 shows 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].

A paired t-test was done to compare the mean direct and indirect cost incurred by the family. A statistically significant difference was found between mean direct cost 18925.0000 (±10590.483) and indirect cost 13462.903 (±9713.540), t=4.190, df=61, p<0.001, which is shown in Table VIII.

According to analysis of variance (ANOVA) test, F value was 10.337 and mean difference of direct cost among father's educational status (p<0.001), which was statistically significant. Moreover, according to Post Hoc (Bonferroni) test, difference found between primary and masters (p<0.005), secondary and masters (p<0.01), higher secondary and masters (p<0.001) and graduate and masters (p<0.005), which were statistically significant (as shown in Table IX).

According to analysis of variance (ANOVA) test, F value was 7.841 and mean difference of total cost among father's educational status found statistically significant (p<0.001). Moreover, according to Post Hoc (Bonferroni) test, difference found between primary and masters (p<0.05), secondary and masters (p<0.05) and higher secondary and masters (p<0.001), which were statistically significant, but no difference found between graduate and masters (p>0.05) (as shown in Table X).

TABLE VIII
ASSOCIATION BETWEEN DIRECT AND INDIRECT COST (PAIRED 'T' TEST)

Type	n	Mean	Standard Deviation	Standard Error Mean	Significance (paired 't' test)
Direct cost	62	18925.000	±10590.483	1344.992	t=4.190
Indirect Cost	62	13462.903	±9713.540	1233.621	df=61 p<0.001

IV. DISCUSSION

ASD is the fastest growing developmental disorder and an emerging public health issue globally which is associated with huge financial burden. This study was conducted to assess the financial burden of family for the children with ASD. A total of 154 children with ASD were included in this study. This study may act as a source of information for future researchers and health policy makers.

Study results revealed that the majority (73.4%) children were male, mean (±SD) age of the children was 6.66 ± 2.97 years and most (88.8%) of them were from urban areas. The findings of the present study have almost similarity with the studies conducted by Amr [13] and Sun, X et al [14].

Among all the children, majority (41.6%) family had monthly income Tk. 20001-40000 and the mean monthly family income was Tk. 41785.71 with standard deviation ± Tk. 23936.45. According to Household Income and Expenditure Survey conducted in 2010 found that, the total average monthly household income was Tk. 11479.00 [15]. A study conducted in Bangladesh [16] showed that, maximum (62%) families with income between $243 and $365 (Tk. 19000 to 28500) and 23% were from families with an income range between $377- $608 (Tk. 29500 to 47500), and 15% were from families with greater than $608 (Tk. 47500) monthly income. In the present study monthly family income is more because per capita income of Bangladeshi people has increased than previous years.

According to the financial burden of the family due the children with ASD, among all, majority (51.9%) families spent Tk. 3800-15000 as direct cost the mean (±SD) direct cost was Tk. 17656.49 ± 9984.35 per month. The variation of direct cost by educational status of father (p<0.001), educational status of mother (p<0.001), educational level of children (p<0.001), use of therapy (p<0.001) were statistically significant. Difference between mean direct cost Tk.18925.00 (±10590.483) and indirect cost Tk.13462.903 (±9713.540), t=4.190, df=61, p<0.001, was found statistically significant. Direct cost included mean (±SD) of direct medical cost Tk. 8786.36 ± 5256.52 and mean (±SD) direct non-medical cost Tk. 8870.13 ± 5657.20.

Direct medical cost mainly included mean (±SD) cost of therapy Tk. 4124.07 ± 2890.26 and mean (±SD) travel cost Tk. 3988.31 ± 2589.84. Direct non-medical cost mainly included mean (±SD) childcare cost Tk. 5000.00 ± 1807.39, mean (±SD) special education cost Tk. 4871.00 ± 3276.96 and mean (±SD) food cost Tk. 2705.84 ± 1104.49. a positive correlation was found among direct medical and direct non-medical cost(r=0.673), which was found statistically significant (p<0.05).

A study was conducted by Konrad [17] revealed that, direct medical and nonmedical costs were up to as much as $72,000 (Tk.5,616,000 approx.) in a year for someone with an extreme case of the disorder, which included medical costs like doctor visits, prescriptions and occupational and speech therapy, and also expenditures like special education, camps and child care.

TABLE IX
ANALYSIS OF VARIANCE (ANOVA) ON DIRECT COST BY FATHER'S EDUCATION

Type of cost	Sum of squares	df	Mean square	F	Significance
Direct cost	3.313E9	4	8.283E8	10.337	P<0.001
	1.194E10	149	8.013E7		
	1.525E10	153			

Dependent Variable	(I) Educational status of the father	(J) Educational status of the father	Mean Difference (I-J)	Standard Error	Significance
Direct cost	Primary	Secondary	-5246.42857	4143.69683	1.000
		Higher secondary	-3773.52941	4019.97640	1.000
		Graduate	-8253.26087	3631.62805	.245
		Masters	-1.46250E4*	3548.44997	.001
	Secondary	Primary	5246.42857	4143.69683	1.000
		Higher secondary	1472.89916	3230.60404	1.000
		Graduate	-3006.83230	2732.27278	1.000
		Masters	-9378.57143*	2620.70398	.005
	Higher secondary	Primary	3773.52941	4019.97640	1.000
		Secondary	-1472.89916	3230.60404	1.000
		Graduate	-4479.73146	2540.72851	.799
		Masters	-1.08515E4*	2420.34630	.000
	Graduate	Primary	8253.26087	3631.62805	.245
		Secondary	3006.83230	2732.27278	1.000
		Higher secondary	4479.73146	2540.72851	.799
		Masters	-6371.73913*	1698.99626	.003
	Masters	Primary	14625.00000*	3548.44997	.001
		Secondary	9378.57143*	2620.70398	.005
		Higher secondary	10851.47059*	2420.34630	.000
		Graduate	6371.73913*	1698.99626	.003

TABLE X
ANALYSIS OF VARIANCE (ANOVA) ON TOTAL COST BY FATHER'S EDUCATION

Type of cost	Sum of squares	df	Mean square	F	Significance
Total Cost	6.262E9	4	1.565E9	7.841	P<0.001
	2.975E10	149	1.996E8		
	3.601E10	153			

Dependent Variable	(I) Educational status of the father	(J) Educational status of the father	Mean Difference (I-J)	Standard Error	Significance
Total cost	Primary	Secondary	-4960.71429	6540.68310	1.000
		Higher secondary	-2185.29412	6345.39466	1.000
		Graduate	-11194.56522	5732.40013	.527
		Masters	-1.84593E4*	5601.10638	.012
	Secondary	Primary	4960.71429	6540.68310	1.000
		Higher secondary	2775.42017	5099.39750	1.000
		Graduate	-6233.85093	4312.79872	1.000
		Masters	-1.34986E4*	4136.69121	.014
	Higher secondary	Primary	2185.29412	6345.39466	1.000
		Secondary	-2775.42017	5099.39750	1.000
		Graduate	-9009.27110	4010.45268	.261
		Masters	-1.62740E4*	3820.43350	.000
	Graduate	Primary	11194.56522	5732.40013	.527
		Secondary	6233.85093	4312.79872	1.000
		Higher secondary	9009.27110	4010.45268	.261
		Masters	-7264.72050	2681.80723	.075
	Masters	Primary	18459.28571*	5601.10638	.012
		Secondary	13498.57143*	4136.69121	.014
		Higher secondary	16273.99160*	3820.43350	.000
		Graduate	7264.72050	2681.80723	.075

Another research conducted by Tarbox [18] revealed that, typically, a child who started an ABA program at the age of three required at least 3-5 years of treatment costing a minimum of US$ 120,000 before the child reaches middle school and often continue into adolescence. Special education services cost was an average of US$ 12,639 (Tk. 985,842 approx.) per student, which was about 2.8 times more than to students receiving general education services. The average cost of occupational therapy services was from US$ 50 to 400 per hour and cost for speech therapy was US$ 100 to 250 per hour. A pilot study was conducted in UK Järbrink [19] found that expenses of education (mean weekly cost £223.82 or $363.48, 2011 US$ or Tk. 23,072 approx.), early intervention therapy (mean weekly cost £144.38 or $234.47, 2011 US$) and health and social services (£20.12 or $32.67, 2011 US$). All of the children were either in a special school setting (e.g. boarding school or private school) or had special support in a mainstream school. A cross-sectional study was conducted in China Wang [20] revealed that the mean annual expenditure for behavioral therapy was 11,072.37 RMB (Tk. 129,542 approx.), which accounted for 54.3% of all health care-related costs for ASD children. Other costs included outpatient care (1532.44 RMB), prescription medications (1240.65 RMB), and transportation and accommodation (2770.62 RMB). Another study was conducted by Sun [21] in mainland China found that the mean monthly expense for intervention and care for one child with ASC was £850 (¥ 8500) (Tk. 87,550 approx.) in Beijing and £697 (¥ 6790) in Qingdao.

Different types of direct costs were found more in USA, UK and China than the present study. The variation may be explained by the facts that these are developed countries with high socioeconomic condition. People of USA, UK and China are health conscious and they could afford high cost of treatment and other relevant services of direct costs of ASD which ultimately increased the total direct costs. Again, governments of these countries have different programs and insurance facilities to support families with ASD children. On the other hand, maximum people of Bangladesh are less educated, less health conscious and because of their low socioeconomic condition they looked for cheap treatment and used to spend less for other associated services of direct cost. As a result, the total direct costs of treatment were less than USA, UK and China.

Regarding indirect cost, majority (56.5%) families incurred Tk. 400-10000 as indirect cost and the mean (±SD) indirect cost was Tk. 13462.90 ± 9713.54 per month. The variation of indirect cost by educational status of father ($p>0.05$) was not statistically significant but the variation of indirect cost by educational status of mother ($p<0.05$) was statistically significant. Indirect costs included mean (±SD) loss of income Tk. 14570.18 ± 9305.07 and mean (±SD) unofficial payment Tk. 525.00 ± 225.20. A study conducted by Horlin [22] in Western Australia revealed that median family cost of ASD was estimated to be AUD $34,900 per annum with almost 90% of the sum (AUD $29,200 or Tk.1,752,000 approx.) due to loss of income from employment. Another pilot study conducted in UK [18] found that average weekly loss of income reported by parents was £231 ($375, 2011 US$) (Tk. 23,800 approx.). A survey was conducted in USA by Mandell [23] revealed that mothers of children with ASDs earn an average of 56% ($14,755) less than mothers of children with no health limitation. Another study conducted in China [24] stated that the average loss of annual income associated with having a child with ASD was Chinese Ren Min Bi (RMB) 44,077 ($7,226) (Tk.563,630 approx.). In present study, indirect cost was mainly due to loss of income as very few parents incurred unofficial payment. Direct costs were higher than indirect cost because treatment, therapy, special education, travel costs and other relevant expenditure of direct costs were borne by the ASD children. Moreover, usually there was no insurance coverage in Bangladesh for developmental disorders like developed countries. However, in USA, UK, China and other developed countries opposite picture was seen. Indirect cost was found more in Australia, USA, UK and China mainly due to loss of income of parents because of good socioeconomic condition and high monthly family income.

Regarding total cost incurred by the family of ASD children, majority (50.6%) spent Tk. 5300-20000 followed by 42.9% spent Tk. 20001-50000 as total cost. The mean (±SD) total cost was Tk. 23076.62 ± 15341.09 per month. The variation of total cost by educational status of father ($p<0.005$), educational status of mother ($p<0.05$), educational level of children ($p<0.005$), use of therapy ($p<0.001$), children attended special school ($p<0.001$) were statistically significant.

A study conducted by Horlin [22] in Western Australia revealed that median family cost of ASD was estimated to be AUD $34,900 (Tk. 2,094,000 approx.) per annum. Another study was conducted in Australia [25] found that the total direct and indirect costs (excluding burden of disease) was $5.8 billion. Another research report stated that in USA the estimated average annual costs per person at $51,000 in 2013, dollars excluding the services provided for free by family members. A pilot study was conducted in UK by Järbrink [19] revealed that the total cost for a child with autism in the study was £689 ($1,119, 2011 US$) (Tk. 70,967.00 approx.) per week which included cost for education, early intervention therapy, health and social services, voluntary support, medication, other costs paid by parent (e.g. for damages, certain food or clothing, toys), and income losses etc. The amount of total cost of was found more in Australia, UK and USA. The variation may be explained by the facts that these are developed countries with high socioeconomic condition, high family income and highly educated. People of these countries are health conscious and expend more for treatment, special education, therapy and other healthcare services. Parents are also enjoying government and private healthcare insurance support and other facilities for ASD children.

V. Conclusion

Autism spectrum disorder is a burning issue and increasingly recognized as a major and growing public health problem in Bangladesh. It poses huge financial burden to the

families of the victims. This study intended to find out the financial burden of family for children with ASD using systematic random sampling technique. Data were collected by face to face interview with semi-structured questionnaire. The study found that maximum children with ASD were under five years, most were from urban areas and average monthly income of maximum family was middle. In this study, direct cost of treatment was more than indirect cost. Major components of direct cost were special education, therapy and travel cost while the largest component of indirect cost was loss of income. Since ASD is a growing public health problem in Bangladesh, so, countrywide proper early diagnostic facilities should be available to measure its actual burden in the country. The study recommended for undertaking cost effective measures like subsidized or free of cost treatment, special education and therapy facilities to reduce the financial burden of families for the children with ASD.

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