
Coping Strategies for Financial Burden of Family for the Children with Autism Spectrum Disorder

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ABSTRACT

Background: Autism Spectrum Disorder (ASD) is a neurodevelopment disorder and an emerging public health issue globally which is associated with huge burden to the family, community and the nation. Study was conducted to find out the coping strategies for financial burden of the family with ASD children.

Methods: A cross-sectional study on 154 children with ASD was carried out from July 2015 to June 2016 where data were collected from two special schools and two specialized hospitals of Dhaka city. Data were collected by face-to-face interview with semi-structured questionnaire following systematic random sampling technique. Informed written consent was taken from the parents.

Results: Majority (73.4%) of the children were male and average monthly family income and total treatment cost was Tk. 41785.7 and Tk. 23076.62 respectively. However, coping strategies were adopted by the family “changing lifestyle” (96.8%), “accepting the reality” (100%), “minimizing family investment” (90.3%). Again, 52.5% families minimized family investment as coping strategies, 52.2% families had financial constraint as consequences of financial burden, which were significantly higher in comparison with others ($p < 0.05$).

Conclusion: ASD foist huge financial burden to the families of affected children. To compensate this financial burden, families adopted different coping strategies like changing lifestyle, taking social support, relying on religion, minimizing family investment, accepting reality etc. Appropriate early diagnostic facilities should be available to estimate the actual burden of the country.

Keywords: Autism spectrum disorder, Changing life style, Coping strategies, Financial constraint

INTRODUCTION

Autism spectrum disorder (ASD) is a complex neurological disorder resulting in impaired social interaction and difficulty in understanding verbal and nonverbal communication. The children with ASD start to show the developmental outcome during early

2.5–3 years and continue thereafter till to adult. Many families face severe financial crises, high out-of-pocket healthcare expenses, and unemployment.¹⁻² Autism appears to affect more children than was previously thought, although this phenomenon could be due to expansion of the diagnostic criteria and

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increased awareness of the condition. Early identification and intervention services may be more effective in children with autism than in children with other developmental disabilities.³

Autism is the fastest growing serious developmental disability and worldwide approximately 1% population are affected by autism.^{4,5} At present, one in 68 children of United States (U.S) have an ASD and the growth rate per year is 10% to 30%.^{6,7} Prevalence rates in Europe, Australia and Canada are similar to those the US but in Japan and China are little higher. Prevalence rate among boys is 5 times more than girls.⁶

In South Korea was estimated to be 2.64% and experts found in India, that every 2-6 children out of every 1000 have Autism.^{8,9} The total number of persons with ASD in Bangladesh, 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 300,000. Prevalence of the ASD in rural community was found 0.75/1000 children.¹⁰

ASD account for about 0.3% of all disability-adjusted life years which impose a huge emotional and economic burden on families. Caring for children with these disorders is demanding, especially in contexts where access to services and support are inadequate. Worldwide, most individuals with such a disorder and their families do not receive any care from health or social care systems.² Families that include a child with one of the ASDs experience considerable stress as they are confronted with extraordinary demands on their time, energy, and financial resources.³ ASD is one of the top three most expensive diagnoses in special education.¹¹

Financial burden refers to the ASD places an enormous burden on families.¹² Autism costs over \$35 billion per year in USA alone and it is expected to increase significantly but unfortunately, autism receives less than 5% of the research funding. Health care costs for individuals with ASD can be as much as 45% higher than individual without ASD.¹³ Parents of girls with ASD tended to experience a higher level of challenges.¹⁴ Families cope up financial burden by changing life style, minimizing family investment, relying on family savings, borrowing money, selling property etc.

MATERIALS AND METHODS

This cross-sectional study was carried out among 154 children with ASD from July 2015 to June 2016 to find out the coping strategies of family for financial burden for the children with ASD. 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 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 sampling technique was followed.

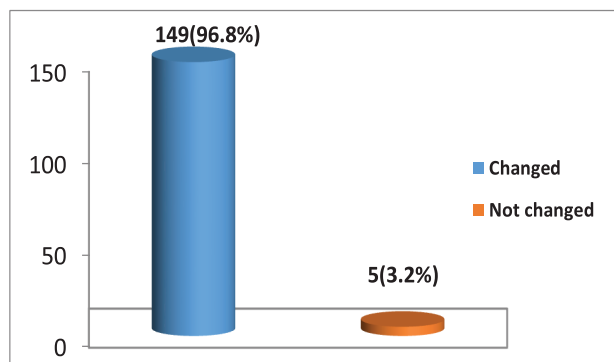
RESULTS

The distribution of children by socio-demographic characteristics shows that the mean (\pm SD) age of the children was 6.66(\pm 2.97) years. The mean monthly family income was Tk. 41785.71 with standard deviation \pm Tk. 23936.45 and the range was Tk. 9000-100000. 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	Percent
Age (years)		
3-5	71	46.1
6-10	66	42.9
11-16	17	11.0
Statistics : Mean \pm SD: 6.66 \pm 2.97, Range: 3-16		
Sex		
Male	113	73.4
Female	41	26.6
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: 41785.71 \pm 23936.45, Range: 9000-100000		

Regarding change of lifestyle, among all families, majority i.e. 149(96.8%) had to change their life style to cope up with the financial burden of children with ASD. While only 5 (3.2%) families didn't change their life style, which is illustrated in the following Fig-1.

**Fig-1:** Distribution of the family by change of lifestyle (n=154)

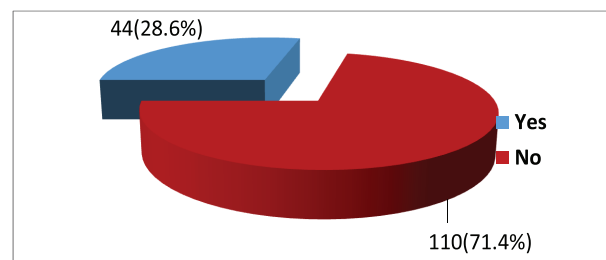
Regarding the ways of life style change, among 149 families, maximum i.e. 140(94.0%) reducing recreational expenses of family members, followed by minimizing food & clothing expenses 93(62.4%), reducing travel expenses 19(12.8%), reducing educational expenditures 11(7.4%) and minimizing treatment cost of family members 9(6.0%), which is shown in the following Table-II.

Table-II: Distribution of the family by ways of life style change (n=149)

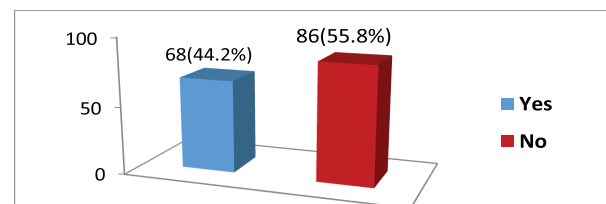
Ways of life style change	Frequency	Percent
Reducing recreational expenses of family members	140	94.0
Minimizing food & clothing expenses of the family	93	62.4
Reducing travel expenses of the family	19	12.8
Reducing educational expenditures of family members	11	7.4
Minimizing treatment cost of family members	9	6.0

*Multiple responses

Among all the family, 44(28.6%) got various social support to cope up with financial burden to maintain treatment of ASD children, whereas 110(71.4%) families didn't get any kind of social support for treatment and they had to pay out of pocket to maintain treatment, which is shown in the following Fig-2.

**Fig-2:** Distribution of the family by social support (n=154)

The study revealed that, out of all, 68(44.2%) families adopted various types of religious activities to cope up with financial burden, whereas 86(55.8%) families didn't adopt any kind of religious activities, which is shown in the following Fig-3.

**Fig-3:** Distribution of the family by religious activities (n=154)

To cope up with the financial burden, among 68 families, majority i.e. 61(89.7%) said regular prayer followed by donating money to poor & distressed people 19(27.9%), spending time in holy places 11(16.2%), entertaining of poor & distressed people 10(14.7%), reciting Holy Quran regularly 7(10.3%), attending religious programs 5(7.4%) and arranging religious rituals at home 4(5.9%) and as illustrated in the following Table-III.

Table-III: Distribution of the family by types of religious activities (n=68)

Types of religious activities	Frequency	Percent
Regular prayer	61	89.7
Donation of money to poor & distressed people	19	27.9
Spending time in holy places	11	16.2
Entertainment of poor & distressed people	10	14.7
Reciting Holy Quran regularly	7	10.3
Attending religious programs	5	7.4
Arranging religious rituals at home	4	5.9

*Multiple responses

Off all families, majority i.e. 120(77.9%) accepted the reality as fate for having a children with ASD followed by 39(25.3%) self-negligence, 33(21.4%) bad luck and 4(2.6%) poverty, which is shown in the following Table-IV.

Table-IV: Distribution of the family by modes of accepted reality (n=154)

Modes of reality accepted	Frequency	Percent
Fate	120	77.9
Self-negligence	39	25.3
Bad luck	33	21.4
Poverty	4	2.6

*Multiple responses

Off the all, 139(90.3%) families had to cope up with financial burden by minimizing family

investment and 15(9.7%) didn't minimize any kind of family investment, which is shown in the following Fig-4.

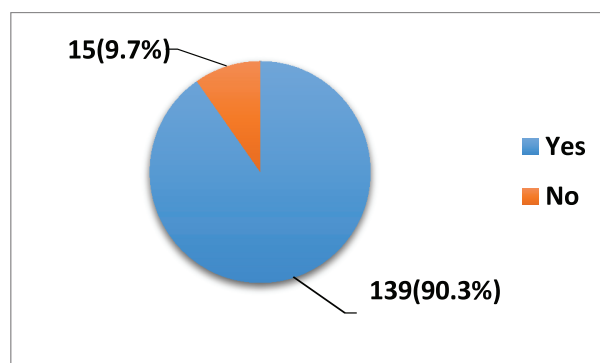


Fig-4: Distribution of the family by minimizing family investment (n=154)

According to the taking social support as a coping strategies, out of 44, majority (63.6%) families incurred Tk. 5300-20000 as total cost, whereas, 36.4% families incurred Tk. 20001-78700 as total cost, this difference of total cost by taking social support was statistically significant [$\chi^2=4.157$, $p<0.05$].

Again, minimizing family investment as a coping strategies, out of 139, majority (52.5%) families incurred Tk. 20001-78700 as total cost, whereas, 47.5% families incurred Tk. 5300-20000 as total cost, this difference of total cost by minimizing family investment was statistically significant [$\chi^2=5.728$, $p<0.05$].

Moreover, maximum (50.3%) families changed their life style to cope financial burden and incurred Tk. 5300-20000 as total cost, majority (51.5%) families relying on religion as coping strategies and incurred Tk. 20001-78700 as total cost, these difference of total cost by changing life style ($p>0.05$) and relying on religion ($p>0.05$) as coping strategies were not statistically significant, which is shown in Table-VI.

Table-VI: Association between total cost and coping strategies

Coping strategies	n	Total cost (Tk.)		Significance
		5300-20000 f(%)	20001-78700 f(%)	
Changing life style	149	75(50.3)	74(47.7)	Fisher's Exact Test =0.181, df= 1, p>0.05
Taking social support	44	28(63.6)	16(36.4)	$\chi^2=4.157$, df= 1, p<0.05
Relying on religion	68	33(48.5)	35(51.5)	$\chi^2=0.219$, df= 1, p>0.05
Minimizing family investment	139	66(47.5)	73(52.5)	$\chi^2=5.728$, df= 1, p<0.05

DISCUSSION

This cross-sectional study was conducted to find out the coping strategies adopted by the family to mitigate financial burden for ASD children. Maximum children with ASD attended tertiary level hospital for specialized treatment and schools for special education. This study may act as a source of information for future researchers and health policy makers.

Study results revealed that the mean age of children was 6.66 years which is consistent with the study conducted by Amr et al.¹⁵ and Khan.¹⁶ Majority (96.8%) families changed their lifestyle to cope up with financial burden, off whom, maximum (94.0%) reduced recreational expenses of family members followed by minimized food & clothing expenses (62.4%), reduced travel expenses (12.8%), reduced educational expenditures (7.4%) and minimized treatment cost of other family members (6.0%). Autism Society¹⁷ stated in a report that the families faced with the loss of lifestyle changes and drastic changes in their family dynamics that may be produced from diagnosis of children with ASD. Another report published in 2014 by CDC⁶, stated that some parents also stopped work to care for their child with ASD. Mothers who were maintaining employment

end up working about 7 hours less per week and earned 56% less than mothers of children with no major health issues. These reports are consistent with the present study.

Among all the families, 28.6% got various social supports to cope up with financial burden to maintain treatment of ASD children, whereas majority (71.4%) families didn't get any kind of social support and they had to pay out of pocket to maintain the treatment. The difference of total cost by taking social support (p<0.05) was statistically significant. In 2020, a study conducted by Selvakumar N & Panicker AS found that parental coping styles and the presence of social support in relationship with developmental disabilities can impact the level of parental distress.¹⁸ Altieri and Kluge found that significance of social support when families were coping with an autism diagnosis.¹⁹ Another study conducted by Meadan et al. indicated that social support from friends, family and spouses reduced depression and increased the well-being in parents.⁷ In the present study, majority families got social support from the Social Welfare Ministry (56.8%) because a good number of respondents children were studying in a special school for autism which is run by Social Welfare Ministry, Bangladesh, is free of tuition fees. Moreover, 27.3% families got support from employer, among them majority were from defense background. Families of defense background gets free treatment facilities in Combined Military Hospitals (CMHs) and waiver of tuition fees in Proyash schools for their ASD children.

To cope up with the burden, 44.2% families adopted various types of religious activities, among them, majority (89.7%) said regular prayer followed by donating money to poor & distressed people (27.9%), spending time in holy places (16.2%), entertaining of poor &

distressed people (14.7%), reciting Holy Quran regularly (10.3%), attending religious programs (7.4%) and arranging religious rituals at home (5.9%). A report published by Autism Society stated that parents can utilize in order to cope with the stress of raising a child with autism include prayer, exercise, deep breathing/relaxation exercise, writing in a journal, keeping a daily schedule of things to accomplish, advocacy, and individual, marital or family counseling.¹⁷ This report supports the present study. Moreover, people of Bangladesh are religious and they adopt different religious activities including donating and entertaining poor and distressed people, spending time in holy places, reciting Holy Quran etc. when there is any family crisis.

Majority (77.9%) families accepted the reality as fate of having a child with ASD. A study conducted by Banach et al. found that the parents felt relieved, felt grief and loss, felt shock or surprise and felt self-blame.²⁰ In the present study majority parents accepted the reality as their child illness as their fate, some parents also admitted their self-negligence, bad luck and poverty.

Among all, most (90.3%) families had to cope up with financial burden by minimizing family investment. The difference of total cost by minimizing family investment ($p < 0.05$) was statistically significant. Overall socioeconomic condition of Bangladesh hardly allows anybody to invest money to combat future economic catastrophe of diseases like ASD, cancer etc.

CONCLUSION

ASD is a burning issue and escalating public health problem in Bangladesh which poses huge financial burden to the families of the victims. This study intended to find out the financial burden and coping strategies of family for children with ASD using systematic

sampling technique. The study found that maximum children with ASD were under five years, three-fourth were male. Average monthly income of maximum family was middle. In this study, direct cost of treatment was more than indirect cost. To compensate the financial burden, families used funds from different sources like family savings and family earning. Coping ways adopted by the parents to minimize financial burden included changing lifestyle and accepting reality. The study recommends to undertake cost effective measures like subsidized or free of cost treatment, special education and therapy facilities to reduce the financial burden of families.

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