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"Variation in Socio-Economic Burden for Caring of Children with Autism Spectrum Disorder in Bangladesh: A study in Dhaka Shishu (Children) Hospital, Dhaka, Bangladesh"

Dr. Asma Hoque[1*], Dr. Mohammad Mashiur Rahman[2], Dr. Afia Akter[3], Dr. Nuzhat Shabnam[4], Dr. Mustafa Mahbub[5]

[1]Resident Medical Officer, MBBS, DCH, MPH, Dhaka Shishu (Children) Hospital, Dhaka, Bangladesh
[2]Registrar, MBBS, DCH, MPH, Dhaka Shishu (Children) Hospital, Dhaka, Bangladesh
[3]Developmental Therapist, Multidisciplinary Training Center, Shishu Bikash Kendra, Department of Paediatric Neuroscince, Dhaka Shishu (Children) Hospital, Dhaka, Bangladesh
[4]Developmental Therapist, Multidisciplinary Training Center, Shishu Bikash Kendra, Department of Paediatric Neuroscince, Dhaka Shishu (Children) Hospital, Dhaka, Bangladesh
[5]Associate Professor and Head, Department of Paediatric Neuroscience, Bangladesh Institute of Child Health (BICH), Dhaka Shishu (Children) Hospital, Dhaka, Bangladesh

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***Corresponding author:** Dr. Asma Hoque

Abstract

Original Research Article

Introduction: It has been suggested that peptides from gluten and casein may have a role in the origins of autism and that the physiology and psychology of autism might be explained by excessive opioid activity linked to these peptides. Research has reported abnormal levels of peptides in the urine and cerebrospinal fluid of people with autism. ***Objective:*** A cross-sectional study was conducted to investigate whether caregiver's variations in socioeconomic status (SES) has direct bearing on challenges of nurturing children with autism spectrum disorder (ASD) in Bangladesh. ***Study setting and period:*** Department of Pediatrics of Dhaka Shishu (Children) Hospital, Dhaka, Bangladesh between *July to December 2018*. ***Results:*** A cadre of caregivers (n = 150) from two types of SES (low-income and middle-high income) were compared based on four domains: (1) accessing and perception of remedial services, (2) utilization and perception of psychiatric services, (3) constraints for being a caregiver of children with ASD and (4) financial expenses of taking care of children with ASD. There is little indication that any particular SES fare well on these domains. Factors to mitigate such predicaments are therefore imperative in order to improve quality of life for caregivers among children with ASD. ***Conclusion:*** The net socio-economic outcome appears to be downward social mobility, as many of them relinquish their income-generating jobs in order to focus on their cognitively, socially and behaviorally challenged children.

Keywords: Socio-economic burden, Autism ASD Caregiver, Bangladesh.

INTRODUCTION

Autism is a developmental disorder affects children, young people, and adults and describes qualitative difference and impairments in reciprocal social interaction and communication behavior combined with a restricted range of interests and rigid or repetitive behavior in variation. It is diagnosed when features meet the criteria defined in the ICD-10 (international classification of diseases, 10th revision) [1] and the DSM-IV-TR (diagnostic and statistical manual of mental disorders, fourth edition, Text revised)' for "pervasive developmental disorder" and have a considerable impact on function. Autism is associated with several coexisting conditions including neuroscience developmental, medical, and mental health problems. Autism was once thought to be an uncommon developmental disorder, but recent studies have reported increased prevalence and the condition are now thought to occur in at least 1% of children [3, 5]. It is being identified in increasing numbers in Bangladesh [6]. In a study conducted by WHO and National Institute of Mental Health the prevalence of Autism is found to be 8 per 1000 in Bangladesh [7]. No single cause has been established yet, although genetic and environmental factors are implicated. A number of risk factors being investigated include genetic, infectious, metabolic, nutritional and environmental, but less than 10 to 12% of cases specific causes have found [8]. Simultaneously the use of alternative treatment approaches in children with autism has increased, but due to significant methodological flaws, the currently available data are inadequate to guide treatment recommendations [9]. In practice, treatment of ASD usually consists of a comprehensive program of educational intervention, speech therapy, behavioral treatment and developmental therapies. Anecdotal reports and parent surveys and a few research studies have indicated some evidence of diminishing the symptoms of autism by use of diets based on food elimination and rotation, as well as through supplementation and alternative treatments based on intestinal healing [8]. The popularity of these diets indicates a need for more in-depth and rigorous research into their efficacy. There is growing evidence that nutritional therapy can really make a big difference to children with autism. Many have severely disrupted digestion, so a major focus must be restoring balance their blood sugar, check for brain-polluting heavy metals, exclude food additives, identify food allergies and possible nutrient deficiencies, and ensure an optimal intake of essential fats. A popular belief that specific dietary changes can improve the symptoms of children with autism. The effectiveness of elimination diets in improving the behavior of children with autism has only recently been scientifically researched [10]. A gluten-free diet is often used for children with autism in combination with a casein-free diet. Both diets are called elimination diets because a particular type of food is eliminated from the child's meals and snacks [11]. One well-controlled study focused on children with autism who had abnormally high protein by-products in their urine, and therefore were more likely to be sensitive to casein and gluten. One group of these children was fed a strict casein- and gluten-free diet for 12 months. This group had significantly fewer autistic symptoms than the remaining children, who were not fed this diet [12]. Another well-controlled study reported no significant improvements in speech for 13 children who followed a gluten-free casein-free diet for 6 weeks [13]. Sucrose or aspartame also affects behavior and cognitive performance in children [14]. There is some evidence that the ketogenic diet may be used in autistic behavior as an additional or alternative therapy 15.The popularity of these diets indicates a need for more in-depth and rigorous research into their efficacy.

Literature Review

Systematically reviewed research on the effects of gluten free and casein free (GFCF) diets in the treatment of ASD. Database, hand, and ancestry searches identified 15 articles for review. Each study was analyzed and summarized in terms of (a) participants, (b) specifics of the intervention, (c) dependent variables, (d) results, and (e) certainty of evidence. Critical analysis of each study's methodological rigor and results reveal that the current corpus of research does not support the use of GFCF diets in the treatment of ASD. Given the lack of empirical support, and the adverse consequences often associated with GFCF diets (e.g., stigmatization, diversion of treatment resources, reduced bone cortical thickness), such diets should only be implemented in the event a child with ASD experiences acute behavioral changes, seemingly associated with changes in diet, and/or medical professionals confirm through testing the child has allergies or food intolerances to gluten and/or casein. Rogalski *et al*.[13] retrospectively examined the efficacy of a gluten-free and casein-free (GFCF) diet intervention as a means to improve verbal/nonverbal communication in children with autism spectrum disorders. Data were analyzed retrospectively from a randomized; double-blind, repeated measures cross over design study that included 13 children aged 2-16 years with autism spectrum disorders. Video recordings of at home parent child play were analyzed. Recordings were made at baseline, after 6 weeks on one of the diets (GFCF or regular diet), and after 6 weeks on the alternate diet. Findings of their study indicated no statistically significant differences in verbal and nonverbal communication outcomes between GFCF and regular diet conditions. While results of this study demonstrate that double-blind clinical trials of diet intervention are feasible, they are inconclusive regarding the efficacy of diet for improving communication. Perhaps due to the relatively short period of diet intervention used. Directions for future research are discussed as well as Implications for clinical practice. Jyonouchi *et al*. [17] study indicated an association between cellular immune reactivity to common dietary proteins (DPs) and excessive prionflammatory cytokine production with endotoxin (lipopolysaccharide, LPS), a major stimulant of innate immunity in the gut mucosa, in a subset of autism spectrum disorder (ASD) children. However, it is unclear whether such abnormal LPS responses are intrinsic in these ASD children or the results of chronic gastrointestinal (Gl) inflammation secondary to immune reactivity to DPs. Jyonouchi *et al*.[17]. Their study includes ASD children (median age 4.8 years) on the unrestricted (n=100) or elimination (n=77) diet appropriate with their immune reactivity. Controls include children with non-allergic food hypersensitivity (NFH: median age 2.9 years) on the unrestricted (n = 14) or elimination (n = 16) diet, and typically developing children (median age 4.5 years, n = 13). The innate immune responses were assessed by measuring production of proinflammatory (TNF- a, IL-1 P, IL-6, and IL-12) and counter- regulatory (IL-1ra, IL-10, and sTNFRII) cytokines by peripheral blood mononuclear cells (PBMCs) with LPS. The results were also compared to T-cell responses with common DPs and control T-cell mitogens assessed by measuring T-cell cytokine production.

Autism Spectrum Disorder

ASD and NFH PBMCs produced higher levels of TNF- A with LPS than controls regardless of dietary interventions. However, only in PBMCs from ASD children with positive gastrointestinal (Gl(+) symptoms, did they find a positive association between TNF- a levels produced with LPS and those with cow's milk protein (CMP) and its major components regardless of dietary interventions. In the unrestricted diet group, Gl(+) ASD PBMCs produced higher IL-12 than controls and less IL-10 than Gl(-) ASD PBMCs with LPS. Gl(+) ASD but not Gl(-) ASD or NFH PBMCs produced less counter-regulatory cytokines with LPS in the unrestricted diet group than in the elimination diet group. There was no significant difference among the study groups with regard to cytokine production in responses to T-cell mitogens and other recall antigens. *Their* results revealed that there are findings limited to Gl(+) ASD PBMCs in both the unrestricted and elimination diet groups. Thus their findings indicate intrinsic defects of innate immune responses in Gl(+) ASD children but not in NFH or Gl(-) ASD children, suggesting a possible link between Gl and behavioral symptoms mediated by innate immune abnormalities. It has been suggested that peptides from gluten and casein may have a role in the origins of autism and that the physiology and psychology of autism might be explained by excessive opioid activity linked to these peptides. Mill ward *et al.*[18] determined the efficacy of gluten and/or casein free diets as an intervention to improve behavior, cognitive and social functioning in individuals with autism. Two small randomized controlled trials (RCTs) were identified (n = 35). No meta-analysis was possible. There were only three significant treatment effects in favor of the intervention: overall autistic traits, mean difference (MD) = -5.60 (95% Cl -9.02 to -2.18), z = 3.21, p=0.001[12]; social isolation, MD = -3.20 (95% Cl -5.20 to 1.20). *z* = 3.14, p = 0.002) and overall ability to communicate and interact, MD = 1.70 (95% Cl 0.50 to 2.90), z = 2.77, p = 0.006)[19]. In addition three outcomes showed no significant difference between the treatment and control group and they were unable to calculate mean differences for ten outcomes because the data were skewed. No outcomes were reported for dis-benefits including harms.

The authors concluded that research has shown of high rates of use of complementary and alternative therapies (CAM) for children with autism including gluten and/or casein exclusion diets. Despite the problems of maintaining the integrity of such diets in the community it is possible to carry out randomized control trials to address these questions and more and adequately powered trials are needed in this area. Experts disagree about the causes and significance of the recent increases in the prevalence of autism spectrum disorders (ASDs) reported by Kim *et al.* [20]. Limited data on population base rates contribute to this uncertainty. Using a population-based sample, the authors sought to estimate the prevalence and describe the clinical characteristics of ASDs in school-age children. The target population was all 7- to 12-year-old children in a South Korean community; the study used a high- probability group from special education schools and a disability registry and a low-probability, general-population sample from regular schools. To identify cases, the authors used the Autism Spectrum Screening Questionnaire for systematic, multi-informant screening. Parents of children who screened positive were offered comprehensive assessments using standardized diagnostic procedures.

Objective

- To find out variations in socioeconomic status (SES) has direct bearing on challenges of nurturing children with autism spectrum disorder (ASD) in Bangladesh.

Methods

This cross-sectional descriptive study was conducted amongst families caring for children with ASD living in the urban area, the capital of Bangladesh. For classification of SES, the definitions implemented by Ministry of National Economy in Bangladesh were adopted [40]. Therefore, a family was considered a Low Income family if its monthly earning was reported as less than 500 Bangladeshi (42,500 BT), while a family which earned 500 Bangladeshi BT or more was considered a Middle-High Income family. A questionnaire was specifi-cally designed to explore the opinions of the caregivers of children with ASD regarding services (See Appendix for questionnaire). The questionnaire dealt with the caregivers’ perception of remedial and rehabilitation services available in the country for their children, their utilization and perception of psychiatric services, constraints of being a care-giver of children with ASD, and the expenses involved in taking care of children with ASD. Operational definitions were developed for multidimensional parameters of outcomes of interest such as satisfaction with provided services and perceived improvement in services or health status. Each of the multidimensional parameters was itemized, and operational definitions and global assessments were developed based on their compo-nent items. For example, a caregiver was considered satisfied with the provided services if he had reported agreement or strong agreement on satisfaction about range of services, number of staff, staff attitude, staff level of expertise, staff cooperation, and quality of services. Perceived improvement of child with remedial and rehabilita-tion services and perceived improvement in health status were assessed through relevant itemized components. In reference to the first time of diagnosis as a baseline, caregivers were asked to report the degree of improvement in terms of verbal communication, eye contact, socialization, ritualistic behavior, temper tantrum, sleep quality, and schooling performance. Then, an overall global assessment of perceived improvement was developed based on these items. Socio-demographic information such as age, gender, nationality, level of education, and occupation amongst caregivers of children with ASD were also elicited. The questionnaire was based on the rationale developed in the Client Service Receipt Inventory [37] and the questionnaire developed by Jabrink and colleagues [36, 35] for gauging SES among children with ASD. The questionnaire was tested on 20 randomly- selected parents caring for children with ASD and validated internally. Inter-rater reliability was established among interviewers to standards of 90 % agreement on overall financial expenses and time spent on caring for children with ASD. Percentage agreement between the raters on final expenses and caring time was found to be 92 %. The validity of our questionnaire was assessed by comparing information obtained through self-filled questionnaire versus questionnaire filled during interview. Convergent validity was assessed using Spearman correlations over overall financial expense (r = 0.81, p \ 0.01) and caring time obtained (r = 0.87, p \ 0.001) which showed large significant correlation, supporting very good convergent validity. Combining all individual psychometric parameters, the global psychometric assessment of the questionnaire indicated that the overall reliability and validity were both high. The final adopted questionnaire with adequate psychometric property was distributed by postgraduate and medical students to the caregivers among children with established diagnosis of ASD. The interviewers were subjected to several tutorials related to quality assurance of conduct of research and to training sessions that included simulation and role modeling before the start of the study. In addition to the information elicited via questionnaire, information on number of professionals, available remedial and rehabilitation services were also gathered from relevant resources. Information on utilization of psychiatric services was obtained from caregivers which was further ‘cross checked’ with medical records where these children have sought consultation. All children attended Behavioral Medicine Clinic at Dhaka Shishu (Children) Hospital, a tertiary care hospital where services for such clinical population are furnished with a catchment that extends to the whole country. Information about financial expenses of caring for children which were reported by families were itemized and compared to the usual expected expense of service at local healthcare and educational facilities attended by children with ASD. The cohort was derived from the database of children with ASD (ASD database) as described elsewhere [6, 53] who have sought consultation at the Department of Behavioral Physician. The caregivers of the children with ASD were identified from the above-mentioned the ASD database. Data were collected during the period from *July 2018 till December 2018*. Chi-square analyses were used to evaluate the statistical significance of differences among proportions of categorical data such as socio-demographic characteristics, indicators of the accessing and perception of remedial and rehabilitation services, indicators of the utilization and per-ception of psychiatric services, and constrains for being a caregiver. The non-parametric exact test (two-tailed) replaced the Chi-square test in case of small sample size where the expected frequency was less than 5 in any of the cells in 2 9 2 tables. The unpaired Student’s t test and the non-parametric test were used to ascertain any significant differences between the mean values of two continuous variables such as the parameters of financial expenses of taking care of children with ASD. All statistical analyses were performed using SPSS software version 13 and p value of \ 0.05 was used for all tests of statistical significance.

RESULTS

This study was 150 families surveyed, 70 (47 %) were low income and 80 (53 %) were middle- high income families. Table 1 shows the socio-demographic characteristics of the participants. In total, 138 (92.0 %) were Bangladeshi families. The majority (73.3 %) of the caregivers had male children with ASD. The majority of the children with ASD rising in houses 126 (84 %), while 20 (13 %) in flats, and very few residing in residential schools (4; 2.7 %). About third of all families reported their children with ASD also have other medical conditions. The majority of families perceived that their children with ASD are marked with moderate to severe degrees of autism. Table 2 shows the caregiver view remedial and rehabilitation services collapsed according to the SES. Overall, the results show that schools are under-staffed in terms of required professionals, especially in remedial services as well as the need for education, physiotherapy, and speech therapy professionals. About half the families noticed an improvement in the level of educational attainment of their children. Nonetheless, about 60 % of the families reported that they were not satisfied with remedial and rehabilitation services dispensed to their children with ASD.

Table-1: Comparison between Low Income and Middle-High Income families in terms of socio-demographic characteristics of their children with Autism Spectrum Disorder, Bangladesh, 2018

Variable	**Total**		**Low income**		**Middle-high income**		**p value**
	(n = 150)		(n = 70)		(n = 80)		
	N (%)		N (%)		N (%)		
Age							0.21
0–4	18	(12.0)	9	(12.9)	9	(11.3)	
5–9	69	(46.0)	28	(40.0)	41	(51.3)	
10–14	45	(30.0)	22	(31.4)	23	(28.8)	
15>	18	(12.0)	10	(14.3)	8	(10.0)	
Nationality							0.38
Bangladeshi	138	(92.0)	66	(94.3)	72	(90.0)	
Gender							0.58
Male	110	(73.3)	53	(75.7)	57	(71.3)	
Female	40	(26.7)	17	(24.3)	23	(28.8)	
Non- ASD affect care & support	48	(32.0)	24	(34.3)	24	(30.0)	0.60
Degree of autism							0.25
Mild	57	(38.0)	24	(34.3)	33	(41.3)	
Moderate	65	(43.3)	29	(41.4)	36	(45.0)	
Severe	28	(18.7)	17	(24.3)	11	(13.8)	
Accommodation							0.98
House	126	(84.0)	59	(84.3)	67	(83.8)	
Flat	20	(13.3)	9	(12.9)	11	(13.8)	
Residential school	4	(2.7)	2	(2.9)	2	(2.5)	
Living situation							0.22
Living with parents	140	(93.3)	65	(92.9)	75	(93.8)	
Living with others	6	(4.0	3	(4.3)	3	(3.8)	
Other	4	(2.7)	2	(2.9)	2	(2.5)	
Non-Working mothers	67	(44.6)	43	(61.4)	24	(30.0)	0.04

Table-2: Accessing and perception of remedial and rehabilitation services among caregivers of with children with autism spectrum disorder stratified by socioeconomic status, Bangladesh, 2018

Variable	**Total**		**Low income**		**Middle-high income**		**p value**
	n = 150		n = 70		n = 80		
	N (%)		N (%)		N (%)		
Professionals in the school							0.02
Educational psychologist	34 (22.7)		15 (21.4)		19 (23.8)		
Occupational therapist	81	(54.0)	35	(50.0)	46	(57.5)	
Physiotherapist	38	(25.3)	21	(30.0)	17	(21.3)	
Speech therapist	36	(24.0)	15	(21.4)	21	(26.3)	
Teacher for special needs children	35	(23.3)	13	(18.6)	22	(27.5)	
Perceived improvement with remedial	76	(50.7)	33 (47.1)		43	(53.8)	0.53
Satisfaction with remedial of remedial	67	(44.7)	33	(47.1)	34	(42.5)	0.15

Table-3: Utilization and perception of psychiatric services with children with autism spectrum disorder (ASD), stratified by socioeconomic status, Bangladesh, 2018

Variable	**Total**		**Low**		**Middle-high**		**p value**
	(n = 150)		income		income		
			(n = 70)		(n = 80)		
	N (%)		N (%)		N (%)		
Continuously attending psychiatric clinic	69	(46.0)	40	(57.1)	29	(36.3)	0.03
Treatment from private clinic	26	(17.3)	7	(10.0)	19	(23.8)	0.02
Improvement in health status after visiting psychiatric clinic	54	(36.0)	28	(40.0)	26	(32.5)	0.16
Satisfaction in services provided	63	(42.0)	39	(55.7)	24	(30.0)	0.001

Table 3: shows the utilization of health services by low and middle- high income families. Overall, 46 % of families continuously sought consultation from public (government) developmental services that fall under the umbrella of psychiatric clinic. The rate of attending psychiatric services was significantly higher among low income families compared to middle-high income families (57.1 vs. 36.3 %, p = 0.03). On the other hand, only 10 % of low income families seek services from private clinics compared to 23.8 % of that among middle-high income families. Such difference was statistically significant (p = 0.02). Overall, 36.0 % of families reported improvement after seeking consultation with designated psychiatry clinic. The rate of improvement was higher.

Table-4: Constrains for being a caregiver of children with autism spectrum disorder (ASD), stratified by socioeconomic status, Bangladesh, 2018

Variable	**Total**		**Low**		**Middle-High**		**p value**
	(n = 150)		Income		Income		
			(n = 70)		(n = 80)		
	N (%)		N (%)		N (%)		
Child with ASD independently fulfill required activities of daily living	58	(38.7)	23	(32.9)	35	(43.8)	0.16
Caregiver left job to care for a child with ASD	12	(8.0)	4	(5.7)	8	(10.0)	0.001
Hired housemaid to provide care for the child with ASD	70	(46.7)	16	(22.9)	54	(67.5)	0.001
A child with ASD previously sent abroad for treatment/diagnosis	53	(35.3)	18	(25.7)	35	(43.8)	0.045
Caregiver cannot take his or her child with ASD to the public places	140	(93.3)	63	(90.0)	77	(96.3)	0.18
Caregiver perceived stereotypical behavior of child with ASD as source of shame or embarrassment	58	(38.7)	25	(35.7)	33	(41.3)	0.62
Caregiver wishes to live in residential area that is close to the health services needed by child with ASD	22	(14.7)	7	(10.0)	15	(18.8)	0.106
Caregiver finds it difficult to regularly commute to medical, social and welfare services centers	16	(10.7)	3	(4.3)	13	(16.3)	0.176
Recipient of welfare from government	15	(10.0)	12	(17.1)	3	(3.8)	0.005

Table-5: Financial expenses of taking care of children with autism spectrum disorder (ASD), stratified by socioeconomic status, Bangladesh, 2018 (calculated in BT)

Variable	Total	Low	Middle-high	p value			
	(n = 150)	income	income				
		(n = 70)	(n = 80)				
	Average	Average	Average				
		(SD)	(SD)	(SD)			
Monthly family income	2051	(218)	525	(33)	2376	(204)	\0.001
Monthly out-of-pocket expenses spent per child	295	(57)	79	(12)	364	(61)	0.002
Time spent in informal care (hours/month)	224	(23)	197	(18)	287	(34)	0.05
Income loss due to lost employment opportunity	830	(109)	254	(24)	978	(132)	0.01
Cost of seeking treatment abroad per year	8,780	(718)	0		8,780	(718)	

Table-6: Distribution of the study patients by specific behaviors (n=40)

Specific behaviors	**Group I (n=20)**	**Group II (n=20)**	***“p* value**
Social relationship	Meant SD	Meant SD	
Pre Range (min-max)	2.86±0.37 2.24-3.40	2.76±0.51 1.76-3.88	0.318"^{5}
Post Range (min-max)	3.67±0.47 2.57-4.81	3.87±0.51 2.88-4.80	0.072^{ns}
^{b}P *value*	*0.001*^{s}	*0.001*^{s}	
Peer interaction			
Pre Range (min-max)	2.43±0.53 1.40-3.40	2.28±0.48 1.00-2.84	0.188^{ns}
Post Range (min-max)	3.25±0.60 2.20-4.26	3.29±0.53 2.42-4.40	0.752^{ns}
^{b}*P value*	*0.001*^{s}	*0.001*^{s}	
Communication			
Pre Range (min-max)	2.58±0.61 1.38-3.54	2.12±0.77 1.30-4.23	0.004^{s}
Post Range (min-max)	3.77±0.61 2.54-4.80	3.65±0.68 2.00-4.60	0.408^{ns}
^{a}*P value*	*0.001*^{s}	*0.001*^{s}	
Sensory responses			
Pre Range (min-max)	2.82±0.59 1.65-3.75	2.96±0.75 1.80-4.86	0.356^{rs}
Post Range (min-max) ^{b}*P value*	3.58±0.55 2.37-4.80 *0.001*^{s}	3.64±0.48 2.75-4.47 *0.001*^{s}	0.604^{rs}

s=significant; ns=not significant
P value reached from unpaired t-test

Table 6: shows specific behaviors of the study patients, it was observed that mean pre social relationship was found 2.86±0.37 in group I and 2.76 in group I. Mean post social relationship was 3.67±0.47 in group I and 3.87±0.51 in group II. Mean pre per interaction was found 2.43±0.53 in group I and 2.28±0.48 in group II. Mean post peer interaction was 3.25±0.60 in group I and 3.29±0.53 in group II. Mean pre communication was found 2.58±0.61 in group I and 2.12±0.77 in group II. Mean post communication was found 3.77+0.61 in group I and 3.65±0.68 in group II. Mean pre sensory responses were found 2.82±0.59 in group I and 2.96±0.75 in group II. Mean post sensory responses was found 3.58±0.55 in group I and 3.64±0.48 in group II. Only mean pre communication difference was statistically significant ($p<0.05$) but others were not statistically significant ($p>0.05$) between two groups. All specific behaviors between pre *aaa'-ecB was* statistically significant (pO.OS) within the groups. Among low income families compared to their counterpart families of other socio-economic status (40 vs. 32.5 %). The rate of satisfaction with psychiatry service was higher among low income families compared to the middle-high income ones (55.7 vs. 30 %; p = 0.001). *Table 4:* shows indicators of difference in perceived constraints for being a caregiver of children with ASD among the two economic groups. The proportion of chil-dren with ASD who appear to have meaningful existence reflecting self-independency was higher among high income families compared to low income families (43.8 vs. 32.9 %). Overall, 8 % of mothers resigned from their jobs because they have to care for their children with ASD while lower income families became recipient of the wel-fare system. The

proportion of mothers who left their jobs among middle-high income families was statistically significantly higher than that among low income families (10.0 vs. 5.7 %; p = 0.001).Table 5 shows financial burden of taking care of children with ASD on families. In both low and middle-high income families, taking care of an autistic child consumes about 15.0 % of the family's monthly income. The income loss due to lost employment opportunity or quitting jobs by mothers was substantial (48.4 and 41.2 %, for low and middle-high income families respectively). The average time spent in hours of informal care per month was found to be higher among middle- high income families compared to low-income families (287 vs. 197 h/month) and the difference was statistically significant (p = 0.05). The average cost of seeking treatment abroad was 8,780 (SD ± 718) US Dollars (USD), and was reported by middle- high income families only. None of the low-income families reported seeking treatment abroad.

DISCUSSION

The present study addresses the least discussed issue for the wellbeing of those with disability and impairment, namely, whether SES has a direct bearing on perceived challenges arising from available remedial and rehabilita-tion, utilization and perception of psychiatric services, and constraints on being a caregiver with children with ASD. It has been estimated that 0.14 per 1,000 children of Bangladeshi children (aged 0–14 years) have ASD [53]. It is obvious that curative medicine has advanced very well in Bangladesh. Caregivers were asked to give their view and of available remedial and rehabilitation services for their children with ASD. Being in the urban area where such services are likely to be available, higher income caregivers were more likely to get access to educational psychologists, occupational therapists, speech therapists and teachers for special needs. Although they acknowledged that they benefitted from such services, they were generally dissatisfied with overall remedial services. This is consistent with what has been observed in other parts of the world: caregivers often complain that their children do not get expected benefit from such services [48]. As such perception is universal, the question remains whether the air of dissatisfaction may stem from the reaction of having children with such unremitting cognitive and emotional problems or whether there is a genuine concern that the ceiling for remedial and rehabilitation services is low. Alternatively, it remains to be seen whether parents have expectations that are unrealistically high. It has been widely established that children with ASD are likely to over-utilize health care services. Based on the WHO (World Health Organization's) measure of the burden of disease (Disability Adjusted Life Year), children with ASD are likely to be a burden to society than Type 1 diabetes, childhood leukemia, and cystic fibrosis [37]. The annual cost of caring for children with ASD on society are estimated to be 35 billion USD, most of which is due to care that extends from the cradle to the grave [37]. In Bangladesh, with the absence of a multidisciplinary team catering to the need of children with special needs, mental health facilities remain the only avenue for addressing behavioral, cognitive and emotional problems among the population with ASD [47]. The present data suggest that caregivers from low SES are likely to have continuity of care with psychiatric services in Bangladesh. Our data indicate that the higher income have little recourse with psychiatric services as operationalized on this study. It is possible that higher SES families are likely to utilize private developmental services as well as travel abroad for further consultation. Although there was mea-surable acknowledgement of the satisfaction towards psychiatric services among both income groups, the low-income group perceived more benefit from psychiatric services compared to their higher income counterpart. It is clear what factors play part on such trend. It is possible that, on one hand, psychiatric services are equated with stigma [12] and on the other; services dispensed may not cater the need for children with devel-opmental disorders who are likely to benefit from con-certed rehabilitation and remedial intervention [34]. Results of this study suggests that 'money matters' but with limitations. Middle-high income caregivers are likely to outshine their lower income in indices such as having domestic help as well as being capable of seeking treatment abroad. This means that disposable income tends to offer high earners the choice of quitting their jobs in order to focus their efforts on the care of their disabled child. Such opportunity does not exist for the presently defined lower SES group. Relevant to the constraints of being a caregiver of a child with ASD, it is noteworthy that the majority of the parents of both SES groups thought that 'eyes of others' matter. Many felt that they cannot take their children to public areas as their stereotypical behavior is likely to attract the attention of others. In the traditional Bangladeshi society, preserving external harmony in a communal society is paramount. Therefore, caregivers are likely to ground their disabled children at home so that they may not disturb 'other' [52]. It is clear that stigma may trigger such precaution. Drawing caregiver endorsement towards perceived constraints, the data from Bangladesh as well as those from other parts of the world suggest that the presence of children with ASD is associated with many challenges. This study confirms results found elsewhere that caring for children with ASD is a costly affair [46]. Moreover, our study indicates that the low income caregivers suffer a disproportionate burden because of monthly out-of-pocket expenses, time spent in informal care and income loss due to lost employment opportunity. As has been found by other researchers, caregivers with disposable income are more likely to indulge in 'doctor shopping' [44]. In Bangladesh, it is a common observation that people go abroad to seek treatment elsewhere [24]. This practice was largely absent among present defined low income care-givers but endorsed among those high-income group. In spite of this, there is no evidence that treatment abroad is likely to bear much needed benefit for the children with ASD since protracted rehabilitation and remedial intervention has been shown to be effective for improving capacity of children with ASD [45]. It is likely that children with ASD are often subjected to a protracted medical examination, but care-givers may overlook the fact that those children would require remedial services. It is possible caregiver, upon realizing that their loved ones are having irreversible behavioral and emotional disorder trigger irrational frantic search for 'cure' which may stem from psychological reaction to cope with reality of having disabled children. There are a number of limitations to this study. The first limitation is that the study is based on a convenience sample taken from those who had previously sought con-sultation at the tertiary care facility and whose details are in the facility's database. It is not clear whether such a group is representative of the situation in the country. In Bangladesh, as in other traditional societies, frequently children with behavioral and cognitive limitations are deemed to be 'possessed' by supernatural forces [12]. The inclination of parents of such children is to consult traditional healers. It is also possible, due to perceived shame; some of the children are likely to be hidden in the house as has been previously observed [47]. As a result, it is possible that some of the parents may not have sought consultation from modern health care intervention. This problem is further exacerbated by the fact that the country has yet to develop comprehensive services for the entire population. This means generalization of the present study should be taken with caution. A second limitation is that some indices of SES were subjectively reported. This research did not take account of overestimation or other of factors contributing to social status. It is possible that, in order not to offend social modesty, some caregiver may depict themselves as 'poor' or otherwise. In cognitive psychology, it has well been established that people who are stressed are likely to underestimate or overestimate many aspects of their life situation [54] and stress and frustration are common in households that have children with ASD [39]. It is possible that such chal-lenging situations may reinforce 'catastrophic thinking' on the part of caregivers. More studies to rule out such con-founding factors are therefore essential. A third limitation is that this study did not correct for the costs that would have been incurred in the absence of autism. For example, some non-autism factors related to delays in schooling, and costs incurred by families may have occurred in the absence of autism. This may have led to some overestimation of costs. Simultaneously, however, autism may have aggravated conditions not considered in this study (e.g. psychological factors such as parental depression and anxiety) which may have led to some underestimation of costs. In summary, this study has shed preliminary light on some of the challenges of having to care for children with ASD. On the whole, caregivers felt that there is a lack of adequate remedial and rehabilitation in the country. Simi-larly, the caregivers expressed reservation in endorsing on the quality of the services offered the mental health pro-fession. The net socio-economic outcome appears to be downward social mobility, as many of them relinquish their income-generating jobs in order to focus on their cogni-tively, socially and behaviorally challenged children.

Limitations of the study

The study population was selected from one selected hospital in Dhaka city, so that the results of the study may not be reflect the exact picture of the country. The present study was conducted at a very short period of time. Limitations of this study include the relatively small proportion of children in the whole sample who received a full diagnostic assessment. Therefore, in future further study may be under taken with large sample size. The conservative approach of considering non participants as non-cases may have resulted in an underestimation of ASD prevalence in the high-probability Regroup. This study found a significant group of children with ASDs who were functioning at various levels in the general population while not receiving services, the general population sample may vary qualitatively and quantitatively in different cultures and communities.

CONCLUSION

There is little indication that any particular SES fare well on these domains. Factors to mitigate such predicaments are therefore imperative in order to improve quality of life for caregivers among children with ASD. On the whole, caregivers felt that there is a lack of adequate remedial and rehabilitation in the country. Similarly, the caregivers expressed reservation in endorsing on the quality of the services offered the mental health profession. The net socio-economic outcome appears to be downward social mobility, as many of them relinquish their income-generating jobs in order to focus on their cognitively, socially and behaviorally challenged children.

RECOMMENDATIONS

It is recommended that a Dietitian should provide support for those individuals who wish to embark on a dietary trial to ensure the diet is nutritionally adequate and advice on the suitability of long-term dietary management. Before embarking on such a restrictive diet careful consideration should be given to the current dietary intake of the person with ASD, do they have marked food selectively and dysfunctional feeding behavior which will affect the nutritional adequacy of the diet. The possible difficulties of achieving dietary adequacy should be discussed. Ongoing nutritional monitoring is essential otherwise these diets may not be nutritionally adequate overtime. The person with ASD who wishes to try the GF/CF diet should be supported by a dietitian who will check and advise on the nutritional adequacy of the diet. A multidisciplinary team approach is strongly recommended both in the management of the diet and the appropriateness of referrals. Further research is needed using larger numbers and investigating the effects of combining a GF/CF with low chemical diet.

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