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An Institution Based Study on Stress and Coping Strategies among Families of Children with Autism Spectrum Disorder

Arkadeb Kar[1], Shuvankar Mukherjee[2], Dipendra Narayan Goswami[3], Gourab Biswas[1], Nabanita Bhattacharyya[4]

[1]Junior Resident, Department of Community Medicine, Calcutta National Medical College and Hospital, Kolkata, West Bengal, India.
[2]Associate Professor, Department of Community Medicine, Raiganj Government Medical College, Raiganj. Uttar Dinajpur, West Bengal
[3]Professor, Department of Community Medicine, Rampurhat Government Medical College and Hospital, Rampurhat, West Bengal, India.
[4]Professor and Head of the Department, Department of Community Medicine, Calcutta National Medical College and Hospital, Kolkata, West Bengal, India.

Corresponding Author: Shuvankar Mukherjee

ABSTRACT

Background: Parents of children with autism spectrum disorder endure more stress than parents of normal children. The cases of autism are increasing day by day. But research on the stress and coping among parents of children with autism spectrum disorders are not adequate in our setting.
Objective: This study tried to find out the relationship between stress and different socio-demographic variables and mediators among the families having children with autism spectrum disorder.
Methods: A cross-sectional study was carried out in an institution for autistic children in Kolkata with 42 subjects. The FISC-ASD scale was used for data collection.
Results: Average ages of the children were 12 years. Most of them were from nuclear families. Correlation coefficient between level of stress and mediators were 0.787, (p <0.000) and between stress and social support was 0.568 (p <0.000)
Conclusion: There were significant relationship between level of stress and different mediators and social support available to the family.

Keywords: Autism, Autism Spectrum Disorder, Coping, Cross-sectional, Mediators, Stress.

INTRODUCTION

Autism spectrum disorder (ASD) is name given to a group of neuro-developmental disorders. It includes a wide range of symptoms, skills and levels of disability. Characteristics of these disorders include difficulties in communication and interaction with others, repetitive or restricted behaviours. It manifests in the first few years of life. [1]

According to Centre for Disease Control and Prevention (CDC) 1 in 68 children has been identified with some form of ASD. [2] Prevalence of autism in India is around 0.20%. [3]

Previous studies have found high level of stress among parents of children with autism. [4-8] There is physical stress of looking after the child throughout the day. Moreover a child with autism may not be able to communicate with parents. Failing to do so can lead to aggressive or self-injurious behaviours. Maladaptive behaviours may prevent the families attending social functions, going out which increases the emotional stress on the family. Taking the child out may be a source of emotional stress also due to people passing comments, staring awkwardly at them. These also affect the marital relationship.

Stress coping is a process of cognitive appraisal of knowing whether an individual believes he or she has the resource to respond effectively to particular stressor. [9]

There are different variables which determine the extent of stress faced by the family, such as, child specific variables e.g. age, sex and severity of the illness, socio-demographic variables and family coping resources and strategies. [6][10]

Studies have consistently shown that coping has a more decisive effect on the stress. [11]

Although the stress and coping strategies of families with autistic children has received lots of attention lately, there are still very few studies done in India. We were unable to find any literature in the settings of west Bengal.

ASD is not a rare condition; still there is lack of knowledge and awareness among general population. This study was intended to have an insight into the stress and different mediators that help these families to cope with such stress so that further initiatives can be taken to help these families.

In this study the level of stress of the families of children with ASD was analysed, and any relationship between stress and different socio-demographic variables and different mediators to cope with the stress were studied.

MATERIALS AND METHODS

This cross-sectional study was conducted in the month of January, 2018 at a special school for autism management in Kolkata. Total students enrolled at the institution were 120. Among them, parents of 90 children were present during the time of the study. Of which parents of 42 children agreed to take part in the study.

Data was gathered using the Family Interview for Stress and Coping in Autism Spectrum Disorder (FISC – ASD) schedule. FISC –ASD schedule is a semi-structured interview schedule to assess and quantify-

1. The stress of the caregivers for children with Autism Spectrum Disorder
2. Coping strategies which may modify the perceived stress (mediators) [9]

This scale is based on the stress and coping theory put forward by Folkman and Lazarus. [10]

There are 2 sections. Section I is to assess the level of perceived stress of the family. It includes daily care stress, family emotional stress, social stress and financial stress. Section II is to assess the mediators which include awareness about the child problem, attitude and expectations from the child, child rearing practices, social support and global adaptation. [9] (Table 1)

Table 1: Showing areas and subscales of FISC – ASD schedule

FISC – ASD			
SECTION – I : STRESS		**SECTION – II : MEDIATORS**	
AREAS	**SUBSCALES**	**AREAS**	**SUBSCALES**
Day care stress	Extra input for care Decreased leisure time Neglect of others disturbed behaviour	Awareness	General awareness Misconception
Family emotional stress	Personal distress Marital problem Other interpersonal problems Effect on siblings and others	Attitudes and expectations	Expectations from the child General attitude Attitude regarding child management
Social stress	Altered social life Social embarrassment	Rearing practices	General rearing practices Specific to training
Financial stress	Financial implications	Social support	Social support
		Global adaptation	Global adaptation

Section 1 has 4 areas and a total of 11 subscales. Whereas section II has 5 areas and a total of 9 subscales. A 4 or 5 point rating scale with scoring instructions is provided for each subscale. [9]

Maximum score attainable in section I was 44 and minimum 0. In section II

maximum attainable score was 36 and minimum was 9.

Variables considered for the study were socio-economic status of the families, level of education and occupation of both the parents, age and sex of the child, family type, and total number of children and serial number of the children with ASD. For socio-economic status Modified BG Prasad scale (2017) was used.

This study was conducted after obtaining permission from Institutional Ethics Committee, Calcutta National Medical College and Hospital. Written Permission was taken from the director of the above said institution for conducting the study. The parents were interviewed after taking informed consent and maintaining their anonymity.

Statistical analysis: Data was analysed using Microsoft excel and SPSS 20.0 (IBM, Armonk, New York, USA). Bivariate analysis was used to find any correlation between stress and different variables. Mann-Whitney U test and Kruskal-Wallis test was used to find out relation between categorical variables such as sex of the child, type of family and education of parents and stress score, and Spearman Rank Correlation test was applied for other numerical variables at 5% significance level.

RESULTS

Average age of the children was 12 ± 4.68 years. 38% in the age group of 5-10 years. 34 of them (81%) were boys. Majority of them (59.5%) were from nuclear families. 54.8% of the mothers were graduate. Whereas 31% of the mothers had post-graduate or higher educational qualifications. Although 71.4% were home-maker. (Table 2)

Table 2: Socio-demographic profile of the study subjects (n=42)

Variables	Groups	Number	Percentage
Age distribution of the children	< 5 years	2	4.8
	5 – 10 years	16	38.1
	10 – 15 years	13	31.0
	> 15years	11	26.2
Sex of the children	Male	34	81.0
	Female	8	19.0
Type of family	Nuclear	25	59.5
	Joint/ extended	12	28.6
	Broken	5	11.9
Educational qualification of the mothers	Post-graduate	13	31.0
	Graduate	23	54.8
	Higher secondary	5	11.9
	Secondary	1	2.4
Occupation of the mothers	Home maker	30	71.4
	Service	9	21.4
	Self-employed/business	1	2.4
	Retired/ left job	2	4.8
Education of the fathers	Post-graduate	8	19.0
	Graduate	30	71.4
	Higher secondary	4	9.5
Occupation of the fathers	Service	28	66.7
	Business/self-employed	12	28.6
	Retired	2	4.8
Socio-economic status (B.G.Prasad scale, 2017)	Upper class	25	59.5
	Upper middle class	16	38.1
	Middle class	1	2.4
Duration of schooling of the children	< 1 years	8	19.0
	1 - 5 years	15	35.7
	5 – 10 years	10	23.8
	> 10 years	9	21.4

Comment: 81% of the children were male and 38.1% were between the age group of 5 to 10 years, 59.5% came from nuclear families. 54.8% of the mothers were graduate and 71.4% were homemaker. 71.4% of the fathers were graduate and 66.7% were employed in services.59.5% belongs to upper class.

Among the fathers 71.4 % were graduate. 66.7 % were employed in services. One of them quit job to look after his child. According to B.G. Prasad scale, 2017 59.5% of the children were from upper class. No study subjects were from lower or lower middle class. (Table 2)
Among the children, 15 (35.7%) were studying in the institution for a duration between 1 to 5 years. 23.8% of the students were studying for 5 to 10 years. (Table 2). Mean years of schooling was 5.61 ± 4.57 years among the study subjects.

Table 3: Median scores of study subjects in different areas of the scale (n=42)

FISC – ASD					
SECTION – I : STRESS			SECTION – II : MEDIATORS		
Areas	Median	IQR	Areas	Median	IQR
Day care stress [0 – 16]	8.5	5	Awareness [2 – 8]	4	3
Family emotional stress [0 – 16]	6	4	Attitude and expectations [3 – 12]	5	3
Social stress [0 – 8]	3	3	Rearing practices [2 – 8]	3	2
Financial stress [0 – 4]	1	2	Social support [1 – 4]	2	2
			Global adaptation [1 – 4]	2	2
Total stress score [0 – 44]	19	9	Total mediators score [9 – 36]	16	9

Comment: Median value of total stress score of the study subjects were 19 and total mediator score were 16.

Table 3 shows that median value of total stress score was 19 and interquartile range was 9. Median value of total mediator score was 16 and interquartile range was 9.

Table 4: Median stress score of the study subjects according to different characteristics (n=42)

Characteristics		Median (IQR)	P-value
Sex of the child	Male	19 (11)	0.478
	Female	19 (6)	
Type of family	Nuclear	17 (9)	0.312
	Joint/ extended	19.5 (11)	
	Broken	25 (18)	
Education of mother	Post-graduate	19 (11)	0.805
	Graduate	18 (11)	
	Higher secondary	21 (7)	
	Secondary	17.00	
Education of father	Post-graduate	18.5 (14)	0.844
	Graduate	19 (8)	
	Higher secondary	18.5 (10)	

Comment: There was no significant difference in stress score across categories of sex of the child, type of family and education of the parents

Stress score of the study subjects were compared according to different socio-demographic profile of the study subjects. Stress score of the study subjects were compared according to sex of the child using Mann-Whitney U test, but no significant difference was not found. (Table 4). Similarly, stress score were also compared according to type of family and education of the parents using Kruskal - Wallis test. Here also no significant differences were found. (Table 4).

Table 5: **Correlation of different variables with total stress score (n=42)**

Variables	Correlation coefficient	P-value
Total mediators score*	0.787	0.000
Per capita income*	-0.562	0.000
Duration of schooling*	-0.352	0.022
Age of the child *	-0.483	0.001
Total number of children	-0.137	0.389
Social support score*	0.568	0.000
Awareness score*	0.613	0.000
Attitude score *	0.652	0.000

*statistically significant at 95% confidence interval.

Comment: Total mediator score, per capita income, duration of schooling, age of the child, social support score, awareness score and attitude score were found to have significant correlation with total stress score.

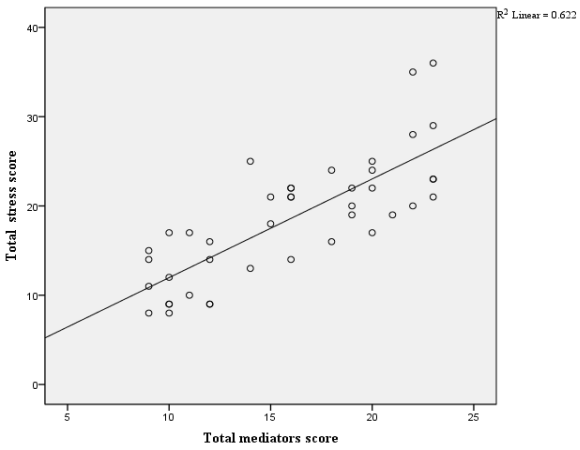

Figure 1: Scatter plot showing correlation between total stress score and mediators score

Comment: There was a positive correlation between stress score and mediators score.

On bivariate analysis significant correlation was found between total stress score and mediators score with a correlation coefficient 0.787. (Figure 1, table 5) Significant negative correlation was seen between stress level and duration of schooling. (Table 5)
Social support score with a median value of 2 was also significantly related with stress score of the family. (Table 5)
Per capita income had a significant negative correlation with stress score with a coefficient of -0.562. (Table 5)
Awareness score, which includes general awareness and misconception of the parents found to have a median value of 4 (IQR 3). Spearman's correlation coefficient for stress score and awareness score was 0.613 (p = 0.000). (Table 5)
Attitude score, which includes expectations from the child and attitude of the parents toward the child was also positively correlated with the level of stress. (Table 3)

DISCUSSION

In this study sample male: female ratio was 4.25:1. The mean ratio found by Frombonne et al was 4.2:1. [12] Werling et al also found that "The prevalence of ASDs is strongly male-biased, affecting 4 times as many males as females, on average." [13]

Previous studies have found that parental stress was high in parents of autistic children. This high level of stress was related with various factors or mediators.

In this study, the scale used i.e. FISC-ASD, had a separate segment for assessing those mediators. This segment included awareness and misconceptions of the parents regarding the condition, attitude and expectations from the child, general and specific rearing practices, social support available and utilized and global adaptation.

This study found that the score obtained in this segment i.e. total mediator score was significantly related with total stress score. Dabrowska et al found in their study that maladaptive coping was a predictor of stress level. [8]

On analysing separately, it was found that social support available and utilized was significantly related with stress perceived by the family. Similar findings were also seen in studies by Bitsika et al**.** [14] Boyd B.A in his study also found that low levels of social support was most powerful predictor for stress among mothers**.** [15] Falk et al showed in their study that socioeconomic support was a predictor of mental health of the parents, particularly depression and stress among the mothers. [16]

Significant association between awareness score and total stress was also present in this study. High stress score was related with poor awareness and misconception on the part of parents. Zaki et al also found that there were significant relationship between awareness and psychological stress of the parents. [17]

Stress was also related with age of the child inversely. This finding collaborates with the findings by Duarte et al. [18]

Our study showed that with increased duration of schooling, stress level decreased among parents. Eikeseth et al, showed in their study that, children in the Early and Intensive Behavioural Intervention group showed significant improvements in adaptive behaviours, maladaptive behaviors, and autism symptoms after one year of treatment, and this change continued into the second year of treatment, albeit to a lesser degree. [19] This finding is also supported by the study done by Eldevik et al. [20]

Athari et al, found in their study that there is a negative correlation between stress and family income. [21] A similar negative correlation between stress and per capita income was also seen in our study.

CONCLUSION

So we can conclude from that study that stress level significantly less among the families with high income, more awareness

level and longer duration of schooling of the children. Well-developed social support system helped the families to cope with the situation effectively. Whereas no such significant association or relation has been found between stress level and sex of the child, type of the family and education of the parents.

Limitations:
It is an institutional based study. So, the study findings cannot be extrapolated to the general population. Sample size was also small. There were no families from the lower or lower middle class, so a large segment of the population was missed out.

Recommendations:
So a community based or multi-centric study with a larger sample size will provide better in-sight into the topic.
Initiatives from government in raising awareness about autism through campaigning, setting up special schools for autistic children may help these families. Initiatives from NGOs and private organisations in providing support to these families in the form of training, rehabilitation of these children will also be helpful.

Conflict of Interest: There was no conflict of interest
Source of Funding: Nil

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