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Parenting Stress of Mothers of Childs with Autism in Bangladesh

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ABSTRACT
Objective: *To examine the parenting stress of mothers of child with autism in Bangladesh.* ***Methods:*** *A descriptive study design was conducted at Autism Specialized School. Eighty mothers were recruited conveniently. Data were collected by using three structured questionnaires (1) The Demographic Data Questionnaire, (2) Childs Social Interaction & Behavior related Questionnaire, and 3) Parental Stress Index (PSI). Descriptive and inferential statistics were used to analyze the data.* ***Results:*** *The mean age of mothers was 38.14±6.41.The mean score of child's social interaction & behavior was .4033±.1790. The scale mean of parenting stress of mothers of child with autism was 3.0736±.4217 . There was a statistically significant difference between child's gender and parenting stress (t=-2.154, p=0.02). Childs social interaction and behavior and parenting stress of mothers of child with autism were significantly related (r=-.271, p=0.044).*
Conclusion: *The study findings provide information for the pediatric nurses that may help in reducing parenting stress of mothers of children with autism. Further predictive study may require for identifying the factors influencing stress of mothers of child with autism.*
Key wards*: Parenting Stress, Mothers, Children, Autism.*

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I. Introduction

Autism is a developmental disability defined by diagnostic criteria that include deficits in social communication and social interaction, and the presence of restricted, repetitive patterns of behaviour, interest, or activities that can persist throughout life (American Psychiatric Association, 2013). Autism is now a days a global health disease which is still undermined in many countries. According to the Centres for Disease Control (CDC, 2018), the incidence rate released in April 2016 showed that 1 out of 68 children was living with an autism diagnosis.. Today's incidence rate shows the rate increased to 1 out of 59 eight years olds, (CDC, 2018). A 2012 review of global prevalence estimates of autism spectrum disorders found a median of 62 cases per 10,000 people (Elsabbagh, Divan&Yun-Joo Koh, 2012).

In Bangladesh, It has been estimated that 1% of world population suffered from Autism which can be explained as a life -long neurodevelopment condition, Institute of Pediatric neuro disorder & Autism (IPNA, 2017). Autism is one of the most priority health issue for the government. Recently, Directorate General of Health Services in collaboration with Institute of Paediatricneuro disorder & Autism (IPNA) of Bangabandhu Sheikh Mujib Medical University (BSMMU) took initiative to identify prevalence of Autism Spectrum Disorder in rural Bangladesh. The study covered six unions of the Raegan upazila to identify Autism prevalence of children aged between 18 months to 36 months. (Seltzer, Greenberg, Floyd & Pettee, 2001)

According to (Diego, Liliana, Valentina & Luigi, 2007) parents of children with developmental disabilities, and found that over 50% of parents aged 50 years or older indicated that they still live with their cchild, compared with a rate of 17% for typically developing children. Like other developmental disorders, autism has no biological makers which make it extremely difficult for parents to accept the child's condition (Diego, Liliana, Valentina & Luigi, 2007). Autism always is characterized by problems of social interaction, such as forming attachments and showing affection this is why it has been considered as one of the most complex developmental disorders (Die Baker, Blacher, Crnic & Edelbrock, 2002). Being ambiguous, the diagnosis of and prognosis for autism is fraught with uncertainty that often placed lifelong burden on parents and sibling of children with ASD, which also present parents with ongoing grief and likely decreases optimism about their own future, as well as the future of their affected child (Volkmar & Klin, 2000). Having children naturally changes the family function and parental role could be a source of stress for many parents. (Pottie, Cohen, & Ingram, 2009) evaluated that parents of children with autism and showed a significant correlation

between the severity of disruptive behaviours of children and parental stress or negative mood is expected to cause an enduring stress and is a demanding responsibility for the parents.

Parenting stress is the incidence of distress or discomfort related to the experience of parenting (Deater Deckard, 1998). While some amount of parenting stress is typical, and even beneficial, significant levels of parenting stress can lead to lower parental self-efficacy of parents of children with autism (Dnnenberg & Baker, 1993). Parents of children with developmental disabilities experience stress, impaired mental health, imparted physical functioning tiredness (Blacher, 1984). Parental stress and health outcome is related to child characteristics such as the severity of the core disability or main diagnosis, the age of the child and the extent of coexisting behaviour problems (Hastings, 2008; Freman & Pery, 1991). Many authors reported higher level of stress among mothers of children with autism (Peishi, Craig, Michaels & Matthew, 2011; Bilgin & Kucuk, 2010; Sawyer et al, 2010). In comparison to parents of normal children, parents of autistic children show an inclination to report higher family stress, and they have severe physical and psychological problems (Bilgin & Kucuk, 2010). Several studies have reported the ending stress eventually shows in the form of various psychological problems such as depression, anxiety, lack of satisfaction in life, and sleep disorders (Phetrasuwan & Shandor, 2009; Lopez, Hoffman, Slieney, Hodge & Gilliam, 2008; Meltzer & Brief, 2008).The study showed that mother's mental health disorder increased physical health problems (Freeman & Perry, 1991). In American one study explained that Socio-demographic and psychological correlates included persistent poverty beginning in early childhood, limited parental education, low family expressiveness, stressful life events and violence exposure made a significantly associated with poorer social competence and family burden (Alice , Robert & Wagmiller, 2010) .

Therefore,the parenting stress of mothers of children with autism may help the professionals such as paediatric health professionals to have more effective communication with these parents and be more supportive (Avdi, Griffin, & Brough, 2000 as cited in Soltanifar et al, 2015). Moreover, there are some study like autism experiences, behaviour problem of children with autism, sleeping problem of parents of children with autism. However, there are very few researches regarding parenting stress of mothers. The study findings may provide information for the pediatric nurses that may help in improving parenting stress of mothers of children with autism. The objective of this study to examine the parenting stress of mothers of childs with Autism

II. Methodology

Study Design

A descriptive correlational study design was used to examine the parenting stress of mothers of children with Autism in Bangladesh.

Study Participants

The sample size was calculated by using G*power analysis with an acceptable minimum level of significant (α) of 0.05. an expected power of 0.80 (1-β), and an estimated population effect size of 0.30 as the medium effect size commonly used in the nursing study. Sample size was 80 with the 10% added to the possibility of attrition.A Convenient sampling technique was used for the study to recruit the sample who met the selection criteria. All the mothers whose children study in selected school; willing to participate and have child's age 3-15 years old.

Instruments

The instrument consist of three sets structured questionnaires (1) The Demographic Data Questionnaire, (2) Child's Social interaction & Behaviour related Questionnaire, and (3) Parenting Stress Index (PSI) (Berry & Jones, 1995). The Demographic Data Questionnaire: This Questionnaire was developed based on the literature reviewed by the researcher. It consists of 14 items including the mothers of 3-15 years old childern with autism.

Child's Social interaction & Behaviour related Questionnaire**:** (The CAST-"Childhood Asperger Syndrome Test" Jo Williams et al, 2005). This instruments was developed based on the literature reviewed by the researcher. It consists of 23 items. The scoring range was 0-1. For each correct answer reseaercher assigned one (1) score and for an incorrect answer researcher assigned zero (0) score. The lower score indicated the lower social interaction & behaviour .

Parenting Stress Index (PSI) (Berry & Jones, 1995): This Questionnaire is developed by the researcher and it consists of 18 items; A structured questionnaire that assess parenting stress of mothers of child with autism in a specialized school. On each item the individual indicates her level of agreement with a statement on a 5- point Likart scale from 1 (strongly disagree) to 5 (strongly agree). Items 1, 2, 5, 6, 7,8, 17 and 18 were reverse scored, (5= strongly disagree to 1= strongly agree).The score of 5-point numerical rating scale was ranged from 1-5. The lower score indicated the higher level of parenting stress. All instruments were validated by three experts from NIANER. All instrument were translated based on the back translation process.

Data Collection

This study was conducted from July 2017 to June 2018 and was approved from the Institutional Review Board (IRB),NIANER Dhaka, Bangladesh. All written consent form was obtained from the participants. Verbal and written informed consent from the subjects was taken who agreed to participate in this study. Autonomy, confidentiality & anonymity were strictly maintained. Prior to data collection, researcher achieved a research ethics certificate from the Global Health Network.

Data Analysis

Descriptive and inferential statistics such as frequencies, percentages, means and standard deviations were used to describe the characteristics of study participants.Inferential statistics such as t-test and Pearson Product Correlation was used to analyze the relationship between demographic characteristics and parenting stress of mothers of children with Autism.

III. Results

Demographic Characteristics of Mothers and their Children with Autism

Table 1 shows the demographic characteristics of mothers the mean age was 38.14 years. About 60% mothers had college and above level of education. (87.5%) mothers were muslim. The majority of the mothers (81.3%) were house wife. Most of the (87.5%) mothers lived in nuclear family. Hundred percent (100%) mothers reported that they lived in urban area and pacca building. Mothers had number of children mean was 2.21years. Monthly family income mean was 36387 taka. The demographic characteristics of children mean age was 10.13 years. The majority of them were male (72.5%). Age mean months was 18.14. And duration of starting treatment mean months was 57.69.

Table 1. DemogrEaphic Characteristics of Mothers and their Childs with Autism (N=80)

Items	Categories	(n)	(%)	M±SD
Mothers Age				38.14±6.408
Educational level				
	School level	32	40	
	College and above	48	60	
Occupation				
	Housewife	65	81.3	
	Others	15	18.8	
Religion				
	Muslim	70	87.5	
	Non-Muslim	10	12.5	
Marital status				
	Couple	76	95.0	
	Non Couple	4	5.0	
Residence				
	Urban	80	100	
Monthly family's income…..(taka)				36387±23185
Types of house you lived in				
	Pacca	80	100	
Number of Children				2.21±.837
Types of family				
	Nuclear	70	87.5	
	Joint	10	12.5	
Child's Age…….(Years)				10.13±3.110
Gender				
	Male	58	72.5	
	Female	22	27.5	
Age of diagnosis (months)				18.14±15.225
Duration of starting treatment (months)				57.69±35.992

IV. Child's Social Interaction and Behaviour with Autism.

Table 2 shows the child's social interaction & behavior. The total mean score was

9.63± 4.364. It was reported that (41.3%) childs with autism participated in playing games with other children easily. About (43.3%) children came up spontaneously for a chat and only (31.3%) could speak by 2 years old. Most of the (76.3%) children enjoyed sports. About (55.0%) children important were fit with the peer group. Only (25.0%) children were easy to interact with others. Maximum (63.7%) children were important to him/her and (52.5%) could dress him/herself. Near about (21.5%) children were good at turn-taking in conversation. Only (22.5%) children could count to 50 without leaving out any numbers. Only (42.5%) children made normal eye contact. Seventy percent children had unusual and repetitive movements. Twenty percent could ride a bicycle. Near about (61.5%) children had odd or unusual phrases and (67.5%) had ever been language delay. (56.3%) childs had ever been attention deficit disorder (ADHD). About 47.8%children had visual difficulties. (35.0%) children could keep a two-way conversation going. (26.3%) children had friends, rather than just acquaintances. (33.8%) children had unusual voice and (27.5%) did prefer imaginative activities such as play acting or story telling, rather than numbers or lists of facts.

Table 2: Child's Social Interaction and Behaviour with Autism

Items	Yes	N (%)
Does he/she join in playing games with other children easily?		33 (41.3)
Does he/she come up to you spontaneously for a chat?		37 (46.3)
Was he/she speaking by 2 years old?		25 (31.3)
Does he/she enjoy sports?		61 (76.3)
Is it important to him/her to fit in with the peer group?		44 (55.0)
Does he/she find it easy to interact with other children?		20 (25.0)
Can he/she read appropriately for his/her age?		11 (13.6)
Does he/she mostly have the same interests as his/her peers?		20 (25.0)
Are people important to him/her?		51 (63.7)
Can he/she dress him/herself?		42 (52.5)
Is he/she good at turn-taking in conversation?		17 (21.3)
Can he/she count to 50 without leaving out any numbers?		18 (22.5)
Does he/she make normal eye contact?		34 (42.5)
Does he/she have any unusual and repetitive movements?		56 (70.0)
Can he/she ride a bicycle (even if with stabilizers)?		16 (20.0)
Does he/she have odd or unusual phrases?		49 (61.3)
Has he/ she ever been language delay?		54 (67.5)
Has he/she ever been attention deficit disorder (ADHD)?		45 (56.3)
Having or visual difficulties?		38 (47.8)
Can he/she keep a two-way conversation going?		28 (35.0)
Does he/she have friends, rather than just acquaintances?		21 (26.3)
Is his/her voice unusual (e.g. overly adult, flat, or very monotonous)?		27 (33.8)
Does he/she prefer imaginative activities such as play acting or storytelling, rather than numbers or lists of facts?		22 (27.5)
Total M±SD 9.62±4.36		

V. Distribution of Parenting Stress of Mothers of Childs with Autism (N-80)

Table 3 Shows the parenting stress of mothers of children with autism. In this study, the majority of the mothers had high score of parenting stress. The total item was 18 out of maximum score 55 about parenting stress of mothers regarding the items with percentage respectively. Most of the (61.3%) mothers agreed on "I am happy in my role as a parent". Regarding "There is little or nothing I wouldn't do for

my child if it was necessary", (38.8%) mothers agreed. About (51.2%) mothers agreed on "caring for my child sometimes takes more time and energy than I have to give" and (45.0%) agreed on "I feel close to my child". Maximum (66.3%) mothers agreed on "I enjoy spending time with my child". About (66.3%) mothers agreed on "my child is an important source of affection for me". Whereas (31.3%) mothers strongly disagreed on "having

child gives me a more certain and optimistic view for the future". Again (33.8%) mothers agreed on "the major source of stress in my life is my child" and (61.3%) agreed on "having child leaves little time and

flexibility in my life".". Here (46.3%) mothers strongly agreed on "the behaviour of my child is often embarrassing or stressful to me" and same answer on "if I had it to do over again,. There are fifty percent mothers who disagreed on "having child has meant having too few choices and too little control over my life". parent" and (75.0%) agreed on "I find my child enjoyable.

Table 3. Distribution of Parenting Stress of Mothers of Childs with Autism (N-80)

Items	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree	M(SD)
	1 n(%)	2 n(%)	3 n(%)	4 n(%)	5 n(%)	
I am happy in my role as a parent	1 (1.3)	19 (23.0)	8 (10.0)	49 (61.3)	3 (3.8)	2.99 ±1.013
There is little or nothing I wouldn't do for my child if it was necessary	5 (6.3)	28 (35.0)	2 (2.5)	31 (38.8)	14 (17.5)	3.12±1.184
Caring for my child sometimes takes more time and energy than I have to give	2 (2.5)	9 (11.3)	1 (1.3)	41 (51.2)	27 (33.8)	4.03±1.018
I sometimes worry whether I am doing enough for my child	6 (7.5)	19 (23.8)	7 (8.8)	36 (45.0)	12 (15.0)	3.34±1.201
I feel close to my child	1 (1.3)	2 (2 5)	5 (6.3)	52 (65.0)	20 (25.0)	2.49±1.136
Ienjoy spending time with my child	1 (1.3)	6 (7.5)	12 (15.0)	50 (62.5)	11 (13.8)	2.65±1.045
My child is an important source of affection for me	1 (1.3)	7 (8.8)	1 (1.3)	53 (66.3)	18 (22.5)	2.43±1.123
Having child gives me a more certain and optimistic view for the future	25 (31.3)	21 (26.3)	5 (6.3)	24 (30.0)	5 (6.3)	3.60±1.279
The major source of stress in my life is my child	11 (13.8)	13 16.3)	3 (3.8)	27 (33.8)	26 (32.5)	3.50±1.458
It is difficult to balance different responsibilities because of my child	2 (2.5)	7 (8.8)	1 (1.3)	42 (52.5)	28 (35.0)	4.10±.499
The behaviour of my child is often embarrassing or stressful to me	4 (5.0)	12 (15.0)	4 (5.0)	23 (28.7)	37 (46.3)	4.01±1.217
If I had it to do over again, I might decide not to have child	19 (23.60)	6 (7.5)	11 (13.8)	7 (8.8)	37 (46.3)	3.44±1.606
I feel overwhelmed by the responsibility of being a parent	3 (3.8)	4 (5.0)	13 (16.3)	53 (66.3)	7 (8.8)	3. 68±.854
Having child has meant having too few choices and too little control over my life	20 (25.0)	40 (50.0)	3 (3.8)	16 (20.0)	1 (1.3)	2.85±1.199
I am satisfied as a parent	3 (3.8)	11(13.8)	3 (3.8)	58 (72.5)	5 (6.3)	2.65±1.092
I find my child enjoyable.	4 (5.0)	6 (7.5)	2 (2.5)	60 (75.0)	8 (10.0)	2.51±1.102
Total M±SD 55.36 ± 7.484						Scale score 3.0736

VI. Relationship of children's social interaction & behaviour with demographic characteristics of mothers and their childs , and parenting stress of mothers of children with Autism

Table 4 shows the relationship of children's social interaction & behaviour with demographic characteristics of mothers and their children , and parenting stress of mothers of children with Autism . There was a t-test having significant difference between gender and parenting stress of mothers of child with autism. The mothers who had female children with autism, they had more parenting stress (t=-2.154, p=.020). Whereas there was a correlation significant relationship between childs social interaction and behavior and parenting stress of mothers of child with autism. The children who had less social interaction & behavior their mothers' parenting stress was high (r=-.271, p=0.044). The result indicated that there was statistical significant

(p=<.005). Among mother age (p=.437) educational level (p=.385), occupation (p=.851), religion (p=.609) marital status (p=..076)), mothly income (p=.216), types of family (p=.258). childs age (p=.122), number of children (p=.224), age of diagnosis (p=.076) and duration of starting treatment (p=.118)), there were no significant different on parenting stress of mothers of childs with autism.

Table 4. Relationship of Childs social interaction & behaviour with demographic characteristics of mothers and their childs ,and parenting stress of mothers of childs with Autism (N-80).

Variables	Categories	M±SD	t/r(p)
Educational level			.
Age			284 (.778)
	School level	3.2698±.4205	
	College and above	3.2415±.4136	
Occupation			.596 (.553)
	Housewife	3.2795±.4078	
	Others	3.2063±.4552	
Religion			.550 (.584)
	Muslim	3.2770 ± .4166	
	Non-Muslim	3.2000±.3912	
Marital status			.951 (.345)
	Couple	3.2573±.4175	
	Non Couple	3.4583±.2458	
Residence			
	Urban	3.2674±.4119	
Monthly family's income…… (taka)			.140 (.216)
Types of house you lived in			
	Pacca	3.2674±.4119	
Number of children…….(persons)			-137 (.224)
Types of family			.813 (.419)
	Nuclear	3.2532 ± .4271	
	Joint (Extended)	3.3667±.2708	
Child's Age…….(.months)			.881 (.122)
Gender			-2.154 (0.020)
	Male	3.2021±.4132	
	Female	3.4394±.3636	
Age of diagnosis (months)			.503 (.076)
Duration of starting treatment			.296 (.118)
Child's social interaction &behavior			-.271 (0.044)

VI. Discussion

A descriptive study design was carried out from July, 2018 to June, 2019. The purpose of the study was to examine the parenting stress of mothers of child with autism. The findings of the present study revealed that there was a significant relationship between children's characteristics, social interaction & behaviour of children, and parenting stress of mothers of childs with Autism (Ewa & Anna, 2017; Pisula & Dorsmann, 2017).

In the present study it was found that there was a statistically significant difference between children's gender and parenting stress. The mothers of female child with autism had more parenting stress. Similar study has revealed that parenting stress was statistically significant by children's geneder (Feizi et al., 2014).

The Center for Disease Control and Prevention (CDC, 2009) reported that the number of male to female children with autism range between 3 to 1 and 4 to 1 and these gender difference were fairly consistent across ethnicities. Perhaps parents in China experience geater pressure from their families and communities, and or assign greater importance, to actively seek services for male children with autism than female The study showed that children's social children (Peishi, Craig, Michaels & Mathew, 2011).

interaction and behavior with autism statistically signifantly related with parenting stress. It means that mothers whose children's had less social interaction and behavior had more parenting stress. The result is consistent with other study showed that a significant correlation between the severity of disruptive behaviours of children and parenting srtrees (Pottie, Cohen, & Ingram, 2009; Tie et al., 2009; Fiez et al., 2014). Another study found that there was a positive correlations between disruptive behaviours of children and parenting depression (Benson et al., 2006; Davis & Carter, 2008). The results have reported that parents of children with developmental problems and children with mental problems had more stress. The findings of the other srtudy are consistent with parenting stress. Also there was a significant difference between the score of mothers of children with chronic physical problems and mothers of children with psychological disorders regarding parent-child dysfunctional interaction *(*$P < 0.01$). The findings of the present study is consistent with study of Fiez et al. (2014).

This study had a few limitations which may affect the findings. For example: the study was conducted in only one setting, Autism specialized school'Society for the Welfare of the Intellectually Disabled Dhaka, Bangladesh (SWID) which could not provide enough sample. Future studies are needed to propose a more complete model for related factors of parenting stress of mothers of child with autism.

VII. Conclusion

The study carried out using a descriptive design from July 2018 to June 2019 at Autism specialized school'Society for the Welfare of the Intellectually Disabled Dhaka, Bangladesh (SWID).The aime of the study was to examine the parenting stress of mothers of childs with Autism in Bangladesh..The total sample of the present study was 80 mothers of children with autism. Convenience sampling technique was used for eligible participants of the study.The mothers of childrens with age range between 3-15 years were the subjects.

The results indicated that the mothers of children with autism had more parenting stress. There was a significant defference between gender and significant relationship between children's social interaction & behaviour with autism and parenting stress. More attention should be given to parents' (in particular mothers') needs. Social support and different coping strategies should be developed to respond positively to individual's changing needs and in buffering parents from the stress of having a child with Autism. The study findings will provide information for the pediatric nurses in Bangladesh that may help in decreasing parenting stress of mothers of children with autism.

VIII. Recommendations

In a country like Bangladesh, where the awareness about autism is still emerging, and the availability of services rather in short supply, there is a great need to develop effective service providers, willing to deal with the individual, the family and the society in general and as a whole. A variety of researchs have shown that the most effective form of parenting when dealing with autism is authoritative parenting, and the study shows that mothers tend to use more of permissive form of parenting which may have an adverse effect on the social ineraction & behavioural problems of children with autism. Hence proper training and intervention can be provided to parents to use more effective form of parenting when interacting with children with autism. Most of the parents have high level of stress, especially mothers, hence they need to have proper counselling so that they can overcome the stress that they are under going and learn proper coping strategies

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