Original Article

Psychological Distress and Perceived Burden among Parents of Children with Autism Spectrum Disorder: A Cross-Sectional Study

*Mahjabeen Aftab Solaiman[1], ASM Morshed[2], Nahid Mahjabin Morshed[3], MSI Mullick[4], HM Mahmud Harun[5]

Abstract

Taking care of children with autism spectrum disorder (ASD) is extremely demanding, both physically and mentally, and can have a negative impact on the family. It takes a lot of time, effort, and patience to meet the extra care needs of the afflicted children. This often causes their parents to experience psychological distress, depression, and other mental health issues. Therefore, we designed the study to investigate the caregiver burden and psychological distress among parents of children with ASD and the associated sociodemographic factors influencing parental burden. This descriptive, cross-sectional study was conducted with parents of 180 children with ASD in three tertiary hospitals in Dhaka, Bangladesh. A pre-validated structured questionnaire was used to collect data, and the caregiver burden was assessed using Zarit Burden Interview and scored to estimate the burden level. The mean age of the children in the sample group was 4.68 ± 0.96 years; 62.8% were boys. Nearly half of the children (46.1%) were diagnosed with ASD in the second year of birth, and comorbidities were present in 31.7%. It was determined that the burden level was significantly higher among mothers of children with ASD than fathers ($p<0.01$). Single parents experienced higher ($p<0.05$) psychological distress than those who were married. Spending long hours on caregiving resulted in poorer caregiving outcomes and increased parenting stress ($p<0.05$). The findings highlight the urgent need for the development of interventions and social support systems to help the parents of children with ASD combat mental health issues.

Keywords: Autism spectrum disorder, Caregiver, Parental burden, Psychological distress, Mental health, Psychological disorders

Introduction

Autism Spectrum Disorder (ASD), one of the most common forms of neurodevelopmental disorder in children, is defined by difficulties in social interaction and communication as well as displays of repetitive behavior.[1,2] Around 1% of the global population is affected by autism spectrum disorder[3], and the prevalence rate has increased dramatically from 1 in 166 children to 1 in 68 in the last few decades, making it a global health crisis.[4] Although it is considered to be caused by a combination of genetic and environmental factors[5], the exact reason for the development of ASD remains elusive. To date, there is no standard treatment available to combat autism, and therefore, extra care is needed for the child with ASD, which in most cases is challenging for the caregiver due to the presence of extensive physical and developmental comorbidities, such as motor deficits, seizure, and delayed self-help skills.[6-8]

Parents are the most crucial element of the family environment as they play a key role in their children's growth.[9] Parents of children with autism shoulder a disproportionate amount of responsibility that comes with caring for people with ASD, such as addressing a child's social, physical, emotional, and educational requirements, which can lead to distress, despair, and anxiety[10-12] Previous studies have reported that caring for children with ASD poses a higher risk of experiencing mental health issues than bringing up children with other disorders or normally developing children.[13,14] The mental and psychological problems among parents of ASD include depression, stress, anxiety, and emotional disturbance, which may, in fact, lead to suicidal tendencies.[15-17] In addition, many parents experience financial difficulties as a result of expensive out-of-

1. *Assistant Professor and Head, Department of Psychiatry, President Abdul Hamid Medical College Karimgonj, Kishoregonj.
2. Associate Professor, Department of Psychiatry, Dr. Shirazul Islam Medical College, Dhaka.
3. Professor & Chairman, Department of Psychiatry, Bangabandhu Sheikh Mujib Medical University (BSMMU), Dhaka.
4. Professor & Ex-Chairman, Department of Psychiatry, Bangabandhu Sheikh Mujib Medical University (BSMMU), Dhaka.
5. Resident Psychiatrist, National Institute of Mental Health, Dhaka

Correspondence: Mahjabeen Aftab Solaiman, Mobile: 01771958002, E-mail: zebin.araaf@gmail. com

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pocket medical expenditures, underemployment or job loss.[18-22] Therefore, it is not surprising that parents of children with ASD often feel strained by their responsibilities as a caregiver.

According to a recent study, around 0.84% of children in Bangladesh are affected by autism[23], and in numbers, nearly 3000 children are diagnosed with ASD. The prevalence rate among boys and girls is one per 94 and 150 children, respectively.[24] The patient registration data at Cambridge Medical University revealed a rise in the number of autistic children seeking medical help, from twelve in 2001 to 105 in 2009.[25] In another nationwide survey conducted in 2013, autism incidence was 0.15 percent among a population of 7200 people in seven upazilas in Bangladesh.[26] In a 2016 research conducted by Bangladesh's Ministry of Social Welfare, autism was found to account for 19 percent of all neurological impairments documented.[23] People in low-income countries, like Bangladesh, have a common propensity to stigmatize persons with mental illness or autism, and their families often experience societal devaluation, discrimination, injustice, and increased level of parental stress.[27] Researchers reported that higher parental stress resulted in restricted father-child interaction, reduced childcare obligation, and a high risk of drug abuse among fathers with autistic children.[28]

The purpose of the current study was to contribute to the literature on autism and investigate the level of caregiver burden and psychological distress of parents of children with ASD. Our study investigated the following hypotheses: Parents having children with autism is more likely to deal with higher stress level and caregiver burden; Mother of children with ASD are more prone to suffer from psychological distress and caregiver burden; socio-demographic variable has an impact on parental stress.

Materials and methods

Study design

This was a descriptive, cross-sectional study, and a pre-validated structured questionnaire was used to conduct the survey. This study was conducted between January 2015 and February 2017 at the Out Patient Department (OPD) of the Institute for Pediatric Neuro-disorder and Autism (IPNA), Bangabandhu Sheikh Mujib Medical University (BSMMU), Out Patient Department (OPD) of Psychiatry, BSMMU and Out-patient Department (Child Guidance Clinic), National Institute of Mental Health (NIMH), Sher -E-Bangla Nagar, Dhaka.

A total of 180 parents of children with autism spectrum disorder participated in this study. The sample size was calculated using power calculation formula: $n_0 = z^2pq / d^2$, where, n_0 = required sample size when population >10000; z = significance level at 95% CI (1.96); p = prevalence (0.0045); q = 1-p; d = degree of accuracy desired (0.01).

The inclusion criteria for this study include the following: Bangladeshi nationality; parents of children diagnosed to have ASD according to DSM-IV criteria[29], absence of intellectual impairment, dementia, psychotic disorders, bipolar disorder, drug addiction, or serious medical conditions (e.g., cardiovascular or pulmonary disorder); not living with another child or adolescent with mental illness or chronic medical condition.

Study tool

The questionnaire was structured after reviewing a number of literature and divided into three sections. The first section of the questionnaire was comprised of parent's personal information, including age, relationship with the child, family structure, marital status, education, employment, and monthly income. The questions in the second section were related to the children with ASD: age, gender, age at which the child was diagnosed with ASD, presence of comorbidities, and duration of caregiving. The final section was designed to assess the severity of the burden and psychiatric disorder among the parents of the autistic child using the Zarit Burden Interview (ZBI, 22-item) **(30)**. It consists of 22 items that are scored on a 5-point Likert scale from 0 (never) to 4 (nearly). The total score of the ZBI interview was calculated and then graded as follows: little or no burden (0-20), mild to moderate burden (21-40), moderate to severe burden (41-60), and severe burden (61-88).

Data collection

Participants, only those who were willing to participate in this survey, were provided the questionnaire to fill it up. Among 240 parents of children with ASD who were approached, 213 parents agreed to participate, and of them, 33 responses were found incomplete and were therefore disregarded. Finally, 180 correctly responded data were transferred for statistical analysis. The participation ratio was 79.5% in this study.

Ethical approval

Ethical approval was acquired from the Institutional Ethics Committee of the Bangabandhu Sheikh Mujib Medical University (BSMMU) before the starting of the data collection. Also, formal authorization was received from the institutions where the study was performed. During the face-to-face interview, individuals assigned to collect the response first explained the purpose and importance of the study to the potential respondents, and their verbal consent was obtained.

Statistical analysis

The collected data were analyzed using IBM Statistical Package for Social Science (SPSS; version 21.0). Categorical variables are expressed as percentages, and continuous variables are presented as mean ± SD, Standard deviation (average age and daily average caregiving time) or mean ± SEM, Standard Error of Mean (degree of burden). Correlation between variables and parent's burden levels were analyzed using the independent sample *t*-test and one-way ANOVA. Responses with multiple answers were defined in multiple response sets before descriptive statistical analysis. p-value less than 0.05 was considered statistically significant.

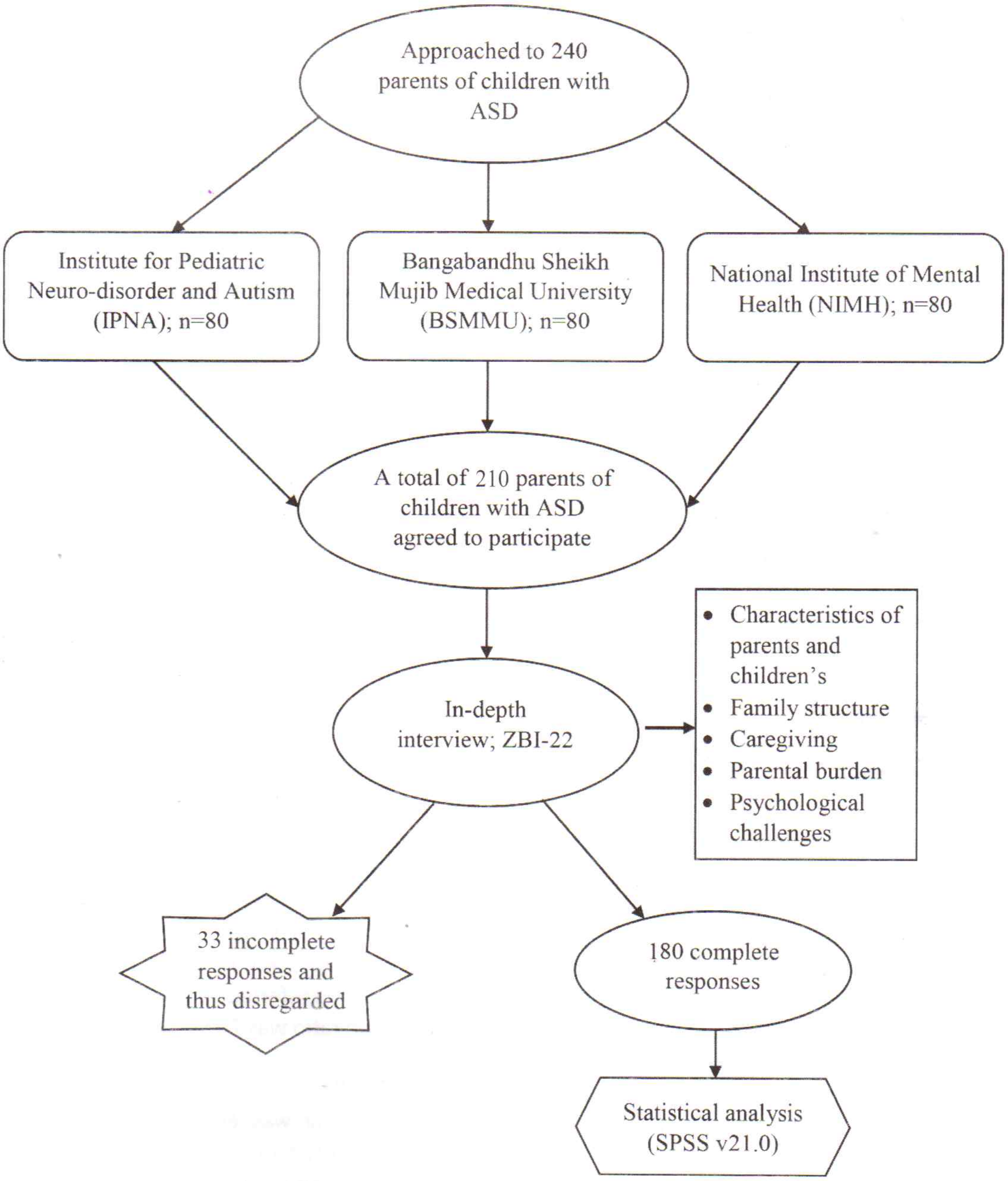

Figure 1. Schematic presentation of sampling and data collection.

Results

The interviewed parents were predominantly mothers, accounting for 61.7% of the total respondents. Large percentages were young parents (65.0%), aged between 21 to 35 years,

55.0% were unemployed, 60.5% had only primary and secondary school education, and 62.2% lived in a joint family. The monthly income of almost half of the parents (48.9%) was between BDT 11000 and 30000, and 78.9% of the participants were married. The mean age of the children in the sample group was 4.68 ± 0.96 years, and the majority (62.8%) were boys. Nearly half of the children (46.1%) were diagnosed with ASD in the second year of birth, and comorbidities were present in 31.7%. On average, parents spent 7.62 ± 2.74 hours daily on caregiving, and 45.6% were caregiving for five years and above (Table I).

The average score of the mothers' degree of burden was significantly higher as compared with the fathers (moderate to severe and severe: $p<0.01$; low and mild to moderate: $p<0.05$). The mild to moderate burden score of older parents was notably higher ($p<0.05$), and the mean score of moderate to severe and severe burden level was significantly higher in unemployed parents ($p<0.05$). Parents who lived in nuclear families ($p<0.05$) and monthly income is below average ($p<0.01$) had significantly higher burden scores (moderate to severe and severe), and the average burden score of single parents was statistically higher than the married (moderate to severe and severe: $p<0.05$; low and mild to moderate: $p<0.01$). The burden scores of the parents of children who have comorbidities were remarkably higher compared with the parents of children with no comorbidities ($p<0.01$). Parents who spent more than 8 hours daily giving extra care to their children had higher moderate to severe and severe burden scores ($p<0.05$) (Table II).

It was found that 65.6% of the parents were diagnosed case of psychological disorder and suffering from extreme psychological distress, and the rest of the other parents acknowledged that they had often experienced mental and emotional stress but never approached a physician for diagnosis. When the responses of the parents were analyzed, it was observed that more than half of the parents (53.9%; n=97) were suffering from major depressive disorder, and the two other most experienced psychological disorders among parents were anxiety (43.3%; n=78) and panic (33.9%; n=61) disorder; 10.6% (n=19) had experienced suicidal ideation (Table III).

Table 1. Descriptive characteristics of children with ASD and their parents (n = 180)

	n	%
Interviewed parent		
Mother	111	67.7
Father	69	38.3
Parents age (mean age= 32.2 ± 6.9 years)		
21 to 35 years	117	65.0
36 years and above	63	35.0
Employment status		
Employed	81	45.0
Unemployed	99	55.0
Education status		
Illiterate	12	6.7
Primary and secondary level	109	60.5
Graduate and above	59	32.8
Family type		
Nuclear family	38	37.8
Joint family	112	62.2
Income status (BDT)		
Low (less than 10000)	18	10.0
Average (11000 to 30000)	88	48.9
High (31000 and above)	74	41.1
Marital status		
Married	142	78.9
Single parent	38	41.1
Gender of the children		
Boy	113	62.8
Girl	67	37.2
Age of children (mean age = 4.68 ± 0.96 years)		
3 years or less	19	10.6
4 years	63	35.0
5 years and above	38	54.4
Age at which the child was diagnosed with ASD		
First year of the birth	36	20.0
Second year	83.	46.1
Third year and above	61	33.9
Comorbidities		
Yes	57	31.7
No	123	68.3
Daily caregiving time (mean time = 7.62 ± 2.74 hours)		
Less than 8 hours	75	41.7
8 hours and above	105	58
Duration of caregiving		
1 to 4 years	98	54.4
5 years and above	82	45.6

Table 2. Distribution of variables with parental burden level among parents of children with autism spectrum disorder (n = 180)

	Level of burden			
	Moderate to severe and severe (n=108; 60%)		Little or no and mild to moderate (n=72; 40%)	
	Mean score ± SEM	n (%)	Mean score ± SEM	n (%)
Mother	63.97 ± 1.65	78 (70.3)	24.91 ± 2.04	33 (29.7)
Father	55.90 ± 2.27	30 (43.5)	18.97 ± 1.50	39 (56.5)
p	0.009**	-	0.020*	-
t	2.680	-	2.388	-
Parents age				
21 to 35 years	53.25 ± 1.14	64 (54.7)	22.43 ± 1.50	53 (45.3)
36 years and above	56.43 ± 1.83	44 (60.3)	27.38 ± 1.63	29 (39.7)
p	0.123	-	0.039*	-
t	1.555	-	2.091	-
Employment status				
Employed	54.66 ± 1.30	50 (61.7)	25.19 ± 1.76	31 (38.3)
Unemployed	59.62 ± 1.62	58 (56.3)	26.85 ± 1.53	41 (43.7)
p	0.021*	-	0.478	-
t	2.335	-	0.714	
Education status				
Illiterate	56.25 ± 5.42	8 (66.7)	26.25 ± 4.37	4 (33.3)
Primary and secondary level	55.22 ± 1.45	67 (61.5)	23.00 ± 1.39	42 (38.5)
Graduate and above	54.39 ± 1.67	33 (55.9)	23.23 ± 2.11	26 (44.1)
p	0.901	-	0.814	-
F	0.105	-	0.207	-
Family type				
Nuclear family	61.62 ± 1.88	37 (54.4)	26.48 ± 1.94	31 (45.6)
Joint family	56.69 ± 1.28	71 (63.4)	22.44 ± 1.45	41 (36.6)
p	0.029*	-	0.092	-
t	2.213	-	1.709	-
Income status (BDT)				
Low	69.20 ± 1.91	10 (55.6)	20.88 ± 2.12	8 (44.4)
Average	64.62 ± 1.87	52 (59.1)	23.89 ± 1.48	36 (40.9)
High	57.35 ± 1.86	46 (62.2)	21.68 ± 1.37	28 (37.8)
p	0.004**	-	0.440	-
F	5.837	-	0.832	-
Marital status				
Married	57.06 ± 1.37	82 (57.7)	13.88 ± 0.90	60 (42.3)
Single parent	62.54 ± 2.29	26 (68.4)	20.42 ± 1.66	12 (31.6)
p	0.049*	-	0.003**	-
t	1.993	-	3.039	-
Gender of the children				
Boy	49.73 ± 0.84	67 (59.3)	22.50 ± 1.54	46 (40.7)
Girl	51.49 ± 1.32	41 (61.2)	25.50 ± 1.86	26 (38.8)
p	0.239	-	0.225	-
t	1.184	-	1.226	-
Comorbidities				
Yes	60.98 ± 1.74	40 (70.2)	25.71 ± 1.82	17 (29.8)
No	53.19 ± 1.15	68 (55.3)	18.87 ± 0.91	55 (44.7)
p	0.000**	-	0.001**	-
t	3.888	-	3.550	-
Daily caregiving time				
Less than 8 hours	52.93± 1.31	42(56.0)	20.58± 2.10	33(44.0)
8 hours and above	57.15 ± 1.45	66 (62.9)	23.15 ± 1.61	39 (37.1)
p	0.047*	-	0.327	-
t	2.009	-	0.988	-
Duration of caregiving				
1 to 4 years	56.62±1.69	63(64.3)	25.60±1.73	35(35.7)
5 years and above	51.87 ± 1.45	45 (54.9)	24.73 ± 1.43	37 (45.1)
p	0.045*	-	0.698	-
t	2.029	-	0.390	-

* p<0.05; ** p<0.01 t = Independent samples t-test; F = One-way ANOVA, Tukey test

Table 3. Distribution of the major psychological disorders that the parents of children with ASD experienced (n = 180)

Psychotic disorder	n	%
Major depressive disorder	97	53.9
Generalized anxiety disorder	78	43.3
Panic disorder	61	33.9
Social phobia	57	31.7
Obsessive compulsive disorder	36	20.0
Bipolar mood disorder	31	17.2
Adjustment disorder	24	13.3
Dysthymic disorder	21	11.7
Suicidal thought	19	10.6
Agoraphobia	17	9.4
Alcohol dependence	17	9.4
Somatoform symptom disorder	14	7.8
Cannabis abuse	13	7.2
Specific phobia	4	2.2
No diagnosis	62	34.4

Discussion

The aim of this study was to investigate the caregiver burden and the major psychological challenges experienced by the parents of children with ASD in three tertiary hospitals in Bangladesh: BSMMU, IPNA, and NIMH. It was evident that the degree of caregiver burden among the parents of children with ASD in the sample group was high, and the majority of the parents experienced mental health issues.

Evidence suggests that mothers of children with ASD are more affected mentally compared to fathers.[29-31] Our findings indicate that the perceived burden scores of the mothers in our sample group were higher than the fathers. The possible reason could be mothers in Bangladesh have more responsibility for their children's upbringing than fathers. In fact, in most societies, women concentrate more on household responsibilities, whilst fathers tend to focus mostly on the family's financial support.[32] In another study by Elçi (2004), where he investigated the impact of social support, stress levels, and coping strategies in families of children with ASD, reported that mothers of autistic children had encountered more challenges and experienced burnout compared with the fathers because they took on the majority of the parenting responsibilities.[33]

Demographic and socioeconomic factors such as employment, monthly earning, marital status, and family structure are linked with the caregiving outcome, caregiver perceived burden, and psychological distress.[34] We observed that parental burden was higher among parents who were unemployed than the parents who worked outside. Most of the unemployed parents, especially the mothers who gave up their job to stay home so that they can meet the extra care needs of their children, faced more challenging conditions because they experienced more economic challenges. However, in a similar study, it was outlined that employed parents experienced higher stress levels because they feel taking care of children with ASD is a complex task and requires personal and professional sacrifices.[35] Economic burden made it difficult for the parents to meet the high medical expenses, particularly those children who had comorbidities. In fact, a portion of the respondents (31.7%; n=57) in our sample group experienced a higher burden ($p<0.01$) because of the presence of comorbidities in their childrens' as their treatment required extra medical attention and cost.

Single parents' reported a higher level of stress than those who were married. Their psychological distress may be the result of extreme emotional pain, relationship conflicts, coparenting disengagement as well as economic disadvantages.[36,37] The correlation between caregivers' burden and family structure is not extensively studied and thus still remains elusive. The findings of our study indicated a higher burden level among parents who lived in nuclear families than those who lived in extended families. This may be because the parents of the joint families might have some sort of support from other members that allowed them to spend more time in caregiving, which might not be available to the parents who lived in nuclear families.

In this study, we noticed a positive correlation between the time spent on caregiving and parents' burden level. The more time spent on caregiving tasks, the poorer the caregiving outcome, resulting in higher parental burden and psychological distress. A cross-sectional study conducted on Jordan's parents of children with ASD reported that negative perception of caregiving outcomes is linked with increased depression and anxiety and the ultimate cause of psychological distress in parents of children with ASD.[35]

We documented that parents who were caregiving for more than five years have lower burden scores, meaning the stress level of parents is inversely related to the age of the children. The stress level of the parents in the earlier years of caregiving was higher, and the burden level decreased as the age of the children with ASD increased, which is consistent with previous findings.[38] Bozkurt, Uysal, and Düzkaya (2019) observed an increased self-confident approach and optimistic approach scores as time elapsed, which might be explained by the fact that with time, parents accepted their children's condition, got accustomed to it or might have found some helping hands.[39]

Findings from this study suggest that parents with ASD children were more likely to suffer from depression and anxiety than any other psychological disorders and were consistent with previous studies.[40-42] In addition, a recent meta-analysis found that the mothers of children with developmental disabilities had a 29% higher risk of suffering from depression than the mothers of typically developing children.[43] An alarming finding of our study was that 10.6% (n=19) of the parents had experienced suicidal ideation at some point of caregiving. This alarming incidence rate is most likely due to underlying depression, but it might also be exacerbated by the fact that parents with ASD children are frequently insulted and humiliated by others.[44]

Limitations

The study was conducted on 180 parents of children with ASD in three tertiary hospitals located in Dhaka, Bangladesh, and therefore, the findings of the study cannot be generalized. It is also worth mentioning that different forms and severity of autism exist, which were not precisely evaluated and might have an influence on the results.[45] We, therefore, cannot eliminate if parents of children with the severe form of ASD are more or less likely to respond differently than the parents of children with mild ASD phenotype.

Clinical implications

Parents of ASD children suffer from life-long psychological distress because they feel that their children should be protected and supported throughout life. Once it has been determined that parents are experiencing mental distress, it is important for the healthcare professionals working with these families to use strategies to help ease some of their distress, therefore ensuring their well-being.

In Bangladesh, interventions for ASD children and social support services for children and their parents are insufficient. Here, families are solely responsible for their children's care, and a lot of families have been left to their own fate. Parents in Bangladesh might be directed to forums and autism-related organizations so that they can share and discuss their experiences, which could help parents facilitate and strengthen the social support system.

Conclusion

The findings of our study highlighted the perceived burden of parents of children with autism spectrum disorder and the psychological impact on the caregivers. This study supports a consistent finding that the perceived burden among mothers of children with ASD is significantly higher than the fathers. Moreover, the degree of burden was influenced by factors such as employment, economic and marital status, presence of comorbidities, and duration of daily caregiving. The findings emphasize the urgent need for the development of interventions and social support systems for alleviating the caregiver burden and improving the mental health of parents of children with ASD, thereby ensuring their overall well-being.

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