

Assessment of Perceived Stress Among Parents Having Children with Autism and Other Neurodevelopmental Disorders: A Cross-Sectional Observational Study

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Conflict of Interest: None

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ABSTRACT:

Background: The burden of Neurodevelopmental disorders is huge. Caring of NDD children is a stressful job. Chronic parental stress can lead to adverse cardiovascular consequences. Addressing stress of parents is crucial to effective and inclusive health policy.

Objective: To assess perceived stress among parents of children with autism and other neurodevelopmental disorders and to compare with neurotypical kids parents.

Method: A cross sectional observational study was conducted among parents attending in hospital, therapy clinics, special and inclusive schools and day care centers and normal parents of Dhaka city and other places. Structured questionnaire of PSS 10 was used to measure their perceived stress along with other socio demographic parameters. Descriptive and comparative statistics were used to analyze the data.

Result: For NDD group, total 120 parents were chosen, among them 60 were fathers and 59 were mothers. ASD was the most prevalent group of NDD (64%) followed by CP (16%), ADHD (9%), Downs syndrome (6%) and others (5%). Stress level in parents having NDD kids is substantially high with a mean of 35.7.

For normal group, total 120 parents with normal kids were chosen randomly. Among the responders 57% were mothers and 42.1% were fathers.

Mean PSS score of fathers were 16. Stress in NDD parents is substantially higher than that of normal group which is significant statistically. High stress is also associated with low education level, low income, severity of disability etc. However weak but non significant correlation of stress and parental sex, duration of parenting, geographical variation also revealed.

Conclusion: Perceived stress is substantially higher in parents having kids with NDDs than parents with neurotypical kids. The finding deserves more attention to this overlooked subgroup of population in implementing health policy.

Key Words: Autism, NDDs, stress, PSS-10

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Introduction

Neurodevelopmental disorders (NDDs), including autism spectrum disorder (ASD), attention deficit hyperactivity disorder (ADHD), Downs syndrome, intellectual disability, and developmental delay, are on the rise globally. ASD alone affects approximately 1 in 100 children worldwide, with even higher prevalence estimates in certain regions (1).

Field-based studies in Bangladesh have reported varying prevalence of autism spectrum disorder (ASD). A large rural community study screening 5,286 children aged 18–36 months found a prevalence of 0.75 per 1,000 children. Other urban and hospital-based studies in Bangladesh also indicate increasing identification of ASD cases, although true population-based prevalence remains limited (2,3).

Children with autism and other NDDs often require intensive, long-term care involving specialized therapies, educational support, and daily supervision. These caregiving responsibilities, which are largely shouldered by parents, impose substantial emotional, physical, social, and financial burdens.

Evidence suggests that parents of children with autism and other NDDs experience higher levels of chronic stress, anxiety, depression, and sleep disturbances compared to parents of neurotypical children (4,5,6). The continuous caregiving role may also limit opportunities for physical activity, healthy eating, and regular medical checkups, thereby increasing susceptibility to noncommunicable diseases particularly cardiovascular disease risk, among these parents.

From a public health perspective, understanding the level of stress in parents of children with autism and other NDDs is essential. Parents are primary caregivers, and their health directly influences the quality of care provided to children with special needs. Moreover, failure to address the health of caregivers can create a dual burden on health systems, with increased demand for services for both the child and the parent.

This thesis aims to explore the cardiovascular disease risk among parents of children diagnosed with autism and other NDDs, with a particular focus on psychosocial stress and behaviors. By adopting a public health

perspective, the study seeks to highlight the need for integrated approaches that not only support children with neurodevelopmental disorders but also promote the long-term health and well-being of their caregivers.

Rationale of the study:

- Autism and other NDDs are largely overlooked sub group of society.
- Their Caregivers are also out of focus.
- Caregiving stress can cause unfavorable cardiovascular consequences.
- Understanding caregiver stress in Bangladesh may help develop targeted psychosocial and preventive cardiovascular interventions.

Materials and Methods:

Problem Statement:

Parents of children with ASD and other NDDs may experience greater stress than parents of neurotypical children, but local evidence comparing these groups is limited.

General Objective

To assess perceived stress among parents of children with autism and other neurodevelopmental disorders.

Specific Objectives

1. To measure perceived stress scores among parents of children with ASD and other NDDs.
2. To compare parental stress levels between neurotypical and NDD groups.
3. To identify socio-demographic and clinical predictors of higher stress.
4. To explore association between stress severity and caregiving characteristics

Study Design: Cross sectional observational study.

Place of Study: Child development centers of Medical college hospital, Dhaka Shishu Hospital, special and inclusive schools and daycare centers in Dhaka city.

Study Period: One Year (January 2024 -December 2024).

Study Population: Parents with kids having

- Autism Spectrum Disorder and other NDDs like
- Attention deficit hyperactivity disorder (ADHD),
- Downs syndrome,
- Intellectual disability (ID),
- Cerebral Palsy (CP) and
- Developmental delay.

Inclusion Criteria**Group A: Parents of Children with Autism/NDDs**

1. Biological, adoptive, or primary caregiving parent of a child diagnosed with:
 - Autism Spectrum Disorder
 - Attention-Deficit/Hyperactivity Disorder
 - Cerebral Palsy
 - Intellectual Disability
 - Other clinically diagnosed NDDs.
2. Parent aged ≥ 18 years.
3. Child aged 2–18 years.
4. Parents have been the primary caregiver for at least 6 months.
5. Able to understand and complete the questionnaire (e.g., Bangla or English).
6. Provides written informed consent.

Group B: Parents of Neurotypical Children

1. Biological, adoptive, or primary caregiving parent of a neurotypical child.
2. Parent aged ≥ 18 years.
3. Child aged 2–18 years.
4. Parent has been the primary caregiver for at least 6 months.
5. Able to understand and complete the questionnaire.
6. Provides written informed consent.

Exclusion Criteria (Both Groups)

1. Parent diagnosed with severe psychiatric illness that may independently affect stress levels, such as:
 - Schizophrenia
 - Bipolar Disorder etc.

2. Parent with severe cognitive impairment preventing questionnaire completion.
3. Parent currently experiencing a major acute life crisis unrelated to child-rearing (e.g., recent bereavement within the last 3 months, major disaster).
4. Parent of a child with severe chronic medical illness unrelated to NDDs (e.g., cancer, end-stage organ disease).
5. Parents unwilling or unable to provide informed consent.
6. Incomplete questionnaire responses.

Research Questions

- Do parents of children with ASD and other NDDs experience higher stress than parents with neurotypical kids?
- Which parental or child factors are associated with higher stress?

Hypothesis:**• Null Hypothesis**

There is no significant difference in perceived stress between parents of children with ASD and other NDDs and parents with neurotypical children.

• Alternative Hypothesis

Parents of children with ASD and other NDDs have significantly higher perceived stress.

Sample Size**Sample Size Determination**

The sample size was calculated using the formula for comparison of two independent means. A previous study among parents of children with Autism Spectrum Disorder reported a mean Perceived Stress Scale (PSS-10) score of 17.7 with a standard deviation of 6.7 (7,8). Assuming a 95% confidence level, 80% power, and a minimum detectable difference of 3 points in PSS score between the study groups, the minimum required sample size was calculated as 79 participants per group. After accounting for a 10% non-response rate, the required sample size became 87 participants per group. To increase statistical power and precision, 120 participants were included in each group, giving a total sample size of 240 participants.

The formula for comparing two independent means was used:

$$n = \frac{(2(Z_{\alpha/2} + Z_{\beta})^2 \sigma^2)}{d^2}$$

Where:

- n = required sample size per group
- $Z_{\alpha/2} = 1.96$ for 95% confidence level
- $Z_{\beta} = 0.84$ for 80% study power
- σ = standard deviation
- d = minimum expected difference between the two group means

$$n = \frac{2(1.96 + 0.84)^2 (6.7)^2}{(3)^2}$$

$$n = \frac{2(2.8)^2 (44.89)}{9}$$

$$n = \frac{703.48}{9}$$

$$n = 78.16$$

Therefore, the minimum required sample size was **79 participants per group**.

After allowing for approximately 10% non-response or incomplete data:

$$79 \times 1.10 = 86.9$$

Thus, the final minimum sample size required was 87 participants per group .

Variables

Dependent Variable

- Perceived stress score(PSS-10)

Independent Variables:

Parent-related

- Age, Sex, Education, Occupation, Income.

Child-related

- Diagnosis, Severity, Comorbidities, Functional dependence

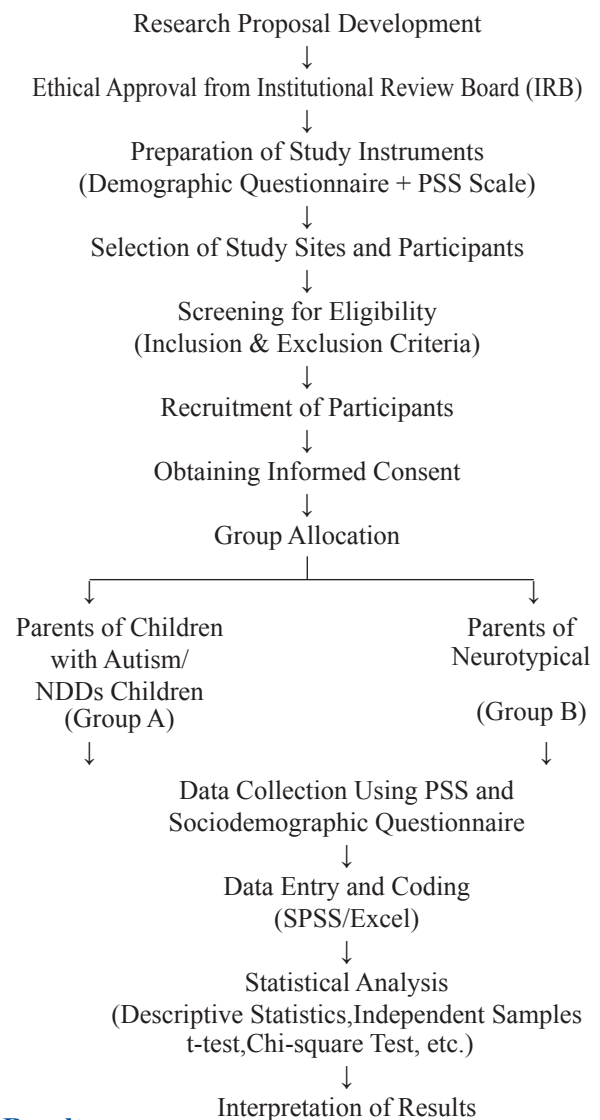
Family-related

- Social support , Number of children, Urban/rural residence

Ethical Considerations

- Institutional ethical approval. {Institute of Biological Sciences, University of Rajshahi. Approval no: 133/320(48)/IAMEBBC/IBSc}
- Written informed consent
- Confidentiality
- Voluntary participation
- Right to withdraw

Study procedure:



Result:

Total 120 parents with normal kids were chosen randomly. Among the responders 57% were mothers and 42.1% were fathers. Their mean age was 38.9 years (Standard Deviation: 9.43). 71.1% of them were from urban areas and 28.1% were from rural areas. 31.4% of them had

single kids and 52.9% had 2 kids and 11.6% had 3 kids. 28.9% of them had educational qualification up to SSC level, 31.4% up to HSC level, 24% of them were graduates whereas 14.9% had post-graduation degrees. Their monthly income ranges from 7 thousand BDT to more than 1 lac BDT (mean:62.38K, median:55.0k, SD:58.64K). PSS score of parents having neurotypical kids shows a range of 26 (mean:16, median:13, SD:6.42).

Mean PSS score of fathers were 16.22(SD:6.370) and those of mothers were 16.04(SD:6.516) which shows no difference in independent sample T test for Independence ($P:0.443$ with Confidence Interval:95%). On the other hand, Pearson Chi square test shows inverse relation of income and stress level, when we categorize the income level in three groups and PSS into three groups (chi square value:36.07, $P<0.001$ with df:4)

Education level of parents is also found to be inversely related to stress level (Chi square value:47.5, $P<0.001$, df:6, CI-95%) .

Most striking findings of the study is the high stress of parents of NDD children. Total 120 parents were chosen, among them 60 were fathers and 59 were mothers. Their mean age was 42.12 years (median 40 years, SD:1.84). 74.4% were from urban areas and 24% from rural areas. 14.9% of the participants education level was up to SSC, 14% up to HSC, 52.1% were graduates and 18.2% had postgraduation degrees. Total group was categorized into three categories on monthly income and most prevalent group was high income group (61.1%) earning more than 1lac BDT, followed by middle income group (18,5%) earning more than 50 thousand BDT and low-income group (17.6%) earning less than 20 thousand BDT.

ASD was the most prevalent group of NDD (64%) followed by CP (16%), ADHD (9%), Downs syndrome (6%) and others (5%). Most parents with NDD kids had 3 children (61.1%) followed by 1 kid (21.4%) and 3 kids (10.3%). Mean duration of parenting of NDD kids is 8.18 years (Mode:7 years, SD:5.33) In consideration with severity of NDD, most children had moderate severity (63%), followed by mild (25%) and severe (12%). Stress level in parents having NDD kids is substantially high, and its statistics is significantly different from that of parents having normal kids as revealed by independent sample T test comparing mean PSS among these two groups ($P<0.001$, df:237, CI-95%)

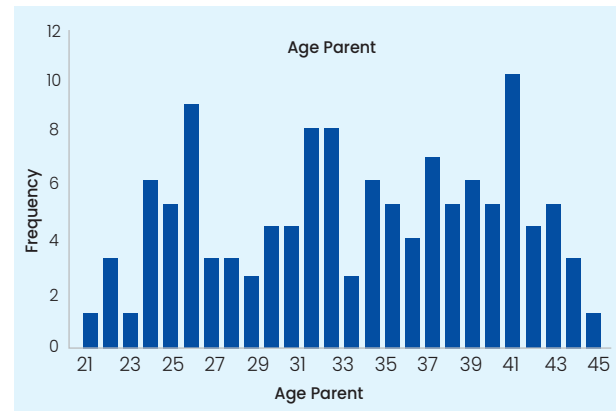


Fig1: Age of parents having neurotypical kids

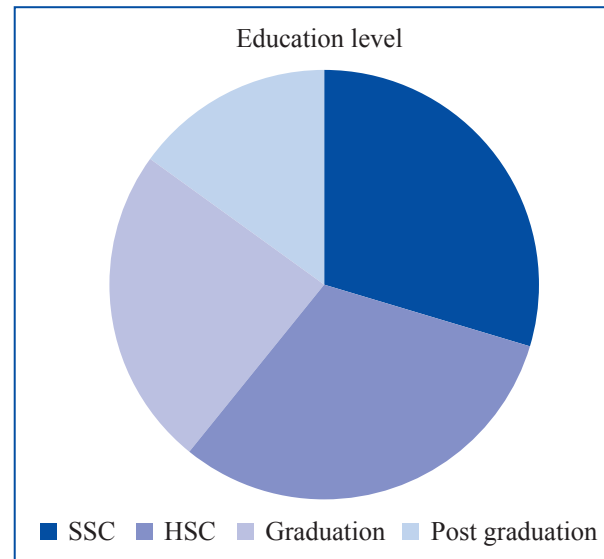


Fig 2: Education level of parents having neurotypical kids

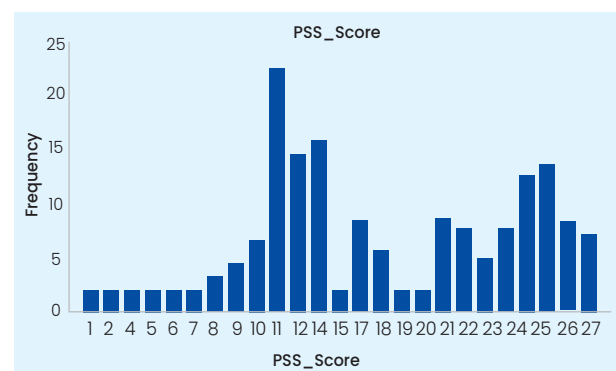


Fig 3: PSS score of parents having neurotypical kids.

Group Statistics					
	Parent	N	Mean	Std. Deviation	Std. Error Mean
Pss_score	Father	51	16.22	6.370	.892
	Mother	69	16.04	6.516	.784

Fig 4: PSS score parents having neurotypical kids

Independent Sample Test									
		t	df	Significance		Mean Difference	Std. Error Difference	interval of the difference	
				One-sided p	Two-sided p			Lower	Upper
Pss_score	Equal variances assumed	.144	118	.443	.885	.172	1.192	-2.188	2.532
	Equal variances not assumed	.145	109.214	.442	.885	.172	1.188	-2.182	2.526

Fig 5: T test for Independence, for relation of fathers and mothers PSS score.

Income level pss_cat Crosstabulation						
			low stress	pss_cat moderate stress	high stress	Total
Income level	low Income	Count	5	5	4	14
		% within Income level	35.7%	35.7%	28.6%	100.0%
	middle Income	Count	15	2	0	17
		% within Income level	88.2%	11.8%	0.0%	100.0%
	high Income	Count	42	0	0	42
		% within Income level	100.0%	0.0%	0.0%	100.0%
	Total	Count	62	7	4	73
		% within Income level	84.9%	9.6%	5.5%	100.0%

Fig 6: Income level and stress level of parents having neurotypical kids.

Chi-Square Tests			
	Value	df	Asymptotic Significance (2-sided)
Pears Chi-Square	36.071 ^a	4	<.001
Likelihood Ratio	33.380	4	<.001
Linear-by-Linear Association	28.089	1	<.001
N of Valid Cases	73		

a. 6 cells (66.7%) have expected count less than 5. the minimum expected counts is .77.

Fig 7: Chi square test for association of Income and stress level in parents having neurotypical kids.

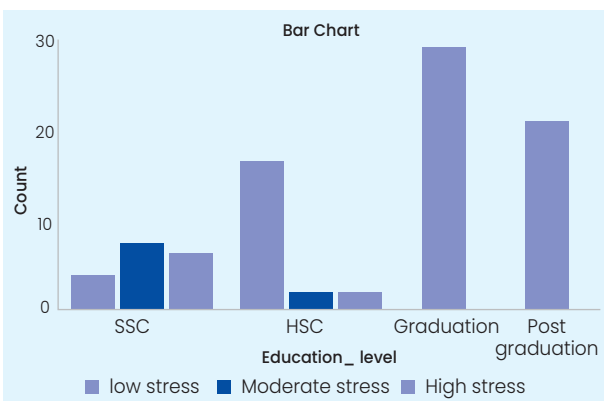


Fig 8: Income and stress level parents having neurotypical kids.

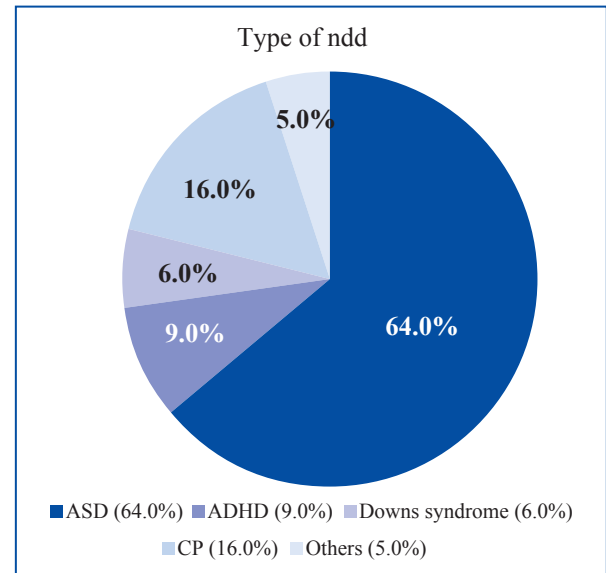


Fig 9: Type of NDDs

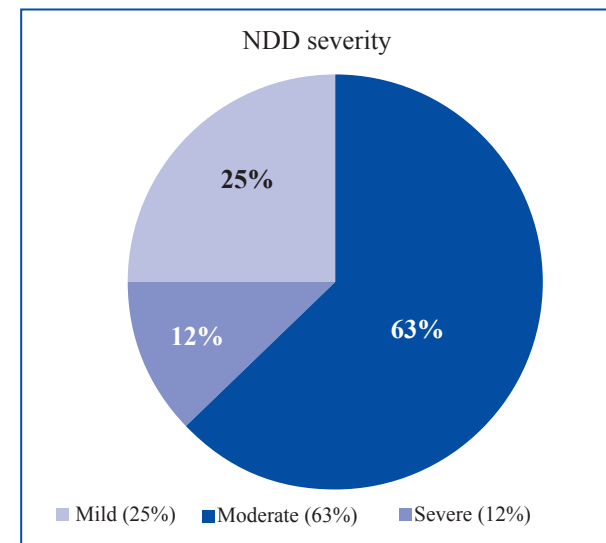


Fig10: Distribution of neurodevelopmental disorder (NDD) severity among children

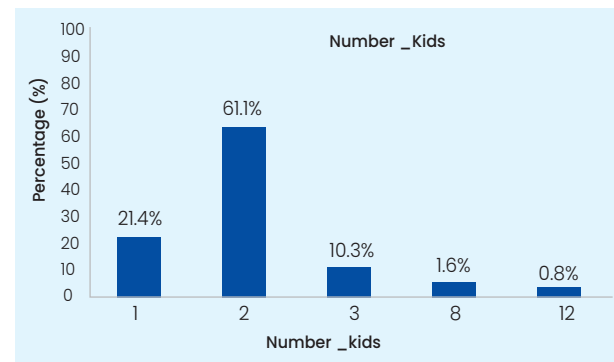


Fig11: Number of kids in NDD parents

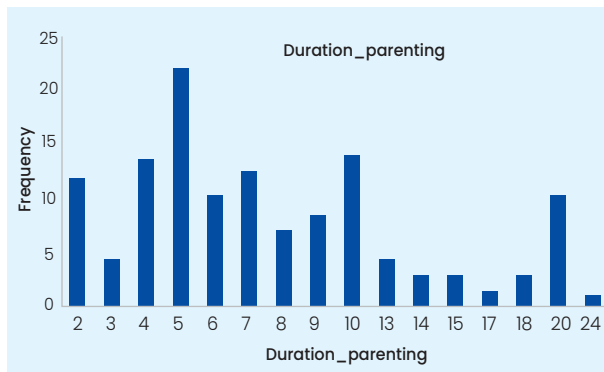


Fig12: Duration of parenting in NDD parents

Statistics		
PSS-level	Valid	119
N	Missing	1
Mean		35.73
Median		36.00
Std. Deviation		2.933

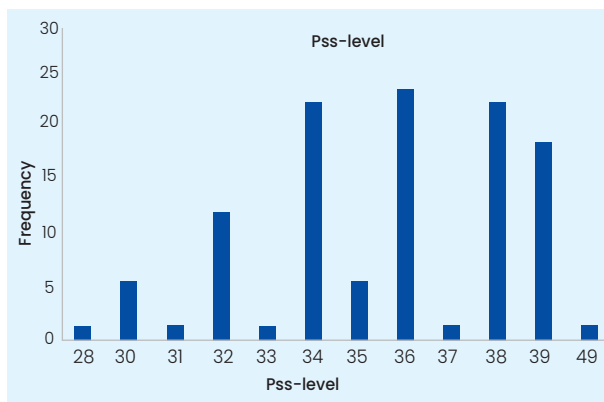


Fig13: PSS score in NDD parents

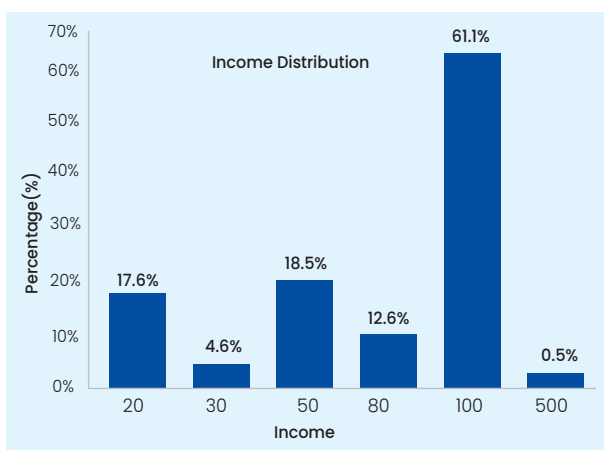


Fig14: Distribution of income in NDD parents

Group Statistics

normal vs ndd		N	Mean	Std. Deviation	Std. Error Mean
PSS-level	normal kids	120	16.12	6.428	.587
	ndd kids	119	35.73	2.933	.269

Independent Samples Test

	t-test for Equality of Means							
	t	df	Significance		Mean Difference	Std Error Difference	95% Confidence Interval of the Difference	
			one sided p	two sided p			Lower	Upper
PSS-level Equal variances assumed	-30.306	237	<.001	<.001	-19.614	.647	-20.889	-18.339
Equal variances not assumed	-30.389	166.816	<.001	<.001	-19.614	.647	-20.889	-18.340

Fig 15: Independent sample test to show differences in PSS scores between normal and NDD group

Discussion:

The present study found significantly higher perceived stress scores among parents of children with NDDs compared with parents of neurotypical children. Income, residence, and number of children also showed significant associations with stress levels. Mean PSS score among parents having neurotypical kids was 16 whereas, in case of NDD parents it was 35. The striking significant difference is statistically proven.

The higher stress levels observed among parents of children with NDDs are consistent with the findings of Smith et al. and Ahmed et al., who also reported significantly elevated parental stress in caregivers of children with autism. Reason behind high stress among parents having NDD kids may include, increased caregiving burden, behavioral and communication challenges of the child, financial strain, social stigma, reduced social support and Concerns about the child's future. We found about two thirds of the total participants were from urban areas for both groups whereas only one third were from rural areas. The data were collected mainly from institutes like hospital special clinics, therapy centers, daycare centers, inclusive schools and special schools of Dhaka city. As the facilities are rare in peripheral areas, parents are often seen shifting the family to Dhaka even if temporarily. This contributes to geographical distribution.

Graduate and post graduate parents are more prevalent among NDD groups of parents. As income is often parallel to education level, it is common for financially well-off families to attend special and inclusive schools which are much more expensive. This fact is consistent with previous studies revealing the association (9,10).

The present study found higher perceived stress among parents with lower educational levels. This may be because less educated parents often have fewer economic and informational resources, limited access to support services, and fewer opportunities to develop effective coping strategies. In contrast, higher educational attainment may facilitate better understanding of child-related challenges and more effective utilization of available support systems, thereby reducing perceived stress.

The present study found significantly higher perceived stress among parents with lower income levels. This finding may be attributed to the increased financial burden and limited access to healthcare, educational, and supportive services experienced by economically disadvantaged families. Financial constraints can exacerbate concerns regarding the child's care and future needs, thereby increasing parental stress. Conversely, higher-income families may have greater access to resources and support systems that help mitigate stress. This finding is consistent with previous research demonstrating that socioeconomic disadvantage is associated with increased parental stress(11,12,13).

The present study demonstrated a weak positive correlation between duration of parenting and perceived stress score ($r = 0.144$). This finding suggests that parents with a longer duration of caregiving tend to report slightly higher levels of perceived stress. However, the association was not statistically significant ($p = 0.119$), indicating that duration of parenting alone may not be a major determinant of parental stress in the study population.

The lack of statistical significance may be explained by the influence of multiple factors other than duration of caregiving, such as socioeconomic status, educational level, family support, severity of the child's condition, coping strategies, and access to healthcare services. These factors may have a greater impact on parental stress than the length of time spent in the parenting role. The present study found a very weak negative correlation

between the number of children and perceived stress score ($r = -0.056$). This suggests that parents with a greater number of children tended to report slightly lower stress levels; however, the relationship was extremely weak. Furthermore, the association was not statistically significant ($p = 0.50$), indicating that the observed relationship may have occurred by chance. The absence of a significant association suggests that the number of children alone may not be an important determinant of parental stress.

A weak positive but non-significant correlation was observed between age of parents and PSS score ($r = 0.146$, $p = 0.119$). This suggests that although older parents tended to report slightly higher stress levels, the relationship was not strong enough to reach statistical significance. Hence, age does not appear to have a meaningful influence on perceived stress in the present sample.

The study concludes that perceived stress among parents is multifactorial. While demographic factors such as age and number of children do not show a significant statistical association, socio-economic conditions appear to have a stronger influence on stress levels. These findings highlight the importance of targeted psychosocial support and interventions, particularly for parents from lower socio-economic backgrounds.

Strengths of the Study:

The study has the following strengths like;

Comparative design, adequate sample size, use of validated PSS scale, Inclusion of both fathers and mothers, local Bangladeshi data where evidence is limited

Limitations of the Study:

The study has the following limitations;

Cross-sectional design (cannot establish causality),- Self-reported questionnaire, Potential recall bias, Limited generalizability.

Conclusion:

The study demonstrates that parents of children with NDDs experience substantially higher perceived stress than parents of neurotypical children. Targeted psychosocial support, caregiver education, and strengthening of support services may help reduce this burden and improve family well-being.

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