

Mental Health Burden Among Caregivers of School-Aged Children (5-12) with Neurodevelopment Disorders in Selected Centre of Chattogram

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ABSTRACT

Caregivers of children with neurodevelopmental disorders (NDDs) face significant psychological and emotional challenges in everyday, particularly in low-resource settings where support systems are limited. In Chattogram, Bangladesh, the mental health burden of these caregivers remains understudied. This study aimed to assess the mental health burden experienced by caregivers of school-aged children (5–12 years) with NDDs in Chattogram and to identify their coping mechanism strategies. A cross sectional study on 68 caregivers recruited from a center for Children with special needs. Data were collected via face-to-face interviews using a structured questionnaire, the 12-item Zarit Caregiver Burden Interview (ZCBI), and the 28-item Brief- COPE Inventory. Descriptive statistics analyzed were sociodemographic profiles, burden levels and coping strategy frequencies. The study found mean age of the caregivers was 34.13 (\pm 4.51) years and 98.8% were female. Majority (85.4%) provided daily support for their child's activities, and 25.6% had education beyond the higher secondary level. Over half (61.7%) reported a high caregiver burden, (30.5%) a moderate burden, and only 9.8% were burden-free. The average duration of caregiving means (4.79 \pm 1.81). Coping strategies revealed a mix of maladaptive and adaptive approaches: denial (5.31 \pm 1.62) was the most frequent, followed by acceptance (5.21 \pm 1.53). There was a statistically significant effect of group on religion coping, $F(7, 60) = 2.93, p = .01$. No significant group differences were observed for the remaining coping strategies (all p s > .05). Caregivers of children with NDDs in Chattogram endure substantial mental health burdens. These findings underscore the urgent need for community-based mental health programs, caregiver training in effective coping strategies, and integration of psychological support into pediatric NDD's care frameworks.

1. Introduction

Neurodevelopmental disorders are a group of disorders occurring early in development characterized by the behavior needed for functioning and social interaction informal or informal settings being affected. The affection can result in circumscribed or global impairment of personal, social, academic or occupational skills [APA,2013]. Within the section of neurodevelopmental disorders of DSM-5, intellectual disability, autism spectrum disorders, communication disorders, specific learning disorders, attention-deficit hyperactive disorders and motor disorders were included [Harris, J.C. DSM-5. 2014]. It's a clinical condition where parents need to focus much than any healthy one. Always needs to take extra care and attention for them. Sometimes parents feel social stigmatization who have neurodevelopment child. The prevalence of neurodevelopmental disorders (NDDs) in children varies globally, ranging from 4.7% to 88.5%. The prevalence of NDDs is influenced by a number of factors, including Study methodology, Socio-contextual factors, Population selection. Evidence from global health databases disclose that about 240 million children globally have developmental disabilities based on parent-reported functional difficulties compared to 290 million children using statistical modeling techniques [DSM-5:PRISMA criteria(2022)]. No health without mental health. About 1 in 8 people suffer from different categories of mental disorders. Mental health is serious public health issue now a day. Mental health seeking behavior is low in under-develop country. Sometimes basic needs cannot meet up also. In Bangladesh, over 2.8 million people were identified as suffering from neurodevelopmental disabilities in a recent survey [Ministry of Health and Family Welfare, Dhaka; 2018].

1.1 Statement of the problem

In comparison to these special children, there are very few care-givers to handle them. Caregivers of children with NDDs are at heightened risk of mental health challenges due to the intensive, prolonged care demands associated with conditions such as autism, intellectual disabilities, and cerebral palsy. In low-resource settings like Bangladesh, where formal support systems for disability care are scarce, familial caregivers often bear the sole responsibility for their child's daily needs, exacerbating psychological strain.

Despite global evidence highlighting caregiver burden, region- specific data from Chattogram—a densely populated urban center with limited healthcare infrastructure remain sparse. Cultural stigma surrounding mental health and disability further compounds caregivers’ isolation, discouraging help-seeking behaviors. Understanding the unique psychosocial challenges faced by this population is critical to addressing gaps in support services and informing policies that prioritize caregiver well-being as part of holistic child disability management. This study was justified by the urgent need to contextualize caregiver experiences within Bangladesh’s sociocultural and economic landscape. Existing research in high- income countries emphasizes adaptive coping strategies and institutional support, but these insights may not translate to settings like Chattogram, where poverty, limited access to mental health resources, and gender disparities shape caregiving dynamics. The predominance of maladaptive coping mechanisms, such as denial, observed in this study underscores the lack of accessible training or psychological interventions tailored to caregivers. By quantifying burden levels and identifying locally relevant coping patterns, this research provides actionable evidence for designing community- based programs, advocating for caregiver-inclusive health policies, and mitigating the long-term consequences of unaddressed mental health burdens, which can perpetuate cycles of disadvantage for both caregivers and children with NDDs.

1.2 Research question

What is the mental health burden experienced by caregivers of school-aged children with neurodevelopmental disorders (NDDs) in Chattogram, Bangladesh, and how do sociodemographic factors and coping strategies influence this burden?

1.3 Study Objectives

1.3.1 General Objective:

- To assess the mental health burden and coping strategies among caregivers of children (5–12 years) with NDDs in selected center of Chattogram, Bangladesh.

1.3.2 Specific Objectives:

- To determine the proportion and severity of caregiver burden using the Zarit Caregiver Burden Interview (ZCBI).
- To identify the most frequently used coping strategies among caregivers using the Brief-COPE Inventory.
- To describe the sociodemographic characteristic of the caregivers.
- To identify the supports required for the child’s activities and types of care provided by the caregivers for their children.

2. Literature Review

The mental health burden experienced by caregivers of children with NDDs is well- documented across diverse cultural and socioeconomic contexts, though its manifestations and intensity vary significantly depending on factors such as the child’s diagnosis, sociodemographic characteristics, and access to support systems. Purpura et al. (2021) highlighted this variability in Italy, where nearly half of caregivers reported moderate to high stress levels, with parents of children with Autism Spectrum Disorder (ASD) and Intellectual Disability (ID) facing greater challenges compared to those caring for children with Attention-Deficit Hyperactivity Disorder (ADHD) or Developmental Coordination Disorder. These findings underscore the critical role of disorder-specific demands in shaping caregiver burden and advocate for ecological, family-centered interventions to mitigate long-term impacts on child development and caregiver well-being. The psychological toll of caregiving is further corroborated by Maridal et al. (2021), WHO identified alarmingly high rates of psychological distress among caregivers in their study, with 90.5% screening positive for common mental disorders (CMDs). Notably, caregivers reported profound negative effects on their economic stability (70%), physical health (65%), social relationships (64%), and future aspirations (81%), emphasizing the pervasive consequences of unmanaged caregiver burden. Similarly, Jhony et al. (2020) found that mothers of children with ASD and ID exhibited comparable levels of psychological distress, though distress was more prevalent among mothers of children with ASD. Younger maternal age and caring for younger children were also linked to heightened distress, suggesting that developmental stages and caregiver life-course transitions exacerbate vulnerability. Sociodemographic factors, including gender, marital status, and socioeconomic status, further modulate caregiver burden. Olagunju et al. (2017) revealed that in Nigeria, 15% of caregivers reported significant burden on the Zarit Caregiver Burden Scale (ZCBS), with 38.3% experiencing psychological distress. Caregivers were predominantly mothers (71.7%), and common challenges included delayed diagnosis (noticed after age 2 in 53.3%) and comorbidities such as seizures (9.1%). In Kenya, Gona et al. (2016) identified intersecting challenges of stigma, financial strain, and limited access to specialized care among parents of children with ASD, who relied on a blend of problem-focused strategies and emotion-focused coping. Cultural and regional disparities are evident in coping mechanisms: Wang and Michaels (2011) noted that Chinese parents of children with ASD prioritized planning as a primary coping strategy, contrasting with the religious and community-based approaches observed in Kenya.

The interplay between caregiving demands and mental health outcomes is further shaped by systemic and interpersonal support. Nadia et al. (2021) found that 90% of parents struggled to manage their child’s behavioral difficulties, with nearly half reporting severe anxiety and two-thirds clinical depression. Access to family support and perceived caregiving competence emerged as protective factors, underscoring the need for targeted psychosocial interventions. Conversely, Souza et al. (2017) in Brazil identified caregiver depression, advanced age (>60 years), and lack of caregiving assistance as key predictors of burden, with low-income, female caregivers bearing disproportionate strain. Bitsika and Christopher (2004) reinforced these patterns, noting that female caregivers, single parents, and those caring for younger children with Down Syndrome faced elevated odds of moderate-to-severe burden. However, regional disparities in research focus persist, with limited data from South Asian contexts like Bangladesh, where stigma, gender roles, and healthcare inequities may uniquely shape caregiver experiences. This gap underscores the urgency of context-specific investigations to inform inclusive, culturally sensitive interventions. Collectively, these studies highlight three

critical themes: (1) Caregiver burden is multidimensional, influenced by diagnosis-specific demands, sociocultural contexts, and resource availability; (2) Adaptive coping strategies (e.g., planning, social support) coexist with maladaptive responses (e.g., denial, emotional withdrawal), often mediated by cultural norms; and (3) Systemic gaps in mental health support perpetuate cycles of distress, particularly in low-resource settings Rulangi et al., (2004).

3. Methodology

3.1 Study Design

Descriptive cross-sectional study

3.2 Study Population

Caregivers of 5-12 years aged children with neurodevelopment disorder attending the study site during the study period.

3.3 Study Site

Nishpap Autism School, Chattogram, Bangladesh.

3.4 Study Period

The study was conducted from March 2025 to May 2025.

3.5 Inclusion Criteria of the Participants

Primary caregivers (aged ≥ 18 years) of children aged 5–12 years diagnosed with an NDD (e.g., autism spectrum disorder, intellectual disability, cerebral palsy) Caregivers providing daily care for at least six months prior to the study

3.6 Exclusion Criteria

Refusal of caregivers to participate.

Caregivers with cognitive impairments or severe psychiatric conditions that hindered their ability to provide informed consent.

3.7 Data Collection Tools

Sociodemographic and caregiving profile: A structured questionnaire captured caregivers' age, gender, education level, marital status, employment status, and daily caregiving responsibilities (e.g., support required for the child's activities of daily living).

Zarit Caregiver Burden Interview (ZCBI-12): This validated 12-item tool assessed caregiver burden across three domains: role strain, personal strain, and guilt. Responses were scored on a 5-point Likert scale (0 = Never to 4 = Nearly Always), with total scores categorized as: 0–20: Little to no burden, 21–40: Mild to moderate burden, 41–60: High burden.

Brief-COPE Inventory: The 28-item Brief-COPE evaluated coping strategies across 14 subscales (e.g., denial, planning, positive reframing). Each subscale comprised two items rated on a 4-point scale (1 = I haven't been doing this at all to 4 = I've been doing this a lot). Subscales were grouped into adaptive (e.g., active coping, planning) and maladaptive strategies (e.g., denial, self-blame).

3.8 Data management and analysis plan

Data collected from the respondents were compiled as Microsoft Excel sheets and statistical analysis was performed using the IBM SPSS-26.0 Statistics software. Both descriptive and inferential statistical analysis was carried out in this study. Continuous variables was described as mean, standard deviation. Categorical variables was presented as frequency and percentage. For analysis the data appropriate statistical test is done. For coping mechanism and burden, special coping analysis sheet and questionnaire preparation done by modified Zarit, Jaws and cope inventory Questionnaire

4. Findings

A total of 68 caregivers were approached for the study. Three participants were excluded due to refusal to participate, yielding a final sample of 68 caregivers who provided informed consent and participated in the research.

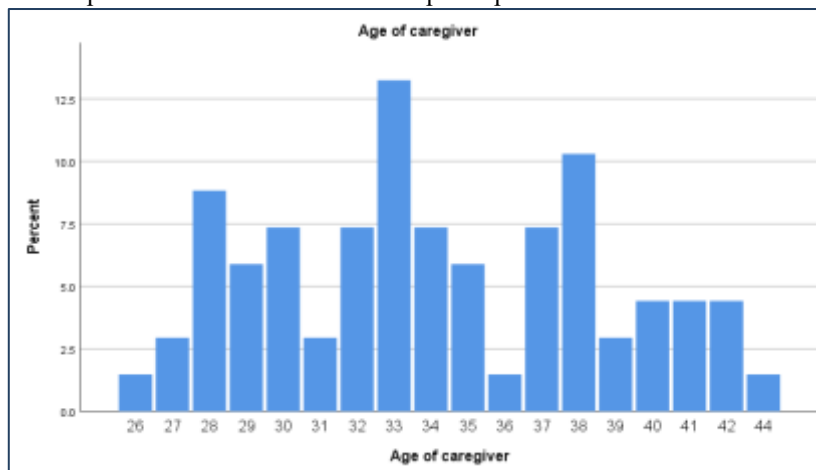


Figure 1: Age distribution of the caregivers (n=68) Source: Research data 2025

Here mean age of caregivers are 34.13 years with SD (± 4.51) and minimum age of caregiver is 26 and maximum age of caregiver is 44.

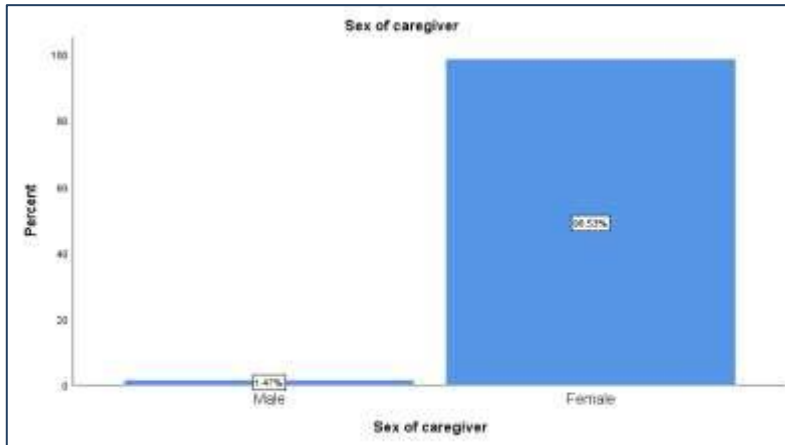


Figure 2: Gender distribution of the caregivers (n=68) Source: Research data 2025

The study sample consisted predominantly of female caregivers (n=67), with only one male participant.

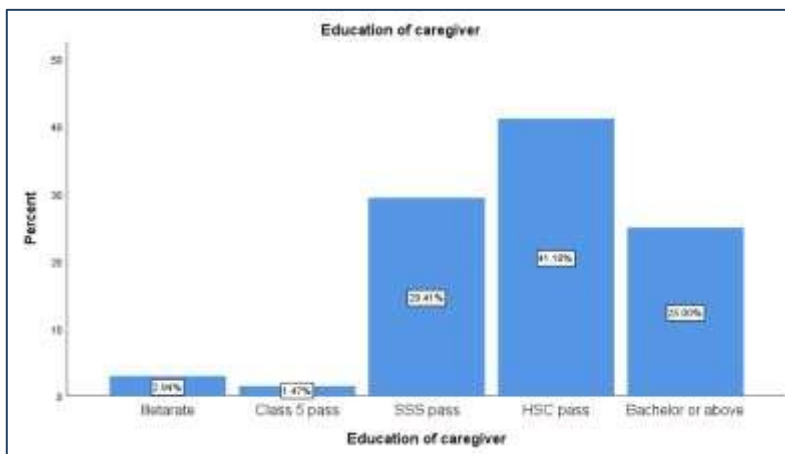


Figure 3: Educational level of the caregivers (n=68) Source: Research data 2025

Caregivers' educational attainment varied: 4.41% had primary education or below (illiterate/Class 5), 29.41% completed Secondary School Certificate (SSC), 41.18% attained Higher Secondary Certificate (HSC), and 25.0% held a Bachelor's degree or higher.

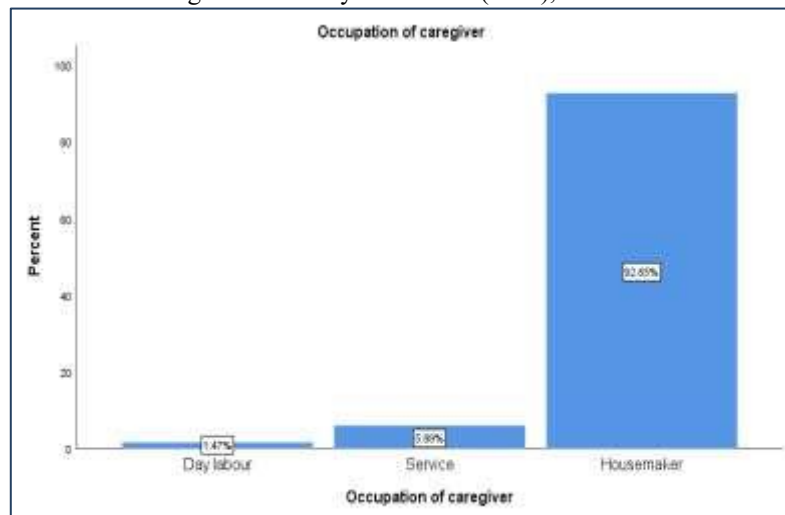


Figure 4: Occupation of the caregivers (n=68) Source: Research data 2025

The occupational distribution of caregivers comprised day labourer (1.47%), service holders (5.88%), and homemakers (92.65%). Notably, the majority of respondents were homemakers, who reported being consistently occupied with providing care and support as primary caregivers for children with NDD.

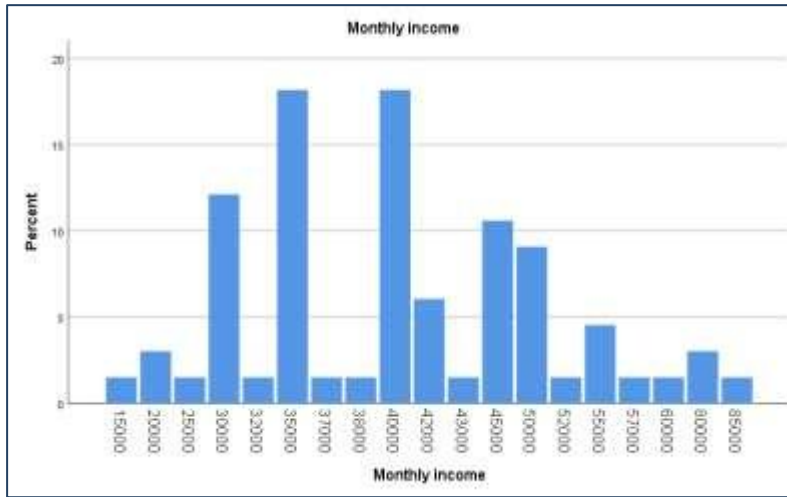


Figure 05: Monthly family income of the respondents Source: Research data 2025

Over 68 caregivers 02 were refused to talk about their monthly income. The mean income is 41393 respectively and minimum range is 15000 and maximum range is 85000.

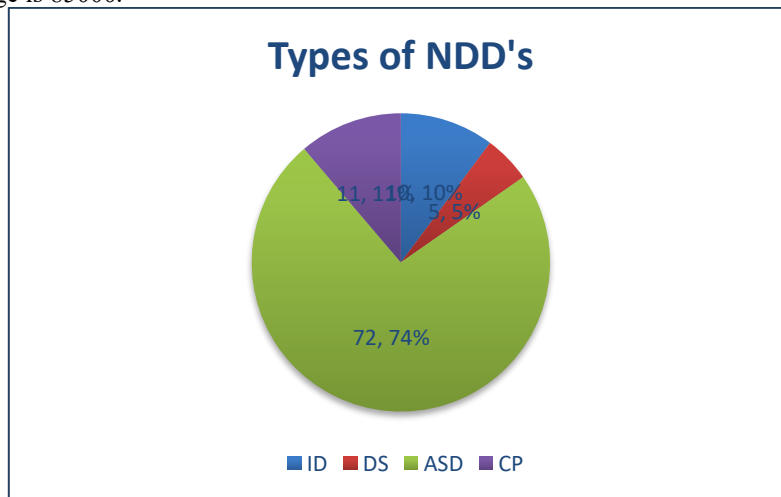


Figure 6: Types of NDD's of Children Source: Research data 2025

From 68 respondents ID 10%, DS 5%, ASD 72%, CP 11%

Table 1: Caregivers burden by Zarit Caregiver Burden Scale

Burden severity	Frequency	Percent
No or mild (Score below 10)	07	10.29
Medium (Score 10-20)	19	27.94
High (Score above 20)	42	61.76

Source: Research data 2025

The Zarit Caregiver Burden Scale (ZCBS) revealed significant burden levels among participants: 61.7% reported a high burden, 27.9% a moderate burden, and 10.2% were burden-free. The mean ZCBS score was 23.74 (SD = 8.06), indicating a moderate-to-high overall burden in the sample

Table 2: Types of care are provided to the children by the caregivers

Types of care	Frequency	Percent
Educating	09	13.13
Providing therapy	18	26.47
Physical needs	11	16.17
Social and emotional needs	11	16.17
Supporting own needs (clothing)	13	19.11
Medical needs	6	8.82

Source: Research data 2025

The distribution of caregiving responsibilities provided to children with NDDs is outlined in Table II. Caregivers most frequently reported providing therapy (26.47%, n = 18), followed by addressing supporting own needs (19.11%, n = 13) and physical needs (16.17%, n = 11) and meeting social-emotional needs (16.17%, n = 11) were equally prevalent. Medical care represented the smallest

proportion of caregiving tasks (8.82%, n = 6). These findings highlight the multifaceted demands placed on caregivers, with therapeutic and daily living support constituting the predominant responsibilities.

Table 3: Daily living activities of the children requiring support

Activities	Frequency	Per cent
Brushing	09	13.23
Toileting	25	36.76
Feeding	15	22.05
Clothing	16	23.52
No support	03	04.41

Source: Research data 2025

Support requirements for daily living activities varied among children with neurodevelopmental disorders. The majority of caregivers (36.7%, n = 25) reported assisting with toileting, followed by clothing (23.5%, n = 16), feeding (22%, n = 15), and brushing (13.2%, n = 9). A notable minority (4.4%, n = 3) required no support, suggesting variability in functional independence across the sample. These results emphasize toileting and clothing as the most prevalent challenges, underscoring the need for targeted interventions to enhance children’s autonomy and reduce caregiver strain in managing daily routines.

Table 4: Descriptive statistics of the Brief COPE subscale scores

Brief cope subscales	N	Minimum	Maximum	Mean	Std. Deviation
Self destruction	68	2.00	7.00	4.3382	1.37797
Active coping	68	2.00	8.00	4.7794	1.60080
Denial	68	2.00	8.00	5.3088	1.62313
Substance use	68	2.00	5.00	3.3824	1.10669
Use of Emotional support	68	2.00	8.00	4.7794	1.63767
Use of Instrumental support	68	2.00	5.00	3.8088	1.04034
Behaviour	68	2.00	8.00	4.7941	1.47171
Venting	68	2.00	8.00	4.9853	1.27540
Reframing	68	2.00	8.00	5.0735	1.55800
Planing	68	2.00	8.00	5.1176	1.51144
Humour	68	2.00	8.00	4.2059	1.48182
Acceptance	68	2.00	8.00	5.2059	1.53135
Religion	68	2.00	8.00	5.0147	1.51108
Self Blame	68	2.00	8.00	4.8971	1.44697

Source: Research data 2025

Descriptive statistics were calculated for the Brief COPE subscales among 68 participants. Overall, participants reported moderate use of both adaptive and maladaptive coping approaches. Adaptive coping strategies (e.g., active coping, planning, acceptance) had an overall mean score of 4.75, whereas maladaptive coping strategies (e.g., denial, behavioral disengagement, self-blame) had a slightly lower mean score of 4.62. Among adaptive strategies, acceptance (M = 5.21, SD = 1.53), planning (M = 5.12, SD = 1.51), and positive reframing (M = 5.07, SD = 1.56) were the most frequently used. Religion (M = 5.01, SD = 1.51) and emotional support (M = 4.78, SD = 1.64) were also commonly endorsed. Humour had a lower mean (M = 4.21, SD = 1.48), indicating less reliance on this coping approach. For maladaptive coping, denial had the highest mean (M = 5.31, SD = 1.62), suggesting a notable tendency toward avoidance-based coping. Self-blame (M = 4.90, SD = 1.45) and venting (M = 4.99, SD = 1.28) were also moderately used. Substance use showed the lowest mean (M = 3.38, SD = 1.11), indicating infrequent engagement in substance related coping. Overall, participants demonstrated a greater reliance on adaptive coping strategies compared to maladaptive strategies. However, the relatively high mean for denial and self-blame suggests that some maladaptive patterns remain present in the study and reflecting the complex psychosocial demands faced by caregivers.

Table 5: Analysis of variance between brief cope and duration of caregiving by caregiver

ANOVA						
		Sum of Squares	df	Mean Square	F	Sig.
self destruction	Between Groups	2.489	7	.356	.171	.990
	Within Groups	124.731	60	2.079		
	Total	127.221	67			
Active_coping	Between Groups	20.006	7	2.858	1.130	.356
	Within Groups	151.685	60	2.528		
	Total	171.691	67			
Denial	Between Groups	25.838	7	3.691	1.470	.195
	Within Groups	150.676	60	2.511		
	Total	176.515	67			
Substance_use	Between Groups	7.799	7	1.114	.900	.512
	Within Groups	74.260	60	1.238		

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	Total	82.059	67			
Emotional_support	Between Groups	24.582	7	3.512	1.358	.240
	Within Groups	155.109	60	2.585		
	Total	179.691	67			
Inst_support	Between Groups	6.580	7	.940	.855	.547
	Within Groups	65.935	60	1.099		
	Total	72.515	67			
Behaviour	Between Groups	15.206	7	2.172	1.003	.438
	Within Groups	129.912	60	2.165		
	Total	145.118	67			
Venting	Between Groups	8.175	7	1.168	.695	.676
	Within Groups	100.810	60	1.680		
	Total	108.985	67			
Reframing	Between Groups	22.881	7	3.269	1.403	.221
	Within Groups	139.751	60	2.329		
	Total	162.632	67			
Planing	Between Groups	14.185	7	2.026	.875	.531
	Within Groups	138.874	60	2.315		
	Total	153.059	67			
Humur	Between Groups	10.110	7	1.444	.632	.727
	Within Groups	137.008	60	2.283		
	Total	147.118	67			
Acceptance	Between Groups	23.494	7	3.356	1.507	.182
	Within Groups	133.624	60	2.227		
	Total	157.118	67			
Religion	Between Groups	38.971	7	5.567	2.930	.010
	Within Groups	114.014	60	1.900		
	Total	152.985	67			
Self_Blame	Between Groups	15.693	7	2.242	1.080	.388
	Within Groups	124.587	60	2.076		
	Total	140.279	67			

Source: Research data 2025

A one-way analysis of variance (ANOVA) was conducted to examine group differences in coping strategies. The analysis revealed a statistically significant effect of group on religion coping, $F(7, 60) = 2.93, p = .01$. No significant group differences were observed for the remaining coping strategies (all $ps > .05$).

Table 6: Tukey HSD test for religion group

Religion			
Tukey HSD ^{a,b}			
Duration of caregiving	N	Subset for alpha = 0.05	
		1	2
2.00	3	4.0000	
7.00	4	4.2500	
3.00	10	4.4000	
4.00	16	4.4375	
8.00	7	5.1429	5.1429
5.00	11	5.3636	5.3636
6.00	14	5.7143	5.7143
1.00	3		7.3333
Sig.		.418	.142

Source: Research Data, 2025

A Tukey HSD post hoc analysis was conducted to assess differences in duration of caregiving among religious groups. The results revealed two overlapping homogeneous subsets. Religion groups 2, 7, 3, 4, 8, 5, and 6 formed the first subset, while groups 8, 5, 6, and 1 formed the second subset. The overlap of groups 8, 5, and 6 across both subsets indicates that these groups did not differ significantly from either subset. The mean duration of caregiving ranged from 4.00 in religion group 2 to 7.33 in religion group 1. Although religion group 1 exhibited the highest mean caregiving duration, the overlapping subsets and non-significant significance values ($p = .418$ and $p = .142$) suggest that there were no statistically significant pairwise differences in caregiving duration among the religious groups. Therefore, religion was not found to have a significant influence on the duration of caregiving among the participants in this study.

5. Conclusion and Recommendations

5.1 Conclusion

This study underscores the profound mental health burden experienced by caregivers of children with NDDs in Chattogram, Bangladesh. Nearly 60% of caregivers reported severe burden, driven by intensive daily care demands such as toileting and feeding, compounded by limited access to respite care. Alarming, over one-third exhibited symptoms of anxiety and depression, yet none sought professional mental health support, reflecting systemic neglect and cultural barriers to help-seeking. While adaptive strategies like positive reframing and planning were employed, maladaptive mechanisms such as denial dominated, highlighting the need for skill-building interventions. Sociodemographic factors—including female gender, lower education, and homemaker status—intensified vulnerability, mirroring global inequities in unpaid caregiving roles. Although religious coping emerged as a culturally resonant strategy, its efficacy in mitigating long-term distress remains unclear. Collectively, these findings emphasize the urgent need to prioritize caregiver mental health as a public health imperative in low-resource settings, where holistic support systems are critical to breaking cycles of disadvantage for both caregivers and children with NDDs.

5.2 Recommendations

Policy Interventions:

Integrate caregiver mental health screening into pediatric NDD's care protocols at government and NGO-run centers.

Allocate funding for respite care services and subsidized therapy programs tailored to caregivers.

- Community-Based Programs: Develop training workshops to enhance adaptive coping skills (e.g., problem-solving, stress management) and reduce reliance on denial. Launch stigma-reduction campaigns to normalize help-seeking behaviors and promote community solidarity.
- Gender-Sensitive Support: Design interventions targeting female caregivers, including peer support groups and flexible income-generating opportunities to alleviate economic strain.
- Research Priorities: Longitudinal studies are needed to assess the long-term impacts of coping strategies and burden on caregiver-child outcomes.
- By addressing these multidimensional challenges, policymakers and practitioners can foster resilience in caregivers, ultimately improving outcomes for children with NDDs and breaking cycles of intergenerational disadvantage.

Appendix

Ethical Approval: Not Applicable

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Conflict of Interest: The authors declare no conflict of interest.

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