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Psychological distress and coping strategies among parents of children with autism spectrum disorder

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Abstract

Introduction: Parenting a child with a neurodevelopmental disorder (NDD) is associated with higher rates of anxiety and depression. Caring for a child with autism spectrum disorder (ASD) may also evoke negative emotions such as guilt, worthlessness, denial, and disappointment. This study aimed to assess psychological distress and coping strategies among parents of children with ASD.

Method: A cross-sectional analytical study was conducted from February to August 2025 in the Child Health and Adolescent Ward of Kanti Children's Hospital, Kathmandu. A total of 190 parents were selected using purposive sampling. Data were collected through structured face-to-face interviews using the K6 Psychological Distress Scale (k6) and the Brief-COPE Inventory(Brief-COPE). Descriptive statistics, chi-square tests, and Spearman's rank correlation were used for data analysis at a 95% confidence interval.

Result: Half of the participants (50%) experienced moderate psychological distress, while 32.1% reported high distress. Most participants (94.7%) demonstrated effective coping strategies. Psychological distress was significantly higher among mothers ($p = 0.012$), parents who had left their job ($p = 0.001$), and those without autism-related training ($p = 0.023$). A negative correlation was observed between distress and coping strategies.

Conclusion: Despite considerable psychological distress among half of the participants, most employed effective coping strategies. Distress was significantly associated with parental role, job status, child's schooling, and training. Enhancing parental training, promoting inclusive education, and providing psychosocial support may help reduce distress among parents of children with ASD.

Keywords: Autism spectrum disorder; Coping strategies; Nepal; Psychological distress

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Introduction

Children with Autism Spectrum Disorder (ASD) often experience poor general health, delayed growth, and co-occurring physical and psychological disabilities.[1] Parental stress is influenced by disruptive behaviors, financial burden, altered social relationships, poor physical health, lack of social support, disrupted routines, and limited coping ability.[2] Caregiver psychiatric distress is associated with poor social support, family dysfunction, greater family impact of the child's condition, problematic child behavior, unfavorable parenting styles, and poor psychosocial functioning.[3] As ASD affects the entire family, additional services are required; however, providers often lack specialized training to address the complex needs of children with ASD and their caregivers.[4] Psychological distress among caregivers is widely reported, with increased prevalence of anxiety and depression.[2]

International studies demonstrate substantial caregiver burden. Severe distress was reported in 35.7% of caregivers in Spain,[5] 65.6% of parents in Dhaka,[6] and nearly half (46%) of caregivers in Nepal.[1] In Sri Lanka, 33% reported depressive symptoms and 30% anxiety,[7] while a Chinese study reported depressive symptoms in 72.5%, anxiety in 80.2%, and both in 67.1%.[8] A 2020 Nepalese study noted that caregivers commonly used positive internal coping strategies.[9]

Limited support services for families of children with autism exist in Nepal,[10] and research on psychological distress and coping strategies among these parents remains scarce. This study aims to assess psychological distress and coping strategies among parents of children with ASD, providing baseline data to support counseling, improve holistic care, and understand problem-focused, emotion-focused, and avoidant coping strategies.

Method

A cross-sectional analytical study was conducted from February to August 2025 among parents of children and adolescents with ASD attending the outpatient department (OPD) and Child Health and Adolescent Ward of Kanti Children's Hospital, Kathmandu, Nepal. A total of 190 parents were enrolled using a non-probability purposive sampling technique.

The sample size was calculated using Cochran's formula, $n = z^2pq/e^2$, assuming a prevalence of severe psychological distress of 13.2%,[6] at a 95% confidence level (Z = 1.96) and a margin of error of 5%. After accounting for a 10% non-response rate, the final sample size was ~190 participants.

Parents aged 18 years and above who were willing to participate in the study and provided informed consent were included. Either the father or mother who resided with and continuously cared for the child or adolescent with ASD was eligible to participate. Parents who were unable to respond adequately during the interview, as identified by the researcher during interaction, and caregivers other than the biological father or mother were excluded from the study.

Ethical approval was obtained from the Institutional Review Committee (IRC-1217) of the Kanti children hospital. Formal permission was obtained from the study center, and informed consent was secured from each participant prior to data collection.

Data were collected by the principal investigator through structured face-to-face interviews conducted in a private room to ensure confidentiality. Approximately 8–9 participants were interviewed per day, and each interview lasted 20–30 minutes. Although both the K6 and Brief COPE are self-report instruments, they were administered in an interviewer-guided format to accommodate variations in literacy levels among participants. The researcher read each item aloud in a neutral and standardized manner and recorded participants' responses without interpretation. Prior to data collection, the instruments were translated into Nepali and back-translated into English to ensure semantic equivalence. A brief orientation regarding the purpose of the questions and response options was provided before the interview. Privacy and confidentiality were strictly maintained throughout the study.

The structured interview schedule consisted of three sections. The first section collected socio-demographic information, including parental age, gender, occupation, family type, child's school enrollment, and autism-related training. The second section assessed psychological distress using the Kessler Psychological Distress Scale (K6).[11] The third section assessed coping strategies using the Brief COPE inventory.[14]

Psychological distress was measured using the validated K6 scale.[11] The K6 is a standardized six-item screening instrument designed to assess serious psychological distress experienced during the preceding four weeks.[11] Each item is scored on a five-point Likert scale ranging from 0 ("none of the time") to 4 ("all of the time"), generating a total score between 0 and 24. The items assess feelings of nervousness, hopelessness, restlessness, worthlessness, sadness, and the perception that everything is an effort. Recoding of K6 scores was performed during data analysis. Scores of 0–4 were categorized as low psychological distress, 5–12 as moderate psychological distress, and 13–24 as high

psychological distress.[12] The K6 has been translated into Nepali and previously used in Nepal.[13]

Coping strategies were assessed using the Brief COPE inventory, which consists of 28 items grouped into 14 coping subscales.[14] Each item is rated on a four-point Likert scale ranging from 1 ("I haven't been doing this at all") to 4 ("I've been doing this a lot"). Scores were calculated by summing the two items within each subscale. Adaptive coping was operationalized as the sum of seven subscales: Active Coping, Planning, Instrumental Support, Emotional Support, Positive Reframing, Acceptance, and Humor (score range: 14–56). Maladaptive coping was operationalized as the sum of five subscales: Denial, Substance Use, Behavioral Disengagement, Venting, and Self-Blame (score range: 10–40). Participants scoring above the sample median were categorized as having adaptive coping, whereas those scoring below the median were categorized as having maladaptive coping. The Self-Distraction and Religion subscales were excluded from the classification.[14,16] The Brief COPE has been translated into Nepali and utilized in previous studies conducted in Nepal.[15] The instrument demonstrates acceptable internal consistency, with a reported Cronbach's alpha of 0.71.[17]

Data Analysis

Data were coded and entered into Statistical Package for the Social Sciences (SPSS) version 16. Descriptive statistics, including frequency, mean, and standard deviation, were used to summarize socio-demographic characteristics, psychological distress, and coping strategies. Associations between socio-demographic variables and psychological distress, as well as coping strategies, were assessed using the chi-square test. The relationship between psychological distress and coping strategies was evaluated using Spearman's rank correlation coefficient. Statistical significance was determined at a 95% confidence interval, and a p-value of less than 0.05 was considered statistically significant.

Ethical Considerations

Ethical approval was obtained from the Institutional Review Committee of Kanti Children's Hospital (IRC-1217).

Written informed consent was obtained from all participants.

Result

We found that most respondents were mothers (70%). More than 60% of the children were aged over six years, representing later childhood. Over half of the participants (57.4%) belonged to nuclear families, and the majority of parents were employed (76%). We also found that most children were male (70%) and attending school (151 children), with 72% enrolled in mainstream schools (Table 1). In addition, most children had received their primary diagnosis within the past year, more than three-quarters had no comorbid illnesses, and a large majority of parents (83.7%) had not received autism-related training, Table 1.

Table 1. Sociodemographic Variables of the Respondents (N=190)

Variables	n(%) / Mean ± SD
Age (years)	34.75 ± 6.31
Parent	
Mother	135(71.05%)
Father	55 (28.95%)
Job Status	
Left job	44(23.16%)
Did not leave job	146(76.84%)
Type of Family	
Nuclear (Single)	109(57.37%)
Joint (Extended)	81(42.63%)
School-Going Child	
Yes	151(79.47%)
No	39(20.53%)
Received Training	
Yes	31(16.32%)
No	159(83.68%)

We found that the largest proportion of participants falling into the "moderate" psychological distress category, followed by the "low" category, and the smallest proportion in the "high" distress category, Figure 1.

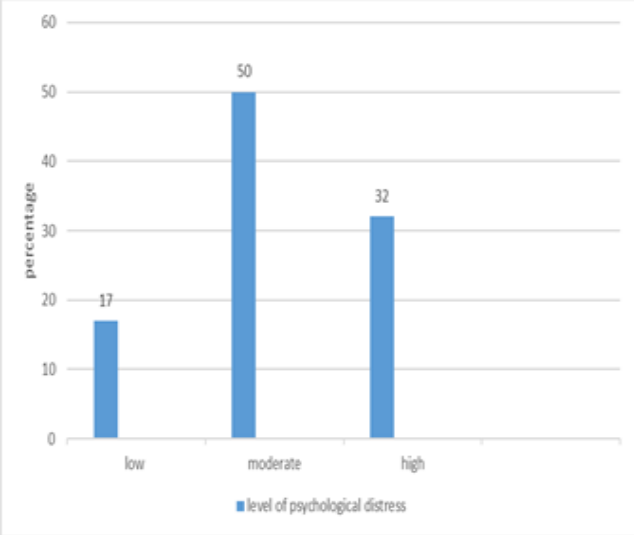

Figure 1. Level of psychological distress of respondents (N=190)

More than 90% of participants reported using adaptive coping strategies, Table 2.

Table 2. Level of coping strategies of respondents (N=190)

Coping Strategy	*f* (%)
Maladaptive coping	10(5.30%)
Adaptive coping	180(94.70%)

We found that several factors were significantly associated with higher levels of psychological distress

Table 3. Association between Sociodemographic Variables and Psychological Distress of Respondents (N=190)

Variables	Psychological Problems		Chi- Square (x^2)	P Value
	Mild to Moderate *f* (%)	High *f* (%)		
Age group in years				
≤35	60(40%)	40(60%)	6.563	0.038*
≥36	69(76.7%)	21(23.3%)		
Parents				
Mother	84(62.2%)	51(37.8%)	7.028	0.030*
Father	45(81.8%)	10(18.2)		
Job status				
left	24(54.5%)	20(45.5%)	5.895	0.052
Not left	105(71.9%)	41(28.1%)		
Family type				
Nuclear	71(65.2 %)	38(34.8%)	3.143	0.208
Joint /extended	58(71.6%)	23(28.4%)		
School				
Yes	108(71.5%)	43(28.5%)		
No	21(53.8%)	18(46.2%)	7.502[a]	0.023*
Training				
Yes	16(51.6%)	15(48.4%)	5.943	0.051
No	113(71.1%)	46 (28.9%)		

*association is significant at the 0.05 level

among participants. These included younger parental age, being a mother (compared to father) and having a school-going child, Table 3.

A statistically significant but negligible negative correlation was observed between psychological distress and coping strategies (Spearman's r = −0.03, p < 0.01), indicating that the association was extremely weak despite reaching statistical significance, Table 4.

Table 4. Correlation between psychological distress and coping strategies of respondents (N=190)

Variables	Psychological problems	Coping
Psychological distress	-	- 0.03
Coping	- 0.03	-

correlation is significant at the 0.05 level

Discussion

The aim of the study was to assess psychological distress and coping strategies among parents of children with ASD. Among the 190 participants, 50% (n = 95) of the respondents had a moderate level of psychological distress, whereas 32.1% had high psychological distress. The present study findings are consistent with studies conducted in Spain among 250 caregivers of children with ASD, which found that 35.7% experienced severe distress. [5] Likewise, a study conducted in Nepal among 63 caregivers of autistic children revealed that almost half (46%) had a high level of psychological distress.[1]

A dissimilar finding was observed in a study conducted among parents of 180 children with ASD in three tertiary hospitals in Dhaka, which found that 65.6% of parents had extreme psychological distress.[8] These differences may be due to variations in population characteristics, sample sizes, and levels of environmental and family support.

The findings of the present study showed a high prevalence (94.7%) of adaptive coping among the participants. Similar findings were reported in a study conducted in Egypt, where parents of children with ASD demonstrated significantly higher use of coping strategies (59%).[18]

A statistically significant association was found between psychological distress and key socio-demographic variables, including parental role, employment status, and life-stage factors (p < 0.05). This aligns with studies conducted in Sri Lanka among parents of children with autism.[8] The findings are interpretable within the context of caregiver burden: the association with being a mother and primary caregiving role that disrupts professional life. The link with having a school-going child highlights the acute stressors of navigating educational systems. Furthermore, the significant association with lack of training suggests that current support programs may not adequately address the core psychological needs of these parents. These results underscore the multifactorial nature of distress, stemming from role strain, systemic challenges, and insufficient targeted support.

A meta-analysis and systematic review of coping and parenting stress in ASD found a small but significant negative correlation between positive coping and stress, whereas maladaptive coping correlated positively with stress.[19] Likewise, a recent study in Malaysia reported that adaptive coping was negatively associated with parental distress, while maladaptive coping demonstrated the reverse, reinforcing the negative correlation.[20]

This study's cross-sectional design limits causal inferences. The use of purposive sampling at a single hospital may affect generalizability. Psychological distress and coping strategies were self-reported, which could introduce recall or social desirability bias. Interviewer administration, though necessary for literacy variations, may have influenced responses. Additionally, potential confounders such as child's condition severity and parental mental health history were not fully controlled.

Future research could use a longitudinal design to explore causal relationships between psychological distress and coping strategies. Larger, multi-center studies with random sampling are recommended to improve generalizability. Studies could also incorporate objective assessments and consider potential confounding factors such as severity of the child's condition, duration since diagnosis, and parental mental health history.

Conclusion

The study demonstrated that half of the participants experienced considerable psychological distress; however, the majority employed effective coping strategies. Psychological distress was significantly associated with parental role and child's schooling. Although coping strategies and psychological distress were significantly related, the association was weak. These findings underscore the need for interventions that strengthen coping skills and address contextual factors contributing to distress among this population.

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Conflict of Interest

None

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None

Author Contribution

Concept, design, and planning: MS, IA, BR, KG; Literature review: MS; Data collection: MS, IA, BR; Data analysis: MS, KG; Draft manuscript preparation: MS; Revision of draft manuscript: IA, BR, KG; Final manuscript approval: MS, IA, BR, KG; Accountability for all aspects of the work: MS

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