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Original Research Article

Knowledge of Autism Spectrum Disorders Among Parents of Under-Five Children: A Baseline Assessment for Early Intervention in Eastern Nepal

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ABSTRACT:

Introduction: Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder characterized by impairments in social communication and repetitive behaviors. Early detection depends heavily on parental knowledge, yet limited data exist from Nepal, particularly among parents of young children. This study assessed parental knowledge of ASD and its association with socio-demographic variables. **Methods**: A descriptive cross-sectional study was conducted among 398 parents of under-five children attending the Pediatric Outpatient Department of Birat Medical College Teaching Hospital, Morang, Nepal, over three months. A non-probability purposive sampling technique was used. Data were collected using a structured, pretested questionnaire (Cronbach's alpha = 0.70) and analyzed in SPSS version 23. Knowledge scores were categorized as low (≤19), moderate (20–24), and high (≥25) based on quartiles. Chi-square and Fisher-Freeman-Halton Exact tests were applied, with $p < 0.05$ considered significant. **Results**: The mean knowledge score was 21.46 ± 3.81 (range 7–30). Although all parents (100%) had heard of autism, only 21.4% had high knowledge, 51.5% had moderate knowledge, and 27.1% had low knowledge. Knowledge was significantly associated with religion, ethnicity, educational status, monthly family income ($p < 0.001$ for all), presence of a child with a chronic condition ($p = 0.035$), and information received from health workers, media, and friends/relatives ($p < 0.05$). **Conclusion**: Despite universal awareness of the term "autism," comprehensive parental knowledge remains limited, with significant disparities across socio-demographic groups. Targeted, community-based awareness programs and routine developmental screening during healthcare visits are needed to promote early recognition and intervention for ASD in Nepal.

Keywords: Autism, Health literacy, Information sources, Socio-demographic factors, Tertiary health care.

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INTRODUCTION:

Autism Spectrum Disorder (ASD) is a neurodevelopmental condition characterized by persistent challenges in social communication, restricted interests, and repetitive behaviors, with onset typically in early childhood.[1] While the exact etiology remains incompletely understood, current evidence points to a complex interplay of genetic and environmental factors.[2] ASD is more than three times more prevalent in boys than girls,[3] and the global prevalence is estimated at approximately one in 100 children.[4]

Early detection and intervention are critical, as they are associated with significantly improved developmental outcomes, including language acquisition, social skills, and adaptive functioning.[5]

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The effectiveness of early intervention is heavily dependent on timely identification, which in turn relies on parents' ability to recognize early behavioral red flags.[6]

In Nepal, autism is still considered a relatively 'new' condition, with limited public awareness and few specialized diagnostic and therapeutic services.[7,8] According to the Nepal Census 2078 B.S., only 4,886 individuals are officially identified with autism among the 647,744 persons with disabilities,[9] suggesting substantial underdiagnosis. To date, no published study has specifically assessed parental knowledge of ASD among parents of children under five years, the critical age window for early detection, in the Morang district or similar settings in Nepal.

Understanding the current level of ASD knowledge among parents of young children is the first essential step toward designing effective, culturally sensitive awareness programs. Such programs can empower parents to seek early evaluation, reduce diagnostic delays, and ultimately improve long-term outcomes for children with ASD. This study was conducted to assess parental knowledge and identify socio-demographic factors associated with it, providing baseline data to inform future public health strategies in Nepal.

METHODS:

A cross-sectional analytical study design was adopted to assess the knowledge of Autism Spectrum Disorders among parents attending the Pediatric Out Patient Department (OPD) of Birat Medical College Teaching Hospital (BMCTH), Morang, Nepal. The study was conducted over a period of three months, from June 2026 to August 2026.

The study population comprised parents of children under five years of age attending the Pediatric OPD of BMCTH during the study period. Parents of children with a pre-existing diagnosis of ASD were excluded from the study. A non-probability purposive sampling technique was employed to select the participants. All parents meeting the eligibility criteria and providing consent during the data collection period were included.

The sample size was calculated using the Cochrane formula for cross-sectional studies: $n_0 = z^2p(1-p)/e^2$, where z = 1.96 (95% confidence level), p = 0.5 (assumed proportion, chosen to maximize sample size as no prior estimate of parental knowledge in this population was available), and e = 0.05 (absolute margin of error). Substituting these values, the initial sample size was calculated as $n_0 = (1.96)^2 \times 0.5 \times 0.5 / (0.05)^2 = 384.16$, which was rounded up to 385.

To account for the finite population, the average monthly OPD attendance of under-five children was 2,072 (based on hospital records from Chaitra month, 2082 B.S.), giving an estimated three-month OPD flow of 6,216. Applying the finite population correction formula, $n = n_0/[1+(n_0-1)/N]$, the sample size was recalculated as n = 385/[1+(385-1)/6216] = 362.59, which was rounded up to 363. To account for an anticipated 10% non-response rate, the final sample size was calculated as n = 363+(10% of 363) = 399.3, which was rounded up to 400. Thus, the calculated target sample size was 400 parents of under-five children.

However, during the three-month data collection period, 398 parents who met the eligibility criteria and provided consent were enrolled, representing 99.5% of the target sample size. Data analysis was conducted on the 398 completed questionnaires.

A structured questionnaire was developed following an extensive review of relevant literature. The tool was prepared in English and then translated into Nepali to ensure comprehension. The questionnaire consisted of two parts:

Part 1: Socio-demographic variables of parents, including age, sex, educational level, occupation, family size, presence of a child with a chronic health problem, whether the parent had heard about ASD, and the source of information about ASD.

Part 2: A knowledge questionnaire comprising 30 items covering four domains: (a) meaning and incidence of ASD, (b) causes, (c) signs and symptoms, and (d) diagnosis and treatment. Each correct response was assigned a score of one, and incorrect responses were scored as zero. The total knowledge score ranged from zero to 30. The knowledge scores were categorized into three levels—low, moderate, and high—based on the interquartile range of the sample distribution. Parents with a score at or below the 25th percentile (≤ 19) were classified as having low knowledge. Those with a score between the 25th and 75th percentiles (20–24) were classified as having moderate knowledge. Parents with a score at or above the 75th percentile (≥ 25) were classified as having high knowledge.

The questionnaire was pretested on 40 parents (10% of the sample) in a similar setting to assess clarity, comprehension, and reliability. Necessary modifications were made based on the

pretest findings. The Cronbach's alpha coefficient for the knowledge section was 0.70, indicating acceptable internal consistency.

Prior to data collection, formal permission was obtained from the Hospital Director and the Head of the Department of Pediatrics, BMCTH. Ethical clearance was obtained from the Institutional Review Committee (IRC) of Birat Medical College Teaching Hospital (Ref. No: IRC-177-2082/83).

Parents were approached in the waiting area of the Pediatric OPD after their child's consultation. The purpose, objectives, and methods of the study were explained to them in Nepali. Written informed consent was obtained from all participants. Parents were assured that participation was voluntary, that they could withdraw at any time without any consequences, and that their responses would remain anonymous and confidential. Anonymity was maintained through coding of the questionnaires.

Data were collected using a self-administered questionnaire in Nepali. For parents who were unable to read or write, a face-to-face interview was conducted using the same questionnaire by the principal investigator. Each questionnaire took approximately 20–25 minutes to complete. Completed questionnaires were checked for completeness on the same day.

Data were entered into Microsoft Excel and analyzed using PSPP 2.1.1 software. Descriptive statistics, including mean, standard deviation, frequency, and percentage, were used to summarize socio-demographic characteristics and knowledge scores. Quartiles (Q1, Q2, Q3) were calculated to categorize knowledge scores. The chi-square test was used to determine the association between the level of knowledge and selected socio-demographic variables. Where the expected cell count was less than five, the Fisher-Freeman-Halton Exact test was applied. A p-value of less than 0.05 was considered statistically significant.

RESULTS:

A total of 398 parents of children under five years participated in the study. **Table 1** presents the socio-demographic characteristics of the participants. The majority of parents were female (83.4%), Hindu (84.4%), and belonged to the Brahmin/Chhetri ethnic group (53.5%). The mean age of parents was 30.41±5.41 years, with 55.3% aged 30 years or younger. Regarding educational status, 36.2% had completed higher secondary education, 29.1% had secondary education, and

Table 1. *Socio-demographic Characteristics of Parents (n = 398)*

Variable	Category	n (%)*
Age of parents (years)	≤30	220 (55.28)
	>30	178 (44.72)
Sex	Male	66 (16.58)
	Female	332 (83.42)
Religion	Hindu	336 (84.42)
	Buddhist	26 (6.53)
	Muslim	22 (5.53)
	Christian	8 (2.01)
	Others	6 (1.51)
Ethnicity	Dalit	13 (3.27)
	Janajati	63 (15.83)
	Madheshi	87 (21.86)
	Muslim	22 (5.53)
	Brahmin/Chhetri	213 (53.52)
Educational status	No formal education	16 (4.02)
	Primary	25 (6.28)
	Secondary	116 (29.15)
	Higher secondary	144 (36.18)
	Bachelor and above	97 (24.37)
Occupation	Homemaker	232 (58.29)
	Service	95 (23.87)
	Business	42 (10.55)
	Agriculture	23 (5.78)
	Others	6 (1.51)
Monthly family income (NPR)	<20,000	63 (15.83)
	20,000–50,000	237 (59.55)
	>50,000	98 (24.62)
Type of family	Nuclear	171 (42.96)
	Joint	227 (57.04)
Family size	≤5	232 (58.29)
	>5	166 (41.71)
	Mean ± SD	5.44 ± 2.23
Number of children	1	190 (47.74)
	2	184 (46.23)
	≥3	24 (6.03)
Age of youngest child	Birth to 2 months	39 (9.80)
	2 months to 5 years	359 (90.20)
Child with chronic condition	Yes	17 (4.27)
	No	381 (95.73)
Heard about autism	Yes	398 (100.00)
	No	0 (0.00)
Source of information	Media	322 (80.90)
	Friends/relatives	147 (36.93)
	Health workers	115 (28.89)
	Teachers	39 (9.80)

**Multiple responses possible.*

24.4% held a bachelor's degree or higher. More than half of the parents (58.3%) were homemakers, and 59.5% reported a monthly family income between NPR 20,000 and 50,000. The majority lived in joint families (57.0%) and had a family size of five or fewer members (58.3%). Nearly half of the parents (47.7%) had only one child. Most children (90.2%) were aged between 2 months and 5 years, and 95.7% had no chronic health condition.

All parents (100%) reported having heard about 'autism', with the most common sources of information being media (80.9%), friends or relatives (36.9%), and health workers (28.9%).

The knowledge scores of parents ranged from 7 to 30, with a mean score of 21.46±3.81 out of a maximum possible score of 30. **Table 2** presents the distribution of knowledge levels among participants. The majority of parents (51.5%) demonstrated moderate knowledge regarding ASD, while 27.1% had low knowledge and only 21.4% had high knowledge.

Table 3 presents the association between the level of knowledge regarding ASD and selected socio-demographic variables. Statistically significant associations were observed between knowledge level and religion ($p < 0.001$), ethnicity ($p < 0.001$), educational status ($p < 0.001$), monthly family income ($p < 0.001$), and the presence of a child with a chronic condition ($p = 0.035$). Additionally, knowledge level was significantly associated with the source of information, including health workers ($p < 0.001$), media ($p = 0.026$), and friends or relatives ($p < 0.001$).

No statistically significant associations were found between knowledge level and age of parents ($p = 0.338$), sex ($p = 0.298$), occupation ($p = 0.414$), type of family ($p = 0.551$), family size ($p = 0.650$), number of children ($p = 0.089$), or age of the

Table 2. *Level of Knowledge Regarding Autism Spectrum Disorder (n = 398)*

Knowledge Level	n (%)
Low knowledge (score ≤ 19)	108 (27.14)
Moderate knowledge (score 20–24)	205 (51.51)
High knowledge (score ≥ 25)	85 (21.36)
Total	398 (100.00)
Mean score ± SD = 21.46 ± 3.81; **Range** = 7–30; **Q1** = 19, **Q2** = 22, **Q3** = 24.	

Table 3. *Association Between Knowledge Level and Selected Socio-demographic Variables (n = 398)*

Variable	Category	Low n (%)	Moderate n (%)	High n (%)	Statistics
Religion	Hindu	77 (22.88)	181 (53.87)	78 (23.21)	
	Buddhist	14 (53.85)	7 (26.92)	5 (19.23)	
	Muslim	13 (59.09)	8 (36.36)	1 (4.55)	$p < 0.001$*
	Christian	1 (12.50)	6 (75.00)	1 (12.50)	
	Others	3 (50.00)	3 (50.00)	0 (0.00)	
Ethnicity	Dalit	5 (38.46)	8 (61.54)	0 (0.00)	
	Janajati	22 (34.92)	28 (44.44)	13 (20.63)	
	Madheshi	32 (36.78)	41 (47.13)	14 (16.09)	$p < 0.001$*
	Muslim	13 (59.09)	8 (36.36)	1 (4.55)	
	Brahmin/Chhetri	36 (16.90)	120 (56.34)	57 (26.76)	
Educational status	No formal education	11 (68.75)	5 (31.25)	0 (0.00)	
	Primary education	15 (60.00)	7 (28.00)	3 (12.00)	
	Secondary education	36 (31.03)	56 (48.28)	24 (20.69)	$p < 0.001$*
	Higher secondary	32 (22.22)	85 (59.03)	27 (18.75)	
	Bachelor and above	14 (14.43)	52 (53.61)	31 (31.96)	
Monthly family income (NPR)	<20,000	30 (47.62)	27 (42.86)	6 (9.52)	
	20,000–50,000	64 (27.00)	121 (51.05)	52 (21.94)	$\chi^2 = 23.40$, $p < 0.001$
	>50,000	14 (14.29)	57 (58.16)	27 (27.55)	
Child with chronic condition	Yes	1 (5.88)	9 (52.94)	7 (41.18)	$p = 0.035$*
	No	107 (28.08)	196 (51.44)	78 (20.47)	

Fisher Exact test. Only variables with significant associations are shown. Full association data are presented in **Supplementary Table 1.*

youngest child (p = 0.634). Detailed association data are presented in **Supplementary Table 1**.

DISCUSSION

This descriptive cross-sectional study was conducted among 398 parents of under-five children attending the Pediatric OPD of Birat Medical College Teaching Hospital, Tankisinuwari, Morang, to assess parental knowledge regarding autism spectrum disorders (ASD) and to determine its association with selected socio-demographic variables.

Globally, the prevalence of ASD is estimated at one in 100 children.[10] There has been a consistent rise in autism cases worldwide.[4,7,11] In Nepal, among 647,744 people with disabilities, only 4,886 individuals are officially identified with autism.[9] This indicates a persistent gap in diagnosis, likely due to limited public awareness regarding ASD.

In the current study, despite 100% universal awareness of the term "autism," only 21.4% of parents had high knowledge, while the majority (51.5%) had moderate knowledge and 27.1% had low knowledge. These findings are consistent with a similar study conducted in India, which reported variations in understanding, awareness, and perception among 200 parents of children aged zero to five years attending a tertiary care hospital.[2] That study also explained that it is challenging for parents to recognize early non-physical symptoms of autism, such as behavioral and speech problems, due to the absence of physical symptoms that would prompt early help-seeking.[12]

Research conducted in Nepal on primary school teachers also reveals larger knowledge gaps. A study in Birgunj found that more than half (57.1%) of school teachers lacked good knowledge regarding autism.[13] Similarly, a study in Pokhara found knowledge deficits among government school teachers regarding ASD.[14] Another study in Kathmandu on preschool teachers showed inadequate knowledge among more than half (54.3%) of respondents.[15] When parents miss early recognition of autism at home, the problem persists as it remains unrecognized in school settings, leading to further delays in diagnosis and treatment. Thus, creating awareness among parents of under-five children is critically important for early diagnosis and treatment.

A qualitative study conducted in Nepal in 2024 also suggested that parents lack the knowledge and skills needed to care for a child with autism, further increasing parental stress in raising the child.[7]

The current study found that parental knowledge levels were highly significantly associated with religion ($p < 0.001$) and ethnicity ($p < 0.001$), highlighting that different cultural and religious groups do not have equal access to awareness campaigns.[9] Knowledge scores were also highly significantly associated with educational status ($p < 0.001$) and family income ($p < 0.001$), which is consistent with findings from other studies.[16] This suggests that parents with higher education and better income have easier access to books, internet resources, and specialist healthcare treatment.

Receiving information about ASD from health workers ($p < 0.001$) and friends/relatives ($p < 0.001$) was highly significantly associated with parental knowledge. This indicates that people in Morang district attending healthcare facilities actively communicate to gain clear understanding regarding ASD and delays in achieving developmental milestones.

A significant association was found between having a child with a chronic condition and parental knowledge ($p = 0.035$). Parents who frequently visit healthcare facilities for a chronic condition are more likely to observe their child's health status, monitor age-specific milestones, and clarify misconceptions during the child's growth and development with healthcare professionals, thus increasing their overall health literacy.

The findings have several implications for clinical practice. Targeted counseling during hospital visits should be strengthened, particularly for parents with lower education and income. Routine developmental screening should be integrated into OPD and immunization visits for earlier identification of ASD symptoms. Healthcare staff should also be trained to communicate complex ASD information in simple, local languages. Finally, community-based awareness programs should be planned to reach parents who may not regularly access hospital services.

This study has several limitations. First, it was conducted at a single tertiary care hospital in Morang, limiting generalizability to other settings. Second, non-probability purposive sampling was used, which may introduce selection bias. Third, data were self-reported, which may be subject to social desirability bias—particularly relevant to the finding that 100% of parents reported having heard of autism. Fourth, the cross-sectional design precludes any causal inference between socio-demographic factors and knowledge levels. Finally,

the study was limited to parents attending a hospital OPD; parents in community settings or those who do not seek healthcare may have different knowledge levels.

Future research should investigate the role of cultural stigma in shaping parental attitudes toward ASD and help-seeking behavior. Additionally, there is a need to design, implement, and evaluate free community-level autism awareness programs targeting uneducated parents, particularly in low-income areas, to bridge the existing awareness gap.

CONCLUSION

This study assessed parental knowledge regarding ASD and identified its association with demographic variables. Parents of under-five children play a critical role in keeping their child healthy, identifying abnormal deviations during early child development, and accessing health services and information for both physical and non-physical illnesses. Health policies and community-level awareness campaigns are identified as key strategies for early recognition and treatment of ASD, through proper mobilization of health manpower and utilization of media to increase health literacy across all segments of the community.

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