Quality of Life and Associated Factors Among Parents of Children with Autism Spectrum Disorder : A Comparative Study in Kathmandu Valley, Nepal

Manish Kayastha[1], Suman Bahadur Singh[2], Khem Raj Sharma[2], Dharanidhar Baral[2], Avaniendra Chakravartty[2], Jyoti Lamichhane[3], Sachit Gurung[4], Bijay Khatri[5]

[1] Ministry of Health, Bagmati province, [2] School of Public Health and Community Medicine, BPKIHS, Dharan

[3] PHASE Nepal, Bhaktapur, [4] Aarhus University, Denmark

[5] School of Public Health, University of Alberta, Canada

Background

The prevalence of ASD has increased globally due to increased awareness and improved diagnostic criteria.(1)

⚠ Caregivers of children with ASD face unique challenges- restricted family activities, time burden, and psychosocial stress.(2,3)

Parents of children with ASD demonstrate significantly higher levels of distress, anxiety, and depression compared to parents of typically developing children.(4,5)

This study explored QoL of parents of children with ASD to help improve service systems and promote wellbeing of children and their parents.

Study Objectives

1

To evaluate the quality of life among parents of children below 12 years with ASD and compare it with parents of typically growing children.

2

To assess the quality of life and its associated factors among parents of children below 12 years with ASD in Kathmandu.

Methodology

Study Design

Comparative Cross-Sectional Study

Sample Size

N = 128 (64 ASD group + 64 Comparison group)

Study Area

Kathmandu Valley, Nepal

Sampling

Purposive Sampling Technique

Population

Mothers of children (=<12 yrs) with ASD vs. mothers of typically growing children of same age group

Data Collection Tool

WHOQOL-BREF

(WHO Quality of Life Brief version)

Study Variables

DEPENDENT VARIABLE

Quality of Life (WHOQOL-BREF)

INDEPENDENT VARIABLES

Socio-demographic Factors

- Age
- Sex
- Religion
- Ethnicity
- Educational Status
- Family Type
- Family Income
- Employment
- Total Number of Children

Child Characteristics

- Age of Child
- Sex of Child
- Severity of ASD

Data Collection & Analysis

Data Collection Tool	WHOQOL-BREF, self-administered, WHO standardized instrument
Data Collection Technique	Structured questionnaire — self-administered by participants
Statistical Software	IBM SPSS Version 26.0
Analytical Methods	Descriptive Analysis • Bivariate Analysis • Multiple Linear Regression
Ethical Approval	IRC of BPKIHS (Code No.: IRC/2494/023) Informed consent obtained from all participants. Approval from organizations and schools were obtained.

Socio-demographic Characteristics of parents (N = 128)

Characteristic	With ASD Group (n=64) n (%)	Non ASD Group (n=64) n (%)
Age: Below 35 years	30 (46.88%)	27 (42.19%)
Age: 35–44 years	28 (43.75%)	34 (53.13%)
Mean Age	35.3 ± 5.3	36.2 ± 4.8
Education: Secondary	16 (25%)	26 (40.63%)
Education: Bachelor	29 (45.31%)	29 (45.31%)
Education: Masters & Above	13 (20.31%)	7 (10.94%)
Employment: Employed	26 (40.62%)	48 (75%)
Family Income (monthly): > NRs 50,000	46 (71.88%)	45 (70.31%)
Family Type: Nuclear	34 (53.13%)	32 (50%)
Only One Child	43 (67.19%)	41 (64.06%)

Characteristics of Children with ASD (N = 64)

Mean Age of Child

4.64 ± 1.42 yrs

73.4% below 5 years

Sex (Male)

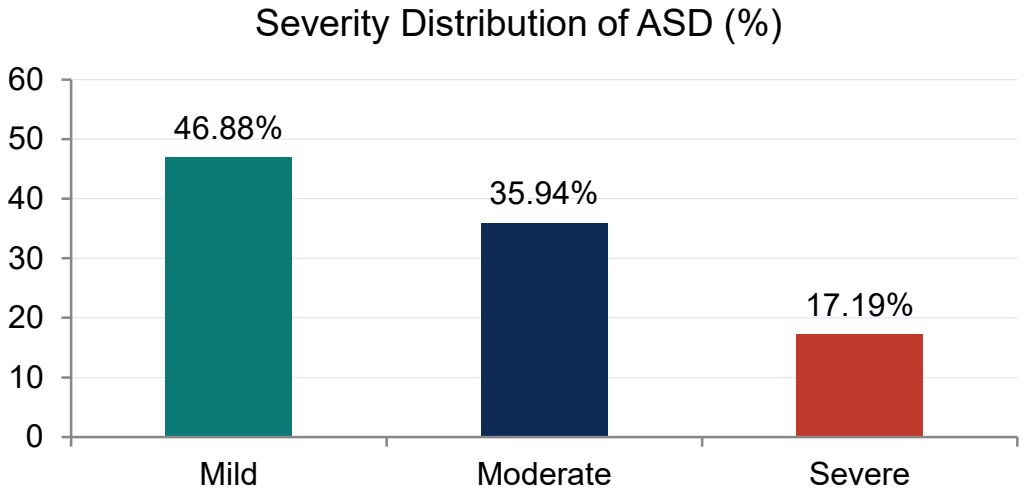
67.19%

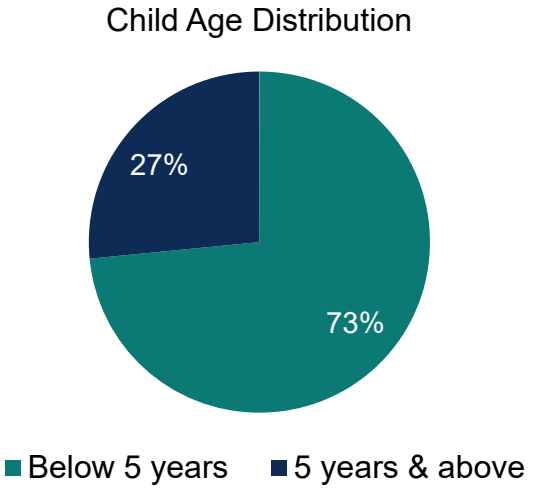
43 out of 64 children

Severity

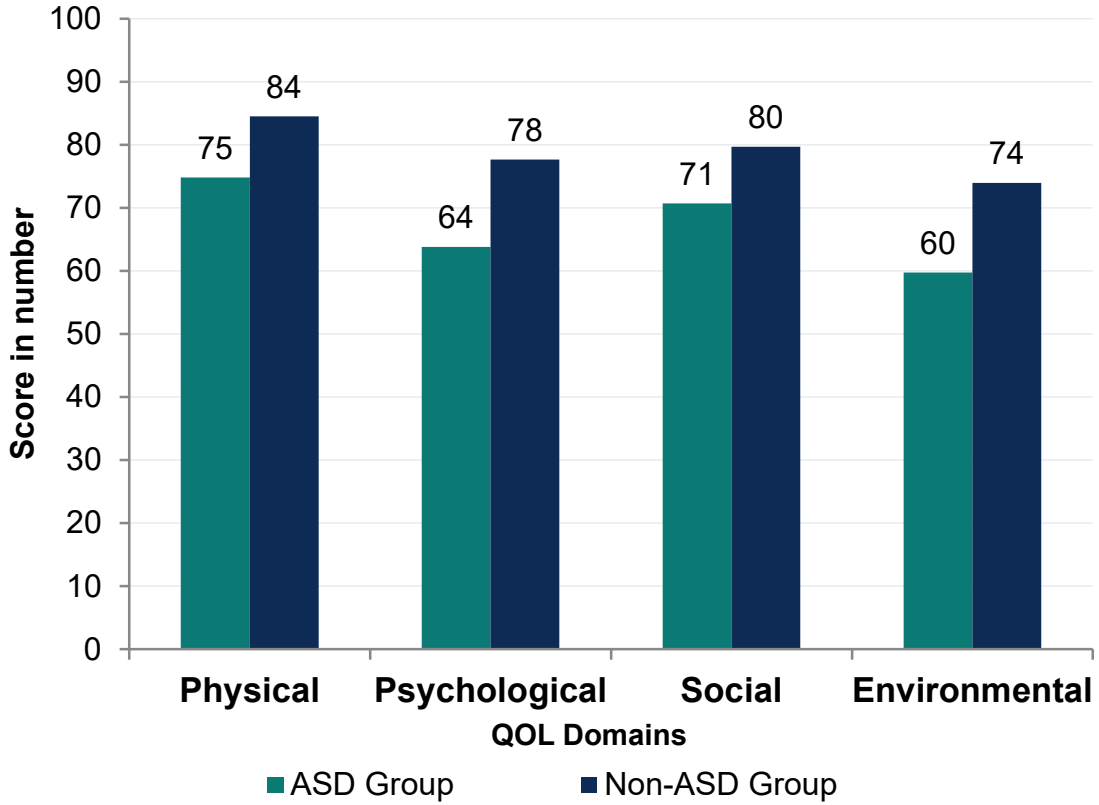
46.88% Mild

35.94% Moderate 17.19% Severe





QoL Comparison: ASD vs. Non-ASD Parents (WHOQOL-BREF)

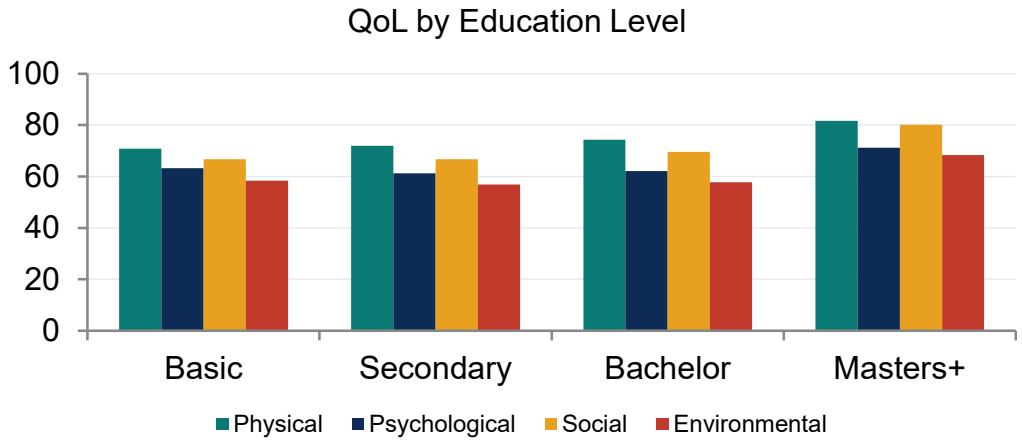


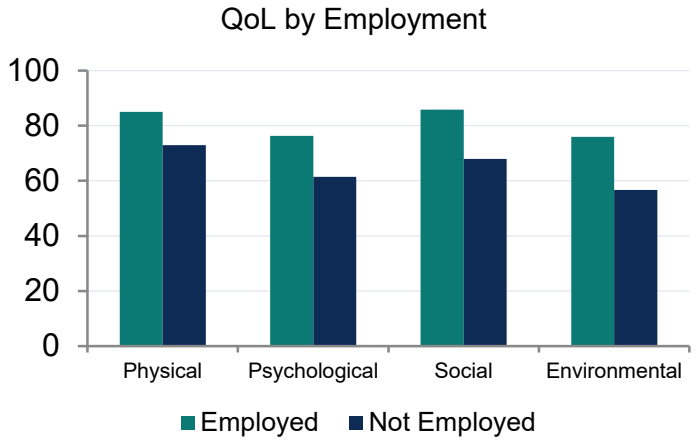
Mean Differences (ASD − Non-ASD)

Physical	−9.66	p < 0.001
Psychological	−13.87	p < 0.001
Social	−8.99	p < 0.001
Environmental	−14.25	p < 0.001

** All domains statistically significant at p < 0.001*

QoL by Education & Employment Status





✓

Higher education → Better QoL across ALL domains ($p < 0.05$)

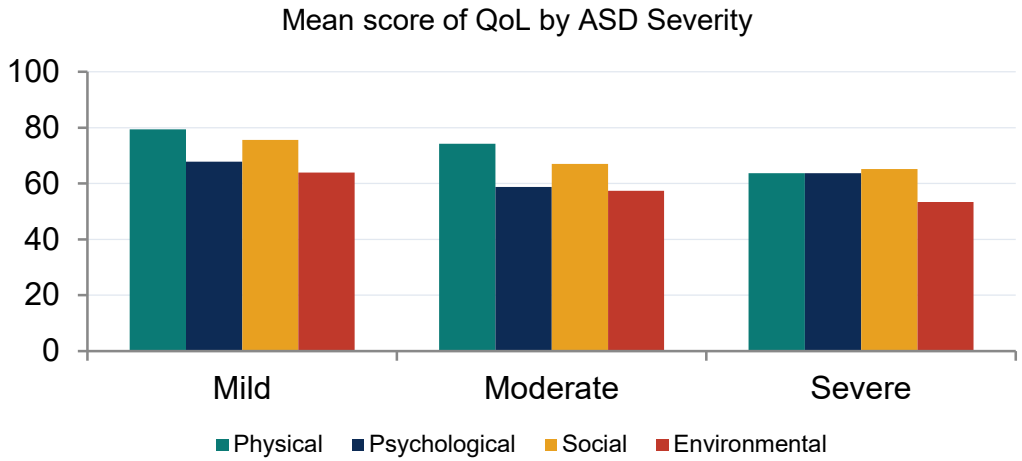
✓

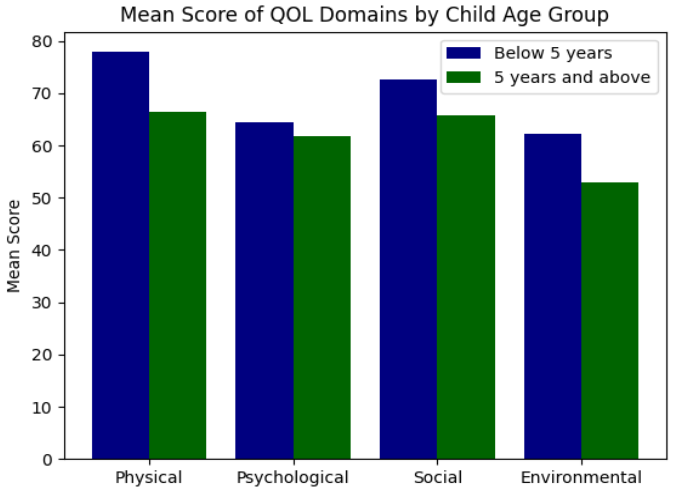
Employment status significantly improves all four QoL domains ($p < 0.001$)

✓

Higher income (> NRs 50K) significantly associated with better Physical, Social & Environmental QoL

QoL by Child Characteristics





- Severe ASD → significantly lower Physical, Psychological, Social & Environmental QoL ($p < 0.01$)
- Older child age (≥ 5 yrs) negatively impacts Physical, Social & Environmental QoL ($p < 0.05$)
- Having more than one child associated with lower Physical, Social & Environmental QoL ($p < 0.05$)

Multiple Linear Regression : Socio-demographic Predictors

Reference categories: Postgraduate (Education) | Unemployed | Income < NRs 25,000

Variable	Physical B (p)	Psychological B (p)	Social B (p)	Environmental B (p)
Education: Basic Level	**-10.76 (0.004) ***	-7.959 (0.059)	**-13.46 (0.001) ***	**-9.936 (0.048) ***
Education: Secondary	**-9.718 (0.001) ***	**-9.956 (0.002) ***	**-13.46 (<0.001) ***	**-11.43 (0.003) ***
Education: Bachelor	**-7.332 (0.003) ***	**-9.085 (0.002) ***	**-10.59 (<0.001) ***	**-10.51 (0.002) ***
Education: Postgrad	Ref	Ref	Ref	Ref
Employment: Employed	1.901 (0.350)	-1.653 (0.475)	0.219 (0.928)	0.032 (0.991)
Employment: Unemployed	Ref	Ref	Ref	Ref
Monthly Income: NRs 50K+	**11.085 (<0.001) ***	3.100 (0.218)	**6.904 (0.007) ***	**8.929 (0.002) ***

** Statistically significant at p < 0.05*

Multiple Linear Regression : Child related Predictors

Reference categories: More than one child | Child age ≥ 5 yrs | Severe ASD

Variable	Physical B (p)	Psychological B (p)	Social B (p)	Environmental B (p)
No. of Children: Only One	**9.623 (<0.001) ***	1.938 (0.423)	**6.008 (0.015) ***	**8.925 (<0.001) ***
No. of Children: >1 (Ref)	Ref	Ref	Ref	Ref
Child Age: Below 5 yrs	**11.501 (<0.001) ***	2.774 (0.279)	**6.831 (0.009) ***	**9.226 (0.002) ***
Child Age: ≥ 5 yrs (Ref)	Ref	Ref	Ref	Ref
ASD Severity: Mild	**15.768 (<0.001) ***	4.141 (0.153)	**10.404 (0.001) ***	**10.445 (0.004) ***
ASD Severity: Moderate	**10.587 (<0.001) ***	-4.941 (0.102)	1.877 (0.539)	3.928 (0.287)
ASD Severity: Severe (Ref)	Ref	Ref	Ref	Ref

** Statistically significant at $p < 0.05$*

Key Findings from Multiple Linear Regression

Physical QoL	• Higher education (postgraduate) → better physical health • Higher income (>NRs 50K) → significantly better physical QoL (B=+11.09) • Having only one child (B=+9.62) and younger child age (B=+11.50) were found to be protective • Mild ASD (vs severe) → B=+15.77; Moderate ASD → B=+10.59
Psychological QoL	• Education level (secondary & bachelor vs postgraduate) was found to be significant predictor • Employment, income, no. of children & ASD severity were NOT found to be significant predictors
Social & Environmental QoL	• Education, income, no. of children, child age & ASD severity significantly associated with social and environmental QoL domains. • Mild ASD (vs severe) → Social: B=+10.40; Environmental: B=+10.45 • Only child → significantly better social (B=+6.01) & environmental QoL (B=+8.93) • Higher income → better environmental QoL (B=+8.93)

Conclusions

Parents of children with ASD have significantly lower QoL across ALL four WHOQOL-BREF domains compared to parents of typically developing children.

Lower education, lower income, having more than one child, older child age, and greater ASD severity are significant predictors of poor QoL.

Policy modifications are needed to help families balance work and caregiving, income supplementation and insurance can alleviate burden.

Autism awareness is slowly growing in Nepal. The government must prioritize awareness programs about ASD and intellectual disabilities at all levels.

References

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Thank You

Manish Kayastha is a public health researcher with a Master's degree in Public Health (MPH) from B.P. Koirala Institute of Health Sciences. He currently serves as a Public Health Officer at the Ministry of Health, Bagmati Province. His research interests include qualitative and quantitative public health research, with a focus on mental health and evidence-based approaches to inform policy and strengthen health systems. He also brings prior experience working with national and international NGOs in implementing community-based health programs.