

Quality of life, stress and its coping strategies among the parents of children with Autism Spectrum Disorder in Kathmandu valley: A mixed method study



Presented By

Sajani Basan

Patan Academy of Health Sciences



Authors

Sajani Basan¹, Amit Arjyal² , Shital Bhandary³

¹ MPH Student, School of Public Health, Patan Academy of Health Sciences

² Assoc. Professor, School of Public Health, Patan Academy of Health Sciences

³ Assoc. Professor, School of Public Health, Patan Academy of Health Sciences



Contents



Background

- Autism spectrum disorder (ASD) is a diverse group of neurodevelopmental disorders distinguished by a certain level of difficulties in social communication and interaction.¹
- Autism affects 1 in 100 children globally (WHO) and 6 per 1000 children in Southeast Asia (systematic review and meta-analysis).^{1, 2}
- Nepal: 4886 individuals (National Population and Housing Census 2021)³

1. WHO Autism. [cited 2024 Jun 8].

2. Shrestha M, et al. Prevalence of ASD among children in Southeast Asia from 2002 to 2022: An updated systematic review and meta-analysis.

3. National population and housing census 2021 Volume 01 National report.

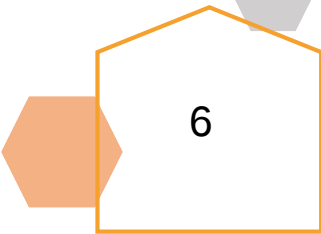
Background

- Parents of children diagnosed with ASD face unique challenges, including caregiving demands, societal stigma, and limited support resources.⁴
- Limited research exists on the psychosocial impacts these parents experience in Nepal, making this study crucial for understanding their struggles.

4. Muhammad N, Baroi B, Rahman Rathi S. Mental Health of Parents with Autistic Children Mental Health of Parents with and without Autistic Children: A Comparative Study

Objective

- This study aims to assess the status of quality of life, stress and its coping strategies among the parents of children with autism spectrum disorder in Kathmandu Valley.
- This research can contribute to developing and implementing family-centered interventions to empower parents, improve their well-being, and enhance their caregiving capacity.



Methodology

Study Design	A cross-sectional study with concurrent triangulation mixed method design
Study Site	Selected autism care centers in Kathmandu Valley
Study Population	140 parents of children with ASD for quantitative component and 11 parents for qualitative component
Sampling Technique	Non-probability purposive sampling technique
Data analysis	STATA/EZR for quantitative data and thematic analysis via RQDA for qualitative data

Methodology: Study Tools

Quantitative Component

Socio-demographic characteristics

Autism Parenting Stress Index

Brief-COPE

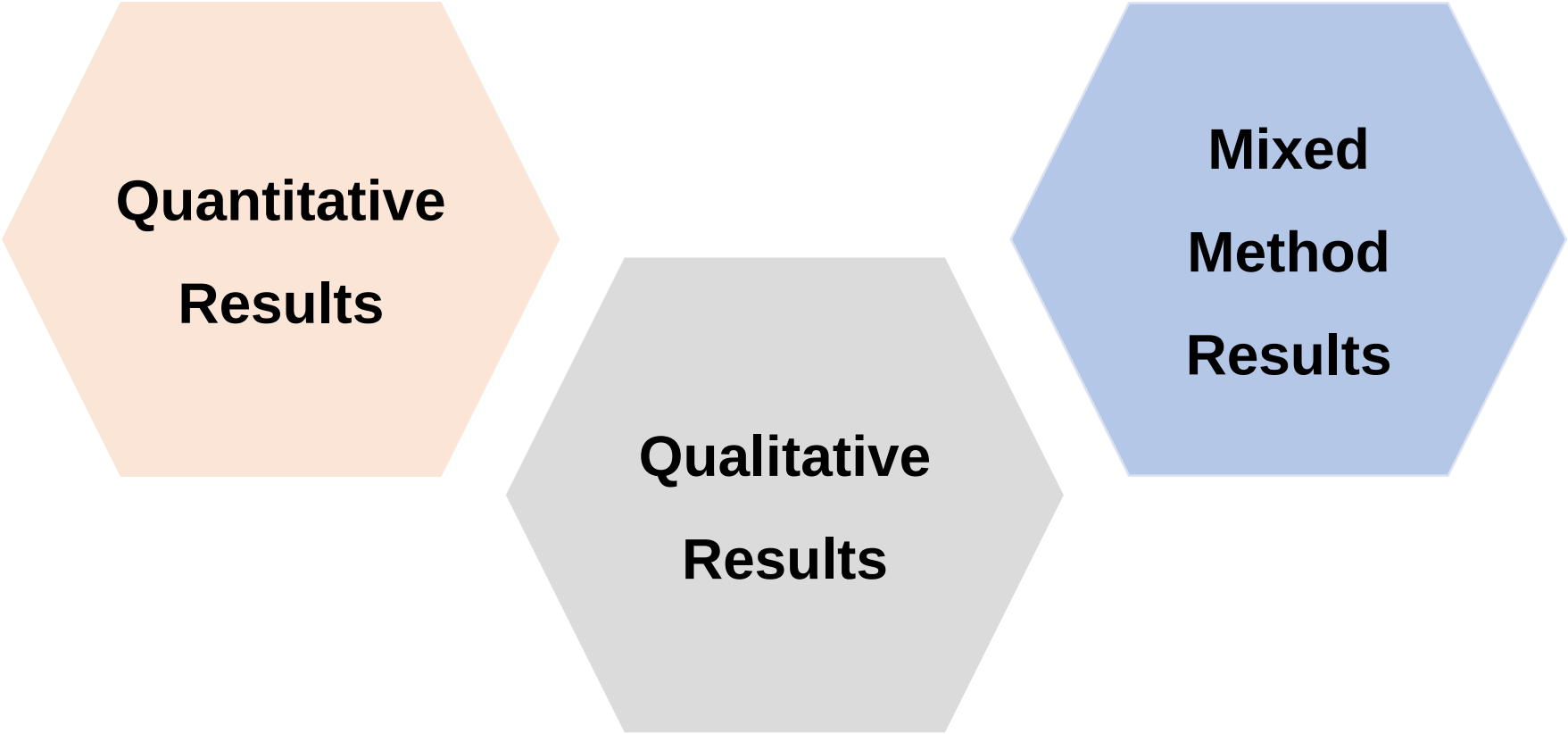
Multi-dimensional Scale of Perceived
Social support

Family Quality of Life scale

Qualitative Component

An open-ended
standardized
interview guide in
Nepali language

Results



The diagram consists of three large hexagons arranged horizontally. The leftmost hexagon is orange and contains the text 'Quantitative Results'. The middle hexagon is gray and contains the text 'Qualitative Results'. The rightmost hexagon is blue and contains the text 'Mixed Method Results'. In the bottom right corner, there is a small orange hexagon and a white hexagon with an orange border containing the number '9'.

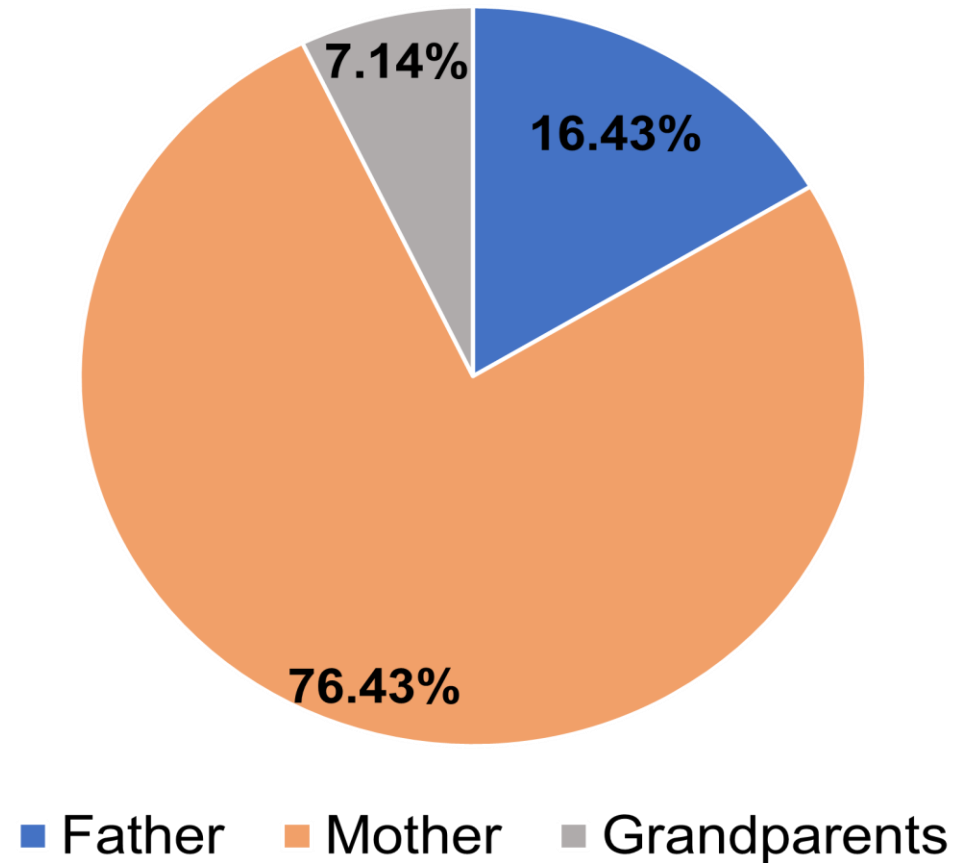
**Quantitative
Results**

**Qualitative
Results**

**Mixed
Method
Results**

Quantitative Results

Relation with child



Stress and Coping Strategies

Most common stressors

- Child living independently in future - 76.43%
- Child's acceptance by others in future - 72.14%
- Child's ability to communicate - 66.43%
- Toilet training delay - 52.86%
- Child's social development - 51.44%

Coping strategies used



Acceptance
Active Coping
Planning
Positive Reframing
Emotional Support
Religion
Self-distraction

Perceived Social Support Among Parents

Sub-scales	Low support N (%)	Moderate support N (%)	High support N (%)
Family	17 (12.14)	20 (14.29)	103 (73.57)
Friends	20 (14.29)	54 (38.57)	66 (47.14)
Significant other	10 (7.14)	23 (16.43)	107 (76.43)
Total scores	5 (3.57)	47 (33.57)	88 (62.86)

Family Quality of Life

Domains	Mean	SD
Family interaction	4.092	0.810
Parenting	3.803	0.841
Emotional Wellbeing	3.61	0.800
Physical/Material Wellbeing	4.107	0.625
Disability-related support	3.85	0.89
Total FQOL scores	3.911	0.675

Correlation between mediating variables and family quality of life

Mediating Variables	Family Quality of Life	
	r	P-value
Parental stress	-0.903	P < 0.001
Avoidant coping	-0.113	0.183
Emotion-focused coping	-0.563	P < 0.001
Problem-focused coping	-0.845	P < 0.001
Perceived social support	0.685	P < 0.001

Bivariate Regression Analysis

Identified the significant predictors of family quality of life:

1. Occupation of parents (Wald's p-value = 0.0024)
2. Occupation of the household head (Wald's p-value = 0.0273)
3. Parental stress (p-value < 0.001)
4. Emotion-focused coping (p-value < 0.001)
5. Problem-focused coping (p-value < 0.001)
6. Perceived social support (p-value < 0.001)

Multivariate Regression Analysis

Occupation of parents:

Unemployed parents had lower family quality of life than homemakers ($p = 0.003$) after controlling for other variables

Emotion-focused coping:

Higher emotion-focused coping → Lower family quality of life ($p = 0.017$)

Problem-focused coping:

Higher problem-focused coping → Lower family quality of life ($p < 0.001$)

Qualitative Results

Social and institutional perceptions of autism

Challenges faced by the parents of children with ASD

Parental stress

Coping strategies adopted by parents

Community and Family Support in Autism Care

Impact of autism diagnosis on family's quality of life

Empowering Parents: Management, Programs, and Personal Actions

Social and institutional perceptions of autism

As soon as people hear the word "autism," they think it is a contagious disease. They don't even let their children play outside with my child. They think that if their children see my child's actions, they will start copying him.

IDI 02

I wonder if it was because I let him watch too much on the phone when he was little. So, sometimes I wonder if my son is like this because I let him watch the phone in the past.

IDI 04

Social and institutional perceptions of autism

My own family members have called my child "crazy" and said things like, "Your child cries all night and doesn't let us sleep. Don't stay in this house. Take him to a mental hospital."

IDI 09

At first, I had enrolled him in a school, but to be honest, the school expelled him because he has autism.

IDI 02

Challenges faced by the parents

It has affected me a lot. Lack of sleep increases my diabetes. When my daughter doesn't sleep at night, and I have to stay awake with her, my fasting blood sugar and everything else stays high. I am on medication for it.

IDI 10

It has been quite difficult. Therapy, school, and his diet—his things, toys, taking him outside, and everything—cost a lot. Since our earnings in Nepal were not enough, my husband had to go abroad.

IDI 09

Parental stress

There are moments when I don't understand what he wants. Since I don't understand him, calming him down becomes very difficult. In those moments, I feel overwhelmed—I feel like crying

IDI 09

My biggest fear is about the future. What will happen tomorrow? As long as I am here, I can take care of him. What will happen when I am not here anymore? That is a major concern.

IDI 05

Coping strategies adopted by parents

I have realized that being sad won't cure autism or improve my child's condition. Instead, I have to forget my sorrow, stay motivated, and move forward. The happier I am, the stronger I will be and being strong will benefit my child as well.

IDI 10

I even changed my religion from Hindu to Christian for my son. After that, there were improvements in my son's health. His health started to be good.

IDI 02

Community and Family Support in Care

I consider myself lucky because my husband supports me, and my family supports me. Not everyone has that.

IDI 10

Once they were told that my child has autism, they seemed to think, "He won't speak, he will remain mute, he is completely ruined." After that, they distanced themselves. Even my husband stopped engaging.

IDI 03

Community and Family Support in Care

From society as well, I have a lot of support. Most of the time, even when I am not around, people look after my child. If my child goes a little further, I know that he will return by himself, so I can be a little relaxed, in case of open spaces. But my neighbors can't be that relaxed—they rush to hold him and bring him back

IDI 07

Impact on family's quality of life

Between my husband and me, it had a significant impact. Taking care of my daughter, struggling to understand her needs, and being exhausted from her care made me upset. When I was frustrated, I would take it out on my husband, and he would do the same to me. My frustration would be directed at him. This caused strain in our relationship.

IDI 10

Impact on family's quality of life

It is not satisfactory. I can't even tell my parents. They are very old now. It should be me taking care of them but they are the ones looking after me. If I fall sick, I have to take my child and go by myself. If my child gets sick, I have to take him by myself.

IDI 02

It is difficult, really difficult, because I don't get time for myself. I don't get time for myself, and even if I need to go somewhere, I have to think a lot.

IDI 06

Empowering Parents: Management, Programs, and Personal Actions

Many parents, after their child is diagnosed with autism, still deny it, saying, "No, this isn't autism, maybe they are just a bit late in speaking, they will speak eventually." Or they don't bring the child out in public, don't want to tell others, and try to hide it. That shouldn't be done. As soon as possible, you should intervene and accept the condition, and teach the child in the right way.

IDI 10

Empowering Parents: Management, Programs, and Personal Actions

It would be beneficial if parents could gather occasionally to discuss challenges, ways to move forward, and what works for different children. If parents shared their experiences with each other, it would give everyone new ideas.

IDI 09

Autism is an even more complex disability. This needs to be understood by the nation. The government needs to introduce policies, provide allowances, free medications, build schools, or whatever is necessary for our children.

IDI 10

Mixed Method Results

Convergent Findings

- Major stressors
- Coping strategies adopted
- Perceived social support
- Parental education and FQoL
- Parental stress and FQoL

Divergent Findings

- Parental occupation and FQoL
- Family type and FQoL
- Family income and FQoL
- Social support and FQoL
- Coping and FQoL

Expansive Findings

- Influence in marital relation of parents
- Cause of ASD
- Acceptance in school and community
- Social withdrawal
- Stigma and misconceptions

Conclusion

- This study highlights that parents of children with ASD face various psychosocial burdens and struggles that affect their quality of life.
- Support systems, including family, community, and institutional resources, play a crucial role in parental well-being.
- There is a strong need for policy-level interventions, including financial support, specialized schools, and public awareness programs to help the parents and children with ASD.

Conclusion: Takeaway Messages

- **Early intervention and acceptance** of ASD are crucial for better outcomes in both children and parents.
- **Community support and social inclusion** can significantly improve parental coping and child development.
- **Government policies and structured programs** are needed to reduce the burden on families and enhance support systems.



- A public health professional pursuing a Master's in Public Health at Patan Academy of Health Sciences.
- Experience in mental health research, and community-based interventions.
- With experience in qualitative and quantitative research, worked with organizations like TPO Nepal and NIDR, Nepal.

A decorative pattern of hexagons on the left side of the slide. It includes a light green hexagon at the top left, a yellow one below it, a grey one to the left of the yellow one, a light grey one below the grey one, a white one with a yellow outline below the light grey one, a blue one to the right of the white one, a yellow one below the blue one, a grey one to the left of the yellow one, and a light grey one below the grey one. There are also some hexagons at the bottom right, including a green one, a small grey one, and a small orange one.

THANK YOU!