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Needs and Experiences of Primary Caregivers Rearing a Child with Autism Spectrum Disorder: A Qualitative Study

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ABSTRACT

Introduction

Autism spectrum disorder (ASD) is a neurodevelopmental disorder that affects both children and their families. Raising a child with ASD presents unique challenges and experiences that this study has aimed to explore to in the Nepalese context.

Methods

A phenomenological qualitative study was conducted with the inclusion of 10 primary caregivers via purposive sampling of children with ASD of age five to ten years and diagnosis of at least six months from January 2024 to November 2024 in a school at Kathmandu, Nepal. Data were collected through face-to-face in-depth interviews with approval from the Institutional Review Committee of NAIHS. (Reference number: 952). Data analysis was done based on Braun and Clarke's (2006) thematic analysis method.

Results

Following six themes as daily parental challenges; Financial constraint; Mixed impact on the health of caregivers; Impact on relationships; Support from government level and quality medical care were extracted based on total 13 subthemes and 54 codes mentioned below with verbatim of participations.

Conclusion

Caregivers on a personal-level reported challenges arising from a lack of knowledge in managing nutritional needs and behavioral issues, along with financial constraints. At the institutional level, special attention was drawn to the lack of autism-specialized healthcare and high financial expenditures when seeking treatment in Nepal. These findings highlight the need for accessible and specialized healthcare services in Nepal with increase in governmental allowance for children with ASD.

Keywords

Autism spectrum disorder; Child development; Mental health; Parenting; Parent-child interaction.

INTRODUCTION

Autism spectrum disorder (ASD) is a neurodevelopmental disorder characterized by deficits in social communication and restricted, repetitive behaviors, which are present from early childhood or may manifest later in adulthood.[1] Co-occurring conditions such as attention deficit hyperactivity disorder (ADHD) and anxiety disorders are also more prevalent in people with ASD.[2] Previous studies have shown that challenges faced by parents are mainly related to managing behavioral difficulties, limited social interaction, and communication problems in children with autism.[3]

Caregivers of children with ASD experience higher levels of stress, stigma and poor physical health.[4,5] Likewise, they have an increased risk of anxiety and depression.[6] Support programs tailored to caregivers' needs could help address daily challenges, improve their health, and enhance family quality of life.[7]

In Nepal, amidst increasing cases of ASD there is limited qualitative research. This study explored on caregivers' experiences and needs promote better family well-being.

METHODS

The research was conducted using a hermeneutic phenomenological approach in which complete bracketing was not followed. The participants were primary caregivers of children with ASD at Nepal Autism School, Kathmandu. The study period was from January to November 2024 A.D. Approval for the study was obtained from the Department of Pediatrics, Nepal Army Institute of Health Sciences (NAIHS), Kathmandu. Ethical clearance was granted by the Institutional Review Committee (IRC), NAIHS (Reference No. 952). In addition, an administrative approval letter was obtained from Nepal Autism School, Kathmandu. The sampling population included primary caregivers of children aged five to ten years with a confirmed diagnosis of ASD for at least six months.

The sample size consisted of 10 primary care givers, selected through purposive sampling, following Creswell (1998), which suggests 5–25 interviews for phenomenological studies.[8] The date, time, and place of the interviews were predetermined and communicated to participants after approval from the study site at a school for children with ASD at Kathmandu.

Written informed consent was obtained and all participants were informed about the use of digital audio recording. Data were collected through in-depth interviews using semi-structured interview guidelines and analyzed using Braun and Clarke's (2006) thematic data analysis consisting of six steps.[9]

Initially, pilot interviews were conducted with three participants. In-depth interviews with participants were voice-recorded and supplemented with field notes, lasting 45–60 minutes. Preliminary data were reviewed and analyzed among the research team before proceeding with final data collection. The subsequent interviews were conducted with the final 10 participants in Nepali language, recorded with consent, and supplemented with field notes consisting of change in non-verbal expressions and tone of voice during the interview process. Researchers bracketed their preconceived ideas during data collection and analysis. Non-verbal expressions of caregivers were also observed, recorded, and transcribed.

All interviews were transcribed verbatim, and transcription was performed concurrently with data analysis. Data were collected until the point of data saturation where no new information was obtained. Firstly, the digital audio recordings were listened to multiple times and verbatim were translated to English language. Data from the interviews were extracted to obtain codes, main themes, and sub-themes. The translated data was analyzed by authors and identification of similar meaning and codes were created. After code generation sub-themes and themes were identified. For maintaining dependability of data, participants were asked to verify transcribed data and amendments were made as per requirement with the finalization of codes and experiences after a short follow-up in-person interviews. The final coding guide was prepared after meticulous refinement consisting of theme labels, category definitions and subthemes. All information was securely stored on a password-protected computer of the researcher. Finally, transcripts were analyzed using qualitative content analysis based on Braun and Clarke's thematic analysis approach. NVivo 14 and MS-Excel 2019 were used in the analysis process.

RESULTS

Sociodemographic of Respondents:

All the primary caregivers in our study were the mother of children with ASD. All the respondents

were married with six out of ten respondents from joint family. All the respondents were residing in Kathmandu at the time of study.

Following themes were generated:

Theme 1: Daily parental challenges:

Parenting a child with autism has its own difficulties, all of the mothers reported experiencing problems due to their child's behavior, such as self-harm, hyperactivity, and overdependence on them for activities of daily living. Half (of respondents mentioned that they lacked knowledge in managing their children's behavioral issues. Further, seven of caregivers faced daily challenges due to the lack of understanding in society regarding the behavior of children with autism. A striking finding was that three mothers reported difficulty in fulfilling nutritional demands and marinating balanced diet.

"My son constantly bangs his head against the wall. I cannot leave him alone." Participant 1

"He doesn't eat white colored food and has not had fruits like apples and bananas for long time. This concerns me about his nutrition." Participant 3

"My child at 6 years has problems going to the toilet. I need to look after her every time." Participant 5

"When he throws tantrum on road people in the vicinity stare at me as if I have kidnapped my own child and they take pictures." Participant 10

Table 1. Theme one with subtheme and codes

Theme	Subtheme		Codes
Daily Parental challenges	I.	Parenting problems	• Self-Harm by the child • Harm to other people specially children • Delay in toilet training • Inability to leave child unattended • Child's peculiar behavior like screaming, head banging, spinning in circles
	II.	Inadequacy to manage the specific needs of a child with ASD	• Lack of parental knowledge on management of behavioral issues of autistic child • Lack of knowledge on nutritious food reinforcement

Theme 2: Financial Constraints

Nine caregivers experienced challenges providing care due to financial constraints, chiefly due to the high cost of therapy materials and fees of care centers. Seven participants reported that government allowances were insufficient. Half of participants had to leave their jobs primarily to care for their child, adding to financial strain.

"We have been given an allowance of 4000 NRS for our kids and one therapy session costs 1500-2000 NRS and many sessions are required in a month and the travel fare is also there. So how are we supposed to manage it?" Participant 3

"Leading a normal life is very difficult. This condition impacts household income severely as one parent needs to be involved with the child full time. The schools are also expensive for autistic children" Participant 6

"My payment has not been reduced I just adjusted my work schedule with his scheduling" Participant 9

Table 2. Theme two with subtheme and codes

Theme	Subtheme		Codes
Financial constraints	I.	Increased expenditure for treatment	• Excessive cost for treatment materials • Excessive fees of care center • High medical cost for therapies
	II.	Decreased source of income on a family level	• Loss of job of care giver • Low allowance by government • Lack of time for income generation activities • Ineffective time management skills for work life balance

Theme 3: Mixed impact on relationships

Eight out of ten participants were satisfied with the support from their spouses. However, three mothers felt that the total responsibility of caring for the child was burdened on them. Most mothers from joint families reported receiving immense support from their family members in providing care for the child. When asked probing questions, none of the mothers mentioned feeling blamed or disrespected by family members. All parents reported a decrease in social gatherings due to stress in managing the child's behavior in social settings, and the inability to leave the child unattended at home.

"I have intentionally reduced social interactions as once someone told me, your child breaks things, go and store him in some place." Participant 1

"My child is not as comfortable with his father as with me so I look after him mostly." Participant 2

"I have an elder son who takes care of my daughter more than me. Most of the time I have to cancel plans with my friends to look after him." Participant 5

"My husband understands our child well. He also has been counseling me through mental stresses and anxieties." Participant 6

"I share my problems with my mother in law. No one has blamed me in my family for the child's conditions." Participant 7

Table 3. Theme three with subtheme and codes

Theme	Subtheme	Codes
Mixed Impact on Relationship	I. Family Dynamics	• Lack of quality time with partner • Unequal work distribution in caring for the child • Marital conflicts • Better understanding • Emotional Support • Better work division among many members • Emotional support • Decrease Social Gatherings • Discontent with the attitudes and judgment of other • Feeling anxious and ashamed of the child's behavioral problems
	II. Social Relations	• Feeling of new direction in life

Theme 4: Impact on the health of the parents

All respondents experienced some form of impact on their physical and mental health. Three respondents reported developing physical symptoms due to the tiring process of caring for the child and the lack of time for medical follow-up. In addition, one parent mentioned that her preexisting health condition worsened after her child's diagnosis. Interestingly, one respondent stated that having a child with ASD encouraged her to take better care of herself. The mental health of all primary caregivers was affected with eight respondents reporting feeling stressed about their child's future, primarily due to concerns about caring of the child after their demise and prognosis of the condition. Three respondents also mentioned that the lack of understanding from people in society aggravated their stress.

"I have not been able not go for regular health checkups for the uterine tumor as frequently because hospital's don't have autism friendly services. I also get tired after giving daily massage as part of treatment" Participant 1

"Once he got diagnosed with autism, my migraines got severe. My mind is filled with so much negativity. We will look after him while we're alive, but what about later? What if my next child is the same?" (Crying)" Participant 6

"As I have to be energetic to take care of my child, so it's become a habit to eat thoughtfully and rest adequately to be healthier." Participant 10

Table 4. Theme four with subtheme and codes

Theme	Subtheme		Codes
Impact on Health of parents	I.	Physical Health	• Fatigue and Exhaustion • Emergence of new physical symptoms • Lack of time for routine health follow up • Increased mindfulness towards health
	II.	Mental Health	• Comparing own child with other peers • Blaming Self for the Condition • Fearful about the child's dependence on caregiver • Stress about future pregnancy • Helplessness due to lack of understanding of the condition

Theme 5: Need for governmental and community support

Half of the respondents reported a lack of adequate knowledge and training in caring for children with autism in the Nepalese context. One parent noted that receiving proper training and coping strategies had improved her mental health. Additionally, seven out of ten respondents expressed dissatisfaction with the disability allowance and government awareness programs, despite the increasing number of children with ASD in Nepal. All participants emphasized the importance of implementing training programs at governmental and community levels.

"Government gives us some allowances, but the amount barely covers 10% of the annual training fee." Participant 5

"At first I did not know if I could do it. Within 5 months of therapy he improved which motivated me." Participant 9

"I was referred for training for parents of autistic children. My turn came 2 years after the date of registering." Participant 10

Table 5. Theme five with subtheme and codes

Theme	Subtheme		Codes
Need for governmental and community support	I.	Revision of Governmental policies and plans	• Need for increase in allowance • Allowance barely covering one therapy session • Proper demographic survey policy making • Cheap care centers by government
	II.	Insufficient training programs for care givers	• Training for parents that are accessible • Long waiting time at training centers • Improved care with proper training
	III.	Awareness at community level	• Awareness through programs on supporting families with children with ASD • Community led care centers for children • Formation of social groups for children with AS

Theme 6: Need for quality medical care:

All parents emphasized the need to improve the quality of care provided to children with autism through various healthcare delivery systems. Three parents reported delays in diagnosis despite timely care-seeking. One parent suggested that having a separate counter and waiting area for parents of children with ASD would be helpful. Six mothers also stated that there was lack of quality care for children with ASD in Nepal with emphasis on lack of parental counselling on management of the child behavioral as well as other medical needs.

"It would be nice if a separate queue and waiting center would be designated for parents of children with Autism in all hospitals" Participant 1

"After the internet search, we went to the hospital when he was about 12 months but the hospital just sent for MRI and ear investigations. A proper diagnosis was made when he was 2 years and 10 months." Participant 6

"There are no good speech therapists. They charge is very high but our child showed no improvement." Participant 7

Table 6. Theme six with subtheme and codes

Theme	Subtheme		Codes
Need for quality medical care	I.	Diagnostic Delays	• Delayed in diagnosis in children with milder symptoms • Lack of knowledge among medical professionals • Increased cost due to numerous referrals
	II.	Inadequate patient care	• Ineffective communication techniques • Lack of ASD child friendly hospital environment • Lack of parental counselling • Lack of specialized care givers

DISCUSSION

Caring for a child with ASD entails heightened responsibility, which demands immense personal sacrifices from primary caregivers. Specifically, caregivers reported that daily challenges were exacerbated by children's behavioral issues, including self-harm, inability to use the washroom independently, and difficulty with self-feeding. Difficulties in maintaining a balanced diet were also noted, consistent with findings from previous studies.[10] All caregivers mentioned a lack of adequate, authentic information on managing tantrums in children with autism, acknowledging that parental training is important, consistent to study conducted in Minnesota.[11] In Nepal, parents also reported limited access to quality care at an affordable cost.[12]

Participants expressed that although government allowances were available, it did not cover a substantial portion of the child's expenses consistent with previous research.[4] The participants had to perform multiple roles, including looking after the child, contributing to daily household chores, and maintaining professional responsibilities. Due to the demanding nature of caring for a child with ASD, including daily massage and therapy they felt exhausted, consistent with findings from other studies.[13] They also described difficulties maintaining their own physical health and concerns regarding their child's future, dependence, and progression of behavioral symptoms. Prior studies similarly found that mothers of children with ASD experienced higher stress and lower psychological well-being compared with mothers of other children.[10]

Despite the challenges of rearing a child with ASD, consistent with findings of a study among 26 married couples that revealed good support from spouse, our findings revealed that eight of primary caregivers perceived adequate spousal support.[4] Participants emphasized that their spouses were not only involved in child care but also helped meet their emotional needs. These findings suggest that raising a child with autism fosters shared responsibility between spouses and strengthens the emotional bond within the marital relationship. Similar results have been reported in previous studies, which concluded that couples develop greater intimacy and commitment when caring for a child with autism.[14] Additionally, another study noted that parents collaborated to manage daily life and stress, organized task division, and maintained a sense of hope, supporting the positive effects of co-parenting relationships observed in our study.[15] However, three participants indicated unequal role division between spouses, with the child rearing burdened on them. Participants from joint families reported receiving support from in-laws and older children. This contrasts with previous research, where mothers were criticized by family members and blamed for their child's disability due to perceived negligence.[16]

Participants in this study experienced stigma related to managing their child's tantrums in

social settings, consistent with findings from a 2012 study.[17] They reported having to endure comments labeling their child as "crazy" and even accusations of kidnapping their own child, which were emotionally distressing. All participants attributed this lack of social support to limited awareness in the Nepalese context consistent with past studies.[16]

Raising a child with autism without adequate resources or future planning heightened participants' child rearing concerns. Participants emphasized that having proper knowledge on caring for the child helped alleviate anxiety. They also noted that the lack of specialized health facilities for children with ASD and the absence of standardized diagnostic protocols contributed to delays in diagnosis and compromised quality of care. Most participants reported that government support, including training programs and allowances, was insufficient in Nepal. They recommended the implementation of awareness programs, improved accessibility to affordable specialized health services and increased financial allowance would enhance quality of life of children with ASD.[18]

CONCLUSION

In conclusion, six themes that were generated in the study highlighted that primary caregivers of children with autism face significant physical, emotional, and financial challenges. Limited knowledge about behavioral and nutritional management with inadequate access to quality healthcare, social stigma, and minimal government support added to caregiver burden. These findings highlight the need for increased awareness, caregiver training, financial assistance, and accessible autism care centers.

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CONFLICT OF INTEREST

No conflict of interest

AUTHOR CONTRIBUTIONS

Author 1: Formal analysis; supervision; roles/writing – original draft; and writing – review & editing. **Author 2:** Conceptualization; data curation; formal analysis; investigation; methodology; project administration; resources; validation; visualization; roles/writing – original draft; and writing and review

Author 3: Data curation; formal analysis; investigation; methodology; project administration; resources; software visualization; writing – original draft; and writing – review & editing.

Author 4: Data curation; investigation; methodology; visualization; writing – original draft; and review

Author 5: Coordination with data collection site; proofreading.

Author 6: Data curation; investigation; methodology; visualization; writing – original draft; and review

REFERENCES

1. Hirota T, King BH. Autism spectrum disorder: a review. JAMA. 2023 Jan 10;329(2):157–68. [DOI | PUBMED | Googlescholar | Full Text]
2. Sanchack KE, Thomas CA. Autism spectrum disorder: primary care principles. Am Fam Physician. 2016 Dec 15;94(12):972–9. [PUBMED | Googlescholar | Full Text]
3. Altiere MJ, von Kluge S. Searching for acceptance: challenges encountered while raising a child with autism. J Intellect Dev Disabil. 2009;34(2): 142–52. [DOI | PUBMED | Googlescholar | Full Text]
4. Amundson D, Lofquist S. Parents' experiences of caring for a child with autism spectrum disorder. Qual Res Psychol. 2015;25(4):452–68. Available from: https://pubmed.ncbi.nlm.nih.gov/25246329 [DOI | PUBMED | Googlescholar | Full Text]
5. Allik H, Larsson JO, Smedje H. Insomnia in school-age children with Asperger syndrome or high-functioning autism. BMC Psychiatry. 2006;6:18. [DOI | PUBMED | Googlescholar | Full Text]
6. Ten Hoopen LW, de Nijs PFA, Duvekot J, Greaves-Lord K, Hillegers MHJ, Brouwer WBF, et al. Children with an autism spectrum disorder and their caregivers: capturing health-related and care-related quality of life. J Autism Dev Disord. 2020 Jan;50(1):263–77. [DOI | PUBMED | Googlescholar | Full Text]
7. Hartley SL, Papp LM, Bolt D. Spillover of marital interactions and parenting stress in families of children with autism spectrum disorder. J Clin Child Adolesc Psychol. 2018;47(sup1):S88–99 [DOI| Googlescholar | Full Text]
8. Bekele WB, Ago FY. Sample size for interview in qualitative research in social sciences: a guide to novice researchers. REPAM. 2022 Sep 18;4(1):42–50. Available from: https://repamjournal.org/index.php/REPAM/article/view/51 [DOI| Googlescholar |

Full Text]

9. Braun V, Clarke V. Using thematic analysis in psychology. Qual Res Psychol. 2006;3(2):77–101. Available from: https://doi.org/10.1191/1478088706qp063oa [DOI| Googlescholar | Full Text]
10. Smith LE, Hong J, Seltzer MM, Greenberg JS, Almeida DM, Bishop SL. Daily experiences among mothers of adolescents and adults with autism spectrum disorder. J Autism Dev Disord. 2010 Feb;40(2):167–78. Available from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2826850/ [DOI | PUBMED | Googlescholar | Full Text]
11. Bennett A. Parental involvement in early intervention programs for children with autism. Social Work Master's Clinical Research Papers. 2012 Jan 1. Available from: https://ir.stthomas.edu/ssw_mstrp/10 [Full Text | Googlescholar]
12. Shrestha M, Santangelo SL. Autism: challenge in Nepal. In: Matson JL, editor. Comprehensive guide to autism. New York: Springer; 2014. p. 2497–507. [Full Text | Googlescholar]
13. Safe A, Joosten A, Molineux M. The experiences of mothers of children with autism: managing multiple roles. J Intellect Dev Disabil. 2012 Dec;37(4):294–302. [DOI | PUBMED | Googlescholar | Full Text]
14. Hock R, Timm T, Ramisch J. Parenting children with autism spectrum disorders: a crucible for couple relationships. Child Fam Soc Work. 2012 Jun;17:406–15. [DOI | Googlescholar | Full Text]
15. Saini M, Singh KP, Gibson M, Morris R, Burke D, Muskat B, et al. Couple relationships among parents of children and adolescents with autism spectrum disorder: findings from a scoping review of the literature. Res Autism Spectr Disord. 2015 Sep;17:142–54. [DOI | Googlescholar | Full Text]
16. Acharya S, Sharma K. Lived experiences of mothers raising children with autism in Chitwan district, Nepal. Autism Res Treat. 2021;2021:6614490. [DOI | PUBMED | Googlescholar | Full Text]
17. Nealy C, O'Hare L, Powers J, Swick D. The impact of autism spectrum disorders on the family: a qualitative study of mothers' perspectives. J Fam Soc Work. 2012;15:187–201. [DOI | Googlescholar | Full Text]
18. Im-Bolter N, de la Roche L. What parents want: a qualitative analysis of a parent-implemented intervention for autistic children. Autism Dev Lang Impair. 2023;8:23969415231189606. [DOI | PUBMED | Full Text]