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Lived Experiences of Parents Raising Children with Autism Spectrum Disorder: Challenges and Barriers in Gilgit-Baltistan

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Abstract

Autism Spectrum Disorder (ASD) is a complex neurodevelopmental condition characterized by impairments in communication, social interaction and repetitive behavior. Despite growing global recognition of ASD, limited research has explored the lived experiences of parents raising children with ASD, particularly in low-resource settings. This qualitative study aimed to investigate the lived experiences of parents of children with ASD in Gilgit-Baltistan. A total of nine parents participated in semi structured interviews. Data were analyzed using Colaizzi's Phenomenological method to capture the depth and meaning of participants' experiences. The findings revealed several interconnected themes, including caregiver burden, emotional distress, family impact, social stigma and processes of acceptance and adaptation. Parents reported significant psychological, social and familial challenges associated with raising a child with ASD. The study highlights the substantial caregiver burden and the influence of social stigma on parental well-being. These findings provide important insights into the lived experiences of parents in a low-resource context and underscore the need for culturally sensitive, family-centered interventions. The results have implications for mental health professionals, researchers and policymakers working to improve support systems for families of children with ASD.

Keywords: Autism Spectrum Disorder, Lived Experiences, Caregiver Burden, Social Stigma, Family Centered Interventions

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1. Introduction

Most parents perceive the birth of a child as a blessing associated with joy and fulfillment; however, when a child begins to show impairments in social communication and interaction, parenting becomes significantly challenging. Consequently, parental expectations, which are often formed before birth, change considerably as parents adjust to the child's developmental needs. Autism has wide-ranging consequences that affect not only the diagnosed individual but also the family's welfare, economic condition, and overall quality of life. This burden is particularly evident in primary caregivers, most commonly mothers, who are responsible for both practical caregiving and managing emotional and social challenges (Iadarola et al., 2019; Rodriguez et al., 2019).

Autism, derived from the Greek word meaning "self," is a neurological disorder in which children appear withdrawn into their own world (Hoogsteen & Woodgate, 2013). It was first described by Kanner (1943), while Asperger (1944) independently identified a similar condition characterized by better language and cognitive abilities. Over time, these conditions were integrated into diagnostic systems such as DSM and ICD, reflecting the evolving understanding of autism as a spectrum. Autism spectrum disorder (ASD) is now recognized as a group of neurodevelopmental disorders characterized by impairments in social communication and interaction, alongside restricted and repetitive behaviors (American Psychiatric Association, 2022; Ostrowski et al., 2024).

Furthermore, ASD presents with diverse symptoms, including difficulty in transitioning between activities, heightened attention to detail, and unusual sensory responses. The severity and needs of individuals with autism vary widely, with some leading independent lives while others require lifelong support. As a result, ASD significantly affects educational attainment, employment opportunities, and social functioning (Ashraf et al., 2022).

Historically, autism was attributed to environmental factors such as parenting style; however, this view was later rejected in favor of biological and genetic explanations. The understanding of autism evolved from a categorical condition to a spectrum, with core symptoms initially conceptualized as a "triad of impairments," later refined into broader diagnostic dimensions. Additionally, challenges in distinguishing core symptoms from associated behavioral issues led researchers to reconsider the inclusion of behaviors such as aggression and self-injury in assessment frameworks (Matson & Nebel-Schwalm, 2007).

From a neurological perspective, ASD reflects differences in brain development and connectivity, particularly between frontal and parietal regions, influencing cognitive processing styles (Lombardo et al., 2019; Belmonte et al., 2004). Over time, the prevalence of autism has increased significantly, from being considered rare to affecting approximately 1% of the population (Zeidan et al., 2022). It is also more common in males than females (Hoogsteen & Woodgate, 2013). Despite increased awareness globally, many individuals, especially adults, remain undiagnosed or face challenges in obtaining a diagnosis (Lenart & Pasternak, 2023).

In contrast, awareness and diagnosis of autism in Pakistan remain limited. Although global prevalence estimates have risen, reported rates in Pakistan are lower due to underdiagnosis and lack of awareness (Anwar et al., 2018; Ashraf et al., 2022). Cultural misconceptions, limited diagnostic facilities, and inadequate professional training further complicate early identification and intervention.

Moreover, raising a child with ASD has a profound impact on parental mental health. Parents often experience stress, frustration, and emotional strain while managing caregiving responsibilities (Iadarola et al., 2019; Rodriguez et al., 2019). Therefore, understanding these multifaceted challenges is essential for addressing the needs of both children with ASD and their families.

2. Method

2.1 Research Design:

This study employed a qualitative exploratory research design to gain an in-depth understanding of parents lived experiences of raising children with Autism Spectrum Disorder (ASD). A phenomenological approach (Morrow et al., 2015) was adopted, as it facilitates the exploration of participants' perceptions emotions and experiences in their everyday lives.

2.2 Sample and Sampling Technique:

A total of nine parents (four mothers and five fathers), aged between 32 and 49 years, participated in the study. All participants had children formally diagnosed with ASD, aged between 5 and 13 years. Participants were recruited from Gilgit City using a purposive sampling technique to ensure the inclusion of individuals with relevant lived experience.

2.3 Data Collection:

Data was collected through semi-structured interviews to explore parents' firsthand experiences of raising a child with ASD in Gilgit. Prior to interviews, a structured Family Background Questionnaire (FBQ) was administered to collect demographic information, including parental age, education, occupation, socioeconomic status, number of children, and child-related characteristics such as age, gender, birth order, ethnicity and medical history.

The interview guide consisted of ten open-ended questions, asked in a consistent sequence across participants. Key guiding questions included:

1. What do you know about autism spectrum disorder (ASD).?
2. What are the key challenges in raising a child with ASD?
3. How has your child's ASD affected your life?

Additional probing questions were used to explore participants' responses in greater depth. Interviews were conducted face-to-face and lasted approximately 45–60 minutes. All interviews were audio-recorded with participants informed consent and subsequently transcribed verbatim to ensure accuracy.

2.4 Data Analysis:

Data were analyzed using Colaizzi's seven-step phenomenological method to ensure a systematic and rigorous interpretation of participants lived experiences. The analytical process involved the following steps

1. Reading all transcripts repeatedly to achieve immersion and familiarity with the data.
2. Extracting significant statements relevant to the phenomenon under study.
3. Formulating meanings from these significant statements.
4. Organizing the formulated meanings into clusters of themes.
5. Developing an exhaustive description of the phenomenon.
6. Identifying the fundamental structure of the lived experiences.
7. Returning findings to participants for validation.

This systematic approach enabled the identification of key themes reflecting parents lived experiences.

Trustworthiness (Rigor of the Study):

To ensure rigor, the study followed the four criteria of trustworthiness:

Credibility: Achieved through in-depth interviews, prolonged engagement, and participant validation.

Dependability: Maintained by consistent interview procedures and systematic analysis.

Conformability: Ensured by keeping data grounded in participants' narratives and minimizing researcher bias.

Transferability: Supported through detailed descriptions of participants and context.

2.4 Ethical Considerations:

Ethical principles were strictly observed throughout the study. Participation was voluntary, and informed consent was obtained from all participants prior to data collection. Confidentiality and anonymity were ensured through the use of pseudonyms, and participants were informed of their right to withdraw from the study at any stage without any consequences.

3. Result

The analysis revealed five major themes regarding the experiences and burdens of parents raising children with ASD: emotional burden, family burden, and social burden, treatment preferences and acceptance and adaptation

Table 1

Thematic Analysis of Parents Raising Children with ASD (N=9)

Themes	Sub-themes	Category	Description
Emotional Burden	Emotional Reactions	Diagnosis Phase	Parents initially experienced shock, sadness and denial following the diagnosis. These emotions evolved into ongoing stress, helplessness and emotional strain in caregiving. Over time, many parents gradually accepted their child's condition.
	Psychological Distress	Ongoing Experience	Persistent emotional distress, anxiety and worry about the child's future.
	Adjustment Process	Adaptation	Gradual adaptation and emotional regulation over time.
Family Burden	Marital Relationship	Spousal Dynamics	Parents experienced marital conflict, lack of spouse support and emotional strain.
	Family Roles	Household Adjustment	Family routines and responsibilities reorganized around the child with ASD.
	Financial Burden	Economic Impact	Increased costs of therapy, medical care, and employment disruptions.
Social Burden	Social Stigma	Community Attitudes	Blame, judgment and misunderstanding from society. Misconceptions about autism and cultural beliefs contributed to negative attitudes.,.
	Lack of Awareness	Cultural Context	Limited knowledge and awareness of ASD within the community.
	Social Isolation	Behavioral Response	Withdrawal from social gatherings and community life.
Treatment Preferences	Treatment Approaches	Professional Support, Cultural Practices, System Barriers	Preference for therapy, autism centers and medical treatment. Use of religious and cultural explanations (e.g., evil eye, fate). Dissatisfaction due to lack of facilities and support services
Acceptance and Adaptation	Coping Strategies	Psychological Adjustment, Spiritual Coping, Child Development	Patience, emotional regulation, behavioral adaptation. Reliance on spiritual coping and Trust in God. Focus on promoting child independence and future well-being.

Thematic Description:

Emotional Burden: Parents reported intense emotional reactions following their child's ASD diagnosis. Common feelings included shock, denial, sadness and frustration. Many struggled to accept the condition initially, experiencing helplessness and ongoing emotional distress. Mothers often expressed deeper emotional vulnerability, including self-doubt and hopelessness, whereas fathers emphasized stress and responsibility in managing caregiving challenges.

Family Burden: Raising a child with ASD significantly affected family dynamics. Many parents reported marital strain, reduced emotional support, and conflicts within extended families. Financial challenges were also prominent, as therapy costs and caregiving responsibilities limited employment opportunities. Additionally, parents described difficulties in balancing attention between the child with ASD and other siblings. In several cases, family life became entirely centered around the child, altering daily routines and priorities.

Social Burden: Social challenges were primarily associated with stigma, limited awareness and cultural misconceptions about autism. Parents frequently reported negative attitudes, blame, and judgment from relatives and the wider community. Cultural beliefs, including supernatural explanations, further intensified these challenges. As a result, many parents avoided social interactions, leading to isolation and reduced participation in community life.

Treatment Preferences: Parents demonstrated varied approaches toward treatment and intervention. While many preferred medical and therapeutic interventions, including autism centers and professional support, others also relied on traditional or cultural beliefs. Some participants expressed dissatisfaction with available services, particularly due to limited facilities in Gilgit. This reflects a gap between parental needs and accessible support systems.

Acceptance and Adaptation: Despite numerous challenges, parents gradually developed coping strategies and adaptive mechanisms. Religious beliefs played a significant role in helping parents make sense of their experiences. Over time, many parents shifted their focus toward improving their child's independence and future well-being. Acceptance was described as a gradual process, involving emotional adjustment, patience, and active engagement in the child's development.

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4. Discussion

This study explored the lived experiences of parents raising children with Autism Spectrum Disorder (ASD) in Gilgit semi-structured interviews. The analysis resulted in five main themes: emotional burden, family burden, social burden, treatment preferences, and adaptation and acceptance. The findings highlight the complex emotional, familial, social, and financial challenges faced by parents of children with ASD, which aligns with the broader understanding of ASD as a lifelong neurodevelopmental condition affecting both individuals and families (American Psychiatric Association, 2022; Ostrowski et al., 2024).

The first theme identified was the emotional burden, including distress related to diagnosis, frustration, and concerns about the child's future. Parents in this study were primary caregivers and were responsible for managing multiple caregiving roles alongside household responsibilities. These demands negatively affected their emotional well-being, leading to feelings of helplessness and pessimism about their child's future. These findings are consistent with previous research indicating higher levels of stress, worry, and emotional overload among parents of children with ASD (Iadarola et al., 2019; Rodriguez et al., 2019). Furthermore, parents reported limited knowledge regarding effective management of ASD, which reflects findings from Pakistani studies highlighting gaps in awareness and understanding of autism (Anwar et al., 2018; Ashraf et al., 2022). Mothers, in particular, expressed heightened concerns regarding long-term care and future dependency of their children.

Secondly, family burden, reflected significant disruptions in family dynamics. Parents reported marital strain, reduced emotional support, and challenges in sibling relationships. The caregiving demands led to a child-centered family structure, often at the expense of other family members' needs. Additionally, financial strain was a prominent issue, as parents had to manage the high costs of therapy and specialized care. These findings are consistent with research suggesting that raising a child with ASD often results in financial hardship and altered family functioning (Hoogsteen & Woodgate, 2013; Lenart & Pasternak, 2023). In Gilgit, the absence of specialized autism centers and limited public mental health services further exacerbates these challenges, requiring families to seek expensive private treatments.

The third theme, social burden, highlighted stigma, lack of awareness, and social isolation experienced by parents. Participants reported negative societal attitudes, blame, and misconceptions regarding autism, which contributed to withdrawal from social activities. These findings are consistent with previous literature showing that stigma and discrimination are significant barriers faced by families of children with ASD (Ashraf et al., 2022; Ostrowski et al., 2024). Cultural beliefs, including supernatural explanations of autism, further intensified these challenges. As a result, parents often restricted their child's social exposure to avoid judgment, leading to increased isolation.

The findings also revealed diverse treatment preferences, with parents relying on both medical and traditional approaches. While some participants preferred professional interventions such as therapy and autism centers, others combined these with religious or cultural practices. This reflects the broader challenge of limited access to appropriate services and lack of standardized care systems in developing regions (Lenart & Pasternak, 2023). The dissatisfaction with available interventions reported by parents further indicates the need for improved healthcare infrastructure and accessible support services.

Finally, the theme of acceptance and adaptation highlighted parents' gradual adjustment to their child's condition. Many parents relied on religious beliefs, patience, and behavioral adaptation as coping mechanisms. Over time, parents shifted their focus toward improving their child's independence and future well-being. This process of adaptation is consistent with existing research indicating that parents move from initial distress toward acceptance and resilience (Iadarola et al., 2019).

The implications of this study suggest that an understanding of parental experiences can guide the development of family-centered interventions aimed at supporting parents emotionally and practically. Parent training programs can help parents understand autism, managing stress and improving well-being. Additionally, social support plays a crucial role in reducing stigma and enhancing coping. Establishing parent support groups and community-based services can help families share experiences and reduce feelings of isolation. Policy-makers should prioritize awareness programs to improve public understanding of autism and promote inclusion of individuals with ASD in society. Increasing awareness and acceptance can reduce stigma and improve the overall quality of life for both children with ASD and their families (Zeidan et al., 2022).

Conclusion

This study provides valuable insights into the lived experiences of parents raising children with ASD in Gilgit. The findings reveal that families face significant emotional, familial, social, and financial burdens. Caregiving responsibilities and children's behavioral challenges were identified as major sources of stress, which were further exacerbated by societal stigma and limited awareness of ASD. These challenges significantly affect parents well-being, daily functioning and overall quality of life. The study highlights the resilience and adaptive strategies parents employ, including emotional adjustment, behavioral adaptation and reliance on spiritual coping, while underscoring the urgent need for comprehensive support systems in low-resource settings.

Implications of the Study

The findings suggest several important practical and policy-related recommendations. There is a clear need for the development of psychological support programs aimed at reducing parental stress and enhancing coping strategies. In addition, improving healthcare services is essential to facilitate early diagnosis and ensure greater access to autism-related interventions. Educational institutions should adopt more inclusive practices by providing appropriate support systems for children with Autism Spectrum Disorder (ASD). Furthermore, public awareness campaigns are necessary to reduce stigma and promote social acceptance of autism within society. At the policy level, increased governmental support is recommended, including financial assistance for families and the establishment of specialized autism care facilities.

Limitations

Despite these contributions, the study has several limitations. The small sample size limits the generalizability of the findings, and the study's focus on Gilgit restricts broader regional representation. The reliance on self-reported data introduces the possibility of recall and response biases. Additionally, the sample lacked diversity, particularly in terms of socioeconomic and cultural backgrounds. Finally, the cross-sectional design of the study does not allow for an examination of changes in parental experiences over time.

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