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EXPERIENCES OF PARENTS RAISING A CHILD WITH AUTISM SPECTRUM DISORDER IN PAKISTAN

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Abstract

Autism Spectrum Disorder (ASD) presents complex challenges for families, particularly in Pakistan where awareness, resources, and trained professionals remain limited. This qualitative study explores the lived experiences of ten parents raising children with ASD, using Colaizzi's phenomenological method. Findings reveal emotional struggles, difficulty accessing diagnosis, financial burdens, social stigma, and coping strategies shaped by culture and religion. The study highlights the urgent need for policy reforms, parent support systems, and culturally contextualized interventions to improve the well-being of families living with ASD.

Keywords: *Autism Spectrum Disorder, Parenting, Experiences, Pakistan, Phenomenology, Qualitative Research*

Introduction

Autism Spectrum Disorder (ASD) is a complex neurodevelopmental condition characterized by challenges in communication, social interaction, and repetitive or restricted behaviors. Globally, ASD has received increased attention in research and clinical practice; however, in Pakistan, awareness and understanding of autism remain limited. Many families encounter difficulties obtaining accurate diagnoses, accessing therapy, and managing societal stigma.

Raising a child with ASD profoundly impacts parents' emotional, psychological, social, and financial well-being. Parents often navigate an uncertain journey, filled with confusion, guilt, and frustration, particularly when early signs of developmental delay appear. Cultural beliefs, societal expectations, and lack of professional knowledge make the process even more challenging in countries like Pakistan.

This study aims to explore, in depth, the lived experiences of parents raising autistic children in Pakistan. It gives voice to their struggles, resilience, coping strategies, and evolving perspectives. Unlike quantitative studies that measure stress levels or prevalence, this qualitative approach uncovers the human story behind autism parenting. The results provide insight into the emotional landscape, structural barriers, and broader socio-cultural context shaping the experiences of these parents.

Literature Review

Research globally has demonstrated that parents of children with ASD experience significantly higher levels of stress, anxiety, and emotional burden compared to parents of neurotypical children. Mourisden et al. (2007) found that ASD-related caregiving is uniquely stressful, exceeding the burden associated with other developmental conditions. Communication issues, behavioral challenges, and difficulties understanding a child's needs contribute to persistent parental fatigue.

Qualitative studies provide deeper insight into how parents interpret and manage autism. Neill (1999) found that parents often misinterpret early ASD symptoms, attributing them to personality traits or temporary delays. Emotional reactions such as guilt, shock, and denial are common after diagnosis. Dugdale (1984) highlighted the dual nature of parenting—simultaneously stressful yet deeply rewarding—especially for mothers who shoulder most caregiving responsibilities.

In Pakistan, the situation is intensified by cultural misconceptions. Autism is often misunderstood as a behavioral problem, a result of poor parenting, or even spiritual punishment. Limited access to diagnostic centers and therapists leaves families struggling to identify appropriate interventions (Azeem, 2014). Stigma is a prominent theme in local literature, where parents report hiding their child's condition to avoid social judgment.

The lack of trained professionals further complicates the situation. Many doctors misdiagnose ASD as hearing impairment, speech delay, or behavioral disturbance. Parents often undergo multiple medical consultations before receiving an accurate diagnosis.

Despite these challenges, resilience emerges as a strong theme. Many parents develop acceptance, adapt their parenting styles, and find strength through religion, community support, or personal determination. Research indicates that parents evolve emotionally over time—moving from confusion and grief to empowerment and advocacy for their children.

Method

This study used a qualitative phenomenological design to deeply explore parents' lived experiences. A total of ten parents (seven mothers and three fathers) participated. Participants were selected through snowball sampling from autism centers in Gujranwala.

Data Collection

Semi-structured interviews lasting 45–90 minutes were conducted. Open-ended questions allowed parents to reflect on:

- Early recognition of symptoms

- Diagnostic journey
- Emotional reactions
- Social experiences
- Financial and educational challenges
- Coping strategies

Interviews were audio-recorded with consent and transcribed verbatim.

Data Analysis

Colaizzi's seven-step phenomenological method was used:

1. Reading transcripts repeatedly
2. Extracting significant statements
3. Formulating meanings
4. Organizing themes into clusters
5. Exhaustive description of the phenomenon
6. Creating fundamental structure
7. Returning to participants for validation

Ethical considerations were ensured, including confidentiality, voluntary participation, and use of pseudonyms.

Results

Thematic analysis revealed seven major themes:

1. Early Recognition of Differences

Parents first noticed speech delays, lack of eye contact, unusual crying patterns, and absence of social engagement. Many attributed this to mobile screen exposure or temporary developmental delay.

2. Emotional Turmoil After Diagnosis

Shock, denial, guilt, fear, and sadness were universal responses. Mothers particularly internalized self-blame, believing they had failed in caregiving.

3. Struggle with Diagnosis and Healthcare System

Most parents faced misdiagnosis and inadequate medical guidance. Several doctors labeled the child as "slow," "stubborn," or "speech-delayed," delaying timely intervention.

4. Social Stigma and Misunderstanding

Parents reported hurtful comments from relatives and neighbors. Many avoided social gatherings due to embarrassment or fear of judgment. Mothers especially felt criticized for their parenting skills.

5. Financial and Educational Challenges

Therapy fees, medical evaluations, and school admissions created financial strain. Special education facilities were limited, and mainstream schools lacked understanding of ASD.

6. Coping Mechanisms

Parents used religious coping ("Allah tests those He loves"), online research, support from spouses, and therapy sessions. Some adapted daily routines to manage meltdowns and behavioral challenges.

7. Growth, Resilience, and Acceptance

Despite hardships, parents reported emotional maturity, strengthened family bonds, and personal growth. Many developed patience, empathy, and a deeper understanding of their child's unique world.

Discussion

This study confirms previous research showing that raising a child with ASD is emotionally demanding, socially isolating, and financially burdensome. In Pakistan, the impact is intensified due to cultural stigma, limited awareness, and inadequate professional training.

The diagnostic delays encountered by parents reflect systemic gaps in healthcare. Without standardized screening procedures, families depend on trial-and-error consultations, often receiving inaccurate information.

Social stigma remains a dominant theme. Parents avoid public spaces to avoid criticism or misunderstanding. Mothers, as primary caregivers, bear a disproportionate emotional burden. However, fathers in this study also reported fear, confusion, and pressure to "fix" the situation.

Despite these challenges, parents demonstrate significant resilience. Religious beliefs act as powerful coping mechanisms. Many parents reinterpret their experiences as spiritual growth or divine purpose. This cultural dimension is crucial in understanding Pakistani families.

The shift from grief to acceptance is consistent with global findings on parental adaptation. Over time, families restructure their routines, adopt new strategies, and advocate for their children's rights and inclusion.

Implications

The study suggests several implications for policy, practice, and research:

For Healthcare System:
- Develop early screening programs
- Train pediatricians in ASD recognition
- Increase availability of speech and behavioral therapists

For Schools:
- Implement inclusive education practices
- Train teachers to manage ASD-specific needs
- Provide shadow teachers and classroom accommodations

For Government and NGOs:
- Create awareness campaigns
- Establish parent support groups
- Offer financial subsidies for ASD therapy

For Families:
- Promote home-based interventions
- Encourage shared caregiving roles
- Strengthen emotional support networks

Limitations

The small sample size and focus on a single geographical region limit generalizability. The study relied on self-reported data, which may involve emotional or recall bias. Fathers were under-represented, reflecting cultural norms around caregiving.

Recommendations

Future research should:
- Include larger, more diverse samples across Pakistan
- Investigate fathers' experiences in depth
- Examine teachers' perspectives on ASD
- Explore long-term impact on family functioning
- Develop culturally adapted intervention models

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