

LIVED EXPERIENCES OF MOTHERS RAISING CHILDREN WITH AUTISM SPECTRUM DISORDER IN PESHAWAR: A QUALITATIVE STUDY

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Abstract

Background of the study: Autism Spectrum Disorder (ASD) is a complex neurodevelopmental disorder characterized by persistent deficits in social communication and social interaction, accompanied by restricted, repetitive patterns of behavior, interests, or activities.

Objective: To explore the lived experiences of mothers raising children with ASD in Peshawar.

Materials & Methods: A qualitative descriptive phenomenological study was conducted among 14 mothers of children with (ASD) in Peshawar using purposive sampling. Data were collected through semi-structured interviews and analyzed using Braun and Clarke's six-step thematic analysis.

Results: Five major themes emerged: emotional journey after diagnosis, daily caregiving challenges, psychological and social impact, coping strategies, and future concerns. Mothers experienced emotional distress and caregiving burden but demonstrated resilience through family support, faith, and hope for their children's future.

Conclusion: Mothers raising children with ASD experience complex challenges but adapt through acceptance, resilience, and support systems. Strengthening family-centered care, autism awareness, and accessible rehabilitation services is essential to improve outcomes for both mothers and children.

Introduction

Autism Spectrum Disorder (ASD) is a complex neurodevelopmental disorder characterized by persistent deficits in social communication and social interaction, accompanied by restricted, repetitive patterns of behavior, interests, or activities. The condition usually manifests during early childhood and affects multiple aspects of cognitive, emotional, and behavioral development. The severity and presentation of ASD vary considerably among children, making it

a spectrum disorder that requires individualized care and intervention (1,2).

In recent years, the global prevalence of ASD has increased because of improved awareness, enhanced diagnostic criteria, and better screening practices. The World Health Organization estimates that approximately one in every 100 children is diagnosed with ASD worldwide, highlighting its growing public health significance (3).

Mothers are often the primary caregivers of children with ASD and play a central role in managing their children's daily activities, healthcare, education, and emotional well-being. Caring for a child with ASD requires continuous supervision, behavioral management, therapy attendance, and advocacy for educational and healthcare services. These responsibilities frequently place considerable emotional, physical, social, and financial demands on mothers, resulting in increased caregiver stress and reduced quality of life (4).

Many mothers experience anxiety, depression, caregiver burden, and social isolation while simultaneously striving to provide the best possible care for their children. Despite these challenges, they often develop resilience, adaptive coping strategies, and a strong commitment to supporting their children's development and independence (5).

In Pakistan, awareness and understanding of ASD remain limited, and misconceptions regarding developmental disorders continue to influence community attitudes. Many families face delayed diagnosis due to inadequate awareness among caregivers and healthcare providers, limited availability of specialized diagnostic services, and insufficient trained professionals. Furthermore, mothers often encounter financial hardship, social stigma, and limited access to evidence-based interventions such as speech therapy, occupational therapy, behavioral therapy, and special education services (6).

Cultural beliefs, religious perceptions, and family expectations further shape mothers' caregiving experiences, particularly in conservative communities where developmental disabilities are frequently misunderstood. These sociocultural factors often affect healthcare-seeking behaviors, acceptance of the diagnosis, and the utilization of rehabilitation services (7).

Peshawar, the capital city of Khyber Pakhtunkhwa, serves as a major healthcare and educational center for the province. Although several public and private institutions provide developmental and rehabilitation services for children with ASD, many families continue to experience barriers related to accessibility, affordability,

transportation, and long waiting periods for specialized care. Mothers frequently become the primary coordinators of their children's medical consultations, therapy sessions, educational planning, and home-based behavioral interventions, placing substantial demands on their physical and psychological well-being (8).

Qualitative research provides an appropriate approach for exploring the lived experiences of mothers because it enables participants to describe their personal journeys, emotions, challenges, and coping strategies in their own words. Unlike quantitative studies, qualitative inquiry seeks to understand the meanings individuals assign to their experiences within their social and cultural contexts, thereby generating a rich understanding of complex human experiences (9).

Although numerous international studies have explored parental experiences of raising children with ASD, qualitative evidence from Pakistan, particularly from Peshawar and Khyber Pakhtunkhwa, remains limited. Most local research focuses on prevalence, awareness, or clinical characteristics rather than the everyday experiences of mothers. Therefore, this study aims to explore the lived experiences of mothers raising children with Autism Spectrum Disorder in Peshawar. The findings are expected to contribute to nursing knowledge, guide policymakers and healthcare professionals, strengthen family-centered autism services, and support the development of culturally sensitive interventions that improve the well-being of mothers and their children (10).

Methodology

Research Design

This study employs a qualitative research design using a descriptive phenomenological approach to explore the lived experiences of mothers raising children with Autism Spectrum Disorder (ASD) in Peshawar.

Study Setting

The study is conducted in Peshawar, the capital city of Khyber Pakhtunkhwa, Pakistan. Participants are recruited from public and private hospitals, autism rehabilitation centers,

developmental pediatric clinics, speech therapy centers, occupational therapy clinics, and special education institutions that provide diagnostic and rehabilitation services for children with Autism Spectrum Disorder.

Study Population

The study population consists of mothers who are the primary caregivers of children diagnosed with Autism Spectrum Disorder. Participants are selected because they have firsthand experience of caring for a child with ASD and are able to provide detailed descriptions of their daily caregiving experiences, emotional responses, and coping mechanisms.

Sampling Technique

Purposive sampling is used to recruit information-rich participants who possess direct experience with the phenomenon of interest. This non-probability sampling technique is commonly used in qualitative research because it enables the selection of participants who can provide comprehensive and meaningful information related to the research objectives (11).

Sample Size

The sample size is determined based on the principle of **data saturation**, which is achieved when additional interviews no longer generate new information or themes. Total of 14 mothers were interviewed (12).

Inclusion Criteria

Participants must meet the following criteria:

- Mothers aged 18 years or older.
- Mothers who are the primary caregivers of a child diagnosed with Autism Spectrum Disorder by a qualified developmental pediatrician, pediatric neurologist, or psychiatrist.
- Children aged between 3 and 12 years.
- Mothers providing care for at least one year after the child's diagnosis.
- Mothers able to communicate in Urdu, Pashto, or English.
- Mothers willing to provide written informed consent.

Exclusion Criteria

The following participants are excluded from the study:

- Mothers diagnosed with severe psychiatric illness that may affect communication or participation.
- Mothers whose children have multiple severe disabilities unrelated to ASD.
- Mothers who are seriously ill or unable to participate in an in-depth interview.
- Mothers unwilling to participate or provide informed consent.

Data Collection Instrument

Data are collected using a **semi-structured interview guide** developed after an extensive review of the literature and consultation with experts in qualitative research, pediatric nursing, and child psychology. The interview guide contains open-ended questions that encourage participants to describe their experiences freely. The interview guide is pilot-tested with two mothers to assess clarity, relevance, and comprehensibility. The pilot interviews are not included in the final analysis.

Data Collection Procedure

Following approval from the Institutional Review Board (IRB) and administrative permission from participating healthcare facilities and rehabilitation centers, eligible participants are identified with the assistance of healthcare professionals.

The researcher explains the purpose of the study, confidentiality measures, voluntary participation, and participants' rights before obtaining written informed consent. Individual face-to-face, in-depth interviews are conducted in a private room within the healthcare facility or another location preferred by the participant.

Interviews are conducted in Urdu or Pashto according to the participant's preference and last approximately **40–60 minutes**. With participants' permission, all interviews are audio-recorded to ensure accuracy. The researcher also maintains field notes documenting participants' non-verbal expressions, emotional reactions, environmental context, and personal reflections.

The audio recordings are transcribed verbatim in the original language and translated into English when necessary. Translation accuracy is ensured through back-translation and review by bilingual language experts.

Data Analysis

The collected data are analyzed using **Braun and Clarke's six-step thematic analysis**, a widely accepted approach for qualitative research (13). The analysis includes:

1. Familiarization with the data through repeated reading of transcripts.
2. Generation of initial codes from meaningful statements.
3. Searching for potential themes.
4. Reviewing and refining emerging themes.
5. Defining and naming themes.
6. Producing the final report supported by participants' quotations.

Coding is performed manually, and similar codes are grouped into categories before developing broader themes that accurately represent mothers' lived experiences.

Trustworthiness

The rigor of the study is ensured by applying **Lincoln and Guba's four criteria of trustworthiness** (6).

Credibility: Credibility is established through prolonged engagement with participants, member checking, peer debriefing, and maintaining detailed field notes throughout data collection.

Transferability: Thick descriptions of the research setting, participants, and findings are provided to enable readers to determine the applicability of the results to similar contexts.

Dependability: An audit trail documenting methodological decisions, interview procedures, coding processes, and analytical decisions is maintained to ensure consistency and transparency.

Confirmability: Researcher bias is minimized through reflexive journaling, bracketing of

personal assumptions, and review of coding and themes by an experienced qualitative researcher.

Ethical Considerations

Ethical approval is obtained from the Institutional Review Board (IRB) of the respective university before the commencement of data collection. Permission is also obtained from the administrators of participating hospitals, autism centers, and rehabilitation facilities.

Participation is entirely voluntary, and written informed consent is obtained from each participant before the interview. Participants are informed that they may withdraw from the study at any stage without any consequences. Confidentiality and anonymity are maintained by assigning identification codes instead of participants' names. Audio recordings, interview transcripts, and study documents are stored in password-protected electronic files accessible only to the research team.

Because discussing caregiving experiences may evoke emotional distress, interviews are conducted with empathy and sensitivity. Participants who experience significant emotional discomfort are referred to appropriate counseling services if required. The study adheres to the ethical principles of **respect for persons, beneficence, non-maleficence, and justice** throughout the research process.

Results

Participant Characteristics

A total of **14 mothers** participated in this qualitative study. The participants' ages ranged from **25 to 45 years**. Most mothers were housewives, while a few were engaged in home-based work or part-time employment. The age of children diagnosed with Autism Spectrum Disorder ranged from **3 to 10 years**. The duration since diagnosis varied from **1 to 7 years**. Most children were receiving multiple interventions, including speech therapy, behavioral therapy, occupational therapy, and special education services.

The analysis of mothers' narratives generated **five major themes** with several subthemes. The themes reflected mothers' emotional responses after

diagnosis, challenges of caregiving, social experiences, coping strategies, and hopes for their children's future.

Overview of Themes

Main Themes	Subthemes
Theme 1: Emotional Journey After Diagnosis	Shock and disbelief; acceptance and adjustment
Theme 2: Living with Daily Caregiving Challenges	Communication difficulties; behavioral management; continuous supervision
Theme 3: Psychological and Social Impact	Emotional exhaustion; stigma and social isolation
Theme 4: Seeking Support and Coping Strategies	Family support; faith and resilience
Theme 5: Expectations and Future Concerns	Education, independence, and uncertainty about the future

Main Themes	Subthemes
 1. Emotional Journey After Diagnosis	• Shock and disbelief • Acceptance and adjustment
 2. Living with Daily Caregiving Challenges	• Communication difficulties • Behavioral management • Continuous supervision
 3. Psychological and Social Impact	• Emotional exhaustion • Stigma and social isolation
 4. Seeking Support and Coping Strategies	• Family support • Faith and resilience
 5. Expectations and Future Concerns	• Education, independence • Uncertainty about the future

Theme 1: Emotional Journey After Diagnosis

Subtheme 1.1: Shock, Fear, and Uncertainty

Most mothers described the period following their child's diagnosis as emotionally overwhelming. Receiving the diagnosis of ASD was reported as a life-changing event associated with sadness, confusion, fear, and uncertainty about the child's future. Many mothers expressed that they initially lacked knowledge about autism and struggled to understand their child's condition.

One participant stated:

“When the doctor told me that my child has autism, I felt that my whole world stopped. I did not know what autism was and I was worried about

whether my child would ever speak or become independent.”(Mother 3)

Mothers explained that the absence of clear information about ASD increased their anxiety. Some participants reported searching for information independently and seeking guidance from healthcare professionals and other parents.

Subtheme 1.2: Gradual Acceptance and Adaptation

Over time, mothers described developing acceptance of their child's condition. They reported that understanding ASD and learning caregiving skills helped them adjust emotionally.

A mother explained:

“At first, I cried every day, but gradually I learned that my child needs my support. I started focusing on his abilities instead of only thinking about his problems.” (Mother 7)

Acceptance was described as a gradual process involving education, experience, and emotional adjustment.

Theme 2: Living with Daily Caregiving Challenges

Subtheme 2.1: Communication and Behavioral Difficulties

Mothers frequently identified communication problems as one of the most challenging aspects of raising a child with ASD. Many children had difficulty expressing needs, understanding instructions, or interacting socially.

One participant shared:

“The hardest thing is when my child cannot explain what he wants. Sometimes he cries or becomes aggressive because he cannot communicate.” (Mother 5)

Behavioral issues such as repetitive behaviors, tantrums, and difficulty adapting to changes were also described as challenging.

Subtheme 2.2: Constant Supervision and Care Responsibilities

Mothers reported that caring for a child with ASD required continuous attention and supervision. They described difficulties balancing household responsibilities, personal needs, and caregiving duties.

A participant stated:

“I have to watch him all the time. Even when I am tired, I cannot relax because he needs my attention.” (Mother 9)

Many mothers reported reduced personal time and difficulty maintaining social relationships due to caregiving responsibilities.

Theme 3: Psychological and Social Impact

Subtheme 3.1: Emotional Exhaustion and Stress

Participants frequently described experiencing emotional fatigue, worry, and stress related to their child's condition. Concerns about treatment progress and future independence contributed to psychological burden.

One mother expressed:

“Sometimes I feel very tired emotionally because I keep thinking about my child's future and what will happen when I am not there.” (Mother 11)

Some mothers reported feelings of sadness and helplessness, particularly during periods when progress was slow.

Subtheme 3.2: Social Stigma and Isolation

Mothers described experiencing negative attitudes and misunderstanding from relatives and community members. Some participants reported that people blamed parenting practices or held misconceptions about autism.

A mother stated:

“Some people say that my child behaves this way because of poor upbringing. These comments hurt me because they do not understand autism.” (Mother 6)

Due to stigma and fear of judgment, some mothers reduced social interactions and avoided public gatherings.

Theme 4: Seeking Support and Coping Strategies

Subtheme 4.1: Role of Family Support

Family support was identified as an important factor helping mothers manage caregiving responsibilities. Emotional encouragement from husbands, grandparents, and siblings helped mothers cope with challenges.

One participant shared:

“When my family supports me and helps with my child, I feel stronger and less alone.” (Mother 2)

However, some mothers reported limited support due to lack of awareness among family members.

Subtheme 4.2: Faith, Hope, and Personal Strength

Many mothers described religious beliefs and personal determination as important sources of strength. Faith helped them develop patience and maintain hope for their child's improvement.

A participant stated:

“My faith gives me strength. I believe my child has a purpose, and I try my best to help him.” (Mother 10)

Theme 5: Expectations and Future Concerns

Subtheme 5.1: Desire for Better Educational and Healthcare Services

Mothers expressed concerns regarding limited autism services, expensive therapies, and shortage of trained professionals. They emphasized the need for accessible rehabilitation and educational opportunities.

One mother explained:

“Therapy is very expensive, and sometimes there are not enough trained people. We need more facilities for children like ours.”(Mother 4)

Subtheme 5.2: Hope for Independence and Acceptance

Despite challenges, mothers expressed hope that their children would achieve greater independence and acceptance in society.

A participant stated:

“My biggest wish is that my child can live independently and people accept him as a normal member of society.” (Mother 12)

Summary of Findings

The findings demonstrate that mothers raising children with ASD experience a complex emotional and social journey. They initially face shock, fear, and uncertainty after diagnosis but gradually develop acceptance and coping strategies. Daily caregiving responsibilities, communication difficulties, social stigma, and limited healthcare resources contribute to significant challenges. However, family support, faith, resilience, and hope for their children's future help mothers continue their caregiving journey.

The findings highlight the importance of family-centered nursing care, improved autism awareness programs, accessible rehabilitation services, and psychosocial support for mothers of children with ASD in Peshawar and similar cultural contexts.

Discussion

This qualitative study explores the lived experiences of mothers raising children with (ASD) in Peshawar. The findings reveal that mothers experience a complex journey characterized by emotional distress following diagnosis, challenges associated with daily

caregiving, psychological and social difficulties, coping mechanisms, and concerns regarding their children's future. The study generates five major themes: emotional journey after diagnosis, daily caregiving challenges, psychological and social impact, coping strategies and support systems, and future expectations for children with ASD. These findings highlight the multidimensional challenges experienced by mothers and emphasize the need for family-centered and culturally sensitive autism care services.

Emotional Experiences After ASD Diagnosis

The present study demonstrates that mothers initially experience shock, fear, sadness, and uncertainty after receiving an ASD diagnosis for their child. Many mothers report difficulty understanding autism and express concerns regarding their child's future development and independence. However, over time, mothers gradually develop acceptance and adapt to their caregiving roles.

These findings are consistent with previous international studies reporting that parents often experience grief-like emotional reactions following an autism diagnosis, including denial, sadness, guilt, and fear about the child's future. Karst and Van Hecke explain that receiving an ASD diagnosis significantly affects family functioning because parents must adjust their expectations and develop new caregiving strategies (15). Similarly, Osborne and Reed report that parents frequently experience emotional distress due to uncertainty regarding their child's development and long-term outcomes (16).

The emotional journey identified in the current study is also comparable with findings from Pakistan. Imran et al. highlight that Pakistani families often experience confusion and emotional distress after an ASD diagnosis because of limited awareness and insufficient information regarding developmental disorders (17). The similarity between current and previous findings suggests that emotional adjustment following diagnosis is a universal experience among mothers of children with ASD, although cultural factors may influence how mothers express and manage these emotions.

Challenges of Daily Caregiving Responsibilities

The current study identifies daily caregiving responsibilities as a major challenge for mothers. Participants describe difficulties related to communication problems, behavioral issues, continuous supervision, and managing therapy appointments. Mothers report that caring for a child with ASD requires constant attention and affects their personal time, household responsibilities, and social activities.

These findings are supported by Hayes and Watson, who report that parents of children with ASD experience significantly higher levels of parenting stress compared with parents of typically developing children. The continuous behavioral management requirements and increased caregiving demands contribute to emotional and physical exhaustion among caregivers (18).

A study conducted in Saudi Arabia also reports similar findings, showing that mothers experience substantial challenges related to children's behavioral problems, dependence, and therapy requirements (19). Likewise, research from India indicates that mothers of children with ASD frequently experience disruption in daily routines due to the child's special care needs (20).

In the Pakistani context, these challenges may be intensified because of limited rehabilitation facilities and shortage of trained autism professionals. Samadi and McConkey emphasize that families in developing countries often face greater difficulties accessing autism-related services due to economic limitations, insufficient healthcare infrastructure, and lack of community-based support programs (21). Therefore, improving accessibility and affordability of autism services is essential for reducing caregiver burden.

Psychological and Social Impact on Mothers

The present study reveals that mothers experience emotional exhaustion, stress, anxiety, and social isolation while caring for children with ASD. Participants describe feelings of worry regarding their children's future and report experiencing misunderstanding and negative attitudes from society.

These findings are consistent with international evidence. Bonis reports that parents of children

with ASD frequently experience psychological stress, reduced social participation, and emotional fatigue due to continuous caregiving demands (22). Similarly, Ludlow et al. identify social isolation and reduced quality of life among mothers because of difficulties managing children's behaviors in public settings and fear of social judgment (23).

The current findings are particularly relevant in Pakistani society, where misconceptions about developmental disorders may contribute to stigma. Families may face blame, shame, or misunderstanding from relatives and community members. A Pakistani study by Anwar et al. reports that stigma and lack of awareness negatively influence families' acceptance of ASD and their willingness to seek professional support (24). Therefore, community awareness programs are necessary to improve understanding and acceptance of children with ASD.

Coping Strategies and Sources of Support

The current study highlights family support, religious beliefs, and personal resilience as important coping mechanisms among mothers. Participants explain that emotional support from husbands, relatives, and healthcare providers helps them manage caregiving challenges. Faith and hope also provide psychological strength.

Previous studies support these findings. Almansour et al. report that social support plays a protective role by reducing stress and improving coping among mothers of children with ASD (5). Similarly, Bekhet et al. demonstrate that optimism, spirituality, and positive coping strategies are associated with improved psychological adjustment among caregivers (25).

However, the current study also identifies variations in family support. Some mothers experience inadequate assistance due to limited understanding of autism among family members. This finding reflects the importance of educating not only mothers but also extended family members regarding ASD and caregiving needs.

Future Expectations and Need for Services

The mothers in this study express concerns regarding their children's education,

independence, and long-term future. Participants emphasize the need for affordable therapy services, trained professionals, inclusive education, and community acceptance.

These findings align with previous research indicating that parents of children with ASD frequently worry about their child's ability to communicate, work, and live independently in adulthood (12). In developing countries, these concerns are often intensified due to limited social welfare systems and inadequate long-term support services.

The findings emphasize the important role of nurses and healthcare professionals in providing education, emotional support, early intervention guidance, and referral services. Nurses can serve as advocates for families by improving awareness, facilitating access to services, and promoting family-centered autism care.

Implications for Nursing Practice

The findings of this study have important implications for nursing education, practice, and research. Nurses working in pediatric and community settings should recognize the emotional and social challenges faced by mothers of children with ASD. Providing counseling, caregiver education, support groups, and appropriate referrals can help reduce caregiver burden.

Healthcare institutions should develop multidisciplinary autism programs involving nurses, physicians, psychologists, speech therapists, occupational therapists, and special educators. Community-based awareness programs are also required to reduce stigma and promote acceptance of children with ASD.

Conclusion

The present study demonstrates that mothers raising children with ASD in Peshawar experience significant emotional, social, and caregiving challenges. Although mothers face stress, uncertainty, and social barriers, they demonstrate resilience through acceptance, family support, faith, and commitment toward their children. Comparison with national and international literature indicates that many experiences are

universal; however, limited resources, cultural beliefs, and social stigma create additional challenges in the Pakistani context. Strengthening autism services, improving awareness, and providing psychosocial support are essential to improving the quality of life of mothers and children with ASD.

Authors Contribution

Introduction: S F

Methodology: TA

Formal analysis: ZA

Discussion: MI

Writing review and editing: HA

All authors have read and agreed to the published version of the manuscript.

Conflicts of Interest

The authors declare no conflict of interest.

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