



RAISING AN AUTISTIC CHILD: A PHENOMENOLOGICAL STUDY OF PAKISTANI MOTHERS

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Abstract

Parenting a kid with autism spectrum disorder (ASD) is a complex set of challenges for women, including concerns about behavioral and mental issues, and social stigma. The prevalence of ASD is widespread in Pakistan and its management is mostly overlooked. This phenomenological study seeks to investigate and comprehend the daily life experiences of mothers raising children with Autism Spectrum Disorder (ASD). The data is collected using semi-structured interviews. The sample size (N=10) is determined by achieving of saturation. The finding highlight four main themes, includes, Pre-Diagnosis Concerns, Reaction after Diagnosis, Challenges of Parenting, and Positive Aspect of Pakistani Culture. The theme of Pre-Diagnosis Concerns encompasses three distinct subthemes consisting of Pre-Diagnosis Maternal Recognition, Behavioral Observations and Knowledge Gaps. This theme explores the interplay between maternal instincts, observable behaviors of child with ASD, and the gaps in understanding the diagnosis process, offering valuable insights into early detection and intervention strategies. The second theme "Reaction towards Diagnosis" includes subthemes of Delay in Diagnosis, Reaction to Diagnosis and Hunting for Management Assistance. This aspect explains the reactions and behaviors of parental of children with ASD engage in after receiving a diagnosis, illuminating the proactive, emotional, and temporal aspects of the diagnostic process. The third theme "Challenges of Parenting" includes Sacrifices and Struggles of Mothers, Financial Strain, Treatment Services, Social Stigma, Rejection from Family, Treatment services, and Positive Aspect of Pakistani Culture. This theme describes the range of obstacles encountered by parents of child with ASD. The forth theme "Positive Aspect of Pakistani Culture" include subthemes

of Support from family members and Support from Spouse. This highlights deeply embedded Pakistani society norms and shed light on the strong networks of family and spouse that is a great support and encourage resiliency and unity in the face of adversity. Pakistani mothers who have children with ASD experience a variety of problems, including physical, psychological, emotional, and social difficulties, as well as a lack of specialist resources. Identifying their specific issues and requirements is critical for assisting them, providing appropriate services and resources, and developing rules and guidelines for culturally competent quality services.

Key words: Autism, Parenting, Challenges, Diagnosis, Treatment, Behavioral issues

Introduction

Caregivers face challenging circumstances while raising a child with autism spectrum disorder (ASD). Impairments in social communication and unique patterns of restricted and repetitive behavior, interests, and activities are the hallmarks of this complicated neurodevelopmental condition. (American Psychiatric Association, 2018). Parents of children with ASD may face significant challenges because these children often struggle with communication and use emotional expressions like crying or yelling to express their needs (DePape & Lindsay, 2015). Caregiving responsibilities can be quite demanding, especially for mothers who are typically the sole caretaker (Miranda et al., 2019).

World Health Organization (WHO, 2019) revealed that the prevalence of Autism Spectrum Disorder (ASD) has increased globally. A study by Baio and colleagues (2018) found that one out of every 59 children in the United States had ASD, whereas the total prevalence in Europe, Asia and North America ranges from one to two percent (Baio et al., 2018).

Even though a few studies have been undertaken in Pakistan to investigate the occurrence, prevalence, and age at diagnosis of ASD, the true prevalence of Autism Spectrum Disorder in Pakistan remains unknown. Rasheed and Ahmed (2019) conducted a systematic review and determined an approximate prevalence of 0.29% to 1.28%. In 2021 Maqbool and his colleagues studies the prevalence of ASD in Pakistan and reported as 1 in 89 children are having ASD. This impairment creates major challenges for individuals with ASD and their families, notably in terms of early identification, access to appropriate services, and societal acceptability. Despite this high prevalence, a notable dearth of research exists on the management and challenges, face by the caregivers of children with ASD.

The individual characteristics and background cultural influence the responses of an individual to challenges (Lee & Fong, 2018). For example, in the Muslim faith, acceptance at times of crisis is associated with obedience and submission to God (Achour et al., 2016). In a comparable manner Pakistani culture is paternalistic, with men expected to provide for their families and women to nurture and care for their children (National Council for Family, 2018) and this household dynamic accepts that mothers will handle prolonged conditions too. With such a background, females can develop heightened physical tiredness as a result of continuing attention for the sick, nursing children, and performing domestic chores. Working women may feel additional stress in their role as mother, even if the proportion of working women in Pakistan is small.

(International Labour Office, 2018).

Understanding the experiences of families, particularly mothers, is crucial to enhance appropriate services, upturn the availability of these services, and subsequently lessen challenges while enhancing their mental health and comfort (Dardas & Ahmad, 2014; Samadi & Mcconkey, 2014). Similarly, ASD carries a stigma, possibly contributing to delayed healthcare seeking. Hence, studying the issues and demands of Pakistani women caring for children with ASD, including their physiological, psychological, interpersonal, and economic strain is critical for supporting suitable and effective interventions.

This study aims to explore the diverse experiences of mothers, rearing a child with ASD, and to provide insight into the difficulties they face. In addition, the research aims to identify service shortages to empower families, and contribute to the improvement of care practices. A phenomenological approach can be particularly useful in this context, as it allows for an in-depth exploration of the lived experiences of parents and the ways in which they navigate the challenges of parenting a child with ASD (Van Manen, 2016). By employing a phenomenological approach to understanding the experiences of parents of children with ASD in Pakistan, this study aims to make visible the often-invisible experiences of this population and shed light on the ways in which they navigate the challenges of parenting a child with ASD in a Pakistani context.

Research Question

The study aims to address the following research questions:

- 1.How do parents of children with ASD in Pakistan describe their experiences?
- 2.What practices are useful for parents of children with ASD in managing parenting challenges?

Method

Design and Setting

In order to understand more about the struggles and everyday experiences that mothers of children with autism spectrum disorder (ASD) face, the phenomenological approach is used. The rationale behind choosing this approach is its capacity to gather genuine stories and analyze the struggles of mothers encounter. In addition, it provides information about the psychological reactions the parent has when their child is diagnosed with this condition (Gona et al., 2016).

Sample

The simple size for current study is ten (10) which is determined by achieving saturation. The mothers caring their children with ASD were interviewed. A special institute offering services for ASD is targeted and convenient sampling is used to recruit these participants. Inclusion criteria consisted of Pakistani mothers having a child diagnosed with ASD and the age children at time of diagnosis should be two to four years, with a mean age of 2.5 years.

Table 1 shows the age range of sample which is 33 to 39 years. Income of participants ranges from twenty-eight thousand to fifteen lac with average on 2 lakh. The level of education is from intermediate to Masters and three of the participants are with professional degree. Two parents are having only child and maximum number of children are 4. The maximum age of child with ASD is ten and minimum is four years and eleven months. Only one mother is working whereas nine mothers are hose wives.

Table 1 Demographic Characteristics of Sample (N= 10)

Initials	Age	Income	Edu	TC	CA	ES
1	35	3.5 lakh	Masters	2	6.4	no
2	38	5 lakh	Masters	3	6	no
3	38	2 lakh	M Phil	3	8	no
4	37	2.5 lakh	MS	1	6.10	no
5	33	2 lakh	MS	4	5.2	no
6	39	28 K	F. A	3	8	no
7	35	1.5 lakh	MBBS	3	8	no
8	39	1 lakh	MBBS	2	10	no
9	35	15 lakh	Pharm D	1	4.11	yes
10	38	3 lakh	Masters	2	6	no

Note: ES= employment status, TC=total children, CA=child age,

Interview Guide

Before data collection an interview guide was finalized and modified on the bases of pilot study. The initial few questions were clarified and rephrased which was causing potential misunderstanding. The guide contains demographic questions, and open-ended questions (Appendix 1)

Procedure

The study participants are scrutiny identified from the group of mothers caring their child with AS. A customized educational plan was given to each participant for one month to be followed at home as an Incentive. Informed consents were obtained from the participants. Data is collected using semi structured interview. All the interviews were conducted in Urdu and English, whatever language is convenient for participants. Each interview lasted for an average of 35 minutes. The procedure of gathering data came to an end after saturation was attained and no additional information was revealed during the interviews.

The participants were asked the main open-ended question, “Please share your thoughts when you first time get to know about your child’s illness.” Follow-up questions were asked for further elaborations if needed.

To protect participant privacy and confidentiality, all audio recordings from the interviews were tagged and fully transcribed in Roman English. For the participants' privacy protection, pseudonyms were supplied. Pseudonyms were employed for all documentation, and the participant's identity was only known by the researchers. Following Roman English transcription, the materials were kept on a password-protected Mac book.

Results

The results are formulated by performing thematic analysis, after reading the transcripts several times to become acquainted with their contents (Nowell et al., 2017). Each interview's complete transcript was coded and organized into digestible sections. Descriptive codes were applied to the relevant units in order to distinguish themes, categories, and keywords. Following a comparison of the variations and similarities between the codes, they were grouped into themes and groups. Following an analysis of each category, the study team further divided the contents of each category into more distinct descriptive subcategories. Two researchers, unaffiliated with the data gathering procedure, were consulted to evaluate the themes and data in order to guarantee the thoroughness, reliability, and objectivity of the analytic process.

The perspective of Pakistani mothers parenting an autistic child were distilled into three main themes and ten subthemes (Table 3). The three primary themes are: (1) the mother's experience with the diagnosis and the first steps toward management; (2) the mother's obligations; and (3) the benefits and drawbacks of raising a kid with ASD. Our study revealed subthemes that fell under each main theme.

Table 2 Themes generated

Themes	Subthemes
Pre-Diagnosis Concerns	Pre-Diagnosis Maternal Recognition Behavioral Observations Knowledge Gaps
Reaction towards Diagnosis	Delay in Diagnosis Reaction to Diagnosis Hunting for Management Assistance
Challenges of Parenting	Sacrifices and Struggles of Mothers Financial Strain Treatment Services Social Stigma Rejection from Family Treatment services
Positive Aspect of Pakistani Culture.	Support from family members Support from Spouse

Theme 1: Maternal Awareness and Response to Pre-Diagnosis Concerns

The first theme that surfaced revolves around the maternal journey during the diagnosis of Autism Spectrum Disorder (ASD). Within this theme, three distinct subthemes reveal: Pre-Diagnosis Maternal Recognition, Behavioral Observations, and Knowledge Gaps.

Pre-Diagnosis Maternal Recognition: Mothers exhibited a heightened sense of concern regarding their child's development even before receiving an ASD diagnosis. They keenly observed various behaviors and patterns that seemed unusual, including compromised social interaction, repetitive movements such as hand flapping, and isolation from social settings. Some mothers initially attributed these concerns to potential hearing problems, believing that speech delays could be resolved over time, drawing from their own experiences or family history. Despite their observations, many lacked awareness of primary symptoms of autism, leading to delays in seeking professional help.

Behavioral Observations: Mothers delineated specific behavioral indicators that prompted their concern, ranging from repetitive actions like flapping hands to atypical patterns of engagement such as fixating on curtains or exhibiting avoidance behaviors like not responding to their name. One mother said

“I noticed Flapping hands, looking at patterns or designs on curtains, toe walking, jumping in excitement, not responding to name, and not calling mama”.

Some mothers also noted instances of regression in their child's development, citing changes in speech, social interaction, and eating habits. One mother narrates sharing her experience *“he regressed in 6 months slowly and gradually, he forgets to talk, starting isolating, he used to stay quiet, he wasn't responding to his name, avoid eye contact, he used to show tantrums and he stop meeting people, he made patterns of eating, attachment with spoons and one plate.”*

These observations contributed to a growing sense of unease and prompted mothers to seek assistance from healthcare providers.

Knowledge Gaps: Despite their instincts and observations, mothers acknowledged a lack of familiarity with the primary symptoms of autism prior to seeking professional guidance. Even a mother with a medical background admitted to limited awareness of autism symptoms, underscoring the pervasive knowledge gap in recognizing developmental disorders. She reported,

“I was aware of autism word as we heard it in medical school, but I didn't exactly know the symptoms. I consulted doctors because I know that something is wrong with her.”

Nevertheless, maternal instincts prompted them to seek medical consultation, driven by an intuitive sense that something was amiss with their child's development.

Theme 2: Diagnosis and Initiation Response and Treatment

The second theme that is developed from the data was challenges of diagnosis and step towards management. It is further consist of subthemes of; Delay in Diagnosis, Reaction to Diagnosis and Hunting for Management Assistance

Delay in Diagnosis: The participants saw unusual behaviors and developmental delays in particular areas of their children, but they did not immediately link them to autism. As a result, they postponed seeking medical assistance for their kids. A mother expressed, *“Initially Autism was new term for me and I didn't know anything about it not even a single word but gradually with passage of time I understand the problem in my kid and start thinking about the management ways.”*

The suspension in seeking assistance was not solely attributed to parental lack of knowledge; rather, in certain instances, healthcare providers contributed to delays in diagnosis. The participants reported that medical professionals did not validate parental concerns and gave false reassurance. As a result of parental and health care providers' lack of awareness, diagnosis was delayed, which was leading to a suspension in treatment starting up. For instance, one mother said, *“when his speech was delay I*

used to visit a doctor on my mother recommendation assuming that the medicine prescribed by the doctor may help my child in speaking, he took medicine for one year but no progress.”

Another participant shared her experience regarding poor diagnosis from the doctors like this *“I went to Doctor with complain of developmental delay but he does not diagnose him as ASD”*

So the lack of awareness of parents as well as mothers caused delay in diagnosis.

Reaction to the Diagnosis: The participants described their reaction to the diagnosis as feelings of sorrow, sadness, shock, silence, crying, denial, guilt, and fear. Some mothers also were shocked and cried profusely the first time they heard about the diagnosis. Two mothers reported that they reacted with continuous denial on confirmation of the diagnosis. Some mothers blamed themselves, some of them reported shock and denial and sometimes others:

“I was in great shock it took me few weeks to get to my normal routine because I didn’t understand that how I am gonna cope up, I came to home and then I search about autism. I start reading about Autism, I asked doctors about Autism, I was not convinced initially because of lack of knowledge.”

Another participant reported, *“When I came to know that my child is with ASD and it is a developmental delay which is effecting his speech and social behavior. It was depressive and hard to believe. This news took me into depression almost probably 2 months or more I wasn’t in my normal state”*

Another participant reported guilt feelings and said *“for the first time I was just crying, it was a horrible feeling, I start blaming myself that it’s my negligence”*

Some of participants reported feelings of guilt as they believe, ASD is caused because of their carelessness for instance they expose their children to screen for long hours. One participant reported, *“I felt guilty and blamed myself because I left him at my mother’s place because I have to go to university”*. Another mother said, *“His screen time was excessive and I think it might be one of the factor of his diagnosis, maybe I did that thing wrong.”*

Hunting for Management Assistance: Another subtheme is emerged the mothers wish to provide best treatment and management to their child. Having a child with ASD developed a state of uncertainty among mothers about their child’s mental, physical and social health. They speculated if this condition is curable or manageable. This was evident in their quotes; for instance, one said, *“I wanted to do best for him at that time and my major concern was to find the best center for therapy and start his management.”* Another participant reported

“My son was suffering in speaking delay but I admitted him in school, but he was expelled from school saying that he will not get any benefit from here and he was disturbing our whole class. Then I start searching for some doctors and visits many doctors. One doctor from PIMS diagnosed him ASD and I was now concerned for proper management and treatment for my child”.

These mothers were worried about the treatment of their child and was looking for the best services. They were hopeful too at the same time and talked about the rewards they gain while bringing up a child with ASD. They are now more enduring, and goal oriented and having meaningful life.

Most of mothers reported that they got a diagnosis of child at age of 2 to 3 years maximum. One of mother even reported that “I got screened her at age of 1.8 years since then I am taking her therapies”. Maximum children started therapies at age of 3 years. Except two mother, one who reported about regression in her child after 3 years of age. As reported by her “he was very social, and he has 5000 to 6000 words but sudden regression in speech and socialization observed which was concerning for us” and another who doesn’t find any concerned treatment.

Theme 3: Challenges of Parents

The parents encountered numerous obstacles, difficulties, and worries related to caring for a child with ASD, including Sacrifices and Struggles of Mothers, Financial Strain, Treatment Services, Social Stigma and Rejection from Family.

Sacrifices and Struggles of Mothers: In order to satisfy the everyday demands of the autistic child, ensure constant management, and provide additional care, mothers stated sentiments of an increased burden of care. The mothers' sleep patterns were disrupted and they became exhausted due to the continual care that the youngsters required. Most of the participants reported that their social activities are vanished even few participants were unable to continue their jobs for effective care of their child. One participant reported “I was working at British Council and I left the job when I came to know about the diagnosis because I couldn't give time there, I went there on and off, and I need someone permanent to handle him as his father is a bread earner therefore I have to quit my job.

Another participant said “I left going out in family gatherings as I never wanted to make him feel bad. I just remember I dine out once in last 2 years”

Participants discussed the increasing demands on their physical health as well as the loss of personal independence and respite. The participants' burden increased when they tried to manage child care duties in addition to other family obligations. One of the participants gave a description. “he does not understand anything, he used to do a lot of throwing and because of his behavior my other kids are suffering, they used to hide his things.”

Another participant reported about hurdles in outings and hangouts as she stated: we took him to spiritual person and while returning home back we stayed in a local hotel. He shouted a lot, and he insisted us to move out. But instead of this if we took him to big hotel where people are less in number than he will settle down easily.” Another mother reported about constant eyes on the child as she isn't aware what he can do in next minute “if I am working in the kitchen I have to be listening to what he is doing or where he is, I have to make sure he is in a safe space all the time and you have to like throughout the day I have to keep my kitchen door locked. I go to the kitchen thousand times a day, so going, opening, coming back and locking it, it's very tough thing and even I have to keep his grandmother's door locked and every day you have to keep these things in mind and whenever I am using a washing machine I have to make sure the door is closed otherwise he is gonna open it or put his hand inside it or put something inside it. You have to make sure that the gate is always locked so he doesn't go outside anywhere”

The mothers' constant provision of care led to emotional exhaustion. Stemming from their caregiving responsibilities, they navigated the complex dynamics of motherhood within the framework of Pakistani familial norms. As a result, they felt alone, helpless, and exhausted. The mothers' lack of proper rest, lack of respite, and exhaustion of their energy in meeting the needs of the child and the family added to their mental and emotional exhaustion.

Financial Strain: Participants shared their experience regarding financial hardship and encounter to obstacles in their quest for access to essential treatment services required for ASD children. One mother ascribed the financial strain to expenses related to travel, medical visits, special diets, and therapy fees—all of which typically exceed their means. One mother said, “My child may get intensive therapies if I had enough money, we left therapies due to financial issues”.

Mainstream schools in Pakistan are reluctant to admit students with special needs, and specialized institutions are too unaffordable. Stated by mother “School did not admit kids with special needs easily, they didn't understand the responsibility they have when they are inducting kids, they just need money.”

The mothers claimed that despite the high cost of services, they received no funding from public or private organizations to meet ongoing costs. Some families were compelled to keep their children at home because they could not afford the tuition at private educational facilities for kids with ASD. To pay for some services, another family depleted all of their resources and took loans.

“When I was taking Musa's therapies it was very difficult to manage the expenditure of the therapy so I talk to my husband for expenses but nothing works. I used all the savings which are ended but therapies are still needed for my child”

Treatment Services: The lack of service providers in Pakistan for people with special needs has surfaced as another subtheme from the data. Even though the efficacy of these centers is debatable, the majority of families are forced to use their services. Some parents think that regardless of their age, behavioral variations, or mental health issues, children with ASD should be integrated with normal children at all school levels. On the other hand, several voiced worries about the potential harm that such integration would cause rather than the benefit to their kids, emphasizing the necessity of keeping kids with autism apart from their classmates. One of the mother of autistic child remarked, "I admitted him in school they expelled him out. We moved to another school, but they didn't let him sit in class with other kids. He used to be with maid outside the class. I talked to principle, and she responded that he disturbs other kids so we cannot allow him to sit with other children."

The participants also reported that mainstream available schools are highly expensive with compromised teaching and infrastructure standards. The participants believed the school staff lacked the necessary training or education to properly address the needs of their children. A participant said, "Schooling is main issue here, no school is ready to admit my child. One school agree and after 6 months they refused to engage him more in school." Another mother stated, "School hain yahan pe jinhy hum special school ka name dety hain I wish wahan pe zada support ho. Yeh problem main nay face kiya jab main nay buaht sy school visit kia. I didn't found them helpful at all." The high expenses and inefficiency may force families to compromised reasonable care for ASD.

Social Stigma: The participants of current study talked about social stigma manifested by stereotyping behavior of society. They shared that ASD child is stigmatized by other family members, neighbors, friends, and strangers. The nature of stigma is ASD child's behaviors include twirling and tantrums, socially inappropriateness, disobedient, and disruptive behavior. The mothers are blamed for social and behavioral problems and are criticized for their inability to control their child's behaviors. This stigma forced impact their social life negatively. One participant said, "People consider Autism as a mental illness, so it hurts a lot." Another participant stated, "People thought that he has some spiritual issue or some kind of brain issue but I know the people in village will not understand."

Rejection from Family: The participants reported that they also face rejection from family member. One participant reported, "my mother in law compare him with other kids and she doesn't even accept him yet as the way he is, we as a parent accepted it but my family doesn't, family criticize us that we did something wrong and is autistic because of our negligence". Some participants reported that siblings of ASD child "feel jealous," as usually mother and whole family's attention revolved around him. One participant reported, "My other kids were raised in different way, they used to say me that I am pampering him a lot. Even my elder one said once that he wished to be autistic so that could get more love from you like you are doing it for him." Another mother said, "At home he needs all my time, I neglect my younger one and that is why he has some behavior issues now."

Some participants said that having to care for an autistic child has affected their marital relation negatively.

Theme 4: Positive Aspect of Pakistani Culture

family members, and support of Spouse.

Mothers stated numerous positive aspects of having a child with ASD in Pakistani culture. The subthemes include support from family members, and support of Spouse.

Support from family members: Most of the participants reported positive response from family especially immediate maternal family. One participant reported, "It was a positive reaction from my family because they started understanding his behavior". Another reported, "They were very supportive. My in laws and parents both supported us. I have very strong support system at home so I am very lucky". A significant social support system from their families is reported by 77% of the participants, in raising their child with ASD.

Support from Spouse: A family brining up a child with ASD defiantly influenced the psychological and social well-being of its members. However, some participants described having a child with ASD as their strength. They claimed because of this child their marital relationship become stronger. The participants reported that they were emotionally and physically supported by their husbands. One participant stated, "We as a couple have a strong bound because of our child." Another reported, "Yes it effected our relationship but his father is understanding."

Discussion

The aim of this study is to comprehend the problems and strengths faced by mothers who are caring for a kid diagnosed with autism spectrum disorder. Based on the findings, it appears that mothers were aware of their children's unusual developmental patterns even before a diagnosis. Concerns were raised over their child's development, cognitive skills, and actions in relation to other kids. They weren't sure, though, if the child's unusual habits were caused by a disease or if they would eventually go away and return to normal. A recent study of Egyptian mothers of children with ASD revealed the same concerns about motor deficits or developmental delays (Gobrial, 2018). Additionally, a prior study (Chao et al., 2018) characterised the sentiments of uncertainty experienced by Taiwanese parents of children diagnosed with ASD as "exhausting" and "very stressful." The majority of mothers experienced anxiety as a result of their child's behavior differing from other children in their age group. Several parents voiced confusion and doubt about the seriousness of the problem, refusing to accept that their child needs medical attention. Certain parents choose to overlook the signs of autism because they were living in denial. It is noteworthy that the participants in the current study were well-educated and held degrees related to healthcare; hence, they swiftly sought medical advice, whereas the majority did not.

In addition, the participants thought that early identification and treatment might result from the proactive comforting reactions of medical experts to early worries raised by parents about a potential development delay in the child. This outcome is aligned with earlier research (Matenge, 2012), which showed that suspensions in proper ASD diagnosis occurred in Nigeria because medical professionals viewed parental concerns as exaggerated anxiety. Similar research suggests that waiting longer to seek or get services may occur when medical professionals disregard a parent's knowledge about their kid (Hoogsteen & Woodgate, 2013; Burkett et al., 2015).

Study participants mentioned concerns and worries regarding the future of the autistic child. Similar fears about an unclear future and conduct that makes parenting more stressful were discovered in the previous researches (Li & Lo, 2016). Mothers frequently worry about whether or not their kids will be able to survive on their own in the future (Li & Lo, 2016).

The experience of mothers being more purposeful, goal-oriented, and disciplined is another element that is emphasized. Mothers saw having an ASD kid as fulfilling Allah's desire and adding significance to their lives. In Islam, the misfortune of rearing a child with a chronic sickness serves as a means of atonement for an individual's transgressions. According to Achour et al. (2016), Muslims believe that accepting and being patient throughout difficult times is a necessary step toward heaven and is associated with devotion to God. Other cultures also endorse this idea of God's gift, with African American parents considering themselves fortunate to raise an autistic. (Burkett et al., 2017).

The idea that a sick child in the family brought the parents closer and improved their marriage is an intriguing finding of a recent study. Burkett et al. (2017) observed similar results, indicating that the presence of an ASD child increased emotional connectedness within the family. The participants shared experiencing physical tiredness from juggling the burdens of caring for the child with ASD, who needs more time and exertion, with maintaining the family's routine. Their heavy family obligations and lack of time for self-care also cause them to become frustrated (DePape & Lindsay, 2015). Previous studies corroborate these findings, indicating that single mothers who are the only

ones responsible for caring a child with ASD may experience feelings of loneliness (Burkett et al., 2017).

Previous research also supports the current study's findings regarding the unfavorable association between siblings. The stigma and unfavorable responses from society toward a kid with ASD cause the healthy siblings to feel ashamed, which damages sibling relationships (Angell et al., 2012).

Through an awareness of the unique experiences and stressors faced by these families, health care practitioners may be better able to support these families in coping, which in turn may improve the health and quality of life for both mother and child. Furthermore, it could be beneficial for nurses to create initiatives, plans, tools, and services that empower these mothers and boost their sense of self-worth, competence, and capacity to manage pressure (Weiss et al., 2015). Helping mothers ultimately helps children, as parenting stress may have a detrimental impact on the efficacy of therapies for children with ASD (Estes et al., 2019). A calm parent may create a space of safety and calm for their child and provide them with the tools they need to effectively satisfy their needs.

Limitations and Recommendations

The current study is designed carefully but there is some limitation which should be addressed in future researches. Firstly, the sample size is small (N=10), which may limit the generalizability of the findings to a broader population of mothers raising children with ASD in Pakistan. A larger sample size could have provided more comprehensive insights into the experiences of these mothers. Secondly, the study may lack diversity in terms of socioeconomic status, educational background, and geographical location among participants, which could restrict the representation of the varied experiences of mothers across different demographics in Pakistan. Lastly, While the phenomenological approach offers rich insights into individual experiences, it also entails a degree of subjectivity in data interpretation, potentially influencing the identification and interpretation of themes.

On the bases of limitations, following recommendations may help the future studies. Firstly, strive to recruit a more diverse sample of mothers from varied socioeconomic backgrounds, educational levels, and geographic regions to capture a comprehensive spectrum of experiences related to raising children with ASD in Pakistan.

Secondly, to enhance the depth and breadth of the information gathered, overlooking potential nuances that could be captured through diverse methods such as surveys, observations, or focus groups.

Integrating multiple data collection methods, such as surveys, interviews, and observations, can offer a more holistic understanding of the experiences of mothers and their children with ASD, complementing the insights gained from a phenomenological perspective.

Conclusions

In conclusion, this study explores the challenges faced by mothers raising children with Autism Spectrum Disorder (ASD) in Pakistan. The research, which used semi-structured interviews, reveals four main themes: Pre-Diagnosis Concerns, Reaction after Diagnosis, Challenges of Parenting, and Positive Aspects of Pakistani Culture. Pre-Diagnosis Concerns reveal the interplay between maternal instincts and observable behaviors of children with ASD, while Reaction towards Diagnosis highlights the emotional, proactive, and temporal dimensions of the diagnostic journey. Challenges of Parenting include sacrifices, financial strain, limited treatment services, social stigma, and familial rejection. The Positive Aspect of Pakistani Culture highlights the robust networks of familial and spousal support that foster resilience and unity. The study emphasizes the need for tailored support, enhanced access to suitable services and resources, and culturally competent policies and guidelines. By highlighting the lived experiences of these mothers, the study highlights the urgent need for concerted efforts to alleviate the burdens associated with parenting children with ASD in Pakistan.

References

1. Achour, M., Bensaïd, B., & Nor, M. R. B. M. (2016). An Islamic perspective on coping with life stressors. *Applied Research in Quality of Life*, 11(3), 663-685. <https://doi.org/10.1007/s11482-015-9389-8>
2. American Psychiatric Association. (2018, August). What is autism
3. Angell, M. E., Meadan, H., & Stoner, J. B. (2012). Experiences of siblings of individuals with autism spectrum disorders. *Autism Research and Treatment*, 2012, Article 949586. <https://doi.org/10.1155/2012/949586>
4. Baio, J., Wiggins, L., Christensen, D. L., Maenner, M. J., Daniels, J., Warren, Z., Kurzius-Spencer, M., Zahorodny, W., Robinson Rosenberg, C., White, T., Durkin, M. S., Imm, P., Nikolaou, L., Yeargin-Allsopp, M., Lee, L.-C., Harrington, R., Lopez, M., Fitzgerald, R. T., Hewitt, A., . . . Dowling, N. F. (2018). Prevalence of autism spectrum disorder among children aged 8 years—Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2014. *Morbidity and Mortality Weekly Report Surveillance Summaries*, 67(6), 1-23. <https://doi.org/10.15585/mmwr.ss6706a1>
5. Buescher, A. V., Cidav, Z., Knapp, M., & Mandell, D. S. (2014). Costs of autism spectrum disorders in the United Kingdom and the United States. *JAMA pediatrics*, 168(8), 721-728.
6. Burkett, K., Morris, E., Anthony, J., Shambley-Ebron, D., & Manning-Courtney, P. (2017). Parenting African American children with autism: The influence of respect and faith in mother, father, single-, and two-parent care. *Journal of Transcultural Nursing*, 28(5), 496-504. <https://doi.org/10.1177/1043659616662316>
7. Burkett, K., Morris, E., Manning-Courtney, P., Anthony, J., & Shambley-Ebron, D. (2015). African American families on autism diagnosis and treatment: The influence of culture. *Journal of Autism and Developmental Disorders*, 45(10), 3244-3254. <https://doi.org/10.1007/s10803-015-2482-x>
8. Centers for Disease Control and Prevention. (2013). CDC—Data and Statistics, Autism Spectrum Disorders—NCBDDD.
9. Chan, K. K. S., & Lam, C. B. (2018). Self-stigma among parents of children with autism spectrum disorder. *Research in Autism Spectrum Disorders*, 48(April), 44-52. <https://doi.org/10.1016/j.rasd.2018.01.001>
10. Chao, K., Chang, H., Chin, W., Li, H., & Chen, S. (2018). How Taiwanese parents of children with autism spectrum disorder experience the process of obtaining a diagnosis: A descriptive phenomenological analysis. *Autism*, 22(4), 388-400. <https://doi.org/10.1177/1362361316680915>
11. Corcoran, J., Berry, A., & Hill, S. (2015). The lived experience of US parents of children with autism spectrum disorders: A systematic review and meta-synthesis. *Journal of Intellectual Disabilities*, 19(4), 356-366. <https://doi.org/10.1177/1744629515577876>
12. DePape, A.-M., & Lindsay, S. (2015). Parents' experiences of caring for a child with autism spectrum disorder. *Qualitative Health Research*, 25(4), 569-583. <https://doi.org/10.1177/1049732314552455>
13. Estes, A., Swain, D. M., & MacDuffie, K. E. (2019). The effects of early autism intervention on parents and family adaptive functioning. *Pediatric Medicine*, 2(21). <https://doi.org/10.21037/pm.2019.05.05>
14. Gobrial, E. (2018). The lived experiences of mothers of children with the autism spectrum disorders in Egypt. *Social Sciences*, 7(8). <https://doi.org/10.3390/socsci7080133>
15. Gona, J. K., Newton, C. R., Rimba, K. K., Mapenzi, R., Kihara, M., Vijver, F. V., & Abubakar, A. (2016). Challenges and coping strategies of parents of children with autism on the Kenyan coast. *Rural and Remote Health*, 16(2), Article 3517. <https://www.rrh.org.au/journal/article/3517>
16. Hermawati, D., Rahmadi, F. A., Sumekar, T. A., & Winarni, T. I. (2018). Early electronic screen exposure and autistic-like symptoms. *Intractable and Rare Diseases Research*, 7(1), 69-71. <https://doi.org/10.5582/irdr.2018.01007>
17. Hoogsteen, L., & Woodgate, R. L. (2013). The lived experiences of parenting a child with autism in a rural area: Making the invisible, visible. *Pediatric Nursing*, 39(5), 233-237.

18. Imran, N., Chaudry, M. R., Azeem, M. W., Bhatti, M. R., Choudhary, Z. I., & Cheema, M. A. (2011). A survey of Autism knowledge and attitudes among the healthcare professionals in Lahore, Pakistan. *BMC pediatrics*, 11(1), 1-6.
19. International Labour Office. (2018). Young women's employment and empowerment in the rural economy Investing in rural people—Jordan. <http://dosweb.dos.gov.jo>
20. Lee, H., & Fong, E. H. (2018). Sociocultural perspective on autism intervention. In M. Fitzgerald & J. Yip (Eds.), *Autism: Paradigms, recent research and clinical applications* (pp. 290- 300). INTECH. <https://doi.org/10.5772/65965>
21. Li, T.-Y., & Lo, J.-L. (2016). The predictors of uncertainty in mothers of children with autism spectrum disorder. *Children's Health Care*, 45(2), 147-164. <https://doi.org/10.1080/02739615.2014.979924>
22. Lin, L. Y., Cherng, R. J., Chen, Y. J., Chen, Y. J., & Yang, H. M. (2015). Effects of television exposure on developmental skills among young children. *Infant Behavior and Development*, 38, 20-26. <https://doi.org/10.1016/j.infbeh.2014.12.005>
23. Maqbool, S., Malik, U., & Zahid, M. (2021). Prevalence of Autism Spectrum Disorder and Associated Factors Among Children Aged 18-48 Months in Lahore, Pakistan. *Cureus*, 13(1), e12699.
24. Matenge, B. (2012). An exploration of the lived experiences of mothers raising children with autism. University of Cape Town.
25. Maulik, P. K., Mascarenhas, M. N., Mathers, C. D., Dua, T., & Saxena, S. (2011). Prevalence of intellectual disability: a meta-analysis of population-based studies. *Research in developmental disabilities*, 32(2), 419-436.
26. Memon, A. M., Rahman, A., & Sajid, S. (2018). Autism Spectrum Disorder (ASD) and attitudes of parents towards ASD in Pakistan. *Journal of Autism and Developmental Disorders*, 48(5), 1627-1637.
27. Miranda, A., Mira, A., Berenguer, C., Rosello, B., & Baixauli, I. (2019). Parenting stress in mothers of children with autism without intellectual disability. Mediation of behavioral problems and coping strategies. *Frontiers in Psychology*, 10, Article 464. <https://doi.org/10.3389/fpsyg.2019.00464>
28. National Council for Family. (2018). *Jordanian Family Report*. Amman.
29. Nowell, L. S., Norris, J. M., White, D. E., & Moules, N. J. (2017). Thematic analysis: Striving to meet the trustworthiness criteria. *International Journal of Qualitative Methods*, 16(1), 1-13. <https://doi.org/10.1177/1609406917733847>
30. Ou, J.-J., Shi, L.-J., Xun, G.-L., Chen, C., Wu, R.-R., Luo, X.-R., Zhang, F.-Y., & Zhao, J.-P. (2015). Employment and financial burden of families with preschool children diagnosed with autism spectrum disorders in urban China: Results from a descriptive study. *BMC Psychiatry*, 15(1), Article 3. <https://doi.org/10.1186/s12888-015-0382-4>
31. Rasheed, M. A., & Ahmed, S. (2019). Autism spectrum disorder in Pakistan: A systematic review of current prevalence and data. *Journal of Pediatric Neurology*, 17(2), 46-50.
32. Saini, M., Stoddart, K. P., Gibson, M., Morris, R., Barrett, D., Muskat, B., Nicholas, D., Rampton, G., & Zwaigenbaum, L. (2015). Couple relationships among parents of children and adolescents with autism spectrum disorder: Findings from a scoping review of the literature. *Research in Autism Spectrum Disorders*, 17, 142-157. <https://doi.org/10.1016/j.rasd.2015.06.014>
33. Shire, S. Y., Baker Worthman, L., Shih, W., & Kasari, C. (2020). Comparison of face-to-face and remote support for interventionists learning to deliver JASPER intervention with children who have autism. *Journal of Behavioral Education*, 29, 317-338.
34. Van Manen, M. (2023). *Phenomenology of practice: Meaning-giving methods in phenomenological research and writing*. Taylor & Francis.
35. Weiss, J. A., MacMullin, J. A., & Lunsy, Y. (2015). Empowerment and parent gain as mediators and moderators of distress in mothers of children with autism spectrum disorders. *Journal of Child and Family Studies*, 24(7), 2038-2045. <https://doi.org/10.1007/s10826-014-0004-7>

36. World Health Organization. (2019). Autism spectrum disorders. <https://www.who.int/news-room/fact-sheets/detail/autism-spectrum-disorders>

37. Zablotsky, B., Kalb, L. G., Freedman, B., Vasa, R., & Stuart, E. A. (2014). Health care experiences and perceived financial impact among families of children with an autism spectrum disorder. *Psychiatric Services, 65*(3), 395-398. <https://doi.org/10.1176/appi.ps.201200552>

38. Zaidman-Zait, A., Mirenda, P., Duku, E., Vaillancourt, T., Smith, I. M., Szatmari, P., Bryson, S., Fombonne, E., Volden, J., Waddell, C., Zwaigenbaum, L., Georgiades, S., Bennett, T., Elsabaggh, M., & Thompson, A. (2017). Impact of personal and social resources on parenting stress in mothers of children with autism spectrum disorder. *Autism, 21*(2), 155-166. <https://doi.org/10.1177/1362361316633033>

Appendix A

Table 2	
Demographics	<ol style="list-style-type: none"> 1. Age 2. Marital status 3. Level of education 4. Employment status 5. Number of children (normal and with ASD) 6. Monthly income 7. Age of child
Opening question	
“ Can you please describe your emotional response upon knowing of your child's diagnosis with Autism Spectrum Disorder.”	
Follow up questions	
<ol style="list-style-type: none"> 1. Kindly explain the symptoms your child exhibited prior to receiving the diagnosis. 2. Could you share the circumstances and timing surrounding the accurate diagnosis? 3. Describe your initial reaction upon knowing of your child's diagnosis. 4. How did your family members respond to your child's condition? 5. Please share your experiences in parenting a child with Autism Spectrum Disorder (ASD). 6. What strategies have proven effective in addressing the challenges of parenting a child with ASD? 7. Have you encountered any strategies that were ineffective? 8. Have you received support from your community or network during this situation? 9. Did you need to discontinue employment and remain at home due to your child's circumstances? 10. Which sources do you consult for information regarding this disorder and its management? 11. In what ways have these challenges impacted you and your family? 12. How would you characterize the relationship between the autistic child and their siblings? 13. Was your autistic child exposed to television, and if so, for what duration? 14. Reflecting on your experience of parenting a child with ASD, are there any aspects you wish you had known or handled differently? 	